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Research priorities for aortic diseases: results of the James Lind Alliance/Vascular Society GBI priority setting exercise

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Plain English Summary

Why we undertook the work: Researchers often focus on what they think is important, which can be different from what patients, carers and clinicians think. For this reason, it can also make it difficult for funding bodies to decide where best to target their limited funding. To address this issue, the Vascular Society of Great Britain and Ireland (VSGBI), with the James Lind Alliance (JLA), undertook a national Priority Setting Process (PSP) to identify the most important areas of vascular research in the UK. This paper presents the results of this process, focusing on aortic condition-related research topics.

What we did: The PSP was undertaken in three main phases. The first was an open-ended survey which aimed to collect the views of vascular healthcare professionals about their research priorities. The second phase was conducted in the same way but was aimed at gathering the opinions of vascular patients and carers about research topics that were most important to them. The third stage brought together the results of the two surveys and created a combined list of both vascular professional and patient research priorities. These priorities were discussed at a final workshop meeting attended by patients, carers and professionals who agreed an ordered 'top 10' list of research priorities for aortic conditions.

What we found: A total of 481 healthcare professionals and 373 patients or carers submitted research priorities about vascular conditions. These were amalgamated into a list of 18 priorities specifically about aortic conditions and were put into an order of importance at a workshop meeting. The final 'top 10' aortic research priorities related to improving how aortic conditions were identified and monitored, finding out how treatment options are decided, supporting recovery after an operation and more ways of predicting those at risk of having aortic conditions.

What this means: We have identified the most important research priorities for aortic conditions and encourage researchers and funders to focus their efforts in addressing these important topics.

Abstract

Background: In order to identify research priorities for aortic disease, a partnership between the Vascular Society of Great Britain and Ireland (VSGBI) and the James Lind Alliance (JLA) was established to capture the interests of a wide group of patients, carers and health professionals. One of the aims of the partnership was to establish the top 10 research priorities in the field of aortic disease.

Methods: A modified JLA Priority Setting Partnership was undertaken, during which healthcare professionals, patients and carers participated independently in two Vascular Society of Great Britain and Ireland (VSGBI)-led Delphi processes identifying research priorities in aortic disease. An aortic Special Interest Group composed of patients and healthcare professionals assessed the two lists of priorities, amalgamating similar priorities and generating a final list for ranking. An offer was sent to various patients, carers and healthcare professionals from different backgrounds with an interest in aortic disease to attend the final consensus workshop where a ranked top 10 list of aortic disease research priorities was produced using a nominal group technique.

Results: A total of 1,231 research priorities relating to general vascular surgery were submitted by 481 clinicians. From these, 162 aortic-specific research priorities were identified and combined into 15 final clinical priorities. In addition, 582 research priorities related to vascular surgery in general were submitted by 373 patients or carers. From these, 24 further aortic-specific research priorities were identified after combining similar priorities. Amalgamation of

the clinician and patient priorities resulted in 18 priorities that were taken to the final consensus workshop, where a ranked top 10 list of aortic disease research priorities was produced. These priorities include themes of diagnosis, surveillance, management, recovery and predisposition.

Conclusion: A collaborative effort between healthcare professionals and patients has identified a ranked top 10 list of aortic disease research priorities. This list will inform and guide clinicians, researchers and funders for the foreseeable future and will support future research that encompasses the important interests and representation of the wider network involved and affected by aortic disease.

