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A mile in their shoes: understanding healthcare journeys of refugees and asylum seekers in the UK

Isobel Talks[1], Buthena Al Mobarak[2], Cornelius Katona[3], Jane Hunt[4], Niall Winters[1] and Anne Geniets[5,*]

[1]Department of Education, University of Oxford
[2]Happy Baby Community, London
[3]Division of Psychiatry, UCL
[4]Helen Bamber Foundation, London
[5]Department of Consultation-Liaison Psychiatry and Psychosomatic Medicine, University Hospital Zurich

Abstract

Refugees and asylum seekers worldwide face numerous barriers in accessing health systems in their new home countries. The evidence regarding who and what helps refugees and asylum seekers facilitate access to and the navigation of the health system in the UK is small. This paper addresses this gap through analysing 14 semi-structured, in-depth interviews with refugees and asylum seekers of different countries of origin in the UK, to identify where, when, and how they came into contact with the healthcare system and what the outcome of these interactions were. It identifies key obstacles as well as 'facilitators' of their healthcare experience and suggests that host families, friends and third-party organisations can all play an important role in ensuring refugees and asylum seekers receive the healthcare they need.

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* Corresponding author: Dr Anne Geniets: anne-kathrine.geniets@usz.ch

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Structured Abstract

Purpose

Refugees and asylum seekers worldwide face numerous barriers in accessing health systems. The evidence base regarding who and what helps refugees and asylum seekers facilitate access to and the navigation of the health system in the UK is small. This paper addresses this gap by analysing 14 semi-structured, in-depth interviews with refugees and asylum seekers of different countries of origin in the UK, to identify where, when, and how they came into contact with the healthcare system and what the outcome of these interactions were.

Approach

Semi-structured in-depth interviews were chosen as the key method for this study. In total, 14 individual interviews were conducted. A trauma-informed research approach was applied to reduce the risk of re-traumatising participants.

Findings

The paper identifies key obstacles as well as 'facilitators' of refugees' and asylum seekers' healthcare experience in the UK and suggests that host families, friends and third-party organisations all play an important role in ensuring refugees and asylum seekers receive the healthcare they need.

Originality

To our knowledge, this is the first qualitative study in the UK that looks at comprehensive health journeys of refugees from their first encounter with health services through to secondary care, highlighting the important role along the way of facilitators such as host families, friends and third-party organisations.

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Introduction

The number of people displaced by war, armed conflict, persecution, or the effects of climate change, amongst other reasons, has risen to unprecedented levels in recent years (UNHCR, 2023). Some of those so displaced come to the UK as refugees (House of Commons Library, 2022a) (defined as people who meet the country-specific criteria for refugee status; Ziersch, 2022: p.2023), others arrive as asylum seekers (House of Commons Library, 2022b; Sturge, 2023), broadly defined as people awaiting determination of their claims for refugee status or other forms of protection (ibid.). However, whilst the number of people seeking refuge in the UK has risen recently (House of Commons Library, 2022), the rate of decision making of their asylum/protection applications has slowed (The Migration Observatory, 2022). The precarious situation that asylum seekers are left in whilst waiting to receive a decision on their immigration status is extremely challenging, and has been shown to impact negatively on both their mental and their physical health (Kleinert et al., 2019; McColl et al., 2008; Refugee Council, 2021). Research has also shown that asylum seekers and refugees tend to have a greater burden of and more diverse healthcare needs in comparison to host populations (Kang et al., 2019; Papadopoulos et al. 2005; Carlsson et al. 2004; Burnett and Peel, 2001; Laban et al., 2004; Tribe, 2002). Yet research carried out in host countries across the world demonstrates that refugees and asylum seekers face numerous barriers in accessing the healthcare that they need (Kohlenberger et al., 2019; Reed et al., 2012; Mangrio et al., 2018; Mårtensson et al., 2020; Nowak et al., 2022; Sheikh-Mohammed et al., 2006; Wångdahl et al., 2015).

Research in the UK has similarly found that multiple obstacles such as language barriers, interpersonal trust issues resulting from months or years of abuse and persecution, and difficulties in discussing their health concerns due to the shame or the trauma that this may trigger, are also negatively affecting the health of refugees and asylum seekers in this context (Bhatia and Wallace, 2007; Bhui et al., 2006; Doctors of the World, 2017; Fang, 2015; Feldman, 2005; Lephard and Haith-Cooper, 2012; Mangrio and Forss, 2017; O'Donnell et al., 2007; O'Donnell et al., 2008; Redman et al., 2011).

As Kang et al. (2019) point out, much of this prior research work took place before charges for refugees seeking to access NHS healthcare were brought in 2017 (Hiam et al., 2018), as part of the 'hostile environment' for irregular migrants that then Home Secretary Theresa May first initiated in 2012 (Travis, 2010). A more recent review of the evidence regarding the access to healthcare experienced by people seeking and refused asylum in Great Britain identified a number of further evidence gaps (Equality and Human Rights Commission, 2021b: p.53). These included a lack of research regarding the "specific experiences of people seeking or refused asylum", with much research focusing instead on "barriers to healthcare among broader migrant populations", as well as "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" (ibid.).

In response to these substantial evidence gaps, this paper presents research which involved speaking with refugees and asylum seekers from a variety of different countries of origin, including both people who have received their right to remain and those still waiting for a decision, about their healthcare journeys within the UK. The intention was that by asking the research participants to tell us about the full trajectory of their healthcare experiences, from first hearing about the health system, through to registering with a local GP and accessing healthcare, a more comprehensive understanding of refugee and asylum seeker health in the UK could be gleaned.

Methodology

The research upon which this paper is based was conducted between May and December 2022, as part of a larger participatory, evidence-based, and trauma-informed refugee health education project at [anonymised for publication], which included a series of participatory focus groups as well as semi-structured in-depth interviews. For this research project, three of the authors of this paper (a female postdoctoral researcher, a female programme coordinator, and a female postgraduate medical doctor, all with either lived experience or with training and experience in working with minoritised groups) collaborated with two London-based third sector organisations supporting asylum seekers and refugees, to design and deliver a health education curriculum in participation with clients of these NGOs. Both

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NGOs allowed us to recruit participants for the project from their client base. The research project received enhanced ethical approval through the [anonymised for publication].

