

Evaluating quality and impact of acute paediatric inpatient care

Defining the domains for a Person Centred Outcome Measure (PCOM) in children and young people admitted with self-harm or eating disorders

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Executive summary

Background and purpose

In the United Kingdom, the prevalence of children and young people (CYP), up to the age of 18 years, accessing acute paediatric inpatient care with mental health problems is increasing, with self-harm and eating disorders particularly prevalent. This initial period of acute inpatient care can involve multiple assessments and interventions in order to meet physical, psychological and social needs. However, there is a distinct paucity of published literature reporting CYP service users' experiences and outcomes of being in receipt of non-specialist inpatient care. Therefore this project aimed to undertake the preliminary work in developing a Person Centred Outcome Measure (PCOM) for this patient group by identifying the domains for a PCOM and establishing how such a measure could be implemented.

Methods

A two phase sequential design was adopted which involved: (1) a rapid review of the literature and (2) an evaluation of experiences and outcomes through stakeholder engagement events with children and young people admitted with self-harm or eating disorders, their parents and carers, and professionals from health, social care and education.

Findings: Rapid review of the literature

- There is a lack of reported outcomes relating to CYP admitted to inpatient care with self-harm within the literature.
- Outcomes reported by CYP appear to relate to aspects of care delivery, communication and the inpatient environment;
- CYP reports predominantly relate to deficits in service provision which is recognised to negatively impact on experience and inhibit recovery and outcome.

Findings: Stakeholder workshops

- In total 96 CYP, parents and carers, and professionals participated in the stakeholder event.
- Disparities in experiences and the implied quality of being in receipt of care were identified.
- Synthesis of findings identified five domains that could be used to develop a PCOM that included: Privacy and surveillance; Receiving holistic care; Making choices and being understood through timely, relevant and appropriate communication; Working together to plan and achieve care goals; and Respect and empowerment
- Variation was evident between CYP stakeholders as to the acceptability of when and how outcomes are measured.

Conclusion

Findings from this project provide the foundations for a PCOM for CYP admitted to acute paediatric care with self-harm or eating disorders to be developed, tested, implemented and evaluated. The domains identified have the potential to be further developed and validated as an instrument with a larger and more diverse sample of CYP.

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Copyright

This is the final report of the 'Evaluating quality and impact of acute paediatric inpatient care: Defining the domains for a Person Centred Outcome Measure (PCOM) in children and young people admitted with self-harm or eating disorders' at the point of 1st October 2015.

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Abbreviations

CYP	Children and Young People
HCP	Health Care Professional

1. Project background and scope

1.1 Children and young peoples' mental health and well-being

The World Health Organisation defines mental health as a,

“state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community” [1].

The causes of mental health problems in Children and Young People (CYP), up to the ages of 18 years, are reported to be complex and multifactorial [2]. Having an ill parent, living in poverty, bullying and having low self-esteem, are just some of the influential factors [2]. The absence of good mental health and well-being can result in the lack of the ability to develop intra- and inter-personal skills, physical, emotional, intellectual and spiritual skills and functioning [2], which can negatively impact upon quality of life in adulthood [3 , 4].

1.2 Deliberate self-harm

Self-harm can be defined as any form of self-injurious behaviour, irrespective of motive or suicidal intent [5]. Common forms of self-harm include behaviours such as cutting, overdosing, hanging or self-poisoning [6].

Each year in England, self-harming behaviour results in over 150,000 Emergency Department attendances, 25,000 of which lead to hospital admission [7]. It is estimated that 13% of CYP self-harm at some point between the ages of 11 and 16, but the actual figure could be much higher due to the secretive nature of self-harm [8]. CYP have more hospital presentations for self-harm than any other age group [9].

Longitudinal data of the general UK population identifies that self-harm in adolescence is a risk marker for: future mental health problems; further self-harm; and substance use problems in early adulthood; as well as poorer educational and occupational outcomes [10]. Therefore, early identification and high quality treatment of CYP who self-harm, to alleviate current distress and reduce the risk of future problems is fundamental [10].

1.3 Eating Disorders

Eating disorders are mental health conditions with psychological, behavioural and physiological characteristics. They are “involuntary and complex” and involve “an unhealthy and unconventional view of and relationship with food weight and shape” [11, p.88].

In the UK eating disorders are reported to affect 1.1 million people [12], however the exact numbers are hard to determine due to the secretive nature of the disorder [13]. However, the peak onset occurs in mid-adolescence and it is estimated that 2 girls/1000 are likely to be newly diagnosed with an eating disorder each year making eating disorders the second most common mental health disorder in adolescent girls after depression [14].

1.4 Why have these conditions been selected?

Nationally the prevalence of CYP accessing acute paediatric inpatient care with mental health problems is increasing, with self-harm and eating disorders particularly prevalent. The initial period of acute inpatient care for these patient groups can involve assessments and interventions in order to ensure safety [15], address their immediate physical needs, and refer to specialist care [16]. Although from a healthcare perspective, the objectives for this discreet part of the CYP pathway of care are clear, the desired outcomes from the perspectives of CYP are not. Therefore, timely and relevant understanding of experiences and outcomes of those in receipt of care is not currently available to inform and develop quality services.

‘No Health Without Mental Health’ strategy [17] identifies that a shift in emphasis is required to put mental health outcomes alongside physical health outcomes. This is congruent with the literature on Patient Reported Outcome Measures (PROMs), which identifies a deficit in non-physical health measures. This could be attributed to the complex nature of the underlying conditions, such as the egosyntonic nature of eating disorders, which may result in outcome measures being reported by patients that are incongruent with their care goals or recovery. However, searches of online databases (such as PROQOLID.org) identify only generic outcome measures that have been developed in relation to quality of life and recovery (such as I.ROC¹) for this patient group. Therefore no specific Person Centred Outcome Measure (PCOM) that assesses the quality and impact of acute, non-specialised, care for CYP (aged 10-18 years) admitted for self-harm or eating disorders exists.

1.5 Scope of project

Project aim

To undertake the preliminary work in developing a PCOM to assess the quality and impact of acute, non-specialised, inpatient care for CYP (aged 10-18 years) admitted for self-harm or eating disorders. Specifically this includes identifying domains for a PCOM to be developed and establishing how such a measure could be implemented.

Project objectives

The aims of this project were satisfied by undertaking the following objectives:

1. Conduct a rapid review of the evidence to identify potential domains for a PCOM
2. Conduct stakeholder engagement workshops with various relevant stakeholders and collect feedback to:
 - a. Evaluate experiences of care
 - b. Establish consensus of PCOM domains
 - c. Assess acceptability of PCOM implementation (modality and timing).

In order to generate evidence, evaluate user experiences, and establish consensus of outcome domains, whilst comprehending the sensitive and complex nature of the conditions under investigation, a two stage sequential design was adopted (summarised in Figure 1).

This project did not satisfy the definition of research as outlined by the Health Research Authority [18], which was confirmed through discussion with a local NHS Research Ethics Committee expert member. Instead this project was classified as a service evaluation with

¹ <http://www.penumbra.org.uk/wp-content/uploads/2013/05/Validation-of-IROC.pdf>

stakeholder engagement. Therefore formal ethical approvals were not required. However, the project was conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, 1996; the principles of Good Clinical Practice, and the Department of Health Research Governance Framework for Health and Social care, 2005.

