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Managing anxiety in men undergoing surveillance in the NHS abdominal aortic aneurysm screening programme: A survey of screening staff in England

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Background: AAA is an enlargement in the aorta that can increase in size and rupture. In England, the National Health Service (NHS) AAA Screening Programme offers screening to all men aged 65 to identify those with an AAA. Men with small or medium sized aneurysm enter surveillance where they receive ultrasound scans annually or every three months respectively. Due to concerns about mortality from AAA rupture, anxiety levels may be high for men and their families and impact on their quality of life.
Aim: To obtain the views of staff providing Abdominal Aortic Aneurysm (AAA) screening on how best to help men in surveillance to manage AAA-related anxiety.
Methods: A cross-sectional online survey of the 38 AAA regional screening services in England was conducted. Four staff with different roles from each service (doctor, nurse, manager and scanning technician) were asked to complete an online questionnaire.
Results: The response rate was 71 % (27/38) for regional AAA screening services and 65 % (99/152) for the staff approached. 93 % (79/84) of respondents strongly or somewhat agreed that men in surveillance may need help to manage anxiety. The size of the aneurysm was rated as the factor most likely to cause anxiety. 63 % (51/81) considered AAA Programme Nurses to be the best people to deliver an intervention. Staff suggested that improved information about AAA and associated risks, group support/networking sessions, and more contact with the screening service were ways of helping with management of anxiety.
Conclusion: Staff providing AAA screening recognised that being in surveillance can cause anxiety for men and their families, and identified that potential interventions, such as organised support groups and improved provision of information, might help manage anxiety. Programme Nurses were considered the ideal healthcare professional to help men in surveillance manage AAA-related anxiety.

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Introduction

An Abdominal Aortic Aneurysm (AAA) is an enlargement in the aorta. AAA can increase in size over time and may rupture.[1] An AAA rupture occurs when the bulge or weakness in the aorta (the aneurysm) bursts open. As the aorta is the main artery that carries blood from the heart to the abdomen this causes internal bleeding that can be fatal.[1] Rupture is uncommon until the AAA reaches 5.5 cm or greater.[2] 3000 people die each year in England and Wales

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from a ruptured AAA.[1] Screening can identify the existence of an AAA.

AAA Screening

National AAA screening programmes have been introduced into a number of countries including Sweden, England, Wales, Scotland, Northern Ireland.[3,4] Regional screening programmes have also been trialled in Italy, Western Australia and New Zealand.[3,4] In the USA AAA screening is recommended for men aged 65-75 years who have ever smoked.[4]

In the United Kingdom the National Health Service (NHS) is the main healthcare provider where healthcare is universally free at the point of delivery. The NHS AAA Screening Programme in England offers ultrasound screening to all men in the year they turn 65. AAA causes significant mortality and morbidity, particularly in older men. Early detection via screening with ultrasound may reduce high mortality rates.[5] Screening is important as the majority of those with an AAA have no symptoms. Only men are screened because they are six times more likely to have an AAA than women.[5] The NHS AAA Screening Programme has been offering screening since 2009, and became fully operational in 2013, at an annual cost of £14 million.[6]

Approximately 300,000 men in England annually are invited to attend a screening clinic for an abdominal ultrasound in the year they turn 65; uptake is high with around 80 % of those eligible attending for screening.[7] Between 1st April 2021 and 31st March 2022, 309439 men were eligible for screening in England, in this timeframe 1,794 aneurysms were found.[7] Men are told the outcome at the appointment. If an AAA is detected, the further pathway depends on its size. Men with a small AAA (3cm-4.4cm) will start to have annual AAA ultrasound scans. Men with an AAA that is classed as medium (4.5cm-5.4cm) will have a scan every three months. Between 1st of April 2021 and 31st of March 2022 approximately 14,600 men were in surveillance and approximately 22,300 surveillance scans were undertaken.[7] When a large AAA is detected (> = 5.5cm) men are referred to a vascular service to assess their suitability for surgical repair.

Psychosocial consequences

Men may experience anxiety when invited for AAA screening, even if they are found not to have an AAA, although this is likely to be a temporary state.[8] There is more concern about the potential for men with screening-detected AAA having raised anxiety levels that affect their health-related quality of life. Anxiety may be related to having AAA or attending surveillance to monitor AAA growth.

