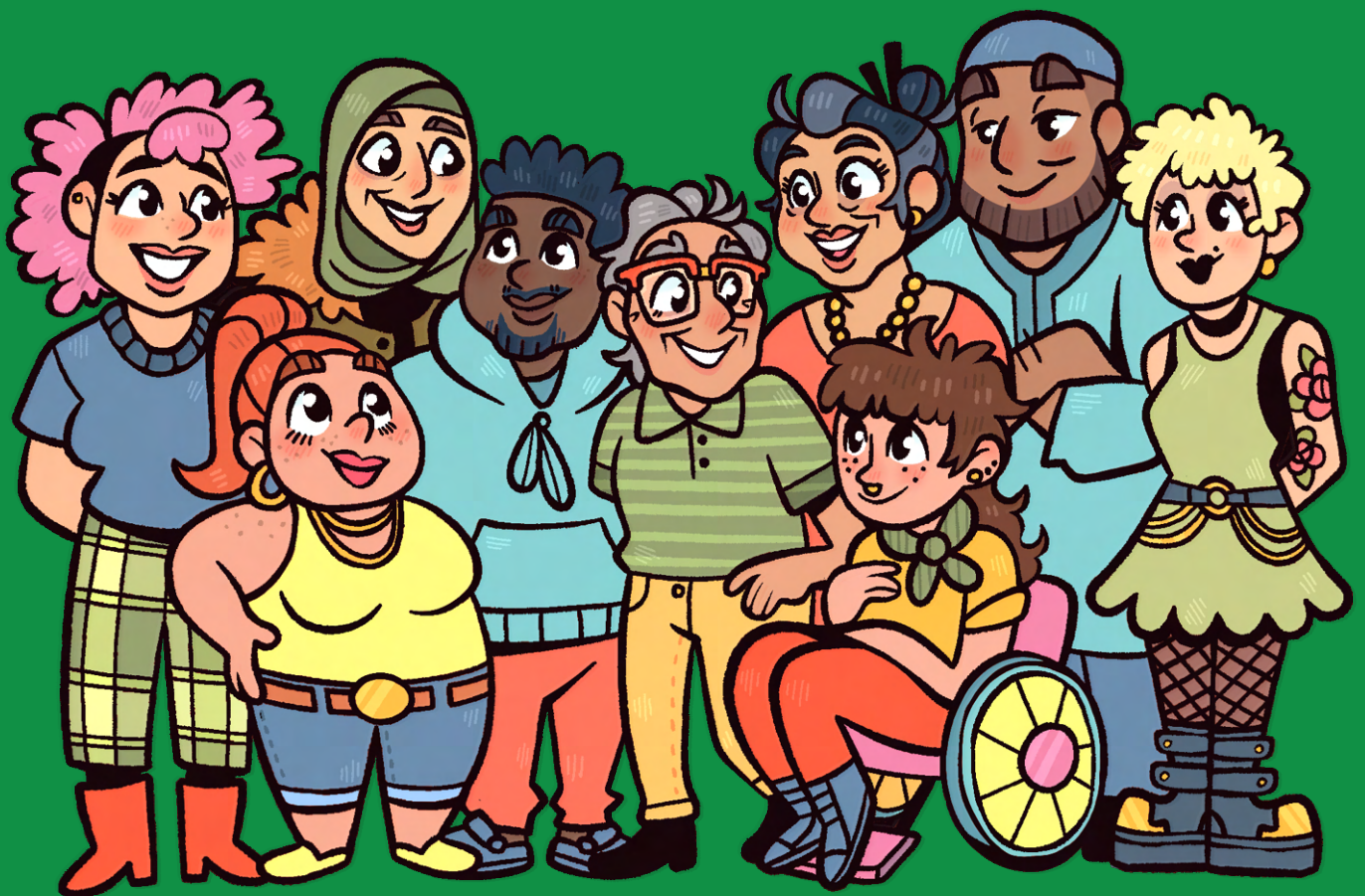


Healthy Communities Together Leads: Adaptive Actions



HCT

Healthy Communities Together

Introduction

Healthy Communities Together (HCT) Leeds works to make health services better for everyone, especially people who are often ignored or treated unfairly. We bring together marginalised communities, the NHS, and local councils to work as a team.

Who We Help:

- Gypsies and Travellers
- Sex Workers
- Refugees and Asylum seekers
- Trans and Non-Binary people

Adaptive Action is a methodology we like to use, offering a structured yet flexible approach to addressing complex issues in uncertain environments. We use Adaptive Action to bring together Experts by Lived Experience as well as those who are in positions of power, to gain a shared understanding of what is happening and move towards action. Through Adaptive Action we can create a space where people can learn from their experiences and work together to influence health systems toward more coherence and greater sustainability.

Adaptive Action follows three key questions:

- 1. What?** – Challenges assumptions and establishes a clear understanding of the current situation.
- 2. So What?** – Encourages creative analysis and meaning-making.
- 3. Now What?** – Guides actionable steps, even in uncertain circumstances.

HCT use of Adaptive Action creates a reflective cycle that continuously adapts and evolves in response to emerging insights.

The Origins of HCT's Adaptive Actions (AA)

The Healthy Communities Together (HCT) partnership introduced Adaptive Actions (AAs) during the COVID-19 pandemic as a new way to work through the complex challenges of health inequalities. Traditional consultation methods, like surveys, public meetings, and interviews, have repeatedly failed to bring real change. The partnership wanted something different that would actually shift power and surface the realities.