Nine of the fourteen refugees and asylum seekers who took part in the in-depth interviews reported in this study were recruited via the two participating third sector organisations. In addition, in light of the ongoing Ukrainian refugee crisis, five Ukrainian refugees were recruited externally via snowball sampling in the local community. All nine of the former interviews, and two of the latter were carried out online via video call, and three of the latter were carried out in person at their host family home or in a local cafe, in line with what was most convenient for the participants themselves. Prior to the in-depth, semi-structured interviews commencing, oral consent for participation in the research was obtained from each of the participants and the process to withdraw from, or raise any concerns about, the research was explained. A trauma-informed research approach (Gum et al., 2023) was applied to reduce the risk of re-traumatisating participants. Participants were asked only to share what they felt comfortable sharing, and the research team checked in with them the day after the interview on how they were feeling and if they required any further support regarding the topics that had been discussed in the interviews.

Semi-structured in-depth interviews were chosen as the key method for this study, because as Rubin and Rubin (1995:1) note, "[q]ualitative interviewing is a way of finding out what others feel and think about their worlds". An interview guide was provided which was refined after a pilot interview and employed flexibly in practice. In total, 14 individual interviews were conducted. They ranged in length from 25 minutes to over an hour.

The table below provides more information on the study participants (pseudonyms are used in order to maintain their privacy):

Table 1 here (see end of paper for all tables)

Participants were offered interpreters to provide translation, and three of the interviewees requested interpretation. The interviews were audio recorded (with the participants' consent), and were then transcribed, coded and analysed by the postdoctoral researcher,

drawing on Carney's ladder of analytical abstraction (Carney, 1990), and using In Vivo coding. As Charmaz (2006:57) argues, In Vivo coding centralises what is important to the participant and helps to "crystallise and condense meanings".

Following the coding process, the data was repackaged and aggregated through the creation of diagrams depicting each of the interviewee's journeys into, and through, the healthcare system in the UK. Through visualising the data in this way, it became possible to identify key 'moments' along their healthcare journeys, highlighting clearly where, when, how and why the research participants came into contact with the healthcare system and what the outcome of these interactions were. This process of mapping their healthcare journeys also brought to the fore key 'obstacles' that obstructed the participants' journeys through the healthcare system, as well as 'facilitators' which eased and assisted with their journeys. This stage of analysis enabled us to draw out broader patterns and themes from the participants' journeys, as well as to highlight aspects that differed. The final stage of the analysis involved bringing the interview transcript data together with the visual health journeys to draw out explanations for why there were shared themes across the stories shared by the participants, as well as differences. Bringing these aspects together and then considering how the overarching findings compared and contrasted with the literature enabled us to construct an explanatory framework, which the following findings section extrapolates in greater detail.

Results

a. Point of Entry to the Healthcare System in the UK

The participants interviewed for this study had a wide variety of experiences with regards to their point of entry into the health system in the UK. For those who had arrived in the UK as refugees, under a specific refugee settlement scheme, the point of entry to the health system had been easier to find. For example, the five female interviewees who came to the UK from Ukraine under the 'Ukraine Sponsorship Scheme', otherwise known as 'Homes for Ukraine', told us that they had been provided information from the British Government about how to register with a GP, and had also received help with this from their host families:

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> *Simon kindly agreed to help me with this. He called back to the admissions office. We were recorded very quickly at a certain time when we could come and during the day we went through the whole process* (Kateryna)

These experiences were in stark contrast to the difficulties faced by the other participants (i.e. the 'asylum seekers') taking part in this study, who had come to the UK informally rather than those who had come under an official refugee resettlement scheme. There were a number of barriers which prevented these participants from having a smooth entry into the health system in the UK. First and foremost, for some of the research participants it was difficult finding out how to enter the healthcare system:

> *Because when I got to this country, based on my circumstances, I was unable to register for any [healthcare], or probably let me say, I don't really have much idea on how to do it, you know?* (Isaac)

The interviewees without an official source of information had to rely on people within their networks to inform them as to how to register for healthcare. These included friends, neighbours, members of religious organisations, host families or landlords. These 'facilitators' played a crucial role in their healthcare journey: many of the participants were unable to speak or comprehend English on their arrival. Without support as to how to navigate this, it was a challenge for the participants, including Rima, to work out how to register for the health system until they met someone who could speak the same language that they did:

> *When I arrived to the UK, I was pregnant in my seventh month so I have to go and register … it was very difficult for me because I didn't know anything about the system … When I came, they put me in a hostel in Croydon … they registered me, took all the information. After one month, they moved me to Southall in London. You know Southall? … Their accent is very difficult for me. I cannot understand anything. I remembered that I was calling my husband and crying because I didn't understand anything, anything at all, yeah …I went to more than two GPs until... and each one told me that there was another one. 'You have to book at this one' … Yeah, I was pregnant,*

> *seven months, it's very heavy to walk (…) So, the first days was very, very difficult, yeah, to register with the GP… (Rima)*

Alongside information and language barriers, another challenge to registering for the health system was a lack of a fixed address or lack of proof of a fixed address and the provision of other details, which are often asked for to complete GP registration. In Samuel's case, he had to register via his friend's GP, using his friend's address, in order to access the system, as a result of having no fixed address.

