Developing a SEL ICS strategy for working with people and communities
Understanding existing insights and best practice engagement methodologies

November 2021

1. Purpose

There is a significant amount of existing insight and best practice, at a neighbourhood, place, and system level, available to us to support in developing the ICS strategy for working with people and communities. Not only will this help to understand existing community priorities and preferences, but it will also ensure we add the greatest value by identifying gaps in engagement work and avoiding engagement fatigue and duplication to begin to work in a more joined up way with our communities.

This document is divided into two parts. The first part looks at engagement work undertaken in the last financial year (2020/21) by a range of organisations on behalf of the NHS. It draws together all of the insights into a summary to identify key insights at a system and borough level; agreed priorities/ pledges and actions already within the system and considers how these insights can inform future ICS engagement. Due to the natural focus on the pandemic over the last financial year, all of the insights analysed focus on recovery, understanding vaccine hesitancy, attitudes towards the vaccine, education, understanding key influences and how to build trust with communities. Future priorities of the ICS will include, but not be limited to COVID recovery, but we anticipate these insights to be transferrable to non-COVID areas of work.

Part two of the document looks at tried and tested engagement methodologies from across south east London and national and international examples of best practice. Drawing on what's already working well will help inform south east London ICS' thinking about what structures and processes will be needed to embed effective engagement and involvement into the organisation and the wider system.

Part 1: Understanding existing insights

2. Overview

In developing this summary, the outputs from many different engagement projects have been analysed. These were selected based on the following broad criteria: health related, project engaging specifically with south east London populations and activity undertaken in the last financial year (to ensure relevance). We are grateful to those teams who have shared their work with us to be a part of this document – it will continue to be updated as we learn about new and existing projects.

Each project was commissioned and undertaken by different organisations for different purposes and at different scales, and we have been mindful of these differences when developing this summary which aims to distil the key themes from across these important projects. Where statements relate to a specific project or statements are supported or contradicted by multiple projects, references have been included so that insights can be traced back to their source.

The project outputs we have reviewed as part of this document are listed in Appendix 1, together with a summary of methodologies, topics engaged upon and specific communities reached. Across all of these projects, over 9,500 local people were engaged during 2020 and 2021.

2.1 Methodologies used

Many engagement methods were used, including:

- Digital and non-digital approaches (where safe to, given government restrictions)
- Participants recruited formally through data sampling and informally through existing networks, leafletting and pop-up events
- Solo engagement through surveys and 1:1 interviews to group engagement through workshops and focus groups
- Approaches that structured engagement such as surveys and interviews, semi – structured conversations with prompts and topic guides to co-production where participants worked in partnership to design engagement

2.2 Topics covered across engagement projects

- 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
- 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

2.3 Specific communities reached

Although the different projects had different aims and perspectives they were seeking to understand, several groups were featured multiple times including:

- Black and minority ethnic communities
- Communities facing multiple social injustices
- Those with mental health conditions
- Those receiving NHS continuing healthcare
- Lambeth, Lewisham, Southwark, Bromley and Greenwich service users

Understanding this will be important in considering who may need to be the future focus for engagement activities.

3 Key insights – system level

A number of the projects we looked at aimed to engage across south east London, or had an even larger geographical base for their work. However, we do not generalise that the feedback presented in this section is indicative of the feelings of the population of south east London. This section looks specifically at insights from these system level projects, the findings of which are

mirrored in some local level projects (insights from these can be seen in section 4) focussed on smaller geographies.

3.1 Experiences of using hospital services face-to-face during the pandemic

- **Experiences were largely positive** –the majority (91%[1]) said they felt comfortable using hospital services face to face.
- Parents and carers, responding on behalf of a child or adult, were less positive (84% and 78% respectively[1]), reflecting **higher levels of concern amongst people with caring responsibilities**.
- The **majority of participants** [1] **say they would feel comfortable using most services** if they needed to in the future.
- There was mixed views about restricting visitors to see patients on wards or accompanying patients for outpatient appointments –**there was particular disquiet about restrictions on visitors to adult and children inpatients**[1]**.**
- **Some population groups** [1] **had difference experiences. Carers consistently show higher levels of concern or unease**–particularly about virtual appointments and staying in hospital as an inpatient. P**atients from ethnic minority backgrounds have higher levels of concern, and lower levels of comfort** using services face-to-face (reflecting wider trends we have seen), and virtually.