Adaptive Actions offered an alternative. They created space for honest reflection, brought professionals together in new ways, and encouraged people to speak from personal experience. Most importantly, Adaptive Actions allowed difficult questions about power, equity, and complexity to be surfaced, rather than ignored or simplified.

The partnership chose Adaptive Actions because:

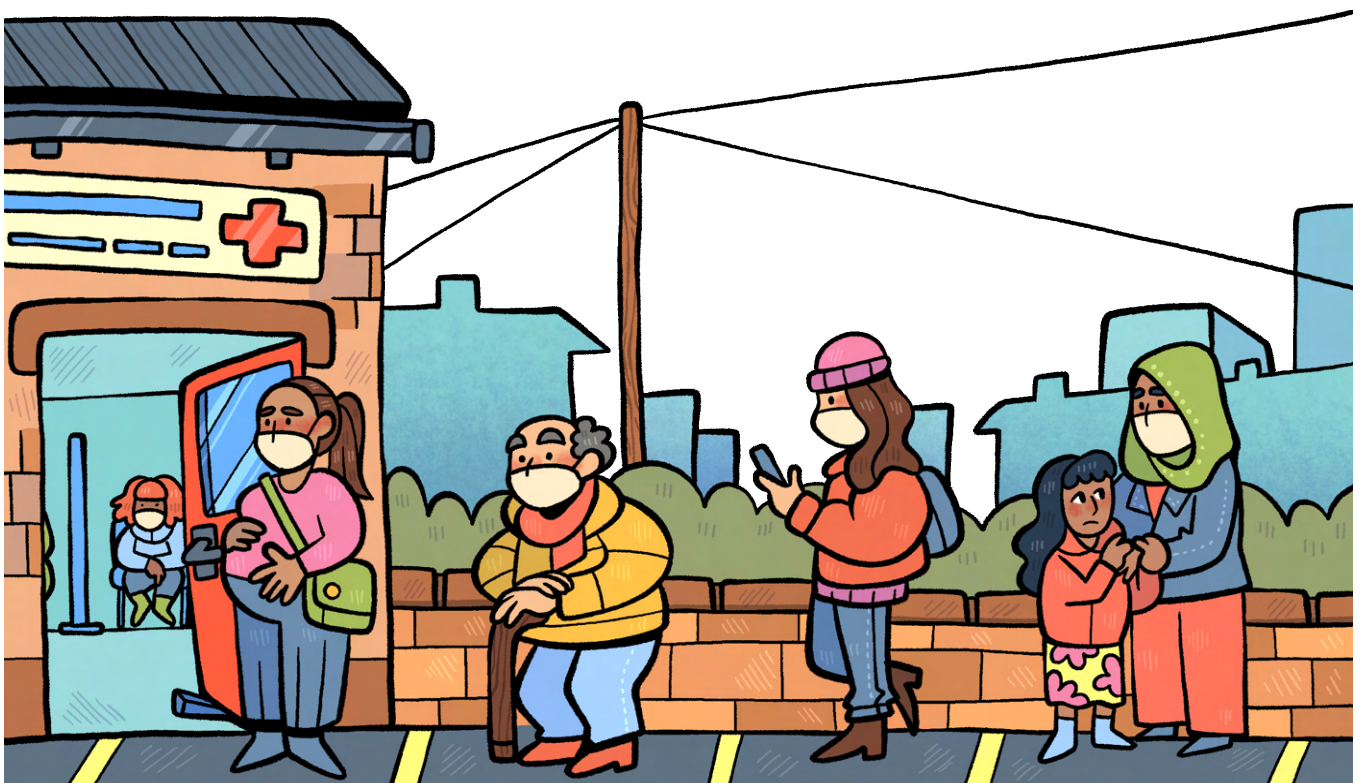
- Traditional methods often led to the same outcomes with little real impact.
- They needed a way to work together that didn't just redesign services but re-organised around real needs, challenged the lack of inclusion, and allowed for flexibility and learning.
- They wanted more meaningful, relational dialogue—not just formal or tokenistic conversations.
- There was a desire to talk openly about power imbalances in the system.
- Health inequalities are complex, sometimes hidden, and need to be explored without oversimplifying.

Phase 1: Trying something new in a challenging time

Phase 1 began during the height of the COVID-19 pandemic. The HCT partnership worked alongside two external consultants. These consultants led the design and delivery of online Adaptive Actions focused on tackling systemic health inequalities. The sessions brought professionals from different statutory bodies together to think and talk differently.

Focus and delivery in Phase 1

- Adaptive Actions in Phase 1 were consultant-led and designed to test what was possible in a highly constrained context.
- Sessions were attended mostly by statutory sector professionals, including hospital trusts, public health, and local authority teams.
- Community organisations and HCT partners weren't yet fully involved in delivery, but this was recognised as a gap, not a goal.
- All sessions were held online due to COVID-19 restrictions.



Online Adaptive Actions in Phase 1

Session 1 – Health Inequalities Adaptive Action

Aim: To explore root causes of health inequalities in marginalised communities, focusing on trust, data exclusion, and systemic change using Adaptive Action.

Participants: A range of professionals working in mental health advocacy services, community grant-making, and participatory research and data analysis in healthcare, and an external consultant as facilitator.

