DEVELOPING MEANINGFUL PUBLIC INVOLVEMENT IN HQIP'S DATA ACCESS PROCESSES AND DATA ACCESS REQUEST GROUP (DARG)

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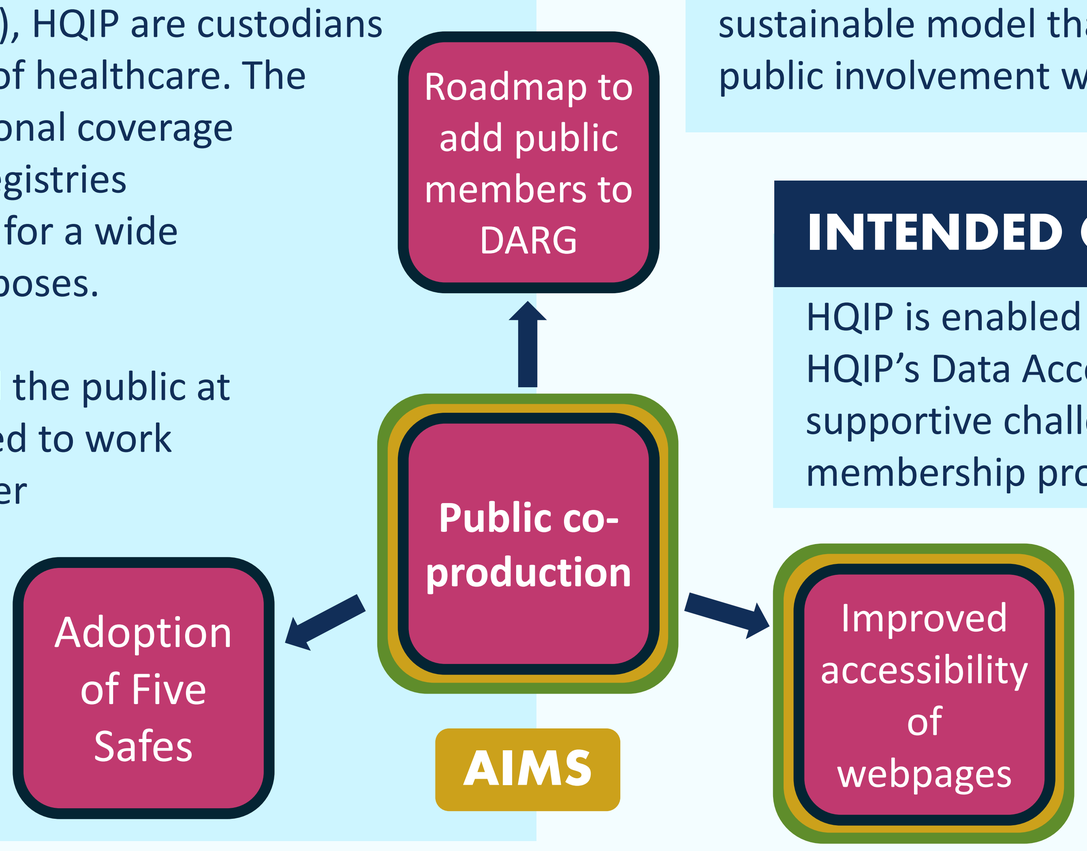
BACKGROUND & AIMS

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 full cohort, national coverage of circa 40 national audits and registries means datasets are sought after for a wide range of research and other purposes.

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), and wider processes.



PRIMARY OBJECTIVE

Work in partnership with public members to co-design a sustainable model that ultimately implements meaningful public involvement within DARG.

INTENDED OUTCOMES

HQIP is enabled to establish public membership in DARG. HQIP's Data Access process benefits from the added supportive challenge and assurance that public membership provides.

TRANSPARENCY STANDARD 2 3 4

APPROACH

Steps taken to achieve our aims:

- Successfully recruited 3 public members to our project team from our SUN enabling us to have meaningful public involvement throughout; all outputs were co-designed.
- Public project team members led or contributed to discussions with other organisations that have established public members 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 and design 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 tutorial/ 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.

PROJECT OUTPUTS

Costed business case – 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
Supporting infographics – to visually display webpage content

IMPACT & INSIGHTS

HQIP approval given

Improved public accessibility and understanding of HQIP's data access processes

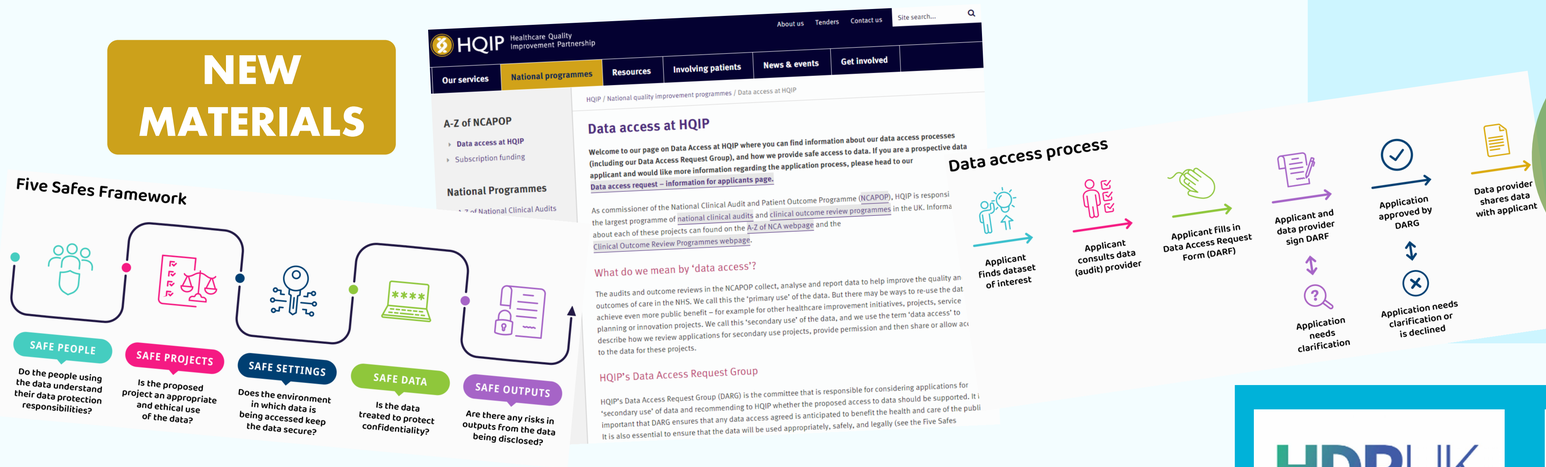
Public members more confident to challenge and question professionals in other settings

Clearer roles and responsibilities of DARG members

Learning for HQIP - first time public members part of a project team
Diversity
New ideas
Challenge

Platform within DARG to promote the patient and public voice

NEW MATERIALS



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