#HealthNow Literature Review 2020: Trends in patient experience when experiencing homelessness

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1. Executive summary

It is well established that not having stable and safe accommodation is an independent factor in determining adverse health and social outcomes and low life expectancies.[1] The COVID-19 pandemic has starkly illuminated and perpetuated the existing health inequalities faced by people experiencing homelessness[2]. It is more important than ever to ensure we understand the patient experience of people who are homeless when engaging with the healthcare system to understand the barriers they face to accessing services and better meet their health needs.

#HealthNow is a UK wide campaign, working towards an inclusive health system where everyone has access to the health care they need; ultimately moving people out of homelessness.

The aim of this report is to understand what the existing literature tells us about the patient experience of using healthcare while experiencing homelessness, highlight gaps in the literature and identify actions. This will inform #HealthNow peer research priorities are decided and provide a contextual basis for the ongoing delivery of the #HealthNow campaign.

The most recent statistics published by the Office of National Statistics showed that 2018 saw the highest increase in deaths of people experiencing homelessness in England and Wales. The mean age of death for men was age 45 and 43 years for women which is 32 and 38 years, respectively, below the life expectancy of the general population.[3]

People experiencing homelessness are more likely to experience poor physical and mental health and often live with multimorbidity (experiencing more than one long-term health problem)[4] due to living conditions and having an increased risk of catching diseases than the general population. Furthermore, people experiencing homelessness commonly face heightened challenges in accessing and utilising health services due to complex personal needs which are underserved by practical, social, systemic, administrative and attitudinal barriers. Consequently, people experiencing homelessness are more likely to present themselves at A and E with advanced illnesses, rather than accessing preventive and primary health services such as the GP.[5] Research shows that many deaths among people experiencing homelessness are often preventable.[6] Research undertaken by University

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[1] Local Government Association (2017) Link
[2] Groundswell (2020) Link
[3] ONS (2016) Link
[4] National Institute for Health and Care Excellence (2016) Link
[5] Homeless Link (2014) Link
[6] Aldridge *et al.* (2019) Link

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College London found that nearly a third of deaths among people experiencing homelessness were treatable.

What is less understood are the reasons *why* there are issues utilising healthcare resulting in poor outcomes for many patients experiencing homelessness. What is it about journeys of care and treatment for people experiencing homelessness that is different or challenging? There is a need to understand these experiences in order to tackle the barriers to accessing healthcare effectively. This report identifies and captures the opinions of people experiencing homelessness from interactions with healthcare services. It has been produced to improve understandings of health inequalities – from the voices of those that experience it first-hand. This includes views on NHS services and/or public health commissioned services while experiencing homelessness. The report also sets out personal patient experiences that relate to specific health conditions of people that are experiencing homelessness.

While feedback from practitioners working with people experiencing homelessness is included in this report, the value and focus of the report are primarily on the views, opinions and stories of patients trying to navigate the health system while homeless. A secondary aim of the review is to serve as a platform to **signpost more research on this topic and subtopics. This will enable the building of a bank of knowledge that** will inform the activities of a national **#HealthNow partnership and system partners** in order to tackle the barriers that result in health inequality**.**

As we gather insight throughout the course of this campaign, the #HealthNow action hub launching in December 2020 will be used to input, revise and monitor the actions that arise – ensuring that actions are followed up and system actors can be held accountable for the delivery of proposed actions. Some of the key issues this literature review identified which will be addressed in the action hub are summarised below:

- People experiencing homelessness often have poor experiences of accessing and interacting with healthcare services and when leaving treatment. This is experienced throughout the healthcare system but the evidence is particularly strong in primary care.

- People experiencing homelessness often felt dismissed by healthcare practitioners based on discourses of drug addiction, stigma and discriminatory attitudes and behaviours.

- The coordination of healthcare plans for those experiencing homelessness are fragmented and paternalistic and often fail to consider the barriers to accessing appointments and long-term treatment.

- Key barriers to accessing healthcare include lack of phone credit, poor access to the internet, lack of ability to travel to healthcare centres, lack of accessible information and assumptions that a fixed address is needed to access services.

2. Background

2.1 Homelessness and inequality

In the patient experience literature, homelessness is often reduced to just rough sleeping. While rough sleeping might be considered the 'sharpest end' of homelessness, homelessness is a broad concept and largely refers to people who do not have access to safe and stable accommodation. This includes rooflessness (or rough sleeping), but also 'sofa surfing', unstable, temporary or short-term tenancies, including 'hostel' provision, inadequate housing (such as overcrowding) or living in unsafe environments (such as domestic violence).

Homelessness is intrinsically linked with Multiple Exclusion and Severe and Multiple Disadvantage – this is where certain subgroups of people experiencing homelessness experience deep social exclusion. Consequently, homelessness should not be viewed as a 'single' issue but is often indicative of other disadvantages such as poverty, adverse childhood experiences, poor health, poor education, family breakdown and substance misuse that might be experienced simultaneously.[7] Researchers advocate that services responses should not be based on a 'single' issue but are coordinated around homelessness 'intersections' (such as health, substance misuse) and take into account the level of complex needs that may span over a number of social issues.[8]

Not all people who are experiencing precarious housing situations have high health needs or will experience poor health outcomes, nevertheless, the relationship between homelessness and poor health becomes more likely when people experience severe challenges in their lives. For example, people experiencing rough sleeping often have highly complex health needs resulting in an average of 11 people dying every week in the UK; more than a quarter are under 40 years old.[9] 80% of people experiencing homelessness have unmet mental health needs,[10] and 73% have physical health issues.[11] These figures are much higher than

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[7] Bramley *et al* (2015) Link
[8] Fitzpatrick *et al* (2011) Link
[9] UCL (2019) Link
[10] Mental Health Foundation (2016) Link
[11] Homeless Link (2014) Link

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the general population. University College London (UCL) recently found that nearly one-third of rough sleepers die from treatable conditions such as tuberculosis, pneumonia and gastric ulcers.[12]

While good work has been done in carrying out Homeless Health Needs Audits to document the types of health needs across the country,[13] it is challenging to develop concrete actions to improve health for people experiencing homelessness without exploring trends in patient experience. It is well known that poor health and the experience of homelessness are inextricably linked. Yet, in discourse about the premature death of people who are rough sleeping, the narrative has mostly focused on a lack of housing.

The health system presents barriers to entry to services and is often difficult to navigate for those experiencing homelessness. There is inconsistency in information among services and staff about the rights of people with no fixed address accessing healthcare. When someone is experiencing homelessness, they are often living chaotic lives, trying to navigate systems working in silos to find a safe place to sleep, secure work, claim benefits and overcome debt – their health is not a priority. People need support to overcome the barriers to accessing health care and treatment.[14]

Local action to address health inequalities for people experiencing homelessness is not strong enough. The government's Rough Sleeping Strategy indicates that *'there is a clear link between homelessness and health and wellbeing, which is not always being made at the local level, which we are keen to address'.* Despite pockets of commissioning of specialist homeless health services, there is a lack of joint strategic action planned to address the barriers to mainstream services which lead to inequalities.

2.2 The #HealthNow Partnership

Groundswell and national homelessness charities Crisis and Shelter have formed the #HealthNow Partnership to take a national approach to overcome homeless health inequalities. Backed by funding from the National Lottery Community Fund the partnership will deliver the #HealthNow programme across the UK over the next four years, working towards an inclusive health system where everyone has access to the health care they need; ultimately moving people out of homelessness. This will directly benefit at least 450 people experiencing homelessness as well as 65 volunteers who have previously experienced homelessness.