About: This session was the first application of the Adaptive Action methodology. Whilst the session was successful, at times the facilitator was under-confident and drifted away from strict adherence of the use of the methodology. The Adaptive Action brought together diverse voices to examine how historical and ongoing marginalisation continues to shape health outcomes. Participants explored lived experiences alongside systemic challenges, highlighting that current inequalities are not random or accidental – they are structural.

Key Learning & Insights:

- **Historical mistrust weakens engagement.**

“A lot of these institutions have been built on structures that oppress people.”

- **Culturally competent care builds trust.**

“People need to be able to trust those they’re working with.”

- **Marginalised groups are invisible in data systems.**

“You won’t find transgender people, you won’t find Gypsies and Travellers in the data... because you’re not collecting it.”

- **White privilege masks the reality of racism.**

"Someone said they are shocked and bewildered that racism is still going on to this degree. That is the privilege; to be oblivious 100%. That's what we mean by white privilege."

- **Tokenism must give way to power-sharing.**

"Let's stop just inviting people to lunch and asking them to share trauma. Let's start paying them to lead."

Session 2 – Health Inequalities Adaptive Action

Aim: To explore systemic inequalities through reflection, community insight, and collaboration.

Participants: A group of professionals working across several public health systems, including, 'Health Visiting' and specialist healthcare services, a professional working with a charitable for-profit entity tackling malnutrition and food poverty, and an external consultant as facilitator.

About: This was the first confident application of the Adaptive Action methodology, allowing participants equal time to share lived realities, examine patterns, and identify leverage points for change. Emphasis was placed on embracing uncertainty and taking small, strategic steps towards change.

Key Learnings & Insights:

- **Multiple systems compound exclusion.**

"We had a traveller in hospital back in January when I first started. When we send the outpatient letter to his address, it's redirected to the nurse. This patient is by the roadside, and he's illiterate, so do you think he's going to turn up to his outpatient appointment if we use that letter?"

- **Systemic inequality is often hidden.**

“How can people be treated so badly and also that (treatment) be hidden. Who knows what an extreme health inequality looks like or mean [to these communities]?”

- **Climate change, food insecurity, and digital exclusion disproportionately affect the most vulnerable.**

“The whole agenda around climate change is very much interlinked with inequality, and its impact is going to affect people who are already disadvantaged.”

- **Privilege, bias, and systemic exclusion need conscious challenge.**

“How can you be aware of your white privilege and use that to change the system in a different way? I believe that as you become more aware of things, it changes how you behave.”

- **Stories must be told with care, avoiding harm while building empathy.**

“We don’t know the how, but, but people get moved by real life stories, don’t they? But they’ve got to be built up gently (to share their story) and not overwhelmed, because if they’re not there leading the way, nobody else is going to be there either, are they?”

Session 3 – Health Inequalities Adaptive Action

Aim: To explore persistent health inequalities affecting marginalised communities, challenge structural health service assumptions, and iterate solutions through Adaptive Action.

Participants: An Advisor from BHA Leeds Skyline, a public health professional from Leeds and York Partnership Trust, and an external consultant as facilitator.

About: While framed as an Adaptive Action, this session took a more conversational and exploratory approach, creating space for frontline voices to share lived experiences of health inequality. Focused on relationship-building and long-term dialogue, the session aimed to surface systemic barriers faced by Gypsies and Travellers, Refugees and Asylum Seekers, Sex Workers, and Trans and Non-Binary communities. The emphasis was on listening without defensiveness, de-sanitising the language of inequality, and fostering trust to support meaningful, community-led change.

Key Learnings & Insights:

- **Marginalised communities are diverse, not monolithic.**

“At the end of the day, we are carrying out surveys on communities or people who we make a lot of assumptions about. Sometimes, we also look at communities in general and think they’re homogeneous when they actually need to be broken down into their particular concerns, needs or challenges to accessing health.”

- **Trust is earned and often missing from healthcare systems.**

“For some of these communities, there is a deep, deep mistrust of medical organisations, especially because of how they have been treated in the past... There was a successful vaccination programme for sex workers, and the reason it worked so well was that they had relationships with the third-sector organisation that was running it. They didn’t necessarily trust the medical side. They may have thought, ‘Well, if they’re behind it, maybe we’ll come in.’”

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- **Health system assumptions vs. lived priorities: a persistent mismatch.**

“Some said they were struggling to access services like sexual health clinics where no one was picking up the phone, and they were told only urgent cases would be seen. Some said that during the pandemic, they lost access to contraception they previously got directly, and had to make unwanted changes. By the end, there was a clear sense of disconnect between public health messaging and the reality communities were facing.”

- **Adaptive Action builds capacity for change, not one-off solutions.**

“Adaptive Action is a simple but powerful methodology rooted in complexity theory. It helps groups make sense of challenging issues by asking three core questions: What? So what? Now what? It’s about connecting people, building shared understanding, and taking small, intentional actions, even without certainty about the outcome. You don’t need to be an expert in complexity; you just need to stay curious, stay connected, and keep learning and adjusting together.”

Session 4 – Health Inequalities Adaptive Action

Aim: To surface systemic and cultural barriers to health and explore relational, community-based alternatives.

Participants: An outreach worker from Simon on the Street, a professional working in health policy, a professional representing Freedom for Girls and working in cancer screening, a professional working in the education sector around learning disabilities, and an external consultant as facilitator.

