**Experiences among undocumented migrants accessing primary care in the United Kingdom: a qualitative study**

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# ABSTRACT

**Introduction**

Immigration is a key political issue in the UK. The 2014 Immigration Act includes a number of measures intended to reduce net immigration, including removing the right of non-EEA migrants to access free healthcare. This change risks widening existing health and social inequalities. This study explored the experiences of undocumented migrants trying to access primary care in the UK, their perspectives on proposed access restrictions, and suggestions for policy-makers.

**Methods**

Semi-structured interviews were conducted with sixteen undocumented migrants and four volunteer staff at a charity clinic in London. Inductive thematic analysis drew out major themes.

**Results**

Many undocumented migrants already faced challenges accessing primary care. None of the migrants interviewed said that they would be able to afford charges to access primary care and most said they would have to wait until they were much more unwell and access care through Accident and Emergency services.

**Conclusions**

The consequences of limiting access to primary care, including threats to individual and public health consequences and the additional burden on the National Health Service need to be fully considered by policy-makers. The authors argue that an evidence-based approach would avoid legislation that targets vulnerable groups and provides no obvious economic or societal benefit.

**Running head**

**Undocumented migrant healthcare access**

# INTRODUCTION

In 2012, an estimated 260,300 people migrated to the United Kingdom from outside the European Union (EU) [[1](#_ENREF_1)]. Immigration is high on the domestic political agenda and is already emerging as a key issue in the run-up to the 2015 general election. Entitlement of non-EU visitors to National Health Services (NHS) care is complex. Department of Health guidelines dating from 1999 define those ‘lawfully living in the UK voluntarily and for a settled purpose as part of the regular order of his or her life for the time being’ as ordinarily resident and eligible to free NHS care [[2](#_ENREF_2)]. Categories treated on the same basis as UK citizens include visitors from European Economic Area (EEA) countries (the European Union plus Iceland, Liechtenstein and Norway) and Switzerland, who hold an E128 form, issued by the competent authority in their own country, or experience emergencies while in the UK, as well as refugees who have leave to remain in the UK or are waiting for a decision on their application [[2](#_ENREF_2)]. Those not ordinarily resident in the UK are not eligible for general practice services, except in emergencies or if immediate treatment is necessary. However, the British Medical Association (BMA), representing the medical profession, advises general practitioners (GPs) that they should use their discretion in registering refused asylum seekers, regardless of their residency status, and notes that there is no formal obligation to provide evidence of identity or immigration status [[3](#_ENREF_3)].

The high political profile of immigration caused the UK government to make an explicit commitment to reduce net migration from outside the EEA/Switzerland [[4](#_ENREF_4)]. Measures designed to achieve this are set out in the 2014 Immigration Act, including policies to address what has been termed ‘health tourism’, the phenomenon of people travelling abroad to access healthcare [[4](#_ENREF_4), [5](#_ENREF_5)]. This removes the right of migrants from outside the EEA/Switzerland to access free NHS care and will impose a health surcharge of £150-£200, payable on the issuance of a visa [[6](#_ENREF_6)].

These changes have elicited several major concerns. First, the new provisions risk widening existing inequalities [[7](#_ENREF_7)] by targeting already vulnerable people [[8](#_ENREF_8)], many of whom have worse physical and mental health than settled populations [[9](#_ENREF_9)]. Second, these measures will create an increased administrative burden, as staff will be required to understand patients’ immigration status and may be required to use new information technologies or expensive software [[8](#_ENREF_8)]. It is feared that costs arising from the Act may outweigh potential direct economic benefits, according to the Department of Health’s own figures due to unavoidable administrative burdens [[10](#_ENREF_10)]. Third, health risks to the settled population may increase due to failure to detect and treat communicable diseases. These concerns are supported by evidence from Spain and Greece, where austerity measures have included reductions in access to care for migrants. For example, in Spain one migrant has already died from extensively drug-resistant tuberculosis (XDR-TB) associated with inadequate access to care [[11](#_ENREF_11), [12](#_ENREF_12)] while in Greece cuts to drug prevention and treatment programmes have been associated with an HIV epidemic [[13](#_ENREF_13)].