Together we will create local #HealthNow alliances of people working in health and social care and who have been homeless themselves in Birmingham, Greater Manchester and Newcastle. Alliances will tackle local barriers to accessing healthcare for people experiencing homelessness informed by peer-led research in those areas. Local #HealthNow

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[12] UCL (2019) Link
[13] Homeless Link (2014) Link
[14] Homeless Link (Unknown) Link

alliance members will use this insight to co-produce solutions to overcome homeless health inequalities in their area. Through our partnerships, we will deliver frontline Homeless Health Peer Advocacy (HHPA), helping people experiencing homelessness address physical and mental health needs across Greater Manchester, Birmingham and Newcastle.

The local activities, insight and changes will inform a national #HealthNow alliance leading to nationwide actions being adopted to improve homeless health, ultimately helping people move out of homelessness.

3. Summary of methods

This literature review is based on a search of the Patient Experience Library, which contains over 60,000 publications on patient experience and involvement. These include surveys, studies and policy documents from sources including government bodies, patient voice organisations, health charities and academic institutions. There was also a call for evidence to which submissions were sent by academic institutions and voluntary sector organisations. The literature review aimed to uncover:

- Literature that directly addressed the healthcare experiences of people who are homeless, and
- Literature that addressed related issues - for example, inequality or social determinants of health

The library contains both formal literature and 'grey literature'. The search covered all documents in the Patient Experience Library up to the 27th September 2019. See Appendix 1 for the full methodology.

4. What the literature tells us about patient experience while homeless

A large body of evidence suggests that patients who are homeless are unnecessarily let down by the challenges they face at the point of access, which continue through acute and secondary care. In this section of the report, the key themes that will be discussed are:

- **Barriers to accessing health care**
  - o This includes issues such as registering and accessing health services, the lack of resources to book and attend appointments, inaccessible opening times, and issues of patients being unaware of their healthcare entitlement.

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- **Homeless service users experience of receiving healthcare**
  - This includes experiences of stigma and discrimination by healthcare staff, the impact of administration systems and the strengths of specialist support.

- **Quality of care received**
  - This includes service users reflections on the admissions procedure, the lack of ownership over personal healthcare support plans and the weaknesses of long term and end of life care. This section will also review current policy and specialist service experiences. Groups of the population that face additional barriers when experiencing homelessness will also be considered.

4.1 Barriers to accessing healthcare

A prominent theme present in the literature is the barriers to accessing NHS and public health commissioned services – particularly primary care services. The ability to register and access healthcare on an ongoing basis is often restricted due to normalised and bureaucratic routines which are aggravated by the personal challenges an individual might be facing. Many studies from across the country show that appointments with GPs and hospitals are gained through competitive process of first come first serve- they can be hard to get, and hard to get to.[15] For people experiencing homelessness, there are additional complications. This section of the review will outline a range of evidence around the challenges in first accessing care. It also suggests that when people have successfully registered for services, they find it difficult to access appointments due to set up of healthcare booking systems which often require the use of a telephone and the internet, in addition to requiring a certain level of literacy.

4.11 Registering for services

Difficulty in registering for healthcare services was a common challenge and theme identified in the available literature – particularly in relation to accessing GP services. However, the literature suggests this was a problem for much broader service use, such as mental health support and accessing dentistry services. This is due to the perceived requirement of having to provide proof of ID and an address when registering or accessing services. This can prevent people experiencing homelessness from being able to access services – and even registering with a GP. Often, qualitative comments in papers from those experiencing homelessness illustrate the difficulties they had with registering and accessing primary healthcare services. While criteria in some organisations may be discretionary, NHS England registration guidelines state that people do not need a fixed address or identification to register and access treatment at a GP surgery. A GP surgery is not allowed to refuse registration on the basis that a patient does not have any identification

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[15] Healthwatch Reading (2017) Link

documents.[16] There have been instances of patients being sent away from surgeries and clinics without being able to access any medical information, advice or medical interventions as they were unable to provide the documents required[17]. This prerequisite of providing an address is not only against regulations[18] but problematic as people who are likely to have a health need are unlikely to have that need met. While a report from Hull and East Yorkshire Mind and Emmaus states that while GPs do ask for a fixed address, many GP surgeries will still register patients; there were many instances where individual surgeries may push for identification in order to access patient records. This can be a frustrating experience for some:

> *"Why does everything have to be about accommodation? Full-time job? Help with mental health? Can't get that because I'm not in full-time accommodation, I can't get accommodation because I'm not in a full-time job. It is always back and forth. And I've got to the point where I'm like what's the point?"[19]*
>
> *"Refused by GP, no photo ID."[20]*
>
> *"People need to have a stable address to access this service. This creates an additional barrier for homeless people."[21]*

Nevertheless, the unnecessary push to present an address still generated shame and anxiety among those experiencing homelessness, with the net effect being they avoid registering with the GP:

> *"I'm still under my old address, but I'm scared to tell them as I do not have a fixed address and think they might get rid of me and I will end up with no GP."[22]*
>
> *"Not being able to produce a utility bill or photographic evidence as I do not have a fixed address and I cannot afford a passport."[23]*

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[16] NHS (2019) Link
[17] Healthwatch East Riding of Yorkshire (2018) Link
[18] NHS (2015) Link
[19] Healthwatch West Berkshire (2018) Link
[20] Healthwatch Salford (2018) Link
[21] Healthwatch Manchester (2017) Link
[22] Healthwatch Lancashire (2016) Link
[23] Healthwatch Lancashire (2016) Link

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The above quotes show that although people experiencing homelessness have the same rights to healthcare as the housed population, for people in this situation it can feel like they have less eligibility in accessing healthcare due to systems not accounting for a range of accommodation arrangements.

The oral health of those experiencing homelessness is often very poor with people experiencing enduring issues of bleeding gums, holes in teeth and dental abscesses causing mouth pain and tooth loss.[24] The reality of being homeless means that there are high levels of sugar intake (from lack of access to healthy food and drink) and often a lack of self-care, plus drug and alcohol misuse, tobacco smoking and lower rates of teeth cleaning. Despite the need to access dental services, the feedback of people experiencing homelessness attempting to access dental treatment mirrors the challenges of accessing GP services. In fact, reports by Groundswell and Healthwatch Reading found that:

"So it's really hard to register a dentist now. Especially if you are on benefits, a lot of them won't accept you. Their excuse is their books are full. That is the general response; they've got their quotas. Because you are on benefits and you are an NHS patient, most dentists have turned to private now, because they don't want to wait for six months to get paid for the work that they do on an NHS patient."[25]

"I've been striked off of that one, because I've been homeless, and I got there to make an appointment, and they'd struck me off, and you can't re-register – they won't let you – and then to try and find another ...and they charge you too..., and I was homeless and living in a tent, not getting no money, and now I'm still not with a dentist."[26]

This shows that registration procedures across different sectors of the health service can be hostile towards people experiencing homelessness. Requiring a fixed address or identification at the point of access or during care is an unreasonable request for those who are experiencing enhanced complexity compared to the general population. The result can be that people experiencing homelessness health needs can be deprioritised in a context of elevated need.

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[24] Groundswell (2017) Link
[25] Groundswell (2017) Link
[26] Healthwatch Reading (2017) Link

4.12 Digital exclusion

People experiencing homelessness do not always have regular or sufficient access to phones and the phone credit needed to manage their health needs and book appointments. This serves as a further practical disadvantage in being able to access and book appointments:

> "If you are running out of credit [on your mobile phone] and it's on hold [to speak to GP receptionist], you're just running out of credit."[27]

> "If they have a phone there can be problems with charging. Many phones owned by homeless persons don't have internet access."[28]

> "Access to health services is impeded by solvable bureaucratic factors around homelessness such as... lack of phone credit."[29]

People who are homeless are facing increasing digital exclusion as the digitisation of health services prevents people from accessing health information and services due to limited online access – and lack of privacy. This has the consequence that 'sporadic internet access means some people cannot access up-to-date information or might miss the benefits of online services'.

