Using patient experiences to develop services for chronic pain

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Abstract

Purpose: The aim of this study was to improve the overall experience for patients using chronic pain services at a large teaching hospital in England. Experience-based co-design methodology was used to gain a greater understanding of patients' experiences and to produce a list of priorities for change when improving the patient experience.

Method: A total of seven video-recorded patient interviews were conducted to capture a range of patient experiences of using the chronic pain service. The interviews were analysed to identify 'touchpoints' which are areas in which patients experienced a heightened emotional response to their interaction with the service or staff. A short trigger film was compiled to illustrate these touchpoints to staff and gain their commitment to improve patients' experiences when using the service. A patient experience event was held at which patients discussed the touchpoints and identified the most significant areas for change that would improve their experiences of using the chronic pain service.

Results: A wide range of touchpoints were identified. The lack of information provided before arriving for a procedure and the need for a short debrief after clinic were prioritised for improvement. Patients valued the development of good relationships with clinic staff and feeling properly listened to for the first time. The patient experience event allowed the key points patients would like to know before a procedure, to be drawn up in a list, which could be passed onto staff.

Conclusion: This study featured collaboration between patients and staff to improve patients' experiences of using chronic pain services. Through patient participation, a comprehensive list of recommendations for service improvement was produced, and possible solutions were identified. The involvement of patients in driving change and re-designing services is shaping a more patient-centred chronic pain clinic and improving the experience for all the patients who use the service.

Keywords

Pain, pain clinics, pain management, experience-based co-design, patient experience, patient-centred care, chronic pain

Introduction

Chronic pain places a high burden on the National Health Service (NHS); in the 2012 national pain audit, 20% of respondents stated that they had attended an Accident and Emergency Department for pain management in the last 6 months.¹ In 2004, an estimated 4.6 million appointments a year in primary care involved the management of patients with chronic pain.² Providing high-quality chronic pain services that

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deliver a positive experience for patients can reduce the burden of chronic pain on the individuals themselves and the NHS as a whole.

However, a recent government white paper in 2010 noted that the NHS scores poorly when responding to patients and lacks a patient-centred approach. It goes on to state that services are more likely to be organised around the clinicians, rather than the convenience of service users.³ Despite the most common mechanism for capturing feedback taking the form of patient questionnaires, evaluation of the National Patient Survey Programme which involved data from 600,000 patients found that utility of surveys was poor and could not be used solely as a basis to improve patients' experiences.⁴

Experience-based co-design (EBCD) is an innovative approach to improving health-care provision in which the quality and utility of evidence is prioritised by interviewing fewer patients. This enhances the interaction between staff and patients, allowing them redesign services together. This improves the patients' experiences and makes the service more patient centred, creating the potential for better outcomes and improved care overall.⁵

EBCD has been used in head and neck cancer services in the United Kingdom, where eight patients successfully worked with staff to bring about service improvements;⁶ a further study compared the methods and results from 10 studies that utilised EBCD at a cancer centre in the south of England.⁷ Together these studies demonstrated quantitative changes in improvement longevity, with two-thirds of the quality interventions sustained at 2-year follow-up.⁷ The authors stated that there are two crucial aspects of EBCD: filmed patient interviews, as they secure commitment to changes, and skilled facilitation of the co-design groups, where improvements are developed. This study also showed that only a few patient interviews were required to bring about 56 separate positive changes.⁷ It has been used in intensive care where it was recommended that all critical care departments should undertake their own version of EBCD.⁸ In Australia, it was found to have strengthened service provider–user relationships.⁹

The Kings Fund has developed an EBCD toolkit, suggesting that 5–15 patients are ideal for EBCD.¹⁰ EBCD works because the power of patients' stories produces an emotional response in staff working within the service, leading to a greater likelihood of developing and implementing change and improvements.

This single-centre qualitative study explored the experiences of a small number of chronic pain patients with the aim of shaping better, more patient-centred chronic pain services for all patients at Lancashire Teaching Hospitals NHS Foundation Trust.