Research in the UK demonstrates the already considerable barriers faced by migrants even when they are entitled to care, including language barriers, perceptions of healthcare workers, lack of support and information, lack of understanding about the UK healthcare system and fears over deportation [[6](#_ENREF_6)]. Several studies in the UK have included the views of migrants themselves. For example, lack of support, information, and confidence in professional interpreters were identified as barriers to accessing primary care by adult asylum seekers and refugees in a north London walk-in centre [[14](#_ENREF_14)]. Perceived stigma associated with refugee status also adversely impacts help-seeking behaviours [[14](#_ENREF_14)]. Asylum seekers may not understand the NHS, as a study in Glasgow indicated [[15](#_ENREF_15)]. Most were from countries with no primary care system and direct access to specialists, giving them unrealistic expectations of the UK health system [[15](#_ENREF_15)]. Similarly, focus groups in England with seventy migrants from southern Africa indicated that confusion about healthcare entitlements by those seeking and providing care combined with financial and deportation fears caused many migrants to avoid formal services and pursue other less safe options with consequent delays in HIV testing and treatment uptake [[16](#_ENREF_16)].

These studies were undertaken several years ago and the situation is rapidly evolving. Thus, there is little research that relates experiences of undocumented migrants accessing primary care in the UK to the changes required by the 2014 Immigration Act. This paper aims to address this gap by exploring the experiences of undocumented migrants trying to access primary care in the UK, their perspectives on proposed additional restrictions to service access, and recommendations for policy-makers.

# METHODS

## Study design and sampling

A qualitative study design was chosen due to the exploratory nature of the research question and the need for narrative accounts. Undocumented migrants, attending services provided by Doctors of the World UK, were purposively sampled to provide a mix of male and female and countries of origin. Clinic support staff, available during the data collection period, were also invited to participate in interviews by a clinic manager.

Doctors of the World UK was selected as the study base due to its work with vulnerable populations. It is a non-governmental organisation providing medical care, support and advocacy for vulnerable people in east London [[17](#_ENREF_17)]. Service-users are migrants, asylum-seekers, sex workers and homeless people from challenging social backgrounds, most of whom have experienced difficulties accessing NHS services. Countries of origin include Afghanistan, Bangladesh, Brazil, China, India, the Philippines, Romania, Sri Lanka and Uganda [[18](#_ENREF_18)].

## Data collection and analysis

The semi-structured question guide was developed based on the literature and using a temporal framework that considers past, present and future experiences of migration and healthcare by participants. Interviews were conducted during June and July 2014 and lasted an average of thirty minutes each. Participants were asked about their decision to migrate, living situation in the UK and experiences accessing health care. An informal interviewing approach was used to encourage participants to share their perspectives and experiences. Professional interpreters were not used, but two participants who did not speak English had a friend or support worker translate.

Thematic analysis was used to identify data themes inductively [[19](#_ENREF_19)]. NVivo 10 was used to code and organise data. Categories and themes were not decided prior to coding, but instead induced from the data itself [[19](#_ENREF_19)]. Notes on each line of transcripts were organised into major categories. Next, selective coding was used once major themes had emerged [[20](#_ENREF_20)]. This involved repeatedly verifying themes after re-checking transcribed data [[21](#_ENREF_21)]. Coding finished when authors were satisfied that analysis was producing no new codes or categories and all data were accounted for in core themes [[22](#_ENREF_22)]. To confirm saturation, authors identified opinions that fit the majority and deviant cases that produced exceptions. Finally, authors compared emergent themes with the existing literature and relevant frameworks to improve validity [[23](#_ENREF_23)]. Agreements and disagreements with existing evidence were addressed through author discussion.

