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What are the experiences
of vulnerable migrants
when accessing
secondary healthcare in
the United Kingdom?

A qualitative study on the impact of health- related
charging and cost recovery programs on access to
secondary care in migrants at the Doctors of the World
clinic in London, England

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ABSTRACT

Introduction

Levels of forced migration globally are greater than at any other point in recorded history, with more than 60 million people forcibly displaced from their homes in 2015.^{1,2} To respond to this 'migration crisis' the British government introduced the new Immigration Act in 2014 which alongside it's Cost Recovery Programme, aimed to recoup costs of healthcare from those with no recourse to public funds; and to highlight those who are not eligible for national services.^{3,4,5} This study explores the experiences of vulnerable migrants when seeking secondary health care, to establish the part of the impact that these new legislative changes have had.

Methods

This study took a qualitative design through thematic analysis of primary and secondary data sources. Data review of Doctors of the World case notes and ten interviews with migrant service users, healthcare professionals and advocacy workers were analysed within the framework of the biopsychosocial model of health.⁶

Results

Fears over denunciation to the Home Office and incurring health related costs resulted in significant delays in accessing secondary healthcare. This in turn increased avoidance of planned consultations and use of emergency services. These deterrent and displacement effects had significant negative impacts on migrants' physical, psychological and social well-being.

Conclusion

This legislation significantly impacts vulnerable migrants' health and is likely to widen the gap of health inequalities. The focus on upfront charging and denunciation causes delayed access to healthcare and are more likely to result in the displacement of healthcare access to the emergency services.

The active role of healthcare professionals in data sharing with immigration officials and in 'chargeability' assessments is still highly contentious.

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1. BACKGROUND AND CONTEXT

1.1 Introduction

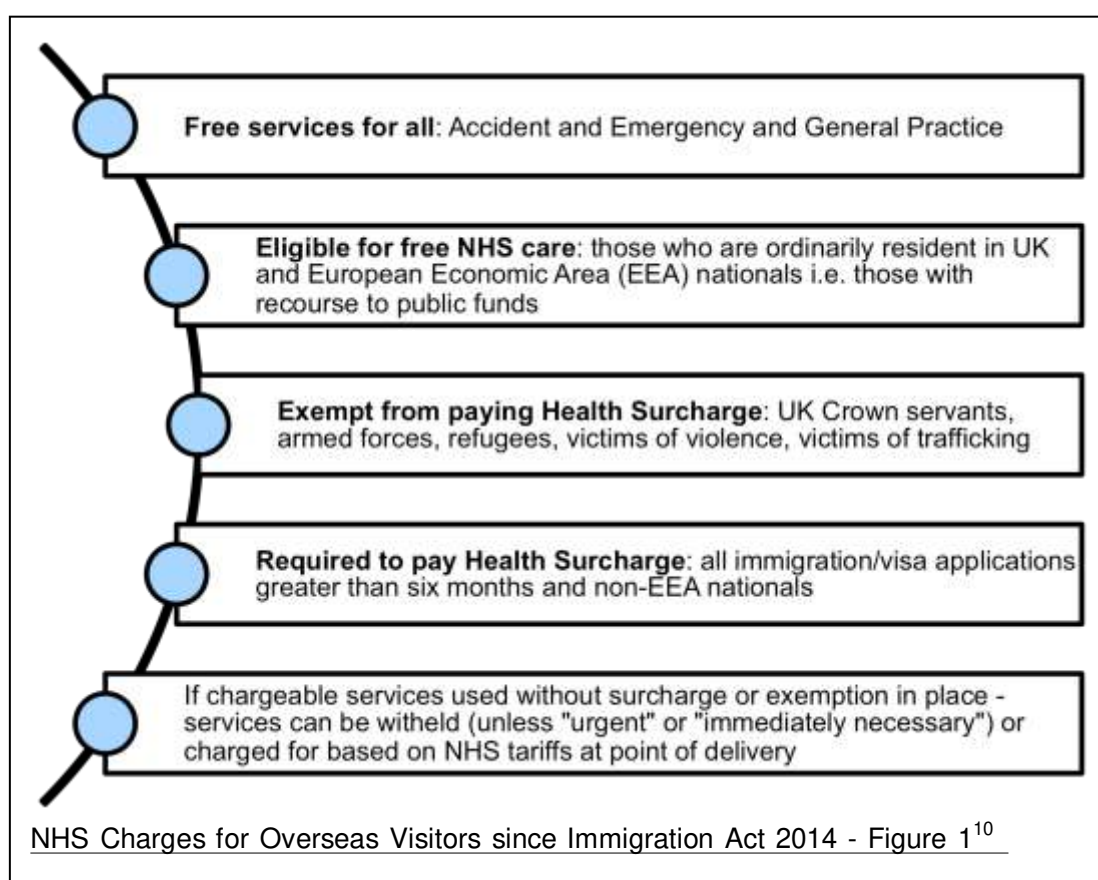
This research paper explores the experiences of migrants in London when accessing NHS secondary healthcare in the context of the ‘hostile environment’ for undocumented migrants in the UK created by recent legislative changes, notably the Immigration Act 2014 and associated regulations which have expanded and reinforced the charges levied in NHS hospitals to most migrants who are not considered ‘ordinarily resident’ in the country.⁴ It has been devised in response to a call for further research in a recent Government-commissioned Ipsos Mori impact assessment of health policy changes for migrants in Britain.⁷

1.2 Migration and British Health Policy

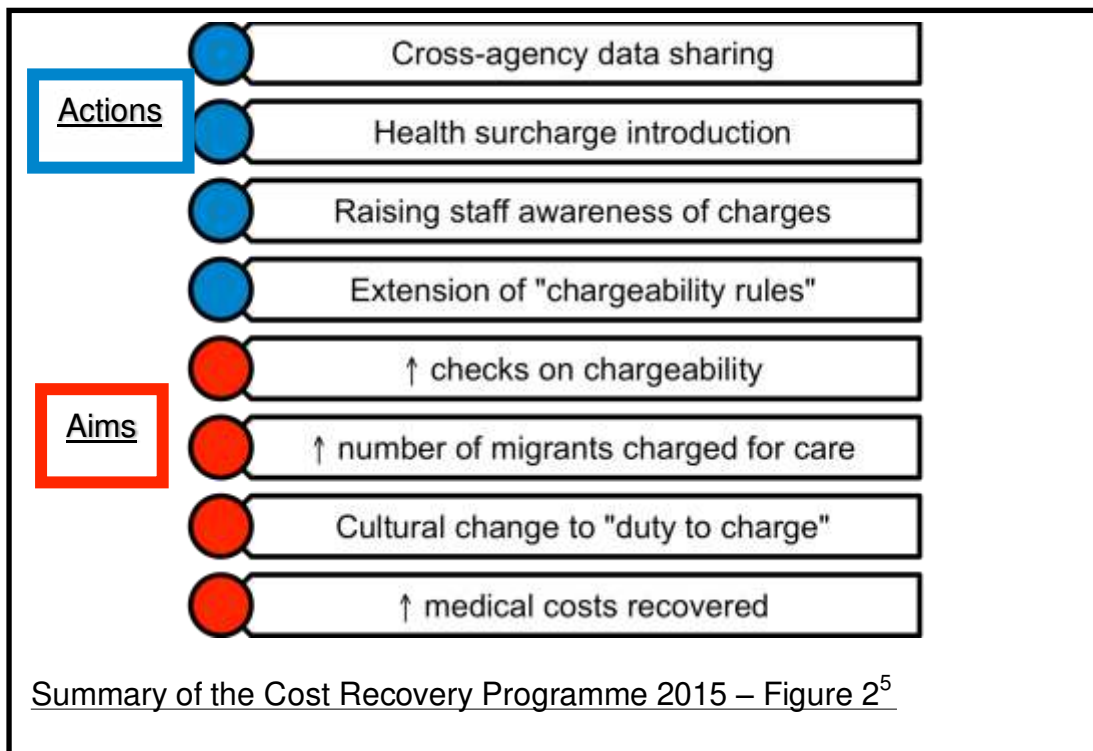
Current levels of migration are greater than during any other point recorded in history, with the World Health Organisation (WHO) estimating that one in seven of the world’s population has migrated from place of birth. Although most of this migration occurs for economic reasons, levels of forcible displacement as the result of conflict, natural disaster and persecution are ever increasing and exceeded 60 million people in 2015. This mobile community of forcibly displaced persons are notably more vulnerable: experiencing higher rates of mental illness, poverty, fertility and destitution than the native population of their host communities.⁸ Therefore, they present complexities to host governments who must balance the health and social needs of both permanent residents and the migrating population.

Countries approach this dilemma in numerous ways, particularly with regards to health. A variety of policy approaches exist, from countries such as Malta, who have no legally-binding requirement to provide healthcare (except in detention centres); to the Netherlands where all healthcare is freely accessible to undocumented migrants providing it is “medically necessary”, and valid proof of lack of funds exist.⁹ The United Kingdom’s (UK) policies sit between these two extremes.

