# REFOCUS: Developing a recovery focus in mental health services in England

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# Abstract

### *Background*

Recovery in mental health services is defined as living a satisfying, hopeful, and contributing life even with any limitations caused by illness. An evidence base for understanding and supporting recovery is needed.

### *Objectives*

To carry out a programme of linked research studies to understand how mental health services can promote recovery.

### *Design*

A two phase, mixed methods study. Phase 1 (theory) involved seven systematic reviews (develop a conceptual framework for recovery; establish its cross-cultural validity; develop a recovery practice framework; review measures of recovery measures; recovery support measures; strengths measures; staff understanding of recovery), development and evaluation of three new measures (INSPIRE for recovery support; IOM for individualised measurement of recovery; SAFE for feasibility assessment), evaluation of existing recovery measure (QPR), national survey, three qualitative studies (conceptual framework validation, staff recovery-oriented practice, black service users), and development of a new manualised REFOCUS intervention. Phase 2 involved a two-site cluster randomised controlled trial of the REFOCUS intervention, with a nested secondary outcome study, process and economic evaluation, interrupted time series analysis, sub-group analysis of black service users, and outcomes comparison. The impact of PPI on the programme was also empirically evaluated.

### *Setting*

Six mental health Trusts in England.

### *Participants*

741 community mental health service users, 1,169 mental health staff and 54 expert stakeholders.

### *Interventions*

The manualised team-level REFOCUS intervention to increase support for personal recovery

### *Main outcome measures*

Survey**:** Recovery Self Assessment (RSA). Trial: Questionnaire about the Process of Recovery (QPR), Client Satisfaction Questionnaire (CSQ).

### *Results*

Phase 1: the conceptual framework for recovery identified characteristics, stages and processes of recovery. It was cross-culturally valid and applicable to current service users. The recovery practice framework identified four domains of recovery support. INSPIRE, SAFE and IOM were developed and evaluated. The national survey identified differences between team managers (n=22), workers (n=120) and service users (n=108), and found higher recovery orientation was associated with improved recovery. The REFOCUS intervention has two elements: recovery-promoting relationships and working practices. Phase 2: the 27-team trial involving 403 service users (297 at follow-up) showed no differences on primary outcomes of QPR (adjusted difference 0.63, 95%CI: -1.4 to 2.3, p=.55), but secondary outcomes of functioning (adjusted difference 5.90, 95%CI 2.6 to 9.2, p<.001) and staff-rated unmet need (adjusted difference -0.80, 95%CI -1·6 to -0·7, p=.03) did improve. Implementation was mixed, and higher-participating teams had higher staff-rated pro-recovery behaviour change (adjusted difference -0·4, 95%CI -0·7 to -0·2, p=·001) and patients had higher QPR Interpersonal scores (adjusted difference -1·6, 95%CI -2·7 to -0·5, p=·005) at follow-up. Intervention-group patients incurred £1,062 (95%CI -£1,103 to £3,017) lower adjusted costs. Black service users did not show improved recovery or satisfaction. Service users who experienced the intervention reported benefits.

### *Conclusions*

The REFOCUS intervention has been modified following its evaluation. The REFOCUS Programme provides a theory base for recovery research.

### *Future work*

The main challenge in supporting recovery is implementation, and pro-recovery care does increase recovery.

**Keywords**

Mental health services research, Recovery, Community, Psychosis, Systematic review, Randomised controlled trial

**Study registration**

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**Further information**

Web-site: researchintorecovery.com/refocus

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## List of Abbreviations

| Abbreviation | Meaning |
|---|---|
| 2Gether | 2Gether NHS Foundation Trust |
| AACP | American Association of Community Psychiatrists |
| ACT | Assertive Community Treatment |
| AMED | Allied and Complementary Medicine Database |
| APQ | Activity and Participation Questionnaire |
| ASSIA | Applied Social Sciences index and Abstracts |
| BME | Black and Ethnic Minorities |
| BPRS | Brief Psychiatric Rating Scale |
| CANSAS-S | Camberwell Assessment of Needs Short Appraisal Schedule - staff |
| CANSAS-P | Camberwell Assessment of Needs Short Appraisal Schedule - Patient |
| CASIG | Client Assessment of Strengths, Interests and Goals |
| CFA | Confirmatory Factor Analysis |
| CHIME | Connectedness, Hope, Identity, Meaning, Empowerment |
| CIM | Community Integration Measure |
| CINAHL | Cumulative Index to Nursing & Allied Health Literature |
| CMHT | Community Mental Health Team |
| CPA | Care Programme Approach |
| CRD | Centre for Reviews and Dissemination |
| CRIS | Clinical Records Interactive Search |
| CRM | Collaborative Recovery Model |
| CSQ | Client Satisfaction Questionnaire |
| CSRI | Client Service Receipt Inventory |
| EFA | Exploratory Factor Analysis |
| EMBASE | Excerpta Medica dataBASE |
| ENMESH | European Network for Mental Health Service Evaluation |
| EPHPP | Effective Public Health Practice Project |
| EPJS | Electronic Patient Journey System |

| | |
|---|---|
| ERFS | Elements of Recovery Facilitating Systems |
| ES | Empowerment Scale |
| FACTOR | Families And Carers Together On Research |
| GAF | Global Assessment of Functioning |
| GAS | Goal Attainment scaling |
| HHI | Herth Hope Index |
| HoNOS | Health of the Nation Outcome Scale |
| HTA | Health Technology Appraisal |
| IAB | International Advisory Board |
| IBSS | International Bibliography of Social Science |
| ImROC | Implementing Recovery through Organisational Change |
| IOM | Individualised Outcome Measure |
| IS | Implementation Scale |
| ITS | Interrupted Time Series |
| KMO | Kaiser-Mayer-Olkin |
| LEAP | Lived Experience Advisory Panel |
| MANSA | Manchester Short Assessment of Quality of Life |
| MARS | Maryland Assessment of Recovery |
| MeSH | Medical Sub-Headings |
| MHCI | Mental Health Commission of Ireland |
| MHCS | Mental Health Confidence Scale |
| MHRM | Mental Health Recovery Measure |
| MICA | Mental Illness: Clinicians’ Attitudes Scale |
| MLQ | Meaning of Life Questionnaire |
| MOS | Medical Outcome Study |
| MRC | Medical Research Council |
| NHS | National Health Service |
| NICE | National Institute for Health and Clinical Excellence |
| NVQ | National Vocational Qualification |
| OpenSIGLE | Open System for Information on Grey Literature in Europe |
| PORT | Patient Outcomes Research Team |
| PoRSAT | Pillars of Recovery Service Audit Tool |
| PPFS | Patient Perception of Functioning Scale |

| | |
|---|---|
| PPI | Public and Patient Involvement |
| PPO | Personalised Primary Outcomes |
| PROM | Patient Rated Outcome Measure |
| PROSPERO | International prospective register of systematic reviews |
| PULSAR | Principles Unite Local Services Assisting Recovery |
| QPR | Questionnaire about the Process of Recovery |
| RAS | Recovery Assessment Scale |
| RATS | Reporting guidelines for qualitative research |
| RBPI | Recovery Based Program Inventory |
| RCI | Reliable Change Index |
| RCT | Randomised Controlled Trial |
| REC | Research Ethics Committee |
| REE | Recovery Enhancing Environment Measure |
| RFS | Recovery Fidelity Scale |
| RIQ | Recovery Interventions Questionnaire |
| RKI | Recovery Knowledge Inventory |
| RMQ | Recovery Markers Questionnaire |
| ROP | Recovery Oriented Practice |
| ROPI | Recovery Oriented Practices Index |
| ROSE | Recovery Oriented Service Evaluation |
| ROSI | Recovery Oriented Systems Indicators |
| RPFS | Recovery Promoting Fidelity Scale |
| RPI | Recovery Process Inventory |
| RPRS | Recovery Promoting Relationships Scale |
| RS | Recovery Star |
| RSA | Recovery Self Assessment |
| RSES | Rosenberg Self-Esteem Scale |
| SAFE | Structured Assessment of Feasibility |
| SAMHSA | Substance Abuse and Mental Health Services Administration |
| SAW | Strengths Assessment Worksheet |
| SBCM | Strengths Based Case Management |
| SCSG | Social and Cultural Sub-Group |
| SF-12 | Short Health Survey Questionnaire-12 |

| | |
|---|---|
| SF-36 | Short Form-36 |
| SI-MH | Satisfaction Index - Mental Health |
| SIR | Social Inclusion and Recovery |
| SISR | Self-Identified Stage of Recovery |
| SIST-R | Short Interview to Assess Stages of Recovery |
| SLaM | South London and Maudsley NHS Foundation Trust |
| SS | Stigma Scale |
| STORI | Stages of Recovery Instrument |
| TRIP | Team Recovery Implementation Plan |
| VIA-IS | Values in Action - Inventory of Strengths |
| WEMWBS | Warwick-Edinburgh Mental Well-Being Scale |

## Scientific summary

### Background

There is a lack of high-quality evidence concerning recovery interventions to increase the recovery-orientation of mental health services.

### Objectives

We carried out a programme of linked research studies aimed at increasing the extent to which mental health services promote recovery. The REFOCUS programme had four objectives.

1. To identify gaps between current and recovery-focussed practice and to understand why those differences exist
2. To develop a manualised and empirically defensible complex intervention to support recovery, based on an explicit and testable model
3. To identify or develop appropriate patient-level process and outcome measures
4. To evaluate the intervention in a randomised controlled trial.

### Methods

The REFOCUS programme was a two-phase, mixed methods study, which took place in England between 2009 and 2014.

Phase 1 (addressing Objectives 1 to 3) was organised into three modules. In the *Define the problem* module, the Conceptual Framework sub-study involved a systematic review and narrative synthesis of existing conceptualisations, models and theories of recovery. The resulting conceptual framework was then validated by (a) a further systematic review addressing its international applicability, and (b) focus groups with current mental health service users from three mental health Trusts. The Recovery Practice Framework sub-study was a document analysis using inductive thematic analysis to develop a recovery practice framework characterising how mental health services can support recovery. The National Survey involved randomly chosen service users from randomly chosen teams in six Trusts, and assessed service user, staff and team leader perspectives on the recovery orientation of their team using the Recovery Self Assessment (RSA). The Staff Perceptions sub-study involved focus groups and interviews with staff from five Trusts to develop a

grounded theory of staff understanding of recovery, followed by a systematic review (PROSPERO 2013:CRD42013005942) to contextualise the theory in the wider literature.

In the *Optimise the intervention* module, the Framework For Black Service Users sub-study used focus groups and interviews with current service users with self-reported black ethnicity to develop a conceptual framework of recovery support for black service users. The Strengths Measures Review sub-study was a systematic review of strengths measures, to identify a measure to use in the REFOCUS intervention. The SAFE Development sub-study developed a new measure and associated reporting guidelines, called Structured Assessment of Feasibility (SAFE), to assess the feasibility of a complex intervention. The Intervention Development sub-study synthesises the evidence and used expert consultation to develop the REFOCUS Intervention, a transdiagnostic multi-professional intervention to improve recovery support from mental health services.

In the *Optimise the evaluation* module, the Recovery Measures Review sub-study was a systematic review of recovery measures, to identify a primary outcome for the REFOCUS trial. The QPR Validation sub-study investigated the psychometric properties of the Questionnaire about the Process of Recovery (QPR), an existing measure of recovery, using two sets of data from current mental health service users. The Recovery Support Measures Review sub-study was a systematic review of recovery support measures. The INSPIRE Development sub-study developed and evaluated a new recovery support measure called INSPIRE in three stages; developing through expert consultation, then piloting and psychometric evaluation with current service users. The IOM Development sub-study developed and evaluated a new individualised measure of outcome for use in trials, called Individualised Outcome Measure (IOM), in four stages: expert consultation, pilot, feasibility and evaluation in the REFOCUS trial.

Phase 2 involved the REFOCUS trial (ISRCTN02507940), a two-site cluster randomised controlled trial comparing treatment as usual with versus without the REFOCUS intervention. Setting was multidisciplinary adult community mental teams providing care co-ordination using the Care Programme Approach. All eligible teams from South London and Gloucestershire were invited to participate. Main service user inclusion criteria were aged 18-65 years, primary clinical diagnosis of psychosis (including schizophrenia, schizo-affective disorder, bipolar disorder), sufficiently well to participate in opinion of staff, and in regular contact with at least one team worker. The primary outcome was QPR, and secondary outcomes included the Camberwell Assessment of Need (CAN) and the Global Assessment of Functioning (GAF). The target analysable sample published in the trial protocol was 336 service users. Outcome evaluation was conducted using intention-to-treat analysis on imputed data, adjusting for baseline scores and using random effects regression with maximum likelihood estimation to account for team-level clustering. Economic evaluation used resource use data from the six months before baseline and follow-up (one year later), with service use costs combined with appropriate unit costs and then compared using bootstrapped regression, controlling for baseline costs.

Process evaluation comprised two sub-studies. The Staff Process Evaluation sub-study involved focus groups and interviews with participating staff and interviews and team-level reports from trainers, to investigate experiences of using the REFOCUS intervention and wider contextual and individual influences on implementation of a complex intervention. The Service User Process Evaluation sub-study used focus groups and interviews with participating service users to investigate experience of the intervention. The Trial Casenote Audit sub-study used an interrupted time series design to investigate the impact of the intervention on responsibility for action in care plans for 950 service users at 7 time points. The pre-planned Secondary Outcome Evaluation sub-study assessed outcomes in relation to recovery (assessed with QPR) and satisfaction (assessed with Client Satisfaction Questionnaire; CSQ) for an epidemiologically representative sub-group of participating service user from the London site with the additional inclusion criterion of black ethnicity. Trial data were used in the Outcomes Comparison sub-study, to understand the relationship between clinical and recovery outcomes using exploratory factor analysis, to investigate change over time using confirmatory factor analysis, and to recommend outcome measures.

A recovery orientation involves greater prominence being given to the experience of service users and carers. Therefore Patient and Public Involvement (PPI) was addressed in three ways. First, people with lived experience were involved in all stages of the study, including as applicants, researchers, analysts and authors. Second, the PPI Impact sub-study quantitatively evaluated the impact of PPI on the REFOCUS programme, by tracking recommendations and their implementation during the first seven months of the study. Finally, the PPI chapter in this report was co-produced with people with lived experience.

**Results**

The Conceptual Framework sub-study identified three over-arching categories from the 81 identified studies. Characteristics comprised thirteen ways people described their experiences of recovering, including recovery being an active and gradual process, a journey, a struggle, and a life-changing experience. The 15 stage models were mapped to the transtheoretical model of change. Finally, five recovery processes were identified: Connectedness, Hope and optimism, Identity, Meaning and purpose in life and Empowerment (giving the acronym CHIME). The updated reviews identified 105 theories and models of recovery from 11 countries. CHIME recovery processes were consistently found with the international papers, indicating some cross-cultural validity, although most current evidence comes from Western and English-speaking countries. CHIME was relevant to current mental health service users (n=48), who put more emphasis on practical support, diagnosis and medication, and scepticism surrounding recovery.

The Recovery Practice Framework sub-study identified 30 documents from six countries. Thematic analysis identified four practice domains of recovery support: Promoting citizenship, Organisational commitment, Supporting personally defined recovery, and Working relationship.

The National Survey (120 service users, 108 staff, 22 team leaders) found RSA ratings of recovery orientation were higher by team leaders than by staff (b=-0.30, p=0.008; 95%CI: -0.53 to -0.08) or service users (b=-0.25, p=0.029; 95%CI: -0.48 to -0.03). Team recovery orientation was associated with recovery (b=.53, p<.001; 95%CI: .32 to .74). Personal experience of mental health problems was reported by 50 (39%) staff, and of being a carer by 100 (76%).

The Staff Perspective sub-study (n=97) identified a core category of Competing Priorities, with sub-categories Health Process Priorities, Business Priorities and Staff Role Perception. The contextualising systematic review (22 studies) identified three sub-categories of staff role perception: Personal Recovery, Clinical Recovery and Service-defined Recovery. Staff understanding of recovery spans all three, and Service-defined Recovery is a new and un-researched influence in mental health systems.

The Framework For Black Service Users sub-study (n=40) identified a core theme of ‘Identity – gaining a positive sense of self’. The Strengths Measure Review identified 12 measures, assessing strengths at individual, interpersonal and environmental levels. The most widely used measure was Strengths Assessment Worksheet (SAW). The SAFE Development sub-study identified 11 implementation studies, from which 95 influences were identified and a 16-item SAFE measure synthesised. SAFE was evaluated against published interventions (n=20), with adequate inter-rated reliability (k=0.84) and test-retest reliability (k=0.89).

The REFOCUS intervention was then developed. It comprises a one-year team-level intervention with two elements. Component 1 is Recovery-promoting relationships, which includes training staff to use coaching in their clinical work. Component 2 is three working practices (WP) which are promoted. WP1 is understanding values and treatment preferences, to maximise person-centred care. WP2 is assessing strengths, to support the development of resilience. WP3 is supporting goal-striving by the service user, to increase their self-management skills. Implementation approaches include staff training, and manager and staff reflection groups. A manual and a testable model were published.

The Recovery Measures Review identified 12 measures, and after mapping these to CHIME and psychometric evaluation, QPR was identified as the primary outcome for the REFOCUS trial. The QPR Validation trial (n=487) evaluated two approaches to scoring QPR, and found the 15-item total score demonstrated adequate convergent validity (r=0.73, 95% CI O.61 to 0.82, p<0.001), test-retest reliability (ICC=0.74, 95%CI: 0.63 to 0.82), internal consistency (α=0.89) and sensitivity to change (r=0.40, 95% CI 0.27 to 0.49, p<.001), and a 1-factor solution fitted the data.

The Recovery Support Measures Review identified 6 measures, none of which could be recommended following mapping to CHIME and psychometric evaluation. Consequently, the INSPIRE Development sub-study developed a new measure of recovery support, based on CHIME and the recovery practice framework. Development involved expert consultation (n=61), pilot (n=20) and psychometric evaluation (n=92). The resulting 27-item INSPIRE measure has two sub-scales. The Support sub-scale showed evidence of adequate convergent validity, internal consistency, factor structure and sensitivity to change. The Relationship sub-scale showed the same, and adequate internal consistency ($\alpha=0.89$) and test-retest reliability ($r=0.75$). A five-item Brief INSPIRE was also developed and demonstrated adequate psychometric properties.

The IOM Development sub-study developed (18 experts), piloted (20 service users) and tested the feasibility (84 service users) of a new approach to individualised clinical end-point measurement in trials. It was then evaluated in the REFOCUS trial (n=340), showing an association with the primary outcome (b=3.3, 95%CI: 2.3 to 4.4, z=6.2, p<.001).

The REFOCUS trial involved 27 teams, from which 403 service users were recruited at baseline, with an analysable sample of 297 (88% of target) at one-year follow-up. Intervention group service users did not differ from those in the control group on the primary outcome of QPR (b=.63, p=.55, 95%CI: -1.41 to 2.67) at follow-up, but did show improvement on two of ten secondary outcomes: staff-rated CAN unmet need (b=-0.80, p=.03, 95%CI: -1.52 to -0.65) and GAF (b=5.90, p<0.001, 95%CI: 2.61 to 9.18). Adjusting for covariates weakened the CAN effect size. High implementing teams in the intervention group had higher patient-rated QPR Interpersonal (b=-1.57, p=.005, 95%CI: -2.66 to -0.48) and staff-rated behaviour change (b=-0.43, p=.001, 95%CI: -0.69 to -0.16) than those in low implementing teams.

Economic evaluation indicated the mean intervention cost per service users was £120 (2012/13). Adjusting for baseline, the cost difference between intervention and control groups was £1,062 (95% CI, -£1,103 to £3,017), i.e. receiving the intervention was associated with lower costs, but the difference was not statistically significant. Service users in the high participation intervention teams had services costs that were on average £657 less than service users in low participation intervention teams, but again this was not statistically significant (95% CI, -£1,555 to £4,783).

The Staff Process Evaluation (n=52, 28 trainer reports) identified coaching training and resources in the manual for WP2 and WP3 as valuable. Two categories of implementation barrier were identified: Organisational readiness for change (NHS, Team, Individual) and Effective training (Engagement strategies, Delivery style and content, Modelling recovery principles). The Service User Process Evaluation sub-study (n=37) identified three categories of experience: Working relationship which supports recovery, Impact of the REFOCUS intervention, and Lack of noticeable change in the service user experience.

The Casenote Audit found no evidence for a change in responsibility for action in care plans after a team started the REFOCUS intervention. The Secondary Outcome Evaluation (analysable n=81) found no evidence of benefit from the REFOCUS intervention in relation to either recovery (QPR; b=-4.93, p=.167) or satisfaction (CSQ; -3.317, p=.001).

In the Outcomes Comparison sub-study, a 3-factor solution best fitted pooled baseline data from the REFOCUS trial. Factors were interpreted as Patient-rated personal recovery, Patient-rated clinical recovery and Staff-rated clinical recovery. Change scores over one year within each factor were correlated, with change in Patient-rated personal recovery (z=3.1, p=.002; ES=.13) but not in the other two factors. Analysis of reliability and factor loading indicated Herth Hope Index (HHI), CAN and Health of the Nation Outcome Scale (HoNOS) as the optimal measures.

The shared experience of PPI was synthesised through co-production. The PPI Impact sub-study found the 172 recommendations from advisors related to scientific, pragmatic, resources, collaboration and committee processed, and identified reasons for non-implementation. Overall, 103 (60%) of recommendations were implemented, and provide a resource for informing future research.

## Conclusions

A total of 15 knowledge contributions and 11 implications are identified, including:

- the REFOCUS programme provides theoretical foundations for recovery-oriented research, and the conceptual framework and the recovery practice framework are already being used in research and policy internationally
- the INSPIRE measure of recovery support and SAFE measure of intervention feasibility can be recommended
- lived experience in the workforce is an under-used resource
- the modified REFOCUS intervention places a greater emphasis on implementation and team-level ownership of change
- evaluating interventions on a service-wide basis in systems which are being continuously re-organised is wasteful, and targeting teams which are stable, well led, ready to change and philosophically oriented towards the intervention may reduce research resource waste
- mechanisms for strengthening PPI though funding, development of service user-researcher capacity and increased expectations of demonstrating PPI impact are needed.

## Plain English summary

The aim of this programme was to increase the extent to which mental health services support recovery. The study was divided into two phases.

In Phase one, we started out by trying to see how recovery is understood and what good practice guidance was already available on supporting recovery. We developed our own measure of recovery support called INSPIRE, and designed a new approach to help staff to support the recovery of service users.

In Phase two, we tested our new approach with people who were receiving care from community mental health teams, comparing those who received the new approach to supporting recovery with those who only received their usual care. We recruited 403 people who received their care from community mental health teams in London and Gloucestershire. Using a measure of personal recovery (Questionnaire about the Process of Recovery - QPR), we did not find any differences between the people who received the new approach and those that received usual care. We did find differences in QPR scores between service users receiving care from teams that did implement the new approach compared to those receiving either their usual care or in teams who were asked to but did not implement the new approach.

Supporting recovery is important and a challenge to deliver in practice. It needs to be tackled at many different levels: by individual workers, teams, organisations and by the wider society.

## Chapter 1: Introduction

In this chapter we describe the background, aims, objectives and rationale to the programme to increase the recovery focus of mental health services, outline the structure of the report and provide a summary of what we have done and how this has changed from the original research proposal. We also provide a programme summary in Appendix 1.

### Background

In mental health, the word 'recovery' has two meanings. The first involves clinical recovery – when someone 'recovers' from the illness and no longer experiences its symptoms. The second involves personal recovery – recovering a life worth living (without necessarily having a clinical recovery). It is about building a life that is satisfying, fulfilling and enjoyable. This understanding of recovery comes from people who have experienced it, and is based on the idea that each person should be able to feel in control of, and take decisions about, their own lives, rather than simply doing what a health professional tells them. This is the meaning of recovery which we use in this report.

There is a policy and professional consensus about the importance of ‘recovery’ in mental health services, defined as “a way of living a satisfying, hopeful, and contributing life” even with any limitations caused by illness[1] [2] [3]. This has recently been elaborated:

> *Recovery is the process of regaining active control over one’s life. This may involve discovering (or rediscovering) a positive sense of self, accepting and coping with the reality of any ongoing distress or disability, finding meaning in one’s experience, resolving personal, social or relationship issues that may contribute to one’s mental health difficulties, taking on satisfying and meaningful social roles and calling on formal and / or informal systems of support as needed*[4]

Mental health is a priority area for the National Health Service (NHS). The context for this research is adult mental health services in England. These services work with adults of working age with a range of mental health problems, including depression, anxiety, schizophrenia and personality disorder.

On the basis of both policy and professional groups, mental health services should promote recovery. Unfortunately, some traditional working practices inadvertently foster dependency, by focussing on what the person cannot do rather than supporting people to find ways of coping with their mental health problems and making the most of their lives and talents. Research is needed to address the important question of how to provide care which is led by the patient's priorities and promotes self-management.

In 2009 the REFOCUS Programme was funded by the National Institute for Health Research through the Programme Grants for Applied Research scheme (reference RP-PG-0707-10040). The original programme summary is shown in Appendix 1. The original proposal required changes for two reasons. First, the proposal was written in 2008, since when new research and changing service structures have emerged. Second, the five year length of the programme was long enough for emerging findings to influence the design. The changes from the original proposal are shown in Appendix 2.

## Aims and objectives

We carried out a programme of linked research studies aimed at increasing the extent to which mental health services promote recovery. We had four objectives:

Objective 1. To define the problem

To improve understanding of what recovery means, how it can be supported by mental health services, to identify gaps between current and recovery-focussed practice and to understand why those differences exist.

Objective 2. To optimise the intervention

To identify and evaluate candidate elements of a complex intervention, manualise the intervention and develop measures of treatment fidelity

Objective 3. To optimise the evaluation

To develop and pilot cross-culturally valid measures of patient-level recovery processes and outcomes

Objective 4. To optimise the trial parameters
To evaluate the intervention in a two-site cluster randomised controlled trial, including outcome, process and economic evaluation

Objective 5. Knowledge transfer
To communicate the findings from the REFOCUS programme to relevant stakeholders, and more broadly to support the development and dissemination of recovery research.

## Programme plan

The scientific framework for the programme was the Medical Research Council (MRC) framework for developing, evaluating and implementing complex interventions for health, published in 2000[5]. The first three stages involve the development of (i) theory based on an appropriate mix of existing and new evidence, leading to (ii) a testable model describing the causal pathway from complex intervention to outcome, followed by (iii) an exploratory trial to evaluate the model in practice. An update to this framework published in 2007 re-framed these three phases as part of one larger iterative activity rather than as sequential stages[6]. The four objectives for the REFOCUS programme are derived from this updated framework.

The programme was undertaken in two overlapping phases. In Phase 1 (June 2009 to August 2012) the focus was on understanding the problem, manualising the REFOCUS intervention, and developing and testing measures for use in the trial. In Phase 2 (April 2011 to December 2013) a two-site cluster randomised controlled trial was undertaken. The final year of the programme (January 2014 to December 2014) involved data cleaning, analysis and dissemination.

## Structure of this report

The structure of this report follows the five objectives. Each objective was addressed through several sub-studies, as described in Table 1.

## Table 1 Sub-studies in the REFOCUS programme

| **Sub-study name** | **Design and methodology** | **Data** | **Output** |
|---|---|---|---|
| **Chapter 2: Define the problem** | | | |
| Conceptual Framework | a) Systematic review and narrative synthesis<br>b) Extended systematic review<br>c) Qualitative using thematic analysis | a) 97 studies<br>b) 115 studies<br>c) 7 focus groups with mental health service users (n=48) | Development and validation of the conceptual framework for recovery |
| Recovery Practice Framework | Qualitative using inductive thematic analysis | 30 best practice guidelines | Development of the recovery practice framework |
| National Survey | Epidemiologically representative survey | 120 service users, 109 staff, 22 team leaders from 28 teams in 6 Trusts | National survey of recovery-oriented practice |
| Staff Perceptions | a) Grounded theory<br>b) Systematic review and narrative synthesis | a) 10 focus groups (n=65) and individual interviews (n=32) with staff<br>b) 22 studies | Contextualised grounded theory of factors impacting on recovery support |
| **Chapter 3: Optimise the intervention** | | | |
| Framework For Black Service Users | Qualitative using thematic analysis | 4 focus groups (n=26) and 14 interviews with black service | Conceptual framework of recovery support for black |

| | | | |
|---|---|---|---|
| | | users | service users |
| Strengths Measures Review | Systematic review | 32 studies about 12 measures | Identification of measure to use in REFOCUS intervention |
| SAFE Development | Focussed narrative review | 11 studies | Structured Assessment of Feasibility (SAFE) measure and reporting guidelines |
| Intervention Development | Evidence synthesis, expert consultation | 56 experts | REFOCUS intervention, model and manual |
| **Chapter 4: Optimise the evaluation** | | | |
| Recovery Measures Review | Systematic review | 35 studies about 13 measures | Identification of primary outcome (QPR) for trial |
| QPR Validation | Psychometric evaluation | 487 service users | Validation of Questionnaire of Processes of Recovery (QPR) |
| Recovery Support Measures Review | Systematic review | 6 measures | Identification of need to develop new measure (INSPIRE) |
| INSPIRE Development | a) Development<br>b) Pilot<br>c) Psychometric evaluation | a) 61 experts<br>b) 20 service users<br>c) 92 service users | INSPIRE measure |
| IOM Development | a) Development | a) 18 experts | Individualised Outcome |

| | | | |
|---|---|---|---|
| | b) Pilot<br>c) Feasibility<br>d) Use in trial | b) 20 service users<br>c) 84 service users<br>d) 340 service users | Measure (IOM) |
| **CHAPTERS 5 TO 8: OPTIMISE TRIAL PARAMETERS**<br>**Chapter 5: REFOCUS trial methods**<br>**Chapter 6: REFOCUS trial outcome and economic evaluation** | | | |
| Trial Outcome And Economic Evaluation | Two-site cluster randomised controlled trial | 403 service users, 532 staff | Evaluation of the impact of the REFOCUS intervention on outcome and resource use |
| **Chapter 7: REFOCUS trial process evaluation** | | | |
| Staff Process Evaluation | Qualitative using thematic analysis | 52 staff (four focus groups n=24, 28 individual interviews), 28 trainer reports | Staff perspective on the REFOCUS intervention |
| Service User Process Evaluation | Qualitative using thematic analysis | 37 service users (2 focus groups n=13, 24 individual interviews) | Service user perspective on the REFOCUS intervention |
| **Chapter 8: Outcome studies** | | | |
| Trial Casenote Audit | Interrupted time series | Care plans for 950 service users at 7 time points | Evaluation of the impact of the REFOCUS intervention on care plans |
| Secondary Outcome Evaluation | Single-site cluster randomised controlled trial | 110 black service users | Evaluation of the impact of the REFOCUS intervention |

| | | | |
|---|---|---|---|
| | | | on black service users |
| Outcomes Comparison | Factor analysis | Pooled trial data comprising 11 measures from 397 service users | Quantitative investigation of the relationship between clinical and recovery outcomes |
| **CHAPTER 9 TO 11: KNOWLEDGE MOBILISATION** | | | |
| **Chapter 9: Knowledge transfer** | | | |
| **Chapter 10: Patient and Public Involvement** | | | |
| PPI Impact | Tracking implementation of recommendations | 47 members of advisory committees. | Quantitative evaluation of the impact of PPI |
| **Chapter 11: Synthesis of findings** | | | |

Chapter 2 provides the theory base for the REFOCUS programme. The chapter addresses what recovery means, and investigates influences on how recovery is supported by mental health staff. Chapter 3 develops the REFOCUS intervention, including a model, manual and implementation strategies. Chapter 4 includes a series of sub-studies relating to evaluation, including reviews of measures, evaluation of an existing measure, and the development of three new measures. The REFOCUS intervention is then evaluated in a randomised controlled trial. Chapter 5 reports the protocol for the REFOCUS trial, Chapter 6 the outcome evaluation, and Chapter 7 the process evaluation. Trial data were used in three outcome studies, reported in Chapter 8.

The three closing chapters integrate and make accessible the knowledge products from the REFOCUS programme. Chapter 9 outlines the dissemination methods used to inform the public, healthcare practitioner and scientific audiences about the study. Chapter 10 addresses the question of how lived experience can be productively used in research. Finally, Chapter 11 synthesises the overall findings from the REFOCUS programme, discusses their relevance to recovery practice and policy, and identifies directions for future research.

Some data were used in more than one sub-study. Data from 92 service users were collected for Dataset 1 used in the QPR Validation sub-study, the psychometric evaluation component of the INSPIRE Development (sub-study) and the feasibility component of the IOM Development sub-study. Data from 20 service users were collected for the pilot component of the INSPIRE Development sub-study and the pilot component of the IOM Development sub-study were collected together. Finally, data collected from 403 service users for the REFOCUS trial were also used in the QPR Validation sub-study (Dataset 2), the evaluation in a trial component of the IOM Development sub-study, and the Secondary Outcome Evaluation sub-study. The Staff Process Evaluation sub-study (52 staff) and the Service User Process Evaluation sub-study (74 service users) collected new data from existing participants in the REFOCUS trial.

A note on language. The term ‘service user’ is used to describe people who are using mental health services, with the exception of when specific terms (e.g. ‘patient-rated’, ‘in-patient care’) are more common. The term ‘carer’ is used to describe family and friends who provide informal support to service users. We recognise that both these terms are contested. We use the terms ‘staff’ and ‘worker interchangeably to describe anyone employed in mental health teams to provide care, and the term ‘manager’ or ‘team leader’ to mean someone who manages staff in a mental health team. Finally, the report deliberately uses person-first language, using terms such as ‘person with psychosis’ or ‘person with a diagnosis of schizophrenia’ in preference to ‘psychotic’ or ‘schizophrenic’.

Ethical approval was obtained for all sub-studies involving contact with service users. Approval for the REFOCUS trial came from East London Research Ethics Committee (REC) 3 (reference 11/LO/0083) on 22.2.11, and for all other sub-studies came from South London REC Office (2) (reference 10/H0807/4) on 28.1.10. Local R&D approval was obtained for all participating sites. The protocol for the systematic review in the Staff Perspectives sub-study was registered in advance of undertaking the review (PROSPERO 2013:CRD42013005942). Other systematic reviews were started before the PROSPERO registration process became available. The REFOCUS trial protocol was published[7] and registered (ISRCTN02507940) in advance of undertaking the trial. The funder had no role in study design, data collection, data analysis, data interpretation, the writing of this report, or the decision to submit any resulting paper for publication.

## Chapter 2: Define the problem

This chapter outlines the problem under study. The Conceptual Framework sub-study developed and validated a conceptualisation of personal recovery, which informed the intervention (Chapter 3) and evaluation strategy (Chapter 4). The Recovery Practice Framework sub-study turns to what mental health services can do to support recovery, and the resulting framework informed the focus of the REFOCUS intervention and the design of the INSPIRE measure. To understand the national picture, the National Survey sub-study surveyed experience of receiving and giving recovery support in six NHS Trusts across England. Finally, the Staff Perceptions sub-study developed a grounded theory of staff experiences in supporting recovery, and then contextualised this theory through a systematic review.

### Conceptual Framework sub-study

Adapted with permission from the published report of this study[8].

### Introduction

A theory-based and empirically defensible understanding of personal recovery is needed as a basis for the REFOCUS programme. More broadly, comprehensive reviews of the recovery literature have concluded that there is a need for conceptual clarity on recovery[9,10]. Current approaches to understanding personal recovery are primarily based on qualitative research[11] or consensus methods[12]. No systematic review and synthesis of personal recovery in mental illness has been undertaken.

The aim of this sub-study was to develop and validate a conceptual framework for personal recovery, in order to provide an empirical basis for future recovery-oriented research and practice. A conceptual framework is defined as "*a network, or a plane, of interlinked concepts that together provide a comprehensive understanding of a phenomenon or phenomena*"[13].

The three objectives were:

a) To develop a new conceptual framework for recovery
b) To consider the international applicability of the conceptual framework for recovery
c) To investigate the applicability of the conceptual framework to current mental health services users.

Objective a) was met through a systematic review using a modified narrative synthesis of the available literature on personal recovery. Objective b) addresses the concern that recovery is an ethnocentric, Anglophone concept, and was met by updating and modifying the systematic review of conceptualisations of recovery and analysing these in relation to their country of origin. Objective c) addresses the concern that recovery conceptualisations are based on atypical ex-patients, and was met by a qualitative study involving current mental health service users. Each of these three studies will now be presented

### Objective a) A new conceptual framework for recovery

### Methods

*Eligibility criteria*

The review sought to identify papers that explicitly described or developed a conceptualisation of personal recovery from mental illness. A conceptualisation of recovery was defined as either a visual or narrative model of recovery, or themes of recovery, which emerged from a synthesis of secondary data or an analysis of primary data. Inclusion criteria for studies were: (i) contains a conceptualisation of personal recovery from which a succinct summary could be extracted; (ii) presented an original model or framework for recovery; (iii) was based on either secondary research synthesising the available literature or primary research involving quantitative or qualitative data based on at least three participants; (iv) was available in printed or downloadable form; (v) was available in English. Exclusion criteria were: (a) studies solely focussing upon clinical recovery[14] (*i.e.* using a predefined and invariant 'getting back to normal' definition of recovery through symptom remission and restoration of functioning); (b) studies involving modelling of predictors of clinical recovery; (c) studies defining remission criteria or recovery from substance misuse, addiction or eating disorders; and (d) dissertations and doctoral theses (due to article availability).

### Search strategy and data sources

Three search strategies were used to identify relevant studies: electronic database searching, hand searching and web based searching.

1. Twelve bibliographic databases were initially searched using three different interfaces: Allied and Complementary Medicine Database (AMED); British Nursing index; Excerpta Medica dataBASE (EMBASE); MEDLINE; PsycINFO; Social Science Policy (accessed via OVID SP); Cumulative Index to Nursing & Allied Health Literature (CINAHL); International Bibliography of Social Science (IBSS) (accessed via EBSCOhost and Applied Social Sciences index and Abstracts (ASSIA)); British Humanities Index; Sociological abstracts; and Social Services abstracts (accessed via CSA Illumina). All databases were searched from inception to September 2009 using the following terms identified from the title, abstract, key words or medical subject headings: ( 'mental health' OR 'mental illness$' OR 'mental disorder' OR mental disease' OR 'mental problem') AND 'recover$' AND ('theor$', OR 'framework', OR 'model', OR 'dimension', OR 'paradigm' OR 'concept$'). The search was adapted for the individual databases and interfaces as needed. For example, CSA Illumina only allows the combination of three 'units' each made up of three search terms at any one time e.g. ('mental health' OR 'mental illness*' OR 'mental disorder') AND 'recover*' AND ('theor$' OR 'framework' OR 'concept'). As a sensitivity check, ten papers were identified by the

research team as highly influential, based on number of times cited and credibility of the authors (included papers 3, 9, 10, 19, 29, 34, 35, 40, 68 and 75 in Online Data Supplement 1). These papers were assessed for additional terms, subject headings and key words, with the aim of identifying relevant papers not retrieved using the original search strategy. This led to the use of the following additional search terms: (‘psychol$ health’ OR ‘psychol$ illness$’ OR ‘psychol$ disorder’ OR psychol$ problem’ OR ‘psychiatr$ health’, OR psychiatr$ illness$’ OR ‘psychiatr$ disorder’ OR ‘psychiatr$ problem’) AND ‘recover$’ AND (‘theme$’ OR ‘stages’ OR ‘processes’). Duplicate articles were removed within the original database interfaces using Reference Manager Software Version 11.

2. The table of contents of journals which published key articles (Psychiatric Rehabilitation Journal, British Journal of Psychiatry and American Journal of Psychiatry) and recent literature reviews of recovery were hand-searched.
3. Web-based resources were identified by internet searches using Google and Google Scholar and through searching specific recovery-orientated websites (Scottish Recovery Network: www.scottishrecovery.net; Boston University Repository of Recovery Resources: www.bu.edu/cpr/repository/index.html; Recovery Devon: www.recoverydevon.co.uk; and Social Perspectives Network: www.spn.org.uk).

*Data Extraction and Quality Assessment*

One rater extracted data and assessed the eligibility criteria for all the retrieved papers with a random sub-sample of 88 papers being independently rated by a second rater. Any disagreements between raters were resolved by a third rater. The acceptable concordance was predefined as agreement on at least 90% of ratings. A concordance of 91% agreement was achieved. Data were extracted and tabulated for all papers rated as eligible for the review.

Included qualitative papers were initially quality assessed by three raters (rating 1) using the RATS qualitative research review guidelines[15]. The RATS scale comprises 25 questions concerning the relevance of the study question, appropriateness of qualitative method, transparency of procedures, and soundness of interpretive approach. In order to make judgements about quality of papers, we dichotomised each question to yes (1 point) or no (0 points), giving a scale ranging from 0 (poor quality) to 25 (high quality). A random sub-sample of 10 qualitative studies were independently rated using the RATS guidelines by a second rater (rating 2). The mean score from rating 1 was 14.8 and from rating 2 was 15.1, with a mean difference in ratings of 0.3 indicating acceptable concordance.

The Effective Public Health Practice Project (EPHPP)[16] quality assessment tool for quantitative studies was used by two rates to independently rate the quantitative studies.

### *Analysis*

The conceptual framework was developed using a modified narrative synthesis approach[17]. The three stages of the narrative synthesis comprised: 1) Developing a preliminary synthesis; 2) Exploring relationships within and between studies; and 3) Assessing the robustness of the synthesis. For clarity, the development of the conceptual framework (Stages 1 and 3) is presented in the Results before the sub-group comparison (Stage 2).

### *Stage 1: Developing a preliminary synthesis*

A preliminary synthesis was developed using tabulation, translating data through thematic analysis of good quality primary data, and vote counting of emergent themes. For each included paper, the following data were extracted and tabulated: type of paper, methodological approach, participant information and inclusion criteria, study location, and summary of main study findings. An initial coding framework was developed and used to thematically analyse a sub-sample of qualitative research studies with the highest RATS quality rating (*i.e.* RATS score of 15 or above), using NVivo QSR International qualitative analysis software (Version 8). The main over-arching themes and related sub-themes occurring across the tabulated data were identified, using inductive, open coding techniques. Additional codes were created by all analysts where needed and these new codes were regularly merged with the NVivo master copy and then this copy was shared with other analysts, so all new codes were applied to the entire sub-sample.

Finally, once the themes had been created, vote counting was used to identify the frequency with which themes appeared in all of the 97 included papers. The vote count for each category comprised the number of papers mentioning either the category itself or a subordinate category. On completion of the thematic analysis and vote counting, the draft conceptual framework was discussed and refined by all authors. Some new categories were created, and others were subsumed within existing categories, given less prominence or deleted. This process produced the preliminary conceptual framework.

*Stage 2: Exploring relationships within and between studies*

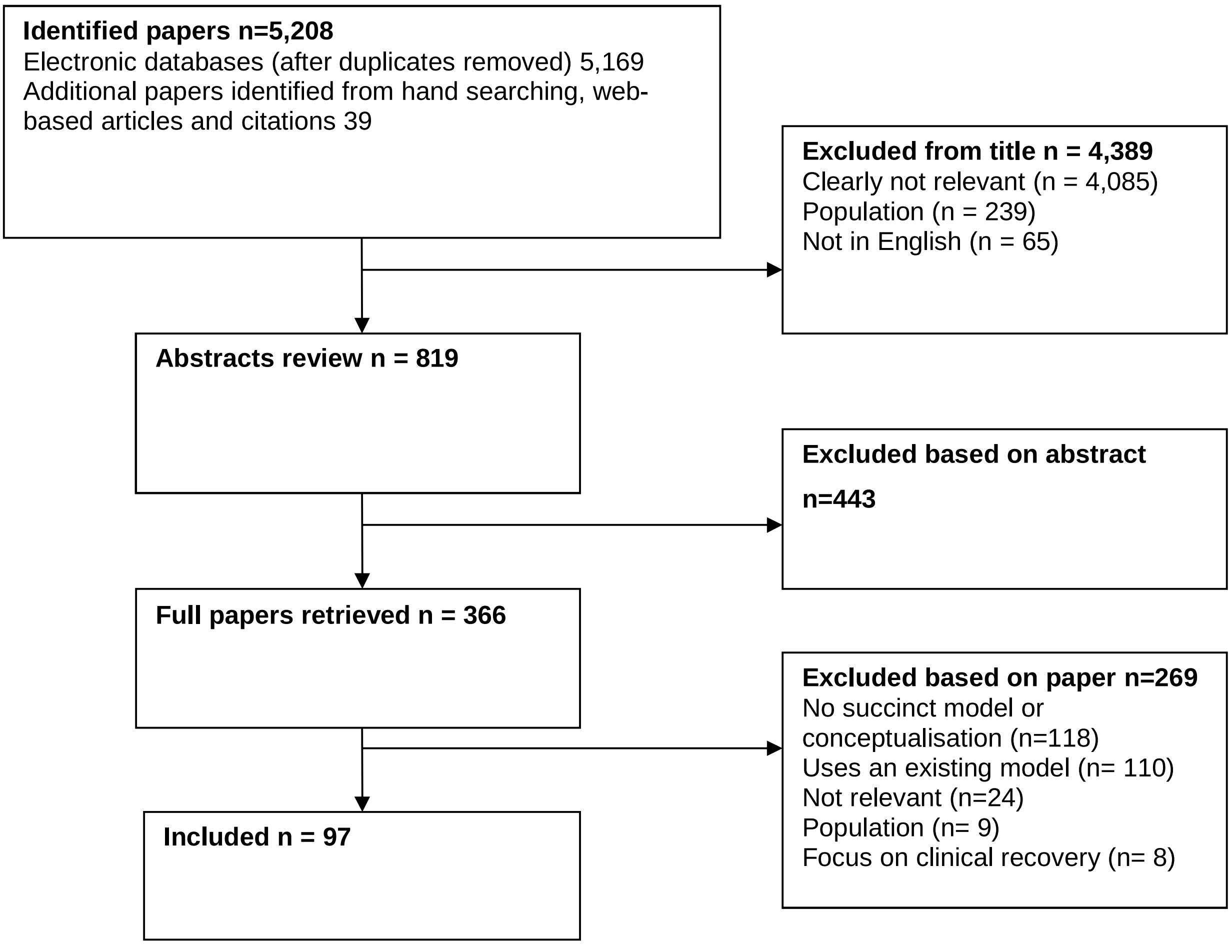
Papers from the full review were identified which reported data from people from Black and Minority Ethnic (BME) backgrounds. These papers were thematically analysed separately, and the emergent themes compared to the preliminary conceptual framework. The thematic analysis utilised a more fine-grained approach, in which a second analyst went through the papers in a detailed and line-by-line manner. The aim of the sub-group analysis was to specifically identify any additional themes as well as any difference in emphasis placed on areas of the preliminary framework. The aim was to identify areas of different emphasis in this sub-group of studies, rather than being a validity check.

*Stage 3: Assessing robustness of the synthesis*

Two approaches were used to assess the robustness of the synthesis. First, qualitative studies which were rated as moderate quality on the RATS scale (*i.e.* RATS score of 14) were thematically analysed until category saturation was achieved. The resulting themes were then compared with the preliminary conceptual framework developed in Stages 1 and 2. Second, the preliminary conceptual framework was sent to an expert consultation panel. The panel comprised 54 advisory committee members of the REFOCUS Programme with academic, clinical or personal expertise about recovery. They were asked to comment on the positioning of concepts within different hierarchical levels of the conceptual framework, identify any important areas of recovery which they felt had been omitted and make any general observations. This is an example of PPI, discussed further in Chapter 10. The preliminary conceptual framework was modified in response to these comments, to produce the final conceptual framework.

## Results

**Figure 1 Conceptual Framework sub-study: flow chart**



The 97 papers comprised qualitative studies (n=37), narrative literature reviews (n=20), book chapters (n=7), consultation documents reporting the use of consensus methods (n=5), opinion pieces or editorials (n=5), quantitative studies (n=2), combining of a narrative literature review with personal opinion or where there is insufficient information on method for a judgement to be made (n=11), and elaborations of other identified papers (n=10). In summary, 87 distinct studies were identified. The ten elaborating papers were included in the thematic analysis but not the vote counting.

The 97 papers described studies conducted in 13 countries, including the United States of America (n=50), United Kingdom (n=20), Australia (n=8) and Canada (n=6). Participants were recruited from a range of settings including community mental health teams and facilities, self-help groups, consumer-operated mental health services and supported housing facilities. The majority of studies used inclusion criteria that covered any diagnosis of severe mental illness. A few studies only included participants who had been diagnosed with a specific mental illness (e.g. schizophrenia, depression). The sample sizes in qualitative data papers ranged from 4 to 90 participants, with a mean sample size of 27. The sample sizes in the two quantitative papers were 19 (pilot study of 15 service users and 4 case managers using a recovery interventions questionnaire[18]) and 1,076 (representative survey of people with schizophrenia[19]). The former was a pilot study of 15 service users with experience of psychosis and 4 case managers using a Recovery Interventions Questionnaire, carried out in Australia. The latter study analysed data from two sources, the Schizophrenia Patient Outcomes Research Team (PORT) client survey, which examined usual care in a random sample of people with schizophrenia in two US states and an extension to this survey which provided a comparison group.

There were various approaches to determining the stage of recovery of participants. Most studies rated stage of recovery using criteria such as: i) the person defined themselves as ‘being in recovery’; ii) not hospitalised during the previous 12 months, iii) relatively well and symptom free; iv) providing peer support to others; or v) working or living in semi-independent settings. Only a few studies specifically used professional opinion - clinical judgement or scores on clinical assessments - about whether people were recovered.

The mean RATS score for the 36 qualitative studies was 14.9 (range 8 to 20). One qualitative study was not rated using the RATS guidelines because there was insufficient information on methodology within this paper. A RATS score of

15 or above, indicating high quality, was obtained by 16 papers and used to develop a preliminary synthesis. A RATS score of 14, indicating moderate quality, was obtained by five papers. Independent ratings by two reviewers of the two quantitative papers rated both as moderate. Given this quality assessment, no greater weight was put on the quantitative studies in developing the category structure.

### *Conceptual framework for personal recovery*

A preliminary conceptual framework was developed, which comprised five super-ordinate categories: Values of recovery, Beliefs about recovery, Recovery-promoting attitudes of staff, Constituent processes of recovery, and Stages of recovery.

The robustness of the synthesis underpinning the preliminary conceptual framework was assessed in two steps; by re-analysing a sub-sample of qualitative studies and through expert consultation.

### *Sub-sample re-analysis*

In addition to the higher quality qualitative studies analysed in the preliminary synthesis stage, an additional five moderate quality (RATS score of 14) qualitative studies were analysed, which confirmed that category saturation had been achieved, indicating that the categories are robust.

### *Expert consultation*

A response was received from 23 (43%) of the 54 consulted experts. Responses were themed under four headings:

- *Conceptual* – dangers of reductionism, separating processes from stages, confusing critical impetus for behaviours with actual behaviour, limitations of stage models;
- *Structural* – complete omissions, lack or over-emphasis upon specific areas of recovery;

- *Language* – too technical;
- *Bias* – potential geographical bias.

In response to this consultation, the preliminary conceptual framework was simplified, so the final conceptual framework has three rather than five super-ordinate categories. Some sub-categories were re-positioned within Recovery Processes, and some category headings changed. Some responses identified areas of omission, such as the role of past trauma, hurt, and physical health in recovery. However, no alteration was made to the conceptual framework as these did not emerge from the thematic analysis. Other points around the strengths and limitations of the framework are addressed in the Discussion. Overall, the expert consultation process provided a validity check on the content of the conceptual framework, whilst we were careful to not to make radical changes which would have been unjustified, given the weight of evidence provided from preliminary analysis of the included papers.

The final conceptual framework comprises three inter-linked, super-ordinate categories: Characteristics of the Recovery Journey; Recovery Processes; and Recovery Stages.

Characteristics of the Recovery Journey were identified in all 87 studies, and vote-counting was used to indicate their frequency, shown in Table 2.

**Table 2 Conceptual Framework sub-study: characteristics of the recovery journey (n=87)**

| **Characteristic** | **N (%) identifying the characteristic** |
|---|---|
| Recovery is an active process | 44 (50%) |
| Individual and unique process | 25 (29%) |
| Non-linear process | 21 (24%) |
| Recovery as a journey | 17 (20%) |

| | |
|---|---|
| Recovery as stages or phases | 15 (17%) |
| Recovery as a struggle | 14 (16%) |
| Multi-dimensional process | 13 (15%) |
| Recovery is a gradual process | 13 (15%) |
| Recovery as a life-changing experience | 11 (13%) |
| Recovery without cure | 9 (10%) |
| Recovery is aided by supportive and healing environment | 6 (7%) |
| Recovery can occur without professional intervention | 6 (7%) |
| Trial and error process | 6 (7%) |

The two highest category levels of the identified Recovery Processes, are shown in Table 3.

**Table 3 Conceptual Framework sub-study: recovery processes (n=87)**

| **Recovery Process** | **N (%) identifying the process** |
|---|---|
| **Category 1: Connectedness** | **75 (86%)** |
| Peer support and support groups | 39 (45%) |
| Relationships | 33 (38%) |
| Support from others | 53 (61%) |
| Being part of the community | 35 (40%) |
| **Category 2: Hope and optimism about the future** | **69 (79%)** |
| Belief in possibility of recovery | 30 (34%) |
| Motivation to change | 15 (17%) |
| Hope inspiring relationships | 12 (14%) |
| Positive thinking and valuing success | 10 (11%) |
| Having dreams and aspirations | 7 (8%) |
| **Category 3: Identity** | **65 (75%)** |
| Dimensions of identity | 8 (9%) |

| | |
|---|---|
| Rebuilding/redefining positive sense of identity | 57 (66%) |
| Over-coming stigma | 40 (46%) |
| **Category 4: Meaning in life** | **59 (66%)** |
| Meaning of mental illness experiences | 30 (34%) |
| Spirituality | 6 (41%) |
| Quality of life | 57 (65%) |
| Meaningful life and social roles | 40 (46%) |
| Meaningful life and social goals | 15 (17%) |
| Rebuilding life | 19 (22%) |
| **Category 5: Empowerment** | **79 (91%)** |
| Personal responsibility | 79 (91%) |
| Control over life | 78 (90%) |
| Focussing upon strengths | 14 (16%) |

The full description of Recovery Processes categories and the vote counting results is shown in Appendix 3.

Within the CHIME framework, connectedness related not only to the connections, relationships and social support individuals have with other people, but also included connections to the wider community and to society as a whole. Different types of support were therefore incorporated within the connectedness category, including peer support, support from professionals, and support from the community, family and friends. Hope was defined as vital to the process of recovery: people needed to have hope and a belief in their own recovery, but also needed others to believe in them. Hope also included the belief that things would get better, which often provided the motivation for change. Part of the process of overcoming mental illness, involved the individual's identity. In particular, redefining and rebuilding a positive sense of identity were identified as key recovery processes. Within the framework, meaning in life was a broad category, including many themes related to finding meaning in life and also meaning associated with the mental illness experience. Sub-categories described different ways individuals could find meaning, including through social roles, goals, employment and meaningful activities. Finally, the CHIME framework included empowerment, which related both to a sense of empowerment within mental health services - such as having control over treatment and having personal responsibility - and also included becoming an empowered member of society.

Fifteen studies developed Recovery Stage models. The studies were organised using the Transtheoretical Model of Change[20], as shown below.

**Table 4 Conceptual Framework sub-study: recovery stage models mapped onto transtheoretical model of change**

| Study Number | Precontemplation | Contemplation | Preparation | Action | Maintenance & growth |
|---|---|---|---|---|---|
| 32 | | Novitiate recovery: Struggling with disability | | Semi-recovery – living with disability | Full recovery – living beyond disability |
| 73 | Stuck | Accepting help | Believing | Learning | Self-reliant |
| 3 | Descent into hell | Igniting a spark of hope | Developing insight / Activating instinct to fight back | Discovering keys to well-being | Maintaining equilibrium between internal and external forces |
| 44 | Demoralisation | | Developing & establishing independence | | Efforts towards community integration |
| 36 | Occupational dependence | | Supported occupational performance | Active engagement in meaningful occupations | Successful occupational performance |

| | | | | | |
|---|---|---|---|---|---|
| 14 | Dependent / unaware | Dependent / aware | | Independent / aware | Interdependent / aware |
| 29 | Moratorium | Awareness | Preparation | Rebuilding | Growth |
| 78 | | Glimpses of recovery | Turning points | Road to recovery | |
| 61 | | Reawakening of hope after despair | Not viewing self as primarily person with psychiatric disorder | Moving from withdrawal to engagement | Active coping rather than passive adjustment |
| 40 | Overwhelmed by the disability | | Struggling with the disability | Living with the disability | Living beyond the disability |
| 35 | Initiating recovery | | | Regaining what was lost/moving forward | Improving quality of life |
| 59 | Crisis (recuperation) | | Decision (rebuilding independence) | Awakening (building healthy interdependence) | |
| 43 | | Turning point | Determination | | Self-esteem |

## Discussion

This is the first systematic review and narrative synthesis of personal recovery. A conceptual framework was developed using a narrative synthesis which identified three super-ordinate categories: Characteristics of the Recovery Journey, Recovery Processes and Recovery Stages. For each super-ordinate category, key dimensions were synthesised. The Recovery Processes, which have the most proximal relevance to clinical research and practice, can be summarised using the acronym CHIME. The robustness of the category structure was enhanced by the systematic nature of the review, the quality assessment of included studies, the category saturation reached in the analysis, and the content validity of the expert consultation. Heterogeneity between studies was explored descriptively. A sub-group comparison between the experiences of recovery from the perspective of BME individuals identified similar themes, with a greater emphasis on Spirituality and, Stigma, and two additional themes: Culturally specific factors, and Collectivist notions of recovery.

### *Implications for research and practice*

Key knowledge gaps relating to recovery are the need for clarity about the underpinning philosophy of recovery[21], better understanding of the stages and processes of recovery[9], and valid measurement tools[4]. This study can inform each of these gaps.

Recovery has been conceptualised as a vision, a philosophy, a process, an attitude, a life orientation, an outcome and a set of outcomes[9]. This has led to the concern that "*its scope can make a cow-catcher on the front of a road train look discriminating*"[22]. An empirically-based conceptual framework can bring some order to this potential chaos. Characteristics of the Recovery Journey provide conceptual clarity about the philosophy. Recovery Processes can be understood as measurable dimensions of change which typically occur during recovery, and provide a taxonomy of recovery outcomes[23]. Finally, Recovery Stages provide a framework for guiding stage-specific clinical interventions and evaluation strategies.

The framework contributes to understanding about stages and processes of recovery in two ways. First, it allows available evidence to be more easily identified. A recovery orientation has overlap with the literature on well-being[24], positive psychology[25] and self-management[26], and systematic reviewing is hampered by the absence of relevant (Medical Sub-Headings) MeSH headings relating to recovery concepts. The coding framework provides key-words for use when undertaking secondary research, and the identification of related terms provides a taxonomy which will be useable in reviews.

Second, the framework provides a structure around which research and clinical efforts can be oriented. The relative contribution of each Recovery Process, investigating interventions which can support these processes and the synchrony between recovery processes and stages are all testable research questions. For clinical practice, the CHIME recovery processes support reflective practice. If the goal of mental health professionals is to support recovery then one possible way forward is for each working practice to be evaluated in relation to its impact on these processes. This has the potential to contribute to current debates about recovery and, for example, assertive outreach[27], risk[28] and community psychiatry[29].

Finally, the conceptual framework can contribute to the development of measures of personal recovery. Compendia of existing measures have been developed[30,31], showing that the conceptual basis of measures is diverse. The conceptual framework provides a foundation for developing standardised recovery measures, and is the basis for a new measure currently being developed by the authors to evaluate the contribution of mental health services to an individual’s recovery. The challenge will then be to incorporate a focus on recovery outcomes, and associated concepts such as well-being[25]**,** into routine clinical practice[32]**.**

*Limitations*

The study has three methodological and one conceptual limitation. The first methodological limitation is that the narrative synthesis approach was modified, and could have been widened. For example, the exploration in Stage 2 of relationships between studies could have considered the sub-group of studies which had higher levels of service user involvement in their design, but it proved impossible to reliably rate identified studies in this dimension. The second technical limitation is that the emergent categories were only one way of grouping the findings, and the categories changed as a result of expert consultation. In particular, the three super-ordinate categories are not separate, since processes clearly occur within the identified stages, and the characteristics of recovery describe an overall movement through stages of recovery. Our categorical separation brings structure, but a replication study may not arrive at the same overall thematic structure. The final technical limitation is that analysis synthesised the interpretation in the paper of the primary data in each paper, rather than considering the primary data directly. Future research could compare papers generated by different stakeholder groups, such as service user-researchers, clinical researchers, and policy-makers.

The conceptual limitation is that this review, whilst synthesising the current literature on personal recovery, should not be seen as definitive. A key scientific challenge is that the philosophy of recovery gives primacy to individual experience and meaning (‘idiographic’ knowledge), whereas mental health systems and current dominant scientific paradigms give prominence to group-level aggregated data (‘nomothetic’ knowledge)[14]. The practical impact is that current recovery research is primarily focussed at the bottom of the hierarchy of evidence[33]. This was our finding, with qualitative, case study and expert opinion methodologies dominating. This has two implications. First, our review approach, which focussed on academic literature, will have missed most of the service user authored literature. Future reviews should therefore include more rigorous approaches to collating grey literature, using databases such as OpenSIGLE (System for Information on Grey Literature in Europe). Second, a motivator for the current study was to provide evidence of the form viewed as high quality within the current scientific paradigm, but several of our expert consultants highlighted the dangers of closing down discourse. Since recovery is individual, idiosyncratic and complex, this review is not intended to be a rigid model of what recovery 'is'. Rather, it is better understood as a resource to inform future research and clinical practice.

*Future research*

This systematic review and narrative synthesis has highlighted the dominance of recovery literature emanating from USA. Culturally, the USA neglects character strengths such as patience and tolerance[34], and favours individualistic over collectivist understandings of identity. Although there were very few studies which looked at recovery experiences of individuals from BME backgrounds, the sub-sample of BME studies indicated that there are important differences in emphasis. There is a need for research to be conducted using a more diverse samples of people from different ethnic and cultural backgrounds, at differing stages of recovery and experiencing different types of mental illness.

The complexity of personal recovery requires a range of theoretical inquiry positions. This review focussed on research into first-person accounts of recovery, where individual meanings of recovery have dominated. This has led to a framework which may under-emphasise the importance of the wider socio-environmental context, including important aspects such as stigma and discrimination. Viewing recovery within an ecological framework, as suggested by Onken and colleague[33], encompasses an individual's life context (characteristics of the individual, such as hope and identity) as well as environmental factors (such as opportunities for employment and community integration) and the interaction between the two (such as choice). A more complete understanding of recovery requires greater attention to all these levels of understanding, for instance, upon how power is related to characteristics of individuals or groups (e.g. race and culture), how staff and service users interact within different stages of recovery and how these interactions change over time. There is also a need for future research to increase understanding about how subtle micro-processes of recovery are operating, such as how hope is reawakened and sustained.

Supporting Recovery Processes may be the future mental health research priority. The 13 dimensions identified as Characteristics of the Recovery Journey capture much of the experience and complexities of recovery, and further research may not have a high scientific pay-off. Similarly, although the Recovery Stages could be mapped onto the Transtheoretical Model of Change[20], there was little consensus about the number of recovery phases. It may therefore be more helpful to undertake evaluative research addressing specific service-level questions (such as whether people using a service are making recovery gains over time[35] or in different service settings[36]), rather than further studies seeking conceptual clarity. Overall, the emergent priority is the development and evaluation of interventions to support the five CHIME Recovery Processes. The subordinate categories point to the need for a greater emphasis on assessment of strengths and support for self-narrative development, a new construction of the contribution of the mental health system being as much about developing inclusive communities and enabling access to peer support as providing treatments, and clinical interaction styles which promote empowerment and self-management. The CHIME categories are potential clinical end-points for interventions, in contrast with the current dominance of clinical recovery end-points such as symptomatology or hospitalisation rates. They also provide a framework for empirical investigation of the relationship between recovery outcomes, using methodologies developed in relation to clinical outcomes[37]. This area of enquiry is currently small[38] but an important priority if potential trade-offs between desirable outcomes are to be identified[39].

Orienting mental health services towards recovery will involve system transformation[40]. The research challenge is to develop an evidence base which simultaneously helps mental health professionals to support recovery and respects the understanding that recovery is a unique and individual experience rather than something the mental health system does to a person. This conceptual framework for personal recovery, which has been developed through a systematic review and narrative synthesis, provides a useful starting point for meeting this challenge.

### Objective b) International applicability

Adapted with permission from the published report of this study[41]

### Introduction

A policy orientation towards personal recovery is present in some countries, and absent in others[42]. Broadly, a recovery approach is enshrined in the policy of most English-speaking countries, somewhat present in German-speaking Europe, and not present in Central and Northern Europe, Asia and Africa. This is reflected in a recent review of recovery developments internationally, which features papers from Australia, Austria, Canada, England, Hong Kong, Israel, New Zealand, Scotland and the USA[43].

This uneven policy endorsement may be due to a range of reasons. These include the absence of any mental health-specific policy in some countries; an opposition to a recovery orientation in principle; and an absence of recovery research relevant to the specific country. The aim of this study was to provide an evidence base to understand better the global distribution of pro-recovery policy, by systematically reviewing conceptualisations of recovery and analysing these in relation to their country of origin. The objectives were to validate the recovery processes identified in the conceptual framework for recovery, and then to use this coding framework to characterise by country the distribution, scientific foundations and emphasis in recovery conceptualisations.

## Methods

This systematic review updated and modified the systematic review and narrative synthesis used to develop the conceptual framework for recovery[8]. The original review collated evidence available until September 2009, and did not report findings by country. Data and the coding framework from the original review were used in this review. Additionally, the original review was updated by including studies published from September 2009 to August 2011, and the synthesis was modified by analysing studies by country of origin.

### *Eligibility criteria*

The same inclusion and exclusion criteria were used as in the original review.

### *Search strategy and data sources*

The same search strategy and three data sources were used as in the original systematic review, with date limits changed to inception to August 2011, and duplicate articles removed using Endnote X4.

### *Data Extraction and Quality Assessment*

For new studies, two raters extracted data and assessed eligibility criteria, with disagreements resolved by a third rater. Acceptable concordance was predefined as agreement on at least 90% of ratings, and concordance of 92% was achieved. For each included paper, the following data were extracted and tabulated: type of paper, methodological approach, participant information and inclusion criteria, study location, and summary of main study findings.

The approach to quality rating for qualitative and quantitative designs was the same as used in the original systematic review. New qualitative papers were quality assessed independently using RATS by two raters, achieving a rating concordance of 93.2%, with disagreements between raters resolved by a third rater. New quantitative studies were quality assessed using the Effective Public Health Practice Project quality assessment tool, with independent ratings made by two reviewers achieving 100% concordance. Additionally, systematic reviews were quality assessed using the National Institute for Health and Clinical Excellence (NICE) guidelines manual[44].

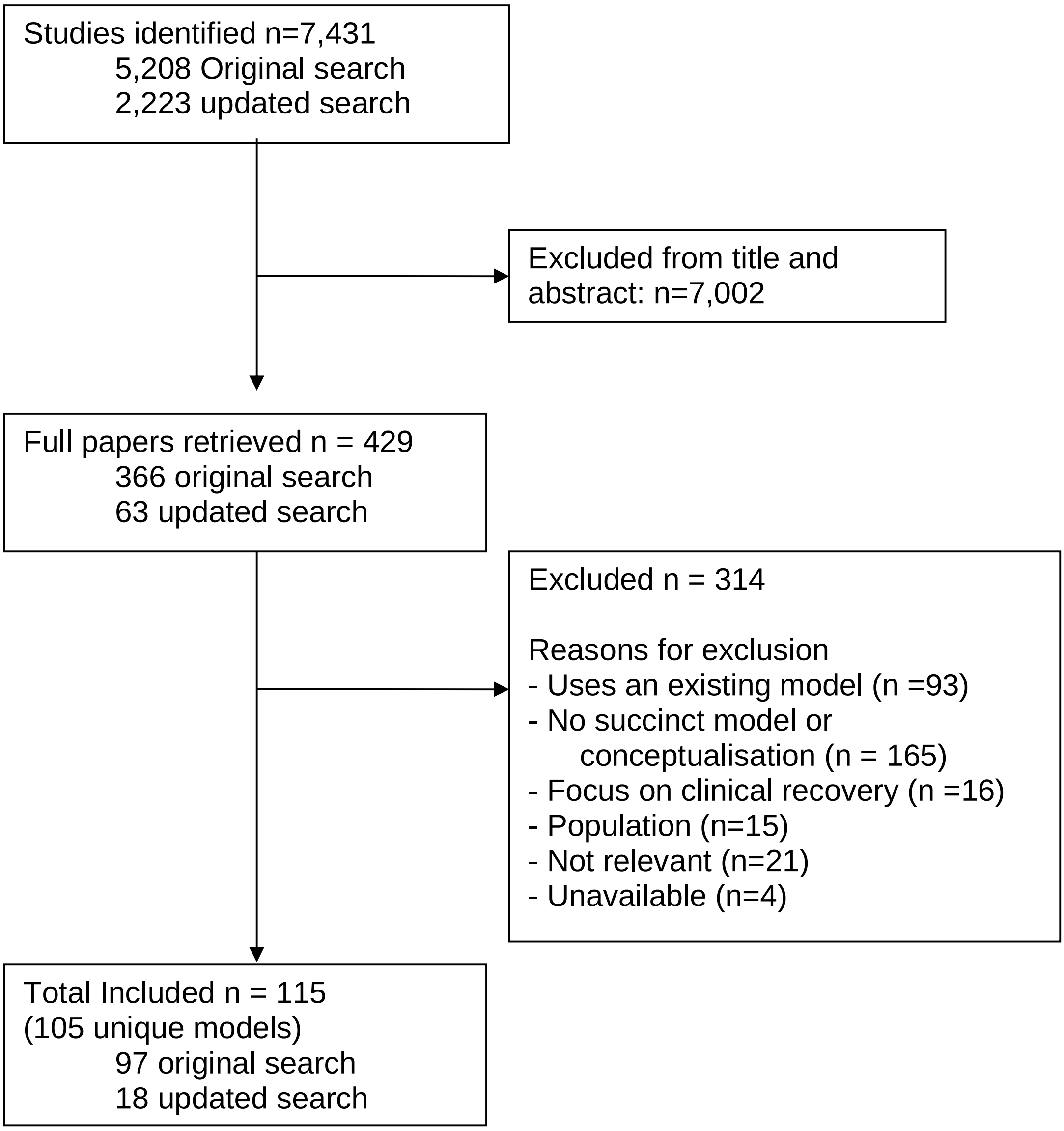
*Analysis*

Data from papers identified in the updated search were deductively coded using the first and second order themes (shown in Table 6) as the coding framework. Once the themes were coded, vote counting was carried out to calculate the frequency of each of the themes. The aim of the vote counting process was to quantify the number of papers in which the themes occurred. This meant that for each paper, a category, if present, was only counted once, regardless of the number of times it appeared in the text. One rater conducted the vote counting for all papers identified in the updated search. To improve the reliability, double vote counting was carried out by another researcher, with disagreements between researchers resolved by discussion. A concordance of 82% was achieved. All papers from both the original and updated search were then grouped by the country in which the studies had taken place, based on the study description and (when not stated) the author affiliations. The frequency of each theme per country was then calculated.

## Results

A total of 115 papers describing 105 conceptualisations of recovery were identified. The flow diagram is shown in Figure 2.

**Figure 2 Conceptual framework sub-study: flow diagram for international review**



The scientific foundations for the 105 conceptualisations of recovery are shown in Table 5, organised by the country of origin of the study.

### Table 5 Conceptual Framework sub-study: scientific foundation of identified models (n=105)

| | USA | UK | Canada | Australia | Ireland | Norway | Sweden | New Zealand | Taiwan | South Korea | Iceland | Mixed | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| n | *49* | *26* | *8* | *7* | *4* | *3* | *2* | *1* | *1* | *1* | *1* | *2* | *105* |
| **Design** | | | | | | | | | | | | | |
| Systematic review | | 2 | | | | | | | | | | | **2** |
| Narrative review | 14 | 4 | 1 | 3 | 1 | | | | | | | 2 | **25** |
| Quantitative | 1 | | | | | | | | | | | | **1** |
| Qualitative | 24 | 12 | 7 | 1 | 2 | 3 | 2 | 1 | 1 | 1 | 1 | | **55** |
| *Mean RATS score* | *14* | *17* | *18* | *12* | *18* | *15* | *14* | *20* | *15* | *16* | *14* | | |
| Consensus methods | 1 | | | | 1 | | | | | | | | **2** |
| Position paper | 6 | 4 | | 3 | | | | | | | | | **13** |
| Book chapter | 3 | 4 | | | | | | | | | | | **7** |

The quantitative study was rated as moderate quality, and the two systematic reviews were rated as 3/5 and 4/5.

To validate the CHIME categories and sub-categories identified in the original review the coding framework was applied deductively to the papers identified in the updated review. The results are compared in Table 6.

**Table 6 Conceptual Framework sub-study: validation of the deductive coding framework**

| | **Original search** | **Updated search** | **Total** |
|---|---|---|---|
| *Number of conceptualisations* | *87* | *18* | *105* |
| **RECOVERY PROCESS** | | | |
| **Connectedness** *n (%) coded* | **75 (86)** | **17 (94)** | **92 (87)** |
| Peer support and support groups | 39 (45) | 13 (72) | 52 (50) |
| Relationships | 33 (38) | 13 (72) | 46 (44) |
| Support from others | 53 (61) | 13 (72) | 66 (63) |
| Being part of the community | 35 (40) | 3 (17) | 38 (36) |
| **Hope & optimism about the future** | **69 (79)** | **16 (89)** | **85 (81)** |
| Motivation to change | 15 (17) | 14 (78) | 29 (28) |
| Belief in possibility of recovery | 30 (34) | 12 (67) | 42 (40) |
| Positive thinking & valuing success | 10 (11) | 5 (28) | 15 (14) |
| Having dreams and aspirations | 7 (8) | 11 (61) | 18 (17) |
| Hope-inspiring relationships | 12 (14) | 3 (17) | 15 (14) |
| **Identity** | **65 (75)** | **17 (94)** | **82 (78)** |
| Dimensions of identity | 8 (9) | 3 (17) | 11 (10) |
| Rebuilding/redefining positive identity | 57 (66) | 15 (83) | 72 (69) |
| Over-coming stigma | 40 (46) | 17 (94) | 57 (54) |

| | | | |
|---|---|---|---|
| **Meaning in life** | **72 (83)** | **18 (100)** | **90 (86)** |
| Meaning of mental illness experiences | 30 (34) | 16 (89) | 46 (44) |
| Spirituality | 32 (37) | 8 (44) | 44 (42) |
| Quality of Life | 57 (66) | 17 (94) | 74 (70) |
| Meaningful life and social roles | 40 (46) | 3 (17) | 43 (41) |
| Meaningful life and social goals | 15 (17) | 15 (83) | 30 (29) |
| Rebuilding of life | 19 22) | 13 (72) | 32 (30) |
| **Empowerment** | **77 (89)** | **17 (94)** | **96 (91)** |
| Personal responsibility | 77 (89) | 17 (94) | 96 (91) |
| Control over life | 77 (89) | 17 (94) | 95 (90) |
| Focussing upon strengths | 14 (16) | 5 (28) | 19 (18) |

Codings in papers identified in the updated search were at least as frequent for nearly all sub-categories as codings in papers identified in the original search, providing some evidence that the coding framework remains valid in more recent studies.

Codings for all papers were then considered. Papers were grouped by country. Codings in the four papers from individual countries (Iceland, New Zealand, South Korea, Taiwan) spanned all five CHIME categories, apart from the South Korea study which coded Connectedness and Meaning in life only. The distribution of coding categories for the seven countries with more than one paper is shown in Table 7.

