



# UCLH national service codesign: Groundswell's engagement with people with lived experience of homelessness

## Introduction

Groundswell have been commissioned by University College London Hospital (UCLH) on behalf of the UK Health Security Agency (UKHSA) to undertake engagement with people who have lived experience of homelessness to contribute to the co-design of a national service model focussed on preventing, treating and eliminating infectious diseases and other public health infections in inclusion health populations.

This report was developed through funding from UKHSA via a UCLH commission. This report does not necessarily reflect the views of UKHSA or UCLH.

## Who are Groundswell?

[Groundswell](#) began in 1996. Our focus was to enable people with experience of homelessness to have a direct voice in influencing services and policy. Groundswell's vision is of an equal and inclusive society, where the solutions to homelessness come from the experiences of people who have been homeless. We believe that lived experience of homelessness and using support services brings unique insight that creates change. Everyone on our volunteer team has experienced homeless, over half our staff too.

[#HealthNow](#) is a national partnership led by Groundswell with the aim of reducing health inequalities for people experiencing homelessness using peer<sup>1</sup>-led approaches. Through the #HealthNow campaign we have established the #HealthNow Peer Network, a network of peers who are volunteering at organisations across England who are passionate about tackling homeless health inequality, all with personal experience of homelessness. The purpose of the network is to: share experiences; learn from one another; promote opportunities to have their voices heard and participate in activities that promote positive change for people experiencing homelessness.

## Our approach

### Steering Group

To ensure our approach to this project was fully co-designed, we recruited a steering group of 7 members of the #HealthNow Peer Network to support the development and delivery of the project plan. In the first steering group meeting we introduced the project, developed a

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<sup>1</sup> At Groundswell we use the term 'Peer' to describe all of our work and roles that are delivered by people with lived experience of homelessness. In this report we use both 'peer' and 'lived experience' to refer to a person with personal experience of homelessness.



group agreement, established milestones, agreed an approach to completing the work and agreed participant incentive process.

To ensure the steering group members were fully supported to participate, we provided additional support such as phone credit. We also invited an Inclusion Health and Infectious Disease expert to meet with the group to help them to understand more about the barriers people face accessing preventative care and treatment and why they are disproportionately impacted by infectious diseases. 3 of the 4 workshops we held were designed and facilitated by members of the steering group. The steering group co-designed the illustrations to visually represent the service they would like to see, co-developed the recommendations, and provided feedback on the report.

### Workshops

To ensure diverse representation in workshops we utilised existing networks that Groundswell are connected to, including:

- Groundswell frontline health staff and volunteers
- The national #HealthNow Peer Network
- The London Participation Network, people with personal experience of homelessness who are connected to organisations across London

We conducted 1 baseline workshop to understand what people understood about infectious diseases, why people from inclusion health groups are particularly at risk and what barriers they may face accessing preventative care and treatment. We discussed what solutions could work and examined the pros and cons of these.

We then conducted 3 workshops that focussed on healthcare delivery outside of traditional settings, the pros and cons of different models, the services that could be offered, where delivery models should go to reach people and how people with lived experience could be involved. The workshop with Groundswell frontline staff and volunteers further explored the role of lived experience in healthcare delivery. We ensured there was time in each workshop for participants to feedback on anything else that should be considered. Notes were recorded on Miro boards for the online workshops and flipchart paper for the face-to-face workshop. Notes were reviewed for accuracy at the end of each session.

In total, we spoke to 51 people across the steering group and workshops.

### Site visit

2 of the steering group members, along with Groundswell's Peer Coordinator, conducted a site visit to UCLH and spent the day with the Find and Treat team, enabling them to see firsthand a model of good practice in mobile healthcare delivery. They asked questions and took pictures and were able to feedback to the other steering group members to help inform the co-design approach.

## What we heard

### Understanding of infectious diseases

The purpose of the baseline workshop was to gauge understanding within the network of infectious diseases. We discussed: definition, examples, and why people experiencing homelessness may be more at risk of contracting infectious diseases.

As all 13 participants at this workshop have experience of the topics of homeless health and health inequalities, the knowledge level in the group was high. When discussing what we mean by infectious diseases the group quickly identified that they felt this was a disease you can catch off another person and that can also be spread between animals and people, using covid as an example of this. We provided the NHS definition<sup>2</sup> of infectious diseases to the group and asked them to list as many examples as they could think of that they felt would be classified as an infectious disease (fig. 1).

