



ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Working collaboratively to develop a patient experience definition and strategy to inform clinical commissioning

Kate Sanders*, Samira Ben Omar and Jonathan Webster

*Corresponding author: Foundation of Nursing Studies, London, UK
Email: kate.sanders@fons.org

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Abstract

Background: Major reforms in the NHS in England have resulted in the creation of Clinical Commissioning Groups, which put clinicians at the forefront of commissioning services. One of the shared strategic objectives of the NHS is 'ensuring that people have a positive experience of care'. With this in mind, a piece of work was undertaken to develop a strategy to embed patient experience in the commissioning process.

Aim: The overall aim of this work was to engage with patients, service users, carers, health and social care workers and representatives from the voluntary sector in north-west London, UK, to develop a shared definition of patient experience and a patient experience strategy to influence the clinical commissioning of care.

Methods: A values-based approach was used to develop the definition and strategy, working collaboratively with clinicians, commissioners, patients, service users, carers and the community. The facilitation of this work was underpinned by four principles: working collaboratively; being evidence based; being asset based; and being continuous and iterative. The principles are described and also used to critique the process and outcomes.

Conclusion: This work was stimulated by the recognition that practice development approaches could be applied to different contexts and settings, including clinical commissioning. It has the potential to draw clinical commissioning and clinical provision much closer together, with engagement, collaboration and decision making focused on improving the quality of care (experience, safety and outcomes) for patients and their supporters.

Implications for practice:

- A values-based approach is an effective way of capturing the voice of patients, service users, carers and the community
- The voices of individuals and communities are crucial in shaping and influencing the development and commissioning of new models of care
- Greater impact may have been achieved if we had worked more collaboratively with providers from the outset
- Although this paper focuses on the commissioning of healthcare services in England, it has wider UK and international relevance if used as a case study for enabling community engagement and participation

Keywords: Collaboration, commissioning, engagement, patient experience, strategy, voice, values

Background

Following the election of a new government in the UK in 2010 and the subsequent publication of *Equity and Excellence: Liberating the NHS*, a government White Paper (Department of Health, 2010a), major reforms in the organisation of the NHS in England began. A key element of these reforms was the creation of Clinical Commissioning Groups (CCGs), the intention being to put clinicians, led by general practitioners (GPs), at the forefront of commissioning community, mental health, acute and voluntary services with and for their local population. According to Dr Michael Dixon (2012, p i):

'Commissioning is first and foremost about patients. Clinical commissioning is about how, as clinicians, we can do more for our patients and vastly extend the depth and range of the possible.'

Further, Philip DaSilva (2012) asserts that:

'To commission is, therefore, to unite the interested parties around a common purpose and a shared understanding of resources – not just money – to increase value and improve quality.'

As is to be expected with such major reforms, new structures and processes have had to be created in a relatively short period of time. Five CCGs in north-west London have formed a 'collaborative', while maintaining their independence as statutory commissioning organisations, for the purpose of sharing expertise and resources, as well as undertaking joint commissioning, service transformation and pathway redesign. The CWHHE Collaborative covers CCGs in central London, west London, Hammersmith and Fulham, Hounslow and Ealing, serving a culturally diverse population of some 1.1 million people.

The CWHHE Collaborative is committed to working in partnership with patients, carers, the wider public and local partners to ensure services commissioned are responsive to the needs of the population. More specifically, the CCGs are committed to the overall quality of care provided.

The Health and Social Care Act (Department of Health, 2012a) sets out key requirements for CCGs to:

- Commission high-quality services
- Identify the quality improvements they wish to secure in services they commission
- Use the commissioning process to drive up continuous quality improvements

The *NHS Outcomes Framework* is intrinsically linked to the local and national quality agenda, which consists of three key areas: patient safety, clinical effectiveness and patient experience, as first set out in *High Quality Care for All* (Department of Health, 2008). One of the shared strategic objectives of the NHS is 'ensuring that people have a positive experience of care'. With this in mind, it was the vision of the director of quality, nursing and patient safety for the Collaborative (JW) to develop a patient experience strategy to ensure patient experience was embedded in the commissioning process – to enable a continuous improvement in patient experience and in the overall quality of care provided locally. To achieve this, JW asked the assistant director for patient experience and equalities within the Collaborative (SBO) and a practice development facilitator from the Foundation of Nursing Studies (KS) to co-facilitate the development of the strategy, using their expertise in community development work, patient and public involvement, the equalities agenda and practice development principles and processes.

Aim of work

The overall aim of this work was to engage with patients, service users, carers, health and social care workers and representatives from the voluntary sector in north-west London to develop a shared definition of patient experience and a patient experience strategy to influence the clinical commissioning of care.

Principles underpinning the development of the patient experience definition and strategy

Conversations between JW, SBO and KS made it possible to establish that there were shared values about the way in which this work should be undertaken. These conversations enabled the identification of a number of key principles that underpinned the approach to developing the patient experience strategy. These are outlined below.

- **Working collaboratively** by bringing clinicians, commissioners, patients, service users, carers and the community together as equal partners; recognising the importance of enabling the inclusion of as many 'voices' as possible, both across the CCGs and considering the nine protected characteristics of the Equality Act (UK Government, 2010)
- **Being evidence based** by building on local evidence of existing insight and intelligence gathered from community research and patient conversations over a period of five years to inform the discussions
- **Being asset based** by recognising the skills and expertise that staff, patients, users and carers bring, not only in terms of their experience of using services but in facilitating conversations with their own peers
- **Being continuous and iterative** by continuously engaging to refine and validate the principles and outcomes outlined in the strategy so the strategy itself is flexible enough to accommodate emerging themes and issues that impact on patient experience

These principles required us to work authentically as facilitators, periodically reflecting on how effectively we were working with them, challenging ourselves and each other. However, we also had to work within the time constraints of the clinical commissioning process; the work was agreed in April 2013 and had to be completed by January 2014.

