MÉDECINS DU MONDE 世界医生组织 DOCTORS OF THE WORLD ムビース LÄKARE I VÄRLDEN MEDICI DEL MONDO FIGTPOÍ TOU KÓGHOU DOKTERS VAN DE WERELD MÉDICOS DO MUNDO MÉDICOS DEL MUNDO 世界の医療団 ÄRZTE DER WELT द्विया के द्वोक्टर MÉDECINS DU MONDE 世界医生组织 DOCTORS OF THE WORLD ムビース LÄKARE I VÄRLDEN MEDICI DEL MONDO FIGTPOÍ TOU KÓGHOU DOKTERS VAN DE WERELD MÉDICOS DO MUNDO MÉDICOS DEL MUNDO 世界の医療団 ÄRZTE DER WELT द्विया के द्वोक्टर MÉDECINS DU MONDE 世界医生组织 DOCTORS OF THE WORLD ム ムビース (GAU के द्वोक्ट) (TOU KÓGHOU DOKTERS VAN DE WERELD MÉDICOS DO MUNDO MÉDICOS DEL MUNDO 世界の医療団 ÄRZTE DER WELT द्विया के द्वोक्टर MÉDECINS DU MONDE 世界医生组织 DOCTORS OF THE WORLD A ムビース (GAU के द्वोक्ट) (TOU KÓGHOU DOKTERS VAN DE WERELD MÉDICOS DO MUNDO MÉDICOS DO MUNDO MÉ DICOS DEL MUNDO 世界の医療団 ÄRZTE DER WELT द्विया के द्वोक्टर MÉDECINS DU MONDE 世界医生组织 DOCTORS OF THE WO



Argentina | Belgium | Canada | France | Germany | Greece | Japan | The Netherlands | Portugal | Spain | Sweden | Switzerland United Kingdom | United States of America

### Doctors of the World UK submission to the United Nations Special Rapporteur on extreme poverty and human rights, on the occasion of his visit to the UK

September 2018

Doctors of the World (DOTW) UK is part of the Médecins du Monde network, an international humanitarian organisation providing medical care to vulnerable populations across the world. In England, 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. We also run a specialist clinic for women and children.

We support just under 2,000 people every year to access the NHS – both primary and secondary (hospital) care. The majority of our patients are undocumented migrants and asylum-seekers whose claims have been refused (60% in 2017), living below the poverty line (70%) and without recourse to public funds. In 2017, eleven percent were asylum-seekers, and the remaining 28% were refugees, EU nationals and undefined. On average, our service users have been living in the UK for 6 years, without ever having been registered with a GP.

The evidence provided in this submission is based on qualitative and quantitative data collected via our clinical services. In addition, it draws on the findings of Equality & Human Rights Commission (EHRC)-funded research into access to healthcare for asylum-seekers and refused asylum seekers (RAS). The study was conducted in 2017 in partnership with Imperial College London and will be published in November 2018. It involved interviews with asylum-seekers and RAS across England, Scotland and Wales, as well as roundtable discussions with professionals supporting these groups.

Our submission presents evidence demonstrating how poverty prevents the fulfilment of the right to healthcare in the UK for migrants in vulnerable circumstances, including asylum-seekers, survivors of trafficking, pregnant women and children. We have responded to specific questions put forward in the call for submissions.

### Background: healthcare charging in England<sup>1</sup>

The NHS is one of the most restrictive healthcare systems in Europe for undocumented migrants. Current healthcare charging policies restrict access to secondary care for RAS and undocumented migrants in England by charging unaffordable fees services that prevent vulnerable and destitute patients from accessing urgent treatment.

New regulations in 2017 introduced an obligation on NHS Trusts to charge up-front for secondary care, meaning those who cannot pay have non-urgent treatment withheld.<sup>2</sup> The changes also mean that all community services receiving NHS funding –including charities– are now required to check every patient's eligibility for free care before they receive a service, and charge or withhold care accordingly. Treatment that a clinician considers 'urgent' or

<sup>&</sup>lt;sup>1</sup> For a detailed summary of entitlement and charging, including group and service exemptions, see attached guide from DOTW UK.

<sup>&</sup>lt;sup>2</sup> The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017.

'immediately necessary' should not be denied or delayed even if a patient cannot pay, but will be billed for afterwards.<sup>3</sup>

# Could you specify how poverty and extreme poverty in the UK intersect with economic and social rights issues (such as the right to health care)?

