

Equality and Human Rights Commission
Research report 122

The lived experiences
of access to healthcare
for people seeking and
refused asylum

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Executive summary

"When you have health, you have everything."

Woman seeking asylum, London

The human right to the highest possible standard of physical and mental health, applies to everyone, and people seeking or refused asylum who live in England, Scotland and Wales should be able to exercise that right in accessing healthcare. But that is not always easy. Our research aims to identify the barriers, both in policy and practice, to people seeking and refused asylum accessing the services they need,¹ and to propose solutions.

Our research comes in two parts. This report examines the barriers and enablers experienced by people seeking or refused asylum when they try to use health services in Britain. It aims to contribute crucial information on the reality of accessing healthcare for these specific groups, and helps fill recognised evidence gaps. By listening to people's personal stories and the views of service providers, our study draws out implications that should be of particular interest to policymakers and the voluntary sector. We have also made recommendations for action drawn from this research and its [partner report](#), which is focused on the policy and legislative context and existing evidence.

Where possible, the research draws out similarities and differences in experiences across England, Scotland and Wales, reflecting the three nations' policy and political contexts. It also tries to look at the specific experiences of people with particular protected characteristics and different types of immigration status. Throughout the report there are detailed personal stories to offer an insight into the varying circumstances of people seeking or refused asylum, including new arrivals and people who have faced multiple relocations.

¹ These are people who have requested sanctuary due to fear or persecution faced in their country of origin, and are awaiting a decision on their application or the result of an appeal against an unsuccessful asylum application.

Both people seeking and refused asylum have requested sanctuary in Britain as a result of fear or persecution in their country of origin. There is evidence that those who have been forcibly displaced are vulnerable to multiple health needs, but often find it particularly challenging to get the care they need. Their health is also likely to be affected by their wider circumstances, such as poverty, poor housing or homelessness, unemployment and isolation.

The findings highlight that there are clear barriers to accessing healthcare both at systemic policy level and in implementation and practice.

An important theme that emerged from the research was the perception from people seeking or refused asylum that recognising ‘asylum seekers are people too’ is sometimes missing from healthcare provision and from the asylum process as a whole, such as the impact of dispersal policy and fears about the asylum process as a whole.

Important barriers linked to policy are the NHS charging regulations and data sharing with the Home Office as well as aspects of asylum policy such as dispersal, and the impact of sometimes multiple accommodation moves. There were descriptions of a direct impact of the charging policy and data sharing agreement (now under review) between the Home Office and NHS Digital on people refused asylum living in England. People also talked about the stress of getting unexpected bills for healthcare and being put off seeking care for fear of deportation and detention, or of accruing bills they could not pay.

People’s experiences indicate considerable fear and misunderstanding about how personal and patient information and data might be used in relation to their immigration status. These fears of UK government policy emerged even where policies were not operating (for example, in Scotland or Wales) or did not apply to particular groups (for example, people seeking asylum), highlighting a “chilling effect” of immigration policy on access to healthcare.

More practical barriers also emerged from our research. These mainly related to: lack of money; limited support for people struggling to communicate because of language barriers; and a general lack of information about rights, entitlements and the healthcare system itself. People also reported that healthcare providers, including non-clinical staff, lacked knowledge and understanding which resulted in them being wrongly denied healthcare. This was sometimes coupled with potentially discriminatory attitudes.

The actual policy on charging for healthcare services, as well as people’s perception of it, emerged as a particular issue for pregnant women. Fear of the possible cost

meant people sometimes did not get antenatal and other maternity care early or often enough. Limited information about the specialist services they needed caused problems for disabled people we spoke to; they also reported that healthcare staff did not know what care they were eligible to receive, and so experienced especially disjointed healthcare. Some people were worried that disclosing conditions they feel carry a stigma (such as poor mental health), might affect their asylum claim.

We heard very few examples of 'enablers' that made accessing healthcare easier for people. Those we were told about highlighted both the need for, and importance of, more holistic, joined-up healthcare. Support from charities and voluntary organisations was often seen as a crucial lifeline for people trying to navigate the immigration and healthcare systems. The empathy of healthcare staff helped people to develop greater trust. Personal resilience and strong social networks were also reported as enablers. On a policy level, the HC2 certificate and universal eligibility to primary and emergency care should in theory help with access to healthcare. However knowledge about entitlements and eligibility was often limited.

This study offers insight that can help fill a clear evidence gap in existing research. However, we recognise its limitations, especially in being able to draw firm conclusions about the differences in experience between England, Scotland and Wales.

Next steps

Our research identified clear themes in terms of ways to improve access to healthcare for people seeking or refused asylum, both from them and from healthcare service providers.

Both groups highlighted the need for better staff training and more effective dissemination of information by the Home Office and healthcare providers. In particular to explain people's entitlements, including improving knowledge on universal entitlement to primary care services and on the exemption from healthcare charging for all people seeking asylum in England and anyone who is or has been in the asylum system in Scotland and Wales.

There was also a recognition of the need to overcome practical barriers by making it easier to get language support, providing more financial support to access healthcare and ensuring a more holistic and joined-up approach between healthcare providers and the Home Office.

There is also a clear need for more examples of good practice to illustrate solutions to some of the challenges people face, and for a detailed analysis of the conditions that create an enabling environment.

Service providers acknowledged the importance of prioritising the human right to health and removing policy barriers that made this unachievable, as well as improving practice to treat people with respect and compassion. The systemic barriers we identified suggest a need for change at the policy and legislation level and targeted action to ensure that access to healthcare is protected by clear separation from immigration enforcement.

The Equality and Human Rights Commission is making [recommendations](#) for improvements in policy and practice to address these findings and to ensure that the human right to health is upheld.

1 | Introduction

‘Everyone has the right to the highest possible standard of physical and mental health, conducive to living a life in dignity.’ [General Comment No. 14 of the UN Committee on Economic, Social and Cultural Rights].

This research aims to explore the lived experiences of accessing healthcare among people currently seeking asylum and those who have had their claim for asylum refused, as well as the experiences of health service providers working with these communities. It examines the extent to which people are able to exercise their rights to access healthcare and where possible, the report outlines differences between those currently in the asylum system and those who have had their claim refused and, between England, Scotland and Wales (as a result of the different legislative contexts).

Our research is intended to be of particular interest to health sector policy makers and commissioners, and to charitable and voluntary organisations that – based on our findings highlighted in both this research and its [partner report](#) – play a vital role in delivering healthcare and related support services to people seeking or refused asylum. We also anticipate that both reports will offer a body of evidence for individuals and non-governmental organisations to draw on.

At the heart of our research are the personal stories told to us by 21 people who were seeking asylum and nine whose applications had been refused. We also gathered the views of 30 health service providers with particular experience of supporting people seeking or refused asylum. Where possible we highlighted differences in the experiences of these two groups as well as those with protected characteristics (such as pregnancy and maternity, disability and age), and between England, Scotland and Wales (as a result of varying legislative contexts, see section 1.1 on the policy position below).

Human rights, including the right to health, apply to everyone regardless of immigration status. This study is set against a body of evidence that people seeking asylum are at a higher risk of complex health needs, compounded by language

barriers and little understanding of the healthcare system and their rights (Equality and Human Rights Commission, 2015; 2018). Despite these higher risks, research suggests that people who are or have been in the asylum system often find it particularly challenging to access appropriate healthcare (Burnett and Peel, 2001). The [partner report](#) to this study of lived experiences offers an evidence-based review of such challenges and why they might arise.

Language, people's reason for migration (such as fleeing violence or persecution), and experiences of health service delivery in their country of origin can all play an important role in determining their access to and use of health services in Britain, and can influence their experience and expectations of the NHS. General confusion exists among refugees and migrants and healthcare service providers about entitlements due to recent NHS changes, controversy over 'health tourism', and challenges registering for health services or accessing secondary care. Accessibility, communication, clarity on GP responsibilities and migrant entitlements all require improvement (Rafiqi *et. al.*, 2016).

Within this report, chapter 2 describes the methodology we used to reach individuals and speak to them about their experiences. Chapter 3 sets out the themes of our main findings and describes the common theme running through people's experiences: that they often felt they were not treated humanely or with respect. Chapter 4 describes where there were enabling factors, and Chapter 5 sets out the barriers people experienced when accessing healthcare. We set out our conclusions in Chapter 7.

The Equality and Human Rights Commission is making [recommendations](#) for improvements in policy and practice to address these findings and to ensure that the human right to health is upheld.

1.1. The policy position

The Home Office is responsible for asylum and immigration policy in Britain and this remains a reserved matter, applied consistently across England, Scotland and Wales. However, health policy is determined separately by the UK (for England), Scottish and Welsh governments.

The UK Government's policy position on immigration is intended to have a cumulative, deterrent effect on people living in Britain without regular immigration status by creating a 'hostile' or 'compliant environment'. Policies in healthcare, such as the NHS visitor and migrant cost recovery programme and the sharing of data

between the Home Office and the NHS, have been linked with this wider immigration policy, which directly affects people who have been refused asylum. This policy position differs in intent from those of the Scottish and Welsh governments, which have stated positions on integration and no restrictions on healthcare for people refused asylum (Scottish Government, 2018; Welsh Government, 2018).

Our [partner report](#) gives a fuller explanation of the policies that affect access to healthcare for people seeking or refused asylum. In summary, there are no restrictions on access to accident and emergency (A&E) and primary care services for anyone, regardless of immigration status, in England, Scotland or Wales. All people seeking asylum across England, Scotland and Wales are exempt from the overseas charging regime and all people refused asylum in Scotland and Wales are also fully exempt from charging. While some people in England who have been refused asylum are not exempt from charging, any 'urgent or immediately necessary' treatment must not be withheld.

2 | Methodology

We explored the detailed views and experiences of 21 people who were seeking asylum and nine whose asylum applications had been refused, and who were currently living in England, Wales and Scotland. We also engaged with service providers, including healthcare professionals and people who work with these two groups in other capacities, for example through charities and voluntary organisations.

2.1 Our approach

We adopted ‘service-user engagement’ (Rose, 2003) approaches through one-to-one conversations and small focus group discussions. We held ‘roundtables’ that encouraged discussion on equal terms to hear from service providers as well as speaking with people individually. A co-production approach made sure discussions were guided by people’s own experiences, and that we handled conversations sensitively and appropriately. The detail of these approaches is explained in Appendix 1.

All the experiences we heard about were analysed through a thematic analysis approach to identify the main themes. Where possible, the analysis also explored whether people’s individual experiences – and how they differ – might be the result of protected characteristics (the nine groups protected by the Equality Act 2010), or living in England, Scotland or Wales.

Throughout this project, we followed principles for carrying out sensitive research and used service-user and feminist research methodologies (Devault, 1990; Renzetti, 1993; Racine, 2003; Rose, 2003; Beresford, 2005).

For all conversations, we engaged with people in a private space:

- ensured they felt confident their details would be kept confidential, and that any responses would be completely anonymised
- made sure they felt comfortable and informed about the aims of the research before any discussions took place

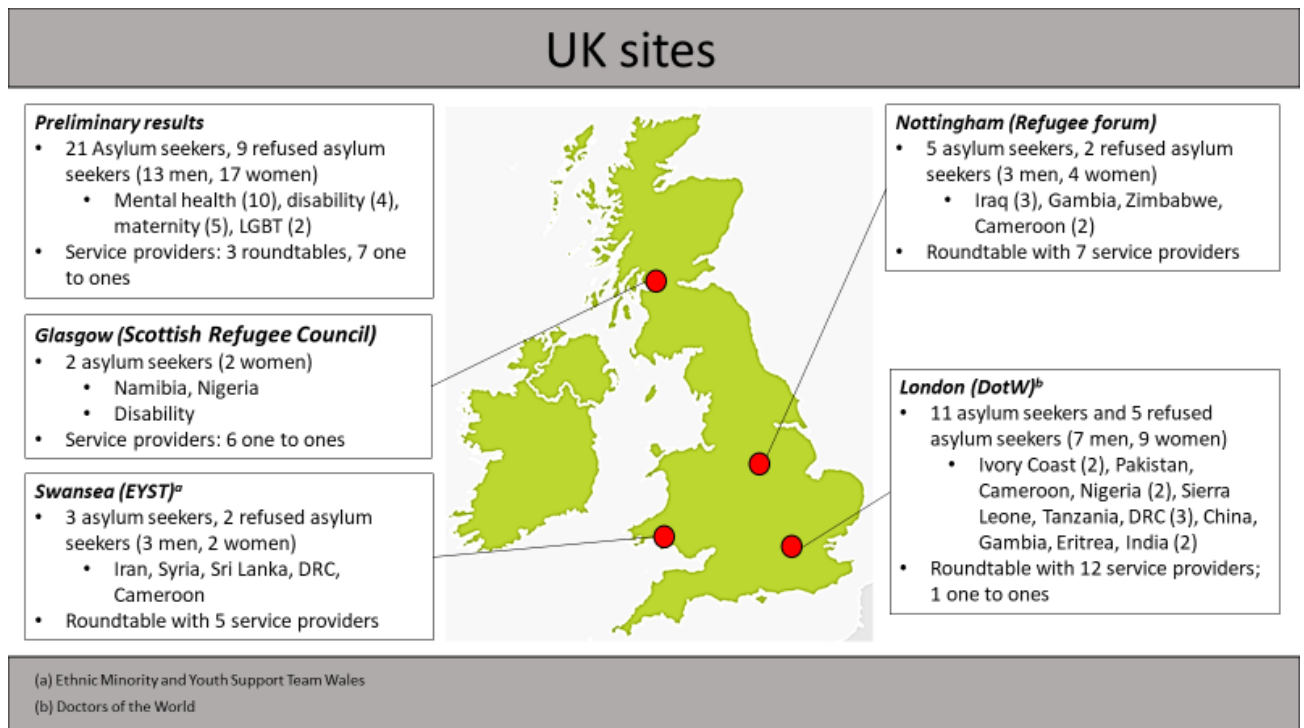
- explained beforehand that they were free to end the discussion at any point, or choose to not answer particular questions, and
- used pseudonyms in case studies.

