



Delays & Destitution:

An Audit of Doctors of the World's
Hospital Access Project (July 2018-20)

October 2020

Contents

.....	1
INTRODUCTION	3
KEY FINDINGS	4
CONTEXT.....	4-6
LEGAL AND POLICY CONTEXT	6-8
METHODOLOGY	8-11
RESULTS	11-17
Total number of participants.....	11
Sex.....	11
Age	12
Immigration status.....	12
Destitution.....	12
Hospital trust/s involved.....	13
Delay in receiving treatment.....	14
Issue/s arising in the case	14
DISCUSSION	17
Relationship between immigration status and other demographic factors and access to treatment.....	17
Length of delay in receiving treatment experienced by individuals	17
Common causes of delay in receiving treatment	18-19
LIMITATIONS.....	19
RECOMMENDATIONS.....	19-20

INTRODUCTION

Doctors of the World (DOTW) UK is part of the Médecins du Monde international network, an independent humanitarian movement. DOTW has been a registered charity in England and Wales since 1998 and runs clinics providing medical care, information, and practical support to people unable to access NHS services. Our patients include refugees, asylum seekers, survivors of human trafficking, people experiencing homelessness, sex workers, migrants with insecure immigration status and Gypsy, Roma, and Traveller communities.

In 2018, DOTW staff and volunteers supported over 2000 patients at the east London clinic and our caseworkers took nearly 13,000 advice-line calls from patients and partner organisations with health access support needs. Demand for our services has continued to increase and in 2019, we provided over 2,400 consultations.

In June 2018, DOTW launched the Hospital Access Project to provide specialist casework support and legal advice to people refused NHS hospital care or non-primary care related NHS services in the community due to their immigration status in the UK and as a result of the NHS Charging Regulations (2015 and 2017).

This report presents the findings of an audit of service user data collected by caseworkers delivering DOTW's Hospital Access Project between July 2018 and July 2020. The study population is 27 individuals who have been assessed by an NHS service as not 'ordinarily resident' in the UK and have been refused access to services. It includes those who have had services withheld pending payment upfront.

All data for this study was collected from service users living in England and seeking to access NHS services in England. Its findings do not apply to Wales, Scotland or Northern Ireland. The laws governing entitlement to NHS services also vary in the devolved nations.

The aim of the audit is to review and improve the quality of the Hospital Access Project service¹ and explore the impact of the NHS charging regulations on people in extremely vulnerable situations in order to inform DOTW's advocacy work, with the following three objectives:

1. Explore the relationship between immigration status along with other demographic factors and access to treatment;
2. Quantify the length of delay in receiving treatment experienced by individuals; and
3. Identify the most common issues arising in cases.

DOTW's advocacy work is driven by the experiences of the people using our services and informed by data collected in our clinical services. By presenting data collected by our Hospital Access Project service, this report sheds light on the challenges service users face accessing NHS secondary and tertiary care, and makes recommendations to reform the healthcare entitlement policy to ensure universal healthcare access in the UK.

¹ A separate report provides a series of recommendations for DOTW to improve the quality of the Hospital Access Project service.

KEY FINDINGS

- 44.4% (12/27) of service users had a refused asylum claim and 37% (10/27) had an outstanding human rights or asylum application, or appeal.
- In total, 44.4% (12/27) of service users could not be removed from the UK due to an outstanding legal case, for example an outstanding human rights application or appeal, an outstanding asylum claim or appeal, or an outstanding judicial review, which meant they could not be removed from the UK until their case had been closed.
- 96.3% (26/27) of service users were destitute, which meant they did not have adequate accommodation or any means of obtaining it or could not meet their other essential living needs.
- The average delay in receiving treatment was 37.3 weeks. 51.9% (14/27) of service users experienced a delay of over six months (26 weeks) and the longest delay was 4.1 years (224 weeks).
- 59.3% (16/27) of service users required an ‘urgent’ or ‘immediately necessary’ NHS service, with an average delay in receiving treatment of 36 weeks. The longest delay for treatment for a life-threatening or serious health condition was 2.5 years.
- In 22.2% (6/27) of cases requiring ‘urgent’ or ‘immediately necessary’ treatment, the NHS trust did not follow the guidance and apply a charging exemption and the service user was wrongly charged for their treatment.

CONTEXT

Although the health conditions of refugees and migrants are similar to those of the rest of the population, worldwide migrants and refugees are known to face increased health risks whilst on the move and in host countries, and experience higher prevalence of certain conditions.² This pattern has been identified in the UK, with migrants experiencing poor access to health services, higher prevalence of certain conditions and worse health outcomes than the general population.³

² The UCL–Lancet Commission on Migration and Health: the health of a world on the move (2018). London.; World Health Organisation (2018). *Report on the health of refugees and migrants in the WHO European Region*. Copenhagen; Burns, R., Aldridge, R. W., Graversen, P., Miller, A. K., Bader, C., Offe, J. & Fille, F. (2019). *Left behind: the state of Universal Healthcare Coverage in Europe*. Stockholm.

