

The unseen struggle: the invisibility of homelessness in NHS data

Report

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Introduction

Inclusion Health groups – including people experiencing homelessness, migrants in vulnerable situations, sex workers, people in contact with the criminal justice system, and Gypsy, Roma and Traveller (GRT) communities - experience some of the worst health outcomes in our society. However, despite the common refrain from Government and the NHS that ‘data saves lives’, these groups are still often ‘invisible’ in health data. This limits services’ ability to understand the effectiveness of the care they provide, and makes it hard for health systems to take population-based approaches to identify and meet these groups’ specific needs.

This CF and Pathway joint paper takes a particular focus on people experiencing homelessness. In it we explore some of the real-world experiences of homeless patients that result from both a lack of data, and from information about a patient’s needs that exist in one part of the system, not being available somewhere else at the time and place that it is needed. We identify lack of meaningful representation in NHS data as a key blocker to consideration in healthcare planning and make a number of recommendations for how health systems could better respond to the needs of homeless patients. Implementing these recommendations would also benefit other inclusion health groups.

What is inclusion health?

Inclusion health is an umbrella term used to describe people who are socially excluded, including individuals experiencing homelessness, who typically experience multiple overlapping risk factors for poor health, such as poverty, violence, and complex trauma.

In this paper we focus specifically on the data and information sharing issues relating to people experiencing homelessness¹. However, it is worth noting that many of the issues explored here apply across all inclusion health groups; poor outcomes and limited access to healthcare are exacerbated by poor quality or non-existent data.

Background

People experiencing homelessness experience extremely poor health outcomes, with an average age of death of [45 years for men, and just 43 years for women](#). They are more likely to experience many common conditions and often at a higher level of severity than the general population. For example, residents of a London homeless hostel were found to have the same level of frailty as 89 year olds in the general population, despite having an average age of just 56 years².

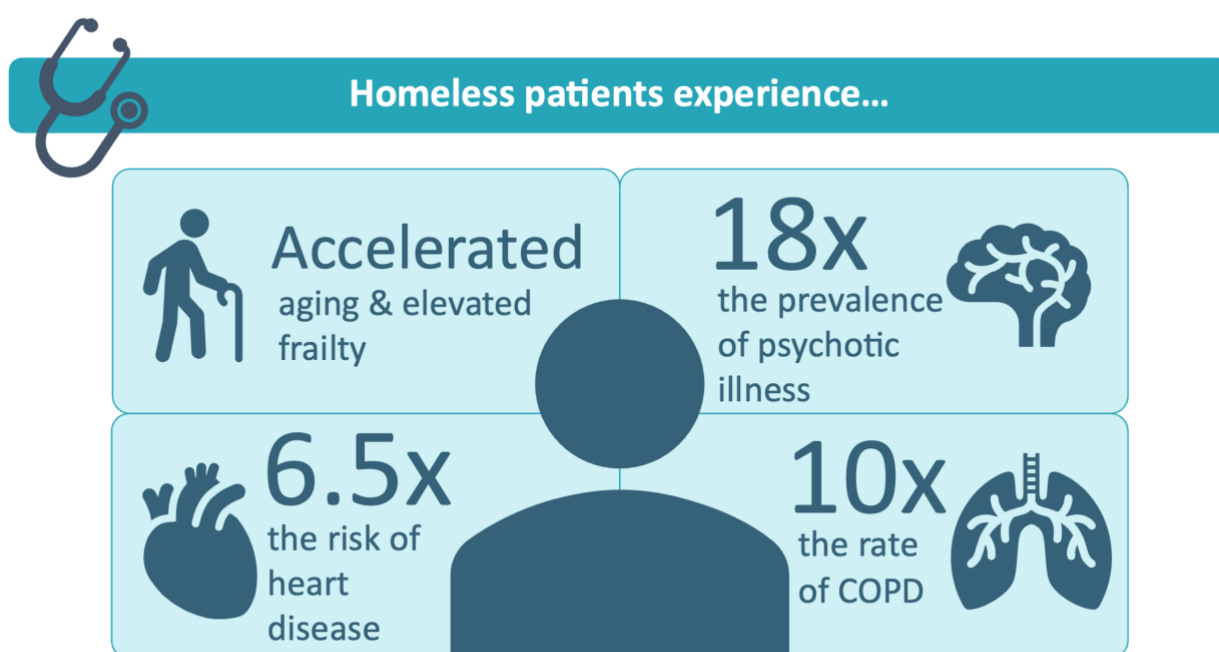


Figure 1 Common conditions and homelessness
[Government guidance for hostels and day centres not helping](#), Pathway, 17 March 2020

