Equality and Human Rights Commission
Research report 121

Access to healthcare for people seeking and refused asylum in Great Britain

a review of evidence

Dr Laura B Nellums, Kieran Rustage,
Dr Sally Hargreaves, Prof Jon S Friedland
Imperial College London

Anna Miller, Dr Lucinda Hiam
Doctors of the World UK

Equality and Human Rights Commission

First published: November 2018
ISBN: 978-1-84206-780-2

Equality and Human Rights Commission Research Report Series

The Equality and Human Rights Commission Research Report Series publishes research carried out for the Commission by commissioned researchers.

Please contact the Research Team for further information about other Commission research reports, or visit our website.

Post: Research Team
Equality and Human Rights Commission
Arndale House
The Arndale Centre
Manchester M4 3AQ

Email: research@equalityhumanrights.com
Telephone: 0161 829 8500

You can download a copy of this report as a PDF from our website.

If you require this publication in an alternative format, please contact the Communications Team to discuss your needs at: correspondence@equalityhumanrights.com

Contents

List of abbreviations and acronyms

AS	People seeking asylum (asylum seekers)
DHSC	Department of Health and Social Care
DOTW UK	Doctors of the World UK
GP	General Practitioner
HIV	Human Immunodeficiency Virus
ID	Identification
MdM	Médecins du Monde
NHS	National Health Service
RAS	People refused asylum (refused asylum seekers)

Acknowledgements

The literature review was carried out by Imperial College London. Primary data was collated from and by Doctors of the World UK (DOTW UK) clinics in England. The summary of government policies and legislative frameworks was written by DOTW UK. The final report and findings were generated collaboratively by DOTW UK, Imperial College London, and the Equality and Human Rights Commission.

Imperial College London
Kieran Rustage, Dr Laura B Nellums, Dr Sally Hargreaves, Prof Jon S Friedland

Doctors of the World UK
Anna Miller, Dr Lucinda Hiam

Equality and Human Rights Commission
Preeti Kathrecha, Rosie Wallbank, Suzanne Devlin

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. 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]

Our research is in two parts. This report summarises the policy and legislative context shaping people's healthcare entitlements, and the existing literature on people's practical experiences of actually accessing healthcare at the right time. Our companion report adds new evidence on individual stories and experiences of both people seeking and refused asylum and healthcare providers, helping inform recommendations for action.

The review looked for evidence of specific variations in people's experiences because of their protected characteristics or where they live (England, Scotland or Wales).[2] The report also presents primary data on barriers to healthcare collected from Doctors of the World UK clinics in London and Brighton.

Our review identified multiple and interlinking barriers across six main themes, as well as evidence of solutions to overcome these. It found limited differences in the experiences between people seeking and people refused asylum.

Our research is intended to be of particular interest to health sector policy makers and commissioners, as well as to charitable and voluntary organisations who are

[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.
[2] Due to the limitations in the available evidence, the ability to do this is restricted.

highlighted in the research as playing a vital role in delivering healthcare and related support services to people seeking or refused asylum.

The main themes from our findings are as follows.

Legislation and policy

There is considerable confusion about who should be charged for what services under the NHS visitor and migrant cost recovery programme in England. It restricts free access to secondary care (for example, hospital and community care) for some people who have been refused asylum, but sometimes people are wrongly denied 'urgent or immediately necessary' treatment they should receive without upfront payment. Related procedures like identification and eligibility checks cause delays, and deter people from using services.

Policies such as unrestricted access to free primary and emergency care and the policy of not withholding treatment that is 'urgent or immediately necessary' because someone cannot pay for it, are enablers to healthcare access, however there was limited evidence from published research on this.

If people are relocated to different accommodation in a different location under the Home Office dispersal policy, this can disrupt their healthcare. This particularly affects pregnant women and people with long-term health conditions who need frequent and continuing care.

Healthcare service providers

Both clinical and non-clinical staff working in different healthcare settings, including GP practices and hospitals, often do not understand what people seeking or refused asylum are entitled to, and may give them inconsistent and inaccurate information. Policies may be applied wrongly. Clinical staff have limited knowledge and experience of meeting people's specific and complex health needs. People seeking or refused asylum may face long waiting times and only be given short appointments. There is evidence staff are unprepared for dealing appropriately with cultural differences, such as religious beliefs and stigmatised or complex issues such as women who have experienced female genital mutilation.

However, people seeking or refused asylum have often found healthcare service providers and staff helpful. Advocacy and support provided by charities and voluntary organisations can mean they get better access to healthcare.

Additional costs in accessing healthcare

The amount of government financial support people seeking or refused asylum are eligible to receive can impact on access to healthcare. Even if people get financial support, they may be unable to afford associated costs such as mobile phone credit to make appointments or to afford public transport to travel to them or to afford over the counter medication. Transport costs are a particular issue for disabled people who require regular healthcare appointments. Pregnant women can struggle to buy enough of the right food to follow nutritional advice.

There is government support available for people seeking asylum and for people refused asylum who qualify for it, including HC2 certificates that cover all or part of the cost of prescriptions and some travel to appointments. But evidence suggests people do not always know about these.

Language and communication

Problems communicating can make it harder for people seeking or refused asylum to find and use healthcare services. Language barriers may also hinder identification of their healthcare needs and delay diagnosis. Miscommunication can lead to misdiagnosis and patients not following advice correctly, including how much medication to take. The review found that people seeking or refused asylum had limited access to interpreting services. What was available was often inadequate or inappropriate, such as friends and family acting as interpreters. Women were at a particular disadvantage due to lower levels of literacy and English language skills, and were also inhibited by cultural factors, such the use of male interpreters in maternity or sexual health services, or when disclosing experiences of domestic or sexual violence.

Professional interpreting services do help overcome language barriers and access healthcare. Reliance on informal support to help communicate raises issues related to privacy, the quality of understanding and consent.

Information and knowledge

There is evidence that people both seeking and refused asylum often do not know what they are entitled to, and are not given enough information (in a form they can understand) on how to access NHS healthcare and the function of specific healthcare services.

When available, information provided by charities and voluntary and non-governmental organisations, as well as by friends, family and communities, can be useful.

Fear, trust and stigmatisation

The review found evidence that people seeking or refused asylum are put off accessing healthcare because they have serious concerns that medical information could be used in immigration enforcement. Some fear that receiving treatment for certain conditions, such as infectious diseases or mental health issues, might affect their asylum application.

It is reported that in England people who have been refused asylum avoid healthcare services due to fear of the consequences of government policies on data sharing (between the NHS and Home Office, for example) and reporting debts from unpaid treatment charges. Cultural and social attitudes, and stigma associated with certain medical conditions, can affect people's decisions to seek treatment. In particular, people with mental health needs or experience of trauma or torture may mistrust health professionals. Previous poor experiences of services, including potentially discriminatory or abusive situations, add to lack of trust.

There is evidence people's positive experiences of healthcare services help to overcome barriers caused by fear, lack of trust and stigmatisation.

Differences in experience based on immigration status

The evidence gave little indication of differences between the experiences of people currently seeking asylum and those refused it. This could be due to the fluid nature of immigration status; even when immigration status changes and someone moves from actively seeking asylum to being refused it, while their policy entitlement or financial support may change, their understanding of what healthcare they are

entitled to, and any misconceptions and fears they have may remain the same. It could also reflect the literature's focus on experiences in primary care, to which both groups have equal entitlement.

The literature demonstrated that some of these barriers affect people refused asylum more acutely. For example, treatment being withheld because of healthcare entitlement policies; people avoiding services because of fears about the cost or being reported to the Home Office; greater financial difficulties because many people refused asylum cannot claim public funds and are not allowed to work.

Next steps

The review's findings show clear barriers to people seeking and refused asylum accessing healthcare that need to be tackled at different levels.

More research is required to address evidence gaps and understand the specific experiences both of people currently in the asylum process and those who have been through it, as well as looking at the specific contexts in different geographical areas. Our partner report begins this process by adding to the evidence base through highlighting the personal stories and lived experiences of people who are, or have been, in the asylum process.

There is a clear need for good practice examples to demonstrate solutions to some of the barriers posed.

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

1.1 The context

Human rights, including the right to health, apply to everyone regardless of immigration status. People who have been forcibly displaced and are seeking asylum are reported to be vulnerable to multiple health needs, but often find it particularly challenging to access appropriate healthcare (Burnett and Peel, 2001).

Their complex health needs may be compounded by language barriers and limited understanding of both the UK healthcare system and their rights. They are likely to experience many social determinants linked to poorer health, such as: poverty; lack of adequate housing or homelessness; unemployment; and isolation (Equality and Human Rights Commission, 2015; Equality and Human Rights Commission, 2018).

Our study examines the specific barriers people seeking or refused asylum face in attempting to access UK healthcare services, and what may enable them to do so more easily. It 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.

1.1.1 Existing evidence

There is an overall lack of available evidence on the experiences of people who are seeking or have been refused asylum (Equality and Human Rights Commission, 2015; Equality and Human Rights Commission, 2016). There is some evidence that in England, these groups have poorer health outcomes as a result of poor access to healthcare services (Nair *et al.*, 2015). But there is little accurate evidence on the situation in Scotland (Scottish Public Health Network, 2016) and no robust evidence on their health outcomes in Wales.

This research aims to address this lack of evidence and identify specific evidence gaps.

1.1.2 Policy responsibilities

The Home Office is responsible for asylum and immigration policy in Great Britain. Rights and entitlements associated with immigration status remain a reserved matter and are consistently applied across England, Scotland and Wales. However, responsibility for healthcare has been devolved so that there are different systems, rights and entitlements in England, Scotland and Wales relating to access to healthcare.

The UK Government's stated policy intention on immigration is to have a cumulative, deterrent effect on people living in the UK unlawfully.[3] Policies in healthcare, such as the NHS charging regime and the sharing of data between the Home Office and the NHS, have been linked with this wider immigration policy, directly affecting people who have been refused asylum. However, the devolved governments in Wales and Scotland have different stated positions on the integration of people seeking asylum[4] and have exemptions for healthcare charges for those who have been refused asylum.[5]

1.1.3 Emerging themes

Our report presents findings from a systematic literature review on access to healthcare for people seeking or refused asylum in the UK, including drawing out any differences of experience across England, Scotland and Wales and how any protected characteristics impact on someone's experience. It also outlines policies, legislation and guidance that shape entitlement and access to healthcare services in England, Scotland and Wales. In addition, we have drawn on data collected from people seeking asylum who attended Doctors of the World UK specialist clinics in England between 2014 and 2017 (see Appendix 1). With little existing published evidence on the specific experiences of people seeking or refused asylum in accessing healthcare, this primary data provides us with an important and rare insight into the individual experiences of these two groups. See Methodology for more details.

[3] This is contained in an interdependent and combined package of policies known as the 'hostile' or 'compliant environment'. They were brought in by the Immigration Acts 2014 and 2016.
[4] The 'New Scots: refugee integration strategy 2018 to 2022'. The Welsh Government's 'Nation of sanctuary – refugee and asylum seeker plan' was being finalised at time of writing.
[5] See 'NHS entitlements: migrant health guide', updated 2018.

The report gathers the information from these various sources into six main themes:

- the impact of legislation and policy on access to healthcare services
- healthcare service providers
- additional costs to access healthcare
- language and communication
- information and knowledge, and
- fear, trust and stigmatisation.

Our partner report on lived experiences provides personal stories of people seeking or refused asylum in accessing healthcare services, and the views of service providers in providing healthcare, in more detail. The themes that emerged from that study – based on individual interviews and group discussions – broadly reflect the same issues, illustrated by real examples of problems faced in practice.

1.2 The process of seeking asylum in the UK

Someone who is seeking asylum is looking for protection from persecution or serious harm in a country other than their own and awaiting a decision on their application for refugee status (European Commission, no date). In the UK, asylum claims are considered under the 1951 UN Refugee Convention or Article 3 of the European Convention on Human Rights (ECHR). Claims are handled by the Home Office, which decides whether the person will be granted refugee status, humanitarian protection, or any other form of leave to remain. In 2017 the UK Government received 26,350 asylum applications,[6] with the largest number of applications from people from Iran, followed by Pakistan, Iraq, Afghanistan, and Bangladesh (Home Office, 2018a). Of asylum decisions made in 2017, while 32% of cases were granted asylum or humanitarian protection,[7] the majority of asylum applications were refused (68%).

People refused asylum have received a negative decision from the Home Office, and have not been granted any form of leave to remain. A significant proportion of asylum refusals are overturned at appeal, with some people going on to be granted refugee status or humanitarian protection; in 2017 38% of appeals were overturned by the courts (Home Office, 2017). Immigration status is therefore fluid, with individuals moving from refused status to active asylum seeker status frequently.

[6] All figures refer to asylum 'main applicants' only and do not include dependants.
[7] All figures refer to asylum 'first decisions'.

These figures also suggest that caution should be applied to the view that people refused asylum have no legitimate basis for being in the UK. When someone has had a negative decision, they can apply to receive support under section 4 of the Immigration and Asylum Act 1999. This is for destitute people who meet certain criteria, including attempting to return to their country of origin. Most destitute people who do not meet this criteria will stop receiving any government support and have 'no recourse to public funds'. This applies across England, Scotland and Wales. The majority of people refused asylum do not receive this support. In 2017, 5,257 decisions to grant section 4 support were made.[8]

While they are waiting for a decision on an asylum application, people who are destitute are provided with support by the Home Office under section 95 of the Immigration and Asylum Act 1999. A new flat rate was introduced in August 2015. Currently, people seeking asylum receive £37.75 for each person in the household to pay for things like food, clothing, toiletries and transport.[9] The total number of people seeking asylum (including dependants) who were in receipt of section 95 support at the end of 2017 was 40,736, of whom 37,716 were in dispersal accommodation and 3,020 were receiving subsistence only.[10]

[8] See the Refugee Council's asylum application statistics.
[9] UK Government asylum support guidance.
[10] See footnote 8.

2 | Methodology

2.1 Literature review

The literature review for this study includes both primary research and 'grey' literature (materials not produced by commercial or academic publishers, such as reports and briefings) relating to barriers to healthcare facing people seeking or refused asylum in England, Scotland and Wales, how these can be overcome, and their lived experiences of accessing healthcare.[11]

While the focus of the literature review is on more recent evidence following the Immigration Act 2014, there were no date restrictions on what was included, or any restrictions based on: language of publication; study design; and whether evidence covered adult or child populations or any particular stage of the asylum process. We adopted this broad scope because there is a general lack of evidence separating out different migrant groups and focusing specifically on people seeking or refused asylum.[12]

To identify all relevant evidence between 1 January 2014 and 1 April 2018, we carried out systematic searches of three databases on the Ovid platform: Embase, MEDLINE and Global Health. Our search strategy included separate keywords relating to the relevant population groups, healthcare, specific outcomes (barriers or enablers) and geographical location (see Appendix 3). The combined results of the database searches were subjected to two rounds of screening to ensure their validity before inclusion in the review (see Appendix 2). We also did a search for grey literature sources, for example, through the websites of important voluntary sector and human rights organisations. Any sources or publications identified from these searches that met the inclusion criteria were included in the review.

