

Airwave Participant Experiences Survey

Summary Report

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INTRODUCTION

Launched in 2004, the Airwave study is the first large-scale cohort of police employees worldwide. Initially designed to study the health impacts of the TETRA communication system, in 2013, the study formally became a tissue bank and its focus broadened to consider other health conditions beyond the communication system itself.

To date, Airwave has had unusually high recruitment and retention rates. By 2012, 42,897 individuals were enrolled in the study from 28 (out of 54) local police forces across the UK – approximately 50% of police employees in these local forces were taking part in the study and only three participants had withdrawn (Elliott et al. 2014). When initial data collection was completed in March 2015, 53,114 police employees from the 28 participating forces across the United Kingdom had been enrolled, of whom 45,567 (85.8%) had completed the self-report questionnaire and 45,514 (85.7%) had completed the health screen.

Until recently, public and patient involvement and engagement (PPIE) were formally incorporated into Airwave via a representative from the Police Federation on the Data Access Committee. However, in 2023, the Airwave team decided to create an Airwave Participant Advisory Group (APAG) to give study participants a more direct voice in the study. In January, a call for expressions of interest for participants interested in joining an Airwave advisory panel was placed in the Airwave newsletter, with candidates asked to complete an ‘Expression of Interest’ form by 31 August 2023. The response to the call was overwhelming, with 348 participants submitting the form and a further 138 starting it but not completing it. The unexpectedly high levels of interest in the APAG amongst the cohort has provided an invaluable opportunity to learn more about their experiences on the study in the form of a participant experience survey.

METHODS

In March 2024, the applicants who were not selected for the Airwave Participant Advisory Group and who had not opted out of further correspondence (N=335) were sent a link to an online survey titled 'Participant Experiences in the Airwave Tissue Bank'. The survey was open for five weeks and respondents were sent two reminders. In total, 241 respondents submitted the survey – a response rate of 72%.¹ Seventy-seven percent of respondents (N=186) indicated their interest in taking part in a follow-up interview, providing further evidence of the highly engaged nature of this sub-cohort.

To encourage participants to provide honest reflections on their experiences in Airwave, the survey was anonymous: IP addresses were not recorded, and no personally identifiable information was requested. It was designed to be short, with a completion time of 10 minutes or less. The survey was divided into three parts: demographic questions, general questions about the Airwave study (e.g., the nature of the study, when respondents joined, why they joined, how many health screens they have completed, etc.), followed by questions about their experience of the study and communication materials. Descriptive statistics were generated for the survey results and free-form responses to the question about what respondents thought should be research priorities were coded in Excel using standard content analysis techniques (see Altheide 1987).

Specifically, categories were created through coding direct responses, followed by a second round of coding in which related concerns were grouped; for example, responses such as 'blood pressure', 'heart health' and 'heart disease' were grouped into a larger category of 'cardiovascular disease' (CVD). In instances where respondents mentioned more than one health issue, these were counted separately. See Appendix 2 for a more specific breakdown of codes within broad categories such as mental health, cardiovascular disease and lifestyle.

DEMOGRAPHIC CHARACTERISTICS OF SAMPLE

Ninety-five percent of respondents identified as white and 77% of respondents were male, with an average age of 56 (median age: 57). Forty-two percent of respondents were still working in the police force and 43% had retired; the majority of respondents (57%) were either current or former constables or sergeants. Thirteen percent of respondents identified as having a disability and, of those, 21% (N=6) indicated that it was acquired on the job.

In terms of how the survey respondents compare with the candidates who submitted an expression of interest to join the APAG, they were, in general, more likely to be white, male and older: 91% of

¹ A further seven respondents started the survey but didn't finish it; thus, the response rate is 74% if they are included. However, it appears as if a minority of respondents (at least six) took the survey twice, because they provided their contact details twice when they were asked if they wanted to do a follow-up interview. It is not possible to remove their survey data, because their contact details were not linked with their survey responses and no IP addresses were recorded to ensure the survey data were anonymous. However, these duplicate responses are unlikely to have affected the overall picture. Also, nine respondents did not complete all the survey questions. Because respondents were told that they could skip any questions they did not want to answer, their responses have been retained rather than excluded from the analysis, which is why the total respondents vary slightly from question to question.

those who submitted expressions of interest were white, 74% were male and the mean age was 54. However, levels of disability were similar across both groups. This means that the survey respondents are broadly representative of the original Airwave cohort as a whole in terms of ethnicity and age, but less representative in terms of gender: 62.9% of the original cohort were male (Elliott et al. 2014).

RESULTS

Understanding of Airwave study

To assess how well respondents understand the study's broadening into a tissue bank, they were asked to determine the veracity of a series of statements on the aims of the Airwave study (see figure 1). While most respondents correctly assessed all three statements as true, a significant minority (23% and 38%, respectively) assessed statements 1 and 3 as either 'false' or indicated that they were 'not sure' of their veracity.