Key words: aortic conditions, clinician, patient, research priorities

Background

In the UK, aortic aneurysm affects approximately 4% or 80,000 men between the ages of 65 and 74 years.[1] With a broad spectrum of rapidly evolving treatment options, advancing methods of management and investigation, many aspects of best clinical practice for aortic diseases are unknown.[2] Aortic diseases are exemplified by aortic aneurysm, the most common aortopathy.[3] Aortic disease research is integral to understanding the disease and guiding optimal management. In addition, it is imperative to consider the research goals and initiatives of all those involved in this vascular condition.[4] To ensure treatment is aligned with the best interests of all involved, robust methodologies used to identify research priorities must be conducted. Disparities between what is traditionally deemed important by the clinicians and that which is perceived to be important by the patients, carers and families is a potential area of mismatch that can distort the areas of investigation. Another important consideration is that continued optimisation of patient care must occur within the constraints of research funding opportunities with finite resources and competitive processes. In combination, these factors demonstrate the need to have well thought out and important discussion involving all relevant individuals.

Optimal aortic disease management is multidisciplinary.[2] Direct treatment of the aneurysm includes surgical and radiological intervention; however, pathways of care extend to a wider network including disease surveillance, rehabilitation and personal and professional support groups. To establish and develop key research priorities for aortic disease, the Vascular Society of Great Britain and Ireland (VSGBI) partnered with the James Lind Alliance (JLA) to conduct a validated research priority setting exercise reflective of both clinician and public interest.[5] The aim was to generate a ranked list of aortic specific research priorities to appropriately direct future research and help set the agenda for impactful studies.

Methods

To identify public research priorities for vascular diseases the VSGBI in association with the JLA undertook a research priority setting exercise. Due to the large scale of this exercise, nine discrete working groups were formed, each focusing on a particular vascular or clinical area and each conducting a separate research priority setting exercise focusing on their particular area. This paper reports the outcomes from the aortic disease research priority setting exercise.

An initial Delphi survey was conducted to obtain clinician priorities, and this was followed by a JLA survey to gather the opinions of vascular patients and carers about their research priorities. The results of the clinician and patient surveys were amalgamated and final workshops held for each Special Interest Group (SIG), where patients and clinicians worked together to agree on a final list of joint research priorities.[6–8]

Scope of the aortic SIG

The remit of the aortic SIG is to support research into the care of patients living with or affected by aortic disease including preoperative, perioperative and postoperative care, and to develop the top 10 aortic research priorities. The top 10 priorities were established through a five-stage process (Figure 1).

Clinician-led Priority Setting Process

A clinician-led Priority Setting Process (PSP) was completed in 2018, which identified nine key vascular condition areas. These areas were obtained from 45 potential topics using a modified Delphi approach. The topics were collected through two rounds of online surveys involving the membership of the VSGBI, Society of Vascular Nurses (SVN), Society for Vascular Technology (SVT) and the Rouleaux Club (vascular surgical trainees). The first round invited any suggestions for research priorities in the broad scope of 'vascular surgery', which were then collated and categorised into pathological topics and research categories by a steering group. Priorities relating to the same fundamental issue were amalgamated. Summarised priorities were then recirculated in the second round for scoring according to importance. These results have been published,[7] and the findings related to aortic disease are presented here.

Patient/carer-led research priority identification process

Patient and carer suggestions for research priorities were collected via an open-ended survey (27 August 2019 to 17 March 2020) which invited participants to submit their own opinions about vascular research priorities that they thought were important. The

