Response to the Independent Chief Inspector of Borders and Immigration's call for evidence: Home Office partnership working with other government departments

May 2018

Introduction

About Doctors of the World UK

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 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. We also run a specialist clinic for women and children.

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 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.

Overview of data-sharing mechanisms and policies in the UK

In England, mechanisms for data-sharing between the NHS and the Home Office are more numerous than in Scotland and Wales. In England, if a non-European Economic Area (EEA) patient has a debt of over £500 outstanding for two months or more, they are referred to the Home Office via the Department of Health and Social Care (DHSC). The Home Office may then use this information to deny any future application to enter or remain in the UK that the patient might make.[1] A hospital trust can also pass patient information, including home address, to the Home Office in order to establish a person's immigration status[2]. In both circumstances the information provided can be used to update Home Office records.

A third key mechanism of data-sharing in England involves NHS Digital's sharing of non-clinical patient data at the request with the Home Office for purposes of immigration enforcement, as laid out in the Memorandum of Understanding (January 2017) between the Home Office, DHSC and NHS Digital.

Hospital trusts in Wales are also able to share a patient's information with the Home Office in order to establish their immigration status[3]. However, unlike in England a trust can only do this with signed consent

[1] Department of Health 'Overseas chargeable patients, NHS debt and immigration rules: Guidance on administration and data sharing' (2016) p.2. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507694/Overseas_chargeable_patients_2016.pdf
[2] Department of Health 'Guidance on implementing the overseas visitor charging regulations' (2007), pp. 98-99. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/666031/UPDATED_Guidance_to_Charging_Regulations_post_23_October.pdf
[3] NHS Wales, 'Implementing the Overseas Visitors Hospital Charging Regulations' (2004) pp. 17-8. Available at: http://www.wales.nhs.uk/documents/overseas-guidance-e.pdf

from the patient. The information shared does not include a person's home address[4]. The guidance states that trusts should take a case by case approach to reporting those with suspected irregular immigration status to the Home Office in consultation with the trust's Caldicott Guardian and recommends trusts seek legal advice[5].

The Scotland, guidance on the matter states that "[hospital] Boards must also pass full details of the nonpayer to NHS Scotland Counter Fraud Services who will liaise with the UK Border Agency"[6].

Evidence submission

The information provided below draws on our first-hand experience of delivering healthcare to migrants in England who as a result of multiple vulnerabilities, are often excluded from healthcare as well as from health services research. Our response is based on research conducted at our clinic and testimony collected from our patients and staff.

Our submission will address the aspect of the Chief Inspector of Borders and Immigration's (ICIBI) call for evidence of which we have direct experience: data-sharing with DHSC in relation to patients who have been charged for NHS-funded care and have failed to make payment.

Disentangling the patient impact of England's different mechanisms for NHS-Home Office data-sharing is difficult as, if a patient is vulnerable to data-sharing under one due to their immigration status, they are likely to be also vulnerable to others and are unlikely to differentiate between them. With this in mind, in Section 1 we present a sample of evidence on the impact of NHS data-sharing with the Home Office *in general* on individual's health and use of services. In following section we present evidence of the impact of data-sharing in order to report NHS debts specifically.

DOTW UK is not always able to speak publicly about our patients and their experiences of accessing healthcare services. Before writing a case study, DOTW UK always obtains informed consent from the patient. Out of fear of being identified, patients with irregular immigration status are often not willing to consent to their cases being shared in this manner. Almost without exception, those who fear their patient record being shared with the Home Office do not give us permission to share their cases or to talk about their experiences publicly. Therefore, the experiences of these patients have not been included in this briefing.

Overview of evidence

Our submission presents qualitative and quantitative evidence, in addition to first-hand testimony from service providers and patients. This evidence and testimony clearly demonstrates that the Home Office's partnership working with DHSC in this manner actively deters vulnerable people living in the UK from accessing essential healthcare, including antenatal care and treatment for acute conditions. In doing this, it contributes to the UK's widening equality gap and potentially threatens public health as well as the future sustainability of the NHS.

