

# Migrant access to maternity care: Lessons from Sweden

## Executive summary

This project explores the impact of Swedish health access policies for undocumented migrants with a close focus on access to maternity care and maternal health outcomes. Set against a comparative backdrop of restrictive UK policy, the project seeks to understand Swedish healthcare policy in this area, explore how it serves the population in practice, learn from the stakeholders who fought for Universal Healthcare Coverage (UHC) in Sweden, and investigate whether data on maternal healthcare outcomes for undocumented women in Sweden supports the application of non-restrictive health access policies in this context. Throughout the study period (28.10.19 - 21.11.19), 20 interviews were conducted with 31 stakeholders representing the voluntary sector, healthcare practitioners and health policy makers.

## Key findings:

The Swedish health policy framework is comparably improved considered in the context of NHS charging regulations in place in the UK. In Sweden, immigration status does not affect a woman's right to access maternity services. This rights-based approach has strong grounding in upholding women and child health, the rights of the child and the workplace rights of medical staff and represents a good example of equitable health policy making which can be replicated in the UK. The policy, however, is not without its 'gaps', and the health rights of undocumented migrants from the European Economic Area (EEA) have ambiguous coverage within the law. Similarly, accessing subsidised health services outside of maternity care remains complex for some undocumented migrants owing to a 'care that cannot be postponed' criteria. In practice, maternity care access policies work well for undocumented women, although staff training and public information on migrant rights and entitlement to healthcare could be improved.

Despite an inclusive policy framework, and although further research exploring the explicit association between health access policy and maternal health outcomes is needed, wider literature reviewed suggests that maternal health outcomes for undocumented migrants are worse than for Swedish nationals and other migrant groups. In the context of a UK policy that actively deters migrants from seeking healthcare, including maternity care, maternal health outcomes for migrant women within the UK are, likely, even more severe.

## Key recommendations – UK policy makers

- Urgently implement policy reform which enables undocumented women to access maternity services on the same basis as UK nationals, such as those introduced in Sweden in 2013.
- NHS charging affects treatment beyond maternity services, and many of the challenges experienced by pregnant women in Sweden before (and in some cases, after) the reform are currently experienced by undocumented migrants in the UK who need NHS treatment and preventative care for a broad range of health issues. In the interests of maintaining the health and human rights of everyone in the UK, the NHS charging regulations should be suspended pending a thorough and transparent equalities impact assessment exploring the relationship between charging legislation and widening health inequalities
- Introduce a rigorous system for monitoring the impact of the NHS charging regulations, including numbers of patients who withdraw from services having been presented with an invoice or asked to prove their immigration status, and late/absent presentation to maternity services on behalf of women affected, being vigilant to the necessity of a firewall to protect this data
- Suspend all data-sharing practices between the NHS and the Home Office to restore patient trust in health services, and ensure the message is communicated via a public information campaign using innovative means to target those affected by previous agreements
- Introduce targeted communications to ensure everyone in the UK understands how to navigate the NHS and their entitlement to NHS services
- Commission research to explore the association between the NHS charging programme and data-sharing practices and maternal health outcomes
- Being vigilant to the needs of a firewall, introduce data monitoring against immigration status into national frameworks monitoring maternal health outcomes in the UK

## Acronyms

ANC	Antenatal care
CS	Cesarean Section
EHRC	Equalities and Human Rights Commission
HCP	Healthcare Practitioner
PALS	Patient Advice and Liaison Service
PIN	Personal Identification Number
PNC	Post-natal care
SEK	Swedish Krona
SMA	Swedish Migration Agency
SMM	Severe Maternal Morbidity
UHC	Universal Healthcare Coverage

# Background

In 2011, the Committee on the Elimination of Discrimination against Women became the first UN human rights body to state that countries have an obligation to guarantee, and take responsibility for, women's timely and non-discriminatory access to maternal health services.<sup>1</sup>

In the UK, a suite of policies expanded in 2015 and 2017 undermine this responsibility and restrict access to health services for undocumented migrants, including women seeking maternity care. Pre-published data collected at the Doctors of the World (DOTW) UK clinic, which sees approximately 2000 patients per year who face exclusion from NHS services, suggests that a high prevalence of cesarean section (CS) rates amongst undocumented patients may be attributed to NHS charging and data-sharing policies which deter women from seeking maternity care and so increase the risk of an unplanned CS.

The deterrent effect of NHS charging policies and data-sharing practices are well-documented<sup>2</sup> and whilst more research is needed, it is hypothesised that avoidance of Antenatal Care (ANC), and so a higher rate of CS<sup>3</sup> can be attributed at least in part to a policy designed to inhibit some members of the community from accessing affordable healthcare. This in addition to the stress caused by the receipt of bills throughout pregnancy, the anxiety around finding the money to pay for treatment and the impact of not being able to pay, and the associated health risks this poses to affected women and their newborn children.<sup>4</sup>

## Rationale: The UK context

### NHS Charging

The NHS was founded in 1948 on the principle that healthcare should be free for everyone at the point of need. However, legislation mandating NHS Trusts to charge some patients for care has been introduced gradually over the years, and expanded significantly since the introduction of 'Hostile Environment' (now so-named 'Compliant Environment') policies in 2015.

In 1977 the National Health Service Act first introduced the concept of entitlement based on 'ordinary residence' allowing the Secretary of State to bill patients for NHS services based on their residency status, which was

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<sup>1</sup> Maternal mortality and human rights: landmark decision by United Nations human rights body (2011). Available from: <https://www.who.int/bulletin/volumes/90/2/11-101410/en/>

<sup>2</sup> Equality & Human Rights Commission (2018). The lived experiences of access to healthcare for people seeking and refused asylum. Available from: <https://www.equalityhumanrights.com/en/publication-download/lived-experiences-access-healthcare-people-seeking-and-refused-asylum>

<sup>3</sup> Milcent C, Zbiri S. (2018) Prenatal care and socioeconomic status: effect on cesarean delivery. Health Econ Rev. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5845483/>

Miani, C., Ludwig, A., Breckenkamp, J. *et al.* (2020) Socioeconomic and migration status as predictors of emergency caesarean section: a birth cohort study, BMC Pregnancy Childbirth. Available from: <https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-020-2725-5>

<sup>4</sup> Maternity Action (2018). What Price Safe Motherhood? Charging for NHS Maternity Care in England and its Impact on Migrant Women. Available from: <https://www.maternityaction.org.uk/policy/publications/what-pricesafe-motherhood-charging-for-nhs-maternity-care-in-england-and-its-impact-on-migrant-women/> 10

restated in the Health Services Act 2006 <sup>5</sup>. Following this, the Immigration Act 2014 expanded the definition of ordinary residence to identify patients without indefinite leave to remain (ILR) in the UK by law. <sup>6</sup> To be 'ordinarily resident' you must be a British citizen, have been granted indefinite leave to remain, or (prior to 1<sup>st</sup> January 2021) be an EU citizen exercising your treaty rights with public healthcare insurance in your country of origin. The provisions in the National Health Services Act 2006 and the Immigration Act 2014 that enable NHS charging are made and modified unilaterally by the Department of Health and Social Care (DHSC).

Current NHS charging policy (the NHS visitor and migrant cost recovery programme)<sup>7</sup> is defined by legislation enacted in The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2015 and 2017. The 2015 regulations introduced a statutory requirement for NHS Trusts to identify and bill patients unable to prove ordinary residence, established the treatment tariff at 150% of the cost to the NHS and introduced the Immigration Health Surcharge.<sup>8</sup> The 2017 regulations introduced a requirement for NHS Trusts to charge all ineligible patients upfront for healthcare, and withhold treatment from those unable to pay. The regulations also increased the range of services included in the charging regulations, affecting services such as health visiting, school nursing, community midwifery, community mental health services, termination of pregnancy services, district nursing, support groups, advocacy services and specialist services for people experiencing homelessness and people seeking asylum. Trusts are also obligated to record a patient's chargeable status on their NHS record.<sup>9</sup> For more information about the detail of NHS charging policies see Appendix 1. <sup>10</sup>

People who cannot pay have their treatment withheld, unless it is classified as 'urgent' or 'immediately necessary' by a treating clinician (although in practice, this classification can be mistakenly determined by members of the overseas visiting team). *Urgent* treatment is defined as care that cannot wait until the person leaves the UK and should take into account pain, disability, and the risk of the delay exacerbating their condition. *Immediately Necessary* treatment is defined as lifesaving, will prevent a condition becoming life-threatening or will prevent permanent serious damage. Maternity services are always categorised as Immediately Necessary <sup>11</sup>. Urgent and Immediately Necessary treatment is not free of charge; patients are billed during their course of treatment, or after it has finished – including for maternity care.