In Britain, the introduction of the Immigration Act in 2014 and subsequent associated Regulations marked a change in immigration policy and health provision for the migrant population.¹⁰ The rights to National Health Service (NHS) care for migrants who are “not ordinarily resident” in the UK changed: with the introduction of an annual surcharge and then further fees and limitations on the availability of secondary care for some groups.⁴ These changes are described in Figure 1.



These changes increased the potential scale of financial ramifications for healthcare use, for those with no recourse to public funds (NRPF).¹¹ Further, in 2015 the UK government introduced the ‘Cost Recovery Programme’ (CRP) to “ensure that the NHS receives a fair contribution for the cost of healthcare it provides.”⁵ This programme focuses on improvement in identifying ‘chargeable patients,’ enforcement of the health surcharge and in the organisation of cost recovery - this is summarised in Figure 2.⁷



The introduction of the CRP and the legislative changes were met with concern from the professional community, about the potential for the “[widening of] the gap of health inequalities” in vulnerable migrant populations.¹² To review these concerns and the progress towards the £500 million reclamation aim of the CRP, an independent Ipsos Mori review occurred in February 2017, and raised the call to research that this paper responds to.⁷

The main findings of the Ipsos Mori review focussed on the economic aims and institutional changes that the Programme had delivered. However, their assessment of the impact of the CRP on migrants found that there was not “any evidence of... significant negative impacts,” but also encouraged the future “widespread appraisal of... unintended consequences.”⁷ This finding is contrary to the current body of literature on the effect of healthcare charges on migrants access to treatment – especially with regards to out-of-pocket payments and to the impacts of debt on health. Indebtedness has been found to impact mental health, suicidality, physical health and well-being.^{13,14} In this context, this paper aims to explore the impacts of the CRP on migrants in the UK in order to establish a greater understanding of the experiences of those most affected by it.

1.3 Health and Migration – the Global Picture

Although this study is concerned with migrant communities within the UK, the proportion of migrating populations who move to developed countries is significantly smaller than those moving to less economically developed areas. Indeed, estimates suggest that 85% of forced displacement occurs to less developed neighbouring countries instead of their more economically developed regions further afield.¹ This results in countries with less infrastructure and resources taking on large numbers of people into already stretched health systems. In these situations, many forcibly displaced people - whether it during internal or international displacement- do not have access to basic shelter, healthcare or safety as per their human right.¹⁵

The United Nations High Commissioner for Refugees (UNHCR) has aimed to protect these basic needs through the 1951 Refugee Convention and the subsequent protection for those with ‘refugee status.’¹⁶ However even with current levels of forcible displacement, those with refugee status make up less than one third of the total – and therefore most do not have access to the protective mechanisms in place for refugees. It is the remaining two thirds of displaced migrants for whom human rights conventions are the only protection in their host communities.¹⁷

Within host communities, governments may consider undocumented migrants (those without asylum, visa or refugee status) to be the rightful recipients of a “moral economy” in line with humanitarian principles.¹⁸ However, these humanitarian obligations can be considered conflicting with the receiving countries’ needs: reducing the burden on public service budgets; and protecting their native population from any importable disease threats.¹⁹ Thus undocumented migrants have been considered as being in a “legal limbo:” with access to basic services being “severely limited” across most European Union (EU) member states.²⁰

This paper will focus on vulnerable migrants: defined as those migrants who were either undocumented, refugee, seeking asylum, or trafficked – those who are more susceptible to isolation and marginalization in terms of healthcare.²¹ Globally, it is this population who have been shown to suffer from significant

health inequalities in comparison to their host communities.^{22, 23}

1.4 Recognised Barriers to Healthcare in Migrant Population

Before investigating any barriers to healthcare that the vulnerable migrant population may experience due to the implementation of charges in NHS hospitals, it is important to understand the barriers that were already in place. These barriers are described as either ‘formal’ -such as a lack of translating abilities or information on services available; or ‘informal’ - usually encompassing prejudiced actions, poor communication or complex application forms.²⁷

Most of the literature on barriers are focused on the access to primary care, with limited evaluation in the UK of access to secondary care (i.e. hospital) services. Obstetric outcomes are the main exception to this, with significant research into the poorer morbidity and perinatal mortality that are associated with migrant groups. This research indicates that barriers to improving perinatal outcomes are due to medical, psychological and social predispositions and that they must be approached holistically to make measurable change.²⁸

Another crucial area for barriers to migrant health equity is the role of external bodies such as government agencies. The controversial struggle between media claims of migrant ‘health tourism’ and the “humanitarian obligation” to provide care is often compounded by threats of immigration agencies.^{29,30} The evidence of fears of denunciation of migrants’ to immigration authorities during access to health care is increasing – a topic particularly relevant to the CRP in the UK, due to the datasharing that occurs between the NHS and the Home Office for the purposes of immigration enforcement.^{31,32, 33}

1.5 Impact of financial crises on health

Although the exact means by which people pay for healthcare is vastly different internationally, the literature about this issue is fundamentally in agreement. Debt and poverty are situations which put individuals and families at risk of significant morbidity in health and mental wellbeing. A cohesive systematic review found that being in debt increases risk of alcohol and drug misuse,

depression, anxiety and suicidal ideation, along with greater rates of marital breakdown and domestic violence.¹⁵ This is echoed with literature done on catastrophic spending on health by the WHO, finding that if healthcare costs drive individuals below the poverty line, they have significantly less social mobility, education and health than their peers.¹³

1.6 Assessing Health and Wellbeing

With such extensive evidence in the global arena of the morbidity associated with poverty and health-related debt, the absence of negative impacts of charging on migrant patients suggested by the Ipsos Mori study is surprising and indeed raises a number of questions. This study aims to evaluate the experiences and needs of migrants within the UK when facing healthcare related costs and the increasing links between the health service and the Home Office.^{33,34}

2 REFLECTIVE METHODOLOGY AND RESEARCH QUESTION

2.1 Study Design

This research takes a phenomenological perspective to understand the experiences of migrants who attended the Doctors of the World (DOTW) clinic in East London when seeking secondary health care, with a particular focus on the impact of healthcare costs.³⁵

Experiences of migrants were explored via semi-structured interviews, and secondary data analysis of historical case notes from the DOTW service user database. Ethical approval was gained both from King's College London and from the DOTW ethics board.

To enable a thorough assessment of the participants' health and wellbeing, literature was consulted about different tools of assessment. Objective measures of pre- and post-morbid status based on disability adjusted life years (DALY's), socioeconomic status and mental health assessment are well-recognised models used by global health conglomerates.²⁵ However this approach is not only time- and cost-intensive within the limits of this study, but would also require national statistics on a population who are by definition often 'undocumented' and outside of national data. Instead, the subjective self-reported status of health and wellbeing was used as a marker – as this has also been well validated by the literature.^{36, 37}

Data was collected on the key areas leading to good health related quality of life that have been implicated in work on the 'healthy immigrant effect:' security in food and shelter, poverty and health.^{38, 39} By focusing on these four areas, we aimed to establish a holistic picture of the service user's wellbeing. The data collection was thus framed around a 'biopsychosocial model' which formed the conceptual framework.⁶ Through this model of conceptualising migrant wellbeing -assessing biological health status, psychological well-being and social security- a holistic assessment was created, in keeping with previously written works on this subject.

2.2 Research Question

The aim of this research is to understand the experiences and needs of migrants when seeking chargeable secondary healthcare in the UK. As the barriers to seeking primary care are well documented in this population, the study will focus on the limitations found beyond this point. To explore the main question in more detail the following separate research questions were posed based on literature review and around the conceptual 'biopsychosocial' framework:

- What is the role of the community/family/friends in access to health?
- What are the physical and psychological effects of charges/debts?
- What is the role of denunciation in health seeking behaviour?

2.3 Participants

The population studied were service users who have attended the DOTW clinic in Bethnal Green between April 2016 and April 2017. This time frame was chosen to include migrant populations who would have been affected by the Immigration Act 2014.⁴ From this one-year period, 2008 people registered with the DOTW clinic that could be considered as 'migrants' (i.e. the UK was not their country of birth). These notes were interrogated for their demographic data and self-reported health and wellbeing status. These demographics were then able to be contrasted with comparable literature to assess the representability of the sample taken against other developed backgrounds. For this research the migrant population studied will be referred to as either participants or service users interchangeably.

Migrants attending the DOTW clinic were chosen as the subject of the research as there was a wealth of previously collected data for which there was pre-existing consent for use in research. However, a significant limitation of using this population in the research was that by the nature of being a population presenting to the advocacy group, they are likely to be less vulnerable and less limited in their ability to seek healthcare.⁴⁰ Yet as this is the first paper in the found literature to explore experiences in British secondary healthcare in this way, the information was considered valuable, albeit potentially less likely to capture the most vulnerable members of the migrant population.