Appendix 1 describes our approaches in more detail.

2.2 Where we did our research

We collaborated with local partner organisations to engage with people seeking or refused asylum and service providers in four cities – London, Nottingham, Swansea, and Glasgow – across the three nations (see Figure 1). Three of these are dispersal locations (London is not). These organisations – the Scottish Refugee Council, Ethnic Minorities and Youth Support Team (EYST) Wales, Nottingham and Nottinghamshire Refugee Forum and Doctors of the World (DOTW) UK (which runs clinics for refugees in London) – offered us safe spaces (such as in their own centres) to hold discussions. We provided interpretation support where this was preferred. Every element of the project was anonymised and confidential. We did not record or request any personal or identifiable characteristics of those who took part, and have protected their identities as much as possible in reporting on this work.

Figure 1 Fieldwork sites



2.3 Who was involved: people seeking or refused asylum

We engaged with 21 people who were seeking asylum at the time and nine whose applications had been refused (although they may also have reapplied) – 17 women and 13 men in total, originating from a range of countries (see Table 1). They included people with specific experience of mental health needs, disability and pregnancy. Two of them identified as lesbian, gay, bisexual or transgender (LGBT).

The people we spoke with lived in Glasgow, Swansea, Nottingham and London, but also had experiences of relocation to other parts of the UK, including Cardiff, Wolverhampton, Leicester, Hartfield in East Sussex, Peterborough, Swindon, Wakefield, Leeds, and Loughborough. Some had been in the UK for a number of years (including since childhood), while others were new arrivals.

2.4 Types of service provider that took part

Representatives of 31 health and social care and other service providers in England, Scotland and Wales contributed to the project. As well as working with people seeking or refused asylum in general across various settings, between them they had specific professional experience of: maternity services; primary care; nursing; infectious diseases; emergency services; asylum support organisations; housing, homelessness or destitution services; community organisations working with specific ethnic minority or migrant groups; charity and voluntary organisation health services; services for people who had experienced trafficking or exploitation; children or unaccompanied minors; legal support; sexual violence; and mental health. Table 2 shows the range of experience represented the service providers with whom we spoke.

Table 2 Profile of service providers

Site	Respondents and type of engagement	Professional experience and healthcare setting
London	Roundtable (12) One-to-one (1)	Mental health Community organisations working with specific ethnic minority or migrant groups Individuals with experience of trafficking, exploitation, torture or other violence Primary healthcare Infectious diseases Housing Homelessness or destitution services
Nottingham	Roundtable (7)	Maternity Primary healthcare Nursing Infectious diseases Emergency services Refugee and asylum support Housing, Homelessness or destitution services Mental health
Swansea	Roundtable (5)	Mental health Nursing Primary healthcare Charity and voluntary organisation support
Glasgow	One-to-one (6)	Refugee and asylum support Children or unaccompanied minors Charity and voluntary organisation health services Legal support Housing Homelessness or destitution services Sexual violence Community organisations working with specific ethnic minority or migrant groups Infectious diseases Nursing

2.5 The limitations of our approach

Although we were able to get an ‘insider perspective’ using this approach, the results only reflect the experiences of a small group of people and may not be representative of those who, for example, are more marginalised or face more significant barriers to engaging with research. Small sample sizes and our focus on specific locations also make comparisons between countries more difficult.

The service providers and healthcare professionals who contributed were all already actively working with people seeking or refused asylum, so were likely to have a particularly good understanding of their rights to access healthcare.

We identified everyone who volunteered to take part through charities and voluntary and community organisations, and this may reflect a certain demographic – people able to engage with these organisations or particularly sympathetic to, or supportive of, the role they play in facilitating access to healthcare.

There are limitations to our ability to distinguish between the experiences of people seeking asylum and those refused it. These are fluid categories. Anyone refused asylum will also have spent time seeking it, and those currently seeking asylum who have put in a fresh claim or have an appeal pending may previously have had an application turned down. It is not always clear from data on accessing healthcare what someone’s immigration status was when this information was collected. This fluidity and challenges in demonstrating status also present challenges for establishing entitlement to healthcare, and thus may also contribute to barriers to accessing care. Therefore, we need to treat differences identified between the two groups with caution. When attributing quotes and personal stories in this report, we give the immigration status the person used to describe themselves.

There are also limits to comparisons we can make between the three nations due to the nature of dispersal policies. As a result:

- people may have lived in more than one place
- we cannot always attribute deterrents and barriers people experience to the policy of the country where they are living – policy in one nation can have an impact on all three. This is explained in more detail in the introduction to this report and the [Access to healthcare for people seeking and refused asylum in Great Britain: a review of evidence](#), and
- we cannot assume that experiences of healthcare provision in one location hold true for other parts of the same country because of the way primary and secondary care is commissioned within NHS trusts and health boards (as well

as varying experiences and knowledge of people seeking or refused asylum across different areas of a country).

3 | Our main findings

The main themes we identified from the analysis of the narratives we heard fall into three categories. These categories form the structure of this report (see Figure 2), drawing on people's actual words as much as possible.

The first category captures the most prominent or impactful aspects of people's experiences when accessing healthcare – that 'asylum seekers are people too' – which is explored below in more detail (see section 3.1).

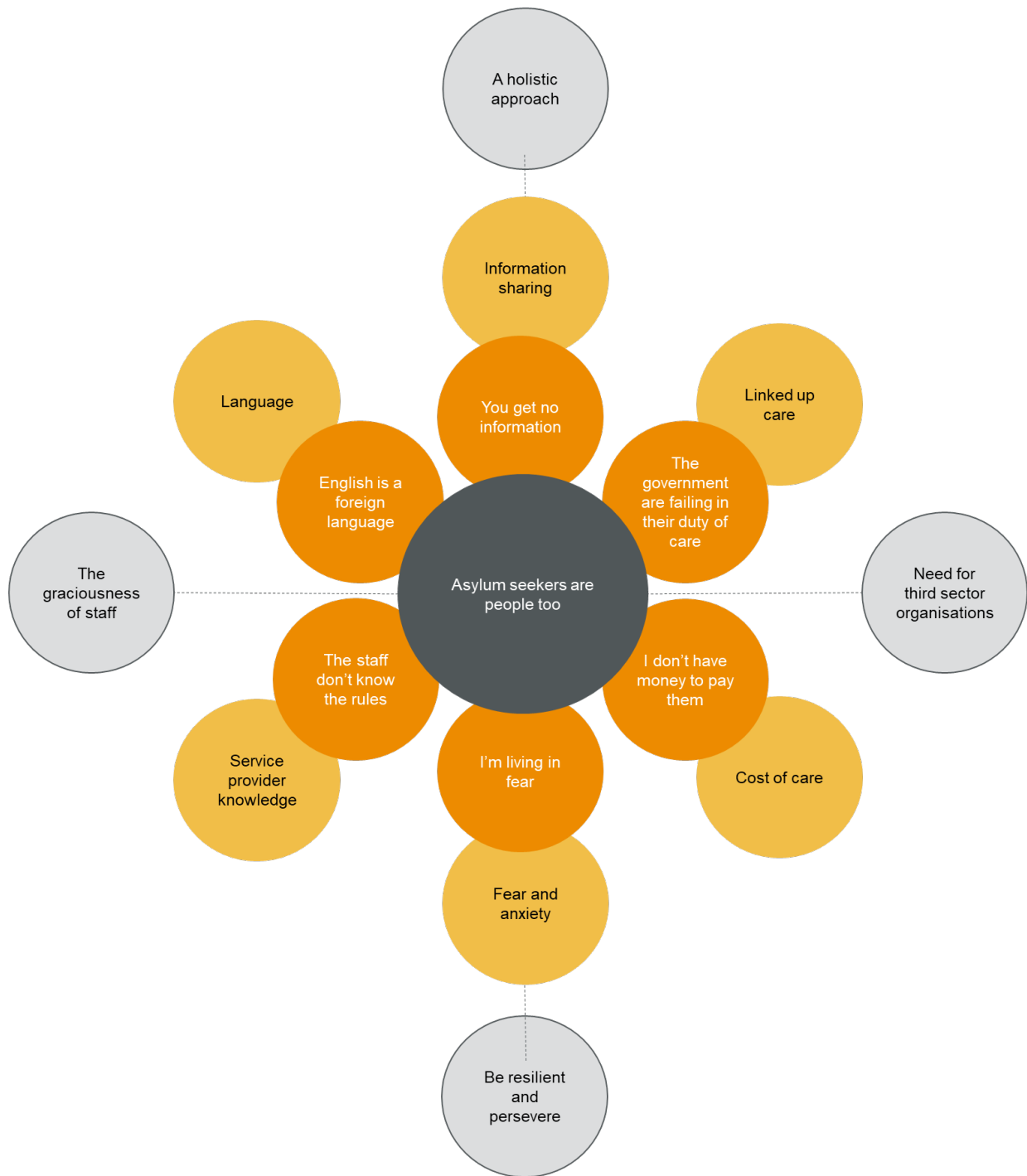
The second category describes the barriers that people experience in accessing healthcare that meets their needs. People who were seeking or had been refused asylum identified a wide range of barriers, including:

- getting 'no information'
- immigration interviews and proceedings and dispersal taking precedence over their health
- not having enough money to pay for services or access services
- 'living in fear' about how their personal data might be used
- staff not knowing 'the rules', and
- English being 'a foreign language'.

Service providers identified some of the same issues, such as the cost of healthcare, 'fear and anxiety', 'language' and their own knowledge, as well as 'information sharing' and a lack of 'linked-up healthcare'. In exploring specific barriers, we have separated out the service provider perspective to show similarities and differences in experiences.

Our third category explores what can enable access to healthcare, including a holistic approach; the role of charities and voluntary organisations in bridging the gaps; personal resilience and social networks; and the empathy of healthcare staff.

Figure 2 Main themes



Legend



3.1 “Asylum seekers are people too...”

Across the narratives, many people described situations in which they had felt that they had not been treated humanely or with respect.

A woman seeking asylum in Swansea told us: ‘An animal wants just a house and to eat. I’m not an animal. I’m a person like you.’

We heard about times when people seeking or refused asylum had not felt equal to others, both when trying to access healthcare and more widely in their local community. They described how this could affect their interactions with healthcare staff. One woman seeking asylum and living in London said ‘a particular issue is the culture of disbelief once you are known to be an asylum seeker. Visible wounds are called self-harm and not treated seriously.’

This idea that ‘asylum seekers are people too’ provided a foundation for discussing other themes and it became clear that the barriers people highlighted were strongly linked to their experience of feeling like they were not being treated as a person. As a woman living in Nottingham who had been refused asylum pointed out: ‘The same heart attack a Home Office worker would have, is the same one I would have. The treatment they need is the treatment I need.’

A woman seeking asylum and living in London highlighted the importance of feeling treated with dignity or humanity beyond health services: ‘I feel like I am Home Office property ... they were my master in all facets of my life.’

It was clear from people’s narratives that they felt that not being treated with humanity was stressful and affected their health and wellbeing. A woman in London who had been refused asylum told us: ‘I am mentally strained, constantly worried, anxious, and find myself forgetting things ... I am just surviving, not living.’

Another woman claiming asylum in London said: ‘In general advice, welcome people well. Put people first.’

But while people seeking or refused asylum were clear about the importance of feeling they were treated with respect, equality and compassion, this was less evident in our interviews and discussions with service providers. Although providers often showed a strong sense of commitment and compassion towards these groups, their narratives did not reflect the same emphasis on treating people as individuals and with dignity and respect.

This could be because the providers were not talking about their own experiences of accessing healthcare, which underlines the value of personal stories in getting the

full picture. It may also reflect the fact that we mainly gathered providers' views through group discussions rather than one-to-one conversations (like the ones with people seeking or refused asylum).

But some providers did think the health service system failed to treat those seeking or refused asylum with humanity, and needed to adopt a more humane approach to their healthcare and rights.

A tuberculosis (TB) specialist from Glasgow told us: 'There should be a more humane way of dealing with health in patients who are destitute ... I think we're failing these human beings who come here to seek refuge, and we're not helping.'