### Denial and delay of healthcare to migrants living in poverty

In 2017, 70% of DOTW patients were living below the poverty line and 29% were homeless or living in unstable accommodation. Indeed, a range of research has emphasised the disproportionate risks of destitution faced by migrant groups in the UK, especially undocumented migrants with no recourse to public funds.<sup>4</sup>

Compounded by this vulnerability, refugees, asylum-seekers and undocumented migrants are also likely to have more acute mental health needs than the general population.<sup>5</sup> One recent UK study emphasized the role of post-migration stressors experienced by asylum-seekers and RAS, and found that being refused asylum was the strongest predictor of depression and anxiety.<sup>6</sup> Data from our clinic supports these findings, as over one quarter of patients in 2017 described their mental health as bad or very bad.

### Impact of NHS charging on vulnerable migrants

### **Deterrence and fear of debt**

Independent research conducted at the DOTW clinic showed that of our patients who were affected by charging, over one third had been deterred from seeking healthcare and had delayed treatment as a result.<sup>7</sup> These patients included heavily pregnant women and individuals suffering from acute conditions, such as cancer, diabetes, fibroids, renal failure and post-stroke complications.

The deterrent effect of charging and the fear of unaffordable debts is compounded by the policy of reporting unpaid NHS bills to the Home Office, to be used against patients in future immigration claims and potentially threatening their ability to remain in the UK. Over half of patients who received a bill had not settled the debt one year later (56%; 18/32), with one still in debt seven years post-discharge.

Interviews and case note extracts highlighted worrying cases such as patients choosing to self-medicate by obtaining drugs online or via social networks rather than presenting for NHS treatment:

"In past month, SU has had two episodes of acute abdominal pain, which she phoned an ambulance for and on at least one occasion was admitted for 5 days. She has been given an appointment for an operation in April to treat this. SU has been sent a bill for ~ $\pounds$ 2600 for her

<sup>&</sup>lt;sup>3</sup> Department of Health and Social Care (2018) 'Guidance on implementing the overseas visitor charging regulations'.

<sup>&</sup>lt;sup>4</sup> S Fitzpatrick, Bramley G, Sosenko F and Blenkinsopp J. (2018). Destitution in the UK 2018. Joseph Rowntree Foundation; Pemberton S, Phillimore J and Robinson D. (2014). Causes and experiences of poverty among economic migrants in the UK. IRIS WORKING PAPER SERIES, NO. 4.

<sup>&</sup>lt;sup>5</sup> Morgan, G, Melluish, 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.

<sup>&</sup>lt;sup>6</sup> Morgan et al 2017

<sup>&</sup>lt;sup>7</sup> DOTW UK (2017). Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances (attached).

first stay in hospital - has no way to pay as receiving £20.70 per week in child benefit alone. Advised we cannot remove the bill, and there may be further from the hospital... Considering not attending operation as solicitor may have said something about outstanding bill harming her application. Advised from our point of view needs to attend operation as we do not know how urgent this is."

Even though some patients had attempted to set up repayment plans, in at least four cases, hospitals had been unresponsive to their requests. A clinic supervisor noted in relation to patients receiving cancer treatment:

"[they would] be happy to pay in small instalments 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).

### Denial of 'urgent' treatment

In addition to deterrence, when patients seek treatment it is sometimes withheld because they cannot afford to pay upfront. In some cases, this is because conditions are incorrectly classified as 'non-urgent' by administrative or clinical staff who therefore wrongfully insist on advance payment and turn patients away.

The government guidance is clear that the exemption from obligatory upfront charging for 'urgent' and 'immediately necessary' treatment is in place to ensure NHS Trusts do not breach the Human Rights Act: "Failure to provide immediately necessary treatment may be unlawful under the Human Rights Act 1998."<sup>8</sup>

The definitions of 'urgent' and 'immediately necessary' protect the right to life<sup>9</sup> but do not fully consider potential breaches of the right to freedom from torture and inhuman or degrading treatment.<sup>10</sup> Decisions made by hospitals in practice often do not consider Article 3. Certain types of care, for example palliative care or treatment for chronic illness, are often not classified as 'urgent', but their denial could certainly amount to a breach of Article 3.

An analysis of the treatment of DOTW's patients with cancer or suspected cancer between 2016-July 2018 showed that of 15 patients given an urgent referral for tests, almost half (7) did not access their specialist appointment within the maximum waiting time. Delays to testing and treatment were caused by patients' fear of debts and being reported to immigration enforcement, as well as by hospitals wrongfully withholding appointments. This included one case where an urgent mammogram for a patient later diagnosed with terminal cancer was denied due to their inability to pay for it upfront (Case study: Imelda in annex). These patients were often highly distressed by unaffordable charges of up to £80,000 for their tests or treatment.