Figure 1 Five-stage process identifying top 10 priorities for aortic disease.
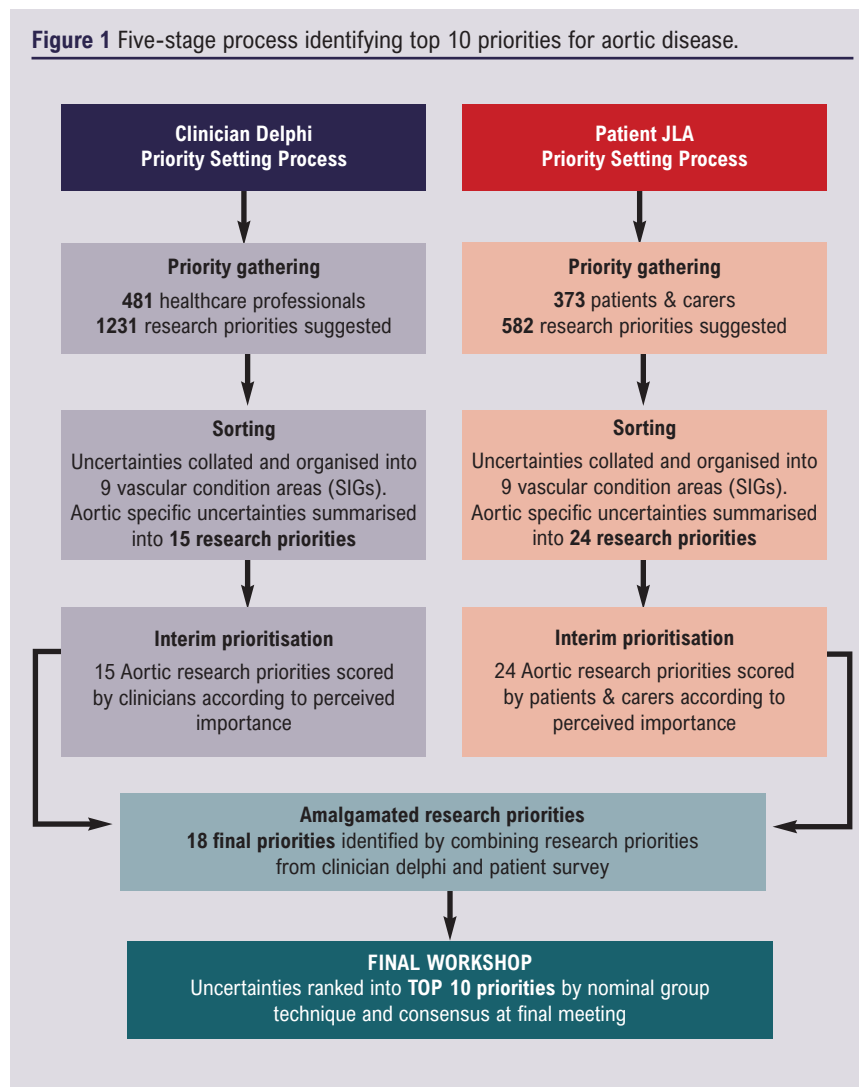
Combining surveys process: sorting, interim prioritisation and amalgamation

The clinician-led and patient and carer-led processes presented 39 aortic research priorities: 15 clinician-derived and 24 patient-derived. The aortic SIG reviewed for duplication or redundancy when amalgamating clinician and patient priorities. Clinician priorities were reviewed with patient input to reword any technical language to ensure patient participants at workshops would understand. To ensure meaningful discussion in the focus group meetings, a final revision process was conducted by the SIG to refine the list of priorities that would be taken forward to the final workshop. This research priority refinement was conducted in alignment with JLA methodology. The JLA advises a maximum of 18 priorities for discussion at a final workshop to promote manageable and invested discussion. Further reduction was therefore performed by categorisation. Categorisation included judging the importance of each of the priorities according to ranking using survey scores. Consideration of bias and inequality assessment (eg, women may have been underrepresented in the Delphi survey as aneurysm disease is 10 times less common in women, so questions regarding sex-specific treatments were considered) was then conducted to take into account the potential influence of participants' demographics and influence on priority selection detailed in Table 1.

survey was available online and in paper format (with freepost return), and copies made available in outpatient clinics. SIGs took a lead in helping to distribute the surveys, with the aim to ensure a representative number of responses gathered for their specialty area. Charities and patient groups were contacted and asked to distribute the survey in newsletters and via websites.