## Table 7 Conceptual Framework sub-study: coding for recovery conceptualisations (n=105), organised by country

| | **USA** | **UK** | **Canada** | **Australia** | **Ireland** | **Norway** | **Sweden** | **Total** |
|---|---|---|---|---|---|---|---|---|
| *Number of conceptualisations* | *49* | *26* | *8* | *7* | *4* | *3* | *2* | *105* |
| **RECOVERY PROCESS** | | | | | | | | |
| **Connectedness** *n (%) coded* | **43 (88)** | **22 (85)** | **6 (75)** | **7 (100)** | **3 (75)** | **3 (100)** | **2 (100)** | **92 (87)** |
| Peer support and support groups | 24 (49) | 15 (58) | 3 (38) | 2 (29) | **3 (75)** | 1 (33) | 2 (100) | 52 (50) |
| Relationships | 20 (41) | 14 (54) | 4 (50) | 1 (14) | 1 (25) | 1 (33) | 2 (100) | 46 (44) |
| Support from others | 29 (59) | 17 (65) | 4 (50) | 4 (57) | **3 (75)** | 2 (67) | 2 (100) | 66 (63) |
| Being part of the community | 18 (37) | 11 (42) | 2 (25) | 0 (0) | 2 (50) | 2 (67) | 1 (50) | 38 (36) |
| **Hope & optimism about the future** | **38 (78)** | **23 (88)** | **6 (75)** | **5 (71)** | **4 (100)** | **2 (67)** | **2 (100)** | **85 (81)** |
| Motivation to change | 10 (20) | 8 (31) | 4 (50) | 1 (14) | 2 (50) | 2 (67) | 1 (50) | 29 (28) |
| Belief in possibility of recovery | 21 (43) | 9 (35) | 3 (38) | 2 (29) | 1 (25) | 2 (67) | 2 (100) | 42 (40) |
| Positive thinking & valuing success | 3 (6) | 5 (19) | 5 (63) | 0 (0) | 0 (0) | 1 (33) | 1 (50) | 15 (14) |
| Having dreams and aspirations | 6 (12) | 6 (23) | 2 (25) | 1 (14) | 1 (25) | 1 (33) | 1 (50) | 18 (17) |
| Hope-inspiring relationships | 7 (14) | 5 (19) | 1 (13) | 1 (14) | 0 (0) | 0 (0) | 0 (0) | 15 (14) |
| **Identity** | **41 (83)** | **21 (81)** | **5 (63)** | **4 (57)** | **3 (75)** | **2 (67)** | **2 (100)** | **82 (78)** |
| Dimensions of identity | 2(4) | 8 (31) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 11 (10) |
| Rebuilding/redefining positive identity | 5 (63) | 5 (63) | 5 (63) | 5 (63) | 5 (63) | 2 (67) | 2 (100) | 72 (69) |
| Over-coming stigma | 28 (57) | 15 (58) | 4 (50) | 2 (29) | 2 (50) | 3 (100) | 1 (50) | 57 (54) |
| **Meaning in life** | **39 (80)** | **24 (92)** | **7 (88)** | **7 (100)** | **3 (75)** | **3 (100)** | **2 (100)** | **90 (86)** |
| Meaning of mental illness experiences | 17 (35) | 16 (62) | 5 (63) | 1 (14) | 1 (25) | 2 (67) | 2 (100) | 46 (44) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Spirituality | 18 (37) | 13 (50) | 5 (63) | 2 (29) | 1 (25) | 1 (33) | 1 (50) | 44 (42) |
| Quality of Life | 31 (63) | 23 (88) | 6 (75) | 3 (43) | 2 (50) | 2 (67) | 2 (100) | 74 (70) |
| Meaningful life and social roles | 21 (43) | 10 (38) | 4 (50) | 4 (57) | 1 (25) | 1 (33) | 0 (0) | 43 (41) |
| Meaningful life and social goals | 9 (18) | 10 (38) | 3 (38) | 2 (29) | 2 (50) | 2 (67) | 1 (50) | 30 (29) |
| Rebuilding of life | 13 (27) | 9 (35) | 3 (38) | 0 (0) | 1 (25) | 2 (67) | 1 (50) | 32 (30) |
| **Empowerment** | **44 (90)** | **25 (96)** | **7 (88)** | **6 (86)** | **4 (100)** | **3 (100)** | **2 (100)** | **96 (91)** |
| Personal responsibility | 44 (90) | 25 (96) | 7 (88) | 6 (86) | 4 (100) | 3 (100) | 2 (100) | 96 (91) |
| Control over life | 43 (88) | 25 (96) | 7 (88) | 6 (86) | 4 (100) | 3 (100) | 2 (100) | 95 (90) |
| Focussing upon strengths | 7 (14) | 6 (23) | 2 (25) | 6 (86) | 0 (0) | 1 (33) | 0 (0) | 19 (18) |

At the top level, there was relative high frequency of coding each CHIME category, with some differences for second level categories.

**Discussion**

A substantial majority – 95 (91%) of the 105 identified conceptualisations – were published in English-speaking countries, primarily the USA (47%) and the UK (25%). The scientific foundation was primarily qualitative research (53%), non-systematic literature reviews (24%) and position papers (12%), with very few systematic reviews (2%) and quantitative empirical studies (1%). Both systematic reviews were undertaken in the UK. In relation to emphasis within each country, there was a relatively similar distribution of codings for each of the CHIME top-level categories across the different countries. There were differences in coding of second-level categories.

At the top level of the coding framework, there was no great variation between countries. This suggests that, at least within English-speaking countries, the five CHIME dimensions do capture key aspects of recovery, and can be recommended as the basis for a common understanding.

At the second level of coding, differences emerge. Connectedness sub-categories were most densely coded in the USA and UK, reflecting their focus on community integration and social inclusion respectively. The importance placed on meaning in life was somewhat higher in the UK and Canada. Finally, a marked emphasis on strengths was present in Australia. This relates to two developments being implemented across the country: the Strengths Model[45] and the Collaborative Recovery Model[46], both of which have a strong empirical evidence base. A focus on strengths is for example prominent in a recent framework for recovery-oriented practice published in Victoria, Australia[47].

This shows that published conceptualisations of recovery in English language publications have primarily emerged from the English-speaking world. This mirrors the distribution of pro-recovery policy. Ideas about recovery are becoming visible in non-English countries, though even the translation of the term varies. In Germany, the term is used in untranslated form[48]. In Hong Kong, a popular translation is 復元 (fu yuan) in which yuan (元) denotes the primordial qi (meaning energy), so recovery means "regaining vitality and life force"[49]. An alternative translation is 復原 (fu yuan), or restoration to an original state, and a third is 復圓 (fu yuan) which involves the broader idea of regaining fullness and completeness. Although all three have the same English phonic, they differ in nuance.

Well-developed understandings of recovery and well-being exist in non-Western cultures. For example, the identity of indigenous Australian people is interwoven with the physical world[50]. Spiritual identity is shared with the land, a description of reality which clearly incorporates a concept of identity quite different from Western psychological, sociological and philosophical understandings. Similarly, Native American Indian conceptions of health involve a relational or cyclical world-view, balancing context, mind, body and spirit[51]. Māori and Pacific Islanders in New Zealand also have a cultural identity influenced by Whānau Ora – the diverse families embedded in the culture[52]. The absence of any substantial reference to these conceptualisations in English-language publications reinforces the concerns raised by others about the wider cultural applicability of 'recovery'[53].

The incorporation of recovery ideas into non-English speaking countries needs to be a two-way process: research from culturally more dissimilar countries would help to highlight both embedded social and political assumptions about the nature of recovery, and the individualistic rather than collectivist focus of current models of recovery. Already, some question the focus within recovery on individuality: "*the recovery approach seems to have taken us in an individualising and personalising direction,*" with a danger of "*losing contact with the strength that people gain from each other, and the value of communities*"[54]. (p. 11). Others are concerned about the embedded sociopolitical assumptions: "*I believe that current transnational forms of organizing social relations are both cultures of compliance and cultures of constraint…these global forces reconstruct people's identities so that they are given few social options for agency. There is a trend in the "recovery" movement to, at best, a constraining and, at worst, an oppressive set of social discourses and* *relations…the language of "recovery" needs to be questioned for its congruency with the type of social actor that is required for the successful spread of the global market economy*" (p. 32), leading some within the service user movement to an oppositional stance: "*The 'recovery' movement is dangerous if it stays solely focused on the adjustment of the individual to social forces by 'recovering'.*" (p. 33)[55]. Knowledge and insights from other cultures may address some of these issues, by refining the dominant understanding of recovery.

This study also showed that the scientific foundation of recovery models and frameworks remains primarily qualitative studies and expert opinion. These forms of evidence are relatively low in the evidence-based medicine hierarchy. This points to the need for a more quantitative evidence base[39].

### Objective c) Applicability to current mental health services users

Adapted with permission from the published report of this study[56].

#### Introduction

An important question is whether the conceptual framework for recovery is applicable to people currently using mental health services. This directly addresses the concern about recovery of how relevant it is to current service users, i.e. whether positive accounts of recovery from people who previously but not currently used mental health services are generalisable to clinical populations.

The aim of this study was to explore the validity of the conceptual framework for recovery, using data collected from focus groups conducted with current mental health service users, and to highlight any areas of deviance between the conceptual framework and the themes generated from the focus groups.

#### Methods

Seven focus groups with individuals using community mental health teams (CMHTs) were held at the team bases within three mental health trusts from June to September 2010. We recruited a convenience sample of working age adults (aged 18-65 years), who were currently using (or had used in the previous six months) community-based mental health teams. The topic guide was developed through PPI (discussed in Chapter 10), and covered four questions: What does recovery mean to you? How has your community mental health worker/team helped or supported you in your recovery? What about the ways that your community mental health worker/team doesn't help or support you in your recovery? What could your community mental health worker/team be doing differently to better support your recovery? Deductive and inductive thematic analysis applying a constant comparison approach was used to analyse the data.

**Results**

Forty-eight individuals participated in the seven focus groups. The focus groups were conducted in three NHS trusts in England: 2gether NHS Foundation Trust (n=2); Leicestershire Partnership NHS Trust (n=2) and South London and Maudsley Foundation Trust (n=3). The characteristics of the participants are detailed in Table 8.

**Table 8 Conceptual Framework sub-study: characteristics of focus group participants (n=48)**

| **Characteristics** | **Participants** |
|---|---|
| Gender (n, %): | |
| Female | 20 (58%) |
| Male | 28 (42%) |
| Age (Mean, SD) | 42.1 (10.4) |
| Ethnicity (n, %): | |
| White British | 16 (33%) |
| White Irish | 1 (2%) |
| White Other | 1 (2%) |
| Black/ Black British - African | 11 (23%) |
| Black/ Black British - Caribbean | 9 (19%) |
| Black Other | 1 (2%) |
| Asian / Asian British – Indian | 2 (4%) |
| Asian / Asian British - Pakistani | 1 (2%) |

| | |
|---|---|
| Asian other | 1 (2%) |
| Mixed race | 2 (4%) |
| Other | 4 (8%) |
| Diagnosis (n, %): | |
| Schizophrenia or Schizoaffective disorder | 19 (40%) |
| Bipolar Disorder | 8 (16.5%) |
| Depression | 6 (12.5%) |
| Anxiety | 1 (2%) |
| Other | 2 (4%) |
| Did not want to disclose | 12 (25%) |
| Mental health team type (n, %): | |
| CMHT | 6 (13%) |
| Support and recovery | 15 (31%) |
| Early intervention service | 5 (10%) |
| Assertive outreach | 9 (20%) |
| Forensic | 1 (2%) |
| Rehabilitation | 1 (2%) |
| Continuing care | 5 (10%) |
| Other | 4 (8%) |
| Did not want to disclose | 2 (4%) |
| Time in MH services years (mean, SD) | 11.6 (7.0) |
| NHS Trust (n, %): | |
| SLAM | 27 (56%) |
| 2Gether | 10 (21%) |
| Leicester | 11 (23%) |

## Discussion

The themes generated from the focus groups provided evidence to support the validity of the recovery processes identified in the conceptual framework for recovery. This broad validation indicates that the CHIME framework is a valid and relevant representation of recovery processes for current mental health service users and is therefore a useful theory-based tool within research and clinical practice.

The analysis also suggested three new second or third order categories within the framework. These were i) practical support; ii) issues around diagnosis and medication, and iii) scepticism surrounding recovery. The additional themes highlight the importance of qualitative work and involving the particular stakeholder group or community within the research to ensure that any underpinning theory is a good fit and appropriate to the particular context.

Other differences emerged, at least in emphasis, between the data from the focus groups and the recovery literature analysed for the narrative synthesis. Within the literature it is often assumed that recovery involves becoming a new person and discovering new social roles[57],[58],[59], with a loss of the old self[60]. Indeed, the most widely cited recovery definition talks about the development of new meaning and purpose[61], whereas Whitwell talks about the “myth of recovery" and returning back to the same as before[62]. In contrast to the literature, participants in the present study expressed more mixed views, with some seeing recovery as returning to a pre-illness life. Although this does not suggest a change to the CHIME framework, this difference in emphasis has now been incorporated into the definition of Identity.

Linked to this shift in emphasis, there was also more concern with issues around medication and diagnosis, with correspondingly less emphasis on people’s own agency in confronting challenges and taking control over all aspect of their recovery journeys.

This study demonstrated that an existing conceptual framework for personal recovery is both valid and relevant for use within clinical practice and research. Despite differences in the participants, particularly in the stages of recovery, the five main recovery processes of the conceptual framework remain relevant to current mental health service users. However, the areas of difference highlighted and the subsequent modifications to the framework, suggest that conceptualisations of recovery in the literature are primarily based on the experiences of current or ex-service users who are further along their recovery journeys than many who currently using services. Consequently, some aspects of the earlier stages of recovery, including the need for practical support, have been under-represented in the recovery literature at present. Furthermore, this study highlights the importance of conducting initial qualitative work to ensure the relevance of any existing concepts to the context and individuals under investigation.

## Recovery Practice Framework sub-study

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### Introduction

Having established an understanding of what recovery means, a second important question is how mental health services can support recovery. This is a complex question, likely to be influenced by cultural factors (e.g. dominant explanatory models), the existing healthcare infrastructure, mental health work-force characteristics, etc. We therefore tried to reduce this complexity by reviewing and synthesising current approaches to supporting recovery internationally.

The aims of this study were (1) to synthesise the characteristics of recovery-oriented practice guidance based on international perspectives and (2) to develop a useful overarching recovery practice framework for translating recovery guidance into mental health practice.

### Methods

*Design*

A literature search was conducted to identify recovery-oriented practice guidance. Each document was analysed using inductive thematic analysis, where analytical concepts and perspectives are derived from the data in a deliberate and systematic way[64]. This approach allows exploration of the way that each document described recovery-oriented practice, allows unexpected themes to emerge and does not restrict the investigation to predetermined concepts or prejudging the significance of concepts.

*Procedures*

The literature search sought to identify guidance that explicitly described or developed a conceptualisation of recovery-oriented mental health practice. A conceptualisation of recovery-oriented mental health practice was defined as: recommendations developed as a guide to mental health services and mental health practitioners on supporting the recovery of people living with mental illness, guidance for users of mental health services to support self-advocacy of best practice and high quality service delivery, an analysis of primary data, or a synthesis of secondary data. In addition, the guidance needed to be available in printed or downloadable form and written in English.

Three data sources were used to conduct the literature search. First, experts were asked to identify influential international policy and practice guidance. Second, an internet search via Google scholar using the key terms ‘recovery-oriented practice’ AND ‘guidelines’ OR ‘standards’ OR ‘indicators’ OR ‘competencies’ was conducted. Third, hand searching reference lists of retrieved documents was undertaken. An electronic database search (e.g. Medline) was not undertaken as policy and practice documents were sought rather than academic articles. The search was conducted in January 2010.

*Analysis*

The characteristics of the eligible documents were identified to describe and define the guidance. The level of service user involvement in guidance development was also rated using three categories: control, collaboration, and consultation[65]. Control involves research where service users take a lead, collaboration is defined as a shared partnership between service users and researchers in the research process, and consultation is where researchers consult service users about the research.

Inductive thematic analysis[66] was used to systematically identify and synthesise the range and diversity of the key concepts of recovery-oriented practice identified in existing guidance. To meet Aim 1, data extracts from each document were selected by two raters based on the following criteria: i) described characteristics of recovery-oriented practice, provided definitions of recovery-oriented practice, or ii) offered standards or indicators of recovery-oriented practice from which a succinct summary could be extracted. Initial semantic level analysis was then undertaken by four analysts. Equal attention was paid to each data extract to identify initial codes, and individual extracts were coded under one or several themes to fully capture their meaning. An initial coding frame was developed; all extracts were double coded by at least two raters, and a third rater resolved any differences.

To meet Aim 2, interpretive analysis was undertaken to organise the themes into practice domains. Thematic maps were used to organise the themes by clustering all codes according to connections in the data, and by considering the patterns and relationships between themes. Additional codes, refinements to the specifics of themes, and thematic patterns continued until theoretical saturation was achieved[66].

### Results

Thirty documents were identified. Documents came from six countries (United States of America, England, Scotland, Republic of Ireland, Denmark and New Zealand), and ranged in length from 3 to 149 pages. Their characteristics are shown in Appendix 4. The nature of the guidance was diverse, with 15 self-ascribed categories of guidance, and varying levels of service user involvement: user-controlled (n=3), collaboration (n=8) and consultation (n=10).

#### *Aim 1: Characteristics of recovery oriented practice guidance*

A total of 498 units of text were extracted from the 30 documents. Each unit of text varied in length from one sentence to one paragraph, and described one or more components of recovery-oriented practice, resulting in 100 pages of coded data. Inductive semantic thematic analysis identified 16 dominant themes.

#### *Aim 2: Develop a conceptual framework*

Interpretive analysis was undertaken to group the 16 themes into practice domains by identifying connections and relationships between themes. Four overarching conceptual practice domains were identified: Promoting citizenship, Organisational commitment, Supporting personally defined recovery, and Working relationship. These are shown in Figure 3.

**Figure 3 Recovery Practice sub-study: first and second level categories**

**Category 1: Promoting citizenship**

*1.1 Seeing beyond the service user*

*1.2 Service user rights*

*1.3 Social inclusion*

*1.4 Meaningful occupation*

**Category 2: Organisational commitment**

*2.1 Recovery vision*

*2.2 Workplace support structures*

*2.3 Quality improvement*

*2.4 Care pathway*

*2.5 Workforce planning*

**Category 3: Supporting personally defined recovery**

*3.1 Individuality*

*3.2 Informed choice*

*3.3 Peer support*

*3.4 Strengths focus*

*3.5 Holistic approach*

**Category 4: Working relationship**

*4.1 Partnerships*

*4.2 Inspiring hope*

The full coding framework is shown in Appendix 5. Each practice domain is as important as the next, and there is no hierarchical order. The grouping of themes and distribution of themes across documents is shown in Appendix 6.

### Discussion

The study presents two key findings: the characteristics of recovery-oriented practice guidance based on current international perspectives, and an overarching recovery practice framework that can be used to aid the translation of recovery guidance into clinical practice. The recovery practice framework was developed using inductive thematic analysis which identified four practice domains: Promoting citizenship; Organisational commitment; Supporting personally defined recovery; and Working relationship.

### *Strengths and limitations*

The study considered a broad range of documents to explore the breadth of recovery-oriented practice, and whilst the sample size was influenced by what was considered feasible for a qualitative analysis, it is substantially larger than is usual for a study of this type. Robust qualitative methodology was used to maximise the quality of the synthesis. The main limitation is the non-systematic approach to identifying the guidance documents. The rationale for analysing widely-used documents is that recovery orientation is a developing area of research and practice, and its evolving meaning is both represented and influenced by prominent policy and practice documents. The literature search was a systematised review rather than a systematic review[67]. Therefore not all existing guidance documents were identified in the search, leading to reduced coverage of important guidance, for example, from Canada[68] and Australia[69]. Informal analysis indicates these documents are consistent with our findings, but the recovery practice framework should be considered a heuristic to be further developed and refined.

### *Implications for policy and practice*

The recovery practice framework is wide-ranging, encompassing socio-political involvement and ethical responsibilities that may be outside the usual sphere of practice. Davidson argues for a conceptual framework that supports the fundamental role of independence and self-determination in enabling people who live with mental illness to exercise their rights of citizenship and to live meaningful lives[70]. It can be a challenging view that promoting citizenship may be the job of the mental health system, leading to the suggestion that '*becoming social activists who challenge stigma and discrimination, and promoting societal well-being may need to become the norm rather than the exception for mental health professionals in the 21st Century*'[25].

The involvement of organisations is also highlighted[71], pointing to the need to develop a whole-systems approach. To operate within a recovery framework, services need to balance the tension between addressing both the priorities of service users, and the wider expectations of the community[72]. Addressing organisational commitment may be difficult, as it challenges the view that the organisation merely provides the infrastructure for service delivery and quality assurance. This raises questions about the purpose of mental health services, and how its effectiveness should be evaluated[23].

The process of supporting personally defined recovery reflects the complexity and dimensions of practice across both evidence based practice and illness experience. This is enhanced by working relationships which recognises the value of therapeutic and real relationships[14]. While the understanding of recovery-oriented practice is still developing, practices that are reflective of the four practice domains should be promoted[70,73].

There is an expectation that practitioners embed recovery support into their existing perspectives on disability and health[74,75]. The recovery practice framework can be used to address this need. One example is viewing recovery-oriented practice within an ecological perspective[76], where the life context, the environment and the relationship between each individual and their environment are considered[77,78]. The recovery practice framework promotes awareness of the impact of ecological factors such as health care systems, societal, and life context influences on recovery[33].

A key challenge for mental health services is the lack of clarity around what constitutes recovery-oriented practice. This recovery practice framework contributes to the understanding of recovery-orientation, and can be used to aid the translation of recovery-oriented guidance into practice.

## National Survey sub-study

### Introduction

Recovery orientation is national mental health policy in many countries, for example in England since 2001[3] and currently[79]. This policy is based on the assumption that there is a link between the recovery orientation of services and the experience of recovery, though this has been under-researched. Kidd and colleagues[80] surveyed 67 Assertive Community Treatment teams in Ontario, Canada, using the Recovery Self Assessment (RSA) scale, and found that recovery-orientation of services was associated with more positive outcomes for service users, such as extent of legal involvement, number of hospital days and episodes, housing, education and employment. They did not link their findings to ratings of personal recovery. The recovery-orientation of services and clinical practice can be assessed from multiple stakeholder perspectives, and the extent to which stakeholders agree in the UK is unknown. In a USA study, Davidson and colleagues found high levels of agreement between directors (managers) and persons-in-recovery (service users)[81].

The proportion of the mental health workforce with ‘lived experience’ (personal experience of mental health problems or supporting someone with mental health problems) is unknown, but dual identity as a worker with lived experience represents a potential resource in the system[82], and increasing this proportion is emerging as a target for organisational transformation[40].

The aim of this study was to determine the current level of recovery-oriented practice in community adult mental health services in England[83]. The objectives were: (1) To compare variations between NHS Trusts, types of team and participant; (2) To explore the relationship between service user ratings of recovery orientation and their ratings of personal recovery; and (3) to test the hypothesis that staff-rated recovery orientation differs between workers with and without lived experience.

## Methods

### *Design*

The study used a cross-sectional survey design. Ethical approval was obtained from South East London Research Ethics Committee 4 (10/H0807/4).

### *Sample and setting*

The study took place in a purposive sample of six NHS Mental Health Trusts in England: Coventry and Warwickshire Partnership NHS Trust, Leicestershire Partnership NHS Trust , 2gether NHS Foundation Trust, Devon Partnership NHS Trust, Tees, Esk and Wear Valley NHS Foundation Trust and Leeds Partnership NHS Trust. Trusts were chosen to provide a mix of different English regions (Midlands, South West, North East, North West), levels of urbanisation, socioeconomic deprivation status, ethnic diversity, organisational size and structures (Foundation or non-foundation).

Teams met the inclusion criteria if they were adult community mental health teams (CMHTs) using the Care Programme Approach (CPA). All team leaders were eligible. Workers were eligible if they had direct clinical contact with service users. Service users within the team were eligible for inclusion if they met the following criteria: i) were aged 18-65 years, ii) had no immediate plans for discharge, iii) were not currently receiving in-patient care, iv) spoke and understoood English, v) were able to give consent, and vi) were sufficiently well to participate (in the opinion of staff).

*Measures*

Recovery orientation of services was measured using the Recovery Self Assessment (RSA), which has parallel versions for team leaders, staff and service users[81]. Each version contains 36 items rating practices associated with supporting recovery. Participants rate the degree to which their team engaged in the practice on a 5-point Likert scale from 1 (Strongly disagree) to 5 (Strongly agree) or Not applicable. The RSA can be scored as a total sum score ranging from 36 (low recovery orientation) to 180 (high recovery orientation; alpha = .94) or as five sub-scales: i) Diversity of treatment options (alpha = .72), ii) User Involvement and Recovery Education (alpha = .84), iii) Life Goals vs. Symptom Management (alpha = .88), iv) Rights and Respect (alpha = .61), and v) Individually-tailored Services (alpha = .64). For our analysis, we used mean RSA scores.

The Questionnaire about the Process of Recovery (QPR) is a 22-item self-report measure of personal recovery[84]. Each item comprises a pro-recovery statement rated from 1 (low recovery) to 5. We calculated a QPR total score following recent guidelines which indicate that 15 (of the original 22 items) can be used to extrapolate a recovery score (alpha = .95)[85]. Staff were asked about their personal experience of mental illness or caring for someone with mental illness. Sample questions included 'Do you have experience of supporting a family member or friend with mental health problems?', 'Have you ever experienced mental health problems?' and 'Have you ever used mental health services?'.

In the survey, staff were also asked ‘Do you have experience of supporting a family member or friend with mental health problems?’, ‘Have you ever experienced mental health problems?’, ‘Have you ever used mental health services?’ (all Yes/No responses) and ‘Have you disclosed this information to your work colleagues?’ (responses of Yes, I am fully open with my colleagues when appropriate; Not fully, but I have disclosed in confidence to at least one of my colleagues; or No).

*Procedure*

We originally intended to recruit from seven NHS Trusts, but for logistical reasons decided to over-recruit in six NHS Trusts instead. In each of these six sites, four teams were randomly selected using a random number generator (www.randomization.com). The team leader was approached and asked for consent for their team to participate, with alternative teams approached, according to randomisation order, if necessary. In each team a convenience sample of five staff were identified, in liaison with the team leader, with alternatives approached where necessary. Also, ten service users were randomly chosen using the random number generator from an anonymised caseload list supplied by the team leader.

Surveys for each participant group – team leader (RSA), staff (RSA) and service user (RSA and QPR) – were offered in multiple forms (post, email or telephone). Participants were asked to either post or email responses direct to the research team or a telephone interview was arranged with a researcher if preferred. Service user participants were also where logistics allowed offered face-to-face interviews, in four of the six sites. Service users were paid by £10 gift voucher, sent in advance of receipt of completed questionnaire (as this increases response rate[86]). Survey data were collected between September 2010 and August 2012.

The dataset was validated by checking for missing data and outliers, with items checked against the original questionnaires to minimise transcription errors. Missing data were imputed using mean replacement following the authors’ guidelines for the RSA measures while this was done when less than 20% of data were missing on the QPR scale.

*Analysis*

Regression analyses were conducted by entering the predictors into the model for each objective (objective 1: respondent type; objective 2: QPR score; objective 3: personal experience) with NHS Trust entered as a covariate. Sensitivity analysis adjusted the model for covariates: age, gender, ethnicity (white vs. non-white), time using mental health services (service user) or length of NHS employment (staff). We used random effects regression models with maximum likelihood estimation using the ‘xtmixed’ command in Stata 11 to account for clustering at the team level as respondents in the same team might not be independent. Bonferroni correction was used to adjust for multiple testing.

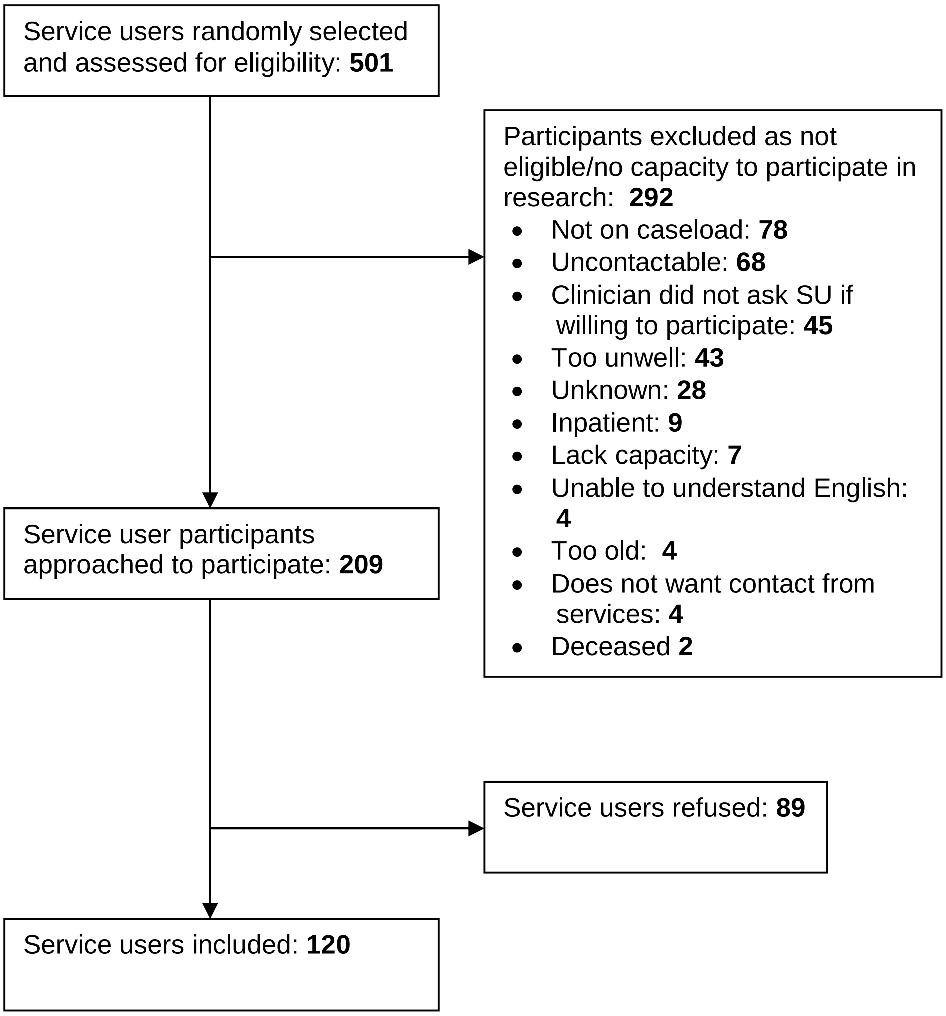
### Results

Seven NHS Trusts were approached, of whom 6 (85%) participated and one did not respond. Four additional teams were recruited from remaining NHS Trusts to replace the four teams from the non-participating NHS Trust, so 28 (100% of target) teams participated, comprising 9 psychosis-specific community mental health teams, 8 community mental health teams, 4 support and recovery teams, 4 early intervention teams and 3 assertive outreach teams.

A total of 22 (79%) of 28 Team leaders and 109 (77% of 140 target) staff participated, comprising nurses (n=58, 44%), social workers (n=25, 19%), support and recovery workers (n=16, 12%), occupational therapists (n=14, 11%), psychiatrists (n=5, 4%), psychologists (n=5, 4%) and other/missing (n=6, 5%). The majority were female (n=90, 70%) and white British (n=119, 92%), with a mean age of 45.0 years (s.d.=8.7), mean time in current post of 6.0 years (s.d.=5.2), and mean time working in mental health services of 16.6 years (s.d.=9.7).

A total of 120 (43%) of the target 280 service users were recruited, as shown in Figure 4.

**Figure 4 National Survey sub-study: flow diagram for service users**



The characteristics of service user participants are shown in Table 9.

**Table 9 National Survey sub-study: service user characteristics (n=120)**

| **Service user characteristics** | | **N (%)** |
|---|---|---|
| Gender | Male | 72 (60) |
| | Female | 48 (40) |
| Ethnicity | White British | 97 (81) |
| | White Other | 4 (3) |
| | Asian/ Asian British- Pakistani | 4 (3) |
| | Mixed White & Asian | 3 (3) |
| | Mixed White & Black Caribbean | 2 (2) |
| | Asian/ Asian British- Indian | 2 (2) |

| | | |
|---|---|---|
| | Black/ Black British- Caribbean | 2 (2) |
| | Black/Black British-African | 1 (1) |
| | Other | 1 (1) |
| | *Missing data* | *4* (3) |
| Self-reported diagnosis | Mood disorder | 40 (33) |
| | Psychosis disorder | 29 (24) |
| | Anxiety disorder | 7 (6) |
| | Personality disorder | 6 (5) |
| | Other | 2 (2) |
| | *Missing data* | 36 (30) |

Responses from staff and team leaders were primarily by post (n=97, 74%), with face-face interviews (n=20, 15%), email (n=12, 9%) and phone interview (n=2, 2%) also used. Responses from service users were by post (n=62, 52%), face-face interviews (n=34, 28%), and phone (n=24, 20%).

Following pro-rating there was complete information for 239 (out of 251) participants on the RSA and covariates, recruited across 28 teams. Service users were more likely to have missing data and therefore be excluded than staff and team leaders (8% vs. 2% staff / team leaders; $\chi^2$(1)=6.4, p=.012). Excluded people did not differ from those included on age, gender, time in NHS, diagnosis or ethnicity. The final sample comprised 108 staff, 21 team leaders and 110 service users (who also had complete information on the QPR).

*Objective 1 (NHS Trust, team and participant variations on RSA)*

Analyses were conducted on 239 respondents across 28 teams with a mean of 9 observations per team cluster (range 1 to 16). There was an effect of clustering at team-level (chi$^2$(2)=4.7, p=0.015; ICC=9%). We therefore checked whether variability across teams was explained by NHS Trust, (e.g. due to distinctive organisational cultures). NHS Trust was entered as a predictor in the null multi-level model, and clustering at team level was weakened (chi$^2$(1)=2.2, p=0.071, ICC=6%) and a 23%

reduction of unexplained variance on the RSA measure across teams was observed. These results indicate that NHS Trust explained some of the variation across teams.

We then investigated whether some types of team were rated as more recovery-oriented than others. The results showed that overall RSA scores varied across team types (Wald(4)=22.14, p<0.001). We ran pairwise comparisons between all team types, as shown in Table 10.

**Table 10 National Survey sub-study: comparisons between team types (n=28)**

| **Team type** | **Pairwise comparisons*** |
|---|---|
| **Early intervention vs. assertive** | b=-0.23, p=0.103 [-0.51 to 0.05] |
| **Early intervention vs. support and recovery** | **b=-0.39, p=0.001 [-0.61 to -0.17]** |
| **Early intervention vs. psychosis** | b=-0.41, p=0.025 [-0.78 to -0.05] |
| **Early intervention vs. CMHT** | **b=-0.67, p=0.001 [-1.08 to -0.26]** |
| **Assertive vs. support and recovery** | b=-0.16, p=0.306 [-0.48 to 0.15] |
| **Assertive vs. psychosis** | b=-0.19, p=0.243 [-0.50 to 0.13] |
| **Assertive vs. CMHT** | b=-0.44, p=0.018 [-0.82 to -0.07] |
| **Support and recovery vs. psychosis** | b=-0.02, p=0.907 [-0.43 to 0.38] |
| **Support and recovery vs. CMHT** | b=-0.28, p=0.217 [-0.73 to 0.17] |
| **Psychosis vs. CMHT** | b=-0.26, p=0.010 [-0.45 to -0.06] |

*significant findings are in bold.

After adjusting for multiple testing, RSA scores were higher among Early Intervention teams than Support and Recovery teams (b=-0.39, p=0.001; 95%CI -0.62 to -0.17) and Community and Mental Health Teams (b=-0.67, p=0.001; 95%CI -1.08 to -0.26). Thirdly, we investigated variability in the RSA mean scores for the three participant groups shown on the next page.

**Table 11 National Survey sub-study: Recovery Self Assessment (RSA) scores by respondent group**

| **Respondent group** | **RSA sub-scale**<br>mean (standard error) | | | | | **RSA total** |
|---|---|---|---|---|---|---|
| | *Life goals vs. Symptom Management* | *User involvement and Recovery education* | *Diversity of treatment options* | *Rights and respect* | *Individually-tailored Services* | |
| Staff | 4.00 (0.05) | 2.95 (0.07) | 3.25 (0.07) | 4.05 (0.06) | 3.56 (0.06) | 3.59 (0.05) |
| Team leader | 4.31 (0.12) | 3.21 (0.13) | 3.47 (0.15) | 4.45 (0.12) | 4.10 (0.12) | 3.90 (0.11) |
| Service user | 3.81 (0.07) | 3.31 (0.08) | 3.45 (0.08) | 3.91 (0.07) | 3.60 (0.07) | 3.63 (0.06) |

Regression of respondent group on mean RSA scores showed that the participant groups differed on their RSA scores (Wald(2)=7.0, p=0.031), with team leader responses higher than staff (b=-0.30, p=0.008; 95%CI: -0.53 to -0.08) and from service users (b=-0.25, p=0.029; 95%CI: -0.48 to -0.03), though the latter difference became non-significant after adjustment. We found no difference between staff and service users (b=-0.05, p=0.432; 95%CI -0.18 to 0.08). The effect of participant type on RSA was still present after including the covariates (Wald chi$^2$ (2) =9.4, p=0.009). None of the covariates was found to be a predictor of RSA mean scores.

Fourthly, we looked for variability in the RSA sub-scales for the three types of participant. 202 participants of the 239 participants had information on all five sub-scales and were included in the analyses. There was a mean of 8 observations per cluster. We compared group scoring across the RSA scales by running a regression analysis of RSA scores on respondent type with random intercept for clustering at the level of team with the model adjusted for NHS Trust and covariates. Overall Wald test and pairwise comparisons are shown in Table 12.

**Table 12 National Survey sub-study: comparison between groups**

| RSA sub-scale: | **1. Life goals vs. Symptom management** | **2. User involvement and Recovery education** | **3. Diversity of treatment options** | **4. Rights and respect** | **5. Individually-tailored Services** |
|---|---|---|---|---|---|
| **Overall Wald test** | **W(2)=18.3,**<br>**p <0.001** | **W(2)=20.1,**<br>**p=<0.001** | W(2)=3.5,<br>p=0.174 | **W(2)=17.4, p<0.001** | **W(2)=20.3,**<br>**p <0.001** |
| **Pairwise comparison (z-test)** | | | | | |
| **Team Leader vs. Staff** | **b=-0.38, p=0.003**<br>**[-0.63 to -0.13]** | b=-0.28, p=0.040<br>[-0.55 to -0.01] | b=-0.22, p=0.179<br>[-0.53 to 0.10] | **b=-0.46, p=0.001**<br>**[-0.72 to -0.19]** | **b=-0.59, p<0.001**<br>**[-0.85 to -0.33]** |
| **Team Leader vs. Service User** | **b=-0.57, p<.001**<br>**[-0.83 to -0.30]** | b=0.11, p=0.452<br>[-0.17 to 0.39] | b=-0.05, p=0.761<br>[-0.38 to 0.28] | **b=-0.59, p <0.001**<br>**[-0.87 to -0.31]** | **b=-0.55, p <0.001**<br>**[-0.82 to -0.28]** |
| **Staff vs. Service User** | b=0.19, p=0.025<br>[0.02 to 0.35] | **b=-0.39, p<0.001**<br>**[-0.57 to -0.22]** | b=-0.17, p=0.111<br>[-0.37 to 0.04] | b=0.14, p=0.123<br>[-0.04 to 0.31] | b= -0.04, p=0.608<br>[-0.21 to 0.13] |

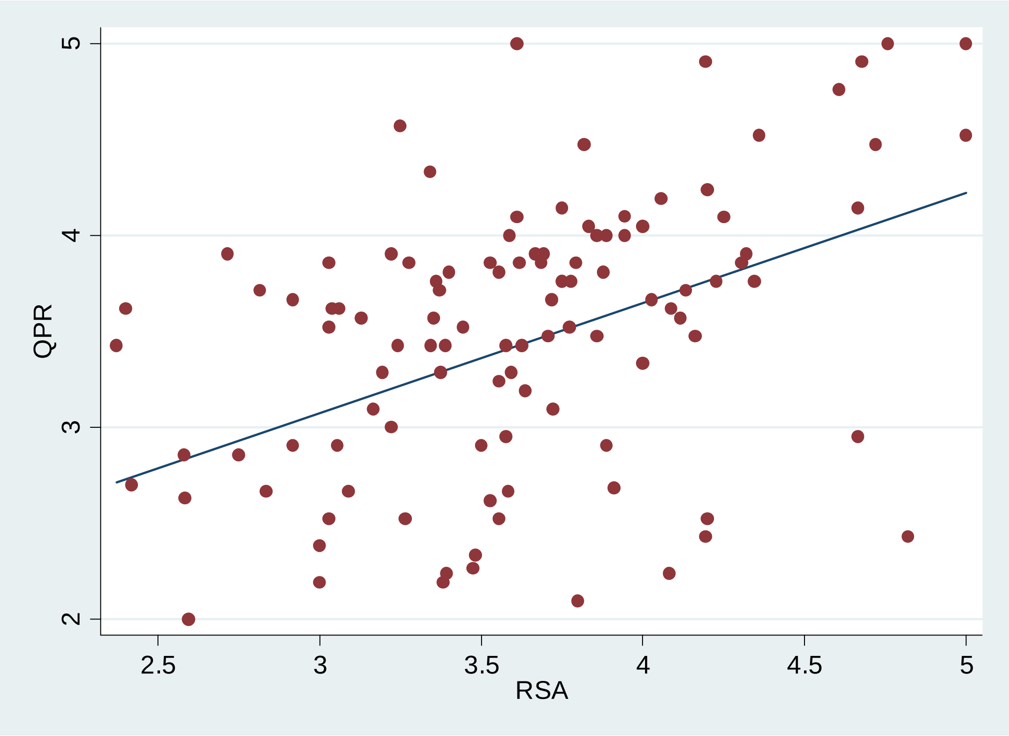
*significant findings after Bonferroni correction shown in bold.

A Bonferroni Correction was used to adjust for multiple testing. The overall Wald Test showed that there was an effect of participant type on four of the five sub-scales. Service users ratings for sub-scale 2 (User Involvement and Recovery Education ) were higher than staff ratings, but the main overall difference was that team leaders rated a higher recovery orientation on sub-scales 1, 4 and 5 (Diversity of treatment options , Rights and Respect, Individually-tailored Services) than both service users and staff.

*Objective 2 (Recovery support and recovery)*

We investigated whether service user ratings of recovery orientation were significantly associated with personal recovery. Analyses were conducted on 110 (of 120) service users, across 26 teams with a mean of 4 observations per cluster , as these participants had complete information on the RSA, QPR and covariates. The scatter plot and line of best fit shown in Figure 5 illustrates the relationship between RSA scores and QPR scores.

**Figure 5 National Survey sub-study: scatterplot capturing the relationship between RSA and QPR scores (n=110)**



RSA scores were positively associated with QPR total scores (b=.53, p<.001; 95%CI: .32 to .74). Adjusting the model for covariates confirmed the results (b=.58, p<.001; 95%CI: .31 to .85).

*Objective 3 (Recovery support and lived experience)*

Among staff and team leader participants, 100 (76%) reported having experience of supporting a family member or friend and 50 (39%) reported having had personal experience of mental health problems. Of those who reported personal experience, 24 (48%) had fully disclosed this experience to workplace colleagues, 16 (32%) had partially disclosed this, and 10 (20%) had not disclosed this. Of the 24 who had fully disclosed their personal experience of mental illness, 19 (79%) reported they had received support and 5 (21%) reported they had not.

Regression analyses were conducted on 130 staff and team leaders across 26 teams (mean of 5 observations per cluster). Staff and team leader RSA scores were not associated with personal experience of mental illness (b=0.09, p=0.273; 95%CI: -0.07 to 0.24) or supporting a family member or friend (b=0.02, p=0.836; 95%CI: -0.15 to 0.19).

## Discussion

In this national survey across England, we compared variations between NHS Trust, team type and participant ratings of recovery-orientation of mental health teams. We identified influences on recovery orientation rating. The site (i.e. NHS Trust) accounted for some variance, as did team type with early psychosis teams having a higher recovery orientation than teams working with longer-term users of mental health services. Team leaders rated a greater recovery orientation than either staff or service users (Objective 1). Service users who rated a higher recovery orientation of the team also rated higher self-assessed recovery (Objective 2). Finally, no association was found in staff between lived experience (either personal experience of mental illness or through supporting a family member or friend) and recovery orientation rating (Objective 3).

*Predictors of recovery orientation*

This study provides preliminary evidence that the overall recovery-orientation scores in English community based mental health teams were high, with some recovery domains being very high (e.g. life goals vs. medication management), and others (e.g. user involvement) lower. The RSA mean scores for team leaders were higher than those of service users and staff, whereas scores did not differ between staff and service users. Candidate reasons for higher team leader scores include social desirability (discussed later), over-optimistic or inaccurate appraisal of practice, and different thresholds for recovery-oriented practice. By contrast, the average RSA scores in a USA study were all higher than we found, and were highest for persons in recovery (service users, mean score = 4.06, n=326), and directors (senior managers, mean RSA = 4.09, n=68), with providers (clinicians, mean score=3.89; n=344) scoring the lowest[81]. These variations in absolute and relative perceptions of recovery orientation, along with our finding of a site-level effect, highlight the need for larger-scale epidemiological surveys with a focus on representativeness.

In the UK, community-based mental health teams serve different clinical populations and include both generic community mental health teams (CMHTs) and specialist mental health teams, such as early intervention and assertive outreach teams. The differences in recovery orientation between these teams may be due to different clinical populations (e.g. proportion of people with psychosis, or length of time using services) or team characteristics (e.g. specialist workforce skills). A study of 67 Assertive Community Treatment (ACT) teams in Canada found no relation between ACT fidelity and recovery orientation, leading the authors to conclude that traditional fidelity measures may not adequately address dimension of recovery oriented service provision[87]. However, integrating evidence-based recovery-oriented interventions into existing service models can be problematic[88]. In relation to early psychosis services, there may be a greater alignment between practice and the broader understanding of recovery held by first-episode services[89] than in services providing longer-term care.

### *Recovery orientation and recovery*

To our knowledge, this is the first empirical study which has found an association between service user perceptions of recovery-orientation of services and their own personal recovery. Key recovery outcomes are connectedness (i.e. social inclusion), hope, a positive identity, meaning and purpose, and empowerment[8]. A moderate evidence base indicates that the relationship between these recovery outcomes and traditional clinical outcomes is weak. For example, recovery indicators are sensitive to stage of recovery whereas clinical outcomes are not[38], and functioning is not associated with recovery[90]. Overall, psychosocial factors emerge as more influential on recovery than neuropsychiatric factors[90], which may have implications for the development of recovery-oriented service models.

### *Recovery orientation and lived experience in staff*

Over a third of staff and team leaders reported having experience of mental illness, less than half of whom had fully disclosed this experience to their workplace colleagues. Three quarters had experience of providing informal support to a friend or relative with mental illness. An identified challenge for organisations intending to translate recovery rhetoric into practice is to transform and rebalance the skill-mix within their mental health workforce, with a much greater involvement of people with lived experience[91]. The existence within the work-force of a sizeable proportion of people with ‘dual identity’ of lived experience and professional expertise represents an untapped resource which may benefit others, e.g. by being more oriented towards strengths-based practice[92], and the mental health system[93]. There have been improvements in employers’ mental health related knowledge, attitudes, employment practices around recruiting and supporting employees with mental health problems. A recent series of surveys suggests that UK employers’ are becoming less likely to perceive employing people with mental health problems as a risk with respect to their reliability or in terms of their colleagues’ reactions to them[94]. Organisations which successfully challenge within-system stigma[95] are more successful at implementing the policy imperative of developing the peer specialist workforce[96]. Therefore mental health organisations may consider the benefits of actively valuing this lived experience within the existing workforce, and supporting staff to disclose this experience to colleagues and service users where wanted and appropriate.

### *Strengths and limitations*

The study had several strengths. The purposive sample from five English regions maximised variation in levels of urbanisation, deprivation and ethnicity. Participating

Trusts differed in size and structure, again providing an ecologically valid perspective from routine service settings.

We also identify limitations. Whilst the teams were randomly selected from all community based mental health teams within the NHS trust, the staff sample was selected via convenience sampling. This may have led to a selection bias, for instance, with workers who strongly felt their practice was recovery-oriented being more likely to participate. Of the 501 service users who were assessed for eligibility, many were not approached for logistical reasons, e.g. 78 were not on the caseload. However, 45 were not approached by staff and 89 refused to participate, which may reduce representativeness.

The QPR measure was developed using a UK mental health population and was recommended in a recent systematic review[97], while the RSA measure was developed in the USA and its cross-cultural validity has yet to be established. A systematic review of measures of recovery support measures identified that some RSA items required service users to comment on service delivery which they could not reasonably be expected to know about, given the way services are configured within the UK, such as whether staff had cultural diversity training[98].

*Clinical and research implications*

This study provides support for the view that information on recovery orientation should be routinely collected. Despite the policy goal of increasing recovery orientation of mental health services, routine outcome monitoring of the recovery-orientation of services is not common practice. Moving beyond the adoption of recovery principles through to persistent implementation of recovery-oriented practice into routine care entails putting effective feedback systems in place for both staff and policy makers[99]. There is little empirical UK based evidence available for workers to gauge whether their work is recovery-oriented or help them reflect upon areas of practice they could target for service development. A study assessing the recovery-orientation of 78 mental health and addiction programmes in Connecticut, USA, involved providing individual services with structured feedback on their RSA total and sub-scale results to help them assess their own progress towards implementing recovery practice[81]. When services disseminated the findings of discrepancies between participant groups in the perception of the recovery-orientation of services, this led to service improvement. Studies comparing staff, carer and service user perceptions of need find differing perspectives, which in routine practice can lead to a shared commitment to provide more needs-led care[100]. Overall, there is evidence that feedback of outcome data can improve the quality of mental health care[101].

This study also provides preliminary evidence consistent with a causal relationship between recovery orientation in a mental health team and recovery experience of the service user. Three criteria for demonstrating a causal relationship have been identified: *association* (the putative cause and effect have temporal and spatial contiguity), *direction* (cause precedes effect) and *isolation* (the effects of a cause are isolated from competing causes)[102]. This study has shown cross-sectional association and isolation. Future research should investigate whether association and isolation are retained in longitudinal designs, and use a repeated measures design to test whether increasing recovery orientation leads to subsequent increase in recovery.

## Staff Perceptions sub-study

### Objective a) Grounded theory

Adapted with permission from the published report of this study[103].

#### Introduction

The survey provides a broad and quantitative understanding of staff perspectives on supporting recovery. More detailed and qualitative understanding is also needed. The aim of this study was to identify factors that help or hinder worker and manager efforts to provide recovery support, by investigating what staff say they do to support recovery.

#### Methods

*Design*

Focus groups and individual semi-structured interviews were used to collect data. Grounded theory methodology was used to shape the research because staff perspectives on recovery support are relatively unexplored[104]. Grounded theory draws on symbolic interactionism, whereby human beings create meanings of the world around them through interaction with others and through their own internal dialogue[105] [106]. Grounded theory therefore recognises the interrelationship between meaning and behaviour and aims to develop a theory that explains the action in the social context under study.

*Data collection*

Ten exploratory focus groups were conducted with staff (n=5) and team leaders (n=5), within five NHS Mental Health Trusts in England (South London and Maudsley NHS Foundation Trust, 2gether NHS Foundation Trust, Leicestershire Partnership NHS Trust, Devon Partnership NHS Trust and Tees Esk and Wear Valleys NHS Foundation Trust). Focus groups were used for early data collection to stimulate group interaction and discussion[107]. These were followed by thirty-two individual interviews with staff (n=18), team leaders (n=6), and senior managers (n=8). Sites were purposively chosen for diversity in geographical region of England, urban/rural balance and for perceived levels of success in implementing recovery-oriented practice.

Staff in community-based mental health teams providing a care co-ordinating function were included in the sampling frame if they had direct clinical contact with service users. Purposive sampling based on site (Trust, type of team e.g. early intervention, support and recovery etc.) and staff characteristics (core profession, grade, job role) was used to maximise the range of views. Participants were approached and recruited by local Mental Health Research Network Clinical Studies Officers (non-London sites) or by the lead author (London site) via the telephone, email or face-to-face.

Separate focus groups were conducted with team leaders and staff at each site to allow perspectives to be shared with others with similar managerial and clinical responsibilities. Each 90-minute focus group started by exploring staff perspectives on barriers and facilitators to providing recovery support, and the initial topic guide was informed by PPI, as described in Chapter 10. The recovery practice framework was used in the early focus groups to organize the topic guide and generate discussion by providing examples of what recovery might mean in practice[63]. However, the discussion aimed to follow individual's interpretation of recovery-oriented practice, prompting the lack of a shared understanding of what recovery means in practice to emerge as an early finding. Barriers and facilitators to providing recovery support were also identified as an influence on how staff understood recovery as applied to their practice (one example is that participant understanding was frequently informed by system messages such as recovery equals service throughput). The aim to investigate what staff say they do to support recovery was subsequently added. The research became progressively focused and theoretical explanations were tested and revised with further data collection[106]. Focus groups took place between May and August 2010, and were audio recorded and transcribed verbatim. The focus group topic guide is shown in Appendix 7.

Focus group data analysis identified a methodological limitation, where participants had difficulty in eliciting individual accounts of recovery-oriented practice in a group context. Interviews (n=32) were therefore conducted to allow deeper probing to explore individual practice examples alongside barriers and facilitators to supporting recovery. Participants with a range of characteristics were sought to test out and refine the emerging theory. For example, staff and team leaders with greater work experience were actively recruited to examine whether they were more likely to support recovery, and those who perceived themselves as successful in supporting recovery in practice were identified and recruited to explore the factors which enabled their success. Senior NHS managers were also recruited to examine the organizational factors identified as instrumental in shaping the meaning and success of supporting recovery. Recruitment continued until theoretical saturation was reached.

The interview schedule for staff and team leaders and a separate interview schedule for senior managers focused on using practice examples of recovery orientation to identify blocks and enablers to incorporating recovery into their routine clinical practice. Both interview schedules were revised iteratively to further explore emergent themes and deviant cases. For example, the category 'competing priorities for practice' emerged from focus group data, and was subsequently explored in interviews. The topic guide for staff and team leader interviews is shown in Appendix 8, and for senior managers is shown in Appendix 9. Interviews were conducted across NHS sites, lasted around one hour, and were audio recorded and transcribed verbatim. Where requested, transcripts were returned to participants for comment and correction. Interviews were conducted between January 2011 and August 2012.

### *Data Analysis*

Iterative inductive analysis of the data was undertaken in line with grounded theory methodology as developed by Strauss and Corbin (1990)[106]. Data analysis occurred concurrently with data collection using NVivo QSR International qualitative analysis software (version 8). Transcripts were read repeatedly to allow the researcher to become immersed in the data. Data analysis began with line by line open coding, and individual extracts were coded under one or several categories to fully capture their meaning. An initial coding frame was developed and axial coding was conducted to propose relationships among categories. As further data were collected, they were coded and categorised using the constant comparison, paradigm and conditional matrix analysis procedures. For example, participants' accounts were compared to identify provisional commonalities and differences; and the scope of study was determined by identifying relationships between micro (individual) and macro (organizational) conditions. Selective coding was undertaken whereby the emerging story line was described and categories that required further development were explored. Memos were kept by the lead researcher (CLB) to record initial impressions, analytic decisions, and the researcher's role in the process to demonstrate the theory was grounded in the data. For example, the lead researcher considered her own understanding of recovery, and previous experience of working in mental health services to enhance theoretical sensitivity. Multiple coding by two other rates was undertaken to reflect on and enhance the awareness of the coding approach.

## Results

A total of 65 staff participated in focus groups, and 32 staff in interviews. Their characteristics are shown in Table 13.

### Table 13 Staff Perceptions sub-study: staff participants (n=97)

| n (%) | **Focus groups**<br>*n=65* | **Interviews**<br>*n=32* |
|---|---|---|
| **Job role** | | |
| Staff | 34 (52.3) | 18 (56.3) |
| Team leader | 31 (47.7) | 6 (18.8) |
| Senior manager | 0 (0.0) | 8 (25.0) |
| **NHS Trust** | | |
| South London and Maudsley NHS Foundation Trust | 13 (20.0) | 16 (50.0) |
| 2gether NHS Foundation Trust | 14 (21.5) | 10 (31.3) |
| Leicestershire Partnership NHS Trust | 12 (18.5) | 2 (6.3) |
| Tees, Esk and Wear Valleys NHS Foundation Trust | 13 (20.0) | 4 (12.5) |
| Devon Partnership NHS Trust | 13 (20.0) | 0 (0.0) |
| **Team** | | |
| Assertive Outreach | 15 (23.1) | 1 (3.1) |
| Early Intervention | 12 (18.5) | 4 (12.5) |
| Forensic | 0 (0.0) | 0 (0.0) |
| Support and Recovery | 32 (49.2) | 18 (56.3) |
| Rehabilitation | 2 (3.1) | 0 (0.0) |
| Supported housing | 2 (3.1) | 0 (0.0) |
| Management | 0 (0.0) | 7 (21.9) |
| Works across teams | 2 (3.1) | 1 (3.1) |
| **Profession** | | |
| Psychiatrist | 2 (3.1) | 2 (6.3) |
| Nurse | 40 (61.5) | 17 (53.1) |
| Social worker | 7 (10.8) | 2 (6.3) |
| Occupational Therapist | 9 (13.8) | 5 (15.6) |
| Psychologist | 1 (1.5) | 2 (6.3) |
| Associate practitioner | 0 (0.0) | 1 (3.1) |
| Vocational Specialist | 1 (1.5) | 1 (3.1) |

| | | |
|---|---|---|
| Support Time & Recovery worker | 2 (3.1) | 1 (3.1) |
| Support worker | 2 (3.1) | 0 (0.0) |
| Exercise and health practitioner | 1 (1.5) | 0 (0.0) |
| Manager (no clinical background) | 1 (1.5) | 1 (3.1) |

The mean age of staff was 45.2 years (range 24-61, s.d.=8.5), and time working in mental health services ranged from 6 months to 35 years. The average number of years qualified was 18 years 6 months (range 30-396 months, s.d.=123.0) with current pay grades ranging from band 2 to consultant. The highest academic qualification of participants ranged from National Vocational Qualification (NVQ) Level 4 to PhD level study. Of the interview participants, six members of staff disclosed personal experience of mental illness, four disclosed experience of using mental health services and eighteen disclosed experience of supporting a family member or friend with mental illness. Additional characteristics of staff participants are shown in Appendix 10.

*Core category and sub-categories*

The developed theory is a result of the interrelationships between a central phenomenon or 'core category' and the sub-categories[106] identified as influencing staff implementation of recovery-oriented practice. Findings identified many implementation challenges alongside a difficulty of articulating examples of recovery-oriented practice. Despite the study focus on success stories, staff appeared to identify more barriers than facilitators to supporting recovery. An early finding was that barriers and facilitators identified by staff shaped their understanding of recovery as applied to practice.

The core category to emerge from the data was Competing Priorities. Participants' accounts of recovery-oriented practice appeared to be informed by priorities across different levels (for example, organizational level, staff level etc.) of the health system. One major challenge for participants was understanding recovery-oriented practice and the compromises that they feel have to be made when supporting recovery. Three sub-categories relating to the competing priorities were identified. The Health Process Priorities category linked with the concept of clinical recovery, and reflected traditional mental health concerns, including a focus on symptomatology and functioning, and the evidence-based medicine view of scientific knowledge. The Business Priorities category involved a view of recovery as a service outcome, with potential trade-offs between quality and quantity. The final category, Staff Role Perception, captured staff views of their role in supporting recovery, which ranged from a custodial orientation to a recovery-orientated model of care, with a corresponding focus of practice from narrow (primarily symptomatology) to a more holistic emphasis.

## Discussion

This grounded theory study investigated staff and manager perspectives on supporting recovery, with the goal of improving understand about how staff support recovery in their practice, and identifying barriers and facilitators to providing recovery-oriented practice in mental health services. A core category of Competing Priorities was identified, describing how staff struggle to make sense of recovery-oriented practice in the face of conflicting demands and priorities of different health system levels. Three sub-categories outlining the competing priorities were identified: Health Process Priorities, Business Priorities and Staff Role Perception.

### *Strengths and limitations*

The study followed the systematic research methodology and procedures of grounded theory[106]. Use of a pre-defined recovery practice framework in early focus groups may have influenced the descriptions of recovery-oriented practice provided by participants, although efforts were made to encourage individual’s own conceptualisations. Data collection and analysis continued until theoretical saturation was reached where the accounts of 97 members of staff (with diverse job roles) were explored, making the scope large for a qualitative study. Participants were recruited using purposive and theoretical sampling strategies. Nursing staff made up the majority of the sample as they were considered the majority of the workforce. While researcher reflexivity was present throughout, researcher interpretation is evident. The pros and cons of having worked in a role similar to that under study, and sharing a staff perspective, were explored in reflective diaries. The findings are specific to the study context, that is five NHS mental health Trusts, from 2010-2012. This study also focused on mental health service community care provision and so did not address staff understanding of recovery as applied to in-patient care.

Overall, there is a discrepancy between the organizational endorsement and expressed intent to promote recovery-oriented practice on the one hand, and the capacity of services and practitioners to operationalise the concept in day-to-day work on the other. Addressing this dissonance will involve the development of professional expectations around recovery-orientation as a primary focus for staff. Concrete examples of what recovery means in practice will help, and existing clinical skills in managing competing priorities need protection. However, only when a shared understanding and unified approach exists across all levels of the mental health system will the vision of recovery-orientation be closer to being fully implemented.

## Objective b) Systematic review

### Introduction

To place the grounded theory into a broader context, we undertook a systematic review and narrative synthesis. The aim of the review was to synthesis primary research investigating staff and manager understanding of recovery-orientated practice in mental health systems, using the grounded theory as a framework for analysis.

### Methods

The review question was: How do clinicians and managers understand the concept of recovery as applied to their practice? The protocol for the review was pre-registered (PROSPERO 2013:CRD42013005942).

#### *Eligibility Criteria*

We sought staff conceptualisations of recovery-orientated practice. Where combined stakeholder conceptualisations of recovery-orientated practice were reported, such as clinician and service user, staff made up at least 50% of participants. We included only English language articles available in printed or downloadable format.

Inclusion criteria for participants were clinicians and managers, defined as workers from any profession (whether paid or voluntary) who provide or manage mental health services, in primary, secondary or tertiary care. Interventions were either explicitly described as pro-recovery or typically aligned with recovery, such as person-centred planning, and provided in routine day-to-day clinical or management work. Outcomes were expressed knowledge or attitudes about recovery-orientated practice, or self-reported or observed recovery-orientated behaviour. Finally, study design comprised empirical primary research papers that utilised established quantitative and/or qualitative research methodology (questionnaire/survey, interviews, focus groups), with a minimum sample size of three participants.

Exclusion criteria were a focus on recovery support in specialist mental health services (e.g. substance misuse, eating disorder) or patient-led organisations (e.g. recovery centers, clubhouse).

*Data sources and search strategy*

Due to the complexity of the search area and the nature of indexing qualitative studies, sequential scoping searches were conducted to test and finalise search terms. The initial search strategy was identified following a review of six pre-selected marker papers, chosen based on expert review of the field and informed by the conceptual framework for recovery[8]. These marker papers were chosen to span a range of study designs and professional groups. The sensitivity of the resulting search was tested by assessing whether the references retrieved from the search included the marker papers. Initial search terms were refined and modified to optimise the balance between specificity and sensitivity. For example, specificity was increased by using specific staff terms (such as professional groups), and the concepts of ‘understanding’ and ‘applied to practice’ were combined to increase sensitivity.

The final protocol comprised search terms identified in the title, abstract, keywords and medical subject headings (MeSH). The search strategy is shown in Appendix 11. Searches were modified for EBSCOhost and PROQUEST.

Six data sources were used:

1. Electronic databases searched from inception until 17 November 2013: PsycINFO, MEDLINE, EMBASE, Cumulative Index of Nursing and Applied Health Literature (CINAHL), British Nursing Index, IBSS, ASSIA, and Scopus.
2. The table of contents from inception until 17/11/13 were hand searched from Psychiatric Rehabilitation Journal, Psychiatric Services, Journal of Psychiatric and Mental Health Nursing, Administration and Policy in Mental Health and Australian e-journal for Advancement of Mental Health.
3. An internet search using Google Scholar (scholar.google.co.uk) was conducted using the search terms 'staff', 'mental health' and 'recovery' to identify grey literature of publishable quality. The first 100 entries were reviewed on 10/02/2014.
4. Expert consultation involving 13 mental health service users, professionals, academics, and researchers
5. Reference lists of included articles were hand searched for additional papers.
6. Articles citing included studies were searched using Web of Science *(*wok.mimas.ac.uk).

### *Data extraction*

Duplicates were removed using Endnote, Version 6. Titles identified in the electronic search were read, to identify those with possible relevance. Abstracts from relevant publications were reviewed, and where they appeared to meet the inclusion criteria the full publication was obtained and assessed for eligibility. A random 20% of the abstracts identified in the database search were independently rated by two raters for eligibility. One protocol deviation was made following retrieval of full text papers, where the decision was made to exclude studies focusing on the attitudes, knowledge or behaviour of students in professional training. Information was received from three authors (e.g. clarity about the sample) before deciding on inclusion.

All full text papers were independently rated by two raters for inclusion. Reasons for exclusion were recorded on an eligibility checklist, and disagreements were resolved through discussion or by a third rater.

### *Quality assessment*

All included studies were qualitative, so quality was assessed using a framework for assessing qualitative research evidence, covering the different stages and processes within qualitative enquiry, and the contribution, defensibility, rigour and credibility of the study (Spencer et al, 2003). Two raters double-rated the quality of all included studies, with 86% agreement.

*Analysis*

Narrative synthesis was used to analyse the data[17], which involves four stages. Stage 1, development of theory, was described in the previous section and was published prior to the review[103].

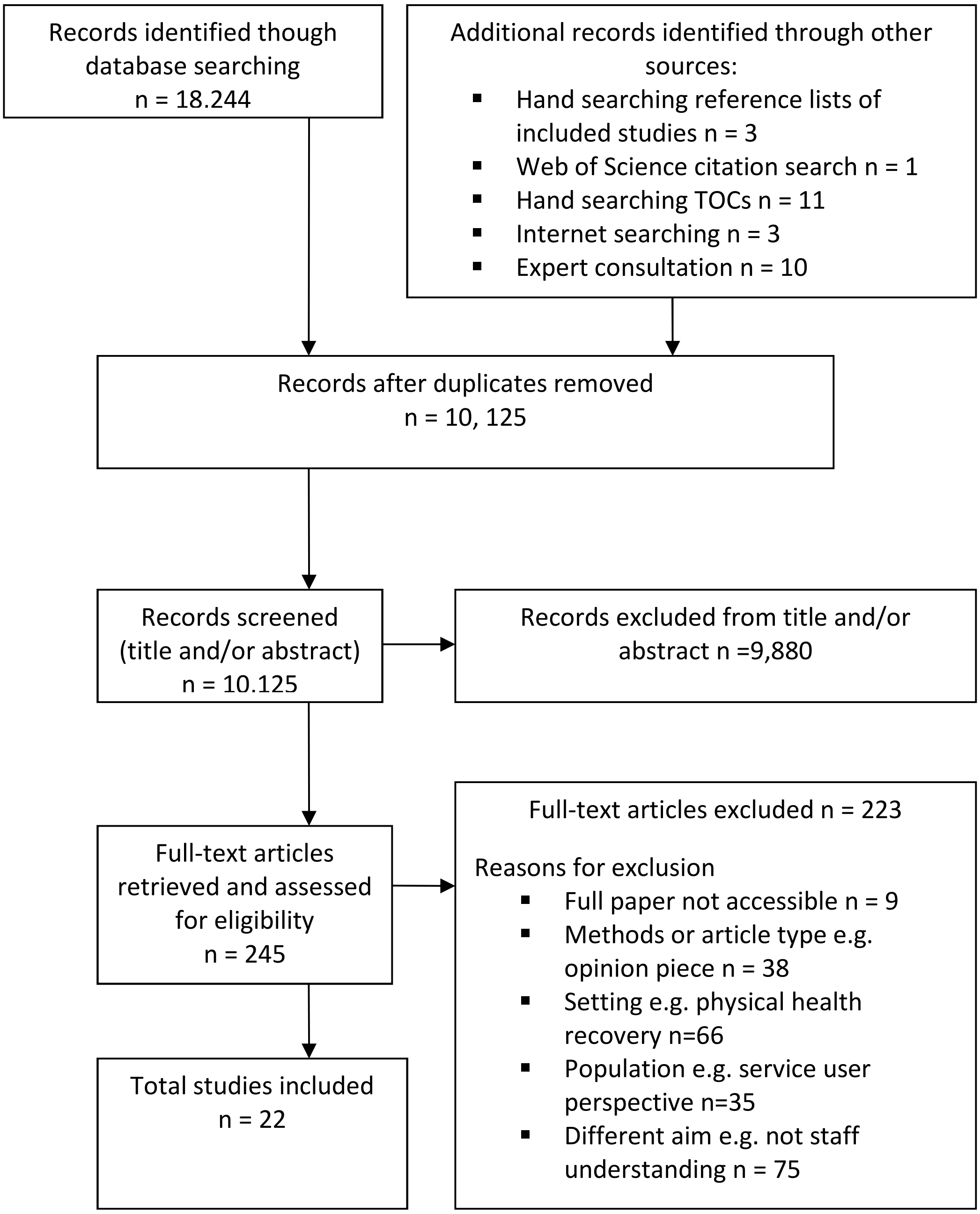
Stage 2 involves development of a preliminary synthesis, i.e. an initial description of findings from included studies. We used two approaches: tabulation and thematic analysis. For each included paper, the following data were extracted: country, service setting, staff group, design, and staff sample size. Two analysts independently conducted this tabulation, and compared coding decisions to maximise reliability. Disagreements were resolved by discussion. The key terms and components of the described conceptualisation of recovery-orientated practice were then extracted, for thematic analysis to identify the themes occurring within the data. The predefined theory was based on a UK sample, so studies conducted in the UK and Europe were used to identify initial categories, and then studies from other countries were grouped and analysed. To identify main categories and sub-categories, relevant extracts from each text were collated and grouped using a line-by-line approach. An initial deductive coding approach was undertaken whereby categories and sub-categories were mapped onto the developed theory. Each category included in the deductive framework was defined to assist consistency of coding between two analysts. Alongside, an inductive open coding approach was also undertaken to identify new categories. Analysis was undertaken using NVivo QSR qualitative analysis software, Version 9. Themes were coded at the descriptive level with little attempt to infer beyond the surface or explicit meaning of the text.

Stage 3 involves exploration of relationships in the data, in order to consider differences within and between the data of included studies. Vote counting was conducted to identify relationships within and between characteristics of each study, including a sub-group analysis by country, profession and health care setting. Stage 4 assesses the robustness of the synthesis, in order to provide an assessment of the strength of the evidence for drawing conclusions and for generalising the findings of the synthesis. Quality assurance approaches are highlighted, and the findings placed in the context of wider literature.

### Results

The flow diagram is shown on the next page.

**Figure 6 Staff Perceptions sub-study: flow diagram**

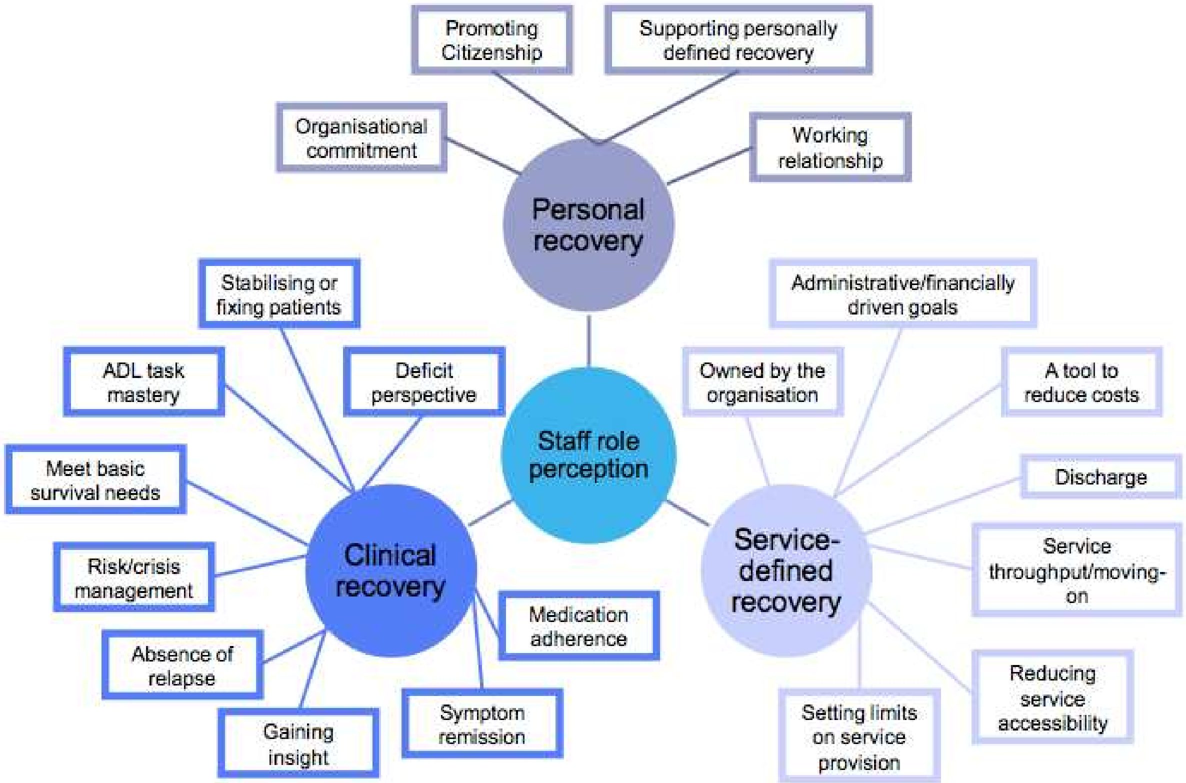


All 22 papers included in the review were qualitative studies reporting an original staff conceptualisation of recovery-orientated practice. Study designs comprised interview (n=10), focus group (n=6), interview and focus group (n=2), participant observation (n=1), Delphi consultation (n=1) and mixed method (n=2) study designs. Studies involved nurses (n=3), case managers (n=3), social workers (n=2), psychiatrists (n=2), team leaders (n=1), occupational therapists (n=1), clinical psychologists (n=1), art therapists (n=1) and multidisciplinary samples (n=8). Service settings were in-patient (n=5), community (n=8), both (n=7) or not specified (n=2). Research took place in USA (n=7), Australia (n=4), Canada (n=4), UK (n=3) and Europe-wide (n=1), Hong Kong (n=1) and Thailand (n=1).

*Stage 2: Preliminary synthesis*

The thematic analysis of the four UK and European papers led to an initial framework with one overarching category, called Staff Role Perception. Staff conceptualisations of recovery-orientated practice fell into three sub-categories: Clinical Recovery; Personal Recovery; and Service-Defined Recovery. These themes were then extended and developed further using the 18 studies conducted outside Europe. No further categories were identified, suggesting the developed theory is not specific to the UK context. The final coding framework is illustrated in Figure 7.

**Figure 7 Staff Perceptions sub-study: coding framework for staff conceptualisations of recovery-orientated practice**



Nine papers reported conceptual uncertainty, finding that recovery-orientated practice is a 'difficult to define' concept. Clinical Recovery involved a focus on the professional as an expert working within an established health infrastructure, with clinical tasks shaping recovery-orientated practice. Personal Recovery involved supporting personally defined recovery through person-centred goals, service user autonomy and a strengths focus. Service-defined Recovery was owned by the organisation, with a focus on administrative and financial goals achieved through service throughput and setting limits on service provision.

*Stage 3: Exploring relationships*

All 22 studies were included in the vote counting process. For the category Personal Recovery, papers were characterised using categories from the recovery practice framework[63], as shown in Appendix 12. Individual studies contained a mean of 2.6 (16%, range 0 to 8) of the 16 categories of Personal Recovery. The categories with the most studies were Holistic approach (8 studies) followed by Social Inclusion, Informed Choice, Partnership and Inspiring Hope (7 studies each).

For the Clinical Recovery and Service-defined Recovery categories (for which no existing frameworks exist), papers were characterised using the inductively-derived lower order categories. Appendix 13 shows the vote counting for the Clinical Recovery category. Individual studies contained a mean of 2.1 (23%, range 0 to 5) of the nine categories of Clinical Recovery. The categories with the most studies were Risk / Crisis Management (9 studies), Medication Adherence and Stabilising Or Fixing Patients (8 studies each). Appendix 14 shows the vote counting for the Service-Defined Recovery category. Individual studies contained a mean of 0.9 (13%, range 0 to 3) of the seven categories of Service-Defined Recovery. The categories with the most studies were Administrative / Financially Driven Goals (6 studies) and Discharge (4 studies).

A sub-group analysis was undertaken to identify differences and relationships between the included studies. Vote counting for this comparison is shown in Appendix 15. Overall, staff understandings span personal, clinical and service-defined recovery. The primary focus of Personal Recovery was a holistic approach and an emphasis on social inclusion, choice and hope-inspiring partnership working.

The primary focus of Clinical Recovery was risk, medication and clinical management. The primary focus of Service-defined recovery was a focus on organisational goals and on discharge.

*Stage 4 - Assessing the robustness of the synthesis*

To ensure a robust synthesis, critical appraisal was undertaken at each stage of the data collection and analysis. A random 20% (n=2,033) of sifted papers were double rated, with agreement on 1,972 (97%). The 61 papers with discordant ratings were obtained in full, and 2 (3%) were assessed as eligible for inclusion. All 245 papers retrieved in full were double rated for inclusion, with 95% concordance. Data relevant to the research question from all included studies were extracted and tabulated independently by two analysts. Finally, the thematic analysis of the preliminary framework using UK and European studies was completed separately by two analysts.

### Discussion

The aim of the review and narrative synthesis was to obtain conceptual clarity about staff understanding of recovery-orientated practice. A total of 22 studies describing original staff conceptualisations of recovery-orientated practice were identified and narrative synthesis was used to identify an overarching category of, Staff role perception, comprising three sub-categories: Clinical Recovery; Personal Recovery; and Service-defined Recovery.

This is the first systematic review and narrative synthesis of staff conceptualisations of recovery-orientated practice. Until now, staff perspectives have been largely absent from the recovery literature. This is consistent with the present review in which only 22 of the 245 papers accessed in full and assessed for eligibility focused on staff understanding. There was no evidence of international differences across the 16 countries represented in the review. Whilst the notions of supporting personal recovery and clinical recovery are well documented, a new concept ‘service-defined recovery’ was identified. All three conceptualisations of recovery-orientated practice can be used when assessing recovery-orientation and supporting implementation of recovery-orientated practice in mental health services.

*Strengths and limitations*

Adopting a transparent systematic review and narrative synthesis methodology addresses some of the criticisms around rigour in qualitative research and increases confidence in the final theory. The robustness of the review was enhanced by the inclusion of three different approaches to validating the framework: double-rating a proportion of papers to assess eligibility; double-coding and data extraction of included papers; and presentation to staff attending an international conference.

A limitation was that the narrative synthesis is a secondary analysis of data that focuses on the interpretations presented by the authors of the original papers, and is not based on primary data. Furthermore, the findings represent one interpretation of the data and should be viewed as a heuristic theory of staff perspectives on recovery-orientated practice.

*Implications*

The findings have two main implications for policy and practice. First, the three staff conceptualisations of recovery-orientated practice provide a framework for assessing the effectiveness of the mental health system in implementing recovery orientation. The identified categories could be used to guide the development and accreditation of services towards a recovery-orientated approach.

Second, given that national mental health policy is aligned around personal recovery, this review indicates two transformation challenges. First, the move from a focus on clinical recovery to a focus on personal recovery. Second, and a new finding, is that our findings are consistent with service user concerns that recovery is being ‘commandeered’ by the system, i.e. using the recovery label to meet service priorities, which tend to focus on reduced financial expenditure rather than improved quality and so may well not align closely with personal recovery.