Patient experience

Patient experience is a term that has been used increasingly in healthcare practice over recent years, in response to documents and guidance that have highlighted the need to improve it where possible (Department of Health, 2008; 2010a; 2010b; UK Government, 2012). A number of definitions of patient experience exist; for example, the Dr Foster *Intelligent Board Report* (2010, p 7) defines it as 'feedback from patients on what actually happened in the course of receiving care or treatment, both the objective facts and their subjective view of it'. The *NHS Patient Experience Framework* (Department of Health, 2012b) offers a working definition consisting of eight key elements, and similarly the NICE Clinical Guideline 138 (National Institute for Health and Clinical Excellence, 2012) provides 14 quality statements relating to patient experience for adults in acute NHS services. However, despite such definitions, it became apparent during initial discussions to plan this work involving CCG engagement leads that everyone had their own perspective on patient experience, and unless it was openly discussed there was a danger that a shared understanding could be wrongly assumed.

While the *NHS Patient Experience Framework* (Department of Health, 2012b) provides a common, evidence-based list of what matters to patients and was welcomed by some as a 'step in the right direction' and one that could help to 'stop people reinventing the wheel' (Cornwall, 2012), it has also been noted that different areas of the framework will be more significant for different communities or groups of patients. It could be suggested, therefore, that reliance on the framework alone might deny individuals, groups or communities the opportunity to engage fully with the notion of patient experience by sharing what is important to them.

Although patient experience is one of the three key components of quality care (Department of Health, 2008), in general it has received less attention from organisations than clinical effectiveness or patient safety (Dr Foster Intelligence, 2010). It could, however, be argued that it is becoming more important. Over recent years, several reports have highlighted significant failures in the delivery of healthcare (Francis, 2010; Parliamentary and Health Service Ombudsman, 2011; Patterson, 2011) and the lack

of focus on patient experience at board level has been cited as a possible cause of these failures (Dr Foster Intelligence, 2010). The Health and Social Care Act (UK Government, 2012) puts patient experience at the forefront and reinforces the use of patient experience information to improve the quality of care. Reflecting this, the ‘ensuring that people have a positive experience of care’ indicator is a measure for demonstrating how well the NHS is doing (Department of Health, 2012a, p 4). As we move forward with the clinical commissioning of services, patient experience will be both a risk and an opportunity in relation to the reputation of service providers (Dr Foster Intelligence, 2010). To some extent, this is evident in the Commission for Quality and Innovation payment framework, which enables commissioners to link organisational income to local quality improvement goals.

Taking all the above into account, it was decided that the starting point for this work should be inclusive discussions about the meaning of patient experience for the population served by the CWHHE Collaborative. This acknowledges that the work is rooted in the values of individuals – what they think is important, matters, or should happen – and is therefore contextually based. By facilitating discourse, it was anticipated that a collective voice could be created that could represent, influence and be involved in decision making.

Overview of development process

Table 1 provides an overview of the process undertaken and the associated timescales. The activities involved will be outlined below.

Table 1: Overview of activities	
Timescale	Activity
June 2013	Initial workshop to develop draft patient experience definition and strategy
July-September 2013	8 workshops and events to facilitate wider community engagement and further refinement of definition and strategy
July-September 2013	Review of relevant documents
October 2013- January 2014	Further sharing of definition and strategy
January 2014	Final workshop to identify priorities and actions
May 2014	Seeking CCG approval and sign-off

Starting point

In June 2013, an initial workshop was facilitated by KS and SBO. It involved a total of 30 participants:

- Patients and carers
- CCG lay/patient representatives
- Delegates from groups that represent the public including health and social care consumer body Healthwatch and the Black and Minority Ethnic Health Forum, a partnership between voluntary and community organisations, healthcare providers, commissioners and local authorities
- CCG patient and public involvement leads
- Members of the CWHHE Collaboration’s quality and patient safety team

Participants were invited using a targeted approach to ensure that the feedback was representative of the views and perspectives of all sections of the community, as well as of frontline staff. This included using existing voluntary and community sector networks, patient and user groups such as the Diabetes User Group and accessing existing GP networks such as CCG locality teams.

The purpose of this workshop was to engage the participants in the development of a draft definition of patient experience and a draft patient experience strategy, and involved three key activities: defining the patient experience and values clarification, followed by a process of member checking.

Defining patient experience

After an opportunity for participants to introduce themselves and to express their hopes for how the group would work together during the workshop, small group discussions based on the [World Café™](#) approach were used to facilitate conversations about patient experience using three questions:

- What is patient experience?
- What characterises a good experience for patients?
- How does experience differ from satisfaction?

Participants were encouraged to share their views and perspectives, recording key points of their discussions on the paper tablecloths. At the end of the three rounds of discussions, participants were invited to offer any final thoughts or insights to the whole group; these comments were captured on a flip chart in view of all participants.

Following the workshop, the notes were typed up and then the key themes and statements were used by KS to create an initial draft definition; it was possible to capture all the contributions in some way in the definition. The definition, along with an audit trail of the theming process and how the contributions had been used, was shared with SBO and JW to allow for critique and contestation and thereby enhance the validity of the definition.

Values clarification

Participants were then invited to participate in a values clarification exercise (Warfield and Manley, 1990), an approach widely used in practice development as a means of developing a shared vision or purpose. Essentially, this invites individuals to share their values and beliefs on a subject – what they think is important and/or should happen. These are then collated and common themes are identified that can then be used to create strategic statements.

Developing a shared purpose is the central element of the NHS Change Model (Finney, 2013). In this model, *shared* means the aligned ‘values, experiences, beliefs and aspirations’ of a group of individuals (Finney, 2013, p 6) and *purpose* represents ‘the “WHY” not the “what” or the “how” of change’ (Finney, 2013, p 6). In the context of this work, a draft shared purpose was created by asking the participants to consider the following statement:

‘In the context of the commissioning process, the ultimate purpose of capturing patient experience is ...’

Participants were invited to respond on sticky notes (one idea per note) and these were collected on a flip chart. They were then invited to do the same with the following statements to help with the development of the strategy:

‘This purpose can be achieved by...’
‘Factors that will enable the achievement of the purpose are...’
‘Factors that will hinder the achievement of the purpose are...’
‘Other values and beliefs I hold about the purpose are...’

Once all the sticky notes were on the relevant flip charts, participants were invited to view the contributions and to add anything further, raise any queries or ask for clarification of any contributions. This was facilitated as a whole group.

All the contributions on the sticky notes were typed up; they were then themed and short descriptors created that described the theme. The descriptors were then used to create statements, which in turn were used to develop the strategy. As with the definition, the draft strategy and audit trail was shared with SBO and JW for verification.

