

Tackling Extreme Health Inequalities Using Health Data: The Case for the Development of Routine Housing Status Recording

One of a series of Pathway Policy Papers to inform the next decade of healthcare

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About the author

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She has considerable experience of health systems and coding and created a homeless and inclusion health template in EMIS which has since been replicated in SystemOne and is well used across the country. She is a great believer in the key role of health data in delivering quality improvement.

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Foreword

We are at a turning point in the long and proud history of our National Health Service. Described as 'broken' by the Secretary of State, there is a clear choice in how the Government restores when developing its 10-year Plan. This choice is between the continued, widespread exclusion of people facing severe deprivation from care, or rebuilding the NHS inclusively, slanting effort and resources towards those people in inclusion health groups, whose needs are among the most complex and severe in our country.

Pathway is publishing these policy papers to inform this choice. Drawing on the expertise of some of our Pathway Fellows and Faculty members, as well as our colleagues with lived experience, we offer to shine a light on what is possible and to offer thoughts and actionable ideas for change. We invite Ministers to take these ideas and the problems they are designed to solve into account when shaping the 10-year Plan.

The challenges described in the papers echo those seen every day by our Pathway hospital teams. Patients who could have received help earlier only receiving it at crisis point, wasting human potential and precious resources. The desperate challenges people face accessing help for combined mental health and substance use problem. The failure of our housing system to provide safe places to recover from illness and to stay well.

It is not like this everywhere, however, and it does not have to be like this forever. The papers point to evidence of what works in health and care services to meet the needs of people in inclusion health groups, as well as beacons of good practice around the country. Together, they show how choices could be made within the NHS to reverse the inverse care law, tilting time and resource towards those who need it most. Prevention is a strong theme throughout, showing how people's problems can and should be addressed before they spiral out of control.

The benefits of action go far beyond health - meeting people's health needs unlocks other gains, addressing underlying risks of homelessness in particular, enabling people to live well and for longer, as the Government wants to see us all do.

I am very grateful to our Pathway Fellows and other experts who have made time, often in the midst of busy clinical and frontline jobs, to share their thoughts and expertise in these papers. Britain led the world with the establishment of the NHS more than 70 years ago. As we write the next chapter of its history, let's make care and compassion for those who need them most central to its mission.

Alex Bax, CEO, Pathway

Summary

- People in inclusion health groups face extreme health inequalities but are often invisible in health care data. This is because the standard ways of identifying people at risk of inequalities does not fit the circumstances or characteristics of people in inclusion health groups.
- The consequences are enormous; these populations are invisible when commissioners are carrying out needs assessments and planning services, invisible to national decision makers when making policy, and invisible when holding services to account for improving outcomes for the sickest in our society.
- Housing precarity is, sadly, a unifying experience of people in inclusion health groups. Housing status is therefore a good proxy for identifying people in inclusion health groups in healthcare data and circumvents the complexities of alternative ways of identification and recording.
- This paper calls on the Government to commit in the NHS 10-year Plan to a better system of recording people's housing status, drawing on a revised set of SNOMED codes. Alone among the recommendations in this series, we think this should start with a pilot, to flush out cultural and operational issues, before proceeding to the national reform needed to make people in inclusion health groups count in healthcare.

What is inclusion health?

Inclusion health is a growing field of research, activism, clinical practice, and care devoted to improving health and social outcomes for the most excluded groups in society. Although much early impetus focussed on improving health services for people experiencing homelessness, over the last 15 years the concept of inclusion health has expanded to cover a range of groups where extreme social and economic exclusion creates extreme health risks and health harms.

The degree of risk and harm observed in inclusion health groups falls far below even the depressing 'normal' range of health inequalities in British society. Disease prevalence rates can be up to 50 times higher than in the general population and mortality gaps between inclusion health groups and the average can be 30 or 40 years. Inclusion health groups can be defined by this observed extreme distance from the general population in terms of health status.

Currently identified inclusion health groups are: people experiencing homelessness, Gypsy, Roma and Traveller people, people engaged in sex work, vulnerable migrants. We now have a strong body of evidence of what works to improve health and care for these groups: NICE published guidance on homelessness in 2022 and NHS England produced a national inclusion health framework in 2023, however there is an 'implementation gap'. The good practice evidence is available but all too often that evidence is ignored or only followed spasmodically.

