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Healthcare access for children and families on the move and migrants

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Healthcare access for children and families on the move and migrants

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Abstract

Background: United Kingdom (UK) National Health Service (NHS) charging regulations have increasingly restricted migrants' healthcare access, as part of the government's intention to create a 'hostile environment' for migrants. With an estimated 144,000 undocumented children living in the UK and increasing public concern that these regulations are negatively impacting migrant health and wellbeing, as well as contravening international child rights agreements, it has become imperative to understand their implications.

Methodology: A mixed methods digital survey was disseminated through communications channels of the Royal College of Paediatrics and Child Health (RCPCH) to their members. Quantitative data were analysed on Stata, and basic proportions were calculated for each response proportion. Qualitative data were analysed using a framework analysis approach.

Results: There were 220 responses, from a range of healthcare professional backgrounds. The majority were not confident in interpreting and applying the charging regulations. 34% reported examples of the charging regulations impacting patient care, analysis of which elicited 7 key themes. Our survey gathered 18 cases of migrants being deterred from accessing healthcare, 11 cases of healthcare being delayed or denied outright and 12 cases of delay in accessing care leading to worse health outcomes, including 2 intrauterine deaths.

Discussion: Our results describe a range of harms arising from the current NHS charging regulations contributing to delays in or denials of healthcare, due to fear of charging or immigration enforcement and confusion around entitlements. This harm affects individual patients, the migrant community and the NHS – often in multiple simultaneous ways. Many patients eligible for NHS care, such as trafficking victims, are not being identified as such. We found the current charging regulations to be unworkable and that harm could not be eliminated simply through improved awareness or implementation.

What is already known

- Excluding certain migrant groups from healthcare access often results in greater health system costs, as demonstrated in several EU studies.
- The NHS charging regulations are a deterrence to healthcare access for certain migrant groups and are a source of harm to individual patients and to public health, as reported by Maternity Action, Doctors of the World, and the British Medical Association. Most of the evidence relates to pregnant women and other adult migrant populations, and is often focused around a number of high profile cases.
- NHS charging regulations are putting a strain on healthcare professionals at a time of already stretched services.

What this study adds

- The NHS charging regulations are having direct and indirect impacts on migrant children and pregnant women, with evidence of a broad range of harms.
- There is a lack of understanding of current NHS charging regulations and their intended application amongst healthcare staff.
- The NHS charging regulations are unworkable and are having a detrimental impact on the wider health system, as well as conflicting with its staff's professional and ethical responsibilities.

Background

Recent NHS charging regulations have increasingly restricted access to the United Kingdom (UK) National Health Service (NHS) for migrants, particularly in England[1]. They have been introduced as part of the government's stated intention of creating a hostile environment' for undocumented migrants in the UK by embedding immigration control within, and restricting access to public services[2]. In this context, and in light of the UK's commitment to uphold the 'highest attainable standard of health' for all children under the UN Convention on the Rights of the Child (UNCRC)[3], it has become imperative to understand the impact of the NHS charging regulations (see appendix 1) on migrant children and their families.

The 2014 Immigration Act[4], changed the definition of 'ordinarily resident' (the condition upon which eligibility for free NHS care depends) and thereby further restricted access to the NHS for people with irregular immigration status[5]. Since then, the charging regulations of 2015 and 2017[1] include: i) charging for most secondary and community care; ii) charging at 150% of the NHS tariff for chargeable patients iii) upfront charging before treatment is provided (unless urgent and immediately necessary); and iv) debts of >£500 being reported to the Home Office. Certain patient groups, such as asylum seekers, refugees, victims of trafficking recognised by the National Referral Mechanism (NRM), and children looked after by the local authority, are exempt from charging. Additionally, some infectious diseases, notifiable infections, and conditions which arise as a result of violence (domestic, sexual, torture, FGM) are also exempt[1]. Care given in Emergency Departments and in Primary Care currently remains free of charge for all, although extension of charging into these services has been proposed[6].

Undocumented migrants in the UK, estimated to be around 618,000 (including 144,000 children)[7], are also facing increasing immigration application fees and cuts to legal aid[8]. The majority of these individuals cannot access employment, rent, or any mainstream welfare benefits[7]. It is therefore increasingly difficult to regularise their immigration status thus driving families and children further into destitution[7]. Being in such precarious situations puts migrants at further risk of exploitation, domestic violence, and modern slavery. This is especially concerning for children, as their immigration status generally depends on their parents'.

Several medical colleges, including the Royal College of Paediatrics and Child Health (RCPCH) have publicly stated their concern on the impact of these regulations on migrant health and wellbeing[9]. As a team of child health professionals, we therefore wished to investigate this impact in relation to the population we care for. We collaboratively conducted a survey of frontline professionals, with the RCPCH policy team, on their views and experiences of NHS charging for children and pregnant women. The survey aimed to understand healthcare professionals' knowledge of and attitudes to NHS charging regulations and to understand the impacts of the charging regulations and wider migration policy changes in practice. This paper presents the survey findings.

Methodology

Ethical approval

Consultation of the Health Research Authority and Medical Research Council ethical approval decision tool found that NHS Research Ethics Service approval was not required for this research in any of the four nations of the United Kingdom.

Survey Design

A mixed methods digital survey was developed by five clinicians and further refined following review by experienced RCPCH researchers. The survey (published in full in appendix 2) was designed for adaptability and comparison with other medical specialties and patient populations. The survey included 12 Likert scale questions and five binary yes/no questions intended to measure practitioners' attitudes towards, and understanding of, policies restricting healthcare access eligibility in migrant groups. It also included three qualitative free text questions, investigating themes of deterrence and delay of healthcare, as well as the wider impacts of hostile policies on migrant children and pregnant women.

Recruitment & participants

The survey was open to participation to all children's health practitioners working in the UK, including paediatricians, healthcare students, midwives, nurses, other doctors, and child health specialists. A variety of recruitment methods were utilised. RCPCH members were emailed via four email bulletins: to those members on specific mailing lists for research and clinical leads, then once to the entire membership who consented to emails (14,598 emails sent in total). Recruitment texts were all within a wider email bulletin including unrelated content. It was also shared five times on a social media platform (Twitter), on which 17,000 people were followers at the time. The proportion of email recipients who are on multiple email lists, or who also engage with the college's Twitter channel is unknown. A targeted recruitment method was also adopted in two London teaching hospitals with large paediatrics departments. In these hospitals, members of paediatrics departments also received an additional email and two researchers orally announced the surveys in departmental meetings (to approximately 500 staff and students).

Data collection

The survey collection period was two months (January - February 2019) in which participants could submit their responses. Participants could submit their responses anonymously either via an online tool (Survey Monkey) using computers or other handheld devices, or in paper format into sealed boxes left in hospital departments.

Data analysis

Quantitative data were analysed on Stata, and basic proportions were calculated for each response proportion. Non-responders were not included in the denominator, therefore the proportion presented is in relation to number of responses per question, not overall participants. Qualitative data were analysed using a framework analysis approach[10]. JB and LM reviewed the data separately, then devised a coding framework independently, then formed a framework by consensus, with overall themes and sub-codes that had an agreed definition. This framework

was then applied independently by LM and two researchers who had not developed the framework (RM and BH). The framework that was developed can be found in appendix 3.

Patient or public involvement

No patients or public were involved in the design or conduct of this research. This was not thought pertinent for our research at this time, as we were seeking to understand healthcare professionals' experiences. Additionally, as those affected by the charging regulations are often in precarious situations in the UK, they are often understandably reluctant to participate in research or publicly describe their stories.

Results

Quantitative Results

In total there were 220 responses to the consultation, however twenty respondents only inputted their profession and location without responding to any other question on the survey. They were thus excluded from subsequent analysis. A range of professionals were included in the survey including midwives, nurses, allied health professionals, medical students and charity workers, with doctors being the most numerous (44.5%), comprising paediatric consultants, trainees, general practitioners, and trust grade doctors. All four nations were represented, although 69.5% respondents were from Greater London.

Figure 1: Survey respondents' demographics, showing their professional role (n=200)

The majority of professionals (53%) strongly disagreed or disagreed that they were confident in the definition of urgent and immediately necessary care. In all questions, the majority of professionals strongly disagreed or disagreed that they were confident in determining which circumstances, conditions and groups patients would be charged in, either upfront or in retrospect. Respondent answers to these Likert scale questions are detailed in table 1.

Table 1: Knowledge of/confidence in the charging regulations amongst respondents

"I am confident in determining/my knowledge of"….						
	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**	**Total**
How to define urgent/immediately necessary	56 (29%)	45 (24%)	42 (22%)	37 (19%)	10 (5%)	190

How to advocate for patients	47 (36%)	32 (25%)	25 (19%)	16 (12%)	9 (7%)	129
When to charge retrospectively	64 (51%)	34 (27%)	15 (12%)	6 (5%)	6 (5%)	125
When to charge upfront	63 (50%)	33 (26%)	13 (10%)	10 (8%)	6 (5%)	125
Which services exempt	73 (38%)	50 (26%)	32 (17%)	23 (12%)	12 (6%)	190
Which conditions exempt	94 (50%)	48 (26%)	19 (10%)	21 (11%)	5 (3%)	187
Which patients exempt	67 (52%)	33 (26%)	10 (8%)	12 (9%)	6 (5%)	128
Which patients chargeable	61 (32%)	58 (31%)	43 (23%)	19 (10%)	9 (5%)	190

Most respondents (60%) felt that the policies of charging migrants for NHS care was unfair, and the majority felt that healthcare professionals should not play a role in implementing charging (58%). The majority of respondents were not confident that they would be covered by their indemnity providers (81% not confident) or the GMC (87% not confident) in case of harm coming to a patient as a result of charging (see table 2).

