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Sick and tired, and afraid:

Assessing the relationship between unpaid hospital bills and the consequences debt can have on immigration status for undocumented migrants at an East London charity clinic.

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Abstract

Background:

In the United Kingdom (UK), general practitioner (GP) consultations and treatment as part of primary care services are free to all, whether registered as a National Health Service (NHS) patient or a temporary patient. However, undocumented migrants face many challenges and barriers to accessing health care, including charges in secondary care and the risk of unpaid hospital bills being reported to the Home Office (the UK's immigration department). This study, conducted in partnership with the charity Doctors of the World UK (DOTW), seeks to assess the effects of charging for health care on care-seeking behaviour for migrants in vulnerable circumstances attending the DOTW clinic in East London.

Methods:

A literature review was conducted exploring the existing evidence on migrants' experiences in relation to accessing health services in order to understand the range of barriers that have been identified. Ten semi-structured interviews were conducted Doctors of the World clinic staff and volunteers exploring the themes identified in the literature review and to identify specific case types observed in the clinic which were affected by secondary charging. Thematic analysis of the interview data was conducted using NVivo. Based on the case types that emerged from interviews, medical records of 773 patients collected by the DOTW clinic from 2015-2016 were analyzed using STATA, to identify the prevalence of these case types using keyword searching and thus provide an indication of the magnitude of impact of hospital charging on the migrants presenting at the DOTW clinic. Based on medical record data, evidence of any effects of charging or concerns about charging on care-seeking behaviour was also collected.

Results:

The literature review identified five categories of barriers to health care for migrants. These related to: culture, ambiguity, language, dispersal, poverty and stigma. Interviews identified two key types of service user case which were most affected by secondary care charges: pregnant women in need of antenatal care and individuals in need of hospital care for non-communicable diseases. Next, medical records of 773 patients over a 2-year period were keyword searched to identify occurrences of these case types. 55 (15.9% of women) pregnant women patients were identified, and 88 (11.3%) patients were suffering from a non-communicable disease (such as cancer, diabetes, kidney failure, etc.), indicating that 143 (18.5%) patients sampled would be affected by health care charges. In addition, analysis of case notes found that 46 (34.3% of chargeable cases) delayed seeking necessary healthcare due to concerns related to charging, including concerns their information would be shared with the Home Office as a result of the charging process.

Discussion:

Charging for healthcare creates barriers and stigma for undocumented migrants in accessing the services they need. Not only are many undocumented migrants vulnerable, and even destitute given that they are not permitted to work, but also may face additional challenges due to poor health and lack of resources to get help. Patients that avoid potentially chargeable care can cause additional costs for the system for late presentations of more complicated disease progression at overburdened Accident & Emergency departments (A&E).

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1. Background and Context

1.1 Barriers to Health Care for Migrants

Migration in the United Kingdom (UK) is a topical matter, with the number of inward migrants increasing annually in recent years. Consequently, there has been much interest in the impact such migration has on social services and public goods, such as the National Health Service (NHS). Many studies have been conducted in the UK on access to the NHS for refugees, asylum seekers and detainees, focusing on the barriers or challenges these individuals face in care-seeking. Identified barriers include: confusion or misunderstanding of entitlements or rights to care – both by migrants and health care staff (Eziefula et al. 2014; Reeves et al. 2006), lack of support and information (Poduval et al. 2015), cultural or linguistic challenges (Stagg et al. 2012; Reeves et al. 2006), and preference to self-medicate (Aung et al. 2010) among many others. Addressing these barriers to health care access offer an opportunity to protect the health of the UK public as a whole, by catching and treating infectious disease and enabling prevention or early treatment of conditions in order to reduce the burden on Accidents and Emergency (A&E), where feasible (Poduval et al. 2015; Britz & McKee 2016). Several forms of health care services are free to all, including treatment at A&E or walk-in centers, treatment for infectious disease, family planning, and compulsory psychiatric treatment (Department of Health, 2012; Stagg et al. 2012). These treatments benefit individuals, but also benefit the greater community.

1.2 Health Care and Immigration Status

Relatively little research has been conducted on access to health care for individuals that fall outside of the asylum system (Stagg et al. 2012; Aung et al. 2010), referred to as undocumented migrants, irregular migrants (see definition in *Appendix 1*). There are many routes to becoming undocumented in the UK, including irregular entry into the country, overstaying a tourist or student visa, losing links with the person on which a visa is dependent (such as with a spousal visa or a Domestic Workers visa), or your asylum claim being refused without any appeal in progress. In 2008 it was estimated there were 533,000 irregular migrants living in the UK. but outside of this there is no clear data on how many people are living in the country without legal status,; perhaps unsurprising given these individuals' imperative to live 'under the radar'.

Many undocumented migrants are "reluctant to seek medical help believing that, by drawing attention to themselves, they will come to the attention of the authorities, which may hasten their deportation." (Reeves et al. 2006). This addresses a unique difference between the asylum system population and undocumented migrants. Undocumented migrants may fundamentally fear accessing health care due to their lack of immigration status and the consequences that being identified by a government body

(such as the NHS) may have on their ability to stay in the country. The issue of migration tensions has become so politically and socially contentious that migrant health policies have even been co-written between the Department of Health (DH) and the Home Office (the UK immigration department) – which one study describes as "inappropriate" (Grit et al. 2012). Singer (2004) agrees, "Health workers should not routinely be put in the position of mixing clinical imperatives with legal enforcement" (Singer 2004). The close relationship between health care and immigration is controversial, and evidence has suggested that limiting rights to health care for undocumented migrants often does little to discourage immigration (Burnett & Peel 2001).

Barriers to accessing healthcare for any group in society could lead to poor health as they avoid treatment and preventative services, potentially increasing public health risks and displacing demand on to A&E services when they face emergency health problems. Doctors of the World UK (DOTW), a charity and non-governmental organization, has established a clinic in East London to provide a safe and confidential service to assist, among others, undocumented migrants to accessing the NHS, seeing approximately 1,500 patients per year.

1.3 Public Health Effects

Frontline health service providers are the first-line of defense against disease (Beckwith 2013). General Practice (GP) surgeries are in an optimal position to detect and diagnose cases of preventable illness by offering medical consultations within their catchment area. However, there are administrative barriers for many to accessing these essential services, with most practices requesting official documents such as government issued identification and formal proof of address (Grit et al. 2012). Although according to NHS England guidance such documents are not required to register with a GP, many migrants without these documents are denied access to health care, or fear providing sensitive, personal information that could be accessed by the Home Office. A DOTW policy brief in 2013 on the importance of equitable health care for all states that "restricting access to primary care removes this preventive, cost-effective public health management tool" (Beckwith 2013). Furthermore, Poduval et al (2015) states that "policymakers 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" (Poduval et al. 2015).

1.4 Charging for Health Care

Charges for overseas visitors using the NHS were first introduced in 1982, and were extended to refused asylum seekers in 2004 with the introduction of the NHS (Charges to Overseas Visitors) (Amendment)

Regulations 2004. However, asylum seekers and undocumented migrants alike do not have the right to work in the UK, making it more difficult for them to cover potential health care costs (Ashcroft 2005; Eziefula et al. 2014). In July 2013, the Department of Health (DH) publication "Migrant Access to the NHS" announced the government's intention to introduce further restrictions on access to NHS Care, culminating in the Immigration Act 2014 which restricted access to NHS care to regular immigrations status. These changes were due to continued political pressure on the NHS budget and media-driven accusations attributing high health costs to non-tax paying migrants (often referred to as "health tourists") (Grit et al. 2012; Britz & McKee 2016; Eziefula et al. 2014; Pollock 2013), though this is largely discredited in NHS data (Hansard 2013). Under these new restrictions, an unpaid hospital bill of over £500 for more than two months would result in the individual being reported to the Home Office and their personal information, such as home address registered at the practice, being shared with immigration officials.

1.5 The Relationship between Health Care Costs, Immigration Status and Care-Seeking Behaviour

Delays in accessing health care by any substantial group can incur increased risks to the general population of disease outbreaks as well as increased emergency costs for otherwise preventable medical issues. There has been much research into the barriers documented migrants face accessing the NHS, but the experiences of undocumented migrants is largely neglected despite recent changes in entitlement and charging of this vulnerable group. The *actual* impact that the aforementioned unpaid medical bills can have on one's immigration status has yet to be thoroughly explored through research, and so this study seeks to assess effect of NHS charges and concerns surrounding them, including undocumented migrants' *fear* of immigration status exposure, on the care-seeking behavior of undocumented migrants.

Furthermore, the study aims to provide public health policy recommendations on how to ensure better access to preventative and timely health care for the undocumented migrant population segment.