4.13 Literacy issues

Issues with literacy and lack of accessible information can make access to services challenging, as well as understanding conditions and treatment pathways. Some literature highlighted that homeless patients felt that the lack of accessibility of printed/online information prevents access to services and treatment compliance:

> "Plenty of information given, but my GP forgot that I cannot read."[30]

> "I have dyslexia and can't read/write easily. This causes anxiety and stress."[31]

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[27] Healthwatch Reading (2017) Link
[28] Healthwatch Reading (2017) Link
[29] Healthwatch England (2019) Link
[30] Healthwatch Lancashire (2016) Link
[31] Healthwatch Salford (2018) Link

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As alluded to in the previous section, it is often taken for granted that everyone has access to the internet and can easily navigate the web. When people experiencing homelessness can actually access the internet, there is then the issue of being able to process the vast amount of information online, which can use complex language. This means that people cannot find the answer that they need, or find a contact number to speak to someone:

> *"Using the internet is all well and good, but there are too many signpost sites. So you want to find help, and you get loads of pointers, but nowhere where there's actual information. And it's like everybody is pointing to everybody else."[32]*

> *"And there are not that many places where you can contact actually in the real world."[33]*

> *"It's like a maze, follow that thing, follow that thing, follow that thing. You get lost too easy. It's good that they're there, don't get me wrong, but there's too many steps."[34]*

4.14 Getting to and from health services

Being able to travel to services was another difficulty experienced by people experiencing homelessness, especially if they were also disabled:

> *"A and E is not good as I cannot easily go there to treat my leg wounds. Also, drug services are too far to walk when you have a wound in your leg."[35]*

> *"Money, transport and a lack of accessible information they can understand were cited by a large proportion of respondents."[36]*

> *"Dentist is in Eccles, so haven't always got the bus fare to get to appointments. Plus, I could have an anxiety attack, which puts my day in reverse."[37]*

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[32] Peter Bedford Housing Association *et al* (2014) Link
[33] Peter Bedford Housing Association *et al* (2014) Link
[34] Peter Bedford Housing Association *et al* (2014) Link
[35] Healthwatch East Riding of Yorkshire (2018) Link
[36] Healthwatch England (2019) Link
[37] Healthwatch England (2019) Link

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Some people are 'unable to get 'follow-up' appointments for health care due to having no fixed abode – non-contactable'.[38] Consequently, people who are experiencing homelessness may only receive partial or short-term treatment.
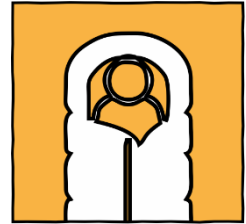
4.15 Understanding and challenges to health entitlements

In Groundswell's Healthy Mouths report, 58% of participants were unsure of what NHS dentistry services they were entitled to. People experiencing homelessness were not always registering with services due to not being sure they were entitled to treatment and were going to A and E instead. This is concerning as many people who experience homelessness felt that receiving dental care helped them 'turn a corner' as they were no longer in pain (or self-medicating) and were able to smile without feeling embarrassed:[39]

> *"Because some people do want to get their teeth done. But because they are challenged with finances, and the lack of information. But if there was a system that was in place to get people to know what they are entitled to, so they can get it done while it is still possible. Do you know what I mean? Then you prevent people from just waiting until it is too late to do the teeth, while they could have known it if there was that opportunity going round the hostel. Maybe through the GP… Once we are registered at the GP, we are given the opportunity to have our teeth checked."[40]*

People who are experiencing homelessness highlighted the importance of knowing their rights to healthcare due to the fear of being turned away. The high levels of need for emergency treatment and lack of treatment can mean that people experiencing homelessness can have to self-medicate to manage pain, or remove their teeth themselves:[41]

> *"I was in a lot of pain when a wisdom tooth didn't come through properly, and it started like rubbing away, and they had to pull it out and stuff. Yeah, it was really painful. I was in pain for months and months. Some days it weren't there, but a lot of the times it was there."[42]*

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[38] Voices 4 Wellbeing (2010) Link
[39] Groundswell (2017) Link
[40] Groundswell (2017) Link
[41] Healthwatch Reading (2017) Link
[42] Groundswell (2017) Link

In terms of eye care, there are restrictions on who can receive a free NHS eye test or receive NHS optical vouchers which are based on the health and income criteria of patients. There are limited NHS funded schemes across the country which deliver free eye care services to people experiencing homelessness[43] – and goodwill is often left to individual ocular organisations and the third sector. One study that briefly touches on people experiencing homelessness interaction with eye care services explains a person's experience; "I need glasses but can't afford them".[44] This signals there is more research needing to be undertaken investigating the eye health of people experiencing homelessness in order to find ways to improve accessibility and affordability of eye care treatment. Another study, although not directly exploring patient experience, has found that a significant proportion of those experiencing homelessness were in need of treatment and regular eye tests,[45] however, entitlement to free services appears to be limited and location dependent.

Experiencing homelessness is not necessarily a prerequisite of receiving free prescriptions. Patients will need to obtain a medical exemption certificate, signed by their GP, in order to receive free prescriptions which in itself may be a challenge given the limited access to primary care. Eligibility criteria include if patients are over 60 or under 16, are in full-time education, are pregnant, have a specified medical condition, a continuing physical disability, have a war pensions exemption certificate, are an NHS inpatient or have a low income and/or claim income support (Benefits). Prescription conditions reinforce the need for easy access to GPs for people experiencing homelessness.

This section of the report starkly demonstrates it is not only about understanding entitlement but the challenges that individuals face in accessing that entitlement.

4.2 Homeless patients experience of receiving healthcare
The feedback from the patient experience literature indicates a skew towards patients having frequent negative experiences in their interactions with healthcare services. This often stems from discourses surrounding the construction of homelessness, meaning that practitioners often treated people with suspicion, as a threat or as having a lack of agency. In fact, the recording of patient housing status on the NHS system often uses fabricated postcodes to internally signal the patient has 'no fixed abode'. However, the growth of specialist services and training for practitioners that focus on how health and social factors cannot be separated indicates a more inclusive and positive experience for those who are experiencing homelessness. The literature suggests that services that offer appointments t

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[43] NHS (2019) Link
[44] Healthwatch Salford (2018) Link
[45] D'ath, Keywood, Styles and Wilson (2016) Link

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that are flexible, longer, more lenient, as well as homelessness service slots, would benefit the health needs of those experiencing homelessness.[46]

4.21 Experience of stigma and discrimination

People experiencing homelessness have reported that they experience stigma and discrimination when they are accessing services, which dramatically affected the quality of their patient experience as they felt like they did not belong in doctors' surgeries and were being judged by the public and health care staff alike. The stigma that people felt was based on judgements on their physical appearance:

"Once they find out if... Well, there is so many things like being a drug user or homeless – you always get second rate medical treatment. They just think you aren't worth treating. They just try and get you out the door, see you later."[47]

"Receptionists…. it's the way they look at you, you know what they are thinking, and it just makes you so uncomfortable…"[48]

"I feel the reception staff at my GP and staff at the hospital do not like me. I have heard them make comments about me."[49]

"I admit that I smell and look scruffy; however, this should not be an issue for the reception staff when booking me in."[50]

