

Raise awareness of epistemic injustice to improve healthcare in England

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About the research

What ill persons say is often dismissed and ignored because of prejudices related to illness and disability. This is an **epistemic injustice**: an injustice committed against such persons when they try to communicate their knowledge, needs and beliefs. Such injustices can have tremendous human and financial costs, including damaging trust in healthcare institutions, undermining diagnosis and care, and preventing improvements to healthcare.

EPIC is a 6-year, multi-university research project, that aims to understand and address the epistemic injustices faced by ill persons. It does this by drawing on interviews and accounts of ill persons and healthcare professionals, real-world case studies of healthcare provisions, and insight from a range of humanities and social science disciplines.



Image: 'Confusion' by medical student Louise Carter. Featured in the Bristol Medical School arts curation '[Out of our Heads](#)'

Policy recommendations

The first step in addressing epistemic injustice in healthcare is to equip healthcare professionals and people using healthcare services to recognise and understand the problem. To this end, we suggest the following:

- Enhance training for healthcare professionals on how common assumptions about ill persons and specific health conditions can give rise to epistemic injustice.
- Commission easy-to-digest guides for health service users about common epistemic injustices in healthcare and why they occur, making these available e.g. on the NHS and Care Quality Commission websites, in GP surgeries, and via Patient Liaison Services.
- Commit to addressing epistemic injustice in key policy documents such as the new NHS Constitution and the NHS 10-Year Plan.
- Track epistemic injustice via the NHS England National Patient and Staff Surveys by including questions designed to elicit information about ill persons' experiences of being listened to and understood.

Key findings

High-quality healthcare requires valuing and incorporating the experiences and insights of ill persons, family members, and healthcare professionals into medical decision-making. But this does not always happen.

Our research shows that **ill persons are more vulnerable to epistemic injustice**: they are unfairly dismissed or discredited when expressing their experiences due to stigma, communication barriers, and institutional shortcomings. An example of this would be if a GP does not take seriously a woman's complaints of pain because they stereotype women as 'over-emotional'. This can erode trust, reduce service engagement, worsen outcomes, and increase the vulnerabilities of ill persons.

We need to **strive for epistemic justice**, ensuring that ill persons, their families, and healthcare professionals are seen and treated as credible sources of knowledge. This is not a matter of superficial validation merely to make the individual feel better. It is a matter of resolving a fundamental issue that continues to grip healthcare provision in England.

Drivers of epistemic injustice

- **Pathophobia**: This refers to the variety of negative attitudes, assumptions, and behaviours about 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.
- **Epistemic objectification**: Many ill persons feel 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.
- **Institutional opacity**: Ill persons and health professionals report experiencing some healthcare institutions as 'institutionally opaque', meaning they don't know how to navigate the institution effectively or make themselves heard within it.
- **Epistemic inflexibility**: Narrow and rigid assumptions about how medical knowledge should be obtained and communicated are common within health services and society. Consequently, ill persons' attempts to share knowledge may be dismissed when they do not use the 'right' language or channels.

Further information

This briefing summarises the interim findings from project EPIC, a 6-year, multi-university, multidisciplinary research project.

EPIC is a collaboration between the universities of Bristol, Birmingham, and Nottingham.

It draws on research methods from a range of humanities and social science disciplines which it applies to first-person accounts of ill persons and healthcare professionals, survey data, archival documents, and case studies.

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Please visit the [EPIC project website](#) for more information.

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