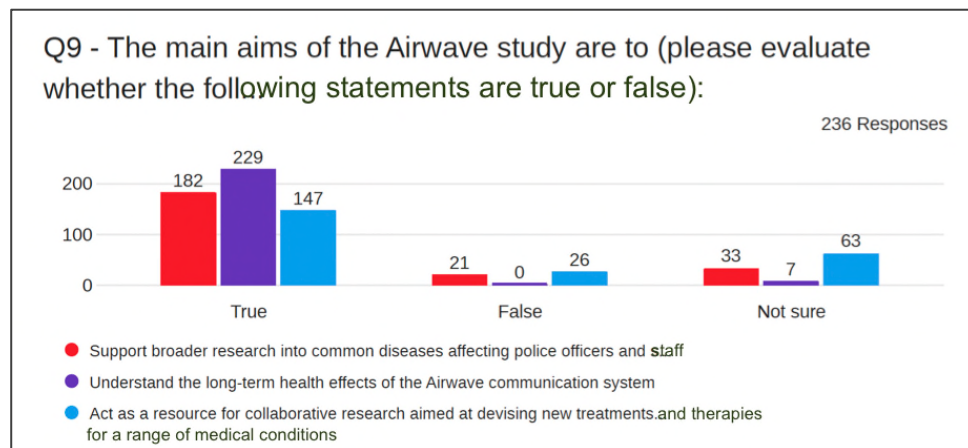


Figure 1. Responses to question on the aims of the Airwave study

To probe the understanding of those who responded 'false' or 'not sure' to statements 1 and 3, they were asked two follow-up questions about their awareness of the fact that the Airwave study no longer exclusively conducts research into the TETRA communication device and querying their views on this. While 66% (N=38) confirmed that they were not aware of the broadened scope of the study, all respondents thought it was a good idea (see figure 2).

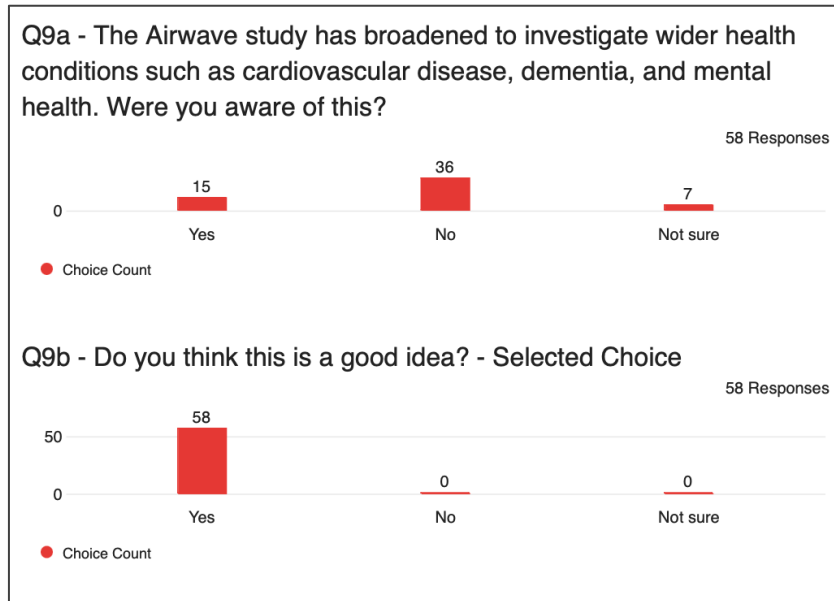


Figure 2. Probes on respondents' understanding of the aims of the Airwave study

Why respondents joined the Airwave study

Respondents were then asked to respond to a series of statements on why they joined Airwave. As figure 3 illustrates, the most strongly endorsed reason was 'A desire to improve the health and safety of police officers and staff'. Ninety-five percent of respondents either strongly agreed or agreed with this statement. The next most strongly endorsed statement was 'Free health screening', followed by 'I was concerned about the health impacts of the Airwave communication system': 69% and 63% of respondents, respectively, either strongly agreed or agreed with these statements. Conversely, responses to the other statements were more variable: staff abstraction time, their local police force's support and the Police Federation's support for the study were not listed as strong motivations to participate.