To be included in the study the service user must be over the age of 18 at time of first presentation, and having migrated from country of origin to the UK. Service users were included in the study regardless of their eligibility for public funds, as firstly questions about specific immigration status can incite fear and be prohibitive in rapport building.²¹

2.4 Data Collection

From the 2008 migrant service users registered at the DOTW clinic, descriptive demographic data was gleaned about age, gender, country of origin and self-reported health. This was assessed from discrete case note data using the WHO's definition of good health being good "physical, social and mental well-being."⁴¹ This demographic data enabled a comparison of the migrant population in DOTW clinics to the wider population in the UK and highlighted inherent vulnerabilities, as described in the literature.^{22, 23, 27,28, 32} Self-reported health was used as a discriminator of health status, as it has been found to have a strong correlation with morbidity data.^{36,}

37, 42, 43

2.4.1 Secondary Source Data Collection

The 2008 case notes from April 2016 to April 2017 were anonymised and searched for keyword terms to highlight a population who may have been affected by health-related payments. Keywords were identified through a snowballing approach: where basic keywords were built on by reading case notes and finding new relevant terms. Examples of these searches are displayed in the table below. The use of this snowball method of keyword searches enabled the inclusion of unexpected abbreviations, culturally specific terms and new routes of enquiry – this is seen in Table 1.

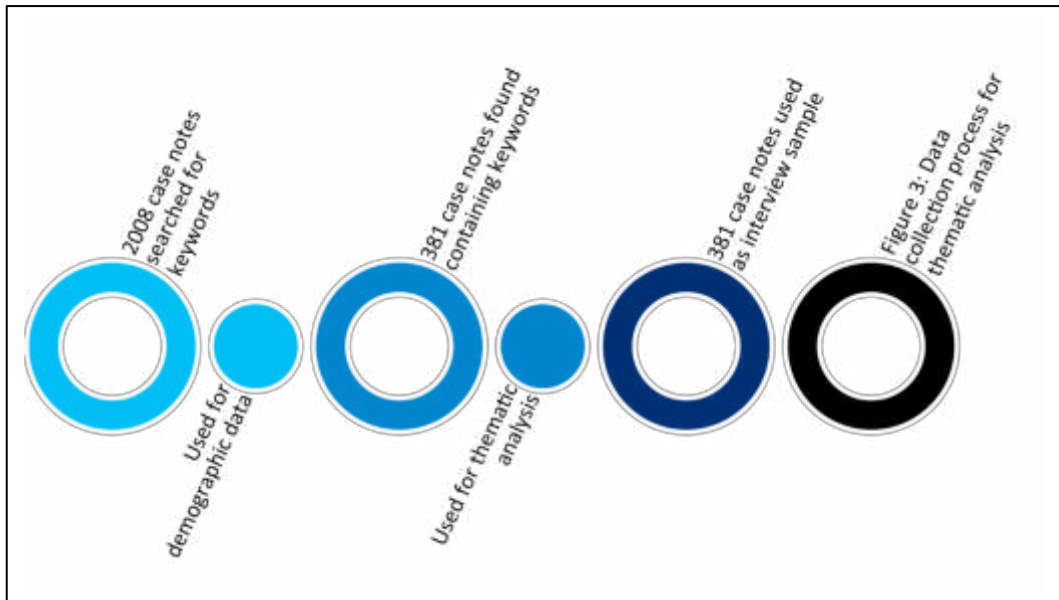
Search 1	Search 2	Search 3
Bill(s/ing) Antenatal Charge(s/ing) Hospital(s) Outpatients Debt(s) Cost(s)	Home Office ANC Scan(s) Consultant(s) Scared Fear With child	HO Ante-natal Cancer Treatment Diagnosed

The case notes that contained keywords related to health-care charging were then read and assessed for relevance. To be included, each case study must have previously consented to DOTW's data sharing and research policy, and be in keeping with one of the following inclusion criteria:

- Person had been seen in, considered for, or referred to secondary care for treatment or diagnosis
- Person had altered health seeking behaviour based on charges or fear of charges
- Person had been in receipt of healthcare-related bills or affected by out-of-pocket payments in the United Kingdom.

The included case notes were then used for in depth secondary data analysis, and were then considered as potential interviewees. This process is summarised in figure 3.

Figure 3: Data collection process for thematic analysis



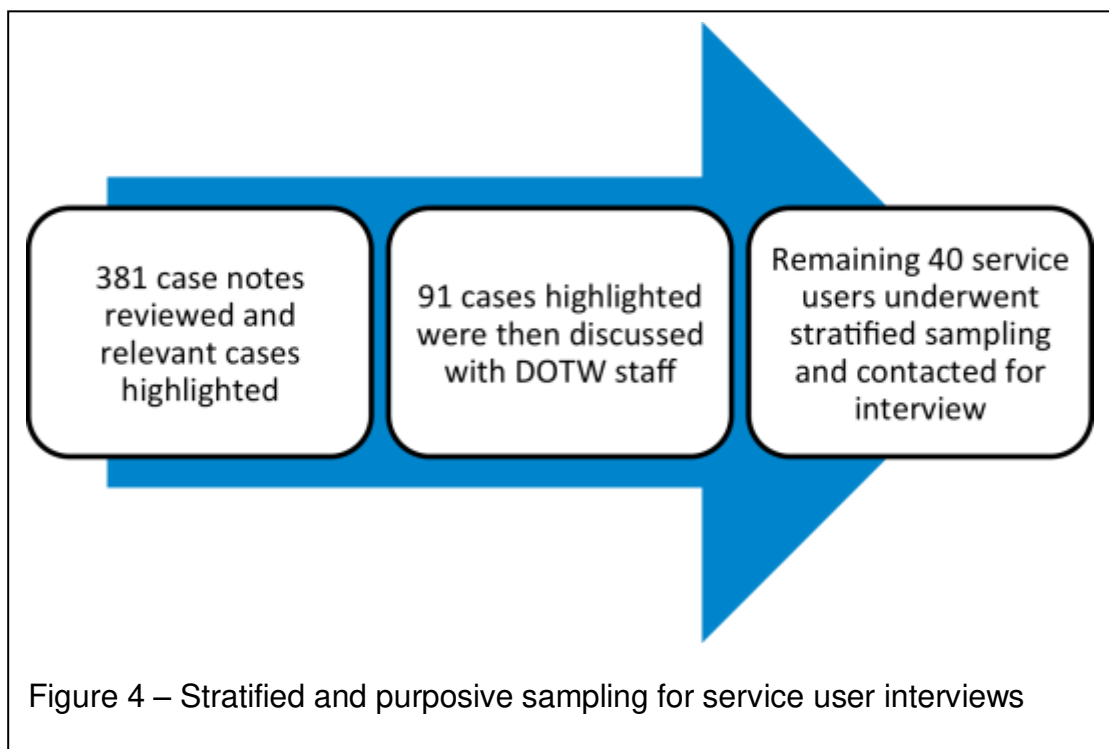
2.4.2 Primary Source Data Collection

Primary data collection was via semi-structured interviews from service users highlighted by case note keyword searches. Interviews were also held with DOTW volunteers and staff, including GPs working in the clinic.

Service users to be approached for interview needed to fulfil the additional criteria below:

- Capable of giving informed consent to take part in interview;
- Able to be contacted via telephone with an appropriate language interpreter;
- Aged 18 or over.

Following the shortlisting of potential participants (91/381), case files were read and discussed with DOTW staff members to exclude further cases due to recent changes in capacity to consent, or specific vulnerabilities. The remaining 40 people then underwent stratified sampling to provide a representative mixture of age, gender and country of origin. In total six telephone interviews were conducted with service users. This is summarised in figure 4.



Interviews were semi-structured and were conducted from the DOTW premises to ensure confidentiality and security for service users. The questions were based around the biopsychosocial model to enable holistic considerations of wellbeing, and extended to cover the research questions posed above. The questions which formed the foundation of the interviews can be found in Appendix 1.

Interviews were also held with two DOTW staff members and three General Practitioners (GPs) who worked regularly in the DOTW clinic. A debt advice service that serves the migrant community of London, and local 'Overseas and Visitor Hospital Managers' (OVHMs) -those that manage the CRP within hospital trusts- were contacted to obtain interviews, but all declined

involvement.

The interviews were all conducted over the telephone excepting one of the staff member interviews from DOTW which was conducted face to face. Interviews were audio-recorded, transcribed and underwent thematic analysis through the use of NVivo10 software.

2.5 Analysis of Research Methods

The conceptual framework of the biopsychosocial model enabled the research to explore the areas detailed in the WHO's definition of good health.⁴¹ The use of self-reported health status is well described as a validated means to assess physical and psychological wellbeing.^{36, 37, 42, 43} However the limitation of this method, lies firstly in the way in which the questions are asked and the possibility of social desirability bias. Work done by the Office of National Statistics show that in self-reporting of health outcomes, if questions were asked by governmental body, results of psychological health –particularly from women– were often skewed.⁴² Secondly, although helpful for holistic assessment of health and wellbeing, this qualitative method of investigating experiences falls short of quantifying changes in morbidity or mortality associated with access to secondary care.

