Learning from people with long-term conditions: new insights for governance in primary health care

Abstract

Internationally, system-wide changes to the structures and systems governing health care aim to improve outcomes for patients, quality of care and access to services. The introduction of top-down centrally driven solutions to governance of health care, at the same time as increasing policy emphasis on greater 'bottom up' patient and public involvement in all aspects of health care, has set up complex tensions for policy implementation and health care practice. This paper explores the interplay of these agendas in the context of changes in primary health care services provided by the National Health Service (NHS) in England. Specifically, it looks at an example of service user involvement in a study (the PEGI study) of professional response to changes in the governance and incentives in the care of people with long-term conditions. This qualitative study was conducted in three Primary Care Trust sites in England. Service users influenced and guided the study throughout. In-depth interviews with 56 health and social care professionals engaged in the development of local policies and the delivery of care for people with complex long-term illness drew on vignettes developed by 32 members from three Service User Reference Groups (SURG). Themes generated by the cross case analysis were validated through these SURG groups. The findings presented here focus on four themes about risk and comparison of professionals'/service users' perspectives of the issues: managing

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risks/consistent support, the risks of letting go/feeling in control, professionalism/helping people to help themselves, and managing expectations/professionals losing out. Service user involvement added value by: validating understandings of governance, framing debates to focus on what matters at the point of care, and enabling perspective sharing and interaction. We suggest that more collaborative forms of governance in health care, that take account of service user perspectives and enable interaction with professional groups, could help to validate processes of quality assurance and provide motivation for continuous quality improvement. We offer a model for 'opening up' collaborative projects to evaluation and appraisal and a process for critical reflection of the interrelationships between the PEGI study context, researcher issues, methods/approach and outcomes/impact of service user involvement.

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What is known about this topic?

- Health care systems internationally have undergone major and rapid changes in governance structures with the aim of improving accountability, transparency and outcomes of care.

- At the same time there is growing policy emphasis on service user (patient, carer and public) involvement in all aspects of health care and research.

- These simultaneous policy agendas have led to complex tensions for policy implementation and health care practice, including how involvement can be successful and authentic in decision-making arenas that have traditionally been closed off to the public.

What this paper adds?

- Service user involvement can add value to research and development work on governance by contributing service user experience-based perspectives of the issues.

- Service user involvement helps to frame debates to focus on what matters at the point of care, enables multiple perspectives to emerge and interaction with professionals that informs a risk sharing approach to governance..

- There is a need to 'open up' collaborative projects to evaluation and appraisal by reflecting on the interrelationships between the context,

professional issues, methods/approach and outcomes/impact of service user involvement.

Introduction

Internationally, system-wide changes to the structures and systems governing health care aim to improve outcomes for patients, quality of care and access to services (Casalino 2011, Ferlie and Shortell 2001). The introduction of top-down centrally driven solutions to governance of health care, at the same time as increasing policy emphasis on greater patient and public involvement in all aspects of health and social care (Rummery 2009), has set up complex tensions for policy implementation and health care practice (Greenaway et al. 2007). Including for example how far public involvement can be successful and authentic in decision-making arenas that have traditionally been closed off to the public. For healthcare practitioners, continuous change and target setting can generate a sense of fatigue, confusion, distracting and competing agendas (Garside 2004). The danger is that if unresolved these tensions will create instability within health care organisations and problems for healthcare practitioners and service users at the point of care delivery (Checkland et al. 2009).

This paper explores the interplay of these agendas in the context of changes in community health services provided by the National Health Service (NHS) in England. Specifically, it looks at an example of service user involvement in a study (The PEGI Study) (Ross et al. 2009) of professional response to changes in the governance and incentives (motivating and enabling factors) in the care of people with long-term conditions. A key value underpinning the study was the

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belief that we need to work together with people with long-term conditions to shape the approach and questions we asked of professionals if we were to understand the complex interaction between the effects of policy and the impact on the professional experience.

