

Insight from marginalised communities to inform ICS strategy development

Engagement Assurance Committee

24 January 2023

Overview and scope of this pack

This work aimed to draw out themes from local engagement work and outputs of system-level engagement work to inform the development of the SEL integrated care strategy.

This pack summarises some of the outputs from engagement projects undertaken by partner organisations in SEL, selected based on following criteria:

- Health related
- Engaged south east London populations
- Undertaken since April 2020 (to ensure relevance)

This pack provides a high level snapshot of the significant amount of insight reviewed as part of the IC strategy development. A final report will be produced to share with SEL ICS partner organisations and the public on the SEL ICS website in the coming weeks.

The insights were provided by organisations from across SEL including Healthwatch.

In the engagement summarised, a mixture of engagement methodologies were used including:

- Digital and non-digital approaches
- Discussions at existing networks using topic guides
- Semi-structured conversations

Topics covered and communities reached in insights reviewed

Insight gained from engagement during the pandemic

- COVID 19: co-producing personalised care for people who have had Covid-19 and their carers; preventing a mental ill-health crisis as a direct result of the impact of the Covid-19 pandemic, addressing health inequalities and vaccine confidence across south east London; understanding patient, carer and public attitudes and behaviours in relation to accessing care and services during the pandemic, vaccine hesitancy and knowledge
- Understanding how to expand Personal Health Budgets across south east London
- Community research and fatigue
- How individual circumstances affect day-to-day lives and health and wellbeing (what is important to communities)
- Surfacing the potential futures black people desire for their health, understanding the experiences of Black NHS workers and identifying how to strengthen relationships between Black communities and Health professionals
- Medical scepticism, distrust and disaffection among diverse black and minority communities in London
- Other barriers to people accessing services, and how these can be removed

A broad range of communities were engaged with. There was targeted engagement with:

- Black and minority ethnic communities
- Migrant communities including refugees, asylum seekers and economic migrants
- LGBTQ+ community
- Young people with mental health issues and/or affected by trauma
- People with learning disabilities
- Organisations working with Gypsy, Roma and Travellers, homeless people, people living with HIV, refugees and asylum seekers

Themes from insights reviewed

- Trust and cultural awareness
- Access issues and virtual services
- Mental health and wellbeing
- Living with long term conditions and / or interconnected complex needs
- Maternal health and children and young people
- Safety
- Finance and work
- Joined up / partnership working across agencies and coproducing services with people and communities

What the SEL insights told us: Trust and cultural awareness (1/2)

- We have consistently heard across engagement work we have done at both a system and local level that people from black and minority ethnic backgrounds have a different experience of health and care services to white British people.
- People's distrust of statutory organisations and the system and differences in cultural views on health and wellbeing is often due to historic experiences of discrimination and racism which crosses over generations and continues to be experienced. Building trusting and meaningful relationships between people and service providers is important to support wellbeing and the reduction of health inequalities. Being listened to and understood is a key part of this as is power and control.
- During the pandemic, service users and patients from ethnic minority backgrounds had higher levels of concern and lower levels of comfort using services. We know people living in the most deprived areas of SEL are more likely to report never having used an NHS hospital service compared to those living in the least deprived areas.
- We have heard from some communities that there is additional stigma faced due to lifestyle including the Gypsy, Roma, Traveller communities, the Rastafari community, people living with or affected by HIV and people who use drugs and alcohol.
- Community leaders and people from Gypsy, Roma, Traveller, migrant, refugee and diaspora communities highlight specific issues blocking their access to health and care services including; language, literacy and cultural barriers, lack of trust in the NHS, complicated forms, not understanding the system and fear of personal data being shared beyond the service and in particular with immigration services.

What the SEL insights told us: Trust and cultural awareness (2/2)

- We heard immigration policies impacts on health inequalities as people from migrant, refugee or asylum seeking communities do not engage with services for fear of deportation.
- We have heard that health debts affect immigration status - owing a debt to the NHS is a ground for refusing applications for permission to enter or remain in the UK - so people do not come forward for treatment or do not go back for further or follow up treatment.
- This distrust in health and care services permeates beyond race and ethnicity. People within the LGBTQ+ community continue to report concerns that health and care staff will not treat them as equals and make assumptions, therefore they must actively hide their sexuality for fear of intolerance. People from the LGBTQ+ community are concerned that they may have to hide their sexuality as they age.
- Local people have told us that cultural views on sexual health and mental health have caused intergenerational issues and create barriers to access. We heard women from certain cultures will only see female health and care staff but are unaware they can ask for this.
- Solutions put forward include:
 - cultural competency training and using trauma, gender and cultural informed approaches to providing care and support;
 - more granular culturally sensitive data collection,;
 - working with local people to coproduce services that work for them and to develop health literacy.