Member checking

The draft definition and strategy were sent to all the workshop participants for comments and feedback. No requests for amendments were received at this stage; SBO and KS assumed that this meant all participants were happy with the outputs as the high level of participation during the workshop suggested any queries or concerns would have been raised.

Ongoing engagement and development

Workshops and events

The communication to workshop participants also asked for their help in the next phase of engagement and development, by identifying meetings, organisations and groups where the draft documents could be shared during July-September 2013. The aim was to capture the views and perspectives of as many stakeholders as possible, for example:

- CCGs' patient and public engagement committees
- Patient and carer groups (including people with long-term conditions, users of maternity services, and those with learning and sensory impairments, dementia or physical disabilities)
- Healthwatch, faith groups, existing networks and partnership boards, black and minority ethnic and non-English speaking communities, people in areas of high inequality
- Health and wellbeing boards, CCG local area teams and public health providers

A number of opportunities were identified (see Table 2). A variety of approaches were used by KS and SBO to engage with the attendees and gain their views and perspectives about patient experience and the draft documents. This ranged from group discussions about what was important to people in terms of patient experience, and round table discussions about the documents and suggested amendments.

Workshop/event	Attendees
Chelsea and Westminster Patient Experience Summit, 17 June 2013	Approximately 150 attendees: staff members
Family Mosaics, 8 July 2013, Central London CCG	Thirty-four attendees: Bangladeshi and Somali residents and residents from the Church Street Estate area
Diabetes service user group, 17 July 2013, Central London, West London and Hammersmith and Fulham CCGs	Eighteen attendees: service users and carers from the tri-borough area (Westminster City, Hammersmith and Fulham, and Kensington and Chelsea councils)
Health and Wellbeing Voluntary Organisations Forum, 23 July 2013, West London CCG	More than 50 participants: voluntary and community sector representatives from West London and Central London CCGs
Community Champions, Ladbroke Grove, 25 July 2013, West London CCG	Six attendees: community champions and project leader
Workshop for people living and working in Westminster, Greenside Community Centre NW8, London, 5 September 2013, Central London CCG	Seven attendees: representatives from diabetes service user group and children's centre; patient representative; CCG employees
Workshop for people living and working in Westminster, Marylebone Road NW1, 10 September 2013, Central London CCG	Six attendees: patients/expert patients; user involvement service managers/leads; member of patient/user panel; student services representative; CCG employee
Workshop for people living and working in Westminster, Victoria Medical Centre SW1V, 12 September 2013, Central London CCG	Seven attendees: Healthwatch, representatives from Breathe Easy and Diabetes UK; carer; expert patient; representative from Migrants Resource Centre

Feedback from these events was collected in a variety of ways, depending on the format of the meeting. These included flip charts capturing small group discussions, facilitators' notes taken during meetings

and shared with the group at the end for verification, directly annotating draft definition and strategy documents, and email communications after events. This evidence was collated by KS and themed.

Review of relevant documents

To extend the inclusion of views and perspectives beyond those represented at the workshops and events, a review of relevant documents and reports was undertaken by KS (see Table 3). Due to the timescales of the project, a pragmatic approach to retrieval of documents was used. This involved the use of local documents known to SBO and others that emerged through discussions at workshops. The documents were read and evidence relating to patient experience was identified and highlighted; the documents were then reread, the evidence was listed in a word document and then themed.

Table 3: Documents and reports reviewed	
Area/organisation	Document
BME Health Forum	<i>A Study into the Experiences of Black and Minority Ethnic Maternity Service Users at Imperial College Healthcare NHS Trust, April 2011-March 2013</i>
Central London CCG	Feedback from the 15 Steps Challenge on Jade Ward, Central London Community Healthcare NHS Trust
Hammersmith and Fulham CCG	<i>H&F LINK: Community Mental Health Services – The Service User Experience in Hammersmith and Fulham, March 2013</i>
	Report from a diabetes workshop, 13th February, 2013
	<i>Joint Strategic Needs Assessment: Community and Voluntary Sector Association Community Consultation Report, May 2010</i>
Hounslow and Hillingdon	<i>Diversity Works: Research Project on Lesbian, Gay, Bisexual, and Trans People who Live, Work, Socialise and/or Use Services in West London. Report, January 2010</i>
Hounslow and Richmond Community Healthcare NHS Trust	<i>Patient Experience Report, 1 April-30 September, 2012</i>
Hounslow CCG	Feedback from Commissioning Intention Public Events, December 2012
	Hounslow Carers Joint Strategic Needs Assessment, April 2012
West London CCG	North-West London Commissioning Support Unit, <i>Patient Experience Report, 2013</i>
	<i>Carers Evidence Pack for Kensington and Chelsea. Joint Strategic Needs Assessment Report, 2012</i>
	Feedback from focus group with clients using Migrant Resource Centre, April 2013
	<i>H&F LINK: Dignity Champion Assessment, West London Mental Health NHS Trust, Ravenscourt and Lillie Wards, 2012</i>

Redrafting of patient experience definition and strategy

The themes that emerged from the workshops and events and the review of documents were checked against those already used to inform the development of the definition and strategy, with additions or amendments made where appropriate. The final documents can be seen in Tables 4 and 5.

Table 4: Patient experience: a definition created by people living and working in CWHHE boroughs

Context of the term 'patient experience'

When referring to a 'patient', we are talking about a person or people, recognising that everyone is a unique individual. Experience is subjective, an individual's perception and reflects how the patient feels about their experience of care.

Patient experience will be affected by expectations. These will be individual, may change over time, will be influenced by the diversity of the patient (culture, age, conditions) and may be affected by previous experiences of services and/or care.

Patient experience includes the whole experience of services (healthcare, social care and third sector) from beginning to end, which for some is 'everything that happens from before you were born until you die' and, in the case of some families and carers, continues beyond death. It spans the whole patient journey: knowing what services are available and how to access them; the first contact by telephone call or appointment letter; interactions with clinical and support staff, as well as smooth transfers between services and/or care providers; experiences of care in all settings, for example home, community or hospital; and experiences of all phases of care, such as preparation for care, acute care, continuing care and aftercare.

