CHAPTER 1

User involvement – a story of our time

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Introduction

There is motherhood, there is apple pie and there is 'user involvement' in health care. Patients, carers, parents and advocates of the sick and vulnerable should have input into the kind of health service we have. They should be consulted about changes to services, and they should be involved in the design of those services. They should help to set the standards by which services are judged, and help to assess whether a particular aspect of the service meets those standards. At every stage, the users of the health service should be offered the opportunity to play an active part in developing, delivering and evaluating *their* service. After all, it is their (i.e. our) taxes which pay for it and their (our) lives which are at stake if things go wrong.

That all of this is taken as given is a measure of how far we have come since the bad days when health services were (many would say) designed for the convenience of doctors, nurses or managers. Patients in hospital had to lie in their beds waiting politely for the 'bedpan round', and their loved ones were banished at the end of the visiting hour by a shrill, uncompromising bell. People in pain from arthritis or a hernia waited months or years for a hospital outpatient appointment, and then went onto another waiting

list for their operation. General practitioners would shut up shop on the afternoons they played golf. If a chief executive wanted to axe the physiotherapy service, he or she did just that. The 'patient journey' (such as it was) was modelled on the Fordist principle of standardised, basic care with no frills and no choice. Few people complained – it was just the way things were.

Was it ever this bad? Probably not, but it is certainly true that over the past 15 years, there has been a sea change in what we in the UK expect of our National Health Service (NHS), and this has mirrored a wider change in expectations for health services across the western world. The first policy document to set out the vision for a transformed, patient-oriented health service in the UK was probably The NHS Plan in 2000.[1] In 2001, David Fillingham, head of the NHS Modernisation Agency (an 'arms length' body funded by the government to help NHS organisations become more efficient and patient-centred) captured the mood of the moment:

> *The NHS has embarked upon a decade of improvement. Over the next ten years the delivery of care will be transformed as The NHS Plan is implemented. Care will be designed around the needs of patients and their carers. Diagnosis and treatment that previously took weeks or months will be completed in days or even hours.* www.modern.nhs.uk, accessed January 2004

The various work programmes underpinning the NHS Plan were described by change management guru Professor Don Berwick of the US Institute of Health Improvement as '... *to my knowledge, the most ambitious concerted systematic improvement effort ever undertaken, anywhere, by any organisation of comparable size*' (Don Berwick, personal communication, July 2004).

And even in those early days of the new millennium, when tension for change was high and the funding allocated for NHS services was rising year-on-year, nobody believed it would be easy. As Chapter 2 illustrates, the research literature suggests that efforts to involve health service users in improving 'their' services have rarely gone entirely to plan.

This book is not a comprehensive guide to every possible approach to user involvement. Nor is it an account of unqualified success or a 'how-to' guide, which will allow you to replicate in any simple way the things that went well. It is a story of a single programme of work, involving hundreds of people, which happened

in inner London in the mid-2000s. It was called the modernisation initiative (MI), and it began when several front-line teams were all lucky enough to share a generous donation of funding from a well-endowed local charity to 'modernise' health services on their patch.

The book describes how the different teams involved in the MI went about involving service users in deciding how the money should be spent and pushing through the changes that were deemed to be needed. And it tells the story of the patients, carers and other service users who came forward to make their contribution. The story of the MI, like all good stories, contains both successes and disappointments and a good many twists in the plot. But it is a real story, and despite not providing easy answers, it does offer useful insights for those embarking on similar challenges.

Most of the chapters in the book are written by the front-line staff and service users who worked on the MI. Three chapters – this introduction, the literature review in Chapter 2 and the discussion and conclusion in Chapter 8 – were written by members of the academic team who were contracted by the funders of the project to evaluate the work (Trish Greenhalgh, Charlotte Humphrey and Ceri Butler), with input from the person who was, at the time, the Director of the MI (Fran Woodard). We have published a full report on this programme elsewhere,[2] as well as some academic papers[3,4] and internal reports on specific sub-projects.[5] The remainder of this chapter gives a summary of what the MI was and how it came about.