It is not just poor living conditions that drive these terrible outcomes. People experiencing homelessness face many barriers to accessing different health and care services. Not having an address or identity documents, stigma among staff, communication difficulties (e.g. language and literacy challenges), and inflexibility in services can all leave people unable to access timely care. Difficulties accessing primary care can then drive an over-reliance on emergency services, increasing demand on already overstretched parts of the system.

Because of their poor health, people experiencing homelessness often need to use multiple different types of care (for example, primary care, mental health services, and addiction services)

¹ The term 'people experiencing homelessness' includes people who are rough sleeping, living in homeless hostels, sofa surfing, and people placed in temporary accommodation.

² Rogans-Watson et al. Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel, Emerald Insight, 2020 September

and these patients also move around frequently. Timely and effective data sharing, and giving frontline staff contemporaneous access to someone's recent history avoids patients having to keep repeating their stories and is important for patients' safety. Unfortunately, this is not the routine experience of patients experiencing homelessness across NHS services.

Below is an illustrative example developed by Pathway and CF, based on real-life case studies, which outlines the difficulties that people experiencing homelessness can come up against.

Jamie is originally from Exeter but is currently living on the streets in Newcastle. He is still registered with a GP in Exeter and has suffered from severe mental illness with associated self neglect for several months.

Jamie attempts to register with a local GP in Newcastle but is initially rejected by several GP practices who ask for proof of address or identification, neither of which he can provide. In the end, a local GP offers to register him as a temporary patient, but this means that his care record is unavailable to both GP and local services.

Unfortunately, Jamie then attends A&E due to an acute episode. He is assessed, and is thought not to need admission, but is noted to need senior review. Because his prior health record from Exeter is largely inaccessible, clinicians are unable to see that there are significant safeguarding concerns. He is allowed to self-discharge, before review. Jamie is told that a follow-up appointment will be organised on the phone number he has given, but he later has no access to his phone after losing it. They do not realise he is homeless, because they have not asked him about his housing status, and he has given a "care of" address and they have not understood this. Unsurprisingly, following discharge Jamie's mental health deteriorates in tandem with a worsening acute episode, after no follow-up is enabled. Without access to a permanent GP, this deterioration is not tracked or assessed.

Weeks later, Jamie attends a different A&E in Newcastle, after his acute episode again worsens. The clinicians do not access his prior care record in Newcastle, so that are not aware that he recently attended a nearby A&E with the same ailment; and because of his now severe mental health crisis, Jamie is unable to tell him this. Care is slow and requires a lengthy procedure to re-diagnose the same problem.

Again, because clinicians cannot access his full care record, they are unable to view his history of mental health problems and Jamie is allowed to self-discharge. Following these traumatic experiences, his severe mental illness increases in acuity and, rather than being treated through early intervention, Jamie is arrested and then sectioned, following a psychotic episode.

Given these extremely poor experiences and outcomes, it is critical that people experiencing homelessness are accurately captured in health service data, that their complex needs are identifiable and visible, and that up-to-date patient data is shared between relevant providers to enhance the quality of patient care.

Expectations for improvement have been set out by NHSE in the form of the [CORE20PLUS5](#) health inequalities strategy, itself now supported by the more detailed, '[national framework for NHS - action on inclusion health](#)'. This focus on tackling health inequalities should help ensure that

systems put the right infrastructure and care pathways in place to support vulnerable patients with these complex sets of needs.

What is the challenge?

We highlight three main challenges with regards to the quality and availability of healthcare data about people experiencing homelessness. These barriers represent different sides of the same problem, and the impact that inaccurate, incomplete and siloed data has on our ability to improve healthcare and health outcomes for people experiencing homelessness.

1. Barriers to accessing primary care – affecting appearance in datasets

GP services are critical to supporting people to maintain their health and manage long term conditions. However, many GP services in the UK are designed to serve individuals with fixed residences. Despite clear NHS guidelines stating that patients have the right to register for GP services without identification or proof of address, many are still wrongly turned away, whether due to poor processes or otherwise³.