³ Doctors of the World UK (2019), *A study on access to GP registration in England Update 2018*. London; Morgan, G., Melliush, S. and Welham, A. (2017), ‘Exploring the relationship between postmigratory stressors and mental health for asylum seekers and refused asylum seekers in the UK’, *Transcultural Psychiatry*, vol. 54, no. 5–6, pp. 653–74. doi: 10.1177/1363461517737188; Fang, M., Sixsmith, J., Lathom, R., Mountian, I. and Sharin, A. (2015), ‘Experiencing “pathologized presence and normalized absence”: understanding health related experiences and access to health care among Iraqi and Somali asylum seekers, refugees and persons without legal status’, *BMC Public Health*, vol. 15, no. 1, p. 923. doi: 10.1186/s12889-015-2279-z.; Majumder, P., O’Reilly, M., Karim, K. and Vostanis, P. (2015), “‘This doctor, I not trust him, I’m not safe’: The perceptions of mental health and services by unaccompanied refugee adolescents’, *International Journal of Social Psychiatry*, vol. 61, no. 2, pp. 129–36. doi: 10.1177/0020764014537236; Woods, A., Wood, C., Thomas, J. and Abraham, M. (2015), ‘G501(P) To assess the functional status, social habits, and worries in a group of unaccompanied refugee and

The United Nations' Sustainable Development Goals commit countries – developed and developing – to achieving universal health coverage (UHC) by 2030, ensuring “all people and communities have access to the health services they need without the risk of financial hardship”. On 7 October 2020, UN Secretary-General António Guterres published a policy brief calling for countries to speed up and scale up investment in UHC and in stronger health systems, declaring: “we cannot wait 10 years. We need Universal Health Coverage, including mental health coverage, now, to strengthen efforts against the pandemic and prepare for future crises”⁴. In defining UHC, the World Health Organization is clear that policies and provisions for health care must include migrants and those without citizenship.

Since 2014, the UK Government has introduced a series of policies and laws that erode access to health services for migrants living in the UK. Asylum seekers whose claims are refused and undocumented migrants are required to pay 150% of the NHS tariff (the list of prices for different NHS services) for most health services, and those who cannot afford to pay have treatment withheld unless it is deemed urgent or immediately necessary.

However, in the years following the introduction of the NHS charging policies, evidence of NHS trusts withholding immediately necessary and urgent treatment has emerged. This has led to delays in vital care provision, preventable distress and patients avoiding health services out of fear of debt and immigration enforcement.⁵

Concerns about the impact of migrant charging policies on patients, healthcare professionals and public health raised by migrant groups, charities, medical professional bodies, and academics have prompted the UK Government to investigate the policy. A 2018 review of the policy received details of 22 cases in which patients were wrongly told they had to pay for immediately necessary or urgent healthcare before receiving treatment. The findings of these investigations have been suppressed.⁶

The policy exempts testing for COVID-19, and treatment following a positive test, from charges. However, similar exemptions for communicable diseases have failed to ensure migrant patients receive treatment without delay.⁷ A qualitative study carried out by DOTW in April found some excluded groups in England weren't coming forward to health services during the pandemic for

asylum-seeking minors and the implications of these on health behaviour and mental health', *Archives of Disease in Childhood*, vol. 100, no. 3, p. A215. doi: 10.1136/archdischild-2015-308599.454; Burnett, A. and Peel, M. (2001), 'Health needs of asylum seekers and refugees', *BMJ (Clinical research ed.)*, vol. 322, no. 7285, pp. 544–7. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/11230074> (accessed: 4 June 2018).

⁴ United Nations (2020) 'Scale up investment in Universal Health Coverage and in stronger health systems'.

⁵ Potter, J.L., Burman, M., Tweed, C.D. *et al.* The NHS visitor and migrant cost recovery programme – a threat to health?. *BMC Public Health* 20, 407 (2020). <https://doi.org/10.1186/s12889-020-08524-9>; Doctors of The World, 'Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances' (2017); Murphy L, Broad J, Hopkinshaw B, *et al.* Healthcare access for children and families on the move and migrants. *BMJ Paediatrics Open*. 2020;4(1):e000588. Published 2020 Apr 13. doi:10.1136/bmjpo-2019-000588; Maternity Action 'What Price Safe Motherhood? Charging for NHS Maternity Care in England and its Impact on Migrant Women' 2018; Maternity Action, 'A Vicious Circle: The relationship between NHS charges for maternity care, destitution, and Violence Against Women and Girls' (2019).

⁶ The Guardian (2019) 'Ministers accused of cover-up over migrant health reports'.

⁷ Potter, J.L., Burman, M., Tweed, C.D. *et al.* The NHS visitor and migrant cost recovery programme – a threat to health?. *BMC Public Health* 20, 407 (2020). <https://doi.org/10.1186/s12889-020-08524-9>.

fear of being charged or reported to the Home Office, despite the exemption,⁸ and reports have emerged of an undocumented migrant dying without seeking NHS care.⁹

LEGAL AND POLICY CONTEXT

There are no restrictions on access to primary care services for people seeking or refused asylum in England, Scotland or Wales.¹⁰ To receive an NHS secondary or tertiary services in England,¹¹ Scotland¹² and Wales¹³ free of charge, a person must be ‘ordinarily resident’ in the UK. This means they must be ‘living lawfully in the United Kingdom voluntarily and for settled purposes as part of the regular order of their life for the time being, whether of short or long duration’¹⁴ and they must have been granted ‘indefinite leave to remain’.¹⁵

Migrants living in the UK who do not have indefinite leave to remain are charged 150% of the tariff for most NHS services¹⁶, and, following new regulations introduced in 2017, NHS trusts are required to recover the estimated cost of the service beforehand, unless this would prevent or delay an immediately necessary or urgent service from being provided.¹⁷

The Department of Health and Social Care (DHSC) guidance defines immediately necessary treatment as:

“That which a patient needs promptly: **to save their life; or to prevent a condition from becoming immediately life-threatening; or to prevent permanent serious damage from occurring. All maternity services** (antenatal, intrapartum and postnatal) must be treated as being immediately necessary.¹⁸”

Urgent treatment is defined as:

“That which clinicians do not consider immediately necessary, but which nevertheless **cannot wait until the person can be reasonably expected to leave the UK**. Clinicians may base their decision on a range of factors, including the **pain or disability** a particular condition is causing, the **risk that delay might mean a more involved or expensive medical intervention** being required, or the **likelihood of a substantial and potentially**

⁸ Doctors of the World (2020) ‘An Unsafe Distance: the impact of the COVID-19 pandemic on Excluded People in England’. (London).

