



Response to the Department of Health and Social Care formal review of ‘The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017’ (“the Amendment Regulations”)

Medact

Medact is a public health charity that works to mobilise health professionals in the UK to effect progressive social change. We primarily conduct research and analysis of different social issues in the UK, use this research to inform and educate health professionals and the wider public, and lobby and campaign for change. We have drawn upon the experiences of our members and other health professionals in our networks, for our response to this Department of Health review.

While we welcome this formal review of the impacts of the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 on vulnerable groups, we are very concerned about its limitations primarily as a result of its scope and timing. These issues also impact on our ability to respond directly to each of the questions as part of the review.

Interested parties to whom details of the review were sent at the end of December 2018 have had an unreasonably short period of time to be able to gather evidence and respond, particularly for NGOs and frontline services. This suggests that the review has not been well publicised by the Department of Health and Social Care (DHSC), narrowing the reach of the review and potentially excluding frontline workers - be they health professionals or those working directly with the groups impacted by these regulations - who may have been able to contribute important input.

The timing of the review, coming two months after the introduction of the Amendments, makes it very difficult to be able to demonstrate evidence of harm as a direct impact of, for example, upfront charges and the extension of charges into community services. As a consequence of this, many of the responses below refer to the harm caused to those with particular protected characteristics and other vulnerable groups by ‘The National Health Service (Charges to Overseas Visitors) Regulations 2015’. However, it is reasonable to assume that harm will only be further exacerbated by the Amendments. We are concerned that this retrospective, but very early, assessment of the impact of the Amendments will create a falsely reassuring and incomplete picture of the actual harm caused to date and that will be caused going forward.

We believe that it is important that a complete and comprehensive review of the impacts of ‘The National Health Service (Charges to Overseas Visitors) Regulations 2015’ on those with protected characteristics and vulnerable groups is undertaken before rolling out extensions via the most recent Amendments. As detailed below, there are grave public health impacts of the deterrent effects of both charging for healthcare and information sharing between NHS Digital and the Home Office for immigration tracing. Deterring vulnerable people who are at

higher risk of serious health conditions puts their direct communities at risk as well as the broader public.

Extending charging into community services

1. Do you have any evidence of how the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, has had a particular impact on persons sharing a protected characteristic?

The 2017 Regulations have been implemented too recently for our members, many of whom are health professionals working within the NHS, to have witnessed impacts on individual patients directly related to these changes. The 2017 Regulations have not been implemented across the board within all NHS Trusts or services now chargeable, and thus it is not yet possible to see their full impacts.

However, our members are able to provide evidence of the impacts of charging outside the community setting as introduced in 2015 and earlier. As such, we are able to deduce that similar and further impacts as detailed in below cases will be experienced as a result of the extension of charging into community and non-NHS provider services.

The community services in which we will be able to see the impact of the extension of charging and ID checks will be **community maternity services, drug & alcohol services, Find & Treat outreach services** and **destitution services**. All of these are services in the community or provided by non-NHS providers which may be accessed by those ineligible for free treatment, those who cannot prove their eligibility, or who may be deterred from seeking treatment as a consequence of cost implications or fear of information-sharing with the Home Office for immigration enforcement purposes.

The protected characteristics that we are currently able to see the impacts of charging and ID checks on in community services and in mainstream NHS services as evidenced by responses to the questions as part of this review are:

- Sex
- Pregnancy
- HIV
- Disability
- Race

We would suggest that DHSC consider consulting the Queen's Nursing Institute to see whether they are able to provide you with any specific evidence of the impact of the 2017 regulations on community services, although it is likely that it is too early for their nurses to give a full picture as well. To our knowledge the QNI has been unaware of this review into the 2017 regulations.

2. Do you have any evidence of how the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, has had a particular impact on any other vulnerable group?

As explained above, we are not able to provide detailed evidence of the impact of the recent Amendments on vulnerable groups. However, our members did explain the deterrent effects of the introduction of charging in community services in particular on migrants (including **asylum seekers, refugees, undocumented migrants** and - as highlighted in the following

question - **failed asylum seekers**). Our members also noted throughout this review the harmful impacts of charging and attempts to identify eligibility on **homeless** and **destitute people**.

Case study 1: Asylum seekers deterred from outreach services due to fear of charging

"I have colleagues who work in outreach clinics for asylum seekers and have innumerable examples of cases of patients who report (and have clear physical evidence of) abuse, torture and psychological trauma who have been afraid to seek help for many reasons of which fear of charges is one."