> *It's not easy if you're a migrant first of all, if you're a migrant and an undocumented person because a lot of stuff they ask that you don't really have. First of all, you must have an address … sometimes they ask you for those methods … like a password … some of us will never have one before so it makes it harder for a migrant … it's hard to get a GP, to see a doctor … I fell sick and one of my friends they took me to his GP … After some time I think that they… I get the treatment but they did … they get used to me going back … I didn't have an address at the time but someone who had an address he… through my friend, you know, that's it, yeah (Samuel)*

For refugees and asylum seekers living in government provided accommodation, whilst they have an address to register with, they are highly likely to be moved regularly and without warning to other accommodation, providing further challenges in accessing the healthcare system as constant re-registration is required. This has further knock-on effects, in that patients may be registered under different NHS numbers at repeated points of entry to the healthcare system, or their medical records may get lost. Delays in medical records following patients further mean that treatment is delayed or interrupted, waiting lists have to be started again, and histories have to be repeated with the trauma that this entails.
As one of the interviewees explained:

> *A[s] [a] new patient, you know, I got new NHS numbers. So when …I was trying to tell the doctor my history of my medicine record, he told me he can't find it. And I remember, oh my goodness, it must be at the first NHS number, but I don't think [of]*

> *the name. Would they be able to find that one or not? 'Cause I've totally not remember what is NHS number (…), they just register me again* (Ming-Yue)

Challenges faced by asylum seekers in particular in accessing healthcare services means many have to rely on third party charitable organisations, such as Doctors of the World or the Helen Bamber Foundation to facilitate entry to the healthcare system in the UK. Nine of the interviewees in this study received help and support from third sector organisations. These organisations play an essential role in helping asylum seekers enter the health system in the UK:

> *I moved from where I was living, so my case also at the Home Office was, like, rejected, so I didn't have any proof of address at that time, so it was hard for me to be registered again, to a new GP. So the Doctors of the World who helped me with that… (Robert)*

A further barrier to registering for the UK health system raised by the participants in this research were fears that if they tried to access healthcare then they would be reported to immigration authorities and deported:

> *You fear for them [the doctors] to go … and [for the doctors to] call the police, that's one stuff you don't want to get involved too much with the doctors (Samuel)*

> *If you have a legal status problem, so those time they don't like to register you, some…so in the meantime, maybe six month, I have no status, like, my case [is] pending. But I remember one day I was in the hospital, I am sick … I saw the police, I ran away from the hospital... (Saiful)*

For some of the interviewees in our study, their point of entry to the healthcare system in the UK was through acute care. For example, for one of the interviewees, the difficulties she faced in registering meant that her first experience with the UK healthcare system was during an emergency situation, which could have potentially been avoided had she been able to register and see a health professional sooner:

> *I think I [was] depressed or I don't know, the mood quite low. I was unwell for a while. So, yes, I go to hospital at night-time. I still, I didn't know what's going on at night-time, but now I think I knew I was, you know, in depression … Because I didn't realise I was sick, so my friends sent me to hospital… and then I have to stay in the hospital until I'm well (Li Mei)*

Finally, for some of the refugees and asylum seekers, their point of entry to the UK healthcare system was when they needed urgent dental care. Participants across the cohort mentioned particular confusion when trying to access dental care in the UK:

> *And when I have to toothache, I tried to call to 111, I tried [getting] help through... have help with them, I just asked them about please book me an appointment because I'm not like... not customer or not client (Tetyana)*

> *There was a period that I had, like, a problem with, you know, my teeth and it was hard, so it took me, like, more than two months. So you have to register first, you have to wait, and I tried to go for an emergency, they were sending me back to my dentist, and you know, as a new register, I had to wait for somehow that, to be seen (Robert)*

b. Navigating primary care

Once the study participants had managed to sign up with a GP, some then went on to receive primary healthcare.

In our study, we found that many of these challenges appeared to be mitigated if the refugees and asylum seekers arrived through a settlement scheme, or if they had support available through their social networks, friends, family or host families, or had access to third sector organisations: For Ukrainian refugees participating in this study, registering with their GP had been relatively smooth as a result of the information and support they received through the 'Homes for Ukraine', friends and their host families, who acted as facilitators. For example, Diana, a Ukrainian refugee, took a friend with her to her GP appointment who was fluent in both English and Ukrainian, in order for her to explain her health needs:

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> *Yeah, my friend, she teaches English. First appointment, I go with her* (Diana)

For other refugees, who did not readily have access to facilitators upon their arrival, navigating the primary healthcare system turned out to be more challenging, as Fatima's and Ming-Yue's examples demonstrate:

> *I always need interpreter, but they don't put interpreter. Like for example, when I want to book an appointment, they say that you have to wait for the Arabic GP, because they've got an Arabic GP there. So, that's why they always don't give me like the appointment when I need, because they say that, 'The Arabic GP is not here at the moment, so you have to wait for him to come, and then we will book you with him' … actually, sometimes when I tell them I need the doctor, they tell me that, 'Go to the hospital,' because they have this lack of services, like they don't have interpreter* (Fatima)

> *[Because] at that time my English wasn't good enough to tell them what I'm suffering [with] and interpreter[s] do help a lot. So because [of] the poor English sometimes the clinic couldn't understand, so make us (…) not have treatment. (Ming-Yue)*

Navigating the complexity around where to get acute care for minor injuries and sickness, which can be difficult even for people with knowledge of the healthcare system, appeared to be a particular challenge for many, and was further compounded by language barriers.
In Fatima's case, she had received conflicting advice about which type of primary care service to utilise:

> *So, sometimes the hospital sent me to the GP, and then the GPs say, 'Go to the hospital.' (…) And actually, I'm feeling frustrated, because one of these times, my child was really very sick. He was vomiting, and he has got diarrhoea, and dryness because of this. And the hospital was saying, 'Go to the GP.' And the GP was saying, 'Go to the hospital.' So, it was really frustrating that you can't get the right service at the right time* (Fatima)

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Our study also found that while digital health systems may have been designed to facilitate easier access and navigation of the healthcare system, for refugees and asylum seekers, who often have limited access and resources to use digital technology, these seem to have added an additional layer of challenges. For example, Rima shared that she had initially struggled to use online systems as they couldn't afford data to access the Internet:

> *Not these days but when I came in the first few months, it was very difficult for me because I lived in the hostel, and I [only] have a certain amount of data* (Rima)