1.6 Addressing the Literature Gaps

Several studies have provided research into the views of migrants themselves, and the challenges these individuals have had in accessing health care in the UK. However, the situation is rapidly evolving, and studies conducted prior to 2014 do not consider the effects of the Immigration Act 2014. This study thereby strives to address the gap in the body of literature regarding the impact charging for care has on health-seeking behavior of this vulnerable population. This is timely, given that the NHS Digital data sharing Memorandum of Understanding (MoU) that was issued earlier this year (Gordon 2017), published a correspondence stating that there was not enough evidence that charging for health care

would negatively impact health-seeking behavior. The results of this study aim to form part of this missing evidence, delivering the heath provider's perspective on the effects of health care charging policies on undocumented migrants in the UK, and potential implications for the health of the general population.

2. Methodology and Research Question

Research Question: What are the effects of charging for health care on care-seeking behavior for undocumented migrants in an East London charity clinic?

2.1 Methodology Justification

A mixed-methods study design was selected for this topic in order to explore the multifaceted aspect of the issue. There are many stakeholders involved in migrant access to health care and the charges affiliated to care, ranging from the NHS, the Home Office, the Overseas Visitors Office, charities and aid organizations, and migrants themselves.

The literature review played a vital role in establishing the baseline of knowledge that has been previously identified regarding barriers to health care for vulnerable and undocumented migrants. Next, the qualitative interviews with charity clinic service providers explored case studies, experiences and perspective of those interacting with, and caring for, the vulnerable and undocumented migrant population. Lastly, the quantitative data analysis of patient medical records provided insight into the scale of impact the barriers had on the patients visiting the clinic in a two-year timeframe. In the discussion, all three components are treated as interlinked, providing a greater foundation for the platform of how charging undocumented migrants for health care further enhances health inequalities in the country.

The project proposal for this study was sent to the partner organization, Doctors of the World UK, on 24 March 2017. Ethics approval was received from King's College London on 6 April 2017.

2.1.1 Partner Organization

Doctors of the World UK was selected as the partner organization for this research due to the organization's work with vulnerable populations, including: migrants, asylum seekers, sex workers, and homeless people from challenging social backgrounds, most of whom have experienced difficulties accessing NHS services (DOTW Website, "What do we do in the UK?").

2.2 Literature Review

A comprehensive literature review was conducted in order to identify the known barriers to health care access for refugees, asylum-seekers and undocumented migrants. These barriers informed the categories of questioning for the semi-structured interview guide as well as providing a basic framework for quantitative analysis. The literature search sought out papers published in English, and was conducted using the online databases PubMed, the Lancet, Elsevier, BMJ, Science Direct, and Google Scholar. Searches were initially conducted in November 2016 and updated in May 2017, without applying restriction on publication date. Search terms used were: ("migrant", "undocumented migrant", "refugee", "transient", OR "asylum-seeker") AND ("health care", "healthcare", "maternity care" "antenatal care" "prenatal care" "pregnancy" "secondary care" "cancer treatment" "diabetes" "kidney failure" "dialysis", "non-communicable diseases" OR "GP access") AND ("UK", "United Kingdom", "England", "Great Britain", OR "London"). In total 47 papers were identified, of which 12 met the inclusion/exclusion criteria and were included in the literature review.

Inclusion criteria	**Exclusion criteria**
• Published in English; • Research conducted in the UK; • Focus on asylum-seekers, refugees, undocumented migrants, trafficked or other types of migrants; • Relates to maternity care or antenatal care; • Relates to secondary care or non-communicable disease treatment • Relates to charging for health care or health care bills/debt/costs; • Relates to immigration status or consequences of deportation.	• Published in any language besides English; • Focus on refugee health only; • International studies without a UK setting; • Studies with no mention of health care costs or bills; • Studies focused only on access to primary care.

2.3 Service Provider Interviews

Semi-structured interviews were then conducted in June and July 2017 with ten (10) Doctors of the World UK (DOTW) service providers. These were: Clinic Supervisors (three), volunteer General Practitioners (GPs) (three), and volunteer Clinic Support Workers (four) in order to gain perspective from frontline staff on the effects of charging for health care on the willingness of migrants in vulnerable circumstances to seek health care. Interviews lasted between 17 and 52 minutes (with an average of 35 minutes). Participants were asked about their role in the Doctors of the World UK clinic, their perception of challenges, barriers and fears faced by the migrant service users they work with in accessing the NHS, the effects of charging for health care on care-seeking behaviour, and opinions on policy recommendations in order to reduce health inequalities (see full interview guide in *Appendix 5*). All interviews except one were recorded (on request of the interview participant) and transcribed verbatim. The interview that was not recorded was transcribed from the interviewer's notes.

Doctors of the World service providers were selected as they are in the unique position to offer a perspective of the influential factors that can shape health policies. In addition, given the long running specialist service provided by the clinic, service providers' specific expertise in relation to undocumented migrant health care in London was considered invaluable. The framing of this type of knowledge plays an important role in policymaking, and is relevant for future policy-shaping recommendations (Poduval et al. 2015; Stone 2002). In this study, no service users were interviewed. However, through Doctors of the World advocacy, the service providers' sharing of case studies were intended to, at least in part, represent undocumented migrants' "silent" voices.

Interview participants were selected and approached with help of the Doctors of the World staff, via an advertisement in the monthly volunteer newsletter and email introductions (*Appendix 2)* in accordance with the inclusion and exclusion criteria below. All interview participants were provided an information sheet (*Appendix 3*) and signed a consent form (*Appendix 4*).

Inclusion Criteria	Exclusion Criteria
• Able to communicate in English • Over the age of 18 • Has been working or volunteering with DOTW for at least 6 months (or working in the clinic for at least 12 shifts)	• Unable to communicate in English • Under the age of 18 • Has been working or volunteering with DOTW for less than 6 months (or has not worked in the clinic for at least 12 shifts)

This type of qualitative research utilized critical theory and positioning, which "view reality not as existing 'out there' but as being produced by particular exploitative social and political systems comprising competing interests where knowledge is controlled to serve those in power" (Grbich, 2013). This was relevant given the marginalized status of undocumented migrants in the UK due to their lack of legal immigration status. The critical theory positioning provided an ideal platform to explore and showcase disparities in healthcare access as experienced by undocumented migrants, as this approach looks at the conditions of vulnerable populations who have little or no public voice, juxtaposed with policies implemented by powerful agencies, in order to understand the ultimate impact of such policies on outcomes for the vulnerable population, and implications for the health of the general population overall.

Qualitative data was analyzed using the software NVivo 11.4 in order to identify and organize themes of variables to be further investigated in the quantitative data set. The use of thematic analysis involved a mapping process of ideas and concepts as well as applying a structured categorization approach of themes and sub-themes into "nodes" (Grbich 2013) (see NVivo coding template and results in *Appendix 6).*

2.4 Quantitative Medical Record Data Analysis

The interviews with service providers informed the quantitative analysis of Doctors of the World medical records and case notes of 773 patients from January 2015-December 2016. This analysis sought to identify how frequently the key chargeable case types which emerged from the qualitative interviews appeared in the data set. These were pregnancy (for antenatal care) and non-communicable diseases requiring secondary care. Additional cases of charging were identified from the long-hand notes of both GPs and clinic support workers. Chargeable cases were specifically sought out in order to understand the potential fears or stigma related to accessing chargeable care, and to understand if delayed care-seeking or late presentation had occurred as a result (see blank templates of the Medical

and Social Forms in *Appendices 7 and 8)*. This portion of the research aimed to assess the rate at which the types of chargeable cases that were highlighted by service providers were encountered in the clinic.

Medical records was analyzed using the software STATA 14. Medical records and social form notes ("strings") were read and coded to create statistical data sets that would indicate delayed care-seeking in chargeable cases of maternity care or secondary care for non-communicable diseases.

3. Results

3.1 Literature Review

The aim of the literature review was to identify the known barriers to accessing health care that were faced by refugees, asylum seekers, and when available, undocumented migrants (from here on all will be referred to as "vulnerable migrants"). The aim of this literature review was to inform the interview guide for the interviews of service providers, as well as the framework for the analysis of patient medical records. One study conducted by Eziefula et al. (2014), broadly categorized the challenges faced by vulnerable migrants in accessing health care into six categories: culture (1), ambiguity (2), language (3), dispersal (4), poverty (5), and stigma (6). These categories were taken as a framework to report the nuanced findings from the wider literature.