Patient experience is broader than satisfaction. You could be satisfied with the outcome of your care – for example, your hip was replaced – but you may have had a bad experience in hospital, maybe experiencing a lot of pain. Similarly, you may not be satisfied with the outcome of an episode of care, for example being told at an outpatient appointment with a hospital consultant that your cancer could no longer be treated, but the experience of receiving bad news could be a 'good' one if you were greeted by friendly staff, your appointment was on time, and you felt cared for by the consultant who was empathetic and able to answer all the questions you and your family had.

From a patient's perspective

When I have a 'good experience' of care, I feel:

- Confident of receiving an accurate diagnosis
- Positive about receiving high-quality, evidence-based care
- Respected, safe, comfortable, peaceful and cared for
- Listened to and understood
- Informed and involved in decision making
- Able to take responsibility for and contribute to my own health as a partner in care
- Assured of having full access to all available resources

A 'good experience' of care is enabled when:

- My care is planned with me and centred on my needs, and is inclusive of my family and carers
- My care is co-ordinated across health, social and third-sector services
- I have easy access to comprehensive services that are responsive, offer choice and provide me with timely treatment and care
- Equipment and resources are available to meet my needs and requirements
- I receive consistent and continued care that helps me to build relationships with staff promoting holistic approaches
- Staff have good communication skills and use clear and appropriate language, providing me with time to talk, ask questions, discuss issues and options, and to be given explanations and information
- Staff are effective at communicating and sharing information with me and also with other staff within and across health, social and third-sector services
- I have access to information about services (including what services are available, how services work, what I can expect and how systems are changing), support, care (including knowing what is best practice), illness and health promotion that is relevant, useful, sensitive, up to date and available in different formats
- I, my family and carers have access to volunteers and the opportunity to learn and gain support from other patients
- The environments where I receive care are appropriate, accessible, clean, welcoming and enable my privacy and dignity to be maintained
- The staff/services/organisations are committed to learning and improving – a no-blame culture in which people take complaints seriously, respond quickly and learn from mistakes
- I am provided with opportunities to get involved in shaping and influencing the service and the organisation as a whole
- Staff have a positive experience of work
- Services are valued and used responsibly by both patients and staff
- Staff:
 - Are professional, honest and accountable
 - Are approachable, kind, compassionate and empathetic
 - Maintain my confidentiality, privacy and dignity and treat everyone with respect
 - Are prepared and informed about me, my care needs and other services
 - Have the right knowledge, attitude and skills, and adhere to policies
 - Work in partnership with me, my family and carers and other professionals
 - Are culturally aware and sensitive to my needs and state of mind, and those of my family and carers
 - Are willing to work across services and to connect with communities

Table 5: Patient experience strategy

In the context of the commissioning process, ***the ultimate purpose of capturing the patient experience is to achieve excellence in care*** by using these experiences to create services that put patients at the heart of decision making, and improving quality and outcomes for physical and mental health through improving services so that they are compassionate, safe, effective and responsive to meet the clinical, social and personal needs of patients, carers and the wider public.

This purpose can be achieved by:

- *Patient experience being valued by all* (government, commissioners, providers and the public), which is demonstrated by a commitment at all levels such that the capture and use of patient experience to achieve excellence in care is seen as a priority and resourced appropriately
- *Intelligent and effective commissioning* that is informed by the patient voice to ensure that it:
 - accurately reflects the needs of patients
 - has a clear focus on quality, equality and value for money
 - inspires providers to achieve excellence
- *Commissioners and service providers being absolutely committed to using a wide range of flexible and appropriate approaches to capture patient experiences* that reach each borough's diverse population to ensure that patient (and potential patient) voices in all their variety are heard and acted on
- *Commissioners, service providers, clinicians, service providers and patients* are all fully engaged and involved as equal decision makers in service commissioning, design, training and selecting
- *Service providers enabling the development and nurturing of effective workplace cultures* that are committed to capturing, understanding and improving patient experience

Factors that will enable this are:

- *Effective leadership*, both professional (at all levels of organisations) and lay, which is based on excellent communication, collaboration and mutual support and respect, that:
 - raises the profile of patient experience to ensure it contributes to decision making
 - brings patients, patient representatives and decision makers together
 - is committed to continuous improvement and challenging complacency
- *Good communication and relationships between all stakeholders* built on trust and transparency that enable shared understanding/goals, and that create opportunities for sharing, learning and peer support
- *Empowered patients* who consistently offer a patient's perspective and encourage others to do likewise, and who are involved in decision making and challenging complacency in both commissioning processes and service provision
- *Empowered staff* (working at all levels and in either commissioning or provider organisations) who are supported to understand why patient experience is important and how they can affect it, and who are equipped with the appropriate knowledge, skills, time and resources to enable change to benefit patients
- *The development of and/or wide access to simple systems* that engage with and are open to all groups to capture, share, learn from, act on and evaluate patient experience

During the period October 2013-January 2014, SBO also attended a number of meetings, including those of community and voluntary organisations and GP localities, to demonstrate how the contribution of participants had been used in the development of the strategy. This provided a further opportunity for critique and challenge with regard to ensuring that feedback was genuinely reflected in the final document.

The definition and strategy were also shared by SBO with the five CCG patient and public engagement committees during the period November 2013-January 2014. There was a request from some of these committees to simplify the definition to a few key themes. While this would have been a simple option to help to move the process forward, it would not have been in alignment with the principle of working collaboratively and enabling the inclusion of as many voices as possible. This challenge demonstrated the benefit of using a co-facilitator model, drawing on the skills and expertise of facilitators working both within and outside the organisations involved. SBO and KS were able to have a critical conversation about their values relating to the inclusion of multiple voices and to enable an alternative solution, which stayed true to these values, to be created instead. This involved creating statements from all the elements of the definition (excluding the context) and then theming them under five headings to create a matrix (see Table 6).