In using the same data set to perform content analysis and to extract potential interview candidates, certain biases are inevitably included. As with all secondary source analysis, bias is held in the hands of those who collect the information and the accuracy with which they record it. Thus, before considering the use of this data set, the training that DOTW volunteers undergo was assessed through active participation to ensure that data was being collected by individuals in an objective manner. The researcher was confident in the time given to service users to express information, the use of appropriate translators and the reliability of data recorded. These actions minimised bias in the secondary source data. Examples of the forms used to record case note data that was analysed in this study can be found in Appendix 2.

By using retrospective data, the control of data collection is not as thorough as with the primary source analysis - but by using the same participant group to

both interview and analyse case-notes – reproducibility was tested. If service users were describing experiences in contrary ways to those described in the case notes, then the case notes could be interrogated for validity. Where concerns were present they could be raised with DOTW if required, thereby increasing the reliability of the data sources.

2.6 Ethics

Research was conducted within the standards of the Belmont Report , in keeping with key ethical principles of beneficence, non-maleficence, justice and respect.⁴⁴ Data was collected and anonymised at the DOTW premises and was only accessed in raw identifiable form in these confidential settings.

Participants were taken through a rigorous consent procedure (see Appendix 3 and 4), and were allowed to withdraw consent at any point. They were informed of their rights to confidentiality unless the information divulged required disclosure, as per General Medical Council guidance.⁴⁵ It was also clarified that their participation in the study would have no effect on their access to DOTW services. Within the principle of non-maleficence, participants' data were stored and encrypted in keeping with the Data Protection Act – with only fully anonymised data included in the disseminated report.⁴⁶ Training on sign-posting of services was also gained by the interviewer prior to interviews with service users in case further referral was required.

To maintain the principle of justice in research, translation facilities were used for interviews to minimise any discrimination of convenience sampling.

3 RESULTS

3.1 Demographic Data

The population of 2008 migrants attending the DOTW clinic in Bethnal Green between April 2016 and April 2017 were assessed for age, gender and country of origin. This data enabled comparison with global statistics to assess if the population studied were representative of the migrant population as a whole – particularly in the UK. Figure 5 and 6 illustrate this information, with the age displayed being the age at first point of registration with DOTW. Therefore it can be seen that the modal ages for migrants to seek help at DOTW are between the ages of 18 and 55 (84%), with similar numbers of men to women seeking help from the advocacy group (1026:980, female:male).

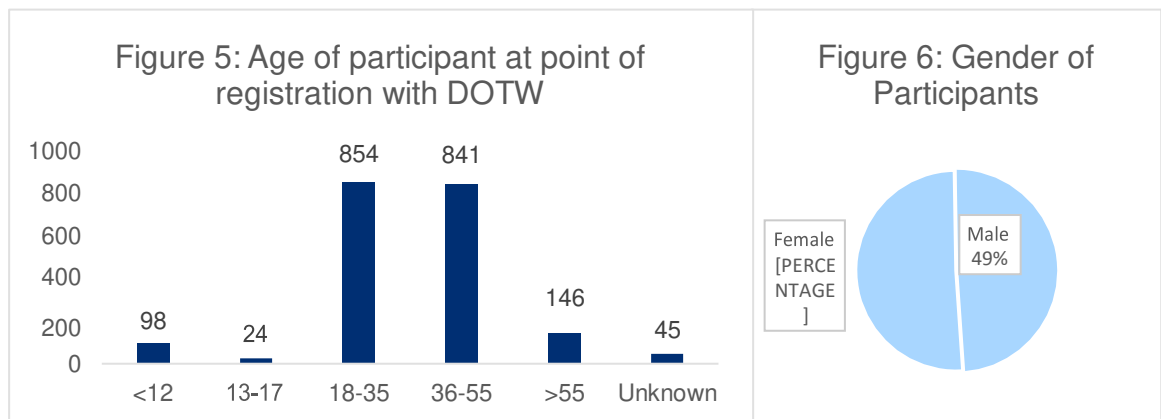
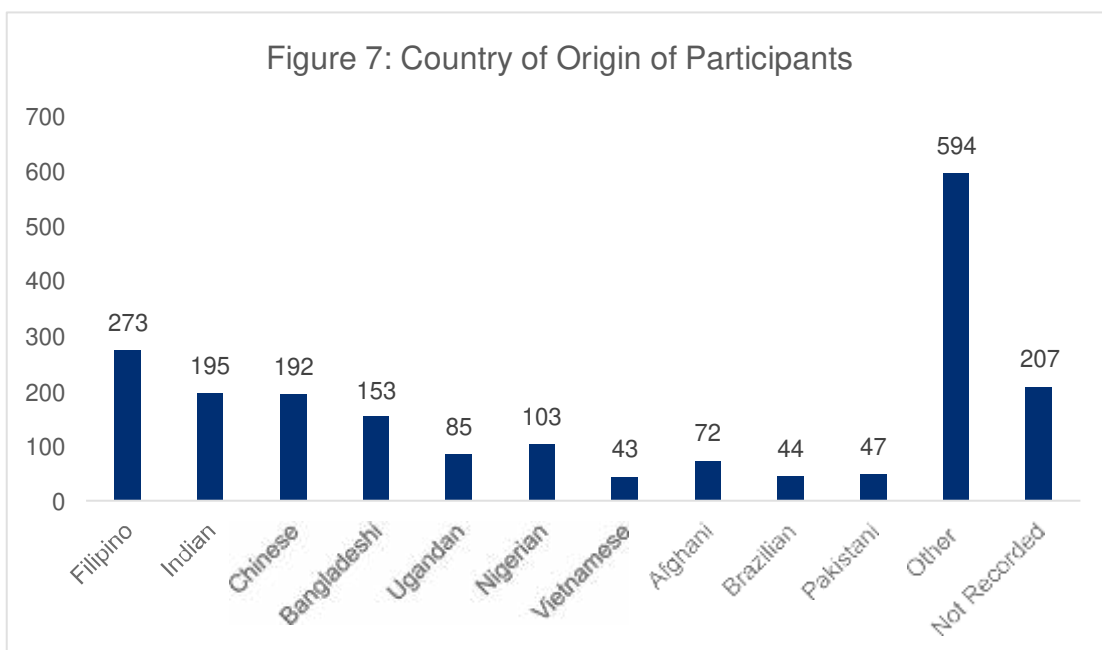


Figure 7 overleaf describes the ten most common countries of origin for the 2008 service users studied. Unfortunately for 207 (10%, 207/2008) of the service users, no country of origin was documented in the case notes.



The most frequent country for the participants to have migrated from is the Philippines, however a sizable proportion (594/2008, 30%) of the total are spread across countries in the world other than the ten most common.

3.2 Self-Reported Health and Wellbeing

Service users are offered a range of discrete options from 'very bad' to 'very good' to describe the state of their psychological and physical wellbeing. To obtain a measure of social wellbeing, service users are asked questions to assess whether they are living above or below the poverty threshold. This was used as a marker of social security and well-being based as per the International Organisation for Migration's work on migrant health.⁴⁷ The results of these subjective descriptions are shown in Table 2 overleaf.

Table 2: Self-Reported Health and Wellbeing of DOTW service users		
How would you describe your physical health as being?		
Very bad		80
	Bad	460
	Fair	617
	Good	439
Very good		78
Unanswered		127
How would you describe your psychological health as being?		
Very bad		117
	Bad	314
	Fair	552
Good		537
Very good		95
Unanswered		186
Do you think you are currently living above or below the poverty threshold?		
	Below	1207
	Above	169
	Unanswered	425
Is your current place of accommodation secure?		
	Yes	595
	No	1114
	Unanswered	299

These self-reported assessments of wellbeing indicate that 60% (1207/2008) of those people studied were reported to live below the poverty threshold. Regarding health, between 2% and 26% of participants have reportedly very bad or bad physical or psychological health at point of registration with DOTW.

3.3 Secondary Source Summary– Case note analysis

From the 2008 service users who had accessed DOTW services between April 2016 and April 2017, 207 were excluded from further analysis due to being minors or because of having incompletely filled case notes inhibiting analysis. The remainder 1,801 service user case notes were anonymised and underwent initial keyword searches as previously described in Table 1 and Figure 3. These keyword searches elicited 381 service users (21% = 381/1801) who had been in contact with secondary care or health related charging. The summary of the most common keywords to have been found in searches of case notes are shown below in Table 3.

Keyword searched for	Number of times described
Bill (ing/s)	161
Debt (s)	5
Charge (ing/s)	17
Hospital	190
Antenatal (ANC/Ante-natal)	57
Cancer	17
Scared (Fear)	119
Home Office (Government/HO)	159

The 381 case notes highlighted from the keyword searches then underwent a period of thematic analysis beginning with the ‘biopsychosocial model’ as the initial framework.⁶ This analysis considered themes in both the primary and secondary sources simultaneously.