## Data Sharing

Close co-operation and data sharing between the NHS and the Home Office has made the NHS charging programme a key tool of the Hostile Environment. A Memorandum of Understanding (MoU) granting the Home

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<sup>5</sup> National Health Service Act 1977. Available from: <https://www.legislation.gov.uk/ukpga/1977/49/part/VI/crossheading/general-provisions-as-to-charges>

National Health Services Act 2006. Available from: <https://www.legislation.gov.uk/ukpga/2006/41/part/9/crossheading/power-to-charge-generally>

<sup>6</sup> Immigration Act 2014. Available from:

<http://www.legislation.gov.uk/ukpga/2014/22/part/3/chapter/2/crossheading/national-health-service/enacted>

<sup>7</sup> NHS visitor and migrant cost recovery programme. Available from: <https://www.gov.uk/government/collections/nhs-visitor-and-migrant-cost-recovery-programme>

<sup>8</sup> The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2015. Available from: <http://www.legislation.gov.uk/uksi/2015/238/contents/made>

<sup>9</sup> The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017. Available from: <http://www.legislation.gov.uk/uksi/2017/756/contents/made>

<sup>10</sup> Adapted from- Patients not Passports: Challenging Healthcare Charging in the NHS (2019). Available from: <https://www.medact.org/wp-content/uploads/2019/04/Patients-Not-Passports-Challenging-healthcare-charging-in-the-NHS-Medact-2019.pdf>

<sup>11</sup> Department of Health and Social Care (2021) Guidance on implementing the overseas visitor charging regulations. Available from:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/864481/Guidance\\_on\\_implementing\\_the\\_overseas\\_visitor\\_charging\\_regulations\\_-\\_Feb\\_2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/864481/Guidance_on_implementing_the_overseas_visitor_charging_regulations_-_Feb_2020.pdf)

Office access to NHS patient address information to support routine immigration enforcement was suspended in May 2018<sup>12</sup>, however some data sharing operations are unaffected by its suspension, the Home Office and Department of Health and Social Care (DHSC) continue to work towards establishing a new means of sharing information, and data sharing remains embedded within the charging programme. Patients with outstanding NHS debts greater than £500 are reported to the Home Office after two months, and this debt affects the success of future immigration applications. There are also concerns that data leaks exist elsewhere in the system, such as when an NHS trust contacts the Home Office to ascertain a patient's residency status.

### NHS Charging and maternity care

UK national guidance recommends women to have had their first antenatal appointment by 10 weeks<sup>13</sup> and the latest data for England show the majority (65%) of women access care in this window.<sup>14</sup> Conversely, pre-published data collected in the DOTW clinic, found 2 in 3 pregnant women had not accessed antenatal care (ANC) by 10 weeks, with 1 in 4 not having at 18 weeks. A further study published in 2017 found a third of general DOTW patients were deterred from NHS services because of the charging regulations.<sup>15</sup>

### *CS rate and maternal health*

When medically necessary, CSs are vital to reduce infant, neonatal and maternal mortality and morbidity, but their efficacy is reduced when rates increase above 10-15% at population level according to the World Health Organisation (WHO).<sup>16</sup> It can be argued that high CS rates are not medically justifiable,<sup>17</sup> particularly considering the risks associated with the procedure, and the increased cost to health services above vaginal delivery.<sup>18 19</sup>

Unlike in the UK, Swedish healthcare policy allows for undocumented women to access all maternity services at a subsidised rate, to the same extent as Swedish nationals. Sweden is therefore a relevant national comparison for healthcare experience and maternal health outcomes in this context. Stakeholders also shared how the policy developed to become more inclusive of migrant populations, the arguments which necessitated a change in the law, and the gaps which remain despite positive reform. These are outlined in the current study.

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<sup>12</sup> <https://www.theguardian.com/society/2018/may/09/government-to-stop-forcing-nhs-to-share-patients-data-with-home-office>

<sup>13</sup> National Institute of Health and Care Excellence (2008) Antenatal care for uncomplicated pregnancies. Available from: <https://www.nice.org.uk/guidance/cg62/chapter/Appendix-D-Antenatal-appointments-schedule-and-content>

<sup>14</sup> NHS Digital (2020) Maternity Services Monthly Statistic. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/maternity-services-monthly-statistics/november-2020>

<sup>15</sup> Doctors of the World (2017) Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances. Available from: [https://www.doctorsoftheworld.org.uk/wp-content/uploads/import-from-old-site/files/Research\\_brief\\_KCL\\_upfront\\_charging\\_research\\_2310.pdf](https://www.doctorsoftheworld.org.uk/wp-content/uploads/import-from-old-site/files/Research_brief_KCL_upfront_charging_research_2310.pdf)

<sup>16</sup> World Health Organisation (2015) Caesarean sections should only be performed when medically necessary says WHO. Available from: [https://www.who.int/reproductivehealth/topics/maternal\\_perinatal/cs-statement/en/#:~:text=WHO's%20statement%20illustrates%20how%20important,on%20achieving%20any%20specific%20rate.&text=9%20April%202015%20%2D%20Since%201985,be%20between%2010%2D15%25](https://www.who.int/reproductivehealth/topics/maternal_perinatal/cs-statement/en/#:~:text=WHO's%20statement%20illustrates%20how%20important,on%20achieving%20any%20specific%20rate.&text=9%20April%202015%20%2D%20Since%201985,be%20between%2010%2D15%25).

<sup>17</sup> Merry, L., Vangen, S. & Small, R. 2016. Caesarean births among migrant women in high-income countries. *Best Pract Res Clin Obstet Gynaecol*, 32, 88-99.

<sup>18</sup> Villar, J., Carroli, G., Zavaleta, N., Donner, A., Wojdyla, D., Faundes, A., Velazco, A., Bataglia, V., Langer, A., Narváez, A., Valladares, E., Shah, A., Campodónico, L., Romero, M., Reynoso, S., De Pádua, K. S., Giordano, D., Kubickas, M. & Acosta, A. 2007. Maternal and neonatal individual risks and benefits associated with caesarean delivery: multicentre prospective study. *BMJ*, 335, 1025.

<sup>19</sup> NHS Choices (2019). Risks: Caesarean Section. Available from: <https://www.nhs.uk/conditions/caesarean-section/risks/>

## Broad impact of the regulations and criticism

NHS charging has a disproportionate impact on destitute migrants living in vulnerable circumstances in communities across the UK. There is a wealth of evidence showing that NHS charges and the presence of immigration status / healthcare entitlement checks in NHS hospitals deters migrant patients from accessing services risking personal and public health<sup>20</sup>. Research from the Equalities and Human Rights Commission found they also have a clear deterrent impact asylum seekers who avoided accessing NHS services because of fear of being charged<sup>21</sup>.

DHSC state that the regulations are necessary to safeguard NHS resource from so named 'health tourism' (for which pregnant women in particular are a popular target in UK media profiling)<sup>22</sup>. However, there is little to no evidence substantiating that the phenomenon is large enough to be constituted an issue<sup>23</sup> or indeed proportionate to the scale and expense of the infrastructure reportedly introduced to tackle it.

All medical royal colleges have called for the NHS Charging Regulations to be suspended because of the risk they present to public health and management of communicable disease<sup>24</sup>, and the Faculty of Public Health (the leading professional body for public health specialists and practitioners in the UK) has stated: "Despite exemptions for charging for many infectious diseases, the regulations risk undertreating and underdiagnosing infectious diseases in undocumented migrants, which may present a risk to both the wider migrant and general populations."<sup>25</sup>

## The health access policy landscape in Sweden

It is important to note that whilst investigating Swedish healthcare access policy, we are investigating a scenario where paying for care, to some degree, is accepted and normalised. The Swedish health system is based on a Beveridge model, where healthcare is delivered publicly and financed primarily through taxation (like the NHS) however 'co-payments' such as contributions for services above base provision, are common. In the UK these services may be referred to as 'chargeable', whereas in Sweden this might be better termed 'no subsidised services available'.<sup>26</sup>

In 2008 the Swedish healthcare system began to provide free emergency care to all persons, regardless of residency. Access to routine maternity care in Sweden therefore became available to undocumented migrants at the same subsidised rate as it is to Swedish nationals, pursuant to legislative reforms introduced in 2013, which brought healthcare access policies in line with those applicable to people seeking asylum. Prior to this

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<sup>20</sup> Doctors of the World UK (2017). Maternity Action (2018).

<sup>21</sup> Equality & Human Rights Commission (2018).

