



Submission to PHE Call for Evidence on Data-sharing MoU between NHS Digital and Home Office

April 2018

Introduction

About Doctors of the World UK

- 1.1 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, we run a volunteer-led clinic and advocacy programme providing basic medical care, information and practical support for people facing multiple vulnerabilities. We also run a specialist clinic for women and children.
- 1.2 In 2016, our volunteers supported 1,924 people to access healthcare and provided over 2,000 consultations. People who come to our clinic include undocumented migrants, asylum seekers, homeless people, drug users and sex workers. All face multiple barriers affecting their access to healthcare such as lack of a permanent address, poor living and working conditions, social isolation, uncertain immigration status, exploitation, language difficulties, poverty and hunger.
- 1.3 The majority of our patients are migrants. In 2016, over half were undocumented migrants (56%), including victims of trafficking and people whose asylum application had been unsuccessful. We also saw short term migrants with a visa or work permit (17%), asylum seekers (15%) and refugees (2%).
- 1.4 Despite living in the UK for six years on average, 89% of patients who came to the DOTW UK clinic were not registered with a GP, despite being entitled to free primary care.
- 1.5 Our women and children's clinic, provides enhanced advocacy support for pregnant women and families with children. We see women who are victims of trafficking, sexual violence and domestic violence. Many are destitute. Research from the clinic showed over two third of women were late accessing antenatal care, with some not accessing antenatal care at all.

Evidence submission

- 1.6 In January 2017, NHS Digital (previously the Health and Social Care Information Centre) signed a Memorandum of Understanding (MOU) with the Home Office and Department of Health and Social Care requiring NHS Digital to share confidential patient information with the Home Office for immigration enforcement. This includes a patient's last known address, date of birth, GP's details and the date registered with a GP.
- 1.7 This submission presents evidence of the impact that the sharing of NHS patient information with the Home Office has on patients, healthcare professionals and service providers. The evidence is predominately drawn from DOTW UK's clinic in London and reflects our experience of the impact of the MOU on our patients. We have also included evidence provided to us by partner organisations, healthcare professionals and service providers.

1.8 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.

Impact on patients and their access to healthcare services

Data from DOTW UK's clinic: quantitative research

- 2.1 DOTW UK's 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.
- 2.2 Médecins du Monde's annual Observatory Report is an observational study of people who are excluded from mainstream healthcare services across Europe.¹ The 2017 Report, 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.
- 2.3 The 2017 Observatory Report 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.

Data from DOTW UK's clinic: qualitative research

Deterrence, Delay and Distress; Research carried out by Kings College London in the DOTW UK clinic, 2017

- 3.1 Independent research conducted at the DOTW UK clinic in 2016-2017 showed that fear of being reported to the Home Office was a significant deterrent to accessing healthcare services.² Interviews conducted with three GPs as part of this research indicated that all three had observed patients' fears around confidentiality and data sharing with the Home Office act as a barrier to both GP registration and urgent hospital care.
- 3.2 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*

¹ 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>

² 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-ccf-4417-9783-d69b016ff74f>

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."

- 3.3 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 than just the GP around the corner?*

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?"*

Needs assessment commissioned by DOTW UK in 2017

- 3.4 Fear around data sharing was also disclosed by DOTW UK patients during an evaluation of DOTW UK's London clinic undertaken by an external consultant in June 2017. Across semi-structured interviews and focus group discussions with patients, a number of respondents reported concerns that accessing healthcare would escalate their risk of being traced by immigration enforcement teams.
- 3.5 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.
- 3.6 Another patient said that when he needed a walk-in clinic he was told he *"would be reported"*, and that *"(he would) be on the first plane back home"*. Similarly, a female patient from Ghana explained that *"most of the people (I know), who don't have a GP is (due to) fear of arrest. That was my barrier – the fear of being reported"*. 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"*.

Patient case studies collected in DOTW UK's clinic

Case Study 1 (February 2018)

Testimony written by volunteer doctor in DOTW UK clinic

- 4.1 Raquel³ 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.

³ Not her real name

She was discharged with steroid medication that was extremely dangerous if cut down too quickly or stopped suddenly.

- 4.2 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.
- 4.3 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.
- 4.4 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 becomes so unwell and that she needs emergency A&E admission again.
- 4.5 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)

- 4.6 Patricia⁴ 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.
- 4.7 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".
- 4.8 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.

Testimony from healthcare professionals and DOTW UK front-line workers

Testimony submitted to DOTW UK by an NHS midwife

- 5.1 An NHS midwife submitted testimony to DOTW UK describing how the MOU had made a patient fearful to disclose important information to her care team: "The woman, a Chinese mother, did not feel she could be honest with midwives about her status and as a result did not disclose the exploitative situation she was living in (she was not being paid or fed enough by the family she was working for)."

Testimony taken from an NHS midwife who has been volunteering at DOTW UK's women and children's clinic for 2 years.