In the context of austerity, a key question is the cost-effectiveness of these different orientations. Clinical recovery may be a financially unsustainable approach, with increasing expectations, higher morbidity and reduced resources. It may be that a personal recovery orientation promotes self-management, leading to reduced service need and hence cost savings. What remains unknown are the resource implications of the third approach we identified – Service-defined recovery. This third approach may have arisen for at least two reasons. First, services have been told through national policy to be recovery-orientated. In the absence of concrete guidance, the management approach of developing key performance indicators (throughput, discharge etc.) have tried to fill the gap. Second, the over-riding need to reduce costs may have led to recovery being used as a justification for service cuts. Both these lead to mis-uses of personal recovery, which have been documented[108]. So the value for money offered by Service-defined recovery, both in relation to outcomes for service users and financial implications, is a priority for future research.

A level of international consensus was evident across 16 countries where the three staff conceptualisations of recovery-orientated practice emerged. Whilst the notions of supporting personal recovery and clinical recovery are well documented, a new concept of service-defined recovery was also identified. All three conceptualisations of recovery-orientated practice must be considered when assessing recovery-orientation and supporting implementation of recovery-orientated practice in mental health services.

### Synthesis of evidence from Chapter 2

The evidence presented in this chapter has directly addressed knowledge gaps. The conceptual framework for recovery developed and validated an understanding of personal recovery which makes more explicit the key features of this paradigm. The recovery practice framework translates these key features into service characteristics, by identifying best practice internationally in supporting recovery. The state of recovery practice and experience across England is illuminated by the national survey, which specifically identifies the un-used resource of lived experience within the mental health workforce. Finally, primary and secondary research about staff perceptions makes visible a previously implicit translation of recovery within mental health systems.

A key contribution of the REFOCUS programme has been the generation of new theory to underpin recovery-related research, both within the remainder of the programme and in other studies. The impact of this theory on the wider policy, research and practice community is outlined in Chapters 9 and 11.

The theory presented in this chapter underpinned the development of the REFOCUS intervention, which is now described.

# Chapter 3: Optimise the intervention

This chapter describes how the REFOCUS intervention was developed. The experience of black mental health service users emerged as a focus, so a framework for understanding recovery within this group was developed. A defining feature of a recovery orientation is a focus on strengths, so a systematic review of strengths measures is described. The development of a new measure assessing feasibility is then reported. Finally, based on these components and the theory presented in the previous chapter, the development of the REFOCUS intervention, model, intervention strategies and manual are described.

## Framework For Black Service Users sub-study

### Introduction

In the narrative synthesis used to develop the conceptual framework for recovery outlined in the previous chapter, 6 (7%) of the 87 studies investigated recovery from the perspective of Black and Minority Ethnic (BME) individuals. These comprised a survey of 50 recipients of a community development project in Scotland[109], a qualitative interview study of African-Americans[110], a narrative literature review[111], a qualitative study of 40 Maori and non-Maori New Zealanders[52], a pilot study to test whether the Recovery Star (RS) measure was applicable to Black and Asian Ethnic Minority population[112] and a mixed method study of 91 males from African-Caribbean backgrounds[113]. These six studies were re-analysed by a second analyst, using a more fine-grained, line-by-line approach to thematic analysis. These papers provide some preliminary insights into a small number of distinct ethnic minority perspectives, which do not represent a culturally homogenous group, although some similarities in experience can be observed. Although these six papers were included in the vote counting process, four of the six BME papers were not used in the first stage thematic analysis. The line-by-line secondary analysis allowed exploration in greater detail any differences in emphasis and additional themes present in these papers.

The main finding of the sub-group analysis indicated that there was substantial similarity between studies focussing on minority communities and those focussing on majority populations. All of the themes of the conceptual framework were present in all six of the BME papers. Despite this overall similarity, there was a greater emphasis in the BME papers on two areas in the Recovery Processes: Spirituality and Stigma; and two additional categories: Culturally specific factors; and Collectivist notions of recovery. In relation to Spirituality, being part of a faith community and having a religious affiliation was seen as an important component of an individual's recovery. In relation to Stigma, BME studies emphasised the stigma associated with race, culture and ethnicity, in addition to the stigma associated with having a mental illness. The new category of Culturally specific factors included the use of traditional therapies, faith healers and belonging to a particular cultural group or community. Finally, collectivist notions of recovery were emphasised as both positive and negative factors. Many individuals discussed the hope and support they received from their collectivist identity, but for others the community added to the pressures of mental illness. Furthermore, the negative impact of the community was felt not only at the level of the individual, but also at the collectivist level, with the whole family being adversely affected by stigma.

However, overall very little research has been conducted into the perspectives of recovery for people from black communities, with even less attention focused on how to support their recovery. Consistently, Jones and colleagues found an absence of attention to race, culture and ethnicity in their review of the recovery literature[114]. Therefore a knowledge gap remains about the meaning of recovery for black individuals who use adult community mental health services within the UK.

This knowledge gap was addressed in a qualitative study which developed a framework of recovery support for black individuals. The study has two aims: i) to understand the meaning of recovery and the barriers and facilitators of recovery both in relation to mental health services and to the wider context of the individual's life; and ii) to identify the types of support and services that individuals feel would support their recovery.

## Methods

### *Design*

Two qualitative methods, individual interviews and focus groups were used to allow for methodological triangulation[115]. The focus groups aimed to gain a breadth of opinions and a group perspective. The topics identified in these focus groups were followed up in individual semi-structured interviews which built upon the emergent themes and included more in-depth personal stories and experiences of recovery.

*Setting*

Four focus groups and 14 individual interviews were conducted in four NHS trusts within England: South London and Maudsley NHS Foundation Trust (SLaM); Leicester Partnership NHS Trust; 2Gether NHS Foundation Trust; and Tees Esk and Wear Valley NHS Trust. The settings were selected to represent a range of metropolitan, urban and semi-rural geographical areas. All interviews and focus groups were conducted at local voluntary or statutory sector properties.

*Sample*

We recruited a convenience sample of black working age adults (16-65), who were currently using (or had used in the previous six months) community-based mental health teams which utilised the Care Programme Approach. Inclusion criteria were self-ascribed ethnicity as black, black African, black Caribbean, African Caribbean, black British or black other; able to understand and speak English fluently; well enough to participate as rated by their clinician or care coordinator; and willing and able to discuss their experience of recovery from mental health problems.

For the focus groups in sites where there was a low proportion of eligible individuals (Leicester Partnership NHS Trust and 2Gether NHS Foundation Trust), a pragmatic decision was taken to increase the eligible sample by extending the inclusion criteria to include individuals from Asian and mixed race backgrounds (where part of the individual's identity was self-ascribed as black).

As the sample used within the study was a convenience sample, characteristics of the individuals who declined to take part were not available. To maximise the variation within the convenience sample, participants were selected to include people with differing levels of service use, time within services, receiving care from different types of team types (e.g. early intervention, assertive outreach, forensic, support and recovery) to ensure a diversity of opinions. Recruitment continued until category saturation was achieved[116].

*Procedure*

Participants were recruited through care co-ordinators within community-based mental health teams and via posters displayed within local community-based organisations and hospital out-patient departments. Additionally, participants were recruited from two voluntary sector BME organisations within South London. Participants received a £20 in the focus groups and £10 in the individual interviews. Prior to the start, participants were given a written information sheet outlining the purpose of the study and were encouraged to ask questions before giving their written informed consent.

Each focus group was moderated by two researchers, one from a professional research background and another who had lived experience of using mental health services (as described in Chapter 10). Each group lasted approximately 1.5 hours. At the beginning of each group, participants completed a brief socio-demographic questionnaire. The topic guide was developed with PPI as described in Chapter 10, and covered participants' understanding of recovery, its barriers and facilitators, and what services would support their recovery. Following the focus groups both facilitators engaged in a reflexive activity to record their initial impressions of the group and any thoughts about the session as a whole.

For the individual interviews, participants were given the choice of being interviewed either by the main researcher or by a black interviewer (from a voluntary sector BME organisation). One individual requested and had their interview conducted by a black interviewer, all other interviews were conducted by the main researcher. Informed consent was obtained from all participants. The individual interviews lasted up to one hour, and involved open-ended question relating to the individual's personal experience of recovery.

*Analysis*

Focus groups and interviews were audio-taped and transcribed verbatim. Transcripts were anonymised and imported into N-Vivo, (version 8, QSR international) for analysis. Thematic analysis was used for the data analysis, following the guidance of Braun and Clarke (2006)[66], using an inductive open coding approach. To improve the reliability of coding, a second rater independently coded a proportion of the focus group and interview transcripts. Both coders agreed on the core category and discussed the relationship of other themes within the core category.

## Results

26 participants took part in four focus groups and 14 individual interviews (including 5 focus group participants) were conducted until category saturation was achieved. Participant characteristics are shown in Table 14.

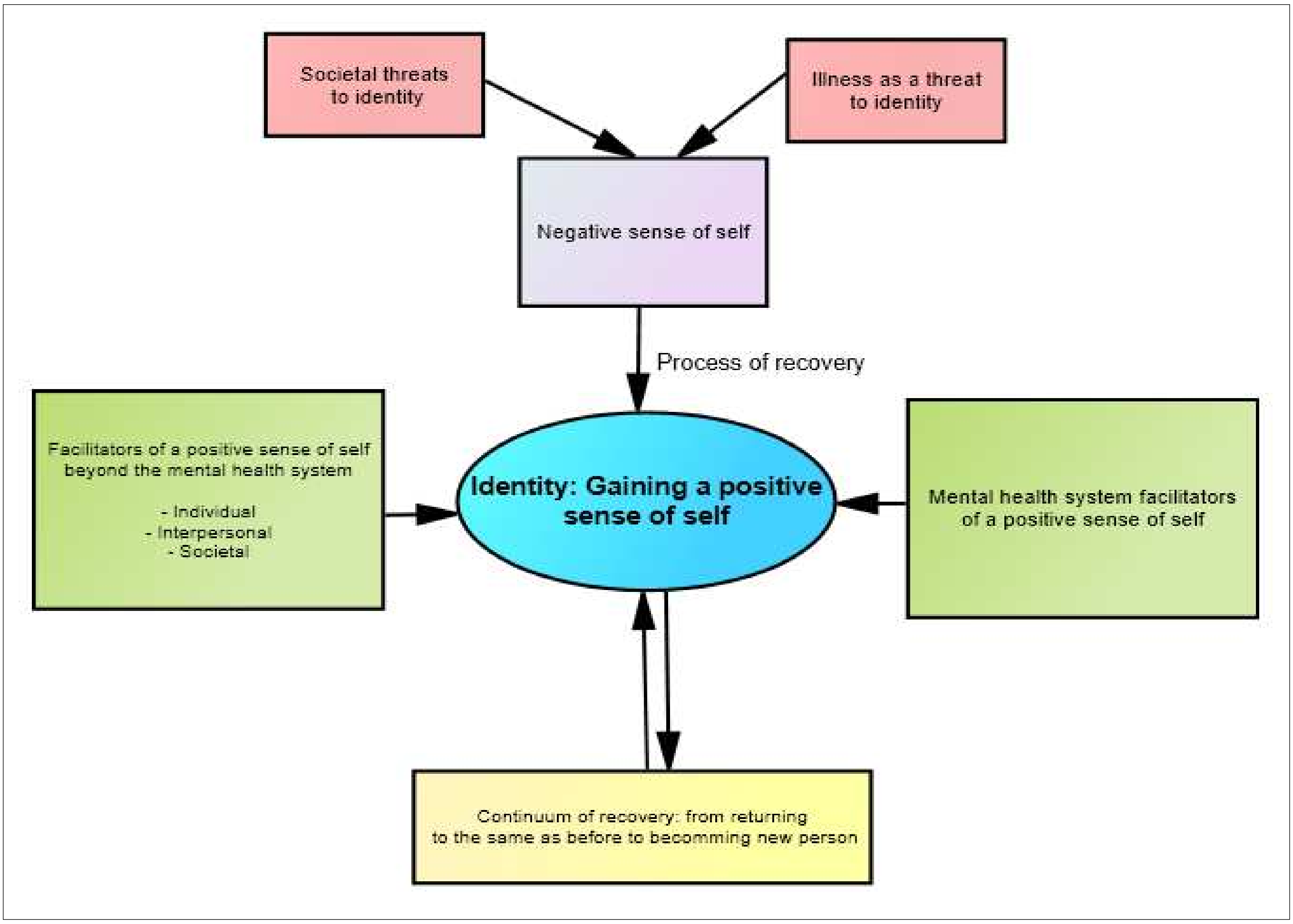
**Table 14 Framework For Black Service Users sub-study: characteristics of participants (n=40)**

| Characteristics | Focus Groups | Individual Interviews |
|---|---|---|
| n | 26 | 14 |
| Gender (N, %): | | |
| Female | 11 (42%) | 8 (57%) |
| Male | 15 (58%) | 6 (43%) |
| Age (Mean, s.d.) | 41.2 (12.4) | 41.9 (10.8) |
| Ethnicity (n, %): | | |
| Black/ Black British - African | 10 (38%) | 5 (36%) |
| Black/ Black British - Caribbean | 7 (27%) | 5 (36%) |
| Black Other | 1 (4%) | 1 (7%) |
| Asian / Asian British – Indian | 2 (8%) | 0 |
| Asian / Asian British - Pakistani | 1 (4%) | 0 |
| Asian other | 0 | 0 |
| Mixed race | 1 (4%) | 3 (21%) |
| Other | 4 (15%) | 0 |
| Diagnosis (n, %): | | |
| Psychosis | 3 (11%) | 1 (7%) |
| Schizophrenia | 5 (19%) | 4 (29%) |

| | | |
|---|---|---|
| Schizoaffective disorder | 6 (23%) | 0 |
| Bipolar Disorder | 1 (4%) | 3 (21%) |
| Psychotic depression | 2 (8%) | 1 (7%) |
| Depression | 2 (8%) | 2 (14%) |
| Other | 2 (8%) | 2 (14%) |
| Did not want to disclose | 5 (19%) | 1 (7%) |
| Mental health team type (n, %): | | |
| CMHT | 2 (8%) | 0 |
| Support and recovery | 9 (35%) | 4 (29%) |
| Early intervention service | 3 (11%) | 1 (7%) |
| Assertive outreach | 3 (11%) | 0 |
| Home treatment team | 0 | 1 (7%) |
| Forensic | 1 (4%) | 1 (7%) |
| Rehabilitation | 1 (4%) | 1 (7%) |
| Continuing care | 3 (11%) | 3 (21%) |
| Other | 2 (8%) | 2 (14%) |
| Did not want to disclose | 2 (8%) | 1 (7%) |
| Time in MH services years (mean, s.d.) | 9.0 (6.1) | 11.2 (7.8) |
| NHS trust (n, %): | | |
| SLAM | 19 (73%) | 13 (93%) |
| 2Gather | 2 (8%) | 0 |
| Tees, Esk and Wear Valley | 0 | 1 (7%) |
| Leicester | 5 (19%) | 0 |

The core category within the analysis which was linked to all other dominant themes and sub-themes was ‘Identity - gaining a positive sense of self’. The full coding framework is shown in Appendix 16, and the coding framework is illustrated in Figure 8.

**Figure 8 Framework For Black Service Users sub-study: diagram showing coding framework**



The core theme throughout the interviews and focus groups was that of identity and in particular gaining a positive sense of self. Often, the mental health problem was expressed in terms of identity and what it meant to the person and their sense of self. Regaining a positive sense of identity was key to recovery regardless of whether the person saw themselves as having a mental health problem, and/or whether they still had symptoms or not. What was important was how the person saw themselves and how they were viewed by and within society. Gaining, or in some cases regaining, a previously positive sense of identity included having a strong identity, high self-esteem, and generally feeling good about yourself.

### Discussion

This qualitative study explored perceptions of recovery and recovery support with black individuals who are currently using community mental health services. The core category from the analysis related to identity and (re)gaining a positive sense of self.

This study adds to the small literature on recovery in minority populations[117,118]. Of particular relevance to the REFOCUS study, individuals described the different ways services could help them feel more positive about their sense of self. The mental health level facilitators including having staff members who valued the person and respected them as an individual with a unique story and background, this included staff avoiding making assumptions about the person based on their race, culture or ethnicity. Individuals also expressed the need for access to the right services and professionals, and how what was considered right for one person, may not be right for another. Rather than a “one size fits all approach” the treatment preferences regarding both services and staff were linked to the person’s beliefs set and values. In essence, one way staff could aid recovery and the promotion of a positive self-image, was by gaining an understanding the person’s values and treatments preferences. This in turn made the individual feel better understood, listened to and valued as a person.

## Strengths Measures sub-study

Adapted with permission from the published report for this study[119].

### Introduction

A consistent theme in recovery-oriented services internationally is a focus on strengths[120]. Staff identified the need for tools to help with this process, so the REFOCUS programme undertook a systematic review of strengths measures, with the goal of identifying a measure for use in the REFOCUS intervention.

### Methods

The aims of this study were to describe and evaluate the available strengths assessments, including their psychometric properties, for use in mental health services. The full systematic review has been published[119], and copyright restrictions mean only a summary can be produced here.

Search Strategy and Data Sources

A systematic literature search using four sources:

1. 12 bibliographic databases were searched from inception to August 2010: AMED, British Nursing Index, EMBASE, MEDLINE, PsycINFO, Social Science Policy (accessed via OVID SP); CINAHL, International Bibliography of Social Science (accessed via EBSCOhost); and ASSIA, British Humanities Index, Sociological abstracts and Social Services abstracts (accessed via CSA Illumina). The search strategy was developed through a scoping search, and is shown in Appendix 17.
2. Hand-searching of the table of contents of five relevant journals and the reference lists of retrieved articles.
3. Web-based searches using Google Scholar and searching of 12 relevant websites.
4. Expert consultation with 54 individuals from professional, researcher and service user-researcher backgrounds.

Identified articles were added to Reference Manager, Version 11[121] and duplicate articles removed.

*Eligibility Criteria*

The inclusion criteria were papers that explicitly described or validated a strengths assessment for use within an adult mental health population (ages 18-65). The strengths assessment could be quantitative or qualitative, and had to explicitly identify and focus on the strengths of the individual. Exclusion criteria were use in non-mental health populations, listing strengths or strengths predictors without identifying the assessment, focused on only one particular strength, and not available in English. Eligibility was rated by one reviewer, with full text of potentially relevant papers retrieved.

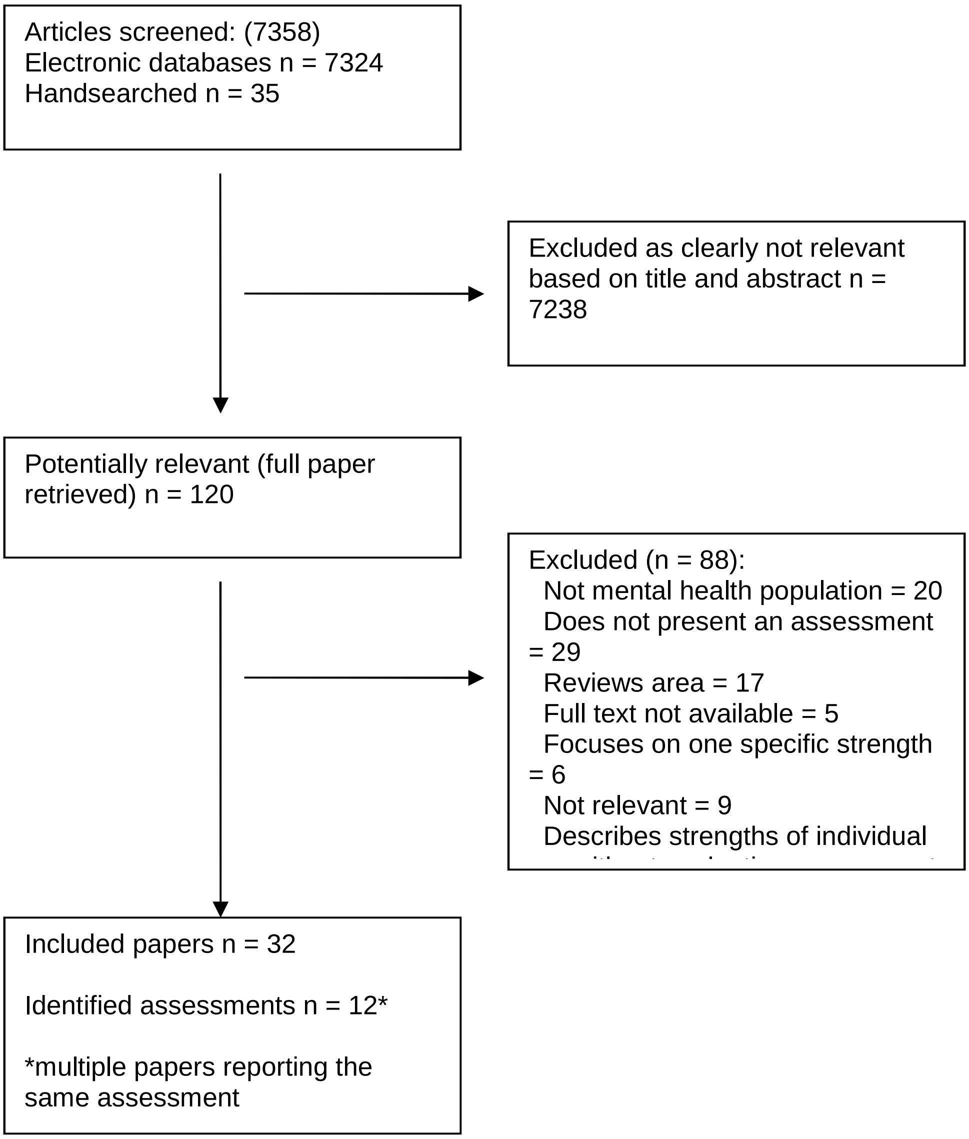
*Data Abstraction and Management*

Data were extracted and tabulated. Assessment items were extracted and themed to reflect the definitions of strengths used in the assessments and in the wider literature. Vote counting identified the number of papers mentioning each theme, and themes included in three or more assessments were organised into an overarching framework by two reviewers, with disagreements resolved by discussion. Psychometric properties of assessments were evaluated against established quality criteria[122].

**Results**

The flow diagram is shown in Figure 9.

**Figure 9 Strengths Measures Review sub-study: flow diagram**



*Operationalisation of Strengths*

The review identified 12 strengths assessment measures, comprising 7 qualitative and 5 quantitative measures. A total of 39 themes were identified from assessment items, which were organised into three categories. The 24 themes rated in at least three assessments are shown in Table 15.

### Table 15 Strengths Measures Review sub-study: strengths themes

| Assessment | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Theme 1: Individual strengths** | | | | | | | | | | | | | |
| Personal / psychological factors, e.g. hope, temperament, optimism | | | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | 10 |
| Dreams, aspirations or goals | √ | √ | √ | | | √ | | √ | √ | | | √ | 7 |
| Skills, talents and competencies | √ | √ | √ | | √ | √ | √ | √ | | √ | | √ | 9 |
| Resilience and coping abilities | √ | | √ | | √ | √ | √ | √ | √ | √ | | √ | 9 |
| Spiritual/ religious | √ | √ | √ | | √ | | | √ | | √ | | √ | 7 |
| Health and health management (physical and mental) | √ | | √ | | | √ | | √ | | √ | √ | | 6 |
| Occupation including vocation and education | √ | | √ | | | | | √ | √ | √ | | | 5 |
| Leisure and interests | √ | | √ | | | √ | | √ | | √ | | | 5 |
| Cognitive | | | | | | | √ | √ | | √ | √ | √ | 5 |
| Commitment to learning and growth | | | √ | | √ | | √ | | √ | | | √ | 5 |
| Substance misuse including overcoming misuse | | | √ | | √ | | | √ | | √ | √ | | 5 |
| Self-concept including ethnicity, sexuality, gender etc. | | | | | √ | | √ | | √ | √ | | | 4 |
| Overcoming weaknesses | | | √ | √ | | | √ | | | | | | 3 |
| **Theme 2: Environmental strengths** | | | | | | | | | | | | | |
| Social supports | √ | √ | | | √ | √ | √ | √ | √ | √ | | √ | 9 |
| Community | √ | √ | √ | | √ | √ | √ | √ | | √ | | √ | 9 |
| Family | √ | | √ | | √ | √ | √ | √ | √ | √ | | | 8 |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Environmental assets and resources | | | | √ | | √ | √ | | | √ | | | 4 |
| Housing / living | √ | | √ | | | | | √ | | √ | | | 4 |
| Political including rights and advocacy | | | | | √ | | √ | √ | | | | √ | 4 |
| Transportation | √ | | √ | | | | | √ | | √ | | | 4 |
| Financial resources | √ | | √ | | | | | √ | | | | | 3 |
| **Theme 3: Interpersonal strengths** | | | | | | | | | | | | | |
| Relationships | √ | | √ | | √ | √ | √ | √ | √ | √ | √ | √ | 10 |
| Solutions | | | | | | √ | √ | √ | √ | | | √ | 5 |
| Options | | | | | √ | √ | | | √ | | | | 3 |

The Individual strengths theme relates to the resources available to the person, including their talents and attributes. The Environmental strengths theme relates to external resources within the person's immediate environment and wider community. The Interpersonal strengths theme relates to strengths arising from the interaction between the person and their environment.

*Research Using Assessments*

The most widely used assessment was the qualitative Strengths Assessment Worksheet (SAW)[45] which has been evaluated as part of the broader Strengths-Based Case Management (SBCM) intervention for individuals with severe mental illness. Ten evaluations of SBCM have been conducted, including three randomised controlled trials (RCTs), four quasi-experimental studies and three non-experimental designs. The quantitative Client Assessment of Strengths, Interests and Goals (CASIG)[123] had been used in two psychometric and two evaluative studies. The quantitative Values In Action – Inventory of Strengths (VIA-IS)[124] had been used in 2 studies.

Evaluation of the psychometric properties of the five quantitative study found that no measure demonstrated comprehensive adequacy. In relation to mental health populations, no measure had evidence of agreement, reliability, responsiveness, avoidance of floor / ceiling effects, or high interpretability. The strongest measure was CASIG, with demonstrated content validity, internal consistency and construct validity. Of relevance to the REFOCUS programme, no included study assessed the feasibility of conducting strengths assessments with individuals with mental illness. Specifically, burden for service users and implications for staff time have not been evaluated.

### Discussion

This systematic review identified and evaluated 12 strengths-based assessments for use within mental health services. The most frequently used measure was the Strengths Assessment Worksheet (SAW). The Client Assessment of Strengths, Interests and Goals (CASIG) was the only quantitative measure to be adequately psychometrically evaluated, showing evidence of internal consistency, construct and content validity. Overall there was a lack of good quality research evaluating the use of the strengths assessments within mental health populations, with limited information about the feasibility of routine use of strengths measures.

*Strengths and Limitations*

The review is the first systematic review and evaluation of strength-based assessments for use within mental health services, using a robust search strategy We identify three limitations. First, the review did not consider strengths measures derived from positive psychology and designed for the general population. For example, the Clifton Strengths Finder[125] and the Realise2 tool[126] assess personal strengths from a performance perspective. These assessments have potential applicability to mental health services[127]. Second, measures not using the terms related to ‘strengths’ may not have been included. Hand-searching reference lists and web-based searching of all identified measures somewhat addresses this limitation. Finally, the term “strengths” was not defined for many measures. The empirical identification of three dimensions of strengths – individual, environmental and interpersonal – could inform future measure development.

There are several points of alignment between strengths-based approaches and recovery. For example, the positive relationship between the service user and worker is central to both. Studies of therapeutic alliance indicate that a positive relationship is valued by both parties[128], with quantitative data supporting the association between positive therapeutic relationships and improved mental health outcomes[129]. This emphasis on relationships emerges both in the conceptual framework for recovery[8] and the recovery practice framework[63].

Overall, only two of the available strengths assessments can be tentatively recommended for routine use: CASIG and SAW. As the REFOCUS intervention involves strengths assessment to inform care planning, rather than for evaluative purposes, useability rather than psychometric adequacy is the most important characteristic. Therefore the most widely used assessment – SAW – will be used in the intervention.

## SAFE Development sub-study

Adapted with permission from the published report for this study[130].

### Introduction

There is an increasing range of interventions available for policy makers and mental health workers to consider, often with reference to changing organisational priorities[131]. However, recommending interventions which cannot be implemented wastes resources, as staff and managers spend time developing services which do not meet expectations, and money is wasted developing and auditing clinical guidelines which contain hard-to-implement interventions. This has led to research into implementation influences with reviews highlighted that the feasibility of an intervention is one important factor in regards to evidence translation[132]. We define the feasibility of an intervention as the cumulative impact of influences on implementation of an intervention within a specific health care system or practice. Across medical disciplines there is need to better characterise what is and is not feasible within practice, to minimise wasted resources, inform prioritisation decisions and improve the effectiveness in health systems. In this study we specifically focus on the mental health system within the NHS in England, as an exemplar in which routine implementation of innovation has been cited as a problem[99].

The NHS Institute for Innovation and Improvement developed the Spread and Adoption tool, which aims to help staff increase the sustainable implementation of innovations within the NHS[133]. This online tool asks individuals to rate agreement with a number of statements grouped into three categories: People, Innovation and Context. Although providing a summary assessment, the tool does not specifically focus on rating the feasibility of the intervention and instead covers a broader range of contextual factors, furthermore, it lacks a clear empirical basis. At present no measure has been specifically designed to assess the feasibility of a complex intervention for implementation in mental health services. Furthermore, despite reporting guidelines such as CONSORT leading to demonstrable improvements in the reporting of studies within high quality journals[134], there are no reporting guidelines which ensure that the paper contains enough information to allow the feasibility of the intervention to be assessed.

This study aims (i) to produce an evidence-based and reliable measure of the feasibility of implementing a specified intervention in mental health services within the NHS, and (ii) to develop reporting guidelines identifying information to report which allows feasibility to be assessed. This involved the development and preliminary evaluation of a Structured Assessment of Feasibility (SAFE) Measure.

## Methods

### *Design*

Focussed narrative review was used to inform the development of a measure, followed by psychometric evaluation and modification of the measure through piloting.

### *Literature search*

Four data sources were used to identify potential studies for inclusion in the focussed narrative review:

1) Google Scholar, NHS evidence and PubMed were searched using the terms “implementation” AND (“barriers” OR “facilitators”) AND “mental health”
2) Table of contents for the journal Implementation Science from January 1999 until December 2010
3) Hand searching the references of retrieved papers for additional citations
4) Recommendations from an implementation science expert.

### *Eligibility criteria*

Inclusion criteria were:

a) available in print or downloadable format (PDF file or Word document) – so dissertations and theses were excluded due to their limited availability

b) the study either focused on mental health or an area directly applicable to mental health such as empowerment or shared decision making in long-term conditions

c) the study was either a primary qualitative study with 10 or more participants, a survey or systematic review of the literature

d) primary studies were conducted within the UK or (for review studies) a proportion of the included studies were conducted within the UK to ensure applicability to the NHS context;

e) the study focused on the implementation of a manualised intervention or guideline at the individual staff, team or service level.

*Data extraction and tabulation*

For each included paper the data extracted and recorded in an online database were: methodology, target population, location, details of the intervention or guideline being implemented and the main implementation barriers and facilitators identified. Quality assessment of qualitative studies used RATS[15] (with poor quality defined as two or more red flags), of quantitative studies used the Effective Public Health Practice Project tool[16], and of reviews used the NICE systematic review checklist[135] (with poor quality defined for both as a negative quality rating, indicating significant evidence of bias). Poor quality studies were excluded.

*Analysis*

To develop the measure, thematic analysis was used to identify implementation influences, barriers and facilitators within included studies. These were tabulated and vote counting used to determine the frequency of each theme across the included papers. Influences which were included in two or less studies were excluded due to limited generalisability. The remaining implementation influences were assessed to check their relevance to characterising the feasibility of an intervention. Only influences that directly related to characteristics of the intervention were included, for example, the amount of training required or whether the intervention was manualised, were included. Each influence was then operationalised as a single question, e.g. the implementation barrier ‘lack of time’ was operationalised as: Is the intervention time consuming? Each item was rated as Yes, Partial, No, or Unable to rate. Anchor points for each item were developed based on the consensus opinion of three NHS workers and two researchers. The draft measure was then piloted and modified by three members of the research team (one NHS worker and two researchers) to ensure the rating categories were comprehensively defined and the measure easy to use.

To investigate the psychometric properties of SAFE, 19 purposively selected papers (reporting on 20 interventions) were rated using the measure[7,136-153]. The interventions were described in trial reports (n=15) and study protocols (n=5), and spanned pharmacotherapy (n=2), psychosocial (n=12) and service based interventions (n=6). Rateability of SAFE items was tabulated. To investigate test-retest reliability each paper was re-rated one week later. To investigate inter-rater reliability, each paper was independently double-rated by a second researchers. Reliability was measured using weighted Cohen's Kappa. Confidence intervals were calculated using Wilson efficient-score method, corrected for continuity with a coefficient >0.75 representing excellent reliability[154]. Cohen's Kappa was calculated for overall agreement between raters and to rate agreement by category (Yes vs. Partial vs. No vs. Unable to rate).

### Results

A total of 299 references were identified in the literature search of which 54 articles were potentially relevant and the full text retrieved. Eleven of the 54 papers were eligible for inclusion[132,155-164]. The most common reason for exclusion was that results were not applicable to the NHS context. Included studies comprised four systematic reviews, two narrative reviews, two survey designs, two semi-structured interview studies and one based on expert consensus. Of the 11 papers, six assessed facilitators and barriers of implementation within the NHS, and five reviewed the international literature, including UK based papers.

Ninety-five implementation influences (i.e. barriers and facilitators) were identified from the 11 included papers. Thirty-nine of these 95 influences related to the characteristics of the intervention so were retained and included in the vote counting shown in Table 16.

**Table 16 SAFE Development sub-study: vote counting of influences on implementation (n=39)**

| **IMPLEMENTATION INFLUENCE** | **Papers identifying the influence** n (%) |
|---|---|

| | |
|---|---|
| Staff skills to deliver the intervention | 9 (82) |
| Applicability of the intervention (to Service users) | 8 (73) |
| Match with staff values, attitudes – does it clash with preferred treatment approach and culture of the team, staff preference? | 8 (73) |
| Staff knowledge to deliver the intervention | 7 (64) |
| Time constraints | 7 (64) |
| Ongoing support and supervision | 5 (45) |
| Outcome expectancy (efficacy) – Do staff think the intervention will work? Etc. | 5 (45) |
| Cost-benefit of intervention (financial) | 5 (45) |
| Cost-benefit (efficacy, risk etc.) – perception of advantage, risks, regret for doing or not doing the intervention | 5 (45) |
| Match with the organisational culture – does it link with values, attitudes of the organisation, is it supported etc. | 4 (36) |
| Match with current practice - Is the intervention breaking routines and habits? Are there contradictory practices or guidelines. Conflict with usual routines and roles | 4 (36) |
| Lack of resources | 4 (36) |
| Flexibility / modifiability – can the intervention be adapted to fit the local context and situation | 4 (36) |
| Guideline / intervention availability including availability of a manual or guide | 3 (27) |
| Confidence in the intervention – lack of confidence in the developer, approach, evidence-based, credibility of the intervention and source. | 3 (27) |
| Lack of reimbursement or incentives to do the intervention | 3 (27) |
| Complexity of the intervention – is the intervention simple or complex | 3 (27) |
| Reversibility and trialability - are the changes permanent or can they be trialled | 3 (27) |
| Service user involvement including in the design of the intervention | 2 (18) |
| Outcome expectancy (observability) – time needed before the results become apparent, are the results observable | 2 (18) |
| Role match – does the intervention challenge the social roles and professional identity of staff. | 2 (18) |

| | |
|---|---|
| Intervention is too rigid, cook book and biased | 2 (18) |
| The intervention challenges staff autonomy | 2 (18) |
| Quality of design of the intervention | 2 (18) |
| Degree to which the action done by the team, organisation or individual is disruptive or radical | 2 (18) |
| Stressful nature of the intervention | 2 (18) |
| Time needed to keep up to date with the intervention | 1 (9) |
| Is the source of the intervention internal or external to the organisation | 1 (9) |
| Forgetting the intervention (content) – forgetting the content of the intervention | 1 (9) |
| Forgetting the intervention (action) – forgetting to do the intervention | 1 (9) |
| Divisibility – being able to separate out components of the intervention to implement at different times | 1 (9) |
| Centrality – does the intervention effect a central or peripheral activity | 1 (9) |
| Duration of change and how long will it take | 1 (9) |
| How much attention does the intervention require | 1 (9) |
| Will staff observe others doing the intervention | 1 (9) |
| Lack of trained supervisors | 1 (9) |
| Lack of opportunities for co-working | 1 (9) |
| Adaption of the intervention for sensory impaired groups | 1 (9) |
| Does the intervention allow for patient preference | 1 (9) |

From the 39 influences, 17 were identified in at least three papers and were used as candidate items for the measure. Items were then selected through a process of consensus and consultation within the research team, by merging items (*e.g.* additional skills or knowledge required was merged with the need for additional training), separating items (*e.g.* cost implications of the intervention was split into cost effectiveness and the cost of setting up the intervention), and deleting one item (concerning the match with staff values, as this could not be rated based on intervention papers alone). This process produced a 16-item draft measure, comprising eight barriers and eight facilitators of implementation. The measure was piloted and modifications made to the descriptions of each category, including defining the Unable to rate category, and adding more detail to items 3 and 14.

Both the Cochrane Collaboration[165] and the Centre for Reviews and Dissemination guidance (CRD)[166] recommend against using summary scores on quality assessments to categorise papers within a systematic review, since items within the scale may have unequal weight. Instead it is recommended that reviewers attend to the individual items of the scale when conducting sensitivity and sub-group analyses. This same approach was therefore adopted for SAFE. The reviewer rates individual items, without providing an overall summary score, as barriers and facilitators differ in their importance depending on the context. This resulted in the final measure, shown in Appendix 18.

*Psychometric evaluation*

The percentage of papers reporting enough information to allow rating of SAFE items is shown in Table 17.

**Table 17 SAFE Development sub-study: rateability of SAFE items**

| Item | **Trial papers (n=15)** n (%) | **Protocol papers (n=5)** n (%) | **All papers (n=20)** n (%) |
|---|---|---|---|
| **13. Cost saving** | 2 (13.3) | 0 (0) | 2 (10) |
| **1. Staff training** | 10 (67) | 1 (20) | 11 (55) |
| **4. Ongoing supervision** | 10 (66.7) | 3 (60) | 13 (65) |
| **3. Time consuming** | 13 (87) | 2 (40) | 15 (75) |
| **7. Costly set up** | 12 (80) | 4 (80) | 16 (80) |
| **5. Additional human resources** | 15 (100) | 4 (80) | 19 (95) |
| **12. Effectiveness** | 14 (93.3) | 5 (100) | 19 (95) |
| **2. Intervention complexity** | 15 (100) | 5 (100) | 20 (100) |
| **6. Additional material resources** | 15 (100) | 5 (100) | 20 (100) |
| **8. Adverse events** | 15 (100) | 5 (100) | 20 (100) |
| **9. Applicable to population** | 15 (100) | 5 (100) | 20 (100) |

| | | | |
|---|---|---|---|
| **10. Manualised** | 15 (100) | 5 (100) | 20 (100) |
| **11. Flexibility** | 15 (100) | 5 (100) | 20 (100) |
| **14. Matches prioritised goals** | 15 (100) | 5 (100) | 20 (100) |
| **15. Pilotable** | 15 (100) | 5 (100) | 20 (100) |
| **16. Reversible** | 15 (100) | 5 (100) | 20 (100) |

Across all studies, 90% of papers did not provide enough information for Cost saving to be rated, followed by Staff training (45%) and Ongoing supervision (35%).

Inter-rater reliability (Kappa = 0.84, 95% CI 0.79 – 0.89) and test-retest reliability (Kappa = 0.89, 95% CI 0.85 – 0.93) were both excellent. Across all responses, inter-rater agreement was 89% (95% CI 0.85 – 0.92) and test re-test agreement was 92.5% (95% CI 0.89 – 0.95). The "partial" category produced the lowest percentage agreement across different raters and time points, as shown in Table 18.

**Table 18 SAFE Development sub-study: agreement for each response category**

| **Response category** | **Agreement**<br>% (95% CI) |
|---|---|
| INTER-RATER | |
| Yes | 84.5 (78.0 – 89.5) |
| Partial | 57.8 (45.5 – 69.2) |
| No | 87.0 (76.2 – 93.5) |
| Unable to rate | 89.4 (76.1 – 96.0) |
| TEST RE-TEST | |
| Yes | 90.7 (84.9 – 94.6) |
| Partial | 72.9 (60.7 – 82.5) |
| No | 89.1 (78.2 – 95.1) |
| Unable to rate | 85.4 (71.6 – 93.5) |

Each item from the developed measure was modified and re-organised to produce reporting guidelines, shown in Appendix 19.

## Discussion

The Structured Assessment of Feasibility (SAFE) scale was developed through a focused literature review which identified barriers and facilitators of implementation specifically related to characteristics of the intervention being assessed. The resulting tool was demonstrated to be useable across a range of studies from simple pharmacological interventions through to complex service level innovations, with the psychometric evaluation indicating that SAFE has excellent inter-rater and test re-test reliability. Across the 15 trial reports and five trial protocols, frequently un-reported aspects included cost information, staff training time and ongoing support and supervision. SAFE Reporting Guidelines were developed to identify the information needed in intervention reports which allow SAFE to be rated.

The pilot study indicated that a number of areas – especially economic costs and staff time constraints – are at present poorly reported in both trial protocols and trial reports. One approach to improving the consistency of reporting within journals is the use of reporting guidelines[134]. The importance of providing reviewers with a means to assess different features of an intervention is highlighted by a study showing that, when sent systematic reviews, up to 63% of respondents indicated that they had subsequently used the review in their policy-making decisions[167]. Use of the SAFE reporting guidelines may support improved characterisation of feasibility.

### *Strengths and limitations*

The SAFE scale is the first useable and reliable measure of feasibility. The ease of use of SAFE suggests it could be easily appended to current evidence review processes across a range of different contexts. The associated reporting guidelines also have the potential to positively impact on the quality of intervention reports, providing systematic reviewers and policy makers with the information needed to evaluate likely implementation.

We identify several limitations. First, the item selection process was not systematic, and it is possible that a wider systematic literature review would have identified additional implementation barriers and facilitators. Second, the review was restricted to mental health services within the NHS, which may limit applicability to other healthcare settings. However, systematic reviews in other settings (such as the US) have identified similar implementation barriers and facilitators for other long-term physical and mental health conditions[158]. Gravel and colleagues[160] assessed the literature across high-income countries with reference to implementing shared decision-making in clinical practice. The vote counting process did not suggest that the barriers and facilitators identified in this review differed from those identified in the primary studies, suggesting a large amount of overlap between high income countries, and across different health conditions. Assessment of the use of the BARRIERS scale[168], which highlights barriers to research utilisation within nursing practice, has demonstrated that identified implementation barriers are stable across time and different geographical locations[169].

Third, only 20 interventions were included in the psychometric evaluation. The papers included in the evaluation did cover a broad range of interventions, including many featured within NICE clinical guidelines. The focus of the psychometric evaluation reflected areas important to a systematic review used for evidence appraisal: multiple reviewers rate included papers (inter-rater reliability) and the review is intended to be reproducible across time (test re-test reliability). Future work could evaluate the use of SAFE within a guideline development process. Finally, the method for developing the reporting guidelines did not follow a proposed methodology for developing reporting guidelines[170].

The Structured Assessment of FEasibility (SAFE) scale represents a novel approach to assessing the feasibility of interventions. SAFE has the potential to be used alongside efficacy and health economic evidence to inform decision-making by commissioners, policy makers and guideline developers. Identification of reporting guidelines for feasibility provides a mechanism for standardising the reporting of this aspect of interventions within high quality peer-reviewed publications. SAFE was used to inform the reporting of the REFOCUS intervention.

## Intervention Development sub-study

## Introduction

The sub-studies reported in Chapters 1 to 3 were used to develop the REFOCUS intervention, which was published as a manual[171]. The manual comprised a description of the intervention, how it was to be implemented in the REFOCUS trial, and a testable description of the causal pathway between intervention and improved recovery, called the REFOCUS Model.

## Methods

### *Design*

The scientific framework for the REFOCUS Programme was the MRC Framework for Complex Interventions[172], which proposes that complex interventions be developed from the systematic use of a clear theoretical basis. The development of the intervention involved three stages: (1) synthesis of theory to identify overarching principles, (2) development and manualisation of the REFOCUS intervention, and (3) development of the testable REFOCUS Model. The intervention built on existing research, synthesised either using systematic or narrative reviews (specifically 'systematized' reviews[67] which use some but not all features of a systematic review). Qualitative studies using interviews and focus groups addressed identified knowledge gaps.

### *Procedure*

#### *Stage 1 (Theory)*

The theory base for the REFOCUS intervention has been presented in this report. Chapter 2 described the general recovery-related studies which provide the conceptual basis for the REFOCUS intervention, and the earlier sections of Chapter 3 report studies addressing specific knowledge gaps relating to the development of the REFOCUS intervention.

#### *Stage 2 (REFOCUS Intervention and Manual)*

A proposed structure for the REFOCUS Intervention was developed by the research team. Expert input was then obtained from five advisory groups: a Lived Experience Advisory Panel (LEAP) of service users and carers (n=8); a steering group of topic-specific experts (n=19); a virtual advisory panel of service users, researchers and other stakeholders with an interest in black and minority ethnic mental health (n=10);

an International Advisory Board of international experts (n=8); and individual consultees (n=11). The five advisory groups were consulted on three aspects of the proposed structure for the REFOCUS intervention. First, how external valid is it, i.e. is it targeting recovery rather than some other aspect of good practice? Second, how feasible is the intervention for implementation in a community mental health team? Third, does the intervention capture the right level of change from current practice, i.e. is the level of ambition appropriate. Consultees were also asked to identify relevant established resources, specific intervention or tools. A particular focus was on ensuring meaningful patient and public involvement, so the impact of the LEAP was evaluated in relation to input from other advisory committees[173], as described in Chapter 10.

A draft manual was then developed, based on the findings from Stage 1 and the advisory committee consultation on the proposed structure. The advisory committees were then consulted again on the draft manual, in relation to feasibility (time, resources, skills), clarity (comprehensibility, clinical fit), presentation (language, concepts, layout) and applicability (overlap with current practice, appropriate level of behaviour change). The draft manual was modified based on responses to produce the final REFOCUS Intervention and REFOCUS Manual[171].

### *Stage 3 (REFOCUS Model)*

The results from Stages 1 and 2 were synthesised to develop the REFOCUS Model. The model comprised a description of the intervention, the proposed pathway from intervention to health benefit, and the outcome. The intervention primarily focused on workers, and understanding of practice change was informed by the theory of planned behaviour[174]. This theory proposes behavioural intent is influenced by attitudes and subjective norms, and by the perceived level of behavioural control. Meta-analysis of health research suggest the theory accounts for over 20% of actual behaviour[175].

## Results

### *Stage 1 (Theory)*

Three underpinning principles were predefined.

1. Meaningful involvement from people with lived experience in the REFOCUS Programme was prioritised, in acknowledgement of the concern expressed by some that the service user-developed notion of recovery can be seen to be ‘hijacked’[55] by services and incorporated into the language of the mental health system without any substantive change to practice. The Patient and Public Involvement approach is described in Chapter 10.
2. There are known inequalities in the experience of service users from minority ethnic groups[176]. The REFOCUS Programme therefore placed a particular emphasis on supporting recovery for black service users, who in England are a minority ethnic group with high psychosis prevalence[177] and problematic pathways to care[178]. As a result the Framework For Black Service Users sub-study was undertaken, which highlighted the importance of the individual’s values and treatment preferences. This emphasis on personalising care was consistent with the findings from non-minority groups, For example, the conceptual framework for recovery identified that recovery narratives are consistent with a stages model, in which the journey of recovery is a continuous and unfolding process rather than a discontinuous one-off experience. Therefore an emphasis on individualised and person-centred recovery support informed the REFOCUS intervention.
3. The intervention was intended to be transdiagnostic. However, as one objective for the REFOCUS programme was to inform clinical guidelines, which are indexed on diagnosis, the evaluation of the intervention will be in relation to its impact on people with psychosis.

The conceptual framework for recovery[8] provided the understanding of recovery which underpinned the intervention. As this emerged as a central building block for the intervention, the framework was also validated across different countries[41] and with current mental health service users[56]. The conceptual framework showed that the process of recovery is complex. Specific identified characteristics which underpinned assumptions about how recovery is supported by mental health services were:

- recovery is individual and unique, so a pro-recovery intervention should be flexible and non-prescriptive

- recovery is an active process which may involve struggle, so recovery can be supported by workers who as far as possible support self-management and goal-striving by the service user
- recovery is possible without cure, so clinical expertise is a resource to offer, but other types of help may also contribute to recovery.

The five key recovery principles which were evident in recovery narratives – Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment (CHIME) – informed the intervention content.

The development of Connectedness relates to the person in their context. This includes both social determinants on health and social factors which increase recovery. Despite reviewing social influences on recovery[179], it was not possible to incorporate a strong focus on supporting connection to the wider community into the intervention.

Identity and Meaning indicated the need to focus on strengths. The traditional focus on amelioration of deficits in mental health services can inadvertently reinforce a negatively socially valorised role as a ‘patient’; a person with little or nothing to contribute to their own recovery and whose main role expectation is to adhere to treatment. The REFOCUS intervention involves training staff to focus as much on amplifying strengths in their clinical work as on ameliorating deficits. The aim of a strengths focus is to support the development of a more positive and valued (i.e. meaningful) identity, with consequent benefits for increased meaning.

Finally, Hope Theory proposes that hopeful thought reflects the belief that one can find pathways to desired goals and become motivated to use those pathways[180]. Based on this theory, and other research assessing hope specifically in relation to psychosis[181], it was proposed that hope and empowerment are both increased by goal-striving – setting, working towards and achieving valued goals. Therefore the REFOCUS intervention built on the existing clinical expertise in treatment planning but with a specific focus on supporting goal-striving by the service user, to complement the treatments provided by the worker.

The validation of the conceptual framework with current mental health service users indicated that the traditional focus of mental health services on practical support, diagnosis and medication remains important. Therefore the REFOCUS intervention is in addition to, rather than instead of, existing care. The same study also indicated that some service users are sceptical about the label ‘recovery’, so the intervention is REFOCUS intervention is not primarily aimed at getting staff to use the term ‘recovery’, but rather at increasing the presence of pro-recovery values and behaviours. Finally, the CHIME framework also informed the evaluation strategy, as described in the next chapter.

The REFOCUS intervention was located within the recovery practice framework[63]. The recovery oriented practice framework identified four practice domains of recovery support: Promoting citizenship (e.g. challenging stigma), Organisational commitment (e.g. workforce planning), Supporting personally defined recovery (e.g. treatments) and Working relationship (e.g. interpersonal style). A preliminary evaluation of candidate interventions at the level of Promoting Citizenship (e.g. community links) and Organisational commitment (e.g. peer-run services) was undertaken using SAFE, and these were deemed infeasible within available resources. Therefore the REFOCUS intervention was located at the Supporting personally defined recovery and the Working relationship levels. Whilst being aware that care is provided in a broader organisational culture, and that the recovery takes place outside of, rather than in, the clinic, the aim of the REFOCUS intervention was to impact on the content and process of care provided between worker and service user.

The Staff Perspectives sub-study found that staff need to balance competing priorities in translating recovery ideas into practice. The development of a shared understanding of recovery can therefore be problematic. Therefore, the REFOCUS intervention was a team-level intervention, aiming to foster the development of a shared pro-recovery culture within a team. Higher organisational levels, such as adult services, was too heterogeneous to directly target. Also, an emphasis in the intervention is on team-level development of a shared understanding of recovery.

The National Survey sub-study found differing perspectives between team manager and front-line worker, indicating that both perspectives need to be considered in implementing a team-level intervention. The REFOCUS intervention therefore uses separate, though complementary, implementation approaches to support uptake of the intervention with team managers and workers.

A summary of the impact of theory on the REFOCUS intervention is shown in Table 19.

### Table 19 Theory informing the REFOCUS intervention

| Sub-study | Theory | Implication for REFOCUS intervention |
|---|---|---|
| Predefined | Meaningful involvement of people with lived experience is needed | People with lived experience are involved as co-applicants, in advisory committees, as researchers, and in analysis and dissemination |
| | Recovery in people from minority ethnic groups is under-researched | The intervention has a strong focus on the service user’s values and treatment preferences |
| | Clinical guidelines are indexed on diagnosis | The intervention is transdiagnostic, but evaluation will focus on people with psychosis |
| Conceptual Framework | Recovery is an individual process | The intervention is flexible and non-prescriptive |
| | Recovery is an active process | The intervention focuses on supporting self-management and goal-striving rather than ‘fixing the problem’ |
| | Recovery is possible without cure and without professional intervention | Clinical expertise is offered as a support, whilst recognising other types of help may also contribute to recovery |
| | Different support is needed at different stages of recovery | The target group is people using community-based mental health services, to reduce heterogeneity |
| | CHIME recovery processes | The intervention content targets these five processes, and CHIME is used to inform the outcome evaluation strategy |
| | Practical support, diagnosis and medication remain important | The intervention is in addition to, rather than replacing, current mental health practice |

| | | |
|---|---|---|
| | Some service users are sceptical about recovery | The term ‘recovery’ and associated concepts are used only where helpful |
| Recovery Practice Framework | Recovery support spans four domains of practice | The intervention targets the domains relating to front-line practice: Supporting personally defined recovery and Working relationship |
| Staff Perspectives | Team members hold differing understandings of recovery | The intervention is provided to teams, and is intended to develop a team-level understanding of recovery |
| National Survey | Team managers and workers differ in their ratings of recovery orientation | Separate but complementary approaches will be used with team managers and workers to support implementation. |

*Stage 2 (REFOCUS intervention and manual)*

A draft structure for the REFOCUS Intervention was developed, with interventions described in outline and organised to correspond with care processes of assessment, intervention and evaluation. The structure comprised four core intervention modules (Knowledge, Values and attitudes, Strengths assessment, Recovery planning and interpersonal style) and five optional modules (Connectedness, Hope, Identity, Meaning and Empowerment). Modules used familiar clinical terminology and the intervention comprised the four core plus one optional module.

Consultation with advisory committees on the draft structure produced 16 responses identifying five main themes: feasibility, implementation, suggested interventions or resources, service user involvement, and language. Feasibility concerns included resources, time needed to implement the manual and the staff skill set. The manual included too many components, and the core and optional structure was over-complicated and made evaluation more difficult. The need was identified for implementation strategies, which identify specifically how the intervention is implemented. References for suggested interventions or resources were accessed and reviewed. Service user involvement would include providing the intervention, i.e. staff training should involve people with lived experience. Respondents did not agree with the use of clinical language, suggesting instead that the language used should represent and be consistent with the concept of personal recovery: "*I think it could be a mistake to try and dress the recovery approach in clinical language as in my experience people see through it and feel uncomfortable with it and we shouldn't be making apologies for what we are trying to achieve*".

On the basis of the consultation, a full draft of the REFOCUS Intervention was developed. Consultation with the advisory committees on the full draft produced 14 responses, with five emergent themes. The theme *service user involvement* related to amplifying the role of service users in the intervention. Adopted suggestions included informing service users about the intervention, raising their expectations to expect recovery-orientated care, emphasising staff-service user relationships involving trust, partnership and mutual respect, and facilitating an experience for staff and service users of working together on a common goal (the Partnership Project, described later). The theme *training practicalities* emerged from staff and researchers, and related to the cost, timing and back-fill arrangements for training. The theme *language* related to ensuring pro-recovery language in the REFOCUS Manual and the issue of including people with English as an additional language. The *implementation* theme related to implementation of the intervention in clinical practice. Finally, many *resources* were suggested and reviewed.

The draft manual was modified to produce the final version of the REFOCUS manual, which was published by the mental health charity Rethink[171]. The manual provides resources to implement the REFOCUS intervention, and was the intervention manual used in the REFOCUS trial described later in this report.

The REFOCUS intervention is a one-year complex intervention with two components, targeting (1) the service user – worker relationship (called Recovery-promoting relationships) and (2) the support offered by the worker (called Working practices).

Component 1: Recovery-promoting relationships

This component comprises several approaches to supporting a partnership-based relationship. Four types of relationships were considered as candidates for use in routine clinical interactions: mentoring, 'real relationships', trialogues and coaching.

Mentoring involves an experienced person (the worker) assisting another (the service user) in developing specific skills and knowledge. The approach is widely used in the business world, and a report of a pilot involving people with lived experience mentoring psychiatrists was located (http://www.dorsetmentalhealthforum.org.uk/recovery.html). However, no research using mentoring as a worker interaction style in a mental health system could be located.

A real relationship is one in which 'each is genuine with the other and perceives the other in ways that befit the other'[182]. Although being perceived as a person rather than a patient is reported by some service users as a turning point in their recovery journey[183], the real relationship concept has emerged from psychotherapy rather than general mental health services, and its usefulness in a context sometimes involving issues of compulsion and capacity is unknown.

A trialogue meeting is a community forum where service users, carers, mental health workers, and others with an interest in mental health participate in an open dialogue. In German-speaking countries, well over one hundred trialogue groups are regularly attended by 5,000 people[184], and international interest and experiences are growing[185]. However, evaluation is limited and its structure makes it difficult to incorporate into routine clinical work.

Coaching was chosen as the focus for the staff training component of the REFOCUS Intervention. Coaching is widely used, has socially acceptable positive connotations relating to strengths (rather than the problem-focussed connotations of ‘therapy’), and has been used in mental health services[186]. For example, the Collaborative Recovery Model uses coaching to support goal-striving by service users[42], and is in widespread use throughout Australia[187]. The focus on autonomy support is derived from self-determination theory[188].

Recovery-promoting relationships were supported using five approaches. First, staff training using a locally-developed Coaching Conversations for Recovery training programme. Both the participant manual[189] and the trainer manual[190] for this approach have been published. Second, the grounded theory developed in the Staff Perspectives sub-study found that staff had a range of opinions about recovery, reflecting their need to balance competing priorities and demands placed on them. The development of a shared team understanding was included as a training goal. Third, staff values underpin practice and ‘staff role perception’ was identified as influential in the systematic review in the Staff Perspectives sub-study, so a goal of staff training was to give a safe opportunity to explore values held by individual workers. Fourth, to give an opportunity for a non role-defined experience of relating to each other (and hence reduce any ‘them-and-us’ beliefs about having little in common), the undertaking of a Partnership Project was encouraged, in which staff and service users from the same team take on a joint and non-clinical task, with a small amount of resources (£500 per team). Fifth, because both parties are active agents in the relationship, the intervention tried to raise expectations in service users about being actively involved in the working relationship, and to encourage them to bring their expertise by experience to inform the clinical discussions.

Component 2: Working practices

Supporting personal recovery involves providing interventions and treatments in the service of the person's recovery, i.e. led by what the individual identifies as needed. Three challenges were identified: planning support based on the individual's values rather than clinical priorities; amplifying strengths as well as ameliorating deficits; and planning care based as much as possible on the goals of the service user. Each led to a specific working practice.

Working practice 1 is Understanding values and treatment preferences. Traditional clinical assessment processes can inadvertently reinforce an identity as a patient[191], whereas if services are to be oriented around the individual then the starting point for assessment needs to be a rich understanding of a person's identity. Consistent with values-based medicine[192], this involves a strong focus on understanding what matters to the individual (i.e. their values) and what if any support they want from mental health services (i.e. their treatment preferences). Only by using such information can recovery support be a partnership process rather than 'something done to' the person. Staff were trained to use three resources relating to Working Practice 1, although it was emphasised that these were optional and other approaches could be used to understand the service user's values and their treatment preferences. The first resource was a Values and Treatment Preferences form, modified from existing resources[193,194], which structured a conversation about the service user. The second approach was narrative, supporting the service user to develop their own story. The third approach was visual, using life mapping[195] as a means of clarifying and communicating the person's values and preferences.

Working practice 2 is Assessing strengths. The Strengths Measures Review sub-study found that strengths can be present at three levels: individual (resources available to the person, including their talents, capabilities, abilities, skills, interests, and personal attributes), environmental (external resources available to the person in both their immediate environment and the wider community) and interpersonal (arising from the interaction between the individual and environmental levels)[119]. It has been proposed that clinical assessment should focus on four dimensions: (1) deficiencies and undermining characteristics of the person; (2) strengths and assets of the person; (3) lacks and destructive factors in the environment; and (4) resource and opportunities in the environment[196]. Traditional clinical assessment focuses on dimension 1, and there is no doubt that ameliorating intrapsychic deficits, such as reducing symptoms or social disability, is an important contribution to recovery. The REFOCUS intervention extended clinical expertise to also include dimension (2). The Strengths Measures Review sub-study identified the Strengths Assessment Worksheet (SAW)[45] as the most widely used and evaluated qualitative measure of strengths. Staff training in using the SAW to inform care planning was therefore included in the REFOCUS intervention. Strengths assessment techniques[197] were also included as resources to support Working Practice 2.

Working practice 3 is Supporting goal-striving. Taking responsibility for one’s life is a key step towards recovery[198]. Consistent with the substantial evidence from research into self-management[199] and shared decision-making[200], helping people to – with appropriate support – do things for themselves is a central orientation of a recovery-focussed mental health service. However, evidence from reviewing care plans indicates that – at least as recorded – actions are primarily undertaken by staff. For example, a review of 3,526 care plan action points for 700 service users found 2,489 (71%) were for staff to action, with only 725 (21%) for joint action and 287 (8%) for action by the service user[201]. Therefore the third working practice was focussed on supporting service users to identify, strive towards and achieve personally valued goals. Resources supporting Working Practice 3 were the GROW Model of coaching[202] to identify and plan actions towards personally valued goals.

The REFOCUS intervention was provided through six implementation strategies.

a) Information sharing – letters were sent to all service users on the caseload of the team, and separate meetings to provide information and raise expectations were held with team staff and service users / carers
b) 1.5 days of personal recovery training sessions for staff, provided to the whole team and involving people with lived experience as trainers
c) two days of coaching skills training for staff, provided to the whole team by experienced coaching trainers

d) five team manager reflection sessions
e) six reflections sessions for team workers
f) reflection in supervision, using a Supervision Reflection Form provided in the REFOCUS manual to focus attention on the working practices and recovery-promoting relationships.

Stage 3 (REFOCUS Model)

The REFOCUS Model was developed to describe the proposed causal pathway form receiving the intervention to improved recovery, and was published as part of the REFOCUS manual[171]. It is shown in **Error! Reference source not found.**.

**Figure 10 Intervention Development sub-study: REFOCUS model**

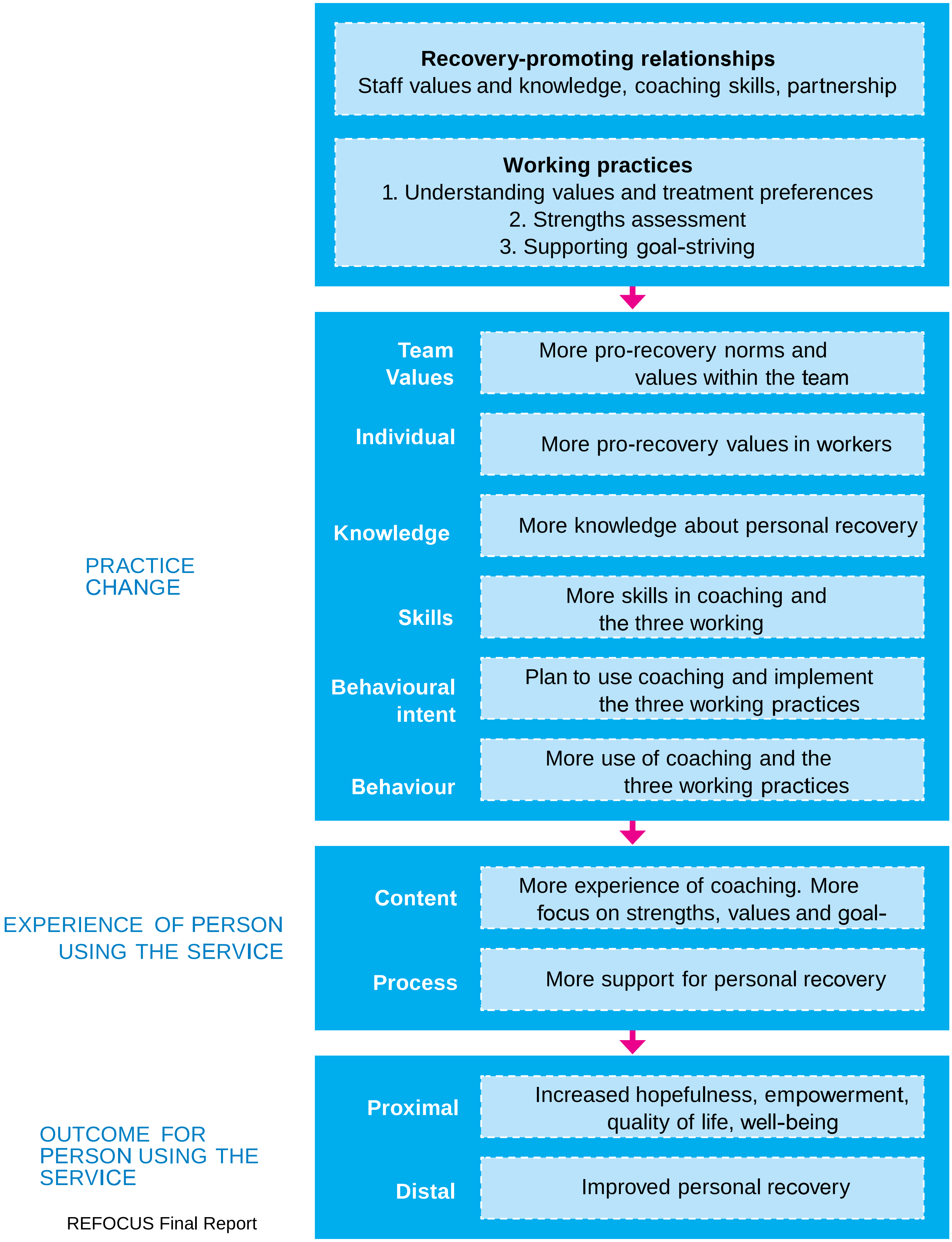


Figure 11 Intervention Development sub-study: REFOCUS model

Staff practice change is based on the theory of planned behaviour. Team and individual values reflect the behavioural influence of subjective norms. Attitude, knowledge and skill reflect the behavioural influence of behavioural control.

### Discussion

The MRC Framework for Evaluating Complex Interventions was used to develop a testable and empirically defensible pro-recovery intervention. The theory base included existing research synthesised through systematic and narrative reviews, and qualitative studies addressing key knowledge gaps. The resulting REFOCUS Intervention is intended to increase the support for recovery provided by mental health teams.

The REFOCUS Programme was funded for five years, allowing 18 months for the intellectual work of developing theory reported in Chapters 2 and 3. This had several advantages. As teams are built not formed, having the time to develop a knowledgeable, reflective and high-performing research team may have improved the intellectual quality of the output. We believe this is more likely to lead to innovation than separate projects over the same length of time. Overall, the intervention is based on a coherent synthesis (and in most cases peer-reviewed publication) of a wide range of evidence. Finally, the timeframe and financial resources permitted the "*higher demands on resources and slower pace of research*" (p.65)[203] required for meaningful Patient Public Involvement, as discussed further in Chapter 10.

The REFOCUS intervention was evaluated in a randomised controlled trial, described later in this report. Evaluation of a recovery-oriented complex intervention is a particular challenge, given the necessary focus on subjective experience. The next chapter describes the sub-studies addressing this challenge.

# Chapter 4: Optimise the evaluation

This chapter focuses on the measurement of recovery. The Recovery Measures Review sub-study systematically reviewed available recovery measures, identifying the Questionnaire about the Process of Recovery (QPR) as a candidate primary outcome for the clinical trial. The psychometric properties of the QPR were investigated in the QPR Validation sub-study. The Recovery Support Measures Review sub-study systematically reviewed measures of recovery support from mental health services. No existing measure could be recommended, so a new recovery support measure was developed and evaluated in the INSPIRE Development sub-study. Finally, a new approach to end-point assessment in trials was developed and evaluated in the IOM Development sub-study.

## Recovery Measures Review sub-study

Adapted with permission from the published report for this study[97]

### Introduction

Evaluating the impact of mental health systems on recovery requires adequate measurement tools. The aims of this systematic review were to (i) identify measures of personal recovery, (ii) evaluate the extent to which the identified measures focus on aspects of recovery defined by the CHIME framework, and (iii) characterise the psychometric properties of each identified measure.

### Methods

Searches were conducted using six data sources.

1. Eight databases were searched from date of inception to May 2012: MEDLINE, PsycINFO, EMBASE, CINAHL, CSA Illumina, TRIP, CDSR, and DARE. The search terms were divided into four domains—personal recovery, mental illness, measure or instrument, and psychometric properties. The terms were identified from the title, abstract, key words, and medical subject headings (MeSH). The search terms were amended for each database as necessary. The search strategy is shown in Appendix 20.

2. 11 Web-based repositories were searched by using the terms “personal recovery,” “mental health,” and “measure.” These repositories were:
    a. Department of Health (www.dh.gov.uk)
    b. Scottish Recovery Network (www.scottishrecovery.net)
    c. Centre for Mental Health (www.centreformentalhealth.co.uk)
    d. Recovery Devon (www.recoverydevon.co.uk)
    e. Repository of Recovery Resources (www.bu.edu/cpr/repository/index.html)
    f. Mind (www.mind.org.uk)
    g. Rethink (www.rethink.org)
    h. National Mental Health Development Unit (www.nmhdu.org.uk)
    i. Mental Health Commission of New Zealand (www.mhc.govt.nz/)
    j. Mental Health Commission of Ireland (www.mhcirl.ie/), and the
    k. Mental Health Commission of Canada (www.mentalhealthcommission.ca/)
3. A search of Google Scholar (www.scholar.google.co.uk) was conducted using the terms “personal recovery,” “mental health,” and “measure.”
4. Abstracts from three international knowledge transfer event series were searched using the terms “personal recovery” and “measure.” The conferences were biennial conferences of the European Network for Mental Health Service Evaluation (1994–2010), annual meetings of the American Psychiatric Association (1999–2009), and Refocus on Recovery knowledge transfer events (2010 and 2012).
5. The table of contents was searched by hand for three journals: Psychiatric Services, International Journal of Methods in Psychiatric Research, and Psychiatric Rehabilitation Journal.
6. Reference lists of included papers were assessed for further measures.

### *Aim 1: Identification of measures*

#### *Eligibility criteria*

Measures were included if they involved the use or validation of a measure of personal recovery, were published in either peer-reviewed or non–peer-reviewed publications, involved a population of working age adults with a diagnosis of any mental illness other than an eating or substance use disorder, and were electronically accessible.

### *Data extraction*

Data were extracted by one reviewer. Results from the search were stored in Endnote version 4. Duplicates were removed. The results were sifted to exclude papers by title. The abstracts of papers that were included by title were read, and excluded if not relevant. Excluded abstracts were double rated by a second reviewer to assess reliability. A concordance level of 98.2% was achieved. If the abstract was judged to be relevant, the full paper was reviewed and a copy of the measure was obtained. A decision was then made whether to include the measure.

### *Aim 2: recovery relevance*

To evaluate the extent to which the identified measures focus on aspects of recovery, four raters independently compared the measures to the CHIME framework in the conceptual framework for recovery. Each item on the measure was mapped to one of the five CHIME framework categories, if possible. Items covering more than one domain were assigned to the domain that it represented most. Items that did not map, and, therefore, did not assess personal recovery, were counted as not mapping. A concordance in allocation to CHIME category of over 70% was achieved between raters.

### *Aim 3: psychometric properties*

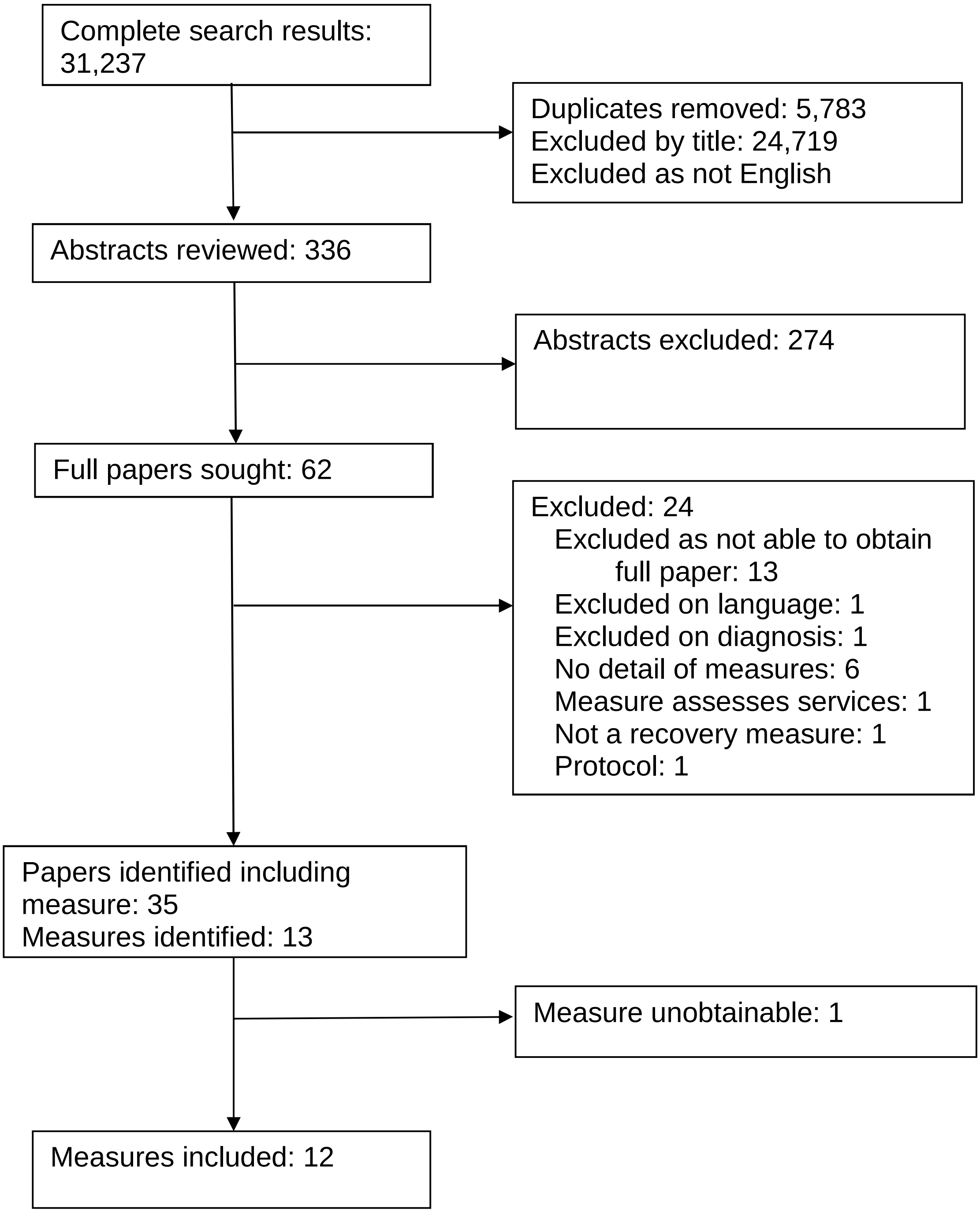
Each measure was evaluated for nine psychometric properties by using criteria modified from several authors[29,30,204]. For each property, the measure was rated as Yes (tested and adequate), No (tested and inadequate), or Unknown (not tested).

## Results

### *Aim 1: identification of measures*

The flow diagram is shown in Figure 12.

Figure 12 Recovery Measures Review sub-study: flow diagram



From 336 abstracts reviewed, the search identified 35 articles for inclusion, which described 13 measures. 16 articles described studies that used a measure as part of outcome assessment, eight articles described measure development, nine reported on psychometric properties, and one article compared measures of personal recovery and clinical recovery. One measure, the Stages of Recovery Scale, was unobtainable and was excluded from analysis. The 12 measures included in the review are described in Table 20.

### Table 20 Recovery Measures Reviews sub-study: description of personal recovery measures (n=12)

| Acronym | Measure | Description | Country of development |
|---|---|---|---|
| IMR | Illness Management and Recovery Scale[205] | 15 items covering personal goals, knowledge of mental illness, involvement of significant others, impaired functioning, symptoms, stress, coping, relapse prevention, hospitalisation, medication, use of drugs and alcohol | USA |
| MARS | Maryland Assessment of Recovery[206] | 25 items covering six domains: Self-direction or empowerment, Holistic, Nonlinear, Strengths based, Responsibility, Hope | USA |
| MHRM | Mental Health Recovery Measure[38] | 41 items covering six aspects of recovery: Overcoming stuckness, Discovering and fostering self-empowerment, Learning and self-re-definition, Return to basic functioning, Striving to attain overall wellbeing, Striving to reach new potentials | USA |
| QPR | Questionnaire about the Process of Recovery[84] | 22 items with two subscales: Intrapersonal and interpersonal | United Kingdom |
| PRI | Psychosis Recovery Inventory[207] | 25 item covering Attitude to illness, Attitude to treatment and Perception of recovery and relapse | Hong Kong |
| RAS | Recovery Assessment Scale[208] | 41 items covering Personal confidence and hope, Willingness to ask for help, Goal and success | USA |

| | | | |
|---|---|---|---|
| | | orientation, Reliance on others and Not dominated by symptoms | |
| RMQ | Recovery Markers Questionnaire[209] | 28 items covering Process factors, Goal orientated thinking, Self-agency, Self-efficacy, Symptoms, Social support and Basic resources | USA |
| RPI | Recovery Process Inventory[210] | 22 items covering six factors: Anguish, Connected to others, Confidence and purpose, Others' care/help, Living situation and Hopeful/cares for self | USA |
| RS | Recovery Star[211] | 10 item measure covering Managing mental health, Physical health and self-care, Living skills, Social networks, Work, Relationships, Addictive behaviour, Responsibilities, Identity and self-esteem and Trust and Hope | United Kingdom |
| SISR | Self-Identified Stage of Recovery[38] | 2 sub-scales: SISR-A measuring recovery stage based on published model (Moratorium, Awareness, Preparation, Rebuilding, Growth)[212]. SISR-B covers four recovery processes: Hope, Responsibility, Identity and Meaning | Australia |
| SIST-R | Short Interview to Assess Stages of Recovery[213] | 5 items measuring the five stages assessed in SISR | Australia |
| STORI | Stages of Recovery Instrument[214] | 50 item measure assessing five stages and four recovery processes assessed in SISR | Australia |

All measures are service-user rated, with the IMR also having a staff-rated version. The two measures cited most widely were the RAS and the IMR. The RAS was used in 13 articles, with four describing psychometric properties, eight which described the use as an outcome measure (three studies each from the United States and Australia and one each from Canada and Sweden), and one comparing service user-defined and professionally-defined recovery measures. The IMR was used in eight articles, including two describing psychometric use and six describing studies that used it as an outcome measure (four from the United States and one each from Sweden and Israel). The only other measure used as an outcome assessment was the Recovery Markers Questionnaire (RMQ) in two studies in the United States.

