

SPOTLIGHT

Improving Inclusion Health Outcomes

Why SPOTLIGHT and who is it for?

[SPOTLIGHT](#) is a new, public, data sharing platform which presents key statistics related to the public health outcomes of inclusion health groups. It has been developed by the [Office for Health Improvement and Disparities](#) (OHID) as an interactive open-access health tool to provide a robust evidence base that supports policy development and commissioning around improving health outcomes and health inequalities, and improve equity of access to health care.

SPOTLIGHT focuses primarily on the following inclusion groups: people experiencing homelessness and rough sleeping, Gypsy, Roma & Traveller (GRT) communities, people in contact with the justice system, sex workers, vulnerable migrants, victims of modern slavery, and people misusing substances.

It includes a range of England-based indicators developed from public-health administrative data sets, relating to primary care, secondary care, mortality, wider determinates of health.

Inclusion health groups typically experience multiple overlapping risk factors for poor health (such as poverty, violence and complex trauma), as well as stigma and discrimination.

People belonging to inclusion health groups are not consistently accounted for in electronic records (such as healthcare databases), which makes them effectively invisible for policy and service planning purposes. SPOTLIGHT would help address this inequity in health intelligence and, therefore, inform policy and enable providers of health and care services to better meet the needs of these most vulnerable individuals.

Support by the VCSE Health and Wellbeing Alliance and Roma Support Group.

The [VCSE Health and Wellbeing Alliance](#) (HWA) is a partnership between the voluntary sector and the health and care system. It enables the sector to share expertise at the national level with the aim of improving services for all communities.

[Roma Support Group](#) (RSG) is a charity supporting Roma communities in the UK since 1998 and a member of the HWA in a consortium led by [Friends, Families and Travellers](#) (FFT).

As a key stage for the development of SPOTLIGHT, OHID has sought support from HWA to engage with relevant inclusion health representatives and People with Lived Experience (PLE). As an HWA member, RSG has worked with OHID through this process over the past year. This work included direct engagement with HWA members representing inclusion health groups, similar representatives outside the HWA and PLE from the inclusion health groups. The engagement consisted of direct discussions with HWA members through the HWA Inclusion Health Sub-Group, a Project Steering Group formed of HWA and non-HWA inclusion health groups' representatives and a series of interviews with PLE from the following categories: vulnerable migrants, people involved with the justice system, sex workers, GRT communities and LGBT.

Aim of the summary

This paper presents views of inclusion health groups' representatives on SPOTLIGHT and provides insights into main health concerns, use of health care services and publication of data as reported by PLE from the inclusion health groups.

Inclusion Health Groups:

People with Lived Experience interviewed through the project were consulted on their main health issues given their own life experiences, health services utilisation and recommendations.

All groups, apart from GRT, mentioned mental health as their main health issue given their life experiences. Those from the GRT communities mentioned health conditions such as diabetes, cancer or arthritis.

Long waiting lists and times at GP practices and A&E, as well as lack of appropriate support (language, health advocates/mediators) were reported as main barriers. Prohibitive costs of dental treatment were also repeatedly mentioned by different representatives. Several community members raised the lack of diversity of NHS staff as an issue.

Recommendations on health service utilisation from community members included increasing diversity of staff, cultural awareness and anti-bias training and increasing language support provision, number of drop-in services and extending opening hours at GP practices. On SPOTLIGHT development recommendations included working in partnership with local charities, publishing data on factors influencing health access to health services.

Insights into main health concerns and utilisation of health services

Vulnerable migrants

"I was an asylum seeker and [...] It was very hard to get support. I never had a doctor, a GP [...] At some point I had a crisis and I just dropped in a clinic as they asked me of my NHS number. I did not have one, they asked me my address and then I blacked out. [...]. Someone called the 999 and I was taken to emergency. I ended up with a £10k bill."

"Vulnerable migrants" is a broad group including people with a diverse migrant background. Interviewees contributing to this project went or are still going through the asylum seeking process.

Main health problems: Mental health is reported as a major concern. Interviewees reported struggling with PTSD and depression.

Health services utilisation: Interviewees reported using their GP and presenting to A&E if a more serious issue occurred.