"My experience… the stigma is straight away as soon as you walked in… as soon as you walked into the practice, the stigma is you were ill-treated by the receptionist for a start. Oh, it's him from the hostel, just sit over there. And we will get round to you… you know. And you could actually feel the tension in the room – or I could – in the room. I have always felt that the receptionist of any practice, whether it be a GP, whether it be dentist, it's your first line of contact, your first point of call."[51]

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[46] Groundswell (2016) Link
[47] Groundswell (2018) Link
[48] Healthwatch Reading (2017) Link
[49] Healthwatch Lancashire (2016) Link
[50] Healthwatch Lancashire (2016)Link
[51] Groundswell (2017) Link

Patients felt that staff behaviours were hostile towards them, and they did not have time or empathy for their needs. Due to the negative discourses surrounding homelessness (particularly around drug use), people felt like they were being moved on or not believed. These comments are disheartening as people experiencing homelessness often have high needs, but they are presented as an inconvenience. This exclusion then becomes internalised by people experiencing homelessness as the stigma they felt when accessing services had an impact on their confidence and self-esteem, and became a rationale for not accessing, hiding from or avoiding services:

> *"You kind of give up on yourself. You do. And you are waiting until things are extreme before you ask for help because you're so used to being ignored and being seen as invisible. That it... you have to get to a breaking point before [you get help]."*[52]
>
> *"Shame, loneliness or lack of confidence as well as not showing up to appointments are given as the reasons within their control for service users not taking up services."*[53]
>
> *"People felt stigmatised because they were homeless - they didn't feel like they had been listened to and felt rushed in and out of surgeries. In some cases, people did not want to be in waiting rooms long due to people staring at them."*[54]

4.22 Administration problems

Booking appointments at surgeries is a competitive process due to limited appointments available.[55] It was clear that people experiencing homelessness found it difficult and frustrating to access healthcare appointments, especially when GP practices have a requirement to call for appointments first thing in the morning, which is not always easy for people depending on their accommodation situation. People experiencing homelessness found that they cannot get through to reception staff and were having to access healthcare through alternative means, which was often more time consuming:

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[52] Groundswell (2018) Link
[53] Peter Bedford Housing Association *et al* (2014) Link
[54] Healthwatch England (2019) Link
[55] Healthwatch Salford (2019) Link

> *"I am registered with one GP. With my GP, I've got to phone them at 8 o'clock in the morning to try and get an appointment, but when you phone them, they are always busy. That's why sometimes I will go to the walk-in centre. Then when you get there they put you in there to see the nurse then if they think you are worse enough to see a doctor, then they send you to see the doctor."[56]*

Communication about outpatient care has also reported being challenging for people experiencing homelessness which often involves delays and interruptions. In some cases, this has meant that people experiencing homelessness have disengaged from care. Other administration problems, such as last-minute outpatient appointment cancellations were also an issue for people who are homeless when using hospitals. Sometimes the services cancel or reschedule appointments, and this is hard for people experiencing homelessness to track, manage and repeatedly find the resources to re-attend appointments:

> *"Administration problems (such as last-minute outpatient appointment cancellations) were an issue for people using hospitals."* [57]
>
> *"Healthwatch Reading heard from two people who had only been told of a cancellation when they arrived at the hospital. For someone who is homeless, this can be especially frustrating as the journey to the hospital can be costly."[58]*

4.23 Specialist services that are tailored to those who are experiencing homelessness/services that are inclusive of those experiencing homelessness

While there were many structural, attitudinal, bureaucratic and institutional barriers that affected access to healthcare, specialist pathways or services, demonstrating knowledge of the complexities of homelessness have been reported to be useful by patients. These services are mainstreamed into GP practices that have enhanced or targeted services to people that are experiencing homelessness. These primary health care services have aimed to coordinate primary and secondary care packages for those experiencing homelessness bearing in mind the challenges those experiencing homelessness face. While there are still

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[56] Healthwatch Reading (2017) Link
[57] Healthwatch Reading (2017) Link

[58] Healthwatch England (2019) Link

inconsistencies in understanding the effectiveness of these services, in general, these services were more aware of the health and social determinants that have caused and exacerbate homelessness. Consequently, services were more empathetic and solution-focused. They were able to take into account the patient's health and social needs:

> *"Specialist health centres that offer services tailored to vulnerably housed people received positive feedback. Staff treated people respectfully and had a better understanding of the challenges that face people without accommodation. However, these services are not widely available."[59]*
>
> *"In some cases, we've heard positive feedback about GPs or Walk-In centre staff when they are sympathetic to their situation and try to accommodate their needs as much as possible."[60]*

Walk-in services were particularly favoured among patients who expressed their use of walk-in services to access timely support. Patients stressed the need to be able to access services flexibly rather than navigate complex appointment booking systems:

> *"I am registered with the walk-in centre, and I can go straight in come out, and I am happy. I have explained to them beforehand that I'm homeless and I get anxious around crowds of people, so I've explained that to them so they are a bit more sympathetic to me and they don't start judging me because (a) I'm homeless and (b) I got issues."[61]*

Respondents who took part in Healthwatch Salford's research have stated that easier ways to make appointments, informed reception staff, flexible opening hours and to be 'better understood' by the doctor[s] would help overcome barriers to accessing healthcare.[62]

4.24 Quality of care
Despite solid statistical evidence cited in many studies stating that people who are experiencing homelessness have significantly higher usage of hospital-based services than the rest of the general public,[63] there are relatively few patient experience reports that

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[59] Healthwatch England (2019) Link
[60] Healthwatch England (2019) Link
[61] Healthwatch Reading (2017) Link
[62] Healthwatch Salford (2018) Link
[63] Homeless Link (2014) Link

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focus on inpatient and outpatient care delivered by NHS Acute Trusts. The section reflects on the experiences of people experiencing homelessness when they are admitted to hospital, during their stay in hospital, when they leave hospital and end of life care. There are also comments on patient-centred policy, practice and personal support plans.

4.25 Admission of patients into inpatient care

The process of admission has been reported to be too focused on the immediate presenting illness and not holistic or pastoral care. This means staff provide care and treatment that fails to always look at patient needs holistically, and instead focus on medical over other social determinants of health:

> *"We heard about the crucial opportunity hospital admission provides to establish homeless people's circumstances and find out the full breadth of their needs. However, we learnt that this is not happening enough and that, in some cases, the results can be life-threatening for the patients involved."[64]*

As homelessness and health needs are intrinsically linked within a network of multiple exclusion, just addressing health needs and not broader wellbeing and practical needs means treatment can be self-defeating.

Furthermore, people who are on opiate substitutes have reported difficulty in accessing this treatment while admitted to hospital or awaiting assessment and that this has an impact on their overall care and treatment, particularly if patients enter into withdrawal:

> *"He is a long-term methadone and alcohol user, but when he asked for methadone on the ward, he was told that he had to wait until he visited his local pharmacy where he normally receives this."[65]*

Additionally, the management of a patient's affairs while in hospital has been identified as a contributing factor to homelessness post-discharge:

> *"Usually, they have not had community support prior to their admission. While they are in hospital, their rent arrears get too large, and eviction proceedings start, and they are not able to do anything about it retrospectively."[66]*

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[64] Healthwatch Reading (2017) Link
[65] Healthwatch England (2015) Link
[66] Healthwatch Hackney and City and Hackney Mind (2018) Link

Groundswell

This comment demonstrates the effects of support that is not joined up. The stress of rent arrears and eviction procedures is not conducive to patient recovery.

