

Accelerated Access
Collaborative
Patient and Public
Involvement
Strategy 2021-26

Contents

| About the Accelerated Access Collaborative | 03 |
|--|----|
| Why Patient and Public Involvement matters | 04 |
| Our Vision and Aims | 08 |
| Delivering our Aims | 15 |
| A Partnership Approach | 18 |
| Support and Learning | 21 |
| Understanding our Impact and Outcomes | 23 |
| Scope | 25 |
| Distribution and Review | 25 |
| Associated Documentation | 26 |
| Appendix | 27 |
| Contact Us | 28 |

About the Accelerated Access Collaborative

Formed in response to the <u>Accelerated Access Review</u> published in October 2016, the Accelerated Access Collaborative (AAC) is a collaboration across industry, government, regulators, patients and the NHS. Our partners work together to accelerate the uptake of ground-breaking health care products to get better care to people faster. AAC members are listed at Appendix 1, we are hosted by NHS England and NHS Improvement.

The AAC supports the whole pathway of transformation; from research and innovation, early stage development through to frontline delivery and mainstream adoption.

Our work focuses on new treatments, new ways to diagnose illness, new healthcare devices and digital products (including those using Artificial Intelligence (AI) technology), changes to treatment pathways and new workforce models.

It includes horizon scanning (or searching) for upcoming healthcare changes that can transform lives. The AAC aims to drive forward patient and public benefits through equality of access, improved patient treatment and outcomes and the wider socio-economic benefits of innovation and research in the NHS.

66

Our goal is simple: speeding up access to the best technologies and products – leading to better care for patients. We are excited by this challenge and are proud to have such a prestigious and wideranging number of member organisations working with us.

Lord Darzi, Chair of the AAC



Why Patient and Public Involvement Matters

Effective research and innovation must have the needs and experiences of patients at the centre. Patient and public involvement brings real benefit to healthcare transformation. Involving diverse groups of patients and the public brings a wealth of insight, perspectives, expertise and experience. Patient involvement challenges our thinking and improves what we do by:

- Ensuring research and innovations are more responsive to and meet people's needs
- Understanding barriers and challenges in access to innovations
- Enabling better pathway planning to deliver better outcomes for patients
- Having a better understanding of health inequalities to deliver better health outcomes
- Building spread and adoption approaches on community insights to better create patient pull and effective uptake
- Supporting and developing public dialogue about current and future health services.

This strategy outlines how we are embedding patient and public involvement across the AAC's work.

We are pro-actively seeking a diverse range of patient and public involvement activity in our work, including from:

- People with Lived Experience (including patients, carers and their families),
- Patient advocate organisations (including charities and community groups that that support patients and families),
- Communities that experience health inequalities or have been under-represented in the development of research and new innovations,
- Members of the public (sometimes called 'lay members'),
- Staff with experience and training in co-production and public engagement.

Equalities and inclusion are at the core of our approach. The COVID-19 pandemic has highlighted a multitude of existing health inequalities¹. This last year has highlighted how some innovations can make significant contributions to addressing inequalities, inclusion and accessibility.

The AAC will build on this, identifying and developing innovations that directly address equality, inequality and inclusion. We recognise inequalities are much wider than health and addressing health inequalities can improve lives in other ways.

In developing genuine and sustained partnerships with patients, carers, patient organisations and wider communities, we can ensure that our research and innovation prioritises what matters most to people.

This strategy has been developed collaboratively with representatives of AAC Board partners, our lived experience patient partners and input from wider system partners.



I'm delighted to see that the voice of the patient is important and appreciated.

Emma Thompson

Lived Experience Partner, Asthma Biologics Working Group, Rapid Uptake Programme

¹ https://www.gov.uk/government/publications/covid-19-review-of-disparities-in-risks-and-outcomes

Figure 2. Logic model: Patient & Public Involvement



Working in partnership with patients and the public:

- People with direct lived experience
- Different communities, including those who have been less well represented
- People experiencing health inequalities
- People who want to enhance health care innovations
- Different involvementapproaches that work well for different communities



Leading to better informed activity:

- Addressing of real world needs and gaps in care
- Targeted research and innovation to what matters most to patients
- Shaping design and delivery around patient insight and lived experience
- ✓ Diverse involvement in design and development - improving accuracy at earlier stages



Resulting in better outcomes:

- Research and innovation that has been designed to improve lives
- Innovations are better able to meet real not perceived need
- Opportunities for greater patient pull in adoption and spread
- Positive impact on addressing access and health inequalities
- More effective health care





Definitions and terminology

We recognise that the patient involvement community uses some key terms differently. We have used the terms 'patients' and 'people with lived experience' for people who have direct experience of a health condition and / or services associated with the condition, we include carers and families in this term.