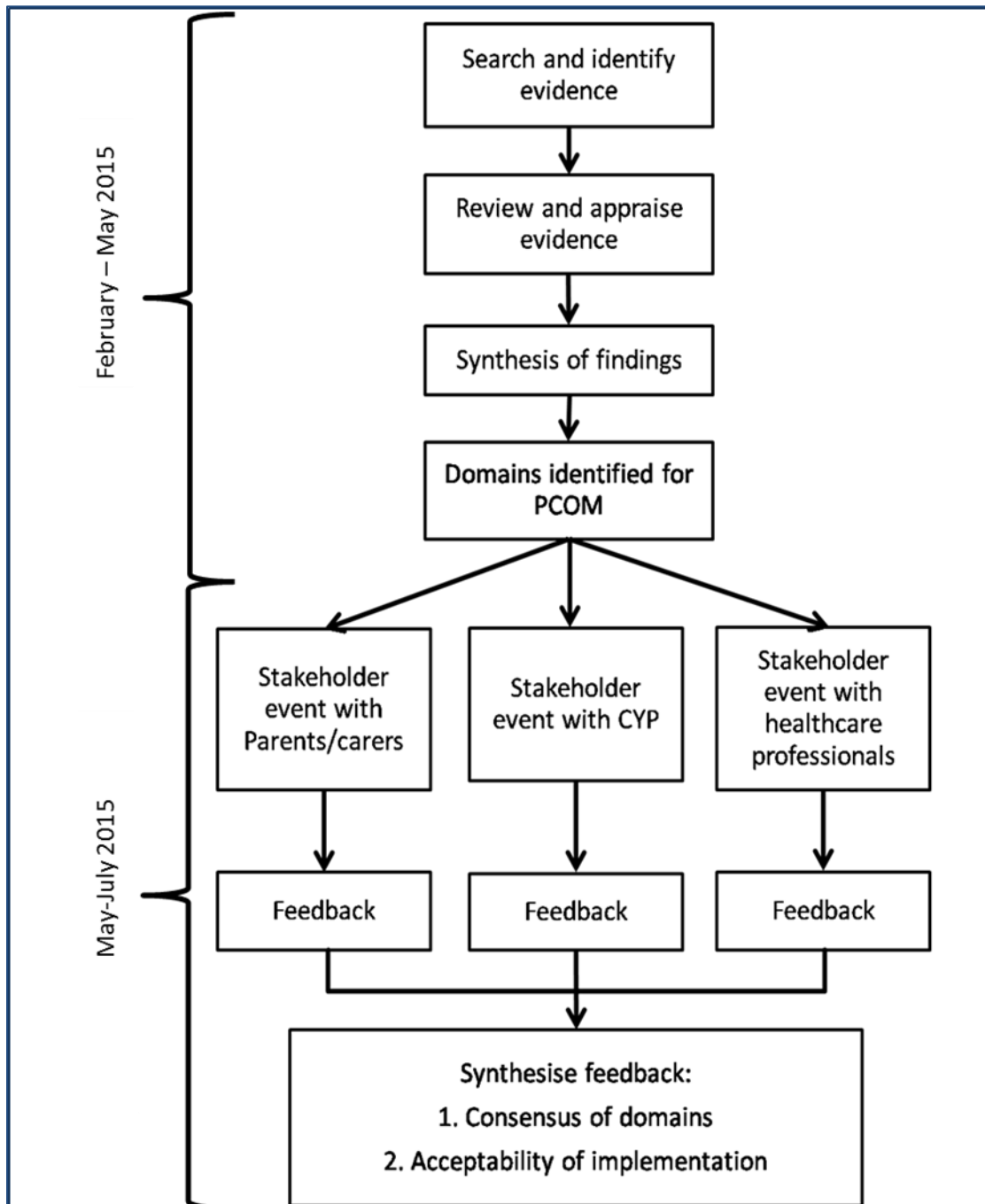


Figure 1: Overview of project design

2. Stage 1: Rapid review of the evidence

2.1 Introduction

Rapid reviews have been identified as a streamlined approach to synthesizing evidence which can be used to inform health care policy and practice [19]. In the context of this project a rapid review was conducted to identify and synthesise existing evidence of outcomes (that include both patient reported outcomes and experiences) of children and young people with mental health problems [20].

2.2 Methods

An eight stage approach as outlined by Khangura, et al. [20] to rapidly review the evidence was used. This included: Step 1 – Needs assessment; Step 2 – Question development and refinement; Step 3 – Proposal development and approval; Step 4 – Systematic literature search; Step 5 – Screening and selection of studies; Step 6 – Narrative synthesis of included studies; Step 7 – Report production; Step 8 – Ongoing follow-up and dialogue with knowledge users.

The aims and remit of the review was developed using the PICO framework outlined in Table 1.

Domain	
Patient/Population	All children and young people 0-18 years old with a mental health condition which includes either self-harm or an eating disorder (a child is defined by the Convention on the Rights of the Child (CRC) as “Every human being below the age of 18 years unless under the law applicable under the child majority is attained earlier”).
Intervention	Admitted as a patient to inpatient care in a non-specialist mental healthcare setting such as a general acute care hospital or Children’s Hospital.
Comparison	None
Outcome	Patient reported outcomes from CYP and their perspectives on the quality and effectiveness of care they receive. Outcomes may include perceptions of therapeutic communication, ward environment, attitude of staff.

Table 1: PICO framework applied to the scoping review

The search strategy was developed through consultation with clinicians, an information scientist and academics. Search terms and sensitising concepts were identified from the PICO framework and refined using an iterative search strategy to test sensitivity and specificity.

- Search terms used included; ‘suicide attempt’, ‘bulimia nervosa’, ‘anorexia nervosa’, ‘bingeing’, ‘self-harm’, ‘hospitalisation’, ‘child’, ‘adolescent’, ‘treatment outcome’, ‘patient centred outcome measure’ and ‘patient centred care’.
- Searches were conducted on eight electronic databases (AMED, EMBASE, HBE, HMIC, PsychINFO, MEDLINE CINAH and ASSIA) that were identified to index relevant papers.

- No date restrictions were applied in order to maximise sensitivity of relevant sources for inclusion.
- Due to the linguistic capabilities of the research team studies were limited to English language only.

All studies identified from the searches were screened by title and abstract by two independent team members using predefined eligibility criteria (outlined in Table 2, below). Full text papers were sought for studies where the team members were uncertain about their eligibility from title and abstract alone.

Inclusion Criteria:
CYP with a primary diagnosis of self-harm or eating disorder
Acute inpatient setting
International literature in the English language
Qualitative empirical studies
Systematic reviews
Quantitative empirical studies
Case studies
Reviews
Exclusion Criteria:
Community healthcare settings
Non English language papers

Table 2: Inclusion and exclusion criteria used to select studies

For studies that fulfilled the inclusion criteria, they were then assessed for methodological quality using the relevant Critical Appraisal Skills Programme (CASP) tool. Data was extracted (including: electronic database, date, author, title, journal, methodology, main findings) from each included study and tabulated into a database using a MS Excel™. Narrative synthesis was then undertaken which involved the use of words and text to summarise the findings [21].

2.3 Rapid review findings

2.3.1 Summary of search results

Database searches yielded 101 papers, with six papers duplicates and therefore eliminated. Of the remaining 99 records, screening by title and abstract identified 78 papers did not satisfy the inclusion criteria. Full texts were obtained (n=16), a further six papers were excluded. Of the remaining 10 eligible papers, a search of their reference lists identified a further three papers that were eligible for inclusion in the review. Therefore 13 papers were included in the review.

2.3.2 Description of studies and assessment of methodological quality

Papers that investigated CYP with eating disorders dominated the evidence (n=11), CYP with self-harm (n=2) was significantly underrepresented in this sample. Three papers [22-24] combined the CYP views and opinions with those of parents/carers and/or healthcare professionals involved in the care of inpatient CYP. From the 13 studies included in this review, 668 CYP participated, with 603 females.

Evidence included international studies from the UK, [25-29], Australia [23 , 24 , 30], Canada [22], USA [31], Finland [32], Belgium, [33] and Ireland [34]. These studies encompassed a range of designs that included: six qualitative studies; four cohort studies; three case control studies; and a literature review.

2.3.4 Summary of narrative synthesis

The narrative synthesis of outcomes, reported by CYP, were categorised into three main areas as shown in Figure 2.