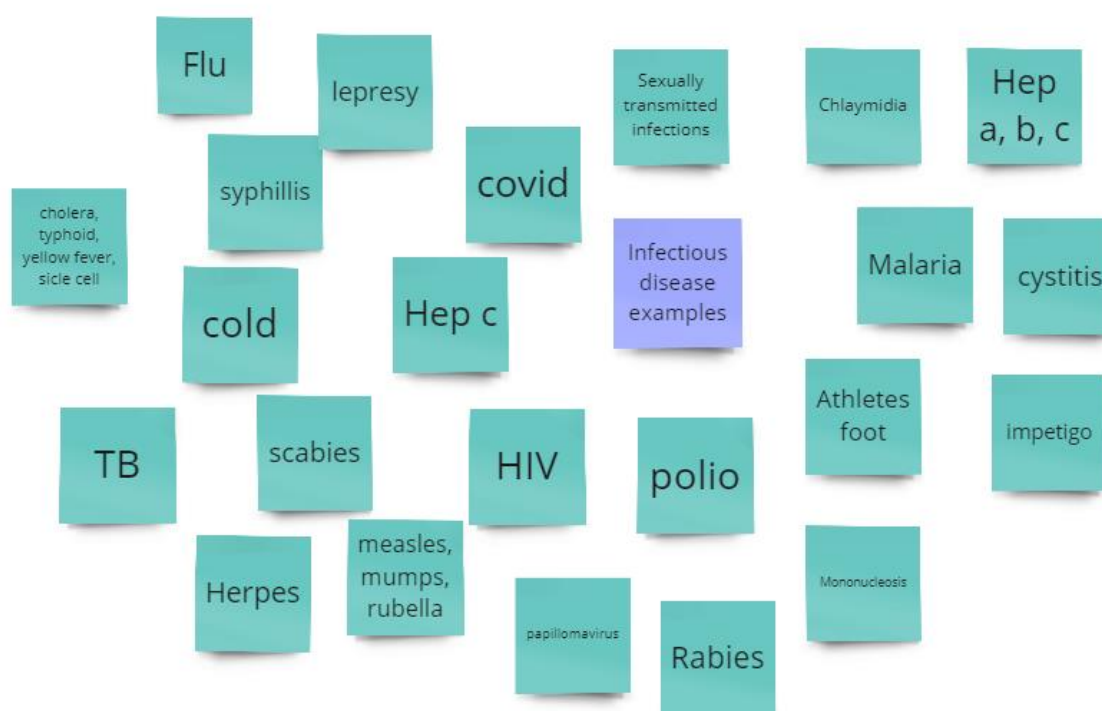


Fig. 1 Infectious disease examples

Many of the reasons we discussed as to why people experiencing homelessness may be more at risk of contracting infectious diseases were directly related to the situation of being homeless:

<sup>2</sup> <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/infectious-diseases/#:~:text=Infectious%20diseases%20are%20caused%20by,from%20one%20person%20to%20another.>

- **Where people were sleeping:** the group acknowledged that when you are experiencing homelessness and living in a night shelter or a hostel, you are often sharing spaces with many other people including while sleeping which can increase the risk of being exposed to respiratory infectious diseases. They also identified that this can be a risk if people are rough sleeping using a tent shared with other people. They identified that whether in accommodation or on the street, it is common to share bedding and clothing which can increase the risk of contracting and spreading infectious skin conditions.
- **Unhygienic settings:** the conditions of some accommodation settings were identified as a risk with poor access to showers, clean cooking facilities and unsanitary conditions. This was particularly recognised for those people who were rough sleeping or squatting where in addition to not having access to fresh, clean water for washing and drinking also have limited access to toilets.
- **Access to healthcare & poor health:** as outlined in the barriers to accessing healthcare section of this report, people experiencing homelessness face significant challenges accessing healthcare. We discussed the impact of this on people receiving good quality information relating to infectious diseases and why people can rely on information from peers which isn't always accurate. This was discussed in relation to conspiracy theories that circulated during covid and how people experiencing homelessness frequently believed these. Barriers to accessing healthcare also mean people may not be up to date with vaccines which can increase infection rates. Lack of access to healthcare and the health issues associated with being homeless may mean people have weakened immunity and are more likely to contract infections. Their general baseline of feeling unwell may impact the likelihood that they will identify symptoms of infectious diseases and seek timely treatment.
- **Limited access to health protection equipment:** the group discussed some of the factors that could increase risk that are correlated with homelessness, such as sex work and intravenous drug use. If people are not able to engage with services or services aren't available, then this can result in unsafe practices such as sharing equipment or unprotected sex.

*“Sharing bedding and clothing or living in close proximity to one another, I met a family living under a bridge and I imagine of one of them got ill the whole family would have got ill.”*

### Barriers accessing healthcare

We asked all participants what they felt the barriers were that could impact whether someone experiencing homelessness could access prevention, diagnosis and treatment healthcare services for infectious diseases. Their responses can broadly be split into the 3 categories commonly used by Groundswell when talking about healthcare barriers: personal barriers are those that are directly linked to the individual; practical barriers are those that prevent someone from engaging with healthcare; systemic barriers are those that are created by the system.