Table 2: Opinions of indemnity and GMC coverage in relation to patient harm resulting from charging regulations amongst respondents

"I am confident that [xxx] would provide me with protection if a patient under my care had their healthcare delayed/ withheld as a result of the regulations"						
	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Total**

Indemnity coverage	79 (62%)	24 (19%)	16 (13%)	6 (5%)	3 (2%)	128
Protection by GMC	89 (70%)	22 (17%)	7 (5%)	7 (5%)	3 (2%)	128

There was a lack of awareness of the Department of Health and Social Care's review into the impact of the charging regulations among respondents, as 71% of respondents were not aware of the review, which took place in 2017. However, 76% reported they felt that there was a need for an independent review of these regulations.

12.4% of respondents had received training on this topic (n=178), whilst 72.3% (n=112) would like to receive further training.

Qualitative Results

34% of respondents reported that they knew of examples of how NHS charging regulations had impacted patient health and care. They were subsequently asked to describe these known cases under three themes: 'healthcare seeking', 'healthcare withheld' and 'wider impact of charging'. Review of the thematic coding following development of the analysis framework elicited seven key themes (detailed definitions of which are in appendix 4) within which the free text answers could be grouped, with several responses cross cutting several themes.

Theme 1 - Fear of consequences of engagement in healthcare.
At least 19 cases detailed of patients and families afraid to come into contact with health services, avoiding attendance or disengaging from care. A recurring narrative was that of fear of receiving unaffordable bills for healthcare. At least six women were reported as having presented late in pregnancy or in labour due to fear of charging. Seven of our respondents detailed a fear of deportation as a consequence of accessing healthcare. Healthcare facilities were seen as being complicit in information sharing with other government agencies, and as such patients were deterred from care due to fear of data sharing, and potential deportation and criminalisation. One respondent detailed that *"Patients at my hospital frequently do not attend with their children as they have overstayed their visa and fear deportation if they come to our attention."*

Theme 2 - Deterrence from healthcare.
Our survey found 18 cases of migrants being deterred from accessing healthcare, including preventative measures such as screening. Respondents raised concern that the charging regulations were leading to racial profiling, having witnessed non caucasian patients being asked to 'prove' their eligibility at a higher rate. Respondents expressed concern that healthcare seeking in this group is already low, and that the charging regulations could be exacerbating this. One answer described experiencing *"Patients presenting to accident and emergency, late,*

where migration status was one factor contributing. Profiling leading to all sorts of people being deterred e.g. both migrants and people with learning disabilities who now feel they need a passport to access care", with several responses detailing *'pregnant women avoiding antenatal care for fear of the huge bill and their details being shared with Home Office"*. Respondents also highlighted that individual cases could resonate throughout migrant communities, with one case of charging or hostility causing widespread fear of accessing healthcare.

Theme 3 - Delay in or denial of healthcare provision.
Our survey gathered 11 cases of pregnant women and children having healthcare delayed or denied outright due to the current charging regulations. One case reported in our survey was of a '*2 year old boy in UK on government resettlement scheme (with full refugee status) turned away from outpatient hospital appointment for* review'. In some cases, this was because care was not deemed 'urgent or immediately necessary', or there was disagreement between healthcare professionals on the level of care which should be provided. In others, a lack of knowledge of exemptions to charging meant that patients had their care delayed or denied. The potential impact of this was outlined by one respondent: *"Treatments that were not immediately life-saving but that were potentially life-prolonging and disability-sustaining withheld for days-weeks whilst entitlement to NHS care clarified"*. The issue of when eligibility was assessed came up in several responses, with non-clinical staff acting as 'gatekeepers' to care. Cases reported in our survey covered a wide range of clinical scenarios, including children with cancer, with one example where a *'child visiting UK presented with leukaemia required intensive care treatment and to start chemotherapy. Had eu passport but resident in Africa. Hospital unwilling to start chemotherapy until £80k deposit funds provided therefore treatment delayed',* congential conditions and those requiring surgery.

Theme 4 - Impact of charging regulations on patient health outcomes.
Our respondents detailed at least twelve cases of delay in accessing or receiving healthcare leading to potentially avoidable health complications or poor outcomes. This includes two cases of intrauterine death in pregnant women who had been deterred from accessing antenatal care. Four respondents told of children presenting in critical condition due to a delay in attendance, with one saying '*I've seen children being brought to ED very sick / not having consulted the gp before because of concerns about this. Also we often see young children which have other health or dental problems discovered incidentally as they have not sought care because of this'*. In many cases, the patient's length of stay was extended due to late presentation leading to increased care requirements. One case described a child *"born with a severe and life limiting condition which could have been detected antenatally if she had received antenatal care at the right time in pregnancy"*, another described the case of an unwell child where the *'case needed to be reviewed by specialist centre to determine treatment options, but they refused to see her as 'not eligible for nhs care'...Case was clearly immediately necessary and she should have been seen regardless. My colleague was able to go back to specialist hospital to advocate for patient and they eventually saw her after an unecessary delay to her care'*. There was also disengagement from, or non-compliance with, prescribed care reported, due to fear of charging or immigration enforcement.

Theme 5 - Current charging regulations unworkable.
Many respondents told of difficulty in understanding and implementing the current charging regulations, due to difficulty interpreting ambiguous language, issues determining eligibility and lack of coordination between clinical and non-clinical staff. There were numerous cases of eligible patients being inappropriately billed or threatened with billing, with one respondent saying *'We know that twice as many people that were technically under these regulations got sent bills than were actually required to pay them.'* It was highlighted that not only is knowledge of exemptions to charging low, they can be hard to identify. One case told of a women who *"had been trafficked into the UK, and her 'partner' had all her documents which she could not access, suggesting she may have been in modern day slavery. She was also being domestically abused. All these criteria could have identified her as exempt from charging, but they were not identified until after the baby was born."* Respondents reported frustration that administrative staff would act independently of clinicians, for example visiting patients on wards to assess eligibility or collect payment for care. In two cases they brought bills to families on clinical wards, causing confusion and distress about whether a child was able to continue receiving care.

Theme 6 - Impact of charging regulations on NHS.
Many respondents felt that the charging regulations were having an undue burden on our health system, and in particular on the staff working within it. Respondents stated that not only did it go against their professional duties as stated by their regulatory bodies, but against their own values and the principles of the NHS. This sentiment was encapsulated by one respondent who said '*I feel exorbitant charging for immigrant children and the undue delay getting things done (procuring equipment, getting consultations) for such children would create a bad reputation. As a doctor I feel stressed and immoral handling this"*. Clinicians told of going beyond their usual duties to help patients navigate the healthcare system and advocate on their behalf against inappropriate charging. They also detailed cases where the charging regulations led to an increased burden on NHS finances and resources, with noting that it was '*costly to the NHS as people often need emergency treatment and hospital treatment for a condition that was treatable earlier on".*

Theme 7 - Context of the wider hostile environment influencing health.
Respondents to our survey gave several examples of the hostile environment impacting on families, including exacerbating socioeconomic inequalities and preventing access to range of services. This ranged from affecting their access to education, to resulting in insecure access to food and shelter. In one reported instance, a *'Child with life limiting diagnosis… parents left them because they knew that unaccompanied children would get healthcare.'* Respondents also highlighted a lack of appreciation of health needs by immigration services, detailing that children could be placed in unsuitable accommodation or far away from the clinical team caring for them.

Discussion

The results of this survey describe a range of harms, arising from various aspects of current

NHS charging regulations contributing to delays in or denials of healthcare. The 'Three Delays' model proposes that delays in timely care can be explained by 1) delays in decision to seek care, 2) delays in accessing a health facility, 3) delays in receiving appropriate care at the facility[12]. This model was originally proposed to explain contributors to maternal mortality in low and middle income countries, but has been adapted to describe delays in other types of care[13,14]. Our survey results demonstrate the model's applicability to children and pregnant women being impacted by the Hostile Environment in the UK. Fear - particularly of charging and of deportation - and confusion around entitlements, are leading to delays in seeking care (themes 1 and 2). Delays in reaching a health facility may be occurring due to destitution and unsuitable housing locations (theme 7). Once patients reach hospital, delays are occurring due to confusions around eligibility or immigration status, or due to denial of care until payment is received (themes 3 and 5). As described in other settings, the three delays can each cause harm in isolation, but even more so when occurring in combination[15]. That patients may be being impacted in multiple simultaneous ways by the hostile environment could explain the extent of the harm described even within this relatively small survey. Importantly, our survey only reflects cases where there was an eventual, although delayed, attendance at a healthcare facility and does not capture harmful outcomes of migrants never accessing health services at all.

