



Response to the Department of Health and Social Care formal review of ‘The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017

Doctors of the World UK

In the UK, DOTW runs a volunteer-led clinic, staffed by GPs and nurses, that helps people who have been unable to access NHS services to get the healthcare they need. In 2016, we saw 1,924 patients. The majority of patients we saw were undocumented migrants and asylum seekers whose claims have been refused (56%). Fifteen percent were asylum seekers, and the remaining 29% were refugees, EU nationals and British nationals or undefined. On average, our service users have been living in the UK almost 6 years, without ever having been registered with a GP. Our responses below are based on our experience of delivering healthcare to these individuals, who are often excluded from healthcare, as well as research and testimony from our clinic.

While we welcome the Government’s formal review of the impact of The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 (‘the 2017 amended regulations’) on vulnerable groups, we have a number of concerns related to the review process and scope which necessarily affect the evidence provided in DOTW’s response.

The timing of the review limits the opportunities for DOTW and other stakeholders to demonstrate the impact on those with protected characteristics and vulnerable groups. This review comes not long after the amendment regulations have come into force and the accompanying guidance released, and has been allotted a very short time-frame for stakeholders to gather evidence and respond (in practice, under one month). It is therefore difficult to accurately assess the full impact of these changes on vulnerable groups. In addition, quantifying the ‘deterrent effect’ of the regulations, which we see in our daily clinical work, is very difficult and would require a level of resourcing to which DOTW UK does not have access.

As a formal review, and not a consultation, it has been narrowly and selectively advertised. As such the review is unlikely to reach the widest possible range of interested parties, which will inevitably undermine the diversity of the submissions provided.

It is important therefore that the Department of Health and Social Care (DHSC) acknowledge that any perceived limitations in the conclusiveness of evidence submitted do not necessarily indicate an absence of impact on vulnerable individuals. In addition, it is essential that DHSC invest in a rigorous impact evaluation of the regulations, and conduct a public consultation on the aspects of the amended regulations not included in the 2016 consultation on NHS cost recovery: upfront charging and recording information against NHS number (consistent identifier). The evaluation should take account of health and wellbeing

outcomes and utilise a multi-method approach to capture the impact of upfront charging on vulnerable populations. This should be carried out in light of DHSC's duties under the Equality Act 2010 and their commitment to reducing health inequalities.

Finally, the review is too limited in scope, focusing on the impact of the 2017 amended regulations, without due consideration of other recent changes which impact on vulnerable groups' access to healthcare services (such as the data-sharing agreement between NHS Digital and the Home Office and 'supplementary' questions added to GMS1 forms about residency status). Additionally, the impact of the original 2015 Regulations on vulnerable groups has not been rigorously evaluated, and as such evidence on the impact of upfront charging from *before* the amended regulations came into force should be taken into account. In our response, we have drawn on evidence from before and after the amended regulations were implemented (noted where relevant below).

[Extending charging into community services](#)

1. Do you have any evidence of how the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, has had a particular impact on persons sharing a protected characteristic?

Sex; pregnancy

The 2017 amended regulations have been implemented too recently for DOTW to provide case studies of individuals affected by the changes. However, based on our experience of working with groups affected and the available evidence, it is reasonable to expect that women and pregnant women will be disproportionately affected by the changes introduced.

Community maternity services

DHSC has not clarified how community midwifery services are classified under the charging regulations and therefore we have highlighted our concerns below as it is likely the inclusion of community services will ensure all maternity services are now chargeable.

The extension of charges into community services disproportionately affects pregnant women. Based in GP practices and health centres, community midwifery teams provide antenatal care and the majority of post-natal care, meaning that most pregnant women will access community midwifery services at some point during their pregnancy. The extension of healthcare charges, and associated eligibility checking processes, will affect all pregnant women. Those who do not have proof of ID or address, including British citizens, will experience delays and some will be denied care.

The extension of charges into community care impacts in particular on vulnerable pregnant women, and those with additional protected characteristic (age, race, religion), for example, black and minority ethnic women, teenage mothers, asylum seekers and undocumented migrants, as these women typically rely more heavily on community midwifery services to access antenatal care.