Case study 2: Homelessness

One health professional in their response highlighted the impact of charging for community services on homeless and destitute people and the deterrence that charging and identification for eligibility for treatment on this particular group of people at higher risk of poor health.

3. Do you have any evidence that the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, may have deterred individuals from seeking treatment?

As explained above, the regulations have been implemented too recently for our members to be able to demonstrate evidence of extension of charging into relevant services to have deterred individuals from seeking treatment from those services. However, as evidenced in our following responses throughout this review, charging in secondary care and information-sharing between NHS Digital and the Home Office for immigration tracing *has* deterred vulnerable groups and in particular those with complex immigration status from seeking or following up on treatment. Extending charging and ID checks in the community and to non-NHS providers of relevant services will compound the deterrent effects already felt and experienced by pregnant women and those who have given birth with complex, precarious or no immigration status, as for all undocumented migrants, failed asylum seekers and even those eligible for treatment such as asylum seekers and people with leave to remain.

We can deduce from the deterrent effect of notification of the cost of certain treatments (see Case Study 2 below), that this effect will likely manifest as a result of the extension of charging in community and non-NHS provider services.

The case studies below provide evidence of the ways in which vulnerable populations, including **undocumented migrants, migrants with precarious or complex immigration status** and **refused asylum seekers** are already impacted and deterred by a) NHS Trust attempts to identify eligibility for free treatment; b) fear of information sharing between the Home Office and the NHS for immigration enforcement purposes; and, c) confusion around eligibility for free treatment and the services that are exempt from charging.

In particular, those vulnerable groups impacted as mentioned above also hold protected characteristics, including **HIV and disability**.

While access to urgent mental health services are protected under the Mental Health Act 1983 - more specifically, if detained under the Mental Health Act - **community mental health services** are not exempt from charging under the latest Amendments. Charging for

mental health services in the community as well as within mainstream NHS services will further compound barriers for migrants (whether undocumented, refugees and asylum seekers) - and in particular refused asylum seekers - from accessing the care and treatment they need.

Rates of PTSD are higher in migrants and in particular refugees, asylum seekers and refused asylum seekers. While refugees and asylum seekers are exempt from charging in mental health community services, attempts to identify eligibility risks deterring them from proceeding with seeking treatment. Confusion around entitlement to healthcare, in conjunction with language, are key factors in barriers for migrants accessing healthcare. Refused asylum seekers on the other hand, as demonstrated in the below case study, are not exempt from charging, and harm is a consequence of this barrier.

Case study 1: Outreach service for vulnerable and excluded populations at risk of TB and BBV

*"I lead the Find & Treat outreach service across London serving vulnerable and excluded populations at high risk of TB and BBV. This service, in accordance with NICE guidance, takes digital radiology to the streets to screen for active TB and provide testing for BBV and offer essential vaccinations. **Our main concern, shared across our community partners, is that the policy has generated the impression that NHS services are NOT free and that presentation to a NHS service will result in Home Office intervention** - people think we now routinely share information with HO - this is having a major impact on our ability to engage with the affected community and prevent TB transmission."*

Case study 2: Deterrence from community mental health service

"Refused asylum seeker with PTSD and depression with psychotic elements received appointment letter from NHS community mental health team stating in the second paragraph that they would need to provide evidence of entitlement to care on arrival for appointment. The person was too fearful to attend unaccompanied."

Case study 3: Dying patient charged for cancer treatment refuses community palliative care services

*"A patient who used all her savings to pay for cancer care now dying of secondaries (which may have responded to second line therapy) has now **refused referral to community palliative care services for fear of bills**. Apart from the suffering from causes amenable to NHS treatment for other patients, her on-going and increasing needs are making considerable clinical and emotional demands on GPs and practice nurses."*

4. Do you have any evidence that the extension of charging into relevant services provided in the community, or to non-NHS providers of relevant services, may have had an impact on public health?

Charging in community and non-NHS provider services have been introduced too recently to note specific cases of the impacts on public health. However, from the answers given to the above questions and from specialist knowledge of the interaction between certain diseases, in particular infectious diseases, and socioeconomic status and living conditions, we feel it is possible to predict that further barriers to accessing care through community and non-NHS services will have negative health implications on certain vulnerable communities.

Research has shown that only one third (32.5%) of all migrants entering the UK registered with a GP, with evidence suggesting that migrant populations with the lowest proportion registered are likely to also have the highest health needs.¹ In examining the reported barriers affecting migrants in the UK to accessing healthcare, a lack of knowledge about rights and rules of the health system is the primary factor², with other factors including having been denied access to healthcare previously.

