

Asthma UK – PPI Framework and Standards in Research

This Public & Patient Involvement Framework is based on the [2018 NIHR standards for Public Involvement in Research](#) and is aimed at researchers. The Framework should be applied as appropriate depending on the project. It is assumed that a research project will be broken down into 'work packages', and the main oversight group will be titled 'project management group'. We appreciate that this is not always the case, and the terminology should be used as guidance.

Standard 1: INCLUSIVE OPPORTUNITIES	
<ul style="list-style-type: none"> • Ensure that researchers/research partners are clear where PPI needs to happen, ideally 3 months in advance • Discuss practical terms and delivery with the research project team at/before the start of the project • Decide the location, timing and frequency of meetings from the outset (e.g. Telecon vs in-person) • If possible, prepare an information pack for volunteers including a short description of volunteers' role and what has been agreed; information is given about the period of time over which involvement will be required and the type of contribution (e.g. partnership, advisory role, reviewer) 	
What Asthma UK expects from you	What you can expect from Asthma UK
<ul style="list-style-type: none"> • Regular communication with Asthma UK by the PI/allocated person, including scheduled calls to update on new decisions affecting PPI within a week of them being made. • Circulate/share meeting minutes within one week of meeting (draft version acceptable) • Agendas shared a week in advance • PPI is a standing item on agenda for 'project management group' meetings, with 3-month forecasting on upcoming activities, and reviewing PPI actions and outcomes • Work with Asthma UK to prepare information pack for PPI volunteers 	<ul style="list-style-type: none"> • Dedicated point of contact to support and advise on PPI • Meeting minutes from 'patient advisory group' shared within one week of meeting/activities • Advice on what PPI activities can be undertaken to add value, and implementing these • Asthma UK representative will provide PPI updates to 'project management group' meetings
Standard 2: WORKING TOGETHER	
<ul style="list-style-type: none"> • Research team has role descriptions for everyone involved, including members of the public, that have been agreed and reviewed • All co-applicants need to share progress of research with the facilitator so that involvement opportunities can be recognised in a timely manner • Researchers/co-applicants provide regular feedback to volunteers so that they can see how and where their contribution to research plans has been incorporated; an annual review with volunteers to check on how they are finding the experience, and what can be improved 	
What Asthma UK expects from you	What you can expect from Asthma UK
<ul style="list-style-type: none"> • Support role description and share brief sentence with: name, role, what work packages they are involved in, responsibilities, what groups they sit on, and contact details if appropriate. • PPI is a standing item on agenda for 'project management group' meetings, with 3-month forecasting on upcoming activities, and reviewing PPI actions and outcomes; all meeting attendees are expected to contribute to these discussions including feedback and evaluation • Annual meeting with PI and work package leads (where relevant that year) to discuss and evaluate PPI as a whole: lessons learnt and forecasting next year 	<ul style="list-style-type: none"> • Asthma UK will lead discussion/facilitation of how PPI has been implemented and evaluation of its effectiveness, and will feedback to volunteers • Asthma UK will act as liaison between volunteers and researchers to facilitate two-way streamlined communication and manage reciprocal workloads • (Annual PPI meeting): Asthma UK will circulate agenda a week in advance, and minutes a week following the meeting
Standard 3: SUPPORT & LEARNING	
<ul style="list-style-type: none"> • Ensure there is a clearly identified point of contact for information and support (researcher/AUK staff) so that volunteers have a key contact or mentor who can provide advice and guidance about involvement in research • All co-applicants to ensure that the study timelines are realistic and negotiated to allow a reasonable amount of time for volunteers to input into the research • Research project team reviews its progress regularly, including how it is doing in involving the public in research 	
What Asthma UK expects from you	What you can expect from Asthma UK
<ul style="list-style-type: none"> • Researchers are open and willing to engage in PPI, including new models of PPI, and with Asthma UK Research and Policy volunteers. 	<ul style="list-style-type: none"> • Dedicated point of contact to support and advise on PPI

<ul style="list-style-type: none"> • PPI is a standing item on agenda for 'project management group' meetings, with 3-month forecasting on upcoming activities • Ensure PPI volunteers have a minimum of 2 weeks for review of documents • Support for an induction session for PPI volunteers • Attend and contribute to annual PPI meeting (with PI and relevant work packages leads) to discuss and evaluate PPI as a whole: lessons learnt and forecasting next year 	<ul style="list-style-type: none"> • Advice on PPI activities that could be undertaken, and the time required for these • Asthma UK to lead on induction activities for PPI volunteers • If requested, Asthma UK can write the PPI section of annual progress reports for the funder
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Standard 4: COMMUNICATIONS

- Volunteers and researchers can identify who they should approach in the research team or Asthma UK if they want to raise a query
- Any questions raised by volunteers/researchers or facilitator to be answered within 5 working days
- Co-applicants to engage with all PPI representatives and facilitators on an equal footing
- Facilitator can advise on feasibility of timeline and likely success of involvement opportunities

What Asthma UK expects from you	What you can expect from Asthma UK
<ul style="list-style-type: none"> • Dedicated point(s) of contact for each workstream / activity. • Respond to questions from Asthma UK within 5 working days • Engage with all PPI representatives and facilitators as equals. Avoid use of jargon and be prepared to expand any technical information into lay language 	<ul style="list-style-type: none"> • Dedicated point of contact, expert in PPI facilitation, to support and advise on PPI • Respond to questions within 5 working days • Regular communication (via 'project management group' meetings and any other frequency agreed at project outset) from Asthma UK on feasibility and timelines for involvement activities

Standard 5: IMPACT

- Ensure that the feedback from volunteers and researchers on their experience of public involvement in the project is routinely recorded, monitored, reported and acted on

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Standard 6: GOVERNANCE

- Ensure that public involvement is a standing agenda item at senior management meetings
- Research team plans the public involvement in their project and then monitors and reviews what they do to learn and improve
- Volunteers are decision makers in developing, delivering, monitoring, reviewing and reporting plans for public involvement in research
- Asthma UK keeps records of resources so that this information can be used for internal review, and design and proposals of future public involvement opportunities *[Asthma UK internal use only]*

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