⁹ Independent (2020) ‘Undocumented migrants dying of coronavirus because they’re too afraid to seek help, MPs and charities warn’.

¹⁰ NHS Choices, ‘NHS general practitioners (GPs) services’; NHS England, ‘Asylum seekers and refugees: how to register with a doctor (GP)’; NHS Inform ‘Healthcare for overseas visitors’; Public Health Wales ‘Refugees And Asylum Seekers’.

¹¹ National Health Service Act 2006, section 175.

¹² National Health Service (Scotland) Act 1978, section 98.

¹³ National Health Service (Wales) Act 2006.

¹⁴ YA, R (on the application of) v Secretary of State for Health [2009] EWCA Civ 225, 2009

¹⁵ Immigration Act 2014, section 39.

¹⁶ NHS (Charges to Overseas Visitors) Regulations 2015, section 7(3).

¹⁷ The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017, section 4(2).

¹⁸ Department of Health & Social Care ‘Guidance on implementing the overseas visitor charging regulations’ pp. 64–6.

life-threatening deterioration occurring in the patient’s condition if treatment is delayed until they return to their own country.”¹⁹

After a review of the charging regulations found they were often misinterpreted or misapplied²⁰, the department published further guidance²¹ for NHS trusts to support them to identify ‘urgent care’:

“If the person is unlikely to leave the UK for some time (which will be the case for some undocumented migrants), treatment which clinicians might otherwise consider non-urgent (for example, certain types of elective surgery) is more likely to be considered by them as urgent. It may not always be clear when a person can reasonably be expected to leave the UK.

“For undocumented migrants... the likely date by which the person can reasonably be expected to leave the UK may be unclear, and will have to be assessed on a case-by-case basis. Those for whom there is **no viable place of return, for example because there are travel or entry clearance restrictions in their country of origin, or for whom there are other conditions beyond their control preventing their departure, should not reasonably be expected to leave the UK until such issues are resolved.**

In some cases, **it will be particularly difficult to estimate the date at which they can be reasonably expected to leave the UK.** Relevant bodies may wish to **estimate that such patients will remain in the UK initially for 6 months**, and the clinician can then consider if treatment can or cannot wait for 6 months, bearing in mind the definitions of urgent and non-urgent treatment given above. However, **there may be circumstances when the patient is likely to remain in the UK longer than 6 months, in which case a longer estimate can be used.**”

Certain NHS services and types of individual are exempt from charges. England, Scotland, Wales and Northern Ireland have different NHS charging regulations and the list of exempt individuals varies. The exemptions in the regulations in England are outlined in Table 1.²² In 2020, COVID-19 was added to the list of specified infectious diseases exempt from charges.²³

Table 1: NHS services and individuals exempt from NHS charges under the regulations in England.

NHS services exempt from charges	Individuals exempt from charges
<ul style="list-style-type: none">● accident and emergency (A&E) services	<ul style="list-style-type: none">● Those who have paid the health surcharge or are covered by

¹⁹ *ibid*, pp. 64–6.

²⁰ Ministerial statement on review of amendments made to the NHS Overseas Visitor Charging Regulations in 2017 (2018).

²¹ Department of Health and Social Care (2018) ‘Upfront charging operational framework to support identification and charging of overseas visitors’.

²² Section 8.

²³ The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2020.

<ul style="list-style-type: none"> ● family planning services (does not include termination of pregnancy) ● diagnosis and treatment of specified infectious diseases ● diagnosis and treatment of sexually transmitted infections ● palliative care services provided by a registered palliative care charity or a community interest company ● services that are provided as part of the NHS111 telephone advice line ● treatment required for a physical or mental condition caused by torture, female genital mutilation, domestic violence or sexual violence 	<p>transitional arrangements</p> <ul style="list-style-type: none"> ● Those with an enforceable EU right to free healthcare ● Refugees and asylum seekers, and their dependents ● Victims, and suspected victims, of modern slavery ● Individuals receiving support under section 95 of the Immigration and Asylum Act 1999 (the 1999 Act) from the Home Office ● Refused asylum seekers, and their dependents, receiving support under section 4(2) of the 1999 Act from the Home Office or those receiving support from a local authority under Part 1 (care and support) of the Care Act 2014 or section 35 or 36 of the Social Services and Well-being (Wales) Act 2014, by the provision of accommodation ● Children who are looked after by a local authority ● Prisoners, immigration detainees and anyone receiving compulsory treatment under a court order or who is detained in a hospital or deprived of their liberty
---	---

METHODOLOGY

Aim: To review and improve the quality of the Hospital Access Project service and inform DOTW’s advocacy work.

Objectives:

1. Explore the relationship between immigration status along with other demographic factors, and access to treatment;
2. Quantify the length of delay in receiving treatment experienced by individuals;
3. Identify the most common issues arising in cases.