4.3 Experience of leaving services when experiencing homelessness

The literature suggests that people experiencing homelessness are unsafely discharged from hospital. This means that they did not have sufficient or holistic onward care plans or support in place to assist their recovery upon discharge. In fact, after being discharged from hospital, many patients returned to rough sleeping which often undid any treatment they had received. This reduces the chances of success that people experiencing homelessness will be able to recover from ill health, leading to many patients experiencing repeat admissions:

"The staff at the hospital were nice [but] eventually, I was discharged back onto the streets. I was re-admitted after two months for the same problem."[67]

"I ended up in A and E after a serious suicide attempt, spent a week on an acute medical ward and then was discharged straight back onto the street again."[68]

"The staff didn't talk to me about my circumstances. All they saw was 'NFA' on the form, and they start getting abrupt with you. Sometimes I was kept in, but then I was discharged at any time – no matter what time day or night, I was discharged onto the streets. I would explain that I was living rough, and I had no way of getting back into the town. They said it wasn't their responsibility – walk. It's between 5-10 miles from City Hospital back into town, I'd say. And I was doubled-up in pain."[69]

"Homeless people told us about being discharged without support – often straight back to the street without accommodation in which to recover."[70]

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[67] Healthwatch England (2015) Link
[68] Groundswell (2018) Link
[69] St Mungos (2011) Link
[70] Healthwatch England (2015) Link

Healthwatch England has noted that while there are guidelines on hospital discharge procedures, these are not legally enforced, neither are they sufficiently tailored to the needs of those facing heightened social exclusion. Consequently, staff are not upskilled and don't have the resources to deal with and advise patients in complex situations – even when homeless patients themselves know what they need:

> *"Department of Health guidelines on hospital discharge represent a set of suggestions, which staff and hospitals are advised to follow, rather than a set of actual statutory obligations… people told us that they found staff to be ill-equipped to support and advise them regarding their options as homeless people."[71]*
>
> *"Almost half said that they needed more general assistance to stay well outside the hospital."[72]*

When referrals for onward care plans are put in place, the main groups affected by delayed transfers of care include people experiencing homelessness. Several housing-based organisations have noted this trend, and there are a number of housing projects that are working on increasing the number of preventative care packages and housing step down units, establishing a more effective protocol and raising the profile of proper discharge.

To compound the situation further, there is evidence that the kinds of support that people need to prevent readmission to hospital or worsening health relate to social determinants of health. This includes accommodation, nutrition and social support needed to recover and engage with ongoing care and treatment, which people experiencing homelessness have difficulty accessing:

> *"Failure to establish a clear understanding of a person's circumstances meant that some homeless people were discharged without basic things such as transport – in some cases being told that they would have to walk – as well as clothing and food."[73]*

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[71] Healthwatch England (2015) Link
[72] Carter et al (2019) Link

[73] Healthwatch England (2015) Link

Another issue that can impact recovery is self-discharge. People experiencing homelessness would often discharge themselves against medical advice due to a lack of procedure for supporting their additional needs. For example, allowing patients to manage their substance addiction, hostility of clinical staff and issues with patients experiencing mental health problems:

> *"But the biggest problem I find with hospitals is that - I was a drug user - and if I get admitted into hospital, I need them to supply me methadone immediately; otherwise I'll start withdrawing… Usually, if you're admitted in the late afternoon or early evening…they're not able to give you any methadone that night until the next day. So with most people, even if they're really, really ill, they'd rather not stay and get treated, they would rather leave the hospital."[74]*

> *"Our clients' health is often debilitated, but bad experiences from local GPs or other health professionals means they are reluctant to stay in hospital."[75]*

4.31 Experience of end of life care

Though there are some notable publications from the Care Quality Commission and St Mungos, there is little in the evidence that sets out the patient experience of people who are experiencing end of life care when experiencing homelessness. The evidence that does exist highlights that people who are experiencing homelessness and who are reaching the end of their life have been reported to face additional challenges in being supported appropriately, have their pain managed and have a comfortable end of life. This has been attributed to a lack of timely identification by services that the patient is reaching the end of their life. Consequently, people who are experiencing homelessness who need palliative care are treated informally by their social networks, or in inappropriate settings such as hostels:

> *"For one homeless person who was caring for a close friend who was also homeless and had drug and alcohol addictions, their issue was that the person was not identified as approaching end of life early enough and, therefore, no end of life care was received."[76]*

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[74] St Mungos (2011) Link
[75] St Mungos (2011) Link
[76] Healthwatch Newcastle and Healthwatch Gateshead (2019) Link

Groundswell

> *"Most homeless people with support needs end up in hostels which are not equipped to meet their care needs. Access to mainstream services such as care homes and hospices is challenging due to the fact that many homeless people have additional needs such as addiction and substance misuse."[77]*

These quotes once again demonstrate the lack of holistic and joined-up approaches towards additional needs such as substance misuse, which means that people are perceived as undeserving of treatment.

These findings flag the need for peer-led research to explore the stories of people who are experiencing homelessness but still acting in the role of 'carer' for their peer groups during periods of illness and end of life. This is an understudied area where there needs to be conversations about developing the pathways of support for carers that are also experiencing homelessness.

4.32 Support plans are not co-produced

Some patients have reported that they feel they haven't been listened to and are excluded from participating in joint decision making about care and treatment options.[78] This means that some people experiencing homelessness may disengage from treatment if it is not tailored to their situation, or feel as if they are not a stakeholder in their own support plans. It appears a significant factor in this form of paternalism is down to assumptions about substance misuse. Healthwatch Croydon found that people experiencing homelessness felt that GPs 'explain away' their health concerns by conflating their health worries with substance abuse and referring individuals to the drug and alcohol team.[79] This reductive trend also relates to access to prescription medication where an overwhelming majority of people experiencing homelessness have to manage chronic and long term pain on a daily basis but were disregarded with short prescription painkillers, rather than being given the choice of alternative therapies. Many people experiencing homelessness felt like they were based on their history of substance misuse or living circumstances:

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[77] Involve North East (2017) Link
[78] Peter Bedford Housing Association *et al* (2014) Link

[79] Healthwatch Croydon (2018) Link

> *"You know they don't actually understand the amount of pain that somebody is in to go to them to say I am in pain, can you help me. They are just like oh, here is a service, go and find it yourself.[80]"*
>
> *"One person said they'd been refused pain medication as they lived in a hostel and it could attract people with substance misuse."[81]*

4.34 Lack in coordination and joined-up care apparatus

There are long-standing issues with fragmented service coordination and capacity issues highlighted within the academic and policy literature. As the 2010 Rochdale report sums up:

> *"A lack of joined-up working between health and social care services was highlighted as a concern, and it was suggested that this can further exacerbate the problems homeless people have."[82]*

While the NHS-commissioned public health services and local authorities are constrained by ongoing budget issues, there is still not enough acknowledgement and pragmatism surrounding the relationship between health and social determinants in relation to homelessness. NHS England guidance[83] on involvement in commissioning, with specific reference to equality and health inequality, mentions people who are homeless but does not go into detail. A "Bite Size Guide", also from NHS England,[84] outlines principles for diverse and inclusive participation, but does not make specific reference to people experiencing homelessness. Consequently, people are treated as a homogenous group and care does not see the whole person, but focuses attention on employing a narrow health lens. Services from different health and social policy sectors are not efficiently joined up, and there is a lack of specialist services tailored to those experiencing multiple exclusion. There are bureaucratic, administrative and eligibility barriers and hostile working practices that further exclude people experiencing homelessness. This is often attributable to stigmatising those that are homeless, alongside excluding treatment for those with substance misuse issues, rather than seeing the need for holistic care packages instead of

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[80] Groundswell (2018) Link
[81] Healthwatch England (2019) Link

