

Developing pathways: using patient and carer experiences

{Smart Guides}
to ENGAGEMENT

For better commissioning

Developing pathways

This guide is part of the **Smart Guides to Engagement** series. It helps clinical commissioning groups (CCGs) adopt an approach to developing pathways reflecting what matters to patients, carers and family members. It offers examples that work and points to sources of help to achieve success. Other Smart Guides can be accessed at www.networks.nhs.uk/nhs-networks/smart-guides

What really matters to the patient really matters for the pathway

As new commissioning arrangements take hold there is an excellent opportunity for commissioners to make sure that positive patient experience is the main component of their vision, strategy, systems and structures for commissioning. Starting with what really matters to the patient and their family is a sound foundation for everything to do with creating effective care pathways that deliver safe, effective outcomes and high levels of user satisfaction.

“Each patient’s experience is the final arbiter in everything the NHS does.” Operating Framework for the NHS in England 2012/2013: <http://bit.ly/13gWk1N>

In recent years NHS staff have spent a lot of well-intentioned time and effort redesigning pathways of care. Much of that effort was ineffective because it did not emphasise the patient experience sufficiently. Users now have increasing power to influence both choice and reputation of healthcare providers and commissioners.

Commissioners working collaboratively with patients, carers and family members can produce gains in pathway design and outcomes. Good engagement is key to this and using the engagement cycle (<http://engagementcycle.org/>) will aid commissioners to undertake this systematically by co-ordinating their engagement activity with the stages of the commissioning cycle itself.

Experience-based design

One tried and tested approach to pathway development is discussed in this guide – the experience-based design approach (EBD). It supports staff to work closely with patients and their families to:

Capture the actual experience they have as they travel through their care pathway

Understand the data so they can really comprehend that experience

Improve the pathway through staff, patients and family members working together to co-design it so it better meets their needs

Measure the impact of any changes not just at the end but also throughout the methodology.

Capture the experience

Tools to help people tell their stories

Understand the experience

Tools for understanding patient and staff experiences

Improve the experience

Tools to turn experience into action

Measure the improvement

Tools for evaluating and measuring the improvement

The EBD process places a strong emphasis on the aesthetics of care, which means how it feels when experiencing the care pathway, what emotions are present for patients and family members during the journey. Research illustrates that patients identify emotional elements of care as more important than those that are more functional or technical.

What this means is:

- Feeling informed and being given options
- Staff who listen and spend time with me or patients
- Being treated as a person, not a number
- Being involved in care and being able to ask questions.

Patients identified these as more important than factors such as efficient processes. That is an essential lesson for everyone involved in pathway development.

What Matters to Patients? Developing the Evidence Base for Measuring and Improving Patient Experience, King's Fund, 2011) <http://bit.ly/NKNVJj>

What's in it for commissioners

Commissioners need to ensure that the care pathways they develop or commission from providers have a sound evidence base and are engineered to deliver safety and efficiency and also take account of the emotional experience of delivering and receiving care. The pathway development approach in this guide will help them understand the emotions felt by patients and this often points to improvements that need to be made within the other aspects of the care pathway.

Emotions matter for patient experience

“Compassion is the humane quality of understanding suffering in others and wanting to do something about it... few hospital patients ever remember what was said to them, or what was done, but the emotional experience is lived a lifetime.”

**Improving the Client and Patient Experience, 2008:
<http://bit.ly/45nxiE>**

Understanding and working with patients on their experience of care is not only the right thing to do, there is also a growing body of evidence showing the positive relationship between aspects of patient experience and clinical quality. Simply put, anxiety and unease impede communications and delay healing.

Will co-producing pathways cost more?

The notion of asking patients what they need as they travel along a pathway of care may provoke anxiety from commissioners and providers in case patients respond by suggesting something that is just not affordable or not clinically appropriate.

The good news is that experience of using the EBD approach could not be more different. Here are some examples of positive things that patients, carers and family members might suggest:

- Identifying steps in the existing process that add no value to them and can be removed (**gain** = cost saving)
- Providing good ideas about how to improve information and communication so they are able to correctly follow courses of treatment (**gain** = better concordance)
- Describing problems relating to safety that can be easily rectified (**gains** = safer care and reduced emotional and financial cost of any incident)
- Providing examples where care impacts on their dignity and causes distress (**gain** = opportunities for improving patient experience)
- Highlighting examples of wonderful care that we can learn from and replicate (**gain** = improving reputation of a service with commissioners and users).

