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Health and Social Care Committee

Inquiry: Community Mental Health Services Terms of Reference

Introduction

The Epistemic Injustice in Healthcare (EPIC) project is a 6-year research project funded by the Wellcome Trust and based across the Universities of Bristol, Birmingham, and Nottingham. It aims to investigate and ameliorate the injustices that obstruct the creation and transfer of knowledge within the health care system, often with dire consequences for service users and their loved ones.

Our interdisciplinary research team of psychiatrists, psychologists, philosophers, legal scholars, and historians is currently conducting a series of case studies to map out the scope of the problem and ways of addressing it. Four of these case studies focus directly on mental health (mood disorders, psychosis, and dementia) and related issues (loneliness).[1]

The research has already yielded significant findings about how service users' contributions can be dismissed and ignored within community mental health, what the consequences of this are, and how this issue can be addressed. We outline these findings below in response to questions 1 and 5 in the Call for Evidence.

Executive summary

High-quality community mental health care requires valuing and incorporating service users' experiences and insights into clinical decision-making. Our research shows that **service users frequently face epistemic injustice** – being unfairly dismissed or discredited when expressing their experiences – due to stigma, communication barriers, and institutional shortcomings. This can erode trust, reduce service engagement, worsen outcomes, and exacerbate existing service users' vulnerabilities.

To address epistemic injustice, we must strive for epistemic justice, ensuring that service users, their families, and health care professionals are seen and treated as credible sources of knowledge. Key steps include:

1. **Improving communication and information-sharing**: This involves reducing barriers within and between mental health services, ensuring clear and accessible information, and offering practical support to service users (e.g., text reminders, assistance with attending appointments).

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[1] https://epistemicinjusticeinhealthcare.org/case-studies

2. **Training staff in the 'agential stance'**: Professionals should be encouraged to validate service users' experiences, legitimise their help-seeking, avoid objectification, affirm individuals' capacity for positive change, and involve them in shared decision-making.

3. **Understand service users holistically**: Mental health is shaped by issues such as accommodation, employment, education, and loneliness. Community mental health services should see them in a holistic context and see such non-medical problems as directly contributing to their mental health.

4. **Addressing the key drivers of epistemic injustice:** This means recognising and counteracting the prejudices against people with mental illness, changing rigid assumptions about how medical knowledge should be communicated and obtained, and making it easier for service users to navigate the mental health services.

5. **Embedding monitoring and measurement of epistemic injustice in existing regulatory and evaluative frameworks:** Key frameworks include the CQC's Community Mental Health survey, the NHS England National Patient Survey, and the NHS Staff Survey. Academic research projects, like EPIC, also have a key role in providing evidence-based metrics and insights.

We believe that implementing these recommendations will help shape a more just, effective, and person-centred community mental health services – one in which service users, carers, and professionals work together to achieve better outcomes.

1. What does high-quality care look like for adults with severe mental illness and their families/carers?

A necessary condition of high-quality care is that mental health service users' knowledge about their mental illness and recovery is taken seriously and used as appropriate in clinical decision-making. This is not a matter of superficial validation merely to make the individual feel better. It is a matter of resolving a deep and fundamental informational, communicative and epistemic impasse besetting health care.[2]

- **Service users' are vulnerable to epistemic injustice**

    Our research shows that service users' contributions are highly vulnerable to being dismissed and ignored.[3] There are several reasons for this, including prejudices about persons with mental health conditions (even within health services). Another reason is that service users often struggle to use conventional medical language and strict institutional procedures to communicate about their problems.[4] These issues – which rank highly amongst mental health service users – can amount to an **epistemic injustice**: an injustice committed against someone in their capacity as a knower, someone with opinions, beliefs and knowledge they are trying to communicate.

    Epistemic injustice comes in different shapes. **Testimonial injustices** work by unfairly denying or deflating someone's credibility, often because of prejudice against them. This happens, for example, if a GP does not take seriously a female service user's mental distress because they negatively stereotype women as 'over-emotional' or as 'prone to exaggerate'. **Hermeneutical injustices** occur when people are unfairly blocked from making sense of or

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[2] Kidd and Carel (2017) Epistemic injustice and illness
[3] Carel and Kidd (2024) Individual vices and institutional failings as drivers of vulnerabilisation
[4] Degerman (2023). Epistemic injustice, naturalism, and mental disorder

sharing their experiences. For instance, someone who lacks the language to understand and describe their symptoms of depression as an illness may be a victim of hermeneutical injustice.

- **The price of epistemic injustice is high**

    In community mental health, epistemic injustice can have a tremendous human cost. It can damage service users' trust in the mental health services and its providers, undermine service provision, reduce compliance and communication, hamper improvements to community mental health services, and exacerbate suffering.[5] (We describe these injustices and the issues that fuel them further below in our response to question 5 on blockers and enablers.).

- **Epistemic injustice affects service users *and* providers**

    Service users are particularly vulnerable to epistemic injustice. Their vulnerability is exacerbated over time by repeated interactions that further reduce their already diminished sense of agency and their willingness and ability to contribute to discussions of their care (e.g. simply staying silent, giving up, refusing to engage).[6]

    Epistemic injustice dovetails with further deep problems in mental health provision: lengthy waiting times, service that is overstretched and under-resourced, stress within staff, etc. This can result in vulnerabilisation: making those who are already vulnerable more vulnerable in particular in their interactions with institutions, such as health and social care.[7]
    However, it is vital to be aware mental health care professionals also face epistemic injustice. When they do, it may put service users at risk. This was starkly illustrated by the recent investigation into the Edenfield Centre scandal, which found that executives and directors minimised the concerns that health care staff raised.