What the SEL insights told us: Access issues and virtual (including telephone) services (1/3)

- A key access issue for people is the move to virtual care, with people expressing unease or experiencing difficulties in having virtual appointments and accessing services virtually (like booking appointments, booking a blood test or smear test or requesting a repeat prescription) in both primary and secondary care. However, the move to remote appointments is welcomed by others.
- We know that not everyone who has access to the internet is confident or able to use it, and some people who are not confident feel that support and training would help with their confidence. Digital exclusion continues to be an issue for homeless people.
- Some people have expressed concern about remote appointments impacting on continuity of care as it is difficult to book appointments with the same health professional.
- People who have language difficulties, who are disabled or who are from migrant backgrounds have reported that the move to virtual and telephone appointments is a significant barrier to accessing health and care services. Not all are aware telephone interpretation is provided, but where they have experienced it there have been issues with the interpretation (gender and ethnicity of interpreter), and ease of being understood by the interpreter and thus the health professional.
- For people who find communication challenging but who do not use interpreters, virtual services make communication more difficult as people report struggling to explain their situation and have difficulties understanding advice or guidance.
- People with learning disabilities have told us that they may need support to attend health appointments and sometimes when they miss appointments due to lack of support on the day, they are discharged from the service and have to start again.

What the SEL insights told us: Access issues and virtual (including telephone) services (2/3)

- People report that they can find it difficult to get through to someone at their GP practice on the phone as there are often long waits and appointments are not always available or they are told to book online. This can cause stress particularly when people are in poor health. Cost of long telephone calls was also raised as an issue.
- It has been reported that people do not find GP websites very easy to navigate for information.
- Some people have reported missing telephone appointments as they were not given a call back window of time. Where people had support workers who, pre-pandemic, would accompany them to appointments, it is difficult for these workers to provide the same level of support with phone consultations where there is no precise set call back time. For others if they are unavailable at the time of the call, they report that this is considered a failed appointment and they have to start the process again.
- Some people, particularly from health inclusion groups, find it difficult to register with GPs due to being wrongly asked for proof of address.
- People also told us they find it difficult getting to see a GP outright.
- Not all communities are aware GPs offer emergency appointments.
- A concern for many local people is how to navigate the complex system. Refugees and asylum seekers can have limited knowledge of how the health and care system works. People experiencing multiple disadvantages in particular can find navigating the complex system too challenging.

What the SEL insights told us: Access issues and virtual (including telephone) services (3/3)

- A significant number of people do not know how to access services or where to go for support, particularly out-of-hospital community and mental health services. Black, African and Caribbean communities were more likely to not know where to go to seek support, further compounded when people are migrants or refugees as there is a lack of information as to what public-funded services they have a right to access.
- We heard that, given some migrants have no right to free treatment, many are holding off accessing health services when they need it and thus allowing health issues to worsen. Some people are concerned about possible links between NHS, particularly GP services, and immigration and sharing data.
- For people who may move around such as Gypsy, Roma, Travellers, homeless people or people in temporary accommodation, there can be difficulties in keeping their place on waiting lists for elective care and having continuity of care.
- Access to dental services has been highlighted as an issue by organisations working with refugee and asylum seekers and homeless communities.
- There is an ask for improvement in information about services, working with community organisations.
- Dedicated in-reach, outreach and working in partnership with specialist (often VCSE) organisations can help support engagement with health and care services and support the development of better relationships between communities and health and care services.
- Solutions put forward include having GP surgeries sign up with Pride in Practice and the Safe Surgeries initiatives and the use of the Inclusion Health Assessment Tool for Primary Care Networks

What the SEL insights told us: Mental health and wellbeing (1/3)

- We know the mental health of people in south east London was severely impacted by the pandemic. However, outside of the pandemic, we know people don't know how to access support and that, for some people, there are delays to accessing mental health support or that there is a lack of mental health support that meets their needs.
- We understand that feelings of loneliness and powerlessness have decreased for some people with the easing of the pandemic, but that this remains higher for older people, people without children, people with a disability and people from the LGBTQ+ community (who report often having no family support around them). Many people are still reporting relatively low wellbeing. Where people are linked into VCSE offered social activities these are valued. The cost of living crisis with people struggling to pay their bills when on a low wage seem to be particularly prevalent for people from a minority ethnic background.
- We know that people who experience digital exclusion or are unconfident can face additional worries and anxiety about trying to go online without adequate support, resulting in the double impact of isolation and increased anxiety.
- We understand that stigma around mental health needs exists within some communities, preventing them from accessing help and support in a timely way, and leading people to accessing services at the point of crisis. For some communities this means via the Mental Health Act and the criminal justice system.
- We know there are pervasive inequalities in access to mental health services.
- People from Black, African, and Caribbean communities are less likely to know where to go to seek support - two in five of whom face a lack of mental health services with people from Latin American communities more likely to report issues around accessing support.

