Research briefing

**Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances**

Doctors of the World UK is an international humanitarian organisation providing medical care to vulnerable populations. In the UK, we run a volunteer-led clinic and advocacy programme with GPs and nurses that helps the most excluded members of the community to get the healthcare they need. In 2016, we saw 1,924 patients, including refugees, asylum seekers, undocumented migrants, victims of trafficking and homeless people. On average, our service users have been living in the UK almost 6 years, without ever having been registered with a GP.

Some people in the UK are not entitled to free NHS hospital care. This includes people on short-term visitor visas, undocumented migrants, and some asylum seekers whose claims have been refused. DoTW UK supports many migrants in vulnerable circumstances who face a range of barriers to accessing health care, including large hospital bills which they cannot pay and which often lead to them being reported to the Home Office (the UK’s immigration department).

In response to these challenges, in 2016-2017 two studies1 were conducted at DoTW UK’s clinic to assess the effect of charging for NHS hospital services on migrants and on their timely access to necessary healthcare. The research was undertaken by two postgraduate students from the King’s College London Centre for Global Health.2 This briefing summarises the findings of this unique and timely research, explores the resulting policy implications and presents DoTW’s evidence-based recommendations.

1. **Key findings**

- Charging deters and delays vulnerable migrants from seeking the healthcare that they need. Approximately 1 in 5 service users in the DoTW UK clinic were affected by health care charging (21%; 381/1801 [Quy 2017] and 18.5%; 143/773 [Ockert-Axelsson 2017]). Of these, over 1 in 3 were deterred from seeking timely health care because of charging (34.3%; 49/143),

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including concerns their information would be shared with the Home Office as a result of the charging process.

- Patients who reported delaying or avoiding care included heavily pregnant women and people suffering from cancer, diabetes, cataracts, kidney failure, fibroids and post-stroke complications.

- The deterrent effect of antenatal care charges was particularly stark, posing a grave risk to the health of mother and child. 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.\(^3\) 1 in 4 had not accessed antenatal care at 18 weeks and in one case, antenatal care was not accessed until 37 weeks of pregnancy.

- Interview participants reported a displacement effect from planned consultations to A&E, likely to lead to both greater cost to the NHS and greater health risks for the patients concerned.

- These deterrent and displacement effects were reported to have had significant negative effects on service users’ physical, psychological and social well-being (Quy 2017).

- Reported charges levied ranged from £40 to £80,000 (Quy 2017, Ockert-Axelsson 2017). The modal amount billed was £2,600 (Quy 2017).

- 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 (Quy 2017). If a patient does not clear their bill in two months, they are reported to the Home Office.

- Interviews revealed that in at least four cases, migrants had offered to set up repayment schemes — following debt advice — to hospitals and had received no response in return.

- Fear of being reported to the Home Office was another significant deterrent for vulnerable migrants from accessing secondary healthcare.

- Health inequalities are growing and are estimated to already cost the NHS £5 billion every year.\(^4\) This research confirms that the Charging Regulations and data-sharing agreements between the NHS and the Home Office actively deter vulnerable people living in the UK from accessing essential healthcare. In doing this, they contribute to the UK’s widening equality gap, potentially threatening public health as well as the future sustainability of the NHS.

2. **Policy context**

From 23 October 2017 under new Regulations\(^5\) introduced by the Government, every hospital department in England is legally required to check patient’s eligibility and charge upfront for care.

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These regulations build on and reinforce existing policy for charging overseas visitors in NHS hospitals, which has gradually been expanded since charging was first introduced in 1982.6

Obligatory upfront charging in hospitals is being introduced in parallel with the extension of charges to NHS community services, such as health visiting, school nursing, community midwifery, community mental health services, termination of pregnancy services, district nursing, support groups, specialist services for homeless people and asylum seekers, as well as to non-NHS providers, including charities and community interest companies.

If a patient cannot prove that they are entitled to free care, they will have to pay the estimated price for their treatment upfront, unless it is considered ‘urgent’ or ‘immediately necessary’. Doctors will have to review each case to decide if care is ‘immediately necessary’ or ‘urgent’ enough to forego upfront charging and charge later, or to refuse non-urgent care where a patient cannot pay.

This change will affect people who are entitled to free care but who may not have easy access to paperwork and passports, such as homeless people, elderly people, those living with mental health conditions and asylum seekers. The inevitable increase in bureaucracy and workload could lead to increased patient waiting times and pressures on staff. And there is a risk that, rather than check all patients’ paperwork, providers rely on ‘racial profiling’ as a means of identifying chargeable patients, thereby increasing health inequalities.

The Government has made multiple commitments to carry out an assessment of the unintended consequences of extending NHS charges on ‘vulnerable people’, pregnant women and children7, but this has not happened.