- **Personal:** mental health, experience of trauma and feelings of self-worth were frequently mentioned as barriers that people can face accessing healthcare as well as fear and anxiety faced by people when they feel that something might be wrong. This can be exacerbated by having to access clinical settings where you feel that people are looking down on you because you are homeless. Perceived and actual stigma and discrimination because of being homeless or having an infectious disease, both from clinicians and other people accessing the service, was regularly cited as a barrier which can lead to a lack of trust in health systems. People's individual beliefs, which can be upheld by lack of access to information, may also create a barrier to accessing support.
- **Practical:** participants recognised that access to specialist services, such as infectious disease provision, is often located in different settings to where people generally access healthcare. This can create barriers in the time and cost it takes to travel to appointments. Also, for people experiencing homelessness who have no recourse to public funds the fear of the costs associated with treatment could also be a barrier. People may not know where to go or how to access the service. Much of the conversation focussed around competing needs that take priority over health when you're experiencing homelessness such as seeking accommodation and food.
- **Systemic:** barriers to GP registration and access for people experiencing homelessness and the attitudes of reception staff were identified as one of the biggest barriers for people accessing healthcare services. Participants felt that there is a lack of understanding amongst healthcare workers of what it means to be homeless. This was particularly mentioned in reference to the move towards digital and remote healthcare access and how people experiencing homelessness may not have the technology, skills or resources to access care in this way, which as well as being a practical barrier, also shows how pathways into services are not designed for people experiencing homelessness and other marginalised groups.

*"It's like homelessness gets in the way of your health when you've got so many other things going on."*

## Health priorities

In addition to discussing infectious diseases, we also asked workshop participants about the health issues that they felt were a priority for people experiencing homelessness (fig. 2).

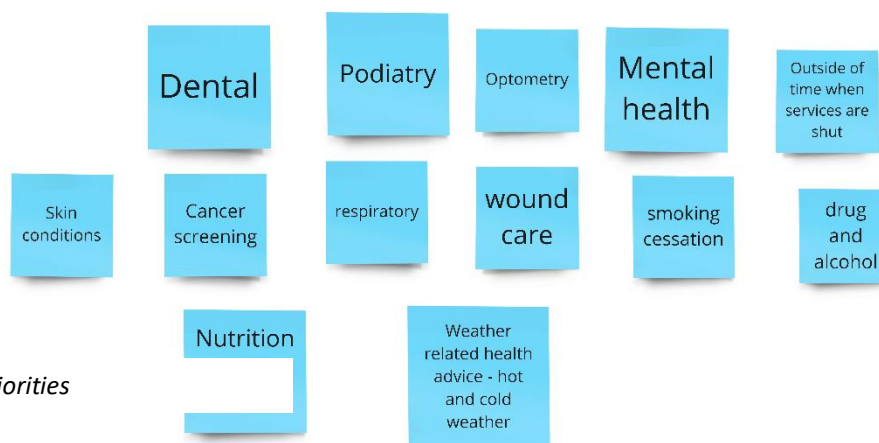


Fig. 2 Health priorities

### What are the solutions?

Following on from the discussions around barriers we asked participants in all workshops what approaches may work best for ensuring people with lived experience of homelessness are able to access preventative, diagnostic and treatment services for infectious diseases. Overwhelmingly, we heard about the benefits of delivering care outside of traditional clinical settings by services established to support the specific needs of people experiencing homelessness, to supplement the delivery in mainstream services. Therefore, much of the co-design work we conducted focussed on the potential benefits and challenges of delivering care using a mobile and outreach approach. Members of the steering group also undertook a site visit to the UCLH Find and Treat team to inform the development of an outreach model.

Given the nature of the work Groundswell and the #HealthNow partnership do, we also explored the role people with lived experience can play in designing and delivering healthcare. Many of the participants are already engaged in volunteer or employment roles, working to deliver healthcare with people experiencing homelessness, so were able to share their unique perspectives on how this can work well in practice.

In addition to designing specialist healthcare services for people experiencing homelessness, we also discussed what needs to change in mainstream healthcare services to better support access and engagement for people experiencing homelessness.

#### Mobile healthcare

As part of the co-design sessions, we discussed the different models of delivering outreach healthcare services to people experiencing homelessness. This was based on models that participants had seen or experienced and known models that exist around the world, specifically the United States, Oslo, and Copenhagen<sup>3</sup>. This led to discussions on the pros

<sup>3</sup> Based on Groundswell's Participation and Progression Director, Rachel Brennan, Churchill Fellowship research: <https://www.churchillfellowship.org/ideas-experts/ideas-library/homeless-healthcare-the-international-experience/>



and cons of individuals delivering healthcare or the use of vehicles for street medicine teams to deliver healthcare to people experiencing homelessness.

Overwhelmingly, it was felt that a model should have a combination of both: a vehicle or vehicles, preferable a clinical van with at least 2 clinical rooms and a multi-disciplinary team of people who can deliver care both on the vehicle, but also extend care on to the streets and in homeless settings such as hostels and daycentres.