⁴ Not her real name

5.2 Interviewer: *Have you seen any cases in which a patient's fear of being reported to the Home Office has impacted on their access to healthcare?*

Midwife: *It's every other case really, people are much less willing to give us [DOTW UK volunteers] their addresses, in comparison to a year ago. People knew about us and knew that we are not in affiliation with the Home Office and so addresses would be willingly given. But now, because we have to tell people that the GP practice will potentially give their home addresses to the Home Office, we are now finding that people don't even want to give DOTW UK their address. Which makes the whole thing much more difficult. You don't know where they are living so you don't know which GP to contact.*

5.3 *We try to persuade [pregnant patients] that they really need to go to the hospital but the fact that they are frightened means that they often need more than one visit with us before we manage to convince them. This means that they arrive, for example, at 12 weeks, if they then have to come back in 3 weeks time, you only can then get them a slot with antenatal care by which time they have missed 1 scan, they've missed blood tests and, if there is anything wrong, it takes that much longer to identify this. Very often, you think you've helped a lady, and then they ring us and say 'sorry, I can't do this' and that's dreadful. And you think, what's going to happen to them? Where are they going to deliver?*

5.4 Interviewer: *And do you ever find out?*

Midwife: *Sometimes not because they then stop answering our phone calls. We either are not able to get in contact with them again or they ring and they say "cancel the appointment". It worries me that this fear of the Home Office is causing [pregnant] ladies to disengage with DOTW UK. And then I don't know what they do. They maybe have a friend who knows what to do in childbirth. We had one lady who came back for a second pregnancy and said they had a private midwife and then went silent and wouldn't tell us anything more about what happened. I think she probably did deliver at home and then decided she wanted to have a second baby in hospital but I am still not quite sure what happened but we had to sit down and inform her that it would cost and about the Home Office. They are in a real fix these women and that conversation is a horrible thing. And I really want them to have antenatal care.*

5.5 Interviewer: *You've been working in the DOTW UK Women and Children's clinic for how long?*

Midwife: *Probably around 2 and half years. And in that time, it's gotten worse. Initially we would always say "your information may be shared with the Home Office if you have to go to hospital and get a bill". But you can't say that anymore. You have to tell them that the GP practice could share where they are living. That's a big change.*

Testimony taken from DOTW UK clinic coordinator

6.1 Interviewer: *Have you seen any cases in which a patient's fear of being reported to the Home Office has impacted on their access to healthcare?*

Clinic Coordinator: *A really worrying recent case was a man who decided not go ahead with GP registration because of the Home Office and his health needs are quite significant. He has been recently discharged from hospital and came to register with a GP. But he decided not go ahead with the GP registration and come off the medication he was given which had a huge impact on his health. I tried to get him to come back to the clinic, because I wanted him to speak to a doctor to explain the implications on his health but he didn't come yesterday and he is not answering his phone to me. It is very worrying. He is making this choice purely because of his fear of the Home Office.*

6.2 *With many patients, what is happening now is that they don't want to disclose to us their address, so we ask GPs to register them with 'no fixed abode' which is not easy. Not all GP practices will do this so it can take us a long time to register people – sometimes in urgent need of a GP and onwards referrals. This is purely because they don't want their details to be disclosed to the Home Office. Also, I know the fear that often comes across is that if they turn up to their GP practice that the Home Office will be there waiting for them. And this is something that obviously terrorizes people. It is a fear that is shared amongst the*

community or through the media. It's difficult because as an organisation we try to make people understand that they must look after their health. The general thing is that people are scared that they will turn up at the hospital or GP.

6.3 Interviewer: How long have people been avoiding healthcare for?

Clinic Coordinator: We had a gentleman yesterday who has been in the country for 11 years – never ever seen a GP. He was here because he fled from his country and he doesn't have anyone else. I remember one particular case who had been in the country for 19 years and when we informed them that his information may be passed from the NHS to the Home Office, he completely refused to register with a GP. He decided to wait for his 20th year in the UK and then to request a naturalisation. And then he will register with a GP. And this is someone with high blood pressure and was taking a friend's medication. So, he was self-medicating and he would not take the risk of having his details on file. Once we told them about the MoU he made the choice that he would not register with the GP.

6.4 Interviewer: If they don't go to the GP, what alternative things are people doing?

Clinic Coordinator: Quite a lot of people self medicate. In the clinic we see people with high blood pressure or diabetes's and because they have friends who have the same conditions, they take friends medication without really knowing and without any monitoring. It is very concerning. Especially when these people have the right to a GP but they are just too scared. But then again, for some people, knowing that the Home Office can access their information, it doesn't make them feel secure.

6.5 Interviewer: With pregnant women, do they then have to disclose their details once they are accessing secondary care?

Clinic Coordinator: We also have a big problem with pregnant women who don't want to disclose their address which makes antenatal referrals difficult. Which hospital to refer them to? We can do referrals without giving an address, just person's name and DOB. But this is not helpful for the hospital and midwives.

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

7.1 Interviewer: Please describe any cases in which a patient's fear of being reported to the Home has impacted on their access to healthcare.

Clinic Coordinator: The most recent case was just this week. We had a 35 weeks pregnant lady who wouldn't give us her address and she refused for us to give her an antenatal care referral, she is not booked in or registered with a GP because of the fear. So for her she was under the impression that to avoid being found out by the Home Office, it would be easier if she is in labour and to just turn up at the hospital and give birth and disappear. , I mean, that is incredibly dangerous.

