

ACCELERATED ACCESS COLLABORATIVE

PATIENT and PUBLIC INVOLVEMENT IN THE AAC

Executive summary

- Historically the AAC has had a good record of engaging and involving health professionals and industry stakeholders, however there has been less involvement of patients, carers and the public.
- This paper describes the approach being taken to developing patient and public involvement (PPI) across the AAC workstreams.
- **Board group members are asked to note the proposed approach agreed by the AAC Steering Group.**

Background

1. Patient and public involvement is integral to the Long Term Plan (LTP). In the context of the AAC, involvement ensures research and innovation addresses the needs of patients and carers, as well as clinicians and health system leaders.
2. AAC Board members have highlighted the importance of involving patients, public and charities in AAC's programmes. The potential benefits of involving patients and the public include:
 - innovations selected for support through the AAC will best meet the needs of patients;
 - innovators will include PPI in design and development of innovations;
 - innovators will benefit from greater understanding of patient's needs and priorities;
 - work commissioned through AHSNs and other organisations will be informed by what matters to patients.

3. A working group, chaired by NHSE/I, was established in July to develop and implement a PPI strategy for the AAC. This Group is made up of representatives with experience in involvement from the AHSNs, the AMRC, NIHR and National Voices. These organisations have a wide range of information and guidance to support PPI which the AAC will draw upon, including:

- **NHS England and NHS Improvement:** Resources on the NHS England Involvement Hub, including good practice examples, case studies and 'bite-sized guides'.
- **National Voices** is a coalition of health and care charities in England with 160 members, bringing charities large and small together. They have published '1 statements' that outline the values people who use services want to see represented in research and innovation.
- **Academic Health Sciences Networks** (AHSNs) have a network of PPI leads across the country and have published guidance on PPI in the digital age.
- **NIHR** has published standards for public involvement in research and fund **INVOLVE** an organisation that has a key role in supporting active public involvement in NHS, public health and social care research. Involve has published guidance and best practice information.
- **AMRC** represents and can provide the link to over 140 medical research charities, who have close patient and public networks and a wealth of experience with PPI. They can bring user perspectives, help surface unmet need and are innovators themselves.

The AAC's emerging principles for involvement

4. The Working Group propose an overarching principle to inform all PPI work going forwards: *People with lived experience (patients and carers) will be involved in all the AAC's workstreams.*

5. This will be achieved by:

- embedding involvement into individual work programmes, rather than creating a separate function;
- not duplicating activity already established by partner organisations;

- ensuring that people involved have appropriate lived experience;
- AMRC and National Voices both sit on the AAC steering group and board and have a role in PPI assurance;
- developing a PPI strategy for the work of the AAC which will set out:
 - i. what involvement will look like for each AAC workstream
 - ii. priorities for phase 1 of implementation (see Table 1 below),
 - iii. a policy detailing what patients and carers can expect in terms of support, travel, expenses and remuneration
 - iv. how NHSE/I and the AAC will work with the AHSNs, the AMRC, NIHR, and National Voices to deliver the strategy.

The Emerging PPI strategy

6. Given the breadth of the AAC, a staged approach to development and implementation of an involvement strategy is recommended:
 - Phase 1 (August to December 2019) focuses on increasing patient pull for innovators including work on: PPI in the rapid uptake products programme; information on PPI for the Innovator Portal and Clinical Entrepreneurs; including PPI in demand signalling.
 - Phase 2 (December to March 2019) includes starting work on: PPI in early stage product selection; developing metrics for PPI, and PPI in real-world testing.
 - Phase 3 (April 2020 onwards): is scoping the longer-term ambitions includes work on increasing the diversity of people involved in research and innovation.