In one study, just 65.5% of rough sleepers were registered with a GP compared with 98.0% of the general population – and 20.9% had been refused registration by a GP or dentist in the past 6 months⁴. However even when they are registered, because homelessness forces people to keep moving, people are often not registered in the area they are in, when they next need to seek care.

After this, other barriers exist. For example, to get an appointment people may be required to phone at 8 a.m. and sit in a telephone queue (requiring credit on a phone, and high levels of organisation). Digital exclusion can also limit their ability to access the service. First-line online registration and appointment booking is standard in many places, presenting another barrier for those without internet access.⁵

As a result of poor GP access, care records can be limited, fragmented, and incomplete making it difficult to fully meet the health needs of people experiencing homelessness. Further, challenges accessing primary care leads to an over-reliance on emergency services. People experiencing homelessness attend emergency departments six times more often than the general population⁵, both because it is their only way to access care, and due to the severity of their health needs escalating without access to primary care. This is despite evidence that they find waiting in A&E harder due to a multitude of factors including complex psychological trauma⁶, stigma and discrimination⁷.

³ <https://www.gov.uk/government/publications/health-matters-rough-sleeping/health-matters-rough-sleeping>

⁴ Elwell-Sutton Tet al., Factors associated with access to care and healthcare utilization in the homeless population of England. *J Public Health*, 2016

⁵ Verity A et al. Inclusion health patient perspectives on remote access to general practice: a qualitative study. *BJGP Open* 2023
<https://doi.org/10.3399/BJGPO.2023.0023>

⁵ <https://www.england.nhs.uk/wp-content/uploads/2022/12/B1263-Supporting-people-experiencing-homelessness-and-rough-sleeping.pdf>

⁶ <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/submit-data/data-quality-of-protected-characteristics-and-other-vulnerable-groups/accommodation-status-homelessness-and-rough-sleeping>

⁷ Moss C, Sutton M, Cheraghi-Sohi S, Sanders C, Allen T. Comparative 4-year risk and type of hospital admission among homeless and housed emergency department attendees: longitudinal study of hospital records in England 2013-2018. *BMJ Open*. 2021 Jul 26;11(7):e049811. doi: 10.1136/bmjopen-2021-049811. PMID: 34312208; PMCID: PMC8314693

2. Barriers to sharing data – affecting current, individual care and future care planning

The many different patient record systems used by both NHS and non-NHS providers often lack interoperability. This means that staff in one organisation can sometimes not easily find out about the care a patient received in another service. For homeless patients who move between places and need support from several services at the same time, improving system interoperability is a vital step towards improving patient care and patient safety.

However even when data systems are interoperable, good and effective data sharing can be difficult to achieve. Data sharing is underpinned by inter-agency data sharing agreements, focused generally within care systems. However these agreements can be very difficult to agree across larger areas as each different agency seeks to satisfy its own information governance rules. Complications or perceived information governance risks in relation to sharing data often result in failed data sharing agreements⁸. This has been true in London, where there are 5 integrated care boards (ICBs), responsible for the health of the populations they serve, bringing together health and care providers and commissioners, and much better progress has been made in local areas such as Bristol.

Data sharing is critical for good care: it allows for proactive measures that improve health outcomes, save costs, improve patient experience, and build trust in clinicians, as well as helping to develop tools that will support specific patient cohorts accessing multiple services, or patients who move geographically. Better data sharing between the different services involved in homelessness would improve collaboration, allow the identification of people who frequently use multiple services and help to target appropriate housing, health and care interventions. It would also improve the efficiency, safety, and effectiveness of existing health care services. When data systems are interoperable, cross-boundary data sharing should also help systems understand health service use by this vulnerable group and pro-actively plan better, more responsive care for the future.



In New Jersey, USA, the Camden Coalition has illustrated what is possible with good data. By bringing together care providers in Camden, the Coalition managed to share and centralise more than 500,000 records of care for 100,000 patients over a twelve-year period, including a large number of patients experiencing homelessness.

Analysis of these records enabled the coalition to identify the highest need, highest cost individuals in the local health system and stage meaningful interventions with a full wrap-around care service. Intervention enabled the emergency monthly cost to drop by a third on average for patients enrolled.