A systematic review of the psychological harms of having an AAA found moderate levels of harm related to recent diagnosis.[9] Results from using AAA specific measures have supported the view that there is a psychological impact due to AAA screening and diagnosis.[10] A cross-sectional survey of 250 Swedish men in screening using an AAA specific measure - the Consequences of Screening in Abdominal Aortic Aneurysm - found that men diagnosed with a screening detected AAA reported more negative psychosocial consequences than men with a normal result.[11] A narrative review of 11 quantitative studies found that men in surveillance had lower health-related quality of life compared to those with negative scans and the general population.[12] A quantitative study in the UK showed agreement with this review - that mental health was worse in those diagnosed with AAA compared with those with negative screens, although this difference disappeared after 12 months.[13] However, the most recent systematic review, with meta-analysis, based on a generic quality of life measure, concluded that current evidence did not support a negative impact on quality of life from being in surveillance.[14] Qualitative research has also revealed a negative impact related to having an AAA, both on men,[15] and their partners.[16] In a systematic review that incorporated both qualitative and quantitative research studies, the findings from the qualitative studies demonstrated significant psychological harm.[9]

Interventions to manage anxiety in men in AAA surveillance

We were unable to find any published research on interventions to manage anxiety in men in AAA surveillance. There is some research in related areas. Firstly, two recent international studies have trialled different interventions for anxiety, or anxiety and depression, related to AAA surgical repair. A Chinese study focused on psychological support delivered by nurses using the Roy-Newman comprehensive model that encompassed information giving, focusing on successful outcome stories, communication, reassurance and education.[17] They noted decreased anxiety and depression scores in the intervention group. A Swedish randomised controlled trial investigating the potential benefit of using an e-Health tool to manage anxiety in patients with an AAA undergoing repair found no overall effect on anxiety due to the low uptake of the app.[18] Secondly, there are evaluations of interventions for managing anxiety related to screening rather than surveillance. For example, a randomised controlled trial of a brief nursing intervention to manage anxiety before breast screening mammography offered information about screening and the mammography in addition to personal emotional support.[19] They found that the intervention group had lower levels of anxiety. Another example was an intervention to manage anxiety and promote preparedness for lung cancer screening.[20] This involved in-person sessions where participants watched a five minute video on a tablet, and were given a 9 page booklet that provided information related to the benefits and risks of screening, what would happen during screening, and what would happen for both positive and negative results. The intervention was found to be both acceptable and feasible.

Aim

We aimed to obtain the views of staff providing AAA screening on how best to help men in surveillance to manage anxiety. We undertook this survey as part of a wider study called Patient Centred AAA Screening Study (PCAAAS). Another component of this wider study focuses on the views of men and their families about AAA-related anxiety and how best to manage it. The results from both screening centre staff and men will be used to develop an intervention to help men in surveillance to manage AAA-related anxiety.

Methods

Design

We undertook a cross-sectional online survey of all 38 NHS AAA regional screening services in England.

Sample

All 38 regional screening services were included. We wanted to include the views of a range of staff so we aimed to sample one of four types of staff roles from each regional screening service: the Clinical Director, the Programme Manager, a Programme Nurse, and

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a Screening Technician. Our projected sample size was 152 participants (assuming four members of staff were contacted at each regional screening service).

Recruitment

The Clinical Director of each NHS AAA regional screening service was contacted via email with an introduction to the study and participant information sheet explaining the survey, including a QR code and hyperlink to the questionnaire. They were asked to complete the questionnaire themselves, and to identify the three other members of the screening team to participate. A letter introducing the survey and a participant information sheet were attached for the Clinical Director to forward to these team members. Participation was voluntary. Two email reminders were sent, one after two weeks and again at five weeks.