Evidence identified through the literature review was classified in terms of whether it presented a potential barrier or enabler to accessing healthcare. Barriers were

[11] Healthcare in detention (in immigration removal centres) was not included in the scope of this report.
[12] The review covered evidence that focused on refugees, people with humanitarian protection and other migrants if it also included people seeking or refused asylum.

defined as circumstances or actions that present obstacles or challenges to the ability to access healthcare, while enablers were defined as circumstances or actions that remove potential barriers or otherwise facilitate access to healthcare.

Thematic analysis (Braun and Clarke, 2006) was used to synthesise the evidence base and identify important themes. These themes were developed into a framework and refined through an iterative process throughout the course of analysis. This method was appropriate given the diverse groups of people seeking or refused asylum represented across the literature, and allowed us to explore their lived experiences and the context in which these were described. We were also able to examine both similarities and differences (such as divergent themes).

The evidence was also categorised according to the population group the data was collected from (people seeking asylum, those refused asylum, or 'mixed refugee and migrant' groups), and by geographical location (England, Scotland, Wales, UK, or unspecified location).

Our review of the existing literature yielded 337 sources. After removing duplicate sources, 267 records were included in the title and abstract screening, and 38 articles were assessed in the full-text screening (of which 12 did not meet the inclusion criteria and were subsequently excluded). Overall, the literature review identified 26 sources: 15 from peer-reviewed journals and 10 from grey literature (see Appendix 4).

The peer-reviewed sources all used qualitative methodology, such as interviews and focus groups, alongside correspondence and editorials in academic journals that provided insight into the views and experience of experts working in the field. The grey literature was dominated by longitudinal reports (often including quantitative descriptive statistics alongside individual case studies), with most describing the experiences of individual organisations in both supporting access to healthcare services and providing healthcare.

Of the 26 sources identified, 16 sources drew on data collected from broader populations, which also included refugees, irregular migrants and economic migrants on working visas. Five sources drew solely on data collected from people seeking asylum, one drew on data solely from those who had been refused asylum, and the remaining three on data from both.

Twelve sources drew on data collected in England or from undisclosed locations in the UK (11). Just two sources drew on data from Scotland, and there were no sources drawing on data collected in Wales, although the sources from undisclosed UK locations may have included data collected from individuals in Wales. It is

therefore not possible to compare or contrast the experiences of people seeking or refused asylum in the three nations. It is worth noting that the partner report to our study looks at the specific experiences of people in Glasgow, Swansea, Nottingham and London and highlights local practices.

2.2 Doctors of the World UK clinic data

Doctors of the World UK (DOTW UK) is part of Médecins du Monde (MdM), an international humanitarian network providing medical care to excluded populations across the world.

DOTW UK runs volunteer-led clinics in London and Brighton and an advocacy programme providing basic medical care, information and practical support for people struggling to access the NHS. People who attend DOTW UK clinics as patients include irregular migrants, (who have overstayed a visa or entered the UK without immigration papers), migrants on working visas, people seeking or refused asylum, and refugees.

All clinic patients complete a social assessment form with a trained volunteer. This form is used internationally by the MdM network, and captures a range of elements of a person's history, such as: experience of the migration process; friendship connections and other social support; living arrangements; housing; family relations; migration status; and access to services, including healthcare services. This information is put into a database and used both to support ongoing advocacy casework for the patient and to monitor and evaluate DOTW UK services.

Data on barriers experienced when accessing healthcare is collected from all patients under the headings outlined in Table 1.

Table 1 List of predefined barriers to healthcare access used by DOTW UK clinics

- Did not try to access healthcare services
- No difficulties
- Administrative problems and issues with documentation in order to obtain non-chargeable costs
- Lack of understanding of knowledge of the system and rights
- Was denied health coverage
- Medical consultation, treatment or deposit too expensive
- Language barrier
- Fears of being reported or arrested
- Previous bad experiences within the health system
- Healthcare cover too expensive
- Health coverage open in another EU country
- Other reasons expressed
- Any barrier

Notes: 'any barrier' = a barrier not listed. It is possible to record more than one barrier.

These predefined barriers are used internationally in the MdM assessment form. In this report we present primary data on the barriers to accessing healthcare services identified by patients who attended DOTW UK clinics (in London and Brighton) from 2014 to 2017. The data has been filtered by immigration status, to identify people seeking or refused asylum.

Although this data is extensive, there are limitations on how it can be interpreted. Responses are collected by volunteers interviewing patients, and there could be differences in those who did and did not respond. Patients may give a biased response, anticipating the answer they think the interviewer wants. Although interpreters are used, there is scope for misunderstanding or different interpretations of the questions by the patient. The full methodology of the DOTW UK clinic data is available in Appendix 1.

2.3 Limitations

Various factors may affect our ability to draw fuller conclusions, and in some cases more research would be needed to fill gaps in the evidence.

Differences between the two groups should be treated with caution. Seeking asylum and being refused asylum are very fluid immigration statuses. Anyone refused asylum will have spent time seeking it, and some people seeking asylum may also have experience of being refused (for example, those who have put in a fresh claim or have an appeal pending). When data is collected from these individuals on their experiences of accessing healthcare, it is not always possible to know what their immigration status was at that time. There is therefore a limit to the extent to which the specific experiences of people seeking asylum, or those refused it, can be identified. We found this also applied to gathering personal stories of the lived experiences for our partner report, when we relied on people's own descriptions of their status at the time.

The data may not cover or reflect the experiences of more marginalised people seeking or refused asylum. The experiences of those who have not interacted with charities and voluntary organisations, healthcare services or non-governmental organisations (NGOs) will not be represented.

Due to the small scale of many of the studies we identified (low number of respondents and largely qualitative), generalisations about these findings should be made with caution.

There is a lack of quantitative research and intersectional research, meaning the experiences of subgroups, such as disabled or lesbian, gay, bisexual and transgender people seeking or refused asylum, is less reported. Our partner report features some specific experiences of people with protected characteristics, including disability.

The research identified is predominantly focused on highlighting barriers to healthcare (reflecting the experience of individuals who have sought out help and support). It may not adequately capture instances in which people seeking or refused asylum are not experiencing barriers to accessing healthcare. Therefore, enabling factors, or examples of when policies are successful in facilitating healthcare, are not being recorded.

More barriers and enablers may be unreported and unrecognised in the evidence due to the challenges in engaging such populations in research, so they are under-represented in the evidence base. Further research is needed on examples of best

practice and important enablers to inform appropriate improvements in healthcare services.

There is an overall lack of available evidence from the literature review from Scotland and Wales, making it difficult to draw comparisons between the three nations. Similarly, the DOTW UK primary data is for clinics in England (London and Brighton) that are not dispersal areas.

3 | Policy context

This section of our study outlines policies and guidance that have an impact on how people seeking or refused asylum may access healthcare services and related financial and other support in England, Scotland and Wales. It covers what they are entitled to, either free of charge or paid for, what information about them may be shared between the NHS and the Home Office, and what advice is available both to people seeking or refused asylum and healthcare service providers.

3.1 Entitlement to healthcare services

To access NHS services in England,[13] Scotland[14] and Wales free of charge, a person must be 'ordinarily resident' in the UK.[15] This means they must be 'living lawfully in the United Kingdom voluntarily and for settled purposes as part of the regular order of their life for the time being, whether of short or long duration'.[16] The Immigration Act 2014 introduced the requirement that, if a person needs permission to enter or remain in the UK, they must have been granted 'indefinite leave to remain'.[17]

There are no restrictions on access to primary care services for people seeking or refused asylum in England, Scotland or Wales.[18]

3.1.1 People seeking asylum

People seeking asylum, and their dependants,[19] can access NHS services in England, Scotland and Wales free of charge. This is because, although they do not

[13] National Health Service Act 2006, section 175.
[14] National Health Service (Scotland) Act 1978, section 98.
[15] National Health Service (Wales) Act 2006. With the exception of the few NHS services, such as dental care, eye sight tests and, in England, prescriptions, where statutory charges apply.
[16] *YA, R (on the application of) v Secretary of State for Health [2009] EWCA Civ 225, 2009*
[17] Immigration Act 2014, section 39.
[18] NHS Choices, NHS general practitioners (GPs) services (PDF); NHS England, Asylum seekers and refugees: how to register with a doctor (GP) (PDF); guidance for Scotland; and guidance for Wales.
[19] England (2017) section 14(4); Scotland (2018); Wales (1989) section 4(c).

have indefinite leave to remain in the UK and therefore are not 'ordinarily resident', all NHS charging regulations include an exemption from charges for those who have made an asylum application.[20]

3.1.2 People refused asylum

People who have been refused asylum can access all NHS services in Scotland and Wales free of charge because, even though not 'ordinarily resident', they are exempt as 'individuals who have made a formal application for leave to stay as a refugee in the UK'.[21]

This is not the case in England, where not everyone refused asylum is exempt, and some of them may have to pay for some NHS services.

3.1.3 Exemptions from charging (England)

The National Health Service (Charges to Overseas Visitors) Regulations 2015 make certain NHS services exempt, including: accident and emergency; family planning (excluding termination of pregnancy); diagnosis and treatment of specified communicable diseases; and sexually transmitted infections.[22] Therefore, people refused asylum in England can access these services free of charge.

If someone refused asylum is a victim of torture, female genital mutilation, domestic violence, or sexual violence, under the 2015 regulations they will not be charged for NHS services to treat any condition caused by these forms of violence, as long as they have not travelled to the UK specifically to get that treatment.[23]

The 2015 regulations also mean a person refused asylum is exempt from all NHS charges if they receive either of the following forms of support: [24]

- Support under section 4(2) of the Immigration and Asylum Act 1999, which is available for people refused asylum (and their dependants) who are

[20] The National Health Service (Charges to Overseas Visitors) (Scotland) Regulations 1989; The National Health Service (Charges to Overseas Visitors) Regulations 1989; The National Health Service (Charges to Overseas Visitors) Regulations 2015, England (2015) section 15(b); Scotland (1989) 4(c); Wales (1989) 4(c).
[21] The National Health Service (Charges to Overseas Visitors) (Scotland) Regulations 1989; The National Health Service (Charges to Overseas Visitors) Regulations 1989, Scotland (1989) section 4(c); Wales (1989) section 4(c).
[22] Section 9.
[23] Section 8.
[24] Section 15(c) and (d).

destitute[25] and face a genuine and recognised barrier to returning to their country of origin. The criteria include: taking all reasonable steps to leave the UK; being unable to leave the UK because of a medical reason or physical impediment as documented by a medical practitioner (women in the late stages of pregnancy, or those with a baby under six weeks old, are accepted as being unable to travel) (Home Office, 2018b);[26] being unable to leave the UK because there is no viable route of return; having applied for judicial review of an asylum claim and been granted permission to proceed; or if the provision of accommodation is necessary to avoid breaching a person's human rights[27] (The Immigration and Asylum (Provision of Accommodation to Failed Asylum-Seekers) Regulations 2005). [28]

- Local authority support (under section 21 of the Care Act 2014 part 1) that is available to people refused asylum who, following a care assessment, are found to need support with accommodation (Care Act 2014),[29] usually as a result of a disability.

This means that destitute women in the late stages of pregnancy (or with a baby under six weeks), whose asylum application has been refused but is in receipt of section 4 support, are not chargeable for NHS services.

Disabled people who receive accommodation support under part 1 of the Care Act 2014 are also not chargeable for NHS services.

3.1.4 Upfront payment for services

Charges for NHS services are 150% of the tariff for the service (The National Health Service (Charges to Overseas Visitors) Regulations 2015).[30] The estimated cost of the service must be paid beforehand, unless this would prevent or delay an 'immediately necessary' or 'urgent' service from being provided (The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017).[31] Under

[25] An applicant for section 4 support must show that they are destitute or are likely to become destitute within 14 days. A person is 'destitute' if they do not have adequate accommodation or do not have enough money to meet essential living expenses for themselves and any dependants.
[26] p. 11.
[27] For example, to avoid a breach of Article 3 of the European Convention on Human Rights (prohibiting torture and inhuman and degrading treatment) or Article 8 (protecting private and family life).
[28] Section 3(2).
[29] Section 18.
[30] Section 7(3).
[31] Section 4(2).

the regulations, hospital trusts should withhold any service that is not 'urgent' or 'immediately necessary', until the patient has paid for it in full.

It is up to a clinician to decide if a service is 'urgent' or 'immediately necessary'. Department of Health and Social Care guidance defines 'immediately necessary' treatment as: 'That which a patient needs promptly: to save their life; or to prevent a condition from becoming immediately life-threatening; or to prevent permanent serious damage from occurring. All maternity services (antenatal, intrapartum and postnatal) must be treated as being immediately necessary' (Department of Health and Social Care, 2018).[32]

'Urgent treatment' is defined as: 'That which clinicians do not consider immediately necessary, but which nevertheless cannot wait until the person can be reasonably expected to leave the UK. Clinicians may base their decision on a range of factors, including the pain or disability a particular condition is causing, the risk that delay might mean a more involved or expensive medical intervention being required, or the likelihood of a substantial and potentially life-threatening deterioration occurring in the patient's condition if treatment is delayed until they return to their own country.'[33]

The guidance also covers timescales and the likely date someone refused asylum may return to their own country. It says NHS trusts 'may wish to estimate that such patients will remain in the UK initially for six months, and the clinician can then consider if treatment can or cannot wait for six months … However, there may be circumstances when the patient is likely to remain in the UK longer than six months, in which case a longer estimate of return can be used.'[34]

3.2 Patient information shared between the NHS and Home Office

Demographic information on NHS patients, such as name, address, date of birth and NHS number, is held on the Personal Demographics Service (PDS) national electronic database. This is managed by NHS Digital in England, Information Services Division (ISD) Scotland and the Welsh Demographic Service.

3.2.1 People refused asylum

Hospital trusts in England send non-clinical information (including 'current address') on someone refused asylum to the Home Office to establish their immigration status

[32] pp. 64–6.
[33] pp. 64–6.
[34] pp. 64–6.

when other ways of checking what the person is entitled to have been exhausted. (Department of Health and Social Care, 2018).

NHS bodies, and debt collection agencies working on their behalf, must notify the Home Office if a patient has debts of £500 or more that have been outstanding for two months or more. The information they share with the Home Office includes the person's home address, and can be used to deny any future immigration application to enter or remain in the UK (Department of Health and Social Care, 2018).