[82] Voices 4 Wellbeing (2010) Link
[83] NHS (2016) Link
[84] NHS (2016) Link

fragmented service delivery. A recent study from Manchester highlights the negative outcomes of fragmented service delivery:

"The mental health support system for homeless people in Manchester is fragmented, vastly complicated and difficult to navigate, creating barriers to access. Services are also under-resourced, waiting lists are too long, and staff often experience stress. Many services lack an understanding of the complex needs of homeless people or fail to acknowledge their rights as patients."[85]

The continuity of care is also an issue where patients were having to spend time re-disclosing their patient history to new medical practitioners. This was a time-consuming experience and prevented a relationship being built between practitioners and patients:

"Sometimes it does feel as if I do repeat myself and that's quite frustrating because I would expect healthcare services to talk to each other if it's concerning my health and my medication and things like that."[86]

"Once you get help, it's like, "You're better now. See you later."[87]

4.4 Gathering patient experience data about people who experience homelessness
People with experience of using healthcare services while homeless do not have the same opportunity to be engaged in giving feedback about services, be involved in their design or decisions about service changes. For example, the Friends and Family Test is not well understood or engaged with by people who are experiencing homelessness and is not being adapted to enable them to participate:

"it is clear that the Friends and Family Test is in need of being adapted for its audience."[88]

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[85] Healthwatch Manchester (2017) Link
[86] Healthwatch Essex (2017) Link
[87] Healthwatch Essex (2017) Link
[88] Healthwatch Cheshire West (2016) Link

Groundswell

Research papers have considered how people experiencing homelessness can help with "diffusion" of healthcare innovations through personal contacts and networks that commissioners and clinicians may not have access to. This is where people experiencing homelessness can get involved in the building and roll out of new healthcare ideas and practice in the roles of co-producer; expert; advocate; relationship builder; relationship broker; planner; presenter; awareness raiser; trainer; networker. This may help in providing a feedback loop to services by giving hard to reach, marginalised and excluded voices a chance of informing and reforming services to be more inclusive.[90]

5. Experience of receiving treatment for specific health conditions

People who are experiencing homelessness have higher rates of mental ill-health and physical health problems than those living in stable accommodation. Unstable accommodation or rough sleeping can create new health conditions or exacerbate existing conditions. This section will focus on treatment received in response to specific health conditions discussed by those experiencing homelessness. While there are many clinical led research reports that evidence the specific health condition of people experiencing homelessness, there is less patient experience data which details the experience of care pathways particularly the care beyond primary care.

5.1 Mental Health

The prevalence of mental ill-health among those experiencing homelessness is a prominent theme in the literature. A report from Healthwatch Hackney finds a strong relationship between mental illness and homelessness, where the two are often dialectical. The rates of suicide of people who are experiencing homelessness have remained consistently over 10% since 2013.[91]

Applying for and accessing homelessness services can exacerbate stress and anxiety for those with mental health needs. People experiencing homelessness were not always sure about the administrative procedures and the time period it could take to get support in

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[89] Healthwatch Cheshire West (2016) Link
[90] Barber *et al* (2019) Link
[91] ONS (2018) Link

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place. In addition, patients commented that practitioner and service user interactions could be better as patients could sometimes feel that practitioners did not have time for them, and would let them down:

> "Better communication or ways to interact with service users."[92]
>
> "More understanding and contact when saying they will."[93]
>
> "the homelessness application process… was especially stressful for people with mental needs… poor communication, long waits and lack of understanding had compounded their mental ill-health.[94]"

The literature has found that it is common for someone to be admitted to hospital for mental health as a result of housing or financial crises. Equally, and as already discussed, patients could often lose their home during hospitalisation due to an inability and lack of support to manage their affairs while hospitalised. This again demonstrates how health and social determinants are intrinsically linked, which services (both health and social care) need to manage and account for:

> "It was common for clients to be admitted to hospital due to a crisis exacerbated by housing insecurity, debt or money worries. Some patients we spoke to had lost their home during hospitalisation simply because they were too ill to manage ongoing debt, rent and service charges or notify relevant people they were in hospital."[95]

A common experience among patients experiencing homelessness is 'dual diagnosis'. This is where mental illness and substance misuse are co-occurring and reinforcing. This is problematic and alienating for people when trying to access accommodation when there is little specialist accommodation for those experiencing dual diagnosis, or ongoing support when back in housing, alongside a lack of accommodation that does not enforce a drug-free policy.

Healthwatch Gateshead found that people who were homeless or living in insecure housing did not receive adequate support as staff felt that their issues were 'too complex'. It is apparent in the literature that frontline services did not always know how to deal with

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[92] Healthwatch Salford (2018) Link
[93] Healthwatch Salford (2018)Link
[94] Healthwatch Hackney and City and Hackney Mind (2018) Link
[95] Healthwatch Hackney and City and Hackney Mind (2018) Link

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trauma and complex mental health problems and consequently avoided providing support or signposted service users elsewhere. One patient noted:

> *"I told a health professional I was raped ten years ago, I was told it was too complex for her to deal with, they gave me a number to ring instead, I never did."*[96]

> *"I sat for an hour... told him about my issues, that I self-harm when I get depressed... they said come back when your treatment's finished for alcohol use. I felt let down; I haven't been back to mental health support."*[97]

Staff in support services do not always have the level of training required to signpost or assist those with chaotic and traumatised lives. People experiencing homelessness and who are using substances are asked to complete treatment first before being able to access mental health support. This approach to treatment fails to recognise how social issues are interlinked needs to be treated and dealt with holistically and seems to be a recurring theme in the literature.[98]

For some people, the need to escalate their problem in order to get the attention of services and get access help was identified as a major issue. People explained how they had to increase the chaos in their lives through self-harm, criminal behaviour or violence in order to get the help they needed. This shows service provision criteria at anything less than a crisis point is not provided. Other coping strategies endured by people experiencing homelessness with mental health issues were not to engage with the support via phone numbers given to service users.[99]

5.2 Eye care

As mentioned, there is very little qualitative data surrounding people experiencing homelessness and their relationship with eye care services. This is perhaps surprising due to the proportion of the population that require ocular correction. A study on eye care found that one in five people experiencing homelessness had ocular pathology. Over 80% needed glasses, and without spectacles, 14% of the patients would have a functional visual impairment. The study raises concerns such as the following:

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[96] Healthwatch Newcastle and Healthwatch Gateshead (2019) Link
[97] Healthwatch Newcastle and Healthwatch Gateshead (2019) Link
[98] Voices 4 Wellbeing (2010) Link

[99] Healthwatch Newcastle and Healthwatch Gateshead (2019) Link

Groundswell

> "Homeless people are prone to losing or breaking their glasses, having them stolen or damaged through violence. Lost or broken NHS glasses can only be replaced with NHS funding if the loss or damage is the result of a medical condition or disability, so homeless people often go for long periods of time without the spectacles they need."[100]

This quote reiterates the need for more to be understood about the eye health of those experiencing homelessness in order to improve ocular health.