Many of the migrants affected by charging and related data-sharing are in vulnerable circumstances, often living in destitution or exploitative conditions, and therefore often struggle to repay their debts, especially in a lump sum. Efforts on the part of such patients to make their debt more manageable are hampered by resistance on the part of the hospital to set up repayment plans. Additionally, patients who are repaying their

[4] NHS Wales, 'Implementing the Overseas Visitors Hospital Charging Regulations' (2004) p. 56. Available at: http://www.wales.nhs.uk/documents/overseas-guidance-e.pdf
[5] NHS Wales, 'Implementing the Overseas Visitors Hospital Charging Regulations' (2004) p. 45. Available at: http://www.wales.nhs.uk/documents/overseas-guidance-e.pdf
[6] The Scottish Government, 'OVERSEAS VISITORS' LIABILITY TO PAY CHARGES FOR NHS CARE AND SERVICES: A GUIDE FOR HEALTHCARE PROVIDERS IN SCOTLAND (2010), p.4. available at: http://www.sehd.scot.nhs.uk/mels/CEL2010_09.pdf

debts in instalments may still be reported to the Home Office (guidance on this matter is unclear[7] and DoTW has received information suggesting this may be the case). Given that the stated aim of this data-sharing is to facilitate cost recovery by NHS trusts and these patients making tangible efforts to support this aim, such reporting is punitive. It only serves to undermine patient trust in the health service and strengthen barriers to healthcare.

1. Fear of data-sharing as a deterrent to seeking necessary healthcare

In previous research and testimony, including evidence provided to the Health Select Committee,[8] DOTW UK has highlighted the impact that fear of data-sharing with the Home Office has on our patients' health-seeking behaviour. While the evidence presented in this section refers to the impacts of data-sharing in general (i.e. through the mechanisms described above), it is important to take into account as such dynamics are equally at play for individuals in need of secondary (chargeable) NHS care. We have presented only a sample of the case study evidence we hold on this issue.

1.1 Research conducted at the DOTW UK clinic

Our volunteers ask all of our patients why they have come to the DOTW UK clinic rather than going to an NHS service. In 2017, 96 people told us that they feared being reported to the Home Office or arrested as a reason for not attending an NHS service.

Médecins du Monde's 2017 Observatory Report[9] shows that 2.2% of responses from patients across Europe reported "fear of arrest" as a barrier to accessing healthcare services. Ahead of all of the European countries included, this barrier was most common in the UK: of all the patients that reported "fear of arrest" as a barrier to healthcare services, just over half (56.1%) were patients in the UK.[10]

Fear around data sharing was also disclosed by DOTW UK patients during an evaluation of the London clinic undertaken by an external consultant in June 2017. Across patient interviews and focus group discussions, a number of respondents reported concerns that accessing healthcare would escalate their risk of being traced by immigration enforcement teams.

When asked what barriers she faced when accessing healthcare, one female Filipino patient responded that she feared "*being arrested*". This sentiment was echoed by a focus group of male patients, who ranked "*fear of being reported to the authorities*" as their second biggest barrier to accessing healthcare. Another man described how, unable to regularise his status, he was too afraid to engage with society – including with healthcare services: "*I can't share with people my status, because of the fear. I can't even work, I've just been staying in the room. I can't even go outside*".

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[7] Department of Health 'Overseas chargeable patients, NHS debt and immigration rules: Guidance on administration and data sharing' (2016) p.2. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507694/Overseas_chargeable_patients_2016.pdf

[8] Memorandum of understanding on data-sharing inquiry, 2018. Available at: https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2017/mou-data-sharing-nhs-digital-home-office-inquiry-17-19/

[9] An observational study of people who are excluded from mainstream healthcare services across Europe, it was produced in partnership with the Institute of Global Health, University College London, includes testimonies and data collected from 43,286 people attending programmes run by Médecins du Monde and partner non-governmental organisations across thirteen Europe countries in 2016, including our UK clinic.