From January 2017 to May 2018, NHS Digital shared non-clinical information about people refused asylum (including their last known address) with the Home Office for immigration enforcement purposes (Department of Health and Social Care and the Home Office, 2018). But in May 2018 the UK Government announced that this arrangement would be amended, to only apply in cases (or suspected cases) of serious crime (HC Deb, 9 May 2018) .

Scottish Government requires NHS Boards to pass full details of a patient previously refused asylum with outstanding debts to NHS Scotland Counter Fraud Services who will liaise with the Home Office (Scottish Government, 2010).

Guidance for hospitals in Wales states that decisions to report a patient's suspected immigration status 'need to be taken in the full light of the patient's circumstance ... there can be a public interest argument for reporting the patient's immigration status this needs to be weighed against not just medical confidentiality but also the medical needs of the patient and the wider public. It adds that each case should be discussed with the hospital trust's Caldicott Guardian (the senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly) (NHS Wales, 2009).

Welsh hospitals may share non-clinical information about someone refused asylum (not including their home address) with the Home Office to establish their immigration status and eligibility to access NHS services. According to the guidance, this situation should only occur 'in exceptional circumstances and when all other avenues of establishing entitlement have been exhausted', and after getting the patient's signed consent.

There is no publicly available information on whether the Welsh Demographic Service shares patient information with the Home Office to support immigration enforcement.

3.3 Policy guidance for health service providers

3.3.1 Primary care

All three nations provide guidance on GP practice registration that draws on each one's general medical services (GMS) contract. However, they interpret the (identical) contracts[35] differently, outlining different obligations for practices when registering patients. NHS England guidance (NHS England, 2017) states that people seeking or refused asylum can register with a GP, and that someone's inability to produce information on their identity or residence is not reasonable grounds to refuse to register them. Guidance in Scotland (Scottish Government, no date) and Wales (NHS Wales, 1999) is less clear, but clearly states that they must provide free emergency treatment.

3.3.2 Secondary care

In England there are two main national sources of guidance on providing secondary care for people not 'ordinarily resident' in the UK that cover those seeking or refused asylum. These are the Department of Health and Social Care (DHSC) 'Guidance on overseas visitors hospital charging regulations' and accompanying 'Upfront charging operational framework' (Department of Health and Social Care, 2018) and the Public Health England (PHE) 'Migrant health guide' (Public Health England, 2018). DHSC also offers an e-learning platform to support providers implementing cost recovery.[36] The DHSC resources focus on application of the NHS charging restrictions rather than facilitating access to care, while PHE's guide offers a more complete overview of the entitlements and barriers faced by people seeking or refused asylum and other migrants.

Guidance for commissioners on considering the needs of people seeking asylum has been produced locally in England (Mind and NHS England, 2015; NHS Midlands and Lancashire Commissioning Support Unit, 2017). These resources cover both those seeking asylum and those who have been refused it, and provide general

[35] In all three GP contracts (England GP contracts, Scotland GP contracts (PDF) and Wales GP contracts):

- It states that a GPs may only refuse an application to register if it has **reasonable grounds for doing so which do not relate to** the applicant's race, gender, social class, age, religion, sexual orientation, appearance, disability or medical condition.
- The only reasonable grounds to refuse an application described is that an **applicant does not live in the practice area.**

[36] DHSC and Health Education England Overseas Visitors Cost Recovery programme.

information regarding the asylum process, barriers, health needs and entitlements. However, the resources we identified are not up to date on NHS charging.

In Scotland, guidance for secondary care providers outlines the process for determining eligibility for charging, and refers to the eligibility of people seeking or refused asylum (Scottish Government, 2010).

NHS Wales produces the main guidance for Welsh secondary care providers on what people seeking or refused asylum are entitled to. This focuses on identification of chargeable patients and entitlement to free care (NHS Wales, 2009).

3.4 Asylum accommodation dispersal policy

Under section 95 of the Immigration and Asylum Act 1999, people seeking asylum can apply for support for accommodation while waiting for their claim (or appeal) to be considered, based on individual circumstances and if they satisfy a 'destitution test' (proving they are, or soon will be, homeless and do not have money to buy essentials). The act introduced a policy of 'dispersal' across the UK so no one local authority area would be overburdened by the obligation to support people seeking asylum.[37]

If a decision is made to grant someone support under section 95, they are then 'dispersed' to Home Office accommodation on a strictly 'no choice' basis. This is normally outside London, and currently provided by three private sector contractors. Pregnancy, healthcare needs and disabilities should be taken into account in determining the type and location of accommodation.[38]

The dispersal accommodation providers should arrange to register people with pre-existing health needs, such as acute mental health and long-term conditions or pregnancy, with a GP within five days. There is no obligation on initial accommodation providers to support people to register with a GP, although people in initial accommodation are entitled to receive a healthcare assessment and services delivered by an onsite healthcare team independent of the Home Office.

Women should be dispersed only once from their initial accommodation during pregnancy, unless they specifically request relocation. This means that dispersal

[37] House of Commons Library (2016), 'Policy on the dispersal of asylum seekers'.
[38] UK Visas and Immigration, 'Healthcare needs and pregnancy dispersal policy' (PDF).

accommodation must be suitable for the woman's needs both before and after birth, and available throughout that period.[39]

3.5 Financial help to access healthcare services

3.5.1 Subsistence support for people seeking asylum

People seeking asylum can apply for financial subsistence support under section 95 of the Immigration and Asylum Act 1999 while waiting for their claim to be considered. Support can be for accommodation or subsistence, according to their circumstances and on condition they satisfy a destitution test.[40]

People seeking asylum receive weekly cash support of £37.75 per member of their household.[41]

Pregnant women or women with young children can apply to get an extra £3 per week. Children under the age of one get an additional £5 per week. Parents can get for a maternity grant of £300 (£250 for those refused asylum), which they must apply for eight weeks before the baby is due and up to six weeks after the baby has been born.

Most people seeking asylum are restricted from working.[42]

3.5.2 Help with healthcare costs

Someone who is seeking asylum in England, Scotland and Wales may obtain a HC2 certificate under the NHS Low Income Scheme. This means they can get help with NHS statutory charges in the same way as a person 'ordinarily resident' in the UK and on a low income (NHS Business Services Authority, no date).

A HC2 certificate entitles a patient to: free NHS prescriptions (in England); dental treatment; sight tests and glasses or contact lenses; and help with the cost of travelling to receive NHS treatment.

[39] UK Visas and Immigration, 'Healthcare needs and pregnancy dispersal policy' (PDF).
[40] House of Commons Library (2016), 'Policy on the dispersal of asylum seekers'
[41] UK Visas and Immigration, 'Asylum support'
[42] UK Visas and Immigration (2014), 'Working in the UK while an asylum case is considered'

People seeking asylum who get accommodation or financial support[43] should be provided with a HC2 certificate by the Home Office (UK Visas and Immigration, no date).[44]

In Scotland and Wales everyone is entitled to free prescriptions.

3.5.3 Subsistence support for people refused asylum

Support under section 4(2) of the 1999 Act is available for people refused asylum (and their dependants) who are destitute[45] and face a genuine and recognised barrier to returning to their country of origin. The criteria include: taking all reasonable steps to leave the UK; being unable to leave the UK because of a medical reason or physical impediment as documented by a medical practitioner (women in the late stages of pregnancy, or those with a baby under six weeks old, are accepted as being unable to travel) (Home Office, 2018b);[46] being unable to leave the UK because there is no viable route of return; having applied for judicial review of an asylum claim and been granted permission to proceed; or if the provision of accommodation is necessary to avoid breaching a person's human rights[47](The Immigration and Asylum (Provision of Accommodation to Failed Asylum-Seekers) Regulations 2005). [48]

People receiving this accommodation or financial support[49] should be provided with a HC2 certificate by the Home Office (UK Visas and Immigration, no date).[50]

They will get £35.39 per person per week on a payment card for food, clothing and toiletries.[51]

Anyone refused asylum, and who does not get support under section 4(2), is no longer eligible for general asylum support once their application has been turned down. This support will stop 21 days after the decision has been made.[52]

[43] Under section 4(2) of the Immigration and Asylum Act 1999.
[44] pp. 6–7.
[45] An applicant for section 4 support must show that they are destitute or are likely to become destitute within 14 days. A person is 'destitute' if they do not have adequate accommodation or enough money to meet essential living expenses for themselves and any dependants.
[46] pp. 11.
[47] For example, to avoid a breach of the European Convention on Human Rights (ECHR) Article 3 (prohibiting torture and inhuman and degrading treatment) or Article 8 (protecting private and family life).
[48] Section 3(2)
[49] Under section 4(2) of the Immigration and Asylum Act 1999.
[50] pp. 6–7.
[51] UK Visas and Immigration, 'Asylum support'.
[52] UK Visas and Immigration (2015), 'Ceasing asylum support'.

3.6 English language and interpretation support

3.6.1 English classes

In England, someone seeking asylum who has been waiting for a decision for longer than six months becomes eligible for free English for Speakers of Other Languages (ESOL) classes (Department for Business, Innovation and Skills, 2011). Local authorities may fund additional English language courses they can access sooner (Foster and Bolton, 2018).

In Scotland, people seeking asylum are eligible for free English classes however long they have been in the country (Scottish Government, 2015) and ESOL is free for all people seeking asylum (and refugees) in Wales (Higher Education Funding Council for Wales, 2010).

3.6.2 Interpretation support

NHS England guidance states that: 'Interpretation and translation should be provided free at the point of delivery, be of a high quality, accessible and responsive to a patient's linguistic needs. Patients must not be asked to pay for interpreting services or to provide their own interpreter' (NHS England, 2018).

According to NHS Inform guidance, patients in Scotland have the right to request an interpreter, sign language interpreter, or other communication support (NHS Inform, no date a). NHS Wales guidance states that Welsh healthcare providers should address 'all language and communication needs' (NHS Wales, 2010).

3.7 Information and resources for patients

The UK and devolved governments and publicly funded bodies provide people seeking or refused asylum with some sources of information on their entitlement to NHS services and how to access them. This is in the form of leaflets, factsheets or oral briefings, as well as practical support from staff during the asylum dispersal process.

3.7.1 Information for people seeking asylum

NHS England has produced a leaflet, available on its NHS Choices website, which covers access to primary care (by registering with a GP) but not secondary care or

community services. Although written in English, it 'may be available in alternative languages upon request' (NHS England, no date).

NHS Inform has published a factsheet 'Healthcare for asylum seekers and refugees in Scotland' on the Scottish Government website (NHS Inform, 2016), although this incorrectly states that people seeking asylum who do not receive Home Office support can only access limited NHS services free of charge. It is available in Amharic, Arabic, Farsi, French, Pashto, Chinese, Sorani, Tigrinya and Urdu.

There are no resources explaining how people seeking asylum can access NHS services in Wales, although the Welsh Government website does provide an outline of healthcare entitlement for 'overseas visitors' (NHS Wales, no date). Guidance from national public health bodies covering primary care only provides limited information on secondary care entitlement, but offers advice on the health needs and barriers faced by people seeking or refused asylum (Public Health Wales, 2009; 2016).

Guidance that applies to people seeking asylum across England, Scotland and Wales states that accommodation providers should support them to access NHS services when they have been dispersed (UK Visas and Immigration, no date). It says those living in initial or dispersal accommodation will get health checks on arrival. Healthcare teams at initial accommodation centres will make appropriate referrals and help people to make appointments to see a GP 'if required'. The guidance does not go into detail about what health checks should include or when support for accessing healthcare services should be provided.

Within a day of arriving at dispersal accommodation, people seeking asylum get a briefing in which they will be signposted to GP registration and a dentist (UK Visas and Immigration, no date). This briefing can be given verbally or in writing, and must be delivered in a language that the person understands. Dispersal accommodation staff will take anyone who needs an urgent GP appointment or has a specified pre-existing condition to register at a practice within five days of their arrival. Pre-existing conditions include: long-term conditions that need regular medication (such as diabetes, heart problems, asthma, epilepsy, haemophilia and non-active TB); HIV, if it has already been diagnosed and no arrangements to continue healthcare have been made before dispersal; and acute mental health issues. Pregnant women and children under nine months will also be helped to register with a GP within five days of moving to dispersal accommodation.

3.7.2 Information for people refused asylum

The Department of Health and Social Care has produced resources, including posters and leaflets, aimed at patients in England who are not 'ordinarily resident' in the UK, advising them that they may have to pay for healthcare, and explaining the circumstances in which their information may be shared with the Home Office .

My Healthy London, a partnership of London clinical commissioning groups and NHS England, has produced 'My right to access healthcare' cards to make it easier for homeless patients to register with a GP. These outline entitlement to GP registration and state: 'My immigration status does not matter' (Healthy London Partnership, 2016). They have been distributed to homeless shelters, drop-in centres and charities across London.

The NHS Inform factsheet 'Healthcare for asylum seekers and refugees in Scotland' (NHS Inform, 2016) also includes advice for people refused asylum, although it incorrectly states that they can only access limited NHS services free of charge.

Although there are no specific resources aimed at helping people refused asylum access healthcare services in Wales, the Welsh Government website offers an outline of healthcare entitlement for 'overseas visitors' (NHS Wales, no date).

4 | Findings

4.1 The impact of legislation and policy

4.1.1 What are the barriers?

Confusion about who should be charged for what

The Immigration Act 2014 and NHS charging regulations introduced in 2015 and 2018 have made complex and rapid changes to who pays what for NHS services. This has led to confusion and inconsistency, which this study identified as a barrier for people seeking or refused asylum (and other migrant groups) in accessing healthcare (Rafighi *et al.*, 2016).

We found that ambiguity about charging policies and specific terms has led to particular problems for people refused asylum in England. The regulations say that 'urgent' or 'immediately necessary' treatment should not be withheld from someone who cannot pay upfront (The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017)[53]. But there is evidence that migrant patients (including those refused asylum) have had lifesaving care withheld or delayed because health professionals have not applied policy correctly or not followed guidance (Doctors of the World UK, 2017c; Doctors of the World UK, 2016a).

We also found evidence patients had been charged for services that should be exempt, such as tuberculosis (TB) treatment, and not been diagnosed or given onward treatment for services that should be free (Paradise and Sadavarte, 2016).

People seeking asylum face similar problems. They have had chemotherapy and palliative care withheld from them (Doctors of the World UK, 2016b) and been billed for treatment (Doctors of the World UK, 2016a). One study reported that numerous pregnant women seeking asylum had been incorrectly charged for maternity services (Feldman 2017).

We also found cases of cardiac surgery and cancer treatments for people not exempt from the charging regulations being classified as non-urgent (Doctors of the

[53] Section 4(2).