⁸ <https://www.strategyunitwm.nhs.uk/sites/default/files/2021/02/Homelessness%20data%20and%20data%20sharing%20strategy%20Unit%20Final%20Report.pdf>

Finally linking non-live records of activity across primary care, secondary care, addictions, mental health, dental, and ambulance records, and beyond the NHS to other areas such as social care and housing, would further improve our understanding of service use by people experiencing homelessness. However, such data linkage is challenged by a multitude of factors.

For example, many data sets within the NHS can be linked using the NHS number as a unique identifier, when permissions are obtained. However care for people experiencing homelessness, for example in addictions or by street outreach, is often provided by organisations external to the NHS, where the NHS number is not used. This also affects day to day data sharing with such services, and results in further challenges to get the right information flowing in cross-sector working⁷. Data linkage is also challenged by limitations in relation to wider consent and permissions, data capability, finance, and time resource.

3. Lack of identification in datasets – affecting population-based approaches

Where they are able to access care, those without a fixed address are often ‘invisible’ as a cohort in healthcare datasets. Data on housing status or homelessness is not collected routinely, nor in a standardised way. This is despite the provisions of the Homelessness Reduction Act (2017) which requires secondary care providers to refer people experiencing homelessness or at risk of homelessness to a relevant Local Authority, with the patient’s consent. Pathway’s recent review of the operation of the so called ‘Duty to Refer’ found compliance with this legal duty was poor in many areas, and recommended further monitoring of its implementation and more basic training for staff.⁹

Frontline healthcare professionals are often not trained to identify people experiencing homelessness by asking the right right questions. Training is needed, because when asked about their address, homeless patients may give a hostel address, temporary accommodation details or their last fixed address, meaning that their homelessness is not flagged in their record. These patients will be invisible to analysts trying to identify cohorts of people experiencing homelessness⁹ and the health risks arising from their poor housing status will remain invisible to the system.

This lack of identification also prevents meaningful population level analysis of mortality rates. Understanding differences in mortality between patients experiencing homelessness and the general population is currently challenging given the limitations of existing data. For example, retrospective analysis of death certificates which mention homelessness has been used to create the [ONS data set on deaths in homelessness](#), but this is not real time data from NHS care records and is therefore limited. Overall, there is a lack of clear data on mortality rates for people experiencing homelessness.

Why is this an issue?

⁹ Beyond the Ward – Exploring the Duty to Refer in Hospital Settings Jan 2024 <https://www.pathway.org.uk/resources/beyond-the-ward-exploring-the-duty-to-refer-in-hospital-settings/#:~:text=Produced%20by%20inclusion%20health%20charity,the%20Homelessness%20Reduction%20Act%202017.>

¹⁰ <https://www.strategyunitwm.nhs.uk/sites/default/files/2021-02/Homelessness%20data%20and%20data%20sharing%20Strategy%20Unit%20Final%20Report.pdf>

The NHS is driven by data. Commissioning and service planning rely on effective patient information, as does the move towards a population health management approach, identifying cohorts of patients requiring more proactive and holistic care than others. Excluding those without a fixed address and being unable to link the impact of housing status on an individual's health hampers our ability to mitigate the negative health impacts of homelessness and target care to those in need.

The NHS is failing people experiencing homelessness, who are often not featured in local NHS datasets because of difficulties accessing care. And then, where people experiencing homelessness do appear in health datasets, they are often not flagged as homeless, or identifiable by their housing status. Data sharing combined with rich and accurate data is vital for a thorough understanding of healthcare utilisation and helps systems design more proactive measures that improve health outcomes, save cost, improve patient experience and build trust in clinicians.

Progress to date

National and local support for change has begun to build, with NHS England and ICBs both leading efforts to understand why health outcomes and experiences differ between population groups. Lessons learnt from broader integration of health inequalities into NHS data processes could help drive the case for change for homeless and inclusion health groups.

Standardised data field

A key goal to enhance visibility of homelessness in the data is to include a housing status code in every NHS dataset and evaluation, which is completed routinely and accurately. There are now housing status field drop downs in the mental health (MHSDS) and community health (CSDS) and emergency care (ECDS) services NHS datasets, which all ask for [accommodation status codes](#), for example including “rough sleeper”, “temporary accommodation” and “night shelter”. The MHSDS and CSDS both have quite comprehensive drop downs, whilst the ECDS is more limited.