The Questionnaire

There is no validated tool. Therefore a questionnaire was designed by the research team to gather data to address the study aims and objectives. The questionnaire content covered: whether staff perceived that anxiety was a problem, how they recognize anxiety in men with AAA, how they currently help men and their families to manage anxiety, the characteristics of interventions in an ideal world and the characteristics of an intervention that would be feasible in the NHS currently. A combination of fixed response questions (often with Likert scales) and free text questions was used. Most scale questions were five or seven point unipolar scales with some having a free text box option to ensure all responses could be recorded. The questionnaire was piloted with two Clinical Directors, a screening Programme Nurse and a Vascular Surgeon. Following the pilot, small changes were made to the question order and questionnaire instructions, for example including a progress bar to show how much of the questionnaire had been completed. Qualtrics^{XM} was used to deliver the online survey.[21]

Ethics

Ethical approval for the survey was granted by the University of Sheffield Ethics Committee. Staff were sent a covering letter by email with a link to the questionnaire; completion of the questionnaire was taken as informed consent. Each regional screening service where staff completed the survey was sent a shopping voucher as a thank you.

Analysis

Fixed response questions were analysed using descriptive statistics. The Chi-squared test was used to test for differences in views by staff role. Free text responses were analysed using content analysis, paying attention to guidance on how to analyse free text comments on questionnaires.[22] Text was entered into NVivo 12, which is a software programme used for the analysis of unstructured text. An inductive approach was used to generate a number of categories and sub-categories which in turn were then grouped into broader categories.[23] The analysis was conducted by [EL] and [JH], who double coded 50 % of responses to each free text question and discussed coding to reach a consensus.

Results

Response rate

71 % (27/38) of the regional screening services who were contacted took part in the survey. 65 % (99/152) of staff completed the questionnaire. Not all participants completed all the questions. Completion rates for each fixed response question ranged from 79 % to 84 %. Numbers completing the free text questions were only slightly lower, ranging from 70 % to 75 %.

Sample description

The 27 regional screening services that participated had a good geographical spread across England.

81 staff members completed the question about their role. The sample comprised 15 Clinical Directors, 20 Programme Managers, 12 Programme Nurses, and 29 Screening Technicians. Five people ticked the option for 'other' and completed a free text response. 82 % (81/99) of respondents completed the question about how long they had worked in the AAA screening service. The majority of staff responding had over five years' experience in the screening service: 75 % (61/81). Only two respondents had worked in AAA screening for less than a year.

Perceptions of anxiety as a problem

When respondents were asked to agree or disagree with four statements relating to whether men diagnosed with a AAA need help to manage anxiety, 93 % (79/84) either strongly or somewhat agreed that men may need help; (46 % (39/84) strongly agreed with this statement). 88 % (74/84) of respondents strongly or somewhat agreed that families of men with an AAA also need help to manage anxiety. These views did not differ by the role of the staff who completed these questions.

In relation to being diagnosed with an AAA and undergoing surveillance, 85 % (72/84) strongly agreed or somewhat agreed that men with an AAA need help managing anxiety related to being in AAA surveillance, and 79 % (67/84) strongly or somewhat agreed that families need help managing surveillance-related anxiety.

Respondents were asked to rate a series of factors most likely to cause anxiety to men in the surveillance programme, from most likely to least likely. The top three factors were: the size of aneurysm (21 %), men who are generally anxious (19 %), and rate of growth of aneurysm (18 %).

How anxiety is currently identified

When asked to identify from a range of options the ways that individual staff identify anxiety in men, 96 % (80/83) of respondents cited men looking or sounding anxious e.g. body language, and 90 % (75/83) said they relied on men saying that they were anxious. Respondents could select more than one answer.

How anxiety is currently managed

When asked to select what approaches the regional screening services take currently to managing anxiety in men and their families, the most common options selected were 'talk to them about their concerns when they join the surveillance programme' (93 %, 78/83), 'talk to them about their concerns when they join three monthly surveillance (85 %, 71/83), 'referral to programme nurses'

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(83 %, 69/83), and 'offer them a leaflet about AAA' (80 %, 67/83). Respondents could select more than one answer and could offer free text comments. Free text responses were offered by 24 respondents and highlighted that some regional services have approaches other than those listed on the questionnaire. These included offering longer appointment times (n = 4), and provision of telephone numbers to contact either the regional screening service, Programme Nurse or Programme Manager (n = 10).

In an open question respondents were also asked what they did as individuals, rather than at a screening service level. 75 respondents gave free text comments. Providing reassurance, giving explanations, and encouraging men to ask questions were highlighted (n = 44), in addition to sharing knowledge to help men increase their understanding n = 32).