Health services provided in the community and by non-NHS providers such as charities play a crucial role in helping vulnerable populations to access healthcare and get screened for certain diseases. From the examples given above and research on the topic, it is clear that the introduction of charging into these services, regardless of the fact that treatment for infectious diseases remains exempt from charging, will serve to further complicate, confuse and deter groups of people already less likely to actively seek treatment.

Infectious diseases

HIV: Late diagnosis of HIV is a continuing problem within the UK, with undiagnosed cases of HIV constituting 12% of all cases. **42% of people diagnosed with HIV in 2016 were diagnosed late.** Any deterrent consequence of the extension of charging into community or non-NHS provider services risks those suffering from undiagnosed HIV spreading the disease.

More specifically, **Black and African men and women constitute a disproportionate number of those diagnosed with HIV in heterosexuals (39%).** As stated above, any deterrent effect felt by the extension of the Regulations to these crucial services, even as a result of misinformation, misunderstanding and fear, puts this particular group at increased risk of late diagnoses of HIV and consequently of spreading the disease.³

TB: The World Health Organisation notes that there are two principal pathways to early TB case detection: the 'patient-initiated pathway', requiring a person with TB actively seeking care when experiencing symptoms; and, the 'screening pathway', requiring the active identification of persons with suspected TB among people who do not actively seek care for signs compatible with the contraction of TB.

In England in 2016, **74% of cases of TB were among non-UK born people.** This is the vast majority of TB cases. **32% of those with pulmonary TB waited over 4 months from onset of symptoms to begin treatment.**⁴ Late diagnosis of TB risks its spreading more widely and particularly within the immediate community. Considering the high prevalence of TB within non-UK born people and particularly within South Asian and African communities

¹ Stagg HR, Jones J, Bickler G, et al., 'Poor uptake of primary healthcare registration among recent entrants to the UK: a retrospective cohort study. *BMJ Open* 2012. <http://bmiopen.bmj.com/content/2/4/e001453>

² According to a 2012 Doctors of the World study, 52% of clients accessing their service in London reported a lack of knowledge of their rights and the health system as a barrier; 40% reported difficulty in gathering documents required to obtain healthcare; 21% reported being denied healthcare Chauvin P, Simonnot N. Access to health care for vulnerable groups in the European Union in 2012: Doctors of the World 2012. <http://www.europarl.europa.eu/document/activities/cont/201302/20130208ATT60776/20130208ATT60776E N.pdf>

³ Figures taken from the Terrence Higgins Trust, 'Facts and statistics about HIV: HIV in the UK'. 2016. <http://www.tht.org.uk/our-charity/Facts-and-statistics-about-HIV/HIV-in-the-UK>

⁴ Figures taken from TB-Alert, 'UK Stats and Targets'. 2016. <https://www.tbalert.org/about-tb/statistics-a-targets/uk-stats-and-targets/>

for whom there are lower than average levels of registration with GP services as noted above, it is clear that these are the communities that will be most negatively impacted by introducing further complication and confusion of eligibility for accessing community and non-NHS provider services.

Destitution

Responses to many of the questions asked as part of this review by our members referred to the disproportionate impact that charging - within community services, non-NHS provider services and more widely in secondary care - would have on homeless or destitute people.

Research shows that 73% of homeless people have reported physical health problems, with 80% reporting some form of mental health problem. 39% report taking drugs or recovering from a drug problem, and two-thirds consume more than the recommended amount of alcohol. It is reported that homeless people disproportionately face barriers in accessing treatment, with **7% being denied access to a dentist or GP.**⁵

Homeless and destitute people are more likely to find difficulty in accessing care, while they are also at higher risk of health issues that require treatment. **Community services and non-NHS providers such as charities provide crucial services for destitute people, whether rough sleepers or those without stable abode, who find difficulty in registering with GPs.** Any further complication or barrier to accessing care introduced by charges either upfront or being billed later for care risks placing further deterrent on destitute people, as well as risking them not attending follow up appointments or treatment. And with BAME people reportedly accounting for 40% of all homeless households, there is a risk that destitute BAME people will be disproportionately affected by further barriers to accessing care through community services⁶ - particularly given the only recently suspended policy to detain and deport rough sleeping EU migrants.⁷

5. Do you know of any examples of good practice or steps that could be taken which might mitigate the issues that you have raised in your responses to questions 1, 2, 3 and 4?