Community midwives play an important role in reaching excluded women and those with complex social factors, such as recent migrants or asylum seekers as well as those with difficulty reading or speaking English, aged under 20, or affected by domestic abuse and alcohol or drug misuse. The National Institute for Health and Care Excellence (NICE) guidance on *Pregnancy and complex social factors* recommends these women are reached through antenatal care provided in the community.¹ Community midwifery teams are often commissioned to provide community outreach programmes, and specialist midwives, such as those with expertise in safeguarding, FGM, refugees and asylum seekers, usually work in the community.

In 2016 DOTW supported 231 women with their pregnancies or family planning who were unable to access NHS care. Many of these pregnant women were living in vulnerable circumstances, affected by trafficking, exploitation (labor and sexual) and domestic abuse.

Both before and since the 2017 amended regulations came into force, DOTW has seen pregnant migrant women in vulnerable circumstances who do not access antenatal care because they fear healthcare bills they will never be able to pay, as well as ID checks and are erroneously deterred by health services demanding a deposit upfront. Research at our clinic in 2016-2017 shows that NHS charges and eligibility checks already created complex barriers to antenatal care and resulted in many women avoiding seeking antenatal care until dangerously late in their pregnancies.² Almost 2 in 3 of the pregnant women in our research sample had not yet accessed antenatal care at 10 weeks of pregnancy (34/55) despite the NICE recommendation for a first appointment by that time.³ One quarter had not accessed antenatal care at 18 weeks and in one case, antenatal care was not accessed until 37 weeks of pregnancy. At least two cases emerged of women contemplating abortion in order to avoid being sent a bill.

Below we provide a selection of brief case studies from DOTW's Women and Children's clinic, collected before the 2017 amended regulations came into effect, which show the barriers that already exist to accessing antenatal and maternity care. By removing access to free community midwifery services, many of which are specifically commissioned to reach excluded women, these women will be further deterred and may not receive any antenatal care.

Refused asylum seeker, antenatal appointments suspended due to inability to pay

Zara presented at DOTW 4 months pregnant because her antenatal appointments had been suspended by the hospital. She had been asked to pay £300 upfront for the first appointment, followed by £5000 for the whole maternity package. She was told she need to pay to continue with care. As a result, the patient missed several antenatal appointments and began to suffer from panic attacks.

¹ <https://www.nice.org.uk/guidance/cg110/resources/pregnancy-and-complex-social-factors-a-model-for-service-provision-for-pregnant-women-with-complex-social-factors-pdf-35109382718149>

² Doctors of the World UK (2017). Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances. Available at: <https://www.doctorsoftheworld.org.uk/Handlers/Download.ashx?IDMF=2a7fc733-ceef-4417-9783-d69b016ff74f>

³ NICE. Antenatal care for uncomplicated pregnancies. Clinical guideline [CG62] March 2008 (Updated: January 2017). <https://www.nice.org.uk/guidance/cg62>

Refused asylum seeker, late booker denied first appointment due to inability to pay upfront

Katerina was 6 months pregnant with her first child when she came to DOTW. On trying to book her first antenatal appointment, she had been told that she needed to pay £6500 upfront before she could get one. DOTW intervened on her behalf and resolved the issue.

Victim of trafficking, late booker, delayed seeking care due to fear of Home Office

Edna was 7 months pregnant when she came to DOTW. She was fearful of seeking antenatal care as she was worried she would be reported to the Home Office and deported or detained, so she had had some scans done by a friend instead. DOTW encouraged her to attend appointments regardless.

Undocumented migrant, late booker, delayed seeking care due to fear of Home Office

Saliha was 3 months pregnant when she came to DOTW. She had not yet had an antenatal appointment because she was scared of being reported to the Home Office and being deported. She already had one child living with her in England. DOTW encouraged her to attend appointments regardless and helped her to register with a GP.

Abortion services

The majority of abortions are provided in the community by the voluntary sector. The extension of upfront charging into NHS community services, including those provided by the voluntary sector, creates a barrier (proving entitlement to free NHS care) for all women trying to access abortion services. And it puts abortion services out of reach of pregnant undocumented women who cannot afford to pay upfront for the service.

