Digital methods to enhance the usefulness of patient experience data in services for long-term conditions: the DEPEND mixed-methods study

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Scientific summary

The DEPEND mixed-methods study

Scientific summary

Background

Patient experience data are critical to ensure the delivery of high-quality NHS services that are sensitive to population needs. However, there are problems with existing patient experience data. Data are often obtained from structured surveys with low response rates. Front-line professionals are often sceptical about the relevance of data based on generic questions and are concerned that vulnerable respondents are excluded. Many organisations collect additional free-text feedback (e.g. comments, complaints, tweets), which may more accurately reflect patient experiences, but such data are difficult to analyse.

We need more research on the best ways to:

1. collect timely and relevant data
2. analyse existing narrative data routinely and systematically
3. support staff to use multiple forms of data
4. use data to stimulate service improvement.

This study provides evidence on appropriate ways to collect, analyse and use patient experience data, focusing on two groups with long-term conditions: those with severe mental illness and those with musculoskeletal conditions.

Aims and objectives

Our main research question was 'Can the credibility, usefulness and relevance of patient experience data in services for people with long-term conditions be enhanced by using digital data capture and improved analysis of narrative data?'.

To address this, we had four aims:

1. Improve the collection and usefulness of patient experience data by helping people to provide timely, personalised feedback on their experience of services that reflects their priorities and by understanding the needs of staff for effective presentation and use of data. To achieve this we:

   ○ explored the perspectives of patients, service users and carers on the timing and method of providing feedback
   ○ investigated the perspectives, needs and current practices of professionals with regard to the collection and use of patient experience data.

2. Improve the processing and analysis of narrative data alongside multiple sources of quantitative data. To achieve this we:

   ○ analysed existing and new narrative data on patient experiences using text mining
   ○ explored different ways of presenting the analysed data.

3. Co-design a toolkit with patients, carers and staff to improve resources for enhancing the collection, analysis and presentation of patient experience data to maximise the potential for stimulating service improvements. To achieve this we:

   ○ co-designed new ways of collecting patient experience data digitally, as well as through alternative methods (e.g. verbal)
   ○ co-designed better methods for interpreting and summarising narrative patient experience data
   ○ developed resources and training for staff.

4. Implement the toolkit and conduct a process evaluation to explore implementation, potential mechanisms of effect and the impact of context. To achieve this we:

   ○ introduced the toolkit to staff
   ○ investigated staff responses to the toolkit and resulting changes in service provision
   ○ explored the impact of the toolkit in specific patient groups and service contexts
   ○ compared text mining with qualitative analysis of feedback
   ○ compared use of toolkit components with usual feedback mechanisms (including costs).

Methods

Setting
We focused on two exemplar long-term conditions: severe mental illness and musculoskeletal conditions. Both are associated with high levels of service use, complex needs and potential barriers to capturing patient experience. Four sites provided variation in service provision: a rheumatology outpatient department in an acute trust and a community team and outpatient department in a mental health trust; in addition, two general practice sites were selected in the same locality, serving patients with both exemplar conditions.

Design
We conducted four workstreams:

1. *Workstream 1: perspectives of patients and carers and staff*. We conducted semistructured interviews and focus groups with staff ($n = 66$), patients ($n = 41$) and carers ($n = 13$) to understand their views on feedback. A thematic analysis was conducted, drawing on techniques of grounded theory.
2. *Workstream 2: analysis and presentation of patient experience data*. We used text mining to analyse the main themes and sentiments using two data sets of free-text comments from existing patient feedback surveys from the two trusts. Five researchers used a framework of common themes to code data from each trust to assess inter-rater agreement. We developed and validated two machine-learning methodologies and a third system combined those systems using confidence thresholds to improve performance. Reporting templates were created for presenting qualitative and quantitative data together and were used for reporting findings to staff, to explore the value of different presentation methods.
3. *Workstream 3: co-design of a toolkit*. We conducted further interviews and focus groups with participants from workstream 1 and additional participants (total staff, $n = 45$; total patients, $n = 20$). We co-designed new tools, drawing on an experience-based design approach, incorporating findings from workstream 2 and insights from our patient and public involvement group. We created a 'trigger presentation' to stimulate discussion and generate tools for workstream 4.
4. *Workstream 4: implementation and evaluation*. New tools and guidance were introduced in specific staff meetings in the sites. We then conducted a process evaluation using interviews and focus groups with staff ($n = 51$), patients ($n = 24$) and carers ($n = 8$), combined with focused observations (41 sessions), to understand how the new tools were used and how resulting data were used by staff. A thematic analysis was conducted and emerging themes were mapped against core constructs of

normalisation process theory to draw out social practices and interactions associated with implementation of the tools. We analysed the volume of patient experience data before and after the introduction of the toolkit. An economic analysis quantified the time and resources required to use the new tools. We compared text mining of free-text responses with qualitative methods.

Results

Workstream 1: perspectives of patients and carers and staff

The qualitative research revealed three main themes:

1. *Lack of understanding and experience regarding the collection and use of patient experience data*. Many patients and carers did not have a good understanding of why patient feedback was collected and how it was used. Many did not have experience of being asked to give feedback and, even when they did, did not think it was likely to have any influence. Staff often felt distant from feedback mechanisms.
2. *The need for more meaningful and positive feedback*. Staff and patients across all settings thought that there was a need to generate more meaningful data and a need for better ways of analysing and using these data. Narrative comments were viewed as more meaningful. Staff were sceptical of current practices, which were perceived to serve organisational targets rather than being useful for informing delivery of care. Many thought that they would be more engaged if data were more specific to their setting.
3. *Methods and tools need to suit the context, and informal feedback should be included*. Staff and patients were often positive regarding the potential value of digital methods and text mining. They talked about the need to consider context, such as the specific experiences of patients, ways of working among staff (e.g. home visits in mental health) and the organisational environment. Staff and patients in mental health settings were more cautious about the use of digital methods. People with mental health problems said more frequently than those with musculoskeletal conditions that they would be unlikely to use digital methods to give feedback, especially when unwell, and would prefer to give verbal feedback to members of staff who they see regularly. Staff and patients in the mental health context talked about the value of having discussions about patient experiences that would be captured as a more formal record. Staff had a lot of time pressures and any new feedback tools should not add burden. Organisations varied in their capacity to adopt digital tools; for example, primary care staff lacked information technology support and in the trusts there were difficulties identifying who might support new tools.

Workstream 2: analysis and presentation of patient experience data

Initial coding of narratives used 11 categories but, because of overlap and inconsistency between coders, these were merged into five categories: (1) staff attitude, (2) care quality, (3) physical environment, (4) waiting times and (5) 'other'. We merged negative and neutral sentiments, following feedback from clinical staff. Both text-mining systems performed well, with the segment-based model performing marginally better than the comment-level model.

Workstream 3: co-design of a toolkit

The co-designed tools comprised:

1. a survey utilising the Friends and Family Test (FFT), with space for free-text comments to be completed using a digital kiosk, a website or a written version of the survey
2. written guidance for staff, patients and carers to support toolkit use
3. new text-mining programs for analysis
4. new templates for reporting feedback from multiple sources
5. a new process for capturing verbal feedback within community mental health services.

Workstream 4: implementation and evaluation

Quantitative analysis of participation

The number of participants was relatively low compared with the number of patients using the services. However, the volume of data obtained after introduction of the kiosk was greater than in the previous period in primary care and in the mental health trust. Rates of participation declined over time in all four sites, reflecting the findings related to problems supporting patients and organisational and technical issues.

Qualitative evaluation

Coherence: perceived value of digital tools for collection and analysis

The construct of coherence refers to the meaning and understanding of new technology and practices. In this case, the initial qualitative research in workstream 1 and the co-design approach in workstream 3 meant that an understanding of 'sense-making' among patients, carers and staff underpinned the development of tools for testing in workstream 4. This helped to maximise a sense of coherence and the tools made sense to staff based on perceived deficits in previous systems. Staff and patients were generally enthusiastic about the kiosks. Staff expected that the kiosks might improve the volume and efficiency of digital data compared with written surveys. However, there was variation between sites, with staff in one primary care site being much more positive. Patients gave more mixed responses and there was also variation among staff in relation to their roles and responsibilities.

Cognitive participation: information and support needs of patients and carers

Cognitive participation refers to relational work to sustain a community of practice for a new intervention. Staff engagement with the new tools varied and observation in the centres indicated that patients were apprehensive to use the kiosks; they mostly would not use them spontaneously but often would participate with support. This made it clear that there was a need for new and specific relational work to sustain the collection of feedback using the digital kiosks; however, staff teams lacked resources and most teams did not have clear motivation to develop a community of support for the tools. Peer support via a 'patient participation group' demonstrated the potential for this in one site.

Collective action: organisational and technical work for sustaining new tools

Collective action refers to the operational work to enact new practices. Low rates of participation highlighted organisational and technical barriers. Staff workload and technical problems were identified as limiting data capture. The level of managerial support for use of the kiosks varied. Collective action varied between the sites, with organisational context being particularly important in the mental health site because a major organisational restructuring took place during the lifetime of the study, which had an impact especially on the ability of staff to operationalise the new verbal feedback process. In the acute trust (site A), some felt that it was ethically wrong to request feedback in case patients felt pressured. The location of the kiosk was highlighted as important, but there were disagreements regarding the optimal location. In one primary care site, introduction of the new tools was more successful. In this site, the senior partner and practice manager were clear champions. In addition, they had a strong patient participation group that provided peer support.

Reflexive monitoring: embedding the new intervention

Reflexive monitoring refers to the work carried out to monitor and appraise new practices. The evaluation period was relatively short. However, staff did reflect on the tools, the data generated and some of the barriers faced in adopting the tools. They were often positive regarding the reports generated to disseminate the feedback and found these to be helpful for stimulating discussion. However, the volume of feedback presented was relatively small and we did not identify any changes to service delivery based on the data during the 9-month evaluation period.

Comparison of qualitative analysis with text mining

The qualitative analysis identified more categories. Estimates of positive and negative sentiments were similar between the two methods in the analysis of mental health data, but different in the data from the acute trust, especially in assessments of 'staff attitudes and professionalism'.

Conclusions

Aim 1: improve the collection and usefulness of patient experience data by helping people to provide timely, personalised feedback on their experience of services that reflects their priorities and by understanding the needs of staff for effective presentation and use of data

Although some have stated that we already collect sufficient data and should shift attention to action in response to data, our study indicates that rates of participation (especially for particular groups) remain a concern.

There was universal acknowledgement that data should be more meaningful than that captured by current brief surveys. Respondents felt that there should be more opportunities to capture verbal feedback, especially in mental health services.

The comparison between different service settings has drawn attention to the importance of context. Although there were some common issues and the potential for some common tools, there is a need to tailor feedback mechanisms. Flexibility, and combining multiple options for feedback, are likely to enhance participation rates.

Aim 2: improve the processing and analysis of narrative data alongside multiple sources of quantitative data

Processing unstructured comments is a challenging task. To solve this, machine-learning classification techniques were used. However, this faced challenges, such as lack of a larger training data set, unbalanced training data, and narratives with complex forms.

Aims 3 and 4: co-design a toolkit to improve resources for enhancing the collection, analysis and presentation of patient experience data and implement the toolkit and conduct a process evaluation

The co-design process led to the development of a model for digital feedback, which was implemented in the four sites. At the start of the study, none of the study teams was routinely collecting patient experience data digitally. We demonstrated that it is possible to enable such routine data capture, with some improvements in data collection, albeit in the short term. However, such tools require additional investment of time and support and there were multiple barriers to adoption, with little evidence of impact over the short period of data collection.

Implications for future research

The findings indicate the need for further research to develop the best ways of enabling more qualitative and informal feedback to be routinely captured and used for service improvement. The study indicates that, when digital methods are used, there is a need for further research into ways of providing guidance and support for people to engage in providing feedback (e.g. through peer support). There is also a need for further research to improve text-mining methodologies for use in service settings and to establish acceptable levels of accuracy and reporting for specific organisational contexts.

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