The housing fields in MHSDS and ECDS data sets were recently updated in response to Pathway lobbying in this area. Pathway has independently developed a set of recommended housing fields in SNOMED for health data sets, alongside key partners. The improvements to these data sets were actioned in response to this work led by Pathway, rather than work led by centralised policymakers, after Pathway had put forward the case for change, which is a significant achievement.

However, as of February 2024 the housing status field in the MHSDS only had a completion rate of 21%, indicating a need to encourage increased completion and probably training.

Pathway also created a [primary care homeless and inclusion health template](#) which is available within EMIS and SystemOne. This has a set of standardised housing fields, and also includes standardised codes for other elements of inclusion health.

Data sharing

Some areas have made good progress in data sharing, and this has significantly improved care and the patient experience. However these cases have been fairly isolated examples of good practice.



Dr Mike Taylor is Lead GP at the Homeless Health Service, a homeless and inclusion health GP service in Bristol. From his desk, Mike has access to the EMIS data-sharing platform used by 106 GP practices in Bristol (covering about one million patients) and Connecting Care, a local electronic patient record allowing health and social care professionals in Bristol, South Gloucestershire and North Somerset to access outline NHS patient information. Through this and the other systems he is able to get contemporaneous information about hospital admissions, mental health and addictions care appointments and events, and is even able to see notes made by hostel workers and send them direct messages.

One of the benefits of this is that it stops potential retraumatisation when patients are asked for the same information repeatedly.

[“You get so sick of retelling your story.”](#)



CF recently supported Greater Manchester ICS with a ground-breaking population health management study that divided Greater Manchester’s population into eight segments, each broken down by age group, including a population cohort of patients experiencing homelessness or substance misuse, and calculated their need, in terms of hospital healthcare resources utilised.

For the first time, by using Greater Manchester’s fully integrated care record, CF was able to identify the specific health complaints of patients experiencing homelessness and identify the cost this imposed on the system. Patients experiencing homelessness or substance misuse in Greater Manchester together made up less than 0.5% of the population, but were responsible for 4% of total healthcare cost, reflecting the very high needs of patients in this cohort.

This was only possible because Greater Manchester has invested in a longitudinal health record that enables analysis over a long period of time and links data at the patient level across all settings of care, including primary care, community care, mental health, social care and acute care using the NHS number.

Matt Hennessy, Chief Intelligence and Analytics Officer at Greater Manchester ICS: “This analysis has supported the system to quantify the importance of, and direct its focus towards, addressing the social determinants of health alongside our efforts to deliver efficient and effective healthcare services.”

An attempt to get better pan-London data sharing across inclusion health services was initiated by Pathway in 2018. However, whilst sharing within ICB areas has improved, interoperability and information governance issues continue to frustrate wider city-wide progress, although the [One London](#) project is working on this.

Data integration

Several initiatives have sought to link data to better understand the healthcare experiences of people experiencing homelessness and to understand how organisations can collaborate to provide the necessary care to meet holistic needs.

The national Homelessness Data England project aims to improve understanding of homelessness and inform interventions through data linkage. It will use local authority data to create a de-identified lookup table that links the Homelessness Case Level Information Collection (H-CLIC) dataset to other government department datasets (e.g. justice, education, health), supporting understanding of factors and outcomes associated with homelessness.

Barriers to progress

As we have identified throughout this article, there are a number of barriers to continued progress.

Restrictions on primary care registrations

Clinicians are unable to view the full medical records of patients who do not have a permanent local registration, delaying care as medical histories have to be repeated and preventing a 'whole patient' approach.

Information governance

Lack of clarity on information governance requirements, including how to uphold and comply with the law, delays improvements in data provision and sharing for homeless patients.

Lack of capital budget

Substantial capital investment is required when updating or rationalising data systems. This is a low priority in the uncertain economic environment but essential to ensuring that homeless patients are meaningfully included in datasets.



Changemakers' competing priorities and lack of engagement

Competing pressures at local and national level mean that inclusion health, and longer-term data infrastructure programmes, are not prioritised.

Stigma

People experiencing homelessness may not readily disclose housing status in healthcare settings, perceiving that it will negatively impact their care.

Data inconsistency and incompleteness

Data on homelessness is recorded differently and is not mandatory. When data on housing status is recorded, it may become out-of-date for people experiencing homelessness. There are difficulties in linking datasets which use different metadata.

Lack of interoperability

The multitude of different systems used to record data makes interoperability and effective data sharing a challenge.

Recommendations

Improving representation of people who are homeless will be difficult but we have developed a set of practical and actionable recommendations that can help drive this agenda forwards.

1. A national data champion for homelessness and inclusion health

NHS England should identify a national champion to prioritise and drive homeless and inclusion health data compliance, quality and interoperability and to make sure housing status (and other key markers for inclusion such as Gypsy, Roma, Traveller ethnicity fields) are included in longer-

term data infrastructure programmes. The champion should work closely with ICBs and NHS providers and third sector and service user representatives to encourage them to respond to these recommendations. NHSE should consider establishing a Homelessness and Inclusion Health board, including champions who can drive this work at the local level and share best practice.

2. Adopt the housing status fields in the MHSDS and CSDS across all health datasets as a common current gold standard

The housing status fields in the MHSDS and CSDS are two current examples of a gold standard in terms of an appropriate level of detail to support patient care coordination and visibility of people experiencing homelessness. These could be chosen as standard and could be adopted in the ECDS and other acute datasets (inpatient and outpatient care), as well as across government departments, meaning housing status fields would be the same across NHS datasets.

3. Incentivise data collection in different care settings

The housing status fields in MHSDS, CSDS and ECDS offer the opportunity to understand the care experiences and outcomes of those experiencing homelessness but Trusts and systems need to be encouraged/incentivised to complete this field. A campaign led by the national data champion could deliver training to Trusts on the importance of completing this information as part of patient triage.

Further, the health champion should explore the potential for these fields to be included in the quality outcomes framework (QOF) metrics, which would incentivise primary care organisations to record housing status and increase visibility in primary care data. By directly linking completion to funding mechanisms, this will directly contribute to improved completion rates.

4. Initiate monitoring of the Duty to Refer brought in through the Homelessness Reduction Act

Hospitals that have good adherence to the Duty to Refer also have better recording of housing status. Better monitoring of the Duty to Refer would result in better recording of housing status, and hopefully also better outcomes for patients in terms of a resolution of their homelessness.

5. Training of frontline healthcare workers to approach conversations about housing status sensitively

Frontline healthcare workers should be trained to approach interactions with patients experiencing homelessness tactfully, to ensure that patients feel safe to share the basic details of their housing status. Training should address the different forms of homelessness including hidden and statutory homelessness, and best practice on how to have conversations sensitively (using a trauma-informed approach) acknowledging that some patients may be hesitant to share their experiences and this kind of information. This would have the effect of improving data quality as well as the quality of care people experiencing homelessness receive.

6. Collate and publicise evidence quantifying the cost of elevated healthcare consumption to articulate the adverse health outcomes seen amongst people experiencing homelessness and promote engagement from providers and policymakers

Better publicising this cost to both providers and policymakers will help organisations to understand the importance of investing in and focussing on homelessness and inclusion health, given financial constraints in the NHS.

7. Consider options to better understand the contribution of gaps in clinical access or quality care to mortality in people experiencing homelessness

Efforts to measure/collect data on deaths in people experiencing homelessness should be redoubled, with a particular focus on determining cause of mortality. This is particularly important as the proportion of deaths related to substance misuse and suicide, for example, is often overstated in comparison to deaths from preventable or treatable health conditions, in part as data frequently comes from coroners' reports investigating unexpected mortality¹⁰. Consistent processes should be adopted to record contributory factors to deaths, including access to quality healthcare, perhaps modelled on 'confidential enquiries', which have previously helped to drive improvements to maternity, mental health and sepsis care.

8. National guidance on information governance to support understanding and process

Working with all the partners listed in NHS England's National Framework for Action on Inclusion Health, clear guidance should be set out for NHS organisations on how to improve data collection, monitoring and reporting on housing status and ensuring that population health management and service integration activity within ICBs identify improving locally held data on homelessness and other inclusion health groups as a priority.

¹⁰ Aldridge RW, Menezes D, Lewer D et al. Causes of death among homeless people: a population-based cross-sectional study of linked hospitalisation and mortality data in England. [version 1; peer review: 2 approved]. Wellcome Open Res 2019, 4:49 (<https://doi.org/10.12688/wellcomeopenres.15151.1>)