<sup>22</sup> <https://www.dailymail.co.uk/news/article-8060765/One-20-labour-ward-mothers-health-tourists.html>

<sup>23</sup> George A, Meadows P, Metcalf H & Rolfe H (2011). Impact of migration on the consumption of education and children's services and the consumption of health services, social care and social services. National Institute of Economic and Social Research. Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/257236/impact-of-migration.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/257236/impact-of-migration.pdf)

<sup>24</sup> NHS charges to overseas visitors regulations: A statement from the Academy of Medical Royal Colleges (2019). [https://www.aomrc.org.uk/wp-content/uploads/2019/03/2019-03\\_14\\_NHS\\_charges\\_overseas\\_visitors\\_regulations.pdf](https://www.aomrc.org.uk/wp-content/uploads/2019/03/2019-03_14_NHS_charges_overseas_visitors_regulations.pdf)

<sup>25</sup> FPH briefing on the NHS Charging regulations for overseas visitors in England (2018). Available from: [https://www.fph.org.uk/media/2158/final-fph\\_briefing\\_nhschargingregs\\_1.pdf](https://www.fph.org.uk/media/2158/final-fph_briefing_nhschargingregs_1.pdf)

<sup>26</sup> New Economics Foundation (2020) Patients Not Passports - Learning from the International Struggle for Universal Healthcare. Available from: [https://neweconomics.org/uploads/files/NEF\\_Patients-not-passports.pdf](https://neweconomics.org/uploads/files/NEF_Patients-not-passports.pdf)

2013 legislation change, undocumented migrants had to cover the full costs of all healthcare, including emergency treatment.<sup>27</sup> Asylum-seeking children and undocumented former asylum-seeking children in Sweden represent an exception and were given the same rights as Swedish children to health, medical, and dental care in 2000.<sup>28</sup>

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<sup>27</sup> Adapted from Mediciens Du Monde (2016) Legal Report on Access to Healthcare in 17 Countries, 'Sweden', Available from [https://www.doctorsoftheworld.org.uk/wp-content/uploads/import-from-old-site/files/2017\\_final-legal-report-on-access-to-healthcare-in-16-european-countries.pdf](https://www.doctorsoftheworld.org.uk/wp-content/uploads/import-from-old-site/files/2017_final-legal-report-on-access-to-healthcare-in-16-european-countries.pdf)

<sup>28</sup> Biswas D, Toebe B, Hjer A, Ascher H, Norredam M (2012) Access to health care for undocumented migrants from a human rights perspective: A comparative study of Denmark, Sweden, and the Netherlands. *Health and Human Rights Journal*, 2013.

Pursuant to the 2008 Law on Health and Medical Services for Asylum Seekers and Others, asylum seekers are entitled to subsidised:

- health and dental care that “cannot be postponed” ·
- contraceptive advice ·
- pregnancy termination ·
- **maternity care (always free of charge)**

For any visit to a health facility or hospital, adult asylum seekers pay SEK 50 (€5) for the initial consultation and around SEK 50 (€5) for most prescribed medicines from a pharmacy. Remaining healthcare costs are covered by the Swedish Migration Agency (SMA). If they have paid more than SEK 400 (€41) for doctor’s appointments, medical transport and prescription drugs within six months, asylum seekers can apply for an additional allowance. The SMA can compensate costs over SEK 400 (€41), and county administrative boards can also reclaim the cost for significantly costly care.

This means that in practice, those seeking asylum in Sweden actually pay less for their healthcare than Swedish citizens for single use, although this is offset by policy stating that Swedish Nationals who need to use the health service frequently have a ‘cap’ on out-of-pocket expenditure at around 1000 SEK. The remaining costs are covered by the Government - those seeking asylum do not benefit from this.

According to legislation introduced in 2013 (Health and Medical Care for Certain Foreigners Residing in Sweden without Proper Documentation Act (2013:407), undocumented migrants have the same access to healthcare as people seeking asylum and Refugees. The Government sets aside a budget to cover healthcare costs for this group. Consequently, undocumented migrants are entitled to subsidised:

- medical examination and medicine covered by the Pharmaceutical Benefit
- health care “that cannot be postponed”
- pregnancy termination
- contraceptive counselling
- sexual and reproductive care
- **maternity care (always free of charge)**

*Adapted from Médecins du Monde (2016)*

The (Swedish) Health Care Act (1997: 143) grants the right to equal care for all patients and stipulates that those with the greatest need for care shall be prioritised.<sup>29</sup> There are no arrangements for data-sharing and co-operation between the health service and immigration enforcement with legal provision specifying a firewall to prevent this.<sup>30</sup>

<sup>29</sup> Swedish Parliament (1982) Health Care Act (1982: 763) Available from: [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag-1982763\\_sfs-1982-763](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag-1982763_sfs-1982-763)

<sup>30</sup> Centre for Reproductive Rights (2018) Perilous Pregnancies, Healthcare for undocumented migrant women in the EU. Available from: <https://reproductiverights.org/document/perilous-pregnancies-health-care-for-undocumented-migrant-women-in-the-eu>

Sweden also ratifies the International Covenant on Economic, Social and Cultural Rights (ICESCR) which recognises the right of all individuals to enjoy the best possible physical and mental health, and the Convention on the Rights of the Child which stipulates childrens' rights to the best achievable healthcare.<sup>31 32</sup> It is also worth noting a that there is no unambiguous integration of these rights into Swedish legislation, and the exclusion of some groups from the best achievable care remains to some extent. In January 2020 the Convention on the Rights of the Child was made law in Sweden, but undocumented children remain affected by restrictive policies which inhibit their parents from accessing subsidised healthcare in some situations.

### *Maternal Health in Sweden*

Global data from 2017 ranks Sweden in the top 10 safest places to give birth, with a maternal mortality ratio of 4:100,000.<sup>33</sup> Sweden has a low c-section rate, with just 16.6% of live births performed by CS, compared to an average of approximately 28% across countries in the Organisation for Economic Co-operation and Development (OECD).<sup>34</sup>

In contrast to the pattern of inclusive policy reform, Sweden's health policies slipped slightly on the MIPEX scale due to 2016 legislation mandating rejected asylum-seekers to lose their LMA (identification) card. This may complicate follow-up care, including access to maternity care.<sup>35</sup>

## Policy mechanics

### Patient level

Introduced in 1947, the Swedish Personal Identity Number (PIN) is requested at point of access for most public services, including healthcare and maternity services. Undocumented residents who do not have a PIN may have a temporary PIN generated when registering at a clinic, although this temporary PIN is only recognised at county level, rather than nationally. Migrants who have leave to remain for longer than 1 year will be allocated a PIN as part of their residency.

People within the asylum process in Sweden are issued an LMA card which expires after 6 months and is renewed automatically whilst their claim is being assessed. Pregnant asylum seekers are required to bring their LMA card to the maternity unit when they book, in place of a PIN.

Undocumented migrants may access subsidised maternity care by declaring their undocumented status when first accessing services and are encouraged to present their temporary PIN every time they engage with health services. The clinic can then invoice the county council, who apply for a reimbursement from the Government to cover the cost of their care.

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<sup>31</sup> United Nations (1966) International Covenant on Economic, Social and Cultural Rights. Available from:

<https://www.ohchr.org/Documents/ProfessionalInterest/cescr.pdf>

UNICEF(1990) Convention on the Rights of the Child. Available from: <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

<sup>33</sup> WHO, UNICEF, UNFPA, World Bank Group and UNPD (MMEIG) (2017). Available from: <https://mmr2017.srhr.org/>

<sup>34</sup> OECD (2019), Health at a Glance 2019: OECD Indicators, OECD Publishing, Paris, Available from: <https://doi.org/10.1787/4dd50c09-en>.

<sup>35</sup> Migrant Integration Policy Index (2020) Available from: <https://www.mipex.eu/sweden>

## Within the health system

The Swedish government allocates funds specifically to cover the cost of health services for undocumented migrants. Stakeholders reported that the invoice process is complex and involves ‘a lot of unnecessary admin’. Health centres will ‘list’ patients as receiving care and are paid by regional authorities to deliver it, then the same authorities process the invoice to receive reimbursement from the State (and they often receive incorrect invoices from health facilities). In some cases, the health centre may send the bill directly to the patient, if they determine them ineligible for subsidised care and the regions also receive enquiries from medical personnel who are unsure how or whether to treat undocumented patients. A representative from one regional authority expressed that they are keen to discourage healthcare staff from asking patients questions about patient immigration status, and for that side of the work to be distinct from the delivery of services. It is the job of the County to determine eligibility for subsidised care; they may access to a list of people within the asylum process, but for undocumented patients this information is not readily available, which means that in some cases they must contact the Swedish Migration Agency (SMA). People seeking asylum and undocumented migrants are also offered a free health check for free by the region.

The Swedish Association of Local Authorities and Regions (SALAR) works to synchronise the work of the regions and advocate for the rights of the regions to the state. Some stakeholders reported that regional feedback requests more money to cover health costs for undocumented migrants, although other stakeholders reported that “there is always money left in the pot”, as many patients do not claim their entitlement to services.

It was the view of one health policy maker that the fact that people seeking asylum already receive a subsidy helps the legislation offering the same rights to undocumented migrants appear “less controversial”. Another explained how civil society groups play a vital role in ensuring people receive healthcare, and that some are paid through taxation to deliver services that statutory structures cannot, or do not want to be seen to be prioritising – such as delivering care to undocumented migrants.

Policy makers believed the law made sense, as the alternative was to see “people die on the street”. In their view, early intervention is needed and is cheaper, and when the context of inaction is so extreme it is hard to even begin a conversation about whether the cost is “too much”. They also noted an incompatibility between the “fluctuation” of the immigration system, and the process of determining eligibility for subsidised care at any given time. In addition, they observed that an increase in private clinics who do not operate the same invoicing process also represented a threat to the equal delivery of care in this context.

In 2016, the State Office (an audit body evaluating the activities of the government and its contractors) conducted a review to determine how the 21 county councils were interpreting and applying the 2013 legislation, by interviewing frontline health staff about their understanding of the law, and the support available to them. Positively, it notes an increase of 56% in service uptake for undocumented migrants in Sweden. However, it also flagged obstacles to the equal application of the law, particularly concerning the knowledge of healthcare practitioners on migrant entitlement to care. Additionally, it was found that most of the interviewed county council representatives thought that it was difficult to decide who to determine as undocumented.