Submitted priorities were assigned to a SIG category for further review. SIGs were tasked with sorting the responses; those considered out of scope (eg, too broad, too specific or answered by existing evidence) were excluded and duplicates were combined and summarised into an overarching priority. A refined list was agreed for the next round of the survey (conducted between November 2020 and February 2021), which invited participants to select their vascular area(s) of interest and to score the priorities within this area using a Likert scale (ranging from 'Extremely Important' to 'Not at all Important' or 'Don't know'). All participants were invited to prioritise the Services Organisation priorities as these contained cross-cutting priorities that would apply to all vascular patients, regardless of their vascular condition.

Final priority setting workshop

The aim of the workshop was to establish research priorities for aortic disease through facilitated, balanced and open conversation between patients, carers and healthcare workers. Participation of patients and carers in the final workshop was welcomed throughout the priority setting stages to ensure multiple opportunities for individuals to demonstrate interest and to share their views. Interested participants who have lived experience of aortic disease were then invited to attend the workshop to determine the top 10 research priorities. In addition, invitation through direct contact was made with patients/carers who are established members of patient representative bodies. Healthcare participants were contacted through direct communication with various national bodies, as well as through direct contacts of the SIG members.

The workshop was held virtually to accommodate COVID-19 restrictions. To address potential accessibility and technical considerations as well as possible, induction sessions were carried out with participants as appropriate. Although presenting some

Table 1 Selection criteria for priorities

	Description of criteria
1	Any research priority that achieved a rank 1–10 described method (Category I)
2	Any research priority that may have not been ranked 1–10 due to the potential lack of diversity or sexual representation in the respondents (Category II)
3	Unranked research priorities deemed important by the members of the panel (Category III)
4	Research priorities deemed to be the same/similar to already prioritised questions or were not specific to aortic disease/the focus of other research priority setting exercises were removed (Category IV)

limitations with the online virtual format potentially being a deterrent for participation, hosting a virtual workshop did enable the opportunity for some stakeholders to attend who ordinarily would not have been able to travel due to needs, caring or employment commitments. The experienced JLA facilitator opened the workshop and introduced the goals for the session. Participants were split into small breakout groups of approximately six, with a balanced representation of patients, carers and healthcare workers. Each small group was facilitated by a JLA representative, and members of the aortic SIG observed. All participants were informed of support services available to them during and after the workshop.

Participants were reminded that the focus of the workshop was to help shape the research agenda with priorities that mattered to people with lived experience and the healthcare professionals who work with them. Participants were asked to consider the priorities on their own merit and not to be concerned about the feasibility of research. Participants had been sent the 18 priorities in advance of the workshop and asked to rank these for themselves before the event. The workshop approach was based on a 'nominal group technique' which allows participants to share their own initial thoughts and priorities. Through a structured and facilitated set of steps of clarification and consolidation, the group comes to a consensus ranking.

Overview of small group discussions

First round of discussion: Each participant was asked, in turn, to share their top three and lowest three priorities with the others in the group. The group was then facilitated to have an open discussion about the differences and similarities of their choices and to discuss any priorities previously not mentioned.

Second round of discussion: The same groups then entered a second round of

discussion. Participants were provided with a shared screen showing an approximate positioning of the priorities on a pre-prepared ranking template, which had been prepared by the facilitator during the break. Participants were then given the opportunity to reconsider their initial set of priorities through discussion. The facilitator moved the priorities on the screen to reflect the agreed order from the group ranked 1–18.

Third round of discussion: The ranked priorities of the three separate small groups were combined by the lead facilitator using a geometric mean of the respective ranked positions. Taking into consideration the potential for anomalous positioning if groups have large discrepancies between ranking of a particular priority, a further round of discussion was held. New small groups were established, again with a balanced representation of patients, carers and healthcare workers, with at least one representative in each group from the initial group. This approach promoted diversity of participants, whilst permitting discussion as represented by previous considerations. Members of the second groups were then asked to review this combined ranking and to clarify their views and the views of others, with the focus on which priorities they wanted to see in the top 10.

Fourth round of discussion: All participants came together as one group to discuss the combined results of the rankings of the three groups.