Background

The National Health Service in England provides a comprehensive range of health services, the vast majority of which are free at the point of use for residents of the United Kingdom. Recent changes in the way services are provided and governed in England have been introduced on the back of longstanding debates about the benefits of increasing and enhancing primary care services (Green et al. 2007). Key changes have been the modernisation of funding and commissioning of primary care (DH 2000; DH 2010a); implementation of systems of incentives that encourage capacity building and quality outcomes in primary care, such as the General Medical Services (GMS) Contract, Quality and Outcomes Framework (QOF) (DH 2003), payment by results (DH 2002), practice based commissioning (DH 2006) (DH 2010a, DH 2012). The Health and Social Care Act brings in the most wide-ranging reforms of the NHS since it was founded in 1948. On 1 April 2013 the main changes set out in the Act came into force to encourage the market, enable contestability and strengthen the role of general practitioners in commissioning. Reconfiguring health services is seen as essential in the context of an aging population with increasing needs for long-term chronic care management (DH 2010b) medical care and other therapies (RCGP 2011). There are 15 million people in England

who have at least one long-term condition (DH 2010b) such as cancer, cardiovascular disease, autoimmune diseases, osteoarticular diseases, renal failure, respiratory diseases, diabetes, epilepsy and human immunodeficiency virus/AIDS, osteoporosis or a long-term mental health condition.

In England the policy drive to place patients at the centre of the NHS is partly in response to the failure of health services to meet patients' expectations of good quality care (Coulter 2002; Goodrich and Cornwell 2008), and partly in response to multiple drivers to increase public participation (and trust) in public services more generally (Newman 2001; Fotaki 2011; Dibben and Davies 2004). Although notions of 'patient' 'public' and 'service user' representation are interwoven, complex and contested (Boote et al. 2002, Beresford 2003; Smith et al. 2008), these issues demand attention as members of the public become stronger players in professional worlds (Russell et al. 2002). In this paper we are using the term 'service user' to mean people with long-term conditions and their carers. In the context of health care different 'mechanisms' for gaining service user perspectives have been identified as including patient surveys, patient groups, clinical trials, health intervention programs, service improvement projects and participation in research: each with differing potential to allow professionals and patients to deliberate, build understanding or share decision-making (Morrow et al. 2013). Similarly, governance can employ different levels of participation (Arnstein 1969); ranging from 'non-participation' (the community is unaware of any decisions taken), 'informing' (telling the community what is planned and to understand problems, alternatives and solutions), 'consultation' (to obtain public feedback on analysis, alternatives and/or decisions), 'collaboration' (to partner

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with the public to develop alternatives, identify preferred solutions, and make decisions), to 'empowerment'; (final decision-making control is in the hands of the public) (Fung 2002). The notion of 'involvement' refers to more active and direct forms of participation, however the term is problematic as it encompass a broad range of activities and can occur within or beyond organisations (Tritter and McCallum 2006), including community or user controlled initiatives which may or may not involve professionals (Turner and Beresford 2005).

Whichever way you look at it service user involvement in health care and research remains, by and large, a process whereby professionals do the inviting, and service users accept the offer. This begs the questions what difference can service user involvement make (Staley 2009; Barber et al. 2011; Barnes and Cotterell 2011) and how can we 'open up' involvement to understand how best service user's perspectives can shape the agenda (Morrow et al. 2013; Boote et al. 2010), get heard and conveyed back to the worlds of policy, science and practice (Barber et al. 2012; Pickard et al. 2006). The study in which we have attempted to do this is described below.

The PEGI study

The aim of the PEGI study (Professionals Experiences of Governance and Incentives) was to explore the professional experience of evolving organisational and governance structures in the context of primary health and social care and in relation to the management of long-term conditions. This qualitative study was

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set within a service user perspective, where service user views and experiences informed the methods of the research (described below) and the exploration of governance as a multi-layered, complex and elusive relational concept. We drew upon Davies et al.'s (2004) definition of governance as the way 'in which organisations and the people working in them relate to each other'. The study was conducted by a multidisciplinary research team with service user leadership (SB), working with the local health and social care sectors in three case study sites (defined by the Primary Care Trust and the Local Authority partner) (see table 1). The study obtained ethical approval from Wandsworth Local Research Ethics Committee in 2006 and research governance clearance from all three sites. Written consent was obtained from all participants. We collected the data in 2007/8 and reported in 2009 (Ross et al. 2009). The study was undertaken in three phases described below.