As the 2011 The King's Fund and NCVO report on health services provided by the voluntary and charity sector identifies, "The work of voluntary and community organisations is wide-ranging, but much of the focus is on upstream preventive and wellness support, as well as advocacy and signposting."⁸ Charity services often provide primary support for those who have not yet accessed, for whatever reason, mainstream NHS services. This includes

⁵ Statistics from Homeless Link, 'The Unhealthy State of Homelessness'. 2014.

<https://www.homeless.org.uk/sites/default/files/site-attachments/The%20unhealthy%20state%20of%20homelessness%20FINAL.pdf>.

⁶ Research conducted by Centrepoin and the *Independent*. Benjamin Kentish, 'Homelessness among ethnic minorities soars under Conservative government, new analysis reveals', the *Independent*. 31 December 2016. <http://www.independent.co.uk/news/uk/home-news/homelessness-ethnic-minorities-rise-conservative-tory-government-theresa-may-david-cameron-welfare-a7502126.html>.

⁷ 'Deporting EU rough sleepers from UK unlawful, High Court rules', BBC News. 14 December 2017. <http://www.bbc.co.uk/news/uk-42354864>.

⁸ N Curry, C Mundle, et al., 'The Voluntary and Community Sector in Health: implications of the proposed NHS reforms', The King's Fund and NCVO, 2011. https://www.kingsfund.org.uk/sites/default/files/Voluntary-and-community-sector-in-health-implications-NHS-reforms-The-Kings-Fund-june-2011_0.pdf.

signposting to the correct services and advocacy for patients with a lack of confidence and knowledge in accessing the services they need.

Given the above responses, particularly relating to the impacts on public health of the introduction of charging into community and non-NHS provider services, we believe that there will be no feasible or workable way for the DHSC or NHS to mitigate the potentially harmful impacts of the legislation on a number of vulnerable groups and more widely on public health. **Community services and health services provided by charities frequently meet needs not met by the statutory services, particularly for vulnerable groups.** The DHSC must be able to evidence that vulnerable groups will not be disproportionately impacted by this change in the regulations, and that satisfactory and effective safeguards are put in place so that those already less likely to access treatment for health needs, including as a result of suffering from symptoms of infectious diseases, will not be further deterred. **The only way to do this is by rolling back this extension to charging.**

In particular, services provided by charities and other non-NHS providers should be exempt from charging, as they can be the first port of call for vulnerable groups, including homeless people and those with complex or no immigration status requiring urgent treatment.

Response from a health professional suggesting a nurse based outreach service

*“A nurse based service providing free open access to refugees and those seeking recognition as refugees was effective in **identifying healthcare needs and in protecting the local community** from contagion at least until access was denied because of change of status. **It is essential that all patients deemed a public health risk should receive access to care free if necessary.**”*

Response from a health professional suggesting recruitment and training of peer educators

“We use peer educators recruited from the affected community to build trust with excluded populations at high risk of TB and BBV.”

The requirement for all relevant bodies to charge upfront for treatment that is not immediately necessary or urgent

6. Do you have any evidence of how the requirement to charge upfront for treatment that is not immediately necessary or urgent, has had a particular impact on persons sharing a protected characteristic?

The 2017 Regulations have been implemented too recently for our members, many of whom are health professionals working within the NHS, to have witnessed impacts on individual patients directly related to these changes. The 2017 Regulations have not been implemented across the board within all NHS Trusts or services now chargeable, and thus it is not yet possible to evidence the full impact of the introduction of upfront charging.

Our members are able to provide evidence of the impacts of charging for secondary treatment as introduced in 2015 and earlier. As such, we are able to deduce that further impacts as detailed in below cases will be experienced as a result of upfront charging on protected characteristics such as **women, pregnancy and HIV.**

Case study 1: Pregnant women deterred from seeking maternity care and subsequent health consequences

*“As a paediatric trainee working in neonates, I commonly see babies of women from immigrant communities who did not receive full (or any) antenatal care, with all the resultant risks to themselves and their babies. **Many of these women would actually have been eligible for free care, but did not appear to know that they were entitled to access to these services.***

*The most striking case I have seen is of a woman who booked her pregnancy too late to have early screening or an anomaly scan, and subsequently gave birth to a baby with multiple significant congenital anomalies. **This was part of a syndrome that would have been picked up on early screening around 12 weeks gestation, if only she had accessed such care.** If picked up early, the mother would have had the opportunity to make informed decisions about the pregnancy, and if she chose to continue it, to plan for life with a severely disabled infant. Instead, the diagnosis was not made until birth and the child sadly died at around 3 months of age with complications from their condition. There are no winners from this scenario: the mother suffered shock and then early bereavement; the medical team lost the opportunity to plan for the care of the child appropriately in advance; the NHS paid for costly neonatal and paediatric care; and the child lived a short and distressed life.*

*I cannot say that upfront charges directly led to this scenario, but **it is extremely clear from my practice that immigrant communities are deterred in many ways from accessing care, with direct impacts on health. Charging is only worsening that situation.***

Case study 2: Pregnant woman deterred from antenatal care

“A woman arrived in labour having not received any antenatal care. She explained that she could not afford it. She wasn't sure how she was going to afford care for the labour and birth, but felt she could not give birth alone at home. I'm sure I don't need to explain how dangerous it is to go without any antenatal care.”