3.2 Attitudes and behaviours around using hospital services face-to-face during the pandemic

- Almost a quarter of those surveyed [1] were using hospital services at least once a month before the pandemic. People living in the most deprived areas were more likely to report never using an NHS hospital service compared with those living in the least deprived areas
- The majority of patients [1] felt comfortable attending a face-to-face appointment, but less so when it was for someone else. These high levels of comfort are despite ongoing concern about coronavirus. Even amongst people who said they were concerned, the majority still said they felt comfortable (84%), though this is lower than seen amongst those who said they were not concerned (95%). There were no significant differences between patients based on when they had used health services (i.e. earlier in the pandemic compared with later in the pandemic). However, there were slight differences by ethnicity here. For example, 90% of white patients felt comfortable compared with 84% of patients from ethnic minorities. Similarly, there was little difference by deprivation.
- Patients and carers [1] were less comfortable visiting an NHS minor urgent care centre/minor injuries units, visiting a hospital A&E/UTC/UCC or staying as an inpatient, compared with accessing a face to face appointment at a GP surgery or having a test for visiting a hospital or community service for a test. On the whole, participants [1] find the **prospect of staying as an inpatient as the most worrisome.**
- Of those who said they would be uncomfortable using a hospital service face-to-face [1], the most **common reason for feeling concerned relates to the perceived risk of catching coronavirus**. Concern was higher when participants were: responding about their family, responding about the person they care for, women, people from ethnic minority groups and

[1] Joint Programme for Patient, Carer and Public Involvement in COVID Recovery: Attitudes and behaviours telephone survey, ***Guy's and St Thomas' Charity, together with King's College Hospital Charity***

some age groups (particularly those aged over 36). There were also some slight socioeconomic differences, with people from the most deprived areas more likely to report higher levels of concern about the virus (for themselves).

- There is a **small group of very concerned people** [1] who say that **nothing could make them feel comfortable about using a face-to-face service**, meaning some patients or carers may choose not to access services when they need to.
- Of those who did not attend their outpatient appointments during the pandemic [1], no longer needing the appointment was the most important reason given for not using the service

3.3 Addressing concerns around using hospital services face-to-face during the pandemic

- Communications ought to provide **reassurance about the level of risk and measures that are in place** to keep patients, carers and visitors safe when attending a health service[1].
- Findings suggest a need for staff to be understanding and compassionate, even more so than in usual circumstances[1].

3.4 Virtual appointments

When we use the term virtual, we mean online using a smart phone or other device, or by telephone.

3.4.1 Outpatient appointments

To improve participants experiences of virtual appointments (outpatients in this particular situation), the following suggestions were made[1].

- **More information in advance and to have a set time** for the appointment.
- Support to help **overcome connectivity and communication issues**.
- **Offering a choice of mode of appointment** or reassuring them that they can be **followed up face-to-face** if necessary is important.

Some expressed unease or experienced difficulties in having virtual outpatient appointments. For some people[1], there appears to be distrust, linked to not having a physical examination and a concern that something may get missed. Some of the measures above may help with this.

In other clinical areas, such as primary care, there were other challenges with virtual appointments [8]. There were long waiting times to make an appointment (a pre-pandemic issue), lack of availability of appointments and feeling confident to articulate symptoms over video call.

3.4.2 Primary care

Half of respondents said that they found access to help from GP practice easy or very easy, although 17% said it was difficult to access support. 50% of patients found that telephone consultations went well, with just 9% agreeing that video consultations worked well. (Bromley primary care access)

Despite the positive response to virtual consultations, residents in Bromley (Bromley primary care access) said that they wanted to return to ‘normality’ with more face-to-face appointments.

Bromley patients commented that phone contact to practices has generally improved, and there are many positive comments describing a more accessible process to get appointments. But this is not consistent through the practices. (Bromley patient survey)

3.5 Impact of the pandemic on mental health

- Many participants[2] have experienced **feelings of powerlessness, isolation and loneliness** since the start of the pandemic. These feelings were **particularly prominent among participants aged 18-34.**
- One-in-three people[2] have been **affected by job insecurity** and a similar proportion are **struggling to pay the bills**. As well as financial insecurity, income loss, and unemployment we also heard about the **stress and anxiety caused by increased workloads** and trying to manage a work/life balance in **new working environments**.
- Around 48%[2] of people don't know where to go for support.
- People from Black, African, and Caribbean community members are more likely not to know where to go to seek support (54%[2]) - two in five of whom face a lack of mental health services.
- Community leaders from **migrant, refugee and diaspora communities highlight specific issues** blocking access to mental health services including **language 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
- A Young Minds study[3] found that 67% of **young people believe that the pandemic will have a long-term adverse effect on their mental health**.
- Covid-19 is further **increasing child maltreatment, gender-based violence and sexual exploitation** because of lack of access to school friends, teachers, social workers and the safe space and services that schools provide. Young people on **Child and Adolescent Mental Health Services (CAMHS)** in particular are feeling[4] **in limbo and lacking support**.
- The negative impacts on children have been **mirrored in research on parents**[5,8] during the pandemic, who have seen **increases in stress, anxiety and depression**. Caregivers have expressed f**eelings of guilt** and grappling with the **stigma of 'not coping'**. Many parents **wanted mental health support** but **did not know** where to get it. Around a third of parents[2] were **not confident** that they are able to cope and were experiencing symptoms of **depression and anxiety**.

