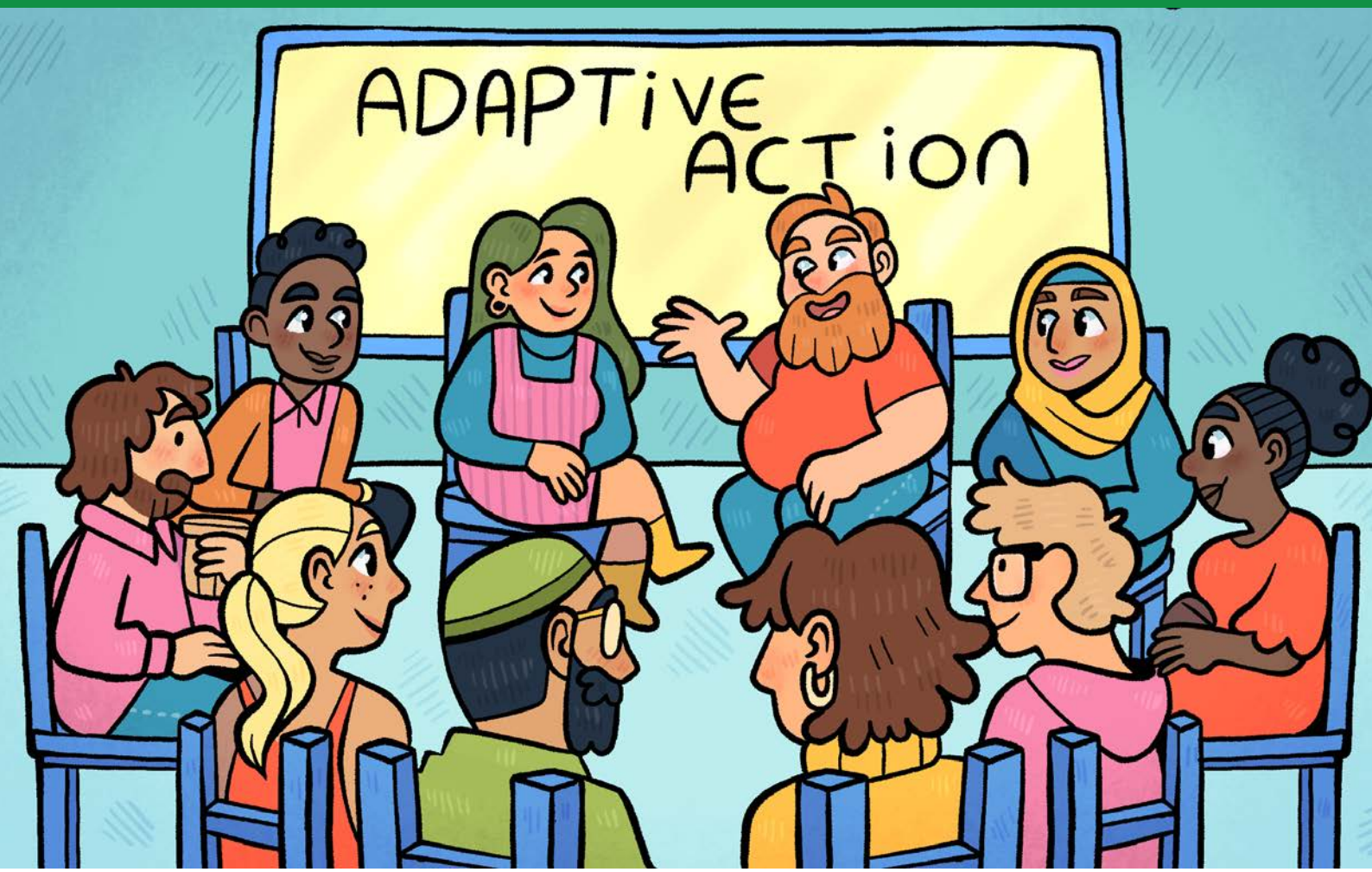
Adaptive Action: Infrastructure Organisations & Representation



HCT

Healthy Communities Together

Overview

On 6th May 2025 HCT facilitated an Adaptive Action session which brought together participants from NHS, Public Health and VCS organisations to critically explore how infrastructure organisations and health systems represent, include, and respond to marginalised communities—particularly within the NHS and broader health structures. The session followed the Adaptive Action framework: **What? -> So What? -> Now What?**

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WHAT? — Identifying Patterns and Challenges

This initial phase focused on surfacing key issues and lived realities that marginalised communities, and their supporting organisations, face when engaging with health systems.