'Possible reasons for these failings could be down to prejudices among healthcare staff. A London GP said: "There is still a lot of stigma and discrimination that is around... Those are still huge barriers"

The right to health being fundamental to the enjoyment of all human rights was captured by a woman seeking asylum and living in London: 'When you have health, you have everything.'

Samuel's story (see below) demonstrates the impact of being treated with a lack of humanity and respect, and how this can lead to challenges in accessing healthcare.

Samuel's story: 'Staff can say what they want'

Samuel arrived here 24 years ago. He currently lives in London and is seeking asylum. When he first arrived, he describes how:

"The hardest aspects have been psychological and emotional. Twenty-four years without papers is difficult. You feel like you're alone."

For over 20 years, he had struggled to access healthcare and, at times has been unable to access the healthcare he needed. He said:

"Accessing care in the UK as an asylum seeker is fine if you have the papers."

But also recounted his past experiences in which he was refused access to a GP because he was seeking asylum. He was refused because he couldn't provide proof of address, as he lives with a friend and has no financial details or bills linking him to the address. In 2015 he approached a third-sector organisation for support in accessing healthcare, though the NGO was located over two hours away from where he was living. The only way Samuel could get healthcare was through mobile or pop-up clinics in different areas (in some cases having to travel great distances). He told the organisation about his difficulties in accessing a GP, and they provided him with a letter from the organisation which enabled him to register with a GP.

“In general, GPs aren’t interested regardless of how sick you are, they still refuse you.”

The NGO also helped him to access prescriptions through the HC2 form. When asked how he had found the organisation, he said he’d been looking for services online that he could access without having to pay. He found out that they would help him and that accessing primary care wouldn’t cost anything.

Now he is registered with a GP, Samuel feels he is “treated with respect” by the doctors and staff, but that previously staff have been hostile and shouted at him. He reported this made him wary about accessing healthcare in the future, and feels, “Staff can say what they want [to me] because I’m an asylum seeker.” He described, “The Government and doctors don’t value you as a human being.”

He also described that he hasn’t accessed any mental health support (for example, counselling), and instead tries to “cure myself.” However throughout the interview, he expressed the sadness and loneliness he experienced, alongside a long period of uncertainty regarding his legal status. He says that issues around his legal status put him off seeking mental health support because it may impact on his application. He also explained he did not want to “be sent to a mental hospital”. This specific concern may be linked to the fear of stigmatisation associated with being diagnosed with a mental disorder or institutionalised, as well as worries about the impact it might have on his application.

4 | What stops people getting the healthcare they need?

4.1 “Immigration interviews and proceedings came before my own life, before the doctors...”

People across England, Scotland, and Wales told us that they feel the asylum process does not respect the human right to health or provide them with access to adequate healthcare, and that their needs are often of secondary importance to the asylum process.

One woman seeking asylum and living in London told us: ‘Immigration interviews and proceedings came before my own life, before the doctors – who I was repeatedly told to cease enquiring about.’

This sentiment reflects both challenges people face accessing care due to healthcare restrictions and the detrimental impact that immigration policy, the asylum system, and dispersal can have on their health.

There was a strong feeling among those we spoke to that the asylum system conflicts with, and takes priority over, healthcare needs and access to services. A woman in London who was seeking asylum said: ‘Tell the Home Office to take care of human life – health should supersede deportation.’

4.1.1 A lack of help to navigate the system

People told us that the asylum process does not properly equip them to understand and exercise their rights to healthcare. Instead their experiences suggest that they often rely on support from charities and voluntary bodies (including non-governmental organisations or NGOs) to fill the gap created by asylum policy, and help them both navigate the asylum system and access healthcare. A woman in Nottingham who had been refused asylum claimed: ‘NGOs are integral – if we don’t have these volunteers, people are going to die at home.’

4.1.2 Breaks in care caused by dispersal

A common theme was the lack of integration between the asylum system and healthcare services. Dispersal had a particular impact on this. We heard about people being moved long distances away from health services they were already using and the challenge they had faced in accessing new ones in the new location.

People also identified a need for the Home Office, asylum accommodation providers and health services to be better linked to ensure a cohesive and adequate level of healthcare and to help people quickly establish healthcare links when they have been moved somewhere new.

People felt their individual circumstances were not always considered. We heard about people with health needs requiring continuity of care who had been relocated sometimes more than once, disrupting and delaying their access to appropriate services. One woman seeking asylum and living in Swansea told us: 'My husband has had to rearrange all his appointments locally [after we were relocated]. That has been a real challenge. We registered to the Home Office not to move us far from the services we were using because of his fragile health, but they didn't listen. After four months they said "You can move back within 1.5 hours," but it wasn't worth going back again – and all of the hospitals would have discharged him already, and he had already started to register here.'

Esther's story (below) includes examples of the way Home Office policy can override health concerns.

Esther's story: The fear of being refused healthcare

Esther came to England in 2000 and is currently living in Nottingham. She applied for asylum, which was refused and her country of origin does not recognise her so she is currently 'stateless'. When she arrived in 2000 she said it was easier to register with a GP than it is now, and required less documentation:

"I don't know what happened over time, but where I've moved it's become harder to register."

She has been relocated to five places across Britain during the course of the asylum process. She described that in some of the places she has been moved to there was strong collaboration between third sector organisations and the NHS to support people seeking asylum in gaining access to healthcare. However, in many places she felt there was a real failing among services to adequately meet the health needs of individuals like herself. In some cases this was exacerbated by an unwelcoming attitude as well as lack of knowledge about entitlements to healthcare, particularly in

primary healthcare settings. In such locations, she was only able to register with a GP after engaging with refugee support organisations, who provided letters to GPs on her behalf.

“With their aid, and letters written for me by [the organisation], I was able to register with a GP.”

Esther also described the numerous health needs she had – including mental health and disability related needs – and her frustration with the Home Office, both with regards to the number of forced relocations, and the impact this had on continuity of healthcare. To illustrate this she gave an example of a cardiologist petitioning to keep her housed locally as she had recently had extensive heart surgery, and so the local teams who had experience with her care and case were best situated to continue her care. However, the Home Office refused, and relocated her, saying there were enough cardiologists in other parts of the country. She voiced her concern about the inequality of healthcare that individuals in her position receive, and that while she understands the need for immigration processes, this shouldn't come at the expense of healthcare.

Esther also expressed a fear of having to reveal her legal status, and the risk of this information being shared:

“So long as you've got no status, that fear won't go ... one receptionist will look at you as a human, the next, as a foreigner.”

She also described fears that she would be denied healthcare because she couldn't pay, and that this was a significant barrier to healthcare.

“Around the time the new laws came in regarding lack of documentation, I was told I would be charged.”

Sometimes Esther felt she only ever received healthcare because of the compassion of staff:

“I was visiting the hospital ... and attempting to get directions to the accounts and finance department, but the receptionist I saw tore up the letter saying I would be discharged and sent me on for my scan.”

Where a compassionate attitude among staff was lacking, however, she faced significant barriers. As she described, “At the moment I am surviving on divine providence.”

However, she cited many instances where she had decided not to attend hospital – because of the fear of being refused access to services, and beyond that, the humiliation at being refused.

“I have fear about whether I will be treated or not at a GP or the hospital ... I don’t want this asthma attack because I don’t know what I’ll find at the hospital. I’m living in fear ... I now feel I need a case worker with me because I don’t know what I’ll find when I get there, but I need these procedures.”

She voiced her concern that even those doctors that are accessible, working hard and never giving up for people in her position, with the changes and increasing restrictions, “I foresee a time when they will have their hands clipped,” and that in the future they may have no option but to protect themselves at the expense of patients. “If it’s so scary now, what more in the long-term?”

Esther also described the importance of charities and voluntary organisations in supporting people seeking and refused asylum to access healthcare. Not only were they instrumental in her experience for directing her to appropriate services and engaging with services to ensure she could access healthcare to which she was entitled, but they also were the primary source for information about health services, and treated her with compassion.

4.2 “You get no information...”

From the narratives, people were commonly frustrated by the lack of information they were given, and the difficulties they faced as a result of trying to access timely or appropriate healthcare. A big part of their concern was the perception that as well as presenting practical and logistical challenges, this had a deeper significance relating to potential denial of their rights.

One woman seeking asylum in Nottingham said: ‘There was never any information or help ... I did not know about and was not informed about my rights.’

A man also seeking asylum in Nottingham suggested people needed to fill in the gaps themselves: ‘Arm yourself with the right information so that you can make your case ... Receptionists will not go out of their way to offer advice or direction.’

Not knowing how to navigate services can have a negative effect on someone’s health. Omar’s story (below) shows the impact that not having enough information can have both on whether someone gets care and whether that care is appropriate.

Omar's story: Lack of information about immigration status and patient rights

Omar came to Britain as a child fleeing violence and persecution in his home country because of his sexual orientation. Upon arriving in Britain he was forced into marriage as a minor with a woman who is a British citizen (which suggests he may have been trafficked). He fled this relationship, and became homeless, following which he was detained because he was in Britain without documentation.

After being released from detention, he made an asylum claim, five years after first arriving in Britain and at which point he was no longer a minor. After applying for asylum, he was dispersed outside of London, to a new area, and as a result of being away from existing support or friends he had established, felt isolated and depressed. Omar chose to move back to London, becoming homeless. He is now in Nottingham.

Omar described the significant challenges he has had registering with a GP with no proof of address and because of his insecure immigration status. He explained that he eventually withdrew his asylum application, out of both confusion and fear, highlighting the lack of adequate information he had received about his case and his rights. He reports being told by staff assessing his asylum application that because he had been married to a British woman, he can't possibly be gay.

On several occasions Omar has sought mental health support relating to feelings of fear, anxiety and depression linked to the intersection of his faith and sexuality, and experience of violence, destitution and homelessness. Despite having attempted suicide a number of times, he was initially told by psychiatric services that they did not feel he had any deep-seated psychological issues. He was, however, eventually admitted to a psychiatric ward, and described that,

“Staff treat you like a crazy person. Their care is like a computer, and there is no advice. I'm prescribed the same anti-depressants and sleeping pills that I was unhappy and uncomfortable with ... I feel as though I'm always playing to the rules of the institution, though am never provided any answers to my queries ... Staff bend rules to their advantage ... I have to fight for little things.”

He described that he was never given access to documentation or records by the psychiatric ward, and was never informed that he was allowed day leave, or that he was a voluntary patient and was allowed to discharge himself.

4.3 The service provider perspective

Many service providers described their view that people seeking or refused asylum are not being given enough information, and what they do get is neither high quality nor easily accessible (both in terms of language and where and how it can be found). It is not routinely provided in a way that can be understood by someone with limited English.

A Nottingham GP said: 'More than half [of these patients] are obtaining knowledge for the first time during their initial health check. It would be good to increase their knowledge of their rights, et cetera, but this puts greater pressure on the amount of time you can spend.'

Providers told us that as a result of this poor and inadequate dissemination of relevant information, patients do not understand the health system or how to access it. They highlighted that ultimately this leads to delays in accessing appropriate care, creating barriers for these groups when engaging with routine service pathways (such as through GPs), and consequently causing them to resort to other services, for example A&E.

A nurse in Glasgow summed it up: 'These patients don't use health services properly. They use A&E, might be admitted, they're not seen as quickly as the general population because they don't understand the healthcare system ... There's a gap ... They're basically just left to get on with it ... We just need more general support [for these groups] on how to access health.'

4.4 "Linked up healthcare..."

Service providers highlighted a general failure to provide linked-up healthcare that would ensure that the often inter-related health needs, or complex mental health needs, of people seeking or refused asylum were properly addressed.

A voluntary organisation in London told us: 'I think generally we could be doing more in a holistic way – especially mental health.'

4.4.1 Lack of flexibility and reliance on voluntary support

In many cases it was clear that health services were targeted too narrowly, and did not fully consider the complex needs of this group. This reduced the potential benefit

or success of any care given, because it was provided in isolation and not in a holistic way or to address someone's multiple health needs.

The view of a TB specialist in Glasgow is that: 'Services have to stop being so rigid. There has to be more flexibility around the care of these patients, and what best meets their needs, instead of what meets clinics' needs.'

We were told that there was a reliance on charities and voluntary organisations to fill the gaps left by services and support both people's healthcare and wider social needs.

A nurse in Glasgow explained: 'I think there needs to be less reliance on charities ... The system needs to be more robust, and not relying on third sector organisations ... These are people and they have needs that aren't being supported. It's not good enough to say these people can seek asylum in the UK, and we don't give them the support they need or require.'

4.4.2 Fragmented care across settings and through transitions

Services in many places do not seem able to cope with times of transition. One woman who had been refused asylum described the lack of continuity of care she and her husband had experienced, due to changes in their legal status as well as a lack of joined-up care between primary and secondary care and across specialities. The couple received fragmented care for multiple health conditions, with potentially a long-term impact on their health.

This woman, from Swansea, told us: 'My husband had to go to hospitals. Waiting time was a problem – really high – especially in London. So I think a lot of his conditions now are in a really bad state due to delayed appointments ... That's what we've done most of our life in the UK – waiting – applications, appointments. Waited one year for an appointment because you can't go forward without approval from a consultant ... There's been times he's been refused and waiting for appeal, but still had to go to appointments.'