This change poses a threat to DOTW's patients' right to safe and accessible abortion services. Many of our service users experience complex social and economic exclusion. In 2016, the vast majority (87%) were living below the poverty line and over one third (35%) were rough sleeping or living in unstable accommodation. Over 1 in 3 reported that they have lacked the help, support, and comfort of a friend and over one quarter (28%) reported having experienced violence. Sex workers, asylum-seekers, refugees, victims of trafficking and other migrants in vulnerable circumstances face an increased risk of sexual abuse and exploitation, both in their countries of origin, in transit and in destination countries.⁴

It is essential that women who are demonstrably vulnerable to exploitation and often living in isolated and precarious circumstances have access to abortion advice and services and can fulfill their right to choose whether or not to have children. At the DOTW clinic we often see women with unwanted pregnancies seeking advice about abortion and the available evidence confirms that refugee and migrant women tend to have greater need for termination of pregnancy services than non-migrants.⁵ Creating additional barriers to such specialized services will deter vulnerable women and risk driving them to cheaper, unsafe abortion providers operating illegally.

⁴ Duckett, M., 2001. Migrants' Right to Health, Geneva: UNAIDS; Davies, A., Basten, A., Frattini, C. (2006) Migration: A Social Determinant of the Health of Migrants. International Organization for Migration Background Paper.

⁵ Vangen S, Eskild A, Forsen L. (2008) Termination of pregnancy according to immigration status: a population-based registry linkage study. BJOG 2008;115:1309–1315.

2. Do you have any evidence of how the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, has had a particular impact on any other vulnerable group?

Migrants, including refugees, asylum seekers and undocumented migrants

The 2017 amended regulations have been implemented too recently for DOTW to provide case studies of individuals effected by the changes. However, based on our experience of working with this group and the available evidence, it is reasonable to presume the following:

The extension of upfront charging and ID checks into community health services is likely to create additional barriers to essential health services which migrants, including refugees, asylum seekers, undocumented migrants, and victims of torture, trafficking, domestic and sexual violence, rely on.

To successfully reach these migrant groups, it is essential that community health services, in particular those delivered by charities and community interest companies, offer a safe, non-threatening and inclusive environment. Implementing ID checks and withholding care if a patient cannot pay is therefore entirely inappropriate and detrimental to the core functions of services which support people in crisis, such as community mental health, drug and alcohol teams, and specialised homeless and refugee outreach services.

Community services are often specially commissioned to reach marginalised communities and individuals unlikely to seek out NHS care. Identifying and charging patients undermines the vital role they play in protecting public health and safeguarding children and vulnerable adults.

Although still eligible to access free community services under the 2017 amended regulations, refugees and asylum seekers will be affected by the changes. DOTW often see asylum seekers and refugees being incorrectly identified as chargeable patients by hospital Overseas Visitors Teams (see case study 2) and it is likely that community services, charities and social enterprises, with less capacity and expertise to carry out eligibility checks, will wrongly identify refugees, asylum seekers (and indeed British nationals) as chargeable and withhold services.

Community mental health services

Refugees, asylum seekers and undocumented migrants are likely to have more acute mental health needs than the general population. These groups include victims of torture, trafficking and domestic abuse, as well as people fleeing war, conflict, persecution and forced marriage. Numerous studies conducted in the UK and elsewhere have highlighted both poorer access to mental health services and elevated rates of mental health problems among migrant and asylum-seeker populations, when compared to native-born.⁶ One recent UK study emphasized the role of post-migration stressors experienced by asylum-seekers and refused asylum-seekers, and found that being refused asylum was the strongest predictor of depression and

⁶ Morgan, G, Melliush, S., Welham, A. (2017) Seeking asylum: Exploring the relationship between postmigratory stressors and mental health for asylum seekers and refused asylum seekers in the UK. *Transcultural Psychiatry*. Doi: 10.1177/1363461517737188; Green, G. et al., 2006. "We are not completely Westernised": Dual medical systems and pathways to health care among Chinese migrant women in England. *Social Science & Medicine*, 62(6), 1498-1509.

anxiety.⁷ Data from our clinic supports these findings, as over one quarter (27%) of patients in 2016 described their mental health as bad or very bad.

The increase prevalence of poor mental health evidenced in these groups means they are more reliant on mental health services. With the majority of mental health services delivered in the community, the introduction of charges will have a disproportionate impact and exclude some of the people at most acute risk of mental health problems in our community from essential support.

3. Do you have any evidence that the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, may have deterred individuals from seeking treatment?

See answers to Questions 1 and 2 above. The extension of charging and ID checks into community services on which pregnant women with complex social factors and migrants, including refugees, asylum seekers and undocumented migrants, more heavily depend will inevitably deter vulnerable patients and those with protected characteristics from seeking healthcare. As outlined above, many of DOTW's patients, including pregnant women, would be unable to pay for the treatment they receive in the community. Checking eligibility and administering charges will compromise the safe and inclusive environment which many community health services seek to create and thus, in our experience, deter patients from attending (see maternity case studies for specific examples).