Aims

1. To explore patients' experiences using the pain services in Lancashire Teaching Hospitals NHS Foundation Trust and to understand what shapes these experiences.
2. To produce a prioritised list of changes, which the participants in the study feel will most improve the experience for all patients.
3. To produce recommendations from the participants on how these priorities could be improved.

Methods

This study used an EBCD framework involving a staged approach to service improvement as shown below:¹¹

Part 1: capturing the experience:

Video recorded interviews were conducted with patients to capture a wide range of experiences of care under the chronic pain team.

Audio recorded interviews were conducted with staff to capture their experiences of providing care to patients with chronic pain.

Part 2: understanding the experience:

Video recorded interviews were reviewed to identify a number of 'touchpoints' during which patients experience heightened emotions during their interactions with services or staff. The touchpoints were then illustrated in a short 'trigger' film which was made by editing all the video-recorded interviews.

A patient experience event was held in where the patients reviewed the 'trigger film' and discussed the touchpoints. Here they produced an emotional map of the highs and lows of their care experiences identifying key priorities for service improvement and making recommendations for change.

Staff audio recorded interviews were analysed to identify the touchpoints they highlighted about providing care.

Part 3: improving the experience:

A staff meeting was held with members of the chronic pain service where they were shown the trigger film to help them to understand how patients feel about the services and inspire them to commit to the service improvement process and patient recommendations. This led to prioritisation of key areas for development and the delegation of these areas to smaller sub groups of staff.

The study design is shown in Figure 1:

A touchpoint is any moment in which a user interacts with a service in some way and experiences heightened emotions. For example, this may be when they go down to theatre and feel nervous.

Figure 1. EBCD study design.

A trigger film is made up of short clips from the patient interviews, to most clearly present the touchpoints and the patient experiences to the staff.

The research team

There were three members of the research team: a consultant who worked in the department, an independent medical student and an independent research nurse with a specialist interest in the EBCD approach.

Population and setting

Patients attending pain services at Lancashire Teaching Hospitals NHS Foundation Trust, a large teaching hospital in the north-west of England, were included. The service manages approximately 1500 new referrals annually providing a multidisciplinary team (MDT) approach to chronic pain management.

Sampling, access and recruitment

Patients were initially recruited based on convenience, with anyone who was eligible and interested in participating being recruited. Patients were selected to provide a balance between new and longer term service users with a variety of backgrounds and age groups. Patients were recruited based on the following inclusion and exclusion criteria:

Inclusion criteria
Those currently under treatment with the pain team
Full mental capacity to enable informed consent process and participation in video-recorded interviews
Aged 18 years and above
Exclusion criteria
Patients with complex regional pain syndrome who follow a more urgent pathway

Data collection methods

Video-recorded interviews were used to explore each patient's experience of using the chronic pain service. Patients were encouraged to share their stories about using the service and discuss what was most important to them through interviews with the medical student, who was not part of their usual medical team, to make it as open environment as possible. The main questions used as the basis of the interview are included in Appendix 2. They were shown the clips from their interview which were selected for use in the trigger film, so that they could comment and have any parts removed if they wished. Then, a 20-minute trigger film of all patients' touchpoints was produced from the individual video recordings. The videos were handled in accordance with the Trust guidance on data protection and information governance procedures. Written, informed consent was obtained from patients prior to conducting the interviews, and they were asked to sign a copyright agreement before any sections of their video were used in the trigger film.

Data analysis

The focus of this study was on patient experiences and finding the common touchpoints to inform the improvement of the chronic pain service. The analysis team (medical student and research nurse) were chosen as they were independent of the department and so would be less likely to be biased to a particular point. Each participant's interview was reviewed by both analysts, with subsequent notes on emotional responses to the subject topic compared for concordance. Where concordance between examiners was found, a touchpoint was noted, which was collectively reviewed using thematic analysis to identify key themes. The video-recorded patient interviews were edited down to produce a concise film. In editing, the focus was to capture emotional appeal that clearly and emotively illustrated the touchpoints previously identified. The trigger film was then collated ready to be shown to staff in the chronic pain team.

Staff audio-recorded interviews

A total of six members of staff were interviewed by the researcher where they were asked about their experiences working within the department and how they thought the experience for patients could be improved. The subsequent analysis was anonymised as far as was practical for the department, and although this project focussed on patient feedback, it is included for completeness.

Patient experience event

A half-day patient experience event was held during which the patients reviewed the trigger film and discussed whether the researcher had captured the key touchpoints and illustrated them appropriately in the film. This was used as a reliability check, to ensure the patients agreed with the analysis done on the interviews. Following this, the patients and researchers explored in greater detail the emotional highs and lows of using the chronic pain service and generated list of main priorities for service improvement. Patients also put forward their ideas for solutions to the challenges they had previously highlighted.

Staff experience event

A meeting was held where members of staff listened to a presentation on the project and viewed the trigger film. Following this, they were provided with a leaflet presenting the most important touchpoints from the patient experience event. This was then followed by a discussion of the themes raised by the group.

Ethics

Ethical approval was gained from North West Preston Research Ethics Committee 16/NW/0286.

Results

A total of seven patients were recruited allowing 319 minutes of video-recorded footage to be collected from 21 hours of patient interviews. In-depth interviews allowed participants' experiences of the service to be better understood, incorporating what had shaped these experiences, how they felt about them and their recommendations for service improvement. A range of patients from different backgrounds and time using the service was interviewed. Of the seven patients ranging from 22 to 69 years of age, three were male and four were female, and their time using the pain service ranged from 8 to 44 months. The touchpoints raised are listed in table 1.

Discussion

Some patients started the interview stating their experiences were very positive and they could not find fault with the clinics; comments of which were used in the trigger film to keep staff engaged and able to appreciate what was working well. Despite initial positive reactions, all of those who were positive at the start of the process did bring up emotional touchpoints where they felt improvements could be made, when pressed with

Table 1. List of touchpoints raised by the patients during their video-recorded interviews.

Touchpoints	Description	Patients quotes	Recommendations
Staff			
1. Patients valued staff empathy and expertise	Patients complemented staff working in the pain department, especially valuing how staff resolved their issues and alleviated anxiety by providing information.	'they understood my needs and how I'm suffering' (patient 4). 'the nurse was great, she was talking, she put my mind at ease' (patient 2).	Staff should remain approachable to help reduce patient anxiety. Staff should be vigilant of the main occasions when patients are anxious in order to better prepare to manage it. All staff should view the trigger film as the positive feedback received from patients will motivate further good practice.
Communication – written			
2. Patients were poorly informed of what to expect from the pain service	A number of patients described experiencing heightened anxiety when they were referred to chronic pain services as they did not think they received any information before their appointment. This led to misconceptions. Staff thought all patients should have received a patient information leaflet. Some did their own research but were rarely satisfied by this.	'I thought that pain clinic was somewhere orthopaedics sent patients to get rid of them' (patient 1). 'I thought pain clinic was somewhere for patients they assumed were making up the pain' (patient 4). 'I wasn't sure [what to expect] I was very nervous before I came' (patient 4).	New information sheets about clinics and procedures should be designed that can be posted to the patients when they are first referred to the pain service. This would inform them about what pain clinic was there for and how it might help them to manage their pain and what to expect from any procedures. The benefits of this would be to reduce waiting times by cancelling the referral for patients who do not feel that the pain service is meant for them and reducing patients' anxiety so that there would be more time for staff to focus on clinical management.
3. Letters of invitation to clinic or procedures failed to give enough information	Four of the patients described not receiving enough information in the letters prior to having procedures done under the service. One patient was informed about what was to happen in clinic by their doctor, which they found very useful. However, this was not experienced by the other patients.	'the letters basically give you the bare minimum of what to expect and if I hadn't been given the information from my consultant I don't think I would have understood what was going to happen as much ... I would have been extremely nervous about what was going to happen' (patient 7).	
4. Patient information leaflets displayed in the waiting area	Patient leaflets lacked colour and visual appeal, so patients often did not notice them or pick them up, even though they may have learned some interesting and useful information from them. The leaflets were presented in a poorly designed stand which prevented the titles from being easily readable without individually picking each leaflet out of the stand, which was off putting for patients with chronic pain who found it painful to move around.	'people can't read them properly as they are in black and white ...' (patient 4). 'people may feel a bit nervous about picking up the leaflets or a bit embarrassed as they don't want to be judged by people in case they pick up a certain one ... like pain and sex they might want to get the leaflet but feel a little embarrassed as everyone is around' (patient 4).	The trust website has a pain clinic section, which the patients thought would be a good place to link to the information to.

(Continued)

Table 1. (Continued)

Touchpoints	Description	Patients quotes	Recommendations
Touchpoints 2 and 3 were considered to be some of the main issues discussed at patient experience event. Their recommendations are further described in Appendix 1			
Communication – verbal			
5. Patient recall of information discussed at appointments	<p>Most patients thought that the staff were very clear when they explained things and they appreciated the extra time that was spent discussing treatments and concepts.</p> <p>As patients were being told a lot of information in a short space of time, they were fearful of missing information or embarrassed as they had forgotten what they had been told.</p> <p>There was normally a health-care assistant (HCA) in the room, who felt he or she could help explain things but was not confident that this was his or her role and so did not contribute.</p>	<p><i>'he actually got one of the models of the spine and tried to show me with that ... It was really good he spent the time to do it'</i> (patient 1).</p> <p><i>'when he told me about follow up appointments I don't remember any of that ... I needed that in writing'</i> (patient 6).</p> <p><i>'you could have a little five minute consultation with the nurse who has been in with you just to run through and make sure you understand what is happening and what is going to happen'</i> (patient 2).</p>	<p>After discussion with staff, a 5-minute appointment with a nurse after the clinic visit sounded unfeasible.</p> <p>However, it was raised that the HCA in clinic could have an expanded role, assisting the patients with understanding. Also investigating the format of the letter to the GP which is also received by the patient, possibly making it more readable to a lay person.</p>
6. Medical jargon	<p>Some patients criticised use of medical terms, whereas others did not find this to be a problem as they would ask staff to clarify the point if they did not understand.</p>	<p><i>'Trying to learn their lingo and what they call things is very hard to understand'</i> (patient 2).</p>	<p>This process itself has alerted staff's attention to reducing the use of medical jargon.</p>
7. Importance of building a relationship	<p>One patient had a disappointing time using the service, as they had not been seen by the same doctor twice while attending the pain clinic. She was asked to fill in a pain diary which was not reviewed with her as she never saw that doctor again. This eroded her trust in the medical professionals looking after her.</p>	<p><i>'I felt' 'forgotten about' and 'frustrated'</i> (patient 3).</p>	<p>The staff were surprised as they did not think patients should have appointments with more than one doctor. This highlighted the need to audit clinic appointments to capture the frequency of this occurrence and to gain a better understanding of why this happens.</p>
Clinical structure			
8. Contacting clinic	<p>Patients had to telephone a number of times and found it onerous to contact the clinic. However, once they did get to speak to someone they were extremely helpful, which the patients praised greatly.</p>	<p><i>'it can take 20 minutes to 2 hours to get through to them, ... phone engaged, no answer ... so frustrating'</i> (patient 5).</p>	<p>An answering phone for the admin office would mean that patients calling could leave a message; therefore, the admin staff would not be constantly distracted by calls. Improvements to the letters received by patients could reduce the number of calls.</p>

Table 1. (Continued)

Touchpoints	Description	Patients quotes	Recommendations
9. Administrative errors	Small errors made by the department could have dramatic impacts on the patients' experiences.	'When I went to the surgeon he said I didn't need to be there, it was an administrative error, which is all fine and good people make mistakes but that administrative error put me in pain for another two days ...' (patient 5).	Arranging for admin staff to view the trigger film would allow them all to have a better understanding of the plight of the patients and hopefully reducing the chance of such errors happening again.
10. Being the only young person in clinic	The youngest participant was 24 years old but had been attending since the age of 19 years. He described feeling uncomfortable being the only young person in clinic waiting room with lots of older people.	'it was very nerve-racking as I was a young person and you don't usually meet many young people with chronic pain ... it would be nice to socialise with in the waiting room' (patient 7).	Clinics could potentially be arranged so that more young people attended at the same time to allow peer support.
11. Clinical environment	Some patients were impressed by the decor. Some patients when asked were quite neutral about the environment. Stating that as they were often not there very long they did not really mind what it was like. Some patients described the seats as uncomfortable and complained that there was no separate waiting room. The patients sit on chairs in a row down one side of the corridor with members of staff passing back and forth to surrounding clinics.	'Lovely little signs up ... little sayings and verses, and there nice they stop people feeling sorry for themselves ... a nice place, a welcoming place' (patient 1). 'The environment was okay as I don't usually wait very long' (patient 4). 'a bit of a thoroughfare' (patient 6). 'uncomfortable seats' (patient 5).	Keep the positive notes on the walls as the patients appreciated them. The pain department needs relocating to a larger area, with a purpose-built waiting room for the clinic. Joining staff and patient voices together on the issue will build a stronger case for this.

GP: general practitioner.

deeper questioning. They would usually provide useful suggestions, stating what worked well but also changes which could be made, allowing the production of a more constructive balanced trigger film rather than a list of complaints.

The patient experience event allowed further exploration of which of the identified touchpoints in the trigger film were the highest priorities for service improvement. The event facilitated comparison of views from different participants, generating a more useful resource for the subsequent staff event. A common touchpoint identified was the provision of pre-clinic information, and the patient experience event allowed us to identify quantitative feedback from patients as to what should be included in such documentation.

The staff often misjudged what was important to patients; one member of staff thought more flexible clinic times would be helpful, for example, Saturday or evening clinics, a point not raised by patients regardless of employment status. This shows the value of the EBCD process in uncovering the patients' real priorities for change. When touchpoint 10 (the experience of being the only young person in clinic) was shown on the trigger film, some members of staff commented that they did not think that they were to socialise with other young people, further demonstrating the discord between the outlook of patients and staff with regard to services.

Tsianakas et al.¹² used EBCD in lung and breast cancer care and found that the information shared with patients in clinic was an important touchpoint. Participants in that study appreciated the way staff spent the extra time to clearly explain what their treatment was going to be and the related side effects, making them feel reassured. Participants with chronic pain described very similar emotions, highlighting the difference that caring and well-informed staff can make to a patient's experience of using NHS services.

This study explored the use of EBCD within a service for patients with chronic conditions, using a methodology which has not been used before to improve services for patients with chronic pain, some of whom will attend the service regularly over many years. These experiences will differ from those of patients in the oncology, emergency, critical care and neonatal settings, where EBCD has been used previously. EBCD has been used in neonatal care, identifying a key touchpoint around the sleeping arrangements in the hospital for fathers, demonstrating the utility of service-specific interventions, and the importance of conducting such work at a local level, identifying pressures exerted on local services.¹³

Accelerated EBCD has been put forward as an equal alternative to the original EBCD method used here, using films from Healthtalkonline, an online experience sharing platform, rather than holding interviews with patients who use the local service.¹⁴ Our experience noted that the majority of touchpoints are specific to

the idiosyncrasies of our individual service and may and are not widely generalisable; Healthtalkonline films could not identify enough specific local issues or requirements which could be resolved by local measure such as department-specific leaflets. While accelerated EBCD offers a quicker and resource-lighter alternative to the method we have used, the value to be gained from the applicability of our findings and the participation of our own patients in contributing to the redesign of their own services has obvious advantages.

The strength of this project materialises from the patient interaction. Spending sufficient time with the patients facilitated an understanding of the patient experience and contributory factors with a greater depth and utility than would be possible with questionnaires in isolation, evident in patient comments such as *'I didn't bother to return the feedback form; it would all have been negative'*.

This process also allowed us to use these patients to drive change through the emotive trigger film that they helped produce and the list of recommendations formed at the patient experience event. The recommendations are comprehensive, covering all parts of the service and include many new ideas, which the staff had not considered nor identified as problems.

There were two main limitations to this study. First was the small number of patients included. It was only possible to recruit, interview and edit the film from seven patients in the 11 weeks available to complete the study; other similar studies have spent a year undertaking the same process. If more time was available and more patients could be interviewed, we might have identified more recommendations for service improvement. Nevertheless, this small-scale study has increased the awareness of staff to the importance patients' experiences and facilitated a willingness for patient-centred service improvement, which is anticipated to have an ongoing impact.

Second, this study also did not necessarily recruit a representative sample of patients to interview as it relied on patients coming forward who were willing to be filmed. This was partly mitigated by trying to choose a range of patients from willing participants; however, it is still likely that some patient groups have not been included. There could have been a sampling bias if the patients were chosen by someone who worked for the department a risk which was mitigated using an independent person in the sampling process. The patients may still have not raised issues because they knew the staff would view the videos; however, the openness of the process is also a strength as it allows further discussion and more in-depth analyses of the patient experience. Ongoing evaluation of the service using similar methodology may help to demonstrate sustained changes in the department. Future studies may benefit from the identification of sampling bias and small sample size as limitations, improving the reliability of future work.

Conclusion

We succeeded in meeting the aims of the study, by gaining a greater understanding of patients' experiences when using the service and producing a prioritised list of service improvements. Participation of staff and patients in discussing their experiences led to recommendations for improvements that staff are willing to action to make a quantifiable difference to the patient experience. This study shows the effectiveness of EBCD in creating patient-centred service improvement, by converting patients from simple service users into the drivers of change.

Conflict of interest

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Appendix 1 Touchpoint 2

The feeling of apprehension due to being in the dark about the service was and what it could offer before they attended was considered to be one of the main problems for patients at the patient experience event. Their solution to this problem was to send a leaflet to all new referrals, with a link on the trust website for further information. From their experience of the service, they would like to have the following information on this leaflet:

- Names of all members of staff.
- Biography of the main members of the team.
- What pain management was about.
- Aim of the service.
- Treatment options available.
- Different specialties in the department that they could utilise.
- Realistic expectation of what to expect and how effective the treatments are.
- Offer of counselling and psychological services.
- General information about parking and where the service is.
- Use of plain English to aid understanding.

Touchpoint 3

Those who attended the patient experience event described the staff as very helpful, when they did finally meet them, but this did not reduce the anxiety they felt

before they attended. They drafted a list of things they would have liked to know before their first procedure based on their experiences:

- What the procedure was.
- How the procedure worked.
- Where would they have it done.
- The process.
- Side effects.
- Advice for after the procedure.

Appendix 2

List of possible questions for the interview

However, these were only a basis, it was important to let the interview flow, noting points of discussion where they reported heightened emotion and explored these areas more thoroughly:

- Could you please tell me in your own words about your time using the chronic pain service?
- What were your expectations before you attended?
- How did this make you feel?
- How did the reality differ to your expectation?
- How did you feel about this?
- What was your experience of treatment using the service?
- How did this make you feel?
- What was your experience with the staff working within the department?
- How did the staff make you feel?
- What were your three best experiences during your time using the service?
- What were your three worse experiences during your time using the service?
- What would you change about the service and why?