AAC (02)

ACCELERATED ACCESS COLLABORATIVE

PATIENT AND PUBLIC INVOLVEMENT IN THE AAC

Executive summary

- Following the Board meeting in March 2021, and the Board's previous commitments to patient and public involvement, an AAC strategy for Patient and Public Involvement (PPI) has been developed. The strategy has a clear set of ambitions, in line with recognised UK standards, and a delivery approach comprising enablers to embed high quality patient and public involvement as well as programme level deliverables.
- AAC partners are themselves undertaking a wide range of patient and public involvement activity across different stages of the research and innovation pathway. Our partnership presents a unique opportunity to combine PPI knowledge, intelligence and expertise enabling greater impact and effectiveness of the AAC's work. A mapping exercise and the establishment of a PPI Advisory group are recommended to ensure we maximise patient and public involvement across the AAC partnership.

Board members are asked to:

- Note the patient and public engagement work already being delivered.
- Consider and approve the AAC Patient and Public Involvement strategy, detailed in full at Appendix 2.
- Commit to strategic partnership working to support patient and public involvement across the work of the AAC, including nominating a PPI lead to work collaboratively on the mapping activity described at paragraph 13, and to support the ethos of activity described at paragraph 14.
- Support the development of a Patient and Public Involvement Advisory group.

Background

1. AAC Board members have previously highlighted their strong commitment to patient and public involvement. Effective research and innovation are built on both understanding the needs of patients and the public and involving them in the design and development of research and innovation. A commitment to involving patients and the public is clear in the

NHS Long Term Plan[1], the national clinical research vision[2], and the national commitment to design in innovation[3].

2. In October 2019 the Board committed to developing an AAC Patient and Public Involvement (PPI) strategy. The development of this strategy was paused in early 2020 in line with re-deployments to focus on the Covid-19 pandemic and work restarted in early 2021.

3. The AAC has continued to proactively engage patients and the public within our work programmes. People with lived experience have been (and are being) recruited to sit in strategic roles within programme working groups. Patients and patient advocate organisations (charities, community organisations) have joined focus groups and online workshops across several AAC programmes, including the Demand Signalling, Rapid Uptake, Innovation Service and Early Stage programmes. We have enhanced patient and public involvement within our grant programmes and commissioned work (such as the Clinical Entrepreneurs Programme). We have developed a strong focus on Equality and Health Inequality Impact Assessments and action plans for individual work programmes. Additionally, staff have accessed training on public involvement planning, methodologies and techniques.

Collaborative development of the strategy

4. The development of the Patient and Public Involvement strategy recommenced following the March 2021 AAC Board meeting, taking account of the new AAC priorities. It has been developed through a collaborative process with patient representatives sitting on AAC working groups, a focused Task and Finish group, and engagement with wider AAC partners and. Those involved are listed at Appendix 1.

5. The strategy is also informed by a desk top review of other similar strategies across the health sector and existing national best practice, guidance and standards in this field[4] [5]

6. The draft AAC Patient and Public Involvement strategy is attached at Appendix 2 for the Board’s consideration.

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[1] https://www.longtermplan.nhs.uk/

[2] https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery/saving-and-improving-lives-the-future-of-uk-clinical-research-delivery

[3] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/910246/InnovateUK_DesignStrategy_Web-Enabled.pdf

[4] https://sites.google.com/nihr.ac.uk/pi-standards/home

[5] https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf

Effective public and patient Involvement

7. Patient and public involvement is more than having patient representatives on committees. Diverse perspectives are vital, including those with lived experience, those who regularly work with networks of people with lived experience (charities and community groups), lay members who bring a citizen perspective, and most importantly those who are experiencing health inequalities and whose voices have been seldom heard. A strong focus on equality, diversity and inclusion runs through the strategy.

8. We propose the development of a Patient and Public Involvement Advisory Group, comprising AAC partners, people with lived experience, charities and patient advocate organisations. The group will include involvement from Patient and Public Voice partners who are inolved in working groups and decision-making forums of individual AAC work programmes. The Advisory group will take a lead on ensuring that the strategy is delivered and is effective. It will support partnership working across the AAC as well as review performance and support continuous improvement.

Delivering the strategy

9. Six aims, aligned to UK National Standards for Public Involvement, are proposed;
   a. Ensure that a diverse range of patients and the public, especially people with lived experience, are involved in influencing the direction and delivery of the AAC work programmes;
   b. Proactively address equality and inclusion in our work;
   c. Work collaboratively across the AAC partnership and wider system partners to embed a culture of patient involvement across AAC programmes;
   d. Support patients and public partners who work with us to have a positive experience of their involvement;
   e. Measure our impact and outcomes;
   f. Communicate our impact.
10. The aims above have an associated action plan, indicated in the strategy on p7. The actions are cross-cutting and are designed to be embedded across the AAC delivery programmes. Individual AAC work programmes have locally held, annually refreshed, patient and public engagement plans with detailed deliverables. Plans at a work programme level are aligned directly with our strategic involvement aims and action plan. This matrix approach ensures that activity at a programme level is effective, high quality and in line with over-arching principles.

11. Our approach to understanding success and continuous improvement is described in the strategy in Chapter 7. Through a phased development approach, the proposed outcomes framework will establish approaches to understand the impact of both patient and public involvement activity (phase 1 commencing Q2 2021/22), and the benefits that patients experience from AAC innovations (phase 2 commencing Q4 21/22). Possible indicators for understanding effective involvement are outlined in Appendix 3, a final set of indicators will be developed and agreed with Performance & Evaluation team, to align with a broader contribution to the AAC Scorecard.