The modernisation initiative

The MI was a system-wide transformational change programme working across the health economy in the London boroughs of Lambeth and Southwark to modernise local health services. It was formed as a local partnership between Guy's and St Thomas' NHS Foundation Trust (GSTT), King's College Hospital NHS Foundation Trust (KCH), Lambeth Primary Care Trust, Southwark Health and Social Care Trust, community groups, patient groups and the independent and voluntary sector. The project was funded by a donation of £15 million from Guy's and St Thomas' Charity (the Charity).

The setting for the MI was Lambeth and Southwark, two adjacent inner London boroughs. This locality has all the challenges of a deprived inner city area – poverty, poor housing, high burden of

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disease, low health literacy, high population turnover, linguistic and ethnic diversity, numerous socially excluded groups and historically fragmented and uncoordinated services. Some individuals registered as patients with different parts of the service did not actually live in the area and, conversely, many residents who used services elsewhere, were not registered, or failed to access services at all.

In 2000, the large and long-established Guy's and St Thomas' Charity decided to invest a substantial sum of money for service transformation. This was something of a break in tradition. An informal local review in the late 1990s had revealed that although the Charity's funds were being drawn on in many ways by local health care projects, the impact of these various grants was unclear except in the case of major building projects. At that time there was growing recognition, more generally, that significant service change is rarely achieved through narrowly focused, short-term, small-scale projects. The idea was mooted among the Charity's trustees that major sustained investment in service transformation on a scale comparable to that required to build and equip a new hospital ward might well deliver better results. Fortuitously, a review of the Charity's accounts at about the same time identified some reserves that could be made available to be spent in a different way without reducing the amount of money already going to the type of projects it had traditionally funded.

Bids were invited from local services for three 'modernisation' projects, with the over-arching principle that the grants made would be large (£5 million per project) and should be used to make a 'big difference' to local services. It was expected that fundamental changes would be made in the way services were designed and delivered; the nature, quality and accessibility of services on offer; the attitudes of staff and (more broadly) the general culture of the services; the balance of power between patients and professionals; the way different parts of the health economy communicated and worked together; and – most significantly of all – the way in which patients, carers and communities were consulted and partnered in the planning and delivery of services.

The vision was thus for a more efficient, more integrated, more patient-focused service which reflected an NHS that was fit for the twenty-first century. The changes were expected to span both primary and secondary care (and, where appropriate, the voluntary and private sectors too) and to cover the entire patient pathway from prevention to end-of-life care. Whilst the pump-priming

money was generous, the costs of the transformed service were expected to be met by the local health economy after the 3-year transformation period was over.

In early 2002, three projects – stroke services, kidney services and sexual health services – were identified in a competitive bidding process as potentially eligible for a grant of £5 million each. Once chosen, the three MI projects moved into an 'invention' phase – a 6-month period of 'energising, consultation, consensus building and discovering ideas' – aimed at refining the proposals, pulling together background information about services across all the partner organisations, identifying clinical champions, looking at ways to involve users, gathering innovative ideas, identifying areas of best practice elsewhere and arranging visits to them to learn more. Workshops were held with patients and voluntary organisations to develop the initiatives and outline applications were worked up for submission to the Charity. In November 2002, the Trustee Board approved funding for all three projects for a 1-year 'incubation' phase to work up implementation plans and consider how progress against goals would be assessed. The major tranche of funding was awarded to the stroke and kidney projects in late 2003, and 6 months later to the sexual health project.

The goals of the three MI projects are summarised in Box 1.1.

The management and governance of the MI was complex. An over-arching MI Board was established with representation from the four participating Trusts and other key stakeholders, and this met quarterly. Within each project, there was a management board which met approximately monthly and received reports from numerous sub-projects. Each project had a manager and lead clinician; the project managers were answerable to the MI Director, who had a clinical background (physiotherapy) but had worked for many years in various change management projects across the NHS. User representation on the different boards and management groups is discussed in Chapter 6.