About: This session continued the successful application of Adaptive Action methodology, focusing on lived experiences of marginalisation within the healthcare system. The conversations emphasised the compounding impact of cultural stigma, policy design, austerity, and gender bias and surfaced ideas for more relational, person-centred alternatives.

Key Learnings & Insights:

- **Migrant communities face institutional exclusion.**

“A lot of people that we work with have no recourse to public funds, which is a real difficulty when you’re trying to access healthcare. For example, they’ve got to pay for prescriptions.”

- **Language barriers complicate logistics, dilute emotion and meaning in care**

““There are difficulties with having to use a translator, not only because it might be a difficult conversation, but also because you’re having to share your story with two people rather than just one. And sometimes, the essence of what someone’s trying to say can get lost in translation.”

- **Mental health support remains reactive, pharmacological, and impersonal.**

“Instead of actually processing the trauma and helping deal with that, they (patients) are just given another prescription.”

- **Biased structures may also contribute to health inequality.**

"I keep coming back to this question: what actually creates health inequalities in the day-to-day of social care? Not just in theory, but right here, in our systems, in our work. And I wonder if part of the answer lies in the rules we follow."

Co-production or community-led designs are more effective than consultation.

"We keep treating the symptoms, but it's not sustainable, and it's definitely not cost-effective. The real work needs to be preventative, and that has to be rooted in communities, with communities."

Reflections at the End of Phase 1

- Professionals engaged enthusiastically, showing an appetite for new ways of thinking.
- However, the sessions lacked lived experience input.
- Power dynamics remained mostly unchallenged, as professionals dominated the space.
- Community involvement was minimal, which narrowed the scope and impact of discussions.

By the end of Phase 1, it was clear that the approach needed to evolve. If the partnership was serious about understanding and addressing health inequalities, then the people most affected couldn't remain on the margins. Their insight and leadership had to be central, not just as consultees, but as co-creators and decision-makers in shaping the work ahead.



Phase 2: Shifting the focus to Community Voices

Phase 2 began with a clear intention: to centre community voices in every aspect of the work. The partnership had learned that without direct involvement from people with lived experience, Adaptive Actions risked becoming another well-meaning but top-down exercise.

This phase focused on shifting power, rebalancing relationships between the system and the community, and creating spaces where those who are most impacted by health inequalities could speak, challenge, and shape direction.

What changed in Phase 2

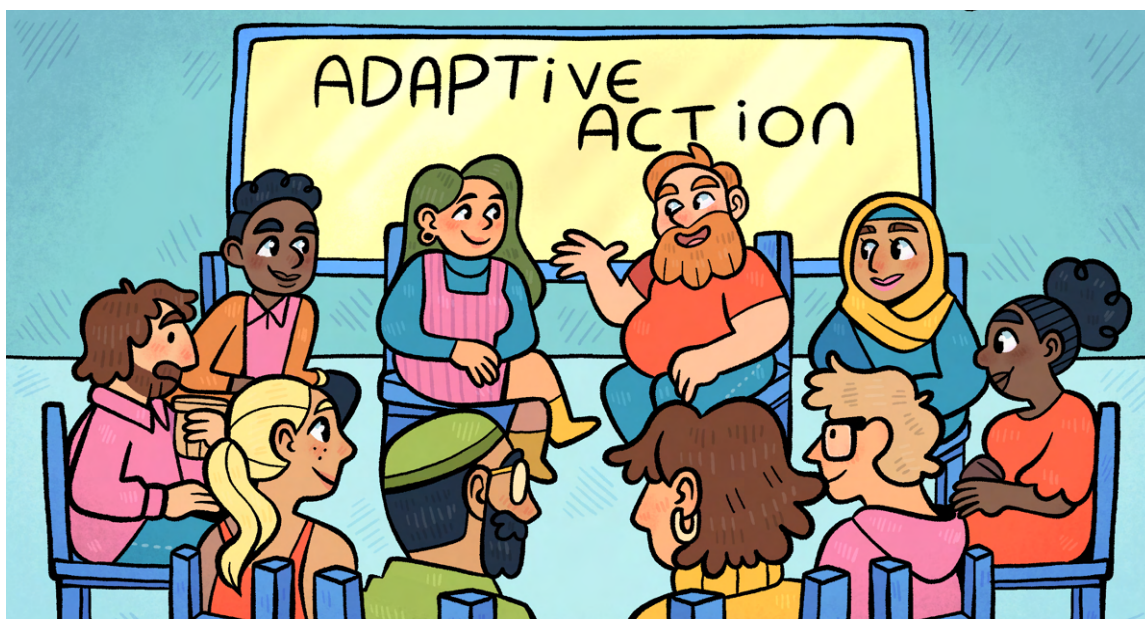
- Marginalised communities including Trans and Non-Binary, Refugees and Asylum seekers, Sex Workers, Gypsies and Travellers were directly involved in Adaptive Actions.
- Sessions moved from being professional-led to community-driven, with a stronger focus on relationships and trust.
- The partnership worked to level out power imbalances by creating environments where everyone's voice could be heard equally.
- The purpose of Adaptive Actions evolved—to challenge systems constructively, without needing to dismantle them entirely.

