

Co-production in HIV research: reflections from a study on building relationships, conducting qualitative research and developing skills remotely



Vasiliki Papageorgiou¹, Husseina Hamza², Joshua Anderson², Jane Bruton¹, Karl Dsouza², Halle Johnson¹, Silvia Petretti², Wezi Thamm², Helen Ward¹

¹ Patient Experience Research Centre, Imperial College London, UK

² Positively UK, London, UK

vasiliki.papageorgiou17@imperial.ac.uk

@vaspapa_

Background to our approach

Co-production in health research involves collaborative partnerships that actively involve people with lived experience in research as co-researchers.¹ Co-production ensures that co-researchers' insights inform the research process and ultimately the outcome.¹

We worked together for over two years in a qualitative research study on the experiences of people living with HIV in the United Kingdom during the COVID-19 pandemic (see Fig 1) and present reflections from our approach.

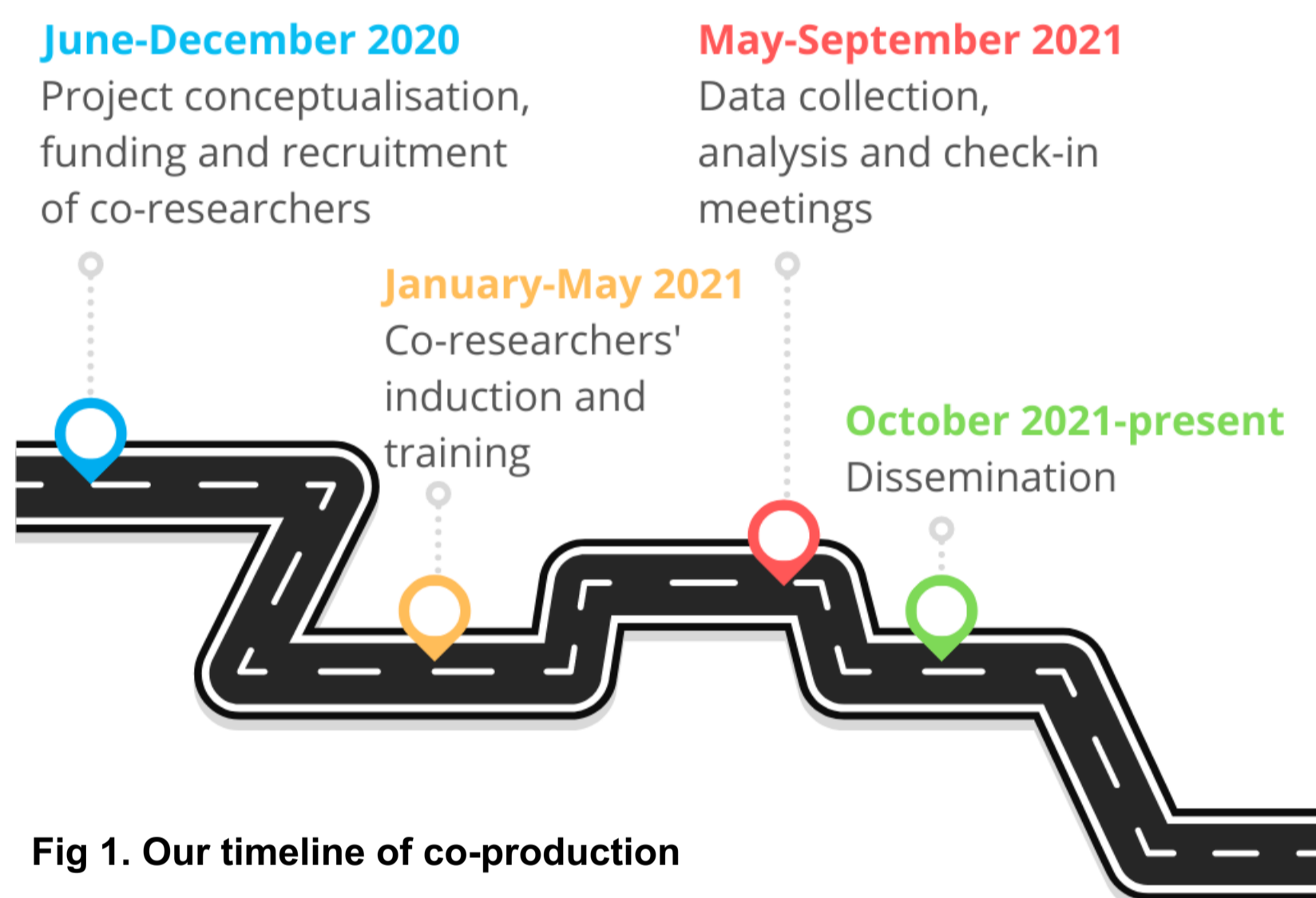


Fig 1. Our timeline of co-production

Acknowledgements

We thank all interviewees, Positively UK and co-production experts who helped to shape the study. We also thank Kabelo Murray (NIHR ARC NWL) for his support with components of the participatory project. Visual notes were created by Federica Ciotti.

Funding was received from the 2020 Rapid Response Seed Fund and Participatory Research Seed Fund (Societal Engagement team, Imperial College London), ESRC LISS DTP and NIHR Imperial BRC.

Reflection 1: Conducting qualitative research

- Peer researchers are acutely aware of the impact of living with HIV, specifically:
 - Living with people unaware of the interviewee's HIV status (e.g., finding a **safe and confidential space** for an interview).
- Some interviews were emotionally charged, and this was felt by peer researchers.
 - Our **training package**² included a session on emotional well-being with techniques such as the emotional wheel.³
 - A safe, reflective space for check-ins** before and after interviews is essential.
 - Peer-led support** can also be invaluable.

Reflection 2: Developing skills remotely