Data were collected from individuals accessing DOTW’s Hospital Access Project (“service users”) between 01 July 2018 and 31 July 2020. Criteria to access the service is as follows:

The individual has been assessed by an NHS service as not ‘ordinarily resident’ in the UK and:

- a) *refused access to an NHS hospital or non-primary care related NHS services in the community; or*
- b) *asked to pay for an NHS hospital or non-primary care related NHS services in the community before accessing the service.*

Data are collected from service users by trained caseworkers during interviews with the patient. Interpreters are used when required via the LanguageLine telephone interpreting service.

This information is then collated and stored in a secure Microsoft Excel database and used to support ongoing advocacy casework for the patient, to monitor and evaluate DOTW services, and to inform and support DOTW’s advocacy work.

All service users included in the data set signed a [form](#) consenting to their personal information being stored electronically on DOTW’s internal database and for their information to be used anonymously as part of statistical or research reports, and in anonymous case studies. Translated versions of consent forms and telephone interpreting services were used to ensure consent was informed.

Table 2: Data collected

Variable	Category	Criteria for assessment
<i>Service users</i>		
Service users	Number of people	
<i>Demographics</i>		
Age	Years	
Gender	<ul style="list-style-type: none"> ● Female ● Male ● Inter-sex ● Non-binary ● Trans ● Prefer not to say ● Other ● Data missing 	
Immigration status	<ul style="list-style-type: none"> ● Asylum seeker ● Refused asylum seeker ● Other type of immigration claim 	

	<ul style="list-style-type: none"> • Data missing 	
Immigration status – barrier to removal?	<ul style="list-style-type: none"> • Yes • No • Unknown • Data missing 	
Destitution	<ul style="list-style-type: none"> • Yes • No • Unknown • Data missing 	<p>Destitution is assessed by a DOTW caseworkers against the following definitions:</p> <ul style="list-style-type: none"> • “someone is destitute if they have gone without two or more of the following for an extended period over the course of a month: food, shelter, heating, lighting, clothing and toiletries” Fitzpatrick et al (2018)²⁴ • a person is destitute if: they do not have adequate accommodation or any means of obtaining it (whether or not their other essential living needs are met) or have adequate accommodation or the means of obtaining it but cannot meet their other essential living needs. Immigration and Asylum Act 1999, section 95(3)
<i>Access to NHS services</i>		
NHS trust/s involved	<ul style="list-style-type: none"> • Yes • No • Unknown 	Possible to record more than one NHS Trust.

²⁴ Fitzpatrick, S, Bramley, G., Sosenko, F., Blenkinsopp, J., Wood, J., Johnsen, S., Littlewood, M., Watts, B., (2018) ‘Destitution in the UK 2018’ (London).

	<ul style="list-style-type: none"> • Data missing 	
Issue/s arising	<ul style="list-style-type: none"> • Immediately necessary treatment withheld • Urgent treatment withheld • Incomplete clinical assessment • Failure to apply exemption • Deterred from accessing NHS services • Diagnostics withheld • Maternity care not assessed as immediately necessary • Other • Data missing 	<p>Possible to record more than one issue.</p> <p>Whether a patient requires urgent or immediately necessary NHS services is assessed by a DOTW caseworker and clinician against the DHSC guidance for NHS trusts (see 'Legal and Policy Context' for definitions).</p>
Length of delay	Weeks	Measured in weeks from when diagnosis made and treatment plan determined to when treatment received.

The data for July 2018 to July 2020 was extracted, cleaned and analysed to explore how demographic factors influence delays in accessing NHS secondary and tertiary services, and other factors that prevent service users from accessing NHS services. Incomplete or unclear data entries were marked 'unknown'. Data from people who had unconsented was removed. A descriptive analysis of the data was carried out using Microsoft Excel.

As the dataset includes potentially sensitive information, we reduced the risk of deductive disclosure when reporting results of the analysis and suppressed results pertaining to small numbers of participants if necessary.

RESULTS

Total number of participants

27 service users were included in the Hospital Access Project audit, and 100% (27/27) of service users were interviewed.

Sex

50.1.9% (14/27) of service users were female and 48.1% (13/27) were male.

Age

The median average was 46.9 years. The oldest service user was 75 years old and the youngest was 4 years old. Age data was missing for 7.4% (2/27) of service users.

