

Commissioning for long-term conditions: hearing the voice of and engaging users – a qualitative multiple case study

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Declared competing interests of authors: none

Published November 2014

DOI: 10.3310/hsdr02440

Scientific summary

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Health Services and Delivery Research 2014; Vol. 2: No. 44

DOI: 10.3310/hsdr02440

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Background

It is estimated that some 15 million people in England have a long-term condition (LTC) and that this number will continue to increase. People with a LTC have, to varying degrees, a long-standing relationship with local health services. Concern about whether or not the NHS meets the needs of people with LTCs emerged in the 1990s and consecutive governments have developed policies aimed at improving service delivery and also patient and public engagement and involvement (PPEI). Both the current and the previous government emphasised the need to improve commissioning for people with LTCs, and PPEI in commissioning was seen as a key policy priority. However, there has been little research that examines the impact or benefit of PPEI in commissioning. This project was designed to explore the role and impact of PPEI in commissioning for people with LTCs. Our original focus was on the activities of primary care trusts (PCTs) as commissioners of health care for people with LTCs. However, from the very beginning of the research period, there were substantial changes to the commissioning structures in the English NHS, with PCTs merging into clusters. With the change of government in 2010, the extent and rate of change accelerated, with the abolition of PCTs and development of a new commissioning structure – initially outlined in the White Paper *Equity and Excellence: Liberating the NHS*, published in July 2010. From January 2011, new ‘Pathfinder’ general practitioner (GP)-led commissioning groups began to develop, leading, eventually, to the establishment during 2012 of new Clinical Commissioning Groups (CCGs). These CCGs took over statutory responsibility for some 60% of the NHS budget from April 2013 to commission local community and hospital services. At the same time, PCT clusters evolved into commissioning support units and NHS England was established with responsibility for 40% of the NHS budget, with a specific emphasis on specialist services, national GP, ophthalmic, pharmaceutical and dental contracts, prison health, armed forces and a number of national public health programmes. Public health, including the commissioning of public health services, moved from PCTs to local authorities. In addition, new structures for PPEI were introduced. This presented challenges for the conduct of the research given the organisational turbulence but provided an opportunity to observe the impact of these changes on PPEI in relation to commissioning services for people with LTCs.

Aims

The project’s initial aim was to examine how commissioners enable the voice and engagement of people with LTCs and identify what impact this has on the commissioning process and pattern of services. A key outcome of the research was to provide guidance for commissioners on the skills and expertise needed by different commissioners, what actions are most likely to lead to responsive services and the most effective mechanisms and processes for active and engaged commissioning for people with LTCs. Our specific objectives were to:

1. critically analyse the relationship between the public/patient voice and the impact on the commissioning process
2. determine how changes in the commissioning process reshape local services
3. explore whether or not any such changes in services impact on the patient experience
4. identify if and how commissioners enable the voice and engagement of people with LTCs
5. identify how patient groups/patient representatives get their voice heard and what mechanisms and processes patients and the public use to make their voice heard.

The research was undertaken during a period of substantial change in the English NHS which enabled us to observe how the NHS reforms in England impacted on approaches to PPEI. While this did not provide an analysis of the position of PPEI in CCGs, once established in April 2013 it did provide useful indications of how PPEI was being developed, and the priority being placed on PPEI, during the development and authorisation stages of CCGs.

Methods

Given the complexity of studying PPEI in commissioning, we used a case study design in order to provide an in-depth, rich analysis in selected areas. The research examined three experiences of PPEI in three LTC groups – diabetes, rheumatoid arthritis and neurological conditions – through three in-depth case studies. Our approach involved reviewing practice across the UK and then focusing on three geographical areas to examine practices of commissioning and purchasing health care for people with LTCs, approaches to patient and public involvement (PPI), patterns of services for people with LTCs and the activities of local patient and voluntary organisations for people with LTCs. The research had five phases and involved participatory and interactive methods of data collection. Methods of data collection comprised documentary analysis, participant workshops, observation of meetings, focus groups and interviews, and the collection of data on service use and patterns of services in the three localities. We were able to involve a wide range of participants and respondents in our study from patient groups, statutory and non-statutory health-care providers, health-care commissioners, clinicians, patient representatives and carers and local authority officers and politicians. Following an initial analysis and synthesis of our data, we presented our findings in a summative workshop and selected a number of exemplars which were assessed for their potential to provide patient benefit by an expert reference group.