In the report, the State Treasury makes several proposals and recommendations that can improve the conditions for applying the law. The report also places responsibility on the County to communicate effectively with

healthcare staff about what the legislation means in practice, including the development of clear guidance, and the availability of meaningful staff training.<sup>36 37</sup>

Several county councils provide all care to undocumented migrants without charge. For example, Skane region took a stance prior to the law change in 2013 and were already delivering subsidised services to this group. There were mixed views as to whether devolved healthcare governance was a strength or a weakness in this context; many believed that it was indicative of a complex legislative framework which some localities felt it simpler to cut across entirely and offer subsidised or free care for all, in the interest of patient health and reducing staff workload. This, and the experience of staff working within healthcare administration, demonstrates that stratifying access to health services by immigration status remains complex – even when the goal is to advance the rights of all patients to care.

#### Data sharing - health and immigration enforcement

There were mixed views on whether people feared accessing services due to a risk of reporting. Some stakeholders said that people were happy to claim that they were undocumented (even in cases where they were not) to receive the services they need. In contrast, others spoke of confusion and mistrust causing people to avoid presentation to any authority, including a health centre. This was attributed to complex legislation, poor communication of rights to affected groups, and historic examples of data sharing. One example regards a heavily criticised case in Malmo where social services agreed to an information sharing request from immigration enforcement which resulted in the raid of a church summer camp– despite stating that undocumented migrants had the same rights to their service as Swedish citizens. Confidentiality principles governing social work are weaker than those in healthcare, but in practice this may not offset the fears of patients seeking care.

Participants expressed that some undocumented women fear accessing maternity services, but this could be attributed to a lack of understanding of their right to care and privacy, rather than a genuine risk of reporting. Police can visit a hospital and ask for someone by name if they have committed a crime warranting a prison sentence longer than 2 years - but being undocumented is not considered a 'crime' in these terms, so would not be a valid reason to request information from a health centre. However, police may not always be clear about the details of their investigation, which presents a minor risk. Stakeholders reported a safeguard in the law which allows staff to simply answer 'yes' or 'no' when asked by Immigration if a patient is staying at a particular healthcare facility. It was found that it is rare for individuals to be traced via the health system, but one participant did share a case where this had happened in Skane region. Concerns remain however, and women in particular fear a data leak risk around registering the birth of a child.

Healthcare professionals and policy makers involved in the invoice process often add additional layers of protection to obscure the identity of patients from immigration. It was reported that when the county is in touch

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<sup>36</sup> The State Office (2016). Care for the undocumented. Final report of the assignment to follow up the law on care for persons staying in Sweden without a permit. Available from: <https://www.statskontoret.se/publicerat/publikationer/2016/ward-till-papperslosa.-slutrapport-av-uppdraget-att-folja-upp-lagen-om-ward-till-personer-som-vistas-i-sverige-utan-tillstand/#:~:text=det%20nya%20regelverket,-,Statskontorets%20%C3%B6vergripande%20slutsats%20%C3%A4r%20att%20de%20flesta%20pappersl%C3%B6sa%20som%20s%C3%B6ker,erlighet%20med%20v%C3%A4rden%20f%C3%B6r%20reskriver.&text=Den%20st%C3%B6rsta%20risken%20f%C3%B6r%20att%20pappersl%C3%B6sa%20inte%20erbjuds%20v%C3%A5rd%20%C3%A4r,har%20bristande%20kunskap%20om%20lagen.>

<sup>37</sup> Swedish Red Cross (2018) Knowledge And Guidance, a prerequisite for good care. Available from: <https://www.rodakorset.se/globalassets/rodakorset.se/dokument/om-oss/fakta-och-standpunkter/rapporter/kunskap-och-vagledning-en-forutsattning-for-god-ward-2018.pdf>

with the SMA regarding a bill, they will often withhold the name of the treating hospital, and health staff may give false information to obscure a patients' location.

## Policy in practice

### How stakeholders perceive the policy in action

A common view amongst interviewees was that women's healthcare is prioritised, and that the access to maternity care policies which enable those without recognised immigration status to access services safely, are working. Women do tend to receive their treatment and if they miss an appointment, it will be rearranged for them.

However, the system is not without its gaps and the situation remains complex for some undocumented women with many stakeholders perceiving that the Swedish authorities had further to go when it came to policy implementation. Establishing meaningful universal access to care goes beyond inclusive healthcare policy and may need to remove barriers for those the policy seeks to benefit, in their communities and in healthcare settings. It was emphasised almost universally that EEA nationals not exercising treaty rights were not accounted for in health access policies, and consequently may often fall through the gaps.

### EEA nationals: ambiguous coverage in the law

Overwhelmingly, interviewees felt that members of the Roma community, including pregnant Roma women were most disadvantaged by Swedish health policy. Interviewees described significant issues integrating some groups such as the Roma population, into the new system after the policy change, including one stakeholder who shared that there had been cases of EU nationals giving birth and leaving their babies in hospital for fear of being apprehended. In theory, EEA nationals with health insurance in their home country are covered by a reciprocal health agreement which entitles them to the same healthcare as Swedish nationals. An EU national is not considered 'undocumented' until they have been living in the country for 3 months without exercising their treaty rights; for many who have lived in Sweden for much longer periods, this is impossible to document. With regards their inclusion in health access policies, the 2013 legislation has been criticised by Amnesty International (AI) as 'vague' with 'inconsistent interpretation' from one region to the next. In a 2018 report they write:

*"Whether people who in Sweden are characterized as "vulnerable EU citizens" are to be considered "undocumented" or not after the first three months of their stay is subject to debate. It is therefore also not clear if after three months they should be able to access subsidised medical treatment under the Act on Medical Care for Undocumented Migrants...the legislative history of the Act indicates that it is "not out of the question... that the proposed legislation on health services and medical services for persons residing in Sweden without a permit may also be applicable to [European] Union citizens in individual cases." The courts and relevant government agencies have failed to clarify what this means in practice and what the criteria are for a person in need of health care to be considered one of those "individual cases".*<sup>38</sup>

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<sup>38</sup> <https://www.amnesty.org/download/Documents/EUR4294032018ENGLISH.PDF>

It is telling that stakeholders interviewed, many of whom were involved in the direct support of EU nationals or regional health policy makers, shared differing perspectives on the entitlement of EU nationals to subsidised healthcare. Some believed that those without health insurance in their country of origin were not included in the 2013 reform, whereas others believed they were covered by the (European Health Insurance Card) EHIC and the reciprocal health agreement, or only entitled to care 'in some cases'. Some spoke of the "burden" that deciding how to classify EEA national patients creates for healthcare staff. Many appeared not to consider them the same 'undocumented migrants' that the 2013 expansion in the law was designed to cover. This ambiguity leaves both Healthcare Practitioners (HCP) and patients unsure about their right to healthcare and leads to mixed implementation. In Stockholm, for example, the County Commissioner (landstingsråd) told AI that their practice is to bill "vulnerable EU citizens" for the full amount, but then to simply write off any debts.

The below figure highlights other common barriers referenced by stakeholders in the equal application of the new law for all undocumented migrants in Sweden. They evidence how any eligibility criteria at all, as opposed to UHC, create practical challenges in application.

#### Healthcare staff perception and access to training

- Training opportunities for healthcare staff on migrant rights and entitlement to care are limited and participation is optional. Uptake is low and varies from region to region
- Some participants were of the view that it is more important to train all HCPs to know the current policy, rather than worry that they will be replaced by more conservative ones
- Occasionally patients are turned away by receptionists or refused care if they do not have their booking number
- Some HCPs may feel that even whilst UHC stands, some groups are less deserving
- Some HCPs wrongly believe that providing subsidised care to undocumented migrants is not allowed, although many do so regardless, citing the value of medical ethics

#### Wrap around support

- The Voluntary sector is needed because the Swedish system only takes care of everybody if working correctly
- Specialist clinics for undocumented migrants, refugees and other migrants still exist, which some patients prefer and find easier to use. They are necessary because there is a lack of knowledge in the regular system.
- All patients accessing care in Sweden are very reliant on the health system as there is limited wrap around care in the community, or 'big nets' available
- Other care elements important during pregnancy i.e. psychological support don't function well for undocumented mothers
- Postnatal care is a less available resource in Sweden than elsewhere in Europe. Many migrants would benefit from follow-up care
- There is a lack of nuanced policy making about migrant needs and a tendency to class broadly as 'refugee related issues'

#### Trust

- There is low uptake of ANC for undocumented migrants who do not want to meet with authorities
- Historic examples of data sharing between social services and immigration has damaged patient trust. Health services can't report undocumented migrants, but fear remains, particularly that children will be removed
- Patients can misunderstand how immigration status relates to health access rights. There is a broad misunderstanding that a refused claim equates to no entitlement to health services.
- Undocumented migrants will sometimes share LMA cards and move around in the system to avoid being traced