## Ethics

Given the sensitivity of the topic and participants’ immigration status, researchers emphasised that participation was anonymous and confidential and participants did not need to share any uncomfortable information. An information sheet, outlining study aims, confidentiality, anonymity, audio-recording and dissemination, was provided and explained to all participants and written informed consent obtained. All audio recordings and transcripts were identified and linked by pseudonym to ensure anonymity and stored securely in password-protected files to ensure confidentiality. Ethics approval was provided by the Research Ethics Committee of the London School of Hygiene and Tropical Medicine.

# Results

Twenty face-to-face semi-structured interviews were conducted, sixteen with undocumented migrant service-users and four with volunteer social support staff. Table 1 shows gender and country of origin for undocumented migrant participants.

[Table 1 about here]

Findings are categorised under three headings, with responses of migrant and staff participants reported separately. First, *migration experiences*, includes reasons for migration and social situation in the UK (e.g. accommodation, finance, support). Second, *accessing healthcare*, focuses on migrants’ awareness of health rights and trying to register with a GP. Third, *implications for policy and practice* includes migrant and volunteer perspectives on potential effects of policy changes and related recommendations. Finally, a *case study* brings together the factors affecting the undocumented migrant healthcare experience in the UK.

## 

## Migration experiences

*Reasons for migrating to the UK*

Most migrant participants said they came to the UK for financial reasons, such as escaping deprivation or seeking education, employment and a ‘better life’. Some had financial burdens placed on them by family members who were sick or unable to work, as a woman from the Philippines explained:

“I decided to stay because my father got sick back home, so we need to support financially. It’s lung cancer, and in the Philippines there is no free medications and everything, so he is staying another fourteen months but then he passed away. And of course there is a lot of debt that we need to pay and ……you cannot earn a living back home.” (13F)

Staff participants described additional reasons reported by migrants with whom they had worked, including violence and human rights abuses. As a support worker explained:

“We’ve had a few cases of people coming from areas of conflict, or for example, we’ve had cases of people from Uganda coming from very dangerous situations and managed to escape. There have also been a couple of cases where there have been direct conflict issues or people who have been worried about being recruited to join conflict forces, who have been able to move out of that situation.”(11M)

*Social situation in the UK*

Most migrant participants continued to face deprivation, without financial support or regular employment, despite their plans for a better life. With inadequate finances, many relied on friends or associates for accommodation. This was often temporary, leading to a transient lifestyle, moving from one place to another without any feeling of belonging or having a home. Some described crowded accommodation, such as an Indian man describing the house in which he lived in London:

Interviewer: Do you live with other people too?

Migrant: There are other people, but we don’t know each other

Interviewer: How many people in the house?

Migrant: I don’t know, we just move in, a lot, about eleven or twelve

Interviewer: Really? How many rooms?

Migrant: Five or six (17-18M)

## 

Support workers reported witnessing similar deprivation among undocumented migrants they sought to help. Most undocumented migrants were reported as living below the UK poverty line. A staff participant described how many of the migrants he supports work illegally for cash in manual labour or the sex trade.

“A lot of them are working, but for cash. We get a lot of sex workers, and general handymen who do side jobs. I think the stat was that over 90% are under the poverty line.”(10M)

**Accessing healthcare**

*Awareness of health rights*

In the UK, asylum seekers and refugees are entitled to register with a GP, although in practice, GPs use their discretion as to whether they will register individuals unable to provide formal proof of identification or address. Accident & Emergency (A&E) services are free to anyone, regardless of immigration status, excluding treatment provided after the patient has been admitted [[3](#_ENREF_3)]. However, migrants interviewed had poor knowledge of their health rights in the UK. Most did not know they could access primary care without payment. A woman from Uganda stated that not only was she unsure of whether healthcare was available without charge, she also believed that migrants were not allowed to access health services even if they were able to pay charges.

“What I knew is that we didn’t have any chance of getting anything, whether we pay or not, when you are illegal here you don’t have any chance of getting those things. So I never tried.”(12F)

Despite most migrants interviewed not being aware of their rights to primary care, many did know they could receive emergency treatment through A&E departments. The knowledge that A&E services were free led many to consider A&E as the first place to seek medical attention rather than seeking primary care from GPs, as stated by a man from Vietnam:

Interviewer: And what do you know about healthcare in the UK? What do you understand your rights are?