3.1.1 Culture

In terms of the cultural barriers that vulnerable migrants faced, studies found that patients often had misaligned expectations of what doctors and other medical professionals were able to do. This was especially prevalent with regard to potentially culturally sensitive issues, such as the treatment of mental health, or conditions associated with one's sexual orientation (Eziefula et al. 2014). Studies also found that many GP practices had discriminatory policies when registering or treating vulnerable migrants, although direct discrimination was often very hard to prove (Britz & McKee 2016). This discrimination sometimes manifested as a perception by service providers or front-line staff that migrant patients would be more frequent users than native-born patients (Stagg et al. 2012), leading them to book more appointments and utilize more of the surgery's resources. Surgery staff were as a result sometimes reluctant to register or book appointments for them. Various divergences between British culture and the native culture of vulnerable migrants have meant difficulty communicating important health-related information, such as when describing symptoms or providing diagnoses.

3.1.2 Ambiguity

Ambiguity was another common barrier for vulnerable migrants in accessing health care in the UK because of a lack of information or guidance about how and what healthcare was available (Poduval et al. 2015; Eziefula et al. 2014; O'Donnell 2007). It was found that manyvulnerable migrants often do not understand their eligibility and entitlement to health care, and often service providers were not well-versed on accessibility protocols for vulnerable patients or able to compensate for patients' knowledge gaps (Reeves et al. 2006; Britz & McKee 2016). The ambiguity of the system was often exacerbated due to a lack of access to technology among migrants.

3.1.3 Language

Language was often a challenge for care accessibility, but not a complete barrier. Vulnerable migrants lacking English speaking and comprehension skills frequently struggled to communicate with service providers and service providers sometimes were not willing to engage with in-person or telephone interpreters given limited appointment time (Eziefula et al. 2014). Friends or family would regularly support individuals who lacked English skills by accompanying them to the GP. However, when no such support networks were available, many vulnerable migrants struggled to negotiate their entitlements to health care, even in situations where they were aware of them (Reeves et al. 2006; Stagg et al. 2012).

3.1.4 Dispersal

It was discussed in some articles that the fragmented structure ('dispersal') of the UK health system often meant that patients had to attend different locations for treatment and continuity of care was more difficult, especially for chronic diseases such as HIV (Grit et al. 2012) or diabetes, where strict regimens and continuous support were necessary for successful treatment (Eziefula et al. 2014). In addition, many vulnerable migrants came from countries with very different health care systems, including for example patient self-referral to specialist care rather than via a primary care gatekeeper (Poduval et al. 2015; O'Donnell 2007). This could cause additional confusion for a vulnerable migrant seeking to receive comprehensive care for a complex ailment.

3.1.5 Poverty

An underlying driver of various challenges that vulnerable migrants faced in accessing care was having limited financial means or suffering a state of poverty, as their immigration status does not allow them to seek formal employment. Health may often be a secondary concern to other basic needs such as food and shelter, especially when there is a risk that treatment would be costly. In addition, poor living conditions and lack of essential resources (Britz & McKee 2016; Eziefula et al. 2014) hindered their ability to travel to clinics (Hemming et al. 2010).

3.1.6 Stigma

Stigma was identified as a complex and multifaceted challenge for vulnerable migrants attempting to access health care. For example, social implications of certain diagnoses (such as for HIV or tuberculosis) (Eziefula et al. 2014) could affect the individual's status or acceptance in their community. However, more complex still was the stigma attached to their asylum or immigration status (Bhatia 2007). "Health tourism" (Grit et al. 2012; Britz & McKee 2016; Eziefula et al. 2014;

Pollock 2013) as a label was mentioned by many sources as a shameful tag often encountered by migrants trying to access health car. This was seen to be driven by media-fueled claims that high health care costs and an unbalanced NHS budget were as a result, at least in part, of the care received by migrants not paying national insurance (NI), though as discussed later in this paper, the data do not support this claim.

In addition, a clear fear was identified about the overlap between health and immigration services in the UK (Stagg et al. 2012), fostering anxiety over potential immigration consequences or even deportation as a result of accessing the NHS (Poduval et al. 2015; Britz & McKee 2016). Political discussions over the last few years on further proposed legal restrictions on health care and reduced funding for social care benefits (Britz & McKee 2016) have fed into this apprehension over the eligibility and accessibility of care for vulnerable migrants. This pervasive stigma and fear present in the national discourse meant that many migrants delayed seeking health care as a result of the potential social discomfort or negative consequences of doing so.

The literature review findings presented above were used to inform the formulation of questions for the semi-structured interview guide (*Appendix 5*), specifically in relation to charging for health care and its effects on care-seeking behaviour within the undocumented migrant population accessing DOTW services in London.

3.2 Qualitative Interviews

Ten (10) interviews were conducted with DOTW service providers. These were: three (3) Clinic Supervision staff members (S1, S2, S3), three (3) volunteer General Practitioners (GP1, GP2, GP3), and four (4) volunteer Clinic Support Workers (V1, V2, V3, V4). The interviews explored the experiences and observations of the service providers when interacting with service users in the Doctors of the World clinic over the last two years, and focused on experiences of health care charging and any changes in care-seeking behavior noted as a result of healthcare charges. The detailed thematic analysis and framework can be found in *Appendix 6*.

3.2.1 Perceptions of Service Users' Understanding of Entitlements

When exploring the relationship between cost of care and care-seeking behaviour, providers noted that "*many people have an idea that they need to pay for primary care*" (S1). That they needed to pay for primary care was a common misunderstanding among service users and was closely linked to the themes of culture and ambiguity that emerged from the literature. As many migrants come from countries where health care is not free, they assume they have no entitlements to care, and the NHS provides little educational outreach in this regard. Ultimately, service users were sometimes lying about their identity to access health care because they do not understand their own rights to care. One

volunteer described cases she had been part of where service users had used fake names to register for a GP, "*it just shows the desperation… [people] are at a point where they need health care, and the only way to get it is to lie*" (V4).

3.2.2 Public Health Risks and Cost-effectiveness

One staff member pointed out "*if you're preventing disease, you're saving money in the long term*" (S2). The benefits of enabling access to necessary care were expressed both in terms of public health and population protection as well as health service rationalization and cost-effective use of health system resources. Another staff member agreed, "*if you [the service user] present late, it's quite possible that that late presentation will mean more complex care and a higher bill than you would have had otherwise*" (S1). Reducing disease is essential to creating herd immunity in the community, and catching early symptoms, or ensuring responsive preventative care can reduce the cost of later treatment, or as one GP put it "*they're [the NHS] going to end up with a lot more expensive emergency care*" (GP3). One volunteer also mentioned that given the status of the UK as a "*rich country*", *it was "just ridiculous to have people who cannot access care*" (V4). Not providing the health care access to everyone was strongly stated by another GP as a way of creating "*a third world pocket in a first world country*" (GP2).

3.2.3 Charging for Health Care

Apart from overcoming the barriers to understanding how to access free primary care, there was the very real threat of charges in secondary care that all ten interview participants mentioned. This often sits alongside the barrier theme of poverty, because most vulnerable migrants (including asylum seekers) are not permitted to work. One GP mentioned that she was skeptical of how much of the owed money was actually being repaid, "*because most of these people don't have the money, otherwise they wouldn't be here trying to get a better life, because they're poor*" (GP2). A volunteer mentioned "*I think it's ridiculous to expect [people who] don't have money to actually pay for their care*" (V4). A supervisor for the Family Clinic, which focuses on providing maternity and early childhood care, said that this was an "*issue of destitute, most of them [the service users] cannot afford the smallest thing that we take for granted, a loaf of bread*" (S3) and continued "*we know for sure 100% that these people will never pay the bill, might as well accept them earlier so the bill is smaller*" (S3). This is further complicated in situations where hospitals refuse to continue treatment if prior bills have not been paid, as observed in cases of cancer treatment (S2). It was emphasized that access to care was often the top priority when helping service users who were in urgent need of chargeable treatment, that they did indeed have the right to receive care, even with the potential of a future bill (GP3). Furthermore, cases of pregnant women not accessing antenatal care because they had "*concerns*" (GP1) or were "*afraid of*" (S3) bills that they would not be able to pay, was "*dangerous*" (GP1) and "*increasing*" (S3).

3.2.4 Home Office Involvement

One of the main reasons that charging for health care is so prominent an issue in public debate is because of the perceived links between the NHS and the Home Office, the UK's immigration department. Many undocumented migrants have built their life in the UK "*below the radar*" (S1, V2, V3) and as one staff member mentioned "*all hospitals must report debt [unpaid hospital bills] to the home office*" (S1). The concern over the repercussions of debt (S1) meant that many service users were "*terrified of being deported or detained because they cannot pay for the maternity or antenatal care*" (S3). This was emphasized as a question of one's human rights (S2), where one GP described it as "*a sort of hierarchy - if you were a true refugee, have you been really treated badly in your country? Or are you just poor, as if that wasn't a good enough reason to want a better life*" (GP2). One volunteer that has worked in the clinic for several years, as well as being a retired NHS nurse, mentioned that "*immigrant status, you know the hostile environment, has become much more acute in the last 18 months – two years*" (V3), alluding to negative public attitudes regarding the connection between immigration and any access to public services, which have become stronger and more closely linked in recent years.

