


Patient Experience Research in Children and Young People's Mental Health Services in England: A Route to Genuine Service Transformation or Just Pretty Pictures and Tasteful Color Schemes?

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Adam Crosier, BA, MSc¹  and Pooky Knightsmith, MA, PhD¹

Abstract

The personalization of service provision and responding to patients' expressed needs are key components of government plans to improve children and young people's mental health services in England. This qualitative study explored the use of patient experience research in these services. Despite national level commitments to listening to and acting on the "patient's voice," both service users (young people) and parents of this group reported never having been invited to participate in patient experience research. Most professional respondents reported that such research was frequently tokenistic and conducted solely to meet an administrative requirement. Senior policy makers justified the limited investment in, and use made of patient experience research, by pointing to what they felt were more urgent priorities facing children and young people's mental health services. These included unprecedented levels of demand and critical underfunding of mental health services and related youth- and community-based services. The conceptualization of patient experience research within the National Health Service (NHS) as a service improvement issue was found to have led to its status being diminished to one concerned with relatively cosmetic matters, such as the color scheme or choice of pictures on the walls of clinics. Senior policy makers argued that it was important to rethink the role and value of patient experience research, and to recognize its unique contribution to addressing the existential questions facing services.

Keywords

patient feedback, patient perspectives/narratives, patient safety, patient satisfaction, children and young people, mental health, qualitative methods

Introduction

Children and young people's mental health services in the United Kingdom face significant challenges in responding to an unprecedented level of demand for care and treatment. In 2017, one in eight 5 to 19 year olds in England had at least one mental health disorder (1). However, according to the National Health Service (NHS) Long Term Plan less than a third of children with a mental health problem access treatment and support (2). The independent regulator, the Care Quality Commission (CQC), described the service as "complex and fragmented" and "too often sub-standard" (3).

Patient experience research for the purpose of service improvement is a relatively novel term to describe a range of social research methods that are used in health and social care settings to capture the views and experiences of service

users. Advocates of patient experience research regard it as an important agent of change that has the potential to humanize and personalize health care. The broad purpose of such research is to enable commissioners of services, as well as service managers and front line staff to understand and respond to the needs and desires of service users (in this case young people and their families), with the goal of tailoring services as far as possible to the needs of individuals.

¹ Word of Mouth Research, London, United Kingdom

Corresponding Author:

Adam Crosier, Word of Mouth Research, 106 Broxholm Road, London SE27 0BT, United Kingdom.
Email: adam.crosier@gmail.com



The Government's proposed strategy to transform children and young people's mental health services (4) and the NHS's own Long Term Plan (5), as well as the NHS Outcomes Framework (6), all endorse a commitment to a more person-centered approach to care and treatment. In order to achieve these goals, patient experience research will need to become an integral feature of operations. Service managers and commissioners require reliable and timely information about the views and experiences of patients in order to know where and when to intervene.

Examples of the types of research that fall under the heading "patient experience research" include a range of qualitative research methods from case studies, patient stories, individual and group interviews, patient journey mapping, observational research, analysis of complaints and informal feedback, as well as surveys (7). In 2013 the NHS introduced a national feedback tool in England, the Friends and Family Test (FFT) as its principal means of obtaining quantitative patient experience information (8). This voluntary survey is available to all patients and asks a single quantifiable question, how likely the respondent would be to recommend the service to a friend or family member. Since 2015, the FFT has also included space for respondents to provide a free text comment. Separately, the CQC manages a range of surveys that explore the views and experiences of different patient groups, including children and young people.

While the use of research to explore patient experience and to bring about change to services is still in its infancy, the philosophy that underpins it has a much longer history. For decades there has been growing demand for a more personalized approach to health care that reflects the role of the patient as an active agent in their own well-being (9). In the United Kingdom, a series of scandals from Shipman to Gosport exposed a culture where the needs of patients were frequently unexplored and ignored, enabling harm to occur either through design or neglect (10).

Method

The study was commissioned by NHS England as part of a programme of work to explore and improve the collection and use of patient experience information in the health service. It involved qualitative interviews with 27 young people aged 16 to 21, with experience of mental health services, 6 parents of this group and 40 health professionals and policy makers.

Inclusion criteria for young people were that they must have had experience of using a mental health service provided by the NHS or a charity before the age of 18. The same criteria applied to parents. The professional group included commissioners, service managers, and clinicians working in the NHS, charities, and online services. All interviews were semi structured. Interviews with young people and parents were conducted by telephone. Most interviews with professionals were conducted face to face. The young people and parents who participated were recruited to the study via a request posted on Twitter, sent by one of the authors (P.K.).

Professional respondents were contacted in a range of locations in England, including London, Leeds, and Bournemouth, and there was some snowballing to recruit additional respondents. All interviews were audio recorded and transcribed verbatim. A content analysis was conducted to identify key themes. This involved a combination of emergent and structured coding and theme identification using a computer spreadsheet. The study's research questions were used to inform the key themes, and emergent ideas were also coded and thematized.