[10] R. W. Aldridge, A. K. Miller, B. Jakubowski, L. Pereira, F. Fille and I. Noret, Falling through the Cracks: The Failure of Universal Healthcare Coverage in Europe, European Network to Reduce Vulnerabilities in Health Observatory Report. (London: 2017). Available at: https://www.doctorsoftheworld.org.uk/Handlers/Download.ashx?IDMF=7d8c2ef9-403a-402d-8571-e8cefbec8d00

1.2 Testimony from GPs working at the DOTW UK clinic

One GP described a case of a woman at high risk of stroke and in need of an urgent referral, but who has too scared to register as she had overstayed her visa:

> **GP1***: "I saw one lady whose blood pressure was so high I referred her to the hospital there and then, which in 25 years I've never done in my life, it was so scandalously high, I thought this lady was going to have a stroke in front of my eyes. And she hadn't, she knew she had high blood pressure, but she was scared to register because she was a visa over stayer."*

Another GP described a case of a pregnant domestic worker with high blood pressure who had not been receiving antenatal care, who was under pressure from her employer not to give their home address. The GP described how this fear, driven by a perception that NHS records were shared amongst government departments, had driven vulnerable patients to backstreet providers:

> **GP3:** "*Some of them go to other places and pay for it, which again I find quite shocking that they go to the Chinese doctor somewhere in Soho and pay for something, or scan, that's sort of …*
>
> **Interviewer:** *And why do you think they would do that, rather go to a Chinese doctor then just the GP around the corner?*
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> **GP 3:** *Because they see it as being safe.*
>
> **Interviewer:** *And what is, what do they, what are they being safe from?*
>
> **GP 3:** *Anybody knowing about them, confidentiality, not being in the system.*
>
> **Interviewer:** *So do you think there is an inherent aspect of the NHS being part of the government that creates fear?*
>
> **GP 3:** *Well it is, isn't it?"*

1.3 Patient case studies collected in DOTW UK's clinic

Case Study 1 (February 2018)

Raquel[1] came to the UK from South America in 2008 to study. Since finishing her studies, she has been undocumented and worked as a full time carer. She had never been registered with a GP in the UK as she was worried about being reported to the Home Office. When her gums started bleeding she knew it was serious but was reluctant to seek medical help because of her immigration status. Eventually the bleeding was so heavy she was rushed to A&E where she was diagnosed with an autoimmune condition. She was discharged with steroid medication that was extremely dangerous if cut down too quickly or stopped suddenly.

Raquel came to DOTW UK's London clinic in February 2018 for help registering with a GP to continue getting the medication. We reassured her that we could liaise with GP surgeries on her behalf as no documents were necessary to register. She asked us if she would be reported to the Home Office and, after learning that her information could be sent from the GP to the Home Office, Raquel decided it was too risky to register. Although the team at DOTW UK wanted to advise Raquel that GP registration was the best way to keep her out of hospital, we couldn't reassure her that her details would be kept confidential.

As Raquel had no way of getting more medication, she decided to cut down on the medication quickly to make it last longer. She knew this was dangerous but felt she had no other choice. This made her extremely unwell and she had another emergency admission to A&E.

Raquel was able to receive more medication on her last discharge from A&E but she knows she faces the same problem when she needs more. She's too scared to get medication from a GP so can only wait until she become so unwell and that she needs emergency A&E admission again.

Since her diagnosis, Raquel has been too unwell to work. She knows that if she had the long term medication supply she was supposed to have, she wouldn't have to countdown till when the next hospital admission might be. She feels guilty about using A&E services so frequently. But Raquel is far too scared to register with a GP.

Case study 2 (2017)

Patricia[1] is a young Ugandan woman who is expecting her first baby. She has been in the UK for five years and her partner is a British citizen. For the first six months of her pregnancy she didn't have any antenatal care at all.