4. Do you have any evidence that the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, may have had an impact on public health?

As noted, many community health services, especially those delivered by charities or community interest companies, serve an essential role in the protection of public health by offering frontline, specialist services to hard-to-reach and vulnerable groups. Treatment and outreach provided by drug and alcohol teams, community mental health services and specialist services for homeless people are key among these. Put simply, these are public health services, and introducing rules which restrict their accessibility for high-risk population groups is a clear threat to public health.

Creating additional barriers to access specialist and outreach services threatens their ability to conduct vaccination and screening programmes among groups who, due to their social and living situations, are potentially at higher-risk of contracting some communicable diseases, such as TB or HIV. Indeed, in 2016 DOTW screened 146 high-risk patients for TB and two received positive diagnoses.

Drug and alcohol treatment services

Extending charges and eligibility checks into drug and alcohol treatment services poses a particular threat to efforts to control the transmission of infectious disease among people who inject drugs (PWIDs). In the

⁷ Morgan et al 2017

UK around 1 in 100 PWIDs is living with HIV⁸ and 53% of people who inject drugs have been infected with hepatitis C at some point⁹. Harm reduction services which are accessed via drug treatment services, such as opioid substitution therapy (OST), are associated with lower rates of transmission of both HIV and Hepatitis C¹⁰. Taking OST is associated with better adherence to HIV medication amongst PWIDs; which in turn leads to better health outcomes and reduced likelihood of onwards transmission¹¹.

5. Do you know of any examples of good practice or steps that could be taken which might mitigate the issues that you have raised in your responses to questions 1, 2, 3 and 4?

The regulations should be withdrawn. Any requirement to charge for NHS community services must be preceded by the publication of: an equality impact assessment; an assessment of the impact of extending charges into community services on vulnerable groups, pregnant women and children; and an impact assessment evidencing the proposed regulations do not breach the Secretary of State for Health's duty to reduce health inequalities under the Health and Social Care Act 2012.

At a minimum, the regulations should be further amended in order to:

- exempt all **community midwifery services, abortion providers and mental health services** from charging and eligibility checks as those with protected characteristics (sex, age, pregnancy) and migrants in vulnerable circumstances are disproportionately reliant on these services.
- exempt all services that protect **public health** from charging and eligibility checks, including public mental health services, drug and alcohol treatment services.
- exempt all services provided by **charities or community interest companies** from charging and eligibility checks.

The requirement for all relevant bodies to charge upfront for treatment that is not immediately necessary or urgent

6. Do you have any evidence of how the requirement to charge upfront for treatment that is not immediately necessary or urgent, has had a particular impact on persons sharing a protected characteristic?

Race; religion or belief

Testimony received by DOTW from an NHS worker at a pilot hospital detailed poor and discriminatory implementation, with late bookers for antenatal care, black or ethnic minorities and those who looked or

⁸ Public Health England (PHE) 'Shooting Up, Infections Among People Who Inject Drugs, An Update 2016'. Available at: gov.uk/government/uploads/system/uploads/attachment_data/file/567231/Shooting_Up_2016_Update.pdf

⁹ Public Health England (PHE) 'Data tables of the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs' Surveillance Update: July 2017. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/633204/UAM_Survey_of_PWID_data_tables_2017.pdf

¹⁰ (Platt L et al, 24th International Harm Reduction Conference, Malaysia, October 2015 – see <http://www.aidsmap.com/Opioid-substitution-therapy-especially-in-combination-with-needle-exchange-reduces-transmission-of-hepatitis-C/page/3007496/>).

¹¹ Nosyk B et al. AIDS 29, 2015 – see <http://www.aidsmap.com/Opioid-substitution-treatment-increases-chances-that-people-who-inject-drugs-will-have-good-adherence-to-HIV-therapy/page/2959599/>

sounded 'foreign' being specifically flagged for interview by administrative and clinical staff. More research needs to be undertaken into the likelihood of discriminatory practice by pressured NHS staff being asked to implement the changes.

Sex; pregnancy

Research conducted at the DOTW clinic showed the detrimental impact of charging rules and upfront charging (before the 2017 amended regulations) on one pregnant woman.¹² After her first antenatal appointment, the woman received a letter from the hospital requesting a deposit of £6,500, suspending future appointments until the debt was paid. Understandably, this caused the patient great distress. As 'immediately necessary' care, antenatal appointments should never be withheld due to payments, however the hospital's incorrect application of the rules rendered them inaccessible to her and her child until DOTW intervened.

