

Working with Experts by Lived Experience:

Community-Led Transformation



HCT

Healthy Communities Together

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.



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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 self-development
- **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 mini-training. 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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