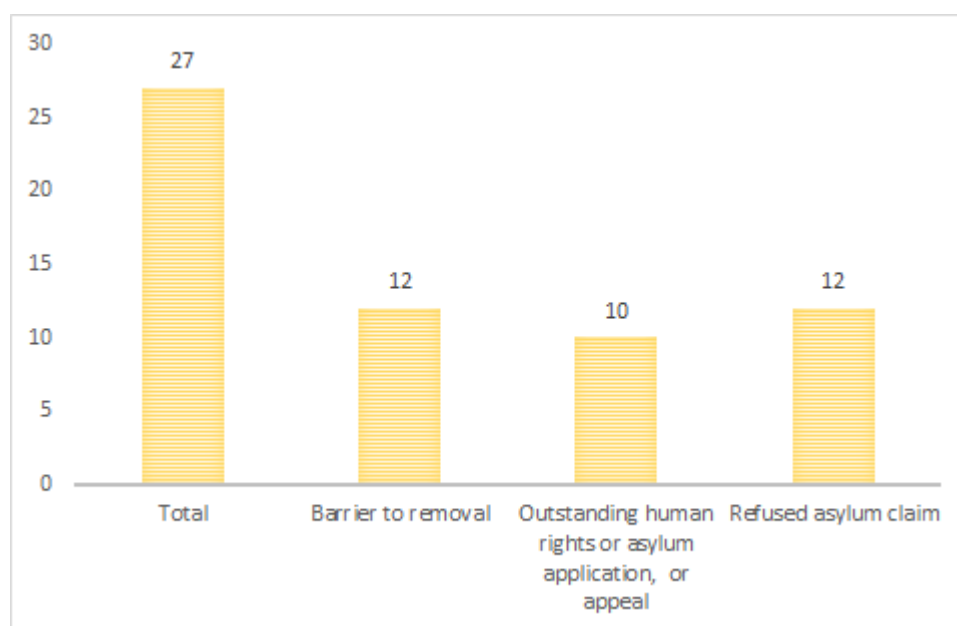
Immigration status

44.4% (12/27) of service users had a 'refused asylum claim' and 37.0% (10/27) of service users had an outstanding human rights or asylum application, or appeal. Immigration status data was missing for 22.2% (6/27) of service users.

Note, the total number of immigration status does not equal 100% because some service users had multiple immigration statuses, for example, an individual may have a refused asylum claim and an outstanding human rights claim.

44.4% (12/27) of service users faced a legal barrier to removal from the UK, for example, an 'outstanding human rights application or appeal', an 'outstanding asylum claim or appeal', or an outstanding judicial review.

Figure 1: Immigration status and barrier to removal



Destitution

96.3% (26/27) of service users were destitute. Destitution data was missing for one service user.

Destitution is assessed by DOTW's caseworkers (see table 2 for definitions).

CASE STUDY: Saloum, 54, undocumented migrant denied palliative care

Saloum (Sal) came to Derby from The Gambia about 10 years ago, having fled in fear of political persecution for his activism against female genital mutilation (FGM). Sal never claimed asylum but worked odd jobs to make ends meet. His friends reported that this work was often exploitative. He had never had any health issues, so had never seen a doctor during his time in the UK.

In December 2018, Sal had been homeless for about two months, staying on friends' sofas, when he collapsed suddenly on the street. He fell unconscious and woke up days later in Royal Derby Hospital, where he was diagnosed with two brain tumours and lung cancer. He was given days to live but after being treated for several days, he was told that as an undocumented migrant he was not eligible for further NHS treatment unless he could pay for it. Being destitute and homeless, Sal would no longer receive the palliative chemotherapy that had been planned. He said: "Somebody came and told [me] they couldn't care for me anymore because of my status... They told me I'd have to pay, and it would be very expensive."

Sal was discharged without any referrals to community care or efforts to ensure he had an appropriate place to stay. He was left without any advice about ongoing care and only with a prescription for anti-seizure medication. He later received a bill for £8,397 for the treatment received before his care was terminated. Sal would have been discharged onto the streets if it hadn't been for his friends who raised money to rent a bedsit for him. His friend said: "He was homeless leaving the hospital. He had to stay on my sofa... Can you imagine someone as sick as him staying on a sofa? Honestly, it's just ridiculous... He's sick and they want him to stay on the street."

After raising some money, Sal's friends found a small bedsit for him to stay in and looked after him in shifts. He was extremely weak, coughing frequently, and drifting in and out of consciousness. Understandably, they were at a loss as to how to properly care for him and felt abandoned by his doctors. DOTW dedicated over 20 hours of case work time to support Sal to register with a GP, to persuade the NHS trust to start the treatment he was entitled to, and to arrange visits from community nurses.

During the course of his illness, the NHS trust continually pressured Sal to pay for his treatment and withheld care because of outstanding charges, despite knowing he was homeless and had no income. This was a great source of stress for Sal right up until his death. His friend said: "Last night, just before he died, he became panicked and anxious and I could see he was scared he might be discharged again because he could not pay for his treatment. I knew him for a long time. He was a very brave soul the way he challenged FGM in Gambia. He had a very tough time in the UK because of the labour exploitation and never really had any time to enjoy his life."

Hospital trust/s involved

The 27 cases involved 34 different NHS trusts in total. In 77.8% (21/27) of cases, one NHS trust was involved and in 22.2% (6/27) of cases, two or more NHS trusts were involved.

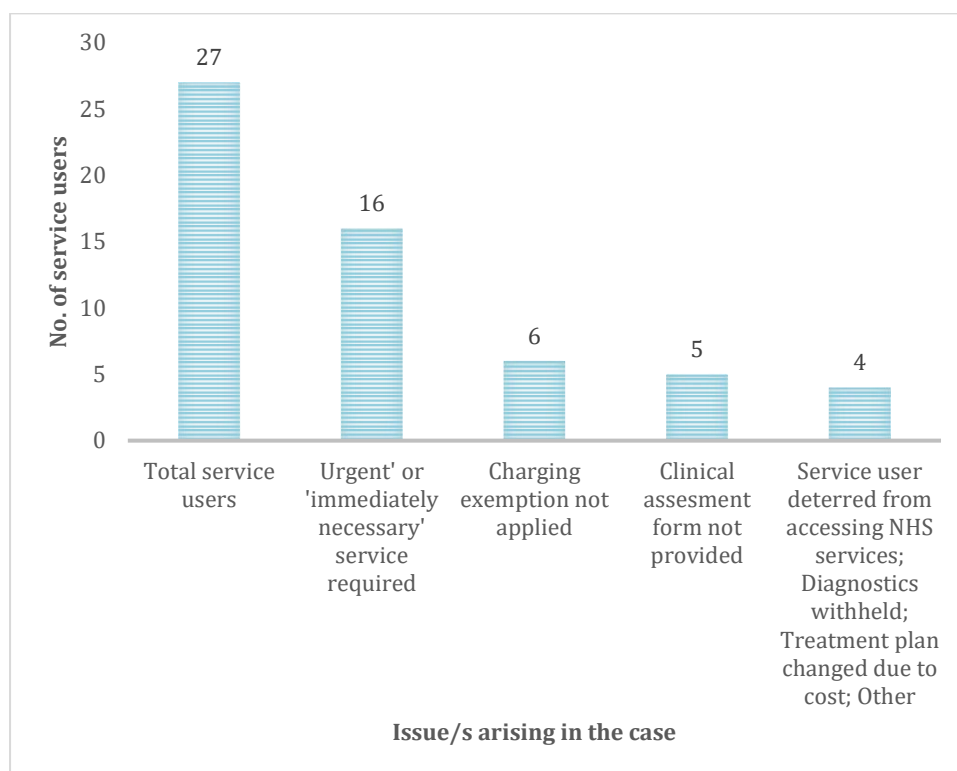
The involvement of an NHS trust in a case does not necessarily mean the trust misapplied the NHS charging regulations or withheld care.