Barriers: Rights given by the asylum seeker status limits access to health services. Interviewees mentioned having access to a health worker rather than a GP before refugee status being granted. Another significant barrier mentioned was around the hostile attitude of health staff, especially receptionists when immigration status is revealed. Also housing insecurity and Home Office (HO) procedures around providing accommodation creates barriers to access health services as people are often moved to new locations. Fear and/or experience of being charged for health services is another barrier limiting health services utilisation due to immigration status. Language was also mentioned as a barrier as some asylum seekers don't speak English.

People involved with the justice system

"I started a toxic relationship which led to me losing this job, then losing my rent, getting arrested and a lot of other issues. I ended up believing that I am better off on streets because I was being refused help from any direction."

Main health problems: Mental health is reported as a main concern. Interviewees reported struggling with depression and self-harm. Lack of housing and lack of immigration support was reported as having a significant impact on health.

Health services utilisation: A preference for going to A&E rather than GP was reported given the long awaiting times.

Barriers: Interviewees reported feeling uncomfortable discussing women's health with male doctors. The cost of dental treatment was deemed prohibitive. Long waiting times at hospitals have been reported as a problem. Communication disputes were also reported as leading to mistrust in the health system.

Sex workers

“Before the Covid there was a drop-in service where we use to go regularly. It wasn’t a fixed time you had to be there. It was open for a few hours and you could just drop in and that helped. [...] We were getting check-ups, issues which were not seen for many years. Not necessarily issues because of lifestyle but things that needed attention.”

Main health problems: Interviewees reported their mental health being a major concern. Interviewees also reported that the Covid pandemic led to closures of drop-in services providing health support and access to medical supplies such as needles or condoms. This is reported as a major concern currently.

Health services utilisation: Interviewees mentioned they rely on pharmacies and that they previously relied on drop-in services and clinics. Interviewees mentioned they were getting condoms and needles through the drop-in clinic and that was positive.

Barriers: Interviewees reported missing morning appointments or struggling to get appointments by phoning in the morning, as they work evenings and nights. Interviewees mentioned that they avoid going to A&E because of long waiting times and that the cost of the dental treatment is prohibitive. Interviewees mentioned many people don't have access to smartphones and therefore would struggle to access digital appointments or book appointments through a digital system.

Roma

“Honestly I lost my confidence and I don’t feel like sharing things with GPs or doctors. I had several appointments where I used the opportunity to share other health issues not necessarily the one which I was there for. And they always told me for another issue book another appointment. Because of that now I don’t feel like talking with them.”

Main health problems: Diabetes and cancer were reported as major health concerns.

Interviewees reported struggling to eat healthy food, as the rising cost of food is a concern. Smoking, especially from a young age, is reported as a problem. Interviewees felt that because of their ethnicity they had to work in more difficult working conditions than other employees, which had a significant impact on their health.

Health services utilisation: Interviewees reported going to A&E, rather than relying on their GP.

Barriers: Interviewees reported a lack of trust in the health system because of past experiences. Discrimination was reported as having a major impact on health, especially in relation to employment, but also to education, health etc. Discrimination was listed as a potential reason for lack of engagement with services. Interviewees also reported very long waiting times at GP practices and for dental treatment. Interviewees reported being dissatisfied with video call appointments.

LGBTQ+

“I am trans and I moved to UK because I need safety. The HO wants to move me in a house with men [...]. I fled because of abuse and violence and they want to put me through this again. They're trying to oppress me. And with this is affecting my mental health a lot.”

Main health problems: Mental health was reported as a main concern. Inadequate housing was reported as having an impact on their health. One interviewee, a trans woman and asylum seeker, reported being housed by the HO in a house with men. The interviewee refused, because she was concerned for her safety and preferred women's-only accommodation.

Health services utilisation: Interviewees reported going to the GP and accessing talking therapy. Also, LGBTQ+ specialised health practices were mentioned.

Barriers: Interviewees reported that not speaking English and not having the confidence to advocate for yourself impacts access to health services.

Gypsy & Traveller

“We just want to be treated as human beings.

I think people should know how difficult it is when you are on constant move and do not have access to registered sites and get sent from places to places.”

