

Engagement and Voice

in Commissioning

Involving patients in commissioning:

what difference does it make?

Workshop held in London on April 16th 2013

Introduction

This workshop was organised to present findings and discuss outcomes from a national study¹ on how patients and the public are involved in local commissioning of healthcare services and how organisations, such as clinical commissioning groups (CCGs), engage with and enable the service user voice to be heard. Over forty invited participants attended on the day, representing both lay and executive leads for patient and public engagement and involvement (PPEI) from a variety of clinical

¹ EVOC (Engagement and Voice in Commissioning) is a 3 year 9 month research project funded by the National Institute of Health Research (DH) and led by Professor Stephen Peckham (London School of Hygiene and Tropical Medicine and University of Kent) in collaboration with colleagues at the University of Hertfordshire. Commenced in 2009 it is running in 3 case study sites in England. Further details about the project can be found at http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1806-261

commissioning groups in England, as well as service user representatives and clinical commissioners.

Diana Whitworth, chair of the EVOC advisory group, welcomed participants and provided an introduction to the workshop. Dr Patricia Wilson, one of the lead researchers for the EVOC project, presented the main outcomes from the research² and questions were invited from the audience. A series of two workshops, focusing on aspects of development of PPEI within the new health architecture, were facilitated by Douglas Smallwood, PPEI consultant.

Questions for the workshops were:

- What difference is public and patient engagement and involvement making to CCGs in:
 - o decision making processes?
 - services that are being commissioned?
 - patient experience of services?
- How will public and patient involvement be sustained beyond authorisation?
 - What actions are needed to sustain it?
 - How can sustainability be established and monitored?
 - How can experience be shared between CCGs to help sustain involvement?

Lesley Goodburn, Head of Communications and Engagement, Staffordshire Commissioning Support Unit, then presented a working model of PPEI³.

² Presentation circulated separately

³ Presentation circulated separately

What difference is PPEI making to CCGs in their decision-making processes?

Cultural shift

Structures for decision-making were acknowledged as being in place, but their adequacy was questioned and there appeared to be little consistency in approach. The need for collaborative working was important but it was unclear if this is happening in practice or in plans. For some, PPIE's impact on decision-making was viewed as too early to be on the agenda. CCGs have been operational in shadow form for some time however PPEI vehicles, such as Healthwatch, are still embryonic. The emphasis at present is more about developing a culture of trust and credibility through listening and providing feedback.

Some informants were sceptical about the CCGs commitment to PPEI in decisionmaking, suggesting that it could have the potential to be another 'tick box' exercise and might not be taken seriously, or even viewed as a 'hindrance'. A few lay representatives felt that their appointments were tokenistic as they were not given full voting rights despite being a member of the CCG Board.

There was recognition that the rhetoric is changing, but questions were raised on a number of concerns, specifically whether this would translate into PPEI in decision-making and how much priority would be given to PPEI? Variation across CCGs is likely. GPs' ability to engage with bottom-up initiatives was also questioned.

Suggestions to enable the process were offered. One involved changing the way that decisions are made, for example, the use of patient stories or case studies in all commissioning meetings, as many CCGs are now beginning to do.

Recruitment and getting involved

There was some discussion regarding the importance of 'new blood' in relation to PPEI recruitment. This approach could bring new ideas to decision-making process.

The importance of a charismatic, powerful PPEI representative was highlighted, although it was acknowledged that there might be concerns around involvement through self-interest. Having some local credibility was also judged as important. PPEI representatives were more likely to be approached if they were already known to the organisation. Their skill was acknowledged – lay members often ask the questions that others (e.g. clinicians) do not ask. There was some discussion on whether being a lay representative was a job, or should it be? It was also questioned whether the general public knew how to be involved.

A number of groups, organisations and initiatives were identified as links to potential involvement. This included the Equality Delivery System and the Expert Patient Programme.

Process

It was observed that the current process for PPEI in decision-making was very limited and that CCGs needed to capture a range of different experiences both negative and positive. There were also thoughts on how decision-making could be operationalised – some noted the difference between single task focused decisions as well as the overall process of decision-making in relation to PPEI, both were seen as equally important but different. It would require GPs to work differently, ensuring that the right people needed to be involved and at the right time. A number of suggestions and examples of how involvement could be implemented were offered including:

- Vertical integration of PPEI throughout care pathways
- Use of the Equality Delivery System (EDS) to involve community in health through the equalities agenda

Issues around communication processes, advocacy and funding were also highlighted. Questions such as how do people know how to air their concerns and in what capacity are people being asked to be involved? Patients as customers have implications for shared decision making.

What difference is PPEI making to the services that are being commissioned?

Resources

Although resourcing PPIE was not a recurrent theme from the research data within the EVOC project, many informants highlighted the impact of resources on service delivery and that CCG agenda had the potential to be dominated by resource issues. But it was not clear whether CCG resources were adequate for PPEI as they appeared to be targeted at 'communications' rather than 'engagement and involvement'. Groups noted that the pressure was to save money; if PPEI could help 'save money' they would be listened to. However, it was noted that conversations between patients/service users and clinicians are different to 'management' conversations – it should be patient focused not resource focused.

Managing expectations

There was a suggestion for clarity e.g., talk openly about 'cost effectiveness' What do commissioners say when public demands cannot be met for financial reasons? e.g. out of hours service returning to local general practice. Feedback needs to be in plain English. There should be clarity in relation to parameters e.g. limited resources.

Examples of PPEI in service redesign

- PCT example was given of a Diabetes care pathway which saw improved outcomes in HbAIc, increased ranking of PCT, with the suggestion of transferability to CCG, who have a chance to do things differently - 'wiping the slate clean'
- EDS impacted on diabetes services (improving data quality)
- Collective voice improved podiatry and stroke redesign

<u>PPEI impact</u>

Although there is a lack of research evidence for PPEI impact, it was agreed that it will be increasingly important, to ensure sustainability of PPEI, to show how it is having an impact on services and that individuals and organisations working in PPEI should collect and utilise the evidence where possible. Evidence exists in the form of case studies where PPEI has changed services, in some cases reducing costs. It was also seen as important to capture the patient journey not just focus on

complaints/compliments. There was a suggestion that NHS Commissioning Board (NHSCB) should hold PPEI intelligence.

Organisational issues and collaborative working

CCGs need to make links between other factors relating to ill health e.g., money and housing. It was noted that Health and Wellbeing Boards acknowledge the social environment and there was a potential bridge between budgets and authorities (however, no incentive to marry budgets and services). CCGs needed to tackle what affects them locally as well as finding an appropriate environment for concerns. Accessibility of services was also highlighted with the hub and spoke model of acute service not seen as helpful.

The level of authorisation for CCGs was also viewed as significant for some as it would affect the ability to commission services and would also impact on the level of PPEI.

There was little evidence on the day of collaborative working between CCGs and CSUs on PPEI.

What difference is PPEI making to the patient experience of the services?

Patient story

Many groups highlighted the importance of the 'patient story' - there was discussion of its use at CCG Board level with the suggestion that each meeting could start with a patient story/experience. It was important to identify both 'good' and 'bad' practice, so as to keep what is working well for patients. This needs a mindset that moves beyond tokenism as experiences need to be heard. It is also important to highlight the change that has been made as a result of the experience. In order for patient experience to make a difference to service – they do not need to be 'technically proficient' - all voices should be heard. Sharing of experience is also seen as really important. It was also seen that capturing the 'wider experience' was required, with a balance between single interest groups, voice of carers etc – the experience does not necessarily need to be disease focused - some case studies could be taken from Practice Patient Groups (PPGs)

Potential overload

Groups highlighted that there was a potential for patient and members of the public to 'burn out' (e.g. moving from LINk to Healthwatch) with the risk of disengagement, this potentially could be addressed by good active feedback.

How will Public and Patient Involvement be sustained beyond authorisation: What actions are needed to sustain it?

Organisational ethos and commitment

CCGs needed to be open and transparent, with a commitment to hear what was being said, with no boundaries between 'them and us'. This meant equal partnership and developing trust. Again, change in culture was advocated as well as truly valuing patient experience, which should be reflected in quality outcomes and improvements. It was observed that patients/service users were not 'numbers' or 'stats' ... '*we have names, views and valuable experiences'*. Questions were raised on whether structures had been put in place to sustain PPEI – it was not clear that they had in some quarters. An understanding of inevitable change was also viewed as important – how long will we have CCGs? The true cost and value of NHS services also needed to be understood by all.

Training & expertise

"PPEI is an art' was expressed by a number of the workshop participants. Appropriate skills need to be developed, as well as guidance through 'good practice' examples to help CCGs develop PPEI. The sharing of good ideas was also highlighted as valuable. GPs need to know how and why to include PPEI – they often showed good intentions but were 'scared' to do it. GPs leading PPEI could turn to Commissioning Support Units for help. Having both lay and clinical PPEI leads on CCG boards was suggested as one method of supporting GPs in PPEI. Recent organisational change

has led to a loss of expertise in the workforce. Sustaining PPEI should therefore include some thought to transferring expertise, highlighting a need to leave a PPEI legacy for those that come afterwards. Ensuring good links with the Local Authority/Health and Well-Being Boards is fundamental as they usually have good expertise in engaging and involving communities. Access to appropriate training for patient and public also required.

Process and Outcome

A number of key points and actions were highlighted in relation to sustainability:

- Mapping provision in the area JSNA, PRG
- Leadership (requires CCG investment and ownership) - need to champion the importance of GP/Clinical input and involvement
- Having clinical & non-clinical PPEI leads
- Adequate resources including administrative support for PPEI
- A 'minder' to ensure commitment & implementation
- Communication Strategy -Groups/individuals to be kept

- Identifying potential areas of involvement e.g. in service redesign, commissioning cycle
- Clear Terms of Reference and glossary of terms (plain English)
- Ensure sustained engagement by identifying a mechanism for refreshing PPEI membership such as co-option and timelimited appointments to Boards/Committees/Groups
- Involve local voluntary organisations and ensure this continues
- Public consultations are useful
- Learning from other successful models of PPEI (e.g. Social Housing)

informed. How are groups and individuals going to be embedded? Feedback is essential.

- re/decommissioning, patient journey, patient feedback, service improvements (this is seen as cyclical)
- Research to evaluate impact of PPEI
- Actions framework/template to focus on
- Clinicians asking (proactively) for patient/service user feedback
- Good structures and methods to coordinate local commissioning with national specialised commissioning

Patients to lead patient reference groups effective patient groups were most often patient, rather than clinician led.

Outcomes

- What difference PPEI input is making
- Dissemination different times and methods used
- Evaluate current position with regular review of outcomes and forward strategy e.g., positives and negatives, new areas of investigation (active work plan)
- Evidence of efficiency e.g., hospital patient groups, mental health patient groups.

How can sustainability be established and monitored?

To establish sustainability of PPEI the CCG will need to develop a level of trust and confidence with its community. Being open, honest and transparent is a key factor for this, as well as having effective channels for communication built into the structures.

Establishing PPEI sustainability	Approaches to monitoring
 Training is needed in PPEI (for lay and executive/employed or 'staff' level) Having sufficient resources (money, personnel) Having leaders and champions with clout Communications – generic - e.g., regular slots in local newspaper – 'getting the message out' 	 Record changes made as a result of PPI (as routine) Evaluate outcomes – having measurable outputs agreed by patients and public Performance dashboard at CCG Board Equality analysis (legal requirement) Through provider contract with 'consequences' National Commissioning Board to

Sustainability versus tokenism.	overview
• Incentivise CCGs and members –	Annual PPIE report
benefits of getting them involved early	• Research – how CCG services look from
on.	different perspectives - 360 degree
Managing politics	(national GP survey, hospital survey,
• Involvement and awareness of JSNA	LINks – compare and contrast)
• Local organisations acting together,	Disseminate research outcomes
shared interests e.g.,	• JSNA and use of LA – powerful
voluntary/charities/M.Ps,	monitoring tool
• Identify specific projects and pathways	• Healthwatch as monitor (issue of
of care in local area with defined project	capacity?)
plans and outcomes	• Use of website – results of feedback –
• Communicating role to each part of PPI	actions taken (you said – we did)
system to achieve critical mass for	• CQC inspection of GP practices
change	• Benchmarking: throughout patient
	pathway and against "most similar
	family" (comparable CCGs)
	• Capturing patient experience over
	time/throughout service changes

Respondents added that it was also important to ensure that CCGs had good Commissioning Support Units to help with monitoring and that there was good use of the media (both negative and positive) including use of social media (Twitter etc). It was not necessary, however, to reinvent the wheel – existing monitoring tools should be used where possible.

How can experience be shared between CCGs to help sustain involvement?

For some this still felt like a bit of a vacuum, but there was acknowledgement that strategies needed to operate both at local and national levels. Would require open and honest relationships with an emphasis on 'share and learn'. It was seen as important to develop relationships with other CCGs so experience could be shared, this relationship should open and honest with an emphasis on 'share and learn'. A number of suggestions were made:

Best ways of sharing experiences:	What to share:	
• Through conferences & forums – e.g. NHS	• Sharing positive examples – cascade	
Clinical Commissioners	experiences out to local organisations	
• Via networks:	(sharing could also include 'bad'	
• PPEI networks such as this	experience and practice)	
workshop	Sharing cases of good practice	
• Utilise existing networks such as		
strategic clinical network		
• Use of press and media		
• Adopting an inclusive approach, for	Other areas to explore:	
example incorporating other groups such as	• Identify CCGs with similar	
teenagers/schools	condition/demographic/equality/economic	
• Getting the right people in the right room	profile	
who make the decisions and hold the	• Identify similar CCGs in terms of practices,	
budgets	both general and acute	
• Meetings with lay members from different	• Benchmarking – Local Area Teams and	
CCGs	NSF	
• Patient Revolution – sharing positive		
patient experience		
• Via a central database/web portal		
Some key conclusions from the day		

- Key findings from EVOC study validated by respondents
- Clarity around 'engagement' and 'involvement', as identified in EVOC presentation
- There is no consistent approach to patient and public engagement and involvement
- Evidence is needed on how different approaches for PPEI impacts on outcomes

- Strong support for approaches such as performance dashboards and patient stories
- CCGs and CSUs should be working more collaboratively on PPEI
- There was an identified need for learning and sharing PPEI including PPEI leadership and skills development for patients, clinicians and other personnel working to support PPEI
- The workshop demonstrated the scope for sharing approaches and experiences

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List of abbreviations

HbA1c	A laboratory test for diabetes showing the average level of blood sugar (glucose) over the previous 3 months.
CCGs	Clinical Commissioning Groups
CSU	Commissioning Support Unit
CQC	Care Quality Commission
LINks	Local Involvement Networks
EDS	Equality Delivery System
EVOC	Engagement and Voice in Commissioning
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LAT	Local Area Team
M.P.	Member of Parliament
NHSCB	National Health Service Commissioning Board, now called NHS England

NSF	National Service Framework
PPEI	Patient and Public Engagement and Involvement
PRG	Patient Reference Group

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Department of Health Disclaimer

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