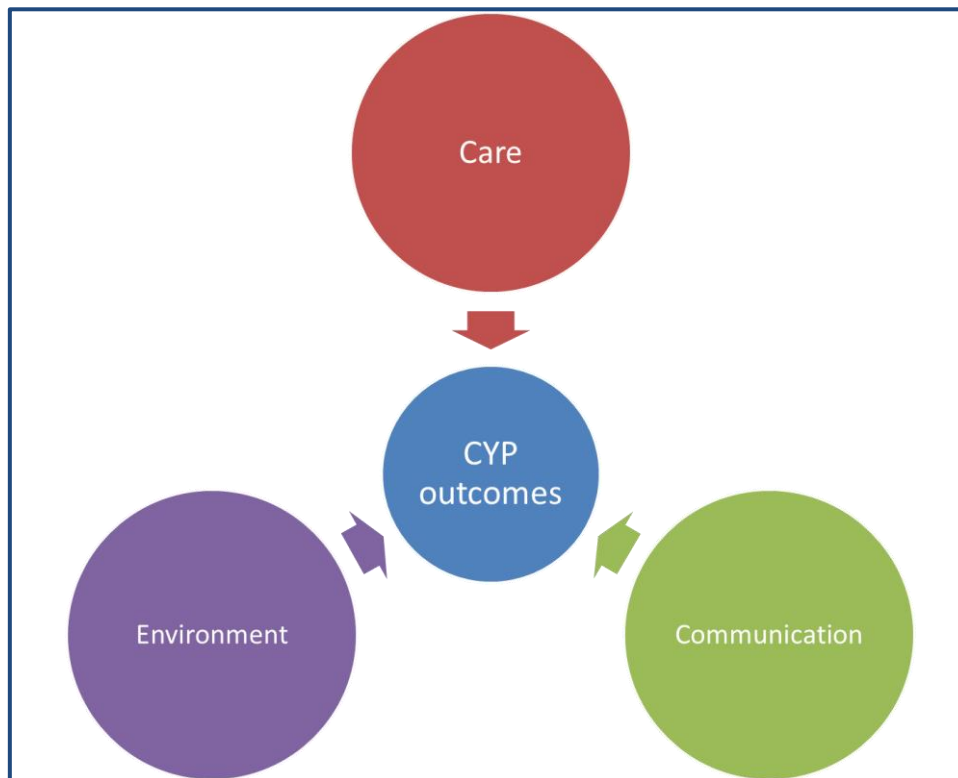


Figure 2: Categories from rapid review

Care

- CYP identified that care received was not integrated. The primary focus on medical stability, with emotional, psychological and social needs secondary. This focus on physical rather than the psychological aspects of health and wellbeing was viewed as counterproductive to recovery. CYP attributed the dominance of physical determinants to being easier for caregivers to measure the effect of medical treatments (e.g. BMI and Ideal Body Weight) rather than tackling underlying psychological issues, thus rendering psychological needs neglected.
- CYP conceptualised inpatient care as a metaphoric prison, where hospitalisation involved 'doing time'. Difficulties were identified in conforming to a 'system' where they felt that their privacy and rights were taken away and they were under surveillance. CYP recognised that this required them to conform to the rules in order to be 'released'.
- Notions of institutionalism were identified from CYP reports with inpatient care conceptualised as punitive and in some cases abusive. Feelings of disempowerment and control were identified with CYP being punished for eating habits resulting in loss of using the telephone, participating in activities and not being allowed to see family members. Coercive practices and custodial roles, regulations and culture were perceived to imitate

prison. However, this view did not reflect all CYP views as for some the environment and structure provided support and stability.

- Uncertainties were identified from CYP reports in relation to the planning of care, and goals of inpatient stay. More 'Community Resource Planning' was requested whereby greater focus was required on discharge planning and making follow up arrangements. Nonprofessional and professional support were seen as equally important, with CYP needing support from parents and the need of understanding and empathy of healthcare professionals.

Communication

- CYP reported struggles between maintaining control whilst realising the need to collaborate and actively communicate with care givers in order to build therapeutic relationships and trust. The need for admission and inpatient care was associated with perceived coercion and pressure. Furthermore, feelings of loss of control over related- (such as eating) and non-related- behaviours to their underlying condition were identified as exacerbating their sense of powerlessness and feelings of inadequacy.
- CYP reported inpatient experiences rendered them isolated and generally confused. Lack of access to relevant information was reported by CYP that related to fundamental aspects of care such as managing meals, activity levels and goal planning. This was perceived to effect self-esteem and social confidence, with CYP recognising that being informed and involved was fundamental to their recovery.

Environment

- CYP reported that the inpatient environment created a sense of removal of the outside world and immobilised real world involvement and development. For some CYP, admissions and readmissions were viewed as opportunities to escape and a place of safety from the complexities and difficulties of the outside world. However, for others the inpatient environment rendered CYP removed from normality and disabled their agency over their own functioning.
- Peer relationships within the inpatient environment were viewed both positively and negatively. Being with 'similar others' was reported to facilitate support and understanding through the sharing of the same experiences. Positive experiences of peer support were associated with feelings of acceptance by others with a similar condition, which contrasted to the stigma experienced from the external world. Furthermore, peer relationships facilitated social functioning which was reported to be a neglected aspect of inpatient care due to the focus being on the improvement of physical health. However, peer relationships were also reported to be detrimental due to competitive interactions, making negative comparisons to others, and imposed segregation. Patients reported having learned and subsequently adopted negative coping strategies, such as self-harming from peers.
- CYPs identified that mixed wards with children experiencing acute, chronic and palliative conditions as well as exposure to younger children were not appropriate. Furthermore, prolonged hospital stays were recognised as having a negative effect on recovery especially in those with younger onset.

From this narrative synthesis a number of themes were identified and developed iteratively by the project team (outlined in Figure 3) which allow for the outcomes of care for these patient groups to be illuminated.

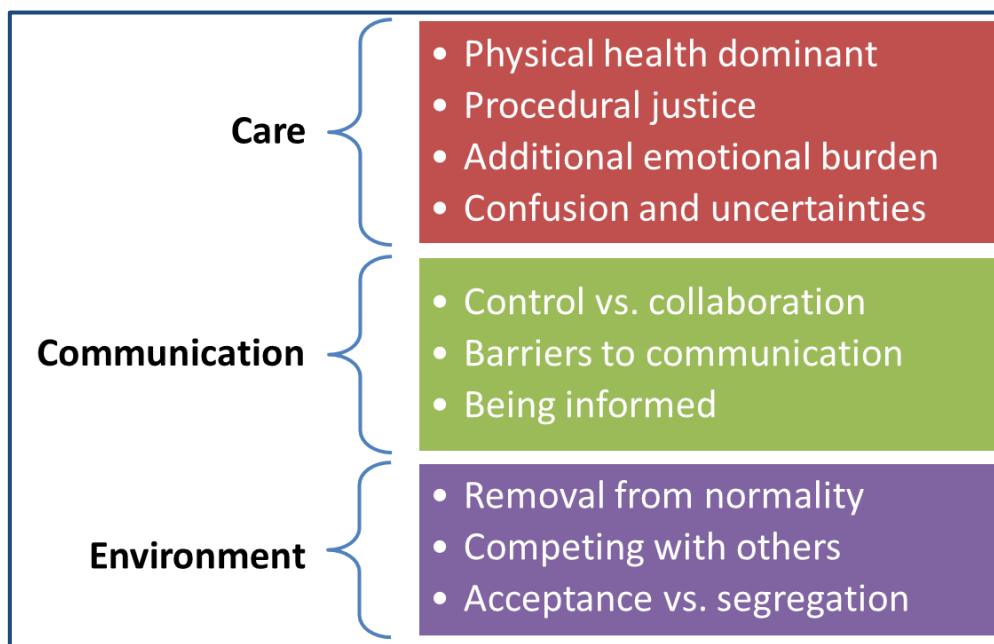


Figure 3: Summary of themes from each category from the rapid review

2.4 Conclusion and implications of review findings

2.4.1 Conclusion

It is evident from this review that:

- there is a lack of reported outcomes relating to CYP admitted to inpatient care following self-harm;
- reported outcomes appear to relate to aspects of care delivery, communication and the inpatient environment;
- CYP reports predominantly relate to deficits in service provision which is recognised to negatively impact on experience and inhibit recovery and outcome.

2.4.2 Implications for next stage of project (Stage 2)

In order for the findings from this review to be used to inform the next stage of the project (stage 2), themes were developed into a number of polarised statements that could then be evaluated by stakeholders in relation to their experiences of receiving or providing care.

Statements were developed by three of the project team and then independently reviewed and further developed by two additional researchers. This process resulted in a total of 25 statements being formulated (outlined in Table 3).

Domain	Statement
Care	" My care focused more on my physical health rather than how I felt"
	"I did not feel that people who worked in the different parts of my care worked together"
	" I felt that I had other problems that were not addressed"
	"I didn't really feel cared for"
	"I was scared about what others thought of me"
	"I didn't know what was happening in my care"
Communication	" I felt that I was being controlled"
	"I needed to work with others to get better"
	" I felt that I was involved in decision making about my care"
	"I felt that I had no voice"
	"I felt that I was pressured to talk"
	" I did not feel that I had the opportunity to talk"
	" I felt that talking wasn't as important than my physical needs"
	"I felt that I understood what was going on"
	"I was active in planning my care"
	" I did not understand because I had no information about what was going on"
" I felt alone because nobody spoke to me"	
Environment	" I had to follow the rules"
	"I felt alone"
	" I felt isolated because I could not see my brothers/ sisters/friends/ parents"
	"I felt like I was being watched all the time"
	"I felt that I didn't have my own privacy"
	"I did not like being with sick children"
	" I felt that I was not understood"
	"I felt that people were judging me"

Table 3: Statements developed from rapid review of the literature

Statements were phrased in a certain way that allowed for them to be adjusted according to the stakeholder group, such as replacing 'I...' for CYP stakeholders to 'my son/daughter...' for parents/carers, or 'CYP...' for professionals.

