# National evaluation of NHS genetics service investments: emerging issues from the cancer genetics pilots

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In seeking to fulfil the ambition of the 2003 genetics white paper, *Our Inheritance, Our Future*, to 'mainstream' genetic knowledge and practices, the Department of Health provided start-up funding for pilot services in various clinical areas, including seven cancer genetics projects. To help to understand the challenges encountered by such an attempt at reconfiguring the organization and delivery of services in this field, a programme-level evaluation of the genetics projects was commissioned to consider the organizational issues faced. Using a qualitative approach, this research has involved comparative case-study work in 11 of the pilot sites, including four of the seven cancer genetics pilots. In this paper, the researchers present early findings from their work, focusing in particular on the cancer genetics pilots. They consider some of the factors that have influenced how the pilots have sought to address pre-existing sector, organizational and professional boundaries to these new ways of working. The article examines the relationship between these factors and the extent to which pilots have succeeded in setting up boundary-spanning services, dealing with human-resource issues and creating sustainable, 'mainstreamed' provision which attracts ongoing funding in a volatile NHS commissioning environment where funding priorities do not always favour preventive, risk-assessment services.

## Introduction

In chapter three of the genetics white paper,[1] the government outlined its ambition for a National Health Service (NHS) in which genetics would permeate every sector, from community provision through to specialist care. While "strengthening existing specialised services" (para.3.1), such as laboratory provision, represented a first step, it was not enough in itself: as the centrality of genetics to healthcare provision became more essential through time, so it was crucial that genetics knowledge and capacity was spread throughout the system. Thus the government declared its intention to "spur the take-up of genetics by other specialties by supporting new initiatives in genetics based care—in the hospital sector, in primary care and in screening programmes" (para.3.3).

   This work was to include the piloting of the so-called Kenilworth Model of familial cancer risk assessment, developed by Macmillan Cancer Support, in six (later increased to seven) sites, as well as other initiatives, including service developments in primary and secondary care, a cascade testing project for a common single-gene disease (familial hypercholesterolaemia), and the

funding of 10 General Practitioner with a Special Interest in genetics projects. The changes in the practice of service delivery that many of these projects would prompt were significant, seeing shifts in provision across sector, organizational and professional boundaries. Thus the Department of Health (DH) commissioned a programme-level evaluation to consider the organizational issues raised by these projects, to be carried out alongside pilots' own internal evaluations.

Among the case study sites selected for the programme-level evaluation were four of the cancer genetics pilots co-funded by Macmillan and the DH. In this paper we present some early findings from our research in these sites, considering in particular the pre-existing sector, organizational and professional boundaries which pilots have encountered, and how pilots have sought to address these boundaries, especially in relation to setting up services, dealing with human resource (HR) issues, and sustaining service delivery beyond pilot funding in a challenging NHS commissioning environment.

## Background

The need for genetic knowledge to be 'mainstreamed' into wider aspects of medicine and healthcare delivery stems from the previously highly specialized nature of this body of knowledge, and the need for others to have access to it and incorporate it into their own practice in the face of booming demand and accelerating awareness of genetic dimensions of health and illness—in the process making more efficient use of specialized services. The perceived isolation of genetics knowledge within specialist centres was considered by policymakers a barrier to joined-up service provision, reflecting wider preoccupations within government around the need for partnerships and networks within and between state agencies that transcend boundaries of various kinds.[2] This view has informed various reforms since 1997 to the British health service, such as the creation of primary care groups and trusts (PCTs), which as 'networks' of health professionals were expected to foster co-operation in commissioning services and tackling public health issues, overcoming the difficulties associated with both 'command-and-control' and market-based mechanisms for governing public services, and forging partnerships with local government.[3,4]