World UK, 2016b; Doctors of the World UK, 2018a; Doctors of the World UK, 2017a). This indicates that the definitions of 'urgent' and 'immediately necessary' are not broad or clear enough to cover such treatment in all circumstances. Individual cases show healthcare service providers get confused about these terms and may change their classification of treatment once patients receive legal representation (Doctors of the World UK, 2017c).

Maternity services should always be classified as 'urgent' and 'immediately necessary' and therefore not subject to upfront charging. However, we found evidence they have been withheld from pregnant women who have been refused asylum who were unable to pay for them (Doctors of the World UK, 2017c). The following example (from England) illustrates this inconsistent application of the charging policy. 'Nadia' had her asylum application refused a few days before she gave birth to twins prematurely by emergency C-section. She and one baby required ongoing care, but sometimes the hospital refused to treat them without upfront payment, and she was billed over £40,000. Nadia was going to stop treatment until her advice workers persuaded her to continue (Feldman, 2017).

Concerns about payment and eligibility checks

People who have been refused asylum and who live in England, must pay in advance to get non-urgent NHS treatment. However, by law they cannot work, often they cannot claim public funds (like benefits and housing assistance) either, and are unable to pay for healthcare services (Fang *et al*., 2015; British Red Cross, 2015).

Carrying out identity and eligibility checks damages patients' trust and confidence in healthcare services (Doctors of the World UK, 2016b). We found these checks can mean people seeking or refused asylum have to wait for services, or are put off using them (Feldman, 2017).

Our study showed that concerns about the NHS overseas visitor and migrant cost recovery programme in England stop people refused asylum from accessing healthcare. High costs are a particular worry (Doctors of the World UK, 2016b; Price, 2016; Pool *et al*., 2009; Fang *et al*., 2015). A study conducted in England with 70 migrants showed that people refused asylum tend to use accident and emergency (A&E) departments to avoid unwelcome questions about eligibility. They may also rely on alternative medicines to treat conditions such as HIV, and delay seeking help until their health needs are advanced enough to be classified as 'urgent' or 'immediately necessary'. Charging policies in England can stop people getting tested or treated, which often means they then have to stay in hospital for longer (Thomas

et al., 2010) and face poorer and more costly health outcomes, as well as increasing the risk to wider public health (Farrington *et al.*, 2016).

We found that pregnant women who are seeking or have been refused asylum avoid maternity care because they think they will have to pay for healthcare services, although charges should only apply to those refused asylum and only after they have had treatment, as maternity services are classified as 'urgent' or 'immediately necessary'. To reduce costs, there are reports of women booking antenatal care late, going to fewer antenatal appointments, and sometimes not accessing maternity services at all and giving birth at home (Feldman, 2017).

Interrupted care because of dispersal

Evidence suggests that moving people seeking asylum between accommodations under the Home Office dispersal policy can cause particular problems by interrupting their care. One study found this was a barrier to HIV care in England, leading to late access to services, compromised care and increased transmission (Creighton *et al.*, 2004).

Pregnant women (receiving section 4 support) in England and Scotland have experienced interruptions and delays in getting both antenatal and routine healthcare at their dispersal destination (Maternity Action and Refugee Council, 2013; Da Lomba *et al.*, 2014).

According to Maternity Action and the Refugee Council (2013), dispersal results in poorer pregnancy and maternal health outcomes for women seeking asylum than other pregnant women. Dispersal not only affects continuity of care, it can leave a woman isolated from friends and family and mean services are not joined up so both women and children are 'vulnerable to gaps and oversights'. It is often left to charities and voluntary organisations to fill these gaps.

When dispersal occurs late in pregnancy, it adds to other complex health needs a woman seeking asylum may face (such as sexual and psychosocial challenges, infectious diseases, female genital mutilation, destitution), and exacerbates the already elevated rates of maternal and child mortality and morbidity in this population (Asif *et al.*, 2015).

4.1.2 What helps?

There is a lack of evidence within the literature on enablers deriving from legislation and policy.

The policy in England that 'urgent' and 'immediately necessary' services cannot be refused on the grounds of a person's immigration status is welcomed as an enabler for people refused asylum that means necessary care is provided without delay (Pool *et al.*, 2009).

The lack of legal restrictions on access to primary care, and clear guidance for GP practices in England on the rights of all patients (including those seeking or refused asylum) to access primary care free of charge and without any form of documentation are in theory enablers to healthcare, In practice, this hasn't resulted in smooth access to primary care and many people are still refused registration with a GP practice (see section 4.4 for further discussion of this).

People refused asylum in England who receive either support under section 4(2) of the Immigration and Asylum Act 1999 or support under Part 1 of the Care Act 2014 are exempt from all NHS charges (The National Health Service (Charges to Overseas Visitors) Regulations 2015, 2015), yet there was no evidence in the literature that this exemption is an enabler to accessing healthcare services. All people who have been refused asylum in Scotland and Wales are exempt from all healthcare charges but, due to limited availability of evidence from Scotland and the absence of evidence from Wales, it is not possible to conclude if this less restrictive policy is an enabler.

4.2 Healthcare service providers

4.2.1 What are the barriers?

Not understanding people's rights

We found that healthcare providers' lack of knowledge about people's entitlement to NHS services is a common barrier (Maternity Alliance, 2002; Da Lomba and Murray, 2014; Doctors of the World UK, 2016c; Fox and Tang, 2016; Rafighi *et al.*, 2016; Falla *et al.*, 2017). There was also a lack of understanding about the differences between migrant groups with varying immigration statuses (Fox and Tang, 2016).

GP practices commonly refuse to register people seeking or refused asylum. Some practices request extensive paperwork from new patients even though checking this is not necessary to register someone (Maternity Alliance, 2002; Fang *et al.*, 2015; Doctors of the World UK, 2016b, 2016c; Fox and Tang, 2016). It can also be hard for those seeking or refused asylum to provide this documentation (Thomas *et al.*, 2010). A study of 1,395 migrants (including people seeking and refused asylum) who visited DOTW UK clinics in 2014 found that a lack of paperwork stopped 29% of

them registering with a GP, and this was the most frequently reported barrier. The same study revealed that registration procedures for new patients can vary within a practice, sometimes depending on who is on duty at the time (Doctors of the World UK, 2016c). In addition, many practice staff do not have the power to decide who to register; instead they rely on senior people who are not always available to make a decision (Doctors of the World UK, 2016c).

Failure to meet specific healthcare needs

Clinical staff had poor knowledge of possible healthcare issues affecting people seeking or refused asylum, such as: the incidence of infectious diseases in a patient's country of origin; how to support someone who has been through trauma such as torture or rape; and vaccination coverage in countries where there is conflict or a limited healthcare infrastructure. This can stop staff accurately assessing individual needs (Maternity Alliance, 2002; Fang *et al.*, 2015). Midwifery staff may lack the expertise to meet the complex needs of pregnant women who are seeking or have been refused asylum (Binder *et al.*, 2012). Another barrier can be poor understanding of a patient's religion and cultural background. There is evidence staff struggle to address either the healthcare needs of women with female genital mutilation or the stigma associated with this practice (Asif *et al.*, 2015).

Long waits for initial GP appointments and onward referrals, and appointments that were too short, were highlighted by one study involving 56 Somali and 10 Iraqi people, including some people seeking asylum (Fang *et al.*, 2015). These issues may be compounded by a lack of understanding of the UK healthcare system and language and communication barriers.

Primary data from people seeking and refused asylum in Doctors of the World UK clinics (2014 to 2017)

Of those reporting barriers:

20% (n=114) of RAS and 19% (n=165) of AS identified administrative problems as a barrier to accessing healthcare.

4.2.2 What helps?

Positive experiences with helpful healthcare providers make it easier to access healthcare, and we found evidence that some people seeking or refused asylum have faced very few issues in using services and feel the healthcare professionals they saw had caring attitudes (Da Lomba and Murray, 2014; Rafighi *et al.*, 2016).

However, there was a lack of evidence in the published literature highlighting good practice or exploring the mechanisms to support the practice.

We did find evidence from sources in England and Scotland that advocacy and support provided by charities, voluntary organisations and healthcare professionals made it easier to access services (The Children's Society, no date; Maternity Alliance, 2002; Pool *et al.*, 2009; Scottish Refugee Policy Forum, 2012; Maternity Action and Refugee Council, 2013; Doctors of the World UK, 2016c; Health Professionals Against Immigration Detention, 2016; Nezafat Maldonado *et al.*, 2018). Examples of this support include helping people register with a GP and understand what they are entitled to and how different services operate (Doctors of the World UK, 2016c). In one study, people seeking asylum said information they got from the health board on arrival in Glasgow made them feel welcomed and cared for. They got advice on how and where to register with a GP, and sometimes had help from an 'asylum support nurse' (O'Donnell *et al.*, 2007).

A British Red Cross study highlights the work of the Asylum Health Bridging Team in Glasgow, where a dedicated NHS service has developed detailed knowledge and understanding of the complex area of rights and entitlements. According to the study, both people seeking asylum and service providers appreciate how midwives in particular take on advocacy and support roles, including helping with paperwork and contacting the Home Office (Fassetta *et al.*, 2016).

However, the literature also suggests there may be an over-reliance on help from charities and voluntary organisations, which should not be seen as a substitute for adequate support from statutory healthcare services (Fang *et al.*, 2015).

4.3 Additional costs related to healthcare access

4.3.1 What are the barriers?

Our research found that any financial barriers people seeking or refused asylum may face in accessing healthcare are compounded by the limited financial support they receive, and the range of other social and financial issues they experience. This means that even small charges can present insurmountable problems (Fang *et al.*, 2015).

Associated costs, including travel

One study identified the cost of transport to appointments (Fang *et al.*, 2015) and of mobile phone credit to contact services as financial barriers to accessing healthcare among people seeking asylum in Scotland (Scottish Refugee Policy Forum, 2012). Another reported that being unable to pay for travel (even when the costs would be reimbursed) could stop torture survivors attending therapy and other health-related appointments, maintaining social contact, and taking part in other activities that might support their rehabilitation (Freedom from Torture, 2013).

The cost of travelling to healthcare services can be a significant barrier for people with a disability because they may need to attend more appointments and public transport may not be suitable (Ward *et al.*, 2008).

Lack of health and wellbeing support

Cost is a particular issue for people who have been refused asylum as most are not eligible for support from public funds. A British Red Cross study of people who have been refused asylum living in towns in England and Scotland found the majority were not on any form of support and (with no money) struggled to survive, relying mostly on charities for food and clothing (British Red Cross, 2017).

An earlier British Red Cross study highlighted the poor physical and mental health and wellbeing of people refused asylum. Their experiences demonstrate that informal resources do not adequately replace statutory support designed to meet essential needs such as food, accommodation and healthcare provision (British Red Cross, 2015).

In a study of pregnant refugee and asylum-seeking women in Scotland, charities and voluntary organisations recognised a gap in support for pregnant women who have been refused asylum. These women qualify for section 4 support if they are ‘destitute’, but only get this six weeks before they are due and receive no money or housing until then. This leaves them open to exploitation and violence from people who are ostensibly ‘helping’ them in exchange for sexual favours or domestic servitude (Fassetta *et al.*, 2016).

Also in Scotland, pregnant women seeking asylum reported that lack of money meant they could not follow GP advice on diet and nutrition to support their pregnancy and maternal health (Da Lomba and Murray, 2014).

4.3.2 What helps?

Overall, we found a lack of evidence on financial enablers for access to healthcare by people seeking or refused asylum.

Being entitled to an HC2 certificate should help, but people need to know how to get one if it is not automatically provided or renewed (Maternity Alliance, 2002).

Other enablers to healthcare described in the literature included financial support from friends and families, for example borrowing funds in order to access healthcare (Da Lomba *et al.*, 2014). However, this emerged as an option for people who felt they had no other choice but to borrow money.

4.4 Language and communication

4.4.1 What are the barriers?

A report by DOTW UK identified language as the third most prevalent barrier for migrant patients (including people seeking or refused asylum) in accessing healthcare (Doctors of the World UK, 2015). Communication issues were frequently mentioned by people whose stories feature in our partner report.

Difficulty using services

Our study found that limited proficiency or literacy in English could stop people understanding the UK healthcare system and communicating effectively with healthcare staff such as receptionists and clinicians. In turn, this can prevent registration with services, onward referral, and being fully aware of when, where and how to seek further healthcare. A particular example is of pregnant women not knowing about, or engaging with, antenatal care (Da Lomba and Murray, 2014).

Language can be a problem in making initial contact with services, such as phoning a GP practice to register or book an appointment (O'Donnell *et al.*, 2007). This was highlighted by someone seeking asylum who explained as part of a qualitative study: 'We didn't have telephone. But ... reception say you don't come, you have to call. We can't speak on phone. If you see on the face it's easier' (Bhatia and Wallace, 2007).

Lack of appropriate support and information

Inadequate provision and availability of interpreting services can stop people getting an accurate or timely diagnosis and understanding clinical and other procedures (The Children's Society, no date; Maternity Alliance, 2002; Scottish Refugee Policy

Forum, 2012; Fang *et al.*, 2015; Paradise and Sadavarte, 2016). This was highlighted in one qualitative study by a person seeking asylum, who reported: 'They said that we provide you interpreter in hospital but in GP we cannot provide you interpreter' (Bhatia and Wallace, 2007).

A lack of information available in languages other than English can affect people's ability to manage their own health as well as access healthcare services. One study of recently arrived migrants in Birmingham (including those seeking or refused asylum) shows that inability to speak English is connected to poor experience of NHS care, and suggests that poor quality interpretation, or lack of it altogether, is likely to result in misdiagnosis of health problems (Lindenmeyer *et al.*, 2016).

We found that when interpretation services are provided, they are not always of good enough quality, or appropriately neutral. This hampers even basic interactions between patients and healthcare services. For example miscommunication between the patient, interpreter and health professional may lead to incorrect diagnosis, or the patient may not understand how to take their medication correctly (O'Donnell *et al.*, 2007).

Interpretation provided by a patient's family members, including children, or other people from their community, can be a barrier to healthcare access because of concerns about the confidentiality and privacy of interactions with services (Fang *et al.*, 2015; Finlay *et al.*, 2017). One study reported that people have reservations about using a person who lives in the same town as their interpreter because they feel 'that some information may go out and be gossip to other friends' (Fang *et al.*, 2015)

This can be a particular barrier for someone who has experienced trauma and violence. It makes them less willing to disclose information to a healthcare professional, so it is harder to assess their specific healthcare needs (Asif *et al.*, 2015).

There is evidence that disabled people face particular language and literacy barriers, and there are not enough interpretation and translation services available for deaf or blind patients who use sign language or Braille (Ward *et al.*, 2008)

Overall, we found that women are likely to face greater language barriers, which last for longer. This is linked to lower levels of education, literacy, and ability to adapt to a new culture (Asif *et al.*, 2015).