4.4.3 The right infrastructure is needed

Some service providers also described instances of linked-up healthcare that show what can be done to support these groups to access appropriate healthcare and to adequately address their healthcare needs. These providers were mainly in Swansea and Glasgow, both long-established dispersal areas with infrastructures in place to make it easier for new arrivals to engage with services.

The Glasgow TB specialist we interviewed explained what happens. ‘When asylum seekers come to Glasgow, the asylum team see them, check their health at that point in time, give them the package and information about GPs, and I think they generally try to get them registered ... [In TB services] we are very flexible in the way we work, and I think sometimes when these patients get TB it’s helpful, because we can engage with other services, we take a holistic approach, because if we don’t engage with other issues, they won’t get well.’

A nurse in Swansea was generally very positive about the set-up there. ‘We all have a responsibility to improve health services. Swansea is great. Swansea links [people seeking asylum] to care, links to NGOs, links to wider community initiatives. This requires a regular and coherent network, which is difficult in a climate of austerity.’

What we heard from people seeking asylum in Scotland and particularly Wales further confirmed the benefits of a joined-up and proactive approach.

In addition to the need for holistic health services, having a more robust support system at times of transition – both between healthcare services and during changes in immigration status – was identified as a way to ensure continuity of care. This could include better signposting or referral to health services for people during dispersal or following detention.

Sarah’s story shows the challenges someone seeking asylum may face because care is not linked-up enough. In her case this was both a result of dispersal policy and disjointedness between health services.

Sarah’s story: Dispersal adds to delays and frustration

Sarah arrived in England, claimed asylum upon arrival, and was relocated within three days to Scotland. While she had support upon arriving in Scotland with registering for a GP, she described the numerous challenges she was still experiencing as a person seeking asylum in trying to get adequate healthcare support for her disabled child, who uses a wheelchair.

Sarah began by describing language as a barrier to accessing healthcare, in particular understanding the Scottish accent and communicating with limited English, and delays and waiting long periods of time to get appointments.

However, she also described specific challenges she had experienced in accessing healthcare for her daughter, including being relocated to accommodation that was several miles away from a hospital, and the challenges she then experienced when she was told that in order to get a wheelchair for her daughter, she had to go to the hospital in person to pick it up.

She described that it has been a struggle to get healthcare for her daughter:

“There hasn’t been anything done for her. Nothing to help her.”

She relates instances where, following dispersal, she had to travel to a new GP with her daughter, and when she attended for her appointment, they told her they were short of doctors and she would have to come back, which was frustrating given the difficulties in travelling to the appointment because of her daughter’s disability.

Sarah also described the significant delays in being able to get appointments for her daughter:

“I asked if the GP could refer my daughter to a children’s hospital or physical therapy. They said they would make an appointment for me and get back to me, and they never did.” Without receiving this healthcare, she was eventually relocated. When she asked her new GP about healthcare options for her daughter, “they said they can’t do physical therapy. I have no idea where to go? At least my old GP said they’d refer.”

4.5 “I don’t have money to pay them...”

4.5.1 Associated costs put healthcare out of reach

Some costs that caused people problems in accessing healthcare related to practical or logistical factors, like being unable to pay for travel to health services or appointments. People mentioned the expense of mobile phone credit and how this might prevent them calling health services – for example to make appointments – particularly when the wait to speak to someone could be lengthy (and thus expensive).

A pregnant woman seeking asylum in London told us: ‘I wish I could get accommodation near the hospital. It costs nearly £20 to travel to the hospital. The distance to the hospital – it’s far! My worry is, when the delivery looks ready, where I am now.’

Respondents also talked about the expense of medication – both prescription and over-the-counter products – and being unable to afford what they or their families needed. This is despite the fact that all people seeking asylum and many people refused asylum are entitled to free prescriptions.

4.5.2 The wider impact of living in poverty

Although some people we spoke to had been informed about HC2 certificates, many others said they felt they had to make choices between paying for medicine and buying other essentials. For example, a pregnant woman in London who was seeking asylum told us: ‘When I take my prescriptions (to the pharmacy), I have been afraid I might be asked to pay, and then I wouldn’t be able to afford it ... then I wouldn’t [buy it].’

Kalani – whose story is told below – explained: ‘We had to choose between food and prescriptions. It was really hard.’

Even those who got free prescriptions found the cost of other medications, such as over-the-counter pain relief, prohibitive. A woman seeking asylum in London said: ‘I used to struggle with prescriptions – sometimes I was required to pay, but then I wouldn’t take it.’

We heard about difficulties linked to not having enough money affecting both health and legal needs, adding to people’s stress about these. A man seeking asylum in Nottingham told us he was asked to pay for a medical certificate from his GP to accompany his asylum application to the Home Office, and he could not afford it. ‘I will be charged £40, which I will struggle to come by. I can’t work, I’m homeless, yet am expected to pay for a report.’

People described how a lack of money affected their health in other ways, for example not having money for food. Kalani’s story (below) illustrates the range of barriers someone seeking asylum may face to get their multiple health needs met, including poverty, a lack of joined-up care, difficulties with registration, unfriendly staff, and fear of accessing health services in case personal data is passed on to the authorities.

Kalani’s story: Worsening health caused by disruption and costs

Kalani described both her and her husband’s experiences accessing healthcare as people seeking asylum in England and Wales. She and her husband had come to Britain 10 years ago. Her first contact with NHS services in England was when she attempted to register at the GP her husband had been able to register with soon after they arrived and sought asylum. Though they were both seeking asylum, shared an address, and he was already registered, she was denied registration because she had been asked for proof of address but could not provide proof of address with her name. She described how at least she had the support of her husband and that had helped her to cope, and that,

“if I was on my own, it would have been very difficult,” and that “they were not friendly, and not very good. If I was on my own, I’d find it really hard to cope with.”

Aside from the challenges registering with a GP, Kalani also spoke about the barriers that language can present to accessing healthcare:

“I spoke some English, so that helped me a lot. If I had less language skills, I would really struggle. I don’t know how a patient could speak to a doctor or see what’s going on with them if they don’t know the words for it. I’m still struggling from time to time to find the right word for the symptom or part of the body. I don’t know how other people would cope.”

An important barrier that she described as particularly challenging for her and her husband was the cost of medication. She explained that her husband had complex health needs, both due to his age, and as a result of being tortured prior to coming to Britain.

“We really struggled. He was diagnosed with a lot of medical conditions, so we had to pay a lot. We had to choose between food and prescriptions. It was really hard.”

She explained that fortunately, they found out from someone else in their community about the HC2 certificate which enabled them to have free prescriptions. But her narrative highlighted that they had only come to this information through word of mouth, and that it was not sufficiently disseminated by health services:

“The GP and staff never mentioned it. We had to ask for it.” She emphasised that the cost of prescriptions in England, and lack of information about how to access free medication had ultimately impacted on his health. “My husband often didn’t take his medication. Because he didn’t want to swap it for food. I think a lot of his conditions now are in a really bad state.”

She also explained that they had experienced a lot of delays in getting healthcare, due to lack of knowledge of the system as well as challenges in being given appointments because of their legal status and questions around their entitlement to healthcare.

“If he was treated sooner ... but we didn’t know this ... we’re not medical professionals. That’s what we’ve done most of our life in the UK – waiting ... We waited for one year for an appointment with a consultant who wouldn’t go forward without approval ... We find it really challenging – the waiting time. His health is going down daily.”

Kalani’s contact with health services on her own behalf has been mainly while giving birth to her two children in Britain. While she said there were some delays in getting

the maternity healthcare she needed, ultimately she was happy with the healthcare she received during her pregnancies, and can see how much pressure health professionals have in their jobs.

When accessing healthcare in England, both Kalani and her husband have been asked about their asylum status, which was a concern to them as they were afraid that this information would be shared – not only with the Home Office, but potentially also with authorities in their home country, who had been responsible for her husband’s torture. She describes,

“We had such a fear of being captured by the Home Office. We knew the NHS was linked and share data with the Home Office, so we were afraid we’d be sent home, deported”.

As a result of this fear, they avoided healthcare if at all possible, which Kalani feels may have affected her husband’s health in the longer term. She told us:

“My husband was having blackouts, and had a problem with his heart, but we were really afraid to go to the hospitals. We didn’t know what would happen if we went there and they checked our application status. So there were times we decided to stay at home and not go. We had to choose – are we going to die, are we going to stay here suffering?”

But the couple also had positive experiences of the health system. For example, when they were dispersed to Wales, they were automatically registered with a GP, seen by central staff who assessed their condition, and identified if they needed and support with physical or mental health, connected them with charities and voluntary organisations, and guided them through the health system.

Though this system greatly facilitated their access to healthcare, Kalani still highlighted the disruption that dispersal had, particularly for her husband who had to find new specialists locally. Despite making the Home Office aware of the fragile nature of her husband’s health, and requesting being relocated within easy access of the services upon which he relied, they were moved too far away to continue to attend these services.

4.6 NHS visitor and migrant cost recovery programme – ‘the charging regulations’

The NHS visitor and migrant cost recovery programme (explained in detail in our [partner report](#)) had a clear deterrent impact on the people we spoke to, even for

people who were exempt from charging. In some cases this put people's health at significant risk.

Pregnancy was a stark example of this. Women both seeking and refused asylum told us they had not sought antenatal care because of their fear of being charged. In some cases this was also linked to fears about their data being shared.

A woman in London who had been refused asylum said: 'I never received any maternity care, nor any other care in general during my pregnancy. I was so scared I didn't ask about pregnancy care. Being part of the system [accessing healthcare] would enable charges to be brought against me, and I also was afraid about deportation. Once immigration know, that's when you're charged – charged for the air you breathe.'

4.6.1 Lack of information about exemption

Charges proved a particular barrier to people refused asylum in England who were not exempt from the charging regulations and therefore not entitled to free secondary care. However, those refused asylum in Scotland and Wales, and people seeking asylum across Britain, shared the same concerns about costs even though they were entitled to free healthcare and exempt from the charging regulations. It was evident from their experiences that there is a lot of inaccurate and poorly disseminated information about people's specific healthcare entitlements.

A woman from Nottingham explained her concerns about being charged because her status as someone seeking asylum meant she could not work and could not afford to pay any healthcare bills. 'I don't have money – I don't work, I don't have money to pay them. That makes me too stressed, because all the time I receive letter I have to pay this bill.'

4.6.2 Impact of unexpected bills and debt collection

These stresses were most keenly felt when people had not been told in at the time of treatment they would be charged for healthcare. In some cases they received substantial bills and were pursued by debt collectors months or years afterwards.

A woman living in Nottingham, who had been refused asylum, said: 'After two years, they started sending bills. Nobody told me that they'd charge you ... This bill is from August last year. And another bill from September. Charging is the biggest problem. I didn't know I was going to be charged ... They don't explain to me ... I go to hospital, but nobody tell you – explain it to you ... I don't have any money to pay this

bill ... Very scary! £7,600 something! I say how I have that money to pay! They make me confused.'

This highlights the deterrent effect that restrictions on entitlement to healthcare and charging are having on these groups. Regardless of whether they are entitled to free healthcare, their ability to pay is limited. Furthermore, it demonstrates poor dissemination of information about charging, and shows how entitlement to healthcare can be misunderstood by both people seeking and refused asylum and health service providers.

4.7 The service provider perspective

4.7.1 Practical problems caused by costs of paying for and accessing care

Service providers also recognise how costs linked to healthcare, and financial worries generally, affect people's access to healthcare.

During one discussion, the clinical lead of a voluntary organisation in London described various barriers people face. 'You've got to have a mobile phone that's charged up with credit. If you ring, you have to ring at a particular time, but then the person may only speak English. The cost of the mobile phone, the call, keeping it charged up. Sometimes you have to pay for glasses or medication, and then you aren't able to get the medication or you aren't able to get the glasses you need.'

A midwife from Nottingham said that getting to appointments could be difficult: 'Just getting to hospital, transportation, they may not have money to get there. For example, pregnant women need frequent care, but can't afford to get to the hospital.'

4.7.2 Misunderstandings and upfront charges

The cost of healthcare – and charging for healthcare – was particularly highlighted as a barrier by service providers in England.

People refused asylum in England, who are not exempt from the charging regulations, face increased restrictions on their entitlement to free healthcare. Service providers discussed this and the potential for misunderstandings resulting in other groups also being charged. Their views and experiences suggest that barriers due to the cost of healthcare are getting worse and are linked to recent changes to the overseas charging regulations.

A London GP described how one man 'said he would pay his medical bills – thousands of pounds – in instalments, but was refused [the opportunity to pay his

debt through a payment plan]’. The GP said: ‘Around ten years ago there was instalment options and it was more lenient, but since 2016 it is now only in exceptional circumstances.’

According to a voluntary organisation in Nottingham: ‘Even if you are eligible you may not be able to prove it, so people are charged up front – unless a clinician says it’s urgent, but then you still get billed retrospectively.’