Involvement of Experts by Lived Experience

It is important to recognise that HCT's approach to engaging members of marginalised communities in Adaptive Actions is not a 'book it and they will come' approach that is often seen within health systems. Instead, relationships have been developed over time with individuals, local communities and with community-based organisations directly working with marginalised communities. We are drawing upon our vast network built upon a foundation of trust and knowledge from working directly with Trans and Non-Binary communities, Gypsies and Travellers, Sex Workers and Refugees and Asylum seekers. HCT champions inclusive, trauma-informed, and sustainable community leadership. We see our community members as Experts by Lived Experience (ELE). We ensure all ELE involvement is always compensated sufficiently. We want to ensure that community voices—not institutions—lead the transformation of health and care systems.

Adaptive Actions in Phase 2:

Adaptive Action (AA) sessions held in-person in Leeds between March 2023 and May 2025. Each session explored how marginalised communities experience healthcare, with a focus on co-producing insights and actions for more inclusive services. Themes included access, discrimination, system design, and representation across urgent care, primary care, mental health, interpreting services, and healthcare infrastructure.



1. Same Day & Urgent Care Services

Date & Location: Thackery Museum of Medicine, Leeds – 27 March 2023

Aim: To understand how marginalised communities use urgent and same-day care and identify barriers to equitable healthcare access across services.

Participants: A group of professionals including, frontline NHS staff working in Urgent and Same-day care, GP practice managers and strategic planners, a community advocacy worker supporting people experiencing homelessness and addiction, professionals from Leeds City Council Public Health and Leeds Health and Wellbeing Partnership, representatives from MESMAC and Leeds Health and Care Partnership, and ELEs from Refugees and Asylum seekers, Gypsies and Travellers, and Sex Worker communities.

About: This Adaptive Action session focused on understanding how the most marginalised communities in Leeds experience urgent and same-day care, such as A&E and walk-in centres. Key conversations centred on delays, communication barriers, and how racial or social bias affects triage and treatment.

Key Learning & Insights:

- **Over-reliance on A&E due to barriers in primary care access.**

"It's just confusion; [the] waiting time, not knowing where to go [or] getting through to one-on-one. You could be on hold for an hour before you can get through. If you've got some[one] collapsing, you need urgent A&E care. If you're going, obviously you're going because it's an emergency [and] you ain't got [the] patience."

- **Discrimination and bias experienced during triage, particularly by sex workers and Gypsy/Traveller communities.**

"Well, you know, we assume that we know what patients should do, so we have that parental attitude towards them. But, actually, they're telling us what they want in ways that we're not really listening to."

- **Lack of cultural competency and trauma-informed approaches among frontline staff.**

"The staff don't have any resources to deliver that (compassionate care) to the patients that they're serving. To me, it feels like the culture in those environments can treat the people who need it the most quite poorly."

- **Complicated and inflexible appointment systems that don't work for marginalised users.**

"How do you make an appointment? How to reach out to [Same-day care]? The obviously way is to ring 111. Any other areas of service hardly come to mind."

- **A general mistrust in the system based on repeated negative experiences.**

"There's a fracture between the relationship of the patient and the healthcare service, and the trust is gone. It makes it really hard to deliver care when you're on that footing with the patient."

2. Primary Care

Date & Location: Thackery Museum of Medicine, Leeds – 27 March 2023

Aim: To deeply listen to the challenges and solutions identified by Trans and Non-Binary individuals, Refugees and Asylum Seekers, Gypsies and Travellers, and Sex Workers, in order to improve their access to primary care services. To focus on understanding barriers, identifying opportunities for better support, and implementing tailored meaningful improvements.

Participants: A senior public health professional, a GP practice-based professional, a healthcare practitioner working in policy and patient advocacy, a Public Health Training Lead, a specialist services practitioner, representatives from MESMAC, Leeds City Council, Leeds GATE, and ELEs from Gypsy and Traveller community, including someone experiencing homelessness.

About: This Adaptive Action session focused on barriers in general practice and access to consistent, respectful, primary healthcare. It built on long-standing issues around discrimination, gatekeeping, and the structural biases baked into seemingly “routine” healthcare.

Key Learning & Insights:

- **Inability to register with a GP (particularly for people with no fixed address or ID).**

“Sometimes you are refused registration [at a GP] because of where you live. So, if you live in a caravan and you’re moving around, you might not be able to register because you can’t prove your address.”

- **Misgendering and use of deadnames.**

“We’re often misgendered from the outset. I still get the wrong name and title written on letters from my doctor sent to my home address... It makes you less likely to want or feel able to reach out for support.”

- **Prejudgement and biased attitudes in healthcare cause harm and reduce trust in communities.**

“People are not looked at as individuals. There is a prejudgement of what they are going to be like, do, or say. And that comes across as discrimination. I’ve seen it happen; where there’s been something like the tone of voice and you see that person withdraw”.

- **Systems that rely too heavily on digital or written communication, excluding those without access.**

“[They] don’t flex that based on people’s communication needs. So, if you don’t read and write, you still get the letter. It’s not going to work.”

“You’ve got to phone your doctor at 8 in the morning at most practices, to get an appointment. What if you’re homeless? What if you haven’t got any signal? What if you don’t own a phone? What if you’ve only just come in from the night before? And then there’s barriers with how you talk. What if you don’t speak English?... These are [all] barriers that people face.”



3. Trans Mental Health

Date & Location: MESMAC, Leeds – 12th October 2023

Aim: To explore trans and non-binary people's experiences of mental health services.