Robert had faced particular challenges in using his mobile phone to fill in health forms from his GP:

> *No, it's easy. It's only my … yeah, it's only sometimes when my GP sends me, like, a referral form to fill or you have to fill sometimes it is hard to fill it up and send it to where I'm supposed to send it. This is where sometimes it is giving me a problem. With the form, like, sometimes it's access, but sometimes, no, it's hard for me to do those self, you know, referral forms, sending me, you know, a form to fill online, yeah, like a link, something like that* (Robert)

A lack of access to data or Internet connectivity, as well as to digital technologies, can also disrupt the ability of refugees and asylum seekers to seek out health information online:

> *Yeah. But I use it when I need it, you know, sometimes because the Wi-Fi and the data and the Wi-Fi and mobile phone too expensive for me to afford it, so yeah* (Ming-Yue)

> *Because it is the money thing in it, so when you have a…you are starving for food, you cannot spend for money for your phone top up or you, like, a transport or everything else. But you have to after phone is like those time like expensive things, so those time we're using like a BT, you know, like BT they make a box all over the London. Yeah, there's one in library or maybe some bank. We use some bank like the cost there are free, they have free Wi-Fi with the box and we use it* (Saiful)

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c. Secondary Care

Most of the interviewees in our study were considered by their GP or by a clinician at the third sector organisation to need secondary care. In some instances, especially where facilitators were present, this worked very well, like in the case of Samuel, whose GP referred him for mental health support.

> *When I became unwell my GP referred me to … a group who have the same stuff, who are going through the same thing, and we have to meet I think once a week … they have one professional or some professional in the ward… I just think that medicine is also helping me but I think the therapy is better … I think first of all you need to trust someone to speak to* (Samuel)

Yet, some of the refugees and asylum seekers we interviewed felt that navigating their journey alone through the healthcare system was lonely, dehumanising even:

> *They should be…they're like so robotic with policies and procedures and everything. Outside the policies and procedure, they really don't care. So it just makes them like a machine. It makes you feel like you are not really, like, having conversation or giving your life to a human being, you just feel like it's a professional"* (Abidemi)

Again, as was the case at the point of entry to the healthcare system and when navigating the primary care system, support from facilitators like friends, third sector organisations, or even GPs who had become allies, helped to mediate and humanise this experience for many:

I don't know. The thing is when you feel… when it's serious and like some of us who don't have confidence it can take some time, days to book an appointment if you don't insist, if you call by phone and you don't get someone to answer at the beginning you give up and you will not see any doctor or see any anybody to speak to. And for me the thing is if I don't get the doctor I have the [third sector organisation] anyway, I call them and we talk about stuff which is really helping me… (Samuel)

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One of the interviewees spoke of how the personal relationship he had developed with his GP, who had been a great source of help and support during his time in the UK, had helped him to get the more specialist care he needed:

> *I don't see her as my GP but I see her as somebody who has always been there for me, anytime you need help, do you understand me?...So, she's been a wonderful woman. Ready to assist anytime, any day. So, she's very, very, you know, when I was explaining she is crying and all things like what I went through, when I was detained, you know? And for that time, I have nobody… I have not friends, I had nobody I can talk to and nobody I share my stress with them…I think I'm still living because, you know, she's part of the why I'm still in this country. Because if she doesn't refer me to the [third sector organization], sure I'd be more worse (Isaac)*

For another refugee, unable to get an NHS dental appointment and in significant pain, her host family facilitated the navigation and even paid for an emergency private dental appointment.

She [the host] helped me book appointment like urgent, and paid for me £70 … I just had antibiotics [for] three days and I'm waiting for treatment… (Tetyana)

d. Ongoing care

Over the course of their healthcare journey, as their experience and contact with the health system in the UK has continued, many of the interviewees have become more confident with navigating the system and getting the care that they need:

> *Yeah, now, I'm more comfortable. I can deal anything with my daughter, the test or the GP or the hospital, yeah, I can deal anything now. Even if I didn't... when I came, I didn't know the translator or I was so shy to ask them about, "Can you repeat? What did you say?" or... now I just, "Please talk slowly. Can you repeat that again?" until I got the idea because if I didn't do that, I miss a lot of things about my daughter and it's something I don't want to happen* (Rima)

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With it, the experience of knowing where to get help and support seems to have made their healthcare journey easier too, and the role of facilitators seems to have become less pivotal on their healthcare journey. In fact, many of the interviewees themselves seem to have become facilitators themselves for others starting out on their healthcare journeys in the UK, be it as friends, neighbours or active members of the third sector organisations that had supported them:

> *I'm [trying] to help people and try to refer them to where they can receive the kind of, you know, assistance I received (…). (Isaac)*

Such peer-to-peer support in gaining access and navigating the healthcare system seems very effective, not just for newly arrived refugees and asylum seekers, but also for the facilitators themselves.

Discussion

This study has provided first-hand accounts of the healthcare journeys that asylum seekers and refugees have taken within the UK. It became apparent from the interviews that there are key access points along the healthcare journey whereby additional support and guidance is required to enable refugees and asylum seekers to have as smooth a passage as possible. It is also clear from the findings that there are particular types of support that would be most beneficial at these different points. These findings therefore make a useful and novel contribution to efforts to improve healthcare provision for refugees and those seeking asylum in the UK.

Mapping these health journeys, from point of entry to the healthcare system, to receiving primary, secondary and ongoing care, it has become apparent that refugees and asylum seekers in the UK face numerous hurdles and barriers to access and utilise healthcare. Some of the difficulties shared with us by the 14 interviewees who took part in this study reflect those identified by participants in other studies too. For example, Kang et al (2019: p.537) also found in their study that refugees and asylum seekers faced multiple difficulties in navigating and negotiating primary healthcare services in the UK, ranging from

'accommodation' of linguistic differences, 'awareness' of the NHS structure, to 'affordability', 'availability' of appointments and lack of 'acceptability' of difference from healthcare professionals. Their paper (ibid.) echoes the particular concerns that our study also found around access to dental care, as does a previous review of research into dental care access for refugees and asylum seekers in highly developed countries, including the UK, which found affordability, communication difficulties, insufficient interpretation, limited knowledge of the healthcare systems and healthcare rights, and negative encounters with healthcare teams to all be significant barriers (Paisi et al., 2020).