4 Key insights – local level

The insights presented in this section focus specifically on feedback from projects working with Lambeth, Lewisham and Southwark services and service users. It is likely that some of the key themes here resonate across a larger geography, but further engagement would be required to test this.

[2] South London Listens, ***South London and Maudsley, South West London and St Georges, and Oxleas (2021)***
[3] Coronavirus: Impact on Young People with Mental Health Needs, ***Young Minds (2021)***
[4] WHO, Joint Leaders' statement: Violence against children: A hidden crisis of the COVID19 pandemic, **World Health *Organization (2020)***
[5] Briefing from CO-Space study https://www.ox.ac.uk/news/2021-01-19-parentalmental-health-worsens-under-new-national-covid-19-restrictions, ***Oxford University (2021)***

4.1 Attitudes towards the COVID-19 vaccine

4.1.1 Planned uptake

- Some people[6] intend to get vaccinated because they were confident it would protect them, it was seen as a pragmatic step to enable travel/avoid further restrictions, wanting life to get back to normal
- Some evidence[8] showed that, once individuals had **undertaken their own research** about the vaccine, they were **less sceptical** about how it had been developed and **more likely to take the vaccine**

4.1.2 Vaccine hesitancy

- **Feeling of distrust in the Government**[6, 7, 8] was common for those who are opposed/unsure about the vaccine and caused people to disengage. This linked to:
    - Messaging around COVID-19 and whether decisionmakers have people's best interests at heart. There were questions about the numbers being presented and a feeling that communities [8] had been lied to and then expected to trust political figures. **Deaths and covid rates** were felt to be presented in a **suspicious** and **scaremongering** way. Young Black people felt overwhelmed by messaging around disproportionality (deaths due to covid, deaths in custody, police brutality) as well as having to contend with the COVID-19 pandemic and the national lockdown. (Greenwich 3 pillars)
    - Feelings of coercion by the government from some black communities[8]
    - Fear that a passport system will be **used against black communities** and **hinder them** returning to ordinary life[8]
    - Using COVID to **have more control** over the population (based on conspiracy theories) [8]
- **Feelings of distrust in the NHS**
    - Concerns about the vaccine linked to **long-standing medical scepticism** [6, 8, 11]within **minority ethnic communities.** Historical mistreatment factored into participants'[11]decision making when it comes to engagement with healthcare. The majority of participants recounted specific previous experiences of outright discrimination in medical settings.
    - **Pharmacological scepticism** [11] **–** "selling" interventions and being motivated by financial reward rather than communities wellbeing
    - **Sharing/ selling of personal data outside of it's intended purpose and without consent**

- Feeling the vaccine was just **not necessary**[6]
- There were mixed views on whether **minority ethnic communities religious and family beliefs** influenced uptake or general perception [6,8]
- Some minority ethnic communities [6,7] preferred to rely on more **familiar/trusted herbal or natural supplements for medical needs**
- For those who are young and healthy, some felt that the **perceived risk** [6] **of becoming unwell from the vaccine** was a more likely and less favourable outcome than catching

[6] COVID-19 lived experience research insights into vaccine hesitancy, ***The Social Innovation Partnership***

[11] Medical scepticism/distrust**,** ***The Social Innovation Partnership***

[7] Vaccine Discovery Insights, ***Rooted by design***

Covid. There was also a lack of understanding as to why they[8] should have the vaccine if it does not stop them from catching or spreading the virus.

- Belief that a **lack of research was conducted**[8] and that the vaccine was developed too quickly/ rolled out too quickly
- A small number chose not to have the vaccine for the following reasons; because the still have antibodies; feeling nervous as to how my body will react and being unclear on the long term effects and having medical reasons for not being able to vaccine due to its impact on the body

4.1.3 Indecision

- People [6,8] needed **further information** to make a decision e.g. what's in it and the side effects, how it works and it's efficacy. Understanding how the vaccine; was tested and assurance processes, impacts health conditions specific to Black communities[7] (e.g. sickle cell disease)
- Concerns over **motives and intent -** scepticism over the speed and rigour of testing, speed of vaccine delivery and whether it has been properly tested, secret agenda around vaccine dissemination to cause harm, worries around mandatory vaccination requirements
- Concerns about level of support available if they have a negative reaction to the vaccine[7]
- Relationships with healthcare professionals are important for addressing vaccine concerns [7] - among some early years staff, 31% who have not had the vaccine were willing to discuss concerns with a GP or attend a webinar to discuss any issues.