In addition to demonstrating harm, our survey results suggest that the NHS Charging Regulations are poorly understood and poorly implemented. Our quantitative data demonstrated that clinicians' knowledge is low regarding exemptions that are meant to protect the most vulnerable. Qualitative responses suggest that many patients who would in reality be eligible for free care are not being identified as such, and are still having their access delayed or denied. Our survey highlighted several cases of trafficked victims being deterred and/or denied care, demonstrating how difficult it is in practice to implement the exemptions to charging, which exist to provide care for the most vulnerable and protect population health. Indeed, to identify those vulnerabilities, a good rapport needs to be built between patient and clinician. This is made almost impossible in the context of fear that surrounds these regulations.

Despite overall understanding of charging regulations being low, several respondents highlighted their personal experience of acting as advocates for patients, for example in identifying exemptions, or by arguing that care is "urgent or immediately necessary" (which allows billing to be retrospective). This reliance on clinical resource for non-clinical activity may impact other areas of service delivery or put increased demands on an already overstretched healthcare workforce.

Our results do not support the argument that harm could be eliminated simply through improved staff awareness or 'better' implementation of regulations. Many patients were described as deterred from making contact with healthcare services, meaning that harm has already occurred before there is opportunity for advocacy. Within the cases described, harms occurring before healthcare was sought included late presentation requiring intensive care management, and two intrauterine deaths. There were several descriptions in the survey of children presenting late in their illnesses directly to the Emergency Department, even though accessing primary care

earlier in their illness would not have been chargeable. This accords with the work done by the Equality and Human Rights Commission which suggests that it is not just specific restrictions, such as upfront charging, which act as a barrier to healthcare access, but the wider policies of the hostile environment[16,17].

Another aspect of the unworkability of the charging regulations is the ethical dilemma in which it places clinicians. Most respondents felt that the charging regulations are unfair, and in free text responses many commented that they felt charging conflicted with their own beliefs or the perceived values of the NHS. The ethical issues are particularly stark when considering charging children and young people specifically. It would be likely to be considered a significant safeguarding issue if, through the actions of a parent or carer, a child were prevented from accessing treatment that is in their best interests[18]. Yet our survey documents multiple cases of children having such treatments delayed or denied due to charging. One respondent highlighted the impossible situation for a family whose child was being treated in intensive care: "*If the family had refused treatment we would have continued anyway in the best interest of the child even if it meant going to court. So in a way we were asking them to pay for something that was out of their control…. It was obviously a lot more than she was expecting or could afford, as [the mother] was distraught.*" Moreover, the routine sharing of data with the UK border agency represents a breach of patient confidentiality and, whilst these regulations are being implemented, clinicians cannot guarantee confidentiality for their patients.

The most significant limitation of this survey is the lack of the patients' voices. Unfortunately, as those affected are mostly in precarious situations in the UK, they are often scared and reluctant to participate in research or publicly describe their stories. Clinicians may have been more likely to respond if they had seen cases of charging in their practice or have pre-existing opinions on the topic, and this may have led to an overestimation in the percentage of clinicians who have seen charging in their practice. In the free text answers, respondents were instructed to keep cases vague to ensure patient confidentiality would not be breached - meaning that the full extent of the impact on those patients could not always be fully described. We also cannot exclude the possibility that where descriptions were very brief, two different clinicians may have been referring to the same patient case, although the researchers reviewing the data found that the descriptions of the cases largely did not suggest overlap.

The UK differs from comparable European countries, including France, Spain, Sweden and Italy, as being more restrictive in healthcare access for undocumented migrant children[19]. An exemption from charging for all children and pregnant women would bring the UK into line with neighbouring countries and reduce the significant safeguarding implications of the current policy. However, the evidence presented here suggests that reversing the charging regulations for children and pregnant women alone will not be sufficient to stop their impact on children. Even if children were exempt from NHS charging, these regulations and the presence of hostile environment policies may still stop families from bringing children for healthcare. Furthermore, even if children themselves can receive free healthcare, charging of their family members can lead to catastrophic health expenditure or avoidable disability which may cause or exacerbate

destitution[20].

Our results are convergent with previous research carried out by the Equality and Human Rights Commission, which looked at the existing evidence on access to healthcare for migrants in the UK[18,19]. The evidence in their reports is mostly drawn from focus group work with migrants, and from the reports of third sector organisations. There is a large overlap in key themes, particularly with regards to fear, staff misinterpretation of regulations acting as a barrier, and the outcome of late presentation. A notable key theme present in other research but not prominent in our results was that of language barriers being a significant obstacle to accessing healthcare. As our survey was based on healthcare staff report rather than direct patient experience, staff may be under-recognising the barrier this creates to patients.

In addition to the convergent themes, our results add additional themes not reported in earlier work. This includes healthcare staff themselves finding the regulations distressing and against their own values. They also highlight specific safeguarding and ethical issues arising from restricting healthcare to children. As our data comes from clinicians and is largely drawn from secondary care experiences, the harms may be more extensive.

Our results appear to contradict the December 2018 statement from the UK Department of Health and Social Care that their internal evidence collection of the impact of NHS charging regulations, which has been kept confidential, did not find any evidence of harm[21]. The awareness of this review amongst our respondents was low (29%), suggesting there may have been a limitation in its reach to front line clinicians.

Conclusion and Recommendations

Healthcare professionals are increasingly being asked to fulfill roles they are not mandated or trained for, and to potentially compromise their own values and beliefs. They have told us that they are seeing harm to the NHS, and to patients - many of whom are particularly vulnerable - as a result of policies introduced to create a hostile environment for migrants. Our survey results also highlight a breach of the UK's commitment to the UNCRC, as we have recorded clear examples of violations to article 24 on children's right to good health and healthcare access.

We therefore recommend:

Revoking current NHS charging regulations

We believe there is sufficient evidence of harm for the current NHS charging regulations to be revoked, thereby restoring the UK's commitment to Universal Health Coverage. The government should urgently suspend these and commission a transparent independent review of their impact – using any harms identified as a basis for a policy environment that upholds migrants' health and human rights.

Adding to the evidence base

Collecting further evidence of the negative impacts of the current NHS charging regulations will serve to strengthen this call for action. A fully independent review of the charging regulations should be commissioned, to robustly assess their impact on patients and professionals. We also encourage the Department of Health to anonymously publish the data from their previous review of the impact of NHS charging regulations for comparison and validation against our data set. We recommend other health professionals to carry out similar surveys and case collection process within their communities of practice, and that other Medical Royal Colleges follow the example of the RCPCH in supporting them to do so. The RCPCH will continue to host an online evidence submission for cases where the charging regulations have impacted patient care or outcomes and encourage health professionals to contribute[22].

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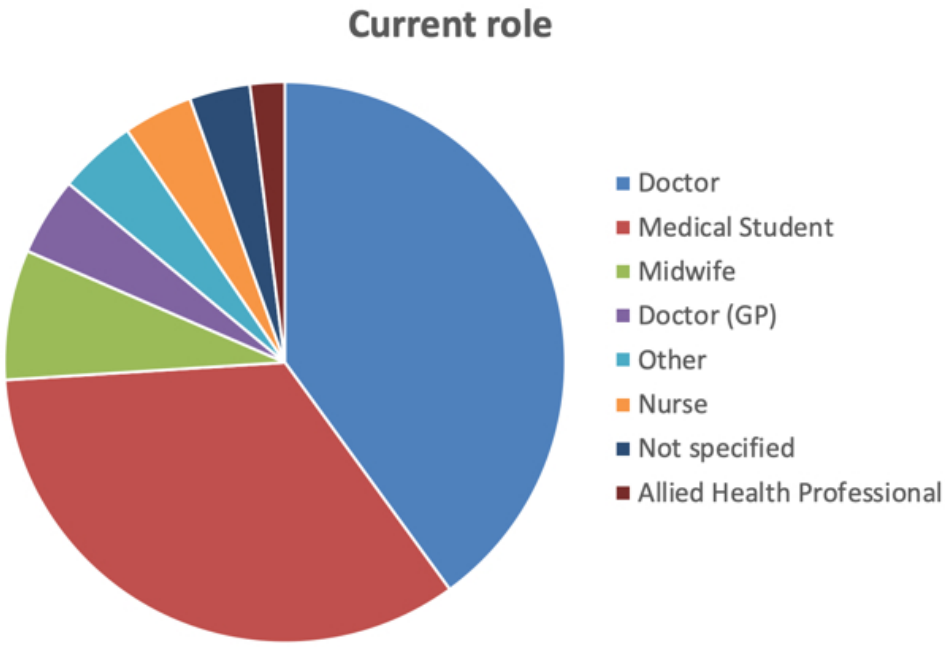
Current role
Doctor
Medical Student
Midwife
Doctor (GP)
Other
Nurse
Not specified
Allied Health Professional

Healthcare access for children and families on the move and migrants

Appendix 1:

Definitions

Undocumented migrant	Migrants whose immigration status is unresolved making them 'undocumented'. This is a fluid status that can evolve with changes in government immigration policy, and changes in personal circumstances. Note: In the case of children, status often depends on immigration status of parents.
NHS Charging regulations	Refers to the National Health Service (Charges to Overseas Visitors) Regulations 2015, the National Health Services (Charges to Overseas Visitors) (Amendment) Regulations 2015 and the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 These are the government regulations on what NHS services are chargeable, who can be charged, and how to implement these.
'Hostile environment'[2]	The UK Home Office hostile environment policy is a set of administrative and legislative measures designed to make staying in the United Kingdom as difficult as possible for people without leave to remain, in the hope that they may "voluntarily leave".