Case study 3: Sex and pregnancy

*At her initial 'booking' appointment at 12 weeks, **one patient was distraught at learning how much she would be charged for her pregnancy, birth and postnatal care.** She explained that she could not afford this and begged for an exception to be made. **She did not access any more pregnancy care with us,** despite repeated contacts to remind her of appointments and scans.*

Case study 4: HIV

*“Some 14 years ago [...] in Blackburn, I managed two public health nurses providing services to asylum seekers awaiting confirmation of their status as refugees. The nurses facilitated access to primary and secondary care services. **On one occasion a HIV positive asylum seeker with open TB whose treatment they supervised was refused refugee status and as a result lost her income and lodgings.** She disappeared into the community probably in Manchester with two contagious diseases and no access to treatment. It is imperative that treatment access is continued to people with contagious disease both for their sake and to prevent their becoming a risk to the communities in which they reside. At the time of this occurrence services were available to asylum seekers but not once their status was not confirmed.”*

Response from health professional on impact of changes on diagnosis of infectious diseases

“The logic of the system is flawed. Patients cannot self diagnose TB, AIDS defining illnesses and liver failure, which have non-specific symptoms that - in the perception of providers - could likely fall under the definition of treatment that is not ‘immediately necessary’ or ‘urgent’.”

7. Do you have any evidence of how the requirement to charge upfront for treatment that is not immediately necessary or urgent, has had a particular impact on any other vulnerable group?

While few of our members are able to provide evidence of the direct impacts of upfront charging for treatment on their patients, due to the fact that the regulations have only recently been introduced, they have provided evidence of the risks of this policy and of the impact that charging in secondary care has had on their patients to date. In particular, those affected have been individuals from vulnerable groups, including **migrants**, including **refugees**, **people with leave to remain**, **asylum seekers**, **failed asylum seekers** and **undocumented migrants**. We can predict that these impacts will be compounded by the requirement to charge *upfront*.

Throughout our response to this review, respondents have drawn on the difficulties of distinguishing between ‘immediately necessary’ or ‘urgent’ treatment, and ‘non-urgent’ treatment, and the dangers associated with upfront charging for treatment that is perceived to be ‘non-urgent’ in this respect.

Case study 1: Delay in receiving treatment for ‘urgent’ care

*“In Oncology the definition of “urgent” or “immediately necessary” is particularly important because it is a very time dependent speciality. I have seen multiple cases where the clinical requirement and definition of “urgency” would be a patient requiring referral and assessment in 2 weeks and treatment within 64 days but patients who are “non-UK residents” have been de-prioritised as a result of their resident status and the need to assess for upfront charges. This has led to not only **delays** in obtaining treatments and the associated clinical impact (not to mention devastating psychological impact) but also adaptations and “downgrading” of suggestions to the perceived ability to pay for the treatments if received in their native country.”*

Case study 2: Undocumented migrants

“I have seen a number of examples of cases where patients who are not legally registered in the UK have not sought help for chronic conditions and significant medical conditions which undoubtedly has led to their premature death because of a belief that their details would be shared with the Home Office.”

8. Do you have any evidence that the requirement to charge upfront for treatment that is not immediately necessary or urgent, may have deterred individuals from seeking treatment?

While it is difficult to evidence deterrence directly as a result of the recently introduced requirement to charge upfront for treatment, respondents highlighted evidence of deterrence as a result of both charges in secondary care and the fear of information being handed over by the NHS to the Home Office for immigration tracing. **It is clear in many instances that the two fears, that of immigration tracing and deportation, and of being charged for secondary care, work in conjunction with each other to deter vulnerable groups of**

patients from seeking care or proceeding with treatment. As such, both must be reviewed for the risk of deterring patients and in particular vulnerable groups requiring care.

Those affected evidenced below are **undocumented migrants**, people with **complex immigration status**, and one who had **paid the immigration health surcharge**.