The exact sums of charges levied were unfortunately rarely included in the case notes (n=75/381), but when stated ranged from £40 for an emergency GP consultation to £80,000 for breast cancer treatment. The modal quantity billed to service users following hospital care was £2600.

Thirty-five service users (35/381) received information of potential charges and instructions about payment prior to being delivered care – which prompted DOTW clinic visits and delayed or prohibited their access to treatment. Out of service users that were noted to have received a medical bill following discharge (32/381), 18 were in receipt of the bill within one year of discharge – with the time increasing to seven years from discharge in the case of one service user. Anonymised excerpts of these case notes (CN) can be found in Appendix 5.

3.4 Primary Source Summary – Semi-structured Interviews

Interviews were held with two staff members from DOTW (DOTW 1 and 2), two General Practitioners (GP’s) who work regularly with migrant primary healthcare, and six migrant service users.

3.5 Thematic Analysis

Delays in seeking healthcare due to fears about costs was a strong theme of

the research, with many participants describing forgoing hospital appointments or treatment because of bills possibly incurred. In the six service user interviews, five had had delayed medical treatment due to either fears of bills or due to being unable to pay for treatment – with these conditions ranging from antenatal care to the management of end stage renal failure. Three of the interviewees were still delaying treatment due to concerns about healthcare related charging, with one still going through active legal battles regarding eligibility to treatment.

“She said she went to the hospital about her breast lump... but then they told her that she would have to pay for treatment which is usually around £50,000-80,000 – which she can’t afford. They then asked her to go back to India for treatment” (CN)

In some such cases, migrants not accessing healthcare because of fees –led to poorer health outcomes and eventually much higher healthcare costs due to emergency presentations. For example, in one case a participant described not taking prescribed medications from the GP due to associated prescription charges. Unfortunately, as her uterine fibroids were not managed with medications, she presented as an emergency to hospital and then was billed for the hospital admission.

“Yes, sometime I’m worried about bill of tablets so I don’t take medicine. I saw my doctor about bleeding being so bad and he sent me to hospital. But now the bill is more than the bill for the tablets.” (SU1)

Another service user was described to have abstained from further treatment after an emergency presentation because of price.

DOTW2: “They took ten hours to treat her and told her she would have to pay more if she was admitted. Her and her partner said they would come back tomorrow as they lived close by”

Interviewer: “Did they go back?”

DOTW2: “No, no they didn’t”

The increased proportion of emergency presentations and delays to seeking healthcare were also found to pose difficulties for the healthcare workers and

DOTW volunteers. They described finding it difficult encouraging service users to seek help in the face of such potentially bankrupting bills and helping them make an informed choice.

“Trying to talk about what are the potential scenarios are and trying to explain it to them, in my sort of not great knowledge about different circumstances they’ve been in and then whether they will or won’t be charged. A) It’s time consuming and complicated and confusing, and also it’s often through a translator so I don’t know how much of the information actually gets through”

These uncertainties were a common theme in interviews with DOTW volunteers and service users, with many describing relying on the advice of external bodies or community members about whether to seek healthcare. This worked out negatively with two interviewees who asked British peers who “don’t know about these things” (SU3) and then were falsely reassured about eligibility to pay.

Fears of denunciation and involvement of the Home Office if they attended hospital, was another strong theme of the research. Migrants fears of being “reported to the Home Office” (SU2) were intimately linked with the hospital bill they were likely to receive – due to awareness of “the possibility of [the bill] affecting immigration perspectives due to unpaid debts” (CN). This fear was predominately described by women seeking maternity care. Delayed presentations to maternity care even amounted to one migrant presenting in labour to the DOTW clinic, having never received antenatal care because “she was scared of maternity bills and being reported to the Home Office” (CN).

The idea of the Home Office having ultimate power and the loss of internal locus of control for individuals was another theme of the research. Migrants descriptions of healthcare being “refused by the Home Office,” (CN) or having their GPs explain that referrals have been cancelled due to contact from the Home Office were common. This fear of denunciation and the Home Office being in ultimate control of their health was an emotive topic for the migrants interviewed. In particular the metaphor of doctors, lawyers and DOTW fighting against the Home Office on their behalf was fervently described. This powerlessness and reliance on external bodies was described by one interviewee about his father and their ongoing legal battle for healthcare:

“Everything is expensive for us, but he needs more. I’m afraid he’ll get worse before the lawyers can help us make the hospital make him better” (SU2)

This “making the hospital” (SU3) do things was a common reason to seek help from DOTW following original consultations. The feeling of the hospital “playing with me”(SU1) and having control over lives was another way that migrants described the loss of power that they felt.

These fears and loss of control have clearly had a significant impact on psychological wellbeing of the participants studied. Migrants’ descriptions of there being “no hope” (SU3), “fears” (SU4), “worries,” (CN) and not being “unable to cope” (SU5), were recurrent indicators of poor mental well-being. Particularly financial worries featured heavily as a cause of anxiety:

“She was sent a bill for ~£2600 for her first stay in hospital – has no way to pay as receiving £20.70 per week in child benefit alone” (Staff2)

“So now he is paralysed down the left-hand side of his body and is worried about being billed for the treatment he will require arfter he leaves hospital” (CN)

In at least four cases, migrants had offered repayment schemes -following debt advice- to the hospitals and had received no response in return. Indeed, it was more common that threats about bills to be paid were preventing migrants seeking the healthcare in the first place than the bills being upheld.

Although there was limited evidence of the actual impact of the healthcare debt on migrant life; social and psychological well-being was evidenced to be affected in other ways. Having to give up work to help family members or not be able to work themselves due to illness were key findings – with stories of reliance of family or friends for child care predominating: *“I can’t care for the child now” (SU3)*. Sacrificing physical health to maintain work was also common with one service user described attending his labouring job the following day after plastic surgery for traumatic finger amputation because *“I don’t get sick pay or nothing,”* and *“I’m a bit worried that my finger ain’t going to heal ‘cos I had to go back to work” (SU2)*.

Miscommunication or lack of communication were other familiar themes in the

research, often relating to hospital and GP staff. Notable examples include patients being turned away from outpatient appointments:

“He turned up for his appointment and was told it was cancelled and to go back to his GP to find out why. His GP then informed him that the Home Office had been in touch to say he was no longer eligible for treatment” (CN)

This use of GP services to both explain eligibility to healthcare and to campaign on the behalf of the patient caused anxiety in the GP’s interviewed. One GP described her difficulties in managing these dilemmas:

“[Service users] don’t know how to get help with it. Um... and what they can do, and um, well they’re just stuck... so people being understandably very upset and coming to see us... and we have to help to communicate back to the hospital about well how complex these issues often are... it’s quite complicated a conversation.” (GP1)

Therefore echoing the Ipsos Mori’s review of the lack of preparation of healthcare professionals to be undertaking consultations about cost recovery.

4 DISCUSSION

4.1 Summary and Interpretation of Findings

This study has found that the fears of and receipt of health-care related bills have affected participants physical, mental and social well-being, causing significant negative effects. From demographic data it can be seen that the population studied are representative of the background population of migrants within Europe, with significantly poorer self-reported health and psychological well-being than the general population in the UK.²⁰

From a physical point of view, the fears of receiving charges for healthcare discouraged migrants from seeking treatment in a timely fashion, which is known to worsen morbidity and mortality rates.^{19, 48} This echoes the present body of literature into out-of-pocket payments, with people often delaying presentation and utilising emergency services more than planned care routes. This displacement effect was considered as a 'possible unintended consequence' by the Ipsos Mori review into the CRP but no evidence was found – this research has found evidence of it.⁷ The predominance of emergency care over routine management of disease was described dramatically by one service user who did not seek medical care for chronic disease management due to cost until he reached extremis in renal failure and so was admitted for emergency dialysis costing tens of thousands of pounds (SU3). This displacement effect -where emergency care is utilised instead of other pathways is more expensive and difficult to plan for – therefore impacting the health system as a whole.^{19, 48}

Although the physical impact of the CRP was not able to be quantified within the realms of this study due to pressures of time and resources. The common theme of lack of early preventative medicine (especially from primary care) due to prescription costs, leading to disease progression was clear. This is not

an area previously found in UK literature about migrant healthcare, though is discussed in detail with regards to other vulnerable members of society – where help to apply for means tested prescription exemptions was found to be revolutionary.⁴⁹ This proves the necessity of the advocacy work done by DOTW and other groups in the charitable sector.

