

ALSPAC Participant and Public Advisory Panel (APPAP)**Terms of Reference****1. Introduction**

- 1.1 ALSPAC, also known as Children of the 90s, has run a participant advisory group since 2005. Since then and following consultation with staff and participants it was agreed that the group should adapt to become a formal PPI panel. The aim of the ALSPAC PPI group is to advise and guide the ALSPAC Executive and Senior Management Team (SMT) through the responsibilities listed below.

2. Remit

- 2.1 The responsibilities of the ALSPAC PPI group are to:
- Provide advice, guidance and feedback on the progress of ALSPAC
 - Provide views to researchers on the acceptability of proposed new studies
 - Provide views on the design and content of new questionnaires
 - Review participant facing written content
 - Provide advice and guidance on policies to support the running of ALSPAC
 - Provide information and advice on participant burden
 - Guide and advise on the dissemination and impact of research findings to study participants and the wider public

3. Membership

- 3.1 The Chair of the ALSPAC PPI group will be either a member of the group or a member of ALSPAC staff. The Chair will be responsible for the agenda and conduct of the meetings; for maintaining a record of proceedings and for producing reports of meetings for the Executive. The ALSPAC engagement team will fully support the Chair in these responsibilities.
- 3.2 There will be around 10 members on the panel. Fifty percent of members will be members of the public with an interest in health research and 50% will be study participants. The ALSPAC team will be responsible for selecting, appointing, removing and replacing all members, including the Chair.
- 3.3 All members, including the Chair, will declare any conflicts that may arise from any other studies or organisations they are working with. Members will be expected to ensure that any information gained during the meeting will be kept confidential.
- 3.4 A quorum exists where at least half of the members are present.
- 3.5 Members will be appointed for the period of the ALSPAC renewal grant (up to July 2024). After this there will be a review every 12 months. Members will be selected from across the UK and will ensure the group is diverse in ethnicity and gender. A diverse range of experience coupled with enthusiasm are key to the group's, and ALSPAC's, future success.
- 3.6 Members are expected to understand and enact the recognised duties and responsibilities of their role. Members will be expected to attend meetings and read

papers sent in advance, play a positive, constructive, and co-operative role in meetings and respond with comments on documents by requested dates.

4. Meetings

- 4.1 The group will meet every eight weeks mainly online and occasionally in person. Members may be contacted in between meetings for advice.
- 4.2 Meetings will last for an average of 1.5 hours and no longer than 2 hours. All documents for review will be sent to members at least 7 days before the meeting date.
- 4.3 The agenda will be generated by the Chair and with others as appropriate in collaboration with the ALSPAC Executive and SMT.
- 4.4 The PPI panel will meet in advance of the ALSPAC Law & Ethics Committee (ALEC) so feedback can be provided from panel discussions on new data collection projects.
- 4.5 Subgroups may be formed to work on specific issues.
- 4.6 Individuals may be co-opted to provide specific advice and expertise.
- 4.7 The Chair of the PPI group is responsible for chairing the meetings. Administrative support for the meetings will be provided by ALSPAC.
- 4.8 Meeting documents will be sent out via email at least one week prior to the meeting. It is expected that members will come to the meetings fully prepared to participate in the meetings.
- 4.9 Minutes of all meetings will be taken and provided to all members. A redacted versions will be available to the general public.

5. Remuneration

- 5.1 PPI panel members will be remunerated in line with INVOLVE guidelines. Panel members should not be worse off for participating and will be remunerated in recognition for their work and service in ALSPAC. The honorarium will be £45 per meeting to reflect involvement which equates to an activity that requires some preparation – 1-2-hour video conference, with related papers to read in advance.
- 5.2 Travel expenses will be provided for the occasional in person meetings.

6. Constitution

- 6.1.1 These terms of reference were endorsed by the ALSPAC Executive on the 19th January 2023.