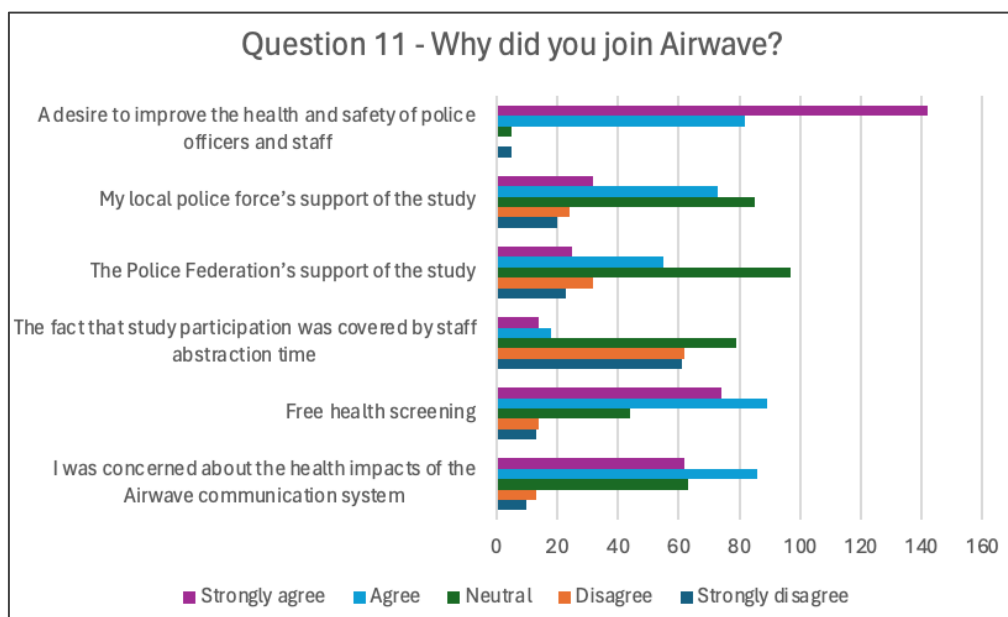


Figure 3. Respondents' stated views on why they joined Airwave

Respondents' interest in the health screening was confirmed in their responses to subsequent questions focusing on how many health screens they had completed: 44% of respondents had completed two screens and a further 28% had completed three. With only one exception, all respondents indicated that they were interested in completing further health screens – although they were informed that the free health screenings were unlikely to be offered in the study moving forward.

To ascertain how engaged they are in health research more generally, respondents were asked about whether they had participated in other health research studies – either at Imperial or elsewhere. Respectively, 47% and 38% of respondents indicated that they had participated in other Imperial or non-Imperial research studies. Notably, there wasn't a great deal of overlap between these two groups: only 26% (N=19) of the former group had participated in non-Imperial studies.

Respondents' experiences of the Airwave study

To maximise the comparability of the data with a satisfaction survey conducted during clinic visits in 2023 when respondents were receiving follow-up health screens, we asked a similar question on the current survey about participants' experiences in the study.² As figure 4 illustrates, the results were broadly similar across both surveys, with the areas of agreement and disagreement where it is generally expected and desirable. However, the respondents in the 2024 participant experience survey were significantly less likely to strongly agree with positive statements like 'I feel proud to be part of the study' and 'I am interested in the study'. Moreover, a minority of participants in both surveys disagreed or strongly disagreed with the statement 'I understand how my data are being used': 4% for the 2024 participant experience survey and 5% for the 2023 clinic survey.

² There are slight differences between the wording of the two questions because a draft version of the clinic satisfaction survey was used to develop the question on the participant experience survey.