Delay in receiving treatment

Delay in receiving treatment is measured in weeks from when a diagnosis is made and a treatment plan determined to when treatment is received.

The median average delay service users faced before receiving treatment' was 37.3 weeks. The longest delay in receiving treatment was 224 weeks or 4.1 years. 33.3% (9/27) of service users experienced a delay of 6-12 months and a further 18.5% (5/27) experienced a delay of over 12 months. In 18.5% (5/27) of cases, the delay in receiving treatment was 0 weeks. 'Delay in receiving treatment' data was missing for 11.1% (3/27) of cases.

Figure 2: Delay in receiving treatment



For service users who required an urgent or immediately necessary NHS service (16/27), the median average delay in receiving treatment was 36 weeks, with the longest delay in receiving treatment at 135 weeks or 2.5 years. Data was missing for one service user (6.3%).

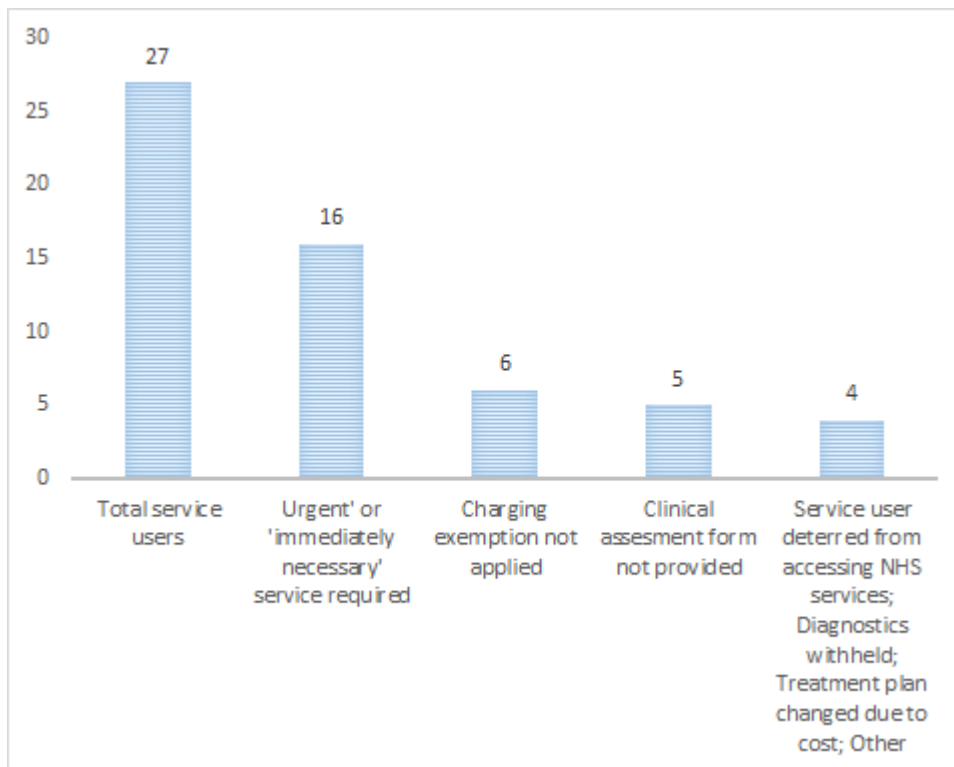
Issue/s arising in the case

The most common issue arising in the cases was 'urgent or immediately necessary service required' (59.3% or 16/27) followed by 'charging exemption not applied' (22.2% or 6/27) and 'clinical assessment form not provided' (18.5% or 5/27).

In 14.8% (4/27) of cases, one of the following issues arose: ‘service user deterred from accessing NHS services’, ‘diagnostics withheld’, ‘treatment plan changed due to cost’ or ‘other’. There was no information missing from this dataset.

Note, a service user’s case may involve multiple barriers so the total number of issues arising does not equal 100%.

Figure 3: Issue/s arising in the case



CASE STUDY: Jean, migrant with an outstanding human rights claim denied cancer care

In June 2018, Jean (not her real name) came to Britain from Azerbaijan on a six-month visa to stay with her adult children. She was in her 70s and had been diagnosed with dementia and a mental health condition. Jean stayed with her daughter and family, and required help completing basic daily tasks, such as cooking and shopping, and it became clear she would not be able to return to Azerbaijan to live alone. Her adult children – her only immediate family members – are British citizens and were unable to relocate to Azerbaijan so, in November 2018, Jean made a human rights claim for leave to remain in the UK on the basis of Article 8 (right to family and private life). She had no income or savings, so her family funded the legal fees.