3. Stage 2: Stakeholder engagement

3.1 Introduction

In line with the NHS Constitution [35], it is imperative that the experiences of stakeholders, such as children and their parents are used to inform and improve accessibility and quality of healthcare. Therefore the second stage (Stage 2) of this project involved meaningful stakeholder engagement to provide opportunities for the experiences and views of a range of relevant people to be heard.

Stakeholder engagement workshops were held as they have been reported to be an inclusive approach to establishing what those who are immediately affected by services want from their care [36]. Specifically the project sought feedback from stakeholders to establish: (1) experiences of care for CYP with self-harm /eating disorders and (2) consensus of domains identified from the rapid review of evidence.

Therefore workshops were conducted with three main groups deemed important to the aims and remit of the project and included:

1. CYP previously admitted to a paediatric inpatient unit due to self-harm or an eating disorder;
2. Parents/carers of CYP admitted for self-harm or an eating disorder
3. Professionals (including but not limited to health, education and social care)

3.2 Methods- Eliciting experiences and feedback of care

There have been many different methods reported in the literature as useful ways to collecting feedback. However, due to the diversity of stakeholders invited to be involved in the project (such as age, ability, developmental level, professional background), methods were selected pragmatically and according to whether they were engaging and sensitive. Therefore both creative approaches that allowed for the evaluation of participant experiences, as well as techniques to identify and gain consensus were used.

3.2.1 Creative approaches

Creative and art-based approaches are useful as sensitive and robust methods of collecting feedback, especially with CYP [37, 38]. Users of art-based methods can express thoughts and experiences that may prove too difficult to put into words. Therefore feedback from experiences of being in receipt, or delivering care, was gathered using two creative approaches.

(a) Visual time lining

Visual story telling is a sensitive and useful method for eliciting experiences [39]. As evaluating CYP experiences and outcomes were fundamental to this project, CYP participants were invited to contribute to a timeline focusing on their hospital admission and pathway of care. They were asked to reflect on their journey, commenting on their experiences and how they were feeling across the timeline using drawings, words or phrases on 'Post it' notes, as shown in Image 1 (page 19).

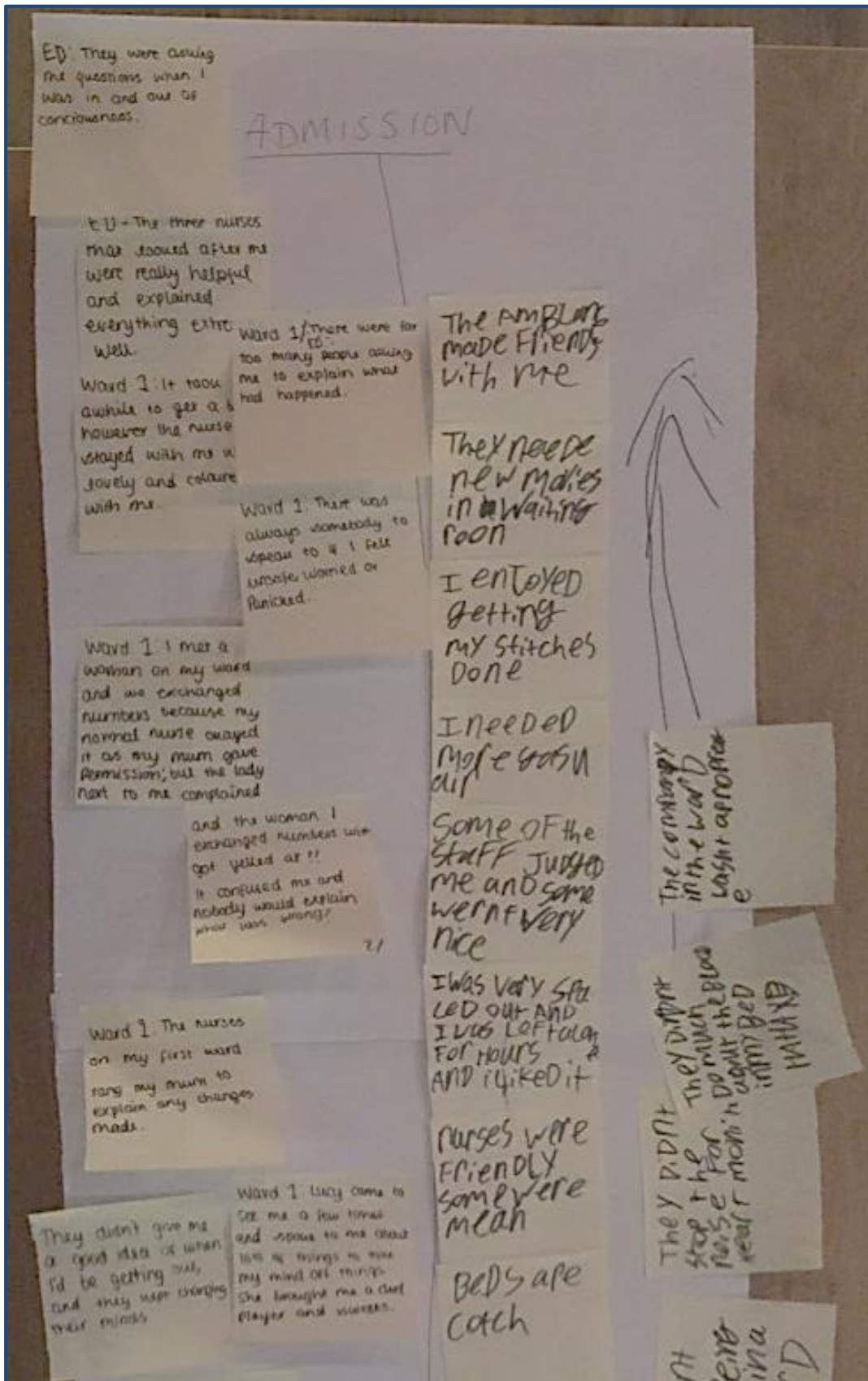


Image 1: Example of visual story telling activity

(b) Experience evaluation

Participants were asked to reflect on their experiences of either being in receipt of care, or delivering care, in relation to three over-arching categories that had been identified from the rapid review of the literature; Care, Environment, and Communication. A fourth category 'Anything else' was created in order to capture information that did not align to the aforementioned three categories. Thoughts, feelings, events and experiences were documented as statements on post-it notes and attached to paper under the relevant category heading, as shown in Image 2.