*Aim 2 (recovery relevance)*

The mapping of items in each measure to the CHIME framework is shown in Table 21.

**Table 21 Recovery Measures Review sub-study: item level mapping to CHIME framework**

| | IMR | | MARS | | MHRM | | PRI | | QPR | | RAS | | RMQ | | RPI | | RS | | SISR | | STORI | | SIST-R | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Items (n) | 15 | | 25 | | 30 | | 25 | | 22 | | 41 | | 24 | | 22 | | 10 | | 9 | | 50 | | 5 | |
| **CHIME category** | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* | *n* | *%* |
| **Connectedness** | 4 | 27 | 1 | 4 | 3 | 10 | 0 | 0 | 4 | 18 | 5 | 12 | 3 | 13 | 4 | 18 | 2 | 20 | 0 | 0 | 1 | 2 | 0 | 0 |
| **Hope** | 0 | 0 | 10 | 40 | 9 | 30 | 1 | 4 | 4 | 18 | 7 | 17 | 7 | 29 | 3 | 14 | 1 | 10 | 4 | 44 | 15 | 30 | 4 | 80 |
| **Identity** | 0 | 0 | 4 | 16 | 5 | 17 | 1 | 4 | 5 | 23 | 2 | 5 | 2 | 8 | 1 | 5 | 1 | 10 | 1 | 11 | 12 | 24 | 0 | 0 |
| **Meaning** | 0 | 0 | 1 | 4 | 4 | 13 | 6 | 24 | 6 | 27 | 1 | 2 | 2 | 8 | 2 | 9 | 0 | 0 | 0 | 0 | 6 | 12 | 1 | 20 |
| **Empowerment** | 4 | 0 | 7 | 28 | 4 | 14 | 2 | 8 | 3 | 14 | 14 | 34 | 2 | 8 | 1 | 5 | 2 | 20 | 3 | 33 | 8 | 16 | 0 | 0 |
| **Items not mapping** | 7 | 47 | 2 | 8 | 5 | 17 | 15 | 60 | 0 | 0 | 12 | 29 | 8 | 33 | 11 | 50 | 4 | 40 | 1 | 11 | 8 | 16 | 0 | 0 |

The QPR was the only measure in which every item mapped to the CHIME conceptual framework and the only measure to have at least 10% of items in each category.

*Aim 3 (psychometric assessment)*

Three measures (MHRM, RMQ and SISR) had no psychometric paper or scale development paper and were therefore excluded from psychometric analysis. More than one psychometric paper was identified for three measures: RAS (n=4), IMR (n=2) and STORI (n=2). Findings from all papers were included in the evaluation. The psychometric evaluation of measures is shown in Table 22.

Table 22 Recovery Measures Review sub-study: psychometric evaluation of measures (n=9)

| **Property** | **IMR** | **MARS** | **PRI** | **QPR** | **RAS** | **RPI** | **RS** | **STORI** | **SIST-R** |
|---|---|---|---|---|---|---|---|---|---|
| Content validity | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Criterion Validity | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown |
| Construct Validity | Unknown | Unknown | Unknown | Yes | Yes | Unknown | Unknown | Yes | Unknown |
| Internal Consistency | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Unknown |
| Test-retest reliability | Yes | Yes | Yes | Yes | Yes | Yes | Unknown | Yes | Unknown |
| Responsiveness | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Yes | Unknown | Unknown |
| Time to complete | Unknown | Yes | Unknown | Unknown | Unknown | Unknown | Unknown | Yes | Unknown |
| Reading age | Unknown | Yes | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown |
| Feasibility | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown | Yes | Yes |

The measure with positive ratings for the highest number of the nine investigated properties was STORI (6 properties) followed by MARS (5 properties), QPR (4 properties), RAS (4 properties), IMR (3 properties), PRI (3 properties), RS (3 properties), RPI (3 properties) and SIST-R (2 properties). The most investigated psychometric properties were content validity (9 measures), internal consistency (8 measures) and test-retest reliability (7 measures). The least tested properties were criterion validity (0 measures), responsiveness (1 measure) and reading age (1 measure) and feasibility (2 measures).

## Discussion

A total of 13 measures of recovery were identified, from which QPR had strongest match with recovery, RAS was most widely published, and STORI, MARS, QPR and RAS had the widest range of demonstrated psychometric properties.

### *Strengths and limitations*

This review had three strengths. First, the methodological rigour advances the field by using more sources of data than existing reviews[29,215,216], double ratings of eligibility as a quality check, including a flow diagram, and by operationalising the definition of recovery. Second, although existing reviews included staff-rated measures and measures of recovery orientation, there was substantial overlap between the measures identified in this review and earlier reviews. Third, the distribution of country of development for the measures (shown in Table 20) supports the findings from the Conceptual Framework sub-study that recovery conceptualisations – at least as present in English language sources – have primarily emerged from the English-speaking world[41].

The review had three limitations. Firstly, it excluded non–English-language papers, so possibly missing some measures. Second, the term “personal recovery” is not a MeSH heading in databases, and, therefore, the search may have lacked some specificity and missed some measures. The use of the large number of search criteria aimed to counter this possibility. Finally, application of the CHIME framework was a subjective process that depended on individual interpretations of the measures and the meaning of each item. Each CHIME category contains many subcategories, so a measure may not adequately assess a category if only a small number of items map to it. An uneven coverage of the CHIME categories in a measure means that the summary score emphasises different components of recovery. CHIME also represents only one conceptualization of recovery, and the use of other frameworks or conceptual backgrounds may have resulted in different findings. Several measures have items not mapping to CHIME, possibly because these items represent other elements of best practice or because CHIME needs to be extended to incorporate other recovery processes. Although the CHIME framework captures an understanding of recovery within the English-speaking world its wider applicability is unknown.

This review identified three knowledge gaps to inform future research. First, no measure has yet had a complete psychometric evaluation, although the RAS and the QPR have the strongest evidence base. Future evaluation of recovery measures should specifically include sensitivity to change. Measuring change will involve an empirically defensible conceptualisation of recovery as a construct—for example, whether it is a continuous process or occurs in discrete stages—and the methodological rigour to ensure best practice in evaluation[217]. Second, there is a need to identify a gold standard measure for assessing criterion validity. Finally, measures need to be evaluated for a range of service settings, clinical populations, and languages.

Of the identified measures, the QPR was identified as most likely to be useable as a primary outcome in the REFOCUS trial. Therefore further investigation of its psychometric properties was undertaken.

### QPR Validation sub-study

## Introduction

The 22-item Questionnaire about the Process of Recovery (QPR) measure of recovery was identified in the Recovery Measures Review sub-study as the only measure developed in England, the measure which best spanned the CHIME categories, and having some but not all psychometric properties established. The 22-item QPR was therefore used for the power calculation for the REFOCUS trial, reported later in this report. However, in addition to the 22-item QPR, the developers subsequently published an evaluation of the psychometric properties of QPR based on a new dataset, which found a 15-item one factor solution. The aims of this study were (i) to provide further evidence of adequate psychometric properties of QPR, in particular to establish sensitivity to change, and (ii) to decide which of the 15-item or 22-item versions of the QPR could be more recommended for future trials.

## Methods

### *Design*

Data from two studies in the REFOCUS programme were used. Dataset 1 came from a psychometric evaluation study undertaken in South London, with data collected between March 2011 and May 2012, which was also used in the INSPIRE Development and the IOM Development sub-studies. Dataset 2 is pooled baseline and one-year follow-up data from the REFOCUS trial (ISRCTN02507940), with data from each team (cluster) collected between April 2011 and December 2013.

### *Measures*

The original **Questionnaire about the Process of Recovery (QPR)** is a 22-item, service user-rated measure of personal recovery developed in the UK[84]. The measure was developed from a qualitative study led by service user-researchers. Each item is scored using a 5-point Likert scale ranging from 0 (disagree strongly) to 4 (agree strongly). The initial version comprised two sub-scales: QPR Intrapersonal (17 items) (range 0-68) and QPR Interpersonal (5 items) (range 0-20), with higher scores indicating increased recovery in both subscales. Adequate internal consistency

(Intrapersonal 0.94, Interpersonal 0.77), construct validity, and test-retest reliability (Intrapersonal 0.87, Interpersonal 0.76) were shown. A subsequent evaluation by the developers of the psychometric properties using a new dataset found a 15-item (range 0-60) one factor solution called QPR Total, which demonstrated adequate internal consistency (0.93) and test-retest reliability (0.70)[85] Both datasets were collected using the 22-item QPR, with the 15-item QPR Total score being extrapolated. In this analysis we refer to the two sub-scales of the 22 item QPR as QPR Intrapersonal and QPR Interpersonal, and the 15-item QPR as QPR Total.

The **Recovery Assessment Scale (RAS)** is a 41-item service user-rated measure assessing five domains of recovery: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others and no domination by symptoms[208]. Each item is scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) with the total score ranging from 41 (low recovery) to 205. Good internal consistency of 0.93 and test-retest reliability of 0.88 have been demonstrated.

The **Warwick-Edinburgh Mental Well-being Scale (WEMWBS)** is a 14-item self report measure which assesses well-being[218]. Respondents are asked to rate their experience regarding each statement over the last two weeks. Each item is scored using a 5-point Likert scale ranging from 1 (None of the time) to 5 (All of the time). In the initial validation study, it demonstrated content validity, internal consistency of 0.89, and test-retest reliability of 0.83.

*Procedure*

Participants were recruited via their care co-ordinator from community adult mental health teams in South London (Dataset 1 and 2) and Gloucestershire (Dataset 2). All participants received payment of £10 for each round of data collection.

Dataset 1 comprised a convenience sample with care co-ordinators identifying people on their caseload who matched the inclusion criteria and who would be willing to participate. Willing participants were then contacted by a researcher who explained the study and answered any questions, before taking informed consent. The information sheet and consent forms were informed by the Lived Experience Advisory Panel, as described in Chapter 10. Participants completed measures with a researcher at three time points: baseline, two weeks and three months. At baseline, participants completed a battery of measures including the QPR, WEMWBS and RAS. Two weeks later, they completed the QPR. Three months after baseline they completed the QPR and WEMWBS. If participants did not complete the measures at the two week point, they were still invited to complete the measures at the three month point.

For Dataset 2, the caseload for each team was randomly ordered. Researchers then contacted the care co-ordinator of each randomised person in sequence until the required 15 participants per team were recruited. The recruitment procedure was as per Dataset 1. Participants completed an extensive assessment battery including the QPR and WEMWBS at baseline. One year later participants completed the same assessment battery including the QPR and WEMWBS.

### *Analysis*

Using Dataset 1, convergent validity was assessed using Pearson's correlation between RAS and QPR Intrapersonal, QPR Interpersonal and QPR Total at baseline. Test-retest reliability was assessed by exploring agreement at the individual level using two-way random effects intraclass correlations between QPR Intrapersonal, QPR Interpersonal and QPR Total at baseline and two weeks. Sensitivity to change was assessed using the correlation between QPR Intrapersonal, QPR Interpersonal and QPR Total and WEMWBS change scores from baseline to 3-month follow-up.

Using Dataset 2, internal consistency was assessed using Cronbach's alpha. Sensitivity to change was assessed using the association between QPR Intrapersonal, QPR Interpersonal and QPR Total and WEMWBS change scores between baseline and 12-month follow-up. This was achieved by regressing each QPR scale change score onto the WEMWBS while accounting for clustering at the team level by using the 'xtmixed' command with maximum likelihood estimation in Stata 11. Site and study arm were entered as covariates in the model in order to reflect the study design. Prior to conducting the regression analysis, change scores were standardised (mean=0, s.d.=1) to obtain a standardised regression coefficient which is equivalent to a regression coefficient. All analyses were conducted on complete cases using Stata Version 11.

Two separate confirmatory factor analyses (CFAs) were conducted using baseline data pooled from Datasets 1 and 2 to assess the fit of the QPR Total solution compared to the 2-scale solution, QPR Interpersonal and QPR Intrapersonal. The CFA analyses were conducted in Mplus 7.2 using the weighted least squares mean variance (WLSMV) estimator[219] taking into account clustering at the team level and adjusting the model for NHS Trust as this captures the study design. Goodness of fit was assessed using several fit indices: $\chi 2$ ($p>.05$), Root Mean Square Error of Approximation (RMSEA<.06), Tucker-Lewis Index (TLI >.95) and Comparative Fit Index (CFI >.95).

## Results

Demographics and QPR scores for both samples are shown in Table 23.

**Table 23 QPR Validation sub-study: participant baseline characteristics**

| | | **Dataset 1** | **Dataset 2** |
|---|---|---|---|
| n | | *88* | *399* |
| Gender | n (%) | | |
| Male | | 62 (70.4) | 256 (64.3) |
| Female | | 26 (29.6) | 142 (35.7) |
| Age | mean (s.d.) | 42.3 (10.5) | 43.8 (10.9) |
| Ethnicity | n (%) | | |
| White | | 37 (44.0) | 228 (57.6) |
| Black | | 40 (45.0) | 109 (27.5) |
| Other/mixed | | 10 (11.0) | 59 (14.9) |
| Unemployed | n (%) | 63 (72.4) | 291 (73.1) |

|  |  |  |  |
|---|---|---|---|
| Single | n (%) | 63 (73.3) | 306 (76.7) |
| QPR mean (s.d.) |  |  |  |
|  | Intrapersonal | 46.33 (9.6) | 48.83 (10.1) |
|  | Interpersonal | 13.73 (2.8) | 13.27 (2.6) |
|  | Total | 41.17 (8.6) | 38.72 (9.1) |

The two samples did not differ in sociodemographic characteristics, other than Dataset 1 had a higher number of participants from Black ethnic background ($\chi^2_{(2)}$= 10.7, p=.005).

*Convergent validity*

In Dataset 1 (n=76), the baseline RAS score was positively correlated with baseline QPR Interpersonal (r=0.46, 95% CI: 0.26 to 0.67, p<0.001), QPR Intrapersonal (r=0.75, 95% CI 0.63 to 0.83, , p<0.001) and QPR Total (r=0.73, 95% CI O.61 to 0.82, p<0.001), indicating adequate convergent validity for each scale.

*Test-retest reliability*

Intraclass-correlations in Dataset 1 (n-91) between baseline and two weeks was ‘good’ for QPR Interpersonal (ICC=0.66, 95%CI: 0.53 to 0.77) and QPR Intrapersonal (ICC=0.75, 95%CI: 0.64 to 0.83), and ‘fair to good’ for QPR Total (ICC=0.74, 95%CI: 0.63 to 0.82).

*Sensitivity to change*

For dataset 1 (n=57), the correlation was moderate between WEMWBS and QPR Intrapersonal (r=0.50, 95% CI 0.28 to 0.67, p<.001) and QPR Total (r=0.47, 95% CI 0.24 to 0.65, p<.001), and low with QPR Interpersonal (r=0.18, 95% CI -0.09 to 0.42, p=.18). For dataset 2 (n=267), regression analyses across all 27 clusters (average cluster size=10, range 5 to 14) showed a moderate association between WEMWBS and QPR Intrapersonal (r=0.39, 95% CI 0.27 to 0.49, p<.001) and QPR Total (r=0.40, 95%

CI 0.27 to 0.49, p<.001), and a low association with QPR Interpersonal (r=0.18, 95% CI 0.07 to 0.31, p=.002).

*Internal consistency*

Cronbach's alpha coefficients for baseline scores in Dataset 2 (n=399) indicated excellent internal consistency for QPR Total (α=0.89) and the QPR Intrapersonal sub-scale (α=0.90). However, internal consistency for QPR Interpersonal was poor (α=0.49). Investigation of factor structure

*Factor structure*

As a first step, we fitted a 1-factor model in dataset 2 (n=399) for QPR total, finding an adequate fit ($\chi^2_{(90)}$=233.2, p<0.001; RMSEA=0.063, 90%CI: .05 to .07; CFI=.97; TLI=.97). Table 24 shows the standardised loadings for all 15 items showing that all items load onto the factor.

**Table 24 QPR Validation sub-study: item loadings in Confirmatory Factor Analysis**

| **QPR Item (original 22 version item number)** | **1-factor model** | **2-factor model** | |
|---|---|---|---|
| | **15 item Total** | **Intrapersonal** | **Interpersonal** |
| Feel better about myself (1) | .60** | .59** | - |
| Feel able to take chances in life (2) | .66** | .65** | - |
| Able to develop positive relationships (3) | .71** | .70** | - |
| Feel part of society (4) | .60** | .57** | - |
| Able to assert myself (5) | .61** | .60** | - |
| Feel my life has a purpose (6) | .64** | .63** | - |
| Experiences changed me for better (7) | .67** | .66** | - |

|  |  |  |  |
|---|---|---|---|
| Able to come to terms with past (8) | .61** | .61** | - |
| Strongly motivated to get better (9) | .73** | .73** | - |
| Recognise positive things I have done (10) | .67** | .69** | - |
| Able to understand myself better (11) | .68** | .68** | - |
| Can take charge of my life (12) | .75** | .75** | - |
| Can actively engage with life (19) | .75** | .76** | - |
| Take control of aspects of my life (21) | .73** | .74** | - |
| Find time to do the things I enjoy (22) | .55** | .56** | - |
| Able to access independent support (13) | - | .53** | - |
| Make sense of distressing experiences (18) | - | .62** | - |
| Weigh up pros and cons of treatment (14) | - | - | .61** |
| Experiences made me more sensitive (15) | - | - | .52** |
| Meeting people with similar experiences (16) | - | - | .26* |
| My recovery has challenged others (17) | - | - | .49** |
| Views of professionals not only way (20) | - | - | .38* |

*** p < .05, ** p < .001**

We then fitted a 2-factor model for the two QPR subscales (Intrapersonal and Interpersonal), also shown in Table 24. This model also offered a good fit ($\chi^2$ (208)=407.5, p<.001; RMSEA=.049, 90%CI: .04 to .06; CFI=.96; TLI=.96), although items 16 and 20 had low factor loadings, indicating they are weakly associated with the latent construct.

## Discussion

The study used two samples to evaluate the psychometric properties of the two sub-scales of the 22 item version (QPR Intrapersonal and QPR Interpersonal) and the 15 item version (QPR Total). Both QPR Intrapersonal and QPR Total demonstrated adequate psychometric properties, whereas QPR Interpersonal did not demonstrate psychometric adequacy.

QPR Intrapersonal demonstrated excellent psychometric properties in all areas tested, apart from moderate sensitivity to change. All items had a loading above 0.5 in the CFA, indicating they capture the intrapersonal scale. By contrast, the QPR Interpersonal sub-scale had poor internal consistency and sensitivity to change and the factor analysis found that two of the five items – item 16 'Meeting people who have had similar experiences makes me feel better' and item 20 'I realise that the views of some mental health professionals is not the only way of looking at things' – had a factor loading below 0.5. This indicates that they are weakly associated with the latent construct and, therefore, do not describe it very well. Anecdotally, we found that Item 20 was more difficult for participants to answer, due to asking about the view of 'some' professionals which participants found confusing. Overall, these results indicate that QPR Interpersonal is not well defined, and constructs with five of more items are generally recommended to define a robust construct[220].

The 15-item QPR Total demonstrated excellent internal consistency and test-retest reliability, adequate convergent validity, and moderate sensitivity to change. These findings reflect the findings of the developers in their study which recommended the 15 item version of QPR[85], showing a Cronbach's alpha of 0.93 and good test-retest reliability (r=0.70). In our study the CFA found that all items loaded above 0.5. As all of the 15 items are in the QPR Intrapersonal sub-scale, there is a great deal of overlap between QPR Total and QPR Intrapersonal.

Sensitivity to change is an important psychometric property if a measure is to be used to measure change over time. The Recovery Measures Review sub-study[97] found a lack of evidence regarding this property for measures of recovery. This is the first study to examine the sensitivity to change of the QPR, and both QPR Intrapersonal and QPR total demonstrated moderate sensitivity to change in both samples, with QPR Interpersonal demonstrating low sensitivity to change.

The strengths of this study are that it provides a comprehensive and independent psychometric evaluation of the QPR, including being the first study to evaluate sensitivity to change. It is also the first study to compare the two versions of QPR.

The limitation of this study is that one of our samples was relatively small. The use of two datasets (although similar in demographic characteristics) can also be seen as a limitation. However, each dataset had advantages, with Dataset 1 allowing evaluation of test-retest reliability at two weeks, and the sample in Dataset 2 sufficiently large to allow CFA.

We identify three implications. First, the 15-item QPR Total scale can be recommended for use in research and clinical practice. Our recommendation reflects its adequate psychometrics, lower burden compared with the 22-item version, and easier interpretation (as a total score, rather than two sub-scales). A shorter version reduces the burden on respondents[221] which is an advantage as people who use services do not like having to complete long outcome measures[222]. Specifically, a shorter measure increases the likelihood of completion, thus increasing the feasibility of the measure[223]. Evidence on how best to support recovery is still developing and there is as yet little evidence on the impact of recovery support on recovery. Having a robust tool to measure recovery will contribute to this goal.

Second, QPR can be used to benchmark services and compare the effectiveness of different services and interventions. The QPR has been recommended by the Implementing Recovery through Organisational Change (ImROC) initiative as part of a suite of measures to assess recovery support[224]. Robust measures of recovery support such as INSPIRE (described later in this chapter) can be used in conjunction with the

QPR to assess the relationship between recovery support and the experience of recovery.

Third, Government policy in England has become more outcome-focused and the introduction of the Payment by Results funding system in mental health services may lead to outcome measurement being more widely introduced. As recovery is a policy aim, services may need to routinely measure recovery. There is a growing interest in the use of Patient Reported Outcome Measures (PROMs), the QPR may have a role in routine outcome measurement in mental health services.

## Recovery Support Measures Review sub-study

Adapted with permission from the published report for this study[98].

### Introduction

The characteristics of recovery identified in the conceptual framework for recovery make clear that there are many influences on recovery, not all of which are in the control of mental health services. An important distinction is therefore between the experience of recovery and the extent to which services support recovery. It is reasonable to expect a recovery-oriented service to maximise recovery support, which may or may not (depending on the variance in recovery attributable to recovery support for a specific individual) greatly impact on recovery. The aims of the study were: (1) to identify standardised service user-rated measures of the recovery orientation of services; (2) to evaluate the conceptualisation of recovery used in these measures; and (3) to characterise the psychometric properties of the identified measures.

### Methods

Searches were conducted using seven data sources.

1. Seven electronic databases were searched: MEDLINE, EMBASE, PsycINFO, CINAHL, CSA Illumina, TRIP and ASSIA. Each database was searched from

inception to February 2011. The search terms are shown in Appendix 21, and were divided into four domains – personal recovery, mental illness, measure or instrument and psychometric properties. Terms were identified from the title, abstract, key words or medical subject headings (MeSH). Search terms were modified as needed for each database.

2. Web searches were undertaken using Google Scholar (‘recovery’ AND ‘mental health’ AND ‘measure’) and the following on-line repositories (‘recovery’ and ‘measure’): Department of Health (www.dh.gov.uk); Sainsbury’s Centre for Mental Health (www.scmh.org.uk); Scottish Recovery Network (www.scottishrecovery.net); Recovery Devon (www.recoverydevon.co.uk); Mind (www.mind.org.uk); Rethink (www.rethink.org); National Mental Health Development Unit (www.nmhdu.org.uk); Boston University Repository of Recovery Resources (www.bu.edu/cpr/repository); Mental Health Commission of New Zealand (www.mhc.govt.nz); Mental Health Commission of Ireland (www.mhcirl.ie); Mental Health Commission of Canada (www.mentalcommission.ca); and US Health Department (www.samhsa.gov).
3. Conference abstracts from two international conference series were searched: European Network for Mental Health Service Evaluation (ENMESH) biannual conferences 1994 to 2008 (2002 and 2004 unavailable) and American Psychiatric Association (APA) annual conferences 1999 to 2009.
4. The table of contents (1990 to January 2011) were hand searched for Psychiatric Services, International Journal of Methods in Psychiatric Research, and Psychiatric Rehabilitation Journal*.*
5. Five existing reviews of measures were searched[30] [29] [225] [226] [227].
6. Eight expert members of the REFOCUS International Advisory Board (comprising clinical researchers, academics, service user-researchers, and mental health workers) were consulted.
7. Reference lists of all retrieved papers were hand-searched.

### *Eligibility criteria*

Measures were included if they i) assessed the contribution of mental health services in supporting personal recovery, ii) had a version rated by service users, iii) produced quantitative data, iv) were written in English, v) the measure and at least one associated psychometric paper were obtainable, and vi) were freely available. Measures were excluded if they assessed clinical recovery (*i.e.* improvement in predefined and invariant outcomes such as symptomatology), personal recovery (*i.e.* the experience of recovery, rather than the contribution of services to recovery), beliefs or attitudes towards recovery, or staff knowledge of recovery.

*Data extraction*

Data were extracted by one reviewer. All papers identified in the search were entered into a database using Reference Manager, Version 11[121]. Titles were reviewed for possible relevance, and abstracts were reviewed where the title appeared relevant. 50% of these abstracts were double-rated by a second reviewer to assess reliability. A concordance level of 90% was considered acceptable, and this was achieved. Where the abstract appeared relevant, the full text of the paper and associated measure were obtained. A decision was made on including the measure following review of the paper.

A search for psychometric data was then undertaken for each identified measure. This search involved both contacting the author of the measure to ask for any relevant unpublished data on psychometric properties and a MEDLINE search using the name of the measure to identify any papers related to the measures and describing any psychometric properties.

*Quality assessment*

To meet Aim 2 (conceptualisation of recovery), measures were evaluated using the CHIME framework from the conceptual framework for recovery[8]. Each item in the identified measures was evaluated against this framework, to ensure the measure assessed what services do specifically to support recovery, rather than overlapping but different aims (for example, having clear discharge procedures or being accessible). Each item was assigned to the most closely matching recovery process. Four reviewers rated each item, and items where there was agreement on rating by at least three of the reviewers were included.

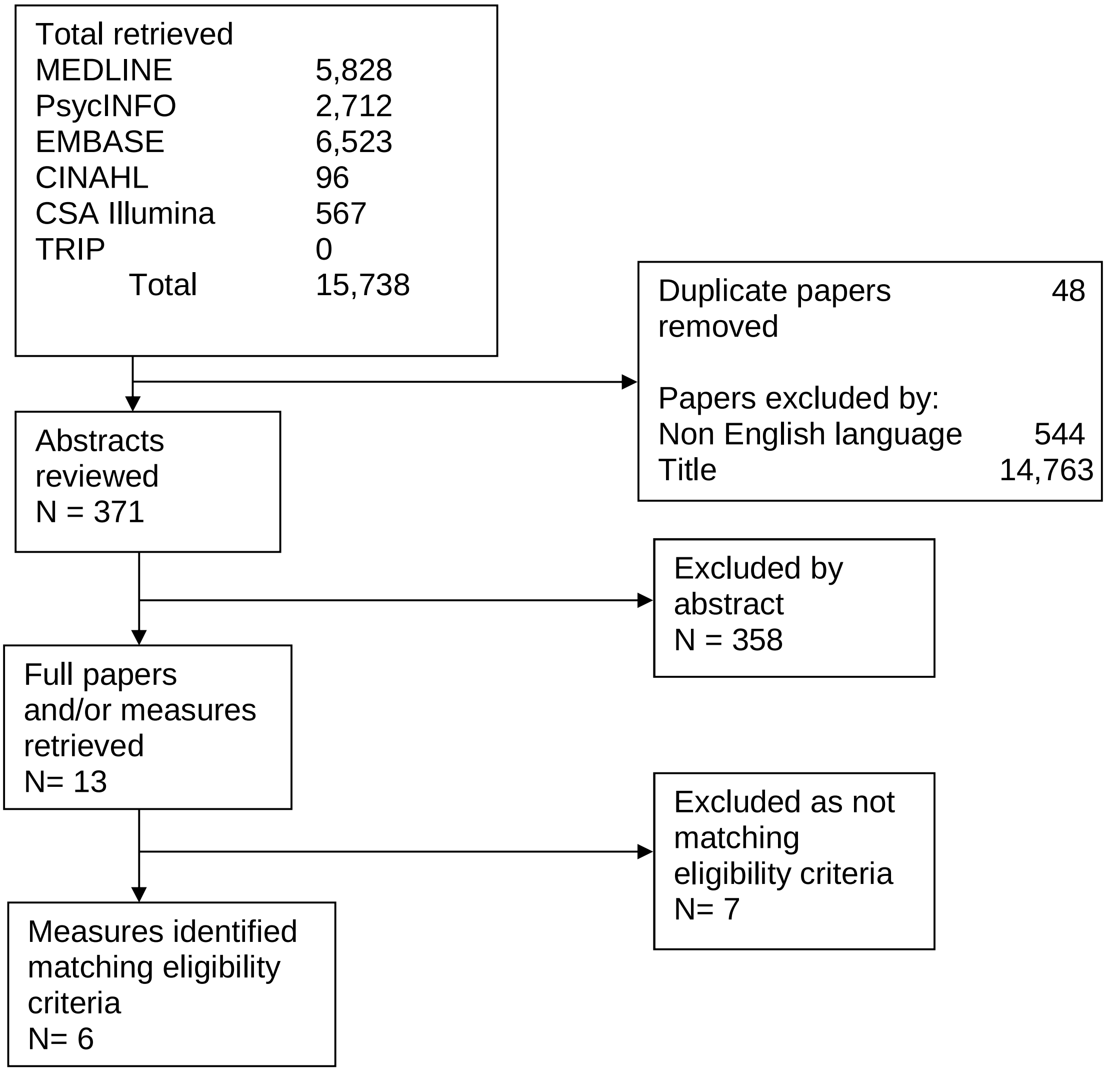
To meet Aim 3 (psychometric properties), measures were evaluated using an amended version of the review criteria developed by the Scientific Advisory Committee of the Medical Outcomes Trust[228]. The following attributes were chosen from the criteria as they cover the main psychometric issues: conceptual model (clear description of the concept being assessed), content validity (expert consultation in development process), construct validity (hypothesis testing with associated constructs), criterion validity (measure score is related to a criterion measure), internal consistency (Cronbach's alpha >=0.7 and <=0.9), test-retest reliability (intraclass correlation coefficient >=0.7), responsiveness (measure can detect change over time), time to complete (minutes) and reading age (12 years or below).

## Results

### *Aim 1 (Identification of measures)*

The flow diagram is shown in Figure 13.

**Figure 13 Recovery Support Measures Review sub-study: flow diagram**



The review identified 13 measures that assessed the recovery orientation of services, six of which met the eligibility criteria. Seven measures did not meet the eligibility criteria and were excluded. The reasons for exclusion were: no published psychometric data (PoRSAT)[229] and (AACP ROSE)[30]; assessed staff recovery competencies only (RPRS)[230]; needed trained assessors (RPFS)[231]; did not provide quantitative data (RBPI)[29]; was unpublished (ERFS) , and was not available (Magellan).

The six included measures identified evaluated different aspects of service delivery. The Recovery Self Assessment (RSA)[81], assesses aspects of the service or particular team, such as '*Staff at this agency encourage me to take risks and try new things*'. The Recovery Oriented Systems Indicators (ROSI)[30] assesses aspects of the organisational system, such as '*Mental health services helped me get housing in a place I feel safe*', and it asks about 'staff' without further specification. The Consumer Evaluation of the Collaborative Recovery Model (CRM)[232] assesses the relationship with a case manager on particular aspects of recovery. The Recovery Interventions Questionnaire (RIQ)[18] assesses relationship with a case manager and mental health services, for example '*I can talk easily with my case manager*'. The Recovery Oriented Practices Index (ROPI)[233] assesses recovery oriented practices, such as '*Program has provided training in recovery, empowerment, or person-centered treatment planning within the last year*'.

The six measures are described in Table 25.

**Table 25 Recovery Support Measures sub-study: characteristics of recovery support measures (n=6)**

| Measure | Versions available | Items | Constructs assessed | Country of origin |
|---|---|---|---|---|
| Recovery Self-Assessment (RSA) | Person in recovery<br>Significant other<br>Service provider<br>Service director | 36 | Extent of recovery-supporting practices | USA |
| Recovery Enhancing Environment Measure (REE) | Service user | Up to 166 (some for particular groups) | Service contribution to recovery and organisational climate as well as other aspects of recovery | USA |
| Recovery Oriented Systems Indicators (ROSI) | Service user | 42 | Recovery orientation of systems | USA |
| Recovery Interventions Questionnaire (RIQ) | Service user<br>Case manager | 50 | Aspects of support and treatment which facilitate recovery | Australia |
| Recovery Oriented Practices Index (ROPI) | Service user | 20 | Recovery-oriented practices | USA |
| Consumer Evaluation of the Collaborative | Service user<br>Case manager | 15 | Perceptions of engaging in recovery-focused practice | USA |

| |
|---|
| Recovery Model (CRM) |

*Aim 2 (Conceptualisation of recovery)*

Items were allocated to the CHIME framework by four raters. Rater disagreement arose due to: items covering more than one recovery process; items not covering any of the recovery processes; items asking more than one question; or a lack of clarity in the items. Table 26 shows the coverage of each process in included measures.

**Table 26 Recovery Support Measures Review sub-study: item-level mapping to CHIME framework**

| **Measure** *n (%)* | **RSA** | **REE** | **ROSI** | **RIQ** | **ROPI** | **CRM** |
|---|---|---|---|---|---|---|
| Items | 30 | 43 | 42 | 50 | 8 | 7 |
| Connectedness | 5 (20) | 8 (22) | 6 (20) | 10 (31) | 1 (12) | 0 (0) |
| Hope | 2 (8) | 3 (8) | 2 (6) | 0 (0) | 0 (0) | 1 (14) |
| Identity | 3 (12) | 4 (11) | 1 (3) | 0 (0) | 0 (0) | 0 (0) |
| Meaning | 5 (20) | 10 (27) | 8 (26) | 6 (18) | 2 (25) | 3 (43) |
| Empowerment | 10 (40) | 12 (32) | 14 (45) | 17 (51) | 5 (63) | 3 (43) |
| **Total** | **25 (69)** | **35 (90)** | **31 (74)** | **33 (66)** | **8 (100)** | **7 (100)** |
| Not mapping | 11 | 8 | 11 | 17 | 0 | 0 |

*Aim 3 (Psychometric properties)*

The psychometric properties of the six measures are characterised in Table 27.

**Table 27 Recovery Support Measures Review sub-study: psychometric properties of measures (n=6)**

| Measure | RSA | REE | ROSI | RIQ | ROPI | CRM |
|---|---|---|---|---|---|---|
| Conceptual model | Yes | Yes | Yes | No | Yes | Yes |
| Content validity | Yes | Yes | Yes | Unknown | Yes | Yes |
| Construct validity | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown |
| Criterion validity | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown |
| Internal consistency | 0.76-0.90 | 0.94-0.97 | 0.95 | 0.64* | Unknown | 0.41-0.69 |
| Test-retest reliability | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown |
| Responsiveness | Unknown | Unknown | Unknown | Unknown | Unknown | Unknown |
| Completion time (mins) | 10 | 40 | Unknown | Unknown | Unknown | Unknown |
| Reading age (years) | 15-16 | 12-13 | 11-12 | 12-13 | 10-11 | 16-17 |

*Not reported for all sub-scales

## Discussion

This systematic review identified six measure of recovery support. None of the measures had undergone complete psychometric evaluation, and neither test-retest reliability or sensitivity to change were reported for any measure. Each measure is based on a different conceptualisation of recovery, so consequently the items covered different domains and used different language.

Internal consistency was assessed for all measures apart from the ROPI. For four of the measures this was calculated for the sub-scales, and for the ROSI it was calculated for the total score. Internal consistency is considered adequate if in the range of 0.70 to 0.90[234], and only RSA had adequate internal consistency. There was evidence of poor internal consistency for RIQ and CRM, and item redundancy for REE and ROSI.

Completion time was only reported for RSA and REE. The 40 minutes for REE is due to the measure assessing personal recovery as well as recovery orientation. This comprehensiveness may make it difficult to use in routine clinical use, where brevity is a key property[223]. Using a criterion of suggested reading age of 12 years[235], reading age was too high for RSA and CRM.

The strengths of the review include the use of a systematic search strategy and varied data sources. The use of double rating in reviewing abstracts was used as a quality improvement approach. The review has three limitations. Firstly, ‘personal recovery’ is not a term used in MeSH search terms and other search engines. ‘Recovery’ has various meanings in these search terms, which could have resulted in missing some relevant references. Secondly, excluding non-English language papers and measures may also have resulted in measures being missed. Thirdly, the conceptual framework for recovery is a novel attempt to conceptualise recovery. Any limitations of the conceptual framework will be reflected in the results of this review. The conceptual framework identifies five processes of recovery which people who have experience mental illness find important. It was not developed primarily to assess the recovery orientation of services and this focus may mean that the conceptual framework does not translate directly to the recovery orientation of services. However, this approach can be used to investigate the conceptualisation of recovery used in existing measures.

This review identifies three knowledge gaps in measuring the recovery orientation of services. First, recovery outcome measurement has not yet evolved to the stage where a gold standard measure of recovery orientation has emerged. Secondly, no single measure shows a good fit with the conceptual framework for recovery, which could indicate that no measure provides good coverage of recovery processes. Finally, none of the measures has shown adequate reliability or sensitivity to change. Overall, none of the identified measures can be recommended for use without further testing. A measure that addresses these shortcomings will provide a significant step forward in the measurement of the recovery orientation of services.

## INSPIRE Development sub-study

Adapted with permission from the published report of this study[236].

### Introduction

The Recovery Support Measures Review sub-study identified that no existing measure could be recommended for routine clinical or research use. There was a specific need for a recovery support measure for use in assessing the process element of the REFOCUS model, when the REFOCUS intervention was evaluated in the REFOCUS trial. The aim of this study was to develop and evaluate a service user-rated measure of staff support for personal recovery.

### Methods

*Design*

Four principles informed the design of the new measure: (a) it has an empirically defensible theory base; (b) it is individualised to reflect the values of the respondent, to reflect the individual nature of recovery[237]; (c) it produces quantitative data suitable for routine clinical and research use, including both monitoring change over time in individuals and aggregation to allow comparison across individuals and teams; and (d) it is rated by the service user[222].

*Procedure*

*Stage 1: Development of first draft*

To meet principle (a) (theory base), the structure of the measure involves two sub-scales derived from the recovery practice framework[63]: Supporting personally defined recovery (called Support) and Working relationship (called Relationship). Supporting personally defined recovery involves mental health staff focusing on how they can support service users in what is important to them. Working relationship highlights that a therapeutic relationship is key for this support to be useful.

The choice of items was theoretically driven. The conceptual framework for recovery identified five recovery processes (Connectedness, Hope, Identity, Meaning and Purpose, and Empowerment) with a coding framework identifying sub-categories for each process [8]. A long-list of candidate items was generated from the coding framework sub-categories. This produced a list of 65 possible items, which were then refined and reduced by a clinical researcher and a service user researcher (as described in Chapter 10), with input from four other researchers. Revised items were then allocated to either the Support or Relationship sub-scale based on content.

Two variants were developed – individual worker and team – as it was not clear which of these service users were best able to rate.

A different scoring format was used for each sub-scale. To meet principle (b) (individualised), Support sub-scale items are weighted for individual importance by the service user. The relationship with the worker was viewed as invariantly important and so was not individualised. This produced INSPIRE version 1.

*Stage 2: Consultation*

Consultation was undertaken to assess content validity by seeking the views of experts in recovery, and to obtain feedback on wording, scoring and layout so as to maximise the feasibility of INSPIRE. An expert consultation was undertaken with 61 participants, including service users, clinical staff, researchers, academics and carers. Recruitment was from three sources: members of a Lived Experience Panel (n=4), attenders at an international recovery knowledge transfer events (n=46), and advisory committees supporting the REFOCUS programme (n=11). Modification following expert consultation produced INSPIRE version 2.

*Stage 3: Pilot study*

A pilot study was undertaken with a convenience sample of people using community mental health teams in South London. The aims were to assess the feasibility of INSPIRE version 2 for the target population, and to address the unresolved question of which variant (team or individual) to progress. A non-standardised feasibility questionnaire was developed to assess brevity, simplicity, relevance, and acceptability, based on an existing definition of feasibility[223].

Service users were approached by clinical staff to ask if they would be willing to participate. If they were, they were contacted by a researcher and a meeting arranged at a place convenient for the service user. The research was explained to the participant and their informed consent was obtained. They then completed (a) either the team or individual worker version of INSPIRE depending on their view of which they felt they were able to complete, and (b) the feasibility questionnaire. Modifications resulting from the pilot study produced INSPIRE version 3.

*Stage 4: Psychometric evaluation*

*Participants and setting*

Participants were a convenience sample of service users from 11 community mental health teams in South London, including generic community mental health teams, forensic and specialist community teams. Inclusion criteria were that participants were (a) well enough to take part and able to complete the measures in the view of staff, (b) able to give informed consent, and (c) had sufficient command of English to complete the measures.

*Sample size*

A sample size of 80 participants was chosen following a power calculation for test-retest reliability. The aim of a power calculation is to ensure that the sample size is both large enough to allow the calculation of inferential statistics and not too large that unnecessary data is collected. With 80% power and p=0.05 (double sided), 40 participants would be sufficient to establish test retest reliability to at least 0.6 with 80% power if the true value is at least 0.8. 80 participants will then give 80% power to detect a correlation of at least 0.3 between scores at T0 and T1.

*Measures*

The *Recovery-Promoting Relationships Scale* (RPRS) is a 24-item measure of recovery-promoting competencies of a mental health worker[230]. Each item is scored on a 4-point scale from 1 (low competency) to 4. The summary score is the sum of all items, ranging from 24 (low competency) to 96. An unpublished report[230] indicates high internal consistency (0.98), and adequate test-retest reliability (0.72). The scale is divided into three subscales measuring worker skill in promoting Hopefulness (7 items), Empowerment (5 items) and Self-acceptance (4 items). The three subscales are sub-components of the Recovery-promoting strategies, i.e., they measure the skill of the worker in promoting each of those areas.

The *Satisfaction Index-Mental Health* (SI-MH)[238] is a 12-item measure of satisfaction with services. Each item is scored on a 6-point scale, with scoring ranging from 1 (low satisfaction) to 6. Six items are reversed. Scores range from 12 (low satisfaction) to 72. The measure has established internal consistency (0.90), test-retest reliability (0.79), and sensitivity to change.

A *Feasibility Questionnaire* was developed for the psychometric evaluation. The feasibility questionnaire consisted of 4 questions with an attached Likert scale to allow quantitative evaluation. It assessed brevity, simplicity, relevance, and acceptability of INSPIRE, and contained space for the researcher to time how long it took each participant to complete INSPIRE.

*Procedure*

Service users were initially approached through clinical staff who asked if they were willing to be contacted by the research team. If they agreed, a researcher explained the purpose of the study and obtained informed consent. The participant completed the baseline measures of INSPIRE version 3, RPRS, SI-MH and the feasibility measure at a venue of their choice. After baseline (called T0), participants were contacted two weeks later to complete INSPIRE (called T1), and again three months after baseline to complete INSPIRE, SI-MH and RPRS (called T2). Some T1 interviews took longer to organise than anticipated, so the time frame for inclusion was extended by 50% to 21 days. Participants were paid £10 for each round of data collection.

*Analysis*

Analysis was undertaken using SPSS Version 20 and FACTOR[239]. Convergent validity of the Support sub-scale was evaluated by correlation with SI-MH, and of the Relationship sub-scale was evaluated using the Pearson product moment correlation with RPRS. To investigate the factor structure exploratory factor analysis (EFA) of the polychoric correlation matrix was undertaken. Polychoric correlation was used as the item responses were ordinal. Exploratory rather than confirmatory factor analysis was used as INSPIRE is a new measure[240]. The Support subscale was tested to establish whether the five theoretical recovery processes (CHIME domains) of Connectedness (items 1-4), Hope (5-8), Identity (9-12), Meaning and purpose (13-16) and Empowerment (17-21) were retained in the factor solution. Due to the sample size of 92 it was not possible to run an analysis using all items in the Support subscale simultaneously, so separate factor analyses were performed on each of the five CHIME domains from the support scale to confirm the unidimensionality of each of the domains.

The Relationship sub-scale was tested using parallel analysis to establish whether a single underlying factor substantially explained the covariance between items[241]. Parallel analysis is a preferred method that was also used as it compares the eigenvalues from the observed correlation matrix to the correlation matrix from the simulated data with the same sample size and number of variables.

Internal consistency was analysed for the CHIME domains in the Support sub-scale, and the Relationship subscale using Cronbach's alpha, with an alpha between 0.70 and 0.90 considered adequate[242]. Test-retest reliability for the Support sub-scale was tested by examining changes in ratings of importance and in Likert-scale scores were examined. For the Relationship sub-scale this was tested by examining the correlation of scores at T0 and T1, with a correlation of at least 0.70 considered adequate. Sensitivity to change for both sub-scales was evaluated by categorising respondents according to change of at least 10% in comparator measure (SI-MH for Support, RPRS for Relationship) and respective INSPIRE sub-scale between T0 and T2. Weighted linear Kappa scores were calculated and effect sizes were then calculated using Hedges' g[243]. This was used instead of Cohen's d as this takes into sample size differences across groups when calculating the pooled standard deviation.

## Results

### *Stage 1: Development of first draft*

INSPIRE version 1 comprised a 34-item Support sub-scale and a 12-item Relationship sub-scale. One issue that was not resolved in the initial development stage was whether the measure would assess support from the team or the individual worker. Existing measures that were reviewed[98] assessed at either the organisation or service level. However, as the relationship between service user and staff member was seen as crucial to recovery support, a second option considered was to assess support from an individual staff member. Two versions were therefore developed for consultation: a team version and an individual worker version.

### *Stage 2: Consultation*

The number of items in each sub-scale were reduced in response to feedback that the measure was too long, from 34 items to 21 in the Support sub-scale and from 12 to 8 items in the Relationship sub-scale. Minor changes were also made to the layout and wording from these consultations. INSPIRE version 2 therefore comprised a 21-item Support sub-scale and an 8-item Relationship sub-scale. The issue of rating a team versus rating an individual worker remained unresolved, so variants for each were developed.

*Stage 3: Pilot study*

The 20 pilot participants were 70% male, mean age of 40.0 years, 50% were White and 30% Black, and 60% self-reported a psychosis disorder with 40% self-reported either having more than one diagnosis or not knowing their diagnosis. Overall, 80% found INSPIRE easy to understand, and 100% were able to complete it. 75% found the length of INSPIRE about right, and no participants found it upsetting. The wording of five items were amended following the pilot.

Pilot participants found rating the team variant more difficult than the individual variant because (a) they had different experiences of support from people from the same team, (b) some had input from staff from more than one team and were not always aware of which team staff came from, and (c) rating one person they had regular contact with made more sense of their experience of using services. Therefore the decision was made that INSPIRE would be worded to rate support from an individual worker rather than a team. This produced INSPIRE Version 3. Therefore, INSPIRE v3 had one version rated for an individual worker that consisted of two subscales. The Support subscale contained 21 items. The Relationship subscale contained 8 items.

INSPIRE version 3 is a 29-item service user-rated measure of recovery support from an individual worker. It comprises two sub-scales: Support (21 items, shown in Table 28) and Relationship (8 items, shown in Table 29). Support items are in five domains (Connectedness items S1-S4, Hope items S5-S8, Identity Items S9-S12, Meaning and purpose items S13-S16, and Empowerment items S17-S21). Support items are rated first for whether the item is important for their recovery (Yes/No). If Yes, support is then rated either on a 5-point Likert scale (0=Not at all to 4=Very much) or as ‘I don’t need support with this’. If No then no rating is made. Relationship items are rated on a 5-point Likert scale (0=Strongly disagree to 4=Strongly agree). The Support score can be calculated when at least one Likert rating is made, and Relationship sub-scale only when all 8 items are rated. Scoring for both sub-scales comprises the mean of all Likert scale ratings converted to a percentage, ranging from 0 (low support) to 100.

*Stage 4: Psychometric evaluation*

92 participants completed measures at baseline. 71% of participants were male. The mean age was 42 (s.d.=10.2, range 20-71). 41 (46%) were Black, 38 (43%) were White, and 10 (11%) were from other ethnic backgrounds. 43 (49%) of participants had received a diagnosis of schizophrenia, 20 (23%) had a diagnosis of bipolar disorder, and 25 (28%) had other diagnoses including depression and mixed (having more than one diagnosis). The majority of participants were unemployed (75%) and single (75%).
Baseline Support sub-scale item-level ratings are shown in Table 28.

**Table 28 INSPIRE Development sub-study: baseline Support sub-scale ratings**

| An important part of my recovery is… | Not important | Important and support not needed | Important and support needed | Support mean (s.d.) | Missing |
|---|---|---|---|---|---|
| **CONNECTEDNESS** | | | | | |
| S1 Feeling supported | 3 | 1 | 87 | 3.1 (0.77) | 1 |
| S2 Having positive relationships | 2 | 2 | 87 | 2.9 (0.90) | 1 |
| S3 Support from people using services | 26 | 1 | 63 | 2.7 (1.06) | 2 |
| S4 Part of community | 14 | 1 | 74 | 2.8 (1.01) | 3 |
| **HOPE** | | | | | |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| S5 Hopeful about future | 6 | 0 | 84 | 2.8 (1.04) | 2 |
| S6 Believing I can recover | 6 | 0 | 84 | 2.9 (0.89) | 2 |
| S7 Motivated to make changes | 13 | 1 | 76 | 2.8 (0.95) | 2 |
| S8 Hopes and dreams for future | 7 | 0 | 84 | 2.7 (1.05) | 1 |
| **IDENTITY** |  |  |  |  |  |
| S9 Dealing with stigma | 18 | 4 | 69 | 2.5 (1.12) | 1 |
| S10 Feeling good about myself | 5 | 1 | 83 | 2.9 (0.91) | 3 |
| S11 Spiritual beliefs respected | 23 | 8 | 60 | 2.5 (1.27) | 1 |
| S12 Ethnicity respected | 26 | 5 | 60 | 2.8 (1.16) | 1 |
| **MEANING AND PURPOSE** |  |  |  |  |  |
| S13 Understanding mental health | 5 | 0 | 85 | 2.9 (1.06) | 2 |
| S14 Doing things mean something | 5 | 1 | 84 | 2.8 (1.00) | 2 |
| S15 Rebuilding life | 7 | 1 | 82 | 2.9 (0.95) | 2 |
| S16 Good quality of life | 8 | 0 | 82 | 2.9 (0.99) | 2 |
| **EMPOWERMENT** |  |  |  |  |  |
| S17 Feeling in control | 5 | 0 | 86 | 2.8 (0.98) | 1 |
| S18 Managing mental health | 3 | 1 | 86 | 3.2 (0.81) | 2 |
| S19 Trying new things | 17 | 2 | 71 | 2.9 (1.07) | 2 |
| S20 Taking risks | 51 | 1 | 39 | 2.5 (1.21) | 1 |
| S21 Building on strengths | 8 | 1 | 80 | 2.8 (1.02) | 3 |

Taking risks (item S20) was rated as not important for their recovery by 51 (55%) respondents. No item was rated as ‘Support not needed’ by more than 10% of respondents. The mean Support sub-scale score was 71.6 (s.d. 18.8).

Baseline Relationship sub-scale item-level ratings are shown in Table 29.

**Table 29 INSPIRE Development sub-study: baseline Relationship sub-scale ratings**

| Item | Strongly | Disagree | Neutral | Agree | Strongly |
|---|---|---|---|---|---|

| | Disagree | | | | Agree |
|---|---|---|---|---|---|
| **R1 Feeling listened to** | 1 | 1 | 11 | 39 | 39 |
| **R2. Feeling supported** | 1 | 2 | 9 | 44 | 35 |
| **R3. Worker believes in my recovery** | 2 | 3 | 19 | 39 | 26 |
| **R4. Takes hopes and dreams seriously** | 2 | 4 | 22 | 40 | 23 |
| **R5. Respects me** | 1 | 0 | 14 | 40 | 35 |
| **R6. Treats me as individual** | 1 | 2 | 14 | 37 | 37 |
| **R7. Supports my decisions** | 1 | 3 | 12 | 46 | 29 |
| **R8. Keeps hopeful for me** | 1 | 1 | 14 | 41 | 33 |

Overall there was a skew towards satisfaction, but the full range of rating points were endorsed for each item. All items were rated by 88 (96%) of participants, with item-level completion rates ranging from 97% to 100%. The mean Relationship sub-scale score was 78.0 (s.d. 16.53).

*Convergent validity*

The correlation between the Support subscale and the SI-MH at baseline was 0.47. This is a relatively low score indicating that the SI-MH may not be assessing the same construct as the Support sub-scale. The correlation between the Relationship sub-scale and RPRS was 0.69, indicating adequate convergent validity.

*Factor structure*

For the Support sub-scale, factor analysis of each CHIME domain is shown in Table 30. For each domain the number of participants who answered ‘yes’ to the item being important and completed the Likert rating is given, with the variance explained and the Kaiser-Mayer-Olkin (KMO) score for each domain.

**Table 30 INSPIRE Development sub-study: factor analysis**

| **Domain** | **n** | **Variance explained** | **KMO score** |
|---|---|---|---|
| Connectedness | 56 | 71.4 | 0.76 (fair) |
| Hope | 70 | 77.1 | 0.74 (fair) |
| Identity | 51 | 75.8 | 0.65 (mediocre) |
| Meaning and purpose | 76 | 82.2 | 0.78 (fair) |
| Empowerment | 37 | 65.2 | 0.55 (bad) |

The KMO scores show that factor analysis is appropriate for each domain other than Empowerment. The results of the factor analysis indicate that each CHIME domain assesses one latent factor, thus supporting the five factor solution.

The Relationship sub-scale items were correlated (inter-item correlation range 0.09 to 0.4 for R3 (Worker believes in my recovery) and over 0.4 for all other items), confirmed by KMO score of 0.83, indicating factor analysis was appropriate. Using the Kaiser criterion of extracting factors with eigenvalues greater than 1, two factors (eigenvalues 4.38 and 1.05) were found. Parallel analysis indicated that there was a one factor solution which explained 64.1% of the variance. A single-factor solution therefore best fitted the data. Factor loading for R3 was 0.38 and for other items ranged from 0.70 to 0.77. Communality (proportion of variance accounted for by the factor) was 0.14 for item 3, and for other items ranged from 0.49 to 0.60. This indicates that the Relationship sub-scale is measuring one latent factor, and item R3 contributes less than other items to its measurement.

*Internal consistency*

For the Support sub-scale, internal consistency was calculated for each CHIME domain. These were all adequate apart from the Empowerment domain: 0.82 (Identity), 0.83 (Hope), 0.84 (Connectedness), 0.85 (Meaning), to 0.95 (Empowerment). For the Relationship sub-scale, Cronbach’s alpha was 0.89.

*Test-retest reliability*

A total of 80 ratings were made at T1 (2 weeks). The mean T1 Support sub-scale score was 67.3 and the mean T1 Relationship sub-scale score was 76.0. The rating of personal importance for Support sub-scale items between baseline and T1 (2 weeks) was stable (predefined as no change for over 90% of respondents) for 15 of the 21 items. The lowest stability was found for item S20 (taking risks) (78%) and then (referring to Table 28) items S12 (85%), S19 (86%), S3 (87%), S9 (87%) and S7 (88%).

The mean item score for items rated on the Likert scale at T0 and T1 showed very little change: only two items changed by more than 0.20 and no items changed by more than 0.29. This indicates that the Likert scores remain stable over time.

For the Relationship sub-scale the intraclass correlation coefficient was 0.75 indicating good test-retest reliability.

*Sensitivity to change*

A total of 53 ratings were made at T2 (3 months after baseline). The mean T2 Support sub-scale score was 69.4 and the mean T2 Relationship sub-scale score was 78.3. Table 31 compares change in SI-MH and Support sub-scale.

**Table 31 INSPIRE Development sub-study: Support sub-scale sensitivity to change**

| | | **Support sub-scale change** | | | |
|---|---|---|---|---|---|
| | | Decreased | No change | improved | Total |
| | Decreased | 4 | 2 | 2 | 8 |
| | No change | 6 | 22 | 4 | 32 |
| | Improved | 1 | 7 | 5 | 13 |
| Total | | 11 | 31 | 11 | 53 |

31 (59%) showed consistency in direction of change, 19 (35%) changed in one scale but not the other, and 3 (6%) changed inconsistently.

Table 32 compares change in RPRS and Relationship sub-scale.

**Table 32 INSPIRE Development sub-study: Relationship sub-scale sensitivity to change**

| | | Relationship sub-scale change | | | |
|---|---|---|---|---|---|
| | | Decreased | No change | Improved | Total |
| | Decreased | 1 | 1 | 0 | 2 |
| | No change | 4 | 22 | 7 | 33 |
| | Improved | 0 | 2 | 0 | 2 |
| Total | | 5 | 25 | 7 | 37 |

23 (62%) showed consistency in direction of change, 14 (38%) changed in one scale but not the other, and 0 (0%) changed inconsistently.

Weighted linear Kappa was calculated for each subscale. For the Support sub-scale the weighted Kappa was 0.27, standard error 0.11. For the Relationship sub-scale the Weighted Kappa was 0.04, standard error 0.09. The Hedges' g effect size for the Support sub-scale and SI-MH is 0.6 for the 'Decreased' group indicating a moderate effect, and 0.8 for the 'Improved' group indicating a large effect. The Hedges' g for the Relationship sub-scale was not meaningful to report as the sample size was too small.

*Feasibility*

Median completion time was 7 minutes, and 79% of respondents completed INSPIRE in 10 minutes or less. Overall, 86% of respondents reported that INSPIRE was 'About right' in terms of length, 94% understood at least most of the questions (53% understanding all), 71% felt most questions reflected their experience (30% all questions reflected their experience), and 87% found none of the questions upsetting.

*Modification 1: INSPIRE*

On the basis of the psychometric evaluation, modifications were made to produce the final version of INSPIRE. Items S20 (Taking risks) and R3 (My worker believes I can recover) were deleted, and the response category ‘I do not need support from my worker with this’ from the Support sub-scale was removed. Psychometric properties were re-calculated for this modified version of INSPIRE.

The Support sub-scale mean score was 71.6 (s.d. 37.4), convergent validity with SI-MH increased to 0.60, EFA found the KMO score for the Empowerment domain increased to 0.75 (fair), and the amount of variance explained increased to 85.1%. Internal consistency for the Empowerment domain changed from 0.95 to 0.83 which is acceptable. Sensitivity to change analysis found 4 (8%) Support scores changed inconsistently with SI-MH.

The mean Relationship sub-scale score was 68.8 (s.d. 15.0), convergent validity with RPRS was 0.69, a one-factor solution increased to 70.5% of variance, with a KMO score of 0.84 (good), and internal consistency was 0.89. Test-retest reliability was 0.75. Sensitivity to change analysis found 2 (4%) Relationship scores changed inconsistently with RPRS. The final version of INSPIRE is shown in Appendix 22.

*Modification 2: Brief INSPIRE*

In response to the median completion time of 7 minutes, a brief version of INSPIRE was also developed for routine use. The five-item Brief INSPIRE consists of one item (S1 ‘Feeling supported by other people’, S8 ‘Having hope and dreams for the future’, S10 ‘Feeling good about myself’, S14 ‘Doing things that mean something to me’ and S17 ‘Feeling control of my life’) chosen from each CHIME domain on the basis of item performance. For each item, the question is ‘My worker helps me with’ and rating is made on the same five-point Likert scale, i.e. the response is not individualised. The mean score was 73.0 (s.d 18.8). Initial psychometric validation was undertaken. Internal consistency was 0.86. An exploratory factor analysis using parallel analysis found a one-factor solution which explained 72.2% of the variance. One factor (eigenvalue 3.1) was found. The KMO score was 0.84. Communality for the five items ranged from 0.35

to 0.69, indicating that the scale is measuring one latent factor. Test-retest reliability was 0.72. Sensitivity to change analysis using SI-MH (n=40) found 23 (57%) showed consistency in direction of change, 16 (40%) changed in one scale but not the other, and 1 (3%) changed inconsistently. The Brief INSPIRE is shown in Appendix 23.

## Discussion

This study reports the development and evaluation of a new service user-rated measure to assess staff support for recovery, and a brief version of this measure. The measure is theory-based, and developed through consultation with 61 experts including people with lived experience of using services, and a pilot study with 20 people currently using services. Psychometric evaluation of convergent validity, internal consistency, test-retest reliability and preliminary evidence of sensitivity to change, along with an exploratory factor analysis to examine the underlying factor structure of the two sub-scales, led to further modifications. The resulting 20-item INSPIRE and 5-item Brief INSPIRE measures have adequate psychometric properties.

Three changes were made to INSPIRE following the psychometric evaluation. One item in the Support subscale, Item S20 (Taking risks) showed a significantly lower level of importance than any other item (40% indicated it was important). This level of importance was consistent with researcher experience from administration of INSPIRE, when participants often stated that they tried to avoid risk, or were told to avoid risk by mental health staff. The idea of 'risk' in mental health services is often characterised as negative and to be avoided[244]. The intended meaning behind the item was that risk would be seen in a positive way but this was not the perspective of participants. As item S19 (Trying new things) also addresses this aspect, item S20 was deleted.

In the Relationship subscale, item R3 (My worker believes that I can recover) was deleted for two reasons. Firstly, it did not fit the one factor model found in the exploratory factor analysis. Also during the administration it was found that some participants would state that they did not know how their worker felt about their recovery or that they had never discussed this. R3 was the only item asking the respondent to rate what the worker believed, rather than their own experience - explaining why this item did not fit the factor model.

The third change was to delete the scoring option of ‘Do not want support from my worker’. This was rarely endorsed by participants (range 0 to 5 endorsements across items), and its deletion reduced rating complexity.

Brief INSPIRE was developed because the use of outcome measures in routine clinical use can be challenging[245], and a very low-burden measure may increase uptake. The brief INSPIRE factor structure indicated one general factor rather than the five correlated CHIME domains, suggesting these five items may load on to a higher-order support factor. Future studies with a larger sample size would be needed to explore the multidimensionality of the Brief INSPIRE.

*Strengths and limitations*

The strengths of the psychometric evaluation were that the sample were recruited from a variety of teams so that there was a variation in the experience they would have of the service. The sample was heterogeneous in terms of ethnicity, reducing the likelihood of bias due to the participant’s ethnic background. The retention rate of participants was good so it was possible to calculate test-retest reliability and investigate the measure’s ability to assess sensitivity to change – the psychometric property that has often been under-investigated in recovery support measures[98]

We identify three limitations. First, the recruitment procedure had to be done via mental health staff due to the requirements of the ethical approval. This could lead to bias as mental health staff may preferentially approach service users to participate with whom they have a good relationship, leading to overly-positive ratings. Second, the limited choice of established comparator measure for sensitivity to change analysis was problematic, as SI-MH assesses satisfaction not perception of support received, and RPRS does not have demonstrated sensitivity to change. Third, although the theory base is derived from personal experiences of recovery and a service user researcher was involved in developing the measure, the process of developing INSPIRE was led by professionals. The resulting measure therefore cannot be considered to be patient-generated[246]. Finally, the lack of facility for interpreters meant that participants who did not have a good command of English could not participate. The research was undertaken in an area of high ethnic diversity and so this may have prevented service users who did not have English as a first language from participating.

*Implications*

Research into how recovery can be supported by services is still developing, and standardised measures will advance the field. INSPIRE is novel in that it assesses the service user experience of support from an individual worker. This differs from existing measures that assess the recovery orientation of services. It is also the first such measure developed in the UK. INSPIRE is also innovative in recording individual preferences, to acknowledge the individual nature of recovery. This combination of an individualised and standardised measure which produces quantitative and aggregable data is unique. Future research might investigate concordance between INSPIRE and non-individualised standardised measures, to evaluate whether the enhanced ecological validity of INSPIRE provides more accurate outcome information than non-individualised measures.

INSPIRE has been tested with adults of working age using statutory mental health services. The wording of INSPIRE is deliberately generic, so as to enhance the potential useability of INSPIRE across other services and systems. Future validation studies might include new target groups such as older adults or children, new systems such as social care or voluntary sector / non-governmental organisations, and in different countries.

INSPIRE has three clinical uses. First, it provides a vehicle for structured conversations between staff and service users to establish the individual's priorities and expectations of support. This is the foundation of person-centred care planning[247]. Second, INSPIRE provides a meaningful measure of change over time, although the sensitivity to change for the Relationship scale requires further investigation as the sample size was too small to be able to calculate meaningfully, and it is unclear whether the modest kappa relates to sensitivity to change in INSPIRE or RPRS. It is plausible for example that an increase in INSPIRE score over time will correlate with improvement in more distal outcomes such as recovery and quality of life, especially when information is actively used in clinical decision-making[101].

Finally, INSPIRE is useable as a benchmarking tool for comparison between groups of service users. The Brief INSPIRE score can be calculated from the INSPIRE score, so routine outcome monitoring might combine data from services using INSPIRE for clinical purposes and from services using Brief INSPIRE as a lower-burden measure. At the team level, this allows identification of recovery support areas which are currently under-addressed, to inform service development. INSPIRE is also a candidate for routine collection at the regional and national level. For example, INSPIRE is currently being introduced across several regions in England as part of the Implementing Recovery through Organisational Change (ImROC) initiative[248], and has been recommended by ImROC for routine use[224]. Translations are underway into Danish, Estonian, German, Italian, Japanese, Russian, Slovenian, Spanish and Swedish. INSPIRE was used in the REFOCUS trial.

## IOM Development sub-study

### Introduction

Randomised controlled trials (RCTs) evaluate the effectiveness of an intervention in relation to a pre-specified primary outcome[249]. Predefining a standardised measure as a primary outcome has several advantages, including informing the power calculation for the sample size, reducing post-hoc ‘data fishing’, and supporting meta-analytic aggregation of findings across studies. However, the use of a single predefined primary outcome to evaluate complex interventions raises four issues.

First, a range of outcome domains exist[23], and as complex interventions may impact across this range[172], a single predefined outcome measure may not capture all changes. Second, some measures may become widely used primarily because they have been used in other RCTs, rather than because of any inherent superiority[250]. Third, pre-specifying the primary outcome for an RCT may not be clinically informative, as recognised in the developing field of clinimetrics[251]. Finally, people who use services may vary in the importance they attach to different types of outcomes. For example, the aim of treatment for some people may be symptomatic improvement, whereas others have social goals (e.g. employment) or personal goals (e.g. to find meaning in their life)[14]. As a result, a predefined outcome measure may not be relevant to the person receiving the intervention.

A number of patient-centred measures and approaches have been developed to address these issues. One approach to personalise evaluation is Goal Attainment Scaling (GAS), which was originally developed for mental health programmes[252]. The GAS process involves the service user, together with the worker, prospectively identifying a number of relevant goals, and then rating their progress on each goal along a five-point scale at follow-up. Although each respondent has different goals, the overall GAS score is standardised so that data can be aggregated and compared across individuals[253,254]. GAS has been effectively used to identify and evaluate outcomes in RCTs in rehabilitation[254,255] and studies with older adults[256,257]. Systematic reviews conclude that GAS shows high sensitivity to change, reliability and validity when used in chronic healthcare and physical and neurological rehabilitation[258,259]. A systematic review of research evaluating the implementation of GAS in occupational health programmes found that goal setting could be implemented in mental health settings and that goal attainment was associated with positive change in clinical outcomes[260]. GAS was also found to be an effective clinical tool among service users in psychiatric day care, with people with a diagnosis of schizophrenia having the highest success rate with 75% achieving a good outcome[261].

Despite this evidence, fully individualised goal setting is not implemented in randomised controlled trials in the mental health field. This may be due to operational limitations associated with GAS[262,263]. In particular, goal scaling relies on a complex formula, making calculation complex in everyday care and rendering interpretation complicated[259]. This may also lead to limited reliability and validity as practitioners may vary in their approach and experience[262]. GAS is based on scaling at baseline and follow-up which may not fully capture the actual level of goal attainment. Finally, in RCTs researchers would most likely be involved in goal selection and scaling of GAS; however, they may not be able to assess whether the goal is realistic at baseline and rate attainment at follow-up.

The aim of this study was to develop and evaluate a new approach to assessing change in RCTs of complex interventions in mental health, by using individualised and positively-valued outcome domains. The objectives were to develop, pilot, and assess the feasibility of the Individualised Outcome Measure (IOM), and then to evaluate IOM in an RCT by assessing whether IOM components 1) capture change over time, 2) co-vary, and 3) are associated with the predefined primary outcome.

## Methods

### *Participants*

Participants were recruited from community-based mental health teams in the South London and Maudsley NHS Foundation Trust (stages 1 to 3) and 2Gether NHS Foundation Trust (Stage 3). Inclusion criteria were being aged 18-65 years, being able to speak and understand English, and being sufficiently well to participate in the opinion of the worker providing community support. In the RCT, service users were participating in the REFOCUS trial (ISRCTN02507940) which had additional inclusion criteria of having a primary clinical diagnosis of psychosis, having no immediate plans for discharge or transfer, not currently receiving in-patient care, not being in prison, not participating in another substantial study, and being in regular contact with at least one worker in the team.

**Measures**

The final version of the Individualised Outcome Measure (IOM Version 3) comprised two components to index individual outcomes: Goal Attainment (GA) and Personalised Primary Outcome (PPO). The GA component is a variation of GAS, requiring service users to identify one personally relevant goal which mattered to them, that they thought they could achieve and which services could help with, at baseline. Service users were asked to identify only one goal as evidence from mental health research showed respondents can focus on one goal at a time[260]. Having one goal also simplifies assessment of change and aids interpretability of the findings. At follow-up, the service user rates how successful they were at reaching their goal on a 5-point Likert scale from 0 (I am further away from my goal) to 4 (I did even better than expected).

After identifying their goal, service users were invited to complete the PPO component, which is a novel approach. It requires the service user to choose the outcome domain which most closely maps onto their chosen goal from a predefined list. Each domain is associated with one standardised measure, which the service user completes at baseline and again at follow-up.

In IOM Version 1, thirteen patient-rated measures were included in the PPO component. The **Activity and Participation Questionnaire** (APQ) is a 5-item measure of social inclusion ranging from 0 to 24[264]. The **Short Form Health Survey** (SF-36) is a 36-item measure of functional health and well-being, consisting of 8 scaled scores each with a score range from 0 to 100[265]. The **Short Health Survey Questionnaire** (SF-12) is a 12-item measure of functional health and well-being, consisting of 2 scaled scores with a score range from 0 to 100[266]. The **Empowerment Scale** (ES) is a 28-item measure ranging from 1 to 112[267]. The **Herth Hope Index** (HHI) is a 12-item measure of hope ranging from 1 to 48[268]. The **Rosenberg Self-Esteem Scale** (RSES) is a 10-item measure ranging from 1 to 40[269] items were recoded so that high scores indicated higher self-esteem levels. The **Stigma Scale** (SS) is a 28-item measure of stigma of mental illness and ranges from 1 to 140 with high scores indicating low stigma[270]. The **Meaning of Life Questionnaire** (MLQ) is a 10-item measure ranging from 1 to 70[271].

MLQ comprises two subscales: Search for and Presence of meaning of life, and only the Presence subscale was used. The **Medical Outcome Study Social Support Survey** (MOS) is a 21-item measure ranging from 1 to 85[272] The **Community Integration Measure** (CIM) is a 10-item measure ranging from 1 to 50[273]. The **Warwick-Edinburgh Mental Well-Being Scale** (WEMWBS) is a 14-item measure of wellbeing ranging from 1 to 70[218]. The **Patient Perception of Functioning Scale** (PPFS) is a 6-item measure with ratings for both community functioning and cognition, rated ranging from 1 to 30[274]. The **Manchester Short Assessment of Quality of Life** (MANSA) is a 12-item measure ranging from to 84[275].

Two additional measures were used. The **Mental Health Confidence Scale** (MHCS) is a 16-item measure of empowerment ranging from 1 to 96 with good psychometric properties[276,277]. The **Questionnaire about the Process of Recovery** (QPR) was the primary outcome of the REFOCUS trial[7,84]. This is a 22-item patient-rated assessment of recovery, with each item rated on a five-point scale from 0 to 4. An overall score was extrapolated by summing 15 of the original 22 items[85]. All scales were coded so that a high score indicated a positive outcome.

### Procedures

The study comprised two stages.

*Stage 1: Development and piloting*

The PPO was developed using a narrative review of outcome domains in mental health[14,225,227,278,279] with specific emphasis on domains valued by service users[280-282]. For each domain, a related outcome measure was sought. This produced the initial version of IOM Version 1, which was consulted on with the REFOCUS advisory boards, comprising a Lived Experience Advisory Panel (LEAP) of service users and carers (as described in Chapter 10), topic-specific experts, a virtual advisory panel of service users, researchers and other stakeholders with an interest in black and minority ethnic mental health, and an International Advisory Board of international experts. The consultation focused on identifying outcome domain omissions, measures for outcome domains which did not have identified measures as well as to improve the content, order and format of the PPO, which consisted of 13 outcome domains and corresponding measures. Following this consultation, IOM Version 2 was finalised.

A pilot study was, subsequently, undertaken with a convenience sample of 20 service users, to assess their experience of completing IOM Version 2. Characteristics of pilot study participants are shown in Table 33.

**Table 33 IOM Development sub-study: characteristics of participants**

| | Pilot study | Feasibility study | RCT evaluation |
|---|---|---|---|
| N (complete data) | 20 | 75 | 340 |
| **Age** (years) | 40.9 years | 42.3 (10.7) | 43.5 (10.8) |
| **Gender** | | | |
| Male | 14 (70) | 51 (68) | 214 (63) |
| Female | 6 (30) | 24 (32) | 125 (37) |
| **Ethnicity** | | | |
| White | 10 (50) | 35 (47) | 203 (60) |
| Black | 6 (30) | 32 (43) | 85 (25) |
| Other | 4 (20) | 8 (11) | 50 (15) |
| **Diagnosis** | | | |
| Psychosis | | | 340 (100) |
| Schizophrenia | 5 (26) | 35 (50) | |
| Bipolar disorder | 5 (26) | 15 (21) | |
| Depression | 1 (5) | 1 (1) | |
| Mixed | 4 (21) | 14 (20) | |
| Other | 4 (21) | 5 (7) | |

The pilot was conducted to identify any necessary change which may improve IOM. Informed consent was obtained and service users were paid £10 for their participation. All service users were able to complete and provide information on the IOM. Following the pilot, three measures of the PPO (APQ, SF-36 and SF-12) were deleted as they were not chosen by any respondent. Additionally, the Empowerment Scale was replaced with the Mental Health Confidence Scale. No changes were necessary for the GA component. Table 34 shows the list of ten outcome domains and their associated measures which constituted IOM Version 2.

**Table 34 IOM Development sub-study: PPO domains and completion rates for feasibility study (n=75) and evaluation in an RCT (n=340)**

| **List of descriptions of outcome domains given to participants** | **Outcome domain being described** | **Measure completed by participants paired with chosen domain** | **Stage 2** | **Stage 3** | |
|---|---|---|---|---|---|
| | | | N (%) | N (%) | Raw mean (s.d.) |
| Feeling more hopeful about the future | Hope | Herth Hope Index | 7 (9) | 47 (14) | 36.14 (5.1) |
| Feeling more in control of my life | Empowerment | Mental Health Confidence Scale | 6 (8) | 26 (8) | 66.95 (17.1) |
| Feeling more positive about myself | Self-esteem | Rosenberg Self-Esteem Scale | 11 (15) | 61 (18) | 26.32 (4.4) |
| Feeling better treated by other people | Stigma | Stigma Scale | 2 (3) | 7 (2) | 51.27 (13.2) |
| Feeling like you have meaning in your life | Meaning of life | Meaning of Life Questionnaire | 7 (9) | 42 (12) | 24.45 (7.1) |
| Feeling supported by other people | Social support | MOS Social Support Survey | 3 (4) | 8 (2) | 71.53 (13.9) |
| Feeling part of the community | Community integration | Community Integration Measure | 3 (4) | 11 (3) | 30.46 (8.1) |
| Feeling better about your life | Wellbeing | Warwick-Edinburgh Mental | 8 (11) | 39 (12) | 45.26 (9.7) |

| | | | | | |
|---|---|---|---|---|---|
| | | Well-being Scale | | | |
| Being able to manage day-to-day life | Daily functioning | Service user Perception of Functioning Scale | 11 (15) | 28 (8) | 16.71 (3.6) |
| Having a better quality of life | Quality of life | Manchester Short Assessment of Quality of Life | 17 (23) | 71 (21) | 55.90 (10.2) |

We then assessed the feasibility of IOM Version 3 using a convenience sample of 84 current mental health service users, whose characteristics are shown in Table 33. They completed IOM at baseline and at 3-month follow-up, and rated their experience of completing IOM, using the form shown in Appendix 24. Participants were paid £10 for each round of assessment.

A total of 75 (89%) service users were able to identify a goal, a relevant outcome domain, and complete the associated PPO measure. The time to identify a goal ranged between 1 and 5 minutes (median=1, iqr=1), and 64 (85%) service users reported the goal was ‘very’ or ‘extremely’ important to them while only 3 (4%) were not happy about being asked. All ten PPO domains and their associated measures were selected and completed (Table 34, column 4). At follow-up, 55 (73%) service users completed both IOM components. There was no association between attrition and any of the sociodemographic variables. For the GA component, 8 (15%) rated the goal as Fully Achieved, 28 (51%) as Partly Achieved and 19 (35%) as Not Achieved. Finally, 36 (65%) individuals rated their original goal as still Very or Extremely important.