Participants: Health and social care professionals including, mental health representative from a non-profit organisational working with the Trans and Non-Binary communities, a former NHS practitioner now working in inclusion training, representatives from MESMAC, and ELEs from the Trans and Non-Binary communities.

About: This Adaptive Action session focussed on the experiences of Trans and Non-Binary people navigating mental health services in Leeds. It was part of the HCT collaboration with the Community Mental Health Transformation Team (CMHTT), aiming to inform the design of inclusive mental health services. Using Adaptive Action methodology, participants shared what is working, what's not, and what needs to change.

The session was facilitated in a neutral, safe space, and all participants were asked to remove lanyards and identifiers of professional status to allow for equitable sharing. The discussion was rooted in lived experience, exploring how services could better support Trans and Non-Binary individuals.

Insights from this session directly informed the development of a second Adaptive Action session, focusing on Trans and Non-Binary inclusion training needs.



Key Learning & Insights:

- **Being misgendered or dead-named, even after correction diminishes trust and support**

"I had one person who misgendered me and I corrected them and they went, 'Oh, you know what I mean?' Like, there was no need for that."

- **Trans communities face long waits, poor mental health outcomes, and remain invisible in data and services**

"Gender affirming health care systems cannot currently meet the needs of our trans communities, which struggles with waiting times spanning years. This is a massive factor why our trans communities are in poorer mental health outcomes, including an increase in suicidality and suicide completion during that waiting time. And yet our trans folk, our trans communities, don't appear in our data or in our services."

- **Trans and Non-Binary communities have to advocate for their own health due to access barriers, only to be criticised and stigmatised for doing so.**

"In my own life, the people I work with and my community are dealing with a lot of frustration and confusion. We're often forced to help ourselves and do things DIY, only to be told by doctors that that's not right, and then we're made to feel demonised, like we're making things worse for ourselves, just for trying to access basic healthcare."

- **Improving how we support trans and neurodiverse people strengthens services for everyone.**

"We all need to work better with all of our communities. When we know that people might be experiencing both their transness and their neurodiversity within a world that hasn't made it super welcoming for all of those communities, in all situations, if we can do better, we are automatically going to improve our services for everybody that accesses them."

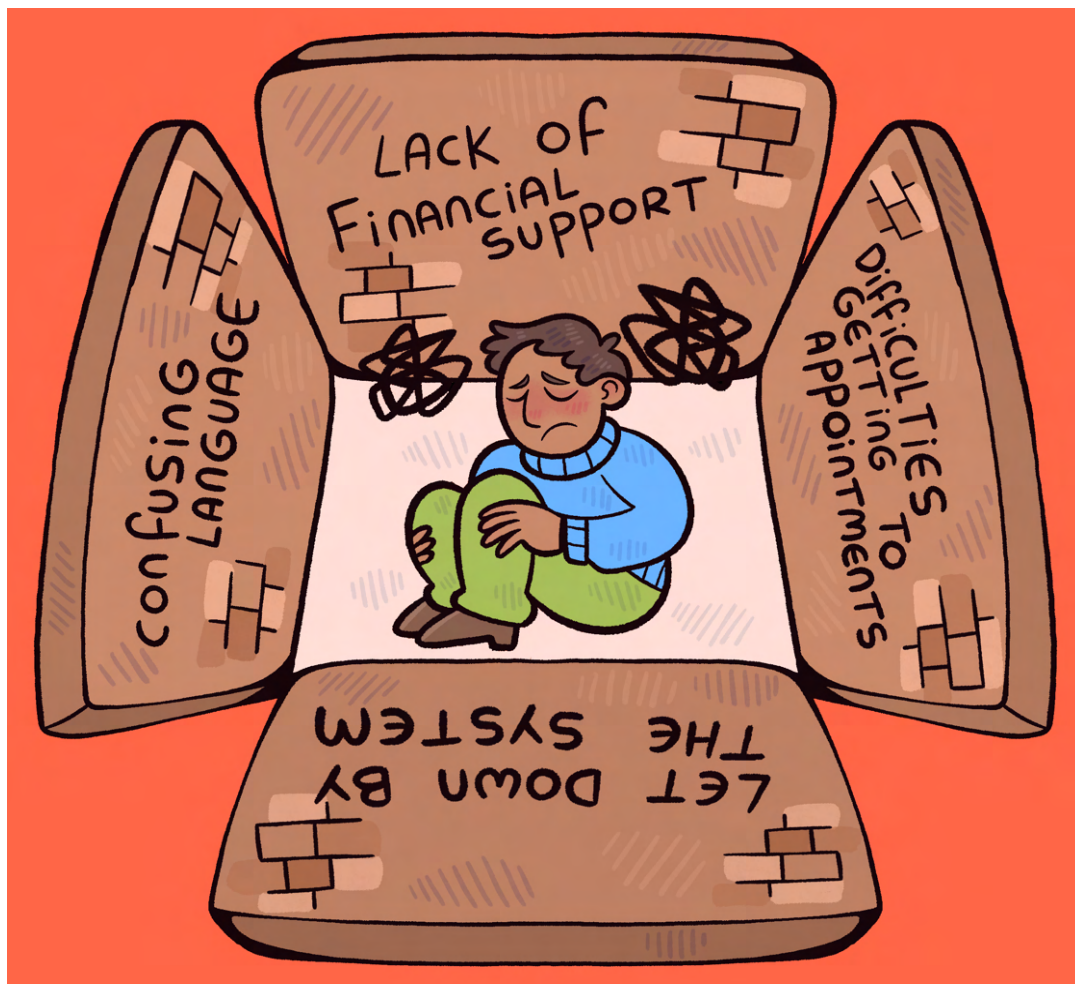
4. Mental Health Crisis

Date & Location: Basis, Leeds, 29th April 2024

Aim: To address the significant mental health disparities faced by marginalised communities, with a focus on improving access to mental health care and enhancing overall experience.