The fears described which caused both deterrent and displacement effects in the participants preventing them from seeking healthcare were also due to the fears of denunciation that are key in the CRP.⁴⁷ The aims of the programme to highlight patients who are eligible to pay and shift to “up front charging” instead of invoicing following the care received, is logical from a cost recovery point of view. However in the case studies presented in this research, service users were deterred by fears of denunciation and cost from key treatments such as antenatal care and oncology services (SU & CN). Professional groups have decried the sharing of non-clinical data with the immigration authorities because of fears of such negative impacts on vulnerable groups, however unfortunately this paper evidences the significant delays that denunciation regulations have made to migrant health.^{50, 51}

Regarding psychological well-being, migrants studied were found to have experienced feelings of stress, anxiety and powerlessness relating to the use of secondary care – either due to fears of the Home Office or of the payments. Those who had sustained debts were being requested to repay sums of money greater than one thousand times their weekly income (CN) and so were referred to local debt advice services, which reportedly helped. (SU) This use of debt advice services was key to service users feeling more in control of the situation they were in, which evidence shows is vital for improving productivity and mental health. Yet, DOTW staff members expressed difficulty with managing this situation, as over the last three years since CRP introduction the pattern of cost recovery and charging has been unreliable: “*So you’re doing a ‘maybe you will be, maybe you won’t be...’*” (GP2) which creates more anxiety with those involved. This was highlighted in the Ipsos Mori review as a limitation of the beginning stages of the programme, unfortunately this area was not further established by this research. To gain more information about the pattern of cost recovery, information would need to be gained from hospital trusts from OVHM’s to establish the patterns of charging across the country. This would

enable more cohesive advice to be given to migrants when deliberating the access to secondary care.

The ethical dilemma that GP's interviewed felt about encouraging migrants to seek healthcare in spite of likely costs incurred, is a topic alien to British healthcare professionals- with the NHS being free at point of delivery for those with recourse to public funds. The struggles felt by doctors trying to stand by professional principles whilst aware of the negative impacts of potential catastrophic health spending for their patients were convincing.⁵² As reiterated in the Ipsos Mori review, healthcare professionals felt profoundly uncomfortable with being in this position, and felt that involvement in cost recovery conflicted with care being given.^{53, 54} From the research, consultants were also being requested not infrequently to comment on whether treatments proposed were "immediately necessary" or "urgent" according to policy (DOTW2 & CN). As their opinions on this were not explored in this study, it would be an interesting topic to explore in future research- regarding the implications of their diagnoses and their awareness of the ramifications.

From a social wellbeing perspective, the research found that the role of family and community were key in supporting service users in their ill-health and in encouraging them to go to hospital. Participants described their community helping with child care and helping with activities of daily living: "*my family is my strength.*" (SU4) This reiterates one of the limitations of the study that the most vulnerable and isolated of the migrant population are likely to not have been reached with the research methodology. Especially as the literature tells us that those with more family or community support have better reported health and social wellbeing in comparison to those who are isolated.^{18, 19, 21}

There was minimal evidence in the research of the socioeconomic impact of the debts encountered, with the majority of service users not yet being in contact with debt collection agencies in spite of invoices received. This may be due to the timing of the study, with the Ipsos Mori review also commenting on the debt collection facilities that hospital trusts had being limited in scope. But it also may be due to the referral processes in place from DOTW to debt advisors that may minimise the affects of these debts. By taking this research

further and examining the enrolment process of the CRP, debt collection strategies enforced by trusts may be more robust and their impact clearer. Although there were many service users who had received charges, only two were currently undergoing active repayment plans, (CN) with many others being in the process of negotiation with the hospital trust. This is another limitation of this study, that national data on debt collection was not accessed due to time constraints of obtaining the data through the Freedom of Information Act.⁵⁵ Future research would be improved by quantitative data on the invoicing process that is in action to understand the scale of unpaid charges on an individual scale, as opposed to the generalised national targets published in Department of Health documents.⁵⁶

4.2 Conclusion

This study has evidenced the significant negative effects of the Cost Recovery Program on the health and well-being of migrants. It has also raised concerns about the preparedness that healthcare professionals have for the management of eligibility of healthcare and the ability to balance this against clinical needs. This research categorically disagrees with the Ipsos Mori review into the unintended consequences on health inequalities in the migrant population – with examples of deterrent and displacement effects evidenced.⁷ Further work in the future on models to quantify health outcomes and levels of avoidable hospital admissions -which have been alluded to in this study- would be beneficial in quantifying the true costs of healthcare for this vulnerable population and driving more equitable policy.

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APPENDIX 1

Indicative Questions/Topics for Migrant Interviews

1. What is your experience of paying for healthcare in the United Kingdom?
2. How did you manage the bill that you were given?
3. Please explain, if relevant, the debt advice that you have been provided with?
4. What impact has this payment made on you? Physically? Mentally? On your friends/family/community?
5. In what way, if any, does your experience of debt affect your use of health care in the United Kingdom?
6. What role did your community/friends/family have in encouraging/discouraging you to seek healthcare?
7. Were you aware of rules about eligibility to care before you sought it?

Indicative Questions for Staff Members/GP's

1. What are your experiences of working with service users with healthcare related debts?
2. How had service users approached the payment of these bills?
3. What is your experience of the impact these health charges have on migrants?
4. (For Doctors of the World staff only) How often do you refer service users to the Mary Ward debt advice service? Have you had any feedback from this service?


APPENDIX 2

Excerpts of Medical and Social Forms – Secondary Source Data

The below images are sections of the Medical and Social forms that are completed by DOTW staff. The data from these forms – in particular the free text sections- formed the basis of the thematic analysis.

Captured

International Observatory



MEDICAL FORM 2016

Please inform about patient rights, anonymized data capture, possibility to refuse to answer with no regard on service provided by A&M

Name of doctor/nurse

1. Service user's number : 2. Consultation date: ____ / ____ / ____
dd * mm * yyyy

GENERAL INFORMATION

Name: 3. Sex: Male
Surname: Female

Nationality: 4. Date of birth: ____ / ____ / ____
mm * dd * yyyy
month unknown use 00

5. Interpreter: No need Present By phone No
If interpreter necessary: - what language

PLEASE READ THE SOCIAL FORM

CHILDREN

	6. ALREADY vaccinated	7. Vaccinated TODAY	Brand, batch, booster #
Tetanus	<input type="checkbox"/> YES-documented <input type="checkbox"/> Unknown <input type="checkbox"/> Probably <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	
Hepatitis B <small>if not all doses received - tick NO</small>	<input type="checkbox"/> YES-documented <input type="checkbox"/> Unknown <input type="checkbox"/> Probably <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	
MMR	<input type="checkbox"/> YES-documented <input type="checkbox"/> Unknown <input type="checkbox"/> Probably <input type="checkbox"/> NO	<input type="checkbox"/> YES <small>Do NOT vaccinate if immunodeficient</small> <input type="checkbox"/> NO	
Whooping cough	<input type="checkbox"/> YES-documented <input type="checkbox"/> Unknown <input type="checkbox"/> Probably <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	

8. Know where to get vaccinations - before you tell them YES
 NO

WOMEN

9. Are you using contraception today: YES NO Not applicable

10. If NO -> would you like contraceptive: YES NO

11. Have you been cut or other FGM YES NO

12. Are you pregnant YES (csp w/o) NO

12.1 Weeks of pregnancy: _____

12.2 Do you want this pregnancy: YES NO

12.3 Wants an abortion YES (csp w/o) NO

12.4 Treated for HIV AFTER becoming pregnant YES NO

12.5 Accessed antenatal care (other than M&M TODAY) YES NO

12.6 Weeks of pregnancy at FIRST antenatal visit: _____

12.7 If NO -> reasons for non-access: _____

MEDICAL HISTORY – including allergies, contraindications, risks factors

13. Violence: current or past experiences YES
 NO

MEDICAL EXAMINATION – current treatment + contraception (class, dose, duration)

Blood pressure Heart rate Weight Height BMI
 ___ / ___ mmHg ___ bpm ___ kg ___ cm ___ kg/m²

HEALTH STATE – diagnosis, symptoms, complaints

14. Health problem? YES if NO -> skip to question 15
 NO

	If YES ->	1 st diagnosis	2 nd diagnosis	3 rd diagnosis
14.1 ICDPC code				
14.2 waiting for diagnosis	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
14.3 Pathology: state	<input type="checkbox"/> Acute <input type="checkbox"/> Chronic <input type="checkbox"/> Unknown	<input type="checkbox"/> Acute <input type="checkbox"/> Chronic <input type="checkbox"/> Unknown	<input type="checkbox"/> Acute <input type="checkbox"/> Chronic <input type="checkbox"/> Unknown	<input type="checkbox"/> Acute <input type="checkbox"/> Chronic <input type="checkbox"/> Unknown
14.4 if CHRONIC -> Pathology: KNOWN before coming to Europe	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Not applicable	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Not applicable	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Not applicable	<input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Not applicable
14.5 Pathology: should have been treated earlier	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
14.6 Treatment / follow-up is	<input type="checkbox"/> Necessary <input type="checkbox"/> Precaution	<input type="checkbox"/> Necessary <input type="checkbox"/> Precaution	<input type="checkbox"/> Necessary <input type="checkbox"/> Precaution	<input type="checkbox"/> Necessary <input type="checkbox"/> Precaution
<i>IF NECESSARY -></i>				
14.7 Accessed CARE for this pathology: BEFORE 1st MdM consultation	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO
14.8 Accessed MEDICINES for pathology: BEFORE 1st MdM consultation	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO	<input type="checkbox"/> YES - fully <input type="checkbox"/> YES - partially <input type="checkbox"/> NO