*Stage 2: Evaluation in a randomised controlled trial*

IOM Version 3 was then evaluated as an outcome measure in the REFOCUS Trial, which is described in Chapter 5. The REFOCUS intervention was developed in the Intervention Development sub-study (Chapter 3), and intended to lead to more collaborative staff-patient relationships, and a greater staff focus on the service user’s values, strengths, and goal-striving. The intended benefits were more patient-centred and recovery-oriented care, and this emphasis on individualised care through a team-based and trans-diagnostic intervention meant that the use of a predefined and invariant primary outcome was problematic in capturing the outcome domain relevant to each service user. The QPR was the predefined primary outcome.

A random sample of 15 service users was recruited from each of the 27 participating teams, and after giving informed consent, they completed a set of measures including

QPR and IOM Version 3 at baseline and at one-year follow-up. Participants were paid £10 for each round of assessment.

*Analysis*

Data from both trial arms were pooled to address our hypotheses. We explored the relationship between attrition (missing vs. present) and socioeconomic variables of gender age, ethnicity, marital status, education and accommodation type for the feasibility study and the trial. Missing data across the outcome scales were pro-rated when less than 20% of items were left blank.

Prior to conducting our analysis, we recoded the IOM components to facilitate analysis. To avoid small cell counts, GA was recoded so that ‘successful’ and ‘even better than expected’ were coded as Fully Achieved, ‘some progress’ was coded as Partly Achieved, and ‘no progress’ and ‘further away from the goal’ were coded as Not Achieved. To combine scores of the PPO, we standardised each measure using z-scores based on population norms from previous research.

*Objective 1 - change over time*

We conducted a regression analysis with no predictors on the PPO difference score between baseline and follow-up to test if the difference was significantly different from 0. Subsequently, we assessed whether change on the PPO was clinically meaningful by implementing the Reliable Change Index (RCI) approach[283] following the Jacobson and Truax’s guidelines[284]:

(x2-x1)/sqrt(2*(s*sqrt(1-rxx))2)

where *rxx* is the Cohen’s alpha (i.e., reliability) value and *s* is the scale standard deviation based on population values. RCI is a standardised measure of change and scores greater than the critical value (i.e., +/-1.96) correspond to reliable change[285]. Using these cut-off points, we could group service users as having ‘Improved’, ‘Not changed’, or ‘Declined’.

*Objective 2 – co-variation*

To assess whether the two IOM components are associated and tap onto the same construct, we regressed the PPO follow-up score on GA, while adjusting for baseline standardised scores.

*Objective 3 – relationship with primary outcome*

We assessed the relationship of the two IOM component with the REFOCUS trial primary outcome (i.e., QPR), as this is a standardised and established measure of a related construct. In order to achieve this, we regressed the QPR change score separately onto the PPO change scores and GA.

In all regression analyses, we accounted for clustering at the team level by conducting random effects regression analyses with maximum likelihood estimation using the 'xtmixed' command in Stata 11. Site and study arm were entered as covariates in the model in order to reflect the study design. Bonferroni corrections were implemented to adjust for multiple pairwise comparisons when appropriate.

### Results

At baseline, 340 (86%) service user participants in the RCT completed both components of the IOM. Table 33 summarises their sociodemographic characteristics. Service users with complete IOM at baseline were more likely to be White British (vs. other; $chi^2(1)=8.5$, $p=.004$), to live in private accommodation (vs. supported; $chi^2(1)=4.6$, $p=.03$) and to have formal qualifications (vs. no qualification; $chi^2(1)=20.9$, $p<.001$).

At one-year follow-up, 239 (of 340) service users completed both IOM components. Service users with complete information at follow-up were more likely to have formal qualifications (vs. no qualification; $chi^2(1)=6.7$, $p=.01$) and to be younger ($t(374)=2.4$, $p=.02$). All ten PPO domains and their associated measures were selected and completed (Table 34, column 5). The goal was rated as Fully Achieved by 63 (26%)

service users, 113 (47%) rated it as Partly Achieved while 63 (26%) reported having made No Progress.

*Objective 1: change over time*

The regression analysis (average cluster size = 9, range 1 to 13) indicated that the change score on the PPO between baseline and follow-up was not different from 0 (z=1.3, p=.18, n=239). The RCI approach indicated that 79% service users did not change over time, as shown in Table 35.

**Table 35 IOM Development sub-study: Reliable Change Index at one-year RCT follow-up (n=239)**

| | **Cut-off (RCI=1.96)** | **Change status n (%)** | | |
|---|---|---|---|---|
| | | **Declined** | **No change** | **Improved** |
| **HHI** | 6.78 | 2 (6) | 26 (79) | 5 (15) |
| **MHCS** | 8.69 | 5 (26) | 8 (42) | 6 (32) |
| **RSES** | 7.30 | 1 (2) | 42 (89) | 4 (9) |
| **Stigma** | 15.39 | 0 (0) | 3 (100) | 0 (0) |
| **MLQ presence** | 8.34 | 1 (4) | 24 (86) | 3 (11) |
| **MOS** | 11.62 | 2 (33) | 4 (67) | 0 (0) |
| **CIM** | 7.70 | 0 (0) | 3 (75) | 1 (25) |
| **WEMWBS** | 8.64 | 3 (12) | 21 (84) | 1 (4) |
| **PPFS** | 2.36 | 2 (9) | 14 (64) | 6 (27) |
| **MANSA** | 11.03 | 4 (8) | 44 (85) | 4 (8) |
| | **Total** | **20 (8)** | **189 (79)** | **30 (13)** |

*Objective 2: co-variation*

Analyses were conducted on all 239 participants with complete information on the IOM. A regression analysis across all 27 clusters (average cluster size = 9, range 1 to 13) showed an association between GA and PPO ($\chi^2(2)=13.8$, p=.001; n=239). Compared to service users who had made No Progress, those who had Partly (b=.32, 95%CI: .09 to .56, z=2.7, p=.007) or Fully Achieved their goal (b=.50, 95%CI: .23 to .77, z=3.7, p<.001) had higher PPO scores at follow-up, while adjusting for baseline scores and accounting for multiple testing.

*Objective 3: relationship with primary outcome*

Regression analysis on all 237 service users with complete information on IOM and QPR (average cluster size = 9, range 1 to 13) showed that the PPO and QPR change scores were positively associated (b=3.3, 95%CI: 2.3 to 4.4, z=6.2, p<.001). Similarly, regression analysis across all 27 clusters (average cluster size = 9, range 1 to 13) showed that GA was associated with follow-up QPR scores ($\chi^2(2)=12.4$, p=.002). In particular, service users who had Partly (b=3.0, 95%CI: 0.8 to 5.2, z=2.6, p=.008) or Fully Achieved their goal (b=4.3, 95%CI: 1.9 to 6.8, z=3.4, p=.001) reported greater recovery scores than those who had Not Achieved their goals, even after adjusting for multiple testing.

## Discussion

A new measure of individualised outcome for use as a clinical end-point in RCTs was developed, by literature review, expert consultation, piloting, assessment of feasibility and then evaluation in the context of an RCT. The IOM has two components, both of which had adequate acceptability and completion rates. Evaluation in an RCT showed that IOM could be used to differentiate between service users who changed versus those who did not change, that the two components (GA and PPO) co-vary, and that both were associated with change in the predefined primary outcome for the trial.

There is growing consensus that individualised approaches may be an effective way to assess outcome in mental health research[14], and a number of measures has been developed to achieve this[236,286,287]. None have yet been evaluated as a candidate primary outcome in an RCT.

For GA, the majority of respondents (66% feasibility study, 72% RCT) reported having made at least some progress on their goal at follow-up. These figures are in line with those observed in previous studies in mental health and rehabilitation[258-260]. For example, 63% of service users with a diagnosis of schizophrenia were found to have made good progress on their goal at 6-month follow-up[261]. These results suggest that the GA component, which is a variation of the GAS, is as effective as the original version at capturing achievement.

The PPO component is a novel approach which requires service users to complete standardised questionnaires associated to the outcome domain linked to the goal. Thus, PPO allowed us to collect rich information associated with progress on one user-valued outcome domain using psychometrically valid questionnaires. The PPO component did not capture any statistical or clinically meaningful change across time (objective 1). Nonetheless, no change was observed on the REFOCUS trial primary outcome, which suggests that change did not occur in the 12-month period of the trial. Hence, implementation and replication in a future trial is needed. PPO scores at follow-up were associated with Goal Attainment (objective 2), which indicates the two IOM components tap onto overlapping domains as originally intended. Finally, PPO change scores were positively associated with change scores on QPR (objective 3). Thus, it appears to capture change levels in similar fashion to that exhibited by a standardised and established questionnaire.

The GA component was also found to be positively associated with both QPR change scores (objective 3). Indeed, service users who had Fully or Partly were more likely to report improved QPR scores than those who had not achieved their goal. These results are in line with research in the rehabilitation field which showed that GAS scores were positively associated with standardised measures of progress in rehabilitation and, hence, captured similar constructs[258,288].

Overall, our results indicate that PPO is sensitive to change as change scores on this component correlate with change scores on the trial primary outcome. It was not possible to establish whether GA was sensitive to change as it was assessed at follow-up only. Indeed, we cannot ascertain whether goal attainment leads to a greater sense of recovery or whether increased recovery leads to goal attainment. In order to address this limitation, future studies may need to implement a mixed-method design so that qualitative data may help us to understand this association. Assessment of goal status was originally omitted at baseline, to simplify implementation and calculations but future studies may incorporate baseline assessment to index change on this domain.

A further limitation of the GA component is that it relies on a one-item question to rate attainment. In contrast, the PPO relies on the use of well-established and standardised questionnaires associated with the relevant outcome domain and selected goal. Based on these considerations, PPO has greater promise as a more informative and comprehensive outcome measure to be used in RCTs. Thus, future RCTs in mental health could consider adopting the PPO as their primary outcome, to maximise the ecological validity (i.e. meaningfulness to each participant) of the outcome evaluation. This would involve participants identifying a goal and then choosing the outcome domain most relevant to their goal. The psychometric properties (e.g., internal consistency, construct validity and test-retest reliability) of the PPO should be further assessed. Future research should also establish whether PPO could be implemented in different types of intervention in mental health research.

Combining the different measures of the PPO list may be criticised for potentially leading to biased results; however, we used a norm-based standardisation process which has been found to overcome these issues[289]. Finally, even though variations of the original RCI exists which take into account the regression to the mean phenomenon[290], research showed that the original RCI approach represents an optimal measure of change[283,291]. The main strength of the study was the large and clinically representative sample recruited for an RCT in mental health, which renders our findings generalisable.

In summary, analysis of feasibility and evaluation of the IOM indicated that this approach can be implemented as an individualised outcome in RCTs for complex interventions in mental health. In particular, our results indicate that future mental health trials could adopt PPO as the primary outcome, as it captures rich information associated with the service user-specified outcome domain.

## Chapter 5: REFOCUS trial – methods

Adapted with permission from the published trial protocol[7].

### Objectives and hypotheses

The REFOCUS trial had four objectives:

Objective 1 was to establish the effectiveness of the REFOCUS intervention developed in the Intervention Development sub-study, and described in the REFOCUS manual[171]. Outcome evaluation was used to investigate whether service users receiving care from intervention teams make more progress towards their personal recovery than those receiving care from control teams. The main study hypothesis was that service users in the intervention arm will experience significantly greater increases in measures of personal recovery (as measured by the QPR) compared to service users receiving care from control teams. The secondary study hypothesis was that black service users in the intervention arm will experience significantly greater increases in measures of personal recovery (as measured by the QPR) and satisfaction (as measured by the CSQ) compared to Black service users receiving care from control teams. Results of the main outcome and economic evaluation are reported in Chapter 6, and of the secondary outcome evaluation and a casenote audit are reported in Chapter 8.

Objective 2 was to validate the REFOCUS Model, using process evaluation to investigate the extent to which the intended consequences of the intervention are as predicted by the REFOCUS Model. Results of the process evaluation are reported in Chapter 7.

Objective 3 was to establish and optimise trial parameters for the REFOCUS Manual, including recruitment and retention issues, fidelity, outcome and economic evaluation, implementation strategies, missing data analysis, and sample size calculation. The results relating to this objective are reported in Chapters 6 to 8.

Objective 4 was to understand the relationship between clinical outcomes and recovery outcomes comprising recovery outcomes of hope, empowerment, well-being, quality of life and personal recovery, and clinical outcomes of symptomatology, needs and social disability. The results relating to this objective are reported in Chapter 8.

In this report we describe an evaluation of the REFOCUS Intervention: a manualised team-level intervention to support personal recovery. We report a multi-site cluster randomised controlled trial comparing outcomes for service users in community mental health teams receiving or not receiving the REFOCUS Intervention. Although the intervention is trans-diagnostic, our evaluation focussed on the impact on service users with a diagnosis of psychosis. We hypothesised that recovery would be improved for service users with psychosis, in comparison with usual care.

### Design

A cluster randomised controlled trial across two mental health Trusts in England. The trial manual[171] and protocol (available at www.biomedcentral.com/1471-244X/11/185)[7] were published, ethical approval was obtained (East London Research Ethics Committee, 11/LO/0083), the trial was registered (ISRCTN02507940, controlled-trials.com), researchers were trained in administration of all standardised measures, and trial conduct was overseen by a Trial Steering Committee.

### Participants

As the intervention is at the level of the team, we used a cluster design with a cluster being a community mental health team, to reduce contamination. Team inclusion criteria were adult, community-based mental health teams providing care co-ordination using the Care Programme Approach (CPA)[292] a national framework for care co-ordination and resource allocation in mental health care. Two sites were used: South London and Maudsley NHS Foundation Trust (SLaM) in south-east London and 2gether NHS Foundation Trust in Gloucestershire. SLaM is the largest mental health trust in the UK, has an annual income of £330m, spent across over 100 sites spanning urban and suburban settings. It employs 4,500 staff in 296 teams, works with 34,128 service users. 2gether is a rural / semi-rural Trust, employing 806 staff in 23 adult mental health teams, and working with 4,301 service users. In both sites, all potentially eligible teams were identified by service managers, and then researchers discussed participation with the service and team managers and lead clinicians.

People who use SLaM services are ethnically diverse, with 37% of people using SLaM services recorded on the clinical information system as coming from a ‘Black African’, ‘Black Caribbean’ or ‘Black other’ background. 2gether is a rural/semi-rural Trust, employing 806 staff in 23 adult mental health teams, and working with 4,301service users. People who use2gether services are ethnically homogenous, with a very small number of black individuals using services. Therefore the secondary study (reported in Chapter 8) was conducted in SLaM only.

Service user participants were identified from each team’s caseload. Inclusion criteria were aged 18-65 years, primary clinical diagnosis of psychosis, e.g. schizophrenia, schizo-affective disorder, bipolar disorder, no immediate plans for discharge or transfer, not currently receiving in-patient care or in prison, speaks and understands English, not participating in substantial other study, is sufficiently well to participate in opinion of staff, and is in regular contact with at least one worker in the team. Exclusion criteria were being unable to give consent or being unknown to, or uncontactable by, the service. The caseload was screened for initial eligibility (age, diagnosis) based on clinical records, staff obtained assent from the service user to be approached by researchers, and then written informed consent and baseline data were obtained from participants by researchers before randomisation.

Staff inclusion criteria were providing clinical input to a participating team, not also providing clinical input to another participating team, and (for service user-identified paired staff) being in regular clinical contact with the participating service user. All staff gave written informed consent and completed baseline assessments before randomisation.

### Control

All participating teams were multidisciplinary and provided care co-ordination for service users. The framework for care co-ordination and resource allocation in mental health care is the Care Programme Approach (CPA)[292]. The CPA process is well-established in the trial sites. Key components of this approach include:

- Systematic arrangements for assessing the health and social needs of people accepted into specialist mental health services
- The formation of a care plan which identifies the health and social care required from a variety of providers
- The appointment of a key worker to keep in close touch with the service user and to monitor and co-ordinate care
- Regular review and, where necessary, agreed changes to the care plan.
- Individuals will continue to receive treatment as usual, directed by the principles and CPA process outlined above.

Individuals within the control teams continued to receive treatment as usual, as directed by the principles and CPA process outlined above.

### Intervention

Teams allocated to the intervention arm additionally received the REFOCUS intervention. The REFOCUS intervention was described in detail in the Intervention Development sub-study (Chapter 3), but in brief comprises a one-year, whole-team intervention to increase community mental health team support for recovery. It aims to impact upon team and individual staff values, recovery-related knowledge, skills and behaviour, and staff-patient relationships. The intervention has two components: behavioural and interpersonal. The behavioural component comprises three desired behaviours by staff, called Working Practices (WPs). WP1 is Understanding Values and Treatment Preferences, and involves focussing on the service user’s values and identity beyond being a patient, and placing their preferences at the centre of care planning. WP2 is Assessing Strengths, and involves using a standardised assessment of personal and social strengths to identify existing and potential resources the service user can build on. WP3 is Supporting Goal-striving, and involves orienting clinical care around goals valued by the service user. These working practices are undertaken in the context of the interpersonal component, called Recovery-promoting Relationships, which included training staff to use coaching skills in interactions with service users, and undertaking a Partnership Project co-produced between staff and service users. Approaches to supporting implementation were: intervention briefing meetings separately for staff and service users / carers about the study; 12 hours (three four-hour sessions) of staff training in personal recovery provided by two trainers (one with a professional background and one with a service use background); 16 hours (one eight-hour day, two four-hour sessions, telephone support, optional booster coaching sessions) of training in coaching for recovery a coaching trainer; six externally facilitated team manager reflection groups to support culture change; six team reflection groups (three externally facilitated, three unfacilitated) to foster experiential learning; and use of a reflective practice tool in individual supervision.

### Measures

The primary outcome was recovery, assessed using the Questionnaire about the Process of Recovery (QPR)[84] which was evaluated in the QPR Validation sub-study. This is a 22-item patient-rated assessment of recovery, with each item rated on a five-point scale from 0 (Disagree Strongly) to 4 (Agree strongly). Three scores are produced: QPR Intrapersonal subscale (17 items), QPR Interpersonal subscale (5 items), and QPR Total score (15 items)[85], all with range 0 (low recovery) to 4 (high recovery).

Scoring and references for remaining measures are given in Table 36.

**Table 36 REFOCUS trial: measures**

| **Measure** | **Name and reference** | **Items** | **Range** | **Desirable score** |
|---|---|---|---|---|
| *PATIENT-RATED OUTCOME MEASURES* | | | | |
| **QPR** | Questionnaire about the Process of Recovery[84,85] | | | |
| | QPR Interpersonal | 17 | 0 to 4 | High |
| | QPR Intrapersonal | 5 | 0 to 4 | High |
| | QPR Total | 15 | 0 to 4 | High |
| **CANSAS-P** | Camberwell Assessment of Need Short Appraisal Schedule – Patient[293] | 22 | 0 to 22 | Low |
| **HHI** | Herth Hope Index[268] | 12 | 12 to 48 | High |
| **MANSA** | Manchester Short Assessment of Quality of Life[275] | 16 | 12 to 84 | High |
| **MHCS** | Mental Health Confidence Scale[294] | 16 | 16 to 96 | High |
| **WEMWBS** | Warwick-Edinburgh Mental Well-Being Scale[218] | 14 | 14 to 70 | High |
| *PATIENT-RATED EXPERIENCE MEASURES* | | | | |
| **CSQ** | Client Satisfaction Questionnaire[295] | 8 | 8 to 32 | High |
| **INSPIRE** | INSPIRE[236] | 27 | 0 to 100 | High |
| *STAFF-RATED OUTCOME MEASURES* | | | | |
| **BPRS** | Brief Psychiatric Rating Scale[296] | 18 | 0 to 126 | Low |
| **CANSAS-S** | Camberwell Assessment of Need Short Appraisal Schedule – Staff[293] | 22 | 0 to 22 | Low |
| **CSRI** | Client Service Receipt Inventory[297] | | | |

|  |  |  |  |  |
|---|---|---|---|---|
| **GAF** | Global Assessment of Functioning[298] | 2 | 0 to 100 | High |
| **HoNOS** | Health of the Nation Outcome Scale[299] | 12 | 0 to 48 | Low |
| *PROCESS EVALUATION MEASURES* |  |  |  |  |
| **RKI** | Recovery Knowledge Inventory[300] | 20 | 20 to 100 | High |
| **MICA** | Mental Illness: Clinicians' Attitudes[301] | 16 | 16 to 96 | Low |
| **PS[1]** | Participation Scale | 3 | Very low to Very high | High |
| **RPS[2]** | Recovery Practice Scale | 15 | 0 to 310 | High |

[1] Unstandardised measure, called REFOCUS Implementation Scale in protocol, and shown in Appendix 25.

[2] Unstandardised measure, called Recovery Fidelity Scale in protocol, and shown in Appendix 26.

Secondary patient-rated outcome measures were hope (HHI), quality of life (MANSA), empowerment (MHCS), well-being (WEMWBS), and met and unmet needs (CANSAS-P). Secondary patient-rated experience measures were satisfaction (CSQ) and recovery support (INSPIRE). Secondary staff-rated outcomes were met and unmet needs (CANSAS-S), functioning (GAF), and social disability (HoNOS). Researchers rated symptomatology (BPRS) and service use in the previous six months (CSRI).

For the quantitative element of the process evaluation, staff completed measures of their recovery-related knowledge and attitudes (RKI), attitudes towards mental illness (MICA), and two unstandardised measures. PS is a staff-rated measure of participation (i.e. attendance and engagement) in the key intervention components of personal recovery training, coaching training, and team reflection sessions. RPS assessed self-rated skills, behavioural intent, and behaviour in relation to coaching, values, strengths, goal-striving, and partnership relationships.

**Procedures**

Teams were allocated on an equal basis to intervention (treatment as usual plus REFOCUS Intervention) or control (treatment as usual), stratified by wave (four SLaM Boroughs, two 2gether localities) to ensure balance. Block randomisation of teams was undertaken by the independent Mental Health and Neuroscience Clinical Trials Unit (MH&NCTU). The dates of wave allocation for SLaM were 1.7.11 (wave 1), 1.10.11 (wave 2), 1.1.12 (wave 3) and 1.4.12 (wave 4). Dates for 2Gether were 1.11.11 (wave 1) and 1.4.12 (wave 2).

The clinical information system was accessed by either SLaM Clinical Studies Officers (CSOs) from the National Institute for Health Research (NIHR) Mental Health Research Network (MHRN), or 2gether Information Analysts, who compiled the list of names, diagnoses, ethnicity and date of births for randomisation. The first 15 service users were selected from the randomly ordered caseload list. In SLaM, two randomly ordered lists of service users with a psychosis diagnosis on the caseload of the team will be generated using a random number table. One list (List A) comprised service users who come from service users who are from black African, black Caribbean and black other backgrounds, and the other list (List B) comprised all other service users. The first 6 service users from list A and the first 9 from list B were selected, giving a total sample of 15 per SLaM team. This ensured epidemiological representativeness in the sample in relation to black ethnicity, and ensured sufficient power to test the secondary study hypothesis. If an individual did not meet inclusion criteria or refused consent to participate, then the next person from the appropriate randomly-ordered list was chosen. Caseload randomisation was undertaken using procedures set out by the Mental Health and Neuroscience Clinical Trials Unit, on the basis of a service user identification number.

Data collection was undertaken by researchers who were trained in all measures, and who had received interviewer training from the REFOCUS Lived Experience Advisory Panel (as described in Chapter 10). Baseline data were collected prior to the allocation date. Teams were contacted four months before allocation, and most data were collected in the month before the allocation date. All staff were asked to complete RKI, MICA, and RPS. Researchers met with service users, who after giving informed consent completed all patient-rated measures (QPR [primary outcome], CANSAS-P, HHI, MANSA, MHCS, WEMWBS, CSQ, INSPIRE) and identified a paired member of staff from their team (either their care co-ordinator or other appropriate professional). Researchers completed BPRS and CSRI with the service user. The identified paired staff were then approached and asked to complete CANSAS-S, HoNOS, and GAF. Teams were then allocated to either intervention or control.

One year after randomisation, all assessments were repeated, with intervention group staff also completing PS. Participating staff, service users and researchers were aware of allocation status at follow-up. Follow-up service user data were sought irrespective of any change in circumstances (e.g. team disbanded, discharged, move to new Trust, in prison, currently in-patient). Data collection began one year after allocation date, with most data collected by one month later. Service user participants were offered £10 for their time after both assessments, and entered into a £50 prize draw. Staff data were collected from the same member of staff where possible, otherwise from an appropriate alternate.

Paper data were transcribed to a secure password-controlled electronic database, independently by both sites. Researchers were trained in data entry and followed a data entry protocol to ensure consistency. Data validation rules were used in the database to reduce transcription errors. Data were linked using a participant identification number only. The file linking the identification number and personal data was password protected and stored on a secure server at SLaM. All identification numbers were checked to ensure match between paper and electronic data, and all missing data were manually checked to ensure correct entry. A random 20% sample of service user-rated (QPR, CSQ and CANSAS-P) and staff-rated (CANSAS-S, GAF, HoNOS, MICA, RKI, RPS) follow-up data were manually checked against paper copies, with agreement of 99.75% (staff) and 99.66% (service users).

Audiotape recordings were destroyed once the transcription had been checked for accuracy. All paper forms were stored in locked filing cabinets at each site, and transferred to lead site (SLaM) at the end of the study. Only the research team had access to paper or electronic data. All members of the study team received MRC Good Clinical Practice training in RCTs, and followed Research Governance arrangements.

### Analysis

The primary outcome was QPR. Our target analysable sample published in the protocol was 336 service users, using a sample size calculation assuming 29 teams with 17% attrition to 25 teams, team-level intracluster correlation of 0.05 (a conservative estimate of the similarity of teams), 15 service users per team with 7% attrition to 14 per team, and parameter estimates of medium standardised effect size (0.4), alpha=0.05 and power 0.8. This drop-out rate is consistent with attrition in previous randomised controlled trials[302]. Analysts were masked to treatment allocation, and used Stata 11. Missing data were estimated for the whole sample (other than the six participants who had died by follow-up) using multiple imputation by chained equation (‘MICE’ command) with 50 imputations. The imputation model reflected clustering at team level, and (as multiple imputation relies on the assumption that data are missing at random (MAR)) included the baseline outcome measures as well as covariates in the imputation model to increase the likelihood of the MAR assumption and improve the estimation of the missing values. Sensitivity analyses showed that the distributions of the imputed items and complete cases were comparable, produced equivalent result patterns, and analysis based on missing data imputed for outcome measures at baseline and follow-up (compared with baseline only) was not associated with increased biased estimates as indicated by Monte Carlo estimates[303].

Our main analysis was conducted using intention-to-treat (ITT) principles (irrespective of whether they received the intervention or not) on the imputed data. Regression analysis was used to assess study arm differences on primary and secondary outcomes while adjusting for baseline scores[304]. We took team-level clustering into account by using random effects regression analyses with maximum likelihood estimation using the 'xtmixed' command. The model was also adjusted for wave, to reflect the stratification design. We used prospective alpha allocation to correct for Type I error inflation due to multiple testing[305]. We set the experiment-wise alpha ($\alpha e$) at 0.10, with the significance level for testing the primary outcome set to 0.05 ($\alpha p$) while the remaining 0.05 of alpha can be distributed equally among secondary outcomes (i.e. $\alpha=0.05/14=0.004$). Scores screening was implemented prior to our analyses whilst model diagnostics were conducted following our regression analyses.

Sensitivity analyses were then conducted, involving adjustment for sociodemographic covariates which may be associated with our outcomes[14]. These covariates, collected at baseline and chosen due to association with primary and secondary outcomes, were gender, age, years using mental health services, ethnicity (white British vs. other), accommodation type (privately owned and rented vs. other), marital status (single vs. relationship), and education (higher education vs. not). Covariates were entered simultaneously into the regression model to assess whether results were modified.

Finally, we conducted post-hoc analyses relating to participation. To assess whether staff participation at team level was associated with QPR follow-up scores, adjusted for baseline, we extrapolated a measure of team participation by pooling the ratings on PS for each team (α=.89), using data only from staff who did not move teams and had both baseline and follow-up ratings. We used a median split to dichotomise intervention teams into High or Low participation, allowing a variable 'Team Participation' (Control, Low participation, High participation) to be extrapolated.

We were also interested in assessing the association between staff participation and follow-up staff process measures for non-moving staff with complete data. We used a median split on PS across all teams, to identify low and high participating staff within the intervention group, allowing extrapolation of a 'Staff Participation' variable (Control, Low participation, High participation).

We regressed service user outcome (missing data estimated following scale guidelines or pro-rated where less than 20% of items were missing) on Team Participation, and staff process measures (for non-moving staff with complete data) on Staff Participation, whilst taking into account clustering at the team level using the Stata 'xtmixed' command, adjusting the model for baseline scores and Trust centre.

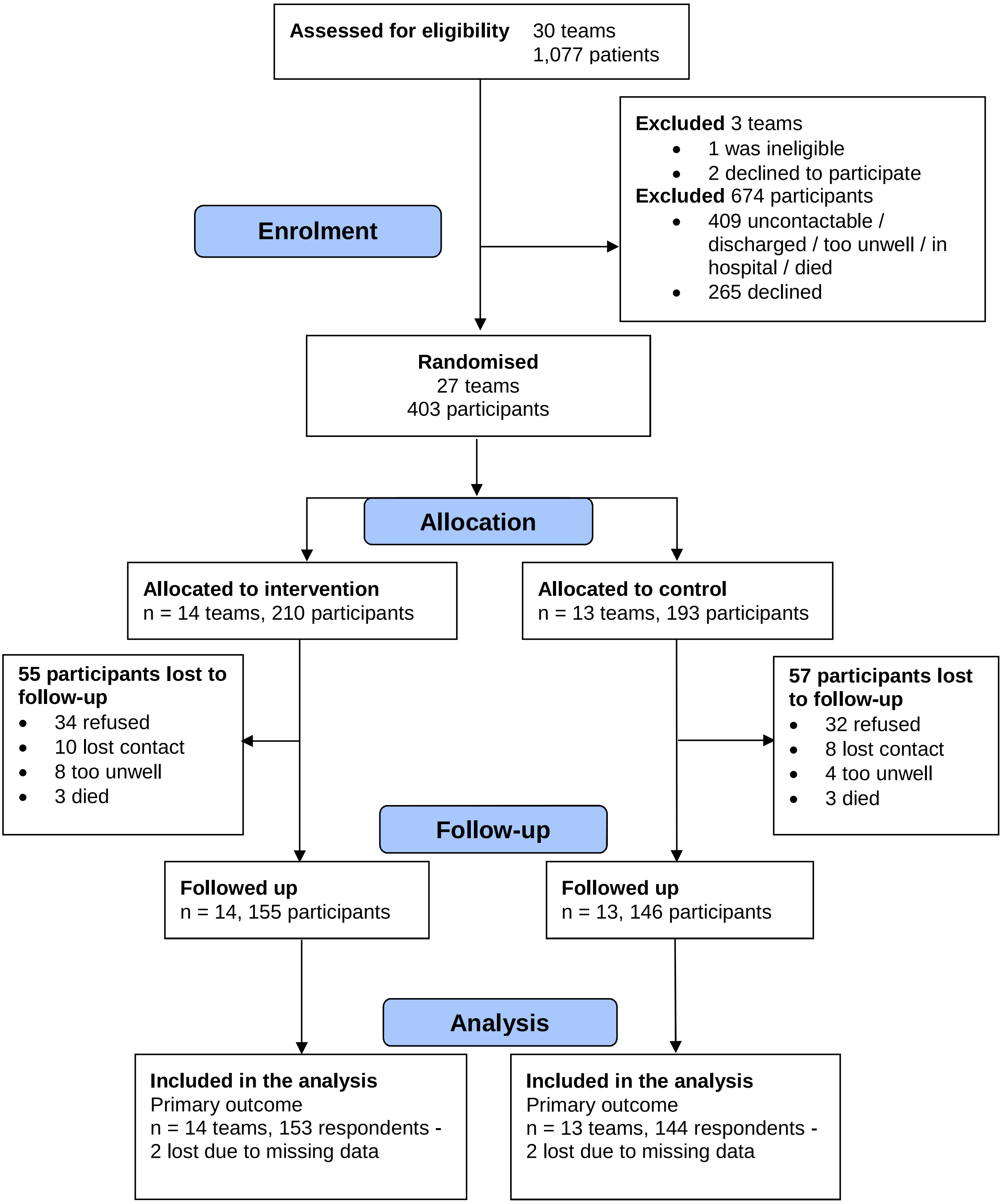
The cost of the intervention was based on the staff time involved in delivering it combined with unit costs for those staff members (derived from unit costs [306] and NHS Reference Costs). These costs were then divided by the current caseload numbers for each team to derive cost per service user. This is a conservative approach because it assumes that the training will only benefit current service users. If we instead assume that future services users may also benefit then the cost would be reduced. Other service use data included contacts with primary and secondary health care services (including days in hospital) and social care. No imputation was used for loss to follow-up, but we used the standard economic evaluation approach that when a service was used but number of contacts not recorded, imputation using median values from complete cases was used. This occurred for a small number of cases and a wide range of services, and was required to allow total costs to be calculated. Costs were calculated by combining the service use data with appropriate unit cost information (NHS Reference costs 2012/13). Costs were compared between the two groups for participants with baseline and follow-up cost data, using a bootstrapped regression model to account for the likely skewed data and with baseline costs controlled for. Costs are reported in 2012/13 UK pounds.

## Chapter 6: REFOCUS trial – outcome and economic evaluation

Adapted with permission from the published report of this study[307]

Between April 2011 and May 2012, 27 teams (18 SLaM, 9 2gether). The flow diagram is shown in Figure 14.

Figure 14 REFOCUS trial: flow diagram



Of the 27 recruited teams 14 (9 SLaM, 5 2gether) were randomly allocated to the intervention arm and 13 (9 SLaM, 4 2gether) to the control arm. Teams comprised 13 Recovery Teams (4 control, 9 intervention), four Psychosis Teams (2 control, 2 intervention), three High Support Forensic Teams (1 control, 2 intervention), three Assertive Outreach Teams (3 control), two Supported Living Teams (2 control), one Low Support Team (1 intervention), and one Early Intervention Team (1 control).

A total of 403 service users were recruited. Baseline characteristics of service users are shown in Table 37.

**Table 37 REFOCUS trial: baseline sociodemographic and clinical characteristics (n=403)**

| | | **Control** | **Intervention** |
|---|---|---|---|
| **SOCIODEMOGRAPHICS** | | *n (%)* | *n (%)* |
| | Male | 127 (66%) | 131 (63%) |
| | Female | 66 (34%) | 78 (37%) |
| | White | 95 (49%) | 115 (56%) |
| | Non-white | 98 (51%) | 92 (44%) |
| | Owned/rented | 22 (12%) | 48 (23%) |
| | Supported | 168 (88%) | 161 (73%) |
| | Single | 158 (82%) | 151 (72%) |
| | In a relationship | 35 (18%) | 59 (28%) |
| | Secondary | 95 (50%) | 111 (54%) |
| | Higher education | 96 (50%) | 96 (46%) |
| | | *mean (s.d.)* | *mean (s.d.)* |
| Age (years) | | 42.99 (11.56) | 44.87 (10.22) |
| Use of mental health services (years) | | 15.52 (10.89) | 16.13 (11.49) |
| **PATIENT-RATED OUTCOME MEASURES** | | | |
| QPR (n=365) | Total | 38.97 (9.10) | 38.53 (9.31) |

| | | |
|---|---|---|
| Intrapersonal | 43.95 (10.10) | 43.77 (10.18) |
| Interpersonal | 12.94 (2.67) | 13.55 (2.43) |
| CANSAS-P Met (n=390) | 3.66 (2.82) | 3.98 (3.33) |
| CANSAS-P Unmet (n=390) | 3.58 (2.79) | 3.54 (3.01) |
| HHI (n=362) | 35.92 (4.94) | 35.25 (4.81) |
| MANSA (n=275) | 4.60 (0.88) | 4.75 (0.97) |
| MHCS (n=335) | 66.38 (14.63) | 65.23 (14.40) |
| WEMWBS (n=373) | 46.68 (10.36) | 47.39 (9.51) |
| **PATIENT-RATED EXPERIENCE MEASURES** | | |
| CSQ (n=380) | 25.51 (5.08) | 25.24 (5.25) |
| INSPIRE Relationship (n=377) | 76.76 (14.95) | 77.77 (17.55) |
| INSPIRE Support (n=396) | 59.39 (20.68) | 65.41 (21.48) |
| **STAFF-RATED OUTCOME MEASURES** | | |
| BPRS (n=349) | 31.90 (9.17) | 33.63 (10.13) |
| CANSAS-S met (n=387) | 5.74 (3.52) | 5.80 (3.67) |
| CANSAS-S unmet (n=387) | 3.50 (2.79) | 3.19 (2.82) |
| GAF (n=379) | 64.15 (14.84) | 64.66 (13.88) |
| HoNOS (n=366) | 10.45 (6.44) | 8.05 (5.08) |
| **PROCESS EVALUATION MEASURES** | | |
| RKI | 2.94 (0.40) | 2.97 (0.38) |
| MICA | 31.37 (6.96) | 30.47 (6.96) |
| RPS | | |
| Skills | 2.73 (0.66) | 2.79 (0.64) |
| Behavioural Intent | 1.68 (0.37) | 1.66 (0.34) |
| Behaviour | 1.74 (0.77) | 1.78 (0.78) |

Service users in the intervention group were more likely to live in privately owned/rented accommodation (chi$^2$(1)=8·92, p=·003), to be in a relationship (chi$^2$(1)=5·6, p=·02) and to be unemployed (chi$^2$(1)=5·7, p =·003), although these differences were not significant after Bonferroni adjustment (adjusted p-value<0·001) to account for multiple testing. Groups differed on HoNOS (t(364)=4·0, p<0·001), but did not differ significantly on any other primary or secondary outcome (p-values ranging from ·02 to ·91) or total costs or process evaluation measure. Overall we conclude that allocation was unbiased.

## Implementation

A total of 28 intervention briefing sessions were run by researchers for service users / carers (14 teams) and staff (14 teams). Attendance ranged from 0 to 25 service users / carers, and 50% to 80% staff attended. 41 of the planned 42 recovery training sessions were run, with 8 to 24 attenders (median 14.4) in session 1, 4 to 21 (median 13.1) in session 2 and 6 to 15 (median 10.4) in session 3. All 42 of the planned 42 coaching training sessions were run, with 12 to 21 attenders (median 14.7) in session 1, 7 to 19 (median 12.0) in session to and 5 to 24 (median 11.3) in session 3. The proportion of staff attending these training sessions cannot easily be quantified because (as discussed in the next section) the high staff turn-over rate complicates the denominator. However, the research team's impression was that the majority of staff attended.

12 of the intended 36 externally facilitated team reflection groups were run, with attendance ranging from 5 to 21 (median 10.0). No formal records were kept of the unfacilitated team reflection groups or the team manager reflection groups due to research team capacity limitations, but the research team's impression was that these did not in general happen. Reasons for reduced engagement were low team motivation and logistical challenges (e.g. difficulties in obtaining cover for whole-team sessions, staff being too busy). There was no evidence of the Supervision Reflection Form being used in supervision sessions. Partnership Projects were events or activities planned and run jointly by staff and service users, with a budget of £500. Overall, five of the intended 14 Partnership Projects were run, comprising building a web-site, Christmas party, and an information session for a service user group (SLaM), and Olympics sports day and three-day outward bound course (2Gether).

Towards the end of their time in the trial, two teams (one intervention, one control) disbanded but it was still possible to obtain follow-up data from service users and paired staff (but not unpaired staff).

**Outcome**

A total of 532 staff participated in baseline and follow-up. Of these, 336 were in the same team at baseline and follow-up, 105 left after baseline, 70 joined before follow-up, and 21 moved between teams (9 to a team in the same arm, 8 from intervention to control, and 4 from control to intervention). Six service user participants (3 intervention, 3 control) died during the study period, each for reasons identified by their worker as un-related to the intervention, and were disregarded for analysis. No harms due to the intervention were reported.

At one-year follow-up, QPR (primary outcome) data were collected for 275 (69%) of the 397 participants. Missing data from baseline and follow-up are characterised in Table 38.

**Table 38 REFOCUS trial: missing data**

| n (%) | **Baseline** | **Follow-up** |
|---|---|---|
| **SOCIODEMOGRAPHIC** | | |
| Age | 27 (7) | |
| Ethnicity | 3 (0·7) | |
| Accommodation type | 4 (1) | |
| Employment | 1 (0·3) | |
| Relationship status | 0 (0) | |
| Use of mental health services | 1 (0·3) | |
| **PATIENT-RATED OUTCOME MEASURES** | | |
| QPR Total | 38 (9) | 128 (32) |
| CANSAS-P | 13 (3) | 119 (30) |
| HHI | 41 (10) | 139 (35) |
| MANSA | 128 (32) | 163 (40) |
| MHCS | 68 (17) | 151 (37) |

| | | |
|---|---|---|
| WEMWBS | 30 (7) | 135 (34) |
| **PATIENT-RATED EXPERIENCE MEASURES** | | |
| CSQ | 23 (6) | 128 (32) |
| INSPIRE Support | 7 (2) | 121 (30) |
| INSPIRE Relationship | 26 (6) | 130 (32) |
| **STAFF-RATED OUTCOME MEASURES** | | |
| BPRS | 54 (13) | 146 (36) |
| CANSAS-S | 16 (7) | 57 (14) |
| GAF | 24 (6) | 76 (19) |
| HoNOS | 37 (9) | 87 (22) |

Missingness for QPR was not associated with any sociodemographic covariate and only CANSAS-P Met needs among the clinical measure (t(388)=2·2, p=·02). Service users with complete information on QPR at follow-up had higher met needs scores at baseline than those with missing data, although the difference became non-significant after adjusting for multiple pairwise comparisons. Rates for secondary outcome data collection ranged from 60% for MANSA to 91% for GAF.

In relation to complete cases (n=255, 121 control, 134 intervention), QPR mean scores were stable between baseline and follow-up in both study arms for QPR Total (control mean(s.d.): baseline 38·6(9·5) vs. follow-up 40·2(10·3); intervention: 38·5(9·8) vs. 40·6(10·1)), QPR Intrapersonal (control: 43·6(10·6) vs. 45·5(10·3); intervention: 43·7(10·6) vs. 46·1(11·1)) and QPR Interpersonal (control: 13·1(2·8) vs. 13·4(2·7); intervention: 13·6(2·2) vs. 13·8(2·6)).

### Intention-to-treat analysis

ITT analysis for all 397 participants from all 27 teams (average cluster size 15, range 13 to 17) indicated that intervention group service users did not differ on QPR Total (b=.63, p=.55, 95%CI: -1.41 to 2.67), QPR Intrapersonal (b=.49, p=.44, 95%CI: 1.71 to 2.70) or QPR Interpersonal (b=.13, p=.75, 95%CI: -.93 to .67) subscales at follow-up. The only differences in secondary outcomes were improved scores on the staff-rated GAF and

CANSAS-S Unmet Need measures (with the CANSAS-S effect being non-significant after alpha adjustment for multiple comparison) in the intervention group at follow-up, as shown in Table 39.

**Table 39 ITT comparison between full imputed arms at follow-up, adjusted for baseline scores and wave (n= 397; 190 control, 207 intervention)**

| | **Regression** | | **ICC** |
|---|---|---|---|
| | b, p-value | (95%C.I.) | |
| **PATIENT-RATED OUTCOME MEASURES** | | | |
| QPR Total | 0.63, p=.55 | (-1.41 to 2.67) | 0 |
| QPR Interpersonal | 0.13, p=.75 | (-0.93 to 0.67) | .05 |
| QPR Intrapersonal | 0.49, p=.44 | (-1.71 to 2.70) | 0 |
| CANSAS-P Met | 0.43, p=.43 | (-0.63 to 1.49) | .10 |
| CANSAS-P Unmet | -0.31, p=.41 | (-1.04 to 0.42) | .03 |
| HHI | 0.65, p=.30 | (-0.59 to 1.88) | .03 |
| MANSA | -0.04, p=.73 | (-0.27 to 0.19) | .01 |
| MHCS | 2.00, p=.23 | (-1.23 to 5.22) | .03 |
| WEMWBS | 0.76, p=.51 | (-1.50 to 3.01) | .01 |
| **PATIENT-RATED EXPERIENCE MEASURES** | | | |
| CSQ | 0.71, p=.20 | (-0.38 to 1.79) | 0 |
| INSPIRE Support | -2.43, p=.41 | (-8.22 to 3.36) | .01 |
| INSPIRE Relationship | -0.39, p=.86 | (-4.66 to 3.88) | 0 |
| **STAFF-RATED OUTCOME MEASURES** | | | |
| BPRS | -1.85, p=.15 | (-4.37 to 0.66) | .12 |
| CANSAS-S Met | 0.07, p=.91 | (-1.29 to 1.16) | .13 |
| **CANSAS-S Unmet** | **-0.80, p=.03** | (-1.52 to -0.65) | .10 |
| **GAF** | **5.90, p<.001** | (2.61 to 9.18) | .01 |
| HONOS | -1.21, p=.07 | (-2.53 to 0.10) | .04 |

After adjusting for covariates, effect sizes were weakened for CANSAS-S Unmet needs (b=-0·68, p=·07, 95%CI -1·42 to -0·006) and GAF (b=5·32, p=·002, 95%CI 2·03 to 8·61), as shown in Table 40. Patterns were not modified across the other scales.

**Table 40 Comparison between arms, adjusting for baseline levels, wave and covariates for imputed data (n=397; 190 control, 207 intervention)**

| | Regression | |
|---|---|---|
| | b, p-value | (95%CI) |
| **PATIENT-RATED OUTCOME MEASURES** | | |
| QPR Total | 0.61, p=.57 | (-1.49 to 2.71) |
| QPR Interpersonal | -0.09, p=.83 | (-0.89 to 0.72) |
| QPR Intrapersonal | 0.51, p=.66 | (-1.76 to 2.78) |
| CANSAS-P Met | 0.36, p=.53 | (-0.77 to 1.48) |
| CANSAS-P Unmet | -0.21, p=.60 | (-0.96 to 0.55) |
| HHI | 0.60, p=.35 | (-0.66 to 1.86) |
| MANSA | -0.06, p=.61 | (-0.29 to 0.17) |
| MHCS | 1.85, p=.25 | (-1.28 to 4.98) |
| WEMWBS | 0.74, p=.53 | (-1.56 to 3.04) |
| **PATIENT-RATED EXPERIENCE MEASURES** | | |
| CSQ | 0.80, p=.15 | (-0.29 to 1.89) |
| INSPIRE Support | -2.05, p=.50 | (-9.99 to 3.90) |
| INSPIRE Relationship | -0.29, p=.90 | (-4.63 to 4.06) |
| **STAFF-RATED OUTCOME MEASURES** | | |
| BPRS | -1.76, p=.17 | (-4.29 to 0.77) |
| CANSAS-S Met | -0.01, p=.99 | (-1.22 to 1.22) |
| CANSAS-S Unmet | -0.68, p=.07 | (-1.42 to -0.06) |
| GAF | 5.32, p =.002 | (2.03 to 8.61) |
| HONOS | -0.89, p=.20 | (-2.25 to 0.47) |

ITT analysis on complete cases is shown in Table 41, and produced an equivalent pattern of results to the ITT analysis with imputed data.

**Table 41 ITT comparison for complete cases between arms at follow-up, adjusted for baseline scores and wave**

| | | **Control** | | **Intervention** | | **Regression** | | **ICC** | **Cohen’s d** |
|---|---|---|---|---|---|---|---|---|---|
| | n | n | Mean (s.e.) | n | Mean (s.e.) | b, p-value | (95%C.I.) | | |
| **PATIENT-RATED OUTCOME MEASURES** | | | | | | | | | |
| QPR Total | 255 | 121 | 40·10 (·64) | 134 | 40·76 (·60) | 0·66, p=·46 | (-1·09 to 2·41) | 0 | ·07 |
| QPR Interpersonal | 255 | 121 | 13·65 (·22) | 134 | 13·60 (·22) | -0·05, p=·87 | (-0·67 to 0·57) | ·01 | ·02 |
| QPR Intrapersonal | 255 | 121 | 46·51 (·70) | 134 | 46·04 (·66) | 0·53, p=·59 | (-1·39 to 2·44) | 0 | ·04 |
| CANSAS-P Met | 271 | 129 | 4·13 (·33) | 142 | 4·41 (·31) | 0·28, p=·54 | (-0·61 to 1·17) | ·05 | ·09 |
| CANSAS-P Unmet | 271 | 129 | 3·88 (·25) | 142 | 3·69 (·24) | -0·19, p=·59 | (-0·88 to 0·50) | ·02 | ·06 |
| HHI | 242 | 113 | 35·41 (·45) | 129 | 36·04 (·42) | 0·63, p=·32 | (-0·60 to 1·86) | ·03 | ·12 |
| MANSA | 182 | 84 | 4·80 (·08) | 98 | 4·88 (·07) | 0·07, p=·49 | (-0·13 to 0·28) | 0 | ·09 |
| MHCS | 221 | 104 | 67·06 (1·14) | 117 | 67·81 (1·08) | 0·75, p=·64 | (-2·36 to 3·86) | ·03 | ·05 |
| WEMWBS | 269 | 121 | 47·24 (·69) | 136 | 48·09 (·65) | 0·85, p=·37 | (-1·03 to 2·73) | 0 | ·08 |
| **PATIENT-RATED EXPERIENCE MEASURES** | | | | | | | | | |
| CSQ | 260 | 127 | 25·31 (·34) | 133 | 25·99 (·33) | 0·68, p=·16 | (-0·27 to 1·63) | 0 | ·13 |
| INSPIRE Relationship | 257 | 125 | 78.68 (1·31) | 132 | 78.34 (1·27) | -0·34, p=·85 | (-3·96 to 3·28) | 0 | ·02 |
| INSPIRE Support | 278 | 135 | 64·57 (1·74) | 143 | 61·53 (1·70) | -3·04, p=·22 | (-7·88 to 1·79) | 0 | ·13 |
| **STAFF-RATED OUTCOME MEASURES** | | | | | | | | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| BPRS | 226 | 103 | 32·07 (·80) | 123 | 30·72 (·73) | -1·35, p=·22 | (-3·51 to 0·81) | 0 | ·13 |
| CANSAS-S Met | 256 | 172 | 5·73 (·43) | 156 | 5·79 (·42) | 0·06, p=·92 | (-1·13 to 1·25) | ·12 | ·02 |
| CANSAS-S Unmet | 328 | 172 | 3·13 (·27) | 156 | 2·26 (·27) | **-0·87, p=·03** | **(-1·63 to -0·11)** | **·11** | **·32** |
| GAF | 309 | 169 | 61·84 (1·06) | 140 | 67·97 (1·16) | **6·13, p<·001** | **(3·03 to 9·23)** | **·01** | **·41** |
| HONOS | 289 | 154 | 10·50 (·46) | 135 | 9·17 (·49) | -1·33, p=·05 | (-2·67 to 0·01) | ·03 | ·21 |

As indicated by the Intra Cluster Correlations, there was an effect of team on QPR Interpersonal, HHI, MANSA, MHCS, BPRS, GAF and all CANSAS measures. Examination of residuals revealed some skewness on the CSQ scale but the results were confirmed using bootstrap standard errors (data not shown). As part of our *post hoc* analysis, we explored the association between Team Participation and follow-up QPR (average cluster size 11, range 7 to 14). We found QPR Interpersonal scores adjusted for baseline varied across Team Participation ($chi^2(2)=8.23$, $p=.016$). Service users in high participation teams had significantly higher QPR Interpersonal scores at follow-up than service users in low participation intervention teams and control teams, as shown in Table 42. Intra Cluster Correlation coefficient was 0.0 for all QPR scales.

**Table 42 Association between team-level participation and patient-rated recovery, adjusted for baseline (n=285)**

| | Control | Intervention | | Overall Wald test | Control vs. Low | Control vs. High | Low vs. High |
|---|---|---|---|---|---|---|---|
| | | **Low participation** | **High participation** | | | | |
| mean (s.e.) | n=144 | n=67 | n=74 | | b, p-value (95%CI) | | |
| **QPR Total** | 40.01 (0.59) | 40.74 (1.08) | 41.30 (0.96) | chi$^2$(2)=1.6 p=.46 | 0.74, p=.55 (-1.70 to 3.18) | 1.29, p=.26 (-0.94 to 3.53) | -0.56, p=.73 (-3.77 to 2.66) |
| **QPR Interpersonal** | 13.54 (0.20) | 12.82 (0.37) | 14.39 (0.33) | chi$^2$(2)=8.2 p=.02 | -0.72, p=.09 (-1.54 to 0.11) | **0.85, p=.03 (0.09 to 1.62)** | **-1.57, p=.005 (-2.66 to -0.48)** |
| **QPR Intrapersonal** | 45.36, (0.65) | 46.18 (1.18) | 46.58 (1.06) | chi$^2$(2)=1.2 p=.54 | 0.82, p=.60 (-1.87 to 3.50) | 1.21, p=.33 (-1.24 to 3.67) | -0.40, p=.83 (-3.93 to 3.14) |

To understand why recovery-supporting relationships may have improved in teams whose staff participated more in the intervention, our process evaluation investigated staff changes in recovery knowledge (RKI; average cluster size 10, range 4 to 18), attitudes towards mental illness (MICA; average cluster size 10, range 5 to 17) and self-rated fidelity (average cluster size 9, range 4 to 16), as shown in Table 43. Intra Cluster Correlation was 0·0 for all measures.

### Table 43 Adjusted follow-up scores for staff-rated knowledge, attitudes and behaviour compared between levels of staff participation

| | Control | Intervention | | Overall | Control vs. Low | Control vs. High | Low vs. High |
|---|---|---|---|---|---|---|---|
| | | Low participation | High participation | Wald test | | | |
| | n<br>mean (s.e.) | n<br>mean (s.e.) | n<br>mean (s.e.) | | b, p-value (95%CI) | | |
| RKI | 129<br>2.92 (.03) | 72<br>2.89 (.04) | 56<br>2.99 (.04) | chi$^2$(2)=3.0<br>p=.23 | -0.03, p=.49<br>(-0.12 to 0.06) | 0.06, p=.22<br>(-0.04 to 0.16) | -0.09, p=.09<br>(-0.20 to 0.01) |
| MICA | 131<br>30.12 (.55) | 72<br>30.78 (.73) | 58<br>30.65 (.82) | chi$^2$(2)=0.6<br>p=.75 | 0.66, p=.48<br>(-1.16 to 2.49) | 0.53, p=.60<br>(-1.46 to 2.52) | 0.13, p=.90<br>(-2.02 to 2.29) |
| RPS | | | | | | | |
| Skills | 114<br>2.87 (.06) | 66<br>2.74 (.08) | 50<br>2.95 (.09) | chi$^2$(2)=3.5<br>p=.17 | -0.14, p=.16<br>(-0.33 to 0.05) | 0.07, p=.33<br>(-0.14 to 0.29) | -0.21, p=.08<br>(-0.45 to 0.02) |
| Behavioural intent | 114<br>1.67 (.03) | 66<br>1.60 (.04) | 50<br>1.68 (.05) | chi$^2$(2)=2.2<br>p=.33 | -0.07, p=.18<br>(-0.18 to 0.03) | 0.01, p=.87<br>(-0.11 to 0.13) | -0.08, p=.21<br>(-0.21 to 0.05) |
| Behaviour | 114 | 66 | 50 | chi$^2$(2)=10.9 | **-0.26, p=.02** | 0.16, p=.18 | **-0.43, p=.001** |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | 1.80 (.07) | 1.54 (.09) | 1.97 (.10) | p=.004 | **(-0.48 to -0.05)** | (-0.08 to 0.40) | **(-0.69 to -0.16)** |

Participation level by staff was not associated with adjusted follow-up scores on MICA and RKI. High staff participation was however associated with self-rated pro-recovery behaviour (chi$^2$(2)=10.92, p=.004). Specifically, intervention team staff with higher participation reported significantly higher scores for pro-recovery behaviours than low-participating staff

### Economic evaluation

Service use in the previous six months at baseline and follow-up showed a high level of contact with GPs and care coordinators, as shown in Table 44.

### Table 44 REFOCUS trial: service use at baseline and follow-up (n=266)

| | n (%) using service | | | | Mean (s.d.) contacts of those using the service | | | |
|---|---|---|---|---|---|---|---|---|
| | Baseline | | Follow-up | | Baseline | | Follow-up | |
| **Service** | **Control** | **Intervention** | **Control** | **Intervention** | **Control** | **Intervention** | **Control** | **Intervention** |
| GP | 98 (77) | 116 (84) | 104 (82) | 115 (83) | 3·7 (4·0) | 3·5 (3·3) | 3·3 (5·0) | 3·2 (3·1) |
| Care coordinator | 125 (98) | 129 (93) | 113 (89) | 113 (81) | 14·9 (13·0) | 10·4 (7·7) | 12·1 (12·9) | 8·2 (7·1) |
| Psychiatrist | 77 (61) | 92 (66) | 82 (65) | 76 (55) | 2·6 (2·8) | 2·9 (3·1) | 2·4 (2·1) | 2·3 (2·5) |
| Other doctor | 27 (21) | 29 (21) | 18 (14) | 23 (17) | 5·6 (17·0) | 2·3 (1·4) | 2·1 (1·1) | 2·6 (2·2) |
| Psychologist | 21 (17) | 15 (11) | 17 (13) | 12 (9) | 8·6 (10·0) | 8·1 (8·8) | 10·4 (9·7) | 6·0 (7·0) |
| Social worker | 13 (10) | 14 (10) | 3 (2) | 9 (7) | 3·9 (3·8) | 8·1 (8·5) | 13·3 (9·5) | 6·9 (7·4) |
| Nurse | 16 (13) | 13 (9) | 21 (17) | 20 (14) | 19·9 (44·0) | 6·6 (6·9) | 18·0 (37·8) | 14·2 (39·1) |
| Occupational therapist | 13 (10) | 10 (7) | 10 (8) | 4 (3) | 8·5 (10·5) | 7·8 (10·2) | 5·4 (7·5) | 49·5 (87·3) |
| Support worker | 32 (25) | 30 (22) | 32 (25) | 29 (21) | 24·4 (21·6) | 29·3 (47·1) | 57·6 (64·2) | 45·2 (60·1) |
| Vocational worker | 8 (6) | 18 (13) | 9 (7) | 11 (8) | 4·8 (7·5) | 5·4 (6·1) | 29·3 (58·5) | 4·1 (4·8) |
| Drug & alcohol advisor | 5 (4) | 6 (4) | 4 (3) | 5 (4) | 15·0 (18·9) | 4·7 (4·3) | 18·5 (20·4) | 14·0 (12·5) |
| Other therapist | 11 (9) | 8 (6) | 5 (4) | 7 (5) | 27·5 (53·4) | 13·0 (11·9) | 16·4 (13·1) | 9·7 (8·2) |
| Psychiatric in-patient | 10 (8) | 13 (9) | 7 (6) | 6 (4) | 44·0 (50·8) | 30·6 (20·8) | 67·3 (65·3) | 59·7 (75·1) |
| Physical in-patient | 6 (5) | 6 (4) | 13 (10) | 7 (5) | 3·4 (4·0) | 3·5 (2·3) | 7·7 (16·3) | 6·0 (7·1) |
| Specialist team | 16 (13) | 12 (9) | 10 (8) | 7 (5) | 20·9 (34·3) | 14·3 (19·3) | 13·0 (10·6) | 9·6 (9·5) |

|  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|
| Day care | 57 (45) | 72 (52) | 48 (38) | 53 (38) | 28·9 (31·3) | 36·0 (61·4) | 35·7 (42·9) | 36·3 (45·1) |

The intensity of the use of some services at baseline and follow-up showed large variation, for example number of contacts with occupational therapists rose from 8 to 50 in the intervention arm, but this was for a small number of participants. Around two-thirds had contacts with psychiatrists at baseline, but this fell slightly to 55% for the intervention group by follow-up. Around one-quarter of participants in both groups had contacts with support workers during each period. At baseline around a half had day care contacts, falling to 38% for both groups by follow-up.

The mean intervention cost was £120, as shown in Table 45, but this varied from £22 to £357.

**Table 45 REFOCUS trial: mean (s.d.) service costs at baseline and follow-up (2012/13 £s) (n=266)**

| | Baseline | | Follow-up | |
|---|---|---|---|---|
| | Control | Intervention | Control | Intervention |
| Intervention | - | - | - | 120 (92) |
| GP | 120 (158) | 125 (145) | 115 (194) | 111 (128) |
| Care coordinator | 542 (484) | 357 (291) | 401 (470) | 247 (264) |
| Psychiatrist | 157 (250) | 191 (285) | 156 (205) | 127 (220) |
| Other doctor | 161 (1089) | 66 (156) | 39 (112) | 58 (180) |
| Psychologist | 190 (684) | 117 (505) | 186 (661) | 69 (349) |
| Social worker | 45 (189) | 93 (405) | 36 (266) | 50 (279) |
| Nurse | 93 (613) | 23 (104) | 110 (610) | 76 (568) |
| Occupational therapist | 63 (303) | 41 (241) | 31 (181) | 104 (1118) |
| Support worker | 176 (448) | 178 (717) | 427 (1213) | 267 (928) |
| Vocational worker | 9 (63) | 21 (84) | 62 (497) | 10 (51) |
| Drug and alcohol advisor | 32 (241) | 11 (68) | 31 (244) | 27 (182) |
| Other therapist | 138 (981) | 43 (235) | 37 (230) | 28 (158) |
| Psychiatric in-patient | 1195 (6228) | 988 (3740) | 1279 (7245) | 889 (6479) |
| Physical in-patient | 93 (619) | 87 (481) | 454 (3207) | 174 (1143) |
| Specialist team | 435 (2440) | 236 (1299) | 161 (707) | 92 (555) |

| | | | | |
|---|---|---|---|---|
| Day care | 305 (697) | 400 (842) | 326 (988) | 302 (758) |
| **Total** | **3754 (7919)** | **2977 (4305)** | **3853 (8320)** | **2752 (8797)** |

The most expensive service was psychiatric in-patient care even though this was used by relatively few participants (6% control group, 4% intervention group). Total service use costs were lower for intervention group participants at both baseline (£2,997 vs. £3,754) and follow-up (£2,752 vs. £3,853). Adjusting for baseline, the cost difference between intervention and control groups was £1,062 (95% CI, -£1,103 to £3,017), i.e. receiving the intervention was associated with lower costs, but the difference was not statistically significant. Service users in the high participation intervention teams had services costs that were on average £657 less than service users in low participation intervention teams, but again this was not statistically significant (95% CI, -£1,555 to £4,783). As there was no significant difference in either cost or primary outcome, further cost-effectiveness analysis was not undertaken.

## Discussion

The REFOCUS trial was a two-site cluster randomised controlled trial which evaluated a team-level REFOCUS intervention in 27 community adult mental health teams. There was no effect on the primary outcome of recovery. Most secondary outcomes did not differ, with the exceptions of improvements in the intervention group for functioning (which remained after adjusting for multiple testing) and staff-rated unmet need (which was not significant after adjusting). Although there was no evidence of changes in staff knowledge, skills or attitudes, self-reported pro-recovery behaviours did increase in staff with high participation, compared to those with low participation. Consistent with this, service users in high-implementing teams had higher scores on QPR Interpersonal sub-scale than service users in low-implementing teams. Finally, the intervention was associated with lower costs, but the difference was not statistically significant.

Why was no improvement shown in the primary outcome of recovery? Four explanations can be considered. First, and the explanation we favour, is that the intervention was inadequately implemented. Staff participation was self-rated by unblinded staff who may therefore have been susceptible to social desirability bias. The bias may be modest, because there is no obvious reason why it would not have an equivalent impact across all intervention arm staff, thus introducing an inflation rather than a bias. Also, the outcome measure was patient-rated. Noting this possibility of bias, however, the study showed that where staff participated more, there was an increase in self-reported pro-recovery behaviours and patient-reported recovery in the relationships sub-scale of the QPR. The qualitative process evaluation nested in the trial and reported in the next chapter investigated the experiences of staff[308], and found evidence that implementation barriers occurred at the individual, team and organisation level. A recent Cochrane review has shown that implementation of treatment guidelines within specialist mental health services is often poor[309]. Implementation of evidence-based interventions in routine practice face three 'translational roadblocks': adoption in principle, early implementation and persistence of implementation[99]. Although policy supports the implementation of pro-recovery intervention (adoption in principle), this may not lead to early implementation. Broader implementation strategies are needed, including leadership and organisational culture[132].

Second, the REFOCUS Intervention may be ineffective in its primary aim of improving personal recovery within the one-year time frame of the intervention. Indeed, the original REFOCUS Intervention was 18 months, and needed to be shortened due to trial recruitment issues. Participants had been using mental health services for an average of more than 15 years, suggesting settled staff-patient relationships. Other studies have showed that trusting relationships with staff can take longer to form than possible in a time-limited intervention[310]. Future research might evaluate the REFOCUS intervention with an inception cohort of new referrals to the team, to test the impact on staff-patient relationships which are less established. Similarly, comparison between different groups of workers (e.g. multidisciplinary versus unidisciplinary teams, teams with versus without peer support workers) would allow contamination at the level of staff and any interaction between worker profession and implementation to be investigated.

Third, existing practice of control group staff may have already been pro-recovery. Control group staff received no formal training through REFOCUS, and although the intervention manual was available to download, we found no evidence of difference in primary outcome in either arm, and little evidence of contamination due to staff movement. For example, many staff in SLaM teams in both arms would previously have received some recovery training[201], so sustained changes in control group cannot be excluded. However, the recovery orientation of participating teams as measured by RKI (control mean 2·94, intervention mean 2·97) was lower than the mean RKI score of 3·94 found in an Australian study[311], suggesting there was not a high recovery orientation at baseline.

Finally, although the choice of endpoint assessment was based on recommendations from a systematic review[97], the QPR has not previously been used as a primary outcome in a trial. In our independent psychometric evaluation of the QPR, reported in Chapter 4, we demonstrated preliminary evidence for sensitivity to change, but this property has not been fully established, raising the possibility of an insufficiently responsive measure failing to detect change. We also demonstrated some psychometric shortcomings for the QPR Interpersonal scale, which may partially account for the relationship found in the trial between implementation and this sub-scale. One perspective which has been advanced is that evaluation of the process of recovery using the outcome-oriented methods of evidence-based medicine is intrinsically problematic, and more sociological approaches are needed[312]. The service user process evaluation reported in the next chapter found that effective implementation was associated with positive changes in process (more open and collaborative relationships with staff), hope and empowerment, highlighting the challenges of capturing the impact of complex interventions. As a minimum, further psychometric evaluation of QPR and other candidate recovery measures is indicated.

In relation to the protocol[7], the main protocol deviation was that efforts to estimate researcher blinding at follow-up were abandoned, when it became clear that being blind to team (i.e. allocation status) was logistically not possible for the researchers.

We identify several strengths. The REFOCUS intervention is theory-based, and the mixed-methods evaluation (reported here in Chapters 6 to 8) in routine clinical settings across two sites included a range of quantitative and qualitative approaches to understanding fidelity, intermediate processes, and outcome. The clinical population is representative, although the inclusion criterion of clinical judgement about being well enough (to allow consideration of the full range of reasons why being approached to participate may not be appropriate) and the relatively good social functioning indicated by GAF and HoNOS scores indicate that the most disabled people on the caseload may not have participated. The full range of adult mental health teams typically provided in NHS Trusts was included, which maximises representativeness.

One limitation is the absence of a pilot study to inform implementation, which might have identified in advance the practice change challenges found in this trial: high staff turnover within teams with low morale as a consequence of significant reorganisation taking place across both Trusts. In relation to the SAFE measure described in Chapter 4, the intervention involves several implementation barriers, including staff training, complexity, human resources and staff time. The staff process evaluation reported in Chapter 7 identified organisational leadership and stability plus readiness to change at team level as predictors of implementation[308], which could provide criteria for inclusion of high-implementing teams in future evaluations.

A second limitation is the recruitment shortfall. The analysable sample comprised 297 against a target of 336, primarily due to a higher-than-anticipated 26% (106/403) service user attrition rate at follow-up. Achievement of an 88% target may mean the study was under-powered to detect difference. For this and other reasons (fidelity, evaluation etc.), the trial would have benefited from the inclusion of a pilot study to test the REFOCUS intervention and implementation strategies

A third limitation is that the design did not stratify by team type, raising the possibility of differential implementation across different team types. The relationship between team type and outcome was not analysed in this study because of the uneven allocation and because categories were derived from team name and may therefore be overlapping, but future trials might more formally establish team type and either use a homogenous sample or stratify by team type.

The REFOCUS trial is relevant to clinical practice. From the staff perspective, our data found that efforts to support recovery lead to improved functioning and may also reduce unmet need for people with psychosis (though not from the service user perspective). It is plausible that conversations between staff and service users about values, treatment preferences, and strengths will translate over time into changes in functioning and assessed need. In this study the observed differences do not seem to have been mediated through changes in the recovery variables studied, indicating a complex relationship between these variables. If the positive impact in high-participating teams is not due to staff bias in rating implementation, then this suggests that the REFOCUS Intervention has the potential to be an effective pro-recovery intervention, if implementation barriers can be addressed. At the societal level, anti-stigma campaigns have been found to make attainment of valued social roles more possible[313]. Within mental health services, the challenge may be to embed as an organisational culture an expectation of partnership-based staff-patient relationships and a focus on the values and treatment preferences, strengths and goals of service users. Fully supporting recovery may therefore require interventions across the whole mental health service, including the service user as an active partner and involving a combination of evidence-based patient-level interventions[108], team-level interventions such as REFOCUS, and organisational transformation approaches[40].

# Chapter 7: REFOCUS trial – process evaluation

A mixed methods process evaluation was conducted in parallel with the REFOCUS trial, following guidance from the Medical Research Council (MRC) framework for developing and evaluating complex interventions[6].

This chapter reports the qualitative element of the process evaluation, which had three aims:

1) To investigate the experiences of staff using the REFOCUS intervention
2) To identify wider contextual and individual influences on efforts to implement complex interventions into existing mental healthcare practice
3) To investigate the experience of service users who received the REFOCUS intervention.

The Staff Process Evaluation sub-study addressed aims 1) and 2), and the Service User Process Evaluation sub-study addressed aim 3).

## Staff Process Evaluation sub-study

Adapted with permission from the published report of parts of this study[308].

### Introduction

The REFOCUS trial took place at a time of national policy changes to mental health care services, such as public sector targets for significant cost-savings, leading to pressures on organisations to re-evaluate their priorities, streamline and reconfigure their services. Additionally, a new financing system, Payment by Results to make payments contingent on independently verified results lead to new organisational initiatives and targets, along with the introduction of Direct Payments from social services to service users, enabling them to buy care services for themselves.

Significant unforeseen organisational changes occurred since the study planning stages which impacted upon the ability of teams to participate in the trial and implement the intervention. In SLaM NHS trust, clinical services were previously configured according to geographical location, with services being provided at a borough level. Before and during the trial, services and care pathways were reorganised around psychiatric diagnosis, creating Clinical Academic Groups (CAG), as part of the preparation for the possible merger of three NHS foundation trusts with King's College London, to form a single academic health centre called King's Health Partners. Other organisational initiatives included the introduction of SLaM recovery care plans, requiring these to be written in the first person. The 2gether NHS trust introduced a local non-discriminatory mental health service model called 'Fair Horizons'. This led to existing teams being merged into 'one stop teams', giving a single access point for all working age adult, older age adult, child and learning disability referrals.

## Methods

We used three data collection methods: individual staff and trainer semi-structured interviews, focus groups with intervention teams, and trainer reports. Topic guides for all approaches were commented on by the REFOCUS Lived Experience Advisory Panel, as described in Chapter 10. Interview and focus group participants were recruited from the two trial sites either face-to-face or via telephone. The majority of interviews and all focus groups were held at community team bases. All participants were provided with an information sheet which outlined the purpose of the study, given an opportunity to ask questions and asked to sign a consent form.

28 face to face, in-depth interviews were conducted with staff and team leaders from intervention teams. A purposive sample with maximum variation (for profession, gender, experience in mental health services, team, intervention wave) were approached to participate. The two inclusion criteria were i) working clinically in a REFOCUS intervention team, and ii) self-reported use of the intervention. Recruitment continued until category saturation was reached. Of the potential interviewees approached, one person refused to be interviewed because they were too busy, whilst another expressed an interest in being interviewed and then was uncontactable. Individual interviews were conducted at mid-point (n=4) and end-point (n=24) between December 2011 and August 2013. The interview guide for staff and team leaders was developed in consultation the Lived Experience Advisory Panel (LEAP) of service users and carers and piloted in the mid-point interviews. It was subsequently revised, with additional questions and prompts being added for each of the intervention components. The final version is shown in Appendix 27. In addition,

three mid-point interviews were conducted with trainers to explore their experiences of delivering the training and working with individual teams. The interview topic guide is shown in Appendix 28. Interviews with staff and trainers were conducted by six interviewers, and lasted between 45 and 60 minutes.

For the focus groups, we recruited a purposive sample of four intervention teams which varied across site and wave (n=24 participants). As recommended by Morgan[107], we invited between six to eight staff to participate in the focus group to represent the range of views within the team. One team initially agreed to participate in a focus group, but then changed their minds when they became aware their team was being disbanded. These end-point focus groups were held at community mental health team bases between January 2013 and July 2013. Focus groups were facilitated by two researchers, and lasted between 60 and 90 minutes. The topic guide for focus groups is shown in Appendix 29.

Separate Personal Recovery (n=14) and Coaching for Recovery (n=14) training reports were prepared for each intervention team. Trainers provided two-page written reports on the six intended practice change areas of team values, individual values, knowledge, skills, behavioural intent and behaviour, set out in the REFOCUS intervention model. The report structure is shown in Appendix 30.

### *Analysis*

Braun and Clarke's six-phase guide for inductive thematic analysis was used with the qualitative data analysis package NVivo (version 9)[66]. Interviews and focus groups were recorded and transcribed verbatim, checked, anonymised and re-read them to increase familiarisation. At participant's request, two transcripts were returned for checking, but no corrections or comments were received. Particular attention was paid to any deviant cases as we were keen to compare and contrast the reasons why practitioners or teams had been especially successful or hindered in their attempts to implement the intervention.

Firstly, a sample of the interviews and trainers' reports were analysed by two analysts to create a list of initial codes, which were then merged, refined and sorted into a hierarchy of more abstract, over-arching and sub-themes. Coders met to review their coded passages and to agree on the major themes, deviant cases and to discuss coding differences to arrive at a consensus. This process of investigator corroboration is designed to maximise the validity and trustworthiness and to safeguard against bias within the analysis process[314]. The initial coding framework was then used to analyse all staff interview (2 analysts), trainer interviews (2 analysts), focus group transcripts (2 analysts) and written reports (3 analysts). Data analysis and collection occurred concurrently. Data collection ended when it was judged that data saturation for the majority of themes had been reached.

## Results

Socio-demographic data on staff (n=41) and team leader (n=11) participants is shown in Table 46.

**Table 46 Staff Process Evaluation sub-study: staff participants**

| | **Interviews**<br>n=28 | **Focus Groups**<br>n=24 |
|---|---|---|
| Mean (s.d.) | | |
| **Age (years)** | 46.76 (10.216) | 44.19 (8.152) |
| **Time qualified (months)** | 228.52 (121.139) | 202.50 (110.534) |
| **Work in mental health (months)** | 213.11 (110.228) | 189.35 (92.723) |
| **Time in post (months)** | 62.93 (59.623) | 54.41 (40.060) |
| **Gender** n(%) | | |
| Male | 11 (39) | 7 (29) |
| Female | 17 (61) | 17 (71) |
| **Ethnicity** | | |
| White British/White Irish/White other | 23 (82) | 16(67) |
| Black/Black British-African/ Black British-Caribbean/Black | 2 (8) | 6 (25) |
| Other | 3 (11) | 2 (8) |
| **NHS Trust** | | |
| SLaM | 19 (68) | 11 (46) |
| 2gether | 9 (32) | 13 (54) |

| | | |
|---|---|---|
| **Job Role** | | |
| Staff | 23 (89) | 18 (25) |
| Team Leader | 5 (18) | 6 (75) |
| **Team type** | | |
| Support and Recovery team | 25 (89) | 22 (79) |
| Forensic, high support team | 2 (7) | 0 (0) |
| Psychosis team | 1 (4) | 2 (7) |
| Low intensity team | 1 (4) | 0 (0) |
| **Profession** | | |
| Psychiatrist | 4 (14) | 2 (8) |
| Nurse | 14 (50) | 12 (50) |
| Psychologist | 2 (7) | 1 (4) |
| Social Worker | 2 (7) | 4 (17) |
| Occupational Therapist | 2 (7) | 1 (4) |
| STR Worker/Support worker | 3(14) | 2 (4) |
| Associate Practitioner | 1 (4) | 2 (8) |
| Physiotherapy technician | 0 (0) | 1 (4) |

*Aim 1 (REFOCUS experience)*

We found that staff were especially positive about the coaching training and the resources within two of the three working practices, highlighting the Values and Treatment preferences guide and the Strengths Assessment Worksheet, as giving them permission for new, structured conversations which led to finding out more about service users. The intervention also facilitated the development of recovery practice by supporting the development of team culture, structures and processes. The hierarchy of themes of staff perceptions of the intervention are shown in Table 47.

**Table 47 Staff Process Evaluation sub-study: hierarchy of themes from staff perceptions of intervention**

| **1. Intervention** | |
|---|---|
| 1.1 Recovery-promoting relationships | 1.1.1 Coaching skills and approach |

| | |
|---|---|
| | 1.1.2 Partnership project |
| 1.2 Working practices | 1.2.1 Values and treatment preferences |
| | 1.2.2 Strengths |
| | 2.2.3 Personally- valued goals |
| | 2.2.4 Electronic recording of working practice conversations |
| **2. Implementation strategies** | |
| 2.1 Information sessions | |
| 2.2 Personal recovery training and reflection sessions | |
| 2.3 Coaching for Recovery training | |
| 2.4 Individual Supervision | |
| **3. Practice change** | |
| 3.1 Staff knowledge of Personal Recovery | |
| 3.1 Staff attitudes towards Personal Recovery | 3.2.1 Recovery now seen as part of role |
| | 3.2.2 Broader focus upon personal recovery |
| | 3.2.3 Challenge to clinician’s illusion |
| 3.3 Staff perspectives on relationships | 3.3.1 Quality of relationship |
| | 3.3.2 Power balance |
| **4. Outcome** | |
| **4.1 Empowerment of staff and service users** | |
| **4.2 Team based approach to recovery** | **4.2.1 Dedicated time for team building** |
| | **4.2.2 Developing culture of challenging practice** |
| | **4.2.3 Recovery practice problem-solving** |

*Aim 2 (wider contextual and individual factors)*

The hierarchy of barriers and facilitators to implementing the intervention were organised under two higher order categories: Organisational readiness for change and Effective Training. The first higher order category, *Organisational readiness for change,* includes three sub-themes: i) NHS trust readiness, consisting of organisational commitment and organisational change, ii) Team readiness, consisting of effective leadership, team stability and composition and recovery practice baseline, and iii) Individual readiness, consisting of attitudes toward the trial and intervention, perceived fit with own existing values, knowledge or practices and willingness to apply to practice. The second higher order category: *Effective training*, includes three sub-themes: i) Engagement strategies and ii) Delivery style and content, iii) Modelling recovery principles. These are shown in Table 48.