Participants: A public health strategist leading mental health transformation, a VCS lead supporting Gypsy and Traveller communities, a peer support worker with lived experience of addiction and homelessness, mental health practitioners working across statutory and community services, representatives from Basis Yorkshire and MESMAC, and ELEs from Gypsy and Traveller and Sex Worker communities.

About: This Adaptive Action session explored the acute mental health crises faced by marginalised groups—ranging from suicidal ideation to institutional neglect. The goal was to explore what support systems exist (or don't) when people are in crisis and how these can be made equitable, compassionate, and effective.



Key Learning & Insights:

- **Services must be safe, welcoming, and non-judgmental to truly support sex workers.**

"We've talked a lot about lived experience, but services need to be a safe space to speak and not feel that you'll be judged in any way when you do."

- **Inconsistent mental health support leads to disengagement, stigma, and deeper isolation for marginalised communities.**

"People from these communities are constantly let down, passed from pillar to post with no consistency and no real mental health support. Then, they don't want to engage anymore. Then comes the anger and frustration, but there's still no help. Instead, they're told they can't come back or access services. Eventually, they are ostracised and isolated even more."

- **Communities believe ongoing healthcare challenges remain, with accountability from services needing improvement.**

"None of this (healthcare challenges faced by trans folk) surprises me, which is quite worrying; but I see a complete lack of accountability from services."

5. Trans & Non-Binary Inclusion Training Needs

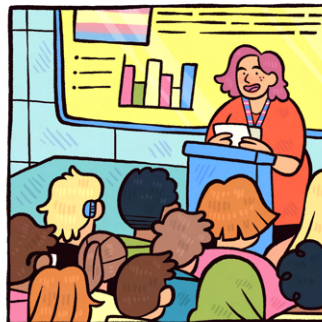
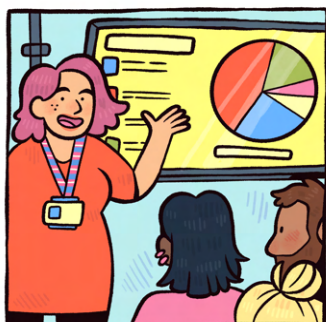
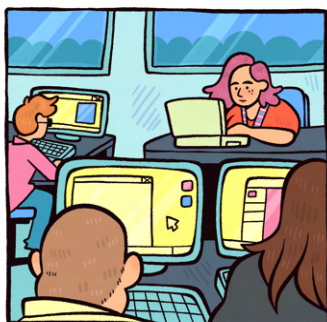
Date & Location: Online, On Zoom, 22nd May 2024

Aim: To identify and address the essential training needs for healthcare professionals, exploring critical questions such as 'What key elements must be included in mental health training?' and 'How can we ensure this training is inclusive and effectively supports marginalised communities in accessing care?'

Participants: Trans and Non-Binary lived experience experts engaged in mental health service co-production, healthcare professionals from Community Mental Health Transformation Team (CMHTT), voluntary-sector professionals involved in LGBTQ+ advocacy and training design, healthcare and mental health practitioners working within Leeds community mental health transformation programmes, representatives from MESMAC, and ELEs from the Trans and Non-Binary community.

About: This session was arranged following a previous Adaptive Action we carried out in collaboration with Community Mental Health Transformation Team. This Adaptive Action underlined the importance of sufficient training for mental health professionals. It focused on what good training looks like for healthcare professionals, what does it need to cover and how can it be delivered better. Participants were asked to share their experiences and insights to co-create a vision of inclusive, effective, and practical training models.

Using the Adaptive Action method, the session emphasised lived experience as a foundation for professional development and systems change.



Key Learning & Insights:

- **Services appear to rely on patients to educate and highlight gaps in awareness and inclusion.**

"I've often had to do a lot of explaining to people about what it means to be non-binary"

- **Trans inclusion training must be co-produced and mandatory to ensure it's prioritised and meaningful.**

"One of the biggest things about training is whether or not it should be mandatory. I think it should be. Not a criticism, but if it's left to the staff member to decide if they need to do that training or not, they may not see it as a priority. And I think the training should be very much co-produced."

- **Healthcare professionals must undergo Trans inclusion training to enhance cultural competency.**

"From both personal experience and from what I've heard from the community, most staff in services like the NHS, know not even the basics of trans healthcare knowledge. So they need a thousand times more training than they actually have."

- **Empathy-led training helps shift attitudes, debunk stereotypes, and build allyship.**

"People are often scared of training because they think they are going to be lectured, overwhelmed, or get it wrong and upset patients. But appropriate training wins hearts and minds. Once people see Trans folks as real, living human beings and not the monsters we are painted as by the media, they'll challenge other people in the workplace."

6. Translation Services

Date & Location: Woodhouse Medical Practice, Leeds, 17th July 2024

Aim: To understand the experiences of refugees and asylum seekers accessing and using interpreting services in healthcare settings, identify key challenges, and explore solutions.