3.2.5 Pregnancy

All ten interview participants spoke about cases they had been involved in with pregnant women and were fearful of accessing antenatal care because of the £5000-6500 bill affiliated to maternity care and delivery for those without access to public funds due to their immigration status. One GP mentioned a case of a patient who had not accessed any antenatal care at 22 weeks, more than halfway through her pregnancy (GP1). The family clinic supervisor even mentioned a case where "*one woman was 7 months pregnant and was contemplating abortion because she could not afford care*" (S3). In the NHS, family planning and sexual health (contraception and sexually transmitted infection testing) are free to everyone, but maternity care and antenatal care are not. The family clinic supervisor stated boldly that "*this is a war against women, it discriminates women unfairly*" (S3). As one volunteer put it "*these people aren't asking for ridiculous things, they're not going for cosmetic surgery (laughs) they're coming to have a baby… they don't particularly want to spend a lot of time in hospital, they just want a safe place to have their baby and then go home again*" (V4).

3.2.6 Non-Communicable Diseases

Unlike pregnancy, treatment for non-communicable diseases and conditions (such as cancers, diabetes, kidney failure, etc.) can be tricky to navigate for the service user given that it is almost impossible to estimate the amount of the final bill or charge they will be responsible for. Some

undocumented migrants receiving cancer treatment "*[would] be happy to pay in small installments because they obviously want to care for themselves, and they want to receive the treatments, but some hospitals I've seen have been very … strict in terms of receiving the payment upfront*" (S2). This drives some patients to self-medicating or buying drugs online, such as in the case of patients with high blood pressure or diabetes: "*[these people] will often receive medication from family or friends, or they get medication sent from back home, wherever that might be, and often the medication is inappropriate, or the doses aren't correct or they're not fulfilling the course of treatment, or getting monitored*" (S1). Paying for treatment of life- threatening or long-term disease can create additional worry and anxiety, as one volunteer mentioned a patient with lymphoma "*he was worried about the bill and the money, so a really difficult situation because he had to have the treatment, but knew that there was going to be this massive bill coming which he had no way of being able to pay*" (V2). Another GP mentioned a case of severely delayed care-seeking as a result of concerns related to charging, in which "*one was a woman who came because she got a lump in her breast, and when I examined her, I would say, definitely as a GP that she [had] breast cancer, so she hadn't accessed in an early stage, because she'd been frightened to go see a doctor*" (GP3). The additional stress of not knowing how to pay hospital costs and the fear of risking deportation becomes a huge barrier for undocumented migrants in wanting to access care in the first place, especially when their condition is more severe and thus potentially more costly.

3.2.7 Health Tourism

Given that maternity care and secondary care can both be costly, there is also a backlash from the media and the public, creating "rumors" (V2) that blame undocumented migrants for taking advantage of the NHS, fueling a belief that they are a major resource burden on the system. One volunteer stated that "*the* Daily Mail *loves to call it 'health tourism' … [but] all the people that we see at Bethnal Green [the location of the clinic] do not come to the UK because of health, they come because they flee, they're fleeing their lives*" (V1). In addition, a clinic supervisor stated "*they [the service users] are vulnerable because they don't just come here for a [general] health reason - to register with a GP or [because they] have a cough - but they come here because this is their last hope*" (S3). There was a consensus among service providers that a more balanced view of the actual cost of 'health tourism' to the NHS budget was needed and that other much greater drivers of growing costs, such as technological innovation and an ageing population should be given proportionate attention in public discourse. However, one volunteer acknowledged that the public is scared of "*[what they] see as opportunism, because they see people receiving things like free health care, perhaps, who sort of exist on the periphery of society, they don't contribute... they don't put anything into the pot to use the sort of cliché* Daily Mail *expression… but of course they're forced to remain at the periphery of societies because as a society we don't allow them to really integrate, we don't allow them to work, we don't allow them to pay taxes*" (V3). This emphasizes a

public fear of the abuse of public goods by a segment of the population that is not viewed as contributors. However, as the volunteer acknowledges it is quickly forgotten that these people are not able to work because they are denied the right to do so.

3.2.8 NHS Moving Forward

Closing the interviews, each participant was asked about the direction they thought the health care system in the UK should take in order to serve vulnerable and undocumented migrants better. One major theme that emerged was the desire to separate the question of immigration status from health care (V3, S3, GP3), boiling down to the belief in a "*right*" (GP3) for everyone to access health care. In addition, the theme of free maternity care was stated by S2, S3, GP2, and GP3, including claims that "*I believe regardless of immigration status or country of nationality, maternity care should be free - the country can afford it*" (S3), and a suggestion that "*maybe even have a fund that can help pregnant patients pay their secondary care bill*" (GP2). The family clinic supervisor stated that "*the government has lost its mind…. frightening women with their immigration status [deportation], when I believe immigration and health care should be two completely separate things*" (S3). One GP mentioned how her observations working in the NHS, and volunteering at the charity clinic has made her realize the changes that have been happening over the last decades, and are being pushed to happen more and more, *"you know that it's basically an American system, where's your ability to pay … how … it fills me with horror, really*" (GP2).

The outcome of the qualitative interviews raised many interesting points of specific case studies shared, including those of pregnant women presenting late in their pregnancy without having received any antenatal care, and individuals suffering from non- communicable diseases unable to continue their treatments because of huge bills and refusal from hospitals to provide further care until debt was settled. These case types were brought into the analysis of medical records and social form data (blank templates of these forms in *Appendix 7 and 8*) from the DOTW clinic in order to identify how frequently they showed up in the clinic, and what percentage of this particular clinic population they affected.

3.3 Quantitative Medical Record Data Analysis

Medical records and social forms of 773 patients presenting at the Doctors of the World clinic in 2015-2016 were searched for the themes of pregnancy (in terms of antenatal care), non-communicable diseases (in terms of secondary care), and other service users with bills or debt in order to identify the magnitude of the undocumented migrant population affected by secondary care charging and to assess any effects on care-seeking behaviour.

3.3.1 Pregnancy

Out of 773 total patient medical records, 345 were female (44.6%) and 55 were pregnant (15.9% of women) at the point of presenting to the DOTW clinic. Pregnant women are entitled to antenatal care, but if they do not have access to public funds due to their immigration status, the antenatal care and delivery of the child are chargeable and they will receive a bill. The NHS offers the first antenatal appointments between 8-14 weeks, in the form of an ultrasound scan and latest guidelines from the National Institute for Health and Care Excellence (NICE) recommend that the first ante-natal appointment be booked by 10 weeks for uncomplicated pregnancies. Of the 55 pregnant women, 34 (61.8%) were ten or more weeks pregnant before they first came to the charity clinic to start the registration process for a GP and to get a referral to a hospital for antenatal care (often taking two-three weeks at minimum to complete). The NHS offers the second antenatal appointment between 18-21 weeks of pregnancy, in which 14 (25%) women had not yet accessed any antenatal care. In one case, a woman first accessed the Doctors of the World clinic at 37 weeks in her pregnancy, only to go into labor three hours after leaving the clinic which assisted her in setting up her first antenatal appointment.

3.3.2 Non-Communicable Diseases

Out of 773 total patient medical records, 88 (11.3%) had some kind of non-communicable disease for which secondary care treatment would incur a charge. This included 18 (2.3%) patients with some type of cancer, the most common being breast cancer (16.6% of total cancer patients), cervical cancer (11.1% of total cancer patients) as well as prostate, oral, kidney, and brain cancers (combined, 5.5% of total cancer patients). Three additional (3.8% of total 88) additional patients were listed as having lumps in their breasts when examined by the volunteer doctors, which would be a strong indicator for breast cancer. Other non-communicable diseases included seven (0.9%) patients with diabetes and 11 (1.4%) patients in which the volunteer doctor diagnosed diabetes, two (0.3%) patients with cataracts, two (0.3%) patients with kidney failure or requiring dialysis, four (5.2%) with fibroids (mostly cases of women who had been raped), and nine (1.2%) patients suffering from post-stroke complications, or who were diagnosed by the volunteer doctors as having had a stroke. In addition, high blood pressure was noted for 23 (2.9%) patients, diagnosed by the volunteer doctors in five (0.6%) patients, and high cholesterol was noted in seven (0.9%) patients. Fifteen (1.9%) patient records mentioned delayed care- seeking for known pain, illness or diseases, by anywhere between two weeks to two years.