- **Community mental health services must strive for epistemic justice**

    EPIC research suggests that high-quality care requires ameliorating these injustices and striving for **epistemic justice**, that is, conditions under which the knowledge that service users, their family members, and different kinds of health care professionals offer is given due credibility and consideration by the decision-making clinical team.

1a. How could the service user journey be improved both within community mental health services and in accessing support provided by other services/agencies?

Given its consequences, ameliorating epistemic injustice is key to improving the service user journey. This can be achieved in the following ways:

- **Share clearer information more effectively**

    There are profound and plentiful opportunities for meaningful communication within mental health care, but these are often hampered by logistical (and lack of funding) problems: slow referrals, long waiting times, appointments that are cancelled, and so on, which can significantly destabilise the ability and willingness of people to engage. There are further epistemic issues. Some service users struggle to either remember at all or arrive in time for

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[5] Kidd at al. (2023). Epistemic injustice in psychiatric research and practice
[6] Kidd and Carel (2021). The predicament of patients
[7] Carel and Kidd (2024) Individual vices and institutional failings as drivers of vulnerabilisation

their appointment and lack support for attending appointments (e.g. social worker support to help the person speak up). This is particularly acute for those with learning disabilities or those who also struggle with substance misuse. Moreover, staff frequently changes, and new staff need to be introduced to the service user's case from scratch; such re-introductions demand significant epistemic labour from the service user and creates a sense of discontinuity.

These aspects of the service user journey would be enhanced by:

1. **Improving internal communication**

   This means, for example, improving communication between different services (e.g. when a service user moves from one area to another) and ensuring that staff have a clear sense of who is holding the service user's case.

2. **Improving communication with service users**

   This means, for example, giving service users a written list of instructions ('what you have to do next'), ensuring that information communicated is understood by the service user, checking and re-checking that the next appointment is in the person's calendar, sending text reminders, and involving family insofar as possible and utilising social care and other services to support further contact.

- **Understand service users within a holistic context**

  Many people with mental health problems also have problems with accommodation, employment, education, and struggle with loneliness.[8] Community mental health services should see them in a holistic context and see such non-medical problems as directly contributing to their mental health. A smoother and more connected journey increases the likelihood of long-term engagement. Returning to logistics, sometimes needing to wait for a letter required for one's benefits claim or council accommodation (causing problems like stopped benefits or eviction) can have a severe impact on the person's mental health. Such entanglements need to be taken into account by community mental health services. Those who are vulnerable are vulnerable across the board, not just in their mental health problems.

  These deep problems require systemic changes marked by the desire to support this group of service users. Our research shows that this desire can drive change and increase the prevalence of epistemic justice. However, as long as life experiences (past and current) are not paramount and service users' specific vulnerabilities are not taken into account and ameliorated, the mental health journey will continue to be unnecessarily fraught for many service users.

- **Train mental health professionals in the agential stance**

  Institutional pressures mean that mental health care providers may end up treating those they truly seek to help in suboptimal ways. One pertinent issue identified by EPIC research is the tendency to reduce the perceived agency of service users. To change this, mental health professionals must be trained in **the agential stance**.[9] This involves five steps:

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[8] Cooper (2023) ['Solitude is not thrust upon any lovable person'](#)
[9] Bergen, Bortolotti et al (2022) [Communication in youth mental health clinical encounters](#)

1. Validating the service user's experiences
2. Legitimising the service user's help-seeking
3. Avoiding objectifying the service user
4. Affirming the service user's ability to make a positive change
5. Involving the service user in decision-making.

1b. How could this be measured/monitored locally and nationally?

The task of measuring and monitoring the impact of epistemic injustice in community mental health and efforts to address it should be shared between the NHS, regulators, and the university research sector.

- Future iterations of the Care Quality Commission's Community Mental Health survey should **integrate questions about epistemic injustice** to begin to track experiences of epistemic injustice systematically. Other parts of the NHS should follow suit, integrating such questions into the NHS England National Patient Survey and the NHS Staff Survey. The wording of such questions should be informed by current research and service user input.

- Our interdisciplinary team on the EPIC project is currently working to provide a clearer picture of the state of epistemic injustice in mental health and the NHS in general. We are developing six empirical case studies, including studies on youth mental health, mood disorders, and loneliness.[10] We would happily share the data from these studies as they emerge.

5. What blockers or enablers should policy interventions prioritise addressing to improve the integration of person-centred community mental health care?

There are several **key drivers of epistemic injustice** impeding the provision of high-quality person-centred community mental health care. These include:

- **Pathophobia**: This refers to the variety of negative attitudes, assumptions, and behaviours that specifically target people who are ill. Examples include disgust, callousness, and morbid curiosity. Often, it intersects with sexism, racism, ableism, and other kinds of prejudice and discrimination.[11]

- **Epistemic objectification:** Service users feel that they are treated as a problem to solve or as a condition waiting to be diagnostically labelled rather than a person with complex interests and goals who can contribute to the interaction.[12]

- **Institutional opacity:** Service users and even staff report experiencing some health care institutions as institutionally opaque, meaning they don't know how to navigate the institution effectively or make themselves heard within it.[13]

- **Epistemic inflexibility:** Narrow and rigid assumptions about how medical knowledge should be obtained and communicated are common within health services and society.

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[10] https://epistemicinjusticeinhealthcare.org/
[11] Kidd and Carel (2021) The predicament of patients
[12] Bortolotti and Murphy Hollies (2023) Why we should be curious about each other
[13] Carel and Kidd (2021) Institutional opacity, epistemic vulnerability, and institutional testimonial justice

Consequently, service users' attempts to share knowledge may be dismissed when they do not use the 'right' language or channels.[14]

Acknowledgements

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[14] Degerman (2023) Epistemic injustice, naturalism, and mental disorder