Table 6: Patient experience matrix

A GOOD PATIENT EXPERIENCE IS CHARACTERISED BY FEELING:	<ul style="list-style-type: none"> • Confident of receiving an accurate diagnosis • Positive about receiving high-quality, evidence-based care • Respected, safe, comfortable, peaceful and cared for • Listened to and understood • Informed and involved in decision making • Able to take responsibility for and contribute to his/her own health as a partner in care • Assured of having full access to all available equipment and resources
THEME	DESCRIPTOR
Information and interpersonal communication	Staff have good communication skills and using clear and appropriate language and providing patients with time to talk, ask questions, discuss issues and options, and to be given explanations and information
	Patients have access to information about services (what services are available, how services work and what they can expect), support, care, illness and health promotion that is relevant, useful, sensitive, up to date and available in different formats
	Services are valued and used responsibly by both patients and staff
	Staff work in partnership with patients, carers, families and other professionals
Dignity and respect	Appropriate environments that are accessible, clean, welcoming and enable privacy and dignity to be maintained
	Staff work in partnership with patients, carers, families and other professionals
Care and treatment	Care is planned with and centred on the patient and is inclusive of families and carers
	Comprehensive services that are easily accessible, responsive, offer choice and that provide timely treatment and care
	Equipment and resources are available to meet the needs and demands of patients
	Patients, families and carers have access to volunteers and the opportunity to learn and gain support from other patients
	Staff are prepared and informed about patients, their care needs and other services
Continuity of care	Care is co-ordinated (from the perspective of patients and staff) across health, social and third-sector services
	Consistent and continued care that helps patients and staff to build relationships that promote holistic approaches
	Staff are effective at communicating and sharing information with patients and also with other staff within and across health, social and third-sector services
	Staff work across services and connect with communities
Organisational culture/staff (clinical and non-clinical) development and support	Staff/services/organisations are committed to learning and improving – a no-blame culture exists in which people take complaints seriously, respond quickly and learn from mistakes
	Staff have a positive experience of work
	Senior managers as well as frontline staff are professional, honest and accountable
	Staff are approachable, kind, compassionate and empathetic
	Staff have the right knowledge, attitude and skills, and adhere to policies
	Staff are culturally aware and sensitive to the needs of and state of mind of patients, families and carers

Working collaboratively

Our first principle outlines our intention to work collaboratively with stakeholders. Participation is seen as essential by NHS England (2013), which states that every level of commissioning systems should: 'be informed by insightful methods of listening to those who use and care about our services' (p 3). Using the voice of the public was a strong message to emerge from the Francis report (2010). Similarly, collaboration, inclusion and participation of stakeholders is identified as a key principle of practice development as a means of facilitating transformation through communicative action (McCormack et al., 2007; 2013). Participation should reach across all community groups, taking into account the protected characteristics of the Equality Act (UK Government, 2010), and those people who may have difficulty accessing services or who lack capacity (NHS England, 2013).

There are many models of community engagement or public participation that can be used to inform this process (for example, Arnstein's Ladder of Citizen Participation, 1969; see also the Engagement Cycle developed by InHealth Associates on behalf of the NHS, 2009). Our intention was to engage in ways that would enable us to move beyond traditional informing and consulting approaches towards stakeholders influencing and shaping the strategic directions of commissioning to enhance the patient experience.

Despite the increasing commitment to enabling collaboration and participation in the shaping of healthcare (and social care) services, there is as yet limited evidence on the impact of service user involvement (Mockford et al., 2012). It seems that defining impact is complex as it depends on a number of factors, such as context, people and resources, and it is recognised that some forms of impact, such as that on strategic decision making, can be difficult to demonstrate (Crawford et al., 2003, cited in Mockford et al., 2012).

A limitation of this work could be that no formal evaluation of the engagement process was undertaken. Evaluation of effectiveness and impact is therefore based on the extent to which others within the CCGs use the definition as a basis for assessing the type of data that are captured and how those data are used to shape and influence commissioning decisions and priorities. Further, the engagement and recommendations that resulted in the development of the strategy put equal emphasis on qualitative and quantitative data and this is reflected in the quality schedule for providers – in the way CCGs use qualitative and quantitative feedback on experience and access to inform the development of plans and proposals.

In terms of reach, the engagement process built on patient and public involvement activity in the boroughs served by the CCGs over a number of years. It also embraced the role of voluntary organisations, recognising the valuable role they play in facilitating engagement with the wider communities (NHS England, 2013). This was reflected in the diversity of the groups involved, which included HealthWatch, migrant centres, patient groups and grassroots organisations such as Community Champions. Engagement was also facilitated by going out into the community, meeting with people at local events and in local venues. It is inevitable that some voices were not heard, but we had to be pragmatic when working within certain timescales. Perhaps this raises a question about when is engagement 'good enough'.

With regard to the engagement of staff and service providers, it is fair to say that there was some evidence that the engagement process had an impact in terms of influencing the decision-making process at the strategy and definition sign-off stage within the CCGs. Patient and public engagement leads were actively involved in the work from the outset, contributing as participants but also as facilitators of the engagement process with patients, service users, patient groups and voluntary organisations. All the PPE leads represented the patient definition and strategy favourably to their CCG boards, and sign-off was relatively straightforward and achieved with each board.

The authors acknowledge that with the benefit of hindsight, there should have been much greater engagement with providers from an early stage. The primary reason this was not achieved was the difficulty of getting representatives of provider organisations together, particularly with the time restraints involved. While staff from some organisations were represented, there was limited involvement of organisations at strategic level. It would have been beneficial to have their involvement, particularly in relation to reporting issues, for example, so that there could have been more transparent discussions about the purpose of the quarterly integrated patient experience reports and an exchange of ideas about the ways in which information could be acted on and presented.

In summary, we believe we successfully engaged patients, service users, carers, health and social care workers and representatives from the voluntary sector from across north-west London, and that these collaborations have enabled the voices of individuals and communities to influence and shape the commissioning process. We acknowledge that collaboration with providers could and should have been wider.

Being evidence based

A broad definition of evidence was used in this work, meaning that the experience of patients, service users and carers, clinical experience and information about the local context (Rycroft-Malone et al., 2004) were all valued. The evidence generated from the engagement process was complemented by existing intelligence, through ongoing engagement work across the boroughs covered by the five CCGs, supported by the available and relevant documents and reports identified in Table 2, alongside national guidance. Priority was given to local evidence over national guidance, while ensuring that we had been inclusive of the equality strands – challenging our perceptions of the evidence base.

If we had had more time, we would have undertaken a wider search for evidence, as this may have provided greater depth of evidence across the equalities. However, when we review the outputs from this work – in particular the patient experience definition – in the light of other literature that inquires into person-centred systems of care to identify what matters to patients/people, there is considerable similarity. For example, the Health Foundation (2014) identifies four principles for person-centred care; affording people dignity, respect and compassion; offering co-ordinated care, treatment or support; offering personalised care, treatment or support; and being enabling. It can be argued that these principles underpin many of the descriptors identified in Table 6.