Healthcare access for children and families on the move and migrants

Appendix 2

Survey questions:

1. What is your current job title?
2. Where do you work?
3. To what extent do you agree with the following statements (1 being strongly disagree and 5 being strongly agree)?
3.1. I am confident in determining who is chargeable for NHS care
3.2. I am confident I know the exemptions to the charging regulations with regards to certain migrant groups
3.3. I am confident I know the exemptions to the charging regulations with regards to certain medical conditions
3.4. I am confident in understanding which NHS services for children and young people are free at point of delivery
3.5. I am confident in understanding which NHS services for children and young people are chargeable up front
3.6. I am confident in understanding which NHS services for children and young people are chargeable retrospectively
3.7. I am confident my indemnity would provide me with protection if a patient under my care had their healthcare delayed / withheld as a result of the regulations
3.8. I am confident the GMC would provide me with protection if a patient under my care had their healthcare delayed / withheld as a result of the regulations, and their health subsequently deteriorated
3.9. I am confident in defining which aspects of healthcare are 'urgent' or 'immediately necessary' to inform whether treatment will be withheld before payment
3.10. I am confident in how to advocate for a patient who is incorrectly being asked to pay or delay treatment related to immigration status
3.11. I feel that the current NHS charging regulations are fair
3.12. I believe healthcare professionals should play a role in implementing charging regulations in the NHS
4. Do you know any examples of how the NHS charging regulations have positively or negatively impacted patient's health and the care they have received?
4.1. Healthcare seeking: Please describe experiences of cases you are aware of in which the introduction of charging, fear of charges / detention / deportation or reduction of eligibility has impacted on a patient's access to healthcare (e.g. being deterred or delayed from accessing healthcare)
4.2. Healthcare withheld: Please describe any cases you have been involved with in which a patient has had healthcare withheld because of the charging regulations detailed above
4.3. Wider impact: Please describe any other health or socioeconomic impact on patients due to up front charging, fear of charging or immigration status. This may include loss of housing, non attendance at education, ethnic profiling, etc.
5. Do you have any other comments about the impact of the charging regulations and immigration act on health, wellbeing or health-seeking behaviours?
6. Were you aware that there was a Department of Health (DoH) review into the impact of the charging regulations?
7. Do you think that there should be an independent review conducted?
8. Have you had training on this topic before?

8.1. If yes, what training did you attend?

9. Would you be interested in attending training on this topic?

Healthcare access for children and families on the move and migrants

Appendix 3

Framework developed for analysis:

Overarching theme

Designation	Code

Culture of fear

A1	Fear of charging
A2	Fear of deportation
A3	Fear of criminalisation
A4	Fear of data sharing
A5	Fear of financial distress / destitution
A6	Fear of impact on immigration status
A7	Basis of fear not specified

Delay in care access

C1	Non attendance at healthcare facilities
C2	Perpetuation of migrant deterrence from healthcare
C3	Cause of delay not specified

Delay in care delivery

D1	Due to excess bureaucracy
D2	Due to need to source financing
D3	Due to issues clarifying migration status
D4	Due to issues clarifying eligibility
D5	Cause of delay not specified

Impact on health outcomes

B1	Death
B2	Foetal death
B3	Health emergency
B4	Late diagnoses
B5	Preventable complications
B6	Inadequate follow up
B7	Long term health consequences
B8	Inability to access preventative healthcare
B9	Reduced quality of care
B10	Impact on population health
B11	Delayed antenatal care
B12	Non compliance with care
B13	Impact on health outcomes not specified

Denial of healthcare

E1	Lack of upfront payment
E2	Inappropriate denial when entitled
E3	Unseen consequences
E4	Cause of denial not specified

Issues determining eligibility

F1	Inadequate record keeping
F2	Staff unaware of exemptions
F3	Non clinical staff determining entitlements
F4	Issue determining eligibility was difficult not specified

Difficulty assessing eligibility

G1	Building rapport to determine eligibility
G2	Assessing cases of trafficking or slavery
G3	Assessing cases of sexual and domestic violence
G4	Staff not trained to assess eligibility
G5	Lack of patient capacity
G6	Evolving eligibility
G7	Complex legal status
G8	Ineligible residency
G9	Complexity of the health system
G10	Reason determining eligibility was difficult not specified

Lack of knowledge of charging regulations

H1	Rumours and misinformation in migrant communities
H2	Non clinical staff gatekeeping access to care
H3	Ambiguity of charging regulations
H4	Inappropriate charging
H5	Overseas visitors teams acting independently of clinicians
H6	Poor communication around patient's entitlements

Wider context of the hostile environment

I1	Distress for patient and families
I2	Withdrawal from education
I3	Abandonment of children
I4	Malnourishment
I5	Impact on housing
I6	Unsafe repatriation
I7	Charging perpetuating destitution
I8	Lack of access to support services
I9	Economic fallout of ill health
I10	Lack of appreciation of health needs by immigration services
I11	Changing status to access healthcare
I12	NHS debts affecting regularisation of status
I13	Deviation from normal practice
I14	Stigma

Wider impacts on clinical staff

J1	Distress to NHS staff due to denying/delaying care
J2	NHS staff or their families unable to afford health surcharge/ access care
J3	Against the duties of healthcare staff as determined by their professional institutions
J4	Antagonistic to personal views and values
J5	Personal fears or fears for families
J6	Reputation
J7	No experience of patient charging
J8	Acceptance of charging regulations

Wider impacts on the NHS

K1	Increased burden on A&E
K2	Increased burden on GP
K3	Increased healthcare resource use
K4	Hypocrisy
K5	Human rights breaches
K6	Futile charging
K7	Discharge difficulties / delays
K8	Discord between health institutions
K9	Increased financial costs of delayed care access / delivery

Clinicians as advocates

L1	Navigation of the health system
L2	Appealing / overriding charging decisions

Patient ethnicity

M1	Racism
M2	Racial profiling

Clinical conditions

N1	Cancer
N2	Complex clinical cases
N3	Life threatening illness
N4	Pregnancy
N5	Surgery
N6	Chronic disease

Healthcare access for children and families on the move and migrants

Appendix 4

Theme	Definition
1. Fear of consequences of engagement in healthcare.	Current NHS charging regulations contribute to a culture of fear within the healthcare environment, that makes patients unwilling or unable to engage in healthcare services.
2. Deterrence from healthcare	Current NHS charging regulations deter migrants, and not just those who have irregular immigration status, from accessing healthcare.
3. Delay in or denial of healthcare provision	Current NHS charging regulations have resulted in the delay or denial of healthcare deemed necessary by clinical staff, affecting patients of all eligibilities.
4. Impact of charging regulations on patient health outcomes	The current NHS charging regulations are having a detrimental impact on patient's health, due to deterrence from care, impact on the delivery of timely or quality care or by influencing the wider determinants of health.
5. Current charing regulations unworkable	The current NHS charging regulations are unworkable in their current form, as both clinical and non-clinical staff are struggling to interpret and implement them in a standardised manner.
6. Impact of charging regulations on NHS	Current charging regulations are having negative impact on the National Health Service, bringing a financial and resource burden, and on its staff, causing emotional distress to those involved in patient care.
7. Context of the wider hostile environment influencing health	The current NHS charging regulations are just one policy used to create a 'hostile environment' for migrants, many of which can have an impact on health and wellbeing.

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Healthcare access for children and families on the move and migrants

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Healthcare access for children and families on the move and migrants

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gathered against the framework. LM and SB performed the further analysis and write up for the qualitative results section. JB and NR performed statistical analysis and made the included figures and tables. SB led on writing the introduction, BH led on writing the discussion, while LM and AS performed full paper editing. AF performed further review with support from RM prior to finalising the paper for submission. LM arranged the materials for submission and liaised with BMJ Paeds open editorial staff. LM is responsible for the overall content as guarantor.

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Abstract

Background: The United Kingdom (UK) National Health Service (NHS) charging regulations have increasingly restricted migrants' healthcare access, in the context of a wider national policy shift over the past few years intending to create a 'hostile environment' for migrants. With an estimated 144,000 undocumented children living in the UK and increasing public concern that these regulations are negatively impacting migrant health and wellbeing, as well as contravening international child rights agreements, it has become imperative to understand their implications.

Methodology: A mixed methods digital survey, covering attitudes towards and understanding of UK healthcare charging, and giving space for relevant case submission, was disseminated through communications channels of the Royal College of Paediatrics and Child Health (RCPCH) to their members. Quantitative data were analysed on Stata, and basic proportions were calculated for each response proportion. Qualitative data were analysed using a framework analysis approach.