> *"Working closely with the programme's nurse practitioner to ensure that the sessions they provide, at the start of surveillance and when moving to quarterly surveillance, include a discussion about the mental health implications of their diagnosis".* (Programme Manager)

Linked to this, the communication and understanding of risk was acknowledged as a difficult concept and framing of risk was therefore considered essential to help manage anxiety (n = 15). In addition, inclusion of men's support networks - such as family - in discussions around diagnosis and surveillance was also viewed as important in supporting men in managing anxiety (n = 16).

> *"I reassure them by highlighting the statistical improbability of rupture at that size; how they can retard the growth of the AAA by good BP control and smoking cessation (where applicable); and by being on a statin/clopidogrel and adopting a healthy lifestyle, they can further reduce cardiovascular risk."* (Clinical Director)

> *"We never shy away from risk of rupture but for the very anxious we try to counterbalance their perceptions"* (Programme Manager)

Ideal approaches to managing anxiety

Respondents were asked to write in free text what might help to manage anxiety in men and their families in an 'ideal world'. The rationale for this question was not wanting respondents to feel constrained by concerns about resources. Respondents identified three main approaches [see Fig. 1]: 1) Information 2) group support/group networking 3) increased contact.

Information

40 respondents reported that provision of information was key. They suggested a number of different formats including group sessions, online, over the telephone and videos. A designated telephone helpline for advice and queries was also proposed. Respondents described the characteristics of this information - that it should be accurate and up to date. The link between provision of information and the reassurance that this could provide was also made by some respondents (n = 9). Information such as provision of risk of rupture statistics as a means of reassurance was also proposed (n = 6), whilst others suggested information about surgery or surgical outcomes as helpful (n = 3).

> *"Speaking directly to them, answering any questions/concerns they may have and providing them with statistical data - screening produces high success rates which is often reassuring to the patient."* (Programme Manager)

> *"We had an open day where men on surveillance were invited to attend and a vascular surgeon spoke about the surgery and the vascular nurse spoke about pre-habilitation and men who had undergone both types of repair were able to talk about their experiences, we had a great deal of positive feedback from this event".* (Screening Technician)

> *"A helpline with a telephone number. Anxiety can be triggered by an external event. So a tel[ephone] number for a national helpline would be good and uniform for the UK."* (Clinical Director)

As well as information about AAA during surveillance, respondents identified the importance of raising awareness of the national AAA screening programme in the general population, as has been done with bowel screening in England (n = 6).

> *"If they knew much more about the screening programme before the invite. Many people don't know anything about the screening programme until they get the invitation. The other way they might know about it is they have heard of someone dying from a ruptured aneurysm. There has been very little (? any) national publicity about AAA screening compared to bowel cancer screening."* (Programme Manager)

> *"I think if we had more awareness of AAA that the men who have them would not feel so anxious or alone."* Programme Nurse

> *"More publicity about AAA should be considered. Most men have never heard of AAA Screening and so don't know what to expect, then if they are found to have an AAA they are taken by surprise and don't always understand. More awareness would help."* (Programme Manager)

Group Support or Networking Sessions

18 respondents suggested, in an ideal world, provision or organisation of group support or networking sessions would be beneficial to helping men and their families manage anxiety by meeting others in similar situations. Respondents from one service highlighted that they already provide 'active programmes' that offer social and exercise groups which they perceived to be a success. Group support sessions that involved health care professionals from the regional screening service were also seen as a way of ensuring that men, and their families, would receive accurate and relevant information, and be able to ask questions, that they might not have the opportunity to do during scan appointments.

> *"Increase in the provision of social programme to enable men with AAA and repaired AAA to mix and build natural support networks and meet other men with AAA. Many men think AAA is more rare than it actually is- meaning they feel isolated and alone. However in [location] we have seen through our AAA Active programme 30+ men meet every week for group exercise and social interaction. They are forming friendships and are speaking about their AAA or their repair within conversations and feedback has been that meeting others with AAA/repair is beneficial to mental health and worry regarding AAA."* (Programme Nurse)

> *"To meet other men with an aneurysm, if we could hold surveillance information evenings or mornings where surveillance men could get together and have a chat. They could also bring a family member. This is something we would eventually like to introduce into our programme."* (Programme Manager)

> *"Support groups allowing an open forum for men to speak about their aneurysms and what it means to them."* (Programme Nurse)