Similarly, there is resonance between the descriptors arising from the patient experience definition and the four constructs of the Person-centred Nursing Framework (McCormack and McCance, 2010). While this framework focuses on nursing, it could be argued that there is some transferability across the caring professions. These constructs comprise prerequisites (the attributes of the nurse); the care environment; person-centred processes; and expected outcomes. What is interesting is that, although we undertook a values-driven process and the descriptors are underpinned by the values and beliefs of patients and communities, unlike the framework, the acknowledgement of the need to work with the values and beliefs of individuals (service users and staff), teams and organisations is not explicit in the definition or strategy. This might be explained by the fact that the framework is theoretical and therefore its use of language may be different to that of a definition (and strategy) created by and for communities. Through the quarterly patient experience reporting, providers are being asked to demonstrate if these values are being realised in practice and they are also being used in the development and commissioning of new models of care, as in the case of the Community Independence Service described above. However, it could be argued that by working much more inclusively with providers from the outset, service providers may have seen the relevance of using these values to inform service improvement work.

We believe that reflecting on these wider principles and frameworks provides some validation for the evidence base that was used in this process, and some corroboration for the local data and the depth of the conversations.

Being asset based

'Asset based' is a term that is associated with community development (see Kretzmann and McKnight, 1993 for a detailed definition of asset-based community development), which is about driving developments by building on and mobilising the assets that are already found in the community. Similarly, [Nesta](#) (an innovation charity with a mission to help people and organisations bring great ideas to life), identifies 'assets' as one of the key principles of co-production of public services – in this context, it is about 'transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services' (Nesta, 2012, p 5). Being asset based in this work was about recognising the skills and expertise that staff, patients, users and carers bring, not only in terms of their experience of using services but in facilitating conversations with their peers. It is acknowledged that this approach is internally focused and relationship driven (Kretzmann and McKnight, 1993) and therefore relied on effective local knowledge and communication to ensure the widest access to communities' assets was achieved.

It could be argued that the development of the definition and strategy was a 'voice-based' initiative (Nesta, 2012), where the focus was on engaging with people to capture their opinions and ideas to facilitate the commissioning of better services rather than 'unlocking the practical skills and capacities of people who receive services' (Nesta, 2012, p 5). However, it is important to note that engagement is not a single, one-off approach; instead it has multiple components, is ongoing and multifaceted, which is reflective of both individuals and communities.

By tapping into the voice-based assets of the community, we had to ensure that we kept true to the voices of the local people and staff. This involved challenging ourselves to use their words and not to translate them into corporate language, acknowledging the knowledge and skills that they contribute. This commitment is reflected in the use of first-person statements in the matrix; an approach that arose from one of the patient and public engagement committees, as although we could hear the voice of individuals in the description, they felt that the 'collective' description sounded passive. By creating first-person statements, the sense is that the voice of the person/people is enhanced, an approach that has interestingly been used by National Voices (2013) in [A Narrative for Person-Centred Coordinated Care](#).

Being continuous and iterative

While the work to develop the patient experience definition and strategy is complete, activity is ongoing to develop this work, reflecting its continuous and iterative nature. On a local level, this is demonstrated in the development of the Community Independence Service. Patients and service users have been involved in developing an 'insight survey'; starting with the patient experience matrix (see Table 6), they reviewed and refined the descriptors to create 10 questions, the responses to which will be used to inform the development of the service. It is also continuing to have an influence at a strategic level, as a similar process has been used to develop the wider quality strategy for the CWHHE CCGs.

Ethical considerations

Although formal ethical review was not required to undertake this work, ethical considerations formed part of all discussions about what we were doing and how we were going to do it. Some of these considerations are reflected in the key principles underpinning our approach, outlined earlier, and the associated discussions above; they are also summarised in the following general principles for ethical practice developed by the Centre for Social Justice and Community Action and the National Coordinating Centre for Public Engagement (2012): mutual respect; equality and inclusion; democratic participation; active learning; making a difference; collective action; and personal integrity. Key ethical topics that have not yet been discussed relate to consent, confidentiality and anonymity, and issues of power.

Consent

To ensure that participants were able to give informed consent regarding participation, prior to most workshops, potential participants were contacted in a variety of ways, including by email or flyers, or by community leaders. At this stage brief information about the purpose of the workshops was provided along with contact details for further information. Participation therefore required someone to attend an event and so their participation was voluntary. In the case of the Chelsea and Westminster Hospital Patient Experience Summit and the Health and Wellbeing Voluntary Organisations Forum, the workshop was built into meeting agendas. People who did not wish to participate were free to leave the meeting during this session.

At the start of all workshops, participants were informed about the purpose of the work, the ways in which we would be working with them to develop the definition and strategy, and how this information would be used. They were invited to ask questions at any time. Where appropriate, participants were given an opportunity to introduce themselves to each other so everyone was aware of who was participating and in what context.

Confidentiality and anonymity

To ensure confidentiality and anonymity in the data collection process, no information was collected that would enable individual people to be identified. Instead the focus was on what was specifically important to them in terms of patient experience – its characteristics or attributes. In most cases, notes were written by participants themselves or by the facilitators in the view of participants, for example by using flip charts. If this was not possible, notes written by the facilitators during the discussions were shared with the groups to allow them to comment on the content.

Democratic participation

It is acknowledged that this work was driven by the CCGs and that KS and SBO were facilitating it on their behalf. There were expected outcomes, primarily the development of a patient experience strategy, and the timescale to achieve this was relatively short. It is therefore possible that these factors could have impacted on the way the work was planned and how it progressed, potentially excluding some patient and community groups that were harder to reach. It has also been previously acknowledged that service providers were not engaged as early as would have been desirable. Ideally, a thorough stakeholder analysis should have been undertaken to explore issues such as stakeholders' levels of power and interest, and the ways in which their participation could have been facilitated.

Within the workshops, attention was paid to facilitating in ways that enabled the involvement of all participants. This included ensuring they were all able to contribute in a meaningful way and given equality of voice, communicating clearly using language everyone could understand and, where required, ensuring additional support was available – for example, a transcriber to create a script for someone with limited hearing.