Pros:

- **Improve timely access to healthcare:** participants strongly felt that delivering care in this way removes significant barriers to accessing care. This would mean that people are able to diagnose issues early and receive treatment quickly which can improve the outcome for the patient.
- **Link into mainstream services:** a mobile health service could be a gateway into other services. This could be through building trust between the patient and the health service or practically by supporting with GP registration, referrals, and appointments.
- **Compassionate and empathetic healthcare:** by actively seeking to engage with people experiencing homelessness and wanting to deliver specialist healthcare, participants felt that the service would deliver healthcare with compassion, empathy and a real understanding of the needs of the people they are working with.
- **Trust:** compassion, empathy, and understanding would support people to build a rapport and trust with healthcare providers, which is critical for delivering care to marginalised populations who often feel like they have been let down by systems.
- **Continuity of care:** it was acknowledged that mobile healthcare delivered by a consistent team could provide continuity of care in a way that is not possible in mainstream services. This can also support people to develop trust with healthcare providers and can prevent people from retelling their story.
- **Flexible access:** a big positive of mobile care identified by participants was that people wouldn't need to book or attend specific appointments. Participants also felt it would be unlikely that they would be limited to a 10-minute appointment.
- **Reduce anxiety:** it was widely discussed that going into a clinical setting, especially when you are experiencing homelessness, can be really daunting and anxiety inducing. Particularly if you fear you won't be treated well. Delivering care where people feel comfortable and safe could dramatically reduce this and lead to a better experience where you can listen and take in what is being said to you.
- **Positive first engagement with services:** care that is delivered somewhere you feel comfortable, with compassion and empathy can really improve the first contact with a health service. Participants felt this would strongly benefit from having clinicians that could go into services such as daycentres and accommodation provision, or even on the street so that the first meeting is less intimidating than going onto a clinical vehicle.
- **Removes financial and time barriers:** one of the greatest strengths of delivering care in this way is that it completely removes the barriers of time and cost to travel to appointments.
- **Greater reach:** with a multi-disciplinary healthcare team who can deliver care on and off the vehicle, the geographical reach would be greater and can improve engagement with the most marginalised populations.

- **Reduce cost and pressure on mainstream services:** it was felt that this would greatly reduce the amount of did not attend (DNA) appointments and the instances of people experiencing homelessness accessing urgent and emergency care. Additionally, the ability to deliver preventative healthcare and early diagnosis and treatment would have long-term cost savings for the NHS.

*“When people were going out to hostels in covid to deliver health they were really connecting with people when they go where they live, people are much more relaxed and so much able to listen. If you take them out of the formal setting you are much better able to listen and that’s a really important part of healthcare.”*

*“Obviously within healthcare the 2 fundamental or critical factors in helping a patient is preceded by early intervention and early diagnosis. So, if a person is out there and not in touch mobile care can be critical in identifying a problem when it is much smaller and more manageable.”*

*“When you go into a formal clinical setting everyone is dressed well, when you are homeless you are not at your best, not looking or feeling your best so it can be really daunting going into that setting and you can be thinking are you going to judge me, how are you going to treat me and in some cases the staff are not very nice too. Outreach services are where you feel comfortable, and you don’t have to worry about this.”*

#### Cons:

- **Privacy:** lack of privacy, even with use of a vehicle, was cited as a significant challenge for delivering care. Particularly as there is nowhere safe to wait and people waiting to access services would be very visible.
- **Stigma:** if the service was well known as a service for people experiencing homelessness or an infectious disease service then this could increase stigma, which could act as a barrier for people accessing care. Participants felt that providing multiple health services in addition to infectious disease service could counterbalance this.
- **Limitations to healthcare provision:** although this is a great way to provide a range of care to people experiencing homelessness, participants acknowledged that there would still be limitations in what could be provided. It was felt that this should form part of the solution and would need to be delivered alongside improvements to access and experience of mainstream health services.
- **Safety and security:** some concern was noted regarding the vulnerability of clinicians delivering healthcare in settings where their personal safety could be compromised. The presence of prescriptions, medication and medical equipment could mean the service is



targeted for theft. Concern was also raised about patients accessing the service and how conflict and safeguarding would be managed.

- **Can replace mainstream services:** people should be offered a choice in where they can access healthcare and be able to access care that is most appropriate to their needs. There is a risk that all people experiencing homelessness would be referred to this service because they are homeless and could disincentivise mainstream services to do better. This could also increase demand on the service and reduce the ability to deliver care to those most in need.
- **Manage demand:** if there was high demand for the service, appointments were longer and care delivered in a person-centred way, this could lead to long queues and waiting times. This could lead to conflict that would need to be carefully managed to protect staff and patients. It could also dissuade people from using the service.
- **Cost:** participants acknowledged that if they could build the ideal outreach service for people experiencing homelessness there would be huge costs associated with this for both clinical and medical equipment, costs and upkeep of a clinical van and staff costs. We also discussed that to make the service cost-effective, geographical location would need to be considered. For example, areas with lower populations or more rural communities might need one service to cover a much larger area whereas high urban areas with a greater population of people experiencing homelessness may need a service just delivering care in that area.
- **Location:** although participants identified an extensive list of potential locations where the service could go, they acknowledged that there may be barriers with permissions, parking, and other practicalities.
- **Hygiene:** how to constantly keep equipment and clinical areas clean and sanitised while on the move and delivering care to high numbers of people was a concern frequently raised by participants.
- **Perceptions of the general public:** proposals to deliver care directly to people experiencing homelessness in the community could be met with resistance from members of the general public. Particularly if it is felt that this would bring people who they deem to be undesirable into their neighbourhoods.