5.3 Oral health

Groundswell's report on oral health and access to dental services found that participants in the study highly valued and understood the importance of taking care of their oral health. However, a significant number of people experiencing homelessness have issues with maintaining good oral health. In fact, 90% of participants had had problems since becoming homeless, including bleeding gums, holes in teeth and dental abscesses. Many people had experienced considerable dental pain, and 70% reported having lost teeth since they had been homeless. Participants shared their experience of challenges in preventative self care and challenges in accessing the dental care they need:

> "When I became homeless I didn't want to stop caring for my teeth but I didn't have the money to look after them. I had a job interview once and I went to the dentist to have a check-up and I asked him if he could clean my teeth. He just said no. He said it's not his job. You need to see a hygienist. It would have made a real difference to my confidence to have had my teeth cleaned. My teeth are falling apart. I've got receding gums which bleed whenever I brush them."
>
> "They [Dentists] need to talk to you like a human being. Because what I have noticed with people since I have been homeless, is that they think you are doing it on your own, they think you just want to do drugs, they think you just want to be on the street. They talk … why don't you get job? Shit like that. And I think that's how a lot of people think, right? Because they just can't comprehend that this shit could be happening in their head."[101]

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[100] Brown (2019) Link
[101] Groundswell (2017) Link

Healthwatch Salford also found that participants were suffering from toothache, including broken and cracked teeth, inflamed gums and tooth decay:

> "Broken wisdom tooth causing intermittent pain."[102]
>
> "Teeth damaged, broken and missing. Can't eat properly."[103]

The circumstances of experiencing homelessness mean people cannot care for their teeth very easily. Respondents were not accessing dental services due to fear, not knowing where to get help or because dentists were at capacity. Poor oral health had a considerable adverse effect on people's quality of life and ability to move on from homelessness. In spite of this, people's trust in dentists was high, and there was significant value placed in oral health. This indicates that with the right support and treatment, people experiencing homelessness could have significantly improved oral health.[104]

6. Experiences of people who experience further marginalisation

Aside from the stigma that people experiencing homelessness may experience due to their accommodation situation, certain groups within the homeless population are exposed to further discrimination due to additional types of status or protected characteristics. At-risk groups include young people, prison leavers, migrants, asylum seekers and refugees, sex workers and those leaving the military. Unfortunately, there is a lack of patient experience data for all these groups, especially in relation to the experience of ex-service people. While there is some statistical information on military veterans experiencing homelessness, there is a distinct lack of qualitative data based on their health and health service experiences. There is a need for more research to be undertaken to understand the stories and experiences of these at-risk groups.

6.1 Migrants, Refugees and Asylum Seekers
The literature shows that migrants, refugees and asylum seekers, are more likely to live in unstable accommodation and have significant unmet health and social care needs. This is due to the costs of living where there is little to no recourse to housing or benefits for those

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[102] Healthwatch Salford (2018) Link

[103] Healthwatch Salford (2018) Link

[104] Groundswell (2017) Link

that do not have residency status. Changes in immigration laws and the impact of fees for healthcare via the NHS cost recovery programme mean that 'migrants' health [is] worse than average'.[105] Demand for and issues with ID and an address mean that migrants, refugees and asylum seekers feel scrutinised and avoid using health services in case they attract the attention of services or fall into debt. Alternatively, they travel long distances to GP practices where they have previously been registered due to tougher administration procedures. Health practitioners, migrants, refugees and asylum seekers have noted that healthcare is no longer about clinical need, but about the policing and surveillance of their status:

> *"Everybody has a problem with documents."*[106]
>
> *"We've been granted asylum now, and my father has to go for dialysis three times a week, for four hours each day, because his kidneys are failing. We still have very little money and no bank account, but I'm just hoping to get my national insurance number soon. Then I can get a job to take care of my parents, and hopefully move out of temporary accommodation."*[107]

This has consequences in terms of excluding migrant, refugee and asylum seekers from health services. Healthwatch found that homeless migrants are left to suffer from dental pain as dental health services do not have transparent administrative procedures in place. Furthermore, interactions with health practitioners can be complicated due to issues around language and cultural barriers, post-traumatic stress and other complex problems, patients not disclosing their illnesses and differences in understandings of patient-doctor interaction and diagnosis/treatment. There is also a lack of patient information as to what services migrants, refugees and asylum seekers are entitled to. As a consequence of healthcare exclusion, people experiencing homelessness are suffering by not accessing treatment and/or are turning to coping strategies such as substance use and misuse:

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[105]Healthwatch Hackney (2020) Link
[106] Healthwatch Croydon (2018) Link

[107] Crisis (2018) Link

> *"A friend of mine, also a rough sleeper, has a pain in her side, but I can't make her visit the GP as she feels intimidated by the reception staff – her English is very basic. Whether this is intentional or not, it means she suffers without treatment."[108]*

> *"I think by and large there aren't traditionally high levels of addiction [In migrant populations?] for lots of different reasons, but we are seeing people that are drinking and taking drugs to numb the pain."[109]*

6.2 Women

Women's homelessness pathways, often determined by domestic violence,[110] can compound their vulnerability to health issues and further abuse while experiencing homelessness. A Groundswell report found that 74% of the women experiencing homelessness taking part in the research self-identified physical health issues, and 64% expressed they had mental health issues. This is exponentially higher than the general population:

> *"But my physical health through being out on the street, I have got a now lifetime illness – COPD. It's a killer. Eventually, I would have to use an oxygen mask. Eventually, I will be bed bound because I won't be able to walk or move without being out of breath."[111]*

The women reported that their experiences of being homeless were stressful, which affected sleep, eating and hygiene patterns. They also experienced a lack of confidence and self-esteem which made it difficult to deal with health problems. Women had to manage their exposure to violence, which services can sometimes fail to spot and mitigate against. Women report being repeatedly passed on and turned away from services. When women receive support, they commented that some treatments and procedures could result in re-trauma.

Intersectional issues such as being female and a migrant compounds women's access to healthcare:

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[108] Healthwatch Croydon (2016) Link

[109] Crisis (2019) Link

[110] Healthwatch Salford (2018) Link

[111] Groundswell (2020) Link

> *"They just refused to care for me because they said you don't have a mental health problem. You're just depressed! That's what they used to say to me. Because you have immigration issues, but you don't have mental health problems. But I was taking anti-depressant before I came to Britain. I didn't understand what they were talking about. And I couldn't be housed. There was nothing there for me. So that's why I ended up getting abused, sexually abused, into porn and things like that."* [112]

Exclusions from health services were particularly acute when migrant women are pregnant or new mothers. Women spoken to stated they were homeless and destitute during all or part of their pregnancies. Women faced charges for NHS maternity care during and after their pregnancies. In fact, migrant women are facing charges for maternity care during and after pregnancy and are being billed at 150% tariff rate.[113] When women were seeking asylum, they reported the negative health impacts of multiple moves (often into inappropriate accommodation) during pregnancy or immediately after the birth, and dispersal away from strong social networks and/or the father of their baby. Some women received little help to register with a GP in their new location or to enrol existing children into school or nursery.

6.3 Sex workers

There is an acute lack of qualitative data from the voices of sex workers in relation to health and homelessness. The existing literature suggests that many sex workers experience homelessness over a long period of time. The impact of homelessness for sex workers is life-limiting, including poor health (including experience diseases such as TB), lower life expectancy, violence, rape and mental illness. Research by Aspinall showed that GP registration is around 83% for sex workers. Registration with dentistry services is much lower. The author found that many sex workers do not inform GPs of their work, which impacts access to care services. This is often based on experiences and/or fear of stigma. As sex workers often work through the day, they find it difficult to access appoints during the daytime. Migrant sex workers found it difficult to access services due to issues with migration status, language barriers and being unaware of how to access services. Many sex workers are not protected and/or screened against sexually transmitted diseases or have access to vaccinations, access antenatal appointments or cervical smears.[114]

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[112] Groundswell (2020) Link
[113] NHS (2016) Link
[114] Aspinall (2014) Link

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6.4 Prisoners and ex-offenders

Prisoners and ex-offenders face high levels of mental health problems, substance misuse, poor physical health, learning difficulties and trauma. However, health and wellbeing are neglected in detention spaces even though there is a raised chance of the spreading of disease. In a report by User Voice, they found that 72% of prisoners stated that it was difficult to very difficult to access healthcare, particularly dentistry, due to long waiting times:

> *"I had to wait four months for a doctor's appointment and had seven appointments cancelled."*[115]

Prisoners also felt judged or looked down upon by medical professionals:

> *"You're left feeling second class and often poor diagnosis is given leaving the health issues getting worse."*[116]

However, patients in prison expressed there were some positive experiences with nurses, substance misuse services and opticians who were able to help treat their outstanding health issues.