Patient preferences matter

“Well-informed patients consume less medicine – and not just a little bit less, but much less. When doctors accurately diagnose patient preferences, an enormous source of waste – the delivery of unwanted services – is eliminated. It is particularly notable that when doctors accurately diagnose the preferences of patients struggling with long-term conditions, those patients are far more likely to keep their conditions under control, leading to fewer hospitalisations and emergency department visits.”

Mulley, Trimble, Elwyn. Patients’ Preferences Matter: Stop the Silent Misdiagnosis.

King’s Fund, 2012 <http://bit.ly/XypzDz>

Stop doing things to and for patients: start doing things with them

Everyone working in healthcare needs to ensure their mindset is not one of spending time, effort and resources on dealing with problems and complaints, but is more one of creating a good service that really meets the needs of patients and families. Time is a finite commodity. Care pathways that do not meet the needs of the people they are designed for result in a poorer service, which wastes time and resources in managing dissatisfaction and often creates additional clinical work.

Experience-based approaches to change aim to move the NHS from a service that does things to and for its patients to one where the service works with patients and supports them with their health needs. Working in this way changes the traditional view of the user as a passive recipient of a product or service. It sees users, carers and family members in a new light: as the co-designers of healthcare products and services.

Find out more about how patients can become leaders in the change process from the Centre for Patient Leadership. <http://centreforpatientleadership.com/>

Importance of good storytelling and listening

This approach to pathway development focuses on supporting patients, carers and staff to tell their stories. These provide a unique view of actual experiences of the whole service rather than only a view of the technical or business process, which lacks the human dimension. Storytelling is at the heart of the EBD approach and centres around encouraging patients and staff to share the story of their journey on the pathway. This can be through conversations, storyboards, diaries, blogs, shadowing or film. Throughout this stage, identifying emotion words that are used to describe the impact of a care experience is important.

What a foundation trust CEO thinks of storytelling

“Working with patient feedback and patient stories on the development of care pathways has radically transformed our approach. I use individual stories that have emerged from this work regularly to talk to all staff about how we can truly focus on the real patient experience of the services we provide.”

CEO, South Tees NHS Foundation Trust

Here's what is involved in an experience-based approach to storytelling, listening and learning from the experience:

Capturing

Getting patients and staff involved sharing their stories in a non-judgmental way.

Observing an environment

Watching what happens carefully is a good place to start. The aim is not to look for a certain symptom that can be matched to a diagnosis, as happens with clinical observation, but rather what happens to and around the patient. This process can also be used with process mapping to reveal the totality of the patient journey, not just what people think happens.

You may be surprised at the sort of insights that emerge from this, for example:

- How long a patient might wait at different steps in the process
- How many times they are approached by staff and asked for information about themselves
- How easy it is to become confused by signs when navigating around a site or building
- The lack of clarity in what staff might consider to be simple instruction.

Understanding

Grasping the feelings that people experience, and when they do, while using a service.

The data includes clusters of negative or positive feelings, as indicated by the patient's use of emotion words as they talk about their experience. These clusters of emotions when mapped along a care pathway depict a touch point, which is an important point in the patient or family member's journey that evokes an emotion, either positive or negative. Touch points are moments when a user interacts with a service, for example phoning a GP surgery for results, seeing the consultant, undergoing a procedure by a nurse, waiting for something to be arranged.

These touch-points help to prioritise improvement actions. Patients and staff can vote on which touch points they think are most important to address. It becomes clear within the map that where there is a point of many strong negative emotions, improvement actions need to be taken. Equally, learning can be taken from points where strong positive emotions feature in the pathway.

Improving

This involves patients, carers, family and staff in developing ideas and potential solutions for improvement.

Working in a collaborative way with users of a service is called co-design. The essence of co-design is to continue to build the relationships between staff and patients and to use their combined knowledge and expertise to design services to really meet the needs of both. Patients and staff become partners in the quality improvement process – the experience experts and the service experts work together to make the changes.