4.1.4 Influences on attitudes and behaviours

4.1.4.1 Social media and news

- Channels such as Twitter, WhatsApp, Instagram and Facebook shared conspiracy theories which were felt influential [8]. One participant had viewed the Panorama documentary which outlined how labs were under pressure to report positive results, even when tests were inconclusive, to meet targets.
- **Fact checking** happened through **news channels,** the **NHS website** and **World Health Organisation**[8]

4.1.4.2 Advertising and celebrity endorsement

- In general it was felt these methods were not effective and that they were "propaganda", with celebrity endorsements feeling particularly inauthentic[8]
- Few had come across campaigns on public transport/ at stations[8]

4.1.4.3 Friends and family

- **Friend and family conversations** are a common source of information and influence[8] – some mentioned friends and family who were clinicians answering questions and dispelling myths

[8] Vaccine knowledge: Thoughts, perspectives and recommendations from young Black people in Southwark & Lambeth, ***Comuzi***

4.1.4.4 Experience of and confidence in the NHS

- Within black communities[8], positive experiences with the NHS didn't encourage uptake of the vaccine
- Negative experiences (misdiagnosis/ inadequate treatment/ perceived experience of receiving different levels of care because of ethnicity) with the NHS did influence vaccine perception[8].
- Black communities[8] trust NHS professionals whom they feel listen to them but believe they will not be objective about the vaccine. Speaking to someone they can relate to (someone who looks like them) is important in building trust
- Despite reservations, black communities do still turn to the NHS for information and advice[8].

4.2 Impact of pandemic on people and communities

There was recognition that the pandemic had had a significant and negative impact on peoples lives, including:

- People left confused by information and a rise in misinformation [8,9]
- Access to healthcare changed, became delayed or stopped for some communities[8, 1]
- Increased bereavements
- Significant impacts on LTCs
- Negative impact on mental health (trigger of new MH conditions or worsening of existing conditions, social isolation, increase in depressions, disruption to health services, challenging living conditions and extended caring responsibilities) Bromley primary care and Greenwich 3 pillars
- Negative impact on physical health (lack of exercise, weight gain, delayed medical appts, social isolation) - Bromley Primary Care
- Increased isolation
- Negative impact on social life - loss in physical social interaction was negatively impacting their mental health (Greenwich 3 pillars)
- Job loss and unemployment – concerns about job offers post-graduation, and potentially getting COVID-19 whilst at work (Greenwich 3 pillars)

In spite of the difficulties expressed, there were some areas of life which were positively impacted by the pandemic; strengthened informal support networks and participants taking a more active role in managing their health[8] (due to longer waiting times and seeking to reduce the risk of catching the virus).

4.3 Experiences of the NHS

4.3.1 Trust in services

- Some black communities[11] linked traumatic experiences in hospital (receiving medication that was not requested or was inadequate and not receiving care) to feelings of disempowerment, and a lack of adequate help (good complaints process) reducing their trust in the system.

[9] Co-producing personalised care for people who have had Covid-19 and their carers in North Lewisham, **Urban Dandelion CIC**

- Research[11] has found that black women are five times more likely to die, and Asian women twice as likely to die, compared with white women during pregnancy or birth. Women's poor experiences with maternity and reproductive services affect their trust in the healthcare system.

4.3.2 Impact of tight NHS budgets and overworked staff

- Effects felt by some communities [11] through GP and nurses' perceived lack of time, care and empathy with poor interpersonal skills and missing a human response and connection. Many participants doubted their GPs effectiveness and preferred accessing specialist or hospital services though some people trust their GPs more than other healthcare professionals.

4.3.3 Empowerment, involvement and control in healthcare

- Some black communities [11] felt they were not empowered to have an active or equitable role in their healthcare or advocate for their own health needs.
- Multiple participants [11] had taken their health into their own hands through alternative treatments and culturally specific, traditional remedies – which are growing in popularity.
- Black and minority communities are becoming more informed about their own health needs and concerns via informal networks which sometimes oppose mainstream norms
  and conventional advice. Some felt healthcare professionals had preconceptions of what is wrong before patients have even shared experiences/ symptoms and many are choosing not to disclose certain activities or treatments to healthcare professionals due to fear of judgment.

4.4 Personal health budgets (PHBs)

4.4.1 Flexibility in care package arrangements

- People with lived experience of PHBs seem to have had a better experience[10] of using PHBs than they had of previous care arrangements - communication and relationship with professionals and increased choice and control over the way their health and care is organised. They value the **choice** and **control** that their PHB gave them
- Feedback[10] suggests a perception that assessors will write support plans according to what they think commissioners will agree which means recipients don't truly get choice in what is available.
- Although there is some choice and control, there is none in respect of staff wages (when employed through direct payment) means there is no flexibility to meet staff's reasonable pay expectations. Flexibility would enable a better use of money as it could prevent high staff turnover and thus save in training costs. Staff turnaround also often has a negative impact on the person receiving the care[10] as they have to get used to new people coming and going as opposed to one (or a few) individual(s). This defeats the point of having a PHB

[10] Reviewing and improving the use of Personal Health Budgets (PHBs) in south east London, ***Disability Advice Service Lambeth: Co production group***

- The use of PHBs in mental health [10] – only those who have been inpatients will have access to this support. PHB pilot programme, which included more than 20 areas offering PHBs for mental health, found that the use of PHBs for mental health resulted in "significant improvement of people's quality of life and wellbeing and were cost effective strong need for a culture shift within the healthcare system and mental health services.

