

Young Voices in Cancer Data Research: Scoping a National Patient Engagement Platform for Children and Young People in Cancer Data Research

Background

Children and young people's (CYP) cancer data holds enormous potential to improve diagnosis, treatment and long term outcomes because routine healthcare data can reveal patterns and needs that might not otherwise emerge. However, cancer data researchers and patients alike face barriers to meaningful engagement on how data is used and shaped.

Objective

A national Public Involvement and Engagement (PIE) scoping project, led by the Public Engagement in Data Research Initiative (PEDRI) and Cancer Research UK (CRUK), to explore how CYP aged 11–25 with lived experience of cancer can engage in cancer data research through a dedicated digital platform. The Good Practice Standards will be applied throughout the project

Methodology

Phase 0

Stakeholder mapping and the establishment of a Scientific Advisory Group

Public consultation

Conducting focus groups and interviews with CYP aged 11–25 with lived experience of cancer, alongside their parents and carers.

Stakeholder engagement

Interviews with cancer data researchers, digital tool developers and communication officers.

Feasibility assessment

Defining platform functionality, reviewing GDPR compliance and consent processes, and planning for effective dissemination of outputs.



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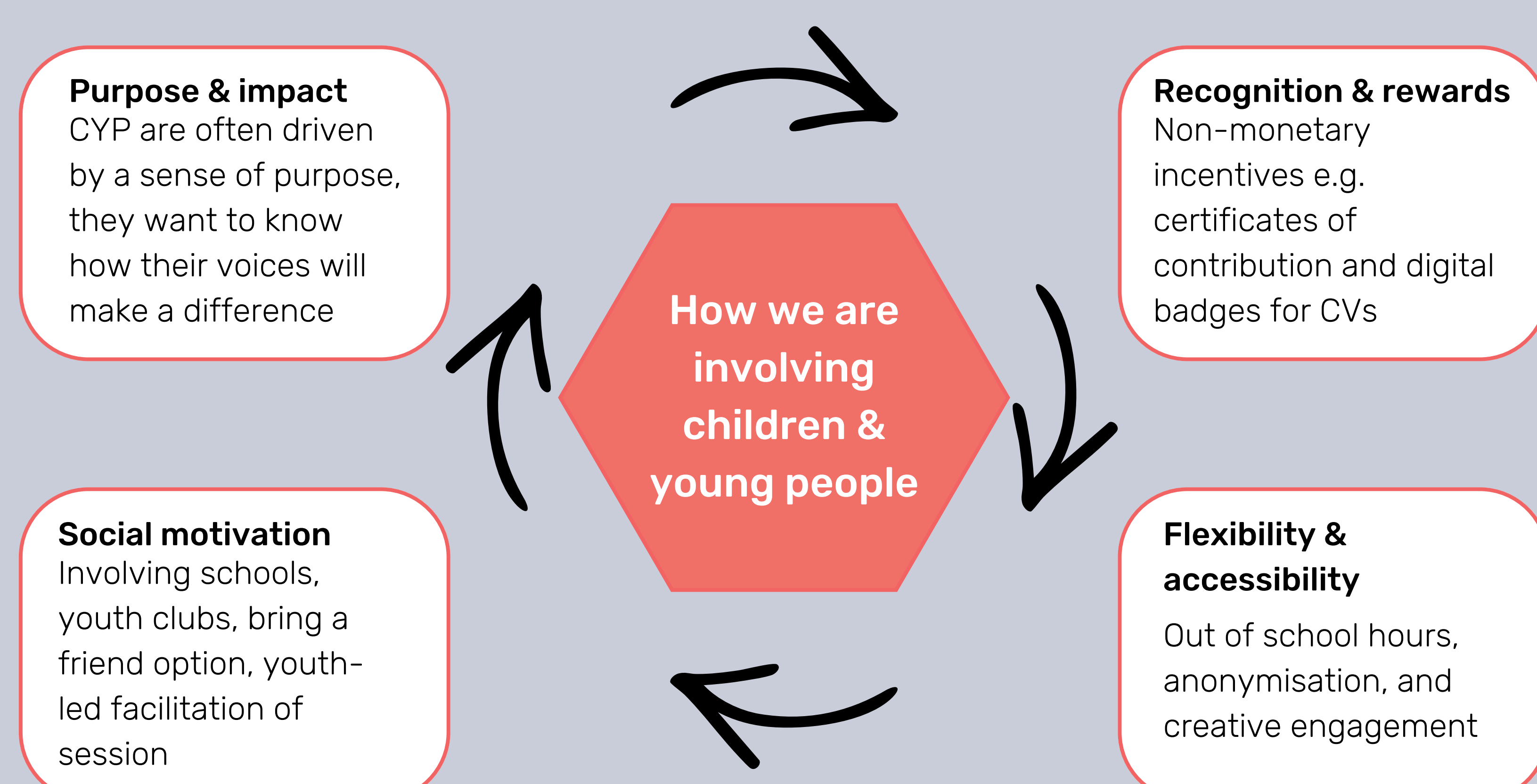
Acknowledgment and Appreciation to Our Scientific Advisory Group