Results: There were 200 responses, from a range of healthcare professional backgrounds. The majority were not confident in interpreting and applying the charging regulations. 34% reported examples of the charging regulations impacting patient care, analysis of which elicited 7 key themes. Our survey gathered 18 cases of migrants being deterred from accessing healthcare, 11 cases of healthcare being delayed or denied outright and 12 cases of delay in accessing care leading to worse health outcomes, including 2 intrauterine deaths.

Discussion: Our results describe a range of harms arising from the current NHS charging regulations contributing to delays in or denials of healthcare, due to patients' fear of charging or immigration enforcement, including potential deportation, and confusion around entitlements. This harm affects individual patients, the migrant community and the NHS – often in multiple simultaneous ways. Many patients eligible for NHS care, such as trafficking victims, are not being identified as such. We found the current charging regulations to be unworkable and that harm could not be eliminated simply through improved awareness or implementation.

What is already known

- Excluding certain migrant groups from healthcare access often results in greater health system costs, as demonstrated in several EU studies.
- The NHS charging regulations are a deterrence to healthcare access for certain migrant groups and are a source of harm to individual patients and to public health, as reported by Maternity Action, Doctors of the World, and the British Medical Association. Most of the evidence relates to pregnant women and other adult migrant populations, and is often focused around a number of high profile cases.
- NHS charging regulations are putting a strain on healthcare professionals at a time of already stretched services.

What this study adds

- The NHS charging regulations are having direct and indirect impacts on migrant children and pregnant women, with evidence of a broad range of harms.
- There is a lack of understanding of current NHS charging regulations and their intended application amongst healthcare staff.
- The NHS charging regulations are unworkable and are having a detrimental impact on the wider health system, as well as conflicting with its staff's professional and ethical responsibilities.

Background

Recent NHS charging regulations have increasingly restricted access to the United Kingdom (UK) National Health Service (NHS) for migrants, particularly in England[1]. They have been introduced as one part of a suite of national policies intended to create a 'hostile environment' for undocumented migrants in the UK by embedding immigration control within and restricting access to public services[2]. Reasons why a migrant child might be undocumented include being born to undocumented parents, being an unrecognised survivor of trafficking, or due to financial barriers to regularise their status. In this context, and in light of the UK's commitment to uphold the 'highest attainable standard of health' for all children under the UN Convention on the Rights of the Child (UNCRC)[3], it has become imperative to understand the impact of the NHS charging regulations (see appendix 1) on migrant children and their families.

The 2014 Immigration Act[4], changed the definition of 'ordinarily resident' (the condition upon which eligibility for free NHS care depends) and thereby further restricted access to the NHS for people with irregular immigration status[5]. Since then, the charging regulations of 2015 and 2017[1] include: i) charging for most secondary and community care; ii) charging at 150% of the NHS tariff for chargeable patients iii) upfront charging before treatment is provided (unless urgent or immediately necessary); and iv) debts of >£500 being reported to the Home Office, which could result in migrants facing immigration enforcement measures such as detention, deportation or the jeopardising of immigration applications. NHS trusts are delegated the responsibility to identify those deemed ineligible for free care and bill them accordingly, through 'Overseas Visitor Managers' or similar offices. Clinical staff are required by the 2017 charging regulations to determine whether a patient's care should be charged prior to treatment, or is deemed 'urgent or immediately necessary' and thus can be billed retrospectively.

Certain patient groups, such as asylum seekers, refugees, victims of trafficking recognised by the National Referral Mechanism (NRM), and children looked after by the local authority, are exempt from charging. Additionally, some infectious diseases, notifiable infections, and conditions which arise as a result of violence (domestic, sexual, torture, FGM) are also exempt[1]. Care given in Emergency Departments and in Primary Care currently remains free of charge for all. Extension of charging into these services has been proposed, however[6], and significant barriers have been noted for migrant families to access primary care beyond financial considerations. For example, much of the paperwork often mandated prior to registration by General Practices, such as photographic identification or proof of address, is incompatible with NHS guidance - and disproportionately impacts vulnerable groups such as migrants[7].

Undocumented migrants in the UK, estimated to be around 618,000 (including 144,000 children)[8], are also facing increasing immigration application fees and cuts to legal aid[9]. The majority of these individuals cannot access employment, rent, or any mainstream welfare benefits[8]. It is therefore increasingly difficult to regularise their immigration status thus driving families and children further into destitution[8]. Being in such precarious situations puts migrants at further risk of exploitation, domestic violence, and modern slavery. This is especially concerning for children, as their immigration status generally depends on their parents'. It is currently unclear whether the UK's exit from the European Union will lead to the loss of formal immigration status for a further cohort of children, and if so, how many children this would affect.

Several medical colleges, including the Royal College of Paediatrics and Child Health (RCPCH) have publicly stated their concern about the impact of these regulations on migrant health and wellbeing[10]. As a team of child health professionals, we therefore wished to investigate this impact in relation to the population we care for. We collaboratively conducted a survey of frontline professionals, with the RCPCH policy team, on their views and experiences of NHS charging for children and pregnant women. The survey aimed to understand healthcare professionals' knowledge of and attitudes to NHS charging regulations and to understand the impacts of the charging regulations and wider migration policy changes in practice. Whilst the charging regulations primarily target short-term visitors to the UK and undocumented migrants, we wanted to also explore whether there are impacts on wider migrant populations, and the paper covers experiences of professionals working with refugees and asylum seekers, as well as undocumented migrants. _

Methodology

Ethical approval

Consultation of the Health Research Authority and Medical Research Council ethical approval decision tool found that NHS Research Ethics Service approval was not required for this research in any of the four nations of the United Kingdom.

Survey Design

A mixed methods digital survey was developed by five clinicians and further refined following review by experienced RCPCH researchers. The survey (published in full in appendix 2) was designed for adaptability and comparison with other medical specialties and patient populations. The survey included 12 Likert scale questions and five binary yes/no questions intended to measure practitioners' attitudes towards, and understanding of, policies restricting healthcare access eligibility in migrant groups. It also included three qualitative free text questions, investigating themes of deterrence and delay of healthcare, as well as

the wider impacts of hostile policies on migrant children and pregnant women.

Recruitment & participants

The survey was open to participation to all children's health practitioners working in the UK, including paediatricians, healthcare students, midwives, nurses, other doctors, and child health specialists. A variety of recruitment methods were utilised. RCPCH members were emailed via four email bulletins: to those members on specific mailing lists for research and clinical leads, then once to the entire membership who consented to emails (14,598 emails sent in total). Recruitment messages were all within a wider email bulletin including unrelated content. It was also shared five times on a social media platform (Twitter), on which 17,000 people were followers at the time. The proportion of email recipients who are on multiple email lists, or who also engage with the college's Twitter channel is unknown. A targeted recruitment method was also adopted in two London teaching hospitals with large paediatrics departments. In these hospitals, members of paediatrics departments also received an additional email and two researchers orally announced the surveys in departmental meetings (to approximately 500 staff and students).

Data collection

The survey collection period was two months (January - February 2019) in which participants could submit their responses. Participants could submit their responses anonymously either via an online tool (Survey Monkey) using computers or other handheld devices, or in paper format into sealed boxes left in hospital departments.

Data analysis

Quantitative data were analysed on Stata, and basic proportions were calculated for each response proportion. Non-responders were not included in the denominator, therefore the proportion presented is in relation to the number of responses per question, not overall participants. Qualitative data were analysed using a framework analysis approach[11]. JB and LM reviewed the data separately, devised a coding framework independently, then formed a framework by consensus, with overall themes and sub-codes that had an agreed definition. This framework was then applied independently by LM and two researchers who had not developed the framework (RM and BH). The framework that was developed can be found in appendix 3.

Patient or public involvement

No patients or public were involved in the design or conduct of this research. This was not thought pertinent for our research at this time, as we were seeking to understand healthcare

professionals' experiences. Additionally, as those affected by the charging regulations are often in precarious situations in the UK they can be difficult to engage and are often understandably reluctant to participate in research or publicly describe their stories.

Results

Quantitative Results

In total there were 220 responses to the consultation, however 20 respondents only inputted their profession and location without responding to any other question on the survey. They were thus excluded from subsequent analysis. This is a similar response rate to that of other surveys disseminated by the RCPCH. A range of professionals were included in the survey including midwives, nurses, allied health professionals, medical students and charity workers, with doctors being the most numerous (44.5%), comprising paediatric consultants, trainees, general practitioners, and trust grade doctors. All four nations were represented, although 69.5% respondents were from Greater London. This may be explained by the fact that London has the largest number of migrants compared with other UK regions[12]. As all the questions included in our survey were not compulsory there was variance in the number of questions answered by our respondents. For our results we have therefore included the number of those who answered the question alongside each, denoted by 'n'.

Figure 1: Survey respondents' demographics, showing their professional role and location within the United Kingdom (n=200)

The majority of professionals (53%) strongly disagreed or disagreed that they were confident in the definition of urgent and immediately necessary care. In all questions, the majority of professionals strongly disagreed or disagreed that they were confident in determining which circumstances, conditions and groups patients would be charged in, either upfront or in retrospect. Those who reported feeling confident in their understanding of the regulations came from a range of healthcare backgrounds and were spread across the country, with no clear commonality between them. Respondent answers to these Likert scale questions are detailed in table 1.