**Table 48 Staff Process Evaluation sub-study: hierarchy of themes about barriers and facilitators**

| **THEME 1. ORGANISATIONAL READINESS FOR CHANGE** | | |
|---|---|---|
| **1.1 NHS readiness** | **1.2 Team readiness** | **1.3 Individual practitioner readiness** |
| 1.1.1 Organisational change<br>- Timing of intervention<br>- Job threats<br>- Increased task demand | 1.2.1 Effective leadership<br>- Attitude (opportunity or threat)<br>- Leading by example<br>- Containing leadership | 1.3.1 Attitudes about trial and recovery |
| 1.1.2 Organisational commitment<br>- Organisational / commissioning priorities<br>- Communication<br>- Resource availability<br>- Existing structures | 1.2.2 Team stability and composition<br>- Stage of team development<br>-Team composition | 1.3.2 Perceived fit with values, knowledge or practice |
| | 1.2.3 Recovery-practice baseline<br>- Understandings of recovery<br>- Shared team approach to risk-taking<br>- Openness to critical reflection<br>- Presence of existing or would-be recovery champions | 1.3.3 Willingness to apply to practice |

| **THEME 2. EFFECTIVE TRAINING** | | |
|---|---|---|
| **2.1 Engagement strategies**<br>2.1.1 Validating existing skills<br>2.1.2 Contracting<br>2.1.3 Voluntary attendance | **2.2 Delivery style** | **2.3 Modelling recovery principles in training** |

## Discussion

This study is the first process evaluation of a recovery-oriented complex intervention nested in an RCT. It identified findings specific to the REFOCUS intervention, and also identified factors which promote or inhibit efforts to routinely embed complex interventions into existing mental healthcare practice.

Benedetto[315] distinguished between "evolutionary" versus "revolutionary" implementation methods, based upon the anticipated degree of organisational or systems change necessary to achieve the desired improvement. The REFOCUS intervention could be classified as having used evolutionary implementation methods. It involved leadership-authorised, external teams and facilitators who created an intervention, assisted with implementation, but did not radically change job descriptions or staffing patterns[316]. In contrast, the Implementing Recovery though Organisational Change (ImROC) programme is using what could be termed revolutionary implementation methods, to enable organisations to assess, plan and evaluate their own recovery against ten indicators. These indicators include establishing Recovery Colleges to drive the programmes forward, transforming the workforce by employing peer support workers, and ensuring organisational commitment in creating a conducive ‘culture’[91]. We have found that in preparatory, qualitative research conducted at trial sites, and in subsequent findings reported here, participants consistently identified implementation barriers and facilitators which can only be influenced at senior executive board level and beyond, hence the need for more restrictive inclusion criteria in future cluster RCTs.

### *Strengths and limitations*

This study focussed upon the perspectives of staff and trainers as part of an evaluation of a complex recovery intervention which was designed to enable staff to increase recovery support for service users who had a primary diagnosis of psychosis. The validity of this qualitative study was strengthened by the use of data triangulation, (sources of data came from staff, team leaders and trainers), methodological triangulation (use of in-depth interviews, focus groups and written reports), investigator triangulation (use of different investigators in the analysis process) and environmental triangulation (two contrasting research settings). These triangulation processes highlighted similarities and differences and enabled these to be examined to deepen the meaning in the data[314].

The number of research studies which look specifically at supporting recovery practice from a staff perspective is limited. Existing qualitative studies tend to examine experiences and views relating to organisational level implementation of recovery initiatives[317],[318] focus upon an the application of recovery practice principles where there may be specific tensions, such as risk[319] or involuntary treatment[320], or focus upon recovery practice within a particular treatment model[321] or setting[322]. This study examines staff perspectives on a complex, team-level intervention to support recovery and gives an insight into their views around individual components of such an intervention. The study sample of 49 participants is relatively large for a qualitative study. The characteristics of participants are diverse and include staff from a range of professional backgrounds, with differing levels of experience and seniority and who work within specialist and generic types of community based mental health team.

Some caution however, should be taken when considering the findings. The interview and focus group sample is purposive, with an inclusion criterion of interviewee's self-reported use of the intervention. The sample does not therefore represent the views and experiences of the entire population of staff working in intervention teams. There is also potentially a recall bias as the interview and focus groups were based on participant's recall of events over the 12 month period of the intervention. Recall bias and discrepancies present problems in terms of accuracy and reliability[323].

As all new programmes or interventions occur within a wider open system, they cannot be kept fully isolated from unanticipated events, policy changes, staff turnover, organisational targets and initiatives, so identifying how these wider contextual organisational and environmental factors influence the uptake and success of an intervention is important. A limitation of this study is the failure to use a programme evaluation approach, such as proposed by Pawson and Tilley[324], to sufficiently link and examine the impact of these policy and organisational changes to the implementation of the intervention.

*Implications*

The findings relating to the REFOCUS intervention have three implications. First, the results support others who have recommended coaching as a means of developing recovery promoting relationships[186]. Staff valued the concrete guidance and skills training they were given to prepared them for having tough as well as motivating, empowering conversations with service users. This has wider clinical relevance given that initiating tough conversations will always part of mental health practice and can be stressful for both staff and service users. The findings also suggest that the intervention helped staff in deciding how to strike a balance between when to provide help and when to step back. This clearly is fundamental to developing empowering relationships which facilitate recovery and has relevance for training of all mental health professionals.

Second, there was some evidence that using the three working practices helped workers expand the focus of care. Some of these conversations directly challenged staff views and assumptions about what their service users were capable of and thereby subtly changed and expanded their view of the person. Shifting staff attitudes and beliefs about the possibility of recovery from severe mental illness, their views of service user strengths, personal resources and capabilities is important step in changing towards a more recovery focussed practice. In a qualitative study of 28 case managers in Indiana, USA, Sullivan and Floyd looked at differences in their recovery practice and beliefs about the likelihood of service user recovery from mental illness[325]. They found that the most hopeful case managers, who had often witnessed individuals succeeding in unanticipated ways, focussed on outcomes which went beyond symptom relief and compliance with medication.

Finally, the team-based approach to training and reflection sessions was singled out as being important in enabling teams to support and critically challenge one another, develop a team recovery identity and a team culture which was conducive to supporting and sustaining recovery practice.

The findings relating to the wider context also have three implications. First, this study highlighted the importance of targeting the transition from practitioner intent to implement to actual implementation behaviour. This was achieved by building in role-plays with colleagues, followed by small-scale, pilot experiences of using the intervention with service users. This exposed practitioners to direct, personalised feedback on the impact of the intervention and enabled negative attitudes and assumptions about likely consequences to be powerfully challenged. The personal recovery training to promoting recovery-oriented practice through knowledge acquisition and values-based training appeared to be less popular and effective. In an observational study of recovery-oriented training in state hospitals, Tsai and colleagues also found that specific/ practical training had a greater increase in staff pro-recovery attitudes compared to general/ inspirational training[326].

Second, consistent with other research[63], our study demonstrates the central importance of organisational commitment. Our study shows how staff evaluate organisational commitment using three markers: *resource allocation* (e.g. ensuring staff duties were covered to allow them to fully engage in training and team reflection sessions), organisational *Key Performance Indicator* metrics, and organisational *outcome measures*. Farkas and colleagues[327] have similarly reported that the implementation of recovery-oriented programmes has been hampered by focussing solely upon the collection of mandatory, routine outcome data on traditional clinical outcomes (e.g. symptomatology, relapse rates and employment) which may be incompatible with recovery outcomes (e.g. self-esteem, empowerment and well-being).

Third, for team-level interventions like this, we found that broader and unrelated organisational change processes greatly impacted upon staff action, directly via staff resourcing and indirectly, through implementation motivation and willingness. As these change processes will doubtless continue and resource allocation in health systems should be sensitive to this context. The fairest test of implementation might not be on an area-wide basis as in this study, but rather preferentially targeting teams that are at a mid-life stage of development, with low staff turnover, leadership capacity to frame involvement as an opportunity rather than a burden, and existing in-team 'champions' for the intervention. This points to the need for methodological extension of cluster RCTs, for example by including an organisational readiness to change measure as an inclusion criterion for selecting *both* organisations *and* individual teams, when evaluating team-level interventions within a RCT.

## Service User Process Evaluation sub-study

### Introduction

The qualitative experience of a recovery-focused intervention, particularly delivered at the team level, remains relatively under-researched. This is an important knowledge gap, given that the perspective of service users is central to recovery. Although studies have focused on the service user experience of care[328,329], less evaluative work has been conducted into the experience of receiving a pro-recovery intervention or service. This study aimed to investigate the service user experience of receiving the REFOCUS intervention[330].

### Methods

*Design*

Semi-structured individual interviews and focus groups were conducted with service users who received care from teams in the intervention arm of the trial.

*Participants*

For the individual interviews a purposive sample of 24 individuals was recruited from 11 of the 14 intervention teams. The purposive sample aimed to maximise variation in trial site, service location, time in mental health services and diagnosis. Inclusion criteria were a) have received the REFOCUS intervention, b) were sufficiently well enough to take part and c) could speak and understand English.

Focus groups were conducted with a convenience sample of individuals who had taken part in two partnership projects: the ‘Let’s Be Well’ website and ‘Outward Bound’ activity day. These were chosen as they represented both sites of the trial and were contrasting types of project.

*Procedure*

A semi-structured interview schedule was developed in collaboration with the REFOCUS Lived Experience Advisory Panel (LEAP), who provided Patient Public Involvement representation to the research programme. The interview topic guide is shown in Appendix 31, and aimed to gather in-depth data relating to the experience of receiving the REFOCUS intervention. The focus group topic guide is shown in Appendix 32, and covered the experience of participating in the partnership project. Focus groups were used instead of interviews to capture the shared experience of these group-based projects.

Snowballing and networking techniques were used to identify service users for the interviews. Staff members who reported using either the working practices or coaching techniques were asked to identify service users with whom they had used the intervention. Additionally, where service users reported experiencing elements of the intervention during the trial outcome evaluation interviews, members of the research team invited individuals to participate. Data collection and analysis was concurrent, with recruitment continuing until category saturation was reached.

Prior to the interview and focus groups, participants were provided with information about the study, written informed consent was obtained and socio-demographic information collected. Interviews and focus groups were conducted by researchers from both trial sites, after receiving training in conducting service user interviews from members of LEAP. The interviews lasted between 35 and 65 minutes and each focus group lasted a maximum of 90 minutes.

At the end of each interview or focus group, participants were given the opportunity to ask questions and to reflect on their experience. All individuals received remuneration for their participation in the study (£20 for the focus groups, £10 for the interviews). Interviews and focus groups were conducted at local community mental health team bases or in the participant’s home. Following data collection, the interviewers recorded their initial impressions and identified emergent themes in theoretical memos.

### *Analysis*

Interviews and focus groups were recorded, transcribed verbatim and anonymised. Transcripts were coded using NVivo qualitative data analysis software version 8. Thematic analysis was used for the data analysis following the guidance of Braun and Clarke[66]. Four interview transcripts were coded inductively by three independent raters to identify pertinent themes within the text. The coders met to discuss the themes and developed an initial coding framework, which made use of the topic guide to help structure the initial inductive codes. Two researchers, including one researcher with a professional / service user background, independently applied the coding framework to the remaining transcripts. The two coders met regularly to iteratively update and modify the coding framework. Any differences in coding were discussed and alternative interpretations of the data recorded as memos. For each of the categories included in the framework, a definition was created. The language of the original data extracts was used to inform their headings and definitions of each category.

### Results

Twenty-four service users participated in individual interviews; 17 from SLaM and 7 from 2gether. One focus group was carried out in each Trust, consisting of 6 and 7 service users respectively. Characteristics of participants are shown in Table 49.

**Table 49 Service User Process Evaluation sub-study: participant characteristics (n=37)**

| | Interviews | Focus Groups |
|---|---|---|
| n | 24 | 13 |
| Gender (N, %): | | |
| Female | 6 (25%) | 8 (62%) |
| Male | 18 (75%) | 5 (38%) |
| Age (Mean, s.d.) | 43.7 (10.3) | 42.7 (8.9) |
| Ethnicity (n, %): | | |
| White British | 12 (50%) | 9 (69%) |
| White Other | 1 (4%) | 0 (0%) |
| Black/ Black British - African | 4 (17%) | 1 (8%) |

|  |  |  |
|---|---|---|
| Black/ Black British - Caribbean | 3 (13%) | 0 (0%) |
| Mixed ethnicity | 2 (8%) | 0 (0%) |
| Other | 1 (4%) | 3 (23%) |
| Did not disclose | 1 (4%) | 0 (0%) |
| Diagnosis (n, %): |  |  |
| Schizophrenia | 6 (25%) | 1 (8%) |
| Bipolar Disorder | 5 (21%) | 3 (23%) |
| Depression | 2 (8%) | 4 (31%) |
| Anxiety | 0 (0%) | 1 (8%) |
| Other | 2 (8%) | 2 (15%) |
| Did not want to disclose | 9 (38%) | 2 (15%) |
| Intervention wave |  |  |
| Lewisham (Wave 1) | 7 (29%) | 6 (46%) |
| Southwark (Wave 2) | 4 (17%) | 0 (0%) |
| Croydon (Wave 3) | 6 (25%) | 0 (0%) |
| Gloucester (Wave 1) | 2 (8%) | 0 (0%) |
| Gloucester (Wave 2) | 5 (21%) | 7 (54%) |
| Mental health team type (n, %): |  |  |
| Support and recovery | 18 (75%) | 9 (69%) |
| Early intervention service | 0 (0%) | 1 (8%) |
| Forensic | 5 (21%) | 0 (0%) |
| Continuing care | 0 (0%) | 1 (8%) |
| Other | 1 (4%) | 2 (15%) |
| Time in MH services years (mean, s.d.) | 14.3 (11.3) | 13.0 (9.7) |

Six participants declined to participate in the interviews. The individuals who refused were from a range of teams across both sites.

Data were organised into three superordinate categories: ‘Working relationship which supports recovery’, ‘Impact of the REFOCUS intervention’ and ‘Lack of noticeable change in the service user experience’. The first and secondary order coding categories are shown in Table 50 below, and the full coding framework is shown in Appendix 33.

**Table 50 Service User Process Evaluation sub-study: superordinate coding categories**

| First Order category | Second Order category |
|---|---|
| 1. Working relationships which support recovery | 1.1 ‘Genuine’ interest in the person<br>1.2 Service user-directed<br>1.3 Collaborative working |
| 2. Impact of the REFOCUS intervention | 2.1 Empowerment<br>2.2 Identity<br>2.3 Hope and optimism |
| 3. Lack of noticeable change in the service user experience | 3.1 Poor delivery of intervention<br>3.2 Lack of noticeable change in the relationship<br>3.3 Barriers within mental health services |

## Discussion

When successfully delivered, the REFOCUS intervention facilitated the building of a pro-recovery relationship between staff and service users which was characterised by increased mutual openness and collaboration. Service users were able to lead conversations and felt that staff got to know them as individuals. Service users were also able to get to know themselves better, with greater awareness of their strengths and values, leading to a more positive self-image. Individuals in receipt of the intervention felt empowered and more hopeful. However, some participants experienced elements of the intervention in the absence of a recovery-promoting relationship. When delivered in this way, these elements were experienced as intrusive and not for the benefit of the service user. Finally, some individuals struggled to notice changes in their relationship with staff and could not describe any new tasks or conversations occurring during the intervention period.

The findings that the intervention increased empowerment, hope and optimism and promoted a positive sense of identity are in line with reported outcomes of quantitative evaluations of recovery interventions. An RCT of a 12-week group intervention using the Recovery Workbook, which covered topics such as recovery and personal goal-setting, was found to significantly increase hope and empowerment compared to control[136]. Similarly an RCT of an 8-week peer-facilitated self-management programme using WRAP found significant increase in hope and quality of life compared to treatment as usual[331], themes common to the present analysis.

*Strengths and Limitations*

This is the first study to explore service user experiences of a team-level pro-recovery complex intervention. The use of a qualitative approach, and the study taking place across two sites, enabled an in-depth and nuanced understanding of service user experience, with increased generalisability. Many mental health services are seeking to become more recovery-focused and this study provides guidance on what service users do and do not find helpful in recovery-promoting relationships and recovery activities.

Three limitations can be identified. First, participants were selected based on self or staff reports of exposure to the REFOCUS intervention, so may not be representative of other service users. Second, the main interviewer helped to develop the intervention and all interviewers were known to be researching a new way of working in community mental health teams, so social desirability bias may have led to over-reporting of change. Finally, asking participants to characterise interactions over the last 12 months may have led to recall bias, or conversely 12 months may not be long enough for changes in soft skills such as staff attitudes to occur[310]

*Implications*

Four implications were identified. First, the resources provided in the REFOCUS manual to support the working practices need to be seen as a means, not an end. Service users reported that the working practices, when successfully incorporated into practice, can help to build a recovery-promoting relationship and are of value to service users. However, some service users described rigid and formulaic implementation of the working practices. Previous research has also found that staff tended to focus on particular tasks as evidence of 'doing' recovery thus, "omitting the underlying philosophy of recovery-orientated practice"[201] [108]. Therefore role play training should support staff to focus on the person not the form, to break away from a prescribed order or focus of the form where needed, and to view tools as something service users and staff work together on rather than the form being something that the staff member 'does' to the service user .

Second, recovery-focussed tools should be integrated into the routine practice of care planning. Participants highlighted how any conversations around values, strengths and goals needed to result in the information discussed and exchanged being used to support the service user's recovery. For example, goals need to be broken down into tangible steps, and available resources identified, including opportunities to use the person's strengths. Consistent with the present study, ethnographic interviews conducted with service users receiving strengths-based care management have highlighted how strengths assessments are particularly useful when combined with collaborative goal planning[332]. Furthermore, practical support from staff to help access the identified resources is seen as particularly important[333].

Third, organisational transformation needs to balance technical skills (such as assessing strengths) with interpersonal goals of more power-balanced and hope-inspiring relationships, and this should be reflected in training given. Service users described how being 'genuinely' caring and supportive, as well as honest and open in a constructive manner, were necessary qualities of a staff member in a recovery-promoting relationship. The qualities valued by service users were similar to those valued by mental health staff identified in a previous study, which highlighted being caring, supportive, respectful and open as essential components of the staff-service user relationship[201]. Participants also valued hope-inspiring, power-balanced relationships with a focus on strengths. These valued relationship characteristics are in line with other research highlighting the central importance of hope in providing recovery-orientated care [334].

Finally, many service users were unable to recall having experienced the REFOCUS intervention, despite being identified by staff as individuals who had received it. One explanation may be that service users who had not attended the trial information session had little awareness of the REFOCUS intervention, the REFOCUS trial, or what they could and should expect from their interactions with staff during the intervention period. Raising service user awareness of the intervention may help them to be more aware of experiencing it, which may help with eliciting their experience of the intervention. Additionally this may help service users to have expectations of recovery-promoting practice from staff. One potential strategy for raising service user awareness of the intervention is to provide individuals with signals that the intervention is in use, such as the use of a handbook. This approach is currently being considered in the Principles Unite Local Services Assisting Recovery (PULSAR) randomised controlled trial to evaluate the REFOCUS intervention within mental health services in Victoria, Australia[335].

Another possible explanation for the lack of noticeable change is that the intervention was implemented in such a way that it was not sufficiently different from routine practice to be noticeable to service users. Indeed, participants spoke about recovery-promoting practice that pre-dated the REFOCUS intervention, with examples of staff already working in a recovery-orientated manner. Where practice was already recovery-orientated, any intervention changes may be subtle and difficult to detect. Furthermore, the intervention was intended to be integrated into practice and may have resulted in 'soft' changes to the relationship between service users and staff.

In line with current best practice[336], nested process evaluations within an RCT are recommended in order to understand the experience of participants receiving a complex intervention. However, in such cases where the intervention is intended to be integrated within routine care, evaluation from a service user perspective is challenging. Alternative approaches might include ethnographic investigations such as participant observation or the recording of interactions, which, although not without their limitations[337,338], may be more useful in detecting subtle changes as a result of the intervention. Action research, which actively involves the service users receiving the intervention in the research process, may be another option to consider.

Despite all these caveats, it is worth noting that service users reported that the REFOCUS intervention, when successfully implemented, supported the development of recovery-promoting relationships and contributed to recovery outcomes.

# Chapter 8: REFOCUS trial – outcome studies

Three sub-studies were undertaken in the context of the REFOCUS trial, and are reported here.

## Casenote Audit sub-study

### Introduction

Working Practice 3 of the REFOCUS intervention aimed to increase goal-striving support provided by staff, because recovery is more supported by goal-striving of the service user where possible towards personally valued goals than by passive adherence to staff-decided treatment[339]. The recovery-promoting relationships and working practices 1 and 2 were also intended to increase the use of shared decision making, collaboration and person-centred care planning. Best evidence suggests that passive decision-making is not optimal in mental health care[200], and the optimal balance between shared and informed is a current debate[340]. Decision-making processes in a recovery-oriented service should be dominated by shared or informed decision-making rather than passive decision-making. It is plausible that these changes will be visible in the recorded care plan. Care plans have the advantage of being routinely collected and mineable. The responsibility for action in a care plan (who will do the action?) has been previously used as a recovery marker in care plans[201]. The aim of this study was to use routinely collected and recorded care plan data to identify who was given the responsibility for each action on a care plan, in order to evaluate the impact of a pro-recovery intervention. The hypothesis being tested was that there would be a reduction in the proportion of staff having sole responsibility for actions in care plans after receiving the intervention.

### Methods

*Design*

An interrupted time series (ITS) design was used to investigate the impact of the intervention. ITS is useful for reducing bias in the estimation of effect size[341]. The rationale for this design was to control for: (a) secular trends by using 7 time points; (b) cyclical patterns in outcome by using two sampling points per year; (c) duration of the intervention by collecting data at 6-monthly time points allowing effectiveness to be identified; and (d) autocorrelation by controlling for dependencies within the dataset. The six-monthly interval was chosen because the intended impact of the REFOCUS intervention was speculated to occur in six-month units (ascending for six months then sustained change), and also because six months is the usual care plan review cycle.

### *Procedures*

The Electronic Patient Journey System (EPJS) is the electronic patient record system used by SLaM, containing records on over 150,000 current and previous mental health service users. Records include both structured data (e.g. demographics, diagnostic codes, team codes) and free text data (e.g. progress notes, service user care plans). The Clinical Records Interactive Search (CRIS) system is an electronic patient record database[342], containing anonymised versions of EPJS data suitable for downloading into statistical packages for analysis.

The CRIS system was used to undertake an ITS analysis of mental health care plans for service users of teams in the REFOCUS trial in SLaM. To allow at least two time points of data collection before the first allocation in July 2011, data were collected at six-month intervals for seven rounds: July 2010 (T1), January 2011 (T2), July 2011 (T3), January 2012 (T4), July 2012 (T5), January 2013 (T6) and July 2013 (T7).

Sampling frame identification was challenging. Approach 1 identified participants through team caseloads. The inclusion criterion was that service users should be on the caseload of the same team across all time points. However, in 10 of the 19 teams this produced a sample size of less than the target 50. This was due to SLaM service restructuring, with some teams only recently formed (n=6) and others in existence but with a different focus and caseload (n=4). Approach 1 was therefore abandoned.

Approach 2 identified participants and then followed them across teams. Service users from all REFOCUS teams with an active care plan in January 2012 (T4) were included, and tracked for previous (T1 to T3) and subsequent (T5 to T7) SLaM service use irrespective of team. Final inclusion criteria were therefore: aged between 18 and 65, clinical diagnosis of psychosis, and on a REFOCUS team caseload in January 2012.

Eligible service users on the caseload of each participating team (n=19) in January 2012 (T4) were identified, and then 50 from each team were independently randomly selected. For each person, gender, ethnicity and date of birth were extracted. At each time point, the person's HoNOS score, service setting (community or in-patient) and care plan were extracted. Each care plan contains one or more action points. Two ratings were made on each action point, blind to team (and hence blind to allocation status). First, the Responsibility rating used an existing coding system[343] to identify who has responsibility for the action: Staff, Service User, Carer, some combination such as Staff / Service user where responsibility was shared, or Uncodeable. Second, whether the action point was Generic or Personalised, *i.e.* whether the person was 'visible' in the care plan. To test concordance, 100 care plans were double rated, and coding guidelines refined until a concordance of 95% was achieved.

*Analysis*

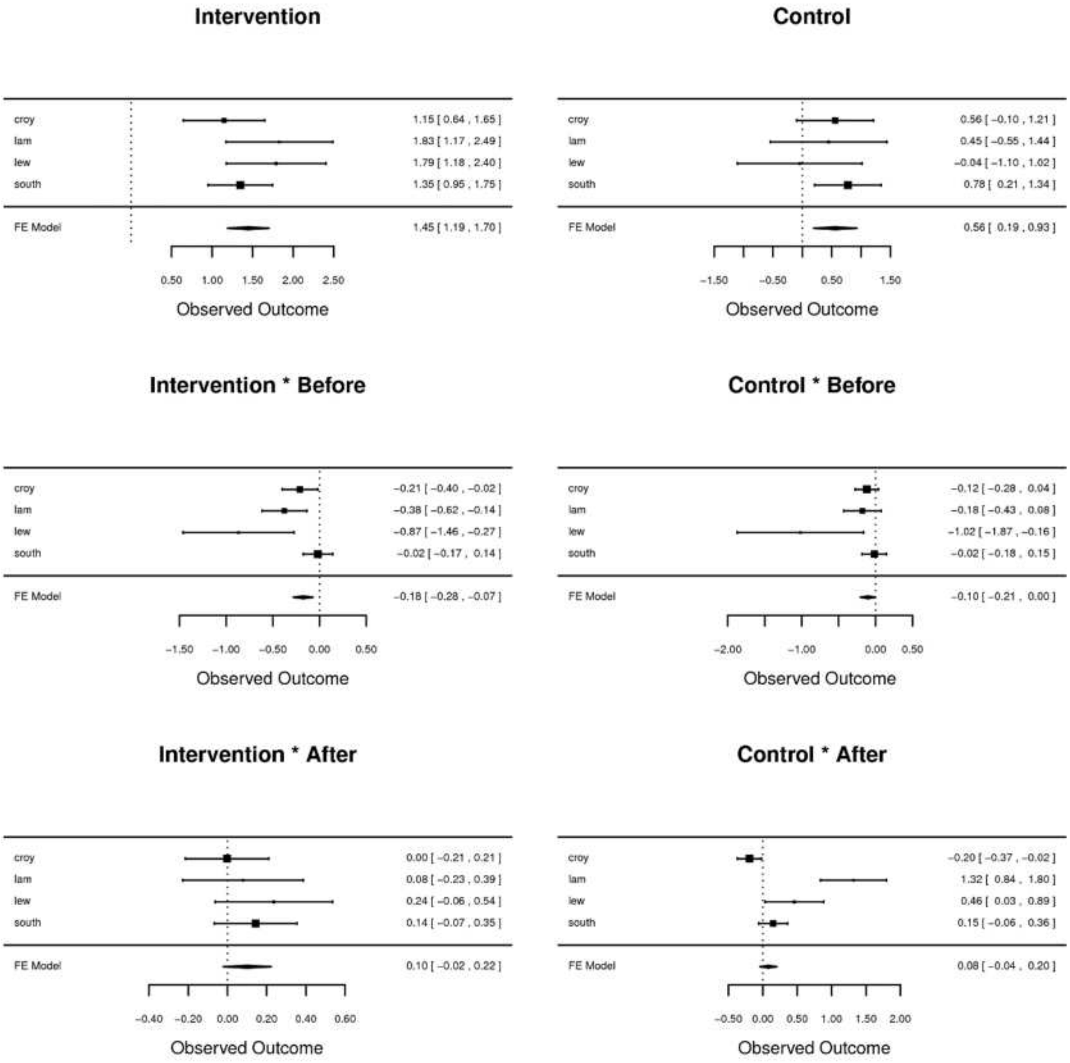
The dependent variable for the regression on Responsibility was created by re-coding to either Staff or Other (any combination including responsibility by someone other than staff, e.g. Staff / Service user, or Carer). Only a small number of Responsibility codings involved carers, so level of service user involvement in responsibility was investigated by re-coding Responsibility to Staff, Staff / Service user and Service user (i.e. treating all other categories as missing). Binary independent variables were Allocation (Intervention or Control), Started (No for control teams or pre-allocation intervention teams), and Setting (community or in-patient).

We fitted a separate model to each block. The models were logistic regressions with as outcome the proportion of care plans which mentioned staff out of those which mentioned either staff or user. Plans which mentioned carers or which mentioned both staff and user were excluded. The predictors were intervention versus control (a two level factor) and time used as two continuous predictors with a break at the intervention time point. These models were of the broken stick type. The slope for time before the intervention point was allowed to be different from the slope after the intervention point with the constraint that they meet at the time point. Separate slopes were fitted for intervention and for control and they met at separate points. By fitting the model separately for each block we were able to allow for the different times when intervention occurred in each block. We then combined the results from the blocks using standard meta–analytic techniques using the **metafor** package[344]. Although the conclusions from the one at a time analyses are fairly clear from a technical point of view it is better to use a multivariate analysis since the parameter estimates are correlated. For this we used the **mvmeta** package[345].

### Results

Figure 15 shows the plots of the log odds ratios for the four blocks for each of the parameters.

**Figure 15 Casenote Audit sub-study: forest plots from univariate meta-analysis**



Each plot also has a summary statistic, and note that the horizontal scale is not the same on the plots. Looking at the plots from left to right downwards we first have the intervention log odds at the point of the breakpoint. The other five plots are all log odds ratios. The second plot shows the log odds ratio for control at the same point. Since these are on the whole positive they imply that at the breakpoint the control group had more staff-only plans than the intervention group, although there is some heterogeneity here. The next two plots show the before slopes for each condition. Since these are negative they imply the proportion of staff-only plans was going down for both groups before starting the REFOCUS intervention. The final two plots show the slopes after starting the REFOCUS intervention. Since these are positive they imply that after starting the intervention, the proportion of staff-only plans was going up, although in both cases the confidence interval includes zero and there is heterogeneity.

Table 51 shows the results of the fixed effects multivariate meta–analysis. For convenience the coefficients are expressed as odds ratios. These are close to the values given in the univariate analyses.

**Table 51 Casenote Audit sub-study: multivariate meta-analysis**

| | Estimate | 95% CI |
|---|---|---|
| Intercept | 4.073 | (3.164 to 5.244) |
| Control (reference category intervention) | 1.550 | (1.083 to 2.221) |
| Intervention slope before | 0.849 | (0.765 to 0.942) |
| Control slope before | 0.902 | (0.814 to 1.000) |
| Intervention slope after | 1.054 | (0.936 to 1.187) |
| Control slope after | 1.011 | (0.898 to 1.139) |

### Discussion

In two previous studies investigating care plans for people using specialist mental health services, we found a dominance of staff taking responsibility for actions. A cross-sectional review of 1,732 action points in the care plans of 244 service users found 1,275 (74%) involved action by staff only[343], and a study involving two rounds of care plan assessment for 700 service users found 4,977 (70%) of the total 7,155 action points involved action by staff only[346]. This was not found in this study. The percentage of care plans where action was undertaken by staff did not significantly change. This finding is consistent with the outcome evaluation from the REFOCUS trial, as presented in Chapter 6.

#### *Strengths and weaknesses*

The methodological rigour of the study is strong. Several quality improvement approaches were used, based on best practice guidance for ITS design[341]. We analysed the intervention independent of other changes, by including control and intervention groups within each wave. The Intervention did not affect data collection, since care plans were recorded routinely as part of the care planning process. The two raters of the care plans were blinded to team, so coding was not biased by allocation status. Rating concordance met the suggested threshold of 90%. The shape of the intervention effect was prespecified: 6 months linear improvement followed by sustained change. The rationale for the number and spacing of the time points is given: seven time points ensures there were two time points before the start of the first intervention and after the start of the last intervention. Finally, data were analysed appropriately using time series techniques.

Overall, no change in care plans was found after teams had begun their participation in the REFOCUS trial.

## Secondary Outcome Evaluation sub-study

### Introduction

A pre-planned sub-study was undertaken within the SLAM site of the REFOCUS trial, with the aim of evaluating the impact of the REFOCUS intervention on black service users (i.e. those on List A in the recruitment procedure described in Chapter 5). Two hypotheses were tested:

- Hypothesis 1 (recovery): Black individuals assigned to the intervention arm will experience greater improvements in recovery as measured by the QPR compared to those receiving standard care.
- Hypothesis 2 (satisfaction): Black individuals assigned to the intervention arm will experience greater improvements in satisfaction as measured by the CSQ compared to those receiving standard care.

### Methods

Data were taken from the REFOCUS trial, as described in Chapter 5. The two primary outcomes were QPR and CSQ. The Client Satisfaction Questionnaire (CSQ) is an eight-item patient-rated measure of general satisfaction with the services received[295]. Items are rated from 1 to 4, giving a total score between 8 and 32 with higher scores representing greater satisfaction with services.

### *Sample size*

To inform the sample size, a retrospective re-analysis was undertaken of CSQ data for black individuals included in the Alternatives study[347]. The Alternatives study was a non-randomised comparison of in-patient alternatives to traditional acute mental health in-patient care across England. The Alternatives study demonstrated an effective size of 0.67 between the intervention and control groups. An effect size of 0.67 equates to a difference of 10.8 on QPR Intrapersonal, 2.5 on QPR Interpersonal and a difference of 4 points on CSQ. This resulted in an estimated sample size for a 2-group comparison of means (alpha 0.05, power = 0.8) of 35 per group for QPR and 36 per group for CSQ. As the trial was cluster randomised, the power calculations took account of clustering by using an intercluster correlation of 0.05, based on 16 teams in SLaM (assuming a 20% attrition rate from the 20 originally planned teams) and an intercluster correlation of 0.05, with equal numbers of clusters in each randomisation group. To account for clustering 44 participants per arm were required. Therefore, the aim was to recruit six participants per cluster. This allowed for an attrition rate of 7% or one participant to drop out per team. The total anticipated sample size for the BME participants was 120 (six participants x 20 teams), based on the above attrition rates and clustering, giving an analysable sample of 89 with power to detect a medium to large effect size of 0.67 (alpha 0.05, power 0.8) on the CSQ and QPR.

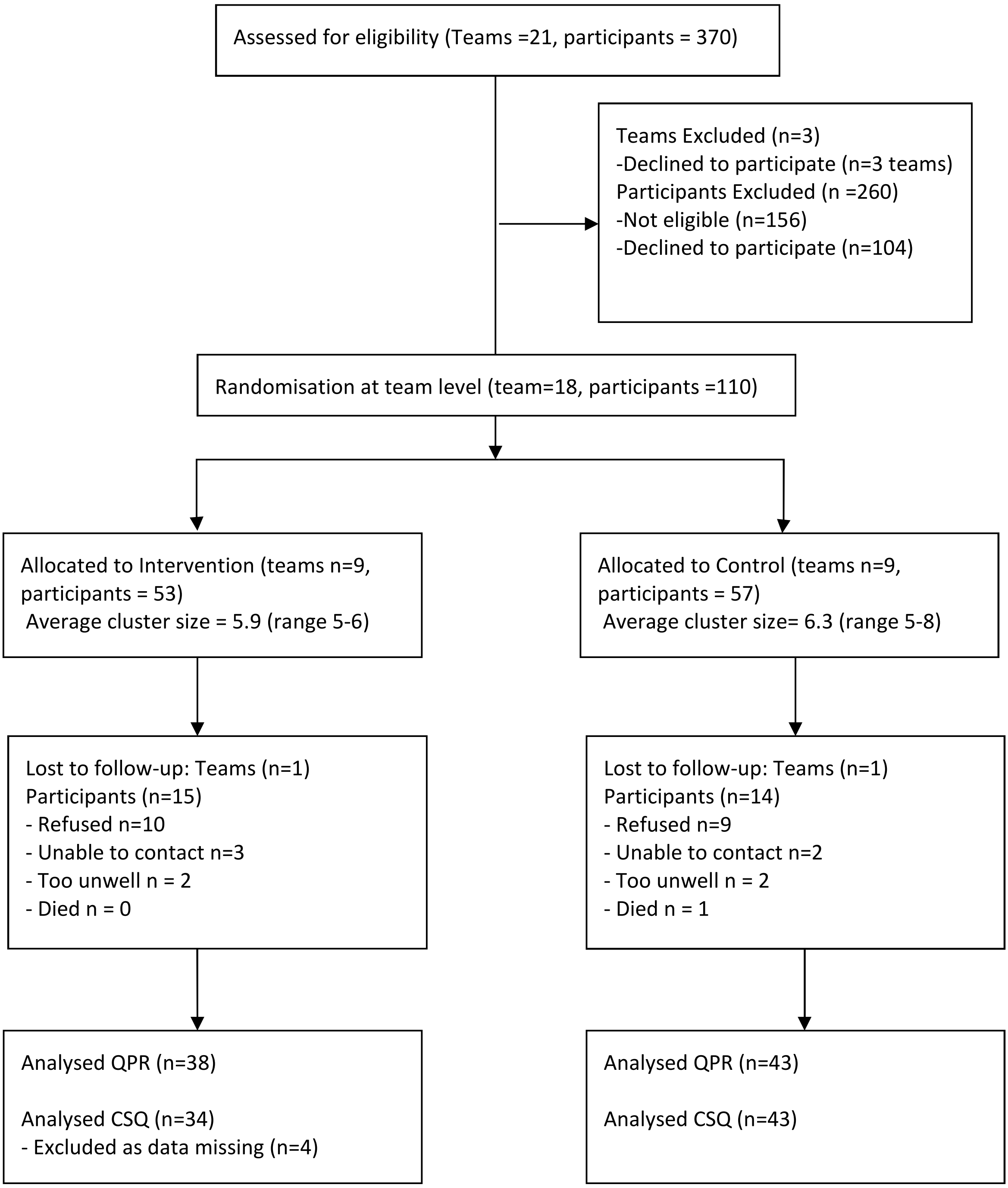
### *Analysis*

The analysis was conducted in STATA version 11, with clustering controlled for through the use of multilevel modelling. The model was fitted within STATA using a mixed-effects regression model using maximum likelihood (xtmixed command). Homoscedasticity was tested when assessing the assumptions of the regression models. Four theoretically driven models were tested for the two primary outcomes: Intervention group (Model 1), Model 1 plus Sociodemographics (Model 2), Model 2 plus clinical covariates (Model 3), and Model 3 plus recovery covariates (Model 4). Model fit was tested using the Akaike's Information Criteria (AIC). As the models were nested, direct comparison was permitted to find the model with the best fit. The AIC comparisons were AIC, Delta AIC and likelihood measure. The Delta AIC shows the difference in AIC scores between each model. The best model is used to calculate the likelihood measure, which indicated the likelihood of the model being the best fit compared to the other models.

## Results

Although it was anticipated that 20 teams would be recruited, a total of 18 were eligible and consented to participate in the trial. Participating teams were randomly allocated on an equal basis to intervention (9 teams) or control (9 teams). The flow diagram is shown in Figure 16.

**Figure 16 Secondary Outcome Evaluation sub-study: flow diagram**



Characteristics of service user participants are shown in Table 52, with significant differences shown in bold.

**Table 52 Secondary Outcome Evaluation sub-study: service user characteristics (n=110)**

| | Intervention n=53 | Control n=57 | Between group p-value |
|---|---|---|---|
| Age (mean, s.d.) | 42.9 (9.0) | 43.6 (11.2) | 0.736 |
| Gender (n, %) | | | |
| Female | 14 (26%) | 23 (40%) | 0.122 |
| Male | 39 (74%) | 34 (60%) | |
| Ethnicity (n%) | | | |
| Black African | 10 (19%) | 14 (24%) | 0.266 |
| Black Caribbean | 34 (64%) | 33 (57%) | |
| Black Other | 0 (0%) | 1 (2%) | |
| Other | 9 (17%) | 10 (17%) | |
| Time in MH services, years (mean, s.d.) | 13.7 (8.5) | 15.2 (10.2) | 0.388 |
| Employment (n, %) | | | |
| Competitive employment | 4 (7.5%) | 1 (2%) | 0.145 |
| Not employed | 49 (92.5%) | 56 (98%) | |
| Hospitalised in last 6 months | 6 (12%) | 4 (8%) | 0.432 |
| QPR | 59.4 (9.2) | 57.0 (10.6) | 0.223 |
| CSQ-8 | 24.0 (5.2) | 25.1 (4.7) | 0.281 |
| HHI | 35.3 (5.1) | 35.9 (4.7) | 0.553 |
| MANSA | 4.6 (1.0) | 4.7 (0.9) | 0.726 |
| INSPIRE Support | 64.9 (21.8) | 56.8 (19.3) | **0.043** |
| INSPIRE Relationships | 73.8 (17.2) | 74.3 (15.8) | 0.898 |
| MHCS | 66.8 (15.6) | 66.3 (14.5) | 0.875 |
| WEMWBS | 47.6 (9.1) | 47.0 (10.4) | 0.776 |
| CANSAS-P Met | 3.3 (2.7) | 3.6 (3.5) | 0.566 |
| CANSAS-P Unmet | 4.2 (3.3) | 4.3 (2.8) | 0.864 |
| BPRS | 33.4 (9.2) | 32.1 (7.9) | 0.457 |
| GAF | 68.7 (13.9) | 64.3 (14.0) | 0.111 |
| HoNOS | 7.5 (4.1) | 10.8 (6.8) | **0.003** |
| CANSAS-S Met | 5.7 (3.8) | 5.1 (3.0) | 0.378 |
| CANSAS-S Unmet | 2.8 (2.1) | 3.9 (2.9) | **0.039** |

Only HoNOS remained a significant difference after adjusting for multiple testing.

Four theoretically driven models were tested for the two primary outcomes. As HoNOS was significantly different between the groups at baseline, it was added as a covariate to all but the unadjusted model (model 1). The models for QPR are shown in Table 53. Bold indicates p<0.1.

### Table 53 Secondary outcome Evaluation sub-study: adjusted models for QPR (n=81)

| Measure | Coefficient (Model 1) | p-value | Coefficient (Model 2) | p-value | Coefficient (Model 3) | p-value | Coefficient (Model 4) | p-value |
|---|---|---|---|---|---|---|---|---|
| Intervention | .878 | .770 | -1.146 | .663 | -4.582 | .055 | -4.934 | .167 |
| Baseline QPR | | | .740 | **.000*** | .741 | **.000** | | **.000** |
| **Socio-demographic variables** | | | | | | | | |
| Age | | | -.1100 | .360 | -.0343 | .770 | .0187 | .929 |
| Borough | | | -.767 | .603 | -.708 | .593 | -.468 | .814 |
| IQ | | | .145 | .125 | . 136 | .104 | .170 | .154 |
| Gender | | | -2.479 | .320 | -2.219 | .324 | .397 | .915 |
| Employment | | | 4.912 | .312 | 4.317 | .336 | 3.331 | .576 |
| Education | | | -.537 | .878 | -5.605 | .088 | -5.013 | .276 |
| Relationship status | | | .0743 | .986 | .258 | .946 | 1.270 | .789 |
| Accommodation | | | -.058 | .975 | -.0192 | .991 | .153 | .276 |
| **Clinical variables** | | | | | | | | |
| Time in services | | | | | -.204 | .155 | -.218 | .305 |
| CANSAS-P Met | | | | | .139 | .640 | .138 | .680 |
| CANSAS-P Unmet | | | | | -.728 | .105 | -.356 | .590 |
| BPRS | | | | | .281 | .110 | .236 | .247 |
| GAF | | | | | .162 | .205 | .118 | .503 |
| HoNOS | | | -.439 | 0.144 | -.764 | **.029** | .768 | **.074** |

|  |  |  |  |  |
|---|---|---|---|---|
| CANSAS-S Met | .805 | **.045** | .624 | .282 |
| CANSAS-S Unmet | 2.00 | **.001** | 1.572 | **.064** |
| Hospital admission | 5.15 | .204 | 4.041 | .518 |
| **Recovery variables** |  |  |  |  |
| CSQ-8 |  |  | .213 | .537 |
| HHI |  |  | -.321 | .482 |
| MHCS |  |  | -.066 | .677 |
| MANSA |  |  | .179 | .954 |
| WEMWBS |  |  | .093 | .730 |
| INSPIRE Support |  |  | -.001 | .996 |
| INSPIRE Relationships |  |  | .008 | .946 |

Model 4 was the best fit to the data. Within all models, there was no effect of intervention group on the QPR. Within Model 4, which was the best fitting model, the only significant predictor of endpoint recovery scores (QPR) was baseline recovery scores.

Table 54 presents the effect of each variable on CSQ. Bold indicates p<0.1.

### Table 54 Secondary Outcome Evaluation sub-study: adjusted models for CSQ (n=78)

| **Measure** | **Coefficient (Model 1)** | **p-value** | **Coefficient (Model 2)** | **p-value** | **Coefficient (Model 3)** | **p-value** | **Coefficient (Model 4)** | **p-value** |
|---|---|---|---|---|---|---|---|---|
| Intervention | .093 | .946 | -2.394 | .068 | -3.347 | **.009*** | -3.317 | **.001** |
| Baseline CSQ | | | .660 | **.000** | .537 | **.000*** | . 423 | **.003** |
| **Socio-demographic variables** | | | | | | | | |
| Age | | | -.062 | .237 | -.019 | .721 | .117 | **.017** |
| Borough | | | -1.789 | **.015** | -2.332 | **.001** | -.203 | .702 |
| IQ | | | .0324 | .445 | .0464 | .224 | .145 | **.000** |
| Gender | | | .565 | .605 | 1.616 | .103 | 5.380 | **.000** |
| Employment | | | -.162 | .942 | 1.395 | .533 | -1.327 | .345 |
| Education | | | 1.275 | .437 | .222 | .892 | .9473 | .462 |
| Relationship status | | | 1.535 | .374 | 2.673 | .113 | 4.394 | **.000** |
| Accommodation | | | -1.092 | .217 | -.971 | .259 | -.164 | .787 |
| **Clinical variables** | | | | | | | | |
| Time in services | | | | | -.076 | .239 | -.268 | **.000** |
| CANSAS-S Met | | | | | .214 | .118 | .147 | .117 |
| CANSAS-S Unmet | | | | | -.346 | **.055** | .329 | **.047** |
| BPRS | | | | | .133 | .105 | .193 | **.000** |
| HoNOS | | | -.089 | .493 | -.021 | .889 | -.046 | .662 |

|  |  |  |  |  |
|---|---|---|---|---|
| CANSAS-P Met | .166 | .423 | -.0522 | .744 |
| CANSAS-P Unmet | .368 | .182 | -.0527 | .794 |
| Hospital admission | -.073 | .974 | -.764 | .594 |
| **Recovery variables** |  |  |  |  |
| QPR |  |  | .083 | .122 |
| HHI |  |  | -.278 | **.014** |
| MHCS |  |  | -.085 | **.032** |
| MANSA |  |  | 3.788 | **.000** |
| WEMWBS |  |  | -.146 | **.013** |
| INSPIRE Support |  |  | .006 | .830 |
| Relationships |  |  | .082 | **.005** |

Model 4 was the best fit to the data. In three out of the four models (Models 2-4), when controlling for the effects of the included covariates, the intervention had a negative effect on satisfaction. The effect of the intervention ranged from reducing satisfaction by 2.4 points (Model 2) to 3.3 points (Model 3). The effect of the intervention on satisfaction was opposite to what was hypothesised. The results of the regression analysis were inconsistent with the mean values which indicated no significant difference in satisfaction between the intervention and control groups at endpoint (mean = 24.5 (4.5) and 24.4 (5.2) respectively). One explanation for this negative finding may be over-fitting of the regression model. Within regression analyses, increasing the number of covariates relative to the number of observations can inflate the coefficients and their related significance. In such cases where over-fitting occurs, the model explains random error and minor fluctuations in the data instead of true underlying effects. In an over-fitted model, the explanatory power of each variable will be low. To test this, the variance explained by the Intervention in Model 4 was calculated. The amount of variance explained by the intervention variable was less than 1%. This suggested that the significant negative effect of the intervention on satisfaction was an artefact of model over-fitting.

### Discussion

Two hypotheses were tested in the REFOCUS trial: that the intervention would lead to significant improvements in personal recovery (Hypothesis 1) and satisfaction with services (Hypothesis 2) as compared to standard care. One hundred and ten individuals were included in the trial. The results indicated that the intervention had no effect on either primary outcome. Possible reasons for this finding are similar to explanations for the main outcome study, reported in Chapter 6.

## Outcomes Comparison sub-study

### Introduction

Objective 4 for the REFOCUS trial was to investigate the relationship between clinical and recovery outcomes. Empirical research in the field of personal recovery is at an early stage of development and the unpredictability of outcomes, with or without treatment, suggests that finding simple associations between these factors may be difficult. It may be that approaches which use multiple sources to conceptualise the different aspects of recovery are needed and this fits with qualitative research indicating that recovery can occur in three domains (biomedical, psychological and social) and can be complete or partial[348]. The small evidence base indicates that clinical and recovery measures assess different aspects of outcome.

The aim of this study was to investigate the relationship between clinical outcomes (which relate to illness and deficit amelioration) and recovery outcomes (which relate to subjective experiences such as hope and empowerment). Objective 1 was to identifying groupings of outcome domains. Objective 2 explored how the identified groupings change over time. Objective 3 was to identify the most informative standardised measure for each grouping.

### Methods

Data from the REFOCUS trial were used. To examine the underlying relationship of the various recovery measures (Objective 1), we conducted an exploratory factor analysis (EFA) with Promax rotation in Mplus 7.2. This approach allowed us to reduce the number of measures of interest into a smaller number of factors to be used in the analysis. We assessed the fit of our model to the data with three goodness-of-fit indices: chi-square ($p>.05$), Root Mean Square Error of Approximation (RMSEA<.06) and the Standardised Root Mean Square Residual (SRMSR <.06). Change scores were calculated subtracting baseline from follow-up scores. Correlations across change scores were analysed using Stata 11.

To investigate change over time (Objective 2), we conducted a confirmatory factor analysis (CFA) on baseline and follow-up data using Mplus 7.2, to compare construct means across these two time points. Prior to conducting the CFA, we tested for measurement invariance to establish whether factor loadings and thresholds were equivalent across time points, which would justify further comparisons. We initially tested an unconstrained model where none of the parameters were fixed to be equal at the two time points (i.e. configural invariance), and then compared this model to a model with a) factor loadings (metric invariance) and b) loadings and intercept (scalar invariance) fixed across time. Measurement invariance was established if (a) the constrained model offered a good fit to the data (defined using model fit indexes: chi-square>.05, RMSEA<.06, Comparative Fit Index (CFI) >.95; and (b) the difference of model fit between the constrained and the unconstrained models was small (ΔCFI<.01, RMSEA<.015).

To identify the most informative measures (Objective 3), we explored Cronbach's alpha coefficients associated with each recovery grouping extrapolated by the EFA, in order to assess their internal consistency and hence to identify the measure that best captures each domain. We assessed the alpha value obtained removing each measure one at the time, and the correlation of each measure with their counterparts (i.e. average inter-item correlation). A reduction in Cronbach's alpha and correlation coefficients, once the measure is removed from the dimension, indicates that the domain describes the dimension and hence is a good fitting measure. This was achieved using the alpha command in Stata 11 with the 'item' and 'std' option, to account for the fact that measures are in different scales.

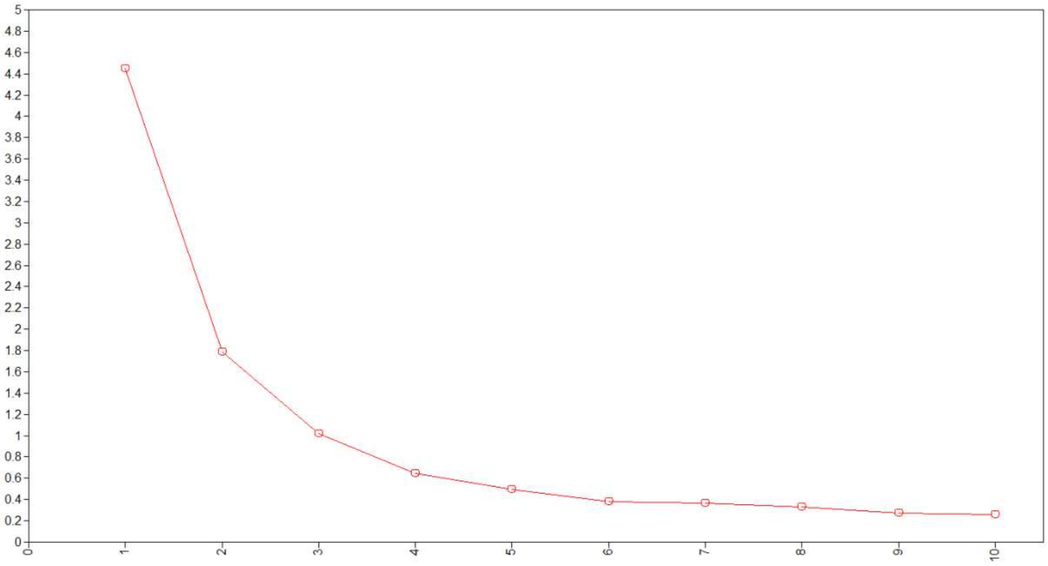
### Results

The sample included 403 service users, of whom 258 (64%)% were male, 309 (77%) single and 210 (53%) white British. The level of education achieved was no qualification or GCSE n=206 (52%), versus A-level or higher qualification n=192 (48%). Mean age was 44 years (s.d. 11) and mean total use of mental health services at time of trial was mean 16 years (s.d. 11).

*Objective 1: Outcome domain groupings*

The loadings of the INSPIRE Support and Relation subscales did not substantially load on one factor but, rather, loaded onto separate factors. Thus, the EFA was performed again after excluding those scales. The scree plot in Figure 17 indicates that three factors had eigenvalues greater than 1.

**Figure 17 Outcomes Comparison sub-study: scree plot graphing eigenvalue against the factor number**



The 3-factor solution offered a better fit to the data (chi$^2$(18)=30.9, p=.004; RMSEA=.04; 90%CI: .01 to .07; SRMSR=.02) compared to 1-factor (chi$^2$(35)=453.5, p<.001; RMSEA=.17; 90%CI: .16 to .19; SRMSR=.14) and 2-factor (chi$^2$(26)=162.3, p<.001; RMSEA=.11; 90%CI: .10 to .13; SRMSR=.06) solutions.

Table 55 shows the factor loadings on the three factors, and their interpretation.

**Table 55 Outcomes Comparison sub-study: promax rotated loadings on the 3 factors**

| | **Factor 1** | **Factor 2** | **Factor 3** |
|---|---|---|---|
| Interpretation | Patient-rated personal recovery | Patient-rated clinical recovery | Staff-rated clinical recovery |
| QPR | **.75** | .10 | .04 |
| HHI | **.93** | -.18 | .03 |
| MANSA | .43 | **.47** | -.08 |
| MHCS | **.78** | .12 | -.04 |
| WEM | **.80** | .05 | .04 |
| BPRS | -.08 | **-.58** | -.04 |
| GAF | .04 | .03 | **.72** |
| HONOS | -.02 | .11 | **-.89** |

| | | | |
|---|---|---|---|
| CANSAS-P unmet needs | .08 | **-.88** | .03 |
| CANSAS-S unmet needs | .07 | -.15 | **-.54** |

Bold p<0.05

The correlation between change scores of individual outcomes from each grouping were calculated. These are exploratory analyses but due to the large number of correlations, we used a conservative level of significance (p<.001). Pairwise correlations between change scores are shown in Table 56.

## Table 56 Outcomes Comparison sub-study: correlation matrix of the difference scores

| | **Patient-rated measures** | | | | | **Staff-rated measures** | | | |
|---|---|---|---|---|---|---|---|---|---|
| | QPR | HHI | MHCS | WEMWBS | MANSA | BPRS | CANSAS-S | GAF | HONOS |
| **FACTOR 1: PATIENT-RATED PERSONAL RECOVERY** | | | | | | | | | |
| HHI | **0.49** | | | | | | | | |
| | **p<.001** | | | | | | | | |
| MHCS | **0.43** | **0.45** | | | | | | | |
| | **p<.001** | **p<.001** | | | | | | | |
| WEM | **0.40** | **0.41** | **0.52** | | | | | | |
| | **p<.001** | **p<.001** | **p<.001** | | | | | | |
| **FACTOR 2: PATIENT-RATED CLINICAL RECOVERY** | | | | | | | | | |
| MANSA | **0.41** | **0.32** | **0.35** | **0.42** | | | | | |
| | **p<.001** | **p<.001** | **p<.001** | **p<.001** | | | | | |
| BPRS | -0.19 | -0.16 | **-0.25** | -0.17 | **0.32** | | | | |
| | p=.003 | p=.01 | **p<.001** | p=.006 | **p<.001** | | | | |
| CANSAS-P | -0.08 | -0.04 | -0.22 | -0.14 | **-0.24** | **0.29** | | | |
| | p=.20 | p=.54 | p<.001 | p = .02 | **p<.001** | **p<.001** | | | |
| **FACTOR 3: STAFF-RATED CLINICAL RECOVERY** | | | | | | | | | |
| GAF | 0.09 | 0.12 | 0.15 | 0.17 | 0.17 | -0.17 | -0.14 | | |
| | p=.18 | p=.09 | p=.03 | p=.01 | p=.01 | p= .01 | p=.03 | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| HONOS | -0.05 | -0.05 | 0.01 | 0.01 | 0.03 | 0.17 | 0.04 | **-0.43** | |
| | p=.45 | p=.43 | p=.84 | p=.89 | p=.62 | p=.02 | p = .52 | **p<.001** | |
| CANSAS-S | 0.01 | -0.02 | -0.01 | -0.06 | -0.03 | 0.03 | **0.23** | **-0.29** | **0.31** |
| | p=.92 | p=.74 | p=.86 | p=.35 | p=.69 | p=.64 | **p<.001** | **p<.001** | **p<.001** |

Bold = p<0.001

Overall, results indicate that change scores within each dimension were correlated.

*Objective 2: Change over time*

To ensure the factor structure is consistent over time, and therefore that confirmatory factor analysis can be calculated by constraining the loadings and thresholds to be equal, measurement invariance was tested, shown in Table 57.

**Table 57 Outcomes Comparison sub-study: goodness-of-fit for different levels of measurement invariance**

| | $\chi^2_{(df)}$ | **df** | **Scaling Correction Factor** | **CFI** | **SRMR** | **RMSEA (90%CI)** |
|---|---|---|---|---|---|---|
| Configural | 274.4 | 145 | 1.00 | 0.97 | 0.042 | .047 (.038 to .056) |
| Metric | 285.4 | 152 | 1.00 | 0.97 | 0.048 | .047 (.038 to .055) |
| Scalar | 330.0 | 160 | 1.04 | 0.96 | 0.052 | .051 (.043 to .059) |

As measurement invariance was present, we compared means across time while holding factor loadings and thresholds equal across time points. We applied a Bonferroni adjustment for 3-pairwise comparisons to account for multiple testing. Service users reported higher scores at follow-up than baseline on factor 1 (z=3.1, p=.002; ES=.13) but no difference was observed for factors 2 (z=0.6, p=.58; ES=.04) or factor 3 (z=1.7, p=.09; ES=.11).

*Objective 3: Choice of standardised measure*

Reliability of the factors and the effects of deleting individual measures from the factor are shown in Table 58.

**Table 58 Outcomes Comparison sub-study: reliability of complete and measure-deleted factors**

| | ***n*** | **Cronbach's Alpha within factor** | **Inter-measure correlation within** |
|---|---|---|---|

|  |  |  |  | **factor** |  |
|---|---|---|---|---|---|
|  |  | *All measures* | *Measure deleted* | *All measures* | *Measure deleted* |
| ***Factor 1: Patient-rated personal recovery*** |  | .90 |  | .69 |  |
| QPR | *399* |  | .87 |  | .69 |
| HHI | *385* |  | .87 |  | .69 |
| MHCS | *380* |  | .87 |  | .68 |
| WEMWBS | *388* |  | .86 |  | .68 |
| ***Factor 2: Patient-rated clinical recovery*** |  | .75 |  | .50 |  |
| MANSA | *384* |  | .67 |  | .51 |
| BPRS | *378* |  | .71 |  | .54 |
| CANSAS-P | *390* |  | .61 |  | .44 |
| ***Factor 3: Staff-rated clinical recovery*** |  | .76 |  | .52 |  |
| GAF | *379* |  | .66 |  | .49 |
| HoNOS | *378* |  | .60 |  | .43 |
| CANSAS-S | *346* |  | .78 |  | .63 |

All factors have good internal consistency. For factor 1 (Patient-rated personal recovery), all measures were good indicators. Taking the factor loadings from the EFA shown in Table 55 into account, the HHI has the highest loading and therefore is most strongly associated with the factor. For factor 2 (Patient-rated clinical recovery), Table 58 indicates that exclusion of CANSAS-P unmet needs was associated with a decreased Cronbach's alpha (α = .61) and average inter-item correlation (r = .44), and therefore the best indicator of the factor. Finally, for factor 3 (Staff-rated clinical recovery), HoNOS was for the same reasons the best indicator.

## Discussion

This study compares patient-rated and staff-rated outcomes over one year. Factor analysis of baseline data produced three factors. Factor 1 – interpreted as Patient-rated personal recovery – comprised four patient-rated measures of recovery, empowerment, wellbeing and hope. Factor 2 – interpreted as Patient-rated clinical recovery, comprised two patient-rated measures of health-related quality of life and unmet need, and a researcher-rated measure of symptomatology. The BPRS has been included in a factor labelled patient-rated clinical recovery because, unlike the other staff measures, it is not rated by the staff member but by the researcher, on the basis of responses from the service user, and so is likely to reflect the service user's views on their symptomatology. Factor 3 – interpreted as Staff-rated clinical recovery – comprised staff-rated measures of unmet needs, social disability and functioning. Factor 1 changed over one year, whereas factors 2 and 3 did not. The optimal measures spanning the three factors are HHI, CANSAS-P and HoNOS.

The development of three rather than two factors in this analysis was unexpected, and further demonstrates the complexity of the concepts under consideration: the generation of a patient-rated clinical recovery factor suggests that although staff and service users have differences in their perception of the level and type of morbidity, there is some overlap and it is meaningful to consider the service user's own view of morbidity and their stage of recovery. This argues against a simplistic view of the relationship between staff and service user ratings. Previous research has shown better agreement between staff and service users on assessing need in domains with defined service response, than those such as intimate relationships[349]. Generally the number of needs identified by staff and service users is broadly similar, with a tendency for staff to identify slightly more needs, but the domains of need identified can differ substantially. Other studies have shown a relationship between patient-rated unmet need and quality of life measures[350] and in a follow up study found that patient-rated unmet need and changing levels of unmet need predicted quality of life[351]. Clinical ratings failed to have a predictive relationship. Our finding supports the value of concurrently assessing staff and service user perceptions of morbidity and need. The Patient-rated personal recovery and Staff-rated clinical recovery factors related well to the concepts of personal and clinical recovery, giving further support to the validity of these concepts. Assessing service user and staff perspectives on clinical recovery alongside patient-rated assessment of personal recovery can be recommended for future mental health research.

Service users reported higher scores at follow-up than baseline on only the Patient-rated personal recovery factor. The lack of change in Factors 2 and 3 provides empirical support for evidence of a desynchrony between clinical and recovery outcomes, hence supporting the finding from the conceptual framework for recovery that clinical and personal recovery are not the same[8]. Recent UK Health policy encourages a focus on personal recovery[352] and based on these findings, interventions intended to promote clinical recovery may not be optimal or sufficient to achieve this. The scope of interventions in standard mental health practice may need to be extended[108].

The possibility of a trade-off between symptom reduction and recovery has been proposed[353]. The findings in this analysis were again interesting and unexpected. We found that changes in the recovery measures were positively correlated with each other, which gives further validation of these ratings as a group, relating to an individual’s recovery. We were interested that the change scores of measures from the personal recovery factor were correlated significantly with the BPRS scores, i.e. that as researcher-rated health and social functioning improved, ratings of personal recovery made by the service user also improved. This argued against a trade-off between personal recovery variables and clinical ratings. In this population studied, it appeared that as service users recovered clinically, their sense of empowerment and hope also improved, suggesting alignment between previously postulated stages of personal recovery and clinical recovery.

The changes in wellbeing scores between baseline and follow up showed significant relationships with global assessments of functioning. The research into wellbeing and the changes in personally defined wellbeing over time is at an early stage of development and such findings add to the view that wellbeing is potentially an important variable to consider as an outcome measure. The CANSAS service user ratings of unmet need were positively correlated with BPRS and GAF changes, indicating that such variables are measuring complex, overlapping constructs.

There are a number of limitations which arise from the design of this study. The study population was limited in size, but appears reasonably representative of service users receiving specialist mental health services in the UK. Participants were undergoing a recovery intervention as were staff so this may have had an impact, particularly in terms of the longitudinal ratings. The findings need to be replicated, ideally in broader populations and including service users with less severe mental health problems. The use of empirical measures of recovery is at an early stage but we believe this may provide important new understanding of the service user experience, in keeping with the increasing importance of recovery-based approaches in mental health services.

It would be reasonable to recommend one scale from each factor in research and routine clinical practice. Based on our data, the measures with the highest factor loading in each area were HHI, CANSAS-P and HoNOS. A further advantage of this suggestion is the use of scales which capture both staff and service user ratings, as there is evidence to suggest that failure to capture the service user's own assessment is problematic[349]. Previous research recommended the use of a global severity measure with CANSAS and HoNOS to provide a detailed characterisation of the service user[37], and our results are broadly comparable although we have highlighted the value of an additional measure focusing on personal recovery.

The study has three implications. First, clinical and personal recovery differ, so research and practice into 'recovery' should make clear which version is the focus. Second, service users and staff have independent perspectives on clinical recovery, and service users have differing perspectives on clinical and personal recovery. This complexity needs to be reflected in health service research designs, and in routine outcome assessment. Third, HHI, CANSAS-P and HoNOS emerge as the most informative measures to use in research and clinical practice.

## Chapter 9: Knowledge transfer

The final module in the REFOCUS programme was on knowledge transfer. We aimed to maximise the dissemination and implementation of the REFOCUS research to diverse audiences of stakeholders. The stakeholder groups we focused on were those in the areas that map on to our objectives, namely people and organisations with general interests in healthcare and/or specific involvement in recovery programmes, policy and research. Since recovery research involves a strong focus on subjective experience, people who use services, including those who participated in our studies, were an important audience for our work.

Our knowledge transfer activities fall into two broad categories: sharing our research (dissemination) and supporting uptake of our research (implementation). In this chapter we describe some of our knowledge dissemination activities. In Chapter 11 we outline national and international implementation of findings from the REFOCUS programme.

### Knowledge dissemination

The following study outputs were directed to either a scientific, mixed or research participant audience.

### 1. International scientific knowledge transfer events

We organised three '*REFOCUS on Recovery*' knowledge transfer events, in 2010, 2012 and 2014. Attendees at these events included mental health service users, carers, workers, managers, researchers and system leaders. *Refocus on Recovery 2010* involved 168 master class participants and 509 participants from 23 countries. Key-note speakers were Simon Bradstreet, Marianne Farkas, Lynne Friedli and Lindsay Oades. *Refocus on Recovery 2012* involved 181 masterclass participants and 343 participants from 18 countries. Key-note speakers were Peter Beresford, Mary O'Hagan, Nic Marks and Mark Ragins. *REFOCUS on Recovery 2014* involved 400 participants from 23 countries. Keynote speakers were Terry Bowyer, Tom Craig, Sonia Johnson, John Larsen, Mary Leamy, Nick Manning, Alison Mohammed, Phil Morgan, Lindsay Oades, Lord Patel of Bradford, Julie Repper, Liz Sayce, Geoff Shepherd, Mike Slade, Alessandro Svettini, Kenneth Thompson, Graham

Thornicroft, Samson Tse and Jan Wallcraft. *REFOCUS on Recovery 2014* had a twitter account [@REFOCUS2014], which was tweeted from 254 times and has 468 followers. The event was also featured on the King's College London website.

### 2. Website

In 2009 we developed the Section for Recovery website (www.researchintorecovery.com), which contained updated webpages disseminating information about the REFOCUS programme. The website was redeveloped in January 2014, and attracts about 2,500 new visitors each month.

### 3. Recovery Research Network

The Recovery Research Network was established by the REFOCUS PI in 2009, and by 2015 has grown to 395 members. Monthly email updates are used to disseminating information about the REFOCUS programme and other studies between members, and the network meets every six months.

### 4. Training manuals

The *REFOCUS manual* was published as a free-to-download PDF by the mental health charity Rethink in 2011[171]. It was translated and published in Icelandic and Italian. The second edition updated this manual, and was also published by Rethink Mental Illness as a free-to-download PDF in 2014[354]. We also collaborated with our coaching trainers to develop *Coaching for Recovery* manuals for participants[189] and trainers[190].

### 5. Public summaries

With input from LEAP, we developed a summary for the public of the REFOCUS programme[355]. This is to be sent to all staff and service user participants in the REFOCUS trial.

### 6. Academic publications

At the time of writing, the REFOCUS team have published 15 peer reviewed papers directly arising from the REFOCUS programme, with a further 8 papers in submission and 8 in preparation.

## 7. Conference presentations

We have presented our work at conferences and other events in Australia, Canada, England, Germany, Hong Kong, Italy, Norway, Portugal and Spain. We made a total of 39 conference presentations (32 oral and 7 posters).

# Chapter 10. Patient and Public Involvement

## Introduction

This chapter was co-produced between members of the Lived Experience Advisory Panel (LEAP) and the REFOCUS researchers. The authors are Trivedi P, Leamy M, Chandler R, Slade M, on behalf of REFOCUS LEAP and REFOCUS researchers.

Public and Patient involvement (PPI) in the REFOCUS programme was characterised by active consultation and collaboration with people with lived experience of using mental health services, either as service users and/or carers[356]. Many of the ideas and concepts of recovery have emerged from these experts by experience, and the mental health system has sometimes been criticised for co-opting or commandeering the recovery approach. One aim of REFOCUS was therefore to place more importance on the crucial knowledge and expertise that service users and carers bring, in an attempt to maintain the integrity of recovery as 'nothing about us without us'. In co-producing this chapter, we have ensured that service user / carer involvement has been proactively extended from the research study into the methodology of compiling this report.

This chapter outlines how PPI was structured within the REFOCUS programme, its beneficial impact, the challenges that arose, and lessons learnt, concluding with recommendations for conduct of PPI in similar studies.

## Methodology

In the final LEAP meeting, the study team submitted a first draft of this PPI chapter for LEAP to review. However, in order to achieve balance in 'interpretative agency'[357] (that is the authorial power to name what is important and what is not from the perspectives of both the study team and PPI participants) a decision was made to work more collectively, embedding a recovery-orientated commitment to co-producing this report on PPI in REFOCUS. We used the following methodology:

- Reflections on PPI were submitted by the Principal Investigator (PI), 3 researchers from the ST (Res1, Res2, Res3), the Chair of LEAP (Chair) and 5 members of leap (LEAP1, LEAP2, LEAP3, LEAP4, LEAP5)

- 2 LEAP members then substantially revised the report structure originally submitted by the study team, using the submitted reflections, informal correspondence and publications to organise the themes of this chapter. 2 members added reflections during this iterative process.
- In order to represent the various views re PPI in this study, the benefits and challenges of PPI were illustrated using relevant quotes from individual reflections.
- Lessons learnt were then summarised, and recommendations for PPI in similar studies formulated
- The PI then reviewed and revised the chapter to maximise coherence with the rest of the final report
- The chapter was then sent to all authors for final comments and approval.

### How PPI occurred in REFOCUS

PPI in the REFOCUS programme occurred in various ways, most notably through input from the Lived Experience Advisory Panel (LEAP). The LEAP was established after the start of the REFOCUS programme, in response to increased demand for service user and carer input into the programme. LEAP was one of five advisory groups set up within the structure of the study. 4 mental health service users, one carer and one service user who was also a carer, were actively involved in LEAP during the course of REFOCUS. Each had a specific interest in research and recovery.

LEAP met as a group 9 times over the study period (median number at each meeting 4, range 2-5). Additionally, some LEAP members met with members of the research team on two occasions, first to provide consultancy around the INPIRE questionnaire and second to provide researchers with training for interviewing service users who experience psychosis. To facilitate cross-panel discussions, two representatives from LEAP were also members of the International Advisory Board.

The Head of Evaluation and Research at Rethink Mental Illness both chaired and facilitated these meetings and acted as a crucial bridge between LEAP and the REFOCUS team. All LEAP meetings (except the last ) were held at Rethink central office, to provide a less power loaded space for discussion than the study team base at the Institute of Psychiatry. Each meeting lasted 5 hours, arranged around lunch to offer a relaxed social and networking opportunity within a formal structure. LEAP members were paid £150 per meeting plus travel. REFOCUS researchers including the PI attended all LEAP meetings, enabling the efficient two way transfer of information, comments, concerns and recommendations.

Most LEAP members engaged in mutually supportive correspondence and critical debate with each other, the Chair and PI between official meetings and through the Recovery Research Network. These less formal opportunities were invaluable in developing trust, breaking down unhelpful them/us oppositions and developing shared understanding of the research endeavour while holding differences in perspective respectfully within it.

Terms of reference for LEAP were established at the first meeting amidst some controversy. These identified the role of LEAP as an advisory body that would critically appraise information about the study and its progress, and bring to senior members of the research team the perspective and expertise of the group's lived experience. The LEAP terms of reference were:

1. To voice lived experiences (from people with personal experience of mental illness & of caring) and specialism relevant to the study throughout the REFOCUS study
2. To provide a forum where diverse perspectives & views can be shared in an open, constructive & non-judgemental manner
3. To be a critical friend providing lived experiences for the study to contribute to its methodological refinement, quality & impact
4. To share lived experiences of recovery & how these may contribute to research on recovery-orientation in services
5. To share lived experiences & knowledge of engaging with mental health services as a service user or carer & how this knowledge may contribute to research on recovery-orientation in services
6. To identify important issues that cannot be encompassed in the REFOCUS study design

7. To promote & disseminate the study in a wider context in collaboration with researchers
8. To advise on how emerging findings from the study may be most effectively presented & disseminated to foster a recovery-orientation in mental health services
9. To contribute to dissemination to a wide range of stakeholders.

In keeping with PPI on most NIHR funded studies, LEAP had no formal decision making power. However, to avoid tokenism and to develop a mutual learning encounter, LEAP asked the PI to document recommendations made by Leap, how they were responded to and the reasons for each response. Monitoring PPI in this way during the first seven months of the study gave valuable case study evidence for the impact of PPI, and was published as a study output[173].

PPI also occurred in other ways.

- Two senior researchers from Rethink, an organisation that advocates for service users and carers, were also substantially involved – one contributed to development of the REFOCUS proposal and was a co-applicant, and the other chaired the LEAP group
- The International Advisory Board, which met annually in the early years of the study, included people with lived experience
- Representatives from Southside Partnership Fanon Care (an organisation which provides mental health services to African and African Caribbean people) and the Afiya Trust (a national charity working to reduce inequalities in health and social care provision for people BME communities) and service users from black backgrounds were involved in the REFOCUS virtual advisory panel
- All recruitment advertisements for REFOCUS posts listed personal experience of mental health problems as a desirable characteristic in the person specification
- One service user researcher was recruited on two 12 week casual employment contracts, to co-facilitate service user focus groups, attend research team meetings and inform development of INSPIRE
- One full-time REFOCUS researcher was appointed, who identified themselves as a person with personal experience of using mental health services and drew

reflexively on these experiences when designing and undertaking the research. At least one REFOCUS researcher had personal experience of supporting someone close to them who had mental ill health, but did not take an explicit PPI or carer led research role. We believe that these researchers are likely to have used their direct experiences in ways that were beneficial to the PPI and recovery dimensions of the programme.

### Where PPI occurred in REFOCUS

The different forms of PPI occurred at various points in the study, as shown in Table 59.