Interpreter: He doesn’t know

Interviewer: If he did need to go and see a doctor does he have any ideas about how he would do that?

Interpreter: He doesn’t know

Interviewer: So what would he do if he had a health problem that he thought needed a doctor’s opinion?

Interpreter: A&E (5M)

## Staff described talking to GP staff who were unfamiliar with healthcare entitlements for migrants and trying to help undocumented migrants worried about deportation or other punishments for trying to access healthcare.

Registering with a GP

Migrant experiences of registering with a GP were mixed. Many described negative experiences of practice staff demanding excessive documentation:

Interviewer: Did you try going to the GP?

Migrant: Yeah I tried, going in my area, all GP’s, but no one was helping.

Interviewer: What did they say?

Migrant: I have to prove my identity, at least one photo, and a letter, or a bill from where I live.

Interviewer: And how did you feel when they said that?

Migrant: Bad because I needed medical attention, very much. (7-8M)

One migrant described how a friend was refused GP registration even though he presented a passport. This was an exceptional case amongst participants. He also talked about inconsistencies between requirements in different practices, which, combined with language barriers created a sense of confusion and helplessness:

Migrant: So before that he went different places and everybody said some kind of different that, “we need that, we need that” and he was just sent from one place to another

Interviewer: It makes it quite difficult

Migrant: Especially when you don’t speak English. (7-8M)

## Implications for policy and practice

All migrants reported being unable to afford to access primary care if the proposed charges were introduced, due to a lack of financial support or regular income. Many migrants interviewed expressed concerns about the effects the introduction of charges for primary care would have on their health. One migrant participant discussed how he already had little money and was struggling to get by, so an added charge for healthcare would be impossible.

Interviewer: And if things did get harder for people like you to see a doctor for example.., how do you think that would affect you?

Migrant: Very much, because I’m always short of money anyway.

Interviewer: … do you think it would be difficult to find money to pay for healthcare?

Migrant: Yeah, cos if you don’t have benefits and you don’t work….”(7-8M)

Staff interviewed highlighted the potential impact of user charges for migrants on public health, including the spread of infectious diseases and the impact on emergency departments if migrants are left without adequate primary care.

“And you will go to A&E when you are really ill won’t you? So it’s waiting until it’s too late…. I don’t know if they think they’re saving money, but I don’t know how much they’re going to save because so many people are going to get sick.”(20F)

When considering policy recommendations, most interviewees expressed a wish for more free clinics, such as those run by non-governmental organisations including Doctors of the World. Many vulnerable migrants see the Doctors of the World clinic as the only place they can trust and obtain support to register with a GP, but illiteracy and limited access to the internet can prevent some from receiving any support at all.

“I want them to have more maybe, like, where I live, it’s difficult for me....there is no….your branch is here, but in Islington, maybe they can give us somewhere in north London as well, because some people need it as well, and some people they are illiterate, they don’t know how to read and see the website, so like that, improve more, that kind of society, this group, that’s all I can say.” (4F)

Staff interviewed advocated better training for general practice staff on existing guidelines for migrant healthcare access and working to change attitudes towards undocumented migrants so that healthcare experiences for migrants in the UK could be improved. This staff member highlighted the stigma that some practice staff associate with undocumented migrants and how this can affect the experience of registering with a GP:

“A lot of people in professional positions don’t understand the policy in place. So lack of communication, that’s one of our biggest issues. And there’s just a huge stigma for people who are undocumented or people who are trafficked into this country.” (10M)