3.3.3 Experience and Impacts of Charging and Debt

Eleven (1.4% of total) patients either had a bill or were going to be issued bills by the NHS, which

amounted to anywhere between £50-£80,000. Fifteen (1.9%) explicitly expressed that they were afraid of being charged for treatment, or had a concern about the potential bills prior to receiving treatment. The 55 pregnant women would also be liable for charging (often around £5,000-£6,500 if no complication in the pregnancy, but possibly higher) given that undocumented migrants do not have access to public funds due to their immigration status. Of the pregnant women, three (5.4%) explicitly expressed that they were afraid of the charges for antenatal care and the potential consequences of being reported to the Home Office. One service user requested information for termination of her pregnancy in order to avoid being sent a bill. Four (7.2%) patients had had midwives, hospitals, or administrators inquiring about their immigration status, with one service user having received a letter from the Overseas Visitors (OV) office requesting a deposit of £6,500 after her first antenatal care appointment, suspending future appointments until the debt was paid.

In total, 143 (18.5%) service users would be affected by charges in maternity care or secondary care, with many fearing the potential bills that could be issued to them, and that the consequences of these unpaid bills could endanger their immigration status, asylum claims, or ability to remain in the country under the radar. Forty-nine (34.3% of chargeable cases) service users (34 pregnant woman presenting later than 10 weeks in their pregnancy and 15 non-communicable disease patients) had delayed seeking care in accessing the NHS, several with listed fears of being charged for care, or the fear of the Home Office being informed about their presence in the country.

4. Discussion and Global Health Impact

The NHS offers several health care services for free, namely: primary care, emergency care, family planning, infectious disease treatment, and treatment of conditions caused by torture (NHS Choices). However, additional health care such maternity care and other types of secondary care will incur a charge for those who do not have access to public funds, unless the individual qualifies for an exemption or entitlement (such as for asylum seekers or victims of trafficking) or low-income support. While these exemptions are in place to ensure access, many individuals are not aware of how to utilize them and delay seeking treatment. Fifty- two percent (52%) of patients of the Doctors of the World (DOTW) London clinic listed a "poor understanding or lack of knowledge of their rights and of the rules of the system [by both service users and providers]," as one of their main problems in accessing care (Doctors of the World Report 2011/2012). This system has also caused some patients to be wrongly refused care, and cost recovery programs are sending health service bills to people that have no income, resulting in discrimination and further restriction of health care for the most vulnerable. At the DOTW Clinic in East London "73% of patients were not registered with a GP even though in the context of the British National Health Service they are eligible to register" (DOTW Report 2011/2012). Many patients that visit the DOTW clinic have delayed seeking health care over fears regarding their rights and cost of care.

As has been identified in this study, even with free primary care, the needs of undocumented migrants extend into secondary care and maternity care, the costs of which are not covered under the current system. Undocumented migrants tend to be some of the most vulnerable in the population, often requiring additional language support and resources. In addition, given their lack of formal immigration status, many are unable to work lawfully or contribute to paying taxes or national insurance (NI), meaning health care bills would be unrealistic for them to be able to pay out of pocket. Since the UK government is looking to increase charging this population for NHS services, this study strives to showcase the unintended consequences of the current system on access to health services for undocumented migrants, and the extrapolated consequences of increased costs to the system and health risk to the general population. Furthermore, it aims to provide substantial data for the formulation and refinement of recommendations to the UK government for NHS health care systems regarding services provided to vulnerable populations.

4.1 Summary of Findings

The findings from the literature review, service provider interviews, and medical record analysis indicate that a substantial proportion (nearly 20%) of the undocumented migrant population attending the DOTW clinic are affected by charges for health care treatment, which provide insight into the implications that the current level of charging has on migrant population. The literature review indicated that vulnerable and undocumented migrants struggle to access health care services due to culture, ambiguity, language, dispersal, poverty, and stigma barriers. These attributes were investigated in the context of the qualitative interviews with Doctors of the World service providers to understand specific case studies in the clinic of observed service users, which included pregnant women, and patients with non-communicable diseases in need of secondary care. Next, these case types were compared with medical records of 773 patients from 2015-2016, which found that 55 (15.9% of women) patients were pregnant, and 88 (11.3%) patients were suffering from a non-communicable disease (such as cancer, diabetes, kidney failure, etc.). In total, 143 (18.5%) patients in the charity clinic were affected by health care charging with over one-third of these patients 49 (34.3% of chargeable cases) delaying seeking health care because of it.

Almost 20% of the undocumented migrant population will be faced with a health care charge or bill that they most likely will not have the means to pay. This can have detrimental effects on their personal finances, given that most are unable to work, with some living in dire circumstances of destitution. Furthermore, UK health policy requires unpaid hospital bills to be reported to the Home Office, which could negatively affect asylum claims or bring them to the attention of the Home Office, which often is one of the largest barriers an undocumented migrant can face as they try to build a better life for themselves and their family. For cases of pregnant women, not accessing care can negatively affect both the mother and child, and create future health care costs for the system of additional unhealthy individuals requiring further medical attention and more expensive treatment.

4.2 Impact on Global Health

Over 60 years ago, our post-World War II forefathers dealt with a very different landscape of migration, as they wrote the United Nations 1951 Convention on Refugees. Today, migration is more widespread, with people moving between countries of economic prosperity and economic hardship, for reasons spanning political, social, economic, and can include escaping war or conflict, discrimination and persecution, seeking family reunification, or simply to follow the dream of having a better life. With these ever- changing patterns of human migration, the migration of disease and health needs are now intercontinental as well. Providing adequate migrant health care and addressing these migrant needs is therefore fundamental to ensuring herd immunity is upheld for the public as a whole in the context

of fast-moving societies and communities.

4.2.1 Discrediting "Health Tourism" and the Impact on the NHS Budget

The effect of charging for health care creates barriers and stigma for undocumented migrants to accessing the care they need. Not only are many undocumented migrants vulnerable and even destitute, given that they are not able to work due to their immigration status, but many also face additional challenges due to poor health and lack of resources to get help. These delays in accessing health care create great public health risks due to lack of preventative care or early-treatment, and can drive up additional costs for late presentations at A&E. In addition, the media-driven scandal that "health tourism" is burdening the NHS can be discredited by government sources. The House of Commons Parliamentary Debate (March 2013) states that the "Prime Minister's spokesperson put the cost to the NHS of "health tourism" at £10 million to £20 million" (Hansard 2013). Given that the entire NHS budget in 2013 was £113.2 billion (NHS Choices), this means that "health tourism" accounts for approximately 0.17% of the total NHS budget. Not only does this indicate that undocumented migrant health is not the problem balancing the NHS budget, but furthermore, providing earlier treatment and preventative care to undocumented migrants, could even further reduce these costs. In addition, as a universal health care system, the NHS is one of the most cost effective compared to other large developed economies. In 2014, health spending in the UK was £179 billion, or 9.9% of GDP, which equates to £2,777 per person. In the United States, health care spending is over 16% of its GDP, which equates to about £6,311 per person. Moreover, the UK has a higher life expectancy than the US, 81.4 years versus 78.8 year, respectively (Office for National Statistics, 2016). Therefore, the UK's National Health Service is an economical choice for a healthy population.

The UK has a strong history of providing universal health care to the people within its borders, based on the principles of preventative care and reducing health inequalities. In the long term, these values help the system save money by providing a fast response to potential threats. However, if undocumented migrants fear accessing health care services due to the potential risk of incurring debt, being reported to the Home Office or even being deported, the philosophy of prevention cannot be upheld. Separating one's immigration status from the ability to access health care means that good public health can ensure the minimization of infectious disease, and reduce costs in emergency spending.

4.3 Research Strengths

Conducting research alongside the Doctors of the World clinic provided a cross-sectional look at a specific proportion of the undocumented migrant population in London. Speaking to the service

providers that work in the charity clinic, who are the primary support for these undocumented migrants, provided unique insight into how the complex interplay between the Home Office and immigration status dictates many people's ability and willingness to access health care services even when they are in great need. By focusing the quantitative data analysis portion on maternity care and non-communicable diseases, more emphasis could be put into analyzing all relevant patient notes in greater detail, in order to understand the contexts of the individuals and the types of situations they found themselves in.