What the SEL insights told us: Mental health and wellbeing (2/3)

- Depression and anxiety and suicide rates are reported to be significantly higher in the Gypsy, Traveller and Roma (GRT) communities than the average population and this is further impacted by low literacy levels. Unchallenged racist bullying of GRT children often leads to poor adult mental health.
- Anxiety, depression and attempted suicide rates are higher within the LGBTQ+ community.
- People have spoken of generational trauma in which mental health issues manifest themselves profoundly due to discrimination experienced over generations and structural racism and discrimination.
- Issues such as domestic violence, housing, and immigration contribute to wellbeing and mental health for many people living in south east London.
- We heard that people who use drugs or alcohol may have to wait longer for MH services than others or that services have different eligibility criteria making it difficult for people living with a dual diagnosis to get holistic support and care.
- We also heard that people who use drugs and alcohol can face stigma as there is a lack of recognition that people may use drugs and alcohol due to previously experienced trauma or adverse childhood experiences, and this can also link with homelessness.
- People living with multiple disadvantages do not always have a linear journey to better health and some people may take steps backwards. Services are not always set up to work with people when this happens. Some people also report feeling that there is little support for people to stay well and in recovery, as services can focus on short term interventions. As a result, people may 'fall out' of criteria for services and have to re-access creating a revolving door.

What the SEL insights told us: Mental health and wellbeing (3/3)

- We also heard that refugees and asylum seekers often have untreated physical and mental health issues which are linked to previous experiences or witness of trauma and torture. This can manifest itself easily and quickly into acute episodes. We understand that access to an early responsive collaborative partnership model of intervention can help people avoid acute episodes. For some there is fear of how reporting mental health issues impacts immigration status.
- Young people have reported being 'dismissed' from services due to 'non-engagement', without understanding why they are not attending.
- We have heard that there are people who are too unwell for IAPT services but not unwell enough to trigger referrals to community health teams, and some young people who have been discharged from services may end up in mental health crises.
- We heard that in traveller communities there can be unresolved issues for children around bereavement due to shorter life expectancy caused by poorer health and higher suicide rates than in the general population.
- We heard that mental health issues are often higher amongst young people from the LGBTQ+ community and many may also be neurodivergent which can lead to greater difficulty in accessing services.
- Having to tell one's story to multiple services can be retraumatising for people.
- Solutions proposed included:
 - using trauma, gender and cultural informed approaches to address mental health and wellbeing
 - increased funding to develop more local community-based activities (prevention focus)
 - commissioning mental health interventions over and above the usual CBT offer as this does not work for some cultures and is often not suitable for trauma

What the SEL insights told us: Long term conditions and people with interconnected complex needs (1/2)

- We have heard from people living with more than one long term condition that they are not always seen as a whole person but sometimes as individual conditions.
- People have told us that they often tell their story many times across different health and social care services and they need a more holistic approach to support with their health and care, and that housing and education are important partners. This is particularly so for in people with learning disabilities.
- Homeless people often have a lot of health physical health needs in addition to often having mental health needs and a way of addressing these is through partnership working between health services and specialist organisations.
- More support is required for people who are aging and living with HIV and who develop other long term conditions, including specific needs of older Black African women who may be migrants or refugees and others. Due to stigma of HIV, other health professionals are not always aware of someone's HIV status. Having integrated or shared care plans should help alleviate this issue.
- We understand that different referral pathways for different conditions can also be problematic for people living with HIV, who may develop other conditions linked to HIV such as cognitive impairment, as some conditions may require referral from a GP rather than within a specialist service.

What the SEL insights told us: Long term conditions and people with complex needs (2/2)

- Peer support is seen as very important for people living with long term conditions, complex needs and multiple disadvantages.
- We have heard that in some communities such as Gypsy, Roma and Traveller communities, the prevalence of long term conditions is higher than the general population, the onset is earlier in life, and the take up of cancer screening is low.
- We have heard that some refugee and asylum families with severely disabled children need family care plans in place so that both adults and children are linked into services, and that a personalised care approach is needed within refugee or migrant families where children have learning disabilities.
- Chronic pain can impact on day to day activities which people may have to give up and it can be difficult for people to understand the impact of pain on their mental health and wellbeing. Often patients do not feel listened to by health and care professionals and feel that they are going round in circles.