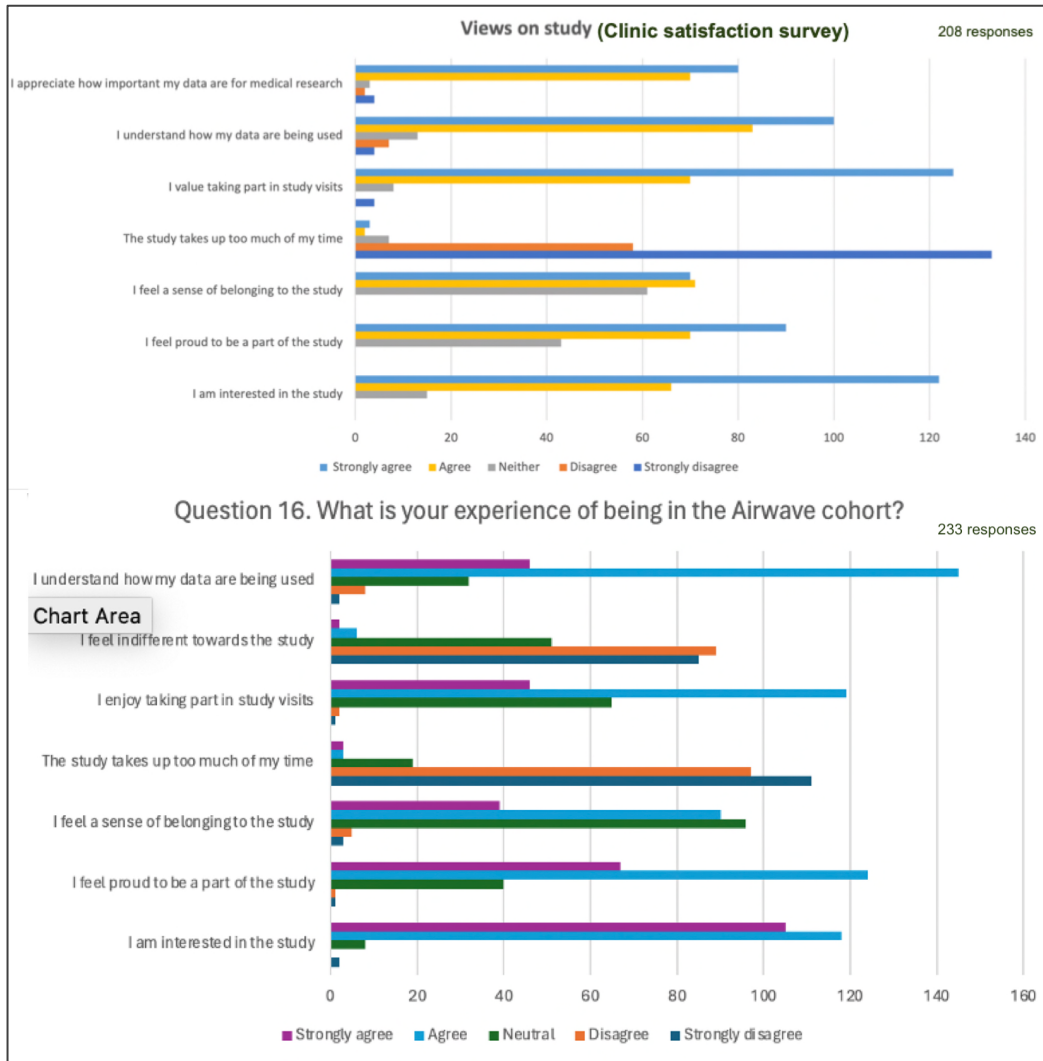


Figure 4. Comparison of results on respondents’ experiences: 2023 clinic survey and Airwave participant experience survey

Respondents’ engagement with Airwave study communications

Sixty-one percent of respondents in the participant experience survey indicated that they had read at least one of the study newsletters; of these respondents, 91% indicated that they had found it useful. In contrast, only 44% of the clinic survey respondents indicated that they had read the 2023 newsletter. The participant experience survey also asked about respondents’ engagement with the study website (see figure 5). The majority indicated that they never (35%) or rarely (47%) look at the website. Of those who confirmed that they have perused the site (N=79), 92% found it useful.

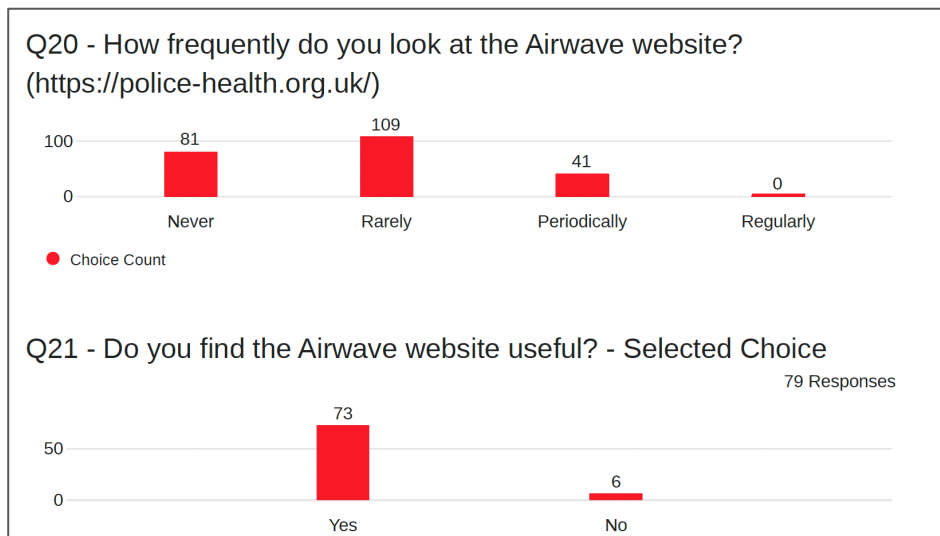


Figure 5. Respondents' engagement with the study website

Considering the relative lack of engagement with the study materials, it is probably not surprising to find that most respondents to the Airwave participant experience survey were not aware of any research findings from the Airwave study or studies drawing on its data: 64% indicated that they were not aware of such findings and a further 22% indicated that they were 'not sure'. Only 17% indicated that they had looked at any of the scientific publications linked to in the newsletter and on the website drawing on Airwave data.

Respondents' interest in the Airwave Participant Advisory Group

A final survey question asked participants about why they had submitted an expression of interest to join the Airwave Participant Advisory Group. As figure 6 illustrates, a desire to learn more about their own health and a desire to support research into the issues affecting police officers and staff were the most common reasons for wanting to join the APAG, followed closely by a general interest in health research. The only statement that the majority of respondents disagreed with was the payment for participating in meetings, suggesting that money was not a motivating factor for their interest in the APAG.