4.4.2 Ongoing support with the process

- Challenges with getting plans amended if there are errors or if changes need to be made, which affects the quality and continuity of their care and support [10]
- Lack of support[10] available to people who have, or manage, a PHB in each borough
- Waiting times and delays within the assessment and reassessment process

4.4.3 Communication and co-production

- Lack of clear, accessible and borough-specific information about PHBs[10] including what are PHBs, what they can be used for, who can access one in the borough, how the PHB process works, where to go for support and how to challenge or appeal panel decisions.
- Need better representation of people with lived experience of PHBs within the CCG, including on decision-making panels. Having contact with Peer Leaders who have vast lived experience of PHBs and a broad understanding of how the system works could provide people with a clearer view of what they could ask for and achieve via their PHB

Part 2: Best practice engagement methodologies

This part of the document looks at best practice engagement methodologies and, more specifically, those that differ to traditional approaches (such as deliberative events, focus groups or surveys). Examples come from across south east London as well as nationally and internationally and aim to help inform the ICS' thinking about what structures and processes will be needed to embed effective engagement and involvement into the organisation and the wider system. This is not a formal evaluation, but a collection meant to inspire the use of differing approaches.

5 Examples of best practice engagement

Table 1: Examples of best practice engagement drawn from existing insights and (inter)national examples

Example	Method	Approach	Learning and/or outcomes
Sussex MSK Partnership	Patient Directors https://www.hsj.co.uk/comment/patient-leadership-for-real-the-sussex-model-for-patient-partnership/7022549.article)	Appointed patient director – an executive role, alongside clinical and operational directors with the aim of ensuring that the systems, processes and culture within the partnership focus on what matters to people who use the services	• Role means that patients are equal in the decision-making • people with lived experience bring wisdom and insights from their experience and suffering, can act as trusted partners to improve experiences and quality, develop systems and process that values and embeds this work so any activities undertaken are sustainable • Partners are paid and also supported with training – attended MDTs and quality/ pathway meetings • Partners do more than share their story/experience – they help to reframe problems, come up with solutions
Collaborative practice approach	Co-production https://static1.squarespace.com/static/5ad4879c5cfd798df87393cd/t/5d6e7dba795d9e0001c63b89/1567522237107/AB_Collaborative-Practice-Brochure-	Worked with GP practices to support GPs, Practice Managers and staff to develop skills and knowledge. Practices invited patients to coproduce solutions to problems that cannot be fixed by medicine alone	• Helped to develop a range of services that connects people to existing offers within the community • Patients are supported to adapt, cope and build resilience, improving their ability to self-manage and live well. • Frequency of clinical appts reduce as patients have access to the support they need (demand reduced by 30% between 2015-2017), improved patient wellbeing by 94%, practice staff develop skills to work

Example	Method	Approach	Learning and/or outcomes
	ONLINE-spreads-2.pdf		better across networks, clinical staff have more time and consultations improve, workforce pressures reduced, sustainable business model
Lewisham co-production	Co-production	Sharing population health data and checking this with local communities	Building relationships with people impacted by Covid-19 provided more insight than population health data. Working closely with local organisations to provided a more holistic approach making for more effective communication.
South London Listens	Workshops	Participants are asked to bring problems and solutions to the workshop. Often, it is left to decision-makers to find solutions, so this approach encourages a more collaborative way of working with greater community buy-in	• It addressed power differences and was worthwhile and realistic • Defined the four South London Listens priorities and co-produced 22 solution focused pledges
South London Listens	Community Listening Campaign	Citizens UK trained 300 community leaders to listen to local people.	• These leaders could reach people who public institutions typically don't always reach. • Through their leadership, over 5,700 people actively engaged in the campaign through one-to-one conversations, and in small group meetings on Zoom, sharing issues, experiences, ideas and solutions
Disability Advice Service Lambeth: Co production group	Co-production group	Members recruited to the group were from Lambeth and Southwark who have experience of one or more of the following: • Using or managing a PHB or DPs • Direct Payments workers with experience of supporting people with PHBs. • People using physical and/or mental health services	Members of the group specifically highlighted the following positive experiences and outcomes: • **Commitment to reciprocity and valuing people's lived experience** and contributions demonstrated by reimbursing members for their time. Members chose to receive gift vouchers at the equivalent of the London Living wage (£10.75 per hour) for two hours per meeting and any additional work carried out for the project. • It increased knowledge, understanding and confidence about the topic being discussed