Initial findings were reported face to face at a specially convened "workshop" session, where participants to the study from each of the 3 key groups (young people, parents, and professionals) were invited. The aim of this session was to validate emerging findings, avoid naïve or misleading interpretation, and explore further the implications of the emerging findings for policy-making and practice.

Results

Service Users' Experiences

The picture that emerged from interviews with children and young people, and with the parent group, was of a service that appeared not to be interested in the views of its clients about how it delivered care and treatment, nor about service users' views about how the service could be improved. None of these respondents reported that they had ever been asked for their views and experiences about any of the mental health services they had used, whether these were provided by the NHS or a charity.

I've had experience of a range of services: patient feedback was never a thing.

Respondents felt there was dishonesty and insincerity paid to the notion of seeking service user feedback. Some reported that NHS services had sought their views about how they were responding to treatment (as part of the clinical process), but not their views of the service overall. The motivation to collect information was felt by patients and parents to be more for the sake of meeting internal organizational requirements (for instance to be able to report on clinical outcomes), than as a result of a genuine interest in the views of service users or a desire to use such findings to adjust the service offer.

I didn't have any expectation that anything would change as a result of me filling out their questionnaires. It felt like it was a way for them to tick a box—to say that I'd done it. But it didn't feel like they were genuinely curious.

Some young people felt that there was a more purposeful disregard for the views of service users.

Some of it is inherent to the fact that you are a young person inside a system. You don't know your rights at all... Until I got a bit of an attitude and learnt how to assert myself, it just wasn't a thing.

Strong Desire to Provide Patient Experience Information

Despite not having been asked their views about the services they had used, all the young people interviewed stated that they would have welcomed the opportunity to provide feedback on their experiences.

I'd be more than happy to give my feedback. I know the importance of feedback and given the importance of the service, I think it's important for them [service commissioners and managers] to know about it.

Respondents were asked how they would have liked to have been asked for their views on their experience as service users. Most were keen for there to be a variety of options available. "I feel that for me personally, talking and in words, rather than using sheets and tick boxes."

The only channel that was considered inappropriate for providing feedback on experiences of services was social media. All respondents reported that their experiences of mental health services were personal and private, and not something they wanted to share via this channel.

Because a lot of mental health is so sensitive, I'd be worried about offending anyone or putting someone off using a service because of my review, because that's just my experience.

The Challenge of Providing Feedback During Mental Health Crises

There was also acknowledgment from some respondents about the practicalities of giving feedback on the experiences of service use for some young people who were experiencing a mental health crisis. These respondents reported that the impact of mental health problems affected the ability of people in the throes of crisis to function in a way that would enable them to provide feedback on their care and treatment.

At the time there was no way [of participating in research]. I'd have been having low key panic attacks about what I was going to say in the sessions. I was not in a good place to be able to give unbiased feedback—it doesn't seem appropriate.

To address this concern, respondents recommended that feedback be sought at different points along the "patient journey," both during the period when treatment was provided, but also some months after its conclusion.

Parents' Experiences

Parents also reported a desire to have more involvement in giving their input to shape how services operate and said that their needs were generally not sought by services. Parents reported that typically it was they who had made the initial appointment for their children to be seen by a health

professional. However, once the medical profession became involved, parents had been effectively excluded from discussions and decisions about their children's care and treatment by service providers. Parents complained that they were not given support about how to help their children at a time when they were in extreme emotional distress. They argued strongly for a systematic approach to the collection, analysis, and use of service user feedback that recognized the importance of families in the care and treatment of their children, and which acknowledged that parents need support too about how they can best help their offspring.

They have never really discussed our role as parents, beyond supporting X to do her CBT. They haven't really looked at the needs of the family as a whole, or of the parents.

Parents, like young people, expressed a lack of confidence in the process of seeking user feedback. Several doubted that mental health services were genuinely interested in their views, and expressed skepticism at the idea that their opinions would be used to shape service development.

And then the other thing that stops you is the thought, "What's going to happen as a result of it?" Will anyone listen anyway—or is it just pointless?

Some parents reported that they would feel unwilling to provide an honest account of their views, if they had any concerns that their feedback might impact the quality of care provided to their children.

I'd be concerned that if I gave a completely honest answer and I was unhappy with the service. I'd worry that it might affect the way they're going to treat us.

Professionals' Views

A culture of listening to the "patient voice"? Most professional respondents described a workplace culture in children and young people's mental health services that was characterized by an expectation that the "patient voice" should be sought and acted on. However, many respondents who worked in NHS services in particular, qualified this response and echoed service users' suspicions about the way such research was viewed in practice. They said that patient experience research tended to be undertaken as an administrative duty to satisfy managers and commissioners, rather than as an activity that they themselves truly valued.

There is a cultural shift more broadly, "how have you incorporated the views of young people?" It is becoming part of the language, and it's just the way things are done. There's an expectation. But it's highly variable about how well it is done.