Due to a lack of research regarding healthcare barriers particularly affecting those seeking asylum, rather than broader migrant groups, and a lack of research into access for asylum seekers and refugees to secondary care, however, our study has also brought to light obstacles less reported in the literature. Some of these are systemic, like the disconnect in the nature of different health services, the need for proof of a fixed address in order to be able to access services (Asif and Kienzler, 2022) or the frequent moves at short notice for asylum seekers living in government accommodation (Koca, 2022), which make the continuity of care near to impossible. Whilst some of the material obstacles identified in this study such as a lack of financial resources to be able to travel to medical appointments or afford certain health services, are reflected in other studies (Kang et al. 2019), the specific concerns that participants raised about being able to afford data and technology in order to access health services have not received as much recognition. A 'digital divide' and income-based lack of access to the digital sphere, as well as a lack of health literacy, has been noted more generally across the UK in previous studies (Estacio et al., 2019; ONS, 2016), as well as a need for eHealth Literacy to combat misinformation (Swire-Thompson and Lazer, 2020). But with some research suggesting that translating online health information into languages spoken by refugee and asylum seeker communities could help them to access and navigate the health system more easily (Knights et al., 2022; O'Mara and Carey, 2019; Samkange-Zeeb et al., 2020), efforts to make data and technology available specifically to these individuals are needed.

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The limitations of the healthcare system in the UK that this study has laid bare, which is in crisis due to chronic underfunding, are experienced not only by asylum seekers and refugees but also by the broader population in the UK beyond. But the specific vulnerabilities faced by asylum seekers and refugees further compound these systemic and material barriers, making it even more challenging to access and utilise the healthcare system. The particular traumas and life experiences that many asylum seekers and refugees have experienced, together with their social isolation also mean that people in these situations often have urgent and profound mental and physical health needs, which make any barriers to accessing healthcare even more difficult to bear.

However, as this study found, there are a number of mediating facilitators involved in asylum seekers' and refugees' healthcare trajectories in the UK. It is important to note that the barriers and hurdles to healthcare described above were not experienced equally across the 14 interviewees. In particular, the interviewees who had been asylum seekers, some with their cases for settlement being initially denied by the Home Office, faced the most obstacles to accessing healthcare. A lack of a fixed address, fears about being reported, lack of resources, and the absence of support from facilitators who could have helped to mediate their experience meant that the participants who had been in this position had struggled the most along their healthcare journeys. Prior charges for asylum seekers to access healthcare (Worthing et al., 2021) were extended in 2017 to include "community services allied to primary care" (Kang et al., 2019), and whilst GP services are supposed to have remained free, research has shown that 13% of vulnerable migrants have been wrongly denied registration due to their immigration status (Patel and Corbett, 2017). Research by The Equality and Human Rights Commission (2018a: p.7) has found that "the NHS charging regulations and data sharing with the Home Office as well as aspects of asylum policy such as dispersal, and the impact of sometimes multiple accommodation moves" have caused significant fear and made it challenging for people seeking and refused asylum to access the care that they need. A recent study of mental healthcare for asylum-seekers and refugees in the UK has further suggested that "the hostile environment created by tightened immigration laws and tracking has increased fear and reduced trust" (Pollard and Howard, 2021: p.12). The recent Illegal Migration Bill, Rwanda policy, and Nationality and Borders Act 2022, which aim to sanction those migrating to the UK for humanitarian purposes, will no doubt exacerbate these issues.

Whilst the participants in this study seeking asylum faced particular barriers therefore in accessing healthcare, those who had arrived in the UK under an official refugee settlement scheme, such as the interviewees from Ukraine, were not immune from difficulties either. Whilst registering for the health system under these schemes was comparatively smoother, ameliorated in some cases by their host families, their journeys through the healthcare system were also fraught with challenges, augmented by a lack of knowledge about how the system operates, and limited English proficiency, as well as finite material resources to be able to pay for health-related expenses.

While the distinction between point of entry, primary and secondary care is often not as clear cut as depicted below, and may happen at the same point of time, depending on the complexity of health problems, the table below summarises the different challenges experienced by the interviewees, and how different facilitators provided support at different points on the journey. Our research found for example that some interviewees used emergency health services for less acute conditions as a result of barriers in accessing primary healthcare, a finding also reflected in research carried out in Europe (Credé et al., 2018).

The table illustrates that some challenges, such as limited language skills, limited digital skills and limited access to technology, as well as psychological factors like fear of being reported to immigration authorities or lack of confidence appear to be more pervasive challenges than others. The table further highlights that the more complex the health problems experience by refugees and asylum seekers are and the more involvement from different health sectors is required early on in their healthcare journey, the more support they will need to navigate the health system.

Table 2 here (see end of paper for all tables)

The interviews showed that, as the refugees' and asylum seekers' journey went on and they gradually familiarised themselves with the system and the language, the role and importance of facilitators as well as the type of facilitators gradually changed. With increased experience, some of the interviewees became facilitators themselves, finding purpose and pride in being

able to give something back to the community. Prior research has shown that peer support and peer mentoring among refugees can enhance resilience and empowerment (Paloma et al., 2020). Peer support groups have also been found to have a positive effect on refugee mental health (Block et al., 2018).

Study limitations

Given the small sample size of this study, the findings reported here will only tell a partial story regarding the healthcare journeys of refugees and asylum seekers in the UK. Additionally, as has been reported previously (Doctors of the World, 2012), studies recruiting participants through third sector organisations may have a positive bias, as the testimonies of those who are not accessing support, who could face even greater marginalisation and access challenges, are not included. While five of the interviewees in our study (i.e. those from Ukraine) were not currently receiving support from a charitable organisation, they had all arrived in the UK under an official resettlement regime and as such may have received additional support not given to asylum seekers arriving in the UK independently. Future research should seek to ensure that the voices of those not receiving support through charitable organisations are documented.