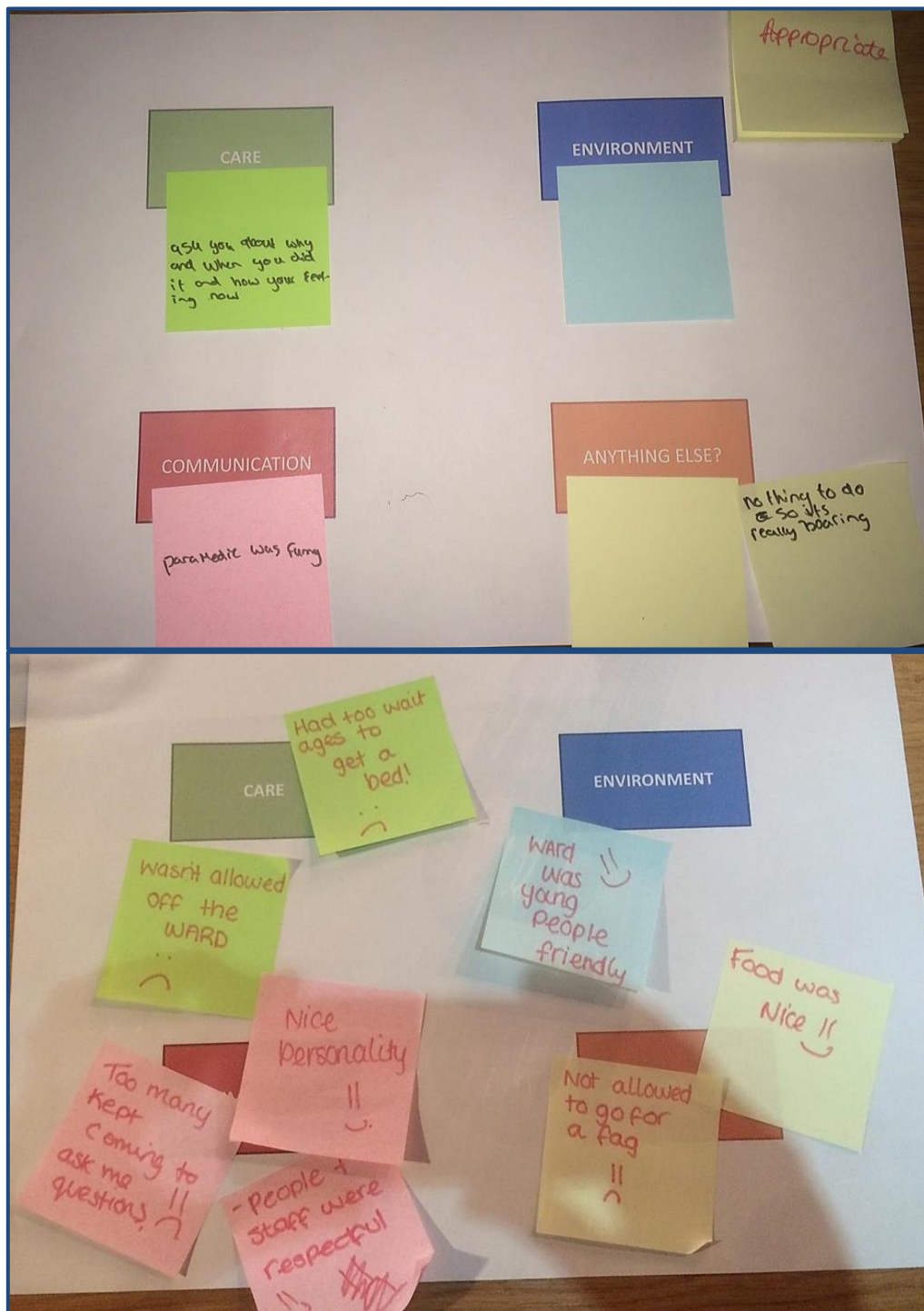


Image 2: Examples of evaluating experiences of care using the four categories

3.2.2 Nominal Group Technique (NGT)

In addition to the creative approaches being employed, the Nominal Group Technique (NGT) was used. This technique is a structured form of group decision-making which allows generation of original ideas to be developed within a group whilst ensuring involvement from everyone [40]. NGT involves the ranking by participants of ideas, statements or domains according to their importance to achieve consensus [41]. This technique was applied to both stakeholder generated statements, developed from the first creative/art based activity, and literature generated statements, developed from the rapid review of the evidence in order to establish consensus from the stakeholder group.

(i) Stakeholder generated statements

Using the ideas generated from the creative activity, participants were asked to individually write notes/comments before contributing their 'most important' statement to the flipchart. Discussion was prevented until everyone had commented on the specific domain, consequently resulting in ideas being shared from every participant [42]. Following on, workshop participants were asked to identify their most important statement for each of the categories. Statements were collated with those of other participants within the group. Each individual ranked from 5 (most important) to 1 (least important) to the flipchart and the other CYPs were then asked to 'vote' on whether they agree and what they perceived to be most important to them.

(ii) Evidence generated statements

For all stakeholder events, each participant was given a booklet of generated statements that were identified from the findings of the rapid review (outlined in Table 3, page 17). Similar to the stakeholder generated statements these were categorised into 'Care', 'Communication' and 'Environment'. Participants were then asked to rank the top five statements according to how much they reflected their experience and outcome following receipt or delivery of care (5- most important to 1-least important).

3.3 Event procedures

3.3.1 Ensuring ethical conduct

Facilitation

All workshops were facilitated by members of the study team that had the experience and skills required for working with and supporting a diverse group of stakeholders (CYP with mental health problems and health/social care professionals). All team members that had direct contact with CYP and parents/carers had enhanced DBS approval. All project staff protected the rights of the project's participants to privacy and informed consent, and adhered to the Data Protection Act, 1998 [43].

Data management

Hard copies of information collected were held securely, in a locked room. Access to this information was limited to the project staff. Computer held data including the project database was held securely and password protected. All data was stored on a secure dedicated web server. Access was restricted by user identifiers and passwords (encrypted using a one way encryption method). Electronic data was backed up every 24 hours to both local and remote media in encrypted format.

Informed consent

For involvement in the stakeholder events, written informed consent was obtained from each stakeholder. Prior to obtaining informed consent, each stakeholder was provided with appropriate written information. It was explained that participation in the project was entirely voluntary and that their treatment and care would not be affected by their decision. It was also explained that they could withdraw at any time. For the participants aged under 16 years, written consent was gained from the parent or legal guardian as well as assent from the CYP.

Participant remuneration

In line with national guidance [44], all CYP, parents and carers who participated in the stakeholder events were provided with a £20 high street gift voucher as a token of appreciation for their involvement. At all stakeholder events refreshments were provided and travel expenses reimbursed

3.3.2 General process

Irrespective of stakeholder group the events followed a similar process in relation to the activities undertaken. This process consisted of the following four activities:

Activity 1: Icebreaker, introductions and getting to know each other

Event facilitators began by explaining the purpose of the event. The icebreaker activity itself is called 'spider's web'. It involves each of the CYP and facilitators throwing a small ball of wool to another and in turn telling the group a fun fact about themselves. The goal is to encourage the CYP to converse with each other and get to know each other in a fun way. Collectively, ground rules were developed and documented to ensure all stakeholders were clear that they could share their experiences in a safe and confidential space.

Activity 2: Evaluating experiences

As described above, this activity involved the application of the creative methods to evaluate and explore experiences of being in receipt of care.

Activity 3: Domain evaluation

This activity involved the ranking of both participant generated domains/statements and those that had been identified from the rapid review of the evidence.

Activity 4: Debrief/Tree of affirmation

Due to the sensitive and potentially evocative nature of the topic being evaluated, a debrief was conducted with all participants. This provided opportunity to:

- a. acknowledge anything they have learned from the event;
- b. disclose anything that has not been covered during the other activities;
- c. reflect on their experience of being involved in the project
- d. ask the facilitators any questions they may have.

3.3.5 CYP Stakeholder event

In order to ensure sensitivity to CYP stakeholders, workshops were divided into two groups based on their reason for admission: (i) those admitted due to an act of self-harm, and (ii) those who have been admitted due to an eating disorder. Potential CYP participants were identified using eligibility criteria, shown in Table 4, which was developed in consultation with the

Consultant Paediatric on the project team. Eligible CYP were identified through retrospective screening of a local hospital admission database.

Eligibility criteria:

- 1. Aged 10-18 years;**
- 2. Admitted to NHS Trust with either eating disorder or self-harm;**
- 3. 6-12 months post admission;**
- 4. Not current inpatient;**
- 5. Not deemed as at risk by clinician.**

Table 4: Eligibility criteria for CYP stakeholder participants

A total of 63 CYP (self-harm injury, n=56; eating disorder, n=7) fulfilled the inclusion criteria and were invited to participate. However, due to the very low numbers of CYP with eating disorders identified from the screening, the eligibility criterion 3 was adjusted to state '6-24 months post admission'. This allowed for an additional 11 CYP admitted with eating disorders to be invited to the event. Invitation letters were sent from the lead clinician to the CYP, or their carers if younger than 16 years old.

The CYP stakeholder events were held on two evenings in May 2015 to ensure that CYP in full time education had opportunity to attend. Through consultation with the local youth service it was identified important that the CYP stakeholder events took place away from the hospital in a non-clinical environment. Therefore both events were held at a local bowling alley as this was identified as a fun and informal environment.

The events were facilitated by members of the project team that included health professionals with expertise in caring for CYP with mental health conditions to provide specialist advice and support if required.

3.3.6 Parents/Carers stakeholder event

The parent/carer stakeholder event was conducted in May 2015 on a weekday evening, in a non-clinical setting, in a central city location.

Eligibility criteria

- Parent or Carer of a CYP aged 10-18 years**
- Their CYP admitted to hospital in past 6-12 months with eating disorder or self-harm injury**

Table 5: Eligibility criteria for parents/carer stakeholders

Similar to the CYP participants, parents and carers were identified from the local admission database using the eligibility criteria, outlined in Table 5. A total of 63 parents and carers of CYP admitted to acute inpatient paediatric care with either self-harm or an eating disorder were invited via postal mail to participate in a stakeholder event.