Participants: Outreach and volunteer workers from refugee forums, a pharmacist, community interpreters from diverse linguistic backgrounds (including Romanian, Sudanese, Eritrean, South African, and Ukrainian), professionals involved in health policy and primary care translation facilitation, representatives from Leeds Asylum Seekers' Support Network (LASSN), MESMAC, and Public Health Leeds City Council, and ELEs from the Refugees and Asylum seekers communities.

About: This Adaptive Action session unpicked the barriers many Migrants, Refugees and Asylum Seekers face in accessing interpreting services in healthcare. There was a focus on lived experiences—highlighting delays, miscommunication, and the emotional toll when people can't express health needs clearly. Learnings from this session directly informed the majority of the content in the new interpreting and translation services specification for primary care that was developed by NHS West Yorkshire Integrated Care Board.



Key Learning & Insights:

- **Clear processes for requesting interpreters are essential to avoid confusion and ensure patients get the right support.**

"I used to go with the person and tell them, for example, a way to book an appointment. I know most of my language, so I can interpret straight away. But when you request an interpreter, they should ask you why, from which language you speak, then they can find the right person to interpret for you."

- **Overreliance on friends and family as interpreters' compromises confidentiality and raises safeguarding concerns.**

"Using friends [as interpreters], yes, we have to be careful. Yes, they can speak English, but they don't understand the confidentiality. They disclose it. Someone that I am close [to] used friends to [help] interpret, and the diagnosis spread everywhere. That puts the patient off. So, [they must] use professional interpreters, just to keep that confidentiality and protect the data."

- **Gender-specific interpreters are vital for safety and dignity, especially in trauma-sensitive conversations.**

"[You are] supposed to be considerate and ask [do you] need a man or a woman to translate your information to the doctor. Some of the ladies want to have a female [interpreter]. Especially if it is about vulnerable people with experience of violence or abuse or worse. I think this is a very important thing, [having] female interpreters."

- **When translation needs are overlooked, patients feel invisible, and the silence speaks volumes.**

When asked, "Who here thinks that their GP takes the need for translation services as seriously as they do?", almost everyone stayed silent.

7. Infrastructure Organisations & Representation

Date & Location: MESMAC, Leeds, 6th May 2025

Aim: To explore the barriers and possibilities for meaningful representation of marginalised communities within health system infrastructure and governance and consider how infrastructure and statutory organisations can better facilitate that representation.

Participants: Health professionals from ICB, NHS, ICS, and Public Health, a Health Watch representative, representatives from Forum Central, and representatives from MESMAC and Basis Yorkshire.

About: This Adaptive Action session examined the lack of meaningful representation for marginalised communities—Trans and Non-Binary people, Sex Workers, Gypsies and Travellers, and Asylum Seekers and Refugees—within health systems. Participants described persistent barriers despite Leeds' strong third sector and stated commitments to inclusion.



Key Learning & Insights:

- **To tackle current inequalities, we must confront and dismantle colonial systems underpinning our institutions.**

"We also have systems that are being founded on colonialism and other obstructions in place, which we have to dismantle, and I guess we need to acknowledge that."

- **Without trust and representation, marginalised communities struggle to access and engage with services.**

"If you already have barriers, you know, actually engaging in those processes is going to be incredibly difficult"

- **Community engagement should be properly resourced, and treated as expert input.**

"Better pay for community members being involved in consultations... really, that's a job."

"We're seeing less funding to escalate and enhance the voices of the most marginalised."

- **Representation means deep community understanding, not just a presence at the table.**

"You shouldn't be sitting around decision-making tables if you're not connected to communities."

- **Decisions made on unrepresentative data lead to flawed outcomes and missed needs.**

"We make decisions based on data that people are [not] represented in, and then if you don't have representative people in the room, you can't interrogate that data."

Conclusion

Adaptive Actions (AAs) were developed as a core methodology within the HCT project to engage with the complexity of health inequalities in more honest, inclusive, and impactful ways. Introduced during the COVID-19 pandemic, AAs offered an alternative to traditional consultation approaches, which often failed to surface lived realities or shift power dynamics.

In Phase 1, AAs were used to bring together professionals across the system: healthcare providers, local authorities, and public health teams, to reflect on persistent inequalities. These early sessions highlighted the need for more direct involvement from communities most affected by systemic barriers.

Phase 2 responded to that learning. Adaptive Actions evolved into community-led, relationship-centred spaces where marginalised voices, including trans and non-binary people, sex workers, refugees and asylum seekers, and gypsy and traveller communities, could shape the agenda. Sessions explored real-world experiences of healthcare access, mental health services, system representation, discrimination and bias, digital exclusion, language and translation barriers, and the impact of structural inequalities, resulting in practical insight and co-produced recommendations for service improvement.

Rather than seeking quick fixes, AAs embraced complexity. They created conditions for learning by breaking power barriers, built trust across differences, and helped shift systems through small, adaptive steps. Most importantly, they modelled a way of working that centres equity, challenges exclusion, and supports more accountable, community-rooted change.

Recommendations

- Involve ELEs in all consultation and participation activities.
- Use methodologies which ensure the expertise of ELEs are valued equally to professionals.
- Recompense ELEs for their hard expertise.
- Ensure strong partnerships and collaboration with VCSE organisations who already work with ELEs.



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