Conclusion

This work was stimulated by the recognition that practice development approaches could be applied to different contexts and settings. All the practice development literature currently focuses on the 'provision' and not the 'commissioning' of services and yet commissioning (which can be invisible to the patient) underpins provision. Clinical commissioning enables commissioners to work and think in new collaborative ways, in which patients and communities are explicitly central to the commissioning process. Practice development also has the potential to draw clinical commissioning and clinical provision far closer together, with engagement, collaboration and decision making focused upon improving the quality (experience, safety and outcomes) for patients and their supporters.

It would have been possible to have accessed a patient experience definition and strategy written by someone else and adapted the content to reflect what we believed was important for our local

populations. However, the greatest outcome is not what is in the definition or strategy that have been created, but the extent to which people engaged with the process and therefore feel ownership of and champion the definition and strategy, and are committed to using it to influence and shape services.

Using this approach meant that the facilitators, providers and commissioners didn't have control of what emerged and how it would be used moving forward. Providers and commissioners are equal participants along with patients and service users, but they have the opportunity to embed the priorities and the approach used within their organisations, as in the case of the CCGs' wider quality strategy. This can create tension or questions about quality assurance in relation to the impact of the strategy because there is no linear implementation process, but it can also provide the opportunity or stimulus to challenge ways of working, traditional approaches to collecting and using evidence and methods of engaging with service users and other stakeholders.

Patients, users and carers participating as equal partners in all aspects of health and care commissioning is fast becoming the norm rather than the exception, so it has become even more crucial to understand and appreciate what good engagement looks like. A number of key implications from developing the patient experience definition and strategy include:

- Engage from the start and bring everyone together
- Engagement must be genuine – bad engagement is more damaging than no engagement
- Engagement is often resource intensive, therefore budgets must reflect the engagement ambition
- Patient, users, carers and the wider community are not the problem but hold the solution

While the authors recognise that this paper concentrates on England in terms of its focus on the commissioning of healthcare services, they believe that if it is used as a case study for enabling community engagement and participation, it has wider UK and international value and relevance.

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Kate Sanders (MSc, BSc Hons, HV Cert, RHV, RN), Practice Development Facilitator, Foundation of Nursing Studies, London; Honorary Senior Lecturer, Canterbury Christ Church University, England.

Samira Ben Omar (BA Hons), Assistant Director of Patient Experience and Equalities, CWHHE CCGs; Self Care Programme Lead, London Clinical Senate.

Jonathan Webster (PhD, MSc, BA Hons, DPSN, RGN), Director of Quality, Nursing and Patient Safety, CWHHE CCGs, London; Visiting Professor, Bucks New University, England; Honorary Senior Research Fellow, Christ Church Canterbury University, England; Honorary Associate, Foundation of Nursing Studies, UK.

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A commentary by Jo Harding follows on the next page.



COMMENTARY

Working collaboratively to develop a patient experience definition and strategy to inform clinical commissioning

Jo Harding

The paper describes a process and methodology used to design a patient experience strategy supported by relevant academic reference material. This is based on a set of collaborative values agreed across five clinical commissioning groups (CCGs) in London. The patient experience focus in the NHS is clearly recognised and referenced. While the article offers limited new or especially innovative opportunities for this area of work, it provides a helpful description to others embarking on a similar approach.

Defining patient experience should not be complex, but it can prove to be. The language can be used interchangeably ranging from experience, engagement, patient-centered care and other descriptions. Wolf (2014) recognises this when stating that there is a need to determine the extent to which clear and formal definitions exist. He provides a 14-year synthesis of existing literature and other sources that have been used to define patient experience.

The executive nurse role in a CCG may differ across organisations but, informed by my expertise and experience, I bring a unique perspective to the role in Leeds West CCG, ensuring that the interests of patients and the community remain at the heart of the CCG's discussion and decisions. As a member of the executive management team I have specific management responsibility as strategic lead for communications and engagement across the organisation, supporting a city-wide approach as appropriate. Patient experience is such a fundamental part of our business that we have a dedicated role for this work in our communications and engagement team at the CCG.

My efforts to elicit patient experiences in my current and previous roles in CCGs have met with mixed success. Even the best planned, most carefully orchestrated events and communications have sometimes been woefully inadequate although we have also had great success. I have vivid memories of travelling miles into the Yorkshire Dales one cold, dark evening in thick snow to facilitate an engagement event to discuss older persons' health – no one attended! I wondered that night where we had gone wrong. It may be useful for the authors to explore the success criteria for capturing patient experiences positively to help readers understand how to avoid pitfalls. The use of experts if you aren't one is a tactic that springs to mind for me.

Domain 4 of the NHS Outcomes Framework (Department of Health, 2012) tasks providers and commissioners with ensuring people have a positive experience of care. Most NHS organisations, as described by the authors, devise some sort of strategy for this. My experience of strategy development and execution is quite extensive but in practice, the resulting product may differ in content and quality from what was hoped for. I wonder sometimes how such strategies are understood by patients and I am interested in the authors' view of patients' understanding and experience of their role and purpose.

The authors state their belief that of the three elements of the quality triangle, 'patient experience' has received less attention than patient safety or clinical effectiveness. What is their evidence for this, other than one cited article? My impression is that clinical effectiveness may get less prominence.

Many working with collaborative arrangements find this difficult to differing degrees at different times. The authors define shared values early on in the process but it would have been interesting to hear the reality of working towards one strategy across five CCGs.

If we want experience to be integral we need to involve providers at an early stage. The authors accept this could have been done earlier. Some providers don't see capturing patient experience (qualitative data) as their role. Engagement with providers appears weak in the study, although the challenges of getting staff involved in this kind of work are recognised. Frontline staff are key in capturing patient experience; we need them to understand the value of experience and empower them to capture it. What are the authors' views on this?

The existing definition of experience in the Dr Foster Intelligent Board Report (Dr Foster, 2010) had resonance for me: 'Feedback from patients on what actually happened in the course of receiving care or treatment, both the objective facts and their subjective view of it'. This links well with our patient leader programme in Leeds, which assumes that people get involved in two different ways: by sharing their own experience or that of their family (patient experience), and by being an objective patient leader and championing the voice of the wider community (their experiences).