7. Do you have any evidence of how the requirement to charge upfront for treatment that is not immediately necessary or urgent, has had a particular impact on any other vulnerable group?

Migrants, including refugees, asylum seekers and undocumented migrants

We have evidence of the negative impact that charging upfront for treatment has on migrants in vulnerable circumstances, including refugees, asylum seekers and undocumented migrants. This evidence is drawn from research and case studies collected in our clinic both prior to and after the 2017 amended regulations, where trusts implemented upfront charging policies despite not being under a legal obligation to do so. We have also provided cases studies that have occurred since the requirement was introduced. The case studies show urgent and immediately necessary care, including diagnostic testing, being delayed and withheld as trusts fail to make decisions regarding the urgent or immediately necessary nature of a patient's condition. In all of the case studies, the patient's eventual access to healthcare came after protracted advocacy by DOTW or the Health Inclusion Clinic in Brixton, a specialist London GP service for asylum seekers and refugees, and, in some cases, legal representation.

Independent research conducted at the DOTW clinic in 2016-2017 (before the amended regulations came into effect) showed that of our patients who were affected by healthcare charging, over one third had been deterred from seeking healthcare and had delayed treatment as a result.¹³ These patients included heavily pregnant women and individuals suffering from a range of acute conditions, such as cancer (including breast, cervical, prostate, oral, kidney and brain cancers), diabetes, cataracts, kidney failure, fibroids, end stage renal failure and post-stroke complications.

This delay and deterrence were found by researchers to have had significant negative effects on patients' physical, psychological and social well-being. Interviews highlighted worrying cases such as patients

¹² Doctors of the World UK (2017). Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances. Available at:

<https://www.doctorsoftheworld.org.uk/Handlers/Download.ashx?IDMF=2a7fc733-ceef-4417-9783-d69b016ff74f>

¹³ *ibid.*

choosing to self-medicate by obtaining drugs online or via social networks rather than presenting for NHS treatment. Delaying treatment for acute conditions was also found to drive inappropriate use of health services, with patients attending emergency services rather than routine appointment to manage or prevent disease. This was described dramatically by one service user who did not seek care to manage his chronic illness due to cost, until he was in renal failure and was admitted for emergency dialysis, ultimately costing tens of thousands of pounds.

Case studies collected at DOTW's clinic and by colleagues at the Health Inclusion Clinic show that urgent and immediately necessary care is being delayed and withheld from children and other vulnerable migrant patients due to the obligation on hospitals to charge upfront and determine eligibility. Case Studies 1 and 2 were collected *after* the 2017 amended regulations came into force.

Case Study 1: Abdel, refused asylum seeker in need of cardiac surgery

Abdel had been in the UK for a number of years, after having fled his home country. He applied for asylum but was refused and could not afford a solicitor to make another asylum claim.

Abdel had been experiencing severe chest pain for a few months and was told by the hospital that without surgery he would be at risk of stroke or heart attack. He was admitted to hospital and received a date for his surgery. However, he was then told he had to pay a £5000 deposit and as he couldn't afford this, he was discharged. He then attended another hospital, where the clinician recommended an urgent x-ray, but he was again discharged as he was found not to be eligible for free care. He and his family were extremely distressed by conflicting messages coming from clinicians and the hospitals' cost recovery teams.

After DOTW challenged the hospital, we found that the clinician had deferred to the OVM's decision that Abdel was not eligible for NHS care; they had not appropriately assessed whether the care would be deemed urgent or immediately necessary by the Department of Health definitions. Indeed, upon contacting the clinician's office we were informed that in their assessment of 'urgency' they had used alternative definitions (and were thereby applying the wrong 'test').

Further correspondence with the clinical team made it clear they were not prepared to make a decision as to the urgent or immediately necessary nature of the patient's treatment, and did not see this as their role:

"I have spoken to the overseas office who are extremely clear that there are 110+ pages of rules and regulations and their role is to assess eligibility for treatment so that as clinicians we can use our time for clinical matters. ...questions about eligibility for treatment must be funnelled through them in order to avoid ad-hoc decisions by clinicians such as us who know nothing about the rules and regulations."

