

# Rebel by Default: Power Bags and Participatory Research with Women Living with HIV

Dr Katharine Low (GKT School of Medical Education, Centre for Education), Dr Ella Parry-Davies (Department of English, Performance@King's Network), Silvia Petretti (Positively UK) Michelle Bockor (Positively UK), Charity Nyirenda (Positively UK), Ellie Angus (Positively UK), Daniel McIlwraith aka Daisy Puller





## PROJECT SUMMARY

The *Rebel by Default* project brought together academic researchers and activist colleagues from Positively UK to co-create an arts-based research process with women living with HIV. The project centred on a series of workshops in which participants designed and produced “Power Bags” — handcrafted textile bags containing meaningful objects that represented their lives, struggles, and aspirations. These objects and practices acted as powerful tools for storytelling, resistance, and connection.

Using creative methods rooted in participatory values, the project fostered safe, affirming spaces where women with lived experience led discussions, shaped the direction of the work, and explored new forms of expression and leadership.

The project culminated in a public exhibition at the Inigo Rooms in May 2024, and has since been presented at national and international events including AIDS 2024 in Munich and British HIV Association 2025. The work will be archived at Bishopsgate Institute, and a dedicated online platform is in development to ensure the legacy continues.

## HOW DID THE PROJECT COME ABOUT?

*Rebel by Default* grew from a long-standing collaboration between researchers at King’s College London and Positively UK, rooted in a shared commitment to challenging health inequalities and centring the voices of women living with HIV. Katharine Low has collaborated with Positively UK since 2016 on projects exploring participatory research and arts-based methods examining the cultural representation of women well with HIV, and this initiative built on that foundation.

The idea for the project emerged from ongoing conversations around how research can better engage with lived experience without being extractive. The team wanted to create a space where participants could reflect on their identities, share knowledge across generations, and imagine new possibilities for change — all through creative, hands-on practice. Inspired by the work of the Women Connected project in the Netherlands, the group developed the concept of Power Bags: textile creations that hold symbolic items reflecting each woman’s personal journey, desires, and struggles.

From the outset, the project was shaped by co-production and collective decision-making. Each person brought a distinct skillset — from activism and facilitation to creative practice and lived experience — enabling a process that was grounded in radical kindness, radical care, collaboration, and resistance.





## WHAT HAPPENED?

The *Rebel by Default* project unfolded through a series of four themed workshops co-facilitated by the project team. Held in the REACH Space at King's, the sessions brought together women living with HIV to reflect on identity, stigma, resistance, legacy and care — and to explore how their lived experiences could reshape research and healthcare narratives.

At the heart of the project was the creation of Power Bags: textile artworks designed and sewn by participants, each containing symbolic items that represented their personal journeys, memories, and dreams. The making process sparked rich conversations about medication, stigma, migration, pleasure, and resilience. One participant stitched in rose thorns to symbolise both pain and strength; another included a Care Bear to represent community, softness, and care. The tactile nature of stitching helped hold difficult feelings and making was approached as a way to regulate emotions, offering a sense of control, flow, and calm.

Workshops opened and closed with informal check-ins, often beginning with Silvia and Michelle collecting groceries for the group and discussing the day's plan over tea. These routines created a rhythm of shared responsibility, reflection, and emotional support. The sessions offered space for play and connection — exemplified by a guest drag workshop led by HIV activist Daisy Puller, which invited participants to explore their alter egos in a space of joy and affirmation.

The project culminated in a public exhibition at the Inigo Rooms in May 2024, where the eight Power Bags were displayed alongside written reflections and documentation of the process. The exhibition foregrounded the creativity and expertise of the women involved, inviting audiences to engage not just with the final objects but with the personal stories, conversations, and acts of care that shaped them. Each bag served as a tactile archive of lived experience, resistance, and imagination, prompting critical conversations about stigma, representation, and the politics of health. The space also included a screening of word maps and a soundscape generated through workshop discussions, as well as opportunities for attendees to leave messages of solidarity, deepening the exhibition's impact as a site of connection and dialogue.



## WHAT WAS THE PROJECT'S IMPACT?

The *Rebel by Default* project created meaningful change on multiple levels: for participants, facilitators, institutions, and wider publics. At its core, the project created space for women living with HIV to lead, reflect, and be recognised as knowledge holders — not only in research, but in shaping narratives about care, illness, and resistance.

For participants, the impact was personal and lasting. Many entered the workshops feeling uncertain about their creative abilities or unsure of what they could contribute. By the end, they had produced deeply meaningful Power Bags and spoken proudly about their work in public. Several women described increased confidence, stronger peer relationships, and a sense of visibility that extended beyond the room. The project made space for joy, play and pleasure—particularly powerful for communities often excluded from such experiences.

Professionally, the project offered new models for participatory, peer-led practice in health research. Facilitators and academics gained insights into co-production, accessibility, and the emotional labour required to do this work well. The tactile methods of the workshops made the project inclusive to people with different literacy, language, or comfort levels with academic discussion — a point reflected in the co-facilitators' commitment to meeting people “where they are.” The collaboration also revealed systemic barriers—like institutional payment processes—that continue to undermine grassroots partnerships and undervalue women's labour. Furthermore, the project acknowledged the time it takes to develop a practice that is meaningful, rather than tokenistic.

Publicly, the exhibition at the Inigo Rooms attracted engaged audiences and sparked important conversations — around stigma, creativity, and collective care. The project was featured at major conferences including AIDS 2024 in Munich and BHIVA 2025, and is now being developed into a co-authored academic publication and digital archive, ensuring the work reaches both professional and activist audiences in the UK and beyond.

## THE TEAM'S TOP TIPS FOR IMPACT

### 1. Start with trust, and share leadership

Build your project on existing relationships where possible. Involve community partners from the beginning, not just as contributors but as co-designers and facilitators. Shared leadership ensures the work is meaningful, responsive, and owned by those most affected.

### 2. Prioritise care in process, not just outcomes

Impact grows from how people feel during the work. Emotional safety, hospitality, and collective rhythms (like check-ins and informal planning spaces) are just as vital as final outputs. Making time for care creates the conditions for real transformation.

### 3. Expect friction, and sit with it

Discomfort can be productive; it is a space to learn from and develop better working practices from. Institutional processes — especially around payments, recognition, and timelines — may not fit community-led work. Rather than hiding this, use it as evidence of what needs to change. Impact includes challenging the systems we're working in.

## FURTHER READING

- **The AIDS Quilt on Google Arts & Culture**  
A powerful digital exhibition that connects *Rebel by Default* to a long tradition of activism, grief, and creativity through stitching.  
[The UK AIDS Memorial Quilt Collection — Google Arts & Culture](#)
- **Catwalk4Power**  
A creative, peer-led project centring women living with HIV, developed by Positively UK and partners. Many of the *Rebel by Default* team were involved in this earlier work, which laid the foundations for this project.  
[Catwalk4Power Toolkit](#)
- **Our Stories Told By Us**  
A community-led archive platform celebrating the lives, stories, and creativity of women living with HIV.  
<https://ourstoriestoldbyus.com>



# POSITIVELY UK

This project was funded by an AHRC Impact Acceleration Account hosted by the Faculty of Arts & Humanities at King's College London, and supported by the Faculty's Impact & Knowledge Exchange team

For further information:  
Email: [ah-impact@kcl.ac.uk](mailto:ah-impact@kcl.ac.uk)  
Or visit: [www.kcl.ac.uk/artshums/research/impact](http://www.kcl.ac.uk/artshums/research/impact)