International Journal of Population Data Science

Journal Website: www.ijpds.org

Developing meaningful public involvement in HQIP's data access processes and Data Access Request Group (DARG)

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Background

As commissioners of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), HQIP are custodians of data from across many areas of healthcare. The high quality and national coverage of circa 40 national audits and registries means datasets are sought after for many purposes.

Introduction

HQIP values placing patients and the public at the heart of our work. We wanted to work with members of our Service User Network (SUN) to research and design how to recruit and sustain public representation in our Data Access Request Group (DARG).

Our primary objective was to work in partnership with public members to co-design a sustainable model that implements meaningful public involvement within DARG.

Our intended outcomes were that HQIP is enabled to establish public membership in DARG, and that HQIP's Data Access processes benefit from the added supportive challenge and assurance that public membership provides.

Methods

We took the following steps to achieve our aims:

- Recruited 3 public members to our project team from our SUN enabling us to have meaningful public involvement throughout.
- Public members contributed to discussions with other organisations with established public membership on their data access committees (IGARD, CPRD, Pioneer) and HDRUK, to gather knowledge on best practice in public engagement with data access processes.
- Fortnightly team meetings to review progress, develop a model for public membership in DARG, and reflect on learnings throughout.
- Invited our public members to observe a DARG meeting to better understand how our data access processes work, and followed this up with a Q&A session.
- Our PPI lead actively supported public members throughout the project, enabling them to self-select how they wanted to contribute, and encouraging them to bring learning from other PPI work they have been involved with.

Results

Our project outputs included:

- A costed business case for establishing public membership within DARG: for HQIP review
- Recruitment resources: promotional materials, role description for public members, public involvement agreement, draft interview tasks and questions
- DARG operating model: amended DARG Terms of Reference, Glossary of terms
- Co-designed webpages: on HQIP's Data Access Processes; inclusion of the Five Safes Framework
- Supporting infographics: to visually display webpage content

Conclusions

This project had the following impact and gave the following insights:

- HQIP approval given for establishing public membership onto DARG
- Improved public accessibility and understanding of HQIP's data access processes
- Clearer roles and responsibilities of DARG members
- A platform within DARG to promote the patient and public voice

https://doi.org/10.23889/ijpds.v9i3.2446

- Learning for HQIP as it was the first-time public members were part of a project team – this brought diversity, new ideas, and challenge
- Public project members more confident to challenge and question professionals in other settings