*“Important to give people care where they are and how they are, but it can lead to a culture where people are detached from mainstream services like GPs and people might not gain confidence to re-engage with other services. Need to make sure people don’t become over reliant on this and disenfranchise themselves for other health services.”*

*“People could be vulnerable or attract stigma if this is a van or health service known for homeless people or sex workers or people with blood borne viruses.”*

As part of the workshops, we asked participants what services they felt should be offered as part of mobile healthcare delivery and where the service should go. In all of the workshops participants initially suggested a huge range of services that covered both health and other

services to meet the needs of people experiencing homelessness that they felt should be a priority. However, further exploration of this led participants to identify that trying to do too many things could prevent the service from meeting the overarching aim of supporting access and engagement with services that can support prevention, diagnosis, and treatment of infectious diseases. Overwhelmingly, participants felt that a range of health services should be offered, as if a service focussed solely on infectious diseases this could result in patients having unmet needs for other health conditions. The service should be able to provide holistic healthcare and have direct links into other services to ensure all health needs can be met.

*“Can’t just treat the infection or symptom. You need to think about everything around the person.”*

Services that participants felt should be prioritised for delivery as part of the outreach model in addition to infectious diseases included:

- GP and support with GP registration
- Nurse and tissue viability
- Mental health assessment
- Mental health treatment, including counselling
- Needle exchange
- Cancer screening
- Respiratory and cardiovascular
- Sexual health advice, treatment, and prevention
- Phlebotomy
- Smoking cessation
- Onward referrals to health services
- Active signposting to other services
- Interpretation and translation services

Other services that participants felt could form part of the service or could be provided through partnerships and co-delivery with other services included:

- Dental
- Optometry
- Podiatry
- Veterinary services
- Clothing
- Food, including food bank referrals
- Alternative therapies
- Accommodation referrals
- Digital support
- Device charging

When we asked people where the service should be delivered, the consensus was that the benefit of this model is that it can go wherever it needs to be. The priority was for locations where people already are, including accommodation settings and where other services for people experiencing homelessness are provided such as soup kitchens and day centres. Participants felt strongly that it is not just location that has to be considered but also time of day and that there are additional benefits for delivering care outside of mainstream service opening hours (fig. 3).



Fig. 3 Where mobile healthcare should be delivered.

As part of the co-design process, representatives from the steering group undertook a site visit to the UCLH Find and Treat team. The purpose of the visit was to see firsthand how an outreach service can work in practice to meet the needs of people experiencing homelessness and from other inclusion health groups. A summary of the peer reflections from the visit are included on the following page.

## UCLH Find and Treat site visit

**Background:** The NHS UCLH Find & Treat Service is designed to meet the needs of vulnerable and excluded members of society. The Find and Treat team operate a Mobile Health Unit, going out to hostels, hotels and Day Centres supporting people to get diagnosed and complete treatment for important public health infections including Tuberculosis, Hepatitis C and more recently COVID-19. Additionally, the Mobile Health Unit provides on-the-spot access to essential immunisations and the team are continuously innovating to outreach additional health opportunities.

As part of their involvement with the UCLH steering group, volunteers with lived experience of homelessness visited the Find and Treat team at the UCLH offices in London to find out more and to get a first-hand glimpse of the service in operation.

**Peer reflections:** After being offered the opportunity for extensive Q&A sessions throughout the visit, our peers were satisfied that the Find and Treat service had a solid understanding of the needs of their target population and were particularly pleased to hear the emphasis on trauma-informed approaches, and an awareness of mental health issues and neurodivergence.

One aspect of the service that greatly impressed our peers throughout their conversations was the value and emphasis placed on lived experience, and there was a clear mutual respect among team members for each other, regardless of roles, experiences, and backgrounds.

The main office for the Find and Treat team was shared with several other organisations including Pathway, and peers felt it apparent that this proximity and shared workspace helped to encourage cross-communication and mutually beneficial interactions, therefore preventing siloed working.

One aspect of the overall approach of the T&T team which really stood out to our peers was the proactive approach taken in communicating with people whose circumstances may have led them to deprioritize healthcare concerns, and it was clear that the team were more than prepared to “go the extra mile” to reach people and to ensure their needs were met.

**Practical delivery:** One of the key components of the Find and Treat service is a vehicle-based Mobile Xray Unit, and additional outreach capacity includes a smaller vehicle, a bike with a trailer, and provision for on-foot delivery.

The vehicle-based options we saw had been specially adapted for the specific needs of the F&T service and have undergone several redesigns during their history to expand and improve their capabilities. The service is eager to innovate and to continue to improve their offer wherever feasible.