Case study 1: Non-attendance as a result of fear of charging and information sharing with Home Office

*"I am a trainee doctor, doing Core Medical Training. **Of the five patients that have been told they are being charged for treatment under my care, all have had serious issues of non-attendance.** The relatives of one patient explained to me the patient was concerned he would be deported if he came to see us in clinic. **Another patient, who was being prepared for dialysis for poor kidney function, explicitly told me he'd prefer not to visit us in clinic or know what preventative medications to take because he couldn't afford it.** Clearly, these charges affect the poor much more substantially."*

Case study 2: Undocumented man dies because of delay in seeking healthcare

*"I personally know of a case where a young man from China died (without doubt prematurely) because of delayed healthcare seeking as he was an unregistered immigrant. **His entire family after he died disclosed that they had delayed seeking help for his significant health problems including end stage renal failure and ultimately coronary heart disease which led to his emergency admission and death purely because they had been concerned they would be reported to immigration authorities.** This had significant implications for the wider community where he lived and immeasurable consequences for him and the family (not just emotional and psychological but also economic as they would have dealt with the disability of his conditions amongst themselves). **I have also dealt with many cases where individuals have delayed health seeking for Oncology treatments due to concern that they would either be blocked from care or again reported to immigration authorities.** This is extremely worrying and has huge negative financial, societal and care implications which affect not just those delaying seeking help but their families, communities and the healthcare professionals then dealing with more advanced, complex and intensive time and resource-heavy cases that could have been dealt with earlier."*

Case study 3: Response from a health professional

One health professional told Medact that within their hospital, there were multiple examples of patients avoiding NHS services as a result of the introduction of upfront charging and fear of information sharing with the Home Office.

Case study 4: Response in relation to below [Case study 1] [Question 12]

The health professional notes that the bill of £5,500 that the woman in question was given for the care that she received may have led to a decision to discharge sooner than she should have or than would have been ideal from a health perspective.

9. Do you have any evidence that the requirement to charge upfront for treatment that is not immediately necessary or urgent, may have had an impact on public health?

See our response for Question 4, and the following responses from health professionals to this question for the evidence of the harm that upfront payments and a fear of seeking treatment can cause on those suffering from the symptoms of infectious diseases.

Upfront charging and its deterrent effect will have a huge impact on public health as well as the DHSC and NHS duty to protect and improve public health. In particular, certain vulnerable communities will be most impacted by these regulations, and the damage this can cause to communities as a whole must be taken into consideration.

Health professionals who have responded to this review have highlighted the grey area between 'urgent' or 'immediately necessary' care and those considered not to be 'urgent'. This can be the difference between a patient requiring treatment urgently receiving that treatment, and often these decisions are made subjectively. This risks the health of the patient, as well as creating more burden and pressure on health professionals. It is important that the DHSC prioritises patient well-being, and rolls back the introduction of upfront payments.

Response from a health professional concerned of the impact of upfront charging on deterring those suffering from TB and HIV or related symptoms - and subsequent risk of transmission

"I am now semi-retired, but when I ran a regional Viral Hepatitis Service I saw many individuals from overseas who were not aware of the fact that they carried a blood borne virus - especially those with chronic Hepatitis B virus. There are over 400 million people in the world who are infected with this chronic viral infection, which can sometimes be transmitted sexually. In some countries infection carries a social stigma so testing is not done. I am concerned that the dual deterrent of stigma and charging will stop individuals coming forward for testing and therapy - if required. This means that infectious individuals may not only miss out on assessment and treatment but also transmit infection to others.

I believe that screening for all infectious diseases should be free on public health grounds. Another example is multi-resistant TB. Theoretically these infectious diseases are supposed to be screened on entry BUT.... is there any evidence that this is done effectively?"

Response from a health professional concerned with the inefficacy of the exemption of infectious diseases

"If a policy of payment being required prior to treatment for contagious disease then it may have the effect of producing foci of contagion in vulnerable communities."

Response from a health professional concerned with the impact of charging on deterring those with symptoms of infectious diseases that often do not appear to require 'immediately necessary' or 'urgent' treatment

"As explained, the logic of the system is flawed. Patients cannot self diagnose TB, AIDS defining illnesses and liver failure. They have non-specific symptoms which, in the perception of providers, likely fall under the the definition of treatment that is not 'immediately necessary' or 'urgent'."