Conclusion and Recommendations

The current status quo of the healthcare provision for refugees and asylum seekers in the UK can be thought of as a prism that, if held up, reflects the weaknesses of the different sectors within the UK healthcare system, and beyond. The systemically siloed nature of the different health services and the resulting disconnect between them make it near to impossible to provide comprehensive care to meet the often complex, multiple healthcare needs of refugees and asylum seekers, which would require cross-sector involvement. Some initiatives have started to tackle these issues, like for example the Respond Project, a 'pragmatic, joined up approach' initiated by a team of primary and secondary healthcare providers in the London borough of Camden (Farrant et al., 2022).

In addition to the need for improved cross-sector care, this study has highlighted the importance of mediating facilitators, such as NGOs, volunteer organisations, host families,

neighbours, friends, or in one case, a GP who became a friend, to facilitate access to and the navigation of the healthcare system for refugees and asylum seekers in the UK. For all the participants that we spoke with, these vital connections not only helped them overcome the systemic and material barriers that otherwise would have held them back from accessing and utilising the healthcare system, but also had helped to humanise their health service experience in the context of an increasingly hostile environment. Indeed, as this study has demonstrated, refugees and asylum seekers often become peer-to-peer facilitators themselves as their journey through the healthcare system continues, finding meaning and purpose in sharing their knowledge and experience with others who are at the start of their journey. Going forwards, more data of the many initiatives already in place is needed to help build an evidence base on best practices to effectively facilitate access to and navigation of the healthcare system and support asylum seekers and refugees on their journeys through it. Ultimately, this will help ensure that refugees and asylum seekers receive the healthcare they need - a crucial part of their journey towards a brighter future.

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Conflict of Interest

No conflict of interest.

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Tables

Name of Participant	Age Range	Country of Origin
1. Li Mei	25 - 34	China
2. Kateryna	35 - 44	Ukraine
3. Samuel	45 - 54	Uganda
4. Robert	45 - 54	DR of Congo
5. Rima	35 – 44	Syria
6. Tetyana	35 - 44	Ukraine
7. Diana	35 - 44	Ukraine
8. Saiful	25 - 34	Bangladesh
9. Abidemi	35 - 44	Nigeria
10. Isaac	25 - 34	Nigeria
11. Ivanna	35 - 44	Ukraine
12. Ming- Yue	25 - 34	China
13. Daniela	35 - 44	Ukraine
14. Fatima	35 - 44	Kuwait

Table 1. Names of participants (figure by authors)

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	Point of entry ⟷	Primary care ⟷	Secondary care
Challenges faced			
Language skills/Lack of interpreters			
	Limited language skills *Interviews 1, 2, 4, 5, 8, 12*	Limited language skills – lack of interpreters *Interviews 4, 5, 6/7, 8, 9, 11, 12, 14*	Limited language skills – lack of interpreters *Interviews 4, 5, 6/7, 8, 12*
Psychological factors			
		Low confidence to seek medical attention and to interact with healthcare staff *Interviews 3, 5, 12*	Low confidence to seek medical attention and to interact with healthcare staff *Interviews 3, 5, 12*
	Fears of being reported to immigration authorities/home office *Interviews 8*	Fears of being reported to immigration authorities/home office *Interviews 3, 8*	Fears of being reported to immigration authorities/home office *Interviews 9, 8*
Lack of resources to afford public transport or get child care for health appointments			
	childcare / lack of public transport *Interview 5*	childcare / lack of public transport *Interview 5*	
			Cost of some dental procedures *Interview 6*
Lack of knowledge about health system, lack of health information			
	Lack of knowledge about system and where to find help *Interviews 1, 5, 10*	Not knowing whether to go to GP or A&E – which service to use *Interviews 4, 6, 8, 12, 14*	
	Lack of health knowledge *Interview 1*		
Being moved frequently			
	Moving frequently, so health records get lost or delayed, or patient gets more than one NHS no. *Interviews 1, 4, 12*		

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	No fixed address/lack of proof of fixed address – can't register for GP *Interviews 3, 4, 8*		
Digital challenges			
	Lack of resources to afford digital devices/connectivity *Interviews 1, 3, 4, 5, 8, 10, 12*	Lack of resources to afford digital devices/connectivity *Interviews 1, 3, 4, 5, 8, 10, 12*	Lack of resources to afford digital digital devices/connectivity *Interviews 1, 3, 4, 5, 8, 10, 12*
			Lacking technical skills to fill in referral forms *Interview 4*
Facilitators mediating the healthcare journey			
Settlement schemes	Settlement schemes providing information *Interviews 2, 4, 5, 11, 14*		
Landlord/Landlady	Landlord helped find GP with specific language skills *Interview 1*		
Friends/Family	friends / family providing information and help with translation *Interviews 3, 5, 10, 12*	friends / family providing information and help with translation *Interviews 3, 7*	
Host families	Host families providing information and helping with translation *Interviews 2, 6, 13*	Host families *Interviews 6, 13*	Host families providing information and helping with translation *Interviews 6, 13*
3rd sector organizations	3rd sector organizations: providing information and helping with sign up and translation *Interviews 4, 8, 10*	3rd sector organizations *Interviews 3, 8, 9, 10*	3rd sector organization *Interviews 8, 10*
Allies within the health system		Allies within the health system, such as GPs or nurses *Interviews 1, 5, 10, 12, 14*	Allies within the health system *Interviews 10, 14*
Local volunteer groups			Local volunteer groups & religious organisations *Interviews 3, 10, 11*

Table 2 Challenges and facilitators of refugees' and asylum seekers' healthcare journeys in the UK (figure by authors)

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References

Asif, Z. and Kienzler, H. (2022), "Structural barriers to refugee, asylum seeker and undocumented migrant healthcare access. perceptions of doctors of the world caseworkers in the UK", SSM - Mental Health, Vol. 2, p. 100088.