Key Themes and Insights Raised:

1. Barriers to Access and Representation

- Services often **aren't located accessibly**, creating immediate obstacles for marginalised communities
- Marginalised groups, including **Refugees and Asylum Seekers, Gypsies and Travellers, Sex Workers and Trans and Non-Binary people,** face inequities before they even access healthcare services.
- Infrastructure organisations are not trusted by marginalised communities. These organisations a representation structures do not always have the expertise and representation within their teams to reach these communities, especially when needs are more complex:

2. Disconnection Between System Decision-Makers and Communities

- A **knowledge gap exists** between decision-makers and the lived realities of communities.
- Leeds' initiatives like **"Big Leeds Chat"** and **"Permission to Speak"** aim to bridge this gap, bringing **real voices** into planning conversations.
- However, a persistent issue is that **those at the table do not understand the lives** of the people they are supposed to represent, especially the most marginalised.

3. Exclusion from Leadership and Decision-Making

- There's a **lack of access to leadership positions** and decision-making forums for people from marginalised backgrounds.
- **Historical and systemic power structures,** including those rooted in colonialism, continue to influence who has a voice.
- Even when data is used, if **people aren't represented in the data or the room,** that data can't be accurately interpreted or challenged.

4. Structural and Systemic Complexity

- The **health system is large, complex, and faceless,** making it hard for individuals—especially from marginalised communities—to navigate or engage with it.
- Engagement with these groups is often **generic** rather than tailored, making it ineffective.
- There's a l**ack of understanding or willingness** among staff to go beyond superficial engagement to reach the most marginalised.
- **Stigma and distrust** further complicate engagement, particularly among groups such as people who use substances or those experiencing homelessness.

5. Tokenism and the Pitfalls of Superficial Inclusion

- Representation is often **tokenistic** — appointing a single representative to a board without real support or power.
- Such individuals face multiple **barriers,** including complex language, inaccessible **data,** and unfamiliar **structures.**
- A need for **supportive environments and training** for representatives was highlighted.

6. Importance and Limitations of the Third Sector

- There is acknowledgment of the strong **third sector** in Leeds.
- These organisations are seen as **key bridges** to engage marginalised voices, especially in building trust.
- However, the **reach and potential** of third-sector organisations are often **underestimated** or misunderstood by statutory services.

7. Intersectionality and Visibility

- Some communities are **more visible** than others, even among the marginalised.
- People may **choose not to participate** publicly in consultation or representation due to **fear, stigma, or trauma.**
- Issues such as **intersectionality** (e.g., race, housing status, addiction) compound barriers and must be understood together.

8. Frustrations with Awareness Training and Engagement Fatigue

•**Surface-level awareness training for staff is insufficient** — there is a need for deep, sustained learning about representation and inequality.

•**Repeatedly asking community members** to share traumatic stories causes burnout and re-traumatisation.

•There is a need for **coordinated learning,** rather than individual organisations collecting the same stories over and over.

So WHAT? — Reflecting on Meaning amd implications

This phase was about meaning-making— identifying resonant themes, analysing insights, unpacking systemic implications and exploring the deeper implications of representation and infrastructure for marginalised communities.

Key Themes and Insights Raised:

1. Persistent Inequalities and Limited Change Over Time

- One participant highlighted how, despite longstanding efforts, health inequalities have remained unchanged—or worsened—over 16+ years for marginalised groups in Leeds. This was deeply frustrating given the commitment seen in some parts of the system.

- There's recognition that while there are strong partnerships (public, third sector), something is missing in converting community voice into actual systemic change.

2. Voice vs Action

- Multiple voices echoed the problem of good listening practices that don't lead to action: *"We're great at listening, but how do we move that into action?"*

- There's a sense of repeated conversations without tangible outcomes, highlighting a gap between voice collection and system-level implementation.

3. Measurement and Accountability

•Participants discussed how outcomes might improve if equality and representation were core to performance targets.

•There's a desire to explore new metrics that incentivise change rather than perpetuating inaction.

