The Vascular Priority Setting Partnership

Setting the Agenda for UK Vascular Research

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The Vascular PSP Top 10 Research Priorities

- ACCESS
- AMPUTATION
- AORTIC
- CAROTID
- DIABETIC FOOT
- PERIPHERAL ARTERIAL DISEASE
- SERVICE ORGANISATION
- VENOUS
- WOUNDS

Background

- Vascular Conditions
- Why Set Priorities for Vascular Research?
- What are the Benefits of a Priority Setting Process?
- How did the Vascular Priority Setting Partnership agree the priorities?

Summary Timeline

Special Interest Groups (SIGs)

Summary of PSP Process

Methods and Results

- Phase One; Clinician Delphi Survey Summary.
- Phase Two; Patient and Carer Survey with the James Lind Alliance.
- Phase Three; Final SIG Workshops: A combined approach.

Next Steps

References

The Vascular PSP Steering Group
Foreword

The Vascular Priority Setting Partnership (PSP)

The Vascular PSP provided an exciting opportunity to gather the unique perspectives of clinicians, patients and carers in identifying priorities for vascular research in the UK.

In 2016, the Research Committee of the Vascular Society of Great Britain and Ireland (VSGBI), chaired by Prof Chris Imray identified the need for a national specialty research strategy. This strategy, was developed with support from the Royal College of Surgeons of England Surgical Specialty Lead (Prof Ian Chetter) and included the formation of a Vascular Research Collaborative to initiate and steer a national vascular research priority setting process (Vascular PSP), guided by the James Lind Alliance (JLA).

This process provided an exciting opportunity to gather the unique perspectives of clinicians, patients and carers with direct experience of living with vascular conditions and in delivering vascular care - over 1800 research questions were submitted - a fantastic achievement!

Although there have been many improvements over the last 20 years, there are still unanswered questions regarding prevention, diagnosis and treatment of vascular disease. PSPs help researchers and policy-makers effectively focus research and limited resources into areas that have the greatest potential health benefits, by systematically identifying gaps in evidence and establishing recommendations for research priorities.

"Priority Setting Processes systematically identify gaps in research evidence."
Foreword

A unique Priority Setting Process

Unlike PSPs undertaken in other clinical specialties, the broad nature of vascular conditions led the Vascular PSP to establish nine special interest groups (SIGs), categorised by an overarching vascular condition. This was a crucial step in helping to manage the large number of responses and to ensure that each area retained their important research questions.

The result was that the Vascular Specialty has effectively conducted nine individual PSPs, producing separate lists of top 10 priorities for research in the following areas:

- Access
- Amputation
- Aortic
- Carotid
- Diabetic Foot
- Peripheral Arterial Disease
- Service Organisation
- Venous
- Wounds

The results of the Vascular PSP will help to set the agenda for vascular research for the foreseeable future.

It is envisaged that the results of the Vascular PSP will set the agenda for vascular research for the foreseeable future. This report presents the work of the Vascular PSP and summarizes the key steps taken towards achieving priorities for vascular research.
Foreword

Vascular patients and healthcare professionals should now advocate these research priorities, helping to direct funding into areas of utmost need and greatest impact.

We now call on funding bodies and decision makers to direct funding towards these priorities and to increase investment in the delivery of new studies in these areas of utmost need.

We encourage researchers to focus their efforts on where potential impact is greatest by developing these priorities into new research studies.

Finally, we urge all vascular patients and healthcare professionals to advocate the top 10s and to get involved in research that will ultimately positively impact vascular patients’ quality of life and improve the services that surround their care.

A huge thank you to everyone who has been involved in the Vascular PSP.

Professor Ian Chetter
Chair Research Committee VSGBI
**Vascular PSP Top 10s**

**Access**

A final workshop was held 25.7.21 and brought together patients and health care professionals to jointly agree a priority list for vascular access research.

- **01** What can be done to make fistulas or grafts last as long as possible?
- **02** What staff education is needed to help them to understand the experience of patients living with a dialysis line, graft or fistula?
- **03** What education do patients need to be given about living with and looking after a dialysis line, graft or fistula and the effect this may have on their quality of life?
- **04** What can be done to avoid narrow segments from forming in fistulas or grafts?
- **05** Is a fistula always the best option for all patients who need dialysis, regardless of age?
- **06** What do patients need to know about the risk of having many procedures to place new fistulas, grafts and dialysis lines and the possibility of damage to the blood circulation system?
- **07** What features of a fistula or graft make it better or worse at providing dialysis?
- **08** What can be done to prevent fistulas becoming enlarged or at risk of a serious bleed?
- **09** What can be done to make needling of grafts and fistulas more accurate to lower the risk of problems?
- **10** What can be done to prevent infections related to dialysis lines?
A final workshop was held 25.1.21 and brought together patients and health care professionals to jointly agree a priority list for amputation research. *Priorities 8a-c were ranked equal.*