By 'involvement', 'engagement' and 'participation' we mean working collaboratively with people to understand experiences, challenges and solutions.

By co-production we mean working jointly and equally with all of our partners, including those with lived experience, to shape, design and deliver work together.



I am hoping that this strategy will place patients' voice at the heart of the AAC's work and that people will be able to see that patients' voices have influenced and shaped this work.

Joanne Beecroft

Lived Experience partner, Asthma Biologics Working Group, Rapid Uptake Programme



Our Vision and Aims

Our Vision

Our vision is to ensure patient and public involvement is at the heart of how we identify and shape research and innovation that will transform lives.



Our Aims

We have co-designed six aims for patient and public involvement drawing on best practice guidance in the UK standards for Public Involvement² and NHS England and Improvement's statutory guidance on public involvement; the '10 pillars' of public participation³.

These aims build on the core principles of valuing lived experience, embedding wider public involvement, co-production, partnerhship working and measuing quality that were set out by the AAC Board in October 2019.

We will establish a Patient and Public Involvement Advisory Group, with members drawn from patient partners, including those with lived experience, charities and other AAC partners. 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 group will focus and report on progress against our aims and ambitions. The group will also act as a forum to share knowledge and insight, review our impact and consider how we continuously improve our engagement with patients and the public. This group will report into the AAC Steering group and Board.

The AAC is hosted by NHS England and Improvement and adheres to the NHS England and Improvement <u>Patient and Public Voice Partners</u> <u>policy</u> and <u>Reimbursement and Involvement Payments policy</u>.



I can wake up in the morning and put meaning, purpose and drive into this work. It finally feels like experts in the field, experts by experience and the public are working together in harmony, listening to each other and valuing what each has to offer in order to create positive change. We can achieve great things together to improve lives and empower patients, carers and their families.

Emma Bates

Lived Experience Partner, Rapid Uptake and other AAC programmes.

² The six <u>UK Standards for Public Involvement</u> in research are hosted by National Institute for Health Research (NIHR) and were co-developed by a <u>UK-wide partnership</u>. They provide a description of what good public involvement looks like and are designed to improve the quality and consistency of approaches and behaviours that are the hallmark of excellence in public involvement.

³ NHS England and Improvement statutory guidance for involving patients and the public in commissioning arrangements

We aim to:





Ensure that a diverse range of patients and the public, especially people with lived experience, are involved in influencing the direction and delivery of our work programmes





Proactively address equality and inclusion in our work





Work collaboratively across the AAC partnership and wider system partners to embed a culture of patient involvement across AAC programmes





Support patients and public partners to have a meaningful and positive experience

5



Understand our impact and outcomes

6



Communicate our impact





Ensure that a diverse range of patients and the public, especially people with lived experience, are involved in influencing the direction and delivery of our work programmes

- Establish an Involvement Advisory group.
- Involve patients and the public, including people with lived experience, in the governance and development of individual work programmes.
 - Develop bespoke patient and public involvement activity, including coproduction approaches, for each of our work programmes.





Proactively address equality and inclusion in our work

- Embed Equalities and Health Inequalities Impact Assessments and action plans across all our programmes.
- Engage with a diverse range of people and communities, especially those who experience the greatest health inequalities.
- ✓ Work collaboratively with our health system partners, including patient organisations and the voluntary, community and social enterprise (VCSE) sector, recognising their trusted role in reaching people with lived experience.
- Ensure that we offer a diversity of ways for people to get involved.

3



Work collaboratively across the AAC partnership and wider system partners to embed a culture of patient involvement across AAC programmes

- ✓ Work with key system partners to better enable national, regional and local patient involvement and co-production in research and innovation pathways.
- Work with partners to enhance patient 'pull' for the adoption of innovations.
- Work together to share and pilot new, creative and accessible engagement methodologies.



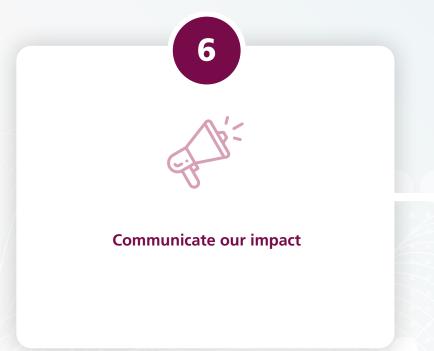


Support patients and public partners to have a meaningful and positive experience

- Ensure that our lived experience opportunities, and our recruitment, expenses and involvement payment policies are fair, accessible and inclusive.
- ✓ Offer support, mentoring and learning opportunities to our lived experience partners including co-developing a training and wellbeing package to support partners.
- ❷ Build the confidence and skills of staff and partners to embed patient and public participation in our work, including working with AAC partners to learn from each other.