Later that year, Jean noticed a lump in her right groin, which was diagnosed as a nodal malignant melanoma – an aggressive form of cancer – in early 2019. Subsequent tests showed she also had a separate cancerous growth in her lung. Jean’s local hospital assessed her as not entitled to free

NHS secondary care services because of her immigration status and informed her family that she would be charged for NHS treatment.

Jean was destitute. With no income or savings, she was dependent on her family for accommodation, food, clothes, and transport, and was unable to pay the invoices for diagnostic tests. Despite having a limited income, her children did their best to make monthly payments to the hospital by taking out loans and credit cards. They had been told that the hospital would report the outstanding debt to the Home Office if they didn't make monthly payments and that this would negatively affect Jean's immigration application.

Later in May 2019, the Home Office refused Jean's immigration application. She appealed the Home Office's decision, and a court hearing was scheduled for three months later. Jean's appeal was based on Article 8 and Article 3 (freedom from torture and inhuman or degrading treatment or punishment).

Jean's local hospital referred her to a tertiary NHS trust to treat her lung cancer. After reviewing Jean, a specialist stated that her lung cancer "could be treated radically as far as possible". Jean was also referred to a third trust for immunotherapy to treat the melanoma. However, this trust would not provide the treatment unless Jean paid £150,000 upfront. The tertiary hospital then cancelled Jean's future appointments.

Jean was unable to afford the treatment and her family members were unable to get further loans or credit cards to cover the cost. Jean's treating clinicians expressed concern at having to make decisions that risked putting the family in a level of debt they would never be able to clear.

Amid fears her cancer was worsening, Jean's family and one of her doctors wrote to her local MP – also the Health Secretary – appealing for help. The doctor's letter explained that "there are excellent treatment options available on the NHS should she be able to access these. Indeed, her lung cancer is potentially curable, as may her melanoma be, if treated at this point. With any delays, there is likely to be spread of her cancer disease, which means treatment would not be possible".

Jean's family also approached Doctors of the World for help. Based on Jean's clinical condition, her inability to leave the care of her family and her outstanding human rights appeal, DOTW was of the opinion that she could not reasonably be expected to leave the UK and the NHS services she required should have been considered 'immediately necessary' and provided regardless of her ability to pay. DOTW's caseworker wrote to all three NHS trusts requesting copies of clinician patient assessment form/s supporting their decisions to withhold care.

By July, Jean was experiencing severe pain in her shoulder. Her GP prescribed morphine and made an urgent referral to her local hospital for assessment. She was given an appointment during which she was told her cancer had metastasised and that she needed an urgent MRI. However, the MRI appointment was then cancelled. One of Jean's clinicians wrote to the trusts raising concerns that he was being prevented from treating the patient. Jean was given a one-off appointment for palliative radiotherapy to manage her pain and re-referred her to the third hospital.

Jean then attended a number of appointments at the third hospital, including a CT scan and an appointment with the melanoma team. At each appointment she was told immunotherapy and systemic chemotherapy would not be provided until she paid in advance.

The patient's son received a letter from the trust's Medical Director stating the trust did not consider the patient's treatment to be urgent or immediately necessary and offered to supply her with a fitness to fly certificate.

On 29 August 2019, Jean's claim for leave to remain in the UK was upheld by the court and she was granted the right to stay in the country. The NHS trusts started Jean's immunotherapy, but it was unsuccessful – her cancer had spread to other parts of her body and become terminal. After receiving end of life treatment to try and extend her life and reduce the pain, Jean passed away on 8 August 2020. DOTW estimated that Jean's treatment was delayed by 34 months. The challenges for Jean's family continue as her son and daughter are in considerable debt.

After a delay, the local hospital did respond to DOTW's request for clinician patient assessment forms. The hospital had conducted a number of assessments at different points in time and on each occasion concluded Jean's treatment was either urgent or immediately necessary. The other two trusts did not provide clinician patient assessment forms supporting their decisions to withhold services.

DISCUSSION

Relationship between immigration status and other demographic factors and access to treatment

This audit of DOTW's Hospital Access Project patient data shows that the **NHS charging policy is being applied to destitute individuals with no realistic prospects of being able to pay for the NHS services they receive.** Nearly all the service users (96.3%) accessing the project were destitute and unable to meet their basic needs. Under the NHS charging regulations, they were charged or asked to pay 150% of the tariff for the service they received or required. The levying of inflated charges against destitute individuals meets the World Health Organization definition of 'catastrophic health expenditure' when a person's health expenditure exceeds 10% of household income or expenditure.²⁵

An independent quantitative assessment of the NHS charging policy commissioned by the UK Government excluded refused asylum seekers and undocumented migrants from its calculations on the assumption that most undocumented migrants have no means to pay and charging them should not be considered potentially collectible revenue.²⁶ The Hospital Access Project data suggests this assumption was correct. It raises questions about the cost effectiveness of the current policy as NHS staff time used for charging and pursuing destitute individuals for NHS services is likely to be a waste of resource.