3.3.7 Professional group stakeholder event

The final stakeholder event was conducted in July 2015 with professional stakeholders. To maximise participation, the professional stakeholder event consisted of three drop-in sessions at various times over a single day. Professionals from local health and social care, education and

the third sector organisations were invited directly, via email from the project team (n=137), and also indirectly, via chain referral from those contacted directly.

3.3.8 Contacting non-attenders

For any eligible participants that were unable to attend the stakeholder events, follow up contact via postal mail, email or telephone was made by the project team to provide an opportunity for their feedback to be captured. Eligible participants were offered to complete Activity 3 (ranking the literature generated domains) and to add any notes or comments they would like to share about their experiences.

3.4 Analysing feedback

Following the stakeholder events, data was collated and entered into a Microsoft Excel™ spreadsheet for analysis to be undertaken. For the CYP and professional stakeholders data were separated into presenting conditions: self-harm and eating disorders.

3.4.1 Thematic analysis

Data from Activity 2 (experiences of receiving care) were analysed using a data driven, thematic analytical approach which was an iterative process. Three of the project team (a child health researcher, a clinician and a psychologist) individually reviewed the raw data collated in the spreadsheets and undertook line by line coding. In qualitative inquiry, a code is a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language based or visual data [45]. Once the statements were coded the researchers discussed findings which involved comparing, contrasting and collapsing.

From this initial coding of the data, the project team proceeded to 'theme the data' - a process used in virtually all qualitative studies when exploring a participant's psychological world of beliefs, constructs, identity development, and emotional experiences [45].

3.4.2 Ranking statements

Data from Activity 3 included the ranking of user and literature generated statements. The total scores were calculated for each statement [46]. From this the strength of the score was calculated using the following equation: (score achieved for the item)/(maximum possible score)x 100, and allowed for the relative importance of the statements to be identified against the other statements [47].

3.5 Key findings from stakeholder events

3.5.1 Summary of participation

In total 96 CYP, parents and carers, and professionals participated in the stakeholder events for this project.

CYP

Of the CYP that were invited to participate in the project 20% (n=15/74) consented to be involved. This was composed of 11 CYP (n=11/56) with self-harm and four (n=4/18) with an

eating disorder. Five CYP with self harm injuries and three with eating disorders attended the stakeholder events. The remaining CYP participated by providing feedback over the telephone.

Parents and carers

Eight out of a potential 63 parents and carers contacted, participated in the stakeholder event. This group was composed of parents and carers of children that had been admitted to hospital with either self-harm, eating disorders, or both. Despite all parent and carer non-attenders being invited via telephone or email to contribute to the project, no additional feedback was collected.

Professionals

Collectively, 74 professionals were involved in the stakeholder engagement activities. The majority of professionals were from healthcare (n=70) and included doctors, nurses and dieticians. However, professionals from education were also represented and included teachers and teaching assistants (n=4). Thirty-six professionals attended the stakeholder events, with the remaining 38 providing separate feedback either face to face, via email or over the telephone.

3.5.2 Feedback from CYP participants

Feedback relating to experiences of being in receipt of acute paediatric inpatient care was collected from CYP participants that attended the stakeholder workshops (n=8).

CYPs experiences of care

CYPs experiences of care (from admission to discharge) were evaluated through the time lining activity. An example timeline is shown in Image 3.

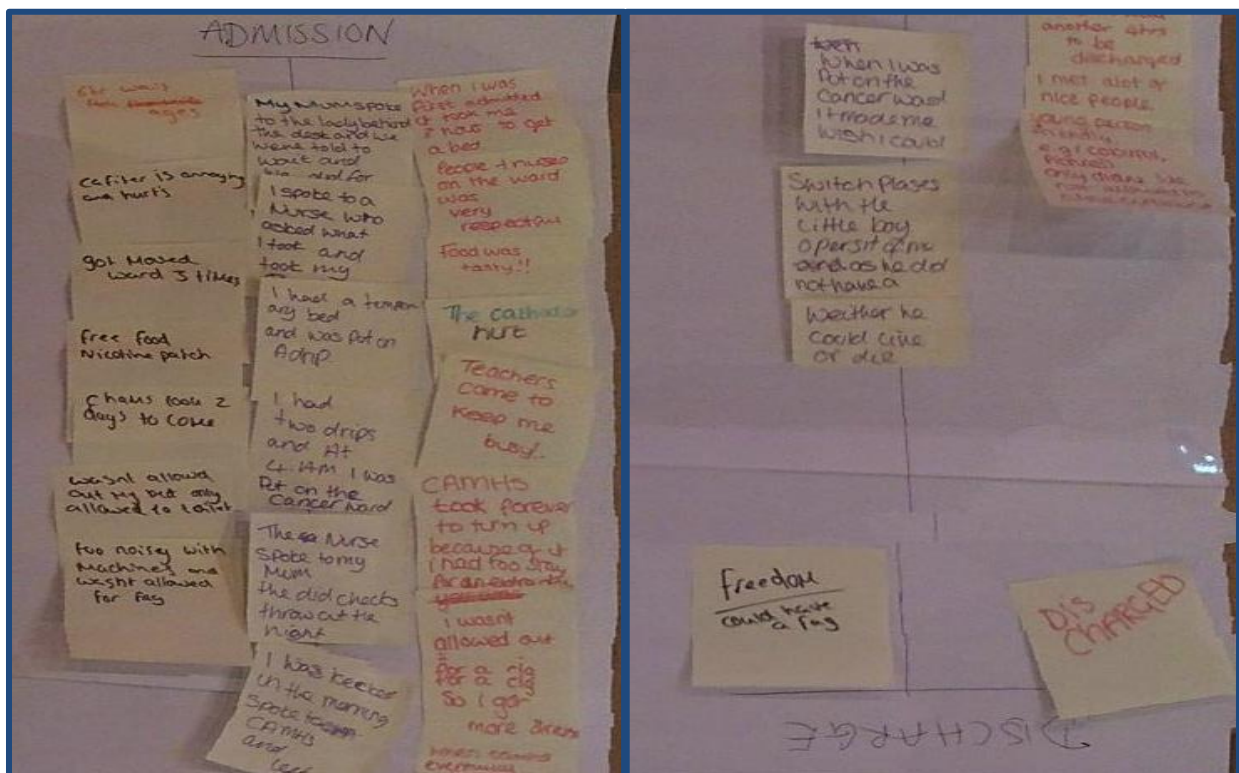


Image 3: CYP feedback from time lining activity

It was evident from this feedback that there was variation in pathways and experiences for the participants that resulted in both positive and negative impact and outcomes being reported. CYP experienced multiple inpatient transitions following initial presentation to inpatient care and delays,

'Got moved ward three times' (CYP2-self-harm)

'CAMHS took 2 days to come' (CYP1-self-harm)

'My mum spoke to the lady behind the desk and we were told to wait and we did for two hours' (CYP4-self-harm)

'☹ lots of waiting for various doctors, appointments and meetings – nerve wrecking' (CYP1-eating disorders)

CYP alluded to the inappropriateness of certain inpatient areas for the receipt of care with examples of recognising the lack of age appropriate environments, or being exposed to additional traumatic experiences and events,

'Babies and toddlers were loud and it would've been better to be with my age group' (CYP3-eating disorders)

'There was different cases mixed it would have been better if it was people in the same situation' (CYP2-self-harm)

'the cases around me weren't appropriate, I watched a man die' (CYP2 – self-harm)

'When I was put on the cancer ward it made me wish I could switch places with the little boy opposite of me as he did not have a choice whether he could live or die' (CYP4-self-harm)

'I was in a ward with cancer patients which were children, it made me feel uncomfortable' (CYP5-self-harm)

Positive experiences of pathways of care were also evident from the CYP time lines. These related to environment, positive interactions with staff, feeling safe and informed, and the opportunity to interact with friends and peers,

'Young person friendly, e.g. colourful pictures, only didn't like not allowed to close curtains' (CYP3-self-harm)

'I met a lot of nice people' (CYP3-self-harm)

'There was always somebody to speak to if I felt unsafe, worried or panicked' (CYP5-self-harm)

'The three nurses that looked after me were really helpful and explained everything really well' (CYP5-self-harm)

'☺ Friends visited me – yay!' (CYP3-eating disorders)

In addition to experiences of care, participants provided information as to how and when it was acceptable to report their outcomes. This differed between the two groups. CYP with self-harm reported that they wanted outcomes measured via an electronic device (such as a tablet or mobile telephone) prior to discharge. Whereas the CYP with eating disorders identified that they wanted to discuss their outcome directly with health professionals at approximately six months following discharge or when they felt they had recovered enough.