The Government has also made public commitments to introduce charges in primary care (including GP services) on a phased basis and expressed an intention to introduce charges into A&E.8

3. Methods overview

The studies used qualitative and quantitative methods to explore the experiences of migrants seeking secondary health care, with a particular focus on the impact of healthcare charges. Both studies undertook semi-structured interviews with key stakeholders (DoTW UK service providers, GPs and migrant service users) and conducted analyses of DoTW UK records and case notes in order to gain an understanding of both experiential knowledge and wider trends.

The study conducted by Quy (2017) conducted interviews with two DoTW staff members, three GPs working as clinic volunteers and six adult DoTW service users in May 2017. Service user participants were sampled for diversity in age, gender and country of origin and had been seen in, considered for, or referred to secondary care, or had encountered or expressed concern regarding NHS charges.

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7 Department of Health made these commitments following recommendations by Home Affairs Committee and Major Projects Authority (both in 2015) that such evaluations took place before cost recovery was extended to other areas of the NHS.
Interviews were audio-recorded, transcribed verbatim and thematic analysis was conducted using NVivo 10.

Analysis of 1,801 case notes and medical records of adult migrant service users, who had attended the DoTW UK clinic between April 2016 and April 2017, examined health and wellbeing indicators.° Case notes were then searched for keywords and phrases which were likely to signify referral to secondary care and/or encounters with hospital charges. Information regarding experiences of charging were extracted from the 381 records identified.

For the second study (Ockert-Axelsson 2017), interviews were carried out in June-July 2017 with ten DoTW clinic staff, including Clinic Supervisors (three), volunteer GPs (three), and volunteer Clinic Support Workers (four). Interviews were audio-recorded, transcribed verbatim and thematic analysis was conducted using NVivo 10. An analysis of DoTW records for consenting service users, spanning January 2015-December 2016, was then conducted (n=773) using keyword searches to identify the frequency with which conditions that were likely to be chargeable (pregnancy and non-communicable diseases requiring hospital care) appeared, in order indicate the proportion of service users who were impacted. Chargeable cases were examined to understand the barriers experienced in accessing care and specifically, to identify any effect on care-seeking behaviour as a result of charging (e.g. deterrence or late presentation). Case notes were coded and analysed using STATA 14.

A limitation of this research was that the service user population studied, by nature of having presented to a health advocacy group, were likely to be less vulnerable and potentially, face fewer barriers to accessing healthcare.°° However, given the stark evidence gap regarding the effects of the introduction of hospital charges on vulnerable groups in England, the research provides essential insights into the hidden impacts of charging, as well as the likely effects of recent and upcoming legislative changes related to the reinforcement and extension of charges in the NHS.

4. Findings

The research findings reinforced the existing body of literature which shows that vulnerable and undocumented migrants struggle to access essential health care services in the UK.°°° Both studies found convincing and consistent evidence that charging in NHS hospitals has deterred and delayed vulnerable migrants from accessing necessary healthcare, including antenatal care and cancer treatment.

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° Self-reported health and wellbeing was considered an appropriate indicator, given existing evidence of its strong correlation with indicators of morbidity (see for example, Chandola T, Jenkinson C. Validating Self-reported health in different ethnic groups. Journal of Ethnicity and Health, 2000; 5(2):151-9)


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Charging in NHS hospitals: evidence of a deterrent effect

Both studies confirmed that approximately 1 in 5 service users sampled (21%; 381/1801 [Quy 2017] and 18.5%; 143/773 [Ockert-Axelsson 2017]) who presented at the DoTW UK clinic were affected by health care charging. Of these, over one third (34.3%; 49/143) had been deterred from seeking healthcare and had delayed treatment, with reasons cited including fears of incurring debt or fear of the Home Office being informed about their presence in the country (Ockert-Axelsson 2017).

Patients who reported delaying or avoiding care 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. Three service users interviewed were still not accessing NHS care at the time of interview (Quy 2017).

Link between hospital bills and fear of being reported to the Home Office

In addition to concerns around debt, both studies also underlined the fear of being reported to the Home Office as a deterrent from seeking healthcare for migrants in vulnerable situations. This barrier was exacerbated by the mechanisms of the Cost Recovery Programme, which encourage hospitals to check patients’ residency status with the Home Office in order to establish if they are eligible for free NHS care, and require them to share patient information with the Home Office if they have been unable to pay their bill within two months. Indeed, one volunteer noted that many service users were “terrified of being deported or detained because they cannot pay for the maternity or antenatal care” (S3; Ockert-Axelsson 2017). In addition, the perceived links between the NHS and the Home Office, which have been laid bare in a recent Memorandum of Understanding (MoU)\textsuperscript{12} formalising arrangements for the NHS to share the personal information of patients of interest to border enforcement, were also a deterrent for many.

These concerns were especially notable among pregnant women interviewed (Quy 2017), with one woman even presenting 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.