DOTW UK had helped her to register with a GP but she then missed two scans and two midwife appointments. She feared the hospital would pass on details, such as her name and address, to the Home Office, who would then find and deport her: "I feel trapped. I'm in a situation where I need to go to the hospital but I can't, because I feel my information might not be confidential".

She came to the DOTW UK London clinic because she was worried that her bump was too small for someone at the end of their second trimester. She wasn't sure what vitamins and supplements to take. She didn't have anyone to ask for advice. After a number of lengthy appointments with our volunteer doctors, we were able to persuade her to go to her antenatal care appointments

2. Data-sharing triggered by unpaid debts: impact on patients

Fear of being reported to the Home Office as a result of incurring NHS debts they cannot repay deters many of our patients from seeking timely healthcare, including heavily pregnant women and cancer patients. In this section we present independent qualitative evidence and DOTW staff testimony, which describe how the threat of being reported to the Home Office as a result of NHS debts acts as a barrier to healthcare for migrants in vulnerable circumstances. In addition, we describe how lack of affordability, resistance on the part of hospitals to setting up repayment plans and lack of clarity regarding data-sharing in cases where repayment plans have been initiated, leave many patients in impossible positions and obstruct their access to necessary healthcare.

2.1 Independent research at DOTW's clinic

Two studies carried out by researchers from Kings College London in 2016-2017 found that debt and fear of being reported as a result of unpaid debts deters and delays vulnerable migrants from seeking the healthcare that they need. Of those affected by charging, over 1 in 3 were deterred from seeking timely health care for these reasons (34.3%; 49/143).[11]

A volunteer interviewed noted that many service users were "terrified of being deported or detained because they cannot pay for the maternity or antenatal care" (S3). Indeed, almost 2 in 3 of the pregnant women in the sample had not yet accessed antenatal care at 10 weeks of pregnancy (61.8%; 34/55) despite the National Institute for Health and Care Excellence (NICE) recommendation for a first appointment by that time. One quarter had not accessed antenatal care at 18 weeks and in one case, antenatal care was not accessed until 37 weeks of pregnancy. Indeed, case notes revealed that one woman presented to the DOTW clinic already in labour, having never received antenatal care, because she was scared of maternity bills and being reported to the Home Office.

Other patients who reported that this had caused them to delay or avoid treatment included people suffering from cancer, diabetes, cataracts, kidney failure, fibroids and post-stroke complications.

Health and wellbeing effects of barriers to care

The deterrent effects noted above were reported to have had significant negative effects on migrants' physical, psychological and social well-being. Interviews highlighted worrying cases such as patients choosing to self-medicate by obtaining drugs online or via social networks rather than presenting for NHS treatment. As one DoTW staff member noted:

"[individuals] 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).

Another GP described a case of severely delayed care-seeking, with potentially serious consequences for the patient's health:

[11] DOTW 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

"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).

With regard to psychological wellbeing, interviews with service users revealed experiences of severe stress, anxiety and powerlessness relating to the use of secondary care, either due to fears of charges or of being reported to the Home Office.

Affordability and repayment plans

Many DOTW UK service users were simply unable to pay the costs of their treatment as many were not permitted to work in the UK and were living in destitution. Indeed, Quy's (2017) analysis showed that almost 2 in 3 service users (60%; 1207/2008) were noted to be living in poverty (earning less than £1,050/month), and over half (55%) were living in insecure accommodation at the point of presenting at the clinic.

Bills associated with maternity care for an uncomplicated birth typically amount to £5,000-£6,500, which is an unmanageable sum for many women. Indeed, at least two cases emerged of women contemplating abortion in order to avoid being sent a bill. Unsurprisingly over half of patients who received a bill following discharge had not settled the debt one year later (56%; 18/32), with one service user still in debt seven years post-discharge.