> *"At our weekly exercise group men will always take the opportunity of being with us to ask questions that they may not have felt able to do before. Also the support of other men with the same condition is very important so ideally each programme would have a group that surveillance men could join."* (Programme Manager)

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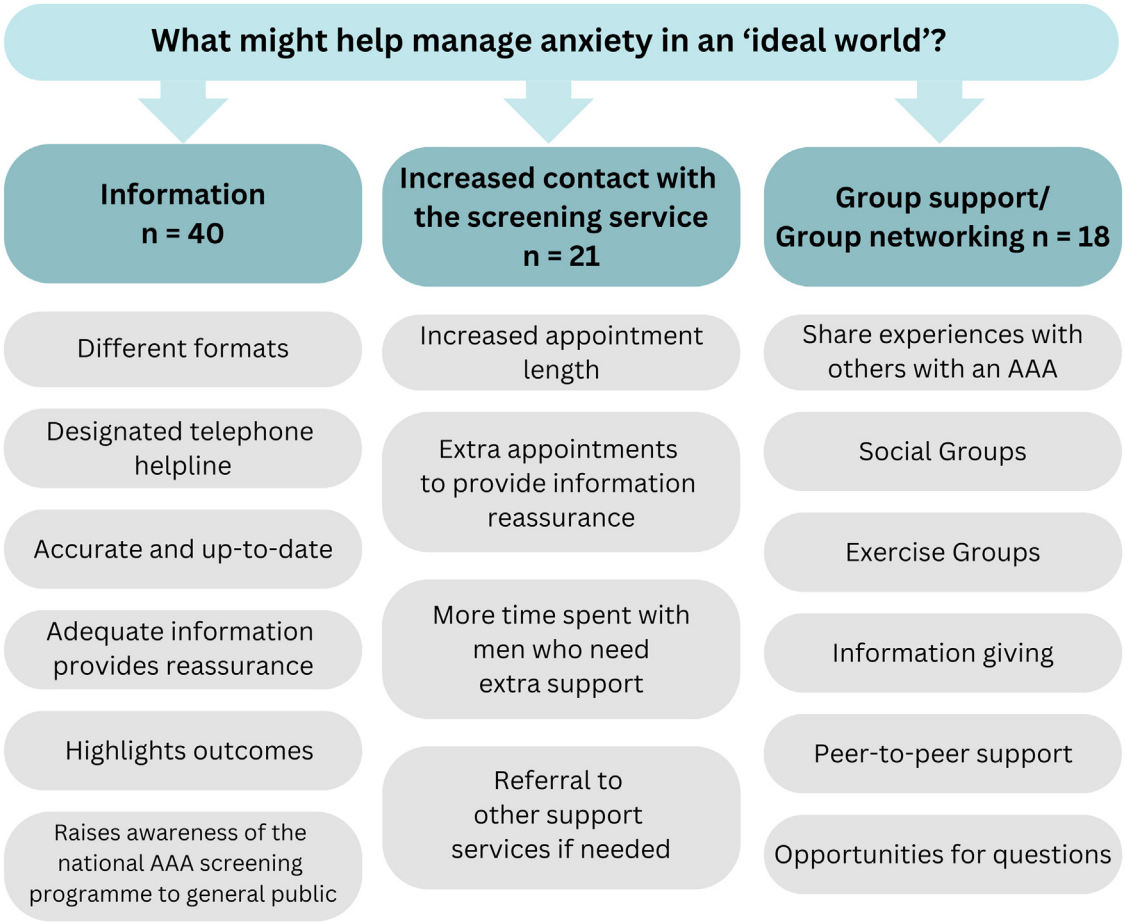

Fig. 1. 'Ideal' approaches to managing anxiety.

> *"Support groups allowing an open forum for men to speak about their aneurysms and what it means to them. We could also offer lifestyle support to patients. If patients don't want to attend a support group, we could do videos of patients who have had the AAA diagnosis talk about what it means to them, what their concerns were at the time, also include patients who have had surgery and talk about their journey."* (Programme Nurse)

Increased contact with the service

Respondents raised the need for increased contact between the regional screening service and men and their families to help manage anxiety (n = 21). This referred to increased length of appointments (n = 9) so that staff could take more time with men who needed extra support. Additional appointments with members of the screening clinical team as a means of providing extra information and reassurance were also suggested (n = 13), as was referral to support services such as their primary care team, or mental health teams (n = 4).