Table 1: Knowledge of/confidence in the charging regulations amongst respondents

"I am confident in determining/my knowledge of"….						
	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**	**Total**
How to define urgent/immediately necessary	56 (29%)	45 (24%)	42 (22%)	37 (19%)	10 (5%)	190
How to advocate for patients	47 (36%)	32 (25%)	25 (19%)	16 (12%)	9 (7%)	129
When to charge retrospectively	64 (51%)	34 (27%)	15 (12%)	6 (5%)	6 (5%)	125
When to charge upfront	63 (50%)	33 (26%)	13 (10%)	10 (8%)	6 (5%)	125
Which services exempt	73 (38%)	50 (26%)	32 (17%)	23 (12%)	12 (6%)	190
Which conditions exempt	94 (50%)	48 (26%)	19 (10%)	21 (11%)	5 (3%)	187
Which patients exempt	67 (52%)	33 (26%)	10 (8%)	12 (9%)	6 (5%)	128
Which patients chargeable	61 (32%)	58 (31%)	43 (23%)	19 (10%)	9 (5%)	190

-

Most respondents (60%) felt that the policies of charging migrants for NHS care was unfair, and the majority felt that healthcare professionals should not play a role in implementing charging (58%). The majority of respondents were not confident that they would be covered by their indemnity providers (81% not confident) or the GMC (87% not confident) in case of harm coming to a patient as a result of their interpretation or implementation of the charging regulations (see table 2).

Table 2: Opinions of indemnity and GMC coverage in relation to patient harm resulting from charging regulations amongst respondents

"I am confident that [xxx] would provide me with protection if a patient under my care had their healthcare delayed/ withheld as a result of the regulations"						
	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Total**
Indemnity coverage	79 (62%)	24 (19%)	16 (13%)	6 (5%)	3 (2%)	128
Protection by GMC	89 (70%)	22 (17%)	7 (5%)	7 (5%)	3 (2%)	128

There was a lack of awareness of the Department of Health and Social Care's 2017 review into the impact of the charging regulations among respondents, with 71% of respondents not aware it had been carried out. However, 76% reported they felt that there was a need for an independent review of these regulations.

12.4% of those who responded to the question of whether they had received training on this topic (n=178) said they had, although we did not assess the details this contained. Of those who responded to the question of whether they would like to receive further training (n=112), 72.3% responded positively.

Qualitative Results

34% of respondents reported that they knew of examples of how NHS charging regulations had impacted patient health and care. They were subsequently asked to describe these known cases under three themes: 'healthcare seeking', 'healthcare withheld' and 'wider impact of charging'. Review of the responses using our analysis framework elicited seven key themes (detailed definitions of which are in appendix 4). Free text answers were then grouped within these, with several responses cross cutting several themes.

Theme 1 - Patient fear of consequences of engagement in healthcare.

At least 19 cases detailed of patients and families afraid to come into contact with health services, avoiding attendance or disengaging from care. A recurring narrative was that of fear of receiving unaffordable bills for healthcare. At least six women were reported as having presented late in pregnancy or in labour due to fear of charging. Seven of our respondents detailed a fear of deportation as a consequence of accessing healthcare. Healthcare facilities were seen as being complicit in information sharing with other government agencies, and as such patients were deterred from care due to fear of data sharing, and potential deportation and criminalisation. One respondent detailed that *"Patients at my hospital frequently do not attend with their children as they have overstayed their visa and fear deportation if they come to our attention."*

Theme 2 - Deterrence from accessing healthcare.

Our survey found 18 cases of migrants being deterred from accessing healthcare, including preventative measures such as screening. Respondents raised concern that the charging regulations were leading to racial profiling, having witnessed non caucasian patients being asked to 'prove' their eligibility at a higher rate. Respondents expressed concern that healthcare seeking in this group is already low, and that the charging regulations could be exacerbating this. One answer described experiencing *"Patients presenting to accident and emergency, late, where migration status was one factor contributing. Profiling leading to all sorts of people being deterred e.g. both migrants and people with learning disabilities who now feel they need a passport to access care"*, with several responses detailing *"pregnant women avoiding antenatal care for fear of the huge bill and their details being shared with Home Office"*. Respondents also highlighted that individual cases could resonate throughout migrant communities, with one case of charging or hostility causing widespread fear of accessing healthcare.

Theme 3 - Delay in or denial of healthcare provision.

Our survey gathered 11 cases of pregnant women and children having healthcare delayed or denied outright due to the current charging regulations. One case reported in our survey

was of a *"2 year old boy in UK on government resettlement scheme (with full refugee status) turned away from outpatient hospital appointment for review"*. In some cases, this was because care was not deemed 'urgent or immediately necessary', or there was disagreement between healthcare professionals on the level of care which should be provided. In others, a lack of knowledge of exemptions to charging meant that patients had their care delayed or denied. The potential impact of this was outlined by one respondent: *"Treatments that were not immediately life-saving but that were potentially life-prolonging and disability-sustaining withheld for days-weeks whilst entitlement to NHS care clarified"*. The issue of when eligibility was assessed came up in several responses, with non-clinical staff acting as 'gatekeepers' to care. Cases reported in our survey covered a wide range of clinical scenarios, including children with cancer, congenital conditions and those requiring surgery. In one reported example, a *"child presented with leukaemia required intensive care treatment and to start chemotherapy. Had eu passport but resident in Africa. Hospital unwilling to start chemotherapy until deposit funds provided therefore treatment delayed".*

Theme 4 - Impact of charging regulations on patient health outcomes.

Our respondents detailed at least 12 cases of delay in accessing or receiving healthcare leading to potentially avoidable health complications or poor outcomes. This includes two cases of intrauterine death in pregnant women who had been deterred from accessing antenatal care. Four respondents told of children presenting in critical condition due to a delay in attendance, with one saying *"I've seen children being brought to ED very sick / not having consulted the gp before because of concerns about this. Also we often see young children which have other health or dental problems discovered incidentally as they have not sought care because of this"*. In many cases, the patient's length of stay was extended due to late presentation leading to increased care requirements. One case described a child *"born with a severe and life limiting condition which could have been detected antenatally if she had received antenatal care at the right time in pregnancy"*, another described the case of an unwell child where the *"case needed to be reviewed by specialist centre to determine treatment options, but they refused to see her as 'not eligible for nhs care'...Case was clearly immediately necessary and she should have been seen regardless. My colleague was able to go back to specialist hospital to advocate for patient and they eventually saw her after an unnecessary delay to her care"*. There was also disengagement from, or non-compliance with, prescribed care reported, due to fear of charging or immigration enforcement.

Theme 5 - Current charging regulations unworkable.

Many respondents described cases in which the current regulations were implemented incorrectly or in a manner which was felt to be harmful to patients and their families. A broad range of different issues relating to implementation were described, including issues determining eligibility, failure to identify exemptions, and lack of coordination between clinical and non-clinical staff.

There were numerous cases of eligible patients being inappropriately billed or threatened with billing, with one respondent saying *"We know that twice as many people that were*

technically under these regulations got sent bills than were actually required to pay them". It was highlighted that not only is knowledge of exemptions to charging low, they can be hard to identify. One case told of a women who *"had been trafficked into the UK, and her 'partner' had all her documents which she could not access, suggesting she may have been in modern day slavery. She was also being domestically abused. All these criteria could have identified her as exempt from charging, but they were not identified until after the baby was born."* Respondents reported frustration that administrative staff would act independently of clinicians, for example visiting patients on wards to assess eligibility or collect payment for care. In two cases they brought bills to families on clinical wards, causing confusion and distress about whether a child was able to continue receiving care.

Theme 6 - Impact of charging regulations on the NHS.

Many respondents felt that the charging regulations were having an undue burden on our health system, and in particular on the staff working within it. Respondents stated that not only did it go against their professional duties as stated by their regulatory bodies, but against their own values and the principles of the NHS. This sentiment was encapsulated by one respondent who said *"I feel exorbitant charging for immigrant children and the undue delay getting things done (procuring equipment, getting consultations) for such children would create a bad reputation. As a doctor I feel stressed and immoral handling this"*. Clinicians told of going beyond their usual duties to help patients navigate the healthcare system and advocate on their behalf against inappropriate charging. They also detailed cases where the charging regulations led to an increased burden on NHS finances and resources, noting that it was *"costly to the NHS as people often need emergency treatment and hospital treatment for a condition that was treatable earlier on"*.

Theme 7 - Context of the wider 'hostile environment' influencing health.

Respondents to our survey gave several examples of the 'hostile environment' impacting on families, including exacerbating socioeconomic inequalities and preventing access to range of services. This ranged from affecting their access to education, to resulting in insecure access to food and shelter. In one reported instance, a *"Child with life limiting diagnosis… parents left them because they knew that unaccompanied children would get healthcare"*. Respondents also highlighted a lack of appreciation of health needs by immigration services, detailing that children could be placed in unsuitable accommodation or far away from the clinical team caring for them.

