

A Proven Patient Public Involvement Engagement Methodology – Delivering Equity in Design, Planning and Co-Producing Healthcare

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BACKGROUND

- Developing stronger patient and public involvement and engagement (PPIE) in the organisation and delivery of healthcare is now central to health reform across Western economies.¹
- Empowerment, achieved by collaboration as opposed to purely consultation, is the route to optimise patient and public involvement and engagement.
- Repeated calls have been made to engage and involve patients and the public and to place them at the centre of healthcare.²
- HCD Economics (HCD) affiliated with the University of Chester (UoC) Faculty of Health and Social Care, working in partnership with Rare Disease Patient Groups has designed a real world methodology that is centred on a collaboration model, to optimise involvement of patients.

METHODS

- Inclusivity is the ethos of HCD/UoC. For each study undertaken, governance is provided by representatives from the following key stakeholder groups; patient community, medical profession, academia and health economists.
- Each of these stakeholders has equal representation as participants in the study expert review group (ERG).
- The main objective of the ERG is to ensure quality standards are maintained and to provide overall study insight.
- Each stakeholder group is duty bound to work at the highest level of involvement with fellow stakeholder groups, review and provide recommendations to protocol and study materials, periodically review the progress of study execution/maintenance of standards and suggest corrective actions if necessary.
- Insights on critical pathways of disease, impact of disease and patient preference are representative subject matters the ERG appraise, with ERG recommendations based on shared-decision making.

RESULTS

- HCD/UoC successfully undertakes studies with the collaborative ERG methodology at the core. For study indications see Table 1.
- Patient community utility and impact (supported pro bono by HCD) include: European Haemophilia Consortium response to Institute for Quality and Efficiency in Health Care³, supplementary evidence for lobbying efforts on impact on work amongst people suffering with rheumatoid arthritis.
- The findings are then published in peer review publications to inform the global community.⁴⁻⁵

CONCLUSIONS

- Inclusion of the patient community as an equal partner in the ERG ensures utility and output of evidence base is comprehensive and on a shared-decision basis.
- The perspective of the patient experience contributes to patient decision making founded on involvement as first principle.
- Future rare disease studies will replicate the HCD/UoC framework, supporting patient community reciprocal relations with payer and government bodies, and the medical community.

Table 1. Results, collaborative studies and planned studies

Collaborative Studies
• Haemophilia
• Von Willibrands
• Sickle Cell
• Ulcerative Colitis
• Crohn's Disease
• Rheumatoid Arthritis
• NASH
• Non Small Cell Lung Cancer
PLANNED STUDIES;
• Systemic Lupus Erythematosus
• Glioblastoma
• Hereditary angioedema

Table 2. Results, utility and impact

Utility and Impact
• Peer reviewed publications
• Congress presentations
• Response to public bodies
• Payer frameworks
• Academic research
• Evidence-based advocacy initiatives

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