A series of online training² for all co-researchers helped people feel ready to collect and analyse qualitative data.

- Working together was a **skills and knowledge exchange** – we trained all together as a group. This promoted inclusivity, reduced the power dynamic and made co-researchers feel like part of a team.
- People's past experiences and abilities were taken into consideration – all our training started with an 'icebreaker' to help everyone feel **comfortable** and **welcome**, and we developed additional material to **support** co-researchers (e.g., conducting Zoom interviews).⁴
- Several useful training materials already exist.** All our training was designed by speaking to other researchers with extensive co-production experience and through consulting literature.^{3,5,6}

Lessons learned and looking ahead

- Establish relationships early on** – nurture these over time and they may lead to long-lasting friendships and collaborations.
- Be flexible in your approach and budget** – accessibility, transparency and fairness are key.
- Training and support** should be well-planned and iterated as the project progresses.
- Ensure time for reflection** – grow and learn together.
- Be creative in sharing your outputs.** An example of one of our outputs can be seen in Fig 2 and the QR code below includes a link to all our outputs, including our co-produced video and training package.

We need to encourage more researchers to develop and share high-quality examples and experiences of co-produced research to support the development of guidelines for good practice as this approach continues to advance.

Reflection 3: Building relationships

- Having **regular check-ins** and **being responsive** are essential to helping co-researchers feel supported.
- Partnering with a community-based organisation** helps provide the right type of support as well as inspiration.
- Co-production can be **tricky to navigate at times**; for example, co-researchers' experienced life events, illness and the impact of the COVID-19 pandemic.
- Working remotely **reduced geographical barriers** and gave us an opportunity to connect in a different way.