### Structural

- There are no accepted means by which an individual can prove their undocumented status, and many services will seek verification before granting access, depending on regional guidance. Often patients will be turned away if they are unable to prove they are an undocumented migrant
- Eligibility is not granted for those in Sweden on a variety of visas, including tourist visas. People waiting on an outcome of a visa decision are not covered. In cases where a pregnant individual is waiting on the outcome of a spousal visa application, their partner must assume healthcare costs whilst the decision is being considered. Pregnant women applying via other routes are not afforded this flexibility
- For general health services, many patients want to know in advance if they will receive a bill. This is complex in emergency situations as eligibility checks cannot be undertaken. In theory, care that cannot be postponed does not incur additional costs, but misapplication of the rules is common, and a fear of charges remains.
- When the region processes invoices, they use patient address as a flag for investigation into eligibility for subsidised care. Addresses from certain countries, i.e. Romania are likely to raise an enquiry, whereas other European countries are more likely to be overlooked
- Even charging a small amount deters destitute EU nationals not exercising their treaty rights from accessing care. This is less reported amongst people seeking asylum and third country nationals.
- The law change was a win, but not a 'full win' as policy makers in each region can still decide whether to provide full healthcare equal to that afforded to Swedish nationals at a subsidised rate
- There are some issues with authorities not registering new babies born to undocumented migrants, as this would grant citizenship for their parents

### Implementation

- Misapplication of the regulations is commonplace. Sometimes HCPs themselves send the link to the guidance to county councils, to point out their invoicing errors
- The system is vulnerable to accidental reporting to immigration enforcement. Some healthcare staff may call immigration with a question, for instance an expired LMA card, which alerts authorities to the status of the patient.
- Some women are misinformed of their rights by the SMA. The Agency can be fined for giving out incorrect information, but it is unclear how this works in practice.

### Political

- Women are always a target group when talking about conserving health service resources and eliminating the migration 'pull' factor. Many participants discussed the changing political landscape and an increase in popularity for the Swedish Democrats who seek to roll back on healthcare access policies for migrants
- Right-wing media discourse blames migrants for a lack of welfare provision. Participants feared it likely that migrants would be affected by cuts first, despite many being afraid to use the system

### Behavioral

- Roma and other EU migrants do not present early for care and are harder to trace for follow-up treatment.
- Sweden has a very low rate of maternal mortality, because of close monitoring by midwifery services during pregnancy. Undocumented migrants do not engage with these services at the same rate as Swedish nationals, do not want to be involved with research, and do not know their rights to healthcare so are often a missing group in data collection
- Some migrants have different expectations of the health service

Many of these observations are also supported in literature produced by the Swedish Red Cross (Svenska Röda Korset), Rosengrenska, and others. Dominant findings concern confusion around the application of 'care that cannot be postponed', the incorrect billing of undocumented patients for non-subsidised care, mixed categorisation of EU migrants after 3 months of residency, and lack of understanding of patient rights on behalf of both patients and healthcare staff.<sup>39</sup>

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<sup>39</sup> Svenska Röda Korset (2018)

A combination of circumstantial and targeted actions prior to the 2013 reform and across subsequent policy conversation have necessitated legislative change and informed public and political consciousness regarding the health access rights of undocumented migrants in Sweden. The timeline below captures the key drivers that brought about change, according to the perception of stakeholders interviewed.

## Policy evolution and advocacy techniques: a timeline

### **2006: The UN Special Rapporteur on the Right to Health:**

In January 2006 the UN Special Rapporteur on the right to health, Paul Hunt, visits Sweden 'to understand how the Government of Sweden endeavours to implement the right to the highest attainable standard of health at the national and international levels.' In a chapter of the report, *Asylum-seekers and undocumented foreign nationals*, Hunt draws a disparity between 'The standard of living, health status and quality of health care in Sweden (as) among the best in the world' and the discriminatory practice of effectively denying healthcare access to certain migrant populations.<sup>40</sup> Highlighting this hypocrisy, the health needs of undocumented migrants and the wider Swedish population and the minimal financial implications of UHC, Hunt writes:

*'While Sweden has ratified many international treaties recognizing the right to health, this human right is less firmly entrenched in Sweden's domestic laws and policies ... They (undocumented migrants) are precisely the sort of disadvantaged group that international human rights law is designed to protect... there are also compelling public health grounds for treating all asylum-seekers and undocumented people on the same basis as Swedish residents ...Indeed, relatively speaking, the costs of including asylum-seekers and undocumented individuals are unlikely to be significant.'*

Accordingly, the Special Rapporteur encourages the Government to reconsider its position with a view to offering all asylum-seekers and undocumented persons the same health care, on the same basis, as Swedish residents. By doing so, Sweden will bring itself into conformity with its international human rights obligations.

The National Board of Health and Welfare writes a letter to central Government following the publication of the report in 2007, advising that they implement the recommendations. Sweden was 'shamed' by the UN report, and there was some media coverage.

### **2008 – Rätt till Vårdinitiativet (The Right to Care Initiative)**

Several multi-agency actors, voluntary organizations, churches, trade unions and others join together in 2008 under the banner *The Right to Care Initiative*, with an aim of expanding healthcare access to policies to everyone in Sweden, regardless of immigration status.

*Rätt till Vårdinitiativet* present a holistic argument focused on the practical implications of withholding affordable health services. A 2008 statement from the group draws on the findings of the Paul Hunt report; shaming health exclusion as 'not worthy of a solidary and democratic society like the Swedish one' and contextualising the

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<sup>40</sup> United Nations (2007) Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt. Available from: [https://www.hrdp.org/files/2015/06/05/UN\\_Special\\_Rapporteur\\_on\\_the\\_right\\_of\\_health\\_Sweden.pdf](https://www.hrdp.org/files/2015/06/05/UN_Special_Rapporteur_on_the_right_of_health_Sweden.pdf)

current restrictions in practice for undocumented migrants in Sweden, including financial disincentive to access health services. The statement also draws on the harm caused to children and the Convention on the Rights of the Child (*‘Children also suffer harm when close adults are denied care’*).

*Rätt till Vårdinitiativet* are the first to highlight the implications of workplace ethics and the stress that limited health access policies place on the HCPs required to implement them (*“Swedish health and medical care staff are exposed to an unreasonable dilemma, when they are forced to deviate from the principle of providing care based on need”*). They champion a rights-based model of healthcare delivery, stating that current policies are not compatible with fundamental human rights of equal value and non-discrimination.<sup>41</sup>

### **2011 - Care as needed and on equal terms - A human right**

In 2011 the ministry of social affairs request a report into healthcare availability for undocumented migrants in Sweden. *Care as needed and on equal terms - A human right* written by Erna Zelwin, finds that undocumented migrants do access health services, but this is frequently via ‘grey clinics’ – health centres operating outside the national health service, run by civil society groups and staffed by volunteer HCPs active or formerly active in public or private healthcare. If care is needed beyond the clinic provision, many volunteer HCPs integrate undocumented patients into their mainstream clinics without charge. Grey clinics also foster informal arrangements with local pharmacies to provide medication to patients. The report finds that the presence of informal healthcare networks does not ‘fully comply with the purpose of what is prescribed in national legislation on the keeping of records and patient safety and certain administrative principles concerning municipal activity.’ It advocates that policy reform should seek to remove barriers for undocumented patients and allow them to access subsidised national healthcare, though acknowledges that the voluntary sector ‘may be needed for some time’ due to fear and mistrust and will be integral to communicating renewed patient rights to those affected.

The report also finds that the current policy ‘is not fully in agreement with the principles of professional ethics’ calling it ‘something that can be regarded as a working environment problem’ for HCPs and observes that most county councils have adopted their own local guidelines for providing care, finding the existing regulation to be ‘unclear and difficult to interpret and relate to in day-to-day care activity’. It dispels anxiety around whether access to health services will act as migratory ‘pull’ (or ‘push’) factor (‘the availability of health and medical services in the country of arrival does not have any major impact either on the decision to enter a particular country or the decision to leave a country where someone is staying without the necessary permit’) and uses a rights-based framework to demonstrate that immigration enforcement activities and the rights of individual to access healthcare must be distinct.

Finally, like the Paul Hunt report, it highlights the incompatibility of Swedish ratification of the UN International Covenant on Economic, Social and Cultural Rights, right to the highest attainable standard of health, and a legislative framework restricting access to healthcare for undocumented residents:

*‘The (UN) Committee has stated that the issue of whether a state is fulfilling its commitments with regard to offering the right to the best possible health for everyone can be assessed on the basis of four different criteria, the AAAQ criteria (availability, accessibility, acceptability and quality). The Inquiry has found in its analysis that while health and medical services in Sweden can be said to meet the requirements of quality and acceptability, as well as being available to an adequate extent, the requirement of accessibility is not met with regard to asylum seekers and undocumented migrants.’<sup>42</sup>*

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<sup>41</sup> Rätt till Vårdinitiativet (2008). Available from: <http://www.vardforpapperslosa.se/undertecknarenny.asp>

<sup>42</sup> State Public Enquiries (2011) Care as needed and on equal terms, a human right. Available from:

Many stakeholders interviewed remarked that the Zelwin report was 'as far as the discussion had come in Sweden'.