The vehicle-based solutions seemed highly modular, and it was clear that a similar approach could be adapted to offer a specialised response to any number of medical concerns. Peers also considered that such a vehicle could also function as a “base of operations” for outreach staff in a given area, in addition to its primary function. The vehicles we saw were well served in terms of technological capabilities, and the onboard IT systems had a connection to the NHS spine and multiple means of remaining online.

The vehicles offered a private space where people might feel more comfortable discussing their health concerns (and an example given by F&T staff regarding prison officers being asked to wait outside resonated particularly well with peers), although there were also reflections that the space might not feel fully private if the vehicle is heavily staffed, due to the confined space.

The NHS branding was seen as a positive, although peers considered that this might not be appropriate in every case, and there was some discussion as to whether magnetic removable signage might be a good approach to take.

The vehicles were designed to be accessible and disability-friendly, which our peers felt was essential, with the inclusion of hydraulic lifts etc.

The vehicles we saw were equipped with active ventilation systems, and the negative pressure environment this created seemed like a sensible and effective approach to counter airborne pathogens. Hygiene was discussed as an important consideration, and while the F&T service vehicles were deep cleaned once a week, our peers wondered if this was sufficient, and whether in a potentially more comfortable and less clinical design, this cleaning frequency may need to be increased.

## Changes to mainstream health services

As previously mentioned, participants strongly agreed that while mobile and outreach services are needed for populations who are often marginalised from mainstream health services, this should complement rather than replace access to mainstream services. Particularly acknowledging that specialist health provision can't meet all the complex health needs of people experiencing homelessness. Therefore, this needs to be delivered alongside a strategy to improve access and engagement with mainstream services. Recommendations to achieve this included:

- **Involving people with lived experience of homelessness:** for mainstream services this included involving people in co-designing solutions to the barriers that exist and in the delivery of solutions. This can include the development and delivery of training and creation of peer roles to support patients to access and engage in services. These will be explored in detail in the next section.
- **Training:** participants recognised that many of the barriers they experience, either directly or with people they are supporting as part of the services provided by Groundswell, could be reduced if all staff had access to good quality training. Participants felt a lot of the focus should be on the person who is the first contact for the service, which was frequently identified as reception staff. In addition to understanding homelessness and barriers people face, participants felt that training needed to focus on building compassion and empathy as this is often lacking. Training should involve people with lived experience and the specialist health services who deliver high quality, compassionate care to people experiencing homelessness, including mobile services.
- **Flexible access:** health services need to have flexible approach to improve access for people experiencing homelessness. This includes considering how they communicate with patients; the use of text messages and letter-based appointments are not always appropriate. People should be offered face-to-face appointments and should have a range of options to book appointments that don't solely rely on digital or remote access. Participants recommended drop-in sessions rather than timed appointments as this could improve engagement and reduce missed or DNA appointments.
- **Collaboration:** participants recognised that to truly be able to support people experiencing homelessness in a holistic way, services all need to work together with the individual. This means health, local authority, housing and VCSE organisations.

*"Can be a lot of learning happening between the teams, the teams in the community can raise awareness and train the other services in the realities people face and these are the solutions available. Giving them insight in a way, that when you're sitting in the GP practice inside that you might not be aware or consider these issues."*

*"Need to have a greater focus on supporting access rather than gatekeeping provision."*

## The role for people with lived experience

Participants across the 4 workshops all agreed that people with lived experience of homelessness should be involved in all aspects of co-design and implementation of a new service. This included being asked similar questions to the ones asked in the workshops we delivered, but that these should be asked to people local to the area where the service will be based who have experience of homelessness. This would ensure that their expert knowledge of the local area, services and systems are considered, which could improve service delivery, ensure better use of resources and result in better health outcomes for people. Many other ways for people to be involved were discussed, including conducting research to influence decision makers and generate evidence for need of a service, and reviewing other models of care to determine what has and hasn't worked previously. Participants also felt that people with experience of homelessness should have a say in deciding who is commissioned to deliver the service and can input to all the implementation stages of the service. It was recognised that all participation should be meaningful, and every effort should be taken to ensure a diverse range of people with different experiences should be included.

*“Every step of the way it’s important to include, there are so many ways you can involve people.”*

When participants were asked how people with lived experience of homelessness could be involved in the delivery of an outreach service, a range of suggestions were made (fig. 4). Many things we heard related to support to engage in the service and support of the patient. This included: the creation of paid and volunteer roles that would promote the service; support people to access the service; and support with any follow up or onward health appointments. It was also felt that peer roles could support people to access and engage with a range of other services that had been identified such as referral into accommodation provision, food bank referrals and support to engage with other healthcare provision. Digital barriers to healthcare were frequently identified by participants, they suggested that with the right training and equipment, peer workers would be able to support people accessing the service to improve their health literacy skills. This could include support to register for a GP; booking appointments; setting up electronic prescribing and ordering prescriptions; finding out about health conditions or services; and registering for NHS services and accessing personal medical records.