However, such inter-sector, inter-organizational and inter-professional networks face a number of barriers to their success. These might broadly be categorized under three headings, as relating to 'politics', 'culture' and 'the nature of knowledge'.[5,6] Politically, boundaries between professions and organizations are difficult to span because it remains in the self-interest of most groups to hoard their knowledge, especially in an NHS where professional hierarchies remain dominant and hospital-based clinicians retain greater power than other professional groups, and those located in other organizations.[7] Such political differences are compounded by a top-down regulatory system operated by central government which remains dominant, despite rhetoric about networks and local discretion, and which imposes performance targets which tend to make individuals and organizations less, rather than more, inclined to share knowledge and co-operate. Alongside this, movements to improve efficiency within the health service, by means of the purchaser-provider split and competition between providers, create further obstacles to inter-sector co-operation and restrict the extent to which any organization can look beyond narrow, economically driven requirements.[8] Culturally, those located in different professions and different organizations or divisions within organizations may not be used to communicating with each other, have little understanding of the pressures faced by each other, and have little basis for forging an effective relationship through which to take forward a 'networked' service. In terms of the nature of knowledge, much of the knowledge (including clinical knowledge but also knowledge about service delivery) that is to be shared between different groups may be tacit (and grounded in experience), and therefore difficult to articulate and present to others. This may be especially pressing in an esoteric field such as genetics, although sharing tacit knowledge about, for example, how best to counsel high-risk (or population-risk) patients may be just as intractable

| Programme | FH cascade audit | Service development projects | Macmillan/DH cancer family history projects | General practitioners with a special interest in genetics | Total |
|---|---|---|---|---|---|
| Number of sites | Five (one co-ordinating centre) | 10 | Seven | 10 (12 GPs) | 32 |
| Sites selected as case studies | None | Three | Four | Four | 11 |
| Interviews conducted to date (in each site) | - | 23 (7/4/12) | 43 (11/12/10/10) | 19 (7/4/5/3) | 85 |

Table 1: Summary of case study sites and interviews conducted

as sharing clinical knowledge, especially if the latter can be broken down and codified with different levels of triage and risk-assessment tools.

As projects that are seeking to 'mainstream genetics' and thereby potentially span a number of boundaries, the cancer genetics and other pilots have faced these and other organizational issues.  It is on these, and on the efforts of pilots to overcome them, that the programme-level evaluation has focused.

**Methods**

The evaluation has taken a qualitative approach, deploying a number of methods in 11 case-study sites, including four of the seven familial cancer risk assessment pilots (two hospital-led, two primary care-led) (see table 1).  Case-study sites were selected on the basis of such characteristics as host sector (primary care / secondary care / tertiary care), lead profession (medic / nurse / genetic counsellor), profile of population served (e.g. socio-economic complexion of locality, rurality, ethnic mix), nature of service provision (what is done, by whom, where) and so on, with a view to obtaining a sample in which variation in each of these variables was included.  This method of selection permits a comparative-case approach,[9,10] the aim of which is to compare processes between sites, so that the importance of different factors may be noted and causality be attributed.  This approach enables generalization not on a statistical basis but through process analysis and the development of theory.

Having identified case-study sites in the course of support provided for pilots' internal evaluators during the first year of our work, research was planned with the lead in each site, identifying key stakeholders in the projects and key events (such as project or steering group meetings) at which decisions about the pilots were made.  Following this, the research itself took three principal forms: tape-recorded semi-structured interviews, varying in length between approximately 40 minutes and two hours, held with stakeholders and addressing the pilots, problems encountered and solutions; observation at events and meetings, including local meetings within the sites and cross-pilot events convened by Macmillan; and analysis of key documents relating to the sites' work, such as minutes of meetings.  A second round of interviews will take place with selected respondents, following up on issues where further information is required, where further developments have occurred, or where further reflection by the participant is of interest.

In the four cancer genetics sites included in the study, some 43 interviews have been carried out with stakeholders (table 1).  Though tape-recorded, these have not all yet been transcribed, and so the results presented here derive from notes taken by the researchers at the time of the interviews, along with data gathered through the observation and documentary analysis components of the research.  The findings presented in this paper draw primarily on the research carried out in the four cancer genetics sites, with occasional relevant insights from the wider research denoted as such.  We aim here primarily to provide a descriptive account of the

issues which have faced and are facing the pilots, and only draw theoretical abstractions to the extent that similar issues may face other start-up services in similar situations.