In 2011, there were 42 organisations participating in the right to healthcare initiative. By 2012, several county councils had widened entitlement and two councils provided care on the same level as for those with citizenship.

### **2013: Health and Medical Care for Certain Foreigners Residing in Sweden without Proper Documentation Act**

The introduction of the 2013 Act brings access for undocumented migrants in line with the subsidised care available to people seeking asylum and is considered a vast improvement, allowing for undocumented migrants in Sweden to access 'care that cannot be postponed' on the same basis as Swedish citizens. Crucially, it also allows pregnant women without residency in Sweden to access the same maternity care as Swedish nationals. However, activists fighting for UHC believe there is further to go to ensure nobody slips through the gaps.

### **2017 The right to healthcare on equal terms - Statement from Rätt till Vårdinitiativet**

In response to the risk presented by the caveat 'care that cannot be postponed' *Rätt till Vårdinitiativet* issue a statement in 2017, profiling the 'current, unclear and difficult-to-interpret legislation' and warning of a resulting 'variation in care' caused by misunderstanding. The group emphasised how the qualification remained incompatible with Sweden's commitments on human rights, instead proffering a health system for all based on fundamental human rights and the right to the best possible health, referring to article 25 of the Universal Declaration of Human Rights. Again, they place emphasis upon the workplace 'environment risk' for doctors created by the ethical conflict of interpreting the distinction and requirement to withhold subsidised care.<sup>43</sup>

#### Other actors

*Rosengrenska Stiftelsen* is a voluntary network of care staff in Gothenburg that provides healthcare to undocumented migrants since 1998. The group disseminate learning, raise the profile of health exclusion, treat those marginalised from health services and ultimately aim to 'abolish themselves'. In their advocacy they work alongside 'Patientnämnden' (The Patient Board) in the Swedish health service, which has a similar function to the Patient Advice and Liaison Service (PALS) within the NHS. Patientnämnden handle financial disagreements when undocumented migrants are charged for their care as tourists, and have limited power or authority to address the broader barriers in the system. *Rosengrenska* remain active since the 2013 legislation change, helping patients who have been wrongly billed, providing small financial support and helping migrants overcome the 'significant obstacles' that remain.<sup>44</sup>

*Stadsmissions* is a national, centrally funded support organisation promoting integration and incorporating Stadsmissions Halsan; the health division, which advocates for patient rights. In some regions they supply a small medical presence at drop-ins to treat patients and answer queries around accessing care, mostly attended

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<https://www.regeringen.se/49b6a1/contentassets/5eb63a85e7364014a30c2905ad712ea0/vard-efter-behov-och-pa-lika-villkor---en-mansklig-rattighet-sou-201148>

<sup>43</sup> Rätt till Vårdinitiativet (2017). Available from: <http://www.vardforpapperslosa.se/default.asp>

<sup>44</sup> <http://www.rosengrenska.org/>

by EU national patients. They successfully advocated for the inclusion of 'Care around abortion' to be included as a subsidised service in the 2013 legislative reform

The *Knowledge Centre for Health and Migration* is a cross disciplinary team that increases knowledge and capacity within the health service and delivers training as part of the public health system. Devolved healthcare governance across the regions creates space between the politics of health access policies and healthcare actors on the ground and allows for a locally defined approach. The 'Knowledge Centres' then disseminate the regional stance to actors on the ground. This is a two-way relationship, as the regions can also ask the Knowledge Centres to help direct local approach. They function as useful advocacy targets for activists fighting for UHC. For instance, an ask may be levied at KCs to make healthcare access and entitlement training obligatory for HCPs, or to alter the text and wording in guidance to implement the policy. Knowledge Centres also provide training, but only to hospital staff/teams who approach them.

### **Policy reform - a 'half law'?**

'Care that cannot be postponed' refers to 'beyond acute care' which is discriminatory in nature as not as encompassing as 'care available at the point of need' which is available to Swedish citizens, and is referred to as 'a half law' by some stakeholders. It remains a problematic distinction in practice for patients and HCPs and interviewees cited problems working with the definition in the treatment of chronic conditions. One participant told the story of an elderly patient with polio who despite attempting to access care several times, was provided with subsidised treatment only when her condition had worsened and she was struggling to walk. Stakeholders shared their frustration that 'care than cannot be delayed' is a meaningless phrase that is incompatible with medical education. It cannot be applied in medicine because it is not a metric used in medical school when determining how to diagnose a course of treatment.

Some stakeholders felt that placing this determination at the discretion of HCPs is a key flaw in delivering equitable healthcare. If a HCP believes that treatment is advisable then it cannot wait in theory, but the caveat can cause HCPs to exercise caution and under diagnose for fear of breaking the law. Some thought that to keep this definition, it must be accompanied by mandatory ethical training. In practice however, because it is incompatible with UHC principles, some felt there is no 'ethical training' that would make the application acceptable morally.

The definition is broad and covers most conditions, but interviewees shared that many HCPs do not know this. The caveat causes particular confusion when prescribing medication. It is often not prescribed to stabilise health conditions i.e. to manage diabetes as some HCPs believe medicine is only to be issued following emergency treatment.

Six regions have since chosen to offer undocumented migrants wider coverage: Sörmland, Västmanland, Östergötland, Västerbotten, Västernorrland, and Gävleborg.<sup>45</sup> Flexibility in regional approach can increase access to services (as pre 2013 when councils began to ignore citizenship distinctions) but leaving the law open for interpretation always presents a risk that eligible groups will be denied access to subsidised services.

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<sup>45</sup> PICUM (2017). Cities of rights: Ensuring health care for undocumented residents. Available from [https://picum.org/wp-content/uploads/2017/11/CityOfRights\\_Health\\_EN.pdf](https://picum.org/wp-content/uploads/2017/11/CityOfRights_Health_EN.pdf)

# Political drivers: increasing access to care

Without access to state financial records, determining how the economics of health access policies work is a challenge. However, an indication can be gained from the various positions of prominent Swedish political parties in 2012, ahead of the 2013 reform. There are several ethical, legal, economic and political motives that influence political advocacy in this area. The below figure represents the stance and reasoning of 4 major political parties in considering whether to expand or contract the rights of undocumented migrants to healthcare. <sup>46</sup>

Social Democrats	Centre Party	Moderates	Swedish Democrats
<p><i>Economic</i></p> <p>Expanding health access will be expensive to the state, but that is not to say the money should not be spent.</p>	<p><i>Economic</i></p> <p>This is not a question of finances but one of humanity. If there is an expense, it will be small.</p> <p>Considers that the cost of preventative care may represent a saving on emergency care.</p>	<p><i>Economic</i></p> <p>Extending rights will not entail major economic changes. Some county councils are already providing this care.</p> <p>It is difficult to estimate true cost due to undisclosed nature of this provision</p> <p>The only potential difference is that money is set aside from the state budget instead of the county council budgets.</p> <p>Migrants tend to be young and healthy, requiring limited healthcare</p>	<p><i>Economic</i></p> <p>Expanding health access will be an injustice towards the Swedish people who pay for their own health services</p> <p>There is a welfare system and insurance system that must be sustainable</p>
<p><i>Rights-based</i></p> <p>The Convention on the Rights of the Child should be incorporated into Swedish law</p> <p>Everyone should receive care on equal terms, according to international conventions, and the right to care is a human right, even in war</p>	<p><i>Rights-based</i></p> <p>The criticism from the UN must be taken seriously and Sweden has an obligation to comply with human rights conventions</p>	<p><i>Rights-based</i></p> <p>Sweden is an international voice on Human Rights, although international treaties represent goals rather than obligations</p> <p>It is not a human right to receive tax-subsidised care, but to receive care that is urgent</p>	<p><i>Rights-based</i></p> <p>International conventions are vague and current legislation is not uncompliant</p> <p>International conventions do not state that everyone shall be entitled to full subsidised medical care.</p>

<sup>46</sup> Modeer Wiking E, (2013) Care as needed and on equal terms - a human right? A study of how Sweden's parliamentary parties reason on the issue of the undocumented's right to care. Available from: <https://lup.lub.lu.se/student-papers/search/publication/3971538>

<p><i>Political</i></p> <p>There is a 'balancing act' between extending rights to a group that you are also telling have no right to remain</p> <p>Considers The health rights of migrants is one of the four key areas of (their) migration policy work</p> <p>Critical of the Minister of Migration for having stopped the proposal (to expand right to subsidised healthcare) from being sent for consultation</p>	<p><i>Political</i></p> <p>Everyone in Sweden, including people seeking asylum and undocumented migrants, should live in equal conditions</p> <p>Certain parties within the Framework Agreement are not interested in the issue.</p>	<p><i>Political</i></p> <p>Diversity and equality is a competitive advantage for Sweden</p> <p>Sweden will not see an increase in immigration following an expansion of rights</p> <p>Developing a too far-reaching rights catalog for persons who do not have a permit to stay in the country is contradictory</p>	<p><i>Political</i></p> <p>Instead of expanding the health access rights of undocumented migrants, we should instead to intensify the work of deporting undocumented people from Sweden by increasing the funding of border control</p>
<p><i>Dominant ideology</i></p> <p><b>Undetermined</b></p> <p>Will not decide on expanding the rights of adults but a congressional decision on the rights of undocumented children, and guidance for county councils to ensure a consistent approach is necessary</p>	<p><i>Dominant ideology</i></p> <p><b>For expanding rights</b></p> <p>A decision should not be based on cost, or a fear that it may send the wrong message, if it is the correct ethical decision</p>	<p><i>Dominant ideology</i></p> <p><b>Against expanding rights</b></p> <p>If the county councils provide more care they do not break any laws, but they have to finance it themselves.</p> <p>Current arrangements are acceptable</p> <p>'Everything is a trade-off and we think this (current policy) is reasonable'</p>	<p><i>Dominant ideology</i></p> <p><b>Against expanding rights</b></p> <p>Satisfied with current legislation giving undocumented migrants the right to emergency care, although undocumented patients should cover the cost</p>