Introduction

The Government has made the reduction of health inequalities a priority, committing to “halving the gap in healthy life expectancy between the richest and poorest regions in England”. This is a response to evidence demonstrating that health inequalities increased in the 10 years prior to 2020 in the UK¹. Ensuring that people facing the most serious inequalities within each region are identified in the data will be key to achieving meaningful success.

The Government has signalled the three shifts it wants to see in healthcare in response to the Darzi review moving from sickness to prevention, from acute care to the community and from analogue to digital. The other papers in this series show what action needs to be taken across primary, secondary and mental healthcare to achieve this, but fundamental reform to data capture and recording is the foundational step for these critical changes to services. This paper considers what can be done to improve data capture for inclusion health groups in order to ensure both preventative and acute health care can be targeted at these groups proactively, to improve the health of the sickest fastest.

The issue with health inequalities data capture

Tackling health inequalities through data can happen at both geographic and demographic level. Health inequalities related to geography are currently be picked up in health data at postcode level. For example, a lower uptake of screening in a particular postcode can be tracked in the data, and this can result in future targeted screening uptake interventions. For people in demographic groups with protected characteristics, such as ethnicity, gender and sexuality, demographic data can be used to drive the provision of particular services and interventions.

However, when using these two methods it is not possible to identify certain specific individuals or cohorts who are at high risk of extreme health inequalities, most notably people within inclusion health groups.

Such people often do not have a permanent address, and/or may be highly transient so will not be picked up in postcode data. These groups are also not identifiable through core demographic data; most mandatory demographic data points relate to protected characteristics, and inclusion health groups are not in themselves protected by the Equality Act 2010.

Protected characteristics It is against the law to intentionally or unintentionally discriminate on the basis of these characteristics	Examples of groups of people at risk of health inequalities who are <u>not</u> 'protected' from discrimination
<ul style="list-style-type: none"> • Age • Gender • Gender reassignment • Disability • Marriage and civil partnership: • Pregnancy and maternity • Race and ethnicity • Religion and belief • Sexual orientation 	<ul style="list-style-type: none"> • Homeless people or those who experiencing homelessness • Vulnerable migrants • Those involved in the criminal justice system • People with addictions and substance misuse problems • Sex workers • Looked after children / young people • People living in remote locations • People who have poor literacy

Table 1: Protected characteristics under the Equality Act 2010 and people at risk of extreme health inequalities who are not 'protected'.

As a result of not being able to identify these individuals as a cohort, many people at high risk of extreme health inequalities remain invisible in the data. Put another way, the groups of people who often have the worst health outcomes in society are not able to be identified in a way that enables their needs to be understood through needs assessments, or targeted via specialist commissioning.

The invisibility of these groups also enables a lack of transparency and accountability for progress in meeting their needs. Neither NHS providers, nor systems such as ICSs, can be held to account by NHS England or the CQC in the absence of relevant data about the needs of people in inclusion health groups, and the extent to which these needs are being met. This absence is also a barrier to NHS England setting clear expectations to the system through its Operational Planning guidance about delivery for people in inclusion health groups, leading to de-prioritisation locally.

In fact, these extreme inequalities often only become evident retrospectively after individuals in these groups have died. This has been underlined by Office of National Statistics work which has looked at the average age of death of people experiencing homelessness (where homelessness has been documented on the death certificate). In the most recent data, 741 deaths were recorded across England and Wales, and the average age of death of men was 45.4 and women was 43.2². This is also likely to be an underestimate in terms of the numbers. The Museum of Homelessness recorded 1,474 deaths of people experiencing

homelessness across England, Wales, Scotland and Northern Ireland through their Dying Homeless project in 2023³.

All these points were highlighted in a recent Carnall Farrar and Pathway partnership paper 'The Unseen Struggle: The Invisibility of Homelessness in NHS Data⁴.'

Policy Background

Approaches to improving health inequalities data capture

Health data in the UK is routinely collected through NHS Digital led national data sets. The NHS national data sets collect information from care records, systems and organisations on specific areas of health and care. They are used to inform policy and to monitor and improve care.