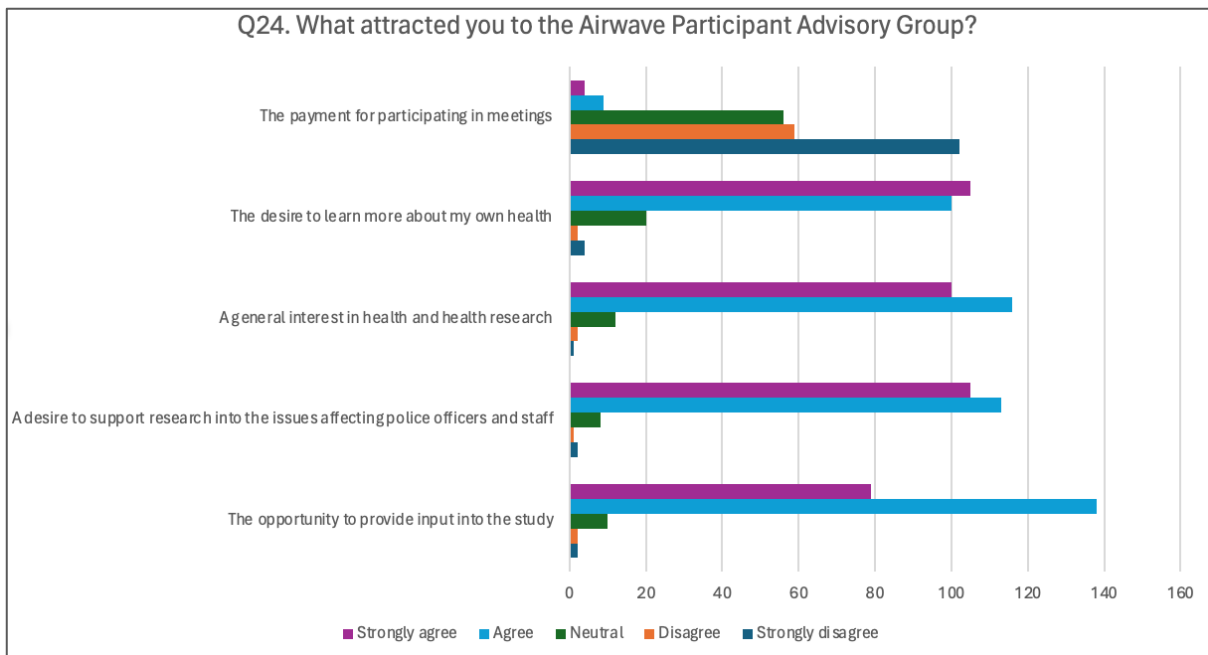


Figure 6. Reasons for submitting an EoI to join the Airwave Participant Advisory Group

Respondents' suggestions regarding health issues they think should be prioritised for research

A total of 189 respondents provided suggestions regarding the health issues they think should be prioritised and these were grouped into 14 main themes. The top five themes were mental health, cancer, cardiovascular disease, hearing and stress, respectively (see Figure 7). Notably, the Airwave communication device was mentioned by 19 respondents.

Although mental health was the most frequently mentioned health issue, certain terms were consistently used such as 'post-traumatic stress disorder' (N=6), 'anxiety' (N=5) and 'depression' (N=3) (see Appendix 2). Dementia was likewise frequently mentioned (N=15) in discussions of cognition. Its frequency suggests that it was more significant to respondents than the health issues we have grouped under cardiovascular disease, which covered an array of different conditions.

It is worth mentioning that many respondents listed multiple health issues that they thought should be explored, often listing issues that they appeared to see as linked. Examples include shift work and mental health, stress and heart health, and musculoskeletal issues and working conditions. This more holistic orientation to health issues is also evident in the fact that several respondents also suggested 'general health' (N=10) as an area of research.

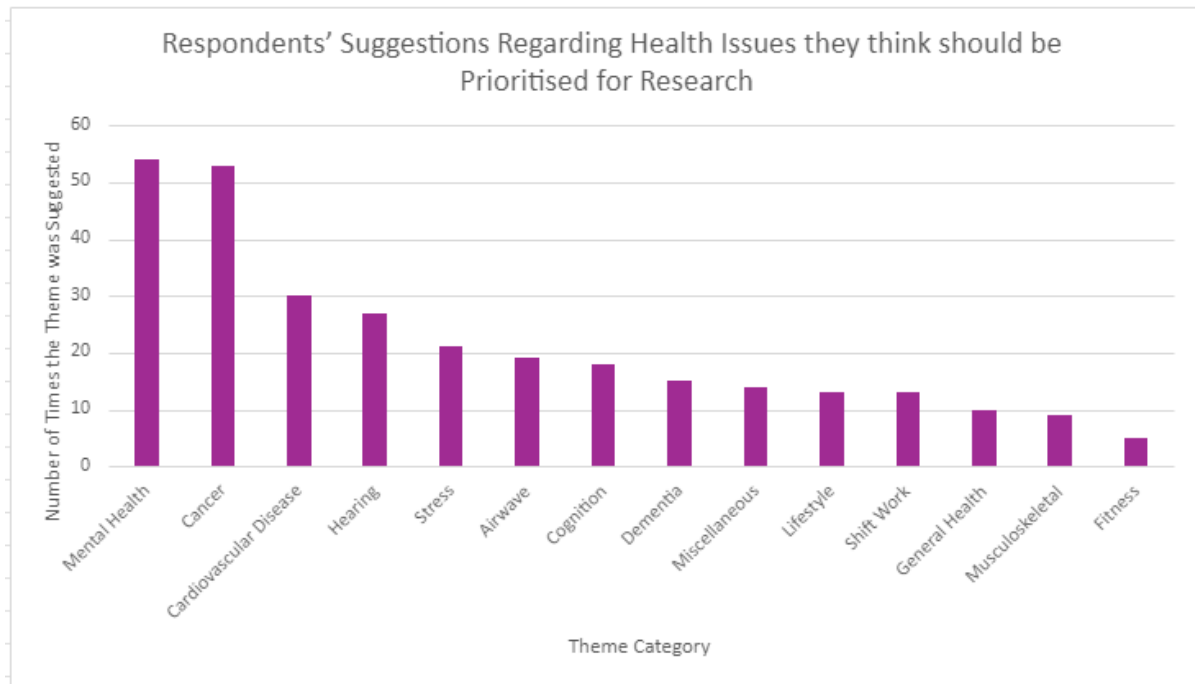


Figure 7. Health priorities for research as described by the Airwave Participant Advisory Group