01. How can we reduce the rates of major lower limb amputations?

02. What are the best ways to support rehabilitation following amputation?

03. How can we improve clinical outcomes for patients following major limb amputation?

04. What are the best ways to prevent or treat pain (including phantom pain) after amputation?

05. How do we improve the information provided to patients undergoing amputation?

06. In a person who has undergone a minor amputation in the foot, how are the chances of a subsequent major lower limb amputation above the ankle reduced?

07. How do you improve healing of the amputated stump?

8a. In a person who has undergone amputation, how do you reduce the chances of amputation in the other limb?

8b. How do we optimise prosthetic limb use following amputation?

8c. When is it appropriate to perform a major amputation?
A final workshop was held 13.04.21 and brought together patients and health care professionals to jointly agree a priority list for vascular aortic research.

01 What is the optimal management of patients with aortic aneurysm disease using individualised risk benefit ratios?

02 What causes aneurysms to grow and/or rupture?

03 Can we develop a test that could diagnose patients at risk of aortic aneurysm/dissection?

04 How do surgeons decide which treatment is best for aneurysms and are these decisions based on the latest evidence available?

05 What is the optimum medical therapy for patients with AAA to minimise expansion / rupture?

06 What causes an aneurysm or is associated with aneurysm formation and how can we prevent one developing?

07 What is the best way to monitor people after treatments to repair aneurysms to make sure they don't develop problems with their repair?

08 How do we make aneurysm surgery safer and reduce the risk of complications?

09 How do we reduce the time it takes to recover from aortic operations?

10 Should siblings be screened for AAA when there is a family history of aneurysm?
Vascular PSP Top 10s

Carotid

A final workshop was held 21.09.21 and brought together patients and health care professionals to jointly agree a priority list for carotid research.

| 01 | Can doctors accurately predict which people with carotid artery disease are most at risk of a stroke? |
| 02 | Is there an association between carotid disease and cognitive decline? |
| 03 | What is the optimal management of patients with carotid disease using individualised risk benefit ratios? |
| 04 | Can the appearance of carotid narrowings (also called plaques) help predict an individual patient’s stroke risk? |
| 05 | What is the best treatment for carotid artery disease? E.g. medicines, life-style changes, intervention. |
| 06 | What can be done to prevent re-narrowing and recurrent symptoms following carotid surgery? |
| 07 | Is screening for carotid artery disease worthwhile, and if so, what is the best screening test? |
| 08 | Following carotid surgery, is surveillance (i.e, scanning to detect re-narrowing) of the treated artery necessary? |
| 09 | Is surveillance of patients with known carotid artery disease worthwhile? |
| 10 | What is the optimal antiplatelet regime following carotid endarterectomy? |
## Diabetic Foot

A final workshop was held 14.06.21 and brought together patients and health care professionals to jointly agree a priority list for diabetic foot research.

<table>
<thead>
<tr>
<th>Number</th>
<th>Question</th>
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<tbody>
<tr>
<td>01</td>
<td>What is the most effective way of preventing diabetic foot ulcers?</td>
</tr>
<tr>
<td>02</td>
<td>What is the most effective way of preventing further amputation after toe amputation for diabetic foot disease?</td>
</tr>
<tr>
<td>03</td>
<td>Why are there delays in referral for diabetic foot disease?</td>
</tr>
<tr>
<td>04</td>
<td>How can outcomes in diabetic patients with foot infection be improved?</td>
</tr>
<tr>
<td>05</td>
<td>What is the best way of improving blood flow to the leg in people with diabetes?</td>
</tr>
<tr>
<td>06</td>
<td>Can risk assessment be improved in patients with diabetic foot complications?</td>
</tr>
<tr>
<td>07</td>
<td>What is the most effective way of preventing recurrence of diabetic foot ulcers?</td>
</tr>
<tr>
<td>08</td>
<td>What factors affect healing time in diabetic foot disease?</td>
</tr>
<tr>
<td>09</td>
<td>How can awareness of diabetic foot complications be promoted?</td>
</tr>
<tr>
<td>10</td>
<td>Is an annual foot check for diabetic foot problems worthwhile?</td>
</tr>
</tbody>
</table>
### Peripheral Arterial Disease PAD

A final workshop was held 14.05.21 and brought together patients and health care professionals to jointly agree a priority list for PAD research.