Table 2 Clinician Delphi results

Summary priorities	Mean scores
What is the best treatment option for 'complex' AAA (eg, short necks, juxta renal, iliac pathologies)?	7.64
What is the optimal management of patients with aortic aneurysm disease using individualised risk:benefit ratios?	7.56
How do we improve long-term outcomes following EVAR?	7.50
What is the optimal post-EVAR surveillance strategy following endovascular AA repair?	7.47
What is the optimum medical therapy for patients with AAA to minimise expansion/rupture?	7.43
What is the best management strategy for type B aortic dissection?	7.29
What is the optimal management of aortic graft infection?	7.27
How can we improve our understanding of AAA biology in relation to promotion and growth?	6.98
What are the most appropriate outcome measures in patients with AAA?	6.86
How do we prevent spinal cord ischaemia during aortic aneurysm repair?	6.77
What is the optimal pathway for patients undergoing AAA repair?	6.76
What is the optimum AAA screening strategy?	6.56
Should EVAR 2 be repeated in the modern era?	6.56
What is the optimal surveillance strategy for 'sub-threshold' aortas?	6.44
Should EVAR 1 be repeated in the modern era?	6.09

AAA, abdominal aortic aneurysm; EVAR, endovascular aneurysm repair.

Results

Clinician research priority identification and prioritisation

A total of 481 clinicians submitted 1,231 research priorities relating to vascular surgery in general. 162 aortic-related research priorities were submitted, 16 of which were excluded outright as they were too specific to single patient experience. The remaining 146 priorities were combined and summarised into 15 clinician priorities for scoring, the results of which are shown in Table 2.

Patient/carer research priority identification and prioritisation

A total of 373 patients/carers suggested 582 research priorities related to vascular surgery in general, of which 140 were specific to aortic disease. After data cleaning (eg, removing nonsensical suggestions) and combining overlapping priorities, 24 research priorities were redistributed for scoring. Forty-eight patients or carers with experience of aortic disease participated in the scoring exercise and the results are shown in Table 3.

Prior to the workshop, the SIG team pooled clinician and patient/carer research priorities, resulting in a list of 18 for discussion (Table 4). In order to reduce risk of bias, these priorities were randomly ordered and each assigned a letter (rather than a number).

Final prioritisation workshop

The final prioritisation process was conducted via a virtual online meeting on 13 April 2021. It was attended by four patients and carers and eight healthcare professionals, with an additional five observers. The final prioritisation resulted in a final 'top 10' research priority list (Table 5). The priorities are ordered according to importance as determined by the workshop. There was general consensus that the list correctly represented the discussions and viewpoints which occurred in the breakout groups.

Discussion

Summary

Ranked research priorities in aortic disease have been clearly highlighted in a way that combines the opinions of all those involved. This robust method is designed to ensure alignment of priorities between clinicians and patients, mitigating disparity between what is deemed important by different perceptions.