While this was ongoing, Abdel was in continuous pain, unable to sleep or leave the house and at risk of a stroke. It took over 23 days, and a lot of input from DOTW, before the clinical team reviewed the Department of Health Cost Recovery guidance and made a decision. During this time,

the patient's condition worsened further and he refused to go to hospital as he felt they would not help him.

Case Study 2: Burhan, 18 month old, Syrian refugee with serious congenital condition

Recently, a Syrian family arrived in the UK as part of the UNHCR/Syrian Vulnerable Persons Relocation Scheme (SVPRS). The parents fled Syria in 2013 due to the war as their homes had been bombed and they feared for their lives. Since leaving Syria, they have lived in a crowded refugee camp in Lebanon, where they married and their two children, aged 18 months old and 6 months old, were born. Unfortunately the baby boy was born with a serious and life-threatening congenital illness. The family were fast tracked to the UK by the UNHCR, as his condition deteriorated significantly and he required urgent specialist treatment and a possible organ transplant. The Health Inclusion Clinic organised for him to have an urgent appointment at a specialist unit in London, which was one of the pilot trusts, when the family arrived in the UK. The case was discussed by our referring GP with the consultant, who accepted the patient and was expecting the family in clinic.

The family attended the appointment, along with their allocated Arabic speaking support worker, who could interpret for the family, arranged by the Local Authority for the SVPRS. The family have been granted refugee status and are entitled to NHS secondary care.

Upon arrival at reception, the family were asked for proof of ID. The support worker was able to provide their UNHCR documents, which included photos, but the Home Office had not issued their ID cards yet. The receptionist was not satisfied with this as ID and spoke to another member of staff, who then queried whether the baby would be entitled to free NHS treatment. It took 40 minutes for the issue to be resolved and for the baby to finally be allowed to attend his appointment. The support worker felt if she had not been present to advocate, the family would have been turned away and the baby, who required urgent medical attention, would not have been seen.

The support workers for the SVPRS have reported a number of Syrian refugees, who have been asked for ID and documentation when attending their hospital appointments. As many of them have recently arrived in the UK, they often do not have this paperwork, and if they did not have an advocate present, would have been turned away from their appointments despite being entitled. This is concerning, as many of the SVPRS patients have required urgent specialist appointments; their refugee status has been granted on medical grounds.

The following patient case studies, collected at DOTW's clinic and by colleagues at the Health Inclusion Clinic, demonstrate the detrimental impact of upfront charging observed before the amended regulations came into force. In light of the very recent introduction of the 2017 amended regulations, this evidence should be given fair and equal weight alongside the rest of the evidence provided.

Case Study 3: Zamir, undocumented migrant with cancer

Zamir and his wife came to the UK to find work and have a better life. They were living undocumented in London for about six months and were staying with different friends and family as they had no secure accommodation. Over a number of weeks, Zamir noticed rectal bleeding and had significant weight loss. He was referred to a London hospital where he had investigations and was diagnosed with cancer. The cancer showed signs of spread and he was referred to another hospital for urgent chemotherapy and surgery.

Despite the fact that his condition was deemed life-threatening, he was told to speak directly to the Overseas Visitors Team (OVT) about his eligibility to receive treatment. After contacting the Home Office regarding his case, they refused to treat Zamir, stating in a letter: “We have no notification of the outcome of his application and at this point we do not have evidence that he has leave to remain in the UK or any notification regarding free NHS care.”

During the course of DOTW’s advocacy on Zamir’s behalf, we also discovered that the second hospital had refused the referral as they felt that the first was trying to ‘pass the debt’, leading to confusion and a lack of ownership of his case. Ultimately, this led to life-threatening delays to urgent care that Zamir was entitled to and great distress for him and his family.

Case Study 4: Deidre, undocumented migrant with cancer

Deidre is from the Caribbean. She came to live in London with her daughter Sally, a UK citizen, after she was widowed. In 2016, Deidre was diagnosed with cancer. A specialist advised her that she was too sick to fly home, and another clinician later confirmed that the need for chemotherapy was ‘urgent’. Despite this, the hospital demanded a five-figure sum before treatment could commence. As a care worker, Sally is not able to pay for her mum’s treatment all in one go.

Doctors of the World supported Sally to challenge the hospital’s decision to refuse the healthcare that Deidre so desperately needed.