What the SEL insights told us: Maternal, children and young people

- We heard that mothers and families often do not know what support and services they can access and often have to ask around in their own communities and networks, particularly within communities whose first language is not English, such as the Latin American community.
- Some child development concepts such as parents playing with their children are not always easily understood across different cultures or generations when this is not the parent's experience.
- Young people do not always feel listened to or valued by health care professionals.
- Traditional healthcare environments can be stressful for young people.
- A more holistic and compassionate approach including wellbeing and mental health should be taken to support young people. We heard that the term 'mental health' is not always used or understood by young people.
- Young people want more choice over their healthcare including who they see, when and where.
- Working to bridge the gap between children and adult services is important, especially for people with learning disabilities and their carers.

What the SEL insights told us: Safety issues

- Young people have reported feeling unsafe due to sexual harassment, housing/environment (drug use), and youth violence.
- We have heard that young people from the LGBTQ+ community find that they do not have spaces to go and hang out where they feel safe as they are often not out at home or in their communities. Experience of hate crime and/or discrimination leads to some young people from this community seeing the world as hostile. They are more likely to be out of education, which contributes to their vulnerability.
- Young people are often unlikely to report a hate crime and are more likely to tell a friend first. Reasons for not reporting are fear or uncertainty, thinking it is normal, and not being taken seriously.
- We were told that hate crime is an issue for disabled people, and for people with leading disabilities 'mate crime' is also a big issue where people pretend to be your friend when they aren't, leading to safety issues and abuse in their own homes.

What the SEL insights told us: Finance, low wages and long shift work

- Low wages, long shift work or working many jobs causes significant stress for adults and children, with many families reporting feeling worried about money all of the time.
- The above often results in children are not able to spend time with their parents.
- Low wages and unemployment is a more prevalent issue for people from black and ethnic minority backgrounds (compared to people from white British backgrounds.)
- As more financial advice and support moves online, people who are already digitally excluded and / or unconfident, are in danger of becoming even more excluded and isolated and experience increased health inequalities.

What the SEL insights told us: Joined up and partnership working

- Lack of accessible, culturally relevant and easy to understand information about how health and care is organised and about specific services such as maternity and children's services was highlighted as a key issue for many communities. Working in partnership with voluntary and community sector organisations would help address this and promote health literacy within communities.
- Having space for communities to come together to support healthy living, sharing information and peer support was highlighted as important.
- Lack of partnership working and lack of defined referral pathways between agencies has been identified as an issue, particularly impacting homeless and diaspora populations and people who may have a complex set of health and care needs and who may be experiencing other issues such as domestic violence, homelessness or insecure housing and / or use drugs and alcohol. People gain the best support and are more likely to stay in services when health and specialist VCSE organisations and statutory health and care organisations work in partnership together.
- It was suggested that a contributory solution to working with south east London residents who have multiple needs would be to develop a trauma-informed approach, incorporating culture and gender issues and asking all ICS partners to actively sign up to this, supported by cultural competency training.
- It was highlighted that in order to address health inequalities, we need to address the root causes and coproduce solutions with local people at place and system level. This would also support the development of health literacy within communities.

Appendices

References / sources of insight

- [Southwark LGBTQ+ Community Consultation 2018-2019](#), Healthwatch Southwark and Southwark LGBT Network, 2019
- Traveller Movement Submission to Women and Equalities Committee Inquiry into the Mental Health of men and boys, March 2019
- [Southwark Stands Together Cabinet Report](#), Southwark Council, September 20220
- [Clear Community Web Impact Report](#), 2020 – 2021
- GP Access Summary Report, Healthwatch Lewisham, 2021
- Digital exclusion and access to health services, Healthwatch Lewisham, 2021
- [Greenwich Young People’s Council Hate Crime Research Report, 2021](#)
- GP access project report, Healthwatch Southwark, 2021
- Digital Inclusion Report, Healthwatch Bexley, March 2021
- A survey of Gypsies, Roma and Travellers with a connection to Southwark and an analysis of Southwark Traveller’s Action Group (STAG) casework, April 2021
- [People’s experience of multiple disadvantage in Lambeth, Southwark and Lewisham: a peer research project](#), Fulfilling Lives Lambeth, Southwark and Lewisham, June 2021
- [Birmingham and Lewisham African Caribbean Health Inequalities Review \(BLACHIR\)](#), March 2022
- [Impact report 2022: our learning and ficnal recommendations](#), Fulfilling Lives, Lambeth, Southwark and Lewisham, May 2022