Case studies collected at our clinic show how charging policies breach vulnerable migrant patients' right to healthcare, including pregnant women, patients with cancer and cardiac conditions.<sup>11</sup>

### Deidre, denied cancer treatment, 2017

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

<sup>&</sup>lt;sup>8</sup> DHSC, 2018

<sup>&</sup>lt;sup>9</sup> Article 3 of the Universal Declaration of Human Rights.

<sup>&</sup>lt;sup>10</sup> Article 5 of the Universal Declaration of Human Rights.

<sup>&</sup>lt;sup>11</sup> See Annex for additional cases.

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 was not able to pay for her mum's treatment all in one go.

Sally and Deidre approached Doctors of the World for help. By this point, Deidre's cancer was terminal. We advocated on Deidre's behalf to challenge the hospital's decision that the care needed was non-urgent. The hospital did not provide evidence that a clinical decision had been made.

On multiple occasions the hospital provided urgent care to stabilize Deidre and discharged her without ongoing care, which then led to emergency readmissions via A&E. At times she didn't have access to pain relief. DOTW also tried to get Deirdre admitted to a hospice for palliative care but this was initially refused and delayed because of her status. In the meantime, Deidre passed away following an emergency admission to hospital with sepsis.

### Antenatal care

According to official guidance, maternity care should always be considered immediately necessary, and provided without delay.<sup>12</sup> However 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, and are wrongly deterred by health services demanding a deposit upfront. Bills for maternity care typically start at £5,000-£6,500.

Research at our clinic in showed that almost 2 in 3 of the pregnant women in our sample had not accessed antenatal care at 10 weeks, one quarter at 18 weeks and in one case, antenatal care was not accessed until 37 weeks of pregnancy.<sup>13</sup> At least two cases emerged of women contemplating abortion to avoid being sent a bill.

Below are two brief case studies from our clinic.

### Zara, antenatal appointments suspended, 2017

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.

### Katerina, denied first antenatal appointment, 2017

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  $\pounds$ 6500 upfront before she could get one. DOTW intervened on her behalf and resolved the issue.

### Poverty in the asylum system and access to healthcare

The EHRC study demonstrates that financial hardship causes asylum-seekers and RAS to deprioritise their (often complex) health needs, and those of their family.

<sup>&</sup>lt;sup>12</sup> DHSC, 2018

<sup>&</sup>lt;sup>13</sup> DOTW UK, 2017

Although asylum-seekers and RAS receiving Section 95/S4 support are exempt from healthcare charges, their inability to afford transport and phone credit to attend and arrange appointments were found to restrict access to healthcare.

Living on their allocated  $\pounds$ 5.39 (S95) or  $\pounds$ 5.05 (S4) per day means that asylum-seekers and RAS must make careful decisions around how to meet their essential needs. Both groups reported that the lack of financial resources acted as a barrier to accessing prescription (usually  $\pounds$ 8.80 per item) and over-the-counter medication. The study also indicated that individuals with protected characteristics under the Equality Act 2010 (such as pregnant women or those with a disability) were more likely to struggle to meet the costs of accessing healthcare and medication.

### Travel and communication costs

An asylum-seeker in London explained how travelling the distance between her home and the hospital uses nearly two thirds of her weekly support:

"I wish I could get accommodation near the hospital. It costs nearly £20 pounds to travel to the hospital. The distance to the hospital – it's far!"

A midwife in Nottingham also explained how travel expenses impacted on her patients: "Just getting to hospital, transportation, they may not have money to get there. For example, pregnant women need frequent care, but can't afford to get to the hospital."

### **Medication costs**

Whilst both asylum-seekers and RAS are entitled to a 'HC2 certificate' which enables them to receive free prescriptions, only asylum-seekers receiving S95 are routinely issued with it. The research showed many were paying for prescriptions.

One Sri Lankan asylum-seeker who had been living in the UK for 10 years explained how prescription costs forced her and her husband to make impossible choices. Her husband had complex health needs, due to his age and as a result of being tortured prior to coming to the UK:

"We really struggled. He was diagnosed with a lot of medical conditions, so we had to pay a lot. We had to choose between food and prescriptions. It was really hard...My husband often didn't take his medication. Because he didn't want to swap it for food. I think a lot of his conditions now are in a really bad state."