4.7.3 Putting off treatment leads to long-term problems

A specific concern raised by service providers related to recent policy changes requiring that chargeable patients in England – those not entitled to free healthcare on the NHS – pay before they can receive treatment, unless it is deemed ‘urgent or immediately necessary’.

The clinical lead of a London voluntary organisation explained: “I think another barrier that has come in recently is the NHS charging ... Health professionals being told there’s a form they have to sign, that if you see somebody who’s a person with no recourse to public funds in particular, that you would have to charge them before you can actually treat them ... I think people often don’t access healthcare until it’s a crisis, and then they end up having to go into A&E for conditions that aren’t identified early: lack of screening, long term conditions going untreated, deteriorating, not managed, physical and mental health issues ... to such a degree that some people have to be admitted, then they’re discharged back on the street, their health deteriorates, and back to A&E.”

Another service provider believed that the cost of implementing the charging regulations was far higher than the cost of giving people refused asylum unrestricted access to healthcare. ‘[People should be] advocating for the fact that prevention is much cheaper than cure. It can be too late when you wait until urgent and immediate care is needed – it costs more, worse health, longer healing (costs admin, costs more for the healthcare system). This costs way more than just allowing access in the first place. It’s easier to allow access to the small minority who aren’t eligible, but you also have many false ineligibles, which ends up costing more too, in terms of working it out, admin etc.’

Charging was identified as particularly challenging for pregnant women who were not entitled to free NHS care (if refused asylum in England). Although maternity care was designated as ‘immediately necessary’, and did not need to be paid for upfront, service providers reported that women were delaying or avoiding healthcare because they feared being charged and unable to pay.

A Nottingham midwife explained: '[In maternity services] individuals can be billed, and even if they aren't chargeable, fear of bills [is] a definitive factor that prevents them from attending. You can book appointments, and people won't go due to charging.'

This fear of having to pay was recognised by a voluntary organisation in London. Its clinical lead said: 'They do fear that if you go to the health service, you will be given a large bill. And I think for women that are pregnant, I think that is a real concern that they'll be immediately issued with a large bill.'

4.8 "I'm living in fear..."

The people we spoke with described a range of experiences related to a fear of accessing services. Both people seeking asylum and those who had been refused it described feeling afraid that if they accessed healthcare services they needed there was a risk of detention or deportation, or a detrimental effect on any asylum application or appeal process. Such fears led them to delay or avoid seeking healthcare in case they were identified by the Home Office, detained or deported.

A woman who had been refused asylum and living in Nottingham said: 'I am worried about data sharing – individuals involved in health services passing on my details. So long as you've got no status, that fear won't go.'

Other people refused asylum commonly had the same concerns, not only in England, where data sharing between health services and the Home Office for immigration enforcement purposes was part of policy, but also in Scotland and Wales, where it was not.

A woman in London who has been refused asylum told us: 'When I came out of detention, I was very traumatised and depressed, but I was too afraid to go there [to the GP] because I was worried the GP might contact immigration officials and I might be deported.'

The same sentiments were echoed by a woman seeking asylum in Swansea. 'We had such a fear of being captured by the Home Office. We knew the NHS was linked and share data with the Home Office, so we were afraid we'd be sent home, deported.'

4.8.1 Erosion of trust in health professionals

These fears have had a clear impact on relationships between patients and providers, limiting people's trust in health services.

A woman seeking asylum in London explained: 'A lack of compassion is not only off-putting when considering accessing care, but it also compounds fears that these individuals may report you ... I am cautious and apprehensive about trusting NHS doctors and staff because of my fear of deportation.'

In the view of a woman who had been refused asylum in Nottingham: 'The Home Office are trying to make us distrust our GPs and doctors ... If you can't confide in your GP, who do you trust?'

In some instances, fear was linked to, and compounded by, the costs of healthcare, having significant implications for people's health and the decisions they make about it.

A woman in London who had been refused asylum told us: 'I still have that fear they might contact immigration and they'll come get me ... It's not just a fear about going to a surgery – it's about being traumatised ... When I found out I was pregnant, I was really frightened. I had no money. I decided I would keep my pregnancy secret and get an abortion.'

People also talked about being scared to see a doctor because of what being ill might mean for their asylum application. They were concerned that if they were not healthy, they would not be granted asylum.

For example, a woman seeking asylum in London told us: 'I was afraid to go to the doctor. I was afraid sometimes that it would affect my asylum case – I didn't know.'

4.9 The service provider perspective

Service providers reported witnessing fear and anxiety among their patients in their experiences of accessing healthcare. In some cases this related to concerns about data sharing, both in England, where there was an agreement to do this for immigration enforcement purposes (although at the time of writing the agreement is under review), and Scotland and Wales, even though these nations do not have the same policy. Providers said this had an impact on people's decisions to seek help, leading to delays in accessing healthcare.

4.9.1 Lack of clear information leads to fear and misunderstandings

A representative from a voluntary organisation in Scotland told us: ‘I think something we’re seeing particularly at the moment is where rumour in the community is meaning people are afraid to come forward for care, or are considering other options, rather than accessing care. For example, people seeking asylum in Glasgow have heard that the NHS in England are either giving info to the Home Office or charging them for care ... Even though it’s not the case in Scotland, they’ve heard the rumour. That can have a chilling impact. People don’t attend care because they’re worried about this.’

Some service providers highlighted an important distinction between fear and anxiety. In many cases they perceived that patients were experiencing uncertainty, discomfort or uneasiness about healthcare, but said this was not necessarily synonymous with fear.

According to a provider from a government body in Swansea: ‘It’s more to do with being nervous about accessing a new system ... Angst about fear of being turned in due to accessing healthcare is alleviated once the Welsh system has been explained.’

4.10 “The staff don’t know the rules...”

What came across clearly in the research is a perception that health service providers (both clinical and non-clinical staff) are not always sure about the policies around entitlement to healthcare and this can pose significant barriers to accessing timely or appropriate healthcare. This was highlighted as an issue across Britain and across different types of healthcare services. As a result, people were refused treatment, faced delays or were billed incorrectly.

A woman who had been refused asylum in Nottingham said: “The receptionist and individuals working in healthcare services don’t know the rules – don’t have the appropriate information.”

4.10.1 Struggling to register with a GP

This issue was particularly evident when it came to registering with a general practice (GP) and receiving primary care. We heard about numerous challenges people experienced in registering with a GP, even though across England, Scotland

and Wales, everyone is entitled to register with a GP and access free primary healthcare, regardless of legal immigration status.

A woman seeking asylum in London told us: “It was difficult to register with a GP. I was only able to in the last four months [but in the UK since 2006]. I don’t know why it was so difficult, but there were times I needed healthcare and couldn’t get it.”

A woman living in Nottingham who had been refused asylum reported: “When I tried to register with a GP, I was told “We don’t accept refugees and asylum seekers that is our policy”.

A woman seeking asylum and living in London explained to us: “When I was released into the community after being detained, I was unable to register with a GP due to being in the country less than three months. The GP would not recognise my time in detention as counting towards these three months. I was told that as I am an asylum seeker, I can’t be registered.”

4.10.2 Inconsistency in information about entitlements

People also described the inconsistencies they experienced when trying to access healthcare, and the impact this consequently had on their own understanding of what they were eligible to access, and the confusion and fears they felt as a result of misunderstandings in the delivery of healthcare. One woman who had been refused asylum and was living in Nottingham recounted how, after arriving at the hospital in an ambulance, she was confronted with having to fill out immigration forms as soon as she arrived and before she could be treated. She described that she now felt fear about seeking healthcare because she couldn’t predict whether she would be treated:

‘I don’t know what I’ll find at the hospital ... I’m living in fear ... Will they favour me, or just let me die ... You can’t say, “Hold on heart attack!”’

People across England, Scotland and Wales emphasised the need to improve the understanding of health service staff regarding entitlement to healthcare and data sharing.

A woman claiming asylum and living in London suggested: ‘It would make a big difference if receptionists and medical staff ... were educated on the rights asylum seekers have, and overall, to be more compassionate.’

Layla's story: Unsympathetic treatment deters people from seeking help

Layla had recently arrived in England when we spoke to her in Swansea. She had applied for asylum and been relocated to three different sites during her first few weeks, eventually ending up in Wales. Her first engagement with health services was positive. She received support registering with a GP upon arrival, being given the vaccinations she needed, and having a thorough health check with her GP about any other possible health needs.

However, the asylum process has been stressful for her, both due to the multiple relocations, but also a lack of information and advice from the Home Office; a lack of communication about her case and in some cases miscommunication. For example she received a letter sent in error telling her she had to vacate the accommodation she had been provided, upon which she became homeless. It was only after an extended period of homelessness that a voluntary organisation arranged a solicitor and it was identified a mistake had been made, at which point she was again provided accommodation by the Home Office. During that that, she described, "I don't eat, I don't sleep."

She reflected on her experience of being in Britain so far:

"Life in this country is not life. Here, it is like hell. I left my country because they want to kill me, but if it doesn't get better here I want to go back for them to kill me. Because every day here I die."

After each relocation, Layla tried to register with a GP. She described the unsympathetic interactions she had with services. For example, upon presenting to a GP surgery to register, she was asked for documentation she didn't have, and after explaining she should be able to register, a receptionist told her "I'm just reception. You go away." On another occasion when trying to register so she could book an appointment for an urgent health concern, the receptionist, after refusing to register her said, "Why do you worry? The Home Office gave you a house, and money for eating." But she describes that those things aren't enough:

"I don't want a house, I don't want money. I want to live like you. An animal just wants a house, and just wants to eat." She says that now she avoids going to any health services because of fears around how she will be treated. "Now I don't go to other places, because people might treat me like I'm an asylum seeker, like my country is not here."

While many of her experiences of accessing healthcare have been negative, she also highlighted some positive interactions. For example, her GP noticed she seemed unhappy, and asked her what was wrong. The doctor then referred her to a

counsellor and prescribed her tablets to help her sleep better. Now she sees her counsellor every week, who she says listens to her problems and gives her advice. She describes how much this has helped her:

“When one person cares for you, you feel better ... When one person hears you, it is so good.” But this positive interaction makes her question why so often she has felt treated differently because of her status. As she put it, “I’m here. See me. I’m here. I’m like other people ... I wish all people could stay in our own country. I’m not on holiday here. I wish there was no fighting, all children were with their families, and that all men were friendly to women. Please don’t judge me. Sometimes I think maybe the world doesn’t want me – doesn’t have a place for me. We’re all people. So why me?”

4.11 The service provider perspective

The service providers we spoke to were very aware of the inconsistencies in understanding and implementing policy on healthcare entitlement. They also reported that lack of information about the rights of people seeking or refused asylum also undermines the ability of healthcare staff to ensure treatment is respectful of those rights.

As a London GP acknowledged: ‘Staff don’t understand the rights of people who are trying to access the service – they think they don’t have a right to primary care, so are sending them away.’

This inconsistency and lack of knowledge of healthcare providers also compounded the confusion for people trying to access healthcare who had limited information about their rights, as a nurse in Glasgow pointed out: ‘Groups seeking asylum ... the destitute, they’re the most vulnerable. They don’t think they’re entitled to it, the health providers don’t think they’re entitled to it. So they’re the most vulnerable. They definitely suffer the greatest.’

4.11.1 The need for education

Service providers have concerns about how this lack of knowledge can affect health outcomes, and those we spoke to – across all three countries – called for better staff education.

A TB specialist from Glasgow explained: ‘Healthcare workers think people who are destitute and have been refused asylum don’t have any right to care ... Social care

have refused to come and assess patients because they have no recourse to public funds ... There's a big challenge ahead to educate staff in services ... Secondary care has the biggest burden of misunderstandings among staff of entitlement.'

But some service providers offered an insight into the practical challenges of training staff and giving them better information. A nurse from Swansea told us: 'Staff turnover is a huge difficulty. You could talk to many people and train them, and then by the next month half of them are gone and you're back to step one.'

4.12 "English is a foreign language..."

While many respondents in our research spoke some English, it was frequently highlighted that language was an important barrier to healthcare. This was particularly the case in identifying how to access the healthcare they needed, booking appointments, communicating their health needs, and understanding the information healthcare service providers gave them.

A man in Swansea who was seeking asylum pointed out: 'A real big problem is the problem of interpreting. When we come here, English is a foreign language.'

An important concern that people reported was being unable to get the healthcare they needed because they could not explain what was wrong with them or understand what the doctors told them to do.

As a man seeking asylum in Swansea said: 'If you can't explain very well your situation, you can die.'

This was a point reiterated by a woman seeking asylum in London: 'Sometimes it's difficult. I hear many, many things, but I don't know how to answer them. When GP asks me a question, I don't know what it means.'

4.12.1 Limited interpreting services

Many people said they had never been offered or provided with an interpreter, and did not know that they could request one.

'I don't have any interpreter at the GP or the hospital, never,' one woman seeking asylum and living in London reported.

Even when interpreting services were available to patients, language still presented a barrier, often because of the quality of the services. A woman seeking asylum in

London described the LanguageLine support (an interpreting service, usually by telephone) used at her practice as 'not great'.

The case study below describes the impact of both the lack of interpreters and the problems created by poor quality interpretation.