DISCUSSION

Overall, the survey provides a useful picture of the views and experiences of members of the Airwave cohort, although the respondents are clearly not representative of the cohort as a whole, especially in terms of gender. Additionally, they are presumably far more engaged than the average member of the cohort, given that all participants had previously submitted an expression of interest to join the Airwave Participant Advisory Group. This is also suggested by the high proportion of respondents (51%) who indicated that they have participated in other research studies at Imperial or elsewhere.

The most significant survey findings relate to participants' understanding of the nature of the study. Despite the efforts of the Airwave team to communicate the broadened scope of Airwave since 2013, the survey indicates that a significant minority of participants (over 25%) are unclear on the fact that that Airwave now focuses on an array of health issues and acts as a collaborative research resource. Also, a small proportion of participants (5%) indicated that they do not understand how their data are being used – a figure that correlates closely with responses on the 2023 clinic satisfaction survey (4%).

In many respects, these findings are not surprising. Although the concept of 'informed consent' is premised on the assumption that participation is only ethical when based on a full understanding of the stated study goals, there is growing evidence of a persistent disconnect between how research is formally framed in study materials and how participants understand the nature of the research itself (e.g., Dixon Wood et al. 2007; Samuel et al. 2017). As Dixon-Woods et al. (2007) observe,

people may simply participate in research for different reasons, or with different values in view, to the ones that researchers or ethics committees prioritise. In particular, healthy volunteers... may value a community ethic or moral imperative as a motivation for participation, be untroubled by the risks and burdens described in the PIL [participant information leaflet], see the need to

understand in detail the precise design and aim of the study as irrelevant, but be more concerned with whether taking part will be useful and promote the common good (pp. 2219-20).

Reassuringly, when participants were informed of the change in the focus of the study, there was universal support for it – every single respondent thought it was a ‘good idea’ to research wider health conditions. This suggests that the lack of awareness of the expanded scope of the study is more of a *communication issue* rather than an *ethical problem*: people have no objection to this broader usage of their data when they learn of it. Indeed, a growing body of research has highlighted that what is most important to participants in biobanks and data-intensive health studies is that the cooperative bargain into which they have entered is ‘maintained in good faith’ (Dixon-Woods et al. 2017). This is increasingly being spoken of as a ‘social license’, where researchers are given an implicit ‘licence to reuse data because of a positive public attitude resulting from their trustworthy and responsible behaviour’ (Muller et al. 2021).

For those participants who were unaware of the expanded aims of the Airwave study prior to completing the survey, their relative lack of concern about the broadened uses of their data beyond the health effects of the Airwave communication system can be explained by their stated reasons for joining Airwave. The single most endorsed statement was a desire to improve the health and safety of police officers and staff, with 95% of respondents either agreeing or strongly agreeing that it played a role in joining the study. In contrast, the specific health effects of the Airwave communication system was the third most popular reason on the list – after the free health screening.

Obviously, these are post-facto assessments of why respondents joined the study rather than a necessarily accurate reflection of their original impetus for participating, but sub-analysis revealed that there were no differences in the pattern of responses between those who were confused about the current aims of the Airwave study and those who accurately understood them (see Appendix 1). This suggests that participants would not see the expanded use of their data for other collaborative health research as breaking the cooperative bargain into which they entered, *even if they had not been fully aware of this* previously.

The responses to the question on why participants joined Airwave also highlight the significance of the free health screening to study participation. This will not be a surprise to the Airwave team, as they have long known the role that the free health screening played in recruitment (see Elliott et al. 2014). However, it does highlight that the lack of continued health screening may be an issue moving forward in keeping participants engaged in the study – especially given that respondents were almost universally interested in further health screens.

It is worth noting that a growing body of literature on why people participate in biobank studies suggests that people are motivated by more than pure altruism. Although the logic of the ‘free gift’ is embedded in UK biobank policies and regulations (see Kanellopoulou 2011; Locock and Boylan 2015), research suggests that a desire to help others is often intermingled with a desire to receive personal benefits (e.g., People, Science and Policy, Ltd 200; Barr 2006; Haddow 2009; Domaradzki and Pawlikowski 2019). Indeed, in their systematic review of the literature on why people

participate in biobanks, Nobile et al. (2013: 43) argue that ‘altruism can never be considered completely uncalculated as it often tends to be more of a reciprocity dynamics or a gift relationship’. Including opportunities for receiving personalised results – along the lines of the hearing sub-study – are likely to help to counteract any potential fallout from the fact that further health screens are not likely to be offered.