All national data sets are created using SNOMED CT (Systemized Nomenclature of Medicine – Clinical Terms) codes. SNOMED CT is a worldwide, systematically organised computer-processable collection of medical terms that all NHS health systems are required to align with.

Historically, in terms of improving data capture, the focus has generally been on improving the identification of migration status, Gypsy, Roma, Traveller populations and people experiencing homelessness, probably because the poor health outcomes of these groups are very well documented. Identifying people in contact with the criminal justice system or engaging in sex work has received less focus. This has probably been due to concern that identifying these characteristics could easily lead to discrimination.

These efforts to improve coding over several years have generated a number of insights that should inform decisions on future reform:

- Many codes to identify vulnerable migrants, such as refugees, asylum seekers, failed asylum seekers and migrant workers, exist, but health care practitioners are often reluctant to use them, due to concerns about historical data sharing between the NHS and the Home Office.
- Codes exist for 'Gypsy or Irish Traveller' and 'Roma' and both these terms were used in the 2021 census, but these codes have not been well used in health care. Gypsy, Roma, Traveller organisations say this is likely to be related to a lack of willingness to self-identify as being from one of these groups, and potentially also due to low literacy levels.

- A considerable number of codes which would potentially identify someone as homeless also exist, but the large number of codes has historically led to a lack of standardisation and consistency in their use. In addition, asking about homelessness has only tended to happen as a result of a judgement call from a practitioner regarding whether someone actually appears to be homeless. Arguably this should have in part been overcome by the Homelessness Reduction Act 2017, which requires secondary care health services to refer anyone who is homeless or at risk of homelessness to the Local Authority with their consent. However, no specific guidance was given about the questions to ask, nor were ways to record homelessness specified within the Act. This problem also applies to migration status and Gypsy, Roma, Traveller recording – deciding who to ask can be complex.

Creating codes, therefore, is only one step – they must be the right codes and patients and the workforce need to be supported to use them.

Housing Status as an essential proxy

The complexity and difficulties described above mean that a different way to identify people in inclusion health groups in health data is required. An alternative to the more detailed capturing of personal characteristics within inclusion health groups is that the routine recording of housing status can be used as a suitable proxy.

This has a number of advantages. Recording housing status is equitable, because it can be applied to everyone. It identifies most people in inclusion health groups by proxy, as housing precarity cuts across all of these groups. It enables understanding of much wider public health issues, particularly how housing status affects health outcomes and health inequalities in general. It also promotes adherence to the Homeless Reduction Act by encouraging providers to investigate the living situations of patients. From a practical perspective, many housing status codes already exist within SNOMED, which cover all types of housing status. Finally, as we know that housing precarity is linked to many other markers of inequality, for example uptake of welfare benefits or missed attendance at school, we know that housing status is of interest to the wider system.

On account of these advantages, experts from Pathway, Crisis, Shelter, MHCLG and the Collaborative Centre for Inclusion Health came together in 2018 to consider what a standard set of housing fields might look like. They created a set of suggested housing fields for use in health data sets which split the codes into two main categories of 'stable' and 'unstable'

housing (see technical note to view the set of codes). This set of codes has now been socialised in many areas of the health system where organisations and partners have shown interest.

Policy and progress so far

The Emergency Care Data Set (ECDS, which applies to Accident and Emergency Settings) adopted some, though not all, of the suggested codes in 2022. The Mental Health Service Data Set (MHDS, which applies to secondary mental health care services) adopted them all in 2022.

While no formal evaluation of the impact of these changes has taken place, early signs are promising. Exploratory work by Transformation Partners in Health and Care indicates that completion rates in London were 80% for the MHSDS⁵ and 66% for the ECDS⁶.

In addition, many local ICB areas have showed interest in recording housing status and have contacted Pathway for advice. Pathway has given advice freely and knows many areas are progressing this work.

What is needed now, to make a reality of the Government's aspirations in response to the Darzi review and to reduce extreme health inequalities, is concerted action from Government and NHSE to bring about a step change in the routine coding of housing status in NHS settings.