- Mr Andrew Blake, University of Oxford
- Dr Colin Mclean, The University of Edinburgh
- Professor Mieke Van Hemelrijck, Kings College London
- Dr Frances Pearl, University of Sussex
- Dr Anthony Moorman, Newcastle University
- Dr Bob Philips, Consultant Paediatric Oncology - Leeds Teaching Hospitals
- Robin Flaig, The University of Edinburgh
- Yvonne Adebola, Public Advisor

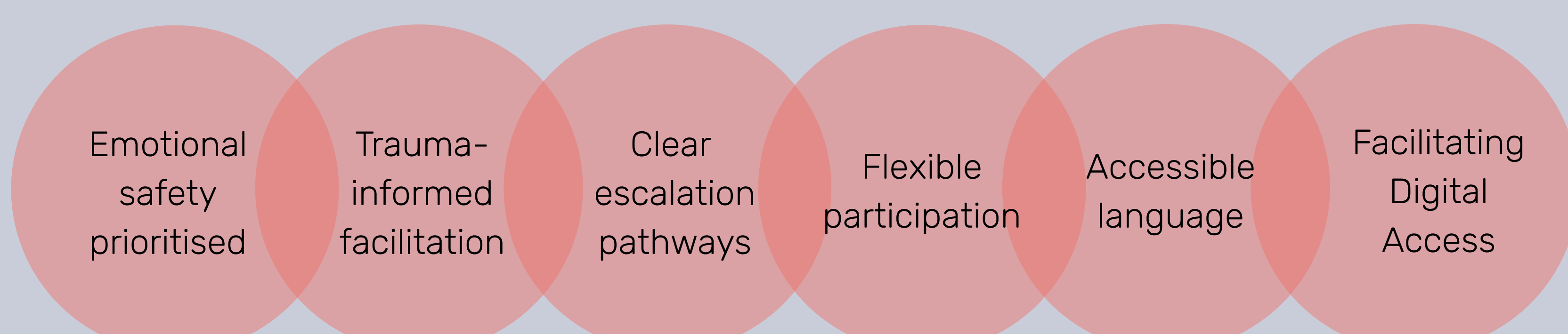
Key challenges

- **Ethics & governance:** Addressing ethical requirements within the CYP lived experience ecosystem, particularly in relation to obtaining parental consent for participants under 16 when formal ethics approval has not been sought.
- **Trust & safeguarding:** Building trusting relationships and safeguarding sensitive discussions.
- **Accessibility:** Considering digital literacy and access, health-related fatigue, and the need for time flexibility.
- **Design:** Embedding inclusive approaches, the use of plain and accessible language, and creative engagement techniques, all grounded in trauma-informed principles.

Public involvement



Evolving approach



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