Ethical clearance for this work was granted by Trent Multi-centre Research Ethics Committee. In accordance with this permission, the identities of the case-study sites and of those participating in the research are not revealed.

## Results

We present findings in terms of three key themes as follows: engaging stakeholders; establishing new roles; and securing a post-pilot future.

### Engaging stakeholders

In many of the sites across the 11 included in the study, contribution to operational and strategic management of the pilot was limited to those directly involved in service delivery. This was less true in the cancer genetics sites than in some of the others, as funding for the former was contingent upon sign-up from a variety of local stakeholders, including cancer networks and commissioners. Nevertheless, even though this buy-in had been achieved on paper, in practice there were frequently difficulties with sustaining engagement from wider stakeholders with competing demands on their time and for whom these were relatively small-scale set-ups with marginal impact on their day-to-day work.

Input from managers into pilots' work was often lacking. Usually, the projects had been initiated and set up by practitioners who had been well placed to diagnose shortcomings with existing care pathways for patients with family histories of cancer, and to come up with solutions to these. On an operational level, this lack of managerial input was frequently not a problem, and as host PCTs and hospital trusts were often less than proactive in attempting to ensure that pilot activity was incorporated into managerial agenda, it was only when difficulties arose that efforts at engagement were made. Often, this was at the point of business planning to ensure post-pilot sustainability; as noted below, the ending of pilot funding coincided with financial and organizational upheavals within the NHS, which made it all the more difficult to gain involvement from managers pressed with other concerns. Difficulties such as these were compounded where there were organizational boundaries to contend with: for example, those between specialist genetics directorates and oncology or mainstream clinical directorates, or between medical and non-medical line management systems; in one case, these divisions were also between different hospital trusts. The two PCT-based sites fared better in this regard, as access to managerial input seemed less constrained by organizational structures.

Other relationships with stakeholders were easier for hospital-based pilots to establish. Success in a number of sites was crucially reliant on compliance from a number of other specialties, and especially from site-specific groups in included hospitals, and pre-existing relationships between hospital staff were useful here. Often, these groups had had their own triaging systems for suspected cancer family histories, and so uptake of the local version of the Kenilworth model was reliant on longstanding existing protocols being abandoned in favour of this new way of working. For primary care- and hospital-based pilots alike, the presence of champions for the service among these other groups was important, including—but not limited to—influential clinicians, often prominent in local cancer networks. Equally important, though, was buy-in from nurses in these groups who had been taking family histories. These champions at every level were often known to practitioners on the pilots prior to start-up, and sympathetic to achieving these kinds of organizational changes. Where persuasion was required, interviewees often noted that different tactics worked better with different parties. Nurses, for example, tended to be won over by changes in provision that meant a better service for patients in terms of convenience and information provision. Doctors and managers, on the other hand, often had to be convinced that there was hard evidence for a change, and leverage provided by nationally accepted guidelines, such as the National Institute for Health and Clinical Excellence (NICE)

familial breast cancer guidance,[11] proved useful here.

As might be expected, the nature of the relationship between, on the one hand, those delivering pilot services and, on the other, consultant clinical geneticists and genetic counsellors in tertiary care varied noticeably depending on the organizational set-up.  In community- and hospital-based projects alike, strong relationships were needed in planning training and education for practitioners at the start of pilots.  After this, the relationships differed.  Where specialists and practitioners on pilots were co-located in hospitals, the former tended to have a general supervisory relationship with the latter, incorporating line management and career development as well as clinical supervision.  As such, clinical governance arrangements tended to be ongoing, dialogical and informal, with difficult or borderline cases discussed and decided upon bilaterally or at team meetings, and seen in terms of continuing professional development as well as patient safety.  Practitioners located in primary care tended to have more formal clinical-governance relationships with tertiary care-based specialists, with cases sent over in batches for verification by specialists.  This was not seen as having adverse implications for patient safety, but in relation to one (non-cancer) genetics pilot, was seen as highly time consuming for the clinical geneticists, who felt they had to double-check every risk assessment carried out by practitioners whose training they saw as inadequate for the roles they had adopted.  In relation to the cancer genetics pilots, primary care-based practitioners tended to be relatively senior and experienced oncology and genetic nurse specialists, who worked autonomously in setting up the service themselves and in drawing pedigrees and carrying out risk assessments.  By comparison, practitioners on pilots hosted by secondary and tertiary care often seemed comparatively protocol-driven, and preferred to defer clinical judgement to genetic counsellors and consultants in case of any doubt.