Women report that cultural factors present additional challenges in communication, such as having to interact with male interpreters in maternity or sexual health

services or when disclosing experience of domestic or sexual violence (Ward *et al*., 2008; Da Lomba and Murray, 2014).

Primary data from people seeking and refused asylum in Doctors of the World UK clinics (2014 to 2017)
Of those reporting barriers, 7% (n=41) of RAS and 10% (n=88) of AS reported a language barrier had prevented them accessing healthcare.

4.4.2 What helps?

Professional interpretation services make it easier to access healthcare. They are particularly beneficial when the interpreter has the health literacy needed to understand and discuss complex medical conditions as well as sensitive or stigmatised topics, such as exposure to violence (Asif *et al.*, 2015). Professional interpreters are associated with improved healthcare, patient satisfaction and health outcomes (Asif *et al.*, 2015; O'Donnell *et al.,* 2007).

We found some evidence that family or friends acting as informal interpreters could help people seeking or refused asylum access healthcare when professional services are not available (Finlay *et al.*, 2017). But this could make the patient less willing to share information.

4.5 People's knowledge of healthcare services and their rights and entitlements

4.5.1 What are the barriers?

People seeking or refused asylum often lack knowledge about their entitlement to healthcare services (Maternity Alliance, 2002; Fang *et al.*, 2015; Rafighi *et al.*, 2016; Doctors of the World UK, 2017b). This is the case even when there are fewer restrictions, such as in Scotland, where prescriptions are free and people refused asylum are exempt from charges (Scottish Refugee Policy Forum, 2012; Da Lomba and Murray, 2014).

Not knowing where and how to find the right services

People commonly do not know: how to register with a GP; how to be referred to specialist services; and when to use A&E services and walk-in services. This is partly because they are used to different healthcare systems, protocols and procedures in their own country (The Children's Society, no date). Studies highlight

the need for easily accessible and standardised guidelines on the healthcare system, structure and access to healthcare for new arrivals (Paradise and Sadavarte, 2016).

Accessing mental health services can be a particular challenge. People may not know what is available, believe it is inappropriate to discuss their mental health needs with a GP, and generally be unsure when it is acceptable and 'safe' to seek help for mental health concerns (Majumder *et al.*, 2015).

Disabled people seeking or refused asylum may find it particularly hard to get information on how to access appropriate care because they are unaware that social services can help (Community Care, 2007).

Poor communication and a lack of cultural understanding about sensitive health concerns can add to people's difficulties. One study found asylum-seeking women were confused about cervical screening services, and fear and embarrassment stopped them asking for more details (O'Donnell *et al.*, 2007).

Not receiving suitable information

The research evidence suggests healthcare staff and both statutory and voluntary services do not provide people seeking or refused asylum with enough accurate information about what they are entitled to (Fang *et al.*, 2015).

For example, women seeking asylum reported that the dissemination of information about antenatal care by staff in Scotland was not accurate (Da Lomba and Murray, 2014).

Language and communication issues can compound the problem (Maternity Alliance, 2002). Studies highlight: a lack of appropriately translated written health information, including details of health promotion and screening services (O'Donnell *et al.*, 2007); the use of jargon that is hard to comprehend; and difficulties understanding the way the NHS functions (Lindenmeyer *et al.*, 2016).

Sources from Scotland report that healthcare information is often provided in a written format (such as leaflets, forms and prescriptions), making it inaccessible to many people in the process of seeking asylum who generally have lower literacy levels (Scottish Refugee Policy Forum, 2012; Da Lomba and Murray, 2014).

Primary data from people seeking and refused asylum in Doctors of the World UK clinics (2014 to 2017)

Of those reporting barriers, 10% (n=56) of RAS and 12% (n=100) of AS reported a lack of understanding or knowledge of the healthcare system.

4.5.2. What helps?

Charities and voluntary and non-governmental organisations often give people seeking or refused asylum advice on their healthcare entitlement and how to access services, backed by practical support (Doctors of the World UK, 2016c; Rafighi *et al.*, 2016).

We found evidence of good practice by the Glasgow health board that told newly arrived people seeking asylum how and where to register with a GP, which made it easier for them to access healthcare (O'Donnell *et al.*, 2007).

Many people seeking or refused asylum seem to rely on friends, family and those in in a similar position for information about how to access healthcare (Da Lomba and Murray, 2014).

4.6 Fear, trust, and stigmatisation

4.6.1 What are the barriers?

People seeking or previously refused asylum may be scared that using healthcare services will have a negative impact on their situation. For example, fear of being arrested was the fourth most common reason not to access healthcare reported by DOTW UK clinic patients in England in 2014 (Doctors of the World UK, 2015).

Fear of personal data being shared with the Home Office

We found evidence that having to provide proof of identity in healthcare services, and worry that the service provider may share their personal details with the Home Office, creates a climate of fear among people seeking or refused asylum (and other migrants) that stops them accessing healthcare (Rafighi *et al.*, 2016; Nezafat Maldonado *et al.*, 2018).

Doctors of the World UK's own patient data shows that some people refused asylum in England, including pregnant women and those with health conditions such as cancer, have avoided healthcare appointments because they were asked to provide proof of identity and they feared being reported to the Home Office (Doctors of the World UK, 2016b, 2017c).

One study found women seeking and refused asylum had not received maternity care because of concerns NHS debt might affect their asylum applications, even though only those already refused asylum (and only in England) should be charged for services after they have received the healthcare they need (as maternity care is

always urgent or immediately necessary). Some of the women had been in and out of the asylum system, having had asylum applications refused and then made new claims, both in the course of a single pregnancy and over several pregnancies, (Feldman, 2017).

Fear of health conditions affecting asylum decisions

People refused asylum sometimes avoid formal healthcare services because they think having certain conditions will affect asylum decisions and lead to deportation. Such fears among patients with communicable diseases (including HIV), have an impact on testing, treatment uptake, poorer individual health outcomes, and onwards transmission (Thomas *et al.*, 2010).

Fear of the stigma of certain conditions

Someone's cultural background can stop them getting care for certain conditions, such as infectious diseases or mental illness, because of perceived or experienced social stigma in their communities. This may put them off telling staff about their condition and taking medication for it (World Health Organization, 2011; Scottish Refugee Policy Forum, 2012).

People with disabilities resulting from torture have reported feeling stigmatised (Community Care, 2007). We found that people seeking asylum who have mental health needs or experience of psychological trauma find it difficult to trust doctors and wider healthcare services (Majumder *et al.*, 2015). Stigma and a desire to conceal their disability can stop disabled people getting the right care, including mental health services (Ward *et al.*, 2008).

A refugee community organisation told one study that it had 10 to 20 'clients' hiding illnesses (including HIV and mental health conditions). They would only arrange individual appointments (for example, to get help filling in a Disability Living Allowance application), often on days when other people were not around. These clients had particular concerns about confidentiality, frequently asking 'who is checking and looking at my file'. A support worker said: 'I think people with physical disabilities they can't hide it even if they try, but those with mental disabilities, psychological problems; they try to hide them' (Ward *et al.*, 2008)

Poor experiences of services

We found that both people seeking and refused asylum in England were put off getting healthcare by bad experiences of contact with services. They reported

discrimination, abuse and receiving different treatment (Rafighi *et al.*, 2016). This is also illustrated by what people said as part of a qualitative study in England. One woman who had been refused asylum said that as soon as a nurse 'realised we were refugees she started not listening to us and treated us differently' (Bhatia and Wallace, 2007). A man seeking asylum overheard a hospital worker on the phone saying he was playing a game and 'just using story to claim asylum' as a 'mentally ill' patient (Bhatia and Wallace, 2007).

Another study found the feeling of being treated 'differently' to the host population particularly stopped people seeking care for mental health concerns (Majumder *et al.*, 2015). Women who could understand English believed they were treated less favourably because providers presumed they could not speak it, causing additional distress when they were already in a vulnerable situation (Fassetta *et al.*, 2016).

Short appointment times and language barriers exacerbate distrust and feelings of stigmatisation because people are unable to fully explain their situation, and this undermines their ability to build a trusting relationship with healthcare staff (Fang *et al.*, 2015).

Trust in services is further damaged if people have previously been refused treatment, and this means they delay seeking care or avoid it altogether. In one case, a man who had been refused surgery and an X-ray was reluctant to follow the advice of both the clinical team and a non-governmental organisation and go to A&E if his condition worsened, believing that the hospital would not help him (Doctors of the World UK, 2017c).

Lack of trust due to past trauma

Exposure to trauma, such as sexual violence or torture, and stress factors of migration, such as exploitation by others, loss of trust in officials and experience of stigma and discrimination in host countries, are often barriers to establishing trust with service providers, according to a study of unaccompanied refugee adolescents (Majumder *et al.*, 2015). In another study, children with experience of the asylum system reported distrust towards healthcare services and practitioners related to trauma and stress they had faced (Woods *et al.*, 2015).

Most sources reporting fear and lack of trust draw on data collected in England (Fang *et al.*, 2015; Woods *et al.*, 2015). We cannot draw comparisons with Scotland and Wales due to lack of evidence: we found only one source based on data from Scotland (Scottish Refugee Policy Forum, 2012) and no evidence from Wales.

Primary data from people seeking and refused asylum in Doctors of the World UK clinics (2014 to 2017)

Of those reporting barriers, 6% (n=36) of RAS and 3% (n=26) of AS identified fears of being reported or arrested as a barrier to accessing healthcare.

3% (n=20) of RAS and 2% (n=15) of AS reported previous bad experience within the health system.

4.6.2 What helps?

Good experiences of healthcare services help people overcome some of the barriers caused by fear, lack of trust and stigmatisation. Overall satisfaction with services, including positive interactions with healthcare professionals and building trust between patients and doctors, is an important factor in the effective provision of healthcare for migrant populations (including people seeking and refused asylum) in England (Rafighi *et al.*, 2016). This is reflected in a study of people seeking asylum who reported frequent positive experiences with healthcare staff such as nurses, receptionists, health visitors, and GPs on arrival in Glasgow (O'Donnell *et al.*, 2007).

4.7 Experiences of patients at DOTW UK clinics

Doctors of the World UK (DOTW UK) run regular clinics in Brighton and Bethnal Green in London, plus 'pop-up' clinics at associated venues (such as the Hackney Migrant Centre), for 'excluded people' (including those seeking or refused asylum). Clinical and other volunteers provide basic healthcare, help with GP registration and access to NHS treatment, and make referrals to specialist services. They also offer screening, counselling and housing advice. DOTW UK was involved in producing the partner report to this review, which features the personal stories of people who have used its clinics.

Between 2014 and 2017, DOTW UK surveyed 1,321 patients seeking asylum (AS) or whose application had been refused (RAS) who came to its clinics. The methodology is explained in Appendix 1.

Of those 1,321 patients:

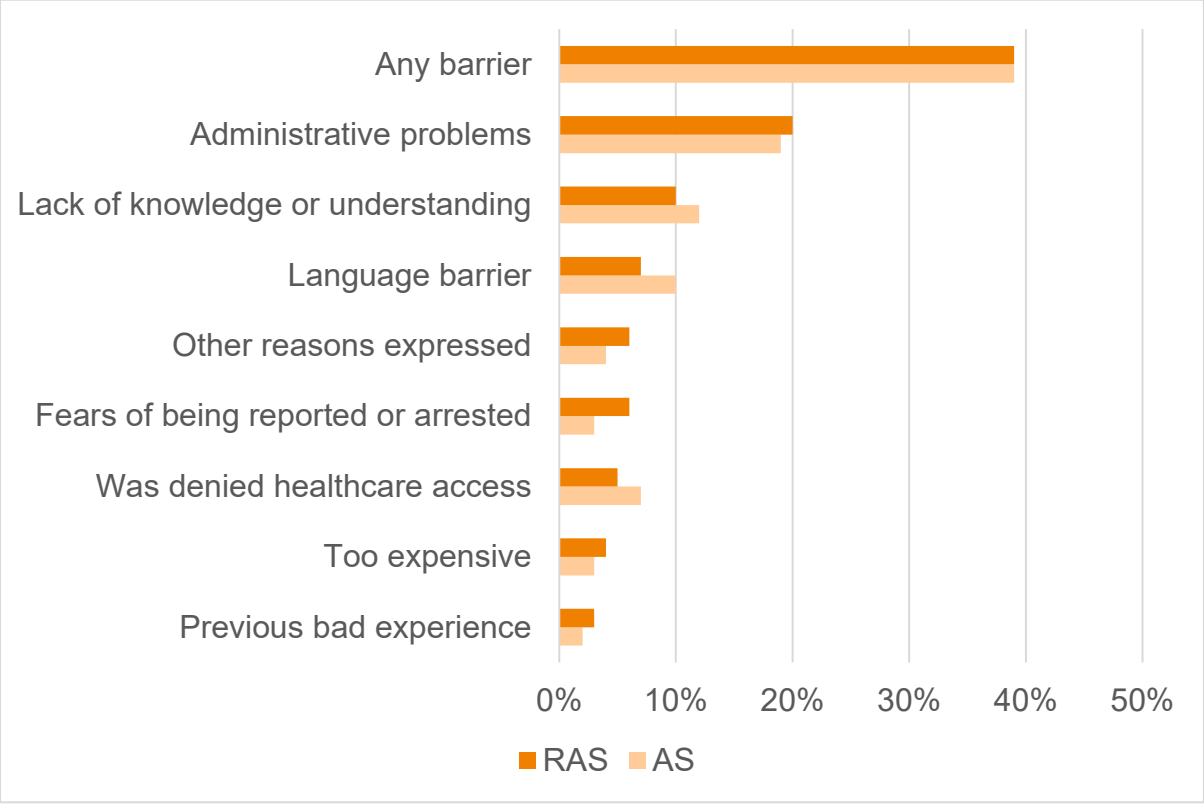
- 523 (40%) were RAS and 798 (60%) were AS
- the majority were male; 38% of RAS (201) and 35% of AS (281) were female
- just under half of both groups – 42% of AS (332) and 43% of RAS (227) – reported experiencing at least one barrier when trying to access healthcare

- around a third – 37% of AS (294) and 31% of RAS (160) – reported they 'did not try' to access healthcare, and
- a small minority – 7% of AS and 6% of RAS – reported 'no difficulties' when trying to access healthcare.

They reported a variety of barriers:

- 20% of RAS (n=114)[54] and 19% of AS (n=165) said 'administrative problems' were a barrier, such as not being able to provide proof of their identity and address
- 12% of AS (n=100) and 10% of RAS (n=56) found that their 'lack of understanding or knowledge of the healthcare system and entitlement to services' was a barrier, and
- 10% of AS (n=87) and 7% of RAS (n=40) reported a 'language barrier'.