Results

The shift in guidance and policy from PPI to patient and public engagement (PPE) seems to be linked with a peripheralization of PPEI activity. We found a greater emphasis on concepts of communication rather than active involvement within CCG developments. PPEI was generally not a key issue in authorisation, the process by which CCGs are assessed against a series of criteria in order to become established commissioning organisations. While many CCGs reported that PPEI was a key priority, there was little evidence in authorisation documentation about PPEI and we did not observe a significant degree of PPEI activity in CCGs. In general, we found that at a CCG level PPEI is also becoming a peripheral activity. Despite this, respondents in our study also identified the development of CCGs as an opportunity to innovate in relation to PPEI but we found little evidence to support such innovation, although at the time of this research CCGs were very new organisations. In addition to changes in rhetoric, we found that there were different understandings of involvement in terms of how it was understood and what is was for between commissioners, providers, patients and the public. It is important that common understandings are agreed if effective PPEI is to be developed.

Case study 1 had a strong pedigree of PPI initiatives but there were few notable examples of service user voice having a major impact on service delivery. While a commitment to PPEI transferred to the CCG board, this intent did not extend to all GPs. The employment of a dedicated project lead to develop the PPEI strategy demonstrated a commitment, but there was a general feeling that the aims of the strategy would take longer than anticipated to achieve. Within the time frame of this study, it was too early to be able to fully evaluate whether or not the service user voice was being heard and responded to in the CCG decision-making processes.

Case study 2 had a long-standing tradition of PPEI initiatives, with a strong emphasis on partnership working. There were a number of examples of service user voice influencing service development and delivery, but we were not able to determine the impact of such involvement. The development

and expansion of patient participation groups was evident in general practice during the research period. During the data collection period, the CCG had formulated only a PPEI draft plan, rather than a strategy, with a GP-lead rather than a dedicated appointment. There were a number of potential PPEI vehicles within the new organisation, such as a membership scheme and patient engagement panel, but it was unclear how these structures would function within the organisation or how PPEI would feed into service development and overall decision-making.

Case study 3 did not have a marked history of PPEI within the PCT, although there were a variety of different methods used to involve and engage with their community. There was little evidence of much meaningful engagement, particularly within primary care, an area of increasing significance for people with LTCs. Some efforts were made to ensure that services were planned to meet the needs of particular sections of the community but these failed, due, in part, to poor PPEI planning and execution. The CCG is better placed to ensure that PPEI is firmly embedded in all areas of commissioning decisions in the future and new staff and structures are planned to enable this to happen. There is a strong commitment and will make a difference, but within the time frame of this project it was not possible to assess any impact.

Given the complexities and range of PPEI and health-care commissioning, it was not possible to demonstrate whether or not PPEI was being done well in our case studies. In particular, assessment of process was hampered by the continuing structural and organisational changes taking place within the English NHS during the period of the research. We did identify some positive impacts in terms of improvements in process and also to initiatives that would lead to patient benefit. However, our findings suggest that the priorities for health care are predominantly driven by national and local policy priorities and clinical priorities. PPEI tends to be framed by these priorities rather than patient and public voices being able to influence the core concerns and priorities. It is interesting to note that the initiative that we identified as being most strongly driven by lay people and also rated most highly by the expert reference group was outside the health-care sector, although having substantial patient benefit. This initiative struggled to gain and sustain relevant support.

The need for sustainability was a constant theme that emerged in our research. There was frustration about constantly changing NHS structures which had an enormous negative impact on PPEI and the contribution that patients and the public were making. In particular, there was a loss of organisational memory with the organisational restructuring and staff changes, causing significant knowledge gaps and disruption in relationships.

Future development of PPEI is dependent on training and development, which is likely to remain under-resourced. Our research also demonstrates that young people and adults have different experiences and perceptions. We found that, for adults, engagement and experience provide the key underpinning for developing involvement in decision processes. For young people, however, the combination of experience and engagement tend to lead to a withdrawal of interest. Further research is needed with young people to understand the reasons for this and how young people's involvement can be supported and sustained.

We did find examples of effective PPEI that had positively influenced agencies. However, much PPEI continues to be undertaken in silos, with little sharing of resources, processes or experience, and there is a need for improved networking and sharing if PPEI is to be effective and beneficial.