Discussion

The results of this survey describe a range of harms, arising from various aspects of current

NHS charging regulations contributing to delays in or denials of healthcare. The 'Three Delays' model proposes that delays in timely care can be explained by 1) delays in decision to seek care, 2) delays in accessing a health facility, 3) delays in receiving appropriate care at the facility[13]. This model was originally proposed to explain contributors to maternal mortality in low and middle income countries, but has been adapted to describe delays in other types of care[14,15]. Our survey results demonstrate the model's applicability to children and pregnant women being impacted by the 'hostile environment' in the UK. Fear - particularly of charging and of deportation - and confusion around entitlements, are leading to delays in seeking care (themes 1 and 2). Delays in reaching a health facility may be occurring due to destitution and unsuitable housing locations (theme 7). Once patients reach hospital, delays are occurring due to confusion around eligibility or immigration status, or due to denial of care until payment is received (themes 3 and 5). As described in other settings, the three delays can each cause harm in isolation, but even more so when occurring in combination[16]. That the 'hostile environment' can impact patients in multiple simultaneous ways could explain the extent of the harm described even within this relatively small survey. This is particularly concerning given the long term health consequences of such adverse experiences and exposure to high stress in childhood[17]. Importantly, our survey only reflects cases where there was an eventual, although often delayed, attendance at a healthcare facility and does not capture harmful outcomes of migrants never accessing health services at all.

In addition to demonstrating harm, our survey results suggest that the NHS Charging Regulations are poorly understood and poorly implemented. Our quantitative data demonstrated that clinicians' knowledge is low regarding exemptions that are meant to protect the most vulnerable. Qualitative responses suggest that many patients who would in reality be eligible for free care are not being identified as such, and are still having their access delayed or denied. Our survey highlighted several cases of trafficked victims being deterred and/or denied care, demonstrating how difficult it is in practice to implement the exemptions to charging, which exist to provide care for the most vulnerable and protect population health. Indeed, to identify those vulnerabilities, a good rapport needs to be built between patient and clinician. This is made almost impossible in the context of fear that surrounds these regulations.

Despite overall understanding of charging regulations being low, several respondents highlighted their personal experience of acting as advocates for patients, for example in identifying exemptions, or by arguing that care is "urgent or immediately necessary" (which allows billing to be retrospective). Yet 80% of our respondents told us they felt disempowered to advocate for their patients on charging issues due to lack of confidence, meaning this can not be consistently relied upon as a means to mitigate the harmful impacts of charging. This reliance on clinical resource for non-clinical activity may impact other areas of service delivery or put increased demands on an already overstretched healthcare workforce. Lack of understanding amongst non-clinical staff on healthcare access can result

in patients not ever reaching clinicians, whilst disagreements within clinical teams may further detriment advocacy.

Our results do not support the argument that harm could be eliminated simply through improved staff awareness or 'better' implementation of regulations. Many patients were described as deterred from making contact with healthcare services, meaning that harm has already occurred before there is opportunity for advocacy. Within the cases described, harms occurring before healthcare was sought included late presentation requiring intensive care management, and two intrauterine deaths. There were several descriptions in the survey of children presenting late in their illnesses directly to the Emergency Department, even though accessing primary care earlier in their illness would not have been chargeable. This accords with the work done by the Equality and Human Rights Commission which suggests that it is not just specific restrictions, such as upfront charging, which act as a barrier to healthcare access, but the wider policies of the 'hostile environment'[18,19].

Another aspect of the unworkability of the charging regulations is the ethical dilemma in which it places clinicians. Most respondents felt that the charging regulations are unfair, and in free text responses many commented that they felt charging conflicted with their own beliefs or the perceived values of the NHS. We did have one respondent detail a case where a person in the UK on holiday was charged for healthcare retrospectively, with the clinician believing this use of the charging regulations to have been appropriate. This was an outlier as the only reported case with a neutral or positive outcome, and so it did not fit into any of the wider qualitative themes.

The ethical issues are particularly stark when considering charging children and young people specifically. It would be likely to be considered a significant safeguarding issue if, through the actions of a parent or carer, a child were prevented from accessing treatment that is in their best interests[20]. Yet our survey documents multiple cases of children having such treatments delayed or denied due to charging. One respondent highlighted the impossible situation for a family whose child was being treated in intensive care: "*If the family had refused treatment we would have continued anyway in the best interest of the child even if it meant going to court. So in a way we were asking them to pay for something that was out of their control…. It was obviously a lot more than she was expecting or could afford, as [the mother] was distraught.*" Moreover, the routine sharing of data with the UK Home Office represents a breach of patient confidentiality and, whilst these regulations are being implemented, clinicians cannot guarantee confidentiality for their patients.

The most significant limitation of this survey is the lack of the patients' voices. Unfortunately, as those affected are mostly in precarious situations in the UK, they are often scared and reluctant to participate in research or publicly describe their stories. Clinicians may have been more likely to respond if they had seen cases of charging in their practice or have pre-existing opinions on the topic, and this may have led to an overestimation in the percentage of clinicians who have seen charging, or consequent harm, in their practice. In the free text answers, respondents were instructed to keep cases vague to ensure patient confidentiality would not be breached - meaning that the full extent of the impact on those patients could

not always be fully described. We also cannot exclude the possibility that where descriptions were very brief, two different clinicians may have been referring to the same patient case, although the researchers reviewing the data found that the descriptions of the cases largely did not suggest overlap.

The UK differs from comparable European countries, including France, Spain, Sweden and Italy, as being more restrictive in healthcare access for undocumented migrant children, with several European countries providing equal health rights to all children regardless of migration status[21]. An exemption from charging for all children and pregnant women would bring the UK into line with neighbouring countries and reduce the significant safeguarding implications of the current policy. However, the evidence presented here suggests that reversing the charging regulations for children and pregnant women alone will not be sufficient to stop their impact on children. Even if children were exempt from NHS charging, these regulations and the presence of 'hostile environment' policies may still stop families from bringing children for healthcare. Furthermore, even if the children themselves can receive free healthcare, charging of their family members can lead to catastrophic health expenditure or avoidable disability which may cause or exacerbate destitution[22].

Our results are convergent with previous research carried out by the Equality and Human Rights Commission, which looked at the existing evidence on access to healthcare for migrants in the UK[20,21]. The evidence in their reports is mostly drawn from focus group work with migrants, and from the reports of third sector organisations. There is a large overlap in key themes, particularly with regards to fear, staff misinterpretation of regulations acting as a barrier, and the outcome of late presentation. A notable key theme present in other research but not prominent in our results was that of language barriers being a significant obstacle to accessing healthcare. As our survey was based on healthcare staff report rather than direct patient experience, staff may be under-recognising the barrier this creates to patients.

In addition to the convergent themes, our results add additional themes not reported in earlier work. This includes healthcare staff themselves finding the regulations distressing and against their own values. They also highlight specific safeguarding and ethical issues arising from restricting healthcare to children. As our data comes from clinicians and is largely drawn from secondary care experiences, the harms may be more extensive.

Our results appear to contradict the December 2018 statement from the UK Department of Health and Social Care that their internal evidence collection of the impact of NHS charging regulations, which has been kept confidential, did not find any evidence of harm[23]. The

awareness of this review amongst our respondents was low (29%), suggesting there may have been a limitation in its reach to front line clinicians.

Conclusion and Recommendations

Healthcare professionals are increasingly being asked to fulfill roles they are not mandated or trained for, and to potentially compromise their own values and beliefs. They have told us that they are seeing harm to the NHS, and to patients - many of whom are particularly vulnerable - as a result of policies introduced to create a 'hostile environment' for migrants. Our survey results also highlight a breach of the UK's commitment to the UNCRC, as we have recorded clear examples of violations to article 24 on children's right to good health and healthcare access.

We therefore recommend:

Revoking current NHS charging regulations

We believe there is sufficient evidence of harm to health and wellbeing for the current NHS charging regulations to be revoked, thereby restoring the UK's commitment to Universal Health Coverage. The current government should urgently suspend the charging regulations and commission a transparent independent review of their impact – using any harms that have been identified as a basis for a policy environment that upholds migrants' health and human rights.

Adding to the evidence base

Collecting further evidence of the impacts of the current NHS charging regulations will likely strengthen this call for action. A fully independent review of the charging regulations should be commissioned, to robustly assess their impact on patients and professionals. We also encourage the Department of Health and Social Care to anonymously publish the data from their previous review of the impact of NHS charging regulations for comparison and validation against our data set.

We recommend other health professionals carry out similar surveys and a case collection process within their communities of practice, and that other Medical Royal Colleges follow the example of the RCPCH in supporting them to do so. The RCPCH will continue to host an online evidence submission for cases where the charging regulations have impacted patient care or outcomes and encourage health professionals to contribute[24].