Phase 1: A detailed contextual analysis was carried out of the organisational context of the three case study sites including: documentary analysis and interviews with senior staff. Service Users Reference Groups (SURG) were established in each case study site. Recruitment of service users varied across the three sites and included: introduction through the Patient and Public Involvement (PPI) leads; recruitment from local GP practices; recruitment from local voluntary organisations; and snowballing of contacts via recruited individuals. Detailed recruitment criteria were developed and agreed (see Ross et al. 2009) and members were recruited to the local groups on the basis of: long-term health condition, their ability to sit through a three hour meeting (based on their own judgement), and local SURG participant selection criteria. Our way of

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working with service users at each study site was informed by five service user representatives with a national perspective, which we called the national SURG. These members were recruited from a previous SURG group that members of the research team had worked with (Smith et al. 2009). The national SURG met twice during the project and provided oversight for the local groups, advice on the research design and service user involvement through the study. Thirty-two service users in total with long-term physical and mental health conditions attended the three SURG meetings (14 people with a physical condition, 15 with a mental health condition, and 3 carers of individuals with a physical condition). These groups took the form of structured discussions designed to elicit stories about people's experience of care. Data from the discussions were subject to thematic analysis (Braun and Clarke 2006) and we identified interrelated themes on 'communication', 'professional behaviour', 'access', 'continuity' and 'individualised, flexible and responsive care'. The themes were used by the research team, in consultation with the national SURG group, to develop two vignettes (one on mental health one on physical health) to be used in interviews with professionals with the aim of grounding the research in service users' experiences (Ross et al. 2005; Richards et al. 2007) and increasing insight into complex issues surrounding caring relationships (Rahman 1996).

Phase 2: In-depth interviews were conducted with health and social care professionals engaged in the development of local policies and the delivery of care for people with complex long-term illness (n=56). The interviews drew upon the vignettes developed by SURG to explore views on team performance, incentives and the experience of managing ambiguity and complexity in care

delivery in the context of organisational change and new partnerships (see Ross et al. 2009 for interview schedule). To recruit participants we worked with local managers to select a locality and associated health and social care teams within each of the three case study sites. A purposeful sample was sought ensuring an information rich and diverse group of experienced professionals and non-professionals. The localities were sampled on the basis of: advice and direction provided by the Trust Senior Managers (so as not to compromise and overburden teams), relatively stable and well staffed teams, commitment to developing new initiatives around long-term conditions, an established partnership agreement with social care. For each team (social service teams, district nursing teams and community mental health or primary care liaison teams and linked practitioners), 1-3 members were approached for interview.

Phase 3: Analysis within cases (localities) and across cases (Sites A, B &C) was undertaken to build the hypotheses and develop theoretical ideas about the mechanisms and incentives that have an influence on the outcomes within the specific organisational contexts. Feedback of the case study findings in each site to SURG and key service manager stakeholders took place to facilitate the refinement of our working hypotheses for supporting organisational development in the sites and elsewhere. These hypotheses (see Ross et al. 2009) were set out in a form that could be tested in practice.

[Insert Table 1 near here]

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Methods

The focus of this paper is to explore the links between professional's views on governance and what service users said about their experiences of services and professionals' behaviour - what aspects both groups see as being important or legitimate and where there are differences in opinion. We drew on the qualitative data from the PEGI study about:

(i)   Service users' experiences of receiving care: captured in three local SURG groups discussions (in phase 1) (covering experiences of good and not so good care and suggestions for improvement). Thirty-two service users with long-term physical and mental health conditions attended the meetings in total; 14 with a physical condition; 15 with a mental health condition; and 3 carers of individuals with a physical condition. (Site A: 12 service users and 1 carer, Site B: 6 service users and 2 carers, Site C: 12 service users).

(ii)   Professionals' experiences of governance and incentives: face to face in-depth interviews (in phase 2) with 56 health and social care professionals engaged in the development of local policies and the delivery of care for people with complex long-term illness (Site A: 19, Site B:19, and Site C:18). These professionals were: community matrons, community nurses, GPs, specialist nurses, practice nurses, physiotherapists, occupational therapists; members of the community mental health and crisis teams and social workers.