Affordability and debt management

Reported charges levied ranged from £40 up to a bill of £80,000 for breast cancer treatment (Quy 2017, Ockert-Axelsson 2017). The modal amount billed was £2,600 (Quy 2017). Many service users were simply unable to pay such large sums as, many vulnerable migrants (including asylum seekers) are not permitted to work in the UK and are 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. 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 (Quy 2017). A DoTW UK staff member described the impossible situation in which individuals are placed by hospital bills that are beyond their ability to pay:

“She was sent a bill for ~£2600 for her first stay in hospital – has no way to pay as receiving

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£20.70 per week in child benefit alone” (S2; Quy 2017).

Interviews also highlighted how patients can be obliged to enter a course of treatment without any accurate indication of what the final cost will be, as this can often be impossible to estimate (Ockert-Axelsson 2017). 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; Quy 2017).

While local debt services were reported to be useful in many cases, options to make debts more manageable, by for example allowing patients to pay in installments, were reportedly resisted by some hospitals. In at least four cases, migrants had offered repayment schemes —following debt advice— to the hospitals and had received no response in return. As one Clinic Supervisor noted in relation to service users receiving cancer treatment:

“[they would] be happy to pay in small installments because they obviously want to care for themselves, and they want to receive the treatments, but some hospitals I’ve seen have been very ... strict in terms of receiving the payment upfront” (S2; Ockert-Axelsson 2017).

Maternal health: an area of particular concern

Pregnant women are entitled to antenatal care, but if they do not have access to public funds due to their immigration status, antenatal care and delivery of the child are chargeable and they will receive a bill. The latest guidelines from the NICE recommend that the first antenatal appointment be booked at 10 weeks for uncomplicated pregnancies. However, almost two thirds (34/55; 61.8%) of pregnant women in the sample were 10 weeks pregnant or more before they presented at the DoTW UK clinic to start the process of accessing antenatal care (registering with a GP and gaining a referral could often take two-three weeks after this point) (Ockert-Axelsson 2017). One in four pregnant women in the sample (25%; 14/55) had not yet accessed antenatal care at 18 weeks and in one case, a woman went without care until 37 weeks (Ockert-Axelsson 2017).

Bills associated with maternity care for an uncomplicated birth typically amount to £5,000-£6,500, which is an unmanageable sum for many women (Ockert-Axelsson 2017). Indeed, at least two cases emerged of women contemplating abortion in order to avoid being sent a bill. Another service user was noted to have received a letter from the hospital requesting a deposit of £6,500 after her first

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13 NICE (2008)
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antenatal appointment, suspending future appointments until the debt was paid and rendering essential care inaccessible to her and her child. One DoTW clinic volunteer expressed frustration over the situations in which women and their children living in the UK are placed:

“these people aren’t asking for ridiculous things ... they’re coming [to the hospital] to have a baby... they don’t particularly want to spend a lot of time in hospital, they just want a safe place to have their baby” (V4; Ockert-Axelsson 2017).

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; Ockert-Axelsson 2017).

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

“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; Ockert-Axelsson 2017).

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. While the use of local debt advice services was key to feeling more in control, participants described feeling there was “no hope” (SU3), “fears” (SU4) and being “unable to cope” (SU5) (Quy 2017). According to DoTW UK case notes, distress related to debts also compounded often severe physical symptoms:

“So now he is paralysed down the left-hand side of his body and is worried about being billed for the treatment he will require after he leaves hospital” (extract from service user case notes; Ockert-Axelsson 2017).

Use of emergency services in place of planned care

Delaying treatment for acute conditions was also found to have a displacement effect, with patients attending emergency services rather than routine appointment to manage or prevent disease (Quy 2017). 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 (SU3; Quy 2017). Another service user described the difficult situation many are placed in, forced to choose between their health and incurring debts they cannot pay. After not taking prescribed medication for her uterine fibroids as she could not afford the prescription charges, her condition worsened. She eventually had to present to A&E for treatment and was billed for the hospital admission:

“Yes, sometime I’m worried about bill of tablets so I don’t take medicine. I saw my
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doctor about bleeding being so bad and he sent me to hospital. But now the bill is more than the bill for the tablets." (SU1; Quy 2017)

Catching early symptoms and ensuring responsive preventative care can reduce the cost of later treatment, or as one GP put it:

“they’re [the NHS] going to end up with a lot more expensive emergency care” (GP3; Ockert-Axelsson 2017).

Lack of preparedness and buy-in among healthcare professionals

Challenges related to lack of understanding and miscommunication among healthcare professionals around the charging policies, compounded service users’ difficulties in accessing care. Case notes and interviews indicated that service users were often exposed to uncertainty and incorrect advice at their GP practices, as well as with hospital staff. Notable examples included patients being turned away from outpatient appointments on the instruction of the Home Office:

“He turned up for his appointment and was told it was cancelled and to go back to his GP to find out why. His GP then informed him that the Home Office had been in touch to say he was no longer eligible for treatment” (extract from service user case notes; Ockert-Axelsson 2017).