Length of delay in receiving treatment experienced by individuals

The Hospital Access Project audit shows **healthcare charging policies are delaying patients' access to NHS services.** Although many NHS patients experience some delay between diagnosis and treatment commencing, and in most cases it is not possible to distinguish normal delays from

²⁵ World Health Organisation, 'Monitoring Sustainable Development Goals –Indicator 3.8.2'

²⁶ Prederi (2013) 'Quantitative Assessment of Visitor and Migrant Use of the NHS in England'.

delay caused specifically by the charging policy, the data suggest the project's service users are experiencing delays longer than the average for NHS patients. NHS patients have a legal right to start treatment within 18 weeks of a GP referral (unless they choose to wait longer or there is a clinical reason for doing so)²⁷ and at the end of March 2020, 79.7% of NHS patients had been waiting for 18 weeks or less.²⁸ For the project service users, the average length of delay was 37.3 weeks from the point of diagnosis (rather than GP referral), more than twice the target time. Approximately 60% (59.9%) of service users faced delays of over six months, with the longest delay recorded extending to over four years (224 weeks). Individuals in need of urgent or immediately necessary services also faced substantial delays (see next section).

Common causes of delay in receiving treatment

The Hospital Access Project audit shows **urgent and immediately necessary NHS services are incorrectly withheld** from individuals who could not reasonably be expected to leave the UK to receive treatment elsewhere. Those requiring either an urgent or immediately necessary NHS service faced a delay of 36 weeks on average, with the longest delay in receiving treatment at 135 weeks or 2.5 years.

This finding indicates that, despite updated guidance from DHSC, the charging policy is **too complex for NHS trusts to apply correctly and many NHS trusts are failing to correctly assess when an individual can reasonably be expected to leave the UK**. In 44.4% of cases, the service user had an outstanding immigration or asylum case, appeal or judicial review and, therefore, by law, could not be removed from the UK. Case study 1 shows NHS trusts repeatedly failing to correctly assess whether the patient could reasonably be expected to leave the UK, despite evidence of a clear need to remain in the UK and an outstanding human rights appeal. In 22.2% of cases, trusts failed to identify and apply a charging exemption, which suggests trusts struggle to apply even the simple elements of the policy.

NGOs and immigration law experts have long raised concerns that the healthcare charging policy places unrealistic expectations on NHS trusts.²⁹ The correct application of the NHS charging regulations requires sound understanding and experience of asylum and human rights law, the appeals process and judicial review, how an application, appeal or judicial review impacts on a person's ability to be removed from the UK, as well as familiarity with Home Office decision-making timeframes, and court and tribunal case timeframes. The Hospital Access Project suggests this concern is well founded and that linking healthcare entitlement to a person's immigration status is unworkable in practice.

²⁷ [NHS Constitution for England \(2015\)](#).

²⁸ NHS England (2020) '[Statistical Press Notice NHS referral to treatment \(RTT\) waiting times data March 2020](#)'.

²⁹ Doctors of the World UK (2017) 'Doctors of the World Briefing: Government Response to "Making a fair contribution"' (London); Doctors of the World (2016) 'Briefing: Department of Health consultation on further NHS charging – "Making a fair contribution"' (London); Joint Council for the Welfare of Immigrants (2018) 'JCWI response to the Department of Health Review on NHS Charging Regulations' (London). Immigration Law Practitioners' Association (2016) 'ILPA response to Department of Health consultation: Overseas visitors and migrants: extending charges for NHS services, 7 March 2016' (London).

LIMITATIONS

Although the DOTW UK data are extensive, there are limitations in how it is collected and used:

- There is missing data which may result in responder bias. Missing data occurred when DOTW's caseworkers and clinicians had insufficient evidence to establish:
 - an individual's immigration status (22.2% of service users)
 - the length of delay in accessing services (11.1% of service users)
- Data are collected by caseworkers in interview format, so there is the possibility of further bias in the form of observer bias and acceptability bias.
- Although interpreters are used if necessary, questions still may be misunderstood or interpreted in different ways, which could result in over- or under-responses.
- Only small numbers of service users were involved. Any significant difference may require statistical analysis and a larger sample.
- Not all NHS trusts recorded misapplied the charging regulations and/or guidance. In some cases, two (or more) trusts were involved and just one trust misapplied the regulations and/or guidance.
- Due to the fluid nature of immigration status, it was not possible for DOTW to ascertain a person's correct immigration status for the whole of the period of time during which healthcare was withheld.
- These data represent those who were able to contact DOTW and therefore are not more widely representative of the broader population.

RECOMMENDATIONS

Based on the findings of the Hospital Access Project audit, DOTW makes the following recommendations to reform the healthcare entitlement policy to ensure the UK meets its commitments to achieve universal healthcare coverage and upholds its human rights obligations. These should be urgently adopted to address the issues identified above and to prevent unnecessary treatment delays and patient suffering.

1. The definition of 'ordinarily resident' is changed to include all individuals living or resident in the UK regardless of immigration status.

Impact/s:

- Ensure NHS services are not withheld for those who are living in the UK and those facing a barrier to removal from the UK due to an outstanding immigration claim, appeal, or judicial review.

2. Introduce an exemption for individuals on low, or no, income.

Impact/s:

- Ensure NHS services are not withheld from an individual because they cannot afford to pay.
- Ensure the policy does not cause anyone to become destitute or pushed into further destitution.
- Ensure the policy does not cause anyone to build up debts to an NHS trust that they cannot afford to re-pay or to be prevented from regularising their immigration status due to an outstanding debt.
- Save NHS resources being used to pursue individuals who are unable to pay.

3. Establish an independent, transparent process whereby individuals can challenge the decisions made by NHS trusts under the charging regulations and resolve cases within two weeks.

Impact/s:

- Ensure the charging policy does not incorrectly delay access to care for longer than two weeks.
- Ensure immediately necessary services are not withheld when an individual cannot reasonably be expected to leave the UK.
- Quickly resolve cases where a charging exemption should have been applied.