References / sources of insight

- [Insights and themes from user research](#), Comuzi, June 2022, as part of a [PEACS / King's Health Partners project to developing a service for Black communities living in chronic pain](#)
- Putting Young People at the Centre of their Health Decisions & Choices, 28 July 2022 (as reported to the London CYP Strategic Forum, 5 September 2022)
- South London Listens survey analysis report, September 2022
- [#HealthNow literature review: how has patient experience changed for people who are homeless](#), Groundswell, September 2022
- [@HealthNow peer research report, 'Knowing where to turn': access to mental health support whilst experiencing homelessness](#), Groundswell, November 2022
- Friends, Families and Travellers, [Health Inequalities experienced by Gypsy, Roma, and Traveller Communities](#), October 2022 (references the All-Ireland Traveller Health Study)
- HSJ article, [The NHS is failing to meet the healthcare needs of refugees | Comment | Health Service Journal \(hsj.co.uk\)](#), 20 October 2022
- <https://www.gov.uk/guidance/improving-roma-health-a-guide-for-health-and-care-professionals>, 3 November 2022
- <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/gypsiesandtravellerslivedexperienceshealthenglandandwales/2022>, ONS, December 2022

References / sources of insight – meetings

- Meeting with an older resident living with HIV, member of Positive People, 27 September 2022
- Meeting with Chair of Southwark LGBT Forum, 27 September 2022
- Meeting with the Haven, older group of people from the LGBTQ community, 28 September 2022
- Meeting with a Rastafari community leader and NHS chaplain, 30 September 2022
- Meeting with ICS Asylum Seekers and Refugees Programme Lead, 30 September 2022
- Meeting with the Director of Vietnamese Mental Health Services, 4 October 2022
- Meeting with Learning Disability and Autism Ambassadors programme coordinators (Advocacy for All and Advocacy in Greenwich), 11 October 2022
- Meeting with Manager and Volunteer Manager, Southwark Travellers Action Group, 11 October 2022
- Meeting with in Bromley Council leads for working with the Gypsy, Traveller and Roma community and Lived Experience Practitioner, Oxleas, who is also a Community Champion in Bromley, 12 October 2022
- Meeting with Mental Health and Wellbeing Coordinator and Alliance Manager, 14 October 2022 and Head of Sexual and Reproductive Health, Metro Charity, 21 October 2022 and report of Metro Service User Forums held in October 2022
- Meeting with CEO, Health and Care Manager and Campaign and Communication Manager, Lewisham Refugee and Migrant Network, 20 October 2022
- Meeting with Partnerships and Research Manager, The Traveller Movement, 19 October 2022
- Meeting with Manager, Vietnamese Family Partnership, 20 October 2022
- Meeting with Manager, Southwark Day Centre for Refugees and Asylum Seekers, 21 October 2022

References / sources of insight – meetings

- Meeting with South East London Learning Disability and Autism Forum, 25 October 2021
- Meeting with Lead Asylum and Refugees, Three Boroughs Health Inclusion Team - Vulnerable Adults & Prevention Services (regarding homelessness), Guy's and St Thomas; NHS FT, 31 October 2022
- Meeting with Deputy Coordinator, Emmaus Greenwich, 3 November 2022
- Meeting with Managing Director, ClearCommunityWeb CIC, 7 November 2022
- Meeting with Coordinator, Ukrainian Support Greenwich Project, 7 November 2022
- Meeting with Director, Red Ribbon Living Well, 8 November 2022 and attendance at their HIV prevention day, 2 Dec
- Meeting with Director, Greenwich Winter Night Shelter, 8 November 2022
- Meeting with Researcher, Migrant Health Research Group, St George's University, 9 November 2022
- Meeting with two Regional Directors, Change Grown Live (CGL), 10 November 2022
- Meeting with Rough Sleeping Coordinator, Royal Borough of Greenwich, 14 November 2022
- Meeting with South East London Learning Disability and Autism Ambassadors, 17 November 2022 and 19 January 2023
- Attendance at Traveller Movement Conference: the Intersection of Poverty, Inequality and Mental Health, 17 November 2022
- Meeting with Homeless Health Peer Advocacy (HHPA) Project Manager, Groundswell, 18 November 2022
- Meeting with Chair of ICB, LGBTQ+ (staff) champions, 18 November 2022
- Meetings with Southwark Latin American Network, 14 December 2022 and 11 January 2023