Understand our impact and outcomes

- Develop a framework of qualitative and quantitative measures, to understand our impact and outcomes.
- Ensure that we are delivering effective patient and public involvement, are benefiting communities and people's contribution is adding real value.
- Review and continuously improve our approach.



- Publish information about the difference that patient and public engagement has made.
- Celebrate successes.
- ✓ Feed back on the outcomes of our involvement, including to those who are directly involved in our work.
- ➢ Be clear where we have taken action in response ('you said../we did /haven't yet done / aren't able to do because.....').

Delivering our aims:

The AAC has six overarching priorities that guide all our work programmes. Work programmes under the AAC's priorities will have bespoke patient and public involvement plans, that underpin and deliver our action plan set out on page 11 to 13.

Workstream leads hold detailed action plans for each programme. The patient and public engagement team, our partners and workstream leads meet regularly to share insights and learning, ensuring an integrated and consistent approach across the programmes.

We set six priorities for the next two years:



Always patient centred

We will value lived experience and ensure patient and public involvement is at the heart of how we identify and shape research and innovation that will transform lives.



Supporting fast and equitable access to proven innovations

Support the NHS to make proven innovations available quicker to all who could benefit wherever you live.



Future proofing tomorrow's care

Being clear to innovators about the NHS's needs and bringing patient and clinical insight to bear on which innovations to prioritise, ensuring a pipeline of innovations that will make biggest difference to patient outcomes.



Empower a culture of innovation

Support programmes and initiatives which embed innovation into NHS culture and ways of working.



Embedding research in the NHS

Improving patient outcomes by embedding research in healthcare practice across all NHS settings and increasing the number and diversity of people accessing and taking part in research.



Focused collaboration with industry

Supporting the growth of the UK's world leading life sciences industry and making the UK one of the most pro-innovation healthcare systems in the world, where all patients can access the best new treatments and technologies.



A Partnership Approach

The AAC partnership includes charities, government bodies, health system organisations, industry and NHS bodies, and people with lived experience. Bringing those with lived experience, patients and the public into the heart of the AAC programmes ensures that our work is rooted in and shaped by real world experience.

National Voices and the Association of Medical Research Charities are part of the AAC Board, bringing vital insight from across their coalition organisations into our direction setting. We work in partnership with a wide range of charities and patient advocates.

We work collaboratively with a range of patient focused organisations to enable us to reach out and genuinely co-produce work with a diverse range of people and communities. These partnerships enable the AAC to link to extensive community networks. Working with trusted partners, we can reach out through their networks to ensure that we are proactively involving people who are often under-represented. We want to ensure that research undertaken in and for the NHS is inclusive and that our programmes support the development of innovations that address health inequalities.

This short animation describes the AAC and the power of our partnership approach.

We are working with the National Institute for Health Research (NIHR) to involve patients and the public in the design and delivery of research in order to improve the reach, quality and impact of research; and to increase the diversity of participants involved in research.

AAC partners include industry, the Association of British Pharmaceutical Industry and the Association of British HealthTech Industries and other developers of medicines and health products. Bringing patients into the development process means that lived experience can shape research trials and inform the whole development process for new treatments and products.

Working with National Institute for Health and Care Excellence (NICE) and the Medicines and Healthcare products Regulatory Agency (MHRA) to bring patient and public views into the guidance, licencing and regulatory processes for new drugs, devices and other innovations.

Our Academic Health System Network (AHSN) partners are focused on local delivery, ensuring that the AAC supported innovations get adopted fast and spread to patients and clinicians across the whole country.

Our government and NHS partners have both a policy and delivery focus. This dual focus supports how we explore patient and public involvement in a systems context, and create patient pull for research and innovation at a national, regional and local level. It helps to embed patient engagement and innovation activity in Integrated Care Systems (ICSs), Trusts, Primary Care Networks (PCNs) and other parts of the health and care system.

66

We need to think about inclusion and equality from the beginning of the innovation process. For example, wearable medical devices are transforming lives for people with type 1 diabetes, but they are almost always only available as white clinical equipment and white skin adhesives. For other skin colours, you often need to buy 'makeshift' sleeves or covers that cover the wearable device. And yet these are technologies which will extend into global markets and populations. It is therefore fundamental to need to embed diversity in every element of research, development and delivery.

Hilary Nathan,

Director of Policy and Communications, JDRF (Type 1 diabetes research charity), Association of Medical Research Charities

Across the AAC, partners are working with patients and the public in different ways, focusing on different parts of the research and innovation development process. Many have their own organisational patient and public involvement strategies and approaches. This partnership brings together an involvement ecosystem that is rich with diverse insight across the whole research and innovation pathway. It is a unique opportunity to share knowledge and maximise the impact of patient and public input and expertise.

Working with partners, we will map our collective patient and public involvement to better enable co-production in innovation pathways.

We will:

- Start from understanding what insight already exists and build on patient and public involvement work happening across the partnership.
- Share knowledge, both in terms of patient insights but also in new ways of working, engagement methods, toolkits and resources and best practice guidance.
- Avoid duplication and engagement fatigue.

AAC partners are committed to the following principles:

- Working towards the ethos of 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 health inequalities.
- Being a dynamic and learning partnership.

Support and Learning

Building a culture of involvement and working together with communities is important to us. We want to support all our partners, staff and patients alike, through sharing skills and experiences, offering support and development opportunities.

We will:



1. Support staff to develop their skills and confidence though training and peer-led development, sharing and adopting best practice guidance for patient and public involvement. We will offer opportunities to practice, reflect and improve.



2. Offer training and support for patient partners to be effective in their roles with dedicated learning and development opportunities, including a framework of training and mentoring opportunities.



3. The right practical tools and infrastructure in place. This will include a clear policy for involvement payments and expenses.



4. Be transparent and accessible in our recruitment, hold accessible events and be creative in exploring new methods of involvement, including developing expertise in a wide range of digital engagement.



5. Build on our digital involvement strategy to ensure that our approaches are accessible, engaging and consider digital inclusion needs, proactively supporting diverse involvement.



6. Work with communities and other engagement specialists across the partnership to ensure we share and adopt best practice.



The induction, training and support has been great. It has helped having this early on and some of it prior to starting our role.

Joanne Beecroft

Lived Experience Partner, Asthma Biologics Working Group, Rapid Uptake Programme





66

I think the support we receive has been fantastic and I am confident in seeking support if I feel I need it.

Louise Reece-Jones

Lived Experience partner, FeNO Working Group, Rapid Uptake Programme

Understanding our Impact and Outcomes

We will review the quality and impact of our approach to patient and public involvement, as well as how our programmes are benefiting patients. We are taking a phased approach to developing an outcomes framework to understand and improve the effectiveness of our patient involvement. We will work with our patient partners to build this framework around what outcomes matter to them.

Patient and public involvement will be spotlighted through our monthly programme reporting and reported regularly to the Board. An annual review of patient and public involvement activity will be reported to the Board and will feed in to the AAC annual report.

We will also investigate how patient and public involvement could feed in to the AAC Scorecard. The Patient and Public involvement advisory group will take a lead in ensuring our engagement activity is effective and we are delivering our aims.



Phase 1

Understanding how our involvement approaches have been effective:

We will focus on:

- What outcomes matter to patients.
- Understanding how well we are delivering our aims outlined in section 3 in full.
- ✓ Have the patient and public involvement plans for specific workstreams been delivered?
- ✓ How can we demonstrate our impact?
- What can we learn and improve?

We will use a combination of quantitative and qualitative approaches to develop a range of indicators that will inform our understanding of success.

Phase 2

Understanding patient benefits from the AAC work programmes

The AAC delivers a wide range of programmes with different data collection requirements and opportunities.

Currently, patient benefit data is broadly collected through uptake information in relation to specific innovations. Patient experience data in relation to uptake is not routinely available.

The PPI team and AAC partners will support AAC work programmes to explore approaches to capture patient benefits at a programme-level, appropriate to innovations.

Scope

This strategy has been developed by AAC partners, including organisations and patients partners. It has been approved by the AAC Board, it applies to the AAC work programmes.

Distribution and Review

The strategy will be publicly available on the AAC website patient and public involvement page. The strategy will be reviewed bi-annually. Comments or suggestions to be considered as part of a review should be forwarded to the Patient and Public Involvement team at england.aacppi@ nhs.net.



Contact us

The Patient and Public involvement team for the AAC can be contacted at england.aacppi@nhs.net

Associated Documentation and Strategies

AAC

Our Year in Focus: 2019/20

The Accelerated Access Review

NHS England and Improvement

- NHS England Accessible Information and Communication Policy
- NHS England's Patient and Public Participation Policy
- 'Working with our Patient and Public Voice Partners: reimbursing out of pocket expenses and involvement payments for Patient and Public Voice.'
- NHS England Safeguarding policies (available from the Safeguarding team)
- The <u>Equality and Health Inequalities Analysis</u> for NHS England's Public Participation Policy
- Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England

Appendix 1: Accelerated Access Collaborative Partners





Academy of Medical Royal Colleges























Medicines & Healthcare products Regulatory Agency





Thank You

To all the lived experience partners and partner organisations who were involved in the co-development of this strategy.