Recognising this is really important – it gives clarity for patients and for commissioners.

NHS England, in collaboration with Macmillan Cancer Support, has announced 10 pilot sites offering a programme of developmental work around commissioning tools and processes that support positive patient experiences. Leeds West CCG will be one of the pilot sites. The authors may want to reference this work as future potential learning and support in delivering their strategy. The pilots will consider:

- What does commissioning for good patient experience look like?
- What support would help commissioners to embed these processes actively?
- What difference does commissioning for good patient experience make?

It was quite difficult to evaluate the quality of the engagement process as there was no information about the people involved or their evaluation of the process and outcome. The authors appear to have relied on established links but it is encouraging to see that they have also reached into the community to seek new links with new people. Equally, the lack of inserted tables at this stage meant I could not see the resultant patient experience definition or draft strategy. Also, the actions for CCGs were not included so I was unable to comment on how valid or realistic these would be from a CCG perspective.

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Jo Harding (MA, HV Dip, RGN), Director of Nursing and Quality, Leeds West CCG, UK.

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A response by the authors follows on the next page.



RESPONSE TO COMMENTARY

Working collaboratively to develop a patient experience definition and strategy to inform clinical commissioning

Samira Ben Omar, Jonathan Webster and Kate Sanders

We would like to thank Jo for her commentary and the questions that she raises, as we welcome the opportunity to say a bit more about the intentions behind this work.

We understand and acknowledge that the development of the patient experience strategy may be neither new nor innovative. However, our focus was not on developing the strategy alone but also promoting an approach that is evidence based, asset based, collaborative and, importantly, continuous and iterative. Our intention in developing the strategy, using practice development approaches, was to ensure that we created a strategic document that was 'living, alive' and locally owned, which underpinned our approach to embedding patient experience in all clinical commissioning activity. It is also important to emphasise that the strategy was the start of the journey, not the end. The approach promoted in developing the strategy has also been shared by the patient experience lead, in her work with the London Clinical Senate to develop a Self-Care Commissioning Framework - the [Made in London](#) project. The report and recommendations of the project clearly highlight the approach as a good practice model for commissioners.

We agree that there is a wealth of evidence and research that captures the definition of patient experience and the suggested paper (Wolfe et al., 2014) will be a useful addition. However, it was important to us to develop a strategy that was locally determined and owned, shaped by feedback from the diverse profile of patients, carers and communities in the CCG areas. When seeking to engage, perhaps it is important to acknowledge that this will involve some 're-invention' as people are given the opportunity to tell their stories and to say what matters to them.

Similarly to Leeds West CCG, the CWHHE CCGs all have a dedicated patient experience role and executive governing body leadership supported by a coordinator. The CCG patient experience team works closely with the embedded CCG engagement leads and this we feel enables us to work with providers proactively and capture data (qualitative and quantitative) as well as personal and community experience through the grassroots engagement with Healthwatch, third sector organisations and at a practice level through our practice and service alerts. The role sits within the CCG's quality directorate, which is embedded in each CCG in recognition that patient experience is fundamental to improving the quality of services commissioned by the CCGs, clinical pathway/service redesign, service transformation and the procurement/re procurement of services and pathways of care .

We understand that Jo did not see the tables in the paper and therefore did not have access to the range of organisations that we worked with to deliver the engagement events. We do not see ourselves as being the 'experts'. The patient experience lead has developed a strong working relationship with local groups and organisations on the ground to enable us to collaborate successfully with them for a wide range of purposes, including the delivery of engagement events. In terms of lessons on engagement, the final paragraph in the paper highlights four key points to bear in mind when considering how

to facilitate 'good' engagement, drawn from our experiences of this work. We recognise that these points are brief and could be further developed through the wealth of published evidence relating to engagement.

Jo raises a challenge to our belief that patient experience receives less attention than patient safety or clinical effectiveness. This is a valid challenge and we acknowledge that patient experience is gaining ground. However, Doyle et al. (2013), in their systematic review of evidence on the links between patient experience and clinical safety and effectiveness, highlight the need for clinicians to 'resist sidelining patient experience as too subjective or mood-oriented, divorced from the 'real' clinical work of measuring safety and effectiveness' (Doyle et al. 2013, p1). Our work reflects the commitment of the CCGs to acknowledge patient experience as one of the 'three central pillars' of quality.

An interesting point relating to the role of staff in capturing patient experience is raised. This is an area where practice development as a methodology has much to offer. The ultimate purpose of practice development is to develop person-centred cultures of care (Manley et al., 2008) and engaging individuals and teams in ways that enable them to learn in and from practice is a key element in the transformation process. It acknowledges the value of helping staff to develop the skills and confidence to use the workplace as a classroom, where patient experience is seen as an important form of evidence that staff can reflect on, learn from and use to plan actions (Dewing, 2010). It is not necessarily about doing more, but perhaps about doing differently. The value of involving staff in these kinds of activities is further supported by the evidence on staff health and wellbeing. This can be enhanced when teams have clear goals and are given time to reflect on these goals and their effectiveness (West and Dawson, 2012; Maben et al., 2012). Having the opportunity to listen to the voice of patients is an important element within this.

In conclusion, the aim of the paper was not to present a 'study' but to share the process, informed by the principles of practice development (Manley, McCormack and Wilson, 2008), of developing a Patient Experience Strategy. We also share our learning from this process, showing the ways in which this has subsequently informed further work. Our view is that the opportunity to share and learn from each other is a multidimensional process that should be welcomed and encouraged. From this, understanding, learning and improvement can grow and flourish.

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Samira Ben Omar (BA Hons), Assistant Director of Patient Experience and Equalities, CWHHE CCGs; Self Care Programme Lead, London Clinical Senate.

Jonathan Webster (PhD, MSc, BA Hons, DPSN, RGN), Director of Quality, Nursing and Patient Safety, CWHHE CCGs, London; Visiting Professor, Bucks New University, England; Honorary Senior Research Fellow, Christ Church Canterbury University, England; Honorary Associate, Foundation of Nursing Studies, UK.

Kate Sanders (MSc, BSc Hons, HV Cert, RHV, RN), Practice Development Facilitator, Foundation of Nursing Studies, London; Honorary Senior Lecturer, Canterbury Christ Church University, England.

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