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**SOCIAL
FORM
2016**Please inform about patient rights, anonymized data capture, possibility to refuse to answer with no impact on service provided by AMU

Name of support/social worker:

1. Service user's number: 2. Consultation date: ____ / ____ / ____
 New information to be captured in database dd * mm * aaaa**GENERAL INFORMATION**Name: 3. Sex: Male
 Female

Surname:

Nationality: 4. Date of birth: ____ / ____ / ____
/ month unknown use 00

Ethnicity (if declared):

5. Unaccompanied minor YES NO6. Interpreter: No need YES - Present YES - By phone NO
If interpreter necessary -> what language7. Reasons for coming to clinic today: Administrative, legal, social
 Medical
 Psychological or PsychiatricService user needs:
.....
.....
.....**LIVING CONDITIONS**

Ask about family issues and possible separation from children - help them get medical coverage

8. Accommodation: Street or emergency centre < 15 days With friends or family
 Organization or charity or hotel > 15 days Place of work
 Camp or slums Personal flat or house
 Squat9. YOU consider your accommodation: STABLE
 TEMPORARY10. This accommodation harms your and/or your children's health YES
e.g. peeling paint, damp, no access to water, no heating, risk of domestic accident NO

IF YES please see why for action

11. Do you have children under 18 years old? YES
 NO

12. If YES → you live with how many: All None
 Some

PERCEIVED HEALTH     

13. How is your GENERAL health? Very good Good Fair Bad Very bad

14. How is your PHYSICAL health? Very good Good Fair Bad Very bad

15. How is your PSYCHOLOGICAL + EMOTIONAL health? Very good Good Fair Bad Very bad

16. In this town, can you rely on someone to help, support, and comfort you, if needed?    
 Very frequently Frequently Sometimes Never

ACTIVITIES AND RESOURCES

17. Do you have a job or activity to earn a living? YES NO

18. In the last 3 months approximately, how much money per month did you have to live on: ABOVE poverty threshold BELOW poverty threshold

*POVERTY THRESHOLD = £1005 per month
 (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/437240/households-below-average-income-1004-05-to-2013-14.pdf)*

ADMINISTRATIVE SITUATION

19. If MULTIPLE ENTRY FOREIGN → Date you began living here: ____ / ____ / ____
mm / year

20. If FOREIGN → Date of your last entry in this country: ____ / ____ / ____
dd / mm / year

21. Why did you leave your country? for political, religious, ethnic, or sexual orientation reasons
 To escape from armed conflict or war
 For economic reasons, to earn a living, had no perspectives.
 Because of family conflict(s)
 For personal health reasons.....
 To join or follow someone
 To study
 To ensure the future of your children
 Other, specify.....

22. Current status in this country? *1 answer only*
 Residency permit (NOT applicable @ e.g. national, minor in France...)

HEALTH COVERAGE AND OBSTACLES TO ACCESS CARE

26. Healthcare costs chargeable?

- 1. Full health coverage, not chargeable (as much as possible in the country)
- 2. Health coverage only for part of costs
- 3. No health coverage at all / fully chargeable
- 4. Free access to GP
- 5. Access to GP but must pay a part
- 6. Access to secondary care but no GP yet
- 7. Access on case by case basis
- 8. Access only in Emergency room
- 9. Health coverage included in visa
- 10. Healthcare coverage still valid in another EU country (only if still resident in another EU country or temporary stay here with valid European Health Insurance card)

27. In the past 12 months, have you faced problems in accessing healthcare or providers?
Indicate barriers spontaneously cited by the patient or that you noticed, prompt 4 times maximum

3

Immigrants' Survey - 2014/15 (Page P2/P3/4)

- 1. Did not try to access healthcare or providers
- 2. No difficulties
- 3. Administrative and documentation problems
- 4. Lack of understanding or knowledge of the system and rights
- 5. Denied health coverage
- 6. Payment for consultation too expensive
- 7. Payment for treatment too expensive
- 8. Language barrier
- 9. Fear of being reported or arrested
- 10. Previous bad experience in health system
- 11. Healthcare coverage too expensive
- 12. Health coverage in another EU country
- 13. Other reasons, specify:

28. In the past 12 months have you given up seeking medical advice/treatment for yourself in this country? YES NO

29. In the past 12 months, have you faced discrimination by a healthcare provider in this country? YES - color or ethnic origin discrimination YES - other, specify: NO

Ask ALL patients this question

APPENDIX 3

INFORMATION SHEET FOR PARTICIPANTS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Invitation Paragraph

Due to ongoing changes in the way that the NHS charges migrants for healthcare, this study aims to show the size and impact of healthcare related debt and payments in migrants. You are being invited to take part in a half an hour interview with a doctor working alongside Doctors of the World, to confidentially discuss your experience of payments for healthcare in the United Kingdom and what –if any- impact these have made to you or on the service users you work with.

What is the purpose of the study?

The study aims to show to the Department of Health –as part of an advocacy piece- the scale of impact of health-related debts and the impact that these have made, in light of more stringent changes to healthcare funding that are being proposed.

Why have I been invited to take part?

You have been invited to take part because either you work with migrants who have experienced healthcare related debt; or you yourself are a migrant to the United Kingdom who has experienced these financial payments.

Do I have to take part?

You do not have to take part in this study and not doing so will not affect any interaction that you may have with Doctors of the World. If you are unkeen to take part, but are aware of a friend, colleague or family member who may be interested please feel free to pass on this information sheet.

What will happen to me if I take part?

If you chose to take part in this study - thank you! First you will be taken through the details of this study again and will be asked to give written consent to take part. You will then have a short discussion with our interviewer for up to 30 minutes, at the Doctors of the World clinic in Bethnal Green, where you will discuss your experience of healthcare related payments/debt and the impacts these have made. Following this interview you will receive travel reimbursement for the distance travelled to get to the Doctors of the World clinic. The interview will then be transcribed and any recordings made will be securely disposed of. The transcriptions from the interview will then become a part of an anonymised research project, the feedback from which you will receive when the study is complete.

What are the possible benefits and risks of taking part?

The main benefit of taking part in this study is so that Doctors of the World can present an up to date and honest account of the difficulties caused by the financial payments imposed on migrant populations – in an aim to improve advocacy in this issue.

There is no risk to your access of healthcare, or your work with Mary Ward debt advice or Doctors of the World through your encounter with this study.

Will my taking part be kept confidential?

Yes, all respondents will be anonymised, and the voice recordings prior to transcription will contain no identifiable data. Following transcription, all respondents will be coded and so not identifiable. No identifiable data will be included in the study or will be published in the reporting.

How is the project being funded?

This project is being funded by King's College London.

What will happen to the results of the study?

The results of the study will first be compiled for Doctors of the World as part of an advocacy piece in June 2017. Following this date, the full analysis will be copied to all interview respondents – if you so wish. The report will be submitted to peer review journals in order to obtain publication across the scientific community, and a summary will be included in the Doctors of the World newsletter.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Dr Jenny Quy; jennifer.quy@kcl.ac.uk; jenny.quy@doctors.org.uk ; 020 7848 5168;

King's Centre for Global Health, Weston Education Centre, Cutcombe Road, London

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

Miss Fawzia Fall; fawzia.fall@kcl.ac.uk; 020 7848 5168;

King's Centre for Global Health, Weston Education Centre, Cutcombe Road, London

APPENDIX 4

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

King's College Research Ethics Committee Ref: LRU!16/17!4181

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.

- 1. I confirm that I have read and understood the information sheet dated 9th January 2017 for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.**
- 2. I understand that I will be able to withdraw my data up to four weeks after my interview**
- 3. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.**
- 4. I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.**
- 5. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications**
- 6. I understand that the information I have submitted will be published as a report and I wish to receive a copy of it.**
- 7. I consent to my interview being audio/video recorded.**

8. I understand that I must not take part if I fall under the exclusion criteria as detailed in the information sheet and explained to me by the researcher.

9. I agree that my GP may be contacted if any unexpected results are found in relation to my health.

10. I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

APPENDIX 5

Secondary Data – Excerpts from Case Notes

This appendix contains anonymised excerpts from free text sections of case notes used in the research. A limited selection of case notes have been included to maintain confidentiality for service users and in the interest of relevance.

These excerpts present a disjointed but compelling story, spread across 381 service users of their experiences of health care in the UK. Where identifiable data was present this has been replaced with 'SU' for 'service user' or parentheses.