Example	Method	Approach	Learning and/or outcomes
		• People working in health and social care in SE London The group underwent training about what co-production was and provided with a co-production mentor to support the process.	• New opportunities for their **professional and personal development** such as taking part in the NHS Peer Leadership Development Programme. • Meeting and **learning from new people** with different lived experience and professional expertise. • Online facilitation which created **greater flexibility in the project** and allowed members to **fit their involvement** alongside other commitments and responsibilities. From their experience of taking part in the project, members identified the following limitations and areas for improvements to ensure more effective and meaningful co-production in the future: • Future co-production work needed to **involve practitioners and decision-makers from start to finish**. This will give people with lived experience shared power and influence in making decision and give them a better understanding of current processes and structures within the CCGs. • The pandemic **impacted on members' ability to consult people with lived experience** beyond the group and to engage with people working in different areas of the NHS. • **Time constraints**: the project required more time than initially allowed • **Lack of diversity:** the group didn't reflect the full diversity of the residents of the 6 boroughs of south east London. More **diverse** and **intersectional** experiences were required • **Facilitation and barriers to participation**: future projects should dedicate more time to **building people's skills and understanding about co-production** and how it differs from other ways of working. In addition, future work should continue to explore ways of

Example	Method	Approach	Learning and/or outcomes
			facilitating and engaging with people that are **flexible** and are not strictly **centred on meeting at a fixed time**. • More time should have been spent **co-producing group values and purpose** to ensure everyone agreed on the role of the group.
AT Beacon Project	Established Health Hubs Presented to church congregation and conducted meet and greets to build rapport	Taking a holistic approach and going to people where they are "trusted voices in trusted spaces" Offered health and wellbeing sessions whilst also discussing experiences and issues with healthcare	• Reached small numbers but those who may not ordinarily engage via traditional methods • Was able to share healthcare information with target demographic groups • Discussions with those who have mental health vulnerabilities but who culturally may not traditionally discuss these issues
Comuzi	Two stage process. Depth-interviews followed by co-design workshops with a small group of interview participants	Co-design promoted openness, idea generation and to practice creativity over immediate feasibility to ensure that those attending were considering all perspectives possible. Ideas were created and filtered (This was achieved by discussing the ideas to determine their feasibility and desirability, to determine which ideas will have the highest potential impact and which could be considered to be low-hanging fruits (simple implementation but can yield quick results). A smaller number of ideas were tested then assessed for risks and opportunities via a RAG system.	• Creative process may identify options that have not previously been considered • Potential for greater buy-in from communities • Solutions are likely to be more effective if created by the communities services are using

Example	Method	Approach	Learning and/or outcomes
The Social Innovation Partnership (Vaccine hesitancy)	Depth interviews	Interviews every 2-4 weeks over a number of months, to understand how views were evolving over time. Interviews were conducted like a conversation, with a prompt guide for interviewers to guide the conversation rather than dictate it	• Offers an evolving view rather than a snapshot as some engagement methods can do • Offers flexibility in what can come up

Part 3: Learning for SEL ICS

Through reviewing existing insights and exploring different engagement methodologies, there is much for SEL ICS to learn as it develops it's own strategy for working with people and communities. This section outlines principles for engagement arising from the data to be considered as well as what the data highlights and how SEL ICS should use this in future planning.

6 Principles for engagement

1) Engagement

- Patients and residents' expertise and experience could be shared more widely and included in all levels of decision making.[9]
- More resource should be allocated to organisations that are committed to improving the health and care of people they serve, in order for them to continuously engage with local communities[9]
- Engagement should take an impartial approach not a coercive one[8]
- Technology should be used to support engagement/research (e.g. online communities, root cause analysis, digital ethnography, online focus groups/interviews, diary and journaling, vox pops, surveys) [12]
- Community research is important to gain a deep understanding of the communities an organisation serves. This means using multi-cultural/lingual teams to identify problems and come up with appropriate solutions/interventions for that community[12].

2) Engaging with specific communities

- **More focus on health issues impacting Black communities.** People from Black communities are often asked the same questions and are rarely see any feedback or outcomes as a result of their participation. People want to feel like they are listened to and influence services, if they can't then engagement feels disingenuous as researchers do not fully understand their lived experience and they are less likely to be involved in future engagement opportunities[7,11,12]. For those not involved, this can result in a lack of engagement, community mistrust, deepening inequalities and ineffective/irrelevant social programmes[12] **.**
- **Address mistrust with the black community through authentically listening and taking action.** There are several ways in which community mistrust can be addressed. Firstly, through gaining a deeper insight and understanding into health issues affecting Black communities (e.g. better reporting on ethnicity data, research into how disease affects Black people)[8].
- **Community mistrust –** communities have often not benefitted from previous research undertaken which leads to mistrust to traditional forms of research/people conducting it
- **Understanding of cultural nuances** helps to uncover deeper insights, community engagement by people with lived experience to develop trust[12].
- **Partner with trusted communities, platforms and leaders** – important that this demographic is communicated to via people they can trust and relate to (community leaders, black healthcare professionals) and can be confident that issues will be tackled. Information can be cascaded throughout communities[8].