4. Representation in Employment and Leadership

- Rather than only consulting communities, several participants pushed for **paid roles** and **leadership positions** for people from marginalised groups.
- Specific mention was made about the near absence of trans individuals in senior leadership or paid roles—visibility and influence remain low.
- There's a fatigue associated with community members constantly having to represent and educate, often for free or at emotional cost.

5. Data Gaps and Structural Exclusion

- A tension exists between the data-driven nature of health systems and the invisibility of marginalised communities in those datasets.
- If marginalised people aren't present in the data, they are often overlooked by systems that rely on metrics to drive decisions.
- Suggestions were made to capture voices more systematically to compensate for missing data.

6. Complexity and Avoiding One-Size-Fits-All

- Solutions need to reflect the complexity and diversity of experiences. It takes time, creativity, and nuanced approaches—not simple fixes.

- Many of the issues are already well understood by community organisations, so repeating consultation can be redundant, and even harmful, unless it's meaningfully developed and acted upon.

7. Systemic Pressures and Leadership Commitment

- Participants acknowledged the system is under pressure (e.g., funding, time), but still questioned why commitments aren't turning into system change.

- Strong leadership was identified as a crucial missing piece: real change requires leaders who embed equity and inclusion into organisational culture and priorities.

- It's not enough to run a one-off workshop; it requires embedded induction, lived values, and accountability throughout an organisation.

8. Value and Compensation of Community Contributions

- Community engagement is often unpaid or underpaid, especially when community members are expected to share personal stories or trauma.

- There's a need for proper recognition (including financial) for the work communities do in contributing to system improvement.

9. Surprise at Shared Global Struggles

- A powerful moment came from a participant who compared marginalised community experiences in the UK with those in the Global South, surprised by the similarity.

- This challenged the assumption that wealthier systems automatically provide better outcomes for disadvantaged groups.

The facilitator noted a range of insights and tensions:

- The distinction between consulting communities versus employing and empowering them.
- System fatigue, but also frustration due to the l**ack of tangible impact.**
- Conflicts between **voice vs data,** and **representation vs tokenism.**
- Recognition of barriers such as **fragmented funding, lack of leadership,** and **insufficient structural change.**
- Suggestions to build on and value existing VCSE (voluntary, community, and social enterprise) work, not duplicate it.

Implications for Future Action

The discussion sets a foundation for moving into the next phase: "Now What?" (i.e., action planning). Key implications include:

- Ensuring community engagement is **resourced, valued,** and led by **communities themselves.**
- Better integration of lived experience into **paid, decision-making roles.**
- Rethinking data and performance systems to include **qualitative insight** and **community-defined success.**
- Developing **leadership accountability** and system-wide induction on equity and representation.
- Making learning and inclusion essential, not a luxury.
- Marginalised people often provide systems feedback which can help make improvements not just for their communities but for wider populations.

NOW WHAT? — Moving to Action

The final phase turned toward practical action, ownership, and systems change. This revolved around identifying practical actions, collective opportunities, and reflections on representation in infrastructure and community health systems. Participants were encouraged to consider:

- What can be done differently?
- What personal or systemic steps could be taken now?
- What lessons have emerged from the discussion?

Key Themes and Insights:

1. Turning Insight into Action

- Participants acknowledged the **systemic barriers** to equity but emphasized, **personal, incremental changes** as leverage points.
- There was a shared belief that **change is possible,** especially through leadership, allyship, and strategic positioning within systems.

2. Representation and Voice

- Many emphasized the need for **authentic representation** of marginalised communities — not just symbolic involvement.
- Representation must be **diverse, flexible, and meaningful,** recognising that not everyone wants the same level or mode of engagement (e.g. board roles vs. informal input).
- There was concern over **tokenism** and ensuring **community members are not overburdened** with expectations to tell their stories repeatedly.
- There is a v**isible absence of community representation in decision-making spaces,** especially from less visible marginalised groups

3. Data and Evidence Challenges

- **Data gaps and mistrust** in existing demographic or experiential data are major obstacles.
- One participant noted it's **not a lack of data,** but rather a **failure to use and trust the data already available,** leading to redundancy and disengagement.
- Need for better use of both **qualitative and quantitative data** — stories, videos, alternative forms of engagement were seen as tools to close this gap

4. Structural Challenges

- Infrastructure and third-sector orgs often **fill systemic gaps** without proper funding or recognition.
- The burden is often **unfairly placed** on grassroots and voluntary orgs, instead of being owned by formal decision-making structures.