- A) In past month, SU has had two episodes of acute abdominal pain which she phoned an ambulance for and on at least one occasion was admitted for 5 days. She has been given an appointment for an operation in April to treat this. SU has been sent a bill for ~ £2600 for her first stay in hospital - has no way to pay as receiving £20.70 per week in child benefit alone. Advised we cannot remove the bill, and there may be further from the hospital. Will email us all communication from the hospital. Gave consent for us to phone overseas team and investigate/arrange payment plan. Considering not attending operation as solicitor may have said something about outstanding bill harming her application. Advised from our point of view needs to attend operation as we do not know how urgent this is. Gave consent to phone her solicitor to talk about this

- B) SU called. She has an appointment on Wednesday at the hospital. She has a breast lump and needs urgent treatment. They asked her to bring ID and proof of address, otherwise she will be charged. Told her that if her doctor told her it is urgent, that she should have the treatment but she will be charged. Informed her that if she gets charged and will not be able to pay the bill, this may affect any asylum claim in the future. She has to ask for legal advice from a solicitor, if that happens.

- C) Has received a penalty charge from NHS for misuse of HC2 certificate - £50.00. Not able to pay. Clarified situation with SU with help of Bengali interpreter. Address on certificate different from address on penalty notice - advised SU this is probably the problem. Spoke with [redacted] at NHS Business Charges. Agreed problem was with different addresses. Also agreed to dismiss the charges. Then was able to change SU's address with NHS. Advised SU that he must phone NHS if he moves/changes his address - appears he is living in

multiple places - almost like couch-surfing.

- D) SU called because she received a bill on Saturday and doesn't know how she will pay for it since she has no income. The bill is for hospital services she used in 2012 (her friend took her to the hospital because she had lost consciousness, MRI was done and stay at the hospital for a few days). Diagnosed with brain tumour in 2002. Needs surgery, but is worried about the fees for it.
- E) He was taken to hospital ... as he had severe chest pain, sweating and tachycardia. Once taken to [hospital], SU was admitted as an inpatient ... He was treated and received an implantable loop recorder for ongoing monitoring He received a bill for his care on, totalling £5910.68... Then the Home Office have sent a letter to his GP informing them of his immigration status to inform them that he is not entitled to some NHS care. Since then his GP surgery have denied him appointments.
- F) SU's friend called to ask if we could get in touch with SU as he would like to register with a GP but is currently in hospital after having a stroke and is unable to attend the clinic. He can speak both Russian and Ukrainian and will require an interpreter. .. Had no other health problems before the stroke. He is now paralysed down the left-hand side of his body and is worried about being billed for the treatment he will require after he leaves hospital
- G) He has tried to register with a GP in the past year, but was refused likely for lack of ID and address. Two years ago he went to the police with severe belly pain, who brought him to the hospital where he had an emergency surgery on his liver. Since then his belly pain has continued for the last two years. SU reports that last week he was again in severe pain, and called an ambulance which took him to King's hospital. He was discharged from there after checking his blood, to see his GP... He has no GP.

APPENDIX 6

Primary Data – Excerpts from Service User Interviews

The following excerpts are taken from service user interviews. Excerpts have been selected based on whether they are used as evidence in the research paper, and if there is no identifiable data included.

A) Yes, I was given a horrible hospital bill. But when I spoke to the clinic they said to talk to my lawyer. My lawyer told me to... to not be paying whilst my case is going through. So I haven't paid any money. I'm wondering if you could help me about this. The problem that I was seeing the doctor is I have many many fibroids and they are giving me lots of bleeding. I was to seeing the doctor last month and he was trying giving to put in a coil to stop the flow and the blood loss but he didn't put it in. I don't know. And now they say they seeing me in 2 months' time to do more things.

Interviewer: I see, yes

And now they be sending me a letter for a new appointment and already a bill for £300. So I called them and I say 'what are you meaning with this bill? They didn't do things with my body. Why have I need to pay?' and they said I was right and stopped the bill. Now I'm scared in as much as I want my health to be treated I am unsure.

Interviewer: What are you unsure about?

Well when I get the bill it affects me – I get high pressure in my body and I stressed. I feel sick again. I say to them 'these bills you keep bringing me is giving me heart attack.' So though the bleeding is making me ill these bills are making me worse. I don't know if going to hospital and they will give me more bill – and I say to them 'these bill are making me worse.' So I don't know. I don't know if the bleeding is more bad than the stress. And the more bill they be giving me the more stress it gives me.

So I don't know. I don't know if to go the hospital is better. Or it is better at home without stress and headaching.

Interviewer: That sounds really difficult, I'm sorry. What have you done to work out what to do?

Well I asked my lawyer whether I should go. And he said I should go. My lawyer said they may be giving me more bills but my health is more.

B) Interviewer: Ok that's helpful to know thank you. Do you mind me asking what are your main concerns about your life and health at the moment?

I'm pretty good right now. A bit worried that my finger isn't going to heal properly cos I had to go back to work. Cos my boss needs me and I don't get sick pay or anything. But right now it's ok.

...

Interviewer: Would having to pay stop you from going, now that you know that some people are asked to?

Yes, definitely. And my boss doesn't let me off work for things like that. So it'd be both really. My boss and the money.

Interviewer: I see, do you ever get help from friends/family or people in your community about things like this?

No not really. The people I work with are mostly British so they don't know about these things. I just try and keep my head down and get on with work.

C) He's not doing that well. He's still got really bad kidney failure and bad diabetes as well.

Interviewer: Mm, yes. And how are you all managing? Are you getting any help?

There is no help. No one is helping him. Not with his GP. Not with the hospital. So we all have to try and look after him. But there is no help. The GP's tried but the hospital they won't accept him. So there's no hope.

Interviewer: Mm I'm sorry it's such a hard situation for you all. How are you managing with the caring then? Are you having to do all of the care? How has that affected your life?

Yea well I have to do the caring, we all do. So I had to give up my work and be part-time. So then there's less money. But we can't not. He needs help every day.

Interviewer: So what sorts of things do you have to do?

Well he needs help with everything, he can't get to the hospital by himself, he can't get food for himself, or get clothes. He can't really get around. He's too sick. I have to do everything.

Interviewer: But you haven't been offered help from the NHS for the care of your father?

No, they said he doesn't qualify for it. He's not allowed. So we have to do it all. It's horrible.

...

Interviewer: Can I just ask a difficult question, did any of you know at the start of all of this that money was likely to be a problem when he became unwell? No! Never! It was all a surprise, he became unwell so quickly and so we had to take him into A&E. We knew his eyesight was bad, and the problem with the diabetes. But not the kidneys. That was a shock. And it's expensive. But we didn't have an option. Without dialysis he would die. How could we say we didn't have money to pay.

Interviewer: That must have been a horrible time for you all

It was. And now I understand that the lawyers need to work on the case, but in the meantime my father, he is getting worse and worse. And no one can help us.

APPENDIX 7

Primary Data – Excerpts from GP and DOTW Staff Interviews

These excerpts were taken from the two interviews that were done with GP's and DOTW staff members who work with migrant healthcare.

A) GP1: Erm... So the main ones that have actually come in with the debts are actually the people who've had surgeries and deliveries at the hospital. And that's through seeing them at the doctors of the world clinic. I haven't actually met anyone who's talked about it in my GP work. And non-maternity ones... err...let me think... There've been people.. I think there have been people who have come to talk to the other ones... Not that they've seen me but I've been kept abreast f it, I've been told about the fees and that puts them off seeking treatment. So they've come in saying, "I've been told I'm going to have to pay for this, I can't afford it, what can I do? Are there any other options?" Where they've gotten through to something being done and then afterwards they've been charged. So it hasn't really been a pre-appointment, that way is more common, when they've already been charged. Often what we see is that when people come with health problems from abroad, or who have needed surgery.. um... and there have been cases where there have been people with cancers and things that doctors of the world have argued for them about regarding the urgently or immediately necessary kind of treatment timescales. So I mean... it's usually people that come in who have already had their bill. It's mainly maternity really that I see it because they have to treat them, um and then afterwards they get sent the bill. That's what I have come across.

B) What are your strategies you have to encourage people to seek healthcare in spite of the costs? Have you come across that? Have you counselled anybody?

GP2: Yes well I think that that is more common, when we're seeing people who're pregnant who either don't know that they're going to be possibly charged afterwards, cos the other issue is that you never know for sure. Cos there's a time between when you're seeing them when they're hopefully, well for example if they're bleeding and they're in the first trimester or second and then between the time that they're going to

be delivering, or even the antenatal appointments they may be charged for afterwards. Often immigration status and things can change, and so, it's actually quite complicated a conversation. And also I'm not an immigration expert and so it's actually quite difficult. Trying to talk about what are the potential scenarios are and trying to explain to them, in my sort of not great knowledge about different circumstances they've been in and then whether they may or may not be charged. A its time consuming, and complicated and confusing, and also this is often through a translator so I don't know how much of the information actually gets through. So you're doing a "Maybe you will, maybe you won't"

C) DOTW2: "They took ten hours to treat her and told her she would have to pay more if she was admitted. Her and her partner said they would come back tomorrow as they lived close by"

Interviewer: Did they go back?

DOTW2: No, no they didn't