In the PEGI study cross case analysis (phase 3) identified key themes across the whole corpus of study data on risk, diversity, ambiguity and conflict (see Ross et al. 2009). In this paper we have chosen to focus We have reported elsewhere on the consequences of changing governance arrangements for the devolution of financial risk to front line staff (Smith et al 2012) and the impact of change on teams and emotions (Allan et al 2013). the theme of risk as this was prominent and consistent in both service users' and professionals' accounts and across all three study sites. We used qualitative analytic techniques (Denzin and Lincoln 2000) to make comparisons of professionals' and service users' views, examining them for convergence and divergence. The analysis aimed to be context sensitive, iterative and flexible (Holloway and Todres 2003) but it involved a number of stages, these were: (i) re-familiarisation: reading discussion summaries and interview transcripts; (ii) emersion: to explore the data in relation to the focus of the issues, the types of language or ways of talking about issues, and the types of information used to substantiate claims/views (e.g. direct experience, policy, research evidence); (iii) coding and extraction: selection of passages of text and coding according to themes (Braun and Clarke 2006) and (iv) refinement of themes: members of the research team examined the coherency of the meaning of each theme (Holloway and Todres 2003) (supporting validity of the analysis), the assumptions underpinning it, the possible implications and the overall story the different themes reveal about risk, governance and professionals'/service users' perspectives of these issues.

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Findings

The findings are presented according to four themes around risk and professionals'/service users' perspectives of these. These are: managing risks/consistent support, the risks of letting go/feeling in control, professionalism/helping people to help themselves, and managing expectations/professionals losing out. Selected quotes from participants are used to illustrate perspectives on each theme.

Managing risks/Consistent support

Notions of risk framed the context in which practitioners viewed the impact of changes in care delivery and was described in terms of dilemmas and uncertainties of managing risk to patients' safety and to professionals themselves with respect to litigation. Not surprisingly staff raised issues about how best to perform within changed systems and the emotional work required 'to do the right thing' (Allan et al 2013). Some participants put forward strong views in the interviews that continuous, top-down, target driven change of governance arrangements was disruptive of existing professional relationships, which created uncertainty exposing patients to unnecessary risk. Although the emphasis of policy change on promoting independent living and care closer to home was valued by professionals, they worried about trying to keep people safe. Participants generally acknowledged that an ongoing relationship with at least one health care practitioner was important. Service users were acutely aware of this issue of 'having one point of contact', particularly in relation to seeking

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support with mental health issues (Table 2). Service users also highlighted the negative effects of getting conflicting advice and being thwarted in accessing the right care at the right time described as 'having to be in crisis before access to services is granted' (Table 3). This issue was captured in the mental health vignette:

> *'All the appointments with his own GP were now taken: John was disappointed since he knew his GP quite well and they had a good supportive relationship….how could he possibly explain everything in 10 minutes to someone he had never met before'* **SURG MH Vignette**

[Insert Table 2 near here]

[Insert Table 3 near here]

Safety was identified as an important factor in the acceptance of change by practitioners caring for people with physical and mental health conditions, although different factors were emphasised. In mental health care, it was recognised that in addition to being exposed to risks of a deteriorating illness, a patient may be a risk to society or a risk to themselves. Interestingly risk was tolerated differently by different professionals and this was reported in ways that suggested that "others" were more risk averse, as demonstrated by this care manager of people with long-term conditions:

> "Many of the other disciplines are quite risk-adverse and say 'Oh no, you know, they can't do this, they can't do that... 'Well, have you tried? Have you asked?' You know, and I mean we know that some discharges will fail, but if you mitigate the risk as much as you can patients deserve a chance (...) I would say that many people in Social Services are quite

risk-adverse, but I think that is probably around their own threat of litigation."**(B03: Care Manager)**

This was understood in terms of the different training, professional and legislative frameworks that govern risk management in different occupational groups in health and social care: that the different disciplines are trained to assess need using specific decision making frameworks:

> "...by having a general referral system within community mental health teams, the patient could be assessed by a social worker one day and another patient by an OT the next day, and have very different needs identified because each professional was alert for and assessed needs differently due to their professional training." **(C04: Community Nurse)**

When we took the findings back to the SURG groups at the end of the study, it was interesting to note that they recognised and were aware of the inconsistencies between professional cultures about the management of risk, particularly between health and social care. For example a woman told us about the health and safety rules that impose constraints on staff giving immediate help to a patient if they fall (Site B).