An extract from DoTW UK patient case notes described the impossible situation in which individuals are placed by hospital bills that are beyond their ability to pay:

"In past month, SU has had two episodes of acute abdominal pain, which she phoned an ambulance for and on at least one occasion was admitted for 5 days. She has been given an appointment for an operation in April to treat this. SU has been sent a bill for ~£2600 for her first stay in hospital - has no way to pay as receiving £20.70 per week in child benefit alone. Advised we cannot remove the bill, and there may be further from the hospital… 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."

This fear can add to the anxiety surrounding treatment of life-threatening or long-term disease, as one volunteer noted with regard to 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).

There was also evidence that efforts to set up reasonable repayment plans were often resisted or ignored by hospitals, placing patients in an impossible situation. This finding is echoed in the wider experience of DOTW caseworkers.

The research found that even though some patients had attempted to set up repayment plans in order to better manage their debt, in at least four cases, hospitals had been unresponsive to their requests. As one clinic supervisor noted in relation to service users 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).

Even where patients were able to set up repayment plans with the hospital, information received by DoTW UK indicates that these patients' outstanding debts were still reported to the Home Office. Indeed, DHSC guidance on the matter does not clarify in any detail that debts that a patient is paying off via a structured plan should not be reported to the Home Office, making it likely that many hospitals would include those with plans in their reporting.[12]

2.2 Testimony from DOTW UK clinic staff

Testimonies from DoTW clinic management staff reveal some of the worrying consequences that fear of being reported to the Home Office as a result of unpaid debts have on the health and health-seeking behaviour of our patients, especially pregnant women. Our clinic staff express real fear for the wellbeing of women and their children who feel that they have no other option other than to avoid incurring debts.

Testimony taken from DOTW UK Women and Children's Clinic Coordinator

Interviewer: *Please describe any cases in which a patient's fear of incurring healthcare charges that they cannot afford has impacted on their access to healthcare.*

Clinic Coordinator: *We have women who were not accessing antenatal care and were not registered with the GP. Once we've explained how the charging works in terms of 'if you don't pay then your information will be shared with the Home Office' and so on, some of them have completely disappeared. We can't get hold of them. These are pregnant women who are not accessing care. Where are they now? That is the fear for us.*

I'll tell you one example. She's a young Brazilian lady who came to us – she was 5 months pregnant and didn't have a GP, isn't accessing antenatal care. We explained how the charges work … [that] they will be charged and their information will be sent to the Home Office [if they don't pay]. The combination of both makes them feel that they might as well stay undocumented and stay under the radar…

We know there are black markets and dodgy doctors who are performing under the radar, you know, we are exposing women to things that we don't know of because they must go somewhere. Are they giving birth at home without any trained professionals attending their birth? We need to think about that.

We've not actually managed to convince some women to access care and that is the biggest fear. We know the women are coming to us but they are not accessing care because of the fear of charges and Home Office receiving their data. And most of the time it's the combination of both.

Testimony taken from DOTW UK clinic coordinator

Interviewer*: Do you find that patients are worried about the Home Office receiving their data if they can't pay, or that they are just worried about the cost?*

Clinic coordinator: *Most of them will say, 'I don't mind paying. I can't pay in one big chunk and can pay in instalments, but I don't want the Home Office to know about me.'*

Interviewer*: The fear is about deportation and detention?*

Clinic coordinator: *Yes. And being sent back.*

[12] Department of Health 'Overseas chargeable patients, NHS debt and immigration rules: Guidance on administration and data sharing' (2016) p.2. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507694/Overseas_chargeable_patients_2016.pdf

Interviewer: *Please describe any cases in which a patient's fear of incurring healthcare charges that they cannot afford has impacted on their access to healthcare.*

Clinic coordinator: *Oh yeah, we've had pregnant women that once that they've received the bill they would say that were not going to go to their next scan because they can't afford it. Without knowing that that cost is already included. It is stopping people from going.*

… The form says that if they can't pay, their information will go to the Home Office. It's threatening.

Even when people set up a payment plan, there is a lack of clarity as to whether their information is already with the Home Office. Even if someone is paying, we don't know what they are doing with their information and it's not made clear to the patient.

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