Guest Editorial

Investigating mental healthcare inequalities associated with forced migration: promise and potential pitfalls of electronic health records

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Summary

There is a lack of data on mental health service utilisation and outcomes for people with experience of forced migration living in the UK. Details about migration experiences documented in free-text fields in electronic health records might be harnessed using novel data science methods; however, there are potential limitations and ethical concerns.

Forced migration is a term used to describe migration under an element of force, compulsion or coercion. It encompasses a broad range of migratory experiences, including, for example, the movements of refugees, people displaced by natural disasters and survivors of human trafficking. It is not a legal term; people with experience of forced migration may be seeking asylum, have refugee status, have no regular immigration status or now be citizens of their host country. Although these individuals are often highly resilient, forced migration can have deleterious impacts on mental and physical health, and this group are traditionally underserved in terms of their health needs.

High rates of mental illness, particularly depression and post-traumatic stress disorder, have been reported among people with experience of forced migration.[1] There are myriad reasons for this, including pre-migration experiences (for example, exposure to conflict) and adverse experiences during their migration journey. Increasingly, post-migratory factors have been associated with poor mental health, such as destitution, poor housing conditions, discrimination, and barriers to employment, education and transport.[2] In the UK, this group faces important barriers to accessing mental healthcare, including unfamiliarity with the healthcare system, concerns about eligibility for free care, lack of interpreting services, dispersal to different areas of the country and mistrust.[2] Despite this, very little is known about mental healthcare inequalities among forced migrants in the UK, including their access to secondary and specialist mental health services, pathways to care and clinical outcomes.

Sociopolitical context

The political and social debate surrounding forced migration has been brought to the forefront of public awareness in recent years. In 2022, 81 130 asylum applications were made in the UK: the highest number since 2002, although data for 2023 suggest these trends may be reducing (https://www.gov.uk/government/statistics/immigration-statistics-year-ending-september-2021/how-many-people-do-we-grant-asylum-or-protection-to). New immigration legislation, in the form of the Nationality and Borders Act 2022,[3] Illegal Migration Act 2023[4] and Safety of Rwanda Act 2024,[5] has also been introduced, bringing with it implications for the living conditions and mental health of those affected. The new pieces of legislation sanction an expansion of the use of immigration detention, more 'quasi-detention' accommodation facilities and longer periods of immigration 'limbo', which are all threats to mental health. Given the changing political and social context in which they live, it is a public health imperative now more than ever that effective methods of monitoring mental health outcomes for this population are established. This issue is particularly salient given a recent study suggesting that UK 'hostile environment' policies designed to deter immigration have been associated with adverse effects on the mental health of racially minoritised people.[6]

The knowledge gap and barriers to addressing it

Our understanding of the appropriateness and effectiveness of the mental healthcare provided for this group is currently being thwarted by a lack of data on people experiencing forced migration. At present, there is no reliable method of ascertaining how many refugees, people seeking asylum and other people with experience of forced migration living in the UK utilise mental health services, what needs they present with and what their clinical outcomes are. Equally important, there is a lack of understanding about their experiences of mental health services and whether their needs are being met. Although it is true that mental health support for this group is often provided through third-sector organisations or faith groups, who may be best placed to provide culturally appropriate care, this should not be used to justify ignoring the responsibility of the National Health Service (NHS) to provide effective mental healthcare for all. Rectifying this situation would align with the NHS Inclusion Health Framework (https://www.england.nhs.uk/long-read/a-national-framework-for-nhs-action-on-inclusion-health/), as 'Understanding the characteristics and needs of people in inclusion health groups' (of which 'vulnerable migrants' are listed as one) is one of five key principles.