*Analysis based on Modeer Wiking, Emma (2013)*

Interestingly, whilst there was greater cross-party support towards not expanding health access rights in policy terms (the Christian Democrats and the People's Party, like the Moderates, were satisfied with current provisions in the law, although willing to continue the conversation), the legislative reform passed in 2013. Analysis indicates that this could be attributed to the value that Swedish society and its politicians place on human rights and democratic values; even the parties satisfied with the legislative framework ahead of 2013 conceded that Sweden is an International voice in human rights and that treaty ratification should be meaningful (and the Left Party and the Green Party agreed that potential costs should not outweigh human rights).

The UK is also a covenant of both the International UNCESCR, and the UNCRC. We can learn here that posing broader questions to UK politicians, such as whether our society places women's health and adherence to international rights doctrine secondary to immigration control and associated messaging, is a position we are comfortable with. Even a transparent debate on the subject and an understanding of political stance and

reasoning beyond the familiar dogma common in the media positioning migrants as a drain on public services is lacking in UK politics, and this may be something to pursue.

## Learning advocacy lessons from Sweden

### *Campaigns should*

- Profile and emphasise existing legislation and statutory instruments ratified by the UK and the disparity caused by policies that threaten national adherence
- Centralise and emphasise the value of preventative care demonstrating the impact of restricting access beyond the NHS, at departmental and ministerial level. How do the priorities of the Home Office threaten the ambitions of the DHSC?
- Use the unions. Support healthcare workers to reprofile their occupation as an employee of the state, owed workplace rights and at risk of undue stress caused by legislation at conflict with medical ethics that lessens their ability to work effectively
- Amplify the value of medical ethics as the strongest moral code within the public sector.
- Cost efficiency reports should not be centralised as they undermine the imperatives of a rights based, UHC approach. Used within a broader campaign however, they can help to illuminate how restricted access to services is often misleadingly packaged as protecting the public purse, and political will often has other drivers.
- In Sweden, when country administrative boards decided to allow subsidised care for undocumented migrants ahead of the legislation change, central government began to lose their influence to mandate others to charge migrants for care. One NHS Trust that sets an example and refuses to implement charging would act as an important rallying point to undermine the legitimacy of the policy on a national scale.
- Introduce 'Knowledge Centres' or expand the remit of similar bodies to advocate for change from a service delivery level and (if successful) safeguard positive policy from rollback by continually evidencing the harm reduction necessitated by the reform
- Ensure those with lived experience of health exclusion are involved in a meaningful way in the design, delivery and leadership of access to healthcare campaigning and think creatively to enable those affected by healthcare charging to be involved safely in its opposition

## Maternal health data

Stakeholders interviewed advised that limited research makes it difficult to prove association between access to maternity care and maternal health outcomes. However, in 2020 after the visit to Sweden a paper was published

on the subject; *Severe maternal morbidity among migrants with insecure residency status in Sweden 2000–2014: a population-based cohort study*, C.Liu et al. The research identifies a clear association between undocumented status and maternal health (or severe maternal morbidity – SMM)<sup>47</sup> by examining a longitudinal data-set of women lacking a personal identification number (a proxy for lack of recognised immigration status) and tracking maternal health outcomes. It found that overall, women with insecure residency status were more at risk of SMM than migrant women with long-term residency, and had a 50% higher risk of SMM when compared with Swedish-born women.

The study draws an association between the overall limited socio-economic status of undocumented women in Sweden, and the general increased risk of SMM that this presents, noting that women in disadvantaged social positions with residency have an increased risk of maternal morbidities, and this is without ‘the fear of deportation’ experienced by women without recognised immigration status. It also observes that women in the sample had a lower rate of planned CS, suggesting reduced engagement with ante-natal services, the study observed a missing BMI in around 20% of cases, - more than double the rate for women belonging to the other two groups, which it suggests may be indicative of delayed ANC engagement.<sup>48</sup>

There is recognition in broader literature that the adverse pregnancy outcomes of undocumented women should be recorded and observed in more detail.<sup>49</sup> This would allow international comparative studies to consider the proportions and experiences of undocumented women represented in different administrative data sets and develop understanding of the particular barriers created by health access policies, amongst other factors.

Whilst the 2020 study does not explicitly draw associations between the access to healthcare policy landscape and maternal health outcomes for undocumented women, it provides a valuable insight into the precarious health needs of undocumented women as they experience pregnancy in Sweden. In a context where migrant and undocumented women already experience existing socio-economic inequalities and associated high rates of SMM, it can easily be extrapolated that the deterrent impact of policies which seek to inhibit access to maternity services can only widen this divide in contexts where they are operational. Notwithstanding these additional risk factors, a lack of access to antenatal care is widely thought to increase the risk of maternal mortality and morbidity.<sup>50</sup>

Using these 2000-2014 longitudinal data, additional analyses should be carried out to ascertain whether there was an increase in timely and overall uptake of maternity services from 2008 onwards, following the legislative change. Given that arguments elsewhere in the literature suggest that late access to health services by those facing health exclusion is a key cause of ill health,<sup>51</sup> answering this question could potentially support the hypothesis that SMM amongst undocumented migrant women correlates directly with a policy framework that inhibits access to care. It follows that this would evidence an urgent need to remove such policies on the grounds of maintaining the health of women and their children. Broadly, this presents a clear gap in the research; we

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<sup>47</sup> Defined using an index developed by the United States Centers for Disease Control and Prevention, found at: <https://pubmed.ncbi.nlm.nih.gov/23090519/>

<sup>48</sup> Liu C, Wall-Wieler E, Urquia M, Carmichael S L, Stephansson O. (2020) Severe maternal morbidity among migrants with insecure residency status in Sweden 2000–2014: a population-based cohort study, *Journal of Migration and Health*

<sup>49</sup> Camarota SA, Zeigler K, Richwine J. (2018) Births to legal and illegal immigrants in the U.S, center for immigration studies

J Passel, D. Cohn (2016) Number of Babies Born to Unauthorized Immigrants in US Continued to Decline in 2014, Pew Research Center

<sup>50</sup> Centre for Reproductive Rights (2018)

<sup>51</sup> Andersson, L., Hjern, A. & Ascher, H. (2018) Undocumented adult migrants in Sweden: mental health and associated factors. *BMC Public Health*

know in detail the maternity access policies in place across Europe – what we do not know is how they translate into maternal health outcomes for the women affected by them.<sup>52</sup>

The literature agrees that migrant groups in Sweden are more likely to experience disadvantages during their pregnancy than Swedish nationals. One cohort-based study conducted (post 2013) finds that of migrant groups comprising refugees, people seeking asylum, and undocumented migrants, all three had a higher risk of poor maternal self-rated health than Swedish citizens, but the latter two groups were more likely to receive inadequate antenatal care and have a higher risk of pre-term birth. This suggests that overall maternal health outcomes are influenced by a variety of factors, but the ‘inadequate access to care’ finding points specifically to the poor implementation of, or communication around, health access policies entitling migrant women to care.<sup>53</sup> This study did not include cases without PIN’s, many of whom are likely to be represented by undocumented migrant women, so the extent of the barriers are lesser explored, though outcomes for this group are identified in the later 2020 research.<sup>54</sup>

Qualitative research does find that undocumented women in Sweden experience anxiety around their ability to access maternity care. A small study carried out in 2015 found that ‘not getting health care’ was considered by undocumented women interviewed to be ‘the greatest risk’ leading to ‘fear for their own and their children’s life’, and studies from other parts of the world suggest that undocumented pregnant women do not have straightforward access to maternity care, and also often suffer from complications in childbirth.<sup>55</sup>

These data reflect the circumstances of women accessing care within a framework that allows for inclusive access to maternity care. The Migrant Integration Policy Index (2020) finds that policy implementation and public understanding in Sweden is satisfactory:

Immigrants with access to the healthcare system are regularly informed about their entitlements ..While more research is needed on migrant health policies, around a dozen MIPEX studies find that inclusive policies reduce gaps in health equity in terms of immigrants’ reported health, chronic illnesses, elderly diabetes and frailty, and even mortality<sup>56</sup>

Despite this assessment (which is in some contrast to the mixed view of academics, and stakeholders interviewed for this project), the barriers and health outcomes evidenced in this work and across other studies demonstrate that some undocumented women continue to experience barriers to healthcare and disproportionate adverse outcome during pregnancy. It follows then, that the situation for women accessing care within an *exclusive* policy framework is likely to be much more severe. There is no UK comparative study in the UK looking at maternal health outcomes, however a broader systematic review exploring the views and experiences of asylum seeking women finds that the same issues of compromised access to healthcare and poor knowledge of maternity services are commonplace.<sup>57</sup> A 2020 study carried out by the advocacy and support organisation *Maternity Action* investigating the perceptions of pregnant women impacted by NHS charging finds

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<sup>52</sup> ORAMMA - Operational Refugee and Migrant Maternal Approach (2017) Approach To Integrated Perinatal Healthcare for Migrant And Refugee Women. Available from: [http://oramma.eu/wp-content/uploads/2018/12/ORAMMA-D4.2-Approach\\_reviewed.pdf](http://oramma.eu/wp-content/uploads/2018/12/ORAMMA-D4.2-Approach_reviewed.pdf)

<sup>53</sup> Liu C, Ahlberg M, Hjern A, Stephansson O. (2019) Perinatal health of refugee and asylum-seeking women in Sweden 2014-17: a register-based cohort study. Eur J Public Health.