Amna's story: Misunderstandings about procedures and services

When we spoke to Amna in London, she was 37 weeks' pregnant and had been in Britain for two years. She had previously been refused asylum, but had reapplied and was currently awaiting a decision on her asylum application.

She requested an interpreter during this interview, so Language Line was used. However during the course of our conversation, and after hanging up with the interpreter, it became clear that there had been numerous misunderstandings through the interpretation provided, highlighting the challenges this can create when using the routine NHS interpreting services – either in research or in a health service setting.

Though Amna had a clear preference to use an interpreter, she explained that she hadn't been offered interpreters when she had accessed health services. On some occasions she had been able to bring a woman she had met who could speak her language:

"I haven't had any interpreter services, but I was not discouraged by language because I had a lady friend. She is new [to England] ... so she would accompany me."

However, it became very clear that during her pregnancy she has faced significant challenges in accessing adequate healthcare due to language barriers. This has resulted in her not having had sufficient antenatal healthcare, as she did not know what it was, that this was available to her, or that she should access such healthcare. Furthermore, she had experienced challenges in understanding the complexities of her pregnancy and the specific healthcare she would need. As a child she underwent female genital mutilation (FGM). She understood that this would affect her delivery, but described how fearful she was of delivering, as she believed she had to have an operation that would involve a high risk of mortality. Although her hospital records show that doctors had given her the option of a caesarean, or of defibulation to allow her to delivery naturally, neither of which presented significant risks to her or her child's life, but this had not been explained adequately to her given her language needs.

In addition to these fears relating to her delivery itself, she also expressed significant concerns relating to her financial situation and her accommodation. She explained that she was destitute, and had been homeless for the duration of her pregnancy. She had just been given temporary accommodation by a voluntary organisation. However, the housing she had been provided was two hours away from her hospital:

“I wish I could get accommodation near the hospital or this centre ... If I could be near this area, I can call people I know to help ... The hospital told me to bring someone, but I can't. I don't have any support.”

She also explained that she was very isolated in this accommodation as she didn't live near anyone she knew, including the organisation that had been providing her support, and had no one to accompany her or provide transportation to the hospital.

“Unfortunately, I don't have any people I know. I don't have anyone around who would be ready to go with me or accompany me. I don't have support from any centre or any other.”

Amna also explained that while she was grateful for the accommodation, she had no money for food, and felt “hungry all the time. I'm tired, I need to eat, I need food,” which she was worried wouldn't be good for her baby. As she explained, “My worry is when the delivery comes, the place I am living now, there is no one who can give me support.”

4.13 The service provider perspective

Language was a dominant theme across our discussions with service providers, whatever sector or country they were in. People's limited proficiency in spoken and written English was seen as a particular barrier to accessing or understanding information. Service providers also highlighted the logistical issues this can create, sometimes compounded by a lack of interpreting services.

As one nurse in Glasgow pointed out: ‘Information is in English for a start. Maybe they can speak some English, but their written English and ability to read English is not [as good]. Some ... are illiterate, so giving them any information that is written down isn't a good idea. They are assisted to register with a GP, and then they're just left to get on with it. Even for myself getting a GP appointment is difficult enough, so individuals whose English is limited, speaking to a receptionist on the phone to get an appointment booked is nigh impossible. So they don't do it and end up pitching up

at A&E. I think there needs to be more information in their mother tongue that is as basic as possible.’

4.13.1 The risks of miscommunication

Providers explained how language barriers could make it hard to communicate critical health information to patients. This could lead to misunderstandings about diagnosis or treatment.

For example, one Nottingham voluntary organisation told us: ‘We had a resident that [thought they had] had a cancer diagnosis. However, there was miscommunication, this was actually a TB diagnosis.’

4.13.2 Fear of disclosing sensitive information

There are additional issues of stigma and gender differences between patients and interpreters, providers said. As a Nottingham midwife pointed out: ‘Women who arrive pregnant aren’t necessarily in the best circumstance – it may be potentially rape’. They may fear that care is provided by males, many women don’t want to use male interpreters, many don’t want to share their experiences or with many different people. Face to face interpreters can raise fears about knowledge getting back to the community.’

This view was seconded by a nurse, whose experience was that: ‘Patients may live in the same communities as their interpreter, or there is a reliance on family-members, which can mean individuals won’t disclose issues in front of them.’

Providers also talked about the logistical challenges in making adequate translation services available. One retired GP asserted that ‘GP surgeries need readily available interpreters’, pointing out that there is only so much information these patients can take in at once, particularly in a foreign language, and they may have questions or not understand what they have been told. This doctor explained: ‘There’s probably not enough coverage of interpreters. You need access to both physical interpreters and LanguageLine, but you need proficiency in training, perhaps depends on the situation – with mental health issues you may want a physical interpreter.’

Another GP in Nottingham echoed this: ‘The importance of interpreters is absolutely key ... Now you can’t book an interpreter any sooner than 48 hours, LanguageLine don’t always have anyone available.’

The need for interpretation also extends beyond primary and secondary care services. It can affect how easily people seeking or refused asylum can get the healthcare they need in other settings, such as pharmacies.

A Nottingham voluntary organisation reported: 'Even if you can access interpreter services in the GP, you have no interpreters at the chemist. There's the example of a chap that needed to take one tablet four times a day. Miscommunication led to him taking four tablets four times a day, which had a sedative effect.'

We also heard from providers how these practical language difficulties could sometimes be made worse by stigma or discrimination within services.

A Glasgow TB specialist told us: 'We hear it when we make appointments and ask for interpreters. It's embarrassing to say – but I hear it from other healthcare professionals, which is very sad. I think there is stigma definitely. I think there is discrimination from healthcare staff – and social care. And people who are employed to help these individuals as well – people who are in a position to supposedly support – I am saddened from what I sometimes hear. There is a lack of empathy.'

5 | What helps people to access the right healthcare?

People seeking and refused asylum also told us about positive experiences of accessing timely and adequate healthcare, and service providers talked about what could be helpful. But overall the individuals we spoke with had far fewer examples of these ‘enablers’ than barriers, which suggests the need for further research into good practice (see the conclusions both to this report and its partner review). It is worth bearing in mind that we mostly identified the people who took part in our study through their links to voluntary organisations (see Methodology), so they will be particularly aware of the support these services can offer.

5.1 A ‘holistic’ approach to healthcare

We heard about people feeling they were treated as a whole person, not just for specific healthcare needs but in their broader health and wellbeing.

A woman claiming asylum in London told us: ‘[The organisation] provided a holistic approach, care for me from my head to my toes.’

Another person seeking asylum explained: ‘I was registered with a GP the first day I came here to Swansea. I went to the doctor for vaccinations. The GP asked about everything – if I felt sick, pain, felt down ... My GP said I was getting depressed, so he transferred me to a [voluntary organisation] doctor – a counsellor – and every week I go there ... When I want advice [another organisation] helps me.’

People we spoke to often highlighted the integral support that charities and voluntary organisations can provide, and said they would like to see healthcare service providers adopt a more holistic approach. This should include not just integrated services, but more consistent application of policies on entitlement, and a better understanding of the complex social factors that add to problems accessing services, and being more sensitive and flexible in response.

Yonas's story: A helping hand to navigate the system

Yonas described his experience of accessing care following his arrival in Cardiff, and disbursement to Swansea. He started by explaining that, in many cases, people seeking and refused asylum had to rely on volunteer or charity organisations. "It's very difficult unless we have the number of a volunteer or charity," describing the importance of such organisations for supporting him and friends of his to access primary care (GP appointments), secondary care (hospital appointments), or even emergency care (speaking to emergency services to call an ambulance). This related both to his experiences of care not being well linked up, and the benefit of having an organisation that knew you and which you trusted, to help you navigate your individual needs, and also to help with logistical things like language and communication. He also described the wider holistic approach of these organisations, which could provide support for accommodation, and classes or education.

However, Yonas did also provide examples where he felt like health services had taken a holistic or joined up approach. For example, he was registered with a GP immediately after arriving in Swansea, and three days later he received a letter from the clinic, and they already knew about his situation and needs, as his details had been passed on from Cardiff. Yonas was given a letter to take to his GP, who contacted him a week later with an appointment. They also made relevant appointments at the hospital for him, sent him a map showing him how to get there, and were helpful in making future appointments too.

"From the clinic they give you the summary and information you need, if you have a refugee problem they send you here [voluntary organisation], sign-post you to the services you need. The clinic try to give you some orientation, which was a very good thing for me....The clinic has all of your situation and can get a GP for you, directions, appointments with a dentist".

Service providers also highlighted the need to go beyond only treating individual health conditions, and to address people's multiple, or more complex, health needs during appointments, as well as the wider social, economic and legal needs of these groups.

A clear example of this is in TB treatment. A TB nurse in Scotland explained: 'We have had increasing numbers of individuals who are destitute ... We see increasing numbers with complexity of social situations ... more who are destitute, no recourse to public funds. And we have no way of helping these individuals ... We have been fighting to get a policy in place for those with active TB and no recourse to public

funds, so the Government will give them a roof over their head for the duration of their treatment ... I've worked with TB cases in the last year and that has worked.'

We heard from service providers working in systems they felt were less restrictive and more joined-up on why this is so important in enabling access healthcare.

A nurse told us: 'Swansea links you to care, links to NGOs, links to wider community initiatives. It requires a regular and coherent network.'

5.2 Bridging the gaps – the role of charities and voluntary organisations

The role of charities and voluntary organisations was described by those we spoke to as crucial in bridging the gaps left by health services and enabling people seeking or refused asylum to get the healthcare they need. It was clear this support was widely appreciated: one woman claiming asylum in Swansea explained that 'they don't look at you just as a number, there is a personal element'.

Voluntary organisations were vital to people not just because they help them access services. People told us such organisations make them feel human, and talked about the comfort, trust, and compassion they felt when seeking support from this type of provider – in stark contrast to how some view statutory services.

A woman in London said: '[They] are very compassionate. It's like they've been an asylum-seeker themselves – the care and empathy they show...'

Service providers also made it clear to us that charities and voluntary organisations are bridging a gap left by statutory health services, and that without their contribution there would be a significant risk to the health of people seeking or refused asylum.

A Glasgow nurse said: 'It's all third-party organisations who are carrying the flag. I don't know how they manage staffing levels, funding, but these sorts of organisations are the ones that are keeping these patients afloat.'

Particularly helpful in a practical way is how they both provide information and signpost people to it. We heard this was essential for getting the right information to patients, and ensuring they had sufficient information to access healthcare.

A London GP explained: 'They don't have that information unless they're in contact with [third-sector] organisations. We've developed a card that has gone out widely. Someone can take the card to a GP and it states, "I have a right to healthcare. I don't need an address. I don't need to show you documentation." So that's very basic.'

Sharing good practice like this card – that you have a right to see a GP – there are positive messages, but I do think it's about signposting to places they will get seen and have supporters. I think there are organisations that are giving out information and the right information on websites and in languages, like the Refugee Council, day centres, soup kitchens, Doctors of the World. So I think they play a huge role in getting people into primary care and advocating for them.'

Service providers also described the value of relationships and trust patients develop with these organisations.

A voluntary organisation in Glasgow pointed out: 'It's a safe place for people to come. They know it's a third sector, they know it's a charity, it's safe to access ... If there's a woman who's a refused asylum seeker, it makes it a bit more comfortable.'

Fateme's story: The difference listening and practical advice can make

Fateme had recently arrived and was seeking asylum in Wales. She had been transferred twice within Wales since her arrival, and highlighted the importance of voluntary organisations in helping her to access healthcare as well as other important needs such as housing, legal support, and social support.

One important example of this was when Fateme told her GP she had been feeling down and not sleeping well, and he suggested she may be depressed. He referred her to a counsellor at a local charitable organisation. She has been able to go once a week to see the counsellor, and emphasised how helpful this had been for her.

"A lady speaks with me about my problems – what's wrong, and gives me advice... [The organisation] is so friendly. When I speak, she just speaks about my problem. So friendly. That lady help me. When I go there, my feelings down. When I leave there, my feelings up ... When one person cares for you, you feel better."

She also described the social and legal support she'd had from a second organisation.

"When I want advice [the organisation] helps me. I had a problem about money support, and they helped me. 3 to 4 times they sent mail to the Home Office."

Fateme also talked about the support she had received through her church community, but about how lonely and challenging it was to have nothing to do, and not be allowed to work or study. "When I stay in my room, it's like hell for me ... Just thinking about everything ... Just waiting. It's so hard for me."

Another positive aspect of her experiences of healthcare was that she found her GP to be helpful. She was offered vaccinations if she wanted, which she then had. He

also referred her to other services in addition to the counsellor at the charitable organisation. She pointed out that though there were challenges, healthcare here was better than in her home country.

A particular frustration linked to not being allowed to go to college or further her education. “I want to learn English, because now I’m here ... College they don’t help me. I am angry with them.”

5.3 Personal resilience and social networks

People’s resilience and perseverance came across clearly in all the stories we heard. Many felt they had to understand their rights and be persistent to get the healthcare and support they needed, with the help of social networks and voluntary organisations to overcome specific barriers and support their individual resilience.