**Table 59 PPI input to REFOCUS sub-studies**

| Sub-study name | Type of PPI |
|---|---|
| Conceptual Framework | Narrative synthesis: LEAP involved in expert consultation stage of narrative synthesis of included papers<br>Validation with current service users: LEAP feedback on interview and focus group topic guides |
| National Survey | Service user participants were offered the option of participating in a telephone or face to face interview with service user researcher |
| Staff Perceptions | LEAP feedback on interview and focus group topic guides |
| Framework For Black Service Users | LEAP feedback on interview and focus group topic guides. Service user researcher co-facilitated focus groups. Virtual advisory panel gave feedback on emerging framework. |
| Intervention Development | Consultation meeting with LEAP on plans for the intervention, implementation strategy and comments on drafts of the manual |
| QPR Validation | LEAP feedback on Information Sheet and Consent Form |

| | |
|---|---|
| INSPIRE Development | Service user researcher employed to develop items for INSPIRE from conceptual framework. Consultation meeting with LEAP to comment on initial draft. |
| IOM Development | Consultation meeting with LEAP on initial options for individualised outcome measures and goal-setting |
| REFOCUS trial | LEAP provided interview training to researchers. REFOCUS service user researcher involved in trial data collection, entry, checking, data cleaning, costing of the intervention. |
| Staff Process Evaluation<br>Service User Process Evaluation | LEAP feedback on staff and service user interview and focus group topic guides. REFOCUS service user researcher involved in analysis of service user focus group and interview transcripts, and co-lead author for service user process evaluation paper. |

**Beneficial impact of PPI**

> *Being involved in REFOCUS has been challenging but also beneficial in many ways. It has given me the incentive and need to consider in greater depth ideas of recovery and the way in which they are being applied in mental health services, and also enabled me to recognize more clearly my own personal journey towards recovery (which was happening well before 'recovery' became such a buzzword in mental health). I'm still critical, but it's been very positive to feel I could (sometimes) be this way and be heard and responded to, even within the unequal power relations inevitably inherent in Refocus.*
>
> [LEAP5]

PPI brought many benefits to REFOCUS, both for the study as a whole and for individuals involved. The benefits of PPI fell into three broad categories:

1. Tangible benefits for the study, which were pre-planned and intended
2. Intangible benefits which were harder to pin down precisely, and often came about as a result of having to address challenges which arose during the course of the study

3. Personal and professional benefits for individuals involved in the study.

### Tangible benefits

#### a) Acting as a 'critical friend'

> *I think it was very important to have the voice of LEAP, especially at the beginning of the project when important decisions were being made.*
>
> [Res2]

> *We had a discussion about how to recruit members to the LEAP, and we decided to approach people with personal experience who had also a keen interest in or prior experience of research involvement. This was because we wanted the LEAP to be in a position to engage with the research study in a way that could offer a critical perspective on this, from a perspective of constructive dialogue. This later became formulated as the 'critical friend' approach.*
>
> [Chair]

> *We wanted to have a critical dialogue with those with lived experience and experts in research, so developing a critical friendship model of involvement was important. It was both challenging and rewarding, and helpful in lots of ways, not least identifying biases and assumptions in the research team.*
>
> [PI]

> *My decision to get involved was based on the word 'critical' in the terms of reference for LEAP. On reflection, it has been a credit to the study team that they have been open to the critical friendship approach which embeds recovery orientated practice into the way we do research.*
>
> [LEAP2]

#### b) Instigating the use of the Recommendations Grid

The PPI Impact sub-study[173], which used the Recommendations Grid, is described later in this chapter.

> *At its first meeting, LEAP asked the study team to keep an involvement log of advice given and action taken. The purpose behind this was originally to reassure LEAP that advice given post design was not tokenistic, but it also made it possible to document the impact of our involvement in the set up phase. This and the impact of other forms of advice given to REFOCUS were published as a study output.*
>
> [LEAP2]

> *At the outset, we wanted to demonstrate that we were genuinely receptive to ideas and suggestions. We did this by recording of recommendations from all our advisory groups and independent experts and reasons for all our research decisions in the first six months of the study and regularly feeding back to advisors, which I felt was innovative and worthwhile. In my opinion, however, if we had continued this exercise throughout the study, other things in the programme would have suffered.*
>
> [Res1]

> *Another innovative idea was the production of the 'Recommendations Grid' … It showed that our comments were valued and had or had not been acted upon and in some cases the reason why.*
>
> [LEAP4]

> *The recommendations grid was a brilliant idea, and something I have not seen used in such a comprehensive and systematic way before. It really helped to show cynics like myself how our advice and recommendations were being responded to and, in about 50% off cases, had an impact on the research study.*
>
> [LEAP5]

> *One mechanism to address concerns about tokenism was to record recommendations and actions taken in order to map the impact and influence of involvement.*

[PI]

### c) Improving the study design

> *The study design was improved through a closer match with the community's needs and interests., e.g. LEAP made the case for culture and ethnicity to be a focus of the research, and this was implemented through extending the study in a number of ways.*

[PI]

> *Having to consider methodology more critically. I believe there is room for LEAP to point to revisions, refinements and alterations and expect the possible to be actioned. Our usefulness is to raise some of the questions that might not be immediately visible for people with little or no experience of being on the receiving end of oppressive practices. In this sense, the work of LEAP could be strategically programmatic not just in REFOCUS but in terms of influencing future projects.*

[LEAP2]

### d) Reviewing and improving recruitment materials and questionnaires

> *I enjoyed very much the practical exercises which LEAP was asked to engage in, e.g. contributing: ideas for the road shows, reviewing recruitment materials, compiling and commenting on the service user questionnaires about their views on their treatment and their recovery progress. Such exercises drew on not only my experiences of recovery from psychosis but also on my practical experiences of service user involvement and sales and marketing experience.*

[LEAP1]

### e) Contributing to the development of CHIME, INSPIRE and the REFOCUS intervention

> *LEAP was heavily involved in the development of CHIME.*

[LEAP2]

*LEAP identified that the planned approach to goal setting in the intervention should be altered to allow people to change their minds over time about their personal goals.*

[PI]

*I had a meeting with 4 LEAP members (and email contact with one other) to consult with them on the development of INSPIRE. This proved extremely helpful in shaping INSPIRE; all members were constructively critical and I appreciated the time and energy they were able to give with this.*

[Res2]

*I felt that there were some meetings in which I had some 'real say'.. The INSPIRE programme, enabled LEAP members to discuss the layout and questions used in the Inspire questionnaire intended for service users. I particularly liked the way in which they were written to include themes of hope, identity, connectedness, meaning and purpose, themes which are often seriously neglected in the day to day care of someone with a mental illness…The second area in which I felt confident to contribute more fully, was towards the plans for the delivery of the Rethink Recovery Training Programme. These were written in a similar way to a lesson plan, my teaching background came into good use here.*

[LEAP4]

### f) Providing training to researchers about interviewing service users

*We asked LEAP members to design and run a half day training course on interviewing people with psychosis for our trial research teams, which was extremely valuable and in hindsight, I wish we'd done it earlier.*

[Res1]

*The training workshop, helped to 'inform' researchers of the difficulties faced by people with psychosis. It included practical exercises and, these received a positive response from researchers. I felt this was an excellent way of passing on valuable lived experiences. This would have benefited from being*

> *implemented slightly earlier in the project.*
>
> [LEAP4]

> *Being asked to deliver the training session indicated our experience was valued; The training itself gave us a really valuable opportunity to link up with some of researchers and this, for me, gave much more meaning to and understanding of each others perspectives and aims. Enabled building of mutual respect.*
>
> [LEAP5]

> *I found the training made me think more about how it feels to be interviewed, and to be aware of my role in this.*
>
> [Res2]

### g) Presenting paper about LEAP experiences of PPI

> *We presented findings from the impact of PPI Case Study at REFOCUS conference 2012. Myself and <researcher> also presented these outputs at INVOLVE 2012.*
>
> [LEAP2]

> *Preparing the REFOCUS conference presentation was very useful in enabling us to review what we had been doing in LEAP, the impact we had had on the study and how the process had been for LEAP, both as a group and as individuals.*
>
> [LEAP5]

### h) Drafting / feeding back, editing lay summary findings for this report

> *It's only right and proper that users/carers should be involved in writing up how they have been involved in research studies and how they felt about it, but this happens too rarely. It was good that REFOCUS researchers came to us with a draft of PPI chapter, but then allowed us to revamp it to how we felt it could better reflect the process and experience of PPI in this project.*

[LEAP5]

### i) Additional (unplanned) tangible benefits

> *REFOCUS was not able to address the gap on recovery for caregivers within budget. However, an unlooked for and indirect impact is that this gap inspired a book to be written on recovery for caregivers*[358] *as a platform for further research.*
>
> [LEAP2]

> *The contribution I found most sustaining at a personal level was the distinct intellectual space provided by LEAP, which differed from the academic settings I normally discuss studies in, and helped me to identify my implicit assumptions about what matters, how things are and how to advance knowledge*
>
> [PI]

> *Another indirect professional impact has been the development of LEAF (lived experience advisory forum) at Sussex Partnership Foundation Trust. It has been a credit to the study team that they have been open to the critical friendship approach which embeds recovery orientated practice into the way we do research.*
>
> [LEAP2]

### Intangible benefits

> *The input from LEAP also provided less tangible benefits, including bringing energy and a sense of the study mattering, fulfilling its role in being a critical friend by enhancing awareness of implicit beliefs, and overall making the process of the study more satisfying, even enjoyable. A final intangible benefit for the study was to challenge the idea that traditional methodologies could be imported without problem to researching recovery. Recovery-oriented research requires the capacity to hold difference between perspectives as part of its process, in order to avoiding over-simplified and formulaic*

*conclusions about the complex spectrum of recovery. In the study, these principles had to be balanced against the scientific requirements to remain pragmatic about what can be measured.*

[PI]

*'Whilst we have received many practical and insightful suggestions on specific research tasks (e.g. input into development of measures, interview guides, intervention manual, patient materials) from the LEAP members, the real benefits are much harder to pin down. We have been fortunate in having group of people, stayed with us through the ups and downs of the research process, and have tolerated long periods of silence from us. They have helped us develop and challenged our thinking, methods and overall approach, not been afraid to point out when they thought we were getting it wrong and insisted that we do things differently. We are very grateful to them.*

[Res1]

**Personal and professional benefits**

*Membership of LEAP has been overall a positive experience as it has drawn on both my theoretical views and practical experience of recovery from psychosis and I feel that these views have been appreciated and valued. I always felt that at the very centre of being involved with LEAP was keeping in focus what we meant by recovery – not just from my own personal recovery story but more universally.*

[LEAP1]

*REFOCUS has been a real learning journey in which I have changed professionally and personally. It did not get everything right in the beginning but this is part and parcel of a learning journey. I am still exploring philosophical questions about the methodological positioning of his research within an epistemological and ontological paradigm shift which I would not have thought of without his encounter.*

[LEAP2]

> *This is my first experience of research, having come from a clinical background I will take these experiences, and the wider experience of trying to involve service users meaningfully with me in my future research posts.*
>
> [Res2]

> *It was rewarding to be asked to input on such important research which is for the benefit of all service users. As a LEAP member I felt a great deal of responsibility in how I approached the meetings and discussions.*
>
> [LEAP1]

> *I have learnt a great deal about the research process. It has been a pleasure to work with such dedicated professionals and I have gained such a lot from this experience. I sincerely hope that the incredible amount of work done by all in this team will be used to help many people's lives change for the better in the future.*
>
> [LEAP4]

> *Personally, the biggest impact has been to become an active member of the Recovery Research Network in which service users, caregivers and researchers regularly meet and exchange views in a nurturing environment which still has critical teeth. It remains a privilege to 'belong' to this group.*
>
> [LEAP2]

> *I've learned a number of things I will do differently in the future, both from LEAP and from our other PPI initiatives, such as employing people with lived experience as researchers or consultants to the study. Overall, the principle of 'nothing about us without us' – partnering in research with people with lived experience — seems to me to be a core principle for ethically defensible science.*
>
> [PI]

### The challenges of PPI

PPI created many challenges, both for involved service users / carers and for researchers in this study. But in many ways this was intended by the research team.

> *Public involvement challenges researchers' values and assumptions, but in this study that was an intended goal and hence experienced as a positive rather than a negative experience.*
>
> [PI]

> *The purpose of setting up the LEAP group was exactly to draw in critical observations and raise them with the researchers on the REFOCUS study – hopefully in a way that would improve the quality and relevance of the study.*
>
> [Chair]

> *Given the scale of the study it is likely that findings from REFOCUS will have the potential to be noticed within a NHS policy and practice context, and it is important that findings are shaped and presented in a way that clearly acknowledges both its strengths and limitations. No study, no matter how large scale, can address everything. The way I see the role of LEAP is to draw on lived experiences and service user research expertise to point out these strengths and weaknesses.*
>
> [LEAP2]

### Challenge 1: The early days of PPI

There was a lively email correspondence even before the first LEAP meeting, and some people declined to be part of the group because of the strength of their feelings. Without doubt, major conceptual and personal challenges occurred for both researchers and service/user carers in the early days of Refocus.

> *I feel moved to express my amazement at the absence of service user involvement in the development of a study about an issue that is so fundamentally about a personal experience and a personal and individual journey: Recovery began as a user/survivor understanding of mental distress and a concept of re-definition of experience apart from services. Whilst I am indeed of the view that services need to be more 'recovery oriented' whatever*

*that means, it is extraordinary how professionally dominated this study is. Public involvement is restricted to the involvement of voluntary sector organisations, and whilst I do acknowledge <Chair's> efforts at getting service user/researchers involved, it is late in the day.*

[Prospective LEAP member who declined to be involved]

*The early days of REFOCUS were defined through controversy over the PPI. There had not been consultation with LEAP in design stage which upset some members. I have also spent some time thinking about the role of LEAP, especially as it has appeared so late in the day. My concern has been the amount of room for meaningful collaboration that can exist in a study whose research methodology was not constructed with service user consultation as part of its process. Not good methodological sense to simply add service user and stir!*

[LEAP2]

*I came to REFOCUS having previously involved the public in research within a study called Housing Decisions in Old Age. So I'm a convert, but I know how much determination and effort it takes for all involved to fully and effectively engage with non-researchers in a research study. Effective PPI needs the research team to have the capacity, energy, and determination to do it well, together with the resources of time and funds. Within the REFOCUS programme, I have always felt there was considerably less scope to be as ambitious in relation to PPI.*

[Res1]

*I found the helpfulness of LEAP input increased as my relationship with members deepened, highlighting to me that PPI needs to be integral not an add-on to a study design, and involves relationships which need nurturing. This points to the need for earlier involvement and PI commitment to the relationship.*

[PI]

### Challenge 2: Issues re methodology

> *The REFOCUS programme chose to use a research design building on a more positivist tradition that utilised RCTs and developed quantitative data. This felt very alien to the very nature of recovery, which seems to require a focus on the experience of the journey and the very individual nature of recovery. Some service users decided not to participate in LEAP as they felt the research was based on a perspective that was alien to most service users. Although the research team had some sympathy towards this viewpoint, they chose to focus on the positivist tradition of research as they felt it generated data that was more valid and the research would be more respected and meaningful. There seemed to be various discussions that focused on the type of data and the approach that such a programme would generate. The team listened at the start, but then focused very much on the approach they wished to take.*
>
> [LEAP3]

> *The absence of a guiding theoretical framework for synthesising multiple perspectives may have contributed to the burden for the research team in responding to LEAP recommendations. Service users and carers were asked to be involved in a research study that sought to use quantitative methods, including a randomised controlled trial, to investigate the experience of recovery. This caused ambivalence for people asked to join LEAP and to identify with REFOCUS, and some felt that this approach to recovery – framing deeply personal experiences in quantitative terms – alienated them from the recovery approach and the user values to which they aspired.*
>
> [PI]

> *I do reflect on the dissonance between the LEAP perspective and the direction of the research. I feel that often traditional forms of research, which although they subscribe to the need for service user involvement in mental health research, often disconnect from the tradition that they purport to support. Perhaps this is more to do with the nature of research and the nature of user involvement, rather than to this project.*

[LEAP2]

*Lived experience presents a different kind of value and a different kind of knowledge to that of ‘service led’ knowledge, and questions were raised whether insights arising from lived experience were compatible with the positivist scientific paradigm underpinning the research design. Incorporating lived experience perspectives often means that service users invest emotional commitment to research, which lends a different perspective to this process. Therefore, evaluation of research by service users may have a strong ethical investment, rather than solely being based on positivist scientific principles of methodological soundness. This underpinned much of the ambivalence. Bringing lived experience into dialogue with the study offered the potential to bring a different kind of knowledge.*

[PI]

*I can see that REFOCUS 'speaks the speak' of dominant research paradigms (which are pretty insensitive generally to issues of cultural difference, power, gender etc.) And, pragmatically, probably has had to speak this speak to secure funding from agencies that are just as blind to the politics of oppression that can inhere in research protocol. Sadly, however, it is this kind of 'speak', for all its shortcomings, that changes NHS practice.*

[LEAP2]

### Challenge 3: Cross-cultural validity

*On reading through the full project proposal I came across the statement that 'To reduce complexity, some important aspects, including BME and carer perspectives, will not be addressed'. which seriously perturbed me and made it impossible for me, as a BME service user, to be involved in the study. Given the over-representation of young Black men in MH services, having a major project like REFOCUS explicitly state that it will* ***<u>not</u>*** *address BME perspectives is extremely worrying, and leads me to conclude that Recovery is being seen as a nice White concept that should not be sullied by BME issues in order to “‘maximise the likelihood of success” of the REFOCUS*

> *project.*
>
> [LEAP5]

> *If BME issues are not going to be addressed, how is it going to be meaningful, for example, to assess cross cultural validity of the study. If the selection of participations is random, it is deeply problematic to proceed in a 'neutral' way. The study team responded to these criticisms by creating a PhD study looking specifically at recovery for BME service users. They also expended considerable effort trying to develop a similar sub study for caregivers. Unfortunately, this was not feasible within budgetary and time constraints.*
>
> [LEAP2]

### Challenge 4: Specific issues re Lived Experience Advisory Panel

#### Structuring of LEAP within the wider project

> *I couldn’t spare one whole day for the meetings travelling from Watford. I did however input into the earlier work on themes to be incorporated into the training, etc. Basically, a half hour by computer was easier and less time-consuming than a whole day out for a meeting. I also had the feeling of being part of the ‘whole’ project team, not just the user advisory part. I also got to read others’ comments which was really interesting as from a varied perspective e.g. Psychologist, psychiatrist and user and from the US as well as the UK. I think it a pity that it is not possible to have this sort of larger team working by email, it's really invaluable to have a trace of what was said about a point and how it was argued.*
>
> [Prospective LEAP member]

> *It was good to be in a user / carer only group, which in theory should have made it possible to share and discuss issues more freely. However, it would have also been useful to have had closer links with other groups, e.g. I became aware during the study that some academics / researchers were really supporting BME issues raised by LEAP members, sometimes in face of quite heavy opposition. It would maybe have been useful to have had some*

> *communication / knowledge re this so we could feel more valued and also work together with like-minded researchers in solidarity to raise important issues.*
>
> [LEAP5]

**Issues of power and control**

> *User involvement was very much on the terms of the REFOCUS programme. Although the team had the responsibility to develop and implement the research, for user involvement to be valid, authentic and meaningful, it needs to respond to the views of service users and carers, not just be tokenistic or consultative.*
>
> [LEAP3]

> *The issue of control over the research has been noted by others as a negative, although we found that careful drafting of terms of reference and the existence of positive pre-existing relationships greatly reduced this issue. Trust was built through all parties demonstrating the willingness and capacity to listen and respond to concerns raised.*
>
> [PI]

> *I felt completely disempowered when I thought my serious concerns re BME issues were not being taken seriously. I therefore used what power I had to include this experience in a chapter I was writing about recovery and sent copies to several people in REFOCUS. Following this, I was contacted by the Chair of LEAP to bring my chapter to a LEAP meeting so it could (with his support) be discussed. This proved a crucial turning point for me, and from then on I tentatively ventured into LEAP and ended up being quite an active member.*
>
> [LEAP5]

> *An aspect I found challenging was being the budget-holder for the PPI component. When the employed research team had a good idea which could be incorporated into their work then no financial pressures were created,*

> *whereas when LEAP members had a good idea for an un-planned (and therefore un-budgeted) contribution there were financial implications which I had to balance – leading perhaps to the impression of more hesitancy on my part in taking up ideas from LEAP than from the employed research team. An alternative arrangement would be to devolve responsibility for the PPI budget to the LEAP Chair. Also, human resources are needed to process advice, and LEAP certainly had lots of suggestions! I had to balance this helpfulness with the capacity of the employed researchers, so when the team were fully engaged in data collection, LEAP meetings were scheduled less frequently. This probably reduced the link between LEAP and the study in the latter stages. One way to retain the connection would be through an alternative approach to involving LEAP in disseminating findings. We budgeted for LEAP members to attend advisory meetings, training sessions etc. but not for writing time. In retrospect this implicitly reflected my experience with research colleagues, where writing is a core part of the job. For LEAP members, budgeting for written contributions might have provided a vehicle for greater LEAP linkage in the second half of the study.*
>
> [PI]

### Issues re Leap being a critical friend

> *Some prospective LEAP members objected to the positivist methodology planned as not in keeping with recovery as a paradigm shift. Although I agree with this view, I could also see that this kind of study needed to be listened to as evidence based practice and make the kind of change I want to see in the delivery of services. You have to be in it to change it in other words but this also begs the question of how far 'it' will change you!*
>
> [LEAP2]

> *I was torn at the start between working constructively together with LEAP to achieve change or staying on the outside to demonstrate opposition. When the issue re exclusion of BME perspectives came up, I did withdraw in anger. Later, I heard by chance that my concerns had been raised at a higher level and a PhD student was to specifically focus on BME aspects in the study.*

> *Following this, I slowly began attending LEAP meetings, and through support of the Chair and some LEAP members, eventually became an active member of LEAP, raising issues of concern and developing mutual respect over time, as I saw that, sometimes, our concerns were taken on board and impacted on the study.*
>
> [LEAP5]

## Team dynamics

> *Some LEAP members requested better introduction to the group, to get to know members better – feeling more 'safe' to share difficult personal experiences. Uncertainty over extent to which the LEAP sufficiently allowed this to happen.*
>
> [Chair]

> *I sometimes felt I didn't know anything about other LEAP members, but could have been because I joined late. I noticed we didn't often have discussions amongst ourselves, and nearly always seemed to direct our comments to the Chair or the researchers who attended. I wonder if it would have been useful to have an induction to LEAP, or done some team building work to enable us to be more open with each other in discussions etc.*
>
> [LEAP5]

> *Need more explicit recognition of knowledge or skills that members bring, in addition to personal experience as service user or carer, with more positive use of different experiences and perspectives. Also, need more recognition of the challenge of evoking personal experiences during formal interactions, and the tension between knowledge paradigms.*
>
> [Chair]

## Recruitment of LEAP members

> *We had a discussion about how to recruit members to the LEAP, and we decided to approach people with personal experience who had also a keen*

*interest in or prior experience of research involvement. This was because we wanted the LEAP to be in a position to engage with the research study in a way that could offer a critical perspective on this, from a perspective of constructive dialogue. This later became formulated as the 'critical friend' approach.*

[Chair]

*Future PPI involvement must continue to include good communication skills, approaching the general public in an open, easy to understand manner. The recent RETHINK and MIND campaigns to encourage more openness about mental health difficulties are an excellent example of this. It is essential that 'new media' such as twitter, face book, is used to capture the attention of the young and technology literate as well as the more traditional methods such as leafleting, posters and good old face to face talking.*

[LEAP4]

### Diversity within the group

*My acquaintance with Professor Mike Slade began through my involvement with University College London's group of academics. Through this acquaintance I was delighted to join LEAP some time later.*

[LEAP]

*I came into the LEAP group in 2009 during the set up of the project. I had very little experience of applied mental health research but quite a lot of experience as an independent recovery trainer with a special focus on people who experience psychosis and caregiving as these are part of my recovery journey. I also brought a critical academic perspective rooted in philosophy of history, temporality and post structural and post feminist theories and critiques of epistemology and ontology. Both are two sides of the same coin because up until very recently psychotic experiences have been constructed as unreal but, and I pinch myself, take up room in the world as having an embodied subjective reality for the person experiencing them. Of Jewish and Irish extraction, I am also culturally positioned between two marginalised ethnic* *groups but identify with neither of them. As someone whose lived experience is both in and outside a range of cultural, medical and philosophical discourses at the same time, I have historically found difficulty in belonging anywhere, or at least not for very long. However, this difficulty can also be a critical strength in nurturing environments.*

[LEAP2]

*I came into LEAP as a service user, PhD student, researcher, with responsibility for the development of service user and carer involvement in social work training at Anglia Ruskin University.*

[LEAP3]

*I learnt of this piece of research through FACTOR (Families And Carers Together On Research). I joined REFOCUS after the project had been approved and was ready to start. My experience of 'recovery' in my own area, was of a 12 week programme 'set up' for a close relative. I wanted to discover if REFOCUS would offer any improvement to our experiences, through a more holistic approach. As a carer for someone with schizophrenia for the past 5 years and knowledge of mental health services in different parts of the country, for the past 35 years, I felt I had lots of personal experience of services and the way the illness effects a person, their relatives and others.*

[LEAP4]

*There was a lot of diversity in the group in terms of personal and professional MH experience and we clearly had a skilled and able group, but sometimes I felt we didn't use that diversity or those experiences in a collective way (although I know individuals did work very hard on their own). Didn't feel there was opportunity to consider how within LEAP we could work positively with our diversity (e.g. of values, life & MH experiences & views, reasons for involvement in LEAP) & how this was going to be a learning as well as a contributory process.*

[LEAP5]

### Chairing LEAP

> *I became involved as the chair of the LEAP as Mike Slade approached me in my role as Head of Research and Evaluation at the mental health charity Rethink Mental Illness. Mike was keen for us to support that people with lived experience of using mental health services and carers were involved in advising the REFOCUS study. At Rethink Mental Illness we wanted to support this research, as it fitted with our general interest in promoting mental health recovery and improving the quality of mental health services, as experienced by people using these. I approached my role as a chair ensuring facilitation of LEAP discussions and at times also more actively contributing to articulate perceptions and views that were coming out from discussions. The meeting structure was relatively formal, but generally it felt to be appropriate given the nature of discussions and LEAP members' experience and expertise both in respect to lived experience of metal health and research issues.*
>
> [Chair]

> *I had some concerns initially re a member of Rethink chairing the LEAP meetings, and not a service user (there are lots around who are very capable of chairing meetings and acting as a conduit to rest of study). However, as I got to know <Chair> I came to really value his chairing and the way he made his values very clear and enabled difficult issues to be brought to the meeting. I also learnt from other LEAP members to be more flexible in my thinking and recognize <Chair's> role as 'independent' and therefore really useful.*
>
> [LEAP5]

> *I very much enjoyed the meetings and over time it has felt like a peer group has been forming. At the meetings I had a sense that people were highly motivated and engaged in frank discussions, while wanting to understand each other's perspectives.*
>
> [Chair]

**Challenges re scheduling and attending LEAP meetings**

> *Keeping meaningful involvement of LEAP through the project (which could be*

*improved at the design stage and in the later, data collection phase) was difficult. For those who did choose to be involved, LEAP members reported that REFOCUS sought to value their contribution and listen to their concerns, which validated their involvement.*

[PI]

*Some of the challenges of PPI were around scheduling the LEAP meetings, balancing the desire to have regular meetings with the practical requirements of needing to schedule them when they would be most beneficial for the specific research tasks.*

[Res1]

*Pity there weren't more members involved and who could attend meetings, but all LEAP members who did attend and research team members were very respectful of each other. I feel that the ad hoc and arbitrary way that LEAP meetings seemed to be called made for lack of continuity and inconsistency: a more regular and structured time table of meetings could have helped with preparation for meetings and with focussing on REFOCUS.*

[LEAP1]

*Felt that the inconsistency of attendance whereby not many members of LEAP seemed to make meetings and when sometimes meetings not as well attended as hoped for were disadvantages to richer and more varied input. Although this was compensated by worthwhile email communication from some LEAP members I feel this was no compensation for face to face inter-action and debate. Perhaps there should have been more than one carer involved to get a spectrum of carer views?*

[LEAP1]

*At the start of the REFOCUS programme there was a high demand for service user input both from the LEAP group and the REFOCUS Advisory Panel. There seemed to be an innate desire to capture recovery as a model that drew on service user experiences as in the personal model of recovery-As they continued with the programme, there seemed less weight and less*

> *enthusiasm to consult with the LEAP group – meetings became annual rather than more frequent. At this stage, it felt very much as if the LEAP group had been marginalised from the operation of the research.*
>
> [LEAP3]

> *I feel some sadness at my own lack of involvement with the LEAP group – possibly through the changes in my own life rather than through the project.*
>
> [LEAP3]

### Style and content of LEAP meetings

> *The first few meetings focused strongly on process, and were very critical of Refocus. Yes many comments were justified, but it is important to work together to overcome some of these problems. Being political needs clever thought: working from the inside and constructively.*
>
> [LEAP]

> *Sometimes I felt that people in LEAP didn't look at the project as it was at the moment, but got stuck with criticising the format of LEAP and the refocus project The project was as it was, with its limitations, and it was important to try to influence the project in its current form rather than becoming too hung up on what might have been if things had been better.*
>
> [LEAP1]

> *Style of meeting was formal and focused on 'paperwork' – more creative and interactive approach could have been used.*
>
> [LEAP5]

### Role of researchers in meetings

> *Initially we thought that the REFOCUS researchers could attend only part of the meeting in order to provide an update and answer questions, but it was decided by the LEAP members that it was helpful to have the researchers present throughout. This I think was in recognition that the researchers were*

> *always keen to listen to LEAP members' concerns and engaged constructively with these.*
>
> [Chair]

> *I sometimes found it off-putting having the researchers there for the whole meeting. They were very nice and respectful but I just felt constrained sometimes and longed to be able to more be me as I usually am with other users. I also felt we tended to address the researchers rather than each other in our discussions. Having some time on our own may have helped build more 'team spirit'.*
>
> [LEAP5]

**Language**

> *Occasionally I felt that I had to probe and question the REFOCUS views and definitions of how recovery is measured and what is means to the individual (especially to those with severe and enduring symptoms): this was always considered in a positive way which reflected the view that objections are merely a request for further information.*
>
> [LEAP1]

> *From the first meeting, I found the structure and language used in the project very complex, and it took me a few meetings to unravel what was going on. It was soon agreed that acronyms should not be used, or as little as possible, and a list of abbreviations provided.*
>
> [LEAP4]

**Lessons learnt and recommendations for future PPI**

Drawing on the benefits of PPI and the lessons learnt from its challenges, we present a list of recommendations of PPI that can be used to inform future studies.

**Structuring PPI into the study**

1. Start early! **Plan PPI in advance** across the full research cycle so it can be used when developing the research idea and design.
2. Plan to **establish PPI in a variety of ways**, e.g. through formation of a LEAP group, employing service user researchers, bringing in service user consultants and facilitators with particular knowledge/skills at appropriate points
3. Firmly **embed PPI into the structural framework of the projec**t, and enable PPI members to engage with wider project collaborators, e.g. by cross representation on different advisory groups, sharing of different minutes and regular, through social media such as Facebook or Twitter, regular electronic newsletters etc
4. Enable **PPI members with specific knowledge or skills** to contribute to other advisory groups and/or researchers on particular issues, e.g. providing training to researchers re interviewing service users
5. Ensure PPI is adequately **resourced in terms of time, energy and money** – it always takes more than you might anticipate
6. **Be Specific** about the PPI tasks planned across the study so that people have clear expectations and resources are focussed on where they add most value.
7. Approach **Research Design Service** to see if they have any funds to support PPI design consultation

**Style of engagement and communication**

1. Appreciate there may be very different perspectives and biases and consider developing a **guiding theoretical framework for synthesising multiple perspectives.**
2. Take time to establish PPI's role as a **critical friend** to the study, acknowledging both researchers' and PPI members' anxieties/concerns and enabling mutual respect to be built so that differing perspectives can be constructively voiced and discussed.
3. Be very aware of inevitable, unequal **power relations** between the researcher team and PPI members. Aim to use power in a positive way with PPI members, rather than over them and make very clear right from the start how much power PPI members can have, e.g. consultative, advisory or taking part in decision making
4. Early jargon busting and/or some training around research terminology would help with issues of **language**

**Recruitment & selection**

1. Make very clear from the start the **purpose of PPI** and what is required of PPI members, but be prepared to modify this according to the professional as well as lived MH experience PPI members bring to the project.
2. When recruiting PPI members, aim to get a **broad selectio**n of members (NB equal opportunities) so that the study can benefit from diverse life and MH experiences, views etc.
3. Before recruiting, hold an **introductory session** to inform potential members what PPI involves in your study so they can get a feel for the project and some of those involved.
4. Put in place a proper **recruitment and selection process** to convey the 'professionalism' of PPI and the commitment that is required on all sides
5. Aim to recruit **at least 10-12 people** so there are likely to be sufficient numbers at each meeting to ensure useful and full discussion
6. Once recruited, provide PPI members with some form of **induction** in order to develop a ‘team spirit’ and offer training as needed

**Meetings**

1. Ensure PPI meetings are scheduled in a way that ensures **continuity and consistency**; and (sensitively) makes clear to PPI members that their attendance is expected and important both for the group and the wider project. Obviously, there will be times when people are unable to attend, but if this is likely to happen over a long period it would be good if they could inform the group in advance.
2. Ensure PPI meetings are **effective and engaging**; consider using more interactive style of engagement as well as formal discussion of paperwork format.
3. Provide opportunities / activities for **differences (and similarities)** to be acknowledged, shared, valued and used productively and sensitively
4. Facilitate meetings to enable **group cohesion** and a diversity of perspectives to be heard. Consider having some time just as the PPI group in order to foster positive team dynamics within the group.
5. **Log** all recommendations emanating from PPI and monitor so the impact of PPI across the whole study can be clearly assessed.

### Conclusions

The most fruitful period of consultation was during the set up phase of the REFOCUS programme, with the Recommendations Grid as a key development in assessing the impact of PPI during this phase. The most fruitful periods of collaboration were in a mid point evaluation of PPI, conference presentations, training of researchers, publications and in the reporting of findings. REFOCUS did not get everything right in the design stage around PPI. However, there is also a funding gap in doing meaningful PPI before a study is funded, which makes many of our recommendations hard to implement. Despite this systemic obstacle, the challenges were largely productive, resulting in the explicitly 'critical friendship' approach to PPI – holding differences in perspective within a shared desire to produce high quality research with us rather than about us. It is anti-recovery to presume that the study team will have all the answers before a learning journey takes place, and it is to the credit of the study team that they rose to the challenge of critique that may have been hard to hear at times and/or impossible to act upon without detracting from other research activities within the research paradigm. We hope that this journey of critical questioning provides a platform for further methodological and epistemological reflection on the design of future studies and translates into organisational change in the way recovery is conceptualised and implemented.

We now report the Recommendations Grid study which was mentioned in the above co-produced discussion of PPI, and is called here the PPI Impact sub-study.

## PPI Impact sub-study

Adapted with permission from the published report of this study[173].

### Introduction

The start-up phase of any study is crucial, since many key design and implementation decisions are evaluated and finalised. Clear guidance exists in relation to oversight committees for studies, including appropriate arrangements for trials to be monitored by a Trial Steering Committee[6]. However, the role of advisory committees - which provide advice and expertise to support the study but without a formal oversight function - has not been investigated. Although it is common to form steering committees to inform research studies, we could locate no empirical evidence regarding the optimal composition and timing of advisory committees, or the nature and impact of their contributions.

The aim of the study reported here was to begin this process, by characterising and evaluating the contribution of various forms of expert input to REFOCUS during the start-up phase, by collecting data during the first seven months of the study. A particular emphasis was on the impact of public involvement, in this case the advisory contributions made from mental health service users and carers. There is an evidence gap on how public involvement improves the quality and relevance of research, since public involvement is “by its nature a complex, social process”[233] (p. 92). The overall goal was to inform the committee and advice infrastructure for future research studies.

## Methods

### *Design*

A case study of contributions from committees and individual experts to one research study.

### *Procedure*

The initial advisory infrastructure for REFOCUS comprised three committees. First, the Steering Group was composed of the 12 applicants and 7 collaborators named in the proposal. The applicants were academic, clinical researchers, user-researchers or service leads who together provided cross-cutting expertise relevant to the overall aims of the Programme. Collaborators brought methodological expertise relevant to specific sub-studies. The Steering Group was chaired by the Principal Investigator, and the terms of reference were to provide methodological and implementation expertise to contribute to the success of the study. The committee met in May and September 2009. As part of the Steering Group, a social and cultural social sub-group (SCSG) was formed from the Steering Group membership in May 2009, which communicated by email.

Second, the Lived Experience Advisory Panel (LEAP) comprised eight experts by experience, i.e. as mental health service users and carers. Recovery ideas have emerged from people with personal or ‘lived’ experience of mental illness, but the mental health system has been criticised for co-opting or commandeering the recovery approach. The purpose of LEAP was to retain the integrity of these recovery values, and the terms of reference were therefore to be a ‘critical friend’ to REFOCUS: bringing the perspective of lived experience to the methodological and implementation decisions. The LEAP committee was chaired by a voluntary sector representative, and met in May and September 2009.

Finally, the International Advisory Board (IAB) comprised nine experts from Australia, England, Ireland, Scotland and the USA. The terms of reference for the IAB were to provide an international perspective both on research evidence and best recovery-related practice in mental health services. IAB meetings were chaired by the Principal Investigator, and one meeting was held in May 2009. Additionally, specific experts were identified and consulted with about specific issues. These experts included both members (n = 9) and non-members (n = 11) of advisory committees, and brought the same range of expertise as the applicants described earlier.

We refer to the three advisory committees and the additional experts collectively as ‘advisors’. The REFOCUS Study began in May 2009, and recommendations made by advisors were recorded until November 2009. All three committees will however continue to operate until the end of the study, with the IAB meeting annually and the Steering Group and LEAP meetings biannually.

A recommendation was defined as a course of action that was recommended by an expert or a committee as advisable, and included both cognitive (i.e. to think about something) and behavioural (i.e. to do something) recommendations. All recommendations were recorded. Recommendations made in committee meetings or afterwards by email as part of a committee follow-up discussion were attributed to the committee. Recommendations made in individual meetings or afterwards by email were attributed to the individual expert (even when they also were members of an advisory committee but were contributing a recommendation outside of a committee follow-up discussion thread). Each recommendation was then discussed by the research team, and a decision about implementation was recorded, comprising either Implemented, Not implemented or Undecided (when the recommendation related to a later phase of the study, such as a reference to include in a resulting publication). The rationale for the implementation decision was also recorded. The content of recommendations was analysed to identify emergent themes and sub-themes.

### Results

Advisors made 172 recommendations to inform the study between May 2009 and November 2009. These comprised 37 from IAB, 20 from LEAP, 36 from the Steering Group, 9 from the SCSG, and 70 from 20 individual experts. The experts comprised two IAB members (making 5 recommendations), seven Steering Group members (making 42 recommendations), and 11 non-members (making 23 recommendations). Although there was some duplication of recommendations from different sources, there was no clear pattern of overlap. The 172 recommendations were grouped into five emergent themes, each with sub-themes, shown in Table 60.

### Table 60 PPI Impact sub-study: recommendations made by advisory committees and experts

| Recommendation theme | Sub-theme | IAB[1] | SG[2] | LEAP[3] | SCSG[3] | Individual experts | Total |
|---|---|---|---|---|---|---|---|
| **1. Scientific** | | **15** | **21** | **12** | **9** | **45** | **102** |
| | *Design advice* | 11 | 14 | 8 | 7 | 33 | 73 |
| | *Suggestion for a study extension* | 0 | 4 | 1 | 0 | 3 | 8 |
| | *Recommendation for intervention content* | 3 | 1 | 1 | 0 | 4 | 9 |
| | *Conceptual suggestion* | 0 | 1 | 2 | 2 | 4 | 9 |
| | *Advice specific to PhDs* | 1 | 1 | 0 | 0 | 1 | 3 |
| **2. Pragmatic** | | **6** | **1** | **1** | **0** | **2** | **10** |
| | *Implementation advice* | 2 | 1 | 0 | 0 | 2 | 5 |
| | *Recommendation for language to use* | 1 | 0 | 1 | 0 | 0 | 2 |
| | *Advice about dissemination* | 3 | 0 | 0 | 0 | 0 | 3 |
| **3. Resources** | | **11** | **8** | **0** | **0** | **19** | **38** |
| | *Published work to consider* | 6 | 1 | 0 | 0 | 3 | 11 |
| | *Unpublished work to consider* | 3 | 5 | 0 | 0 | 3 | 11 |
| | *Expert person / group to contact* | 2 | 2 | 0 | 0 | 13 | 17 |
| **4. Collaboration** | *Ongoing contact about specific issue* | **0** | **0** | **0** | **0** | **4** | **4** |
| **5. Committee** | *Role and composition of committee* | **5** | **6** | **7** | **0** | **0** | **18** |

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| **Total** | **37** | **36** | **20** | **9** | **70** | **172** |

[1]International Advisory Board. [2]Steering Group. [3]Lived Experience Advisory Panel. [4]Social and Cultural sub-group

Examples of Scientific recommendations included accessing an existing database (Design advice), involving carers (Study extension), using video clips as a training aid (Recommendation for intervention content), and to consider the cyclical nature of recovery (Conceptual suggestion). Examples of Pragmatic recommendations included liaising closely with trial sites (Implementation advice), revising the term ‘manual’ (Recommendation for language to use) and providing online information about the study (Advice about dissemination).

The Resources recommendations identified publications or other experts to access. Examples of Committee recommendations included composition, terms of reference, cross-committee representation and circulation of minutes, and clarity about role in decision-making in REFOCUS. An example of a Collaboration recommendation was the request by an expert to liaise in the future about a Department of Health initiative on personalisation. Most recommendations were either strengthening existing components or adding new components to the study protocol. Very few recommendations either proposed removing study components or contradicted other recommendations.

The criteria for implementing recommendations were not specified in advance, but discussions about implementation were observed by the research team to involve three implementation criteria: scientific value; pragmatic value; and paradigmatic consistency. One reason not to implement the recommendations was where it added little or no scientific value, such as involving a new advisor with the same expertise as an existing advisor. The pragmatic criterion related to recommendations which did strengthen the current design but with unmeetable cost (in time and money) implications for the study, such as developing a new focus on social capital interventions. Finally, recommendations were sometimes not implemented on paradigmatic grounds when the suggestion was reasonable from within an alternative frame of reference but incompatible with the goal of contributing evidence within the evidence-based mental health paradigm. For example, the term ‘manual’ (for the randomised controlled trial intervention) was criticised since pro-recovery working is individualised, but retained as the standard term used in clinical practice.

Overall, for recommendations to be implemented they had to add scientific value, be viable within the study resources, and be consistent with the overall scientific framework being used.

Most recommendations from committees were implemented. For IAB, 6 (16%) recommendations were not implemented, comprising 2 Scientific, 2 Pragmatic, 1 Committee and 1 Resources. For LEAP, 4 (20%) were not implemented (3 Scientific, 1 Pragmatic) and 3 (12%) were undecided (3 Scientific). For the Steering Group, 5 (14%) were not implemented (3 Scientific, 1 Resources, 1 Committee) and 6 (17%) were undecided (6 Scientific). For the SCSG, 1 (11%) Scientific recommendation was not implemented. Finally, 9 (13%) recommendations from experts were not implemented (6 Scientific, 3 Resources) and 35 (50%) undecided (22 Scientific, 10 Resources, 2 Pragmatic, 1 Collaboration). The non-implementation proportion therefore range from 11% to 20% across the different sources of advice. The recommendations specifically relating to committees covered amendments to the terms of reference, new members to invite, frequency of meetings, copying minutes between committees, joint meetings and cross committee representatives, and the role and impact of public involvement.

The research team identified two benefits from the advice. First, the overall research quality was (in the judgement of the research team) improved, by considering a broader range of issues. Second, there was greater confidence that the research was both internationally innovative and of a high methodological quality. The costs identified by the research team (in addition to the financial costs in convening the committees) were the increased demands on researchers to think through and come to a view about each issue raised, the time taken to revise the study protocol, and the consequent slower progress in relation to study deadlines.

## Discussion

This observational study found three main results. First, advisory committees and experts contributed to the study in four ways: scientific advice relating to design questions; pragmatic advice relating to maximising the likelihood of successful implementation and dissemination; providing links to wider resources; and offering opportunities for collaboration. A fifth category of recommendations, on the composition and processes of the advisory committees, did not contribute to REFOCUS and accounted for 10% of the overall recommendations. Second, 103 (60%) of the 172 recommendations were implemented in order to improve scientific quality. The wide range of recommendations presented challenges to the research team. Three preliminary categories for 'implementation criteria' were identified: scientific (is it valuable?); pragmatic (is it possible?); and paradigmatic (is it consistent?). Third, it was helpful to record non-implemented recommendations as a means of informing future research. For example, LEAP recommended a research focus on carers, which as we discuss in Chapter 11 was not implemented. Making this decision visible ensures it is both more amenable to debate within the study and can inform future research planning.

On the basis of our findings, we can make six recommendations for other large studies.

1. Have a clear rationale for each advisory committee. The rationale is best expressed as an agreed terms of reference, and the discussion leading to agreement can both help the committee to form and provide guidance to shape future input.
2. An early concern of committees is inter committee communication. Our experience suggests that copying of minutes between each committee should be the norm, and that each committee should be offered the opportunity to have representatives on the other committees.
3. Match the scope of advisory committees to the study. We found that recommendations were adding value, and did not in general contradict each other. This suggests a comprehensive advisory committee structure will improve the quality of decision-making for studies which include a start-up phase during which final design decisions or piloting are undertaken.
4. Public involvement has a mixed impact. In our study, which had a start-up phase, the impact was on balance very positive. The main cost was time and progress, and the importance of this cost would increase in studies with less start-up time.

5. Carefully consider the match between the scientific paradigm applied in the study and the contribution of different types of knowledge and expertise, and how this will impact on possibilities for taking on advice. Although there may not be an easy fit between for example a positivist approach and knowledge arising from lived experience, it may still be possible to take important learning through careful facilitation and mutual willingness to listen and learn. A concrete approach to valuing different forms of knowledge is to acknowledge and record the recommendations and areas of scientific enquiry which, although potentially desirable, cannot be addressed in the study.
6. Responding to recommendations used up research team resources. The burden on the research team in responding to recommendations should be minimised. The three decision-making criteria which evolved over time were scientific, pragmatic and paradigmatic. Using these criteria in other studies may reduce the cognitive and time costs on the research time in responding to recommendations.

# Chapter 11. Synthesis of findings

## Introduction

Modifications to the REFOCUS Intervention are identified, and then the overall contribution of the REFOCUS programme is summarised. Some of the important areas not addressed in the work programme are highlighted. The impact of the REFOCUS programme is then considered, and recommendations for future research are then proposed.

## Modifications to the REFOCUS intervention

The REFOCUS trial showed no overall effect on recovery, and only modest evidence of benefit on secondary outcomes. There was evidence that more comprehensive implementation would have increased effectiveness, both from the quantitative analysis of high implementing teams and from the qualitative reports from service users. The REFOCUS intervention has been modified in response to the trial results.

The basic structure of the intervention – recovery-promoting relationships and three working practices – is unchanged. However, Working Practice 2 (previously Assessing strengths) has been re-named Assessing and amplifying strengths, to reflect a greater focus on action rather than assessment processes. No modifications were made to the coaching training, but the recovery training has been re-named as ‘working practice training’ and amended to have a greater focus on the REFOCUS manual and less on the history of the recovery movement. The intervention content has been simplified, with elements abandoned which the process evaluation suggested were either un-used (supervision form) or sporadically used (Partnership Project, recording in clinical information systems). A stronger focus has been placed on the link between coaching and the working practices. The reflection groups have been retained as an important element supporting reflective practice, but their frequency has been changed from externally imposed to internally generated, so as to increase team ownership. The coaching for recovery training has also locally been used in in-patient settings, with good (though not formally evaluated) results.

Therefore the specific focus on community services has been changed to a focus on adult mental health services.

Four implementation strategies are now used.

### 1. A one-day workshop on REFOCUS and recovery

This is led by a recovery expert, and aimed at workers, service users and carers from the team or service that will be implementing REFOCUS. The learning objectives are:

- To understand empirically-supported conceptual frameworks for recovery and recovery support
- To have a broad overview of evidence-based pro-recovery interventions
- To know about the aims and content of the REFOCUS Intervention
- To reflect individually and as a team on recovery-related values and attitudes
- To notice and value existing relevant expertise and experience in workers

### 2. A one-day Working Practices training

This is facilitated by one trainer with professional experience and one trainer with lived experience. The training is for all workers from the same team / service. The learning objectives are:

- To understand the theory and aims of the three working practices
- To have role-play experience of introducing and using each working practice
- To understand that the working practices lead to action to support recovery – so collecting information is a means not an end in itself
- To understand that person-centred support is the goal, so individualised rather than invariant practice is the aim
- To be able to identify barriers and solutions around using the working practices in routine practice

### 3. A 2-day REFOCUS Coaching for Recovery training

This is facilitated by experienced coaching trainers, and is for all workers from the same team / service. An option of additional half day recall sessions can be added if desired. The learning objectives are:

- To demonstrate how a coaching approach supports the implementation of recovery focused practice
- To equip clinical and support staff with knowledge of the core competencies required for working effectively with a coaching style
- To develop the participant’s capacity and enable them to embed a coaching style within their clinical practice
- To build the capacity and capability of teams, services and the organisation to successfully implement the REFOCUS Intervention’s three working practices through the development of a coaching ethos

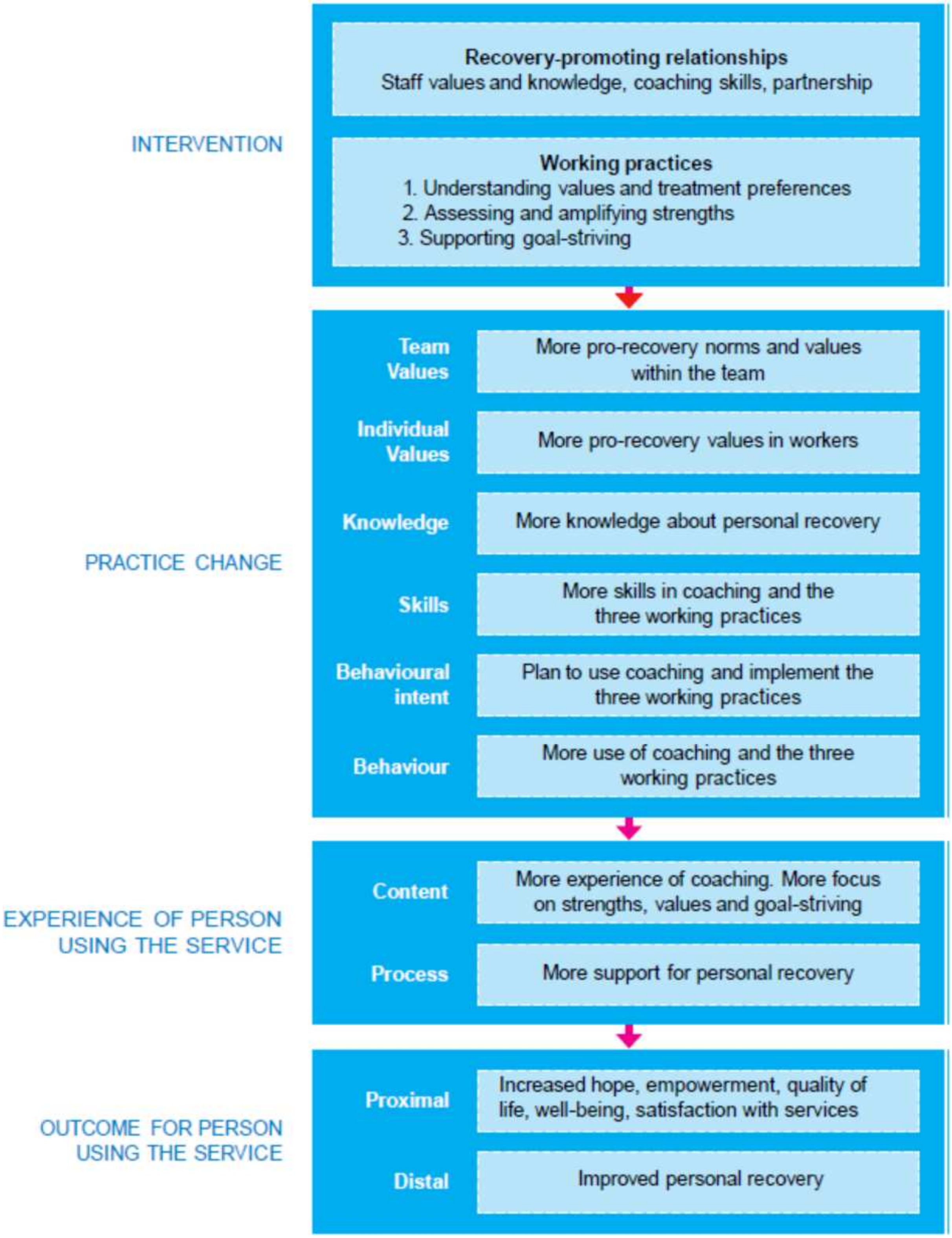
### 4. Support for practice change

Sustained practice change is needed, so each team / service implementing the REFOCUS intervention will need to develop a clear plan for how to build on existing pro-recovery strengths and embed the REFOCUS intervention into practice. Suggestions include:

- Internally or externally facilitated reflection groups
- Action learning sets
- Audit
- Booster training sessions
- Recovery Champions
- The Team Recovery Implementation Plan (TRIP)[359].

The REFOCUS model was modified, as shown in Figure 18.

## Figure 18 Modified REFOCUS model



The modified REFOCUS intervention was published as a free-to-download manual[354].

### What did the REFOCUS programme achieve?

The REFOCUS programme used a wide range of methodologies, including systematic and narrative reviews, document analysis, survey, qualitative interviews and focus groups, interrupted time series, development and psychometric evaluation of three new (SAFE, INSPIRE, IOM) and one existing (QPR) measure, and a cluster randomised controlled trial with mixed-methods evaluation. Throughout the programme, the aim was to maximise coherence whilst undertaking research which would have wider relevance beyond the REFOCUS programme.

In the *Define the problem* module, the REFOCUS programme laid a theory base for the REFOCUS intervention and for wider recovery research. The conceptual framework for recovery provides an empirically defensible operationalisation of 'recovery'[8]. As this was so foundational, the framework was validated cross-culturally[41] and with current mental health service users[56]. For services, the recovery practice framework identifies the need to target recovery initiatives at different levels within the mental health system[63]. The national survey identified that front-line service user – staff dyads have a broadly similar and less positive view about recovery orientation than team managers. Finally, we used both a grounded theory[103] and systematic review[360] approaches to identify the competing priorities staff experience in relation to recovery-oriented practice.

In the *Optimise the intervention* module, three studies were undertaken to address specific knowledge gaps. The framework for understanding recovery in black service users developed a conceptualisation which emphasises identity, and informed the Values and Treatment Preferences working practice. The systematic review of strengths measures[119] identified the Strengths Assessment Worksheet for inclusion as a resource in the REFOCUS intervention. The development of the SAFE measure helps to highlight the influences on feasibility of a complex intervention[130]. All findings were then integrated to provide the theory base for the REFOCUS intervention, a pro-recovery team-level intervention. The REFOCUS model and manual were published[171].

The *Optimise the evaluation* module addressed the complex issue of measurement of recovery through a range of methodologically rigorous studies. A systematic review of recovery measures[97] identified the QPR as an appropriate primary outcome, which was then psychometrically evaluated. A systematic review of recovery support measures identified no recommendable measure[98]. A new measure called INSPIRE was developed and evaluated[236], using the conceptual framework for recovery and the recovery practice framework as theoretical bases. Finally, a methodological innovation in the individualisation of the primary outcome for use in trials was developed and evaluated.

In the *Optimise the trial parameters* module, the REFOCUS intervention was evaluated in a cluster randomised controlled trial[7]. Evaluation included clinical and recovery outcomes[307], economic evaluation of resource consequences, casenote audit, and process evaluation from both staff[308] and service user perspectives. Data from the REFOCUS trial were also used to investigate the impact specifically on black service users, and to understand the relationship between clinical and recovery outcomes.

The *Knowledge transfer* module involved a number of dissemination strategies, including formal knowledge transfer events, networks, publication of free-to-download manuals[171,189,190], web-based information, academic and practitioner journal articles, and conference presentation.

Given the focus on recovery, the contribution of Patient and Public Involvement was particularly important. The PPI chapter of this report was co-produced by the research team and people with lived experience, and also includes an empirical evaluation of the impact of the Lived Experience Advisory Panel on the REFOCUS programme[173].

**What did the REFOCUS programme not address?**

There were many important areas which the REFOCUS programme was not able to address adequately, including:

1. The contribution of service users to implementing the REFOCUS Intervention was insufficiently maximised. The challenge of course is that it is easier to directly influence the worker side of the service user – worker dyad. For example, workers can be required as an employment expectation to attend training, whereas service users cannot. This meant that the resource of lived experience was insufficiently harnessed in the REFOCUS intervention[108]. Only modest efforts were made to raise service user expectations, through an information session and a letter. A more effective strategy would involve actively targeting both sides of the relationship. Emerging approaches include making 'credible role models of recovery' more visible[361], employing peer support workers in services[362] and supporting active involvement in clinical decision-making[363].
2. The contribution and experience of family and friends to recovery was not addressed. Carers are clearly central to supporting recovery[358], often spending a far greater amount of time with the service user than any mental health worker, and influencing the service user's experience of connectedness. Apart from some involvement as LEAP members, the study did not incorporate the perspective of carers. There is only a small and primarily qualitative[364,365] or survey-based[366] evidence base concerning carer perspectives on recovery. As carers are so influential on recovery[367], this is an important evidence gap. The modest empirical evidence base on carers and recovery needs to be increased in future research.
3. The REFOCUS intervention did not address two of the four domains of the recovery practice framework. The Organisational Commitment domain is being addressed in England through the Implementing Recovery through Organisational Change (ImROC) national programme (www.imroc.org)[248]. The ImROC programme is consistent with the REFOCUS programme in being based on the view that '*If recovery is really going to be the defining feature of our mental health services, there needs to be a fundamental change in the quality of day-to-day interactions*' (p.2)[71]. However, the ImROC approach focuses on

organisational transformation. Other national approaches are underway in Australia[368] and USA (samhsa.gov/recoverytopractice).

4. The Promoting Citizenship domain – what in the UK is called social inclusion and in USA community integration – was also not systematically addressed, despite it being suggested that "*supporting people using mental health services from accessing normal citizenship entitlements is a central (i.e. not an optional extra) part of the job*"[25] (p. 9). Indeed, it has been suggested that "*the largest contribution by mental health services to supporting recovery may come from enabling the empowerment of service users to experience the full entitlements of citizenship*" (p.52)[369]. Although we published a review in this area[179], we were not able to incorporate the review findings into the REFOCUS intervention. This has been highlighted as a weakness of the REFOCUS programme[370], and there is an urgent need for new and evaluated approaches to increasing social cohesion and social capital[371].
5. One approach to increasing recovery support is to increase staff wellbeing, because of the link between workforce morale and care practices. However, although we explored the possibility of a staff wellbeing module, this proved too complex to progress.
6. Our national survey reported in Chapter 2 found that nearly 40% of staff had personal experience of mental illness and recovery. There is evidence that workers with 'dual identity' as professionals who have used mental health services face stigma in disclosing (e.g. as shown in our national survey), but that this group are an under-used resource in the mental health system[93]. The REFOCUS programme did not harness this resource.

## What was the impact of the REFOCUS programme?

Some impacts of REFOCUS programme can be identified.

The conceptual framework for recovery has become influential internationally. It has been cited 179 times (Google Scholar, accessed 6.1.15) and is being used as a theory base for other studies. For example, CHIME has been used in:

- a Norwegian study using interpretive phenomenological analysis to investigate how people with severe mental illness relate to mental health professionals[372]
- an Australian study using CHIME to characterise recovery-oriented support by families and the family's own recovery journey[373]
- a Canadian qualitative study evaluating a Housing First randomised controlled trial[374]
- an Australian study relating recovery to adolescent mental health services[375].

The recovery practice framework has been cited 72 times (Google Scholar, accessed 6.1.15). It has been used as the organising framework for recovery-oriented national mental health policy in Australia[47].

The INSPIRE measure is recommended for national use in a quality and outcomes briefing paper by the ImROC programme[224]. It is being used by a number of services in England, especially in the context of Recovery Colleges. The INSPIRE measure is being translated into a number of other languages, including Danish, Estonian, German, Italian, Japanese, Russian, Slovenian, Spanish and Swedish.

The REFOCUS intervention is being taken forward in a number of ways:

- In England the REFOCUS Intervention is being introduced and evaluated in Mental Health Trusts participating in the Innovation Network following from the Schizophrenia Commission[176]
- In Ireland, training in the REFOCUS intervention has been given to *Advances in Ireland* mental health services
- A large study called PULSAR is underway in Australia, to develop a cross-culturally validated adaptation of the REFOCUS intervention for services in Victoria, to extend the intervention into primary care, and to evaluate the intervention in a cluster randomised controlled trial. Further information is at:

  http://www.med.monash.edu.au/scs/psychiatry/southern-synergy/health-services/pulsar.html.

**Recommendations**

Table 61 identifies what, in our view, are the main knowledge contributions and implications for practice and research priorities arising from the REFOCUS programme. The order of presentation follows the order of sub-studies.

**Table 61 Knowledge contributions and future research priorities**

| Sub-study | Knowledge contribution | Implication |
|---|---|---|
| Conceptual Framework | The conceptual framework for recovery provides both an empirically defensible operationalisation of recovery for research purposes, and a clinically challenging re-framing of the core purpose of mental health services | The next phase of research should address the integration of the conceptual framework with the understanding of recovery held in non-Western and non-Anglophone cultures. |
| Recovery Practice Framework | The recovery practice framework gives a means of locating recovery interventions within the system | The domain of Promoting citizenship has the least developed evidence base, yet because recovery occurs in the community not in the clinic, it may have the highest potential for health gain. Citizenship-oriented interventions and initiatives are needed |
| National Survey | Workers with dual identity of lived experience may make up the majority of the workforce | Research involving workers with dual identity is needed, to reduce barriers to disclosure and to develop approaches to integrating lived experience into professional practice |
| National Survey | Team managers have a more positive view of the recovery orientation of teams than either front-line workers or service users. | |

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|---|---|---|
| National Survey | A higher recovery orientation was associated with higher recovery | Our data indicate that recovery orientation is an empirically defensible national policy. |
| Staff Perceptions | Conflicting and perhaps unmeetable expectations are placed on mental health staff. The use of management techniques as a means of running mental health services and meeting budget management and external reporting demands has exacerbated this challenge | The impact of service-led recovery – the *de facto* development of a new definition of recovery within mental health services – is entirely unknown and requires urgent evaluation. |
| Framework for Black Service Users | A positive identity emerges as central to recovery for black service users. | Given the consistency of this finding from non-majority populations with the person-centred literature evaluated with majority populations, our data highlight the need for greater training of mental health workers in academic knowledge about, and interventions to promote, a positive identity. |
| Strengths Measures Review | The SAW is the most widely used strengths measure, and the CASIG is the most psychometrically evaluated measure. |  |
| SAFE Development | Insufficient attention is paid to the likelihood of successful implementation of complex interventions in mental health systems. The use of |  |

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|---|---|---|
|  | SAFE reporting guidelines may start to make feasibility challenges more visible, and the use of the SAFE measure in the guideline development process may increase the focus on interventions which can actually be implemented on time, to an adequate quality and at scale – thus reducing resource waste. |  |
| Recovery Measures Review and QPR Validation | The 15-item QPR can be recommended for recovery research in England. |  |
| INSPIRE Development | The INSPIRE measure is an improvement on the previous generation of recovery support measures, with a sound theory base, psychometric evaluation including adequate sensitivity to change, and demonstrated usefulness in a randomised controlled trial. INSPIRE can be recommended for research and routine clinical practice. |  |
| IOM Development |  | The PPO component of the IOM can be recommended for further evaluation as an innovative approach to individualised clinical end-point measurement in mental health trials. |

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|---|---|---|
| REFOCUS trial and Secondary Outcome Evaluation | The REFOCUS intervention was not associated with improvements in primary outcomes of recovery or (for black service users) satisfaction. There was some evidence of improvement in secondary outcomes of staff-rated unmet needs and functioning. |  |
| REFOCUS trial | Where the REFOCUS intervention was implemented, the primary outcome of recovery improved and service user experience was positive. The second edition of the REFOCUS manual reflects learning from the trial, and places a greater emphasis on implementation of the training and team-level ownership of change. |  |
| Staff Process Evaluation |  | Implementation of the REFOCUS intervention was inadequate. In part this was due to the attempt to include all eligible teams, in order to maximise generalisability. The search for generalisable service models may not be the most efficient use of research resources, in the context of an NHS which is constantly being reorganised making the achievement of |

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|  |  | consistency (in workforce, service structures, organisational priorities, etc.) somewhere between difficult and impossible. A better approach to evaluating a complex intervention might involve targeting teams or services for inclusion which are stable, well led, ready to change and philosophically oriented towards the intervention. |
| Service User Process Evaluation | Service users who experienced the REFOCUS intervention were positive about it | Evaluating a complex intervention which is intended to be integrated into routine practice is challenging, and new evaluative approaches need to be developed. |
| Outcomes Comparison | Service users can differentiate between clinical recovery and personal recovery, and clinical outcomes do not change in synchrony with recovery outcomes | An evaluation strategy should include more than one measure and perspective, and our data indicate that patient-rated hope (assessed with HHI) and needs (assessed with CANSAS) and staff-rated social disability (assessed with HoNOS) is the optimal combination |
| PPI Impact Study | Our empirical data showed that PPI improved the design, implementation and dissemination of REFOCUS programme findings. | The impact of PPI can be strengthened by (a) the development of funding mechanisms for PPI prior to grant submission; (b) the development of |

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|  |  | service user – researcher capacity; and (c) a funder expectation that meaningful PPI will be both present and demonstrated [PPI Impact sub-study] |
| Knowledge gaps not addressed in the REFOCUS programme |  | Empirical research is needed:<br>1. to increase the contribution of service users to implementing the REFOCUS intervention<br>2. to understand, support and maximise the contribution of family and friends to recovery<br>3. to increase staff wellbeing in order to increase the recovery support they provide<br>4. to develop and evaluate interventions to support people with mental illness to experience the normal entitlements of citizenship |

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*Virtual Consultation Panel*
A 12-person panel comprising black individuals with lived experience of mental health services and / or people from any background with expertise conducting research with individuals from black backgrounds.

*Trial Steering Committee*
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## Contributions of authors

The role (job title, area of specialty) of each author is as follows:

1. Prof Mike Slade (Professor, Health Services Research) was Principal Investigator with overall responsibility for the study.
2. Dr Victoria Bird (Researcher, REFOCUS programme) led the Framework For Black Service Users, Strengths Measures Review and SAFE Development sub-studies and contributed (including design, data collection and analysis, and dissemination) to other sub-studies.
3. Ruth Chandler (PPI Lead and service user / survivor researcher, PPI) led the co-production of Chapter 10 and advised on other sub-studies.
4. Dr Eleanor Clarke (Researcher, REFOCUS programme) co-led the Staff Process Evaluation sub-study and contributed (including data collection and analysis) to the REFOCUS trial.
5. Prof Tom Craig (Professor, Social Psychiatry) contributed to the design of the study, and supported the data collection for several sub-studies.
6. Dr John Larsen (Head of Evaluation, anthropology) chaired the LEAP and provided support for design and dissemination for several sub-studies.
7. Dr Vanessa Lawrence (now Dr Vanessa Stockwell) (Lecturer, qualitative research) provided methodological and analytical support to the qualitative sub-studies.
8. Clair Le Boutillier (Researcher, REFOCUS programme) led the Recovery Practice Framework and Staff Perceptions sub-studies and contributed (including design, data collection and analysis, and dissemination) to other sub-studies.
9. Dr Rob Macpherson (Consultant Psychiatrist, health services research) was site lead for the 2Gether trial site and led the Outcomes Comparison sub-study.
10. Prof Paul McCrone (Professor, Health Economics) contributed to the design of the study and led the economic evaluation of the REFOCUS trial.
11. Dr Fran Pesola (Statistician, quantitative analysis) led the analysis of the REFOCUS trial outcomes and the Outcome Evaluation sub-study, and contributed to other sub-studies.

12. Genevieve Riley (Clinical Studies Officer, health services research) co-ordinated data collection in 2Gether and contributed to the design and analysis.
13. Geoff Shepherd (Professor, health services research) contributed to the design and dissemination of the study findings.
14. Graham Thornicroft (Professor, community psychiatry) contributed to the design and dissemination of the study findings.
15. Genevieve Wallace (Researcher, REFOCUS programme) co-led the Service User Process Evaluation sub-study and contributed (including data collection and analysis) to the REFOCUS trial.
16. Julie Williams (Researcher, REFOCUS programme) led the INSPIRE Development, Recovery Support Measures Review and QPR Validation sub-studies and contributed (including design, data collection and analysis, and dissemination) to other sub-studies.
17. Dr Mary Leamy (Programme Co-ordinator, REFOCUS programme) had day-to-day responsibility for the study and co-ordinated all sub-studies.

All authors contributed to the dissemination of the study findings, and critically revised the content of this report.

## Publications

*Academic papers*

1.1 Slade M, Bird V, Chandler R, Fox J, Larsen J, Tew J, Leamy M (2010) *The contribution of advisory committees and public involvement to large studies: case study*, BMC Health Services Research, **10**, 323.

1.2 Leamy M, Bird V, Le Boutillier C, Williams J, Slade M (2011) *A conceptual framework for personal recovery in mental health: systematic review and narrative synthesis*, British Journal of Psychiatry, **199**, 445-452.

1.3 Le Boutillier C, Leamy M, Bird VJ, Davidson L, Williams J, Slade M (2011) *What does recovery mean in practice? A qualitative analysis of international recovery-oriented practice guidance*, Psychiatric Services, **62**, 1470-1476.

1.4 Slade M, Bird V, Le Boutillier C, Williams J, McCrone P, Leamy M (2011) *REFOCUS Trial: protocol for a cluster randomised controlled trial of a pro-recovery intervention within community based mental health teams*, BMC Psychiatry, **11**, 185.

1.5 Bird V, Le Boutillier C, Leamy M, Larsen J, Oades L, Williams J, Slade M (2012) *Assessing the strengths of mental health service users - systematic review*, Psychological Assessment, **24**, 1024-1033.

1.6 Slade M, Leamy M, Bacon F, Janosik M, Le Boutillier C, Williams J, Bird V (2012) *International differences in understanding recovery: systematic review*, Epidemiology and Psychiatric Sciences, **21**, 353-364.

1.7 Slade M, Williams J, Bird V, Leamy M, Le Boutillier C (2012) *Recovery grows up*, Journal of Mental Health, **21**, 99-104.

1.8 Tew J, Ramon S, Slade M, Bird V, Melton J, Le Boutillier C (2012) *Social factors and recovery from mental health difficulties: a review of the evidence*, British Journal of Social Work, **42**, 443-460.

1.9 Williams J, Leamy M, Bird V, Harding C, Larsen J, Le Boutillier C, Oades L, Slade M (2012) *Measures of the recovery orientation of mental health services: systematic review*, Social Psychiatry and Psychiatric Epidemiology, **47**, 1827-1835.

1.10 Shanks V, Williams J, Leamy M, Bird V, Le Boutillier C, Slade M (2013) *Measures of personal recovery: A systematic review*, Psychiatric Services, **64**, 974-980.

1.11 Bird V, Le Boutillier C, Leamy M, Williams J, Bradstreet S, Slade M (2014) *Evaluating the feasibility of complex interventions in mental health services: standardised measure and reporting guidelines*, British Journal of Psychiatry, **204**, 316-321.

1.12 Bird V, Leamy M, Tew J, Le Boutillier C, Williams J, Slade M (2014) *Fit for purpose? Validation of a conceptual framework for personal recovery with current mental health consumers*, Australian and New Zealand Journal of Psychiatry, **48**, 644-653.

1.13 Leamy M, Clarke E, Le Boutillier C, Bird V, Janosik M, Sabas K, Riley G, Williams J, Slade M (2014) *Implementing a complex intervention to support personal recovery: A qualitative study nested within a cluster randomised controlled trial*, PLoS ONE, **9**, e97091.

1.14 Le Boutillier C, Chevalier A, Lawrence V, Leamy M, Bird V, Macpherson R, Williams J, Slade M (2015) *Staff understanding of recovery-orientated mental health practice: a systematic review and narrative synthesis*, Implementation Science, **10**, 87.

1.15 Le Boutillier C, Slade M, Lawrence V, Bird V, Chandler R, Farkas M, Harding C, Larsen J, Oades L, Roberts G, Shepherd G, Thornicroft G, Williams J, Leamy M (2015) *Competing priorities: staff perspectives on supporting recovery*, Administration and Policy in Mental Health and Mental Health Services Research, **42**, 429-438.

1.16 Pesola F, Williams J, Bird V, Freidl M, Le Boutillier C, Leamy M, Macpherson R, Slade M (2015) *Development and evaluation of an Individualised Outcome Measure (IOM) for randomised controlled trials in mental health*, International Journal of Methods in Psychiatric Research, **24**, 257-265.

1.17 Slade M, Bird V, Clarke E, Le Boutillier C, McCrone P, Macpherson R, Pesola F, Wallace G, Williams J, Leamy M (2015) *Supporting recovery in patients with psychosis using adult mental health teams (REFOCUS): a multi-site cluster randomised controlled trial*, Lancet Psychiatry, **2**, 503-514.

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1.19 van der Krieke L, Bird V, Leamy M, Bacon F, Dunn R, Pesola F, Janosik M, Le Boutillier C, Williams J, Slade M (2105) *The feasibility of implementing recovery, psychosocial and pharmacological interventions for psychosis: comparison study*, Implementation Science, **10**, 73.

1.20 Williams J, Leamy M, Bird V, Le Boutillier C, Norton S, Pesola F, Slade M (2015) *Development and evaluation of the INSPIRE measure of staff support for personal recovery*, Social Psychiatry and Psychiatric Epidemiology, **50**, 777-786.

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1.22 Leamy M, Clarke E, Le Boutillier C, Bird V, Choudhury R, Macpherson R, Pesola P, Sanger K, Williams J, Williams P, Slade M 2016 *A national survey of recovery practice in community mental health teams*, British Journal of Psychiatry, **209**, 340-346.

1.23 Macpherson R, Pesola F, Leamy M, Bird V, Le Boutillier C, Williams J, Slade M (2016) *The relationship between clinical and recovery dimensions of outcome in mental health*, Schizophrenia Research, **175**, 142-147.

1.24 Slade M, Trivedi P, Chandler R, Leamy M (2016) *Developing involvement during a programme of recovery research*, Journal of Mental Health Training, Education and Practice, **11**, 244-255.

1.25 Wallace G, Bird V, Leamy M, Bacon F, Le Boutillier C, Janosik M, Macpherson R, Williams J, Slade M (2016) *Service user experiences of REFOCUS: a process evaluation of a pro-recovery complex intervention*, Social Psychiatry and Psychiatric Epidemiology, **51**, 1275-1284.

*Other outputs*

1. Slade M, Leamy M, Bird V, Le Boutillier C (2013) Mental health services and recovery. In (Thornicroft G, Ruggeri M, Goldberg D eds) “Improving Mental Health Care: The Global Challenge”, Chichester: John Wiley, 40-56.
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3. Grey B, Bailey S, Leamy M, Slade M (2014) REFOCUS Coaching Conversations for Recovery. Trainer Manual, London: Slam Partners.
4. Grey B, Bailey S, Leamy M, Slade M (2014) REFOCUS Coaching Conversations for Recovery. Participant Manual, London: Slam Partners.
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## List of Appendices

## Appendix 1 Original programme summary

The Summary of Proposal from the funded grant is shown below.

### Aims and objectives

This proposal will develop recovery-focussed (a) quality standards, fidelity measure and outcome measures; (b) manualised interventions; and (c) randomised controlled trial evidence.

### Background and rationale

There is a policy and professional consensus about the importance of ‘recovery’ in mental health services, defined as “a way of living a satisfying, hopeful, and contributing life” even with any limitations caused by illness. This has recently been elaborated: “Recovery is the process of regaining active control over one’s life. This may involve discovering (or rediscovering) a positive sense of self, accepting and coping with the reality of any ongoing distress or disability, finding meaning in one’s experience, resolving personal, social or relationship issues that may contribute to one’s mental health difficulties, taking on satisfying and meaningful social roles and calling on formal and / or informal systems of support as needed” . Mental health is an NHS priority area. The emerging evidence base for values, interventions and evaluation methodologies all inform the proposal.

### Research plans

The proposal utilises the latest MRC framework for evaluating complex interventions and relates to adult mental health services in England.

*Module 1. Define the problem*

Mental health services are insufficiently recovery orientated, but the extent of the problem is unknown. Quality standards will be developed. In relation to these standards, national prevalence will be investigated by (i) using a national dataset of mental health services; (ii) a national survey of 60 representative team managers, which will also involve asking 10 patients from each team to complete a recovery measure. Focus groups (n=15) will identify contextual blocks and enablers of recovery implementation.

*Module 2. Optimise the intervention*

A systematic review will identify the evidence for pro-recovery interventions. These will be evaluated against four criteria: clinical effectiveness; cost-effectiveness; meaningfulness; and feasibility for implementation in the NHS. A manualised intervention will be developed.

*Module 3. Optimise the evaluation*

Candidate recovery outcome measures will be identified through review, and then evaluated in 80 patients and 80 staff to establish their concurrent, content, consensual and cross-cultural validity, internal consistency, test-retest reliability and sensitivity to change. Two innovative approaches to identifying personal primary outcomes will be investigated – selecting from a predefined list and using recovery-focussed goal attainment scaling. Fidelity scales will be developed and piloted.

*Module 4. Optimise trial parameters*

A cluster randomised controlled trial will investigate the impact of the intervention manual developed in Module 2. The trial will involve 30 teams from London and Gloucestershire, with 10 patients and 10 staff participating from each team. Evaluation will use standard clinical outcomes, resource consequences, and the standardised recovery outcomes and individualised outcomes piloted in Module 3. Process evaluation will identify factors influencing implementation.

*Module 5. Knowledge transfer*

A multi-level approach to influencing NHS practice will be used, including: publication of a scientific book, training manual and information leaflets; scientific and practice-focussed conferences; web-site development; and exploring feasibility of a user-led social enterprise business to provide training and consultancy to the NHS.

**Projected outputs and dissemination plan**

The outputs will be a robust evidence base for assessing and increasing the extent to which adult mental health services focus on promoting recovery. The findings will be disseminated in six forms: a report co-published with Rethink (the largest severe mental illness charity in the UK); a scientific book; an information leaflet; scientific and practice-focussed conferences; on-line web-based resources; and by exploring the feasibility of setting up a user-led social enterprise consultancy business, employing service users and staff to provide training and consultancy to mental health services in England.