Case Study 5: Djibril, refused asylum seeker with cancer

Djibril says that when he was refused cancer treatment he was “very scared and desperate [...] and worried that [his] days were numbered”. He had arrived in the UK 17 years earlier, fleeing political persecution in his home country. He claimed asylum, but this was turned down. Twice the Home Office has tried to return to his home country – yet on each occasion the local authorities refused to allow him back. He remained living in limbo in the UK.

In 2016 he was diagnosed with cancer and told he needed surgery, but the hospital cancelled the operation because his asylum case had been refused. Djibril’s medical notes explained that there was a risk of the cancer spreading if he did not receive treatment. Despite this, the hospital declined to treat him unless he paid for the surgery in advance. Unable to pay upfront or return home, Djibril came to Doctors of the World. The treatment was provided after a significant delay and after we supported Djibril to get legal help to challenge the hospital’s decision.

Case Study 6: Abel, refused asylum seeker with latent TB

Abel was a 36-year-old homeless refused asylum seeker. He had been arrested for his political beliefs and fled from his home country, as he feared for his life.

The Health Inclusion Clinic carries out screening blood tests on new patients. In 2014 when we first met this man, we diagnosed him with latent tuberculosis, following a positive IGRA blood test. We referred him to our local TB/chest clinic, where he was treated for his latent TB, according to NICE clinical guidelines, as he was at risk of reactivation of his TB. He completed this treatment and we did not see him in our clinic again until recently when he presented with chest pain. He seemed very anxious when he was seen by our GP. She wanted him to have some basic blood tests and an ECG (electrocardiogram, tracing of the heart) to exclude a serious underlying cause of the chest pain.

He was sent to the local hospital's ECG department to get an ambulatory ECG. This man went to the hospital, which is one of the pilot trusts, and was turned away by admin staff because he did not have the documentation and because the computer system had a record of an unpaid hospital bill. A clinician was not contacted to discuss the cancellation of his ECG, which was being done urgently to investigate chest pain and exclude potentially serious causes.

A caseworker from the Health Inclusion Clinic contacted the overseas department, who sent a copy of an old hospital bill for nearly £800, which had been issued for his treatment for latent TB. We advised them that treatment for TB was exempt and that he was incorrectly billed for this. The patient had received this hospital bill in 2014. He had become extremely anxious about the bill, as he had no way of paying it, and so he had avoided accessing healthcare until he developed the chest pain. Our caseworker also contacted PALS who advised us to send the patient to A&E if we were concerned about his chest pain; a totally inappropriate use of services when a doctor in primary care had already assessed him.

8. Do you have any evidence that the requirement to charge upfront for treatment that is not immediately necessary or urgent, may have deterred individuals from seeking treatment?

As noted above, independent research conducted at the DOTW clinic in 2016-2017 (before the 2017 amended regulations came into effect) showed that approximately 1 in 5 service users who presented at the clinic were affected by healthcare charging.¹⁴ Of these, over one third had been deterred from seeking healthcare and had delayed treatment as a result. These patients included heavily pregnant women and individuals suffering from a range of acute conditions, such as cancer (including breast, cervical, prostate, oral, kidney and brain cancers), diabetes, cataracts, kidney failure, fibroids, end stage renal failure and post-stroke complications.

Deterrence is also reflected in a number of the cases studies above (e.g. case studies 1 and 6). They show patients, having been refused care that is urgent or immediately necessary, give up accessing health care services.

¹⁴ DOTW (2017)

9. Do you have any evidence that the requirement to charge upfront for treatment that is not immediately necessary or urgent, may have had an impact on public health?

Case study 6 provided by the Health Inclusion Clinic (see question 7) demonstrates the public health risk posed by upfront charging. A young man, with a history of TB, was both afraid to access and then refused healthcare because the hospital trust (incorrectly) held records of an outstanding bill for communicable disease treatment.

10. Do you know of any examples of good practice or steps that could be taken which might mitigate the issues that you have raised in your responses to questions 6, 7, 8 and 9?

The regulations should be withdrawn. Any requirement to charge patients upfront for NHS healthcare must be preceded by the publication of: a public consultation on upfront charging; an assessment of the impact of upfront charging and checking patient paperwork on access to services, health outcomes; an evaluation of the pilots taking place in hospital trusts; an impact assessment evidencing the proposed regulations do not breach the Secretary of State for Health's duty to reduce health inequalities under the Health and Social Care Act 2012; and a human rights impact assessment on upfront charging.