The risks of letting go/Feeling in-control

A key recent policy shift has been towards individuals taking increased responsibility for their own care. Service users generally felt positive towards this agenda and wanted to be more informed and engaged (Table 3). As one of the service users with a physical health condition told us *"If I know what is going on, I feel more positive and in control".* While professionals were supportive of

patients having responsibility for their care, concerns were expressed about responsibility for managing risk at a distance and the legal implications of 'letting go':

> "I would say that we are encouraged to take risks with clients in the interests of their, you know, being able to learn from experiences and not being too curtailing of their personal freedoms. But if anything goes wrong (…) watch the flashy lawyers and barristers and the inquiry and all the rest of it" **(A15: Social Worker)**

Therefore part of making a good decision was the importance of being able to 'prove it' and professionals considered that in the current climate, they needed to be transparent and auditable or as one social worker described it "bullet proof" (B09:CPN).

In general though, the professionals had very clear, positive views about service user's involvement in their own care and the majority believed that encouraging people with long-term conditions to be more involved was the key to improving confidence, self esteem and quality of life. This team manager described how patients and family members were involved in the planning of care:

> "It's evolving and we actually get them to sign the care plan and that they understand what's going on and I mean encourage family members also to write in the notes if there's anything they want to know. So I really do feel that the continuity for those people is there and it's preventing crisis management and it's a more co-ordinated caseload management and around enabling as well.**" (B10: Community Manager)**

Involving patients in their care was seen to lead to positive outcomes, according to this community matron:

> "I think when people can manage their condition better I think generally it lends itself to them feeling much better about themselves, they have better self-esteem, are hopefully less depressed, less anxious, more controlled, more empowered." **(A23: Community Matron)**

Professional identity/ Helping people to help themselves

This theme arises from the extent to which professionals identified with their field of professional practice and its scope in relation to patient care. There are links to the previous discussion and the view that professional cultures and codes inform decision making about risk management, which could be construed as a barrier to teamwork. Different approaches were seen to hinder co-ordinated planning, for example the community psychiatric nurse described the nurse's tendency to do things for the patient in contrast to the social worker's effort to promote independence:

> "I think the nurses go a little bit more...to meet the clients, pick up prescriptions and collect medication but SWs say the client should go themselves." **(B11: Community Psychiatric Nurse)**

Although strong professional identity was valued in the sense of making a distinctive contribution, it was also seen to hinder teamwork for example most practitioners recognised that continuity of care, duplication and being assessed/cared for by a number of different practitioners, who often did not communicate with each other, was a negative experience:

> "In fact one nurse went in with the district nurse as part of her induction, to a patient who was having six different services in and none of them were talking to each other." **(C16: Community Nurse)**

Prominent in the discussions with the SURG was the sense of confusion from "having to start from scratch each visit which can be painful" and preferring to see

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the same person (Table 2). These themes of access to the right professional expertise and continuity resonated strongly with the SURG in all sites. Service users talked about care like a "game of snakes and ladders" with blocks and gateways (Site C) and questioned "how does it all link together?" (Site B). Drawing on their experiences service users were very able to make clear suggestions for how care could be improved (Table 4). These suggestions focused on helping people to help themselves by providing information about services available, listening and treating patients as individual people active in their own care, and helping them to feel safe and supported.