## What are the implications of child poverty for the rights enumerated in the Convention on the Rights of the Child?

The threats to healthcare rights created by the NHS charging regime for migrants living in poverty equally apply to children.

One case study from our clinic demonstrates the impact these policies can have on children:

### Omar, denied treatment for growing tumour

Omar, 17, came to the UK with his family from Somalia for a better life. They had been living undocumented in London for one year when his GP found a tumour in Omar's shoulder and referred him to hospital for treatment.

At the hospital, the Overseas Visitors Manager identified Omar as an undocumented migrant and refused treatment unless Omar's family paid in advance. They could not afford to pay and their request to pay in instalments was denied. Omar was discharged without treatment.

Following discharge, Omar's GP issued repeat prescriptions for painkillers. Omar came to DOTW's clinic 3 years later in constant pain, dependent on painkillers and with visible wasting of his left arm. With intervention from DOTW, he was eventually treated and a repayment plan was set up for his family.

# Which areas of the UK should the Special Rapporteur visit in light of the poverty and human rights situation in those locations?

The Special Rapporteur should ensure he visits localities accommodating high numbers of asylum-seekers under the government's dispersal programme, whereby asylum-seekers and RAS in receipt of S4 support are sent to designated accommodation. In the final quarter of 2016, the North West supported almost double the number of asylum-seekers compared with the three next highest regions (9,491 individuals).<sup>14</sup>

# Which individuals and organizations should the Special Rapporteur meet with during his country visit to the UK?

DOTW UK would be honoured to host the Special Rapporteur for a visit to our clinic in east London, where he could meet with our clinicians to discuss their experiences of helping individuals living in poverty to fulfill their right to adequate healthcare.

### **Conclusions and recommendations**

The research and patient case studies presented above provide clear evidence of how current UK government policies with regard to a) NHS charging and; b) asylum support, intersect with poverty to result in breaches of individuals' rights to health and healthcare enshrined in international human rights law.

The newly instituted charging regime is increasing barriers to healthcare for people in extremely vulnerable circumstances, who often already face complex social, cultural and linguistic barriers to accessing essential services. We have shown that not only are those living in poverty deterred from seeking healthcare they need, including antenatal appointments, but they are also being denied treatment for acute conditions, such as cancer, for which early intervention increases the chance of recovery.

The new rules have been implemented without any human rights impact assessment or adequate assessment of their impact on vulnerable groups and those living in poverty. By denying treatment if a patient cannot pay in advance and by pursuing destitute individuals with unaffordable debts, the UK government is systemically undermining the right to health for migrants, many of whom have lived in British communities for a number of years.

<sup>&</sup>lt;sup>14</sup> https://www.gov.uk/government/publications/immigration-statistics-october-to-december-2016/asylum#support-provided-to-asylum-seekers

### Annex

### Supplementary case studies from Doctors of the World UK's clinic

### Denial of 'urgent' treatment, contd.

### Abdel, denied urgent cardiac surgery, 2017

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 administrator'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. Further correspondence with the clinical team made it clear they were not prepared to decide as to the urgent or immediately necessary nature of the patient's treatment:

"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 funneled 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 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.

#### Djibril, delayed cancer treatment, 2017

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.

#### Imelda, denied urgent mammogram, 2018

Imelda had lived in the UK for around 10 years. She worked a few irregular jobs, as a carer, babysitter and cleaner, and so she could send money back to her two children in The Philippines. She lived with supportive friends, who helped her with food and accommodation.

Imelda came to our clinic with a breast lump. Even though she was worried that the lump could be cancerous, she had waited six months to seek help as she had been too fearful of being reported to the Home Office.

The DOTW GP who saw Imelda was concerned. Although Imelda was quickly referred for a mammogram, she was turned away on the day of appointment because she couldn't prove to hospital administrators how long she had lived in the UK. This experience was very upsetting for her, further compounding her distress. She eventually was able to get a mammogram in another hospital, where she was diagnosed with breast cancer and began treatment.

Dr. Ruth Taylor, the GP who first saw Imelda, explained why her case was so worrying: "Cancer care is urgent because any delays increase the chance that the cancer can spread and become harder to treat. It is impossible to tell when [Imelda's] cancer progressed to a terminal stage, but it can be said with certainty that barriers related to her immigration status were the cause of the two unnecessary delays to her diagnosis, thus reducing the chance of successful treatment."

#### Zamir, delayed cancer treatment, 2016

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 Oversees 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 lead to life-threatening delays to urgent care that Zamir was entitled to and great distress for him and his family.