5. Support and Accessibility in Engagement

Calls for more **accessible and supportive environments for community** involvement:

- Adjusting formats for engagement
- Providing logistical, emotional, and financial support
- Recognising and accommodating multiple barriers (e.g., stigma, discrimination)

Concrete Commitments:

- Embed representation into strategic plans (e.g., 10-year health plan).
- Promote allyship and leadership development with marginalised communities.
- Reimagine commissioning and planning practices through a lens of equity.

Proposed and Reflected Actions

Individual Commitments:

- Continue influencing within NHS and local authorities to **prioritise equity from service evaluation and review through development and design.**
- Advocate for better **data practices** and representation in commissioning and planning
- Strengthen efforts around **neighbourhood health** focused on marginalised groups.

Organisational/Systemic Ideas:

- Promote **allyship programmes** and leadership matching with communities.
- Use examples of **effective leaders who challenge cultural norms** to inspire and model better practices.
- Embed representation efforts within strategic frameworks like the 1**0-year health plan.**

Representation & Inclusion Actions:

- Tailor engagement strategies to **different types of community members.**
- **Support lone voices or Reps** better in governance spaces.
- Challenge structures that **delegitimise community-led research,** such as in the case of trans healthcare research being ignored or undermined.

Reflections and Challenges Identified

- **Representation is complex:** It's not enough to have someone at the table — their authority, support, and legitimacy must also be ensured.
- **Frustration exists** at the slowness of change, but hope remains in **small wins and consistent advocacy.**
- There's an urgent need to move from **"good people doing good work" to systemic, embedded approaches.**
- A **power shift** is necessary, both in decision-making and in valuing knowledge held by communities.

The Adaptive Action session closed on a note of **deep reflection and a strong call to action**, affirming that:

- **Everyone has a role** — whether in influencing decisions, shaping structures, or advocating from within communities.
- Infrastructure organisations need to go **beyond maintaining systems** to **actively transforming them.**
- The conversation must continue, but grounded in p**ractical steps and visible accountability.**

Post-Session Conversations and Reflections

Following the formal AA session, further discussions focused on trust, sustainability, and institutional accountability. Participants reflected on **data, lived experience, representation, and structural barriers,** especially around services for **trans individuals and other marginalised communities.**

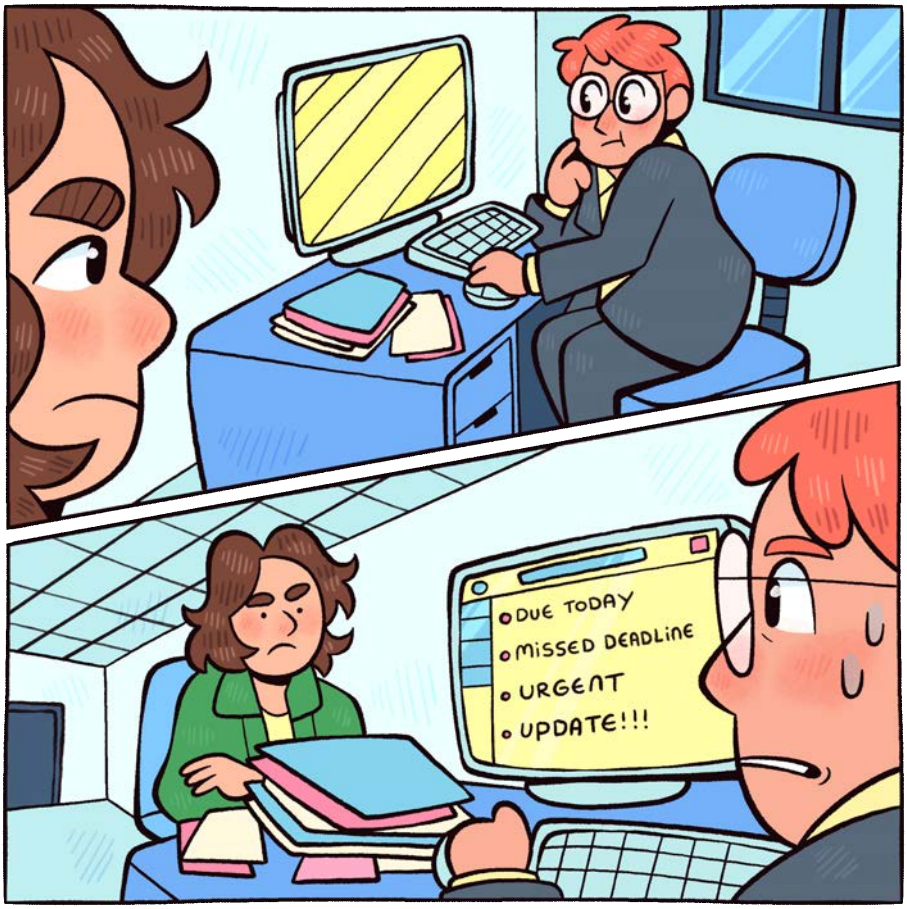
Key Themes & Points:

1. Trust & Marginalised Communities:

- **Trust is central,** especially for trans people, who are often not believed regarding their own health needs.
- This **lack of trust** in their self-assessment and care decisions is described as **dangerous.**
- **Organizations' distrust of each other** and of community members' knowledge is also a barrier.

2. The Role of Data:

- Participants express frustration that although data exists, it is often ignored, misinterpreted, or financial and quantitative data is prioritised over lived experience or qualitative insights.
- Some services manage to convince commissioners of need without "hard data", but this is not consistent.
- There's a **disconnect** between the stated goals to reduce health inequalities and the actual **data being used,** which is often **financial, not health-based.**
- The group acknowledges **incremental improvements** in understanding and flexibility, but emphasizes **this is not enough.**



3. Systems & Structural Problems:

- **Health systems are fragmented,** often due to commercial data systems that don't integrate well.
- **Capitalist legacies** and **competitive service models** undermine collaboration and effective data sharing.
- Pressure on the system creates a mindset of **maintaining status quo,** rather than improving conditions for the most marginalised.

4. Healthy Communities Together (HCT):

- The HCT programme focused largely on **engagement with GPs and primary care**, particularly around **barriers faced by marginalised groups.**
- There is **acknowledgement that the work has value,** but uncertainty about how to **sustain or embed it going forward.**
- Participants agree that the programme has created **valuable learning and lived experience training**, but more is needed to **translate this into policy or structural change.**

5. Lived Experience & Community Involvement:

- A consistent theme is the **value of involving people** with lived experience in designing and evaluating services.
- Examples include **translation services** in primary care that lacked complaint mechanisms—highlighted by community input.
- There is a **call to embed these voices meaningfully,** not just as token input.

6. Workforce Representation & Accessibility:

- Marginalised communities face **systemic barriers to employment,** especially in reaching management positions.
- Current volunteer-to-paid-work pathways are insufficient, as **marginalised people face additional structural challenges** (e.g., time, energy, unpaid labour).
- Proposals include r**ole-specific development schemes** and **reduced-risk employment pathways** with **extra training and support** to bridge experience gaps.

7. Role of Institutions & Future Actions:

- There is interest from **institutions like Healthwatch and public health authorities** to **support, amplify, and learn from HCT's findings.**
- A **"call to action"** emerges: services must move beyond intentions to **practical implementations** that truly support health equity.
- There's also a focus on **training systems like the Health and Care Academy,** which were meant to embed this understanding systemically but often didn't materialize.

Reflections and Questions Raised:

- How can the momentum of programmes like HCT be sustained post-funding?
- **How can the learning from HCT be integrated systemically?**
- What structural levers (e.g., training, workforce policies) can make inclusion systemic?
- How can lived experience be balanced with system demands for quantitative data?
- How can we **design more representative services** by having marginalised people at every level of decision-making?

Conclusion & Call to Action

This Adaptive Action session illuminated not only the scale of systemic barriers but also the commitment and creativity within communities and allies. It underscores the importance of trust, community voice, braver systemic decisions, and better representation—especially as HCT winds down and participants look toward embedding lasting change in a constrained system.

We must move from token gestures to systemic change.

That means:

- Empowering and compensating lived experience.
- Embedding inclusion in leadership, data, commissioning, and accountability structures.
- Building trust through long-term relationships, not short-term consultations.

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