[12] Moments to Movement, ***Centric***

- Whilst **targeting a specific community** (for example those with a physical disability) we need to be **aware of intersectionality** and that engagement be reflective of the diversity of residents within those communities[10]

3) Communications

- **Provide information that is easy to understand and neutral.** Communications should be in plain English, succinct and include information from a variety of sources. Information should also be supported by images, video and audio options. Translated materials are important, particularly for older generations where English might not be their first language[8].
- **Tailor communication styles to audiences**. Some information formats may not be preferable for certain demographics. Some audiences prefer interactive engagement (e.g. social media, podcasts), whilst this might not be suitable for an older demographics. A range of communications channels should be used to reach a wide audience[8].
- **Be more transparent.** Organisations should be more transparent about the data they are using and how it is calculated and presented. They should also be honest about what they know and what they don't know[8].

7 Suggested next steps

A. <u>Understanding ICS priorities</u>

The insights analysed in this report relate to very specific areas of health such as inpatient healthcare for certain conditions, mental health, personal healthcare and attitudes and behaviours around COVID vaccine uptake. The ICS will have it's own areas of work and priorities.

Mapping should be undertaken to align these insights to ongoing ICS priorities to understand gaps and understand upcoming opportunities to feed insights in and build on these with new engagement where needed.

B. <u>Hearing from different communities</u>

The insights analysed focus on experiences from certain sections of the south east London population, including:

- Black and minority ethnic communities
- Communities facing multiple social injustices
- Those with mental health conditions
- Those receiving NHS continuing healthcare
- Lambeth, Lewisham and Southwark service users

It will be important to ensure representative engagement with all communities by 1) continuing to map and monitor ongoing engagement across the system 2) understanding existing relationships and working with trusted leaders and partners to develop relationships and trust where there is none 3) map gaps in engagement to prioritise work with identified communities in the future

C. <u>Building trust and encouraging engagement</u>

It is clear that, in particular for black communities, there a is fractured relationship with engaging with the NHS. Insight has shown that people trust people they know and people that share their experiences, truly listen and those who represent their identities on a cultural and physical level. Engagement fatigue has meant that many in the black community, and potentially other communities, are less likely to engage because their experiences have shown that it does not make a difference. Working differently with local people and communities through approaches such as co-production has clear benefits but also requires a change in culture.

Continuing to build trust with communities to move towards sharing power. SEL ICS will need to demonstrate what difference has been made and be transparent. Sharing power will require internal cultural change and education for staff, local people and communities about a new way of working.

D. Purposeful engagement

Engagement needs to be meaningful and add value – patients and public should have opportunity to input into decision-making and solve problems at the earliest stage. It is important that people are engaged about things they can genuinely change.

Understanding what local people and communities can genuinely change within the ICS will be important, both in relation to the way it communicates and engages but also the content of that engagement.

E. Avoiding duplication

Existing engagement outlines recommendations, actions and pledges to be taken at organisational and system level.

Understanding engagement priorities for all organisations within the SEL system will support in optimising planning and support in having one conversation with communities.

Appendix 1: Insights at a glance

Research/ insight	Date engagement occurred	Geographical reach	Numbers engaged	Specific communities targeted	Methodology	Topic/ purpose
Joint Programme for Patient, Carer and Public Involvement in COVID Recovery: Attitudes and behaviours telephone survey, ***Guy's and St Thomas' Charity, together with King's College Hospital Charity***	May 2021	Pan- London	1501	Targeted sample of those using any of the following services at Guy's and St. Thomas NHS Foundation Trust (including Evelina London Children's Hospital the Royal Brompton and Harefield Hospitals), or Kings College Hospital NHS Foundation Trust between November 2019 and May 2021: • A&E/ Urgent care • Inpatients • Outpatients • Community services	Telephone survey	To understand patient, carer and public attitudes and behaviours in relation to accessing care and services during the pandemic.
Co-producing personalised care for people who have had Covid-19 and their carers in North Lewisham, **Urban Dandelion CIC**	2021	Lewisham	20 people with lived experience	Minority ethnic communities and communities with multiple social injustices	Quantitative analysis of population health data series of virtual and co-production workshops	Co-producing personalised care for people who have had Covid-19 and their carers in North Lewisham