Recording when a patient is an overseas visitor

11. Do you have any evidence of how the requirement to record a patient's overseas visitor status has had a particular impact on persons sharing a protected characteristic?

Sex; pregnancy

As demonstrated by the selected maternity case studies provided in our response to Question 1, fears and concerns related to data sharing and confidentiality deter many pregnant women from seeking antenatal care. As a result, we see many women who are late bookers to antenatal care and who do not attend antenatal appointments. Telling a woman that their chargeability status will be recorded against their NHS number is likely to exacerbate fears that the information that is being collected will be used for immigration enforcement, and can only serve to deter them from attending antenatal and post-natal appointments. Poor attendance to antenatal and maternity appointments puts both mother and child at risk of poor health outcomes.

12. Do you have any evidence of how the requirement to record a patient's overseas visitor status has had a particular impact on any other vulnerable group?

Migrants, including refugees, asylum seekers and undocumented migrants

Many migrants, including asylum seekers, refugees and undocumented migrants, may be deterred from accessing public services due to distrust and fears around data sharing and confidentiality. Research in the UK, including studies conducted in the DOTW clinic, has confirmed that concerns around confidentiality

are a key barrier to accessing healthcare for migrants and include fear of being identified by the Home Office and detained or deported.¹⁵¹⁶

Telling a patient that their chargeability status will be recorded against their NHS number is likely to exacerbate their fears that the information that is being collected will be used to apprehend them at a later date and increase any distrust they have in the health service. Such perceptions can only serve to deter patients from seeking further healthcare.

In addition, a person's eligibility for charging changes with their immigration status, which can often be fluid, and the recording of a patient's chargeability status on their record risks that errors in recording or out-of-date information act as a barrier to a patient accessing care. When confronted with incorrect refusal of care, or incorrect charging, many vulnerable patients, in particular migrants with English as a second language, find it difficult to advocate for themselves and can be deterred from care. A case study provided by the Health Inclusion clinic demonstrates the consequences of incorrect recording of chargeability status on a patient seeking urgent healthcare. It was collected *after* the 2017 amended regulations came into effect.

Case study 7: Adaeze, victim of trafficking

Adaeze is a 47 year old woman who has been with our service for many years due to her complex medical and mental health problems. She was a victim of trafficking and has been granted 12 months of leave to remain. She is seen regularly at a local London hospital, as she is on the waiting list for a dual organ transplant. I referred her urgently to the relevant specialist clinic at the same hospital, as she had some worrying symptoms that needed investigation after agreement with the Registrar on call. When she arrived at reception, the receptionist informed her that she could not be seen as the computer stated that she was not entitled to NHS care. Our patient explained to the receptionist that there was a mistake. The receptionist called down someone from the overseas office, who was incredibly rude to our patient. She asked our patient for proof that she had leave to remain, which our patient did not have on her. She was told that she could not be seen, but did not discuss the clinical need with a doctor. The patient said this all happened in front of a waiting room full of people and was humiliating. Fortunately this patient can speak fluent English and is fully aware of her entitlements, due to her complex medical problems. She stood her ground and was insistent that she had to be seen. The doctor in the clinic ignored the overseas officer and assessed our patient.

After we found out about this incidence, we checked the NHS spine, which incorrectly states that she liable to charging. Her solicitor is now writing a formal complaint to the overseas office to get this resolved. We are positive that there are many patients who have incorrect data about their liability for charging on the NHS spine.

¹⁵ Seedat F, Hargreaves S, Friedland JS. Engaging new migrants in infectious disease screening: a qualitative semi-structured interview study of UK migrant community health-care leads. PLoS One. 2014 Jan;9(10):e108261.

¹⁶ DOTW (2017)

13. Do you know of any examples of good practice or steps that could be taken which might mitigate the issues that you have raised in your responses to questions 11 and 12?

The regulations should be withdrawn. Any requirement to record a patient's 'overseas visitor status' against NHS number (consistent identifier) should follow a formal public consultation and publication of an equality impact assessment.

HIV, sexual health and infectious disease departments not being required to check the eligibility of patients accessing their services should be explicitly included in the Department of Health and Social Care *Guidance on overseas visitors hospital charging regulations* and this should be communicated clearly to relevant clinicians and non-clinical staff.

Finally, the Department of Health should carry out a comprehensive assessment on the implications for patient confidentiality that recording chargeable status will have, which should invite input from voluntary sector advocates, Public Health England, the National Data Guardian and patient representatives/patient groups.