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.

Bhui, K., Craig, T., Mohamud, S., Warfa, N., Stansfeld, S., Thornicroft, G., Curtis, S. and McCrone, P. (2006), "Mental disorders among Somali refugees: developing culturally appropriate measures and assessing socio-cultural risk factors", Social Psychiatry and Psychiatric Epidemiology, Vol. 41 No. 5, pp. 400-408.

Block, A.M., Aizenman, L., Saad, A., Harrison, A., Sloan, A., Vecchio, S. and Wilson, V. (2018), "Peer support groups: evaluating a culturally grounded, strengths-based approach for work with refugees", Advances in Social Work, Vol. 18 No. 3, pp. 930-948.

Burnett, A. and Peel, M. (2001), "Health needs of asylum seekers and refugees", BMJ, Vol. 322 No. 7285, pp. 544-547.

Carlsson, J.M., Mortensen, E.L. and Kastrup, M. (2005), "A follow-up study of mental health and health- related quality of life in tortured refugees in multidisciplinary treatment", The Journal of Nervous and Mental Disease, Vol. 193 No. 10, pp. 651-657.

Crede, S.H., Such, E. and Mason, S. (2018), "International migrants' use of emergency departments in Europe compared with non-migrants' use: a systematic review", European Journal of Public Health, Vol. 28 No. 1, pp. 61-73.

Charmaz, K. (2006), Constructing Grounded Theory, Sage, London.

Doctors of the World (2017), "Closing the gaps in healthcare access", available at: www.doctorsoftheworld.org.uk/wp-content/uploads/import-from-old-site/files/DOTW_UK_A5_leaflet_AW.pdf (accessed 8 November 2022).

Doctors of the World (2018), "Registration refused: a study on access to GP registration in England 2018", Doctors of the World, available at: www.doctorsoftheworld.org.uk/wp-content/uploads/2019/08/Registration-Refused-fnal.pdf

Equality and Human Rights Commission (2018a), "The lived experiences of access to healthcare and for people seeking and refused asylum", Report 122, www.equalityhumanrights.com/sites/default/files/research-report-122-people-seeking-asylum-access-to-healthcare-lived-experiences.pdf (accessed 17 November 2022).

Equality and Human Rights Commission (2018b), "Access to healthcare for people seeking and refused asylum in Great Britain: a review of evidence", Report 121, available at:

www.equalityhumanrights.com/sites/default/files/research-report-121-people-seeking-asylum-access-to-healthcare-evidence-review.pdf (accessed 17 November 2022).

Estacio, E.V., Whittle, R. and Protheroe, J. (2019), "The digital divide: examining socio-demographic factors associated with health literacy, access and use of internet to seek health information", Journal of Health Psychology, Vol. 24 No. 12, pp. 1668-1675.

Farrant, O., Eisen, S., van Tulleken, C., Ward, A. and Longley, N. (2022), "Why asylum seekers deserve better healthcare, and how we can give it to them", BMJ, Vol. 376, p. n3069.

Feldman, R. (2006), "Primary health care for refugees and asylum seekers: a review of the literature and a framework for services", Public Health, Vol. 120 No. 9, pp. 809-816.

Gum, A.M., Goldsworthy, M., Guerra, L., Salloum, A., Grau, M., Gottstein, S., Horvath, C., Fields, A., Crowder, J., Holley, R., Ruth, L.J. and Hanna, K. (2023), "Trauma-informed patient and public-engaged research: development and evaluation of an online training programme", Health Expectations, Vol. 26 No. 1, pp. 388-398.

Hiam, L., Steele, S. and McKee, M. (2018), "Creating a 'hostile environment for migrants': the British government's use of health service data to restrict immigration is a very bad idea", Health Econ Policy Law, Vol. 13 No. 2, pp. 107-117.

House of Commons Library (2022a), "Resettled persons by local authority", Excel Spreadsheet, Statistics as of December 2022, available at: https://commonslibrary.parliament.uk/research-briefings/sn01403/#::text1⁄4In%202021%2C%20there%20were%20around,applications%20for%20every%2010%2C000% 20people (accessed 17 April 2023).

House of Commons Library (2022b), "Supported asylum seekers by local authority", Excel Spreadsheet, Stastics as of December 2022, available at:

https://commonslibrary.parliament.uk/research-briefings/sn01403/#::text1⁄4In%202021%2C%20there%20were%20around,applications%20for%20every%2010%2C000%20people (accessed 17 April 2023).

Kang, C., Tomkow, L. and Farrington, R. (2018), "Access to primary health care for asylum seekers and refugees", British Journal of General Practice, Vol. 69 No. 685.

Kleinert, E., Mu¨ller, F., Furaijat, G., Hillerman, N., Jablonka, A., Happle, C. and Simmenroth, A. (2019), "Does refugee status matter? Medical needs of newly arrived asylum seekers and resettlement refugees – a retrospective observational study of diagnoses in a primary care setting", Conflict and Health, Vol. 13 No. 1.

Knights, F., Munir, S., Ahmed, H. and Hargreaves, S. (2022), "Initial health assessments for newly arrived migrants, refugees, and asylum seekers", BMJ, p. 377.

Koca, B.T. (2021), "Bordering, differential inclusion/exclusion and civil society in the UK", International Journal of Urban and Regional Research, Vol. 46 No. 1, pp. 65-81.

Kohlenberger, J., Buber-Ennser, I., Rengs, B., Leitner, S. and Landesmann, M. (2019), "Barriers to health care access and service utilization of refugees in Austria: evidence from a cross-sectional survey", Health Policy, Vol. 123 No. 9, pp. 833-839.

Laban, C., Gernaat, H., Komproe, I., Schreuders, B. and De Jong, J. (2004), "Impact of a long asylum procedure on the prevalence of psychiatric disorders in Iraqi asylum seekers in The Netherlands", Journal of Nervous & Mental Disease, Vol. 192 No. 12, pp. 843-851.