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>What can be done to improve outcomes in patients with severe circulation problems to their legs?</td>
</tr>
<tr>
<td>02</td>
<td>What is the optimal exercise prescription for patients with poor circulation to the legs? How can we improve provision and access to exercise programs?</td>
</tr>
<tr>
<td>03</td>
<td>How can we diagnose patients with poor circulation to their legs earlier and better? Would this make a difference in the long term?</td>
</tr>
<tr>
<td>04</td>
<td>How can we educate other doctors and health care workers so that they gain a better understanding of the consequences of a diagnosis of poor circulation to the legs?</td>
</tr>
<tr>
<td>05</td>
<td>How can we help educate better those patients who have poor circulation to their legs?</td>
</tr>
<tr>
<td>06</td>
<td>How can we make it easier for patients to get help for this problem (poor circulation to the legs)?</td>
</tr>
<tr>
<td>07</td>
<td>What are the best ways to reduce the leg pain symptoms seen with patient with poor leg circulation without performing an operation?</td>
</tr>
<tr>
<td>08</td>
<td>How can we slow down any progression of symptoms in those patients with poor circulation to their legs?</td>
</tr>
<tr>
<td>09</td>
<td>How can we stop patients getting poor circulation to their legs?</td>
</tr>
<tr>
<td>10</td>
<td>How can we reduce cardiovascular risk in PAD patients?</td>
</tr>
</tbody>
</table>
Vascular PSP Top 10s

Service Organisation

A final workshop was held 09.07.21 and brought together patients and healthcare professionals to jointly agree a priority list for vascular service research.

01 How can regional vascular services best be organised and delivered to provide the best outcomes and experience for vascular patients?

02 What can be done to ensure that GPs and other healthcare staff have a better understanding of vascular disease?

03 What can be done to make sure that people with vascular problems get to see the most appropriate professionals as quickly as possible?

04 What is the best way to help people with lifestyle changes such as diet, smoking cessation and exercise?

05 How can awareness of vascular disease be improved amongst people with vascular symptoms and the general public?

06 What can be done to improve communication between healthcare professionals and people with vascular disease?

07 What can be done to make sure that everyone involved in treating vascular patients communicates better with each other?

08 New and emerging technologies; how should they introduced and evaluated?

09 What can be done to make sure that everyone gets fair and equal access to the best vascular treatment, regardless of individual characteristics?

10 How can better treatments be developed for vascular conditions that do not require major operations?
A final workshop was held 27.09.21 and brought together patients and health care professionals to jointly agree a priority list for venous research.

**01** How can all patients be given the opportunity to access the specialist assessment and treatment they need?

**02** How can awareness and education of venous disease be improved?

**03** How can leg symptoms and tissue damage be prevented and treated in people with deep venous disease including deep vein thrombosis (DVT)?

**04** How can varicose veins be prevented from happening or coming back after treatment?

**05** How can the number of patients actually using compression treatment be improved?

**06** How can leg symptoms and tissue damage be prevented and treated in people with superficial venous disease?

**07** How can venous leg ulcers be made to heal more quickly?

**08** What is the best type of compression for patients with venous disease and how do we improve compliance?

**09** How can pain be better controlled in venous leg ulcers?

**10** How common is pelvic vein incompetence and is treatment effective?
A final workshop was held 18.05.21 and brought together patients and health care professionals to jointly agree a priority list for vascular wounds research.

01 How can patient involvement in the decisions about their wounds be improved?

02 How can healing of open wounds be accelerated?

03 How can quality of life be improved in patients with open wounds?

04 How can woundcare be personalised to meet patient circumstances or needs?

05 Which service configuration is associated with the best outcomes in wound patients?

06 How can communication between clinicians in wound care services be improved?

07 How can consistency in assessment, diagnosis and management in patients with wounds be improved?

08 How can wounds be prevented from becoming infected?

09 How can wound healing be optimised in vascular patients?

10 How can communication be improved with patients with wounds?
Background

Vascular Conditions

Vascular conditions encompass circulatory problems and include a range of complex and often urgent or emergency procedures. They are one of the largest contributors to morbidity and mortality globally, accounting for 40% of deaths in the UK, with estimated health and care costs of £9 billion in the UK annually (1). Vascular work also frequently overlaps with other specialties that also treat patients where there is a risk of damage to arteries and veins (2) and this is reflected in the broad range of research questions submitted during this process.

Vascular conditions account for 40% of deaths in the UK. Estimated health and care costs of £9 billion (1).

Despite the enormous disease burden and rising costs of vascular conditