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Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study

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Scientific summary

The EURIPIDES multimethod study

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Scientific summary

Background

The core principles of NHS care are based on patient-centred care and include compassion, dignity, autonomy and choice. A strong patient voice is considered crucial to living up to these principles. As a result, all NHS providers are required to collect and report on patient experience data. However, there is little evidence about what to measure, how best to collect this information or how to use data to improve service quality. Given significant investment in local solutions, new top-down approaches are unlikely to be widely adopted. We therefore opted to examine current practice in the collection and use of patient experience data, to describe existing practice and to identify ways in which processes could be optimised to support service improvements. We studied inpatient mental health services on the grounds that these are important and costly services that are often unpopular with service users and are places where serious incidents occur.

Aims and objectives

We set out to understand how, and under what conditions, patient experience feedback processes could be used to support the improvement of health care in NHS adult inpatient mental health settings in England. Our primary research question was as follows: which approaches to collecting and using patient experience data are the most useful for supporting improvements in inpatient mental health care?

Our specific objectives were to (1) complete a systematic review to identify evidence-based patient experience themes relevant to inpatient mental health care (aim 1); (2) identify, describe and classify approaches to collecting and using patient experience data to improve inpatient mental health services across England by conducting a national survey of patient experience leads (aim 2); (3) use the information from the national survey to populate a sampling frame to select diverse sites for six in-depth case studies, in which we would interview those who deliver and receive these services to conduct a realist evaluation of what works, for whom, in what circumstances and why (aim 3); (4) identify which types of patient experience measures and organisational processes facilitate effective translation of these data to service improvement actions, and present these findings to a consensus conference of experts (including service users and carers) at which recommendations about implementing best practice would be agreed (aim 4); and (5) model variation in resources (costs) associated with adopting new ways of collecting and using patient experience data and associated service improvements, the obstacles to this and the value (i.e. cost) of the evidence required to convince NHS commissioners and providers to alter the way in which they deliver inpatient mental health care (aim 5).

Design

The Evaluating the Use of Patient Experience Data to Improve the Quality of Inpatient Mental Health Care (EURIPIDES) study was underpinned throughout the five work packages by a realist research design. Realist evaluation is a way of evaluating a particular programme in context, which, in our case, was the use of patient experience data in adult inpatient mental health settings in NHS England. The purpose of this approach is to refine the understanding of how a programme or intervention works in particular settings. Realist evaluation is theory driven, starting and ending with programme theories, which represent testable hypotheses about how a programme works and how this is influenced by the setting (context) in which different activities take place.

The study comprised five work packages: a systematic review to identify salient inpatient experience themes (work package 1, aim 1); a survey of patient experience leads in all NHS mental health trusts in England with > 50 adult inpatient mental health beds, to describe and explore the current practice of collecting and using patient experience data, and to populate a sampling frame for work package 3 (work package 2, aim 2); in-depth case studies at sites selected using the work package 2 findings, in which research data were gathered and analysed using a realist approach (work package 3, aim 3); a consensus conference to agree recommendations about best practice in the collection and use of mental health inpatient experience data (work package 4, aim 4); and health economic modelling to estimate the resource requirements of and barriers to the adoption of best practice, as agreed in work package 4 (work package 5, aim 5).

Setting, participants and data sources

The study took place in England, where there were 57 eligible NHS providers of inpatient mental health care. The six work package 3 case study sites were drawn from across England and included trusts serving urban, rural and mixed populations, as well as trusts with diverse socioeconomic and ethnic compositions. Patient experience leads from 47 (of the 57) eligible trusts took part in work package 2 interviews. Six NHS trusts participated as case study sites in work package 3; as part of the case studies, we conducted at least one service user interview on each of the 39 adult inpatient wards that comprised the entire inpatient estate of these providers. Data were obtained through interviews with 62 service users, 19 carers and 101 NHS staff. The work package 4 consensus conference was attended by 44 participants.

Patient and public involvement

The EURIPIDES study was designed with three forms of patient and public involvement at its core: first, through the participation of a co-investigator as a member of the project leadership team who was a survivor researcher with overall responsibility for patient and public involvement across the project; second, by employing survivor researchers as co-researchers alongside the research fellow and research associates during the data collection and analysis phases of the project; and, third, through the recruitment of a patient and public involvement team, comprising people with personal experience of inpatient care or of informal caring for someone receiving inpatient care. Patient and public involvement team members played a critical role in the design of the research tools, in designing coding frameworks and in reflecting on the data throughout the analysis. In this way, patient and public involvement team members helped to refine the programme theories that evolved over the course of the study.

Results

Systematic review of inpatient experiences (work package 1)

The systematic review of salient aspects of patients' experiences of inpatient mental health care (work package 1) was the largest of its kind and included 116 eligible papers. We identified four themes: the importance of high-quality relationships; averting negative experiences of coercion; a healthy, safe and enabling physical environment and ward milieu; and authentic experiences of patient-centred care.

Survey of mental health trust patient experience leads (work package 2)

The survey (work package 2) was the first-ever national survey of patient experience leads in NHS mental health trusts in England. We found that patient experience work was rarely embedded in these organisations and, although well regarded, was insecurely funded and vulnerable to cost improvement pressures. Most trusts collect patient experience data (most commonly using the Friends and Family Test), albeit in ways that varied both within and between trusts. We found that few trusts had robust

or extensive processes for analysing these data in any detail and we found little evidence that patient feedback led to service change. When changes did occur, they tended to be environmental in nature, rather than cultural.

In-depth case studies (work package 3)

Analysis of data from the six work package 3 case studies was undertaken in two stages. We first undertook a thematic analysis that spanned all four stages of the patient experience data cycle, for which we coined the acronym CRAICH (collecting and giving, receiving and listening, analysing, and quality improvement and change). In the second part of our analyses, we developed 154 context–mechanism–outcome configurations to understand how, for whom, in what circumstances and why underlying generative mechanisms were activated. In keeping with the work package 2 findings, most of the work package 3 data related to the conditions necessary for collecting and receiving meaningful data. The five themes identified in the first phase were wellness, the importance of feedback, relationships and communication, resources, and power.

Key findings (identified from context–mechanism–outcome configurations) included the ability of patients to provide feedback about their experiences even when unwell, and the consequences (in terms of loss of trust) when staff are unwilling to listen at these times. We highlighted the importance of positive (and negative) feedback as a source of information to improve services and the need to provide adequate resources for staff to receive informal feedback, which is often preferred by those giving it. We found that, like the quality of care itself, honest and meaningful feedback was likely to be given only when patients trusted staff. This trust was easily undermined, for example when staff failed to address instances of racial abuse between patients. Patients were wary of giving feedback before discharge for fear of persecution; this anxiety was shared by carers, who often felt excluded by staff. We also found that patients and staff were more likely to contribute to giving and collecting feedback if they were confident that these data would be acted on; hence, feedback about feedback is key.

Patient experience data alone are not sufficient to inform substantial service improvement. Instead, patient experience data need to be triangulated with safety and outcomes indicators to support and drive quality improvement in inpatient mental health services. When this is done, there are gains to be made. However, we found that patient experience data were often treated as necessary only for regulatory compliance (in the form of the minimally informative results from the Friends and Family Test).

Consensus conference (work package 4)

We held a meeting attended by 44 stakeholders (including experts by experience) to review the study findings and agree actionable conclusions. To facilitate the consensus conference and to ensure that we were able to present the final study findings in the form of actions that might form the basis of a future intervention, we presented the results of work package 3 in the form of ‘rules’. These were based on the programme theories that were developed and refined by means of realist evaluation. The 18 rules set out recommendations about how to collect, analyse and use patient experience data to improve the quality of care in adult inpatient mental health settings.

Health economic modelling (work package 5)

To examine the cost-effectiveness implications of collecting and using patient experience data and of adopting best practice, three logic models were created. Two logic models representing low- and high-intensity patient experience data processes (as identified in work package 3) were developed. A third model was created to illustrate how implementing patient experience feedback could improve cost-effectiveness in the delivery of inpatient care, using the example of alleviating boredom on the ward. In the absence of prospective data, we sought to compare the costs (obtained using standard unit costs for activities characterised from our work package 3 case study data) and potential benefits of these two archetypes.

This economic modelling revealed that the costs of collecting patient feedback (i.e. staff time) far outweighed all other aspects of the patient experience data cycle. Although it might be argued that some of this time is part of routine patient care, investment in collecting patient experience data carries substantial risks given the dearth of evidence showing that these data currently lead to substantive improvements in patient care.

Conclusions

Patient experience work is insufficiently embedded in most of the mental health trusts that we surveyed and visited. To have an impact on services and those who use them, this work needs to be informed by the 'rules' we have elucidated in the course of this project. Far more attention to the analysis and interpretation of patient experience data is needed, particularly to ways of triangulating these data with outcomes and safety data to improve services.

Implications for health care

Collecting and acting on patient experience feedback needs to be seen as everyone's business and as essential to the delivery of care. Although our findings indicate that some types of feedback are available only near to or at the point of discharge, patients are never too ill to reflect on their care. We also learned that patients will give meaningful feedback only to those they trust and only if they are confident that the information they provide will be acted on. Positive and informal feedback needs to be valued far more highly than at present. Front-line staff need to see what happens to the feedback they collect and receive. They need to associate this less with regulation and complaints, and instead see this as a driver of quality improvement and as a source of empowerment to make meaningful changes to the care they deliver. We also need to find ways to allow carers and families to provide feedback safe from worries about how this might affect their loved ones. Consideration of data held in silos is unhelpful and counterproductive; although outcomes and safety data can show what is happening (as well as trends), patient experience data often hold explanatory power and help explain the reasons why something is happening. We recommend targeted, intelligence-led, co-ordinated patient experience enquiry.

Recommendations for research

We recommend that consideration be given to supporting research to:

- develop and validate –
 - ways of ascertaining time spent on patient experience activities (and especially the collection of patient feedback, which distinguishes this from the delivery of clinical care)
 - the benefits that accrue as a result of service improvements that are informed and shaped by the use of patient feedback
- develop and evaluate an intervention (or suite of interventions) to implement the rules identified in work package 4 for ensuring optimal practice in collecting, receiving and listening to, as well as acting on, patient experience data and making service improvement changes in response to patient experience data.

This intervention will need to be context-specific and tailored to the circumstances of participating services while retaining fidelity to core principles such as triangulating patient experience, safety and outcomes data.

Study registration

The systematic review (work package 1) is registered as PROSPERO CRD42016033556.

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