



NHS Grampian Research Awareness and Engagement Report

A short summary of our survey findings

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This report contains a short summary of the NHS Grampian Research and Development findings from our research engagement survey. This survey was carried out between September and October 2018. The findings are the first of its kind in Grampian and to our knowledge, Scotland as well.

Introduction

NHS Grampian has been developing a programme to improve public engagement and involvement in research. This is a vital programme to encourage more participant input in research design, and putting the participant at the heart of research. As part of this programme, NHS Grampian wanted to establish the current levels of engagement in research. This report details their findings from their research engagement investigation.

Methods

An electronic survey was disseminated around social media and email by NHS Grampian, the University of Aberdeen and Robert Gordon's University. Paper copies of the survey were also handed out to clinics in Woodend and Aberdeen Royal Infirmary. The full question set can be found in Appendix 1. These surveys were released on the 13th of September 2018 and this report was collated using the feedback received up until the 16th of October 2018.

Results

We collated the electronic and printed snap survey responses to create a summary of NHS Grampian's engagement. In total, there were 206 electronic responses and 129 print responses, totalling 335 by 16th of October 2018. The full questions are detailed in Appendix 1.

Results on research engagement

Our first question asked if participants had heard of clinical research before (Figure 1). It can be seen that the majority of individuals had heard of clinical research before. If respondents had answered yes, then they were asked to advise where they had heard of research before. This had numerous available answers, and the option to add additional information. This question allowed for individuals to select more than 1 answer if applicable. The most popular available option was through their work (29.15%), with TV (17.31%) and NHS Grampian messages (14.84%) as the next most popular options. The most common answers which were added to the additional information section were through word of mouth, SHARE, the news and the University.

Have you heard of clinical research (including clinical trials) before?

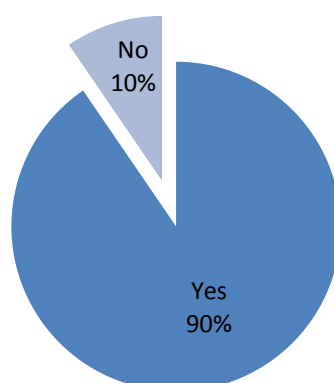


Figure 1: Percentage of respondents who have heard of clinical research previously.

The next question we asked participants was regarding their previous involvement in clinical research, with the responses demonstrated in figure 2. Figure 2 shows that the majority of respondents had not been involved in clinical research. For those who had, they were asked an additional question on how they had been involved. The most commonly selected response was through work (46.31%) and as a research participant (44.97%). Individuals also mentioned being part of patient involvement groups, and being involved through university. This question allowed for individuals to select more than 1 answer if applicable.

Have you ever been involved in clinical research?

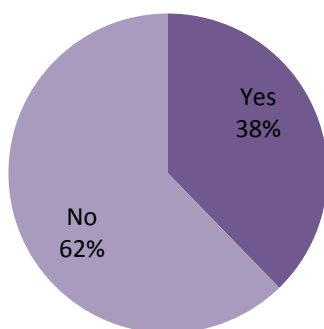


Figure 2: Percentage of respondents who have or have not been involved in clinical research previously.

The next question participants were asked was if they would be willing to take part in clinical research, with the response demonstrated in figure 3. It can be seen that the majority of individuals responded positively, answering either yes or maybe. These answers made up 72.29% of the total responses to this question.

Would you take part in clinical research?

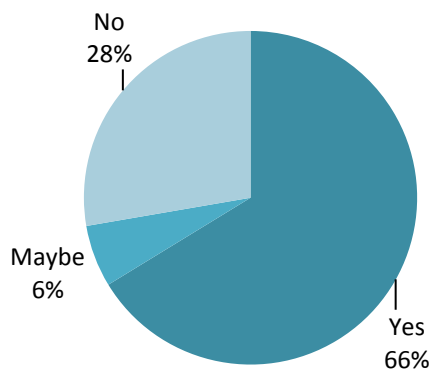


Figure 3: Percentage of respondents who would take part in clinical research.

Participants went on to answer a question on if they would be interested in finding out more about clinical research, as shown in figure 4. The majority of the participants responded positively, and would like to know further information (70%). For those who answered yes, they were asked to answer an additional question on what they would like to know about clinical research. Similar to earlier in the survey, there were answers provided and room for additional comments. Participants were able to select as many answers as they wished. The most popular answer from the ones available was to hear success stories about research (28.31%), however the remaining 3 options had a similar response rate. Explaining the basics of research was selected by 27.49%, hearing personal stories option was selected by 23.82% and addressing research concerns was 18.94%. Participants also added that they wanted to know what research was being carried out, why it was being carried out and the unsuccessful research stories.

Would you be interested in finding out more about clinical research?

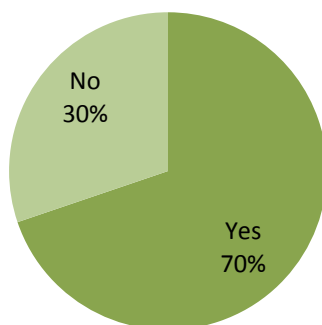


Figure 4: Percentage of respondents who would like to find out more about clinical research.

Participants were asked if they had any concerns about research, and were able to select multiple answers or add additional comments in the free text box. Out of the provided answers, the most commonly selected was concerns regarding safety (40.53%), the second most commonly selected was that individuals were unsure about how clinical research works (34.85%). The least commonly selected answer was that the terminology was unclear (12.21%). There were several comments provided in the free text boxes which included not having any concerns, data security, if they were eligible to take part due to other health conditions, sponsorship and data usage.

General information on respondents

The survey had 2 questions on our respondents for general information. The first, demonstrated by figure 5, asked participants to select their age range from the available groups. It can be seen that the majority of participants were aged between 19-64 years (84.66%).

Respondents by age range

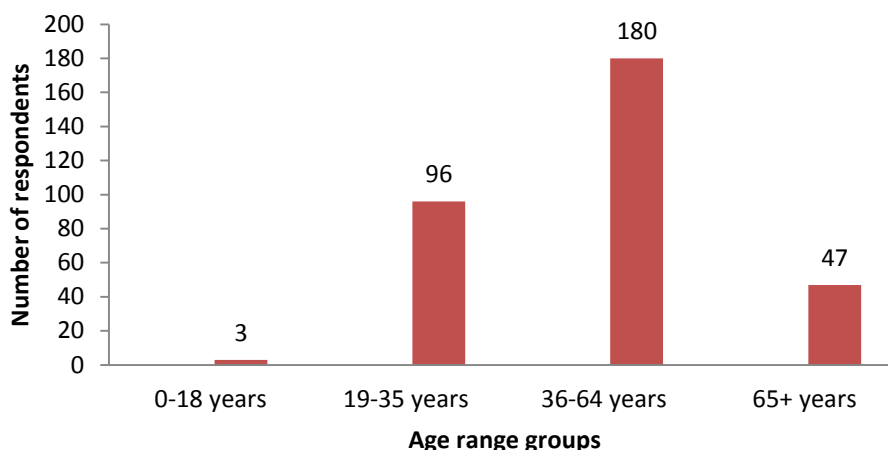


Figure 5: Graphical depiction of the age range of our respondents.

We also asked respondents what methods of communication the most effective (in general) were, not relating to research communications. This question listed a set number of options, and participants could select as many as they wished. As shown in figure 6, the most effective communication was social media (25.78%) and the second most effective was websites (19.14%). All options did have votes, but the method with the least votes was apps (4.94%).

Best Communication Method

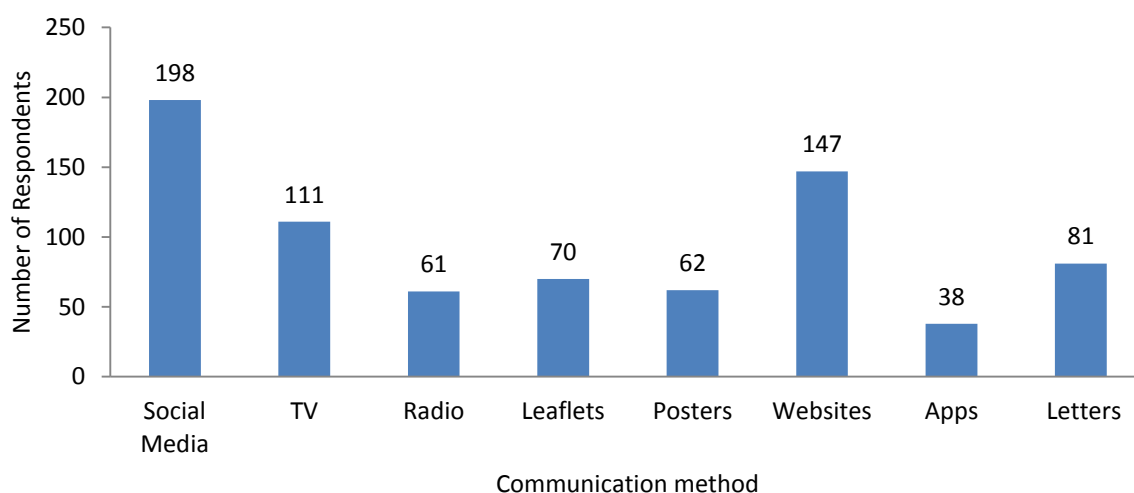


Figure 6: Graph demonstrating the votes received for each communication method for general communication for respondents.