Response from a health professional concerned that while infectious diseases are exempt from charging, that this policy is unworkable

"Infectious disease are supposed to be exempt on Public Health grounds but this is fundamentally flawed for the simple reason that patients ultimately diagnosed with TB,

HCV, HIV etc present with a myriad of pathology and clinical diagnosis can be a protracted affair. If you unwell but have concerns that you are likely to be charged and brought to the attention of HO if you seek care then you are unlikely to think to yourself 'don't worry...my non-specific symptoms are possibly attributable to a serious infectious disease which is exempt from charging due to public health grounds so I'll go and see the Doctor and hope that it's TB!' This is a reality - people will avoid care - duration of infectiousness will increase - the end point is onward transmission, severe disease and preventable death."

Response from a health professional about the impacts on vulnerable communities of the burden of care for those suffering several co-morbidities

*"As illustrated in the cases where I know patients and their families have delayed seeking help for a number of significant co-morbidities, this will have inevitably had a large negative impact in terms of the communities being impacted by the disability of those living with these conditions. We know that increased DALYs have a huge socioeconomic impact and the caring responsibilities being left to those immediately surrounding the individual rather than seeking support from services available will have led to financial, psychological and even health burden themselves to these families and communities. **This has knock on impact to the health of the entire population when pockets of communities are isolated and excluded from receiving treatment and support.**"*

10. Do you know of any examples of good practice or steps that could be taken which might mitigate the issues that you have raised in your responses to questions 6, 7, 8 and 9?

Until the Department of Health can provide evidence that both healthcare charging in secondary care and the NHS Digital-Home Office Memorandum of Understanding on data sharing for immigration tracing do not deter people from seeking care, and until a well-publicised public consultation *preceding* the introduction of upfront charging and the extension of charging in community services and services delivered by non-NHS providers, these regulations should be withdrawn.

We are concerned that the DHSC has not sufficiently cross-examined the possible impacts of the latest regulations with the duty to protect and improve public health and with equalities guidance on the NHS. We are also concerned that the DHSC has ignored repeated concerns raised by health professionals, charities working to support migrant populations with their health needs and others *prior* to the introduction of upfront payments.

As highlighted by the health professionals who responded to this review, the negative impacts of the Amendments **cannot be feasibly mitigated to reduce harm caused for vulnerable communities** (including asylum seekers, refused asylum seekers, undocumented migrants, and homeless and destitute populations), those with protected characteristics (including pregnant women, those who are HIV+, those living with disabilities and on the basis of race).

Response from a health professional

*"My experience of working with patients from very vulnerable groups is that **health literacy is frequently low, and navigating the NHS very challenging, especially if English is a second language**, so messages need to be simple and clear. In this context, I think it is difficult to see how steps could be taken to 'mitigate' charges. **If***

charging exists at all then that is the message that will get through; people will not always understand a complex set of exemptions or provisions that are designed to mean they actually do have access in some situations. Charges need to be abolished, not mitigated.

Response from a health professional

“Roll back all upfront charges immediately.

The NHS is premised on the principle of universal and comprehensive care. This fundamentally undermines this and there is absolutely no justification for doing this in terms of 1) evidence to my knowledge that as a proportion of our population that any more migrants are seeking healthcare in this country than in 1948, in fact the number may even be decreasing but of course it is very difficult to measure and perhaps more importantly 2) that the substantial cost of implementation of charges and the costs of the negative impact of introducing charges will in any way mitigate against the cost of the very small number of those seeking it who are not UK residents.

As a doctor, being involved in the assessment of who is eligible for care is also in direct conflict with my professional duty to provide the best possible care without discrimination against patients. Introducing upfront charges and also requiring professionals to be involved in identifying these patients is discriminatory and undermines good practice.”

Response from a health professional about using community outreach

“Outreach using peers as trusted advocates to engage the affected community.”

Response from a health professional

“There could be healthcare professionals that are advocates for patients with regards to entitlement to healthcare.”

Response from a health professional regarding pregnant women deterred from seeking or unable to afford care

“Best practice would have been to make sure these women did not have to pay for any of their care.”

Recording when a patient is an overseas visitor

11. Do you have any evidence of how the requirement to record a patient’s overseas visitor status has had a particular impact on persons sharing a protected characteristic?

The key impacts felt by the duty for NHS Trusts to identify the status of patients for whether they are overseas visitors, and what their eligibility or entitlement to care is, is that of racial or ethnic profiling. From responses from health professionals amongst our networks and cases that Medact staff have heard of directly, often the perception by patients asked for their nationality and residency status, and coupled with questions about their ethnic background, has led the patients to feel as though they are being profiled and treated differently as a result of their skin colour, features and/or accent, and that this profiling is a result of the duty to identify eligibility to NHS services.