Research/ insight	Date engagement occurred	Geographical reach	Numbers engaged	Specific communities targeted	Methodology	Topic/ purpose
South London Listens, ***South London and Maudsley, South West London and St Georges, and Oxleas***	Ongoing since June 2020	South London	Over 6000	Mental health service users (three mental health Trusts in south London (South London and Maudsley, South West London and St Georges, and Oxleas)	3 virtual summits, and a Community Campaign (1:1 conversations, focus groups and survey)	Preventing a mental ill-health crisis as a direct result of the impact of the Covid-19 pandemic
Reviewing and improving the use of Personal Health Budgets (PHBs) in south east London, ***Disability Advice Service Lambeth: Co production group***	September 2020 – March 2021	Lambeth and Southwark	15	People with experience of using PHBs or Direct Payments and accessing health and care services, including mental health services.	6 co-production meetings, survey and case studies	Understanding the aim of Personal Health Budgets (PHBs) in relation to the NHS Long Term Plan and recommendations for a way to expand PHBs across the six boroughs of South East London
Addressing Health Inequalities and Vaccine confidence across South East London, ***AT Beacon Project***	2021	South East London (Lambeth, Southwark and Lewisham)	64 (+ more)	African/ Caribbean communities	Established weekly Health Hub at St Mark's Church Kennington, twice weekly health hub at St John's Church, Angell Town Community outreach – vaccine Q&As, workshops and leafleting	Addressing health inequalities and vaccine confidence across South East London

Research/ insight	Date engagement occurred	Geographical reach	Numbers engaged	Specific communities targeted	Methodology	Topic/ purpose
Moments to Movement, ***Centric***	2021	N/A	N/A	Minority ethnic communities and communities with multiple social injustices	Community outreach by researchers with lived experience	Community research and fatigue
COVID-19 lived experience research insights into vaccine hesitancy, ***The Social Innovation Partnership***	2020	Lambeth and Southwark	50	Have pre-existing health issues, who are at higher-than-average health risk, but below the threshold for shielding • Are part of single parent families with kids at home • Are working outside the home on low wages, have lost work, are on reduced hours or are working zero-hour contracts • Are in other precarious economic situations: self-employed (creatives, etc.), people let go prior to government cut-off who can't access support, are falling through benefits net / outside the scope of government policies / 'no recourse to public funds'	Interviews	COVID-19 lived experience research insights into vaccine hesitancy

Research/ insight	Date engagement occurred	Geographical reach	Numbers engaged	Specific communities targeted	Methodology	Topic/ purpose
				• Two-parent families who are economically vulnerable • Individuals who have caring responsibilities other than for their children and who are economically vulnerable		
Vaccine Discovery Insights, ***Rooted by design***	2020	SEL wide	150	Black communities	Depth conversations	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**,** ***The Social Innovation Partnership***	June 2021	Lambeth, Southwark and Lewisham	115	Diverse working age black and minority communities (a spread across all three boroughs, a range of ages, ethnicities and there was a good balance split between male and female participants)	Semi-structured interviews	Medical scepticism, distrust and disaffection among diverse black and minority communities in London

Research/ insight	Date engagement occurred	Geographical reach	Numbers engaged	Specific communities targeted	Methodology	Topic/ purpose
Vaccine knowledge: Thoughts, perspectives and recommendations from young Black people in Southwark & Lambeth, ***Comuzi***	*2021*	Lambeth and Southwark	20	Young black people aged 18-35 (efforts made to ensure a diverse mix. Sampling included a mix of: genders, geographies, ages, incomes, religious views and attitudes towards the subject matter, those who had had and not had COVID)	1:1 depth interviews and two co-design workshops	COVID-19 Vaccine knowledge (part of a wider programme to create equitable access to trusted information about the vaccine)
Covid 19 Vaccination Take Up Survey: Early Years & Childcare & Public Health, ***Royal Borough of Greenwich***	2021	Greenwich	186	Staff working in early years settings	Survey	To provide a picture of vaccine hesitancy or concerns and take up in the childcare sector to inform data and intelligence led actions and targeted support by Public Health and Early Years & Childcare Service
Primary care access during the COVID-19 pandemic (Bromley), ***NHS South East London Clinical Commissioning Group***	2020	Bromley	1311	Bromley patients accessing primary care	Survey and telephone interviews	Understanding impacting on physical and mental health, experiences of access to primary care services and understanding what elements of the new ways of working patients would like to keep, what other services patients

Research/ insight	Date engagement occurred	Geographical reach	Numbers engaged	Specific communities targeted	Methodology	Topic/ purpose
						would like to see and how primary and community care could be more joined up
Youth engagement findings report, ***RevolYOUtion London***	2021	Greenwich	230	Young people aged 17-25, those engaged broadly reflected the makeup of the borough as reflected in ONS data	Semi-structured interviews and focus groups	How young people can be better supported during the COVID-19 pandemic by the local council