The onus on GP services to both explain eligibility and, at times, to advocate on behalf of the patient caused anxiety in the GPs interviewed. One described her difficulties in managing these dilemmas:

“[Service users] don’t know how to get help with it. Um... and what they can do, and um, well they’re just stuck... so people being understandably very upset and coming to see us... and we have to help to communicate back to the hospital about well how complex these issues often are... it’s quite complicated a conversation.” (GP1; Quy 2017)

Doctors interviewed were unsure how to manage the tension between their duty of care and their awareness of potential negative impacts of unmanageable health costs, a discomfort was also noted in the Government-commissioned impact assessment of the Cost Recovery Programme.14

5. Conclusions and policy implications

- The findings clearly demonstrate the unintended consequences of the NHS Cost Recovery Programme, and related Regulations, which pose serious risks to public health; place

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increased cost pressures on overstretched emergency services and; call into question the UK’s commitments under human rights law.\textsuperscript{15}

- The findings presented show the large sums of money being charged to NHS patients, leaving vulnerable people with debts they are unable to clear, even months and years later. The fear and distress created by these debts (or the prospect of them) deters many people from accessing necessary healthcare. This has worrying implications for recent policy changes which reinforce and extend charging in the NHS and require patients to pay upfront and in full, unless their care is deemed urgent or immediately necessary.\textsuperscript{16}

- Many people for whom NHS secondary care is chargeable are living in poverty and payment plans are often the only way for them to cover the cost of their care. By removing this option, which upfront charging does by default, these patients will simply not be able to access care. This highlights the urgent need for clear guidance from the Department of Health to ensure that a range of debt-management options are available to patients that need it.

- Fear of being reported to the Home Office is another significant deterrent for vulnerable migrants from accessing secondary healthcare. This is likely to intensify and extend to primary care given the recent formalisation of patient information-sharing between the NHS and the Home Office.\textsuperscript{17}

- Echoing Government-commissioned research\textsuperscript{18}, the findings also highlight pressing concerns regarding the preparedness of healthcare professionals for the effective and equitable implementation of the charging Regulations, as well as their ability to balance these imperatives against clinical duty and medical need.

- Given the above findings, Government plans to extend upfront charging into primary care are likely to dramatically impact upon the accessibility of NHS care and exacerbate barriers to care experienced by vulnerable groups, including pregnant women.

6. Recommendations

The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 should be withdrawn.

The Department of Health should suspend the MoU\textsuperscript{19} which formalises and reinforces the sharing of confidential patient information between the NHS and the Home Office for use in immigration enforcement.

At a minimum, any regulations to extend charging into new areas of care and / or introduce upfront charges should:

- exempt all services that protect public health, including public mental health services, drug and alcohol treatment services and community midwifery services.


\textsuperscript{16} The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017.

\textsuperscript{17} Department of Health and Home Office (2017).

\textsuperscript{18} Ipsos MORI (2017)

\textsuperscript{19} Department of Health and Home Office (2017).
exempt all services provided by charities or community interest companies.

• exempt all abortion providers.

• retain free universal access to primary and emergency care for everyone living in the UK.

• exempt asylum seekers whose claims have been refused, as in Northern Ireland and Scotland.

• exempt destitute people living in the UK, who are unable to pay costly healthcare bills.

• exempt children and pregnant women living in the UK and retain their exemption from prescription charges.

• require all decisions to withhold healthcare pending payment to be: 1) subject to a second clinical opinion and, (2) open to appeal by the patient.

• be accompanied by Department of Health guidance for hospitals and doctors which:
  (a) outlines how to implement the regulations in a way that is not discriminatory and does not violate human rights or increase health inequalities;
  (b) outlines appropriate arrangements for developing repayment plans which are achievable for patients, especially those on low incomes and in vulnerable situations and;
  (c) confirms that routine identity documents checks should not be carried out in services where NHS charges do not apply, such as infectious disease services and A&E, or in maternity services.

The government should carry out and make public the results of:

• an assessment of the impact of extending charges into community services on vulnerable groups, pregnant women and children;

• an assessment of the impact of upfront charging and checking patient paperwork on access to services, health outcomes and patient waiting times, including an evaluation of the ongoing pilots taking place in hospital trusts;

• an impact assessment evidencing that 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;

• an assessment of the human rights impact of upfront charging and the extension of charges, specifically of its impact on the right to adequate medical and social care;

• a public consultation on the parts of the regulations not included in the 2016 consultation on NHS cost recovery: upfront charging and recording information against NHS number (consistent identifier).