

Embedding meaningful patient and public involvement from application to dissemination: lessons from IMP²ART

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Background and Aim:

Patient and Public Involvement (PPI) is increasingly recognised as essential for developing person-centred respiratory care, yet meaningful involvement throughout the research lifecycle remains challenging. Improving the Implementation of Asthma Self-Management as Routine Treatment (IMP²ART) aimed to improve asthma self-management support in UK primary care. We describe how meaningful PPI was embedded throughout IMP²ART, and the impact on our work.

Methods:

Throughout IMP²ART we collaborated with 16 members of the public who had lived experience of asthma. Our public co-applicant/PPI Lead and deputy PPI Lead attended all management group meetings and whole team meetings. We communicated with our UK-wide Patient Advisory Group through regular hybrid meetings and via emails. NIHR UK standards for Public Involvement in Research were followed. To ensure public contributors were kept informed of how their contributions influenced IMP²ART, we used a "you said..., we did..." feed-back process.

Activity: IMP²ART PPI group involved in future applications.

Impact: Sustainability of PPI group and activities. Future grant applications had PPI input from very beginning. Established relationships and friendships between PPI group and IMP²ART team.

Extending the IMP²ART programme to Evaluate Equity Issues: IMP²ART-E

Activity: Impact of PPI recorded after every activity.

Impact: Highlighted what worked well and what needed improved in our PPI activities and methods. Provided evidence for public contributors of the impact of their involvement with IMP²ART.

Activity: PPI group created video content for asthma patient website.

Impact: Real people living with asthma sharing their perspectives and tips on how to manage asthma made the videos patient-centred, authentic and relatable.

Living with Asthma



Activity: Designing conference presentations and posters.

Impact: Results shared focussed on what mattered to people living with asthma. Creative skills development for public contributors.

Activity: Public contributors as co-authors on peer reviewed articles.

Impact: Helped make results easier to understand for wider public. Built public trust. Skills development for public contributors. Recognition beyond "thank you" vouchers.

COVID-19 information for people living with asthma: A rapid review of publicly available information

JACI IN PRACTICE

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Identifying priorities

Design

Activity: Public co-applicant.

Impact: Genuine structural involvement in designing individual work packages and overall research programme. Increased the knowledge and skills of the research team by bringing the lived experience perspective.

Activity: Public contributor steering group members.

Impact: Public contributors had a deeper understanding of project. Public contributors were "equal" team members. Lived experience in project governance.

Activity: Public contributors informed website design.

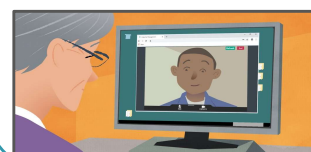
Impact: Website layout was patient-centred and accessible for users.

Living with Asthma



Activity: Public contributor piloted screen sharing for asthma reviews.

Impact: Explored the accessibility of different screen sharing softwares, prior to undertaking project consultations.



Implementation

PPI throughout the research cycle

Grant development

Dissemination

Analysis and interpretation

Undertaking project

Activity: Public advisory group of 16 members, who worked with us throughout IMP²ART, were presented results at various stages.

Impact: Supported research team to interpret the data through a lived experience lens. Gave valuable context to results.

Activity: Co-designed participant documents, including: consent forms; topic guides, information sheets.

Impact: Consent forms were understandable, therefore "informed" consent was obtained. All participant documents were accessible and engaging.

Discussion:

Embedding meaningful PPI throughout IMP²ART improved the relevance, accessibility and patient-centredness of research outputs. Collaborating with public contributors ensured we viewed IMP²ART through a wider lived-experience lens, enabling us to produce a programme of work that was relevant and accessible to those it sought to benefit.

Key Learning:

Meaningful PPI is enabled by sustained relationships, clear feedback on impact, appropriate support and opportunities to contribute across all stages of research. Our approach is transferable to other research and can enhance the development, implementation and dissemination of interventions.