Upon leaving prison, ex-offenders said there is often a lack of continuity of care where they are not properly supported to be reintegrated into the community. As a result, ex-offenders are at risk of experiencing homelessness. A report on continuity of care for people leaving prison found that "half of the male prisoners we interviewed were anticipating being homeless on release and half of the female prisoners were technically homeless but relying on friends and family for accommodation support".[117] It states that "being homeless on release disrupts the continuity of care as it is more difficult for prisoners to get health care in the community without a fixed address".[118] This means that in many instances, ex-offenders are unable to register with a GP and are left with untreated conditions such as addiction and poor mental health. In fact, ex-offenders are likely to experience disability and illness over a decade earlier than the general population.

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[115] User Voice (2018) Link
[116] User Voice (2018) Link
[117] Sainsbury Centre for Mental Health (2008) Link
[118] Sainsbury Centre for Mental Health (2008) Link

Groundswell

6.5 Young people

Homelessness has a significant impact on the long-term health and wellbeing of young people, and LGBT young people are more disadvantaged than others. Young people that become homeless are more likely to misuse drugs and alcohol, experience nutritional and infectious diseases and face anxiety and depression and other mental health problems.[119]

While it is clear in the literature that there are positive patient experiences of support, a large body of literature suggests unmet needs are related to unaddressed mental health issues where there is a lack of specialist mental health services. Services are often unwilling to work with young people if they are deemed to have needs that are too high, are not from the local area and/or are considered too much of a risk to others:

> *"I wish I was given more help with my depression because I felt that in that area I wasn't really taken seriously... if I was given more help, perhaps I wouldn't be in the situation I am in now" (in relation to GP).*[120]

9. Conclusion

Where possible, this report aimed to reflect the voices of those who have accessed healthcare services while experiencing homelessness. However, there are significant gaps in the literature where we know very little on certain social group's experiences of homelessness, health and service interaction. The overarching theme is that the people's interaction with the healthcare system can be negative, exclusionary, and unproductive. The risk of homelessness and poor health are compounded when there is not efficient service and preventative policy apparatus to effectively deal with the multiple exclusions and complexities that people are experiencing when homeless.

It is clear from the review of the literature that some health and social care systems at acute, primary and secondary levels are failing to meet the health (and social) needs of those experiencing homelessness. This stems from the registration process, eligibility and appointment booking apparatus to the admissions, discharges and onward referrals of those experiencing homelessness. There appears to be limited space within the services and systems they operate within to screen, adapt to and provide sufficient care for those with no fixed address or with different and complex

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[119] Hagell and Shah (2018)Link
[120] Homeless Link *et al* (2018) Link

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social and cultural experiences.

Consequently, treatable problems are being left until they become serious illnesses, with A and E becoming the first point of call for those who are homeless and unable to access less acute health services. Negative attitudes towards people experiencing homelessness based on perceived levels of social risk (and drug addiction) mean that people are less likely to seek help when they need it and can mean they disengage from services. There is learning to be taken from services that accommodate the needs of those with complex lives. This needs to be mainstreamed into overarching models of health management systems and delivery alongside more access to specialist training. This will also save on health costs in the long run.

What next?

Each year #HealthNow will be carrying out peer research to inform local and national decision making and devise action plans to achieve the #HealthNow vision of an inclusive health system where everyone has equal access to the health care they need.

The insights from this literature review will be utilised to support the design of this research and inform the action plans.

The #HealthNow Steering Group which is comprised of system actors will be contributing towards a #HealthNow Action Hub where key actions which need to be taken to address system barriers can be viewed alongside supporting evidence and progress made. You can find the action hub at www.groundswell.org.uk from late December 2020.

You can find out more about the #HealthNow campaign here: https://groundswell.org.uk/healthnow/.
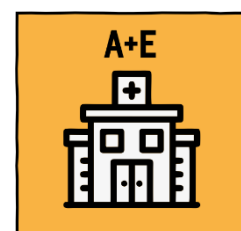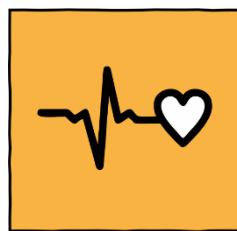
Appendix 1 – Full methodology

The search terms were as follows:

homeless, homelessness, hidden homeless, hidden homelessness, rough sleepers, sofa surfing, street homeless, homeless BME, homeless care leaver, homeless disabled, homeless families, homeless LGBTQ, homeless mental health, homeless women, homeless youth, offender, rural homeless, veteran, alcohol, homeless drug, homeless substance, substance misuse, adverse childhood experiences, hospital discharge homeless, inequality, social determinant, trauma, housing first, temporary accommodation.

The documents selected for this report covered a wide range of topics including patient experience, policy, service quality and commissioning.

The initial search results were refined via a three-stage process:

- De-duplicate
- Ensure relevance
- Separate 'homeless specific' reports from 'wider issues' reports.

The process was carried out as follows:

Step 1: <u>De-duplicate</u>

Some reports appeared under more than one search term. So to get a sense of the true size of the evidence base on the healthcare experiences of people who are homeless it was necessary to de-duplicate the results. Across all search terms, the initial search delivered 11,958 results. After de-duplication, the number of documents was reduced to 3,074.

Step 2: <u>Ensure relevance</u>

The search functionality in the Patient Experience Library looks for the search term that has been entered (e.g. 'homeless') in the document title, in its subtitle and the main text of the document. An algorithm then assigns a relevance score to the results, from 100 (high relevance) down to 20 (low relevance).

Within the search results were many documents that featured the search term only in passing. An example would be the Healthwatch Bolton Annual Report 2014/15, which, across 16 pages, contains just one instance of the word 'homeless'. That was sufficient to bring it into the search results for "homeless", but the document (understandably, as it is an annual report) offers no real learning about the healthcare experiences of people who are homeless. To deal with this, the de-duplicated search results were further refined, with the

elimination of any documents having a relevance score of less than 50. That brought the total number of documents down from 3,074 to 1,053.

Step 3: <u>Separate 'homeless specific' reports from 'wider issues' reports.</u>

A final refinement was to take documents that were specifically about the healthcare experiences of people experiencing homelessness and separate them from documents that were about wider issues such as inequality or substance misuse.

To achieve this, the search terms were divided into two groups: 'homeless specific' and 'wider issues'. This gave a final set of search results as follows:

- Healthcare experiences of people experiencing homelessness: 281
- Wider issues: 772

Limitations

The literature review was carried out mainly via a series of searches in the Patient Experience Library - the national evidence base for patient experience and involvement. The library contains over 60,000 documents, from both formal and 'grey literature' sources, including government bodies, health charities and academic institutions. It does not, however, contain documents that are held behind journal paywalls, or other literature that would typically be for sale from booksellers.

Most of the library content is from 2012 onwards, although some are older (the oldest document in this literature review is from 2003). Generally speaking, older literature is not available to the library, for two reasons:

- Because it exists only in hard copy, and the library only has the capacity to collect documents in digital format.
- Because literature published from the 1970s onwards by government-funded patient voice initiatives (Community Health Councils, Patient and Public Involvement Forums, and Local Involvement Networks) was never catalogued and archived, and so has been lost.

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Out of homelessness