A partnership approach

12. Across the AAC, partners are working with patients and the public in different ways, focusing on different parts of the research and innovation pathway. The AAC can bring together an involvement ecosystem that is rich with diverse insight across the whole pathway. This is a unique opportunity to share knowledge and maximise the impact of patient and public input and expertise. We propose to work with partners to map this involvement ecosystem, aiming to:

    - Understand what insight already exists and build on patient and public involvement work happening across the partnership.

    - Share knowledge and intelligence, both in terms of patient insights but also in new engagement methodologies, toolkits and resources and best practice guidance.

    - Avoid duplication.

13. To deliver this collaborative mapping we ask AAC partners to nominate a PPI lead to join a task and finish group, chaired by the AAC delivery team in NHS England and Improvement, to undertake this project.
14. The strategy asks that AAC partners commit to its deliverables and the ethos of the following principles in our joint AAC endeavours.
    - Working towards achieving the UK standards for Public Involvement in our respective AAC work programmes;
    - Being effective with our collaborative resources, skills and knowledge;
    - Having a proactive focus on addressing health inequalities throughout the pathway of innovation; addressing equity, access and inclusion and ensuring new innovations do not inadvertently exacerbate heath inequalities;
    - Being a dynamic and learning partnership.

Reporting and governance

15. Patient and public involvement will be reported to the PPI Advisory group, AAC Steering group and Board on a regular basis. Activity will also feed in to the AAC annual report. We will work with the Performance and Evaluation team to explore how this might be reflected in the AAC Scorecard.
16. The Patient and public involvement Advisory group will take a lead in ensuring our engagement activity is effective and delivering our aims.

Term and Scope

17. The term of the strategy is five years, from 2021 to 2026, with a review point in 2023.
18. The scope of the strategy applies to AAC work programmes, and partners collaborating on these programmes. It is designed to be a blueprint for effective involvement across our joint work. It does not replace partner's own organisational patient and public involvement strategies and policies.

Design and Accessibility

19. This will be a public facing strategy and, once approved, will be designed for reader accessibility and impact.

Board members are asked to:

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- Support the development of a Patient and Public Involvement Advisory group.

Author:

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Appendix 1: People contributing to the co-development of the Patient and Public Involvement Strategy

Lived Experience Partners

- Emma Bates - Lived Experience Partner
- Emma Thompson - Lived Experience Partner
- Emma Thorpe - Lived Experience Partner
- Hattie Ridley - Lived Experience Partner
- Joanne Beecroft - Lived Experience Partner
- Karyss Dyett - Lived Experience Partner
- Louise Reece Jones - Lived Experience Partner

AAC Contributing Partners

- David Dexter, Parkinson's UK, on behalf of National Voices
- Hilary Nathan, JDRF (Type 1 Diabetes Research) on behalf of Association of Medical Research Charities
- Saumu Lwembe and Laurie Olivia, National Institute for Health Research
- Sian Rees, Academic Health Science Network
- Victoria Thomas, National Institute for Health and Care Excellence
- Victoria Bates, Jennifer Harris, Association of the British Pharmaceutical Industry

Appendix 2: The Accelerated Access Collaborative Patient and Public Involvement Strategy 2021-2026 (draft)

Appendix 2 DRAFT
PPI strategy 2021-202

Appendix 3: Possible Indicators for understanding effective involvement (to be agreed with Performance & Evaluation team)

Aim	Understanding effective delivery
1. **Ensure that people with lived experience are involved in influencing the direction and delivery of the AAC work programmes;**	• Delivery plans for specific AAC workstreams have been achieved • Narrative examples of patients leading / influencing change • Case studies • Numbers of patient partners involved in governance or influencing roles • Demographic monitoring of those involved • Explore indicators of culture change • Number of patient involvement hours • Narrative around the range and diversity of programme areas with embedded involvement activity

2. Proactively addressing health inequalities in our work programmes;	• EHIAs completed and action plans developed / underway / completed • Number of engagement events held • Numbers of people involved in above sessions • Demographic monitoring of those involved • Diversity of engagement approaches used (including where focused on under-represented communities) • Narrative understanding of accessibility adjustments to meet needs of participants • Evaluation feedback from focus groups, roundtable events • Storytelling / quotes / feedback
3. Collaborate effectively with AAC Board and system partners;	• Metrics or impact information from partners • Information supporting uptake / local engagement • Information about patient indicators for programmes, (for example increase in devices used, patient experience)
4. Support patients and public partners who work with us to have a positive experience of their involvement;	• Feedback from patient partners • Survey of patient representative experiences • Number of patient representatives' well-being / development plans in place • Number of patient and public partners attending training • Number of courses attended. • Evaluation feedback from PPV partners attending training. • Impact of the training on PPV partners- improved confidence, influencing skills, etc. • Staff attending PPI training • Evaluation feedback from staff attending PPI training sessions. • Number of sessions/ topics delivered • Exit interviews / survey • Baseline survey and track longitudinal development
5. Ensure that patient and public involvement is focused on impact and outcomes;	• individual programme delivery plans achieved / milestones / output / locally focused outcomes • (measurement info as per other aims) • Patient benefit framework (to be developed)
6. Communicate our impact	• Quotes, case studies, stories of success from a patient perspective • Annual report content • you said / we did information