Themes	Codes	SH	ED
• Burden of repetition	Burdened by questioning; Same questions- different people	✓	✓
• Good communication	Nurse as mediator; Inclusion of parents; Respectful staff/positive interactions; Feeling catered for; Privacy; Continuity of communication; Accessibility to therapeutic communication	✓	
• Sense of normality	Distraction; Nurses developed a therapeutic communication		✓
• Inclusive communication	Family centred care/inclusion of parents; Clarity of expectations; Feeling understood		✓
• Uncertainty	Uncertainty about treatment; Uninformed- lack of communication; Unsafe/uncomfortable	✓	
• Surveillance	Lack of control; Lack of freedom; Feeling constrained	✓	✓
• Feeling less important	Misunderstood; Complex case; Recognising difficult/unpopular patient; Observing disparities in care provided		✓
• Access to therapeutic communication	Person centred care; Negotiated care; Taking time to care; Appreciation of nursing care; Good care/friendly staff		✓
• Focus on physical care	Physical health assessment; Physical care priority over mental health		✓
• Inappropriate ward environment	Young children around; Other 'sick' children/ observing others= exposure to trauma; Hospital does not cater for CYP with Eating disorders or self harm; Lack of privacy; Desire for specialist facilities; Wanting space; Disruptions/noise; Isolation; Lack of peer communication	✓	✓
• Inclusive environment	Chilled/calm; Having space; Feeling catered for; Accessibility to therapeutic communication; Friendly patients	✓	✓
• Imposed restrictions	Not allowed to go for cigarette /constrained; No entertainment/ boredom; 'Normal' activities are restricted; Having no agency over actions-feeling 'controlled'	✓	✓

Table 6: Themes and codes identified from the CYP stakeholder feedback (ED= eating disorder; SH= Self-harm)

Thematic analysis

CYP experience data was subjected to thematic analysis and resulted in 12 themes being developed from 49 codes. Table 6 outlines each theme and associated codes and identifies the CYP data according to group from which they emanated from. It is evident from this analysis that similar and conflicting experiences and themes emanated from both between and within each group of respondents.

Ranking of CYP generated statements

Following thematic analysis of the feedback, CYP generated statements or topics were ranked by the CYP according to their importance. As outlined in Table 7, the top five statements with the greatest strength score for CYP admitted with self harm injuries related to both positive (Parents being involved in communication; being given space) and negative aspects of care (not being allowed privacy; not being allowed to make choices; boredom). These aligned to factors relating to the hospital environment, communication, and choices/boundaries.

Statements	Total	Strength of vote score
Was not allowed to close the curtain :(so had no privacy	22	88%
Nurses spoke to my mum about how I feel and what I was going through	23	92%
Whilst I was waiting I was left alone which was good	19	76%
Not allowed for a fag so I was kicking off and really angry	25	100%
There was no entertainment	20	80%

Table 7: Statement ranking totals and strength of vote score of CYP generated statements from CYP admitted with self harm injuries (n=5)

Ranking of CYP generated statements from those admitted with an eating disorder (outlined in Table 8) identified that the area with greatest importance and strength score related to aspects of care, communication and environment. CYP rated positive behaviours from health professionals such as being open, honest and transparent with them as important. Rankings indicated that CYP perceived the lack of understanding from professionals about the condition, absence of a specific environment to care for CYP with the condition, and delays in receiving care as also important.

Statements	Total	Strength of vote score
Not many carers understood eating disorders :(15	100%
Good to have a more specific ward for people with eating disorders	15	100%
Drs + nurses were nice	14	93%
Transparent and explained things when asked	14	93%
Doctors did not know when they would visit- lots of waiting for appointments	12	80%

Table 8: Statement ranking totals and strength of vote score of CYP generated statements from CYP admitted with eating disorders (n=3)

CYP ranking of literature generated statements

Ranking was then conducted with the literature generated statements from the rapid review. Analysis of the data for each group, as outlined in Table 9 and Table 10 allowed for the top five statements to be identified from the strength of vote score.

Statements	Total	Strength of vote score
“ My care focused more on my physical health rather than how I felt”	33	60%
“I felt that I didn’t have my own privacy”	30	54%
“I felt that I was pressured to talk”	27	49%
“I did not like being with sick children”	25	45% ^{equal fourth}
“I did not feel that people who worked in the different parts of my care worked together”	25	45% ^{equal fourth}

Table 9: Statement ranking totals and strength of vote score from CYP admitted with self harm injuries (n=11)

Statements	Total	Strength of vote score
“ I felt that I was not understood”	14	70% ^{equal 1st}
“ My care focused more on my physical health rather than how I felt”	14	70% ^{equal 1st}
“I felt that I had no voice”	13	65%
“I felt that I didn’t have my own privacy”	10	50% ^{equal 3rd}
“ I felt that I had other problems that were not addressed	10	50% ^{equal 3rd}
“I felt that I was pressured to talk”	10	50% ^{equal 3rd}
“ I had to follow the rules”	9	45% ^{equal 4th}
“I felt like I was being watched all the time”	9	45% ^{equal 4th}
“I was scared about what others thought of me”	9	45% ^{equal 4th}
“I didn’t know what was happening in my care”	9	45% ^{equal 4th}
“I needed to work with others to get better”	9	45% ^{equal 4th}

Table 10: Statement ranking totals and strength of vote score from CYP admitted with eating disorders (n=4).

Between the two groups of CYPs, similarities existed for statements that had the highest strength of vote score. Both groups rated, “My care focused more on my physical health rather than how I felt” as most important, with other statements including, “I felt that I was pressured to talk” and “I felt that I didn’t have my own privacy” ranked in the top five.

However, differences between the groups were also evident. For CYP admitted following self-harm (Table 9) inappropriate environment for receipt of care, and lack of inter-professional working to deliver their care, were considered important topics that they could relate to.

In contrast, CYP admitted with eating disorders (Table 10) attributed importance to statements that related to conforming to rules and being watched, not being understood, fear of being stigmatised, not being informed, and not having a voice. However, as evident from the statements in Table 11 the strength of vote score was the same for a number of rankings. This made it challenging to distinguish between statements.

3.5.3 Feedback from parents and carers

Analysis was conducted with data from the parent and carer ranking of literature which generated statements from the rapid review. The top five statements were identified from the strength of vote score, outlined in Table 11.

Statements	Total	Strength of vote score
“My son/daughter felt that they were not understood”	29	73%
“My son/daughter felt that they had other problems that were not addressed”	28	70%
“My son/daughter felt that they didn’t have their own privacy”	24	60% ^{equal 3rd}
“ My son/daughter's care focused more on my physical health rather than how they felt”	24	60% ^{equal 3rd}
“My son/daughter did not feel that people who worked in the different parts of their care worked together”	23	58%
“My son/daughter was scared about what others thought of them”	21	53%

Table 11: Statement ranking totals and strength of vote score from parents and carers (n=8)

It was evident that the parents and carers most important statements related specifically to care and the environment in which care were delivered. Statements receiving the highest strength of vote score included, “My son/daughter felt that they were not understood” and “My son/daughter felt that they had other problems that were not addressed”. These indicate the importance of professionals understanding their child and working in a way that addresses their holistic needs. Furthermore, other statements that were ranked as important indicate that care delivery focuses on physical health and delivery is disjointed between professionals.

3.5.4 Feedback from professionals

Finally, analysis was conducted with data from the professionals who had ranked the literature generated statements from the rapid review. Similar to the CYP groups, these were divided into groups based on reason for admission. The top five statements were then identified from the strength of vote score and are presented in Table 12 and Table 13.

Despite being ranked separately and, in most instances, by different individuals from the professional group, commonalities existed between the ranking of statements for the two groups. Statements including “CYP felt that people were judging them”; “CYP were scared

about what others thought of them”; “ CYP’s care focused more on their physical health rather than how they felt” received highest strength of vote score. These relate to stigmatisation and the physical focus of care being delivered.

Statements	Total	Strength of vote score
“CYP were scared about what others thought of them”	157	63%
“CYP felt that people were judging them”	148	59%
“ CYP felt that they were not understood”	136	54% ^{equal 4th}
“CYP didn’t know what was happening in their care”	135	54% ^{equal 4th}
“ CYP's care focused more on their physical health rather than how they felt”	123	49%
“CYP felt like they were being watched all the time”	116	46%

Table 12: Statement ranking totals and strength of vote score from Professionals in relation to self-harm (n=50)

Statements	Total	Strength of vote score
“ CYP's care focused more on their physical health rather than how they felt”	87	62% ^{equal 1st}
“CYP were scared about what others thought of them”	87	62% ^{equal 1st}
“CYP felt like they were being watched all the time”	83	59%
“CYP felt that they didn’t have their own privacy”	81	58%
“CYP felt that people were judging them”	69	49% ^{equal 4th}
“CYP did not feel that people who worked in the different parts of their care worked together”	68	49% ^{equal 4th}
“ CYP felt that they were being controlled”	68	49% ^{equal 4th}
“ CYP felt that they had other problems that were not addressed	57	41% ^{equal 5th}
“CYP didn’t know what was happening in their care”	58	41% ^{equal 5th}

Table 13: Statement ranking totals and strength of vote score from Professionals in relation to Eating Disorders (n=28)

Furthermore, surveillance and lack of information about care, related to other statements that received high scores from the professional group. It was evident that these top ranking statements for both groups of conditions related to aspects of care and the inpatient environment as opposed to communication.

3.6 Synthesising findings from across stakeholders

Top ranking statements from each stakeholder group were collated to explore the level of consensus across the different groups, outlined in Table 14.

Statements	CYP Self-harm	CYP Eating Disorders	Parents / carers	Professionals (Self-harm)	Professionals (Eating Disorders)	Domain
Environment	"I felt that I didn't have my own privacy"	✓	✓	✓	✓	1
	"I felt that I was not understood"		✓	✓	✓	2
	"I felt like I was being watched all the time"		✓		✓	1
	"I felt that people were judging me"				✓	5
	"I had to follow the rules"		✓			4
	"I did not like being with sick children"	✓				3
Care	"My care focused more on my physical health rather than how I felt"	✓	✓	✓	✓	2
	"I was scared about what others thought of me"		✓	✓	✓	5
	"I did not feel that people who worked in the different parts of my care worked together"	✓		✓	✓	4
	"I felt that I had other problems that were not addressed"		✓	✓	✓	2
	"I didn't know what was happening in my care"		✓		✓	3
Communication	"I felt that I was pressured to talk"	✓	✓			3
	"I needed to work with others to get better"		✓			3
	"I felt that I had no voice"		✓			4
	"I felt that I was being controlled"				✓	4

Table 14: Comparison of stakeholder top ranking statements across groups.

Domain 1:	Privacy and surveillance
Domain 2:	Receiving holistic care
Domain 3:	Making choices and being understood through timely, relevant and appropriate communication
Domain 4:	Working together to plan and achieve care goals
Domain 5:	Respect and empowerment

Table 15: Five domains developed from top ranking statements

This clearly identified that across the groups there were shared issues that were important. In particular, the focus of inpatient care on physical health, stigma and fear of what others thought of CYP, issues of privacy and surveillance were recognised as important.

Congruence across groups was further illuminated through the development, and allocation, of domains from the top ranked statements. Five domains were identified by the project team (shown in Table 15) which encompassed all statements (shown in Table 14).

4. Discussion and conclusion

From the information presented in this report, this project has fulfilled its aims and objectives in generating evidence through a rapid review of the literature, as well as evaluating user experiences and establishing consensus of domains through stakeholder engagement that can collectively inform the development of a PCOM.

4.1 Evaluating CYP experiences of inpatient care

- Both the rapid review of the literature and the stakeholder feedback suggest that the impact and outcomes of care for CYP admitted with self-harm and eating disorders vary.
- Both positive and negative experiences were documented in the evidence as well as identified by CYP service users. These appear to relate to care delivery, communication and environment.
- Disparities in experiences and the implied quality of being in receipt of care indicate the need for a measure to be developed and implemented to enable services to evaluate the outcome of their acute inpatient hospital provision.

4.2 Consensus of domains for a PCOM

- From our findings there were clear issues of what was important to stakeholders with congruence of ranked statements across groups which related to experiences and outcomes of care, communication and the inpatient environment.
- Synthesis of findings identified five domains (shown in Figure 4) that could be used to develop a PCOM.

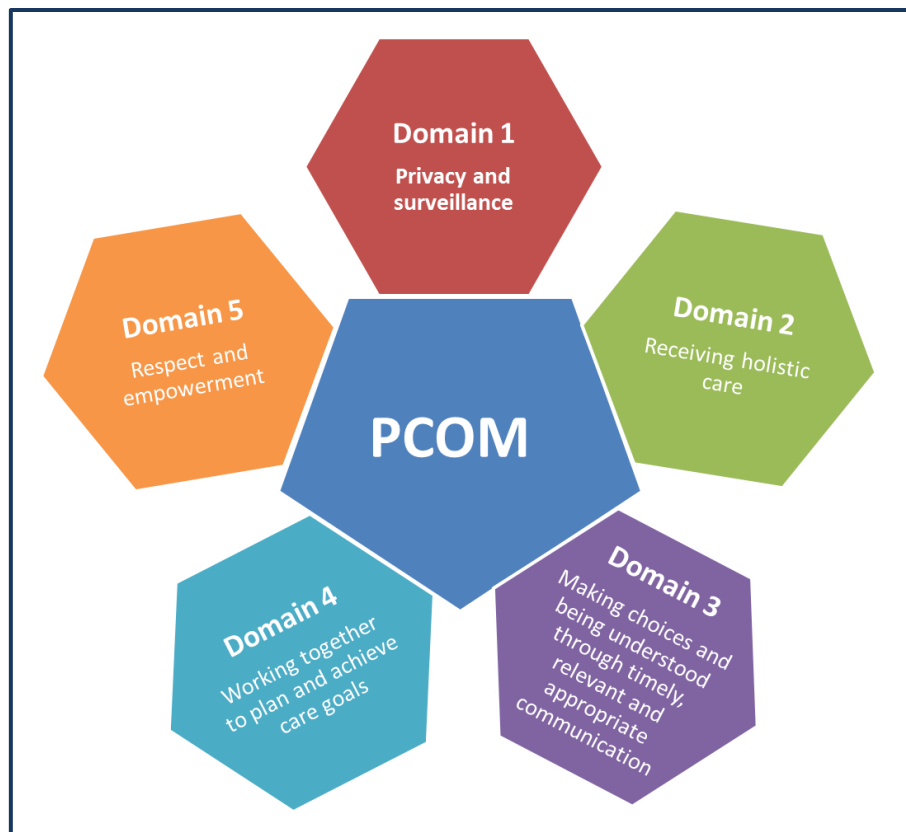


Figure 4: Domains for a PCOM

4.3 Establishing the acceptability of PCOM implementation

- From the CYP stakeholder feedback it is evident that the acceptability of when and how outcomes are measured varied between the two groups of presenting conditions.
- For CYPs admitted with self-harm, consensus that measures should be employed prior to discharge and an electronic platform would be an appropriate method for collection.
- In contrast, CYP admitted with eating disorders identified a preference of measuring their outcome through direct discussion with a health professional and this was to be undertaken following their discharge from hospital.
- Therefore any subsequent PCOM developed to evaluate the outcome for these patient groups needs to have the flexibility in how and when it is implemented to satisfy these diverse needs.

4.4 Project limitations

- This project was conducted with stakeholders from a specific geographical region within England. Therefore the findings outlined in this report may not reflect the perspectives of service users or providers from other parts of the country.
- Despite inviting a large number of CYP and parent and carer stakeholders to participate in this project, only a limited number chose to be involved. Despite the depth and richness of the feedback elicited from these participants, it is not known whether their experiences were different from those that did not take part.

4.5 Recommendations for developing a PCOM

- To our knowledge this is the first project that has undertaken the preliminary work in identifying the domains for the development of a PCOM to evaluate the quality and impact of acute paediatric inpatient care for CYP admitted with self harm injuries or eating disorders.
- This project has formed the first phase of a programme of research that will conclude in a PCOM for CYP admitted to acute paediatric care with self-harm or eating disorders being developed, tested, evaluated and implemented.
- The next logical step is for the domains identified from this project to be further developed and validated as an instrument with a larger sample of CYP admitted to acute inpatient care with self harm and eating disorders that vary in age, ethnicity, demographics, outcomes and geographical location.

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