Recommendations

The routine recording of housing fields presents a meaningful and deliverable way forward to monitoring and reducing health inequalities for the most vulnerable members of our society. Progressing the development work that has already taken place also has considerable buy-in across the statutory and third sectors. The Government has a major opportunity through the NHS 10-year Plan to take concrete action to make this a reality. Given what we know about the complexities of implementation in this area, we recommend an iterative approach, learning from progress so far, then formally piloting a national approach, followed by full roll out.

This would be a low cost, high impact intervention, that would drive a measurable difference in extreme health inequalities within the 10-year Plan term. Over the long term, progress in

this area would enable preventative interventions to be targeted at a greater number of people at risk of health inequalities.

The Government should commit to the following actions in the 10-year Plan:

Short term

Capture the learning from existing work to improve recording of housing status. This should include:

- Evaluating the impact that has been made by the existing housing status changes in the ECDS and MHSDS; and
- Promoting the housing codes to volunteer Integrated Care Boards, supported by an evaluation.

Medium term

Establish a major pilot of routine recording of the recommended housing status field recording for a specified period in A&E, general practice and outpatient settings. The insights gained from the short-term review should inform the design and implementation of the pilot.

Long term

Implement a major reform programme, based on the learning from the pilot, to drive coding and recording of a revised set of housing codes at national level. This will involve significant workforce involvement and investment, to drive the culture and behaviour change necessary to underpin meaningful recording.

A more detailed implementation plan is at Annex A.

A full technical note is at Annex B.

Lived Experience Perspective

Sahar Khan, Lived Experience Programme Volunteer, Pathway

People in inclusion health groups are too often excluded from society and services, and being invisible within healthcare data is yet another example of this. Because many people in these groups have unstable and insecure housing, improved recording of housing status would be an effective way to identify these patients within healthcare data. In turn, this would help us to improve care, monitor progress and engage in effective long-term planning for these groups.

We also live in a time where the application of Artificial Intelligence to healthcare data has huge potential to improve healthcare delivery and outcomes. However, without data improvements, such as better housing status recording, these technologies will not benefit people in inclusion health groups, and they will be, once again, left behind.

Implementing and piloting improved housing status recording would be a really positive step in the right direction. However, it needs to be done thoroughly; piloting in different sites around the country, fully engaging both staff and patients with education and information programmes, and with adequate funding over a longer time period.

However, there are some important considerations that need to be addressed for better housing status recording to work. Because many people in inclusion health groups have had poor experiences in healthcare settings (being stigmatised, discriminated against and treated unkindly), there can be a lack of trust in services and a lack of feeling safe. Due to these experiences, people may be unwilling to disclose information about their housing status, for fear of how they will be treated. This is also true for other important sensitive information, such as immigration status and ethnicity.

For this data to be collected accurately and responsibly, healthcare settings need to feel safer and more inclusive for people. Staff need to be trained in trauma-informed, holistic approaches, to be able to ask questions about housing status in a sensitive way that makes people feel safe and secure. Additionally, patients will need to have clear information about why services are asking for this information, in order to build trust about how the information will be used.

There also needs to be education, for both staff and patients, about different types of accommodation. Patients who struggle with housing instability may not always know exactly what type of accommodation they are in, and staff and patients may have different understandings of different types of accommodation. This is important for getting accurate and good quality data.

Finally, we also need to see improvements in data and information sharing between services – this can be especially challenging for people in inclusion health groups, as they often have to move between areas (e.g. asylum or temporary accommodation), changing essential services such as GPs. When information is not properly shared, it impacts quality of care and means people have to constantly reshare sensitive and often difficult information.

