Working with Experts by Lived Experience: Community-Led Transformation





Introduction

The Healthy Communities Together programme has placed **Experts by Lived Experience (ELEs)** at the heart of systems change, ensuring that community voices—not institutions—lead the transformation of health and care systems. Through workshops, mentoring, leadership development, and creative participatory methods, HCT has championed **inclusive, trauma-informed, and sustainable community leadership.**

This report highlights the practical work undertaken with marginalised groups including **Trans and Non-Binary people, Sex Workers, Gypsies and Travellers, Refugees, and Asylum Seekers**—and shares lessons learned, successes achieved, and the challenges ahead.

HCT has engaged with ELEs through:

- Workshops and Leadership Development (in partnership with Learnest)
- Service Co-Design and Advisory Roles
- Stakeholder Panels
- Training Delivery
- Adaptive Action and Participatory Methods



Importantly, every ELE was compensated for their time and expertise financially,

and barriers such as travel costs were actively removed reinforcing a genuine commitment to equitable, accessible engagement.



HCT Leeds is funded by The National Lottery Community Fund.

Empowerment Through Training & Development

Workshops

Developed with **Learnest**, we carried out a range of workshops designed to:

- Equip ELEs with tools for advocating for themselves and their communities when navigating systems
- Build skills in leadership, communication, and selfdevelopment
- Empower community members to lead change not just participate in it

Reach and Impact

- Workshops have been well received, with attendance ranging from 2 to 7 people.
- Many participants engaged selectively, attending sessions that aligned with their interests.
- Workshops provided a space for skill-sharing, reflection, and connection.
- Certificates of completion recognised participant commitment and inspired continued engagement.

"These workshops gave me a real sense of belonging." – Ayman, Asylum Seeker

" The workshops gave me the tools... to be more effective in what I do. " — Shiv, Trans community member

Oct 2024 – Jan 2025

Hosted in trusted community venues: MESMAC/LASSN, Leeds GATE, and BASIS we delivered 28 workshops exploring the following themes:

- Building Personal Support Networks
- Advocacy & Public Speaking
- Leading & Supporting Others
- Self-Development & Confidence

Jan 2025-May 2025

We ran an additional **Leadership Lab** series of 16 workshops hosted in the same trusted community spaces. These workshops focussed on:

- Voices for Change (Advocacy & Influence)
- Building Stronger
 Communities (Leadership)
- **Present Like a Pro** (Public Speaking)
- Sustainable Activism (Resilience & Conflict Navigation)

Train the Trainer: From Participants to Peer Educators

HCT supported five ELEs to complete a **Train the Trainer programme** with Community Links (Jan-Feb 2025).

The course covered:

- Training design and delivery
- Facilitation techniques
- Peer feedback and reflection

Graduates now co-deliver community sessions, creating a **multiplier effect** for local empowerment.



"What stood out was preparing and delivering a minitraining. It gave me so much to think about." - Hala, from Refugee community

Learning and Challenges:

- Engaging specific communities—particularly Sex Workers and some Gypsy and Traveller groups—was more difficult than anticipated.
- The original delivery model didn't fully account for the importance of existing trust and relationships.
- We adapted by joining pre-existing groups at Leeds GATE and Basis, which saw some engagement, though limited.
- In hindsight, this aspect of the work may have been more effectively delivered by trusted community workers that were already embedded in those spaces and communities.
- Despite these challenges, we still had meaningful opportunities to explore key themes and offer valuable support.

Mentorship: Deepening Impact Through Relationships

Launched in March 2025 in partnership with **Learnest**, the HCT mentorship programme provided **tailored one-to-one guidance** for ELEs from our communities, seeking sustained personal and professional growth.

- Eight ELEs receiving tailored, one-to-one mentorship.
- Delivered by Learnest and focused on skills chosen by mentees.
- Sessions prioritised reflection, confidence-building, and leadership development.
- Mentoring has supported both personal growth and professional development.
- Mentees have used the space to think about future goals, with some focusing on community action and others on career aspirations.
- In some cases, mentoring has addressed urgent needs, including support accessing foodbanks and IT equipment.
- Outcomes included facilitation roles and deeper engagement.

"It opened my mind... I want to give back to the community."— Akhona, from Refugee community



Training Development: Advancing Trans & Non-Binary Inclusion in Healthcare

In collaboration with Trans and Non-Binary ELE's and Inclusive Health, HCT co-developed comprehensive **trans and non-binary inclusion training** for healthcare professionals.

- Featured video stories from trans and non-binary community members
- Delivered by trans trainers with support from Community Mental Health Transformation and GP Confederation
- Emphasised lived experience as expertise in health education

This model proves that **authentic**, **community-led** training drives more meaningful cultural change in health systems.



Healthcare professionals that attended the training highlighted:

"Having a trans trainer made a huge difference. Their insights were invaluable."

"The trainer's personal experience helped massively to make it relatable and impactful."

"The content was well-researched, up-to-date, and sourced. The real-life experiences shared were moving and eye-opening."

Case Study: Engaging Sex Workers

A dialogue between HCT's Jamie Fletcher (MESMAC) and Amber Wilson (Basis) offered vital insights into **best practices for engaging sex worker ELEs**. It's important to note that this learning can be applied to many of our marginalised communities.

- **Relational, not transactional:** Trust takes time. Relationships are built long before participation.
- Trauma-informed practice: Safe spaces are essential.
- Flexible funding frameworks: The way HCT was funded enabled adaptation rapid response to community needs.
- Peer-led research: Builds authenticity and community trust.
- Valuing community wisdom: Lived experience is equal to academic insight.
- Intersectionality matters: Sex work intersects with mental health, addiction, and housing issues.
- **Avoid tokenism:** True co-design requires diverse voices, not just the most vocal.
- **One size doesn't fit all:** Community diversity must be honoured. Support beyond engagement: Compensation, emotional safety, and follow-up are essential

Challenges

- **Consultation fatigue:** Communities need to see tangible outcomes
- **System rigidity:** Institutions struggle to adopt flexible, co-designed models
- **Policy misalignment:** Structural barriers limit responsiveness



Recommendations for Systems

To sustain and expand on HCT's work, health and care systems must:

- **1. Embed ELEs in decision-making**, not just consultation
- 2. Diversify engagement methods to reflect different community needs
- 3. Invest in community peer-led training and research as lasting models
- 4. Fund mentorship and leadership roles with long-term support
- **5.Adopt flexible, relational practices** at all levels—not just in pilots
- 6.Challenge stigma through comprehensive inclusive and reflective training

Conclusion

HCT's partnership with ELEs offers a **blueprint for ethical**, **impactful engagement.** By centring lived experience, investing in leadership, and committing to real-world action, the programme has empowered marginalised communities to lead meaningful change.

Looking ahead, sustained investment and system-wide transformation are essential. Only by valuing community knowledge at every stage—from design to delivery—can health and care systems become truly inclusive.



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Healthy Communities Together Leeds is supported by The King's Fund and funded by The National Lottery Community Fund, the largest community funder in the UK.



Designed and illustratred by Molly Pukes / Molly Grimshaw