Although the results of the survey seem to suggest that police support for the study – in the form of endorsement from the Police Federation and their local police force, along with the provision of staff abstraction time for participation – weren’t a major consideration, these findings need to be treated with caution. This is not just because respondents are being asked to reflect on their decision to join the study years after the fact, but because this subset of Airwave participants appear to be highly motivated to participate in health research, which is unlikely to be the case for the overall cohort. It is possible that for many participants, these factors *did* play a positive role at the outset in lending credibility to the study, etc., even if they didn’t consciously influence people’s decisions to participate.

In terms of participants’ experiences in the study, what is most striking about the results is their degree of broad overlap with the findings of the 2023 clinic survey. The only significant difference was that participants in the current survey were less likely to strongly agree with positive statements like ‘I feel proud to be part of the study’ and ‘I am interested in the study’. These results seem counter-intuitive, given that the survey was conducted with a highly engaged part of the cohort who had previously submitted an expression of interest to join the APAG. However, this may relate to the context of the two surveys and the fact that the former was conducted while participants were receiving a health check – presumably the context in which their interest in the study, and general positive feelings about being part of it, would be at their peak.

Given the gaps the survey highlighted in some participants’ understanding of the study, the findings on their engagement with study communications are particularly important to consider. Clearly, respondents are not consistently – or, at least, consciously (more below) – engaging with the newsletters and website: the two primary forms of communication used by the Airwave research team. It is also likely that rates of engagement are considerably lower within the cohort as a whole. Notably, the percentage of respondents who indicated that they had read the latest newsletter were significantly lower for those who completed the 2023 clinic survey (44%) than for those who completed the participant experiences survey (61%), with the former more likely to be reflective of the cohort as a whole.

That said, there is also a distinct possibility that people’s recollection of their engagement with the newsletter and website are inaccurate. Notably, information about the APAG was disseminated via the 2023 newsletter, and participants had to apply to join the group via the Airwave website, which suggests that the number of participants who have looked at least one newsletter is closer to 100%, and raises questions about the claim by 37% of respondents that they have never viewed the website.

Regardless of the veracity of the survey data on the communication materials, communication is an area where further work is clearly warranted – although this may well be a matter of creating more *memorable* materials and messages rather than changing communication platforms entirely. This comes across clearly in the responses to questions about whether respondents were aware of research findings from the Airwave study or studies drawing on its data. Although 64% of respondents indicated that they were not aware of any such findings, one page of the 2023 newsletter was dedicated to presenting research findings, which were clearly labelled as such.

The issue therefore seems to be how information is being communicated and processed – a point that may well hold for the study aims themselves (notably, ‘tissue bank’ is probably not a meaningful term to the lay person). This seems a key area that would benefit from input from the APAG; indeed, the conversations held during the APAG workshop indicate that they have many valuable insights to offer regarding how study communication might be improved.

In terms of why respondents submitted an expression of interest to join the APAG, the only response that particularly stands out is the strong disavowal of the financial incentive offered via participation. Instead, the respondents’ desire to join the advisory group seems to have been driven by the same factors that drove them to join the Airwave study in the first place: namely, a desire to support research into the health issues confronting police staff and officers and to learn more about their own health.

CONCLUSIONS

Overall, the participant experience survey confirms that members of the cohort who were keen to join the Airwave Participant Advisory Group are supportive of the direction of the study and feel invested in it. Notably, participants and the research team appear to be on the same page in terms of what they consider to be research priorities moving forward. However, in order to retain the investment of the cohort long-term, it is important that opportunities for personalised feedback are offered where possible, as this is clearly a key part of why participants joined the study in the first place and their continued participation and interest.

The survey suggests that there is room for improvement in terms of study communications in order to clarify the nature of the Airwave tissue bank and highlight the key research findings to date. However, the *form* of these communications may be more important than the *medium*, given that participants have clearly had more engagement with the study newsletters and website than they recall.

The APAG will be an invaluable resource moving forward in helping to ensure that messages are communicated in a way that maximises understanding, engagement and recall and we offer suggestions below for specific areas that would benefit from their support:

- How to frame the study on the website in more lay-friendly terms, avoiding academic terms like ‘tissue bank’.
- The best format for presenting information about the study – e.g., videos, Q&A, infographics.

- Future newsletters would benefit from the APAG’s feedback prior to circulation to ensure that key intended messages are clear.
- As we will be conducting follow-up interviews with survey respondents who indicated their interest in such, the interview guide we develop would benefit from the APAG’s input before we embark on this phase of the study.