Respondents described a spectrum of understanding and practice about patient experience research. While a

minority pointed to a small number of practitioners who were felt to be leading the field in the use of patient experience research for service transformation, the more common response was one of skepticism and disengagement, with many health professionals reporting some degree of antagonism to the enterprise.

There was a widely shared perception among frontline staff in Child and Adolescent Mental Health Services (CAMHS) services in particular, that patient experience research was of relatively low importance, and was regarded as a chore that consumed limited staff time and funds. Invariably, these respondents reported that resources were invested in the collection of patient experience research, and that this information was forwarded to others in the NHS for collation and analysis. However, it appeared that there was rarely any analysis reported back to services that would assist with service design or development. Overall, these staff viewed the patient experience enterprise as a drain on resources and a pointless activity.

There are too many people you have to report to—your own managers, commissioners, Children and Young People IAPT, NHS England, and all the short-term funding projects. Nothing maps on to anything else, so you have to invest resource into all of this. This is a huge part of running a CAMHS currently.

Several respondents commented that the reason for some of the antagonism toward patient experience research was because of fears about what may be reported from such research. They suggested that patient experience research had the potential to reveal inadequacies with the current provision of services, and to expose a power imbalance between professionals and their clients, that some service providers would prefer not to have to address.

Overall, I think that patient experience is not taken very seriously in services. I think there is a lot of lip service paid to this. A lot of health professionals are scared of asking people what they think about their service and afraid of what they will hear . . . I think it is fundamentally a fear about losing control.

As further evidence of the low regard in which some professional respondents held patient experience research, several respondents reported that they felt that in their role as clinicians and frontline staff, better able to understand the needs of the service user population and to advocate on behalf of young people.

To be honest we know what their views are already.

Mental Health Charities Were More Enthusiastic About Patient Experience Research

There was a contrast in the attitude to patient experience research between respondents from NHS and non-NHS

services. Overall, respondents from non-NHS services reported a significantly more positive attitude than their counterparts in the NHS. There was a much greater recognition of the importance of listening to service users in order to develop a “service offer” that was responsive to the expressed needs of children and young people with mental health concerns.

Our service was designed originally on the basis of what young people said they wanted. That’s our philosophy and always our first question. It’s a necessary position. No one is forcing young people to use the service. No one is even encouraging them particularly, so it’s got to be good or they won’t come back, or they’ll tell us it’s rubbish. For us it’s a case of constantly tweaking.

Furthermore, some non-NHS respondents felt that CAMHS service providers’ failure to take seriously the role of patient experience research and to seek feedback from service users, meant that these services failed to grasp that their services were actively harming the mental health of some young people.

My sense is that [at our service] we get young people coming to us who have found that the CAMHS experience is stigmatizing. They don’t want to be made to feel like a mental health patient—that’s not how they see themselves. And they don’t like the way that they’re treated there.

Discussion

This study explored the way in which patient experience research is understood and used in children and young people’s mental health services in England. It identified a strong desire among young people who have used these services and the parents of this group, to be asked about their experiences of the care they receive.

Among professionals there was widespread knowledge of a rhetorical commitment to the values underpinning patient experience research, but little evidence that this commitment was translated into practice in any meaningful way at either commissioning or service management levels.

The disjuncture between the rhetoric and the practice was explored with both frontline staff and policy makers. Among NHS respondents, frontline staff were largely unimpressed by the reality of patient experience research and felt burdened by the requirement to conduct research, which detracted from their ability to provide treatment and therapy. They identified the limitations of the various research methods but reported few benefits.

If the commitments made by government and NHS to make health services more personalized and responsive to the needs of patients are to be realized, patient experience research will need to be accorded much greater prominence. Currently however, despite the significance given to this subject by politicians and evident in strategic plans, there

remains a near complete disconnect between rhetoric and practice. In a context where children and young people's mental health services struggle to function because of a combination of unprecedented levels of demand, inadequate funding and a stressed and burnt out workforce, patient experience research is seen as a relatively low priority.

The challenge for those who feel that patient experience research truly has the power to transform services, is to change this perception. So, can patient experience really deliver anything more than cosmetic changes to service provision? If it is to do so, it will need to demonstrate its core purpose lies as being part of the answer to the structural challenges of demand, funding, and workforce issues, and not as an optional extra.


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ORCID iD

Adam Crosier  <https://orcid.org/0000-0002-6050-1638>

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Author Biographies

Adam Crosier is a social researcher with expertise in hard to research topics and socially marginalised groups. He has worked on national and international studies to inform and evaluate health promotion interventions on HIV prevention and non communicable diseases. He led the research function of England's first national social marketing agency for health, and has a keen interest in innovative research methods to better understand the needs and experiences of those whose voices are frequently left unheard by policy makers.

Pooky Knightsmith is a specialist in child and adolescent mental health. She is a keynote speaker, lecturer, trainer and the author of many books. She develops and shares practical, evidence informed ways to promote mental health, and is the Chair of the Children and Young People's Mental Health Coalition.