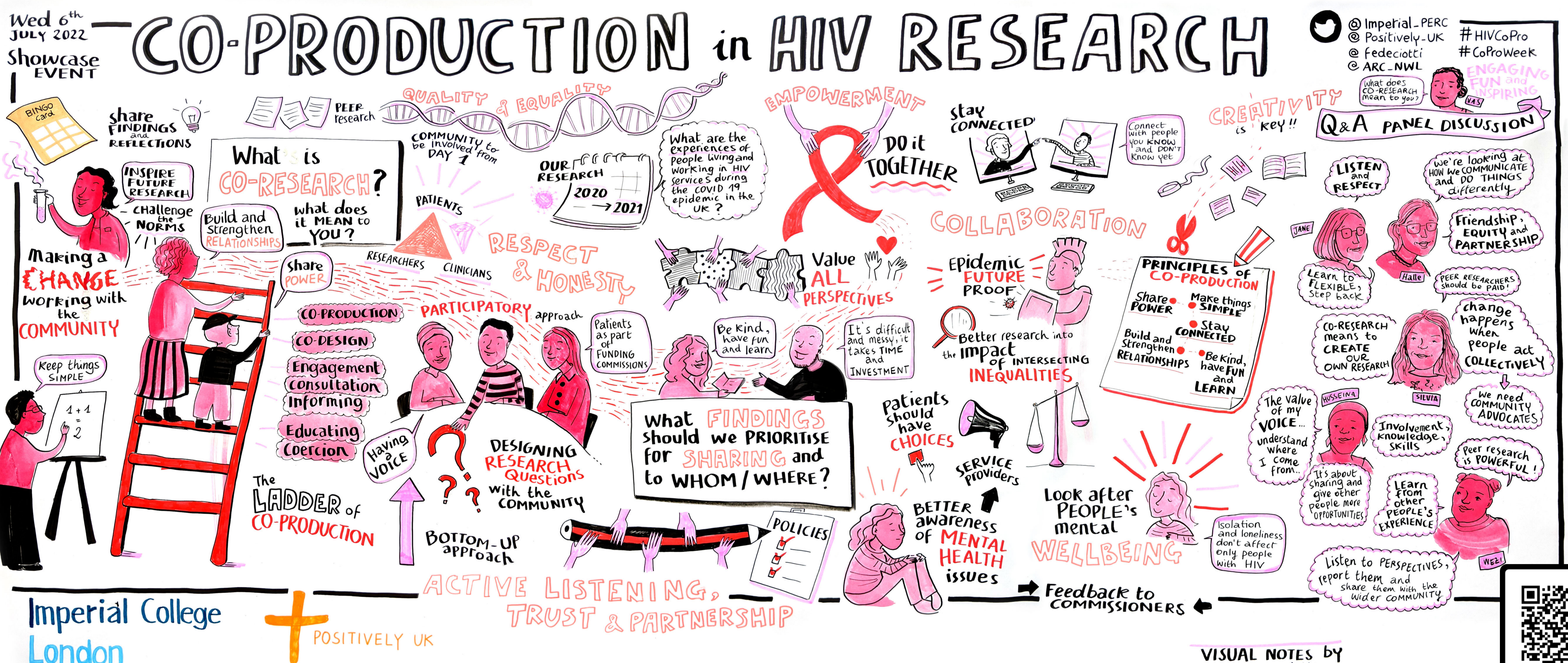


Fig 2. Our visual notes from a co-produced showcase event held in July 2022 to disseminate study results and share experiences of co-production

References

- Hickey G, Brearley S, Coldham T, Denegri S, Green G, Staniszewska S, et al. Guidance on co-producing a research project. 2018. Available from: <https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/Guidance-on-co-producing-a-research-project-2022.pdf>
- Papageorgiou V, Bruton J, Johnson H, Ward H. Peer Research Training Resource. Patient Experience Research Centre, Imperial College London. 2022. Available from: <https://doi.org/10.25561/94819>
- AIDS Bereavement and Resiliency Program of Ontario. Essential Tools for Support and Stability: Worker Resource Kit. 2016. Available from: <https://abrpo.org/resources/essential-tools-for-support-and-stability/>
- Papageorgiou V, Bruton P, Johnson H, Ward H. Supporting material for co-researchers. Imperial College London. 2022. Available from: <https://doi.org/10.25561/100339>
- Ibáñez-Carrasco F, Watson JR, Tavares J. Supporting peer researchers: recommendations from our lived experience/expertise in community-based research in Canada. *Harm Reduction Journal*. 2019; 16(1):55.
- Dewa LH, Lawrence-Jones A, Crandell C, Jaques J, Pickles K, Lavelle M, et al. Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties. *Health Expectations*. 2020; 24:134–46.



SCAN ME

VISUAL NOTES BY
www.federicaciotti.com