In summary, the MI consisted of three linked projects, each of which was ambitious, multifaceted and oriented to transforming what was seen as an old-fashioned service in both primary and secondary care. They shared an over-arching vision (to make a 'big difference' to services locally and change them in a patient-centred way) and governance structure but their detailed goals and work plans were very different. Aside from being one of the largest and most challenging change projects ever undertaken in the UK health

Box 1.1 Goals of the three MI projects as set out in early business plans

Stroke
- Prevent people having strokes and encourage healthy lifestyles
- Ensure early detection of strokes
- Provide rapid access to early evidence-based interventions and treatments for all stroke patients
- Provide high quality, timely, consistent rapid access to rehabilitation within the community
- Facilitate people to have the best quality of life whilst living with the consequences of having a stroke (long-term support)

Kidney
- Prevent people developing kidney disease
- Increase the ability of primary care professionals to manage the early stages of kidney disease
- Reduce the waiting times in outpatient clinics and on dialysis units
- Improve the experience for patients staying on the wards
- Increase the treatment choices available to dialysis patients
- Increase the number of transplant operations by increasing the number of living donor operations
- Ensure appropriate supportive care is provided to patients when necessary
- Ensure appropriate services are provided to enable patients to 'live well' with kidney disease

Sexual health
- Reduce rates of sexually transmitted infections (STIs) and unintended pregnancy
- Reduce the number of people with undiagnosed asymptomatic STIs by increasing screening opportunities
- Increase opportunities for people to manage their own sexual health in supported environments
- Improve knowledge about sexual health and sexual health services especially in high-need communities

- Improve waiting times, staff attitudes and clinic environments
- Focus specialist resources on specialist need and developing additional capacity
- Establish a network that enables services to work together to consistent, evidence-based standards
- Improve the patient experience of using existing services by reducing waiting times

economy, the MI also offered a unique opportunity to learn lessons about how transformational change happens and how best to go about it.

An independent evaluation of the MI was commissioned by competitive tendering and the contract awarded to an interdisciplinary team of academics from University College London, King's College London, University of Surrey and University of Leeds. The evaluation was funded from August 2005 until July 2008 – somewhat later than the projects themselves. The Charity's requirements of the independent evaluation were that it should provide both formative feedback to support the implementation of the MI (hence, the evaluation team presented regularly to the MI Board and to a separate Evaluation Advisory Group) and summative feedback on the overall success of the programme (hence, we produced a lengthy final report to the Trustees). In addition, the evaluation team was asked to generate learning about the relationship between context, mechanism and outcome in service transformation and explore the implications for the funding of similar initiatives in the future.

The design of the evaluation took account of the fact that each of the three MI projects had many objectives and multiple work streams operating within and across the local health care system and community at a variety of levels, and that these different initiatives were likely to change organically with time. The approach taken was realist evaluation, which uses a variety of methods (mainly but not exclusively qualitative) to explore the interplay between context, mechanism and outcome.[6] In realist terminology, user involvement can be thought of as a 'mechanism' by which service transformation might be achieved, and this 'mechanism' will be more or less successful in different contexts. For those interested

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in academic aspects of how realist evaluation was applied to this programme of work, please see our published papers.[3,4]

Whilst this book can be read without a detailed knowledge of the academic aspect of realist evaluation, the key questions addressed by all the chapters, especially the analysis sections in Chapters 7 and 8, might usefully be expressed in the format used by Pawson and Tilley[6]: 'What works, for whom, in what circumstances when seeking to involve users in service transformation?' Furthermore, the very broad mechanism of 'user involvement' can be divided into a number of more specific sub-mechanisms – for example, working with service users to co-design services (see Chapter 3); using patients and carers as teachers to convey the illness experience and user priorities to staff and also to support other patients (see Chapter 4); co-producing information with service users (e.g. making leaflets or DVDs, see Chapter 5); or appointing service users to formal leadership and governance roles within a project (see Chapter 6). These sub-mechanisms might be employed in isolation or (perhaps better) synergistically with one another.

The next chapter completes this introductory section by offering a brief literature review on what is already known about user involvement in service transformation. The four subsequent chapters, which comprise the main section of the book, consider the four different sub-mechanisms for involving users and give examples from the different sub-projects in the MI of where these sub-mechanisms met with success, failure or partial success. The final section of the book synthesises the learning across all three projects and different approaches to user involvement by considering the various tensions and paradoxes which are inherent in attempts to involve users in service transformation (see Chapter 7) and offering some recommendations for future policy and research (see Chapter 8).

References

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