Participants felt that people with lived experience should not be limited to providing peer support and that with training and supervision they could deliver healthcare interventions and could move into recognised NHS roles such as Health Care Assistant or Social Prescriber. In addition to dedicated lived experience roles, recruitment of all roles, including clinical, should positively encourage applications from people with a variety of different lived experiences including mental health issues, homelessness, and people with experience of

being a refugee and asylum seeker. This could be supported by providing a positive environment where lived experience is valued, and people are encouraged to develop skills and personal boundaries in discussing their lived experience.



Fig. 4 How people with lived experience of homelessness could be involved in the delivery of a health outreach service

As Groundswell frontline staff and volunteers are directly delivering peer advocacy and peer support to people experiencing homelessness, we utilised their unique insight and experience to explore the reasons why health services should involve people with lived experience in their delivery and also what they might need to consider to do this well.

We approached the question on the benefits of involving people with lived experience of homelessness in the delivery of healthcare services from 3 perspectives: the patient; the service; and the peer worker or volunteer.

- **The patient:** for the patient having someone who is on your side, has faced similar challenges and has come through them can support people to easily develop trusting relationships. People who have a shared history of experiences often have genuine empathy for people and can provide a positive role model that things can get better. They have an innate understanding of what it means to be homeless and have first-hand experience of the systems and the barriers people face. Participants talked about ‘speaking the same language’ as the people they are supporting. In some cases where language was a barrier this can be literal, in other cases they meant translating health jargon and information in a way that the person can relate to, resulting in a better understanding of their health.
- **The service:** from the perspective of the service, involving people with lived experience can improve their service delivery by advising on the best way to deliver care and providing useful feedback on services. They can help the whole team by providing valuable insight on

the reality of the homelessness experience, including experience and impact of trauma, and the barriers people face accessing care. They can support the service to manage the complex needs of patients and support with the management of any conflict that arises between the patient and the service. Person-centred, peer-led support can improve engagement with the service which in turn can improve people's health which ultimately save money and save lives.

- **The lived experience worker or volunteer:** participants spoke passionately about how they feel that they have been able to turn the negative experiences they have had into something positive that can benefit others. Directly supporting people has enabled them to develop confidence in themselves and their own abilities. It has also been credited with giving people a purpose which has been hugely important in their own recovery from homelessness and other forms of disadvantage. The acquisition of new skills and knowledge, combined with practical work experience, has supported people to achieve their progression goals, including moving into employment. Being part of a supportive team and developing positive relationships with others was also identified as one of the benefits of their role.

*"Wonderful sense that all my trauma, scars and wretched mistakes I've made I have learned from, and others can too."*

*"it's a privilege to be there when no one else is."*

*"Volunteering helps me in all sorts of ways. It takes me out my own head, and it gives me peace of mind."*

*"If they can do it, I can do it. I'm living proof that things can get better."*

*"This person gets me, I'm not going to have to over explain myself and everything else."*



We asked participants what they felt were the key things that services proposing involving people with lived experience in their delivery should consider across 3 main areas: recruitment; training; and support.

- **Recruitment:** the main advice was that lived experience is recognised as being more valuable than learned experience, including qualifications and previous work history. This should be reflected in the person specification for the job advert and in the application and interview process. Any role involving people with lived experience should be meaningful and not tokenistic. Job descriptions should clearly outline what the role would involve and why it is important. Consideration should be given to advertisement and promotion of the role. Participants recommended linking in with local services, particularly those with Employment, Education and Training Teams, and advertising in homelessness publications such as The Big Issue or The Pavement.
- **Training:** extensive training should be provided before a person starts delivering in the role, this should include role play based on real life situations to help prepare the person in a safe environment. Ongoing training should be provided and should be based on need. Training that peers identified as useful included: advocacy; managing difficult situations; safeguarding; mental health; digital and IT; understanding addiction; risk assessment and risk management; and vaccine uptake. They stressed that a crucial part of training is shadowing, and that people should only move on from shadowing when they feel comfortable and confident to.
- **Support:** participants discussed a range of support that they currently receive that they felt was really important and that other services considering using peer workers and volunteers should provide. Practical support such as travel expenses for both staff and volunteers are crucial, especially if they need to support patients to attend a range of appointments. It shouldn't be a financial burden for volunteers so any other expenses they may incur should be factored in including food, phone credit and data. People should benefit from a supportive line manager or volunteer manager who would understand personal triggers and how to manage these appropriately. Counselling and access to clinical supervision and/or reflective practice should be offered, recognising that the work can trigger and re-traumatise people. Workers and volunteers should be supported to improve and manage their own health and wellbeing. People should be supported to identify and move towards their own personal development goals. Crucially, lived experience team members should be treated the same as other staff members.