A man seeking asylum in London said: ‘My advice would be that you need to stand up for yourself, as you may well be alone.’

A woman who had been refused asylum explained: ‘I have now largely educated myself about my rights, with the help of [third sector] organisations.’

People also told us other resources that contributed to their resilience and made them better able to cope as well as find services to meet their health needs.

‘Social groups have been a great help for emotional and mental health. Don’t isolate yourself,’ advised a woman seeking asylum in London.

Another said: ‘It’s important to educate yourself, both as to your rights, about the language, and mostly for your own knowledge and aspirations ... Nothing should be an excuse to care.’

A woman in Swansea described how social support kept her afloat emotionally: ‘Church people help me. I think they are like angel. They tell me, “we are your family”, and they show me that they are my family. When I have a problem, I can speak with them. When I go there, they help me.’

Support networks were also informal – a man in London told us his ‘main source of emotional support and help’ was his friends.

People highlighted the importance of social support in sharing information, explaining how they learned about how and where to access services, their entitlement to care,

and the existence of voluntary organisations, through ‘word of mouth’ that spread among their communities and social networks.

‘Friends have been a great help with healthcare and advice,’ a woman refused asylum said.

Service providers also recognise how individual resilience can benefit people’s general wellbeing as well as helping them access services and cope with their circumstances.

A nurse in Swansea told us ‘getting people out and being active’ was one of the best bits of the job.

However, these findings need to be understood on the context of the specific circumstances of people who are seeking or have been refused asylum. While the resilience and perseverance many people show is remarkable, many have experienced trauma and fled persecution. Relying on their individual resilience to access healthcare should not be a policy solution.

Sephora’s story: The importance of resilience and knowing about your rights

Sephora came to Britain 10 years ago, fleeing torture and abuse, and was detained on arrival. During detention she asked to see a doctor as she was experiencing severe bleeding, but was told she would have to fill in a form and it would be a two week turn around, and so was only able to see a nurse. Eventually she was able to see a doctor who gave permission for her to be released to a hospital.

Following her release from detention into the community, Sephora was unable to register with a GP. She was told by the GP practice they would not recognise her as she had been in Britain for less than three months, and that her time in detention did not count towards this. She was also told that, as someone seeking asylum, without proof of address or passport, she could not register.

Sephora sought support from a voluntary organisation, which contacted the practice on her behalf and she was “suddenly registered with the GP.” But prior to learning of this organisation, she had “no idea or information about foundations that could help.” Since then, she has had support from charitable and voluntary sector organisations for her legal case, helping her to access healthcare, and providing counselling.

“When I was in detention, there was never any information or help, and I did not know about and was not informed about any rights I may have.”

She says she has now largely educated herself as to her rights, with the help of these organisations. She described that, even as someone seeking asylum, she is

cautious and apprehensive about trusting NHS doctors and staff due to the fear of deportation, and would like to see NHS doctors educated on how to create an open atmosphere. When asked what advice she would give to other people seeking and refused asylum, she said she would tell them:

“To be resilient and persevere, and that it is important to contact [voluntary sector] organisations.”

She also noted it is important to educate yourself about your rights and the language, both for your own knowledge and aspirations and to integrate yourself to enable access to care. She would also tell someone not to suffer stigma and her own wariness of the NHS means she would also suggest someone ‘only trust’ voluntary sectors providers.

5.4 Compassion and empathy from healthcare staff

People told us how some service providers had gone out of their way to support them and make it easier to access healthcare, and the importance of this to them.

A woman from Nottingham told us: ‘I feel very safe at my GP ... I trusted my GP when I was referred for psychological treatment, and that was important in my experiences of good care.’

But as one woman from London pointed out, this empathy or compassion among service providers should not be something out of the ordinary; instead it should be a core element of good practice and their obligation to any patient. As she put it: ‘The care and empathy they show is not magic.’

Kiza’s story: A warm welcome in Wales for new arrivals

Kiza arrived in Wales six months ago. He hasn’t had any significant health problems since arriving, with the exception of some regular hospital appointments. However he has been in situations where he has had to call emergency services for a friend, and described,

“Sometimes when a bad thing happens to an asylum seeker, we try to call the emergency number, and have to call too many times – it’s very difficult to get them to come to you. Sometimes when we try ourselves it’s very difficult unless we have the number of a volunteer or a charity, and get a good result ... When a volunteer has arrived to help, an ambulance hasn’t been able to attend.”

He attributed some of these difficulties to language, and not being able to communicate needs well enough to emergency services or other healthcare providers.

Though he described these frustrations, he then also gave examples of the positive aspects of the system in Swansea. He explained that three days after he first arrived in Wales, he received a letter from a clinic, and they already knew about his situation, and only needed to finalise paperwork. They sent him a letter to take to his GP who would contact him. The GP was in touch a week later and gave him an appointment. They also provided him an appointment at the hospital. He related,

“The way the information was given was a good thing for me ... I arrive in Swansea, I don't know anybody, but two days later receive a letter telling me about my appointment, with a map to get there. From the clinic, they give you the summary and information you need, if you have a refugee problem they send you to [a third sector organisation], signpost you to the services you need. The clinic try to give you some orientation, which was a very good thing for me. When going out of the clinic you have a map, know who to contact. The clinic has all of your situation and can get a GP for you, directions, and appointments with a dentist, and the GP, clinic, dentist etc. will write to you as they have the details they need.” He reported that “The doctors and nurses that I met were lovely – very kind.”

6 | Emerging differences by country and protected characteristic

The chapter presents variations in the data we collected in England, Scotland and Wales to identify differences in people's experiences of accessing healthcare in the three nations. It also looks at the experiences of individuals by protected characteristic (see Appendix 2 for more details).

6.1 Differences associated with countries

We heard about challenges in accessing adequate information on entitlement and access to healthcare across all three nations, but these were particularly notable in England. People seeking asylum reported better provision of information and more joined-up services in Swansea than in other locations. People seeking asylum in England highlighted weak links between the dispersal system and healthcare providers, resulting in poor access to care.

Differences in healthcare charging policy (see Introduction) were reflected in what people in England who had been refused asylum told us – they were asked to pay for secondary care and reported substantial (and sometimes unexpected) hospital bills.

People both seeking and refused asylum are exempt from NHS charges in Wales and Scotland, so the cost of accessing healthcare seemed less of an issue in these countries than in England. However, people across all countries indicated that the policy of charging for NHS services did have an effect on their access to healthcare. There was a perception that an individual might be charged for healthcare as a result of the policy in England. In fact one service provider described how a healthcare practitioner in Scotland incorrectly attempted to apply English policy regarding charging.

Costs associated with accessing healthcare, such as travel and phone credit to arrange appointments, were also reported as barriers in all three nations.

People we spoke to in England said policies on sharing patient information between healthcare systems and the Home Office created a climate of fear that deterred both those currently seeking asylum and those previously refused it from using health services. This fear was reported less by people we spoke to in Wales and Scotland. But concerns about data sharing in England appear to have spread, and led to apprehension among people in Scotland where there hasn't been the same agreements in place.

We discuss the impact of charging and data-sharing policies and other relevant regulations in more detail in our [partner report](#).

We found some notable examples of good practice in certain countries. There seem to be better links between the asylum system and healthcare service providers in Swansea and (to some extent) Glasgow, resulting in better continuity of care.

People we spoke to in Wales said initial health assessments they had in Cardiff provided a direct link to local services when they were dispersed to Swansea. And once in Swansea they were either immediately registered with a GP, or a practice quickly contacted them to sort out registration. People in England generally had quite a different experience; several spoke of their difficulties accessing GP services. But we cannot assume these examples amount to widespread variation between the countries. Individual experiences in certain areas of a country may not reflect what happens in other areas. And it is worth noting that Swansea and Glasgow are both well-established dispersal areas.

6.2 Differences associated with protected characteristics

Our research captures the lived experiences of a diverse group of people seeking or refused asylum, including 10 with experience of mental health needs, five women who have been pregnant since arrival in Britain, four disabled people and two who identify as lesbian, gay, bisexual or transgender. Sometimes these characteristics have had a further impact on the barriers to healthcare already experienced by people seeking or refused asylum.

The disabled people we interviewed appeared to face more challenges in accessing healthcare than other people we spoke to. They commonly reported that the information available focused on general services rather than the specialist services they needed and that it could be hard to get referred to these services because healthcare staff lacked knowledge about their eligibility.

Those with mental health conditions in particular reported disjointed services as a challenge to getting appropriate help; they were often passed between multiple services and organisations. They were also reluctant to disclose information about their condition or seek help because of fears about the negative impact this might have on their asylum application.

Women more commonly reported facing challenges accessing healthcare because of limited language proficiency or literacy, and lack of appropriate interpretation support. It seemed that using family or community members instead of professional interpreters could inhibit women from disclosing experiences of abuse or sensitive health information.

Our findings suggest NHS charges are a significant barrier to maternity services for pregnant women, and put an extra burden on them. Both actual and perceived charging policy sometimes deterred women from accessing maternity care, whether they were seeking or refused asylum. This fear of having to pay for services had a particular impact on their timely use of antenatal care. Charges placed a significant (and at times unexpected) burden on these women – one told us that fear of healthcare charges influenced her decision to have a termination. There was also evidence of confusion or inconsistent understandings around entitlement to care and charging among both women and service providers, which had a detrimental impact on timely access to needed care.

7 | Conclusions

Our research provides an insight into the personal experiences of people seeking and refused asylum in accessing healthcare in England, Scotland and Wales, as well as the views of service providers working with these populations. These findings support and add to the evidence in the [partner report](#), published alongside this research.

The overarching theme from the research was that ‘asylum seekers are people too’. What people told us highlights how important a humane and person-centred approach to providing healthcare is, and the impact the absence of such an approach may have.

These findings suggest that there needs to be a greater emphasis on ensuring a human rights based approach to the process of claiming asylum and accessing healthcare services. Healthcare services must support human rights and be set up to help people seeking or refused asylum to realise their right to health – a right enshrined in human rights law that applies to everyone, regardless of immigration status.

7.1 The barriers people face

From listening to people it became clear that what stops them getting the care they need is either ‘systemic’, and as a result of national policy (whether intentionally or not), or practical, which may stem from policy but relate to everyday issues like a lack of money.

Important barriers linked to policy are the NHS charging regulations and data sharing with the Home Office as well as aspects of asylum policy such as dispersal, and the impact of sometimes multiple accommodation moves. There were descriptions of the direct impact of the charging policy and data sharing agreement (now under review) between the Home Office and NHS Digital on people refused asylum living in England. People talked about the stress of getting unexpected bills for healthcare

and being put off seeking care for fear of deportation and detention, or of accruing bills they could not pay.

There was also an overall fear of the asylum process, and how people's health information might be used in it.

People misunderstood, or were unclear about, how patient information and data were used by the Home Office and healthcare providers. They were often confused about what healthcare they were entitled to and whether they would be charged for it. This seemed to be the case even among people whose location and status meant there were no restrictions on accessing free healthcare (for example, in Scotland and Wales).

The main practical barriers people told us about were: a lack of money, problems communicating in English (and no support to overcome these); and a lack of information clearly explaining their rights and entitlements and how to find their way round healthcare services.

Another important barrier was a lack of knowledge and understanding of healthcare providers, including non-clinical staff, often coupled with potentially discriminatory attitudes that meant people seeking and refused asylum were wrongly denied healthcare.

7.2 Enablers to healthcare

Unfortunately, few 'enablers' appeared in people's stories, but one message that came through clearly was the value of holistic, joined-up healthcare, and the need for more of it.

Support from charities and voluntary organisations was often a crucial lifeline for people trying to navigate the immigration system and healthcare services. And the empathy of healthcare staff helped build greater trust. People also felt their own personal resilience and strong social networks played a part in enabling them to receive the care they needed. We heard positive accounts about elements of policy, such as HC2 certificates, that helped people get treatment and medication.

Our findings offer real insight into potential approaches both to improve access to healthcare for people seeking or refused asylum and to support the staff who provide these services. However, what has emerged from our research is certainly not exhaustive and there is a need for more research to explore more examples of good

practice and initiatives occurring on a local level across England, Scotland and Wales.

7.3 Differences by UK location and immigration status

People's experiences were broadly similar across the three nations, possibly because immigration and asylum policy is a reserved matter and so consistent across Britain. Asylum accommodation dispersal policy meant that many of those we spoke to had moved between England, Scotland and Wales.

The same issues came up in stories we heard from both people seeking asylum and those whose applications had been refused, suggesting their experiences were generally similar in spite of different entitlements and support structures.

However policies on data sharing and charging for healthcare targeted at people refused asylum in England did pose particular barriers for them. What also became clear was that poor dissemination of information to the public and to providers contributed to confusion about these policies among both individuals and service providers. This led to fears among people they did not actually apply to, and affected the decisions they made about healthcare.

7.4 The impact of protected characteristics

People's protected characteristics can have an impact on the barriers they experience to healthcare. We spoke to disabled people, people with mental health conditions, and women, including pregnant women, experienced unique barriers, or who felt the impact of some barriers more severely. People told us that they avoided or were unable to access the healthcare they need.