## Appendix 2 Summary of changes to original REFOCUS programme

This table shows the specific tasks planned when the application was funded in 2009, and the work undertaken in the REFOCUS programme towards each task.

| Task originally planned | Work undertaken | Description |
|---|---|---|
| **Module 1: Define the problem** | | |
| 1.1 Development of Team Quality Standards | **Completed** | The Recovery Practice Framework was developed, which provided a conceptual understanding of service support for recovery. It informed the unplanned development and evaluation of a new measure (INSPIRE). The DREEM measure was substituted for Recovery Self Assessment (RSA), which has better psychometric properties and versions for different stakeholders including staff and team leaders. The use of an existing standardised measure meant that piloting to modify the measure was not necessary. |
| 1.2 National Survey using Routine Data | **Not completed** | A scoping exercise was undertaken in relation to the Mental Health Minimum Dataset, and (as envisaged in the original proposal) the data were found to be insufficiently precise and complete to be useable. |
| 1.3 Survey of Representative Teams | **Partly completed**<br>The survey had a smaller sample size than planned (28 rather than 60 teams) | Recruitment to the survey proved more challenging than anticipated, despite the survey being extended from 12 to 42 months, and extra placement students and researcher time being allocated. Specific challenges were navigating the complex R&D governance arrangements for a national study, differing policies nationally on the involvement of Clinical Studies Officers in data collection, and working |

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| | | with services where there were no existing professional relationships with the study team. |
| 1.4 Identification of Contextual Blocks & Enablers | **Completed**<br>12 focus groups were run (15 originally planned but theoretical saturation was achieved with 12).<br>**Extended**<br>In addition, unplanned interviews were also conducted with 32 staff and 15 service users, and an unplanned systematic review of staff understanding of recovery was undertaken. | This task was extended as one of the researchers undertook a PhD on staff experiences, which involved unplanned extensions to (a) develop a grounded theory and (b) conduct a systematic review. |
| **Module 2: Optimise the intervention** | | |
| 2.1 Systematic Review of Interventions<br>2.2 Evaluation of the interventions | **Modified**<br>We developed a conceptual framework for recovery.<br>**Extended**<br>We evaluated the conceptual framework in relation to its cross-cultural validity and its relevance for current mental health service users. We developed a new and unplanned measure of feasibility called SAFE, which includes reporting guidelines for trials. We developed a new framework for recovery support for black individuals. | The original plan was to review ‘pro-recovery interventions’. A scoping review indicated that the absence of an operational definition of ‘pro-recovery’ made the review unfeasible. Therefore we developed (systematic review), validated (systematic review) and evaluated (qualitative study) the conceptual framework for recovery. As the work on the intervention manual was well progressed by this time, we did not undertake the originally planned effectiveness and economic modelling of a wide range of interventions. However, we used the implementation science findings collated towards the planned review to develop an unplanned feasibility measure. The framework for black service users was developed as one of the researchers undertook a PhD on black individuals and recovery |

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| 2.3 Development of Manual | **Completed**<br>The REFOCUS manual comprises intervention, model and implementation strategies | |
| **Module 3: Optimise the evaluation** | | |
| 3.1 Review of Measures | **Completed**<br>An unstructured narrative review of measures was planned<br>**Extended**<br>We completed three further systematic reviews of measures (recovery, recovery support, strengths) | This task was extended as one of the researchers undertook a PhD on recovery measurement |
| 3.2 Cross-Cultural Validation | **Completed**<br>We evaluated the psychometric properties of an existing measure (QPR)<br>**Extended**<br>We developed and evaluated a new measure of recovery support (INSPIRE) | INSPIRE was part of the measurement PhD |
| 3.3 Clinical Trial End-Point Measurement | **Completed**<br>The Individualised Outcome Measure (IOM) was developed, piloted, evaluated and then used in the REFOCUS trial | |
| 3.4 Development of Recovery Fidelity Scales | **Completed**<br>The Recovery Fidelity Scales and Implementation Scale were developed and used in the REFOCUS trial | |
| **Module 4: Optimise the trial parameters** | | |
| 4 Cluster Randomised Controlled Trial | **Completed**<br>Two-site cluster randomised controlled trial including casenote audit, outcome, process and economic evaluation<br>**Extended**<br>An unplanned sub-group analysis of the impact of the intervention on black individuals was added. The process evaluation was | The RCT was completed with a larger sample size (403 rather than 300 due to the nested sub-group analysis) and a shorter length (12 months rather than 18 months due to recruitment rate).<br>The sub-group analysis was added as part of the PhD on black individuals and recovery. |

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| | extended from a planned 20 interviews across all stakeholders to involve 52 staff (28 interviews, 24 in focus groups), 28 trainer reports and 37 service users (24 interviews, 13 in focus groups) | The process evaluation was extended as a response to the implementation challenges experienced during the REFOCUS trial. |
| Module 5: Knowledge transfer | | |
| 5 Dissemination | **Completed**<br>**In addition to academic outputs, we hosted three major knowledge transfer events, published the REFOCUS intervention manual with Rethink Mental Illness, and developed a web-site (researchintorecovery.com). As planned, the feasibility of a social enterprise business was explored by Rethink, and a decision made not to progress.**<br>**Extended**<br>**We started the Recovery Research Network, which now comprises 395 active recovery researchers and has met biannually since 2009.** | The REFOCUS programme was of a sufficient size to create national momentum through a recovery research network. |

## Appendix 3 Conceptual Framework sub-study: full coding framework and vote counting

| Recovery Processes | N (%) of 87 studies |
|---|---|
| **Category 1: Connectedness** | **75 (86%)** |
| *1.1 Peer support and support groups* | *39 (45%)* |
| 1.1.1 Availability of peer support | 22 (25%) |
| 1.1.2 Becoming a peer support worker or advocate | 17 (20%) |
| *1.2 Relationships* | *33 (38%)* |
| 1.2.1 Building upon existing relationships | 19 (22%) |
| 1.2.2 Intimate relationships | 9 (10%) |
| 1.2.3 Establishing new relationships | 8 (9%) |
| *1.3 Support from others* | *53(61%)* |
| 1.3.1 Support from professionals | 42 (48%) |
| 1.3.2 Supportive people enabling the journey | 27 (31%) |
| 1.3.3 Family support | 26 (30%) |
| 1.3.4 Friends and peer support | 18 (21%) |
| 1.3.5 Active or practical support | 4 (5%) |
| *1.4 Being part of the community* | *35 (40%)* |
| 1.4.1 Contributing and giving back to the community | 21 (24%) |
| 1.4.2 Membership of community organisations | 13 (15%) |
| 1.4.3 Becoming an active citizen | 11 (13%) |
| **Category 2: Hope and optimism about the future** | **69 (79%)** |
| *2.1 Belief in possibility of recovery* | *30 (34%)* |
| *2.2 Motivation to change* | *15 (17%)* |
| *2.3 Hope-inspiring relationships* | *12 (14%)* |
| 2.3.1 Role-models | 8 (9%) |
| *2.3 Positive thinking and valuing success* | *10 (11%)* |
| *2.4 Having dreams and aspirations* | *7 (8%)* |
| **Category 3: Identity** | **65 (75%)** |
| *3.1 Dimensions of identity* | *8 (9%)* |
| 3.1.1 Culturally specific factors | 7 (8%) |
| 3.1.2 Sexual identity | 2 (2%) |
| 3.1.3 Ethnic identity | 4 (5%) |
| 3.1.4 Collectivist notions of identity | 6 (7%) |
| *3.2 Rebuilding/redefining positive sense of self* | 57 (66%) |
| 3.2.1 Self-esteem | 21 (24%) |
| 3.2.2 Acceptance | 21 (24%) |
| 3.2.3 Self-confidence and self-belief | 11 (13%) |
| *3.3 Over-coming stigma* | 40 (46%) |
| 3.3.1 Self-stigma | 27 (31%) |
| 3.3.2 Stigma at a societal level | 32 (37%) |
| **Category 4: Meaning in life** | **59 (66%)** |
| *4.1 Meaning of mental illness experiences* | *30 (34%)* |
| 4.1.1 Accepting or normalising the illness | 22 (25%) |
| *4.2 Spirituality (including development of spirituality)* | *36 (41%)* |
| *4.3 Quality of life* | *57 (65%)* |

| | |
|---|---|
| 4.3.1 Well-being | 27 (31%) |
| 4.3.2 Meeting basic needs | *18 (21%)* |
| 4.3.3 Paid voluntary work or work related activities | 19 *(22%)* |
| 4.3.4 Recreational and leisure activities | 8 (9%) |
| 4.3.5 Education | 7 (8%) |
| *4.4 Meaningful social and life goals* | *15 (17%)* |
| 4.4.1 Active pursuit of previous or new life or social goals | 15 (17%) |
| 4.4.2 Identification of previous or new life or social goals | 8 (9%) |
| *4.5 Meaningful life and social roles* | *40 (46%)* |
| 4.5.1 Active pursuit of previous or new life or social roles | 40 (46%) |
| 4.5.2 Identification of previous of new life or social roles | 34 (39%) |
| *4.6 Rebuilding of life* | *20 (23%)* |
| 4.6.1 Resuming with daily activities and daily routine | 12 (14%) |
| 4.6.2 Developing new skills | 8 (9%) |
| **Category 5: Empowerment** | **79 (91%)** |
| *5.1 Personal responsibility* | *79 (91%)* |
| 5.1.1 Self-management | 60 (69%) |
| Coping skills | 25 (29%) |
| Managing symptoms | 22 (25%) |
| Self-help | 12 (14%) |
| Resilience | 25 (29%) |
| Maintaining good physical health and well-being | 12 (14%) |
| 5.1.2 Positive risk-taking | 17 (20%) |
| *5.2 Control over life* | *78 (90%)* |
| 5.2.1 Choice | 31 (36%) |
| Knowledge about illness | 17 (20%) |
| Knowledge about treatments | 7 (8%) |
| 5.2.2 Regaining independence and autonomy | 23 (26%) |
| 5.2.3 Involvement in decision-making | 23(26%) |
| Care planning | 35 (40%) |
| Crisis planning | 7 (8%) |
| Goal setting | 12 (14%) |
| Strategies for medication | 25 (29%) |
| Medication not whole solution | 11 (13%) |
| 5.2.4 Access to services and interventions | 13 (15%) |
| *5.3 Focussing upon strengths* | *14 (16%)* |

## Appendix 4 Recovery Practice Framework sub-study: documents identified in the review (n=30)

| | Country | Type of document | Self-ascribed document classification | No. of items extracted | Level of service user involvement |
|---|---|---|---|---|---|
| 1 | USA | Policy | Goals and principles | 10 | Collaboration |
| 2 | England | Policy | Standards | 4 | Consultation |
| 3 | England | Policy | Not specified | 7 | None specified |
| 4 | New Zealand | Policy | Competencies | 10 | Control |
| 5 | England | Policy | Capabilities | 10 | Consultation |
| 6 | England | Policy | Principles | 12 | Collaboration |
| 7 | England | Policy | Principles | 6 | None specified |
| 8 | England | Policy | Recommendations | 17 | Consultation |
| 9 | Scotland | Policy | Knowledge, skills and values framework | 3 | Consultation |
| 10 | New Zealand | Policy | Vision | 15 | Collaboration |
| 11 | Republic of Ireland | Policy | Criteria | 27 | Consultation |
| 12 | England | Policy | Not specified | 1 | Consultation |
| 13 | USA | Research based | Indicators | 53 | Consultation |
| 14 | England | Book chapter | Components | 3 | Collaboration |
| 15 | USA | Book chapter | Standards | 126 | Consultation |
| 16 | England | Book chapter | Characteristics | 6 | None specified |
| 17 | USA | Opinion | Not specified | 8 | Control |

| | | | | | |
|---|---|---|---|---|---|
| 18 | USA | Opinion | Standards | 23 | None specified |
| 19 | UK | Opinion | Steps | 21 | None specified |
| 20 | USA | Opinion | Standards | 16 | Collaboration |
| 21 | USA | Opinion | Implementation framework | 12 | None specified |
| 22 | USA | Opinion | Components | 19 | None specified |
| 23 | New Zealand | Opinion | Framework | 7 | Control |
| 24 | England | Opinion | Action points | 24 | None specified |
| 25 | USA | Practice based | Standards | 13 | Collaboration |
| 26 | USA | Practice based | Principles | 8 | Collaboration |
| 27 | Denmark | Practice based | Goals | 12 | Consultation |
| 28 | England | Practice based | Standards | 10 | Collaboration |
| 29 | England | Practice based | Vision and principles | 5 | Consultation |
| 30 | England | Practice based | Benchmark | 10 | None specified |

## Appendix 5 Recovery Practice Framework sub-study: coding framework

### Category 1: Promoting citizenship

*Seeing beyond the service user*
    Challenge discrimination, stigma and inequality
        Promote mental well-being in the community
*Service user rights*
    Advocacy
*Social inclusion*
    Housing support
    Social network
    Community integration
        Community opportunities
*Meaningful occupation*
Valued life roles and social roles
    Identity
    Spirituality
    Giving back to others
    Employment and training

### Category 2: Organizational commitment

*Recovery vision*
*Workplace support structures*
    Leadership
    Policies and procedures
*Quality improvement*
    Services are directed by and responsive to service users, families and carers
    Routine evaluation and service improvement
*Care pathway*
    Service accessibility
        Location and physical environment
        Continuity of care
        Long-term commitment
    Inter-agency working
*Workforce planning*
    Workforce diversity representative of community it serves
    Recruitment guided by recovery values
    Staff support
        Staff knowledge, skills and values
        Lifelong learning and reflective practice
        Evidence based practice
        Supervision and appraisal
        Staff health and wellbeing
        Foster hope and optimism in staff

### Category 3: Supporting personally defined recovery

*Individuality*
    Empowerment and self-determination
    Personalisation

*Informed choice*
    - Access to information and options
    - Personal choice
    - Shared decision-making
    - Goal striving
        - Goal attainment
        - Celebrate achievements
    - Positive risk taking
        - The right to make mistakes

*Peer support*
    - Self-management
        - Access to resources
    - Recovery narratives

*Strengths focus*
    - Natural supports

*Holistic approach*
    - Wellness and crisis planning
        - Mental well-being
        - Physical well-being
        - Dual diagnosis
        - Medication
        - Psychological therapies
            - Alternative therapies
            - Advance directives
    - Care co-ordination

**Category 4: Working relationship**

*Partnerships*
    - Service user independence and autonomy
        - Respect and value people as individuals
    - Work creatively
        - Support stages of engagement
        - Promote risk self-management
    - Reduce coercion

*Inspiring hope*
    - Service user primacy
    - Value and believe in service users

## Appendix 6 Recovery Practice Framework sub-study: characteristics of recovery oriented practice

| Guidance | PROMOTING CITIZENSHIP | | | | ORGANISATIONAL COMMITMENT | | | | | SUPPORTING PERSONALLY DEFINED RECOVERY | | | | | WORKING RELATIONSHIP | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Seeing beyond service user | Service user rights | Social inclusion | Meaningful occupation | Recovery vision | Workplace support structures | Quality improvement | Care pathway | Workforce planning | Individuality | Informed choice | Peer support | Strengths focus | Holistic approach | Partnerships | Inspiring hope |
| 1 | | | | | | X | X | X | X | X | X | | | X | X | |
| 2 | X | | | | | | | | | | | | | | X | |
| 3 | X | X | X | X | X | | | X | X | | X | | | | | |
| 4 | X | X | X | | X | | X | | X | X | X | X | | X | X | X |
| 5 | X | X | | X | | | X | X | X | | X | | X | X | X | X |
| 6 | | | X | X | X | | | X | | X | X | | X | X | X | X |
| 7 | X | | | | X | | | | | X | | | X | | | |
| 8 | X | | X | X | | X | X | | X | X | X | | | X | X | X |
| 9 | X | X | X | X | | | X | | X | X | X | X | X | X | | X |
| 10 | X | X | X | X | X | X | X | | X | X | | X | | X | X | |

| | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 11 | X | X | X | X | X | X | X | | X | X | X | X | X | X | X | X |
| 12 | | X | | | | | | | X | | | | | | X | |
| 13 | | X | X | X | X | X | X | X | X | X | X | X | | X | X | |
| 14 | | | X | | | | | | | | | | | | | X |
| 15 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
| 16 | | X | | | X | | X | | | X | X | | X | X | X | X |
| 17 | | | X | X | X | X | X | | X | | X | X | | X | | X |
| 18 | | X | X | | X | X | X | X | X | X | X | X | | X | | |
| 19 | | | | X | X | | X | X | | X | X | | X | X | X | X |
| 20 | | | X | | X | X | X | X | X | X | X | | X | X | X | X |
| 21 | | | X | X | X | X | X | | X | X | X | X | X | | X | X |
| 22 | | X | X | X | X | | X | X | X | X | X | X | | X | X | X |
| 23 | X | X | X | X | | X | X | | | X | X | X | | X | X | X |
| 24 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
| 25 | X | | X | | | | | | X | X | X | | | | | X |
| 26 | | | X | | X | | X | X | | X | | | X | X | X | |
| 27 | | | X | X | | | X | | X | X | X | | | | X | X |
| 28 | X | | X | | | | X | X | X | | X | | | X | | |
| 29 | X | X | X | X | | X | | | X | X | X | X | | X | X | X |
| 30 | X | | X | X | | | | | | X | X | | | | | X |

| | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Total** | **16** | **15** | **23** | **18** | **17** | **13** | **21** | **13** | **21** | **23** | **24** | **13** | **12** | **21** | **21** | **20** |

## Appendix 7 Staff Perceptions sub-study: focus group topic guide

Aims:
1) *To explore what participants think helps or hinders implementation.*
*2) To explore what participants identify as potential solutions to implementation barriers.*

**What helps implementation?** Facilitating factors (25 mins)
*Link: We've been hearing about recovery oriented practice and what recovery means to you, I'd like to start by asking…*

*What helps you and your team to promote recovery?*

- Knowledge: Are you familiar with this approach?
- Skills: Do you know how to work in a recovery-oriented way?
- Social/professional role and identity: Some people say that this approach might challenge professionals' roles and identity. What do you think?
- Beliefs about capabilities: How well equipped or confident are you that you can work in this way?
- Beliefs about consequences: Do you believe that promoting recovery in services is a good thing?
- Motivation and goals: Are there other things that you would like to do or achieve that might interfere with this approach?
- Memory, attention and decision-making processes: Do you think you will have to pay more attention to work in this way and will you remember to do it?
- Environmental context and resources: To what extent do physical or resource factors facilitate or hinder you and your team from promoting recovery?
- Social influences: To what extent do social influences facilitate or hinder you and your team from promoting recovery (peers, managers, other professional groups, service users, carers)?
- Emotional regulation: To what extent do emotional factors facilitate or hinder?

**What prevents or hinders implementation?** Barriers (25 mins)
*What prevents or hinders you and your team from promoting recovery?*

**Implementation solutions** (25 mins)
*What solutions would you recommend to address these identified barriers?*

## Appendix 8 Staff Perceptions sub-study: staff and team leader interview topic guide

### 1. Staff perceptions of recovery

What is it that you hope to achieve in your practice with clients? What are your priorities and goals for practice? *What is important?*
I'd like to ask you to describe an example where you have supported a person's recovery

### 2. Barriers and facilitators to implementing recovery – Individual

Describe how, and to what extent *you* have been able to implement recovery orientated practice
What is it that enables YOU to support recovery?

### 3. Barriers and facilitators to implementing – Team practice

Describe how, and to what extent *your team* has implemented recovery orientated practice
What is it that enables YOUR TEAM to support recovery?

**Are there any [other] factors that influence whether or not you or your team are able to support a person's recovery?**

## Appendix 9 Staff Perceptions sub-study: senior manager interview topic guide

### Section 1: Understanding and supporting recovery

*Recovery can be interpreted and understood in many ways, how would you describe it?*

### Section 2: Barriers and facilitators to supporting recovery

*How would you describe the core business of this organisation?*
*Has the introduction of care pathways and/or clinical academic groups enhanced recovery support?*
*In your opinion, do any practice models support recovery more than others, e.g. Early Intervention Services vs Recovery & Support?*

### Section 3: Gap between system and service users priorities

*How does the organisation put the priorities of the service user first?*
*In your opinion, are there any tensions between your understanding of recovery and the reality of what happens in practice?*

## Appendix 10 Staff Perceptions sub-study: staff characteristics (n=97)

| Mean (SD) | **Focus Groups**<br>n=65 | **Interviews**<br>n=32 |
|---|---|---|
| **Age** (years) | 45.43 (8.116) | 44.58 (9.344) |
| **Time since Qualified** (months) | | 228.52 (121.139) |
| **Time in Mental Health Services** (months) | 207.78 (105.496) | 209.81 (120.736) |
| **Time in post** (months) | 50.58 (46.785) | 66.84 (66.735) |
| **n (%)** | | |
| **Gender** | | |
| Male | 26 (40.6) | 13 (40.6) |
| Female | 38 (58.5) | 19 (59.4) |
| Missing | 1 (1.5) | 0 (0.0) |
| **Ethnicity** | | |
| White British | 50 (76.9) | 28 (87.5) |
| White Irish | 2 (3.1) | 1 (3.1) |
| White Other | 1 (1.5) | 2 (6.3) |
| Black/Black British-African | 5 (7.7) | 1 (3.1) |
| Black/Black British-Caribbean | 2 (3.1) | 0 (0.0) |
| Black Other | 3 (4.6) | 0 (0.0) |
| Asian/Asian British-Other | 1 (1.5) | 0 (0.0) |
| Missing | 1 (1.5) | 0 (0.0) |
| **NHS Trust** | | |
| South London and Maudsley NHS Foundation Trust | 13 (20.0) | 16 (50.0) |
| 2gether NHS Foundation Trust | 14 (21.5) | 10 (31.3) |
| Leicestershire Partnership NHS Trust | 12 (18.5) | 2 (6.3) |
| Tees, Esk and Wear Valleys NHS Foundation Trust | 13 (20.0) | 4 (12.5) |
| Devon Partnership NHS Trust | 13 (20.0) | 0 (0.0) |
| **Job Role** | | |
| Clinician | 34 (52.3) | 18 (56.3) |
| Team Leader | 31 (47.7) | 6 (18.8) |
| Senior Manager | 0 (0.0) | 8 (25.0) |
| **Team** | | |
| Assertive Outreach | 15 (23.1) | 1 (3.1) |
| Early Intervention | 12 (18.5) | 4 (12.5) |
| Forensic | 0 (0.0) | 0 (0.0) |
| Support and Recovery | 32 (49.2) | 18 (56.3) |
| Rehabilitation | 2 (3.1) | 0 (0.0) |
| Supported housing | 2 (3.1) | 0 (0.0) |
| Management | 0 (0.0) | 7 (21.9) |
| Works across teams | 2 (3.1) | 1 (3.1) |
| **Profession** | | |

| | | |
|---|---|---|
| Psychiatrist | 2 (3.1) | 2 (6.3) |
| Nurse | 40 (61.5) | 17 (53.1) |
| Social worker | 7 (10.8) | 2 (6.3) |
| Occupational Therapist | 9 (13.8) | 5 (15.6) |
| Psychologist | 1 (1.5) | 2 (6.3) |
| Associate practitioner | 0 (0.0) | 1 (3.1) |
| Vocational Specialist | 1 (1.5) | 1 (3.1) |
| Support time and Recovery worker | 2 (3.1) | 1 (3.1) |
| Support worker | 2 (3.1) | 0 (0.0) |
| Exercise and health practitioner | 1 (1.5) | 0 (0.0) |
| Manager (no clinical background) | 1 (1.5) | 1 (3.1) |
| **Highest Qualification** | | |
| NVQ 4 | 0 (0.0) | 1 (3.1) |
| HND | 0 (0.0) | 4 (12.5) |
| Bachelors | 0 (0.0) | 13 (40.6) |
| Masters | 0 (0.0) | 10 (31.3) |
| PhD | 0 (0.0) | 2 (6.3) |
| Missing | 65 (100) | 2 (6.3) |
| **Grade** | | |
| Band 2 | 1 (1.5) | 0 (0.0) |
| Band 3 | 2 (3.1) | 2 (6.3) |
| Band 4 | 0 (0.0) | 1 (3.1) |
| Band 5 | 6 (9.2) | 1 (3.1) |
| Band 6 | 17 (26.2) | 12 (37.5) |
| Band 7 | 2 (3.1) | 5 (15.6) |
| Band 8a | 0 (0.0) | 2 (6.3) |
| Band 8b | 1 (1.5) | 3 (9.4) |
| Band 8c | 0 (0.0) | 1 (3.1) |
| Band 8d | 0 (0.0) | 1 (3.1) |
| Consultant | 2 (3.1) | 2 (6.3) |
| Professor | 0 (0.0) | 1 (3.1) |
| Social Services | 2 (3.1) | 0 (0.0) |
| Student | 1 (1.5) | 0 (0.0) |
| Missing | 31 (47.7) | 1 (3.1) |

## Appendix 11 Staff Perceptions sub-study: systematic review search terms

| | **Search Terms (free text terms)** identified in the title, abstract or keywords (subject headings specific to each database included). | **Concept** |
|---|---|---|
| 1 | "mental illness" OR "mental disorder" OR "mental disease" OR "mental health" OR mental adj2 problem$ OR psychol$ adj2 (health or problem$ or disorder$ or illness$) OR psychiatr$ adj2 (health or illness$ or disorder$ or problem$ or disabilit$) | All mental illness (not diagnosis specific) |
| 2 | 'recover$' | Recovery (truncated terms covering recovery orientation, recovery promotion, recovery support etc) |
| 3 | Staff OR worker$ OR "care coordinator$" OR personnel OR employee$ OR clinician$ OR professional$ OR practitioner$ OR provider$ OR leader$ OR manager$ OR physician$ OR psychiatrist$ OR doctor$ OR nurse$ OR "occupational therapist$" OR "social work$" OR psychologi$ OR "peer support$" OR "vocational specialist$" OR volunteer$ OR student$ OR "decision maker$" | Staff |
| 4 | mean$ OR define$ OR comprehen$ OR opinion$ OR view$ OR belief$ OR knowledge$ OR perspective$ OR attitude$ OR discourse$ OR theor$ OR experience$ OR perception$ OR rhetoric OR awareness OR translat$ OR implement$ OR operationali$ OR philosoph$ OR appl$ OR understand$ OR conceptuali$ OR interpret$ OR value$ OR behavio$ | Understanding and Applied to practice |
| 5 | 1 AND 2 AND 3 AND 4 | |
| 6 | Limit to English Language AND Remove duplicates | |

## Appendix 12 Staff Perceptions sub-study: vote counting for Personal Recovery category

| | Promoting Citizenship | | | | Organisational Commitment | | | | | Supporting Personally Defined Recovery | | | | | Working Relationship | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Seeing beyond service user | Service user rights | Social inclusion | Meaningful occupation | Recovery vision | Workplace support structures | Quality improvement | Care pathway | Workforce planning | Individuality | Informed choice | Peer support | Strengths focus | Holistic approach | Partnerships | Inspiring hope | **Total** |
| 1 | | | | | | | | | | | | | | X | | | 1 |
| 2 | | | X | | | | | | | | | X | | | | | 2 |
| 3 | | | | | | | | | | | | | | | | | 0 |
| 4 | | | X | | | | | X | | | | | | | | | 2 |
| 5 | | X | | | | | | | | X | | | | | X | | 3 |
| 6 | | | | | | | | | | | X | | | | X | X | 3 |
| 7 | | | | | | | | | | | | | | X | X | | 2 |
| 8 | | | | | | | | | | | X | | | X | X | | 3 |
| 9 | | | | | | | | | | | | | | | | | 0 |
| 10 | | | X | X | | | | | | | | | | X | X | X | 5 |
| 11 | | X | X | | | | X | X | | X | | | X | X | | X | 8 |
| 12 | | | X | X | | | | | | | | | X | X | | | 4 |
| 13 | | | | | | | | | | | | | | | | | 0 |
| 14 | | | | X | | | X | | | | X | | | | | | 3 |
| 15 | | X | | | | | | | | X | X | | X | | X | X | 6 |
| 16 | | | | | | | | | | | | | | X | | | 1 |
| 17 | | | X | | | | | | | | | | | | | | 1 |
| 18 | | | | X | | | | | | | | | | X | | X | 3 |
| 19 | | | | | | | | | | | | | | | | | 0 |
| 20 | | | X | X | | | | | | X | X | | | | | X | 5 |
| 21 | X | | | | | | | | | | X | | | | X | | 3 |
| 22 | | | | | | | | | | | X | | | | | X | 2 |
| **Total** | **1** | **3** | **7** | **5** | **0** | **0** | **2** | **2** | **0** | **4** | **7** | **1** | **3** | **8** | **7** | **7** | **57** |

## Appendix 13 Staff Perceptions sub-study: vote counting for Clinical Recovery category

| | Deficit Perspective | Medication Adherence | Symptom Remission | Gaining Insight | Absence of Relapse | Risk / Crisis Management | Meet Basic Survival Needs | Activities of Daily Living | Stabilising Or Fixing Patients | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | | X | X | | | X | | | | **3** |
| 2 | X | | X | | | | | | | **2** |
| 3 | X | | | | | | | | X | **2** |
| 4 | | X | X | | X | | | X | X | **5** |
| 5 | X | X | | | | | | | | **2** |
| 6 | | X | | X | | | | | X | **3** |
| 7 | | | | | | X | X | | | **2** |
| 8 | | X | | X | | X | | X | X | **5** |
| 9 | | X | X | | X | | | X | X | **5** |
| 10 | X | X | X | | | X | | | X | **5** |
| 11 | | X | | | | | | | | **1** |
| 12 | | | | | | | | | | **0** |
| 13 | | | | | | | | | | **0** |
| 14 | | | | | | X | | | | **1** |
| 15 | X | | | | | X | | | | **2** |
| 16 | | | | | | X | | | X | **2** |
| 17 | | | X | | | X | | | X | **3** |
| 18 | | | | | | | | | | **0** |
| 19 | | | | | | | | | | **0** |
| 20 | X | | | | | | | | | **1** |
| 21 | | | | | | X | | | | **1** |
| 22 | | | | | | | | | | **0** |
| **Total** | **6** | **8** | **6** | **2** | **2** | **9** | **1** | **3** | **8** | **45** |

# Appendix 14 Staff Perceptions sub-study: vote counting for Service-defined Recovery category

| | Owned by the organisation | Administrative / financially driven goals | A tool to reduce costs | Service throughput / moving-on | Discharge | Reducing service accessibility | Setting limits on service provision | **Total** |
|---|---|---|---|---|---|---|---|---|
| 1 | | | | X | | | | **0** |
| 2 | | X | | | X | | X | **3** |
| 3 | | | | | | | | **0** |
| 4 | | | | | | | | **0** |
| 5 | | | X | | | | X | **2** |
| 6 | | | | | | | | **0** |
| 7 | X | X | | | | | | **2** |
| 8 | | X | | | X | X | | **3** |
| 9 | | | | | | | | **0** |
| 10 | X | | | X | | | | **2** |
| 11 | | | | | | | | **0** |
| 12 | | X | | | | | | **1** |
| 13 | | | | | | | | **0** |
| 14 | | | | | X | | | **1** |
| 15 | | X | | | X | | X | **3** |
| 16 | | | | | | | | **0** |
| 17 | | X | | | | | | **1** |
| 18 | | | | | | | | **0** |
| 19 | | | | | X | | | **1** |
| 20 | | | | | | | | **0** |
| 21 | | | | | | | | **0** |
| 22 | | | | | | | | **0** |
| **Total** | **2** | **6** | **1** | **2** | **4** | **1** | **3** | **19** |

## Appendix 15 Staff Perceptions sub-study: comparison by country, service setting and professional group

| Study | Country | Service setting | Professional group | Clinical recovery | Personal recovery | Service-defined recovery |
|---|---|---|---|---|---|---|
| 1 | Australia | In-patient | Nurses | X | X | X |
| 2 | USA | Across settings | MDT | X | X | X |
| 3 | UK | In-patient | Nurses | X | | |
| 4 | Thailand | In-patient | Nurses | X | X | |
| 5 | Australia | Community | Social workers | X | X | X |
| 6 | USA | Community | Case managers | X | X | |
| 7 | Canada | Across settings | MDT | X | X | X |
| 8 | USA | Community | MDT | X | X | X |
| 9 | Hong Kong | Across settings | Psychiatrists | X | | X |
| 10 | UK | Across settings | Team leaders | X | X | X |
| 11 | Europe | In-patient | MDT | X | X | |
| 12 | New Zealand | Across settings | Occupational therapists | | X | X |
| 13 | Australia | Not known | MDT | | X | |
| 14 | UK | Across settings | Clinical psychologists | X | X | X |
| 15 | USA | Not known | Social workers | X | X | X |
| 16 | Canada | Community | MDT | X | X | |
| 17 | USA | Across settings | Psychiatrists | X | X | X |
| 18 | Australia | Community | Art therapists | | X | |
| 19 | USA | Community | Case managers | | | X |

| Study | Country | Service setting | Professional group | Clinical recovery | Personal recovery | Service-defined recovery |
|---|---|---|---|---|---|---|
| 20 | Canada | Community | MDT | X | X | |
| 21 | Canada | In-patient | MDT | X | X | |
| 22 | USA | Community | Case managers | | X | |
| | | | **Total** | **17** | **19** | **12** |

## Appendix 16 Framework For Black Service Users sub-study: coding framework

**Core category: Identity - Gaining a positive sense of self**

**1.Defining the self**

- **1.1 Multiple dimensions and identities of a person**
  - 1.1.1 Collectivist identity
  - 1.1.2 Individualistic elements of identity
  - 1.2.3 Importance of occupation for defining the self
  - 1.2.4 Religious and spiritual identities
  - 1.2.5 Illness is not the whole identity
- **1.2 Comparisons with others**
  - 1.2.1 Upward and downward social comparisons
  - 1.2.2 Comparisons with others
  - 1.2.3 Normalising the experience
- **1.3 Having a strong identity**
  - 1.3.1 Being able to tell your story
  - 1.3.2 Being an empowered individual
  - 1.3.3 Having a greater understanding of yourself and your experience
  - 1.3.4 Having connections with strong people - positive role models and success stories
  - 1.3.5 Regaining a sense of worth

**2.Negative sense of self**

- **2.1. Societal level threats**
  - 2.1.1 Family or community lacking understanding
  - 2.1.2 Social disadvantage
  - 2.1.3 The attitudes of society
- **2.2.Illness as a threat to identity**
  - 2.2.1 Loss of the person
  - 2.2.2 Lower self-esteem - having a negative self-image
  - 2.2.3 Negative experience of the mental health system

**3.Continuum of recovery - from returning to the same as before to becoming a new person**

- **3.1 Returning to the same as before**
  - 3.1.1 Having the same life as before
  - 3.12 Learning to or starting to enjoy things again
  - 3.1.3 Returning to your old self
  - 3.1.4 Being able to do the same things as before
- **3.2 Recovery is about change – becoming a new person**
  - 3.2.1 Moving forward in life
  - 3.2.2 Development and change in personality
  - 3.2.3 Becoming a new person
- **3.3 Meaning of recovery depends on meaning of illness**
  - 3.3.1 The meaning of recovery
  - 3.3.2 The meaning of the 'illness' experience
  - 3.3.3 Help seeking experience

**4. Mental health System level facilitators of gaining a positive sense of self**

- **4.1 Being treated as an individual**
  - 4.1.1 Focusing on the whole person
  - 4.1.2 Staff valuing and accepting difference
  - 4.1.3 Valuing the individuals own story

- **4.2 Support from the right services and professionals**
  - 4.2.1 Services are there when you need them
  - 4.2.2 Peer support
  - 4.2.3 Importance of medication as a support
  - 4.2.4 Help to meet your goals and ambition
  - 4.2.5 Help seeking outside of the mental health system
  - 4.2.6 Ensuring the person's basic needs are met
  - 4.2.7 Access to a range of services including talking therapies
- **4.3 Staff as a facilitator of a positive identity**
  - 4.3.1 Communication with staff
  - 4.3.2 Down to the individual qualities of staff members
  - 4.3.3 Having staff members or someone who understands you
  - 4.3.4 Partnership working

**5. Facilitators of a positive sense of self beyond the mental health system**

- **5.1 Individual / intrapersonal level facilitators of a positive identity**
  - 5.1.1 Coping and living with the illness
  - 5.1.2 Hope and optimism - you can recover
  - 5.1.3 Importance of occupation
  - 5.1.4 Planning for the future
- **5.2 Connecting with people - interpersonal facilitators of a positive identity**
  - 5.2.1 Overcoming isolation
  - 5.2.2 Practical support
  - 5.2.3 Sharing the problem
  - 5.2.4 Support from family and friends
- **5.3 Community and societal level facilitators of positive identity**
  - 5.3.1 Race, culture and ethnicity as a support
  - 5.3.2 Overcoming discrimination
  - 5.3.3 Importance of the community
  - 5.3.4 Importance of religion and spirituality
  - 5.3.5 Empowerment – being an empowered citizen

## Appendix 17 Strengths Measures Review sub-study: search strategy

**Strengths terms**
strength$ adj based
personal adj strength$
strengths.
character adj strength$
solution-focus$.
solution adj building
client adj strength$
capacity adj3 (orientat$ or building
strength$ adj2 virtue$
need$ adj strength$
asset.mp.
patient$ adj strength$
person$ adj strength$
individual adj strength$
diagnostic adj strength$
virtue$
abilit$ adj based
capabilit$ adj based
forte
talent
skill$ adj based
achievement$ adj based

**Author search**
(rapp charles or rapp charles a or rapp charlie).au.
(chamberlain r m or chamberlain r n or chamberlain ronna or chamberlain ronna l).au.
goscha richard j.au.
(seligman m e p or seligman martin or seligman martin e or seligman martin e p or seligman martin e p ed).au.
(park n or park nan s or park nan sook or park nansook).au.
(peterson c or peterson chris or peterson chris h or peterson chris l or peterson chris l ed or peterson christopher or peterson christopher m or peterson christopher wayne).au.

**Known scales or terms unlikely to be picked up by the above terms**
values in action
VIA adj strength$
client assessment of strength$
interest$ and goal$

**Assessment / approach keyword terms**
approach$
model$
assessment
questionnaire$
survey
perspective$
practice
inventory.
therap$.mp.
measur$.mp.
motivation$ adj interview$
coaching
theor$
classification
orientat$
stateg$
evaluat$
case adj manage$
interview$.
manual$.
treatment.
intervention.

CASIG
positive adj psychology OR positive psychology/
authentic adj2 happ$
4-D adj2 strength$

**MESH heading terms**
Measurement/
Practice (Psychology)
Interviews/
Models/
Questionnaires/
Surveys/
Clinical Practice/ or exp Practice/
Strategies/
Coaching Psychology/
Treatment/
Inventories/
Problem Solving/
Models, Psychological/
Models, Nursing/
Needs Assessment/ or "Outcome and Process Assessment (Health Care)"/ or "Self Assessment (Psychology)"/ or "Outcome Assessment (Health Care)"/
Interview, Psychological/ or Interview/
Questionnaires/
psychological model/ or model/
outcome assessment/ or psychologic assessment/ or occupational therapy assessment/ or clinical assessment tool/ or nursing assessment/ or clinical assessment/
self evaluation/ or "evaluation and follow up"/ or clinical evaluation/ or evaluation/

## Appendix 18 SAFE Development sub-study: SAFE measure

SAFE assesses the extent to which an intervention is feasible for implementation in mental health services in the National Health Service (NHS) in England.

The reference for this measure is:

> Bird VJ, Le Boutillier C, Leamy M, Williams J, Bradstreet S, Slade M (2014) *Evaluating the feasibility of complex interventions in mental health services: standardised measure and reporting guidelines*, British Journal of Psychiatry. DOI:10.1192/bjp.bp.113.128314.

The measure comprises two sub-scales: Blocks (8 items) and Enablers (8 items). Circle **one** answer for each item.

---

### BLOCKS SUB-SCALE

*These items are blocks to implementation.*

**1. Do staff require specific training to deliver the intervention?**

Yes Partial No Unable to rate

**Yes**: *The intervention requires more than four hours of training*
**Partial**: *The intervention requires up to four hours of training*
**No**: *The intervention does not require any specific training*
**Unable to rate:** *Not enough information provided to rate item*

**2. Is the intervention complex?**

Yes Partial No Unable to rate

**Yes:** *The intervention is made up of more than three separate components*
**Partial:** *The intervention contains two or three separate components*
**No:** *The intervention only has one component*
**Unable to rate:** *Not enough information provided to rate item etc*

**3. Is the intervention time consuming to provide?**

Yes Partial No Unable to rate

**Yes:** *The intervention requires more than two hours per week of work (per client)*
**Partial:** *The intervention requires more half an hour but less than two hours or work per week (per client)*
**No:** *The intervention requires less than half an hour per week (per client)*
**Unable to rate:** *Not enough information provided to rate item*

4. **Does the intervention include/require ongoing support and supervision?**

Yes Partial No Unable to rate

**Yes:** *The intervention requires an extra weekly supervision or support session*
**Partial:** *The intervention requires an additional monthly supervision or support session*
**No:** *The intervention does not require any additional support sessions or supervision*
**Unable to rate:** *Not enough information provided to rate item*

5. **Does the intervention require additional human resources?**

Yes Partial No Unable to rate

**Yes:** *The whole team is required to provide the intervention.*
**Partial:** *More than one member of staff are involved in providing the intervention*
**No:** *The intervention can be provided by one member of staff*
**Unable to rate:** *Not enough information provided to rate item*

6. **Does the intervention require additional material resources?**

Yes Partial No Unable to rate

**Yes:** *Sizeable resources or special equipment which staff would not usually have access to e.g. a dedicated room, instruments, art materials*
**Partial:** *The intervention requires additional but readily available resources e.g. computers*
**No:** *The intervention does not require any additional resources that staff would not usually have access to*
**Unable to rate:** *Not enough information provided to rate item*

7. **Is the intervention costly to set up?**

Yes Partial No Unable to rate

**Yes:** *The intervention is likely to be too costly to provide without extra funding*
**Partial:** *The intervention is likely to require other costs to be de-prioritised*
**No:** *The intervention cost is low*
**Unable to rate:** *Not enough information provided to rate item*

### 8. Are there known adverse events associated with the intervention?

Yes Partial No Unable to rate

| | |
|---|---|
| **Yes:** | *There are known serious adverse events associated with the intervention* |
| **Partial:** | *There are known adverse events associated with the intervention* |
| **No:** | *There are no known serious or adverse events associated with the intervention* |
| **Unable to rate:** | *Not enough information provided to rate item* |

---

## ENABLERS SUB-SCALE

*These items are enablers of implementation.*

### 9. Is the intervention applicable to the population of interest (e.g. adults using community mental health teams)

Yes Partial No Unable to rate

| | |
|---|---|
| **Yes:** | *The intervention has been designed for the population of interest* |
| **Partial:** | *The intervention has been designed for a general mental health population or can be adapted to be applicable to the population of interest* |
| **No:** | *The intervention is not applicable to the population of interest* |
| **Unable to rate:** | *Not enough information provided to rate item* |

### 10. Is the intervention manualised?

Yes Partial No Unable to rate

| | |
|---|---|
| **Yes:** | *All aspects of the intervention are manualised* |
| **Partial:** | *Some components of the intervention are manualised* |
| **No:** | *The intervention is not manualised* |
| **Unable to rate:** | *Not enough information provided to rate item* |

### 11. Is the intervention flexible (i.e. can be tailored to the context and situation)?

Yes Partial No Unable to rate

| | |
|---|---|
| **Yes:** | *The intervention is flexible and can be tailored to the context and situation* |
| **Partial:** | *Elements of the intervention can be tailored to the context and situation* |
| **No:** | *The intervention cannot be tailored to the specific context* |
| **Unable to rate:** | *Not enough information provided to rate item* |

**12. Is the intervention likely to be effective (i.e. evidence based and expected to produce positive outcomes)?**

*Yes Partial No Unable to rate*

**Yes:** *There is an established evidence base regarding the effectiveness of the intervention (e.g. clinical trials)*
**Partial:** *There is some evidence for the effectiveness of the intervention (e.g. case studies but no clinical trials)*
**No:** *There is no evidence base for the intervention*
**Unable to rate:** *Not enough information provided to rate item*

**13. Is the intervention cost saving?**

Yes Partial No Unable to rate

**Yes:** *The intervention has been demonstrated to save costs*
**Partial:** *The intervention has been demonstrated to be cost neutral and/or cost effective*
**No:** *The intervention is not cost saving or cost effective*
**Unable to rate:** *Not enough information provided to rate item*

**14. Do the intended goals of the intervention match the prioritised goals of the NHS?**

Yes Partial No Unable to rate

**Yes:** *The primary aims of the intervention match values NHS outcomes e.g. improving mental health and wellbeing, supporting clinical and personal recovery, promoting good physical health, improving service satisfaction, reducing stigma and discrimination [Taken from No Health Without Mental Health, 2011, Department of Health]*
**Partial:** *The secondary aims of the intervention match the current valued outcomes*
**No:** *The primary and secondary aims of the intervention do not match the current valued outcomes of the NHS*
**Unable to rate:** *Not enough information provided to rate item*

**15. Can the intervention be piloted?**

Yes Partial No Unable to rate

**Yes:** *The intervention can be piloted by a few members of staff AND with only a few service users*
**Partial:** *The intervention can be piloted by a few members of staff OR*

*with a few service users*
**No:** *The intervention cannot be piloted*
**Unable to rate:** *Not enough information provided to rate item*

### 16. Is the intervention reversible?

Yes Partial No Unable to rate

***Yes:*** *It is possible to stop the intervention without harmful, or unwanted, effects*
***Partial:*** *It is possible to stop the intervention, but there are likely to be some harmful, or unwanted, effects*
***No:*** *It is not possible to stop the intervention without serious adverse effects*
***Unable to rate:*** *Not enough information provided to rate item*

---

### Scoring

It is recommended that no overall summary score is used, as barriers and facilitators differ in their importance depending on the context. See the SAFE paper (reference given on page 1) for further discussion of using SAFE ratings.

## Appendix 19 SAFE Development sub-study: SAFE reporting guidelines

| Item | | Descriptor |
|---|---|---|
| **INTERVENTION** | | |
| 1 | Details of the intervention components | The complexity of the intervention should be specified, this includes recording and listing how many separate components make up the intervention. |
| 2 | Intervention manual | Is the intervention manualised? The report should contain details of any intervention manuals developed or used. |
| 3 | Flexibility | Can the intervention be tailored to different contexts and environments? |
| 4 | Ability to pilot the intervention | Can the intervention be piloted with a few individuals or within one or two teams? |
| 5 | Reversibility | Are the effects of the intervention permanent or can the intervention be stopped at any point within any harmful effects. If there are likely to be adverse effects associated with discontinuing the intervention, these should be reported. |
| 6 | Population | The intended population of the intervention should be described. For example is the intervention aimed at people with a particular diagnosis or using a particular service? The ability to adapt the intervention for use within other populations should also be reported. |
| **RESOURCE CONSEQUENCES** | | |
| 7 | Staff training | Do staff require any specific training to deliver the intervention? If yes, details of the training should be reported. This includes the name of any specific training, the length of training e.g. does it last two half days, three hours etc. and any details about booster training sessions. |
| 8 | Support and supervision | Any ongoing support and supervision required to deliver the intervention should be reported. This included details about how much supervision is recommended and the format of supervision, e.g. Individual, group, peer supervision etc. |
| 9 | Time costs | How much time does the intervention require per client per week? |
| 10 | Human resources | What human resources are required to deliver the intervention? |
| 11 | Material resources | what material resources are required to deliver the intervention? |
| 12 | Set-up costs | Where possible the cost implications of the intervention should be reported. Any estimated costs associated with setting up the intervention should be reported. |
| **EVALUATION** | | |
| 13 | Efficacy | This relates to the existing evidence base for the intervention or any theoretical evidence base. For instance is there supporting evidence that the |

| | | |
|---|---|---|
| | | intervention is efficacy of the intervention? Has the effectiveness of the intervention been established in previous clinical trials? |
| 14 | Outcomes | What are the intended outcomes of the intervention? What are the primary outcomes? What are the secondary outcomes? |
| 15 | Cost saving | Any information relating to the costs of the intervention should be reported, including the potential costs saved. Is there evidence of cost saving? Has the cost effectiveness of the intervention been assessed or estimated? |
| 16 | Adverse events | Are there any known adverse events associated with the intervention? What adverse events might be anticipated? |

## Appendix 20 Recovery Measures Review sub-study: search strategy

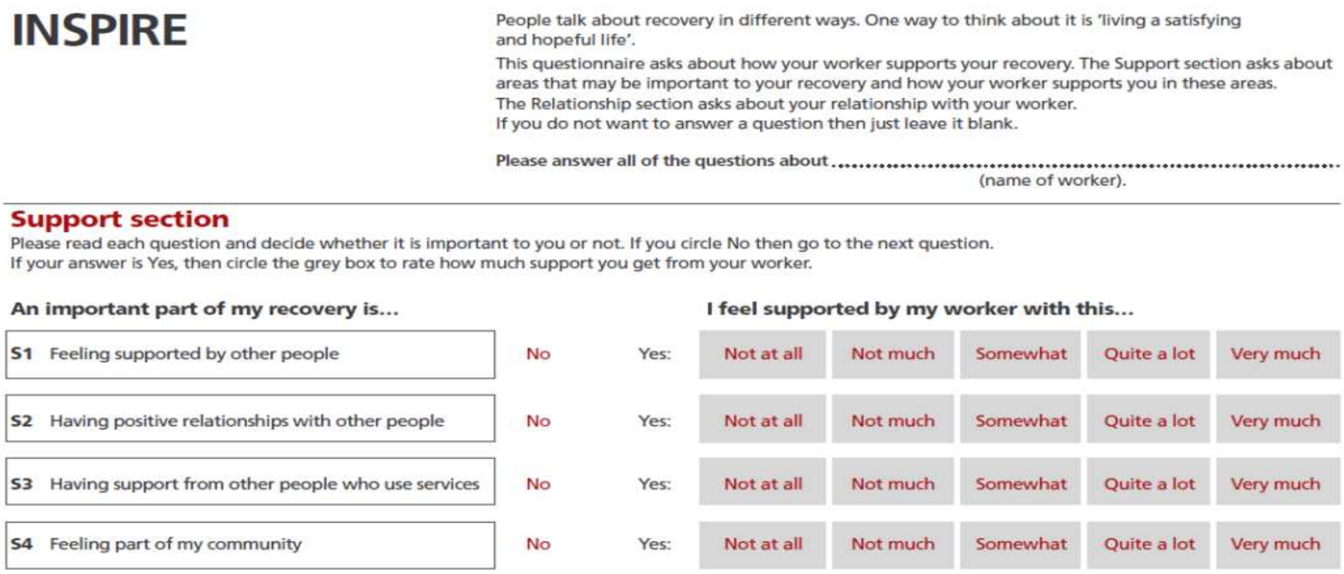
| | |
|---|---|
| **Search terms** | Recovery, personal recovery, wellness; mental adj well being; recovery orientation; recovery promotion (key words as no MeSH headings)<br>Mental illness; mental disease (EMBASE MeSH heading); mental disorders (MEDLINE and PSYCINFO MeSH headings) psychiatric disease/disorder/illness; chronic mental illness; mood disorder (MeSH headings in EMBASE, MEDLINE and PSYCINFO); psychosis (MeSH heading in EMBASE, and PSYCINFO), schizophrenia plus keywords for all the above<br>Measure/Instrument<br>Outcome assessment, outcomes research, measurement (MeSH headings in EMBASE; outcome and process assessment (MeSH heading in MEDLINE); measurement, treatment effectiveness evaluation, treatment outcomes (Mesh headings in PSYCINFO); Keywords: questionnaire; rating adj scales; standardised adj tests; surveys; scale; instrument; inventory; index; assessment; profile; rating and tool; self adj report; self adj assessment; self adj administer$; self adj rate$; service adj user adj rated; client adj rated; user adj defined; process adj measure$; outcome adj measure$;<br>Psychometric properties<br>MeSH headings:<br>EMBASE: reliability; validity<br>MEDLINE: ‘reproducibility of results’; reliability; validity<br>PsycINFO: statistical reliability; statistical validity<br>Keywords: reliability; validity; stability; test adj construction; validation adj process; validation; shorten; modify; change; compar$; adapt; revis$; alter; increase; improve; design$; generat$; construct$; correlation; ‘gold standard’; psychometric adj characteristics; internal adj consistency; alpha; beta; cronbach’s; creat$; scale adj develop$; develop$; pilot; test$; assess$; evaluat$; soundness |

## Appendix 21 Recovery Support Measure Review sub-study: search strategy

| | |
|---|---|
| **General search filter used** | Recovery, personal recovery, wellness; mental adj well being; recovery orientation; recovery promotion (key words as no MeSH headings)<br>Mental illness; mental disease (EMBASE MeSH heading); mental disorders (MEDLINE and PSYCINFO MeSH headings) psychiatric disease/disorder/illness; chronic mental illness; mood disorder (MeSH headings in EMBASE, MEDLINE and PSYCINFO); psychosis (MeSH heading in EMBASE, and PSYCINFO), schizophrenia plus keywords for all the above<br>Measure/Instrument<br>Outcome assessment, outcomes research, measurement (MeSH headings in EMBASE; outcome and process assessment (MeSH heading in MEDLINE); measurement, treatment effectiveness evaluation, treatment outcomes (Mesh headings in PSYCINFO); Keywords: questionnaire; rating adj scales; standardised adj tests; surveys; scale; instrument; inventory; index; assessment; profile; rating and tool; self adj report; self adj assessment; self adj administer$; self adj rate$; service adj user adj rated; client adj rated; user adj defined; process adj measure$; outcome adj measure$;<br>Psychometric properties<br>MeSH headings:<br>EMBASE: reliability; validity<br>MEDLINE: ‘reproducibility of results’; reliability; validity<br>PsycINFO: statistical reliability; statistical validity<br>Keywords: reliability; validity; stability; test adj construction; validation adj process; validation; shorten; modify; change; compar$; adapt; revis$; alter; increase; improve; design$; generat$; construct$; correlation; ‘gold standard’; psychometric adj characteristics; internal adj consistency; alpha; beta; cronbach’s; creat$; scale adj develop$; develop$; pilot; test$; assess$; evaluat$; soundness |

## Appendix 22 INSPIRE Development sub-study: INSPIRE

A section of the INSPIRE Support sub-scale:



**INSPIRE**

People talk about recovery in different ways. One way to think about it is 'living a satisfying and hopeful life'.

This questionnaire asks about how your worker supports your recovery. The Support section asks about areas that may be important to your recovery and how your worker supports you in these areas.
The Relationship section asks about your relationship with your worker.
If you do not want to answer a question then just leave it blank.

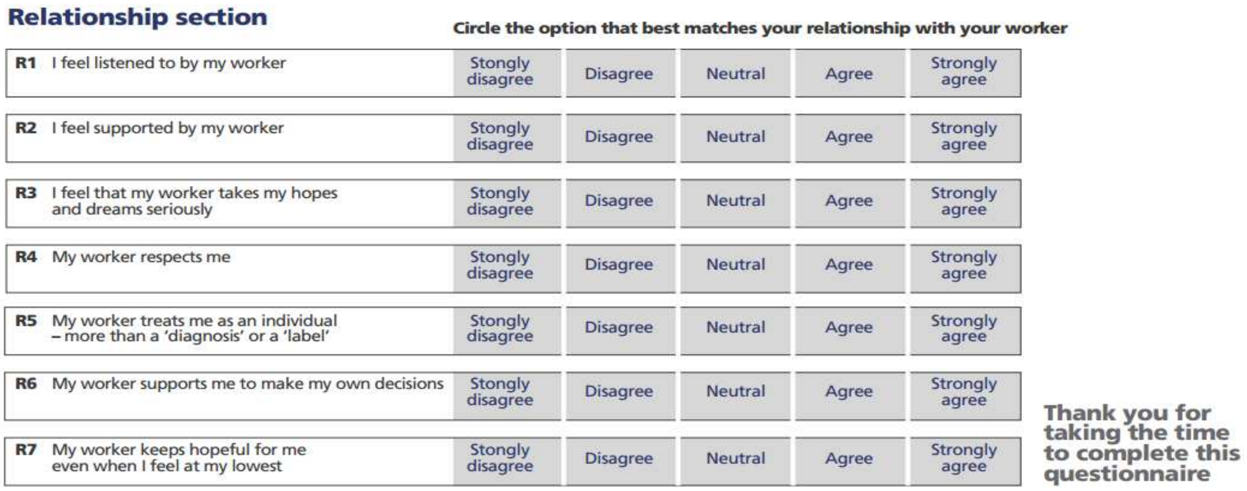
Please answer all of the questions about .................................................................................
(name of worker).

**Support section**

Please read each question and decide whether it is important to you or not. If you circle No then go to the next question.
If your answer is Yes, then circle the grey box to rate how much support you get from your worker.

| An important part of my recovery is... | | | I feel supported by my worker with this... | | | | |
|---|---|---|---|---|---|---|---|
| **S1** Feeling supported by other people | No | Yes: | Not at all | Not much | Somewhat | Quite a lot | Very much |
| **S2** Having positive relationships with other people | No | Yes: | Not at all | Not much | Somewhat | Quite a lot | Very much |
| **S3** Having support from other people who use services | No | Yes: | Not at all | Not much | Somewhat | Quite a lot | Very much |
| **S4** Feeling part of my community | No | Yes: | Not at all | Not much | Somewhat | Quite a lot | Very much |

The INSPIRE Relationship sub-scale:



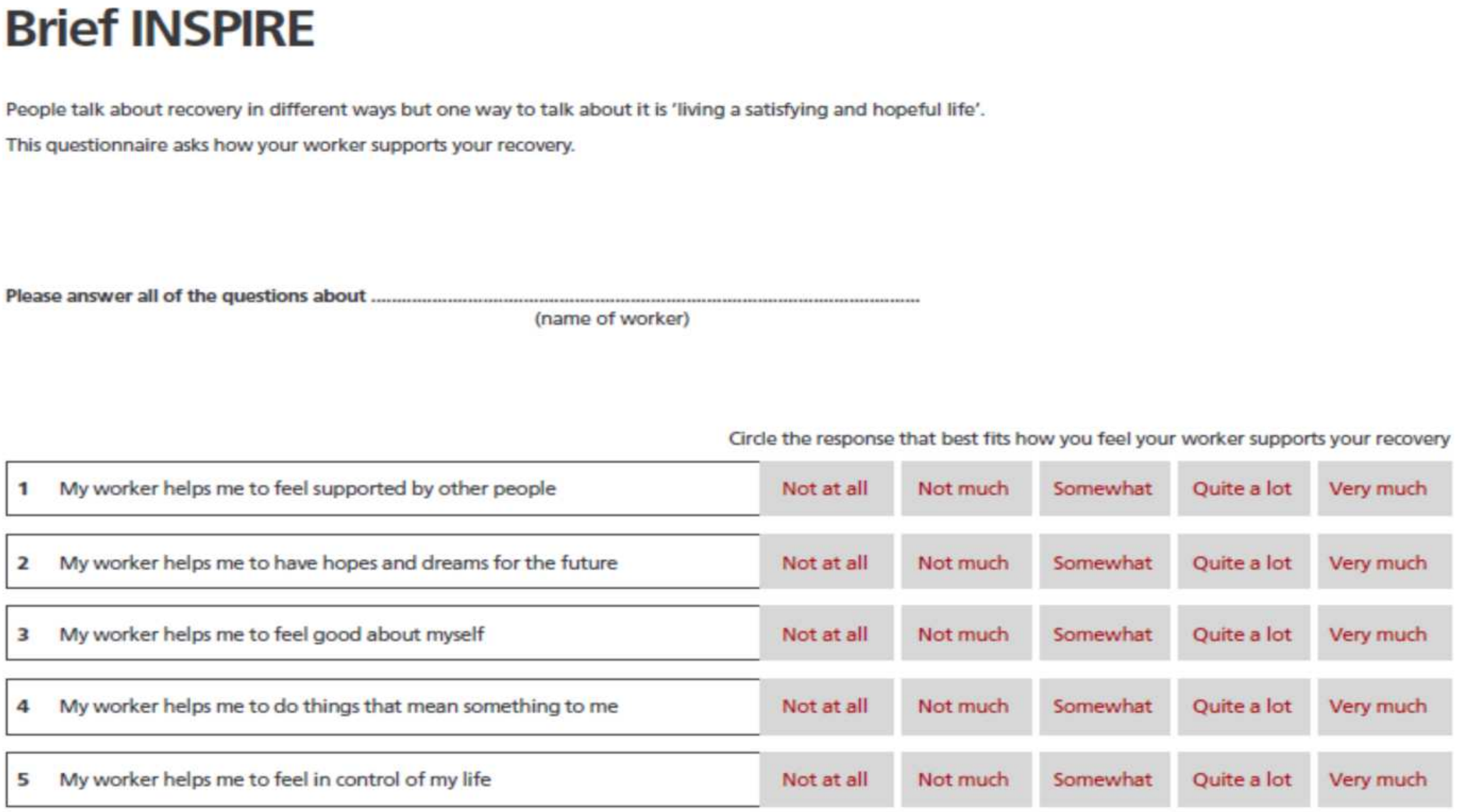
**Relationship section**

| | Circle the option that best matches your relationship with your worker | | | | |
|---|---|---|---|---|---|
| **R1** I feel listened to by my worker | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |
| **R2** I feel supported by my worker | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |
| **R3** I feel that my worker takes my hopes and dreams seriously | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |
| **R4** My worker respects me | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |
| **R5** My worker treats me as an individual – more than a 'diagnosis' or a 'label' | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |
| **R6** My worker supports me to make my own decisions | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |
| **R7** My worker keeps hopeful for me even when I feel at my lowest | Stongly disagree | Disagree | Neutral | Agree | Strongly agree |

**Thank you for taking the time to complete this questionnaire**

INSPIRE can be downloaded from researchintorecovery.com/inspire

## Appendix 23 INSPIRE Development sub-study: Brief INSPIRE



# Brief INSPIRE

People talk about recovery in different ways but one way to talk about it is 'living a satisfying and hopeful life'.

This questionnaire asks how your worker supports your recovery.

**Please answer all of the questions about** ........................................................................................................................
(name of worker)

Circle the response that best fits how you feel your worker supports your recovery

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | My worker helps me to feel supported by other people | Not at all | Not much | Somewhat | Quite a lot | Very much |
| 2 | My worker helps me to have hopes and dreams for the future | Not at all | Not much | Somewhat | Quite a lot | Very much |
| 3 | My worker helps me to feel good about myself | Not at all | Not much | Somewhat | Quite a lot | Very much |
| 4 | My worker helps me to do things that mean something to me | Not at all | Not much | Somewhat | Quite a lot | Very much |
| 5 | My worker helps me to feel in control of my life | Not at all | Not much | Somewhat | Quite a lot | Very much |

Brief INSPIRE can be downloaded from researchintorecovery.com/inspire

## Appendix 24 IOM Development sub-study: Individualised Outcome Measure

1. **We are looking at how people can live their lives in the way they want to. Think of a personal goal that matters to you, that you think you can achieve and that services could help you with**

*Things to think about if needed:*

- *Are there areas of your life you would like to improve or change?*
- *If you could change one thing in your life, what would it be?*
- *Suppose you woke up one morning and by some miracle everything you ever wanted, everything good you could ever imagine for yourself, had actually happened - your life had turned out exactly the way you wanted it. What would your life look like?*

*Goal:*

*Time to identify:* *mins*

2. **How important is the goal to you now?**

0 Not at all important
1 A bit important
2 Quite important
3 Very important
4 Extremely important

3. **How did you feel about being asked to identify a goal?**

0 I really was not happy to be asked to identify my goal
1 I was not very happy to be asked to identify my goal
2 I didn't mind being asked to identify my goal
3 I was happy to be asked to identify my goal
4 I was very happy to be asked to identify my goal

4. **Please look at the list of areas of life and identify which one area is most relevant to your goal:**

| **Area of life** | **What this means** | |
|---|---|---|
| *Is your goal about…* | | |
| Hope | Feeling more hopeful about the future | HHI |
| Empowerment | Feeling more in control of my life | MHCS |
| Self-esteem | Feeling more positive about myself | RSES |
| Stigma | Feeling better treated by other people | SS |
| Meaning in life | Feeling like you have meaning in your life | MLQ |
| Social support | Feeling supported by other people | SSS |
| Community integration | Feeling part of the community | CIM |
| Well-being | Feeling better about your life | WEMWBS |
| Daily functioning | Being able to manage day-to-day life | PPFS |
| Quality of life | Having a better quality of life | MANSA |

*Things to think about if needed:*

- *What does the goal mean for you?*
- *What difference will meeting the goal make?*

- *If you met your goal which area of life would it impact on most?*
- *Which area of life will your goal impact on most?*
- *Even though there's not a perfect match, which measure most closely reflects what you want your goal to achieve for you?*

*If no match is possible, stop here.*

*Time to identify area of life:* *mins*

*Related measure:*

**5. How easy was it to identify the most related area of life for your goal?**

0 Really difficult
1 Quite difficult
2 Medium
3 Quite easy
4 Really easy

**6. How closely did the questions in the questionnaire match your goal?**

0 Entirely different
1 A bit similar
2 Quite similar
3 Very similar
4 Identical

**7. Did you feel that the questionnaire was relevant to your life?**

0 Not relevant at all
1 A little bit relevant
2 Quite relevant
3 Very relevant
4 Extremely relevant

**8. Did you understand the questions in the questionnaire?**

0 I did not understand any of the questions in the questionnaire
1 I only understood a few of the questions in the questionnaire
2 I understood most of the questions in the questionnaire
3 I understood all of the questions in the questionnaire

## Appendix 25 Participation Scale

Please rate your levels of Participation, Value (for your clinical work) and Burden (how much time it took) on this scale:

**Information sessions**

| | **Very low** | **Low** | **Quite low** | **Quite high** | **High** | **Very high** |
|---|---|---|---|---|---|---|
| A1. Participation | | | | | | |
| A2. Value | | | | | | |
| A3. Burden | | | | | | |

**Personal recovery training**

| | **Very low** | **Low** | **Quite low** | **Quite high** | **High** | **Very high** |
|---|---|---|---|---|---|---|
| B1. Participation | | | | | | |
| B2. Value | | | | | | |
| B3. Burden | | | | | | |

**Coaching and working practices training**

| | **Very low** | **Low** | **Quite low** | **Quite high** | **High** | **Very high** |
|---|---|---|---|---|---|---|
| C1. Participation | | | | | | |
| C2. Value | | | | | | |
| C3. Burden | | | | | | |

**Team reflection sessions**

| | **Very low** | **Low** | **Quite low** | **Quite high** | **High** | **Very high** |
|---|---|---|---|---|---|---|
| D1. Participation | | | | | | |
| D2. Value | | | | | | |
| D3. Burden | | | | | | |

**(*Team manager/leaders only*) Team manager/leader reflection sessions**

| | **Very low** | **Low** | **Quite low** | **Quite high** | **High** | **Very high** |
|---|---|---|---|---|---|---|
| E1. Participation | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| E2. Value | | | | | | |
| E3. Burden | | | | | | |

**Supervision reflection**

| | Very low | Low | Quite low | Quite high | High | Very high |
|---|---|---|---|---|---|---|
| F1. Participation | | | | | | |
| F2. Value | | | | | | |
| F3. Burden | | | | | | |

**Service user partnership strategies**

| | Very low | Low | Quite low | Quite high | High | Very high |
|---|---|---|---|---|---|---|
| G1. Participation | | | | | | |
| G2. Value | | | | | | |
| G3. Burden | | | | | | |

# Appendix 26 Recovery Practice Scale

## Section A. Importance of each of these activites for your clinical practice

Please rate the importance of each of these activites for your clinical practice.

(0 = Completely unimportant, 1 = Somewhat important, 2 = Moderately important,
3 = Important, 4 = Extremely important)

| | | **0** | **1** | **2** | **3** | **4** |
|---|---|---|---|---|---|---|
| A1 | Using recovery coaching skills in your work with service users | | | | | |
| A2 | Understanding the individual values of the service users you work with | | | | | |
| A3 | Assessing the strengths of the service users you work with | | | | | |
| A4 | Working with service users to help them to identify and work on the goals that are important to them | | | | | |
| A5 | Being involved in a Partnership Project with service users | | | | | |

## Section B. Current level of skill for each of these activities

Please rate your current skill level for each of the following.

(0 = No skills, 1 = Limited skills, 2 = Moderate skills, 3 = Skilled, 4 = Highly skilled)

| | | **0** | **1** | **2** | **3** | **4** |
|---|---|---|---|---|---|---|
| B1 | Using recovery coaching skills | | | | | |
| B2 | Understanding the individual values of service users | | | | | |
| B3 | Assessing the strengths of the service users you work with | | | | | |
| B4 | Helping service users with goal-striving | | | | | |
| B5 | Being involved in a Partnership Project with service users | | | | | |

**Section C: Behavioural intent**
Please rate your intention to undertake the following?
(0 = no intention of undertaking activities with any service users, 1 = intend to undertake activities with some service users, 2 = fully intend to undertake activities with all service users)

| | | 0 | 1 | 2 |
|---|---|---|---|---|
| C1 | I intend to use recovery coaching skills when working with service users | | | |
| C2 | I intend to work with service users to understand their values and treatment preferences | | | |
| C3 | I intend to assess the strengths of the service users I work with | | | |
| C4 | I intend to work with service users to identify and work on their goals | | | |
| C5 | I intend to get involved in a Partnership Project with service users | | | |

**Section D: Actual behaviour**
Please rate your actual behaviour in the last nine months.
(0 = not completed activities with any clients, 1 = completed activities with less than 25% of my clients, 2 = completed activities with between 25% and 50% of my clients, 3 = completed activities with between 50% and 75% of clients, 4 = Fully completed activities with all clients)

| | | 0 | 1 | 2 | 3 | 4 |
|---|---|---|---|---|---|---|
| D1 | I have used recovery coaching skills when working with service users | | | | | |
| D2 | I have worked with service users to understand their individual values and treatment preferences | | | | | |
| D3 | I have completed the ‘values and treatment preferences’ box on the clinical information system | | | | | |
| D4 | I have assessed the strengths of the service users I work with | | | | | |
| D5 | I have completed the ‘strengths assessment’ box on the clinical information system | | | | | |
| D6 | I have worked with service users to identify and work on their goals | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| D7 | I have completed the ‘identification of goals’ box on the clinical information system | | | | | |
| D8 | I have been involved in organising a Partnership Project with service users | | | | | |

**Section E: Other recovery-promoting activities**

Please list any other recovery-promoting activities you have been involved in, in the last nine months:

E1.

E2.

E3.

E4.

E5.

## Appendix 27 Staff Process Evaluation sub-study: staff interview topic guide

### Section 1. Personal Recovery training

- What was your experience of the personal recovery training?
- Please can you give me an example as to how the recovery training has affected your practice?
- How (else) would you like to use the recovery training in your clinical practice?

### Reflection sessions

- How are you finding (did you find) the team reflection sessions?
- How has reflection supported you to implement the REFOCUS intervention?
- Have you been able to complete the supervision reflection form?
- TEAM LEADERS ONLY: How are you finding the team leader reflection sessions?

### Coaching training

- How has the coaching training altered how you work with service users?
- Please could you give me an example of how you use coaching skills:
- How many of your clients would you say you have you used coaching skills with, a rough percentage?

### Information session and manual

- Did you attend the information session?
- What was the information session like?
- Have you used the manual?
- How have you found the manual has affected your practice?

### Using the intervention

- How do you explain or introduce the intervention to your service users?
- How do you link the intervention into your everyday work?

### Working practices: Values and treatment preferences

- Can you give an example in the last 6 months of when you have been able to discuss values and treatment preferences with clients?
- How many clients have you discussed treatment values and preferences with?
- Did you use the VTP guide? How did you find using the VTP guide?
- Did you use any other approaches to talking to people about their values and treatment preferences?

### Working practices: Assessing Strengths

- Please can you give me an example in the last 6 months of when you have assessed a clients strengths?
- How many of your clients have you assessed strengths with?
- How did you find the strengths worksheet?

### Working practices: Goals

- Has it been possible to support goal striving and the identification of personally valued goals? How and with what effect?

- Please can you give me an example?
- Has it been possible to record all these things (strengths, vtp, goals) on the clinical information system?

**Working relationship**

- Has the REFOCUS intervention changed your relationships with clients and how? [own values, coaching skills, raised expectations of service users]
- Do you feel the language you use with your clients has changed in the last 6 months?
- Has the balance of power changed? If so can you give an example of a shift in the power balance since starting the REFOCUS intervention?
- Has the way you view the duty of care and how it fits with recovery principles changed?

**Partnership Project**

- Has your team bid for the Partnership project money?
- If yes, please describe the project / activity the money was for.
- How have you found being involved in a partnership project?
- If no, Why do you think your team haven't applied? What barriers have you faced?

**General comments**

- Is there anything else you would like to say about how you found implementing the REFOCUS intervention?
- Which parts of the REFOCUS intervention did you think were feasible?
- Would you change the REFOCUS intervention either the content or the implementation strategy? If so, how?
- What changes do you think service users have noticed from your use of the REFOCUS intervention?
- Is there anything else you would like to say about the REFOCUS intervention?

## Appendix 28 Staff Process Evaluation sub-study: trainer interview topic guide

### Teams

- From your experience, are there any teams that stand out from the crowd in terms of successfully supporting recovery? What is it that makes these teams inspirational?
- How come these teams are successful and not others? [Values, attitudes, skills etc]
- What is your perception of each team's leadership – and the requirements of a team that is managed to support recovery [qualities, skills etc]?
- Is there anything that you feel would be helpful for us to know in terms of team dynamics?
- Have you noticed any changes in the teams that have returned for follow-up training?
- What are team's priorities and goals for practice?
- Can you give any examples from your training of times where teams have supported recovery?

### Individuals

- Are there any individuals that stood out from the crowd in terms of successfully supporting recovery? What is it that makes these people different? Why are some people more successful than others? [theoretical sampling]
- In general terms, do you think are staff aware of how they can support recovery? A number of organisational-level barriers to implementing recovery have been highlighted in interviews with staff, but I sense that if barriers were removed, staff might still not be able to support recovery? What do you think?
- How do people feel about challenging power in practice?
- Can you give any examples from your training of times where individuals have supported recovery? Have staff been able to identify examples of supporting recovery?
- Do you have any overall impressions that would be helpful for the research team to know?

## Appendix 29 Staff Process Evaluation sub-study: focus group topic guide

### Team understanding and experiences of recovery

- When I say the phrase “Personal Recovery” what thoughts immediately spring to mind?
- As a team, how have you found implementing the REFOCUS Manual with your service users?

### Barriers and facilitators to implementing recovery

- Can you tell me what it’s been like for your team to try and implement the REFOCUS intervention?
- If implementation has been perceived as successful, what is it about your team that enables you to successfully support recovery?
- If implementation has been perceived as low, what would further support your team to implement the REFOCUS Manual?

This focus group was designed to help us understand the extent to which the REFOCUS intervention has been implemented, and what has helped or hindered your team in doing this. Are there any other important points that you would like to discuss before we close the discussion?

## Appendix 30 Staff Process Evaluation sub-study: trainer reports

*At the end of the Personal Recovery/Coaching for recovery training course (i.e. after the three sessions), please complete one report for each team covering:*

- What were your impressions of the training overall?
- What worked well and what didn't work well?
- How well was the training received?
  - By the team managers/leaders
  - By the psychiatrist
  - By the rest of the team
- Were the team able/willing to apply the training to their practice? What helped and hindered this?

## Appendix 31 Service User Process Evaluation sub-study: interview topic guide

- Tell me a little bit about yourself
- In the last 6-9 months have you experienced anything which you feel has had a significant impact on your life or wellbeing, e.g. hospital, treatment, life events, significant others?
- Has the way staff talk to you changed in the past 6-9 months?
- Do staff listen to you and what you have to say?
- Has your relationship with staff changed due to these things you’ve noticed (refer back to examples given)? What has been positive about the change in this relationship past 6-9 months?
- What has been negative about the change in this relationship?
- Do staff talk to you about living a satisfying life?
- Have you attended any information sessions with other service users where researchers have talked to you about the REFOCUS project (add in date of session)
- Have you been involved in a REFOCUS partnership project with other service users and staff members in this team? (Add in specific event or project)
- Have staff asked you about the things that are important to you and your care in last 6-9 months?
- Have you talked to staff about the things that you are good at and the people and things which support you in the last 6-9 months?
- In the last 6-9 months have staff talked to you about the areas you’d like to work towards in the future and the goals you would like to achieve?
- What other ways have staff supported your recovery or wellbeing?
- Do you have any other comments?

## Appendix 32 Service User Process Evaluation sub-study: focus group topic guide

### Describing the specific project

- Tell us about your Project
- How did the project get started?
- Did anything happen that made the project difficult?
- What do you think helped the project to be successful?
- Is this project different to the types of things you would normally do and discuss with staff?

### Understanding the experience of the partnership project

- What was it like to be involved in the project?
- How did being involved in the PP make you feel?
- What have you learnt?
- Do you think anything has changed because of the project?
- Do you feel there have been any changes in how you relate and talk to the staff or each other because of the project?
- Do you have any advice for other people looking to set up a Partnership Project?

### Experience of services

- Has your experience of services changed within the last year?
- Have you had any new conversations with staff in the last 12 months
- What has been the impact of these changes?

Is there anything else you would like to say about the project or supporting recovery?
How has reflecting back on project in this focus group been for them?

## Appendix 33 Service User Process Evaluation sub-study: coding framework

- **WORKING RELATIONSHIPS WHICH SUPPORT RECOVERY**
  - **‘Genuine’ interest in the person**
    - Talking more
    - New topics of conversation
    - Feeling staff are interested
    - Being seen as a person
    - Increased mutual trust and respect
  - **Service user-directed**
    - Service user-led conversations
    - More power balanced
    - Partnership project
  - **Collaborative working**
    - Breaking goals down into manageable steps
    - Help with motivation
    - Discussing valued personal qualities
    - Planning how to use strengths
- **IMPACT OF THE REFOCUS INTERVENTION**
  - **Empowerment**
    - Increased self-confidence
    - Independence
  - **Identity**
    - Knowing self better
    - Positive self-image
  - **Hope and optimism**
    - Thinking positively
    - Belief in the possibility of change
- **LACK OF NOTICEABLE CHANGE IN THE SERVICE USER EXPERIENCE**
  - **Poor delivery of intervention**
    - REFOCUS is not remembered by service users
    - Formulaic delivery
    - Interest experienced as intrusion
    - Asking for asking’s sake
  - **Lack of noticeable change in the relationship**
    - Decision-making power remains with staff
    - Disagreement is pathologised
    - Focus on medication remains
    - Previous negative experiences of services
    - Service user not wanting the relationship to change
    - Staff not wanting the relationship to change
  - **Barriers within mental health services**
    - Lack of suitable services
    - Time pressures
    - Continuity of staff