7.2 Another example, which is quite common, is the lady you have just interviewed. She is booked to give birth on Monday next week, the hospital doesn't know where she lives, we don't know where she lives, she doesn't have a GP [Our volunteer doctor] tried to convince her today to go and she agreed but last time she agreed to go as well and she didn't. She was actually crying today as well. She doesn't want her husband to come with her because he is undocumented as well so doesn't have support and perhaps everyone in her network is undocumented and she won't have anyone during birth. She said she is scared and she asked me if they will put handcuffs on her when she has given birth, I mean, this is the fear women have of the Home Office and detention and being deported.

7.3 Interviewer: She hadn't seen anybody before that?

Clinic Coordinator: No, all of that is actually just fear. And most of the cases that we see now, almost all of the cases that we have seen this year, none of them are willing to share their home address.

7.4 Interviewer: You have noticed a change?

Clinic Coordinator: *Yes, especially in terms of actually sharing their address. Before, people had the fear but I have a feeling now that perhaps the community or the people they know – the data sharing – is now common knowledge and they are all aware of it. That’s why perhaps we are getting women who don’t want to share their addresses with us. I feel like most of them are actually aware of the MoU between NHS Digital and the Home Office because none of them want to share the address with us.*

Testimony from DOTW UK patient (survivor of sex trafficking, undocumented), March 2018

7.5 *I had no GP so then I went to the emergency room at the hospital because of the miscarriage. ...We don’t have any chance to register with the GP because it means that you have to provide all of your information and then if it goes to the Home Office it will be a disaster for people.*

7.6 *My fear is that if I provide my address to your organisation or the social services like the NHS, not purposefully, you could give my information to the Home Office. If my address information gets to the Home Office, I cannot say what is going to happen but [it] is a scary thing for me. I do think your organisation or all the social services, they do not wish to disclose on purpose my address but now the information access is everywhere they could access my information because I am undocumented and they could find me.*

Impact on healthcare professionals and service providers

8.1 Since the MOU became public in January 2017, DOTW UK has changed the advice it gives patients about the risk of their data being shared with the Home Office by the NHS. Previously, we advised patients, although there was a risk that the NHS would share their information with the Home Office, the risk was low and linked to the NHS charging programme. As of January 2017 our advice to patients is as follows:

‘Know Your Rights – FAQs’, DOTW UK website (updated January 2017)

CAN THE HOME OFFICE ACCESS MY INFORMATION IF I SEE AN NHS DOCTOR?

Doctors of the World is an independent non-governmental organisation.

We will never share your information with the Home Office, the government’s immigration department.

We are not part of the NHS.

But the Home Office can now go to the NHS to get information on patients they have had contact with (those who have claimed asylum, have reported to the Home Office or have been detained).

If you have never been known to the Home Office, this will not affect you and you can access the NHS without the Home Office knowing about you (unless you receive a hospital bill of over £500 that goes unpaid for more than two months).

If you have been known to the Home Office, the Home Office could ask the NHS to pass on your information to them.

The information shared would not be your medical notes, but could be other private information of yours, such as your address.

IS IT SAFE FOR ME TO ACCESS NHS CARE WITHOUT THE HOME OFFICE FINDING OUT ABOUT ME?

If you **are not** known to the Home Office, you should be safe to access the NHS without the Home Office finding out about you.

If you **are** known to the Home Office, or have been in the past, they currently have the right to ask the NHS for your current details.

If you would like to understand more regarding how this issue might affect you, please [call our advice line](#).

If you are unwell and need to see a doctor, you can visit our clinic. We will never share your information with the Home Office.

In an emergency you should still visit A&E or call 999 where you are not obliged to give personal information to receive treatment.

- 8.2** DOTW UK has been approached by a number (7) GP practices over the past year asking for advice about the MOU and how they can protect patient's home address from being shared with the Home Office. An example of a GP practice changing its registration policy in order to protect patient's personal information is provided by a GP working in Greater Manchester:
- 8.3** *"In light of MoU between NHS Digital and Home Office at my GP practice in Bury, Greater Manchester we have advised asylum seekers who wish to register with the practice that they do not need to provide their home address. We simply require that they provide an address within our practice catchment area at which they can regularly access mail for themselves for example, a friend or relative. This is as we understand that those going through the asylum seeker process particularly those who are appealing a Home Office decision have valid concerns that the Home Office will use personal demographic data provided to the practice for purposes of immigration enforcement.*
- 8.4** *"This may deter them from seeking appropriate healthcare despite their needs and they are all entitled to free primary care regardless of immigration status. The majority of asylum seekers register with their correct home address, however, a small proportion have provided the address of a close family member or friend. One particular patient has provided the address of the local mosque which he attends several times a week having discussed this issue with the local imam and has received letters for imaging investigations to this address. Provided that patients can regularly access post at the address provided then this does not provide any difficulties with regards to providing healthcare and should enable contact tracing if required with respect to communicable diseases".*