[Insert Table 4 near here]

Managing expectations/Professionals losing out

Ideally then managing risk and providing "good care" was seen as helping patients feel happier in themselves with the aim to improve wellbeing. However, this is easier said than done, and for some caring over a long period of time can set up its own strains in relation to the need to accept the limitations of what is achievable:

> "It's quite interesting to get to know somebody, understand them, get to the bottom of their problems and start the thing off. It's slightly less fascinating to flog it through to the bitter end…..it's something that we're working on within our team." **(B22: Community Mental Health Team)**

Increasing pressures of work overload, resulting from perceptions of constantly-changing policies and paperwork and lack of time to do the job properly was reported as causing emotional stress and dissatisfaction. Practitioners knew that

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service users valued staff who gave them enough time to express themselves and patience in explaining everything they needed to know without being judgemental (Table 2). This issue was recognised by the SURG, who acknowledged the difficulties professionals have in providing services whilst also dealing with rapid system change, and the resulting feelings of disengagement. In Site B, for example, this was described in terms of professionals themselves "losing out" because of the disruption to the continuity of care and lack of time.

Discussion

The overall findings of the PEGI study provide insights into how concepts of governance and incentives are being applied and interpreted in health care practice and how professionals on the front line are making sense of it all. The findings presented in this paper illustrate the points of divergence and convergence of professional's and service users' views around the theme of risk as it plays out in the context of change and uncertainty. The main limitation of our findings is that service user participants were people with long-term conditions; whose views may not reflect the experiences of other service user groups or people who do not access health services as frequently. In the discussion we focus firstly on the 'added value' of service user involvement in terms of validating professional understandings of governance, framing debates to focus on what matters at the point of care, and enabling sharing and interaction of multiple perspectives. Secondly we put forward a model for 'opening up' collaborative projects to evaluation and appraisal that will advance methodological approaches for involving service users in research.

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Validating understandings of governance

Our findings show that for service users and practitioners alike, governance is inextricably linked to the way people connect with, contribute to and benefit from organisations. This understanding extends Davies' (2004) definition of governance as the 'way in which organisations and the people working within them relate to each other'. Gaining a sense of agreement on the importance of particular governance issues from both professional's and service user's perspectives helps to validate understandings of a complex and multifaceted concept. At the same time our findings illustrate there is considerable variation in professional's perspectives of actual risk and a tendency for all professionals to consider themselves less risk averse than others. Inevitably different professional cultures, identities and expectations on risk management can have a negative impact on service users who understandably felt frustrated by what they see as inconsistency and confusion.

Framing debates to focus on what matters at the point of care

By framing discussions about governance in terms of service user values and expectations of good care, more appropriate questions can be asked about the nature and function of systems and structures of governance so that it is truly 'fit for purpose' (Casalino 2011). In the PEGI study beginning with the service users' experience of care with their long-term conditions helped to formulate the questions and the approach, which gave a sense of authenticity to the inquiry (Hughes and Huby 2004). In this study vignettes helped to ground the

professional interviews in the context of the patient experience (Finch 1987) and to engage the professional's interest (Hughes and Huby 2004). Practitioner's concerns centred around managing patient risk and balancing individual rights with risk avoidance in the context of new models of partnership. Not surprisingly this concern aligned with service users' views about the importance of continuity.

Enabling perspective sharing and interaction

Our findings clearly show the value of sharing multiple perspectives in advancing understanding of governance and the potential benefits of professional/service user interaction in the process of constructing understandings. These findings extend Davies (2007) suggestions of an approach to governance that is based in discourse and involvement. It leads us to suggest that a new form of engagement in governance is needed to acknowledge the more participative role of people who are receiving care but also contributing knowledge and skills to services (Kennedy et al. 2005). Our suggestion has resonance with notions of collaborative governance (Newman et al. 2004) in which participants representing different interests are collectively empowered to make a policy decision or recommendations to decision-makers. Some models of collaborative governance have been criticized for drowning out minority opposition (Fung 2002) through power and resource imbalances (Ansell and Gash 2008). Yet, as Bates and Robert (2006) observe the act of bringing patients and staff together to hear the others' stories works as a dynamic catalyst for change and improvement, which could overcome change fatigue (Garside 2004). Further research is need to examine 'governance spaces' (Taylor 2007) in relation to existing structures, systems and pathways (Smith and Ross 2007); and to

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examine how collaborative governance can feed into quality assurance and improvement through such spaces (Ferlie and Shortell 2001, McLaughlin 2004). In the next part of the discussion we put forward a model to support critical evaluation and appraisal of such collaborative projects.