Table 3 Patient/carer James Lind Alliance (JLA) results

Summary priorities	Mean scores
What methods, including digital technology, can be used to ensure that people with acute aortic conditions such as aneurysm rupture or dissection are diagnosed quickly and treated without delay?	4.67
When should people with aneurysms be offered an operation to repair their aneurysm and how quickly should this be done if this is required?	4.54
How do surgeons decide which treatment is best for aneurysms and are these decisions based on the latest evidence available?	4.53
How do we make aneurysm surgery safer and reduce the risk of complications?	4.42
What is the best way to monitor people after treatments to repair aneurysms to make sure they don't develop problems with their repair?	4.36
What causes aortic dissection, and can the risk be picked up and/or prevented before it happens?	4.36
What causes an aneurysm or is associated with aneurysm formation and how can we prevent one developing?	4.36
What causes aneurysms to grow and/or rupture?	4.36
How common are complications after aneurysm repair and how can the chances of developing such complications be minimised?	4.34
How can the risk of another aneurysm or other long-term aortic complications after aneurysm repair be minimised?	4.34
Can we develop a test that could diagnose patients at risk of aortic aneurysm/dissection?	4.31
Does having an aneurysm affect life expectancy, how can any effect of having an aneurysm be minimised and how can the patient and doctor achieve this?	4.25
What is the rate of aneurysm growth or aortic growth after dissection?	4.19
Can keyhole techniques and robotics make operations to repair aneurysms safer?	4.18
Can small aneurysms that are not at risk of causing harm to be prevented from growing into larger high-risk aneurysms?	4.16
How do we effectively diagnose and treat those with a genetic cause to their aortic aneurysm?	4.14
How can we encourage more men to attend screening?	4.04
How do we reduce the time it takes to recover from aortic operations?	4.00
Should women be screened for AAA?	3.97
Aneurysms behave differently in women compared to men but both men and women are treated the same way. Should we develop sex-specific pathways to care for people with aneurysms?	3.94
How often are other problems detected when performing scans for an AAA and is there any benefit in doing anything about these findings?	3.90
Should siblings be screened for AAA when there is a family history of aneurysm?	3.86
Should genetic testing be carried out on everyone with an aortic condition?	3.85
What is the optimal age to screen for aneurysms?	3.83

AAA, abdominal aortic aneurysm; EVAR, endovascular aneurysm repair.

Strengths and limitations

The JLA process is acknowledged to be a snapshot in time, and a different group of participants may have determined an alternative collection of priorities. To mitigate the impact of this, it is important that not all aortic research is limited to addressing the top 10 priorities. Additionally, in order to add new voices and thoughts, it is essential to include patients and representatives at all stages of research planning and delivery. The use of virtual platforms for the prioritisation workshops had potentially both positive and negative

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Table 4 Pooled clinician and patient/carer research priorities: assigned letter rather than numbers regarding randomised order

ID	Research priority
A	How can the risk of another aneurysm or other long-term aortic complications after aneurysm repair be minimised?
B	How do we make aneurysm surgery safer and reduce the risk of complications?
C	When should people with aneurysms be offered an operation to repair their aneurysm and how quickly should this be done if this is required?
D	What is the optimum medical therapy for patients with AAA to minimise expansion/rupture?
E	What methods can be used to ensure that people with acute aortic conditions such as aneurysm rupture or dissection are diagnosed quickly and treated without delay?
F	How do we reduce the time it takes to recover from aortic operations?
G	How do surgeons decide which treatment is best for aneurysms and are these decisions based on the latest evidence available?
H	What is the optimal management of patients with aortic aneurysm disease using individualised risk:benefit ratios?
I	Aneurysms behave differently in women compared to men but both men and women are treated the same way. Should we develop sex-specific pathways for aneurysms?
J	What causes an aneurysm or is associated with aneurysm formation and how can we prevent one developing?
K	What is the best way to monitor people after treatments to repair aneurysms to make sure they don't develop problems with their repair?
L	Does having an aneurysm affect life expectancy, how can any effect of having an aneurysm be minimised and how can the patient and doctor achieve this?
M	Should siblings be screened for AAA when there is a family history of aneurysm?
N	What causes aneurysms to grow and/or rupture?
O	Can keyhole techniques and robotics make operations to repair aneurysms safer?
P	What is the best treatment option for 'complex' AAA (eg, not suitable for standard stent grafts) or low-risk standard operations (eg, short neck, iliac pathologies, juxtarenal)?
Q	Can we develop a test that could diagnose patients at risk of aortic aneurysm/dissection?
R	What is the rate of aneurysm growth or aortic growth after dissection?