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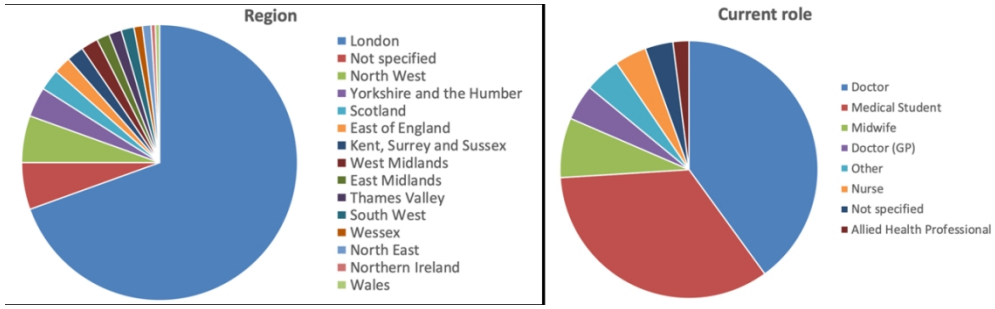
Region
London
Not specified
North West
Yorkshire and the Humber
Scotland
East of England
Kent, Surrey and Sussex
West Midlands
East Midlands
Thames Valley
South West
Wessex
North East
Northern Ireland
Wales
Current role
Doctor
Medical Student
Midwife
Doctor (GP)
Other
Nurse
Not specified
Allied Health Professional

Healthcare access for children and families on the move and migrants

Appendix 1:

Definitions

Undocumented migrant	Migrants whose immigration status is unresolved making them 'undocumented'. This is a fluid status that can evolve with changes in government immigration policy, and changes in personal circumstances. Note: In the case of children, status often depends on immigration status of parents.
NHS Charging regulations	Refers to the National Health Service (Charges to Overseas Visitors) Regulations 2015, the National Health Services (Charges to Overseas Visitors) (Amendment) Regulations 2015 and the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 These are the government regulations on what NHS services are chargeable, who can be charged, and how to implement these.
'Hostile environment'[2]	The UK Home Office hostile environment policy is a set of administrative and legislative measures designed to make staying in the United Kingdom as difficult as possible for people without leave to remain, in the hope that they may "voluntarily leave".

Healthcare access for children and families on the move and migrants

Appendix 2

Survey questions:

1. What is your current job title?
2. Where do you work?
3. To what extent do you agree with the following statements (1 being strongly disagree and 5 being strongly agree)?

3.1. I am confident in determining who is chargeable for NHS care
3.2. I am confident I know the exemptions to the charging regulations with regards to certain migrant groups
3.3. I am confident I know the exemptions to the charging regulations with regards to certain medical conditions
3.4. I am confident in understanding which NHS services for children and young people are free at point of delivery
3.5. I am confident in understanding which NHS services for children and young people are chargeable up front
3.6. I am confident in understanding which NHS services for children and young people are chargeable retrospectively
3.7. I am confident my indemnity would provide me with protection if a patient under my care had their healthcare delayed / withheld as a result of the regulations
3.8. I am confident the GMC would provide me with protection if a patient under my care had their healthcare delayed / withheld as a result of the regulations, and their health subsequently deteriorated
3.9. I am confident in defining which aspects of healthcare are 'urgent' or 'immediately necessary' to inform whether treatment will be withheld before payment
3.10. I am confident in how to advocate for a patient who is incorrectly being asked to pay or delay treatment related to immigration status
3.11. I feel that the current NHS charging regulations are fair
3.12. I believe healthcare professionals should play a role in implementing charging regulations in the NHS

4. Do you know any examples of how the NHS charging regulations have positively or negatively impacted patient's health and the care they have received?

4.1. Healthcare seeking: Please describe experiences of cases you are aware of in which the introduction of charging, fear of charges / detention / deportation or reduction of eligibility has impacted on a patient's access to healthcare (e.g. being deterred or delayed from accessing healthcare)
4.2. Healthcare withheld: Please describe any cases you have been involved with in which a patient has had healthcare withheld because of the charging regulations detailed above
4.3. Wider impact: Please describe any other health or socioeconomic impact on patients due to up front charging, fear of charging or immigration status. This may include loss of housing, non attendance at education, ethnic profiling, etc.

5. Do you have any other comments about the impact of the charging regulations and immigration act on health, wellbeing or health-seeking behaviours?
6. Were you aware that there was a Department of Health (DoH) review into the impact of the charging regulations?
7. Do you think that there should be an independent review conducted?
8. Have you had training on this topic before?

8.1. If yes, what training did you attend?

9. Would you be interested in attending training on this topic?

Healthcare access for children and families on the move and migrants

Appendix 3

Framework developed for analysis:

Overarching theme

Designation	Code

Culture of fear

A1	Fear of charging
A2	Fear of deportation
A3	Fear of criminalisation
A4	Fear of data sharing
A5	Fear of financial distress / destitution
A6	Fear of impact on immigration status
A7	Basis of fear not specified

Delay in care access

C1	Non attendance at healthcare facilities
C2	Perpetuation of migrant deterrence from healthcare
C3	Cause of delay not specified

Delay in care delivery

D1	Due to excess bureaucracy
D2	Due to need to source financing
D3	Due to issues clarifying migration status
D4	Due to issues clarifying eligibility
D5	Cause of delay not specified

Impact on health outcomes

B1	Death
B2	Foetal death
B3	Health emergency
B4	Late diagnoses
B5	Preventable complications
B6	Inadequate follow up
B7	Long term health consequences
B8	Inability to access preventative healthcare
B9	Reduced quality of care
B10	Impact on population health
B11	Delayed antenatal care
B12	Non compliance with care
B13	Impact on health outcomes not specified

Denial of healthcare

E1	Lack of upfront payment
E2	Inappropriate denial when entitled
E3	Unseen consequences
E4	Cause of denial not specified

Issues determining eligibility

F1	Inadequate record keeping
F2	Staff unaware of exemptions
F3	Non clinical staff determining entitlements
F4	Issue determining eligibility was difficult not specified

Difficulty assessing eligibility

G1	Building rapport to determine eligibility
G2	Assessing cases of trafficking or slavery
G3	Assessing cases of sexual and domestic violence
G4	Staff not trained to assess eligibility
G5	Lack of patient capacity
G6	Evolving eligibility
G7	Complex legal status
G8	Ineligible residency
G9	Complexity of the health system
G10	Reason determining eligibility was difficult not specified

Lack of knowledge of charging regulations

H1	Rumours and misinformation in migrant communities
H2	Non clinical staff gatekeeping access to care
H3	Ambiguity of charging regulations
H4	Inappropriate charging
H5	Overseas visitors teams acting independently of clinicians
H6	Poor communication around patient's entitlements

Wider context of the hostile environment

I1	Distress for patient and families
I2	Withdrawal from education
I3	Abandonment of children
I4	Malnourishment
I5	Impact on housing
I6	Unsafe repatriation
I7	Charging perpetuating destitution
I8	Lack of access to support services
I9	Economic fallout of ill health
I10	Lack of appreciation of health needs by immigration services
I11	Changing status to access healthcare
I12	NHS debts affecting regularisation of status
I13	Deviation from normal practice
I14	Stigma

Wider impacts on clinical staff

J1	Distress to NHS staff due to denying/delaying care
J2	NHS staff or their families unable to afford health surcharge/ access care
J3	Against the duties of healthcare staff as determined by their professional institutions
J4	Antagonistic to personal views and values
J5	Personal fears or fears for families
J6	Reputation
J7	No experience of patient charging
J8	Acceptance of charging regulations

Wider impacts on the NHS

K1	Increased burden on A&E
K2	Increased burden on GP
K3	Increased healthcare resource use
K4	Hypocrisy
K5	Human rights breaches
K6	Futile charging
K7	Discharge difficulties / delays
K8	Discord between health institutions
K9	Increased financial costs of delayed care access / delivery

Clinicians as advocates

L1	Navigation of the health system
L2	Appealing / overriding charging decisions

Patient ethnicity

M1	Racism
M2	Racial profiling

Clinical conditions

N1	Cancer
N2	Complex clinical cases
N3	Life threatening illness
N4	Pregnancy
N5	Surgery
N6	Chronic disease

Healthcare access for children and families on the move and migrants

Appendix 4

Theme	Definition
1. Fear of consequences of engagement in healthcare.	Current NHS charging regulations contribute to a culture of fear within the healthcare environment, that makes patients unwilling or unable to engage in healthcare services.
2. Deterrence from healthcare	Current NHS charging regulations deter migrants, and not just those who have irregular immigration status, from accessing healthcare.
3. Delay in or denial of healthcare provision	Current NHS charging regulations have resulted in the delay or denial of healthcare deemed necessary by clinical staff, affecting patients of all eligibilities.
4. Impact of charging regulations on patient health outcomes	The current NHS charging regulations are having a detrimental impact on patient's health, due to deterrence from care, impact on the delivery of timely or quality care or by influencing the wider determinants of health.
5. Current charing regulations unworkable	The current NHS charging regulations are unworkable in their current form, as both clinical and non-clinical staff are struggling to interpret and implement them in a standardised manner.
6. Impact of charging regulations on NHS	Current charging regulations are having negative impact on the National Health Service, bringing a financial and resource burden, and on its staff, causing emotional distress to those involved in patient care.
7. Context of the wider hostile environment influencing health	The current NHS charging regulations are just one policy used to create a 'hostile environment' for migrants, many of which can have an impact on health and wellbeing.