7.5 Next steps

Hearing about the experiences of both people seeking and refused asylum, and the views of a range of service providers, has given us an insight into approaches to improve access to healthcare for these groups. Many of the suggestions made by people receiving services and those providing them are similar.

The people we spoke with recognise the need for better and more easily available language support, and a holistic and joined-up approach that recognises a range of healthcare needs and is effectively linked to the work of charitable and voluntary organisations. They see the need for healthcare staff to have better training and for the Home Office and providers to make sure people get the right information, especially about their entitlements.

The provision of financial and language support, as well as information that meets the needs of people seeking or refused asylum, is enshrined in policy and could therefore be easily improved by reviewing the relevant policies.

The systemic barriers we identified suggest a need for change at the policy and legislation level and targeted action to ensure that access to healthcare is protected by clear separation from immigration enforcement.

There are other specific areas where further research is needed. For example, we want to better understand the lived experiences of people seeking or refused asylum in Scotland and Wales, where there is limited evidence available. The nature of dispersal policy also restricts comparisons that can be made between the three nations.

An important finding identified in our study was that more examples of good practice are needed, including information on what conditions are required for these to work and offer solutions to the barriers we have highlighted. This includes addressing specific challenges experienced by people with protected characteristics. Additional research might identify positive and promising practices that could be applied at a national level.

The Equality and Human Rights Commission is making [recommendations](#) for improvements in policy and practice to address these findings and to ensure that the human right to health is upheld.

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Appendices

Appendix 1 Engaging with individuals

Our approach to engage with people seeking or refused asylum

When engaging with a person seeking or refused asylum we will ensure that they are fully informed, feel comfortable and safe, and stress that everything they share with us will be anonymised and confidential and that they may change their mind or stop at any point, with no obligation or pressure to speak with us. We will also ask them about their preference for using an interpreter. We will be located in a private room at the relevant participating centre, and service providers from the centre will be on hand to provide any support or help that may be needed or desired by the person seeking or refused asylum prior to, during, or following our conversation.

We will begin by explaining the background to the project, including that the work is for the Equality and Human Rights Commission, and what its aim and output will be. We will also provide them with written information about the project and what it involves, and which reiterates that there is no pressure for them to participate, that it is anonymous and confidential, and that they may change their minds, pause or take a break, or stop at any point. We will ensure individuals also have the opportunity to ask any questions they may have about the project, and provide them with our details so that they may contact us at any point.

These conversations will be structured with the intention of gathering these individuals' lived experience and narratives. Thus, they will be structured in an open-ended way, and will be led by the individual. This means that the below prompts will be used as a guide for the interviewer, to keep in mind important areas that it might be useful to explore with these individuals, but that the priority is to ensure that the conversation is not prescriptive and any questions are open ended – not leading.

Our approach is centred on enabling individuals to guide what is meaningful in the conversation. The below questions will not be asked verbatim, nor will these topics arise in this order, as the content of the conversations will emerge organically through the interviewee led open-ended approach and in whatever way is most comfortable (sensitive, appropriate) for the individual.

Questions and prompts

Can you tell me about the first time you accessed NHS services in the UK?

- How was your health assessed and by whom?
- How did you know where to go for healthcare?
- Who did you ask, where did you find information from?

What was this first experience with NHS services like?

- Can you tell me about anything that prevented you from getting the care you needed or made it harder?
- Can you tell me about anything that made it easier to get the care you needed?

Have you ever accessed or wanted to access maternity services?

- Were there any things that prevented or delayed you from getting antenatal care or care after your pregnancy?
- Were there any things that made getting this type of care easier?

Are you registered with a GP?

- How did you find out about where and how to register with a GP?
- When did you register with a GP?
- Can you describe what your experience was like with your GP?
- Are there things that prevented or delayed you from registering with a GP?
- What would help to make this easier?
- What has your experience been like with your GP?
- How frequently would you say you go to the GP?

Can you tell me about times you were in contact with other NHS services?

Is there anything about you that you think makes it easier or more difficult to get the right care when you need it?

What were some things that kept you from seeking care or made it difficult for you to get care?

What do you think the outcomes might be if you don't get the care you might need?

Have you had enough information about what services are available to you?

- Did you know where to go if you had a problem or a concern?
- How did you learn about what NHS care you could access?
- Where did you learn this information?

- When did you learn this?

Do you know whether you are entitled to free healthcare on the NHS or not?

- Did you know if you would be charged for any of these services or how much they would cost?
- Have you ever been charged for any services you received?
- If so, what were the charges for?
- Were you charged up front, or later on after you received care?
- Who explained the charges to you and did you understand them?
- What was done to address these charges – if you could or could not pay?

Does the possibility of being charged influence when or where you have sought healthcare, or whether you would get care in the future?

Can you tell me about any ways in which your legal status in the UK has impacted on whether you seek care, and when and where you seek care?

- Do you worry about people finding out about your legal status? What do you think could happen?
- Does the risk that your information might be shared with the Home Office affect whether or not you get care, or when and where you would get care?

What guidance would you give other people like you for accessing healthcare in the UK?

What do you think might prevent other people like you from getting the care they need?

What do you think could help people like yourself get earlier or better care?

- How could the healthcare system be improved?
- What could health service providers like nurses or doctors do to help?
- What other kinds of support would be beneficial?

What particular services or organisations have been helpful to you? How?

Can you tell me about any other things you worry about relating to your:

- Health?
- Your legal status?

Have you ever accessed or wanted to access mental health services?

- Were there any things that made this difficult or prevented you from getting the mental healthcare you needed?

Our approach to engage with service providers

The roundtable will be held in a private room at each relevant site. Before beginning the roundtable, all individuals will receive information about the project, including its aims and outputs. We will ensure that all individuals are fully informed, feel comfortable and safe, and stress that everything we discuss will be anonymised and confidential. Individuals may also change their mind, take a break, or elect not to speak with us any further at any point. We will also ask about any preferences for translation or interpretation.

We will begin the roundtable by explaining the background to the project, including that the work is for the Equality and Human Rights Commission, and that the findings from the project will be written up into a report, which will not include any personal or identifying information. We will also ensure everyone has an opportunity to ask any questions they may have about the project, and provide them with our contact details.

These conversations will be structured with the intention of gathering these individuals' lived experience and narratives. Thus, they will be structured in an open-ended way, and will be led by the individual. This means that the below prompts will be used as a guide for the facilitator, to keep in mind important areas that it might be useful to explore, but that the priority is to ensure that the conversation is not prescriptive and any questions are open ended – not leading. Our approach is centred on enabling individuals to guide what is meaningful in the interview. The below questions will not be asked verbatim, nor will these topics arise in this order, as the content of the conversations will emerge organically through the individual led open-ended approach and in whatever way is most comfortable (sensitive, appropriate) for these individuals.

Prompts

Can you talk about your professional experience in relation to people seeking and refused asylum's access to and engagement with health services in the UK?

What are the important points of access or engagement?

We would like to understand the care pathways for people seeking and refused asylum when they seek access to healthcare. For example:

- When their initial health screening takes place?
- Who carries out an initial health screening with these groups?
- How do these individuals know where to go for healthcare?
 - Who do they ask, or where do they find this information?

- Information about, and access to GP surgeries
- What information is available (and what isn't adequately available) around entitlement to free healthcare, what care they might be charged for, how to address these charges?
- What information is available (and what isn't adequately available) regarding data sharing between NHS services and the Home Office?
- Access to appropriate mental health services
- Access to pre and peri-natal care
- Continuity of care

Can you describe other services where there may be barriers in accessing timely or appropriate care?

Barriers:

What are some of the important barriers to healthcare experienced by people seeking and refused asylum? Why do these barriers exist?

Do you have any experiences when you felt unable to provide the healthcare you wanted to or felt was needed?

- What barriers prevented you from doing so?

How do you think these barriers might be improved?

Whose responsibility is it to pursue these improvements?

Enablers:

What are some of the enabling factors that facilitate the delivery of effective health services for people seeking and refused asylum?

Can you describe things that, in your experience, work well to help these individuals access timely and appropriate care?

How much responsibility do health service providers take themselves to try to facilitate access or improve practice?

How can these enablers be disseminated or implemented more widely?

Do you have any examples of improvements that have been made either by you or in the sector? How well did they work, or not?

Differences in experience:

Can you tell me about any factors that make experiences of accessing healthcare differ across different communities of people seeking and refused asylum?

- Can you talk about whether in your professional experience, protected characteristics (for example, older people, disabled people, women) have contributed to differences in people seeking and refused asylum's experiences of accessing healthcare?
- Can you talk about any differences in access to or the quality of care received for people with mental health needs or experiences of trauma?
 - How have these needs contributed to differences in people seeking and refused asylum's experiences of accessing healthcare?
- Can you talk about how experiences of accessing healthcare may differ based on the location in which these individuals are accessing care?

Policy:

Can you talk about any changes you have seen in experiences of accessing care among people seeking and refused asylum following changes in national and local policies?

Can you talk about any examples of good and bad policy decisions you have encountered in your professional experience?

What if any effects do you think data sharing between the NHS and the Home Office has had on access to and engagement with health services in these groups?

What if any effect do you think charging in health services has on access to and engagement with care in these groups?

What advice would you give to people seeking or refused asylum to help them access health services in the UK?

Is there anything else you would like to discuss or share? Can you think of anything relevant to what we have discussed that we haven't had the opportunity to talk about or which I might not have known to ask?

Appendix 2 Findings by protected characteristic and country

The summary of findings below highlights the range of differences in lived experience relating to protected characteristics and country, as explored throughout our thematic analysis of people’s comments.

Themes	Differences by protected characteristic	Differences by country
Asylum seekers are people too	Patients with protected characteristics may face additional stigma or discrimination due to these factors, for example, disability, ethnicity or sexuality. Patients with mental health needs may face additional stigma or discrimination.	Substantial differences in policy exist in England. These are largely restrictive in nature and may challenge the perceived rights of people seeking and refused asylum when compared to Scotland and Wales and to international legislation or standards.
You get no information	This barrier was particularly present among participants with mental health needs, as well as those with limited English proficiency or literacy. A participant with experience of disability also described the significant lack of information available on how or where to access healthcare to meet these special needs.	Challenges in accessing adequate information were cited across all countries, but seemed to be particularly significant in England, while more joined-up healthcare and improved provision of information to people seeking asylum was reported in Wales.

Themes	Differences by protected characteristic	Differences by country
<p>Immigration interviews and proceedings came before my own life, before the doctors</p>	<p>Linkage to mental healthcare appears inadequate, with one participant recalling being essentially passed between multiple services and NGOs. People with disabilities as well as those with multiple or complex health needs described the particular challenges they faced associated with disjointed healthcare.</p>	<p>Services appear to be better linked within Wales compared to England, with continuity of healthcare provided to individuals being dispersed to Swansea from Cardiff. Similarly, services also appear better linked within Scotland compared to England. However, there are still concerns that overall there is inadequate provision of healthcare.</p>
<p>I don't have money to pay them</p>	<p>This was a significant barrier for maternity healthcare in England. While urgent and immediately necessary, and thus not necessarily charged up front, such healthcare is charged at the 150% tariff. Pregnant women, including people refused asylum, described the significant (and unexpected) burden these charges presented, as well the impact that fear of charging had on timely and sufficient access to maternity healthcare, as well as termination of pregnancy.</p>	<p>In both policy and practice, England is more restrictive in terms of charging and entitlement to healthcare compared to Scotland and Wales, charging for many elements of secondary healthcare. Theoretically, healthcare is free in Wales. However, there are still factors such as transport to consider, and concerns around charging were still expressed by some participants. In theory, healthcare is also free in Scotland. But financial factors, including associated costs such as transportation or phone credit, are still barriers.</p>

Themes	Differences by protected characteristic	Differences by country
I'm living in fear	People with mental health conditions described concern that disclosure of such conditions would negatively affect asylum proceedings, thus enhancing the fear and apprehension they experience.	Within England, the Home Office and NHS have a memorandum of understanding* allowing data to be shared between the two services, and which is directly implicated in worsening the climate of fear people seeking and refused asylum experience. (From May 2018, data can only be shared for people convicted of serious crimes).Less restrictive policies appear to be associated with less fear and anxiety in both Wales and Scotland. However, fears regarding data-sharing and charging policies in England have permeated the other nations and are now a source of fear and apprehension among migrants, despite the fact they are not applicable to people in Scotland (though some mechanisms are in place to allow this in some cases).
The staff don't know the rules	This barrier was experienced across groups. However, in some cases people with more complex health needs or	In Scotland, there were reports of insufficient clarity regarding country-

Themes	Differences by protected characteristic	Differences by country
	disabilities who needed referral for specialist services described a lack of knowledge among staff regarding their eligibility for such healthcare.	specific policy and that staff may apply incorrect procedures.
English is a foreign language	Some women experienced particularly significant challenges relating to language due to more limited language proficiency or literacy.	Language barriers were reported across countries, though specific challenges in understanding the Scottish accent were noted.

Contacts

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