> *"In an ideal world slightly longer appointment… to allow us time to develop a rapport. It would also give men more time to ask the questions that they might not, if they feel rushed."* (Screening Technician)

> *"To have enough time to answer their questions and to be honest in managing their care. If very anxious to refer to the (AAA) nurse practitioner who can give another to talk through again what will happen. To refer to a specialist in anxiety maybe via the GP." (Screening* Technician)

A small number of respondents (n = 3) from three different providers, each in a different role, said that they were happy with what their provider currently provides and did not think anything more was needed.

Feasible approaches to managing anxiety

When asked to write about what might be feasible within the NHS rather than ideal, to identify more realistic interventions, 70 staff responded with a range of different suggestions; some of these reflected responses that were given for the 'ideal world' question. Provision of information in a wide range of formats was the most reported response (n = 18). Having a dedicated telephone helpline, which men could use to access information and support as and when they needed was also suggested by many (n = 14) because men can forget questions whilst they are at a clinic, or may become anxious between visits. More contact with a Programme Nurse was highlighted (n = 11); and more specifically having a follow-up phone call after appointments, or between annual appointments (n = 6). Having the option to refer men for specialist mental health support or counselling was proposed (n = 10), and training for staff within the screening service to support men with anxiety was also suggested (n = 4).

Organised group support (7/70) or group education days for men and their families (6/70) were also suggested as a feasible way for men to access information and social support. It was suggested that being able to talk to others experiencing the same health condition and related anxieties can be therapeutic.

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Provision of information, access to support groups, and more contact were three suggestions that were found in both the 'ideal world' and 'feasible' responses. However, in the 'ideal world' responses increased contact was specified as more contact with a Programme Nurse, and access to a telephone helpline.

Recommended characteristics of any intervention to manage anxiety

When asked what staff thought was important to consider in the development of an intervention to manage anxiety, the top three options rated as *very important* were: available in different languages 66 % (54/81); offered to all men, rather than targeted at men specifically identified as anxious 63 % (51/80); and offered face-to-face 33 % (27/80). Most highly rated as *important* (49 % (39/79)) was the intervention having different parts so men can pick and choose what that want to use. The 17 free text responses generally covered what format an intervention should take (n = 13) with the majority suggesting that it should be offered in a variety of media (face-to-face, telephone, online, written) so men and their families had a choice. Some respondents did note, however, that as the cohort of men that an intervention would be aimed out is aged 65 and older that it was important that there was not a reliance on delivering an intervention digitally.

Ideal delivery of any intervention

The majority of respondents, 63 % (51/81), believed that an AAA screening Programme Nurse would be the right person to deliver any intervention to manage anxiety. Programme Nurses were described as the first point of contact once a man enters surveillance. It was suggested that there is also more flexibility in being able to offer additional appointments or longer appointments with a Programme Nurse if needed, as opposed to the time constraints that might apply when attending for their annual/three-monthly scan. The second placed choice for intervention delivery was the 'other' option completed by 18 % (n = 15). Of these 15 free text responses, 6/15 suggested that a multi-person approach was best. There was little differentiation across the roles of those that nominated the Programme Nurse as the most appropriate person to deliver an intervention.

Discussion

Summary of findings

The survey had a 71 % response rate for the regional screening services approached, with a 65 % staff response rate. The study findings showed that AAA screening service staff recognise that being in AAA surveillance can cause anxiety for some men and their families, with 93 % of respondents strongly or somewhat agreeing that men in surveillance may need help to manage anxiety. The size of the aneurysm was rated the factor most likely to cause anxiety. Screening service staff were able to identify a number of different approaches that they believed could feasibly be used to help with management of anxiety for men and their families. Respondents suggested that improved information about AAA and associated risks, group support/networking sessions, and more contact with the screening service were ways of helping with management of anxiety. 63 % (51/81) considered AAA Programme Nurses to be the right people to deliver an intervention.

Placing findings in the context of other research

This study is unique in examining the perceptions of screening service staff about how best to help men manage anxiety. One other study we found involved staff views regarding the introduction of multi-component cardiovascular health screening into the existing AAA screening programme.[24] Although that study had both a different focus, and different methods, there were some similarities in terms of findings. For example, participants aimed to provide a positive patient experience.