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APPENDIX 1

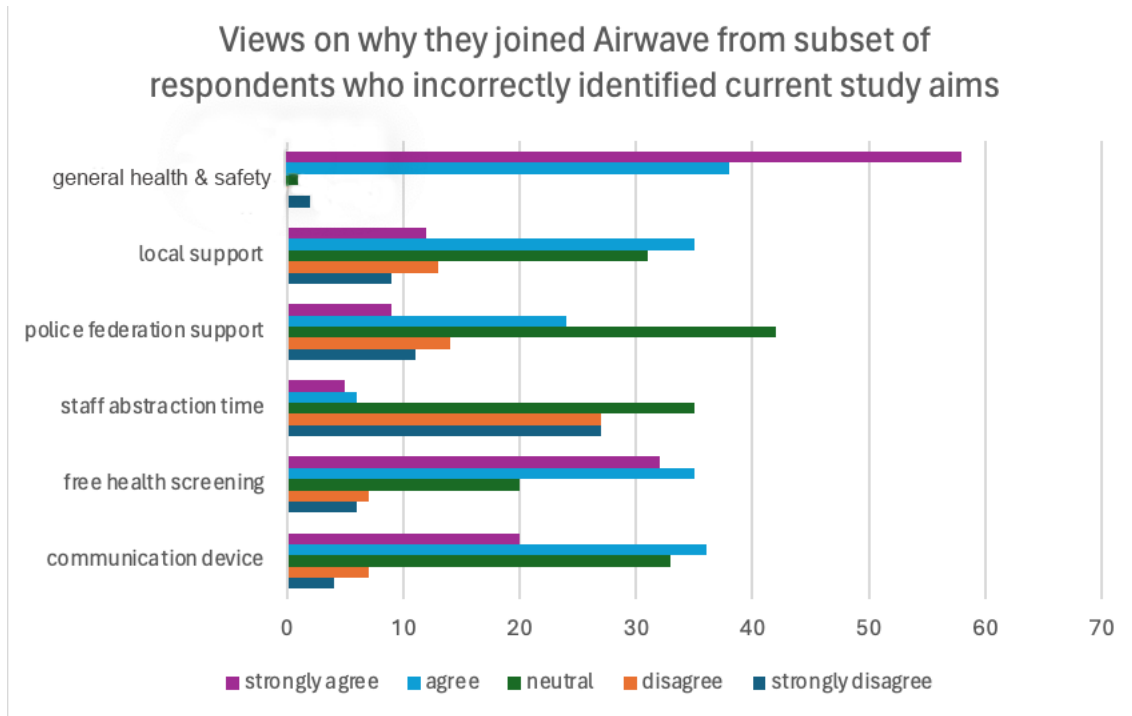


Figure A1. Views of respondents who incorrectly identified the study aims

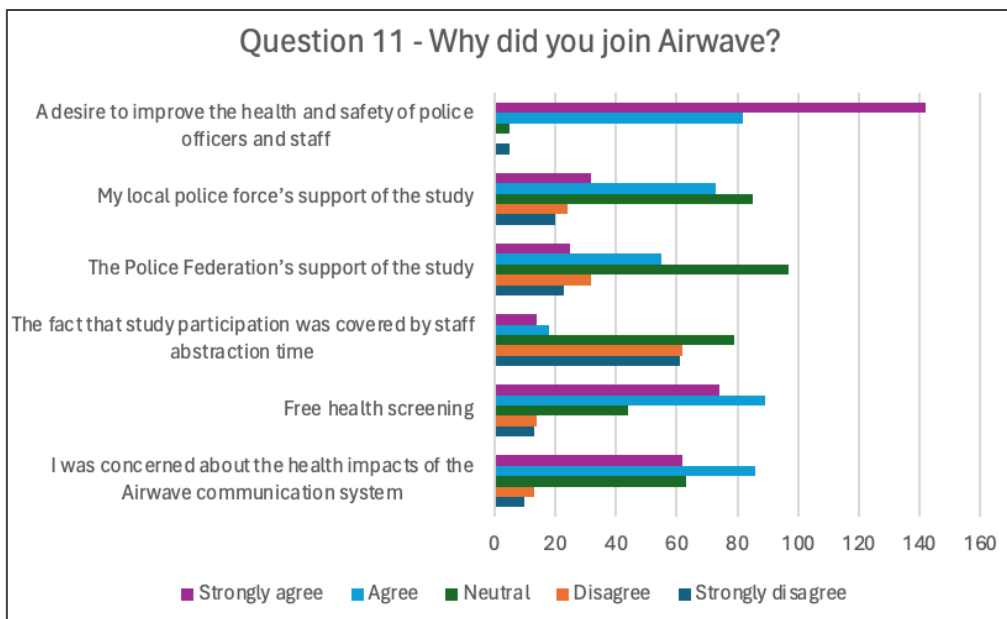


Figure A2. Views of all respondents to the same question

APPENDIX 2

Theme	Theme Count	Sub-Theme 1	Theme Count	Sub-Theme 2	Theme Count	Sub-Theme 3	Theme Count
Mental Health	54	PTSD	6	Anxiety	5	Depression	3
Cancer	53						
Cardiovascular Disease	30	Heart Disease	7	Blood Pressure	7	Stroke	2
Hearing	27						
Stress	21						
Airwave	19						
Cognition	18						
Dementia	15						
Miscellaneous	14						
Lifestyle	13	Diabetes	9	Obesity	5	Diet	3
Shift Work	13						
General Health	10						
Musculoskeletal	9						
Fitness	5						

Table A3. Health priorities for research as described by the Airwave Participant Advisory Group, Main and Sub-Theme Count Breakdown.