A major barrier to understanding mental health service utilisation and outcomes among this group is a lack of migrant health databases or data collection systems disaggregated by migration status. Also contributing to the knowledge gap are the myriad methodological and ethical challenges to conducting primary research with this population. Where there is a paucity of primary data on a topic, existing databases can be invaluable resources. Electronic

health records (EHRs) are sources of routinely collected data that contain a wealth of information on clinical characteristics of individuals who encounter health services. EHRs allow clinicians to code specific information in structured fields; however, immigration status is not reliably coded across all systems. This limits the utility of EHRs in researching health outcomes by immigration status. Increasingly, novel data science techniques are being used to harness data within EHRs, particularly where relevant information has been poorly captured in structured fields. Using data science to increase the visibility of traditionally underserved groups is a key objective of Health Data Research UK's DATAMIND hub (datamind.org.uk), and people with experience of forced migration fall into this category.

Natural language processing (NLP), an application of machine learning, can help identify specific domains within unstructured free text in clinical records. NLP has already been deployed to research a range of domains within mental health EHRs, such as occupation[7] and violence.[8] NLP models that code for instances of forced migration could allow researchers and clinicians to identify refugees, people seeking asylum and others with experiences of forced migration, within EHRs, thereby 'unlocking' the wealth of information they hold on health outcomes and inequalities. Mental health EHRs are likely to be a useful starting point for the development of an NLP model for forced migration, as they may be more likely to contain detailed information on patients' personal histories and life stories, compared to records from other medical specialties.

Data linkage is another promising avenue for harnessing valuable mental health data. Linkages now exist between mental health EHRs and a range of other UK databases, including Hospital Episode Statistics and national census data (https://www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-data-linkages/). Linking mental health EHRs to other databases that do contain structured fields about forced migration is therefore a possibility. This approach has been used to research mental health service use among refugees in countries where linked national registers exist.[9]

Pitfalls and ethical concerns

There are several potential pitfalls to the novel data science approaches discussed. First, NLP algorithms are only as useful as the training data used to develop them. The barriers to accessing healthcare for some migrants could therefore have a significant impact on the generalisability of the data, as EHRs only capture those who encounter health services, and not those who do not. The methods also rely on clinicians accurately documenting immigration status in the clinical record, and it is not clear to what extent this is currently the case.

There are also ethical concerns regarding the extraction of instances of forced migration from EHRs. For example, in the UK there is the potential for this information to be used to identify migrants to charge for healthcare (https://www.gov.uk/guidance/nhs-entitlements-migrant-health-guide), or used in data sharing with the Home Office for the purpose of immigration control.[10] Without careful consideration as to application, methods deployed across health records to identify people who have experienced forced migration could potentially reduce public trust in the health system, owing to concerns about confidentiality and data sharing. As an example, a data-linkage pilot project jointly run by the Office for National Statistics and the Home Office is underway, which aims to link data on resettled refugees to both Home Office Exit Checks and NHS Personal Demographic Service data.[11] Despite the project's aims of informing resource allocation for

vulnerable populations and increasing public awareness of societal issues, any collaboration with the Home Office is likely to contribute to concerns about data sharing and to a sense of mistrust among those whose data it concerns. As some migrants already face significant barriers to care, any additional concerns about how their data may be used could have an untoward effect of creating an additional barrier.

In light of these limitations, attention must also be paid to improving the routine collection of migration data in healthcare settings. Recent work in the area of ethnicity recording may provide guidance. A project exploring the perspectives of community members and healthcare workers revealed that concerns about discrimination and a lack of understanding as to how their data will be used prevented some patients from wanting to disclose their ethnicity to health professionals.[12] Non-disclosure is problematic because it compounds the issue of missing data and makes minority groups even more invisible within health data-sets. Although these findings may also be relevant to people with experience of forced migration, there are likely to be additional obstacles to the reporting of immigration status, such as fears related to immigration control and entitlements to free healthcare, which are harder to overcome without change at a governmental policy level.

Conclusions

Given the current lack of primary data in this area, methodologies such as machine learning or data-linkage applied to mental health EHRs have the potential to transform the public understanding of this underserved group's mental health needs. However, the ethical benefits of better information need to be weighed against the potential unintended consequences of this technology. Careful consideration must be given to how algorithms could be used and for what purposes, with the overarching aims being to improve health, reduce inequalities and 'do no harm' in the process.

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Author contributions

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