Discussion

Our survey demonstrates the current research engagement in the public of NHS Grampian. It demonstrates that there is an interest in clinical research within the public, and that there are still many people who wish to find out more about clinical research. It is also promising that the majority of the respondents would like to be involved in research, or at least consider the possibility of being involved. We had expected a lower percentage of respondents to have been involved in clinical research, but as the majority seem to be involved through their work, it is understandable that this type of individual is more likely to take part in the survey. The majority of our participants were aged between 19-64 years, which given it was mainly completed online (and disseminated by email and social media), is not surprising. However, it would be beneficial to have a larger input from the 0-18 and 65+ age groups. A better representation of these age groups may have had an impact on the results, including the communication channels.

We were pleasantly surprised that so many individuals have already heard of clinical research, although we were expecting participants who already had some interest, the figures were higher than expected. We did consider that the University of Aberdeen and Robert Gordon's University activities to increase Research Engagement and Involvement may have had an impact already on the public awareness of research. However, this is hard to determine without a more detailed investigation.

Successes and Limitations

The survey was created to establish an initial idea of engagement in NHS Grampian. However, using the social media and email channels to promote this increases the likelihood that there are individuals who are not based in Grampian completing the survey. There is also an increased risk of bias in the data, as individuals who are already interested in research are more likely to complete the survey than those who are not. We also noted that the communication method with the highest votes was social media, which may be where the participants found the survey – and could have biased their response. However, using social media and emails allowed for more individuals to be captured than using printed surveys alone. Only 129 printed surveys were completed, where as 206 electronic surveys were completed during the same timeframe.

Due to the nature of the survey design, limited information was able to be captured. To ensure that the survey is quick enough for individuals to complete, we tried to limit the number of questions given, which may in itself limit the quality of the data. As part of the survey design, not every question had to be completed to be submitted, as we felt this kept the print and electronic surveys in line. We also felt that this may encourage more respondents; however, we acknowledge that this would increase the risk of missing data.

The way that the electronic system is designed, allows us to only receive summary reports rather than individual electronic survey submissions – resulting in limited data analysis compared to the printed survey responses. Although this is not necessary for this report and its outcomes, it could have been useful to look for data trends in respondents by age groups or communication methods.

Although there are some limitations to the data presented, this is the first research engagement survey carried out in NHS Grampian, or NHS Scotland to our knowledge and that in itself is

important. It has allowed us to capture a range of individuals, including those who do not want to take part in research – suggesting that different groups have engaged, (not only participants with research interests). The use of free text boxes in answers allowed participants to put forward ideas or suggestions that our team had not considered previously. Having information on the best communication method also allows our team to better target our work in future to the appropriate channels, to ensure maximum impact.

Although this survey has numerous limitations, it has allowed us to create a starting point to improve and work on research engagement within NHS Grampian. The engagement has been better than expected for this area, and it looks to include responses from a range of individuals. Having the electronic and printed surveys may have been helpful for us get this wider range. We can now use our learning from this survey to help direct our future research engagement work. We can also use our learning to build more effective methods of determining engagement in future, to ensure a more representative sample is included.

Appendix 1 – Clinical Research Snap Survey Questions

Have you heard of clinical research (including clinical trials) before? (please tick one only)

Yes

No

If Yes, **where did you hear about clinical research?** (please tick as many as you wish)

TV

Through my work

Newspapers

My doctor or nurse

NHS Grampian messages (e.g. adverts, websites)

Other

Social Media (e.g. Facebook, Twitter, Instagram)

Additional information can be added here.

Have you ever been involved in clinical research? (please tick one only)

Yes

No

If yes, **how have you been involved in clinical research?** (please tick as many as you wish)

As part of my job

As a research participant

As part of an involvement group

Would you take part in clinical research? (please tick one only)

Yes

No

Maybe

Would you be interested in finding out more about clinical research? (please tick one only)

Yes

No

If yes, **What would you like to hear about clinical research?** (please tick as many as you wish)

Address research concerns

Hear personal stories about research

Success stories

Explain the basics of clinical research

Other

Additional information can be added here.

Do you have any concerns or queries about clinical research? (please tick as many as you wish)

Safety Concerns

I am unsure about how it works

The terminology is unclear

Other

Additional information can be added here.

What is your age range? (please tick one only)

0-18 years

19-35 years

36-64 years

65+ years

In general, what is the best way for information to reach you? (please tick as many as you wish)

Social Media

Posters

TV

Websites

Radio

Apps

Leaflets

Letters