4.4 Research Limitations

This study was conducted at only one London clinic, and undocumented migrants in other parts of London or the UK may not be represented, given that these individuals would most likely not be able to travel to East London. Limitations of the interviews included sole interview bias and language skills limited to English. Extension of the interview participants beyond DOTW staff and volunteers, to for example GPs practicing externally or other health and social care stakeholders who come into contact with the vulnerable groups concerned, could have potentially provided another perspective on the issue which may have further enriched the data. In addition the inclusion of service user interviewees would have provided an additional and important perspective. Limitations of the medical record data analysis were based on the fact that notes that may have contained possible spelling mistakes would not be picked up in keyword searches, as well as researcher interpretation bias.

4.5 Further Research

Although there are many ethical and logistical complexities to interviewing vulnerable service users, their insight could be useful and could be the topic of a future study to complement these findings. Additional valuable research could include in-depth cross-sectional case studies of individuals that are directly affected by charging for health care (be it pregnant women, or individuals suffering from non-communicable diseases), which would provide greater depth to the literature in order to understand care-seeking behavior and delays more comprehensively from the individuals' perspective. This could include robust qualitative and quantitative data that records the struggles faced by undocumented migrants in dealing with health care costs, charging practices, and how undocumented migrant navigate trying to access care while protecting their ability to stay in the country despite lack of formalized immigration status. The issue of charging is complex and has many layers, but by investigating service users in terms of their fears and rationale, policy can be formulated to best serve them.

4.6 Conclusion

In the United Kingdom, health is considered a human right, and open access to health care services creates a healthier society for everyone. In this study, it was investigated how the ability for the community to rely on its herd immunity becomes challenged and how health care costs for the system are ultimately increased if a proportion of the population is unable to access timely health care due to their fear of being charged for treatment or undesirable consequences to their immigration status. In order for the UK to continue to enjoy a healthy and productive labour force, it is necessary to limit any restriction to accessing health care for all sub-segments of the population. Potential solutions could include a defined separation which disallows data-sharing between the Home Office and health care services, and a special fund for maternity care or secondary care treatment for people who are unable to work.

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Appendix 1: Immigration Status: Definitions & Abbreviations

Ordinary Resident	A person living in the UK for a settled purpose (i.e. work or study).
Refugee	A person who has a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country. (1951 Convention on Refugees)
Asylum Seeker	A person who has applied for, and is still waiting for a response, to become a refugee under the 1951 United Nations Convention on Refugees.
Undocumented Migrants	
Failed Asylum Seeker	A person who has exhausted all legal means of seeking asylum.
Economic Migrant	A person who seeks work abroad as opportunities are unavailable in their home country.

(Reeves et al. 2006)

Abbreviations:

A&E Accidents & Emergency

DH Department of Health

DOTW Doctors of the World

GP General Practice/ Practitioners

HIV Human Immunodeficiency Virus

MoU Memorandum of Understanding

NI National Insurance

NHS National Health Service

NHSE National Health Service England

NHSD National Health Service Digital

NGO Non-Governmental Organization

PHE Public Health England

UK United Kingdom

Appendix 2: Interview Participant Advert

PARTICIPATION ADVERT FOR DOTW VOLUTNEER NEWSLETTE

We would like to invite DOTW volunteers (GPs, Nurses, Clinic Support Workers, and Case Workers) to participate in a study to ***Evaluate fears of undocumented migrants in seeking healthcare*** conducted alongside Doctors of the World UK and King's College London.

We are conducting this researcher with the aim to encourage the UK government to increase NHS service access to vulnerable groups.

We invite you to be involved by **participating in an interview** to help us identifying specific fears that you have observed in DOTW Service Users in terms of accessing health care. Please note that **all interviews are strictly confidential and anonymous** and no identifying information about you (including your name, birthdate, or post code), will be shared publically.

Please see the information sheet attached for more in-depth details about this research. If

you have any questions, please do not hesitate to contact the researcher:

[redacted]
Email: [redacted]
Phone: [redacted]

Thank you for considering being part of this research.

Appendix 3: Information Sheet

INFORMATION SHEET FOR PARTICIPANTS

REC Reference Number: LRU-16/17-4305

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: Evaluating fears of undocumented migrants in seeking health care

Introduction

In the United Kingdom, the NHS offers several health care services for free to ordinary resident status holders of the UK, namely: primary care, emergency care, family planning, contagious disease treatment, and treatment of conditions caused by torture. However, eye exams and glasses, dental checks, secondary care, and outpatient appointments are chargeable, and prescription medications incur a fixed cost, unless the individual qualifies for an exemption or entitlement (such as for asylum seekers or victims of trafficking) or low-income support. While these exemptions and entitlements are in place to promote/ensure access, many individuals are not aware of how to utilize them and delay seeking treatment. 52% of patients of the DOTW London clinic listed a "poor understanding or lack of knowledge of their rights and of the rules of the system" as their main problem in accessing care. This system has also caused some patients to be wrongly refused care and cost recovery programs are sending service bills to some people that have no income, resulting in discrimination and further restriction of health care for the most vulnerable. At the DOTW Clinic in London "73% of patients were not registered with a GP even though in the context of the British National Health Service they are eligible to register."

What is the purpose of the study?

Since the UK government is looking to increase charging of NHS services, research is necessary to assess the effects of the current systems on access to health services for vulnerable groups. This research should serve to provide substantial data for formulation and refinement of recommendations to the UK government for NHS health care charging systems regarding services provided to vulnerable populations.

Why have I been invited to take part?

You have been invited to participate in this study to understand from your perspective what are the fears and challenging to accessing health care for undocumented migrants in the UK.

Do I have to take part?

Participation is voluntary. You do not have to take part. You should read this information and if you have any questions, you should email the researcher [redacted] at [redacted]. Do not agree to participate until all your questions have been answered.

What will happen to me if I take part?

If you agree to take part in this study, you will be invited to participate in a semi-structured interview with the researcher lasting between 30-90 minutes. The researcher will ask you a series of questions along the themes of fears and challenges to accessing health care.

What are the possible benefits and risks of taking part?

There are no direct benefits of participating in this study. However, the findings from this study may contribute to UK policy changes that affect access to health care to vulnerable groups.

There are no foreseeable risks in participating in this study. It is possible that you may not wish to answer all the questions and withdraw your participation. Please note your participation can be terminated at any time, and if you wish to withdraw your data from the study after the interview has been completed, you can do so up until 15th of July.

Will my taking part be kept confidential?
Yes, participating in the study will be completely confidential. All information you share will not be linked to your name, birthdate or postcode.

How is the project being funded?
This is a project as part of [redacted] MSc course dissertation. The funding is provided by King's College London.

What will happen to the results of the study?
The results of the study will be analyzed for the purpose of a Doctors of the World report on fears and challenges to seeking health care of undocumented migrants. In addition it will be presented as part of [redacted] dissertation project to King's College London, and may be published in a scientific journal.

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:

[redacted]
Email: [redacted]
Phone: [redacted]

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:

Ms. Fawzia Fall
Teaching Fellow – Department of Global Health Email:
fawzia.fall@kcl.ac.uk
Phone: 02078485168

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 4: Consent Form

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.

Title of Study: Evaluating fears of undocumented migrants in seeking health care

King's College Research Ethics Committee Ref: LRU-16/17-4305

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 24th of March, Version 1 for the above study. I have had the opportunity to consider he information and asked questions which have been answered satisfactorily.**

2. ***I understand that I will be able to withdraw my data up to 15th of July.** ☐

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. No personal details (such as my name, birthdate, or post code) will be shared publically or published as part of this study.** ☐

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 agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would/would not be identifiable in any report). ☐

7. I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. ☐

8. I consent to my interview being audio recorded. ☐

9. 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. ☐

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: Interview Guide

Welcome and Introduction

Make participant feel comfortable. Make small talk and ask about how they are feeling, what they have been up to today, etc. Introduce oneself and the concept of the researcher.

Go over Information Sheet and Sign Consent Form

In detail, go through every point of the information sheet and ensure that participate understand the scope of the researcher. Allow for as many questions and as much time as necessary. Discuss use of recording device. If recording device is to be used, do not turn on until after the name and introduction.

Start of Interview

Ask participant to tell you about themselves, their background, and their role at the DOTW clinic.

Access to Health care

Ask participant about their experiences with service users accessing the NHS or health care services in the UK, and what types of challenges they faced.

Challenges to Accessing Health care

Explore different types of challenges to health care such as cultural, ambiguity, language, dispersal, poverty and stigma. Include discussion over what fears they have been told about from service users or observed associated with accessing health care in the UK.

Charging for Health Care

Ask participant about their service users' experiences, or fears of, being charged for accessing health care in the UK.

Immigration Status and Legal Changes

Ask participants about their experiences with service users and immigration in the UK and how it affects their service users' health care-seeking behavior.