A significant and ongoing problem for the pilots centred around the engagement of external stakeholders in primary care, especially general practitioners (GPs).  For many of the pilots, primary care was to be the principal or sole source of referrals to the service, but securing the compliance of GPs was a challenge that took much time and effort, if it was surmountable at all.  Once again, established relationships were important in generating trust in a novel service.  For example, in one primary care-based site, the practitioners' prior contact with individual practices as community nurses proved helpful.  Interviewees in some sites, though, commented that a few GPs were disinclined to refer at all to a nurse-led service, and sent all suspected cases, including asymptomatic family history referrals, to a secondary care-based consultant (who forwarded them on to the service!).  Where GPs had been successfully engaged, it was often attributed to success in communicating the benefits for GPs in terms of worried patients who could be dealt with elsewhere, and by demanding as little attention from GPs as possible.  Indeed, often it was by engaging practice staff other than GPs—practice managers and nurses— in the first instance that pilots sometimes gained access to general practice.  Plans for workshops and presentations for GPs were often replaced by short, snappy information leaflets with clear referral instructions.  For similar reasons, and in the face of fewer referrals than they had been anticipating, some sites abandoned 'level one' training for GPs altogether, instead permitting referrals of all concerned patients without any need for triaging by GPs.  More generally, some sites noted an increase in referrals from GPs through time: awareness of the existence of provision, and faith that (as a pilot) it was not about to disappear overnight, took time and determination to establish among referrers.

In services that were open to self-referrals, meanwhile, interest was often present from the start, though not always among the constituencies that pilots were most eager to engage.  Increasing uptake from ethnic minority groups, in particular, proved an intractable challenge for many of the sites, despite various strategies adopted to try to make services more accessible.  And while service-user involvement was valued in several of the sites in terms of contributions to, for example, publicity and information provision that was seen to increase overall uptake, it was less successful in helping to address a problem which has long plagued the health service:  widening provision to so-called 'hard-to-reach' groups.  Interviewees commonly felt that this was a

difficulty that was too complex and multifactorial to be successfully tackled through any intervention that could be achieved through relatively small-scale service redesign.

*Establishing new roles*

In many of the pilots, services were to be delivered by practitioners operating in new or unusual roles.  This presented challenges in terms of role definition and recruitment.  Across all the genetics case-study sites, cancer and non-cancer, and in keeping with the comment above about the general absence of managerial input into their activity, there had been little or no input from human resources departments into this work.  Job descriptions, educational programmes and competence definitions were largely defined in consultation between the clinical members of project teams, with input from human resources managers only at the point of calculating grading and pay scale.  Training and education, meanwhile, were negotiated locally with specialist geneticists in the absence of any 'off-the-shelf' educational programmes for those working in these kinds of 'hybrid' roles, which meant that training could be timed to fit in with other commitments during the busy early stages of pilots.