'Opening up' collaborative projects to evaluation and appraisal

In this part of the discussion we reflect on our methods to involve and learn from service users in the conduct of this research. We put forward a framework adapted from the context of service user involvement in nursing, midwifery and health visiting research (Smith et al. 2005) to 'open up' the interrelationships between contextual issues, researcher issues, approach/methods and the outcomes/impact of involvement in the PEGI study (Figure 1). The contextual issues describe the central questions of the research; the meaning of governance, professionals' experiences and the needs of people with long-term conditions. In terms of researcher issues, although the project researchers were all highly skilled and experienced researchers with a social science background, they were less confident about entering into the new, somewhat uncharted territory, of building relationships with service users as collaborators in the research. We addressed this by providing informal learning, service user leadership (SB), team discussion and email support.

[Insert figure 1 near here]

Advantages of the approach were that SURG groups enabled us to develop insight, knowledge and working relationships with service users over time; and provide information that could inform local service improvements. However, establishing SURG groups, ensuring engagement throughout the study and enabling opportunities for the service users to not only understand the nature of the research, but also to feel they were influencing its methods and outcomes was a process that required time and skills. The role of local researchers and service user leadership (SB) was essential for facilitating perspective sharing and spreading knowledge beyond the groups (Ansell and Gash 2008). Members of national SURG were able to inform and influence decisions about why service users were involved and which types of information were important (Morrow et al. 2013). Together with the use of vignettes this helped to focus the interviews on service user experiences, overcome ambiguities about service users' roles and representation in the SURG (Rhodes et al. 2001), while respecting individual service user's personal experiences of health and illness. This framework helps to show clear outcomes of involvement and the types of impact on the research (Staley 2009). Service users supported effective local dissemination and development of the research. Working with the SURG group to develop a framework to collect data from professionals, we were able to ground the interviews in a service user perspective and therefore shift from the more abstract ideas and language of organisational governance, to the emotional and individual experience of working in teams providing care to service users.

Conclusions

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The PEGI study shows that governance encompasses more than formal legal and reporting structures, for service users and practitioners alike, governance is inextricably linked to the way people connect with, contribute to and benefit from organisations. Service users recognised and expressed a good understanding of the dilemmas and uncertainties, as well as the different cultures and changing systems within which professionals operate. Our findings support arguments for investment in new forms of collaborative governance in health care that take account of service user perspectives and give authority to service users' views. The framework we put forward here could help to develop and evaluate such collaborative projects.

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Table 1: Study sites

Site A: Contextual summary

- Site A is based in one of the largest of the inner London boroughs and includes an area covering approximately 13.4 square miles and a population of approximately 265.000. The population is 66% white, 12% Black Caribbean, 9% Black African and 3.8% South Asian. There is a predominantly young population with an average age of 35, against a national average of 39. Seven of the 18 wards are among the most deprived in England.
- There are high rates of CHD, cancers, mental health problems, stroke and teenage pregnancy in the site. There is a significantly higher than average incidence of mental illness; predominantly psychosis. The Mental Health Partnership Board brings together the Local Authority, PCT and MH Trust to oversee provision and development of mental health services.
- The PCT was set up in 2002. There are a total of 50 GP practices with a total registered list size of 273,750.

Site B: Contextual summary

- The organisation and delivery of health and social care in Site B was undergoing a fundamental restructuring at the time of the study. This restructuring involved the creation of a county wide single organisation PCT that could work preventatively and more effectively manage long- term illness. This restructuring involved the amalgamation of five former PCTs. The new PCT serves a population of over a million people and in 2007 had around £1.2 billion to spend on local healthcare.
- In order to provide a complete service to patients, the PCT works closely with partners in social care, the voluntary sector, local boroughs and hospital colleagues.
- The PCTs Health Economy now comprises four acute trusts, one third of an ambulance trust, one mental health trust, one PCT and an increasing range of private providers. 156 GP practices operate within the PCT.