Figure 1 RAS and AS reported barriers to accessing healthcare, DOTW UK clinics, 2014 to 2017 [55]



[54] 'n' is the number of patients.
[55] 'Medical consultation, treatment or deposit too expensive' and 'healthcare cover too expensive' are presented jointly as 'too expensive' in figure 1

5 | Conclusions

5.1 Conclusions

Our review of the available evidence on what healthcare people seeking or refused asylum can access in England, Scotland and Wales, and the factors that may help or hinder them doing so, uncovered six main themes. These were: legislation and policy; healthcare service providers; financial resources; language and communication; information and knowledge, and fear, trust and stigmatisation.

Although factors associated with each theme shaped people's access to healthcare, all of them were interlinked, and our findings need to be viewed as a whole to appreciate the complete picture of people's experiences.

The right to health is enshrined in human rights law. It applies to everyone, regardless of immigration status. However, our findings suggest there are many areas where action is needed to ensure this right is fully realised for people seeking or refused asylum.

5.1.1 What stops people getting the healthcare they need?

Two types of barriers emerged – ones that are the result (intentionally or not) of legislation and policy and others that arise in everyday practice.

The review identified a range of concerns and misunderstandings about the policy on charging for NHS treatment, which meant people avoided or delayed using services. There was evidence that policy was applied inconsistently and sometimes wrongly, resulting in people being denied free treatment, even when this was urgently required.

There are reports the Home Office dispersal policy interrupts and delays care, causing particular problems for pregnant women and people with complex health needs (such as disabled people).

There is evidence that service providers and staff often lack knowledge of basic and universal rights to healthcare, as well as specific entitlements based on immigration

status. As a result, people are wrongly refused GP registration or asked for unnecessary paperwork. Guidance on GP registration for providers in Wales and Scotland is not as clear as it is in England. Furthermore, clinicians may be unaware of the health needs that could stem from the experiences of people seeking or refused asylum, and be unable to meet these properly.

There were frequent reports of a lack of money stopping people getting the right care, including being unable to afford transport to appointments or for mobile phone calls to arrange them. People refused asylum can struggle to buy essentials like food because they cannot work or, in most cases, cannot claim public funds.

Difficulty speaking or reading English meant some people found it especially hard to access services, explain their needs and understand their treatment. Communication problems were compounded by a lack of both professional interpreters and information in a format people could understand.

Several sources reported that people's fears about the consequences of national policies meant they avoided or delayed using healthcare services, or mainly went to A&E. There were specific concerns about their data being shared and any unpaid charges being reported to the Home Office. People did not get treatment for certain conditions because of perceived stigma associated with them. The evidence noted mistrust of service providers and health professionals based on poor previous experiences.

5.1.2 What can help people get the right care?

The literature reported few examples of good practice and enabling factors. While many policies should be enablers of healthcare, such as GP registration and the provision of free primary care for everyone regardless of immigration status, in practice these are not well understood or applied. Often people did not know about financial help available, such as HC2 certificates and free prescriptions in Wales and Scotland.

Many of the enablers identified came in the form of information, advocacy and practical support from charities and voluntary organisations and people's own networks. These could be seen as filling a gap left by statutory services, and viewing them as 'enablers' should be treated with caution. The provision of interpreting services was reported as enabling people to overcome language barriers and access healthcare. However, interpretation was often provided informally by a family member or friend, which may be inappropriate and reflects a gap in the availability of professional interpreters.

There was evidence that people had positive experiences because of good relationships with healthcare staff and trust between them and their doctor. This helped to overcome stigmatisation and to correct misunderstandings, for example about charging.

5.1.3 Does immigration status make a difference?

Most sources do not clearly distinguish between people seeking asylum and those refused it, so it is not possible to draw firm conclusions about any differences in their experience. This also reflects the fluid nature of immigration status, with people moving between the two groups, and suggests there is a gap between policy defined by people's legal status and much more nuanced and individual experiences in practice.

Doctors of The World UK primary data showed that similar proportions of people seeking and refused asylum reported similar amounts of difficulty in accessing services and similar barriers. It is worth noting the literature's focus on experiences in primary care, to which both groups are equally entitled.

5.1.4 Do protected characteristics create extra barriers?

The literature reports that women, particularly when pregnant, and disabled people face additional challenges in accessing healthcare.

For example, dispersal can interrupt continuity of care, which is especially important to pregnant women and people with long-term conditions who need regular appointments.

A lack of money may mean women cannot afford to follow nutritional advice during and after pregnancy, and disabled people struggle to pay for transport to regular appointments.

The evidence suggests women may generally have lower levels of education and literacy, making it hard for them to get the information they need. They may be inhibited from using male interpreters in maternity or sexual health services or when disclosing experience of domestic or sexual violence.

The review noted a lack of adequate interpretation and translation services for those using Braille or sign language.

There are particular issues around trust and stigma for women with female genital mutilation (which healthcare staff may be unprepared for), people with infectious diseases and mental health conditions (which they may believe will affect their

asylum application), experiences of psychological trauma or disability resulting from torture.

5.2 Evidence gaps

There is a limit to the extent to which the specific experiences of people seeking or refused asylum can be identified in the current literature.

The evidence is predominantly focused on barriers to healthcare among broader migrant populations and the specific experiences of people seeking or refused asylum are under-represented.

Studies are mainly qualitative and reflect small sample sizes. A lack of intersectional research means the experiences of subgroups, such as disabled or lesbian, gay, bisexual and transgender people seeking or refused asylum, are less known. More barriers and enablers may be unreported and unrecognised in the evidence base due to the challenges in engaging such populations in research.

There is a lack of evidence that distinctly addresses the impact of various policies on people seeking or refused asylum when they try to access healthcare services.

The review also noted a stark evidence gap on the experiences of these groups in Scotland and Wales, making it difficult to draw comparisons between the three nations. Charging for healthcare, data sharing agreements between the NHS and the Home Office, and the availability of information about healthcare services all vary across England, Scotland and Wales, and more research is needed to understand the extent to which these differences affect access to healthcare by people seeking or refused asylum.

There is also little regional data from individual dispersal areas – the DOTW UK primary data used in this report was collected from its clinics in London and Brighton, neither of which are dispersal areas.

In addition, the review identified an absence of data on people's experiences of secondary care, both in hospital and community settings, with most literature looking at access to primary care. In light of recent policy developments in England that restrict free access to secondary care for people refused asylum, further research in these settings is needed to establish the impact of such policies on both groups. This will enable policy makers and health providers to better respond to their needs and uphold their entitlements.

5.3 Next steps

These findings highlight that there are clear barriers to accessing healthcare that need to be addressed at policy, implementation and practice levels.

More research is needed to address the evidence gaps outlined above to understand and respond to the specific experiences of people currently in the asylum process and those who have been through it, as well as exploring differences according to geographical area. This should include more research to identify what factors affect the barriers identified in this research and which ones can reduce those barriers. This will inform improvements.

There is also a clear need to provide examples of good practice to demonstrate workable solutions to some of the challenges faced by people seeking or refused asylum in accessing healthcare.

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.

References

Asif, S., Baugh, A. and Wyn Jones, N. (2015), 'The obstetric care of asylum seekers and refugee women in the UK', *The Obstetrician & Gynaecologist*, vol. 17, no. 4, pp. 223–31. doi: 10.1111/tog.12224.

Bhatia, R. and Wallace, P. (2007), 'Experiences of refugees and asylum seekers in general practice: a qualitative study', *BMC Family Practice*, vol. 8, no. 1, p. 48. doi: 10.1186/1471-2296-8-48.

Binder, P. Borné, Y., Johnsdotter, S. and Essén, B. (2012), 'Shared language Is essential: Communication in a multiethnic obstetric care setting', *Journal of Health Communication*, vol. 17, no. 10, pp. 1171–86. doi: 10.1080/10810730.2012.665421.

Braun, V. and Clarke, V. (2006), 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77–101.

British Red Cross (2015), 'Poor health, no wealth, no home: a case study of destitution'. [accessed: 15 October 2018].

British Red Cross (2017), 'Can't stay. Can't go. Refused asylum seekers who cannot be returned'. [accessed: 15 October 2018].

Burnett, A. and Peel, M. (2001), 'Health needs of asylum seekers and refugees', *BMJ (Clinical research ed.)*, vol. 322, no. 7285, pp. 544–7. [accessed: 4 June 2018].

Care Act 2014: Part 1, The National Archives. [ONLINE]. [accessed: 5 June 2018].

Community Care, 2007. Barriers to supporting asylum seekers and refugees | Community Care. [accessed: March 16, 2018].

Creighton, S. Sethi, G., Edwards, S. and Miller, R. (2004), 'Dispersal of HIV positive asylum seekers: national survey of UK healthcare providers', *BMJ (Clinical research ed.),* vol. 329, no. 7461, pp. 322–3. doi: 10.1136/bmj.38189.674213.79.

Da Lomba, S. and Murray, N. (2014), 'Women and children first? Refused asylum seekers' access to and experiences of maternity care in Glasgow'. [accessed: 15 October 2018].

Department for Business, Innovation and Skills (2011), 'English for Speakers of Other Languages (ESOL) equality impact assesment' (PDF). [accessed: 14 June 2018].

Department of Health and Social Care (2018), 'Guidance on implementing the overseas visitor charging regulations'. [accessed: 5 June 2018].

Department of Health and Social Care and Home Office (2017), 'Memorandum of understanding between the Home Office, NHS Digital and the Department of Health'. [accessed 8 November 2018]

Doctors of the World UK (2015), 'Access to healthcare in the UK: Healthcare access – state of play and recommendations'. [accessed: 15 October 2018].

Doctors of the World UK (2016a), 'Doctors of the World UK evidence to the Public Accounts Committee inquiry on "Recovering the cost of NHS treatment for overseas visitors"'. [accessed: 12 June 2018].

Doctors of the World UK (2016b), 'Doctors of the World briefing: Department of Health consultation on further NHS charging – "Making a fair contribution"'. [accessed: 7 June 2018].

Doctors of the World UK (2016c), 'Registration refused: A study on access to GP registration in England 2016'.

Doctors of the World UK (2017a), 'Closing the gaps in healthcare access: The United Kingdom'.

Doctors of the World UK (2017b), '2017 observatory report: Falling through the cracks: The failure of universal healthcare coverage in Europe'.

Doctors of the World UK (2017c), 'Response to the Department of Health and Social Care formal review of The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017'.

Doctors of the World UK (2018a), 'Doctors of the World UK statement on NHS hospitals withholding "non-urgent" care'.

Equality and Human Rights Commission (2015), 'Is Britain fairer? The state of equality and human rights'. [accessed: 12 June 2018].

Equality and Human Rights Commission (2016), 'Is England fairer? The state of equality and human rights 2016'. [accessed: 12 June 2018].

Equality and Human Rights Commission (2018), 'Is Britain fairer? The state of equality and human rights 2018'. [accessed: 25 October 2018].

European Commission (no date), 'Asylum seeker - definition(s)'. [accessed: 7 June 2018].

Falla, A., Veldhuijzen, I., Ahmad, A., Levi, M. and Richardus, J. (2017), 'Limited access to hepatitis B/C treatment among vulnerable risk populations: an expert survey in six European countries', *European Journal of Public Health*, vol. 27, no. 2, pp. 302–6. doi: 10.1093/eurpub/ckw100.

Fang, M., Sixsmith, J., Lathom, R., Mountian, I. and Sharin, A. (2015), 'Experiencing "pathologized presence and normalized absence"; understanding health related experiences and access to health care among Iraqi and Somali asylum seekers, refugees and persons without legal status', *BMC Public Health*, vol. 15, no. 1, p. 923. doi: 10.1186/s12889-015-2279-z.

Farrington, R., Saleh, S., Campbell, S., Jundi, A. and Worthington, E. (2016), 'Impact of proposal to extend charging for NHS in England', *The Lancet,* vol. 388, no. 10043, p. 459. doi: 10.1016/S0140-6736(16)31150-3.

Fasseta, G., Da Lomba, S. and Quinn, N. (2016), 'A healthy start? Experiences of pregnant refugee and asylum seeking women in Scotland'. British Red Cross. [accessed: 15 October 2018].

Feldman, R. (2017), 'The impact on health inequalities of charging migrant women for NHS maternity care: a scoping study'. [accessed: 15 October 2018].

Finlay, F., Dunne, J. and Guiton, G. (2017), 'G54(P). Children acting as interpreters', *Archives of Disease in Childhood*, vol.102:A23.

Foster, D. and Bolton, P. (2018), 'Adult ESOL in England – House of Commons briefing paper no. 7095' (PDF). [accessed: 14 June 2018].

Fox, H. and Tang, E. (2016), 'GP attitudes to migrant health care across Europe', *British Journal of General Practice*, vol. 66, no. 647, p. 313. doi: 10.3399/bjgp16X685405.

Freedom from Torture (2013), 'The poverty barrier: the right to rehabilitation for survivors of torture in the UK' (PDF). [accessed: 15 October 2018].

HC Deb (9 May 2018) v640 col. 756. [accessed 8 November 2018[.

Health Professionals Against Immigration Detention (2016), 'Open letter from health professionals against immigration detention', *The Lancet*, vol. 388, no. 10059, pp. 2473–4. doi: 10.1016/S0140-6736(16)32118-3.

Healthy London Partnership (2016), "My right to access healthcare' card: guidance' (PDF). [accessed: 18 June 2018].

Higher Education Funding Council for Wales (2010), 'Widening access to refugees and asylum seekers' (PDF). [accessed: 14 June 2018].

Home Office (2017), *National statistics: Asylum*. [ONLINE]. [accessed: 4 June 2018].

Home Office (2018a), *How many people do we grant asylum or protection to?* [ONLINE]. [accessed: 4 June 2018].

Home Office (2018b), 'Asylum support, section 4(2): policy and process'. [accessed: 5 June 2018].

Immigration Act 2014, The National Archives. [ONLINE]. [accessed: 4 June 2018].

Lindenmeyer, A., Newall, D., Phillimore, J., Redwood, S. and Griffith, L. (2016), 'Health across borders: recent migrants' experiences of managing their health and wellbeing in the UK and the implications for health policy and practice' (PDF). [accessed: 15 October 2018].

Majumder, P., O'Reilly, M., Karim, K. and Vostanis, P. (2015), '"This doctor, I not trust him, I"m not safe': The perceptions of mental health and services by unaccompanied refugee adolescents', *International Journal of Social Psychiatry*, vol. 61, no. 2, pp. 129–36. doi: 10.1177/0020764014537236.

Maternity Action and Refugee Council (2013), 'When maternity doesn't matter. Dispersing pregnant women seeking asylum'. [accessed: 15 October 2018].