Screening service staff identified AAA Programme Nurses as having a key role in helping men in AAA surveillance, and therefore would be the ideal person to deliver any anxiety management intervention. However, in practice this may prove difficult as between April 2021 and March 2022 of the 2,654 men who had a small or medium AAA detected at initial screen, or men who had a medium AAA at their annual surveillance scan, only 64.5 % had a nurse assessment within 12 weeks of their conclusive scan.[25] Given that research has shown that decreased quality of life and increased stress related to AAA is more prevalent in the first year after screening,[8,13] any anxiety management intervention would have to be delivered in a timely manner. International research has highlighted how specialist nurses have an essential role in providing information and support to men in AAA screening at regular reviews.[26]

Respondents suggested a range of ways of providing information, with many recognizing that the age of men would prohibit sole reliance on digital interventions. This is supported by a qualitative study that examined patient experiences of using an eHealth intervention throughout the AAA repair journey which found that less than half the participants used the tool, and noted that familiarity with, and attitude to, e-Health in general was a major influence.[27] The study also highlighted that the psychosocial support offered as part of the intervention was key to alleviating patients' emotional burden. It seems likely that any intervention to be developed should be offered in a variety of formats to ensure that it is acceptable to the target audience.

Men who are already anxious, the size of the AAA and rate of AAA growth were identified by respondents as the factors that were most important in contributing to anxiety. Other qualitative research involving men in AAA surveillance has suggested that the size of an AAA is an abstract concept and hard to understand for some men who are unsure of what the measurements mean.[26] Increased growth rate was seen as a significant concern, with stable measurements providing reassurance.[26] Related to this, our respondents proposed that talking about the size of an AAA in terms of 'framing risk' with regards to rupture would be one method of helping men to manage anxiety.

Similarly to our study, the importance of providing detailed information, educational support and having time set aside to discuss worries and concerns has also been identified in other studies.[27] A systematic review of health-related quality of life and experiences in patients with AAA in surveillance in Sweden also concluded that lack of information and knowledge about AAA can cause unnecessary worry or concerns.[14] It seems that giving the right information in the right way is important given that poor timing and an overwhelming amount of information have been identified as factors causing anxiety in AAA surgery care.[28]

Strengths and limitations

A key strength of this survey was the range of different roles and locations of the staff that completed it. There was representation from each staff role within the national screening programme and from 27/38 different regional screening services across England in both urban and rural locations. However, it should be noted that screening technicians made up 36 % of the sample which may have had an impact on the results; there was an underrepresentation of AAA Programme Nurses who made up 15 % of the sample.

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Implications

This survey was conducted as part of a wider study –The Patient Centred AAA Study (PCAAAS); more information about the study can be found at http://www.sheffield.ac.uk/scharr/research/centres/hcru/pcaaas. The findings will be used alongside a survey of men in surveillance, and interviews with men and their families, to develop an intervention to help men to manage anxiety related to AAA surveillance.

Conclusion

Screening service staff recognise that being in AAA surveillance can cause anxiety for men and their families and that more support is necessary. Provision of accurate, personalised and timely information to all men that attend screening, in a range of formats, as well as networking groups, were identified as feasible and desirable ways of helping men to manage anxiety. Programme Nurses were considered the ideal healthcare professional to help men manage AAA screening related anxiety.

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Declaration of competing interest

None.

In the interests of transparency the authors would like to highlight that three of the authors have roles in the NHS AAA Screening Programme; Alan Elstone is the Professional Clinical Advisor (Nursing), Mr Akhtar Nasim is the National Surgical Lead, and Professor Gerry Stansby is the Research Lead.

CRediT authorship contribution statement

Elizabeth Lumley: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Jane Hughes:** Writing – review & editing, Visualization, Validation, Formal analysis, Data curation. **Alan Elstone:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Jo Hall:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Niall MacGregor-Smith:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Jonathan Michaels:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Akhtar Nasim:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Stephen Radley:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Phil Shackley:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Gerry Stansby:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Emily Wood:** Writing – review & editing, Validation, Resources, Methodology, Investigation, Funding acquisition, Formal analysis. **Alicia O'Cathain:** Writing – review & editing, Visualization, Validation, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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