The pilots had mixed experiences of recruitment.  Least difficulty was encountered by those pilots which sought to expand the roles of existing personnel, rather than recruiting new staff.  When recruiting, some pilots had little difficulty in attracting applicants, but others struggled to find suitable candidates and consequently had to redefine job descriptions or grades to make them more attractive to a broader range of suitable candidates,  To some extent, the degree of difficulty pilots encountered in recruiting seemed associated with local labour markets, although differences between the precision of person specifications between pilots was striking: one pilot did not specify a nursing background as necessary for its core posts (though ended up appointing nurses, who were seen to embody the necessary skills); others were exacting in their requirements for nurses with genetic experience and certain skills, such as language skills.  The fixed-term nature of posts where the role related solely to the pilot work was seen as another deterrent to potential applicants. Overall, however, the unusual nature of the posts, which often incorporated project management, educational and research components as well as delivery of a clinical service, seemed in practice not to be a significant obstacle in itself to recruitment.  Rather, it meant that applicants were often self-selecting individuals with unusual career histories and aspirations, often with experience of deviating from the normal career ladder and with little fear of doing so again.

Pilots which attempted to involve GPs in their service-delivery work sometimes found this difficult to put into practice, with some GPs who had expressed a desire to do this work and develop an interest in genetics subsequently finding this difficult to enact due to pressure of day-to-day work.  Where GPs were involved in service delivery, there was not in practice a difference between their caseload and that of non-medical practitioners, although previously developed communication skills were seen as an advantage, and GP involvement in a service bought a certain amount of extra credibility with other GPs.

*Securing a post-pilot future*

With initial pilot funding periods of between two and three years, many respondents were of the view that they had been faced with a difficult task: setting up, recruiting to, training for, publicizing and making successful a service which could then hold its own in an NHS commissioning environment that proved to be more hostile than anticipated due to the budgetary pressures faced by PCTs.  When initially opening their doors to referrals, pilots had adopted different strategies with regard to publicity and throughput: some feared inundation with an unmanageable flow of referrals if too much awareness-raising activity was undertaken with GPs and the public;[12] others sought to 'drum up' as much interest as they felt acceptable under NICE guidance.  In the event, no service found the volume of referrals overwhelming, and many found that generating the kind of throughput required for sustainability was only being approached with little pilot time left.  At the time of writing, the future of none of the services

was certain, but many were hopeful that ongoing funding might be achieved through one route or another. Given this uncertainty, though, there was considerable reluctance to continue to attempt to increase activity given there might soon not be a service for patients to utilize.

Given their relatively low levels of throughput, proving a case to commissioners in terms of cost-efficiency was not possible for many of the pilots. Even where a case could be made around efficiency savings to the health service, interviewees had found that commissioners were considerably less receptive to potential future savings due to early detection and quality-adjusted life years saved than they were to demonstrable immediate savings, for example through the cessation of inappropriate screening provided to patients who had been risk assessed under previous protocols. In some sites, such a case could be made; in others, patients already being screened were not targeted by the services, or the numbers in screening programmes were too small for any significant cost saving to be made.

Pilots had a mixed experience of the role of cancer networks in their efforts at sustainability. Sign-up at the point of bidding for pilot funding did not always translate into support for mainstreaming as part of local delivery plans, although in some networks, enthusiastic coalitions of influential clinicians, managers, commissioners, and patient and carer group members had helped to push preventive services up the agenda and at least create a climate in which funding possibilities could be discussed. Elsewhere, however, the picture was stark: there was too little money to fund existing cancer services and to ensure that imperative priorities around cancer imposed by central government were met. As one cancer network manager put it, "No-one's asked me in the time I've been here, 'Account for what you're doing on cancer genetics', and they ask me that question about a whole lot of other things." To this extent, the saturation of cancer as a clinical area with centrally defined targets was a barrier, rather than a lever, to funding of these services, which were marginalized.

With cancer networks largely unwilling to make mainstream funding for the pilots a priority for PCTs, then, services explored some of the other routes by which funding might be secured. Some hospital-based services were considering devising tariffs for funding through payment by results, although this meant further complications for pilot staff, who found themselves in extensive consultations with trust managers, calculating cost and required volume to break even. In at least one trust, the feeling was that funding by this route carried too much risk given the wider financial climate in the NHS. Some sites sought further short-term funding from various sources which, it was felt, would enable them to produce an evidence base sufficient to secure mainstream funding on the basis of patient benefits and efficiency savings. In other pilots, service delivery was made by core-funded staff as an add-on to their primary role, and here, the cessation of pilot funding was less of a risk to the service, though it often meant that wider publicity and educational activities were unlikely to continue.