## 

## Case study

The story of one of the migrants interviewed highlights the interdependency of barriers and enabling factors for migrants accessing primary care. A middle-aged woman from Uganda moved to the UK in 2002 after being separated from her exiled family. She travelled with a group of migrants and has since been living illegally in London. After years of moving from place to place she now lives in a one bedroom flat with a friend and the friend’s sons, relying on cash handouts to survive. She has only begun accessing medical care in the last year, after hearing about Doctors of the World UK from a friend. Previously, she was too afraid to try to register with a GP and believed she had no entitlement to care. When she finally came to the Doctors of the World clinic she was found to have very high blood pressure, almost requiring admission because it had been left untreated and risen to a dangerous level:

*“When you have something and it is not treated, even if it is treated after a long time, then it is too late. Like when I came here and my pressure was high, I was so scared when the lady said I want you admitted*.” (12F)

Staff helped her to find a GP and, although the experience was difficult at first, she is now happy with the care she receives. She is certain she would not be able to afford to pay charges for primary care and is scared about the potential consequences of delayed treatment. She recommended that everyone should receive free access to primary care as, in her words, “*If there is someone who needs treatment they should offer it, because it is important regardless of what you are, whether you are a citizen or not.*” (12F)

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# Discussion

This study contributes the perspectives of undocumented migrants and non-governmental staff working closely with them, on access to primary care in the UK to the debate on the planned introduction of NHS charges. Most migrants left difficult circumstances to seek a better life. Doctors of the World data from 2013 shows that 36% of their service-users reported political, religious, ethnic, and sexuality discrimination, or fleeing from violent political conflicts as reasons for coming to the UK, while 37% reported primarily economic reasons [[24](#_ENREF_24)]. Yet many are living in hardship in the UK, with poor access to information and little understanding of their healthcare entitlements.

Many migrants already face challenges accessing primary care, due to limited understanding of current guidance on access to care by practice staff and inconsistencies in practice requirements. Participants described similar negative experiences when trying to register with a GP, including inappropriate requests for paperwork, inconsistencies between practices and language difficulties when communicating with practice staff. Despite poor information and fears, most migrants understood that they could access free emergency treatment from A&E services. This, coupled with concerns about registering with a GP, led many to consider A&E the most suitable option for accessing healthcare in the UK.

None of the migrants interviewed indicated they would be able to afford charges to access primary care. Many suggested they were resigned to having to wait to access care when they were much more unwell and could use A&E services. In 2013, Doctors of the World conducted 1,044 social and medical consultations at its London clinic, with 1 in 4 of those attending having been denied healthcare elsewhere [[24](#_ENREF_24)]. Many migrant participants reported that the Doctors of the World clinic was the only place they could gain support to register with a GP. Staff highlighted the potential consequences for already overstretched emergency departments of having to manage poorly-treated infectious diseases and chronic health conditions, raising the question of whether significant health system savings could ever be made if migrants delayed treatment until they had more serious and complex conditions.

These findings support existing findings from literature on health and access to care for undocumented migrants, described as a ‘vulnerable and easily scapegoated group’ [[6](#_ENREF_6), [25](#_ENREF_25)]. Akhavan and Karlsen identified perceived inequalities and discrimination against migrants and their perceived powerlessness over their own health in Sweden, which resonates particularly with migrants in this study given misinformation about primary care access or with negative experiences of treatment by GP staff when trying to register [[26](#_ENREF_26)]. Studies in the UK also found a lack of knowledge about health rights and entitlements and insufficient language skills among migrants and providers, raised by many of the undocumented migrants interviewed, particularly when trying to register with a GP[[14](#_ENREF_14), [16](#_ENREF_16)]. Financial concerns and fears over deportation leading to avoidance of formal health services and pursuit of less safe options [[14](#_ENREF_14), [16](#_ENREF_16)]. Findings of this study were not consistent with those of Aung *et al*, who found poor primary care usage by Burmese migrants in London due to dissatisfaction with services [[27](#_ENREF_27)]. These findings suggest that once registered, migrants were happy with the care they received from clinicians.