<sup>54</sup> Liu C et al (2020)

<sup>55</sup> Rosenlundh J, Barkensjö M (2015) “A constant anxiety: Undocumented women experience of care during pregnancy ”- a qualitative interview study. Gothenburg University

<sup>56</sup> MIPEX (2020)

<sup>57</sup> P. McKnight, L. Goodwin, S. Kenyon. (2019) A systematic review of asylum-seeking women's views and experiences of UK maternity care. Available from: <https://www.sciencedirect.com/science/article/pii/S0266613819301317>

that the scheme deters women from accessing care, affecting their 'willingness to see a midwife or a doctor when they were not well' and that invoices and hospital letters 'induced a high level of fear and anxiety, affecting their physical as well as mental health'.<sup>58</sup> A 2019 report informed by data from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2015-17 found that reluctance to access services as a result of the charging programme may have been a factor in the deaths of 3 women.<sup>59</sup>

A 2016 WHO review of migrant maternal health policy frameworks in Europe finds that availability and affordability restrict migrant women from accessing maternity care, insufficient or delayed access to care increases the risk of complications and that assuring universal access to care will improve migrant maternal health.<sup>60</sup> Steps to necessitate this are outlined in a policy framework mapping exercise carried out by the Centre for Reproductive Rights in 2018. It calls on policy makers to remove laws and policies that restrict undocumented migrant women's access to affordable maternity care and prohibit the reporting of those women seeking care to immigration enforcement<sup>61</sup> which the findings of this project support.

Stakeholders believed that, broadly speaking, maternity and other health services are available for undocumented migrants in Sweden and in many cases residents without immigration status realise their right to care. Clear issues remain around policy implementation, staff training, public information and communication and building trust between state services and undocumented women.

## Discussion

For the purposes of this piece of work, there is much the UK can learn from Sweden on the matter of legislating for all women to access affordable maternity care safely, beginning with adopting a similar framework entitling women to the same subsidised maternity services as UK nationals, and eliminating the real or perceived threat of data sharing between the NHS and the Home Office.

In carrying out this study, it also became clear that the struggle for UHC in Sweden presents learning too for those fighting for equitable access to care in the UK. Their journey depicts a two-tier approach - an advocacy push to move the situation from hostility to an improved scenario, as characterised by the 'care that cannot be postponed' criteria. Whilst this cannot represent the finish-line on health and human rights grounds, it creates space for further negotiation in the fight for UHC when paired with robust ongoing defence of the initial policy reform. There is also scope to discuss the gender discrimination inherent in charging for maternity care, as bills are only levied towards women in the UK.

What is evidenced is the complexity introduced when any caveat on subsidised care is aligned with an individual's nationality or immigration status, particularly considering the situation for EEA nationals, women awaiting the outcome of a visa application and the administrative challenges incurred by the invoicing regions.

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<sup>58</sup> Maternity Action (2018)

<sup>59</sup> MBACE (2019)

<sup>60</sup> Keygnaert I, Ivanova O, Guieu A, et al. (2016) What is the Evidence on the Reduction of Inequalities in Accessibility and Quality of Maternal Health Care Delivery for Migrants? A Review of the Existing Evidence in the WHO European Region. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK390809/>

<sup>61</sup> Centre for Reproductive Rights (2018)

Swedish political parties were unafraid to discuss UHC in the context of Swedish health access policies, referencing their commitment to international treaties and the value of Human Rights on all sides of the debate. Such transparency is complicated in the UK (DHSC withhold the findings of a Public Health England (PHE) impact assessment exploring the effects of the charging regulations on affected patients), but activists can work to press politicians to defend hostile healthcare policies on these grounds and raise the profile of Human Rights in the conversation.

No healthcare policy landscape is static. The changing political climate and tightening of restrictions for refused asylum seekers all represent a threat to inclusive healthcare access in Sweden, and ongoing monitoring of harm reduction is necessary to prevent roll-back on health inclusive policies.

### Recommendations for policy makers

- Urgently implement policy reform which enables undocumented women to access maternity services on the same basis as UK nationals, such as those introduced in Sweden in 2013
- NHS charging affects treatment beyond maternity services, and many of the challenges experienced by pregnant women in Sweden before (and in some cases, after) the reform are currently experienced by other undocumented migrants in the UK who need the support of the NHS. In the interests of maintaining the health and human rights of everyone in the UK, the NHS charging regulations should be suspended pending a thorough and transparent equalities impact assessment exploring the relationship between charging legislation and widening health inequalities
- Introduce a rigorous system for monitoring the impact of the NHS charging regulations, including numbers of patients who withdraw from services having been presented with an invoice, and late/absent presentation to maternity services on behalf of women affected, being vigilant to the needs of a firewall to protect this data
- Suspend all data-sharing practices between the NHS and the Home Office to restore patient trust in health services, and ensure the message is communicated via a public information campaign using innovative means to target those affected by previous agreements
- Introduce targeted communications to ensure everyone in the UK understands how to navigate the NHS and their entitlement to NHS services
- Commission research to explore the association between the NHS charging programme and data-sharing practices and maternal health outcomes
- Being vigilant to the needs of a firewall, introduce data monitoring against immigration status into national frameworks to monitor maternal health outcomes in the UK

# Conclusion

The academic data supports a connection between delayed access to or avoidance of ANC and poorer maternal health outcomes. It also evidences that migrant women experience challenges accessing health services, both in Sweden and in the UK. In the UK, studies exemplify NHS charging as a demonstrable deterrent creating fear for women who in many cases, choose to delay or avoid interaction with maternity services. The opinion of international health bodies supports the role of the state in ensuring equal access to maternity services for all women, and international human rights treaties uphold the right to healthcare for all. It follows that there is a logical connection between NHS charging and data sharing practices, and poor maternal health outcomes for the women affected by them. Research to explicitly explore this association is vitally needed.

Sweden has a model which should ensure no mother experiences pregnancy and birth without the support of the national health service which the UK should look to emulate, as explored in this work. It remains evident that complicating UHC with citizenship eligibility will always result in complex legislation, time consuming application criteria and mistakes on the ground. This alongside confusion for patients and a high administrative burden for doctors and authorities. One stakeholder used the image of a fence to describe the battle to level-up health access so those on one side, with immigration status and those on the other, without it, had an equal right to services and asked, wouldn't it be easier to tear down the fence entirely?

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Médecins du Monde, Sweden  
Doctors of the World, UK  
Rätt till Vårdinitiativet  
Dept for Newborn, Child and Adolescent Health, WHO  
Union for Undocumented Migrants

Transcultural Centre, Stockholm  
Rossengrenska  
Stadsmissions  
Svenska Kyrkan  
Svenska Kyrkan, Bergsjön  
Flyktinghälsan  
Knowledge Centre for Health and Migration, Malmö  
PICUM (Platform for International Co-operation on Undocumented Migrants)  
Maternity Action  
Centre for Reproductive Rights

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## Appendix 1

The following groups of people are exempt from all NHS charges:

- Non-EEA nationals who have paid the health surcharge  
as part of their visa application to enter or remain in the UK;<sup>11</sup>
- Refugees (those granted asylum, humanitarian protection or temporary protection under the immigration rules) and their dependents;
- Asylum seekers (those applying for asylum, humanitarian protection or temporary protection whose claims, including appeals, have not yet been determined), and their dependents;
- Individuals receiving section 95 support and refused asylum seekers, and their dependents, receiving section 4 support or local authority support under Part 1 of the Care Act 2014;
- Children who are looked after by a local authority;
- Victims, and suspected victims, of modern slavery;
- Those receiving treatment under the Mental Health Act;
- Prisoners and those held in immigration detention and;
- Refused asylum seekers in Scotland and Wales.

*Survivors of torture, female genital mutilation, domestic violence, sexual violence will not be charged for treatment needed as a result of their experience of violence (including mental health treatment).*

The following services are exempt from the NHS charging regulations:

- A&E
- Family planning (excluding termination of pregnancy)
- Treatment for communicable disease