Secondary Care

Ask participants about their experiences with service users who are pregnant or require secondary care treatment (such as for non-communicable diseases). Encourage case studies.

Further Comments

Ask participant if they have any further topics they would like to discuss regarding the health care system in the UK and access to care for undocumented migrants.

Closing

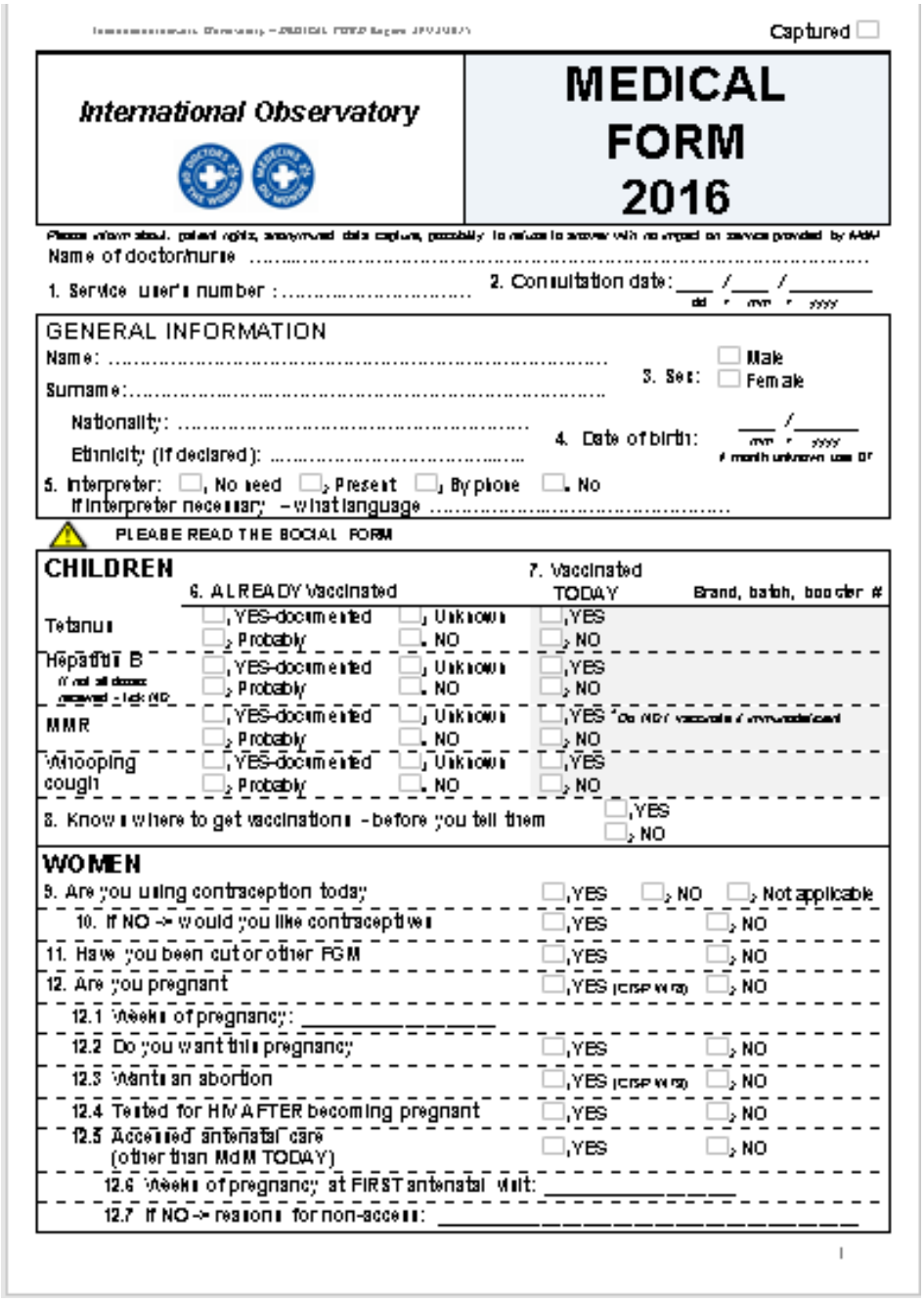
Thank participant for their time in taking part in this research. Reassure participant that all information will be kept confidential and that their anonymity will be upheld. Let participant know the status of the research and when results will be published.

Appendix 6: Interview Coding

Node	Number of Sources	Number of References
Cost of Care	10	92
Immigration	10	83
Pregnancy	10	59
Documentation	9	37
Language	6	26
Delayed Care	3	23
Secondary Care	7	23
Migrant Needs	5	21
Education	3	13
Understand System	3	12
Public Health	6	11
NHS Digital	3	9
Entitlements	3	8
Cultural Stigma	3	6
Health Tourism	6	6
Inequalities	3	6
Discrimination	3	5
Safety	1	2
Torture	1	2
Economic Migrant	1	1
No Help	1	1
Time Limit	1	1

Appendix 7: Patient Medical Form Questionnaire

The below images are sections of the Medical form that is completed by DOTW staff.



Captured ☐

International Observatory

MEDICAL FORM 2016

Please inform about: patient rights, anonymized data capture, possibility to refuse to answer with no impact on service provided by MdM

Name of doctor/nurse .....

1. Service user's number : ..... 2. Consultation date: ___ /___ /_____ dd / mm / yyyy

GENERAL INFORMATION

Name: .....

Surname: .....

Nationality: .....

Ethnicity (if declared): .....

3. Sex: ☐ Male ☐ Female

4. Date of birth: ___ /_____ mm / yyyy if month unknown use 07

5. Interpreter: ☐ 1 No need ☐ 2 Present ☐ 3 By phone ☐ 4 No

If interpreter necessary – what language .....

⚠ PLEASE READ THE SOCIAL FORM

CHILDREN

	6. ALREADY Vaccinated		7. Vaccinated TODAY	Brand, batch, booster #
Tetanus	☐ 1 YES-documented ☐ 2 Probably	☐ 3 Unknown ☐ 4 NO	☐ 1 YES ☐ 2 NO	
Hepatitis B (if not all doses received – tick NO)	☐ 1 YES-documented ☐ 2 Probably	☐ 3 Unknown ☐ 4 NO	☐ 1 YES ☐ 2 NO	
MMR	☐ 1 YES-documented ☐ 2 Probably	☐ 3 Unknown ☐ 4 NO	☐ 1 YES ☐ 2 NO	Do NOT vaccinate if immunodeficient
Whooping cough	☐ 1 YES-documented ☐ 2 Probably	☐ 3 Unknown ☐ 4 NO	☐ 1 YES ☐ 2 NO	

8. Knows where to get vaccinations – before you tell them ☐ 1 YES ☐ 2 NO

WOMEN

9. Are you using contraception today	☐ 1 YES	☐ 2 NO	☐ 3 Not applicable
10. If NO -> would you like contraceptive	☐ 1 YES	☐ 2 NO	
11. Have you been cut or other FGM	☐ 1 YES	☐ 2 NO	
12. Are you pregnant	☐ 1 YES (circle wks)	☐ 2 NO	
12.1 Weeks of pregnancy: _____			
12.2 Do you want this pregnancy	☐ 1 YES	☐ 2 NO	
12.3 Want an abortion	☐ 1 YES (circle wks)	☐ 2 NO	
12.4 Tested for HIV AFTER becoming pregnant	☐ 1 YES	☐ 2 NO	
12.5 Accessed antenatal care (other than MdM TODAY)	☐ 1 YES	☐ 2 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 experience ☐ 1 YES ☐ 2 NO

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

Blood pressure	Heart rate	Weight	Height	BMI
___ / ___ mm Hg	____ b/m	___ kg	____ cm	____ kg/m²