AAA, abdominal aortic aneurysm

Table 5 Final ordered list of top 10 research priorities in aortic disease

Rank	ID	Research priority
1	H	What is the optimal management of patients with aortic aneurysm disease using individualised risk:benefit ratios?
2	N	What causes aneurysms to grow and/or rupture?
3	Q	Can we develop a test that could diagnose patients at risk of aortic aneurysm/dissection?
4	G	How do surgeons decide which treatment is best for aneurysms and are these decisions based on the latest evidence available?
5	D	What is the optimum medical therapy for patients with AAA to minimise expansion/rupture?
6	J	What causes an aneurysm or is associated with aneurysm formation and how can we prevent one developing?
7	K	What is the best way to monitor people after treatments to repair aneurysms to make sure they don't develop problems with their repair?
8	B	How do we make aneurysm surgery safer and reduce the risk of complications?
9	F	How do we reduce the time it takes to recover from aortic operations?
10	M	Should siblings be screened for AAA when there is a family history of aneurysm?

AAA, abdominal aortic aneurysm
This table demonstrates the final rank of the research priorities. Ranking was established through consideration of both the arithmetic and geometric scoring methods. For priorities K and B the geometric method resolved the tie between 7 and 8.

impacting factors by both facilitating and hindering participation. Travel challenges (eg, frail patients, large geographical distances) were essentially negated by this process. Technical literacy requirements and access may have limited certain participation. Workshop feedback gathered from a follow-up survey was positive overall. Most participants expressed that they enjoyed the process and found it provided an opportunity to learn from others. Some participants highlighted their personal preference for priorities that were excluded from the final top 10 or a preference for a different order; however, this is not uncommon for PSPs that use a consensus approach. There were comments regarding requests to further edit and merge some of the priorities due to perceived overlap. This was addressed directly during the workshops where emphasis was placed on respecting the methodology that had gone before in summarising priorities for the workshop. Most participants found the online format and length of the workshop acceptable, but it was suggested that the final session could have been longer to allow the new groups to fully discuss the rearranged priorities.

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Implications for future research

Each of the top 10 priorities identified through this extensive process must now be scrutinised to determine the appropriate related research priorities, how these relate to existing evidence and current research, and what research design best addresses these priorities. Finally, it is hoped that funding bodies and decision makers will direct funding towards these priorities and increase investment in the delivery of new studies in these areas of greatest need and highest impact.

KEY MESSAGES

- Establishing relevant patient priorities through collaborative decision making.
- Top 10 priorities addressing a need for improved post-operative care, better understanding of the natural history of aortic disease and personalised intervention strategies.

Table 6 Patient perspective

What is the optimal management of patients with aortic aneurysm disease using individualised risk:benefit ratios?
The main blood vessel in the body (the aorta) may become dilated (an aortic aneurysm). As this dilation gets larger the risk of it rupturing increases. Rupture is usually associated with fatal bleeding. Aortic aneurysm surgery aims to prevent an aortic rupture. The risks of aortic surgery are not insignificant and vary from patient to patient, therefore not every patient with an aortic aneurysm benefits from surgery. However, those patients who would have gone on to rupture their aneurysm will. Some people with aneurysms don't ever come to harm from it and, in these people, surgery puts them at risk without being of benefit. Currently, the surgeon will consider a patient for surgery when the aneurysm has reached a certain size. However, some people who might benefit from surgery don't get offered surgery because they are considered too unfit to survive the operation. We need more research to assess in depth the implications, risks and benefits of surgery and no surgery for individual patients with aortic aneurysms.

What causes aneurysms to grow and/or rupture?
Aortic aneurysms form very slowly over time. When an aneurysm is small, they don't cause a problem. As they get bigger they can rupture, which is often fatal. People found to have small aneurysms are therefore usually monitored to check their aneurysm hasn't grown to a dangerous size. This period of monitoring is an opportunity to offer treatment to prevent aneurysms growing, and prevent rupture and the need for surgery. Currently, there is no proven treatment to slow aneurysm growth. The only things we do know about aneurysm growth is that aneurysms in smokers grow faster and those in people with diabetes grow slower. Research is required to determine what factors cause aneurysms to grow or rupture. This may then allow us to identify treatments to prevent aneurysm growth and rupture.