Annex A – Implementation Plan

	Concept	Comments
<u>STEP 1(a)</u>	Formal evaluation of the impact that has been made by the existing housing status changes within the ECDS and MHSDS, looking at the extent to which the housing fields have been filled in, and what the enablers and barriers are.	<u>Would require:</u> <ul style="list-style-type: none"> • Partnership working with ECDS and MHDS teams • IT support from NHS Digital for comparative data extraction • Interviews of staff and patients • Evaluation Team
<u>STEP 1(b)</u> Concurrent with 1(a)	<p>Promotion of suggested set of housing fields to volunteer ICBs with voluntary pre-set evaluation process.</p> <p>Voluntary evaluation process to also be promoted to ICBs already in a change process, again looking at the extent to which the housing fields have been filled in, and what the enablers and barriers are.</p>	<u>Would require:</u> <ul style="list-style-type: none"> • NHSE or DHSE managed comms process • Evaluation support
Review evaluation data, iterate housing fields set based on practical understanding from STEPS 1(a) and 1(b).		
<u>STEP 2</u>	<p>A formal pilot of routine recording of the recommended housing status field for a specified period e.g. in A&E, GP setting and/or outpatient settings.</p> <p>The implementation, workforce and culture complexities are such that we are recommending an initial pilot to generate lessons for full roll-out.</p>	<u>Would require:</u> <ul style="list-style-type: none"> • Considerable organisation, partnership and recruitment of sites • Training and buy in of receptionists and staff • Local IT support to make changes • Interviews of patients and staff Evaluation team
Review evaluation data, publish, and plan whole systems change approach on the basis of the findings.		

Annex B – Technical Note

In 2018 a group of experts from Pathway, Crisis, Shelter, MHCLG and the Collaborative Centre for Inclusion Health, came together to consider what a standard set of housing fields might look like.

The group sought to develop a set of fields that were:

- Limited in scope
- Acceptable to patients
- Understandable by patients
- Understandable and easy to deliver by receptionists and administrative staff
- Useful to clinicians
- Fit for purpose for research, enabling health outcomes to be tracked across different housing types
- Aligned to SNOMED

To inform the process, the following existing data sets were reviewed:

- NHS Digital mental health, community and emergency care data sets
- NTDMS – National Drug Treatment Monitoring System Classification
- FEANSTA – European Typology of Homelessness and Housing Exclusion (full data set of 13 fields)
- MHCLG data requirements for H-CLIC returns

A group of fields were then decided on which split the codes into two main categories of 'stable' and 'unstable' housing.

<u>STABLE HOUSING</u>	<u>SNOMED CODE</u>
Lives in own home	160943002
Lives in local authority rented accommodation	491751000000100
Lives in housing association rented accommodation	491761000000102
House rented from private landlord	160940004
Lives in warden-controlled accommodation (older persons specialist housing)	224221006
Lives in care home	248171000000108
Lives in nursing home	160734000
Lives with family	224133007
Lives with friends	224131009
Student hostel (university or college accommodation)	224682008
Armed forces accommodation	224683003
Accommodation tied to job	224217004
Lives in mobile home or caravan	242721000000106

Lives on boat	700209003
UNSTABLE HOUSING OR HOMELESS	
Living in temporary housing	247521000000104
Lives in bed and breakfast accommodation	160744003
Living in hostel	266939009
Sleeping rough	224229008
Sleeping in night shelter	224231004
Living in refuge	864131000000100
Lives in squat	266940006
Living temporarily with family ('sofa surfing')	381751000000106
Living temporarily with friends ('sofa surfing')	381751000000106
OTHER	
Hospital inpatient	224225002
Intermediate care	892601000000108
In prison	791591000000107
UNKNOWN / DOES NOT WANT TO DECLARE	
Accommodation type: unknown	1066881000000100
Accommodation type: does not want to say	94411000000102

Table 2: Suggested housing status codes for NHS health teams

Volunteers with lived experience of homelessness were consulted on this set of fields, including one group with 22 participants. They clearly understood the potential benefits of the recording housing status in health data, and in other government data sets, and were broadly supportive.

However, they did raise very sensible points which included:

- They felt the reason for recording housing status would need to be explained, and ultimately it would benefit from a public information campaign.
- They were concerned regarding changes to housing status, and whether there was any evidence that housing status would be asked about and updated regularly and thus be accurate on records.
- They wondered if people would be likely to be asked for eligibility information if they were recorded as having a 'homeless' housing status.
- They felt some people might feel sensitive about giving homelessness information, and felt that this would need to be managed carefully e.g. at reception desks.
- There was a concern that some 'catch-all' categories like 'Lives in hostel' cover a wide variety of different situations. However, they recognized the need for a limited set of fields.

- Lastly, they felt we would need to know whether being asked about housing status could ever put someone off accessing services.

These were all relevant and legitimate concerns that would benefit from exploratory work.

References

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- ⁶ Processing Cycle and Emergency Care Dataset. NHS England. <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/emergency-care-data-set-ecds/data-quality>