Main health problems: Interviewees mentioned cancer, arthritis and COPD being main health concerns. Interviewees reported that because of housing conditions (sometimes living in places without heating, electricity or running water), they developed health problems. Interviewees reported that having access to a permanent site improved their access to doctors and dentists.

Health services utilisation: Interviewees reported that registering for and accessing GP services has been problematic when living on unauthorised sites. GP registration is no longer mentioned as a problem once living on an authorised site. Interviewees reported initial attempts to go to GP followed by going to A&E if accessing GP fails or takes too long.

Barriers: Interviewees reported being refused registration at GP practices, on the basis that they would move around a lot and because they were unable to provide proof of address. Interviewees reported long waiting times at GP practices.

SPOTLIGHT: recommendations from People with Lived Experiences

“I think it is good as long as the government is using the data for the better of the people. As long as this will be about providing solutions I think this data base will be good. It has to be solution focused. Also it needs to avoid bad things developing out of this, like people being removed from the country.”

All PLE interviewed had overall positive opinions on the SPOTLIGHT development. Interviewees have seen this as good initiative and all mentioned hopes that this will bring better changes for their communities. Concerns raised included limitations on data availability, especially around people who don't access health services, or those not disclosing certain conditions, such as mental ill health, for fear of being stigmatised. People were also concerned about the publication of data that might lead to unwanted outcomes, such as data that might lead to people being removed from the country, or data on transmissible diseases which might lead to further stigmatization. Interviewees also raised that the data should be completely anonymous. Some participants reflected that SPOTLIGHT should be action orientated and all used the opportunity to make recommendations both for SPOTLIGHT but also for health services as well.

The main recommendations for health services include:

- Work to inform people, regardless of their background, on their rights to access health services
- Work to raise awareness of the various health services points of contact available
- Get more training on challenges people experience when trying to access health service such as challenges experienced by those living on unauthorised sites.
- Provide health support to all regardless of immigration status

Recommendations on improving access to health services specific to each inclusion health group engaged

Vulnerable migrants:

An emphasis and better communication around the fact that everyone is entitled access to health services is needed. Interviewees reported vulnerable migrants often don't know what they're entitled to, or that the GP is not the only point of contact or place to access support. Interviewees suggested that health professionals should be more aware of discrimination.

People involved with the justice system

Health professionals should be more inclusive and provide health support to all, including those with no immigration status.

Sex workers

Interviewees emphasised the need for distribution of condoms and needle exchange service open late. They mentioned the equipment for needle exchange has recently been changed and that the quality is dissatisfactory, increasing the need to undertake more sex work, because they end up spilling the substances. Their specific recommendation is to reinstate evening drop-in service at a central location near where they will be spending their working hours. These services should include legal information and signposting to other non-medical services such as benefits and accommodation. All information (appointments, results, etc.) should also be sent as simple SMS as although they all have phones, most of them have simple phones with no email or internet access.

Roma

More language support, especially Romanes (Roma language) interpreters, is needed. More Roma staff employed in the NHS would make a difference for the community.

Gypsies & Travellers

Health professionals should be aware of how difficult it is to be constantly moving and not having access to a registered site.

LGBTQ+

More therapists from the LGBTQ+ community with experiences in dealing with cases of sexual assault are needed. More health professionals from diverse backgrounds are needed.

The main recommendations from People with Lived Experience for SPOTLIGHT include:

- Work in partnership with local charities to try and collect more data.
- Include information on factors that impact people's health, such as insecure housing, insecure accommodation for nomadic people, poverty or lack of access to employment.
- Include information on factors that impact people's access to health service, such as ability to speak English
- Include information on people's country of origin
- Include breakdown information such as gender or age

Issues raised by the steering group members

There was across the board agreement on the lack of data, reported by all inclusion health groups on following themes:

- Accessing primary and secondary care
- Digital exclusion
- Administrative exclusions
- Early pregnancy care
- Sexual violence and modern day slavery and trafficking
- Sex trafficking

The group also raised concerns around the indicator 'vulnerability' as a potential issue, as its definition of vulnerability is too vague.

Steering Group Members also reflected on the main health needs to be addressed through the SPOTLIGHT. These include:

- Accessing early pregnancy services
- Accessing post natal depression services
- Children immunisation
- Accessing health services while using drugs and alcohol