This of course risks the NHS’ duty to eliminate discrimination and victimisation under the Equalities Act 2010, and the duty to identify residency and overseas visitor status again risks

detering patients with complex immigration status from seeking treatment or attending important follow-up appointments. As has been evidenced throughout this response to the review, the confusion surrounding eligibility - on the parts of patients and health professionals within the NHS - particularly for vulnerable groups, leads to deterrence and risks individual and public health.

Case study 1: Perceived racial profiling

“Two patients feel they have been racially typed on entering A&E and been given forms to fill in. One sat next to the reception desk and saw that few who were white were being given the forms and everyone who was black was.”

Case study 2: Treatment told to Medact staff member by an NHS patient

Prior to the introduction of the latest Amendments, a British citizen of Middle Eastern background sought treatment at A&E and was asked by a receptionist what their nationality was, how long they had lived in the UK and the ethnic background of their mother, all before asking what they were seeking treatment for. The patient was concerned that they were being racially profiled for the purpose of identifying eligibility for follow-up treatment if necessary, and felt as though first and foremost they were being seen as someone who may not be eligible rather than a patient seeking treatment.

Case study 3: Treatment told to Medact staff member by an NHS patient

Prior to the introduction of the latest Amendments, a British citizen of Middle Eastern background sought treatment at A&E. She spoke of her confusion as to the presence of immigration enforcement officials within the hospital, but also that upon arrival, the receptionist immediately asked her about her nationality, residency status and ethnic background. When the patient questioned the receptionist as to why she was being asked these questions and whether she had to answer them, the receptionist allegedly asked her whether she had watched the TV programme ‘UK Border Force’ and that it was “a very interesting show”. The patient reported of her belief that the questions she was asked were linked to her having been racially profiled as someone who may not be eligible for free follow-up treatment, and her worry that the receptionist in question was able to obscure her own prejudices against migrants to the UK with a duty to identify eligibility.

12. Do you have any evidence of how the requirement to record a patient’s overseas visitor status has had a particular impact on any other vulnerable group?

The confusion surrounding the identification of overseas visitors and their eligibility for certain secondary treatments has led to situations leaving patients feeling unfairly and insufficiently treated, and, as evidenced by the case below brought forward by one of our members, this can and does result in patients discharging too early and potentially discontinuing treatment.

As evidenced below, this requirement also leads to situations in which patients are discriminated against on the basis of their **race** and **ethnicity**, and in which patients feel as though they are being questioned on that basis.

Case study 1: Confusion around eligibility for overseas visitors who have paid immigration health surcharge; Impact on confidence in treatment received; Lack of clarity around “urgent” care

*“I was on the ward, a lady had applied for British residency. Her daughter is a British resident and has a British passport. **She had paid the immigration health surcharge***

for her mother as part of the residency application. The overseas visitor manager came on the ward and saw the patient after 10 days of being on the ward. It was handed over to me that she was not entitled to care. There was no writing in the notes or any documentation I could find. I spoke with the daughter who explained the situation and I documented in the notes that she had applied for residency for her mum and paid the surcharge. **The following day, the OVM documented in the notes that she was not entitled to care but there was no reasoning why. It wasn't just documented to clarify whether care was urgent or immediately necessary.** She was later that day presented with a £5500 bill for her care. She spoke with the registrar about the care for her mother and whether we weren't doing things because of the question of her entitlement to care. We reassured her that we were treating her based on what she had come in for. It was discussed with the consultant and documented that the care was urgent and immediately necessary. **The impact for the family was huge uncertainty and lack of clarity when the initial residency application was put in and the health surcharge was paid about their entitlement to healthcare.** They were understandably frustrated that they had spent over a week in hospital and then been presented with this bill. **The daughter was really worried about her mother and concerned that she was not getting the care she needed.**

Fundamentally - if someone has applied for residency and paid the immigration health surcharge, I believe they should be entitled to care."

13. Do you know of any examples of good practice or steps that could be taken which might mitigate the issues that you have raised in your responses to questions 11 and 12?

The requirement to record patients' overseas visitors status should be withdrawn until a formal assessment has been conducted of the implications on the DHSC and NHS' equalities duties.

The DHSC should also complete a comprehensive public consultation over the impacts on patient confidentiality of this requirement, particularly in light of concerns raised by the Health Select Committee on NHS Digital's data sharing agreement with the Home Office for immigration tracing. There is a considerable mistrust and fear on the part of patients with complicated immigration status to seek treatment, even for life-threatening ailments, as a result.