Conclusions

The findings set out in this report identify some key areas where improvements to practice in relation to PPEI can be made. In particular, these findings point to two broad areas of action. The first relates to the framework or infrastructure arrangements for PPEI and how PPEI can be supported in the NHS and other organisations. To combat short-termism and the fragility of PPEI activities, sufficient resources need

to be invested in sustaining relationships and infrastructures – including training and sharing experience across sectors. Developing a shared language and understanding is also important. The second area of action relates to the process for PPEI and how it should be undertaken. These action areas are relevant to national organisations (and the new regional structures and organisations developing within the reformed English NHS) and to local commissioners (the CCGs) and service providers. PPEI is not a linear process. There is a circular process and this is, in itself, extremely fragile. This circular process can be ‘*virtuous*’, in that good engagement can lead to improved involvement if it is not tokenistic or has sustainability. However, where involvement is tokenistic or ends, patients and the public become disengaged and less involved, and this can be described as a ‘*vicious circle*’.

We identified three areas that frame approaches to PPEI and provide an analytical framework for evaluating PPEI within the context of commissioning. Developing approaches to PPEI needs to be framed by asking whether or not it is **moral** – PPEI as a right for the tax-paying citizen in a democracy, and the moral argument of ‘nothing about me without me’; whether or not it is **approached methodologically** – PPEI as a tool for quality improvement, improved patient safety and increased efficiency; and how the **policy imperative** is enacted – PPEI undertaken as a policy imperative. This provides an approach that begins to help shape a potential evaluative frame for PPEI by asking, for example, whether or not everyone has a voice, if quality has been improved, or if PPEI has been implemented as per policy.

In addition, the research identified a number of key methodological issues and areas for further research that should be considered by research funders and researchers undertaking research in the area of PPEI. In particular, we identified key challenges for undertaking research on PPEI with young people and recommend further specific projects with younger people on examining PPEI in health care.

Implications for national organisations

- National agencies should ensure that training and development programmes on PPEI for commissioners, providers and patients and the public are implemented; these can be delivered nationally or support local training and development initiatives.
- National organisations such as NHS England and National Healthwatch need to develop monitoring criteria for PPEI.
- There needs to be clarity about terminology with agencies being specific about the meaning of terms such as engagement and involvement. These terms carry different meanings to different people.
- National and regional agencies need to develop and support a sustainable environment for PPEI in which local relationships can develop and flourish.
- At a regional level, organisations need to ensure that resources and structures for PPEI are shared, for example supporting networks, sharing resources and jointly supporting infrastructures.

Implications for health-care commissioners and providers

- Commissioners need to embed PPEI throughout the commissioning cycle.
- Commissioners need to understand that strategies for engagement, while important, are not substitutes for involvement; this is a contributing stage but does not constitute active participation.
- Commissioners and providers need to agree measurable outcomes of PPEI with patients and public, and evaluate these annually.
- Commissioners and providers need to work together on PPEI as providers have more opportunities for engaging with patients and carers.
- Commissioners, providers, patients and the public should work together to develop a shared vision of PPEI.
- Agencies should participate in existing networks and forums, such as participation in a neurological network.
- Agencies should co-operate on the mapping of local PPEI.

- While PPEI requires an organisation-wide approach, organisations require dedicated resources (staff, funding) for PPEI.
- Commissioners and providers should develop a shared framework for evaluating PPEI and its outcomes, for example in relation to improved patient experience and safety.
- Indicative data should be collected to understand the local contextual enablers and barriers to implementing PPEI.
- PPEI processes and structures should enable the voice of the public who are the most vulnerable, such as people with long-term health conditions (mental health problems, dementia, learning disabilities) or long-term socioeconomic conditions (homeless people, traveller groups, sex workers, refugees, asylum seekers, prisoners/ex-offenders, people living with persistent poverty/lower levels of education), and those from black and ethnic minority communities.
- A highly visible and accessible main point of contact for the public should be provided, focusing on relational integration such as the fostering of relationships and trust, and consistently providing timely and informative feedback.

Recommendations for future research

- Our research suggests that further research is urgently required to examine how PPEI is being developed within the reformed English NHS. Our research has demonstrated the fragility of PPEI and how reorganisation can impact negatively on PPEI processes and developments.
- Research on PPEI among young people and children requires dedicated research projects where all resources and activity are focused on accessing, involving and supporting young people.
- This project has demonstrated the value of linking research between similar research projects – in this case linking with the Department of Health Policy Research Unit in Commissioning and the Healthcare System research on CCGs – and allowing the pooling of data.
- This project has demonstrated the value of participative and iterative methods for investigating PPEI and researchers should be encouraged to utilise similar methods in future studies.
- There is still a need for research to measure the potential economic costs/benefits of PPEI.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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The research reported in this issue of the journal was funded by the HS&DR programme or one of its proceeding programmes as project number 08/1806/261. The contractual start date was in November 2009. The final report began editorial review in August 2013 and was accepted for publication in March 2014. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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