Maternity Alliance (2002), 'Mothers In exile: maternity experiences of asylum seekers in England'. [accessed: 15 October 2018].

McColl, H., Tsangarides, T. and Schleicher, T. (2015), 'Pregnant women in immigration detention centres', *Archives of Women's Mental Health*, vol.18, pp. 287–8. doi: 10.1007/s00737-014-0488-6.

Mind and NHS England, (2015), 'Commissioning mental health services for vulnerable adult migrants: guidance for commissioners' (PDF). [accessed: 14 June 2018].

Morgan, G., Melluish, S. and Welham, A. (2017), 'Exploring the relationship between postmigratory stressors and mental health for asylum seekers and refused asylum seekers in the UK', *Transcultural Psychiatry*, vol. 54, no. 5–6, pp. 653–74. doi: 10.1177/1363461517737188.

Nair, M., Kurinczuk, K., Brocklehurst, P., Sellers, S., Lewis, G. and Knight, M. (2015), 'Factors associated with maternal death from direct pregnancy complications: a UK national case–control study', *British Journal of Obstetrics and Gynaecology*, vol. 122, no. 5, pp. 653–62.

National Health Service Act 2006, The National Archives. [ONLINE]. [accessed: 4 June 2018].

National Health Service (Scotland) Act 1978, The National Archives. [ONLINE]. [accessed: 4 June 2018].

National Health Service (Wales) Act 2006, The National Archives. [ONLINE]. [accessed: 4 June 2018].

Nezafat Maldonado, B., Murphy, L., Jones, L., Miller, A. and LeDeaut, D. (2018), 'Changes to NHS charges: what does this mean for our most vulnerable patients?', *The Lancet*, vol. 390, no. 10114, pp. 2766–7. doi: 10.1016/S0140-6736(17)33302-0.

NHS Business Services Authority (no date), HC2 certificates (full help with health costs). [ONLINE]. [accessed: 6 June 2018].

NHS England (2017), 'Primary medical care policy and guidance manual'. [accessed: 4 June 2018].

NHS England (no date), 'Asylum seekers and refugees: How to register with a doctor (GP)' (PDF). [accessed: 6 June 2018].

NHS England (2018), 'Guidance for commissioners: interpreting and translation services in primary care' (PDF). [accessed: 8 November 2018].

NHS Inform (2016), 'Healthcare for asylum seekers and refugees in Scotland' (PDF). [accessed: 15 October 2018].

NHS Inform (no date a), 'Access: your rights when using NHS services in Scotland' (PDF). [accessed: 14 June 2018].

NHS Inform (no date b), *Contact us*. [ONLINE]. [accessed: 14 June 2018].

NHS Midlands and Lancashire Commissioning Support Unit (2017), 'Guidance for considering the needs of Asylum Seekers and Refugees in commissioning health services' (PDF). [accessed: 14 June 2018].

NHS Wales (1999), WHC (99)32 'Overseas visitors eligibility to receive free primary care'.

NHS Wales (2009), 'Implementing the Overseas Visitors Hospital Charging Regulations: guidance for hospitals in Wales' (PDF). [accessed: 6 June 2018].

NHS Wales (2010), 'Doing well, doing better: standards for health services in Wales' (PDF). [accessed: 6 June 2018].

NHS Wales (no date), *Overseas visitors*. [ONLINE]. [accessed: 18 June 2018].

O'Donnell, C., Higgins, M., Chauhan, R. and Mullen, K. (2007) '"They think we're OK and we know we're not". A qualitative study of asylum seekers' access, knowledge and views to health care in the UK', *BMC Health Services Research*. vol. 7, no. 1, p. 75. doi: 10.1186/1472-6963-7-75.

Paradise, C. and Sadavarte, V. (2016), 'An audit of the initial health assessment of unaccompanied asylum seeking children at a UK university teaching hospital'.

Pool, E., Preston, H. and Schim van der Loeff, I. (2009), 'Health care for refused asylum seekers: evidence over ideology', *The Lancet*, vol. 374, no. 9688, pp. 437–8. doi: 10.1016/S0140-6736(09)61435-5.

Price, J., 2016. *Legal and Policy Briefing: Access to Healthcare for Migrants in Wales*.

Public Health England (2018), *NHS entitlements: migrant health guide*. [ONLINE]. [accessed: 5 June 2018].

Public Health Wales (2009) *New healthcare guidance for asylum seekers*. [ONLINE]. [accessed: 6 June 2018].

Public Health Wales (2016), *Refugees and asylum seekers*. [ONLINE]. [accessed: 6 June 2018].

Rafighi, E., Poduval, S., Legido-Quigley, H. and Howard, N. (2016), 'National Health Service principles as experienced by vulnerable London migrants in "Austerity Britain": a qualitative study of rights, entitlements, and civil-society advocacy', *International Journal of Health Policy and Management*, vol. 5, no. 10, pp. 589–97. doi: 10.15171/ijhpm.2016.50.

Sadavarte, V. and Jainer, R. (2016), 'Impact of unaccompanied asylum seeking children (UASC) on the looked after service (LAC) in the UK. Should there be a unified approach in Europe?', *European Journal of Pediatrics*, vol. 175, no. 11, pp. 1486–7.

Scottish Government (2010), 'CEL 09: Overseas visitors' liability to pay charges for NHS care and services'. [accessed: 4 June 2018].

Scottish Government (2015), 'Welcoming our learners: Scotland's ESOL strategy 2015-2020' (PDF). [accessed: 14 June 2018].

Scottish Government (no date), *Overseas visitors*. [ONLINE]. [accessed: 14 June 2018].

Scottish Public Health Network (2016), 'Improving the health of migrants to Scotland: an update for Scottish directors of public health' (PDF). [accessed: 3 November 2017].

Scottish Refugee Policy Forum (2012), 'A fairer Scotland for asylum seekers and refugees in a time of austerity?'

The Children's Society (no date), 'Barriers and solutions to accessing healthcare'. [accessed: 15 October 2018].

The Immigration and Asylum (Provision of Accommodation to Failed Asylum-Seekers) Regulations 2005, The National Archives. [ONLINE]. [accessed: 5 June 2018].

The National Health Service (Charges to Overseas Visitors) (Amendment) (Wales) Regulations 2004, The National Archives. [ONLINE]. [accessed: 4 June 2018].

The National Health Service (Charges to Overseas Visitors) (Amendment) (Wales) Regulations 2009, The National Archives. [ONLINE]. [accessed: 4 June 2018].

The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2004, The National Archives. [ONLINE]. [accessed: 7 June 2018].

The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017, The National Archives. [ONLINE]. [accessed: 4 June 2018].

The National Health Service (Charges to Overseas Visitors) (Scotland) Regulations 1989, The National Archives. [ONLINE]. [accessed: 4 June 2018].

The National Health Service (Charges to Overseas Visitors) Regulations 1989: Regulation 4: Overseas visitors exempt from charges, The National Archives. [ONLINE]. [accessed: 4 June 2018].

The National Health Service (Charges to Overseas Visitors) Regulations 2015, The National Archives. [ONLINE]. [accessed: 4 June 2018].

Thomas, F., Aggleton, P. and Anderson, J. (2010), '"If I cannot access services, then there is no reason for me to test": the impacts of health service charges on HIV testing and treatment amongst migrants in England', *AIDS Care*, vol. 22, no. 4, pp. 526–31. doi: 10.1080/09540120903499170.

UK Visas and Immigration (no date), 'Healthcare needs and pregnancy dispersal policy' (PDF). [accessed: 6 June 2018].

Ward, K., Amas, N. and Lagnado, J. (2008), 'Supporting disabled refugees and asylum seekers: opportunities for new approaches' (PDF). Metropolitan Support Trust. [accessed: 15 October 2018].

World Health Organization (2011), 'Tuberculosis control in vulnerable groups'.

Woods, A., Wood, C., Thomas, J. and Abraham, M. (2015), 'G501(P) To assess the functional status, social habits, and worries in a group of unaccompanied refugee and asylum-seeking minors and the implications of these on health behaviour and mental health', *Archives of Disease in Childhood*, vol. 100, no. 3, p. A215. doi: 10.1136/archdischild-2015-308599.454.

YA, R (on the application of) v Secretary of State for Health [2009] *EWCA Civ 225*. [ONLINE]. [accessed: 4 June 2018].

Appendices

Appendix 1 Collecting data at DOTW UK clinics

Data is collected from all patients attending Doctors of the World UK (DOTW UK) clinics, by trained volunteers using a 'social assessment form' developed by DOTW UK parent organisation Médecins du Monde. Interpreters are used when required via the LanguageLine telephone interpreting service.

Data on barriers experienced when accessing healthcare is collected under the headings listed below (Table 3). More than one barrier can be selected by each respondent.

Table 3 Barriers to accessing healthcare

- Did not try to access healthcare services
- No difficulties
- Administrative problems and issues with documentation in order to obtain non-chargeable costs
- Lack of understanding of knowledge of the system and rights
- Was denied health coverage
- Medical consultation, treatment or deposit too expensive
- Language barrier
- Fears of being reported or arrested
- Previous bad experiences within the health system
- Healthcare cover too expensive
- Health coverage open in another EU country
- Other reasons expressed
- Any barrier

This information is then collated and stored in the DOTW UK electronic database. The data for 2014–17 was extracted, cleaned, and analysed to explore the specific barriers that people seeking asylum (AS) or previously refused asylum (RAS) experience.

Data cleaning was carried out manually to establish each person's correct immigration status and ensure AS and RAS were accurately identified. Incomplete or unclear data entries were marked 'unknown'. Data from people who had opted out was removed.

A descriptive analysis of the data was carried out using Microsoft Excel to compare proportions (as percentages) of AS and RAS reporting 'no difficulties', 'did not try', and 'any barrier' when trying to access healthcare. Then each barrier was calculated as a proportion of the total barriers for each group (AS or RAS).

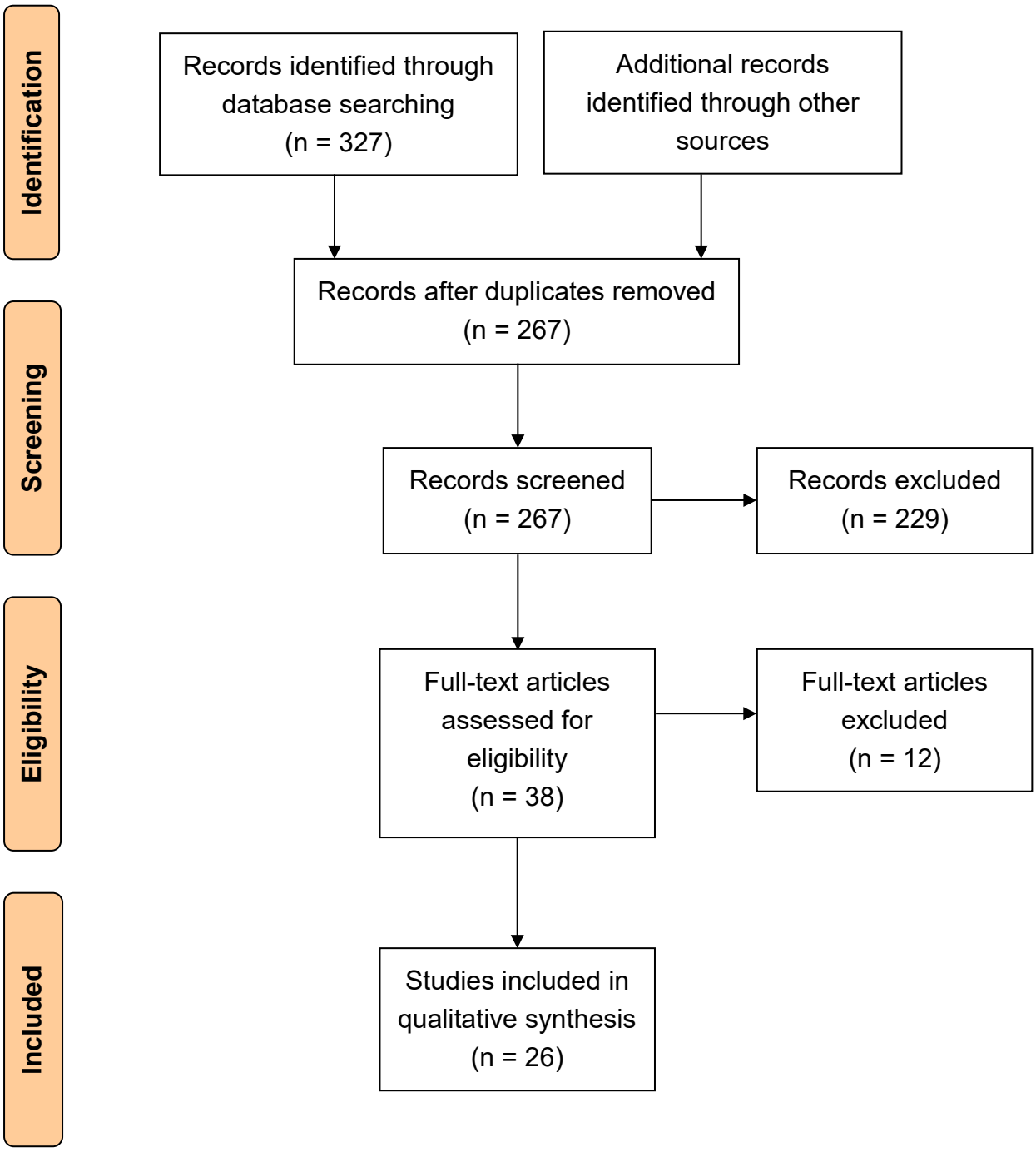
Although the DOTW UK data is extensive, there are limitations in how it is collected and used:

- there are gaps in those patients who responded, which may result in responder bias
- data is collected by volunteers in an interview, so there is the possibility of further bias in the form of observer bias and acceptability bias
- as respondents can select more than one option, there may be inconsistencies in the data, and
- although interpreters are used if necessary, questions still may be misunderstood or interpreted in different ways, which could result in over- or under-responses.

Also, only small numbers of patients were involved. Any significant difference may require statistical analysis.

Appendix 2 Systematic review flow diagram

The PRISMA (preferred reporting items for systematic reviews and meta-analyses) diagram below depicts the flow of information through the different phases of our review to assess the lived experiences in accessing care among people seeking and refused asylum within the UK. It maps out the number of studies (or 'records') we identified and included or excluded.



Appendix 3 Search strategy

To identify all relevant evidence for our review, between 2014 and early 2018 we carried out systematic searches of three databases on the Ovid platform: Embase, MEDLINE and Global Health. Our search strategy included separate keywords relating to the relevant population groups, types of healthcare, positive and negative impacts and geographical location – details are given below.