PCT-based pilots, though, found that rather wider justifications for continued funding could be drawn upon in appealing to a broader range of stakeholders, including public health, the professional executive committee and GPs, for whom an easy point of referral, providing more effective management of patients than could be provided with existing provision, was an important concern. PCT mergers presented an extra complication here, though. The identities of decision makers changed; proposed services had to ensure accessibility across an often much larger geographical area. Further, newly merged PCTs, which may have had rather different approaches to delivering on, for example, public-health agenda, were just beginning to define their strategies and expectations, so that pilots sometimes had to recast themselves to ensure that their ethos and rationale fitted in with these new priorities.

**Discussion and conclusion**

Though small in scale, the changes that many of the genetics pilots have attempted to effect with limited time and resources have necessitated engagement with disparate elements of diverse local health economies, and as such it is not surprising that they have encountered difficulties and had

varying degrees of success in overcoming these.  Pilots have dealt with the political, cultural and epistemological barriers they have come up against in various ways contingent upon local circumstance, and in a way that defies any single 'checklist' of solutions.  Nevertheless, some general points may be made from the experiences of the cancer genetic risk assessment pilots that are likely of wider significance to others attempting to shape similar change.

Firstly, established relationships and 'social capital'[13] were of central importance not only in fostering collaborations that led to the initiation of pilots, but also in gaining trust and 'buy-in' from parties beyond pilot staff whose co-operation was essential to making services work.  In many cases, this required well established relationships—or extensive work on developing these—across organizational and sector boundaries, and quickly developing a working knowledge of the particular pressures facing disparate professional groups.  Secondly, and following this point, a sensibility to the priorities of other groups was often instrumental in achieving wider organizational and behavioural change—for example among referrers—that might assist the establishment of pilot services.  Where a key lever for change for secondary care clinicians and managers, then, was (quantitative) evidence with direct bearing on their practice, for other groups, such as GPs and nurses, rather different benefits of service redesign—relating for example to the coherence of the care pathway and the perceived benefit for individual patients— were likely to appeal, as noted elsewhere.[14]

Thirdly, despite initial buy-in from cancer networks (upon which pilot funding from Macmillan and the DH was contingent), ongoing engagement could not be relied upon, above all as networks faced increasingly directive instruction from central government.[15]  Fourthly, the panoply of targets associated with cancer was not necessarily advantageous to these pilots. Though present in the Cancer Plan, in the absence of time-limited and binding work plans, genetics was prone to be of relatively low priority for cancer networks and PCTs alike, especially in a constrained financial environment.  Anxiety reduction and even long-term preventive and cost-saving potential also held little sway, and it was in purely (short-term) economic terms that hospital-based, and to some extent PCT-based, pilots had to justify themselves—a difficult task given the short lead-in time provided by pilot funding.  This last point serves to underline the continued importance of national policy context despite current emphasis on local discretion. Fifthly, given the uncertainty of further funding, there was concern among several interviewees that a return to the *status quo* would mean not only a loss of know-how and capacity built through the pilots, but also inconvenience for referrers and anxiety for patients, whose expectations had been inappropriately raised.

Many of these issues are undoubtedly generalizable throughout the NHS; while no single issue was necessarily crucial on its own to the viability of the pilots, taken together, they do nevertheless indicate the kinds of organizational issues that may be of relevance in considering whether and how to set up similar services in other locations.  It is also important to note that many of the features of the pilots are likely atypical of the wider NHS.  As sites which were successful in obtaining pilot funding in the first place, they are by definition trailblazers in this field, and certain features of their work—the combinations of stakeholders, the particularity of practitioners' career pathways, the pre-existing relationships present in many of the sites—may not exist or be easily replicable elsewhere.  If this is the case, careful developmental work in creating organizational contexts receptive to change—as well as early consideration of the practicalities of sustainability through 'mainstreaming' of funding and provision—becomes all the more important.

## Acknowledgements

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