Co-designing in action

‘Whole pathway in a room’ workshops are ways to encompass experiences and views from patients and staff from different stages of the pathway as well as commissioners. Getting them all together with patient organisations who support people through the whole pathway, and also social services, can provide rich insights to feed into the co-design process as well as building valuable relationships.

Measuring

To evaluate the impact of the interventions using both qualitative and quantitative data. Teams are able to determine the desired experience for both staff and patients and then measure against this promise. They may want to take this further by developing local metrics for patient and staff experiences.

Experience led re-design can be applied to all conditions. This case study shows it being used to identify improvements in an end-of-life care programme: <http://bit.ly/1aungwW>. It explains the challenges working in this collaborative way presented for commissioners and how they overcame them to create a new pathway that was more acceptable to those receiving care and those delivering the care.

Putting the data to use in pathway design and monitoring

Storytelling is just the beginning. Putting the data to use and how patients, carers and family members are involved in pathway redesign and monitoring its impact are crucial. Here are some things to help ensure that happens:

- Every redesign group should identify how service user and carers or family members can contribute to the work and then ensure they are part of the group from the outset
- All business cases should have clearly involved pathway users and make it obvious what their contribution to redesign was
- Users can help troubleshoot the proposed redesign before it goes live to identify blockages and problems
- Users should contribute to identifying standards built into the pathway, which matter to them
- Users should contribute to the contract specification process so providers know what's important to the patient experience in the new pathway and how it will be monitored from the user perspective. Patient-focused outcome measures can be devised jointly
- The intelligence that flows back into the commissioning system from people using the pathway must become part of the evaluation and improvement process so providers understand what they can do to increase their quality outcomes.

“What matters more than raw data is our ability to place these facts in context and deliver them with emotional impact.”

Daniel Pink – A Whole New Mind, 2008

Additional pathway perspectives reflecting patient, carer and wider experiences

This guide has highlighted the experience-based design (EBD) approach devised by the NHS Institute. But this should not detract from additional processes and perspectives drawing on patient, carer and staff experiences, which can also inform pathway engagement, design and monitoring. These could include using facilitated focus groups and walking the pathway – where commissioners, staff and patients together walk through the different services that patients use to better understand together how the services work.

Self-management on the long-term conditions pathway

A major part of the pathway for someone living with a long term condition will be self-management. The commissioning guide, Self Management Support and Shared Decision Making for Long Term Conditions (NHS Advancing Quality Alliance, June 2013: <http://bit.ly/185S7L4>). It provides guidance and examples to encourage a shift in relationships to where patients with long-term conditions expect and are able to be routinely involved in decisions affecting every aspect of their lives.

Things CCGs can do now to start co-producing pathways with patients

- Be role models for involving patients by actively working in partnership with patients and family members
- Start with the patient, listen to their needs, and design the experience to meet those needs
- Help patients, carers and families to understand local healthcare provision
- Embed patient experience as a key dimension of quality
- Ensure patients have access to personalised care
- Ensure continuity of care and track experience along patient pathways as well as by individual service
- Understand the challenge and scope for improving patient experience in individual organisations
- Create capability in tools and methods of patient experience
- Evaluate and support provider organisations to deliver a positive patient experience by developing shared patient experience goals as part of developing good working relationships
- Align incentive systems so they recognise and reward innovative patient experience measurement and improvement in local organisations.

Get Smarter – find out more

Patient Voices: www.patientvoices.org.uk explains the rationale and process for gathering and learning from patient stories.

Various resources including those developed by the former NHS Institute are now hosted by NHS Improving Quality: www.nhsiq.nhs.uk

Experience-based design resources: <http://bit.ly/10udftQ>

Maher, L. Partners in Care (2012): <http://bit.ly/13kTozW>

De Vine, Lai, Zea. (2012) The Human Factor in Service Design. (McKinsey Quarterly) <http://bit.ly/wEs6OI>

Experience-led care www.experienceledcare.co.uk and examples using this approach in service redesign <http://bit.ly/196Vghf>

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