1. asylum-seek* OR asylum seek* OR refused asylum-seek* OR refused asylum seek* OR failed asylum-seek* OR failed asylum seek* OR rejected asylum-seek* OR rejected asylum seek*
2. healthcare OR NHS OR National Health Service OR GP OR general practitioner OR primary care OR secondary care OR treatment OR inclusion health OR mental health OR maternity OR NHS charging OR cost recovery OR health reform OR health service* OR access to care
3. experience* OR lived-experience* OR lived experience OR barrier* OR deter* OR obstacle OR cost OR facilitator OR enable OR access* OR promote*
4. England OR Scotland OR Wales
5. 1 AND 2 AND 3 AND 4

Appendix 4 Sources included in the systematic review

Table 2 Sources included in the systematic review of literature 2014 to 2018

*Please note: Where sample sizes are provided (N =), this relates to research specifically involving migrant groups in the data collection. Those sources listed without sample sizes are studies conducted with health service providers or individuals working in the field of migrant health, or studies in which a sample size was otherwise unavailable. Wherever possible, sample sizes have been broken down by specific group. N = denotes total sample size; n = denotes individual migrant group sample size.

Academic sources

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Falla *et al.*, 2017	Qualitative study or surveys	People seeking asylum and undocument ed migrants [United Kingdom]		Uncertainty among clinicians and service providers as to entitlement to care among				

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				people seeking asylum (specifically in regard to viral hepatitis B or C treatment)				
Fang *et al.*, 2015	Qualitative	Refugees (n = 15), people seeking asylum (n = 12) and persons without legal status (n=8) (N =	Evidence of a lack of any ongoing support once an individual is refused asylum.	GPs failing to register individuals – linked to not having a stable home address. People seeking	Recourse to accessing public funds or financial support ceases once an individual is refused asylum.	Language barriers are also a cited concern – many AS have very little or no English. Cited that without an	Individuals are uncertain of the workings of the healthcare system, and unsure as to whether	A lack of time in appointment s makes it difficult to fully explain situations but can also mean that trust

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
		101) [United Kingdom]		asylum are generally reliant on charities and NGOs There are conditions of 'normalised absence' in which past history and experiences of AS and RAS are discounted from the healthcare	Issues in even attending GP appointments (transport costs).	interpreter it is impossible to go to the doctor. Miscommunication between the patient, interpreter and doctor can lead to incorrect diagnoses. Interpreters are considered essential	they are eligible to access GP, dental and other specialist services. There is evidence of inconsistent advice given to AS and RAS by statutory and voluntary services.	generation is insufficient.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				process (AS and RAS often seek wellbeing as well as health). Individuals often cite the long waits associated with the UK system as an issue, and the lack of time in appointment		but are rarely available. Interpreters are often from the same community as the patients, and so confidentiali ty is a real concern.		

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Farrington *et al.*, 2016	Correspondence	People seeking and refused asylum [England]	The need to check eligibility could delay the provision of treatment for individuals. Restriction to primary care is harmful to individuals and wider public health in general.					

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Finlay *et al.*, 2017	Abstract	People seeking asylum and refugees [United Kingdom]				May have to use children as interpreters. Can alleviate barriers such as confidentiality concerns. However, children may lack fluency, medical knowledge, and be party to sensitive		

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
						information related to a parent.		
Fox and Tang, 2016		Migrants – including people seeking and refused asylum [United Kingdom]		There is often confusion and uncertainty as to who can access primary care (and how). Many do not know that documentation is unnecessary, including				

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				reception staff and GPs themselves.				
Health Professionals Against Immigration Detention, 2016	Correspondence	People seeking asylum and refugees [United Kingdom]	Detention itself poses a health risk and restricts access to care.	Obviously highlights that there are movements in support of AS and RAS accessing treatment.				
McColl, *et al.*, 2015)	Abstract (qualitative)	Pregnant asylum-seeking women in detention		Antenatal care and provision appears to be				

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
		[United Kingdom]		inadequate in detention. Detention can therefore directly act as a barrier (and policies are therefore indirectly accountable). Potential breaches of NHS and National Institute for Health and Care				

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				Excellence (NICE) guidelines.				
Majumder *et al.*, 2015	Qualitative	Unaccompanied refugee adolescents (N = 15) [England]						Trust is a significant barrier, perhaps due to pre-migratory experiences and trauma. Nevertheless, it can limit engagement with services.
Morgan, Melluish and	Cross-sectional	People seeking and refused	RAS experience greater					

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Welham, 2017		asylum (N = 97) [United Kingdom]	barriers to healthcare and current policies are unlikely to help this and are likely to exacerbate distress in RAS.					
Nezafat Maldonado *et al.*, 2018	Correspond ence	Migrants and overseas visitors – focusing on people seeking and refused						Information checks and charging will increase the climate of fear.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
		asylum and homeless people [England]						
O'Donnell *et al.*, 2007	Qualitative study: In-depth interviews and focus groups	People seeking asylum (n=52) arriving in Glasgow, Scotland		Health board provided information on how and where to register with a GP, facilitating engagemen t with care. In some cases asylum support	The cost of purchasing medication (particularly over-the-counter medication such as pain killers) was raised as a barrier.	Participants reported problems in accessing interpreter; interpretatio n services were more reliable in GP practices than inpatient stays. The need for	Participants reported it was helpful to receive information from health board about where and how to register with a GP. However, some migrants did not receive	There were some reports of discriminato ry or stigmatising behaviour from service providers towards people seeking asylum.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				nurses provided support in registering and conducted a health check. Theme: participant reported feeling welcome and cared for as a result of this process.		interpreter in pharmacies and also when ringing surgeries was also highlighted. Participants also reported not being sent appropriate interpreter (for example, correct language).	the information they needed.	

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Paradise and Sadavarte, 2016	Retrospectiv e analysis	Unaccompa nied asylum-seeking children (N = 25) [England]		Initial health assessment s may be lacking or subjectively interpreted and inconsistentl y applied.		Lack of interpreters and social workers (for unaccompa nied asylum-seeking children) can present barriers in some cases.		
Pool *et al.*, 2009	Correspond ence	People refused asylum [England]	People refused asylum are counted as overseas visitors					

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
			(opens them up to prospect of charging).					
Rafighi *et al.*, 2016	Qualitative	'Vulnerable migrants' – defined as adult non-EEA seeking asylum, refugees, undocument ed, low-skilled and trafficked migrants susceptible to		Healthcare professional attitudes are generally caring, with people seeking asylum reporting positive experiences . There is confusion			Individuals don't necessarily understand their rights or entitlement to care. However, improving this knowledge is facilitated by NGOs and	Individuals will actively avoid seeking healthcare due to a fear of arrest or even deportation.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
		marginalised healthcare access (N = 16) [England]		among service providers regarding entitlement to care catalysed by the rapidly changing legislation in this area. Some gatekeepers such as receptionists are also cited as			charities and voluntary organisations.	

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				representing a barrier, with disrespectful attitudes. Some individuals equally highlighted the general respect afforded them by all healthcare staff.				
Sadavarte and Jainer, 2016	Abstract	Unaccompanied asylum-seeking				Language and cultural barriers are		

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
		children (N = 108) [United Kingdom]				common to all.		
Woods *et al.*, 2015	Abstract (qualitative)	Unaccompanied refugee and asylum-seeking minors						A majority of the interviewed children said they had issues accessing health services, while 42% said if they had an issue they would share it with no

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
								one, or had only one specific person they might call upon.

Grey literature sources

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
The Children's Society, no date	Web article	People seeking asylum and refugees [United Kingdom]				Language and cultural barriers cause great concern and misunderstanding among families	AS may not know what services are available to them, or will not be familiar with services that are very different to their home country.	There can be stigma surrounding mental health diagnoses. Individuals may also fail to disclose certain conditions or health needs for fear this will affect their asylum claim.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Da Lomba and Murray, 2014)	Report	People seeking asylum (N = 9) [Scotland]	The policies themselves have a direct impact in terms of the insecure housing provided, coupled with the limited recourse to funds that some pregnant women may experience.	GP surgeries have lacked knowledge in the past as to entitlement – potential lack of training of frontline registry staff and clinicians themselves. A mixed bag, many interviewed	Women have cited the direct impact of asylum support provision presenting a monetary barrier, with examples of individuals struggling to pay to attend health-related appointment s and	Language barriers can act as a barrier to attending antenatal classes. There are many instances when interpreters cannot be provided, even if a patient has requested one be	Mixed experiences among women about knowing whether there were antenatal and maternity-related support or classes, which was not always disclosed by healthcare staff.	

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				participants recount no issues at all.	having to resort to borrowing money from friends for taxis while in labour, and actively saving money in case of an emergency (labour). The limited fiscal support also presents a barrier to accessing	present – there are also issues if the interpreters are male (confidentiality and the fact it is maternity care).	Women seeking refused asylum have access to information, but this can often be in written form, which may not be readily accessible to the patient. Women did not realise	

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
					appropriate nutrition and diet as recommend ed by healthcare professional s.		they could be reimbursed for travel costs related to their maternity care, or in covering extra incurred costs. Friends and other people seeking asylum	

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
							became the primary source of information.	
Doctors of the World UK, 2015	Report		Administrative and legal barriers are the most commonly cited (29% of responses).			Language barriers are third most prevalent barrier (14% of individuals).	Lack of knowledge is second most prevalent barrier (17% of individuals).	Fear of arrest or detainment was the fourth most prevalent barrier (11%).
Doctors of the World UK, 2016b	Briefing		Individuals must now provide upfront proof of entitlement to care,	Refused GP registration when requiring care for trafficking (there is no	Pregnant woman in severe pain but afraid of being charged.		An individual needing palliative cancer treatment was initially	Individual requiring treatment for breast cancer refused to attend

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
			cited as a barrier inciting distrust and loss – authors to follow up on a woman needing cancer treatment, and again in the case of a woman refused GP registration. Individual initially refused	legal requirement for any documentation)	Woman needing two separate rounds of cancer treatment was billed for both, could not pay and was threatened with legal action by the hospital.		refused (hospital overseas visitors manager determined he was not entitled to healthcare). Perhaps highlights policy issues in general.	appointments after being asked to prove their entitlement to care.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
			cancer treatment as it was deemed not urgent? Specific terminology is open to interpretatio n.					
Doctors of the World UK, 2016c	Report			Individuals are often barred from registering with a GP – most commonly due to	Doctors of the World UK, 2016c	Report		

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				lacking proof of identity (29%) and proof of address (29%), but also due to immigration status (6% of 700). In Doctors of the World UK's experience refusal and registration seem to be				

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				inconsistent. Lack of access to the GP manager, or gatekeeping issues, were also a significant barrier (20%), for example, being unable to speak to the practice manager or				

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				whoever was responsible for registration – indicating a lack of knowledge of eligibility criteria.				
Doctors of the World UK, 2017b	Report						People seeking asylum likely to be particularly affected by lack of knowledge and	

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
							administrative barriers.	
Doctors of the World UK, 2017c	Report	Data collected from 1,924 people, including undocumented migrants (56%), short-term migrants with a visa or work permit (17%), people seeking asylum	Legislative terminology may be too open to interpretation or subjective whims. This is indirectly seen through the direct actions of staff failing to determine what is	Individual incorrectly charged for latent TB screening and treatment (exempt from charging). Was given an £800 bill, which caused the individual to avoid treatment	RAS being asked to pay up front for antenatal care, or having their care suspended while pregnant. Resulting in missed appointments and anxiety. One woman			Multiple accounts of pregnant women being too fearful to access antenatal care for fear of being reported to the Home Office and subsequently being deported.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
		(15%) and refugees (2%)	urgent and immediately necessary. One individual refused cancer surgery despite the fact there was a significant risk of the cancer spreading.	until in severe pain.	(four months pregnant) asked to pay £300 up front, followed by £5,000 for future care. Another (six months pregnant) tried to book her first antenatal appointment. Attempted to charge			Individuals in need of surgery (cardiac) have refused to access care due to previous experiences and beliefs that the hospital would not (rather than could not) help them.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
					her £6,500 up front. Individual at risk of heart attack or stroke booked for surgery but discharged when could not pay a £5,000 deposit. The clinician in this case had been unsure as to whether care was			

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
					urgent or necessary, and even said it was not the clinician's role to determine this.			
Maternity Action and Refugee Council, 2013	Report	People seeking and refused asylum [United Kingdom]	The dispersal experienced by pregnant AS and RAS can itself present a barrier to care.					

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
Maternity Alliance, 2002	Report	People seeking asylum [England]		Staff lack the knowledge of the context of people seeking asylum. Registering with a GP can be difficult.	While HC2 forms are provided, the actual procedures involved in retrieving and filling in these forms is cumbersom e and a barrier.	Lack of translation and language support	Lack of knowledge of UK procedures and systems is a barrier, compounde d by language.	
Scottish Refugee Policy Forum, 2012	Report	People seeking asylum and refugees [Scotland]		Registry with a GP can be even more difficult for individuals	Despite helplines such as NHS 24 being free from	Language barriers present a barrier to registering with and	There is a lack of clarity for newly arriving AS in how to	Accessing mental health services can be challenging

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				who have been refused. Some services may provide help to those that are 'street homeless' but RAS with temporary accommoda tion may not be able to access these services	landlines, accessing these services via a mobile could present a monetary barrier.	accessing GP or health services.	register with a GP – compounde d by language barriers.	for some people due to associated stigmatisatio n, which may be more prevalent or a greater concern in these individuals' countries of origin.

Authors	Study or source type	Migrant groups covered	Themes covered: A. Policy and entitlement	Themes covered: B. Service provider-related factors	Themes covered: C. Additional costs to access healthcare	Themes covered: D. Language and communi-cation	Themes covered: E. information and knowledge	Themes covered: F. Fear, trust and stigmatisa-tion
				despite no longer receiving support or getting little support.				

Contacts

This publication and related equality and human rights resources are available from our website.

Questions and comments regarding this publication may be addressed to: correspondence@equalityhumanrights.com. We welcome your feedback.

For information on accessing one of our publications in an alternative format, please contact: correspondence@equalityhumanrights.com.

Keep up to date with our latest news, events and publications by signing up to our e-newsletter.

EASS

For advice, information or guidance on equality, discrimination or human rights issues, please contact the Equality Advisory and Support Service, a free and independent service.

Telephone	0808 800 0082
Textphone	0808 800 0084
Hours	09:00 to 19:00 (Monday to Friday) 10:00 to 14:00 (Saturday)
Post	FREEPOST EASS HELPLINE FPN6521

Published: November 2018

ISBN: 978-1-84206-780-2

You can download this publication from

www.equalityhumanrights.com

Published: November 2018

ISBN: 978-1-84206-780-2

Equality and Human Rights Commission