These findings support concerns that further restrictions on access may increase public health risks and costs to the NHS [[6](#_ENREF_6), [28](#_ENREF_28)]. Concerns about risks of infectious disease increases were highlighted by Steele *et al’s* description of increasing infectious disease rates and worsening non-communicable disease outcomes in Spain and Greece following restrictions to healthcare access for migrants [[8](#_ENREF_8), [11](#_ENREF_11), [13](#_ENREF_13)]. The concerns expressed by undocumented migrants interviewed in those countries that they could not afford to pay to for preventive primary care and would instead wait till their condition became too severe to ignore suggests that this could become a greater problem in the UK.

The findings do not support arguments by supporters of the 2014 Immigration Act that it will reduce systematic abuse of the health system. Hanefeld *et al,* in the largest study of medical tourism so far, showed that those who travel to the UK for medical treatment are overwhelmingly those seeking expensive private procedures that generate substantial income (7% of patients generated 25% of private income)[[28](#_ENREF_28)]. Undocumented migrants interviewed in this study were consistent with Hanefeld’s findings, as none had travelled to the UK to access free medical care and the vast majority were not even aware that they were entitled to primary care.

## 

Increasing immigration poses real challenges to the NHS, and more research on migrant health and access to care is needed to inform effective policy [[25](#_ENREF_25)]. For example, comparison of a larger sample of undocumented migrants in different countries or regions, a longitudinal study to assess experiences and health outcomes among undocumented migrants after implementation of the 2014 Immigration Act, and research on the effects on national disease and financial burdens of restricted preventative care would all be important.

Inevitably, this study has some limitations. These relate to location, language, and time. The study was conducted at one clinic in London and experiences from undocumented migrants living outside of London may differ. Interviews only included migrants who spoke English, or had someone with them who could translate, thus excluding the views of migrants unable to communicate in in English. This group could be more vulnerable or report more negative experiences than our sample. Its strengths include access to undocumented migrants who had difficulty accessing primary care in the UK. In 2013 Doctors of the World conducted 1044 social and medical consultations at their London clinic. 91% were living below the poverty line and 90% were not registered with a GP. 1 in 4 had been denied access to healthcare [[29](#_ENREF_29)]. Using the Doctors of the World clinic as a setting for our study gave us access to this vulnerable group who will be affected by government proposals to restrict access to care. Working with Doctors of the World also gave us access to staff who were regularly working with migrants of different backgrounds and were able to give us their perspective on the proposed changes.

## CONCLUSION

Undocumented migrants are a vulnerable group in the UK, requiring support rather than isolation. Existing guidance on access to care for all migrants needs to be clearer and more accessible. Staff working in primary care need better training on government guidance and regulations. Additionally, policy-makers need to examine the financial consequences of limiting access to primary care among migrants, as less preventative treatment can be expected to lead to migrants presenting to secondary care with more serious complications and a greater financial burden on the NHS. The authors hope that additional evidence will encourage a shift away from legislation that targets vulnerable groups.

**Conflicts of interest**

None declared.

**Author contributions**

SP conducted interviews, coded and analysed data, and prepared the manuscript. NH contributed to supervision and data interpretation, and critically reviewed the manuscript. LJ and PM contributed to study conceptualisation, recruited and provided information to interviewees, and critically reviewed the manuscript. MM contributed to data interpretation and context, and critically reviewed the manuscript. HLQ supervised the study, conducted interviews, contributed to data analysis and interpretation, and critically reviewed the manuscript. All authors approved the version for submission.

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**Table 1: Migrant participants’ gender and country of origin**

|  |  |  |  |
| --- | --- | --- | --- |
| **Country of Origin** | **Male** | **Female** | **Total** |
| **Belarus** | 1 | 0 | 1 |
| **Brazil** | 0 | 1 | 1 |
| **Ghana** | 1 | 0 | 1 |
| **India** | 4 | 1 | 5 |
| **Moldova** | 1 | 0 | 1 |
| **Philippines** | 0 | 2 | 2 |
| **Sierra Leone** | 1 | 0 | 1 |
| **Uganda** | 0 | 3 | 3 |
| **Vietnam** | 1 | 0 | 1 |
| **Total** | **9** | **7** | **16** |