HEALTH STATE – diagnosis, symptoms, complaints

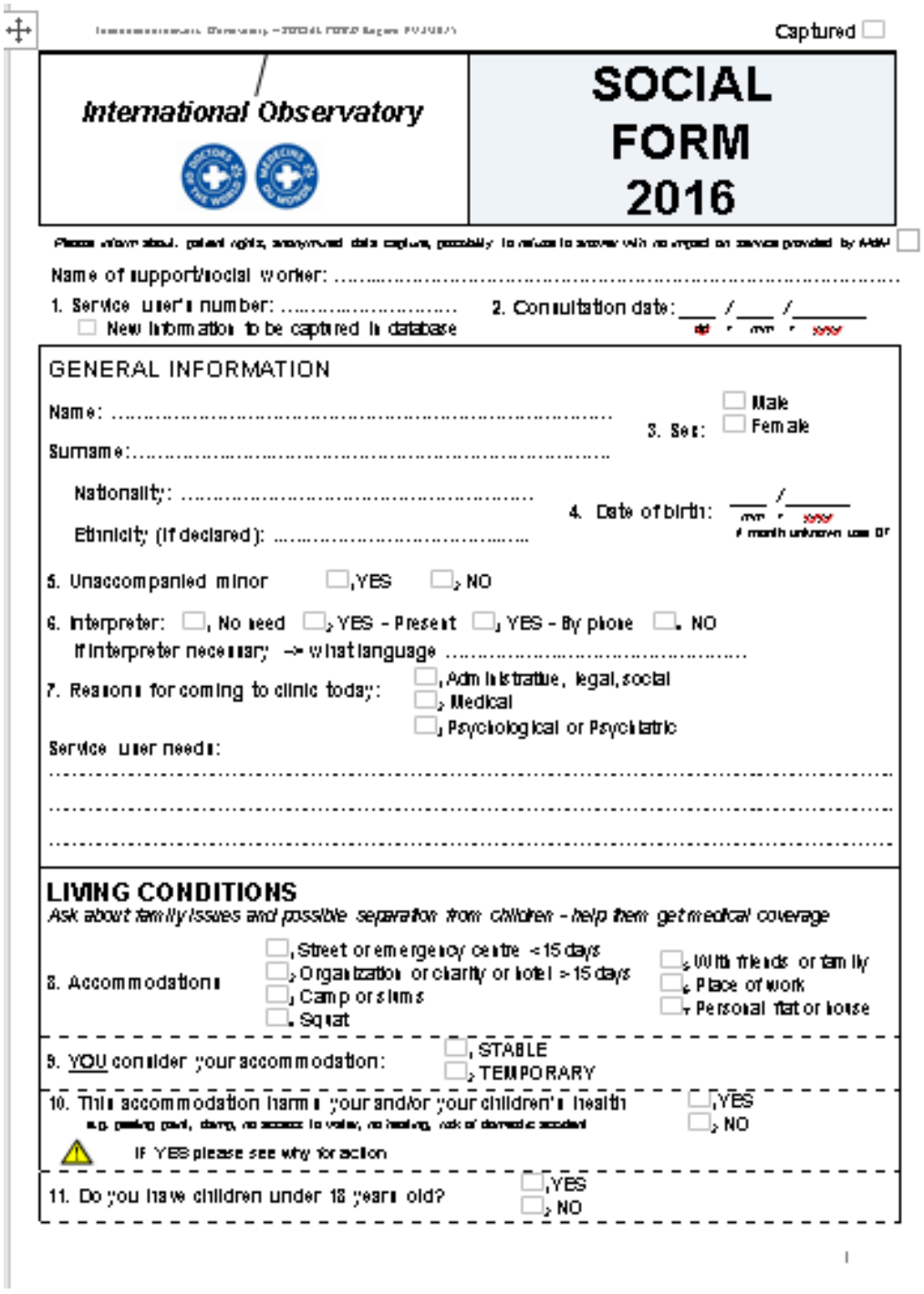
14. Health problem? ☐ 1 YES ☐ 2 NO — *If NO -> skip to question 15*

If YES ->	1st diagnosis	2nd diagnosis	3rd diagnosis
14.1 ICPC code			
14.2 Waiting for diagnosis	☐ 1 YES ☐ 2 NO	☐ 1 YES ☐ 2 NO	☐ 1 YES ☐ 2 NO
14.3 Pathology state	☐ 1 Acute ☐ 2 Chronic ☐ 3 Unknown	☐ 1 Acute ☐ 2 Chronic ☐ 3 Unknown	☐ 1 Acute ☐ 2 Chronic ☐ 3 Unknown
14.4 If CHRONIC -> Pathology KNOWN before coming to Europe	☐ 1 YES ☐ 2 NO ☐ 3 Not applicable	☐ 1 YES ☐ 2 NO ☐ 3 Not applicable	☐ 1 YES ☐ 2 NO ☐ 3 Not applicable
14.5 Pathology should have been treated earlier	☐ 1 YES ☐ 2 NO	☐ 1 YES ☐ 2 NO	☐ 1 YES ☐ 2 NO
14.6 Treatment / follow-up is	☐ 1 Necessary ☐ 2 Precaution	☐ 1 Necessary ☐ 2 Precaution	☐ 1 Necessary ☐ 2 Precaution
If NECESSARY ->			
14.7 Accessed CARE for this pathology BEFORE 1st MdM consultation	☐ 1 YES - fully ☐ 2 YES - partially ☐ 3 NO	☐ 1 YES - fully ☐ 2 YES - partially ☐ 3 NO	☐ 1 YES - fully ☐ 2 YES - partially ☐ 3 NO
14.8 Accessed MEDICINES for pathology BEFORE 1st MdM consultation	☐ 1 YES - fully ☐ 2 YES - partially ☐ 3 NO	☐ 1 YES - fully ☐ 2 YES - partially ☐ 3 NO	☐ 1 YES - fully ☐ 2 YES - partially ☐ 3 NO

2

Appendix 8: Patient Social Form Questionnaire

The below images are sections of the Social form that is completed by DOTW staff.



Captured ☐

International Observatory

SOCIAL FORM 2016

Please inform about patient rights, anonymized data capture, possibility to refuse to answer with no impact on service provided by MSF ☐

Name of support/social worker: .....

1. Service user's number: ..... 2. Consultation date: ___ / ___ / _____
   dd / mm / yyyy
   ☐ New information to be captured in database

GENERAL INFORMATION

Name: ..... 3. Sex: ☐ Male ☐ Female

Surname: .....

Nationality: .....

Ethnicity (if declared): .....

4. Date of birth: ___ / _____
   mm / yyyy
   If month unknown use 07

5. Unaccompanied minor ☐ YES ☐ NO

6. Interpreter: ☐ No need ☐ YES - Present ☐ YES - By phone ☐ NO
   If interpreter necessary -> what language .....

7. Reasons for coming to clinic today: ☐ Administrative, legal, social ☐ Medical ☐ Psychological or Psychiatric

Service user needs:

.....

.....

.....

LIVING CONDITIONS

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

8. Accommodations: ☐ Street or emergency centre <15 days ☐ Organization or charity or hotel >15 days ☐ Camp or slums ☐ Squat ☐ With friends or family ☐ Place of work ☐ Personal flat or house

9. YOU consider your accommodation: ☐ STABLE ☐ TEMPORARY

10. This accommodation harms your and/or your children's health ☐ YES ☐ NO
    e.g. passive gas, damp, no access to water, no heating, risk of domestic accident
    ⚠ 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 ☐1 All ☐2 Some ☐3 None

PERCEIVED HEALTH

13. How is your GENERAL health?	☐1 Very good	☐2 Good	☐3 Fair	☐4 Bad	☐5 Very bad
14. How is your PHYSICAL health?	☐1 Very good	☐2 Good	☐3 Fair	☐4 Bad	☐5 Very bad
15. How is your PSYCHOLOGICAL + EMOTIONAL health?	☐1 Very good	☐2 Good	☐3 Fair	☐4 Bad	☐5 Very bad

16. In this town, can you rely on someone to help, support, and comfort you, if needed? ☐1 Very frequently ☐2 Frequently ☐3 Sometimes ☐4 Never

ACTIVITIES AND RESOURCES

17. Do you have a job or activity to earn a living? ☐1 YES ☐2 NO

18. In the last 3 months approximately how much money per month did you have to live on: ☐1 ABOVE poverty threshold ☐2 BELOW poverty threshold

POVERTY THRESHOLD = £1005 per month
(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/437240/households-below-average-income-1994-95-to-2013-14.pdf)

ADMINISTRATIVE SITUATION

19. If MULTIPLE ENTRY FOREIGN -> Date you began living here: ___/___/_____ (dd / mm / yyyy)

20. If FOREIGN -> Date of your last entry in this country: ___/___/_____ (dd / mm / yyyy)

21. Why did you leave your country? *Multiple responses possible*

☐1 For political, religious, ethnic, or sexual orientation reasons
☐2 To escape from armed conflict or war
☐3 For economic reasons, to earn a living, had no perspectives.
☐4 Because of family conflict(s)
☐5 For personal health reasons
☐6 To join or follow someone
☐7 To study
☐8 To ensure the future of your children
☐9 Other, specify.....

22. Current status in this country? *1 answer only*

☐1 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

- ☐ 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?
☐ 1 YES
☐ 2 NO

29. In the past 12 months, have you faced discrimination by a healthcare provider in this country
Ask ALL patients this question
☐ 1 YES – color or ethnic origin discrimination
☐ 2 YES – other, specify: .....
☐ 3 NO