Can we develop a test that could diagnose patients at risk of aortic aneurysm/dissection?
The only way to find out if someone has an aneurysm or not is to scan them using ultrasound, CT or MRI scans. This can pick up aneurysms and abnormalities of the aorta. In some people the aorta can appear normal before they suffer from an aortic tear (dissection). For this reason, a scan cannot always predict aortic problems. A test such as a blood test to identify people at risk of aneurysm or dissection would reduce the amount of imaging scans that need to be done. For people at risk of dissection without any previous signs of aortic dilation, a blood test may be the only way to identify this risk.

How do surgeons decide which treatment is best for aneurysms and are these decisions based on the latest evidence available?
When treating people with aneurysms, medical and surgical teams rely on information obtained from clinical experiments where new methods and treatments have been tested. Clinical experiments are those tests and research priorities that are answered by looking at the outcome of practices within the care of patients. Deciding which treatment is best relies on individual teams having the latest information available to them and on these teams interpreting this information properly. We don't know if this happens or if it has any effect on the treatment patients receive. Research to investigate this is important as it will ensure that all patients receive the latest and best treatment for their aneurysm.

What is the optimum medical therapy for patients with abdominal aortic aneurysm (AAA) to minimise expansion/rupture?
The only treatment available to prevent aortic aneurysm rupture is surgery. There are significant risks of harm with this surgery. Therefore treatments that prevent a small aneurysm from increasing to the point where surgery is required would prevent patients being exposed to these risks. Research is required to investigate which medical therapies slow down or stop progressive aneurysm dilation and its associated complications.

What causes an aneurysm or is associated with aneurysm formation and how can we prevent one developing?
Most aneurysms are detected once they have already formed. What causes an aneurysm to start and when this happens in life is unknown. If this could be identified, then treatment could be started early in those people at risk to prevent them ever forming an aneurysm. Research is needed to understand the process of an aneurysm forming and to investigate drugs to stop the process from happening.

What is the best way to monitor people after treatments to repair aneurysms, to make sure they don't develop problems with their repair?
The aim of surgery to repair an aneurysm is to prevent the rupture of the aneurysm. Surgery can either be open surgery (with a cut) or minimally invasive 'keyhole' surgery where the aneurysm is lined with a stent. Following surgery, a small number of patients develop complications (more commonly after stenting) and therefore it is important to monitor patients after surgery usually with follow-up scans. We need more research to determine the optimum follow-up scan regime in terms of safety, effectiveness and value for money.

How do we make aneurysm surgery safer and reduce the risk of complications?
Aneurysm repair is a relatively high-risk operation. This is particularly the case where the repair is done for an aneurysm that has burst (ruptured). For planned surgery the risk of major complications is about 10% and the risk of dying is about 2–3%. For emergency surgery these risks are much higher; about one in three people don't survive. Research is required to assess what can be done before, during and after surgery to improve these outcomes.

How do we reduce the time it takes to recover from aortic operations?
Recovery from aortic surgery, especially open surgery, can be prolonged. Research is required to investigate ways to reduce this recovery time.

Should siblings be screened for AAA when there is a family history of aneurysm?
AAA can run in families, and it is known that people's genetics can increase the risk of developing an aneurysm. If someone has a first-degree relative with an AAA, their risk of developing an AAA is about 5–10 times greater than usual. Screening for AAA involves an ultrasound scan to look for an AAA in individuals at risk but who have not specifically requested the scan. Research is required to assess whether screening for AAA in brothers and sisters of patients with AAA is acceptable, safe, effective and value for money.

Conclusion

This collaborative effort between healthcare professionals and patients has identified the top 10 research priority areas focused on aortic disease which will guide researchers, clinicians and funders for the foreseeable future.

The patient perspective

In Table 6 each priority has been presented using terminology to improve clarity and understanding.

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