Site C: Contextual summary

- Site C is based in a city on the south coast, with a population of 246,000. Five percent of the population is under five, 19.5% under 15, and 21% over 60. There is very little ethnic diversity, although the ethnic minority population is growing. Parts of the PCT are in the "most deprived" national quartile for all deprivation indicators, and overall it is the 76th "most deprived" area in England. There are marked disparities within the city between the least and most deprived wards.
- There are a number of developments in services for individuals with long-term conditions. These include an expanded use of brokerage to ensure that contracts for day care, supporting people and domiciliary care are maximized, the reorganization and expansion to four posts of third tier management to ensure more capacity to address issues around intermediate care, and joint working with the PCT on mental health.
- The PCT was established in April 2001 and gained teaching PCT status in April 2003. The PCT serves a population of 240,000 people, covering an area of 16 square miles, and shares the same boundary as the City Council. The health community is facing considerable financial challenges and is implementing a financial recovery plan. The PCT is responsible for providing primary care and a range of community services, including intermediate care, rehabilitation and healthcare for older people.

Table 2: Servicer Users' experiences of good care

Mental Health Conditions	Physical Health Conditions
Service Users' experiences of good care	
Communication: information and explanation	Communication: information and explanation
Good quality listening	Clear and timely information giving and explanation
Not being rushed	'If I know what is going on I feel more positive and in control'
Assumptions not being made	
Good communication between professionals and primary and acute sectors	Ways in which professionals behave
	Interpersonal skills valued such as 'gentleness', inclusiveness and being respectful of patients and to 'to each other'
Ways in which professionals behave	
Professionals and key workers going beyond their remit 'never giving me the feeling that I am a nuisance'	Attitudes of professionals: 'she treats me as a person and takes time with me'
Access to services	Good care is about having 'time': getting the details right and when 'everything kicks in'
Access to services when they are needed: offering a safety net	
Continuity	Individualised and responsive care
Seeing the same person: not having to start from scratch each visit which can be painful	Approach and care tailored to the home environment
	Having someone with an overview
	Involvement
	Feeling involved in my care and in control of myself and my future

Table 3: Servicer Users' views of less good care

Mental Health Conditions	Physical Health Conditions
Service Users' views of less good care	
Communication: information and explanation	Communication: information and explanation
Conflicting advice from different professionals	Not understanding the system e.g. community matron 'don't understand her purpose'
	Lack of explanation leads to feeling blocked by the system e.g. 'can't do this because of that'
Ways in which professionals behave	
'Every health problem is seen as part of my mental health problem: I am exasperated!'	Ways in which professionals behave
Not being taken seriously; feeling stigmatised; and a 'burden'	Professionals who are offhand and who do not want to listen to your view
Assumptions that medication is the be all and end all	'Professionals who do not respect you or your property'
Access to services	Access to services
Access to services limited by attitude e.g. gate keeping; availability e.g. shortage of social workers; rationing of services e.g. reductions in access to emergency care	Problems making GP appointments
Having to be in crisis before access to services is granted	Rehabilitation services stopped certainly after the allocated 6 week period irrespective of further need
	Individualised, flexible and responsive care
Continuity	'Little things get forgotten'
No-one is monitoring the overall picture	
A high turnover of CPNs	

Table 4: Servicer Users' views of how care could be improved

Mental Health Conditions	Physical Health Conditions
Service Users' views of how care could be improved	
Communication: information and explanation	Communication: information and explanation
A folder containing services that are available to you	A folder containing services that are available to you
Ways in which professionals behave	Ways in which professionals behave
'Treating people like you want to be treated'	Treating patients as individuals
For professionals to give time to listen	Taking account of individuals
	Involve expert patients in training for health professionals
Access to services	The 'common denominator is training'
More day care, specialist services, talking therapies and comfortable environments where people can feel safe (half way houses)	Access to services
Training for GP receptionists (gatekeepers)	Flexible access to services
	Individualised and responsive care
Continuity	Put 'people first'
Continuity of care and more face to face contact	'Treat patients as individuals and with dignity'
Incentives for CPNs to stay in post	
Individualised, flexible and responsive care	
Individual, whole person, flexible care	
Move from being risk adverse to positive risk assessment	

Figure legend

Figure 1: Analysis of service user involvement in the PEGI study (adapted from Smith et al. 2005)