## Homeless Health Peer Advocacy

Groundswell have been delivering Homeless Health Peer Advocacy (HHPA) in London since 2010. This service is delivered by a team of volunteers and paid staff members who all have personal experience of homelessness who are recruited and trained to support people currently experiencing homelessness to address physical and mental health issues and is commissioned by both Local Authorities and NHS bodies. We work to improve people's confidence in using health services and increase their ability to access healthcare independently. In return the programme provides staff and volunteers with: the opportunity to develop skills and practical work experience; coaching to identify progression goals; support to achieve progression goals including overcoming any barriers; a supportive environment which includes access to clinical supervision; and all expenses related to the role.

Clients referred into the programme can access support to book and attend medical appointments; understand information about health and make choices about next steps; navigate complex healthcare systems; support clients to find out information about health and health services; support to pay for travel to appointments.

Initially established in Westminster, Groundswell now delivers HHPA in 14 London boroughs and has supported partner organisations to set up their own services based on HHPA in 10 other locations in the UK and Ireland. In a year HHPA London supports 650 Clients attend 4,500 appointments. The average appointment is 2.5 hours meaning our frontline team offer about 11,250 hours of one-to-one support a year. We plan and run 368 Health Promotion sessions a year attended by 2,500 people. Our Health Promotion team also work with our Communications Team to produce up to date health resources aimed at people experiencing homelessness and staff supporting them.

### Case study:

Andy\* a 41-year-old man was referred to Groundswell in 2021, at the time he was residing in a hostel. Andy had complex mental health needs, PTSD, anxiety disorder; Hepatitis C; and was regularly smoking cannabis. He was also on a daily methadone script. Andy was getting treatment for Hepatitis C from a local service but needed support addressing his other health needs.

Adrian, a Care Navigator at Groundswell, met with Andy at his hostel to explain his role and the support he could offer. Working together they identified that Andy struggles to ask for help as he lacked confidence approaching GPs and Consultants. He felt let down by services that he found to be unsympathetic and unsupportive and whom he believed were not taking his mental health seriously. This left him deflated and he found himself missing vital appointments. Andy also had difficulty walking long distances which was a barrier for attending appointments. Adrian worked with Andy to remove these barriers. He was able to book and attend appointments with Andy and supporting to arrange and pay for travel so that Andy didn't need to walk to appointments. Adrian was also able to advocate for Andy in appointments so that he could express his wishes in a clear and confident manner. With Adrian's support, Andy had a mental health assessment and was provided with a treatment plan. Adrian supported Andy to engage with appointments and kept in contact with him in between appointments to discuss how he felt he was progressing with his health to see if any additional support was required. In addition to accessing mental health services, Andy started working towards achieving and sustaining his own accommodation and drastically reduced his cannabis use.

***"Before I worked with Adrian and Groundswell, I was anxious, tired and feeling worthless. I couldn't keep vital appointments or in some cases I couldn't get appointments. I am a different person, I have started to lose weight, my mental health is in a better place than it has been for a long time and I am now making plans to move on in to my own place"***

*\*Name has been changed*

## Recommendations:

1. A health outreach model is the recommended delivery model to supplement mainstream services in the delivery of infectious disease healthcare to people experiencing homelessness, particularly for initial contact and engagement with healthcare services. This could significantly support people to overcome the personal, practical, and systemic barriers they face accessing healthcare.
2. Care should be delivered using a combination of vehicles (such as clinical van, bike, or car) and practitioners equipped with mobile healthcare packs so that care can be extended beyond the vehicle into homelessness settings and on the street where appropriate.
3. Teams should be multi-disciplinary and cater for a range of health needs in addition to infectious diseases. Different health services could utilise the clinical vehicle using a rota system to maximise use. Delivery of services should be flexible and adaptable delivered based on the individual needs of the population.
4. Services should promote employment and volunteering opportunities for people with lived experience of homelessness. In addition to creating lived experience roles the service should encourage recruitment at all levels of people with experience of homelessness and other forms of disadvantage and support people to talk about their lived experience in a positive way.
5. Services should meet people where they feel comfortable and link in to existing services including daycentres, food banks and accommodation provision as well as in areas where people not engaged with services may be or services are limited.
6. Services should be delivered at a range of times, including times when mainstream services are shut.
7. The healthcare service should proactively work with services that help people experiencing homelessness meet their other needs. This can be through active signposting, referral mechanisms or co-location of services.
8. The service should provide proportionate care based on population size. For example, while one service might be needed to cover one ICS footprint, other ICS' could jointly finance and provide access to a service over a wider geographical area.
9. This service should complement and not replace access to mainstream services for people experiencing homelessness and should have formal processes in place to support referral and engagement into mainstream services. The service should also support improvements in mainstream health services.
10. Wherever the service would be located there should be meaningful engagement and participation with local people who have experience of homelessness to inform the design, commissioning, implementation, and delivery of services to ensure services are tailored to local needs.

Thank you for ensuring people who have personal experience of homelessness have had the opportunity to contribute in a meaningful way to the development of this project.

The delivery of this project would not have been possible without the dedication, commitment, and contribution of the steering group members. Groundswell would like to acknowledge and profoundly thank Fatima, James, Joanne, Kiran, Rani, Sahar and Tony.