McColl, H., McKenzie, K. and Bhui, K. (2008), "Mental healthcare of asylum-seekers and refugees", Advances in Psychiatric Treatment, Vol. 14 No. 6, pp. 452-459.

Mangrio, E. and Sjögren Forss, K. (2017), "Refugees' experiences of healthcare in the host country: a scoping review", BMC Health Services Research, Vol. 17 No. 1, p. 814.

Martensson, L., Lytsy, P., Westerling, R. and Wångdahl, J. (2020), "Experiences and needs concerning health related information for newly arrived refugees in Sweden", BMC Public Health, Vol. 20 No. 1.

Miles, M. and Huberman, M. (1994), Qualitative Data Analysis: An Expanded Sourcebook, Sage, London. Nowak, A.C., Namer, Y. and Hornberg, C. (2022), "Health care for refugees in Europe: a scoping review", International Journal of Environmental Research and Public Health, Vol. 19 No. 3, p. 1278.

O'Mara, B. and Carey, G. (2019), "Do multilingual androids dream of a better life in Australia? Effectiveness of information technology for government translation to support refugees and migrants in Australia", Australian Journal of Public Administration, ', Vol. 78 No. 3, pp. 449-471.

Paisi, M., Baines, R., Burns, L., Plessas, A., Radford, P., Shawe, J. and Witton, R. (2020), "Barriers and facilitators to dental care access among asylum seekers and refugees in highly developed countries: a systematic review", BMC Oral Health, Vol. 20 No. 1, p. 337.

Paloma, V., de la Morena, I., Sladkova, J. and Lopez-Torres, C. (2020), "A peer support and peer mentoring approach to enhancing resilience and empowerment among refugees settled in Southern Spain", Journal of Community Psychology, Vol. 48 No. 5, pp. 1438-1451.

Papadopoulos, I., Lees, S., Lay, M. and Gebrehiwot, A. (2004), "Ethiopian refugees in the UK: migration, adaptation and settlement experiences and their relevance to health", Ethnicity & Health, Vol. 9 No. 1, pp. 55-73.

Patel, A. and Corbett, J. (2017), "'Registration refused: a study on access to GP registration in 'England", Doctors of the World UK, London.

Pollard, T. and Howard, N. (2021), "Mental healthcare for asylum-seekers and refugees residing in the United Kingdom: a scoping review of policies, barriers, and enablers", International Journal of Mental Health Systems, Vol. 15 No. 60.

Reed, R.V., Fazel, M., Jones, L., Panter-Brick, C. and Stein, A. (2012), "Mental health of displaced and refugee children resettled in low-income and Middle-income countries: risk and protective factors", The Lancet, Vol. 379 No. 9812, pp. 250-65.

Refugee Council (2021), "Living in limbo: a decade of delays in the UK asylum system", available at: https://refugeecouncil.org.uk/information/resources/living-in-limbo-a-decade-of-delays-in-the-uk-asylum- system-july-2021 (accessed 4 September 2022).

Rubin, H. and Rubin, I. (1995), Qualitative Interviewing: The Art of Hearing Data, Sage, London.

Samkange-Zeeb, F., Borisova, L., Padilla, B., Bradby, H., Phillimore, J., Zeeb, H. and Brand, T. (2020), "Superdiversity, migration and use of internet-based health information – results of a cross-sectional survey conducted in 4 European countries", BMC Public Health, Vol. 20 No. 1, p. 1263.

Sheikh-Mohammed, M., Raina MacIntyre, C., Wood, N.J., Leask, J. and Isaacs, D. (2006), "Barriers to access to health care for newly resettled Sub-Saharan refugees in Australia", MJA, Vol. 185 Nos 11/12.

Sturge, G. (2023), "Asylum statistics", House of Commons Library, available at: https://researchbriefings.files.parliament.uk/documents/SN01403/SN01403.pdf

Swire-Thompson, B. and Lazer, D. (2020), "Public health and online misinformation: challenges and recommendations", Annual Review of Public Health, Vol. 41 No. 1, pp. 433-451.

The Migration Observatory (2022), "Asylum and refugee resettlement in the UK", available at: https://migrationobservatory.ox.ac.uk/resources/briefings/migration-to-the-uk-asylum (accessed 12 December 2022).

Travis, A. (2013), "Immigration bill: Theresa May defends plans to create 'hostile environment'", The Guardian, 10 October, available at: www.theguardian.com/politics/2013/oct/10/immigration-bill-theresa-may-hostile-environment

Tribe, R. (2002), "Mental health of refugees and asylum-seekers", Advances in Psychiatric Treatment, Vol. 8 No. 4, pp. 240-247.

UNHCR (2023), "103 Million forcibly displaced people worldwide", available at: https://www.unhcr.org/refugee-statistics/#::text1%E2%81%844At%20the%20end%20of%202021,below%2018%20years%20of%20age.&text1%E2%81%844Between%202018%20and%202021%2C%20an,a%20refugee%20life%20per%20year (accessed 17 April 2023)

DOI: https://doi.org/10.1108/IJMHSC-06-2023-0060

Wångdahl, J., Lytsy, P., Mårtensson, L. and Westerling, R. (2015), "Health literacy and refugees' experiences of the health examination for asylum seekers – a Swedish cross-sectional study", BMC Public Health, Vol. 15 No. 1, p. 1162.

Worthing, K., Galaso, M.M., Wright, J.K. and Potter, J. (2021), "Patients or passports? The 'hostile environment' in the NHS", Future Healthcare Journal, Vol. 8 No. 1, pp. 28-30.

Ziersch, A., Walsh, M. and Due, C. (2023), "'Having a good friend, a good neighbour, can help you find yourself': social capital and integration for people from refugee and asylum-seeking backgrounds in Australia", Journal of Ethnic and Migration Studies, Vol. 49 No. 15, pp. 3877-3899.