Table 1: Phase 1 of PPI activity

AAC area of work	Aim of PPI	AAC Programme	What will be done by October 2019
<p>Product selection</p>	<p>To ensure that products supported meet the needs and priorities of patients.</p> <p>To ensure patients and charities are helping to promote the adoption of supported innovations.</p>	<p>Rapid Uptake Products (RUPs) – current products</p>	<p>Mapped the existing current and planned PPI across different products</p> <p>Initial meeting with charities on PIGF held 3 October</p> <p>First 2 RUP product workshops with charities and people with lived experience planned for October.</p>
		<p>Early Stage products</p>	<p>Consider the role of PPI in selection of Early Stage Products</p> <p>Consider the role of PPI as supported products are developed</p>
<p>Innovation Ecosystem</p>	<p>To ensure that patients and charities inform AAC policies and that policies reflect the needs of patients</p>	<p>Innovation Portal</p>	<p>Overview of PPI ready to be uploaded onto portal</p>
		<p>Demand Signalling</p>	<p>First round of NHSE/I LTP research and innovation workshops included people with lived experience.</p> <p>AMRC member workshop to identify cross-cutting areas of unmet need.</p> <p>National Voices review of unmet need underway</p>

		Increased patient demand for proven innovation	Case studies from charities and AHSNs requested and being analysed
Commissioned work	To ensure that the work we commission includes appropriate PPI.	AHSN assurance	Plans in place to include a review of PPI as part of AHSNs Q2 review
		SBRI	CVD call used to explore how best to include PPI
		Clinical Entrepreneurs	Overview of PPI ready to be included in handbook

Board members are asked to note the proposed approach to involving patients and the public in the AAC's workstreams

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Appendix 1: Phasing of PPI work

AAC Area	AAC Prog	PPI activity	Phase 1 July-Dec	Phase 2 Jan-March	2020 -21
Product selection	RUPs	Support for appropriate PPI with current products	Work starts	Work continues	PPI imbedded
		Future product selection includes PPI	Work starts	Work continues	PPI imbedded
		RUP - patient demand	Work starts	Work continues	Work continues
	Early stage products	Future product selection includes PPI	Work starts	Work starts	Work continues
		Support for appropriate PPI as products develop		Work starts	Work continues
	AI programme	Explore role of PPI in AI programme	Work starts	Work continues	Work continues
Innovation Ecosystem Policy	Innovation Portal	Portal includes overview of PPI and links	Work starts	Work continues	Work completes
		Charities involved in portal design	Work starts	Work continues	Work continues
		PPI framework sets expectation for PPI in product development	Work starts	Work continues	Work completes
		PPI guidance for innovators developed	Work starts	Work continues	Work completes
	Demand Signalling	NHSE/I demand signalling includes appropriate PPI	Work starts	PPI imbedded	PPI imbedded
		Unmet needs where innovation is required are identified	Work starts	Work completes	complete
	Adoption and spread	Develop and test models for increasing patient demand	Work starts	Work continues	Work continues
		Develop metric for monitoring impact of PPI in work of AAC		Work starts	Work continues
	Testbeds	Understand current PPI in real world testing and agree what support is needed	Work starts	Work continues	PPI imbedded
	Expand NICE Assessment of digital products	Assessment includes PPI representatives and considers PPI in product development		Work starts	Work continues

	Increase diversity	Develop and test models for increasing diversity of people involved in research and innovation			Work starts
Commissioned work	AHSN activity	AHSN assurance includes PPI representatives and reviews local PPI practises	Work starts	Work continues	PPI imbedded
		Consider what guidance and support AHSNs need to embed PPI		Work Starts	Work completes
	SBRI	SBRI selection includes PPI representatives and considers PPI in product development	Work Starts	Work continues	PPI imbedded
	Clinical Entrepreneurs	Guidance on PPI included in handbook	Work starts	Work completes	
		Sessions on PPI included in "sandpit" programme	Work starts	PPI imbedded	PPI imbedded
Comms	All AAC activity	Information for Charities on what the AAC means for them	Work Starts	Work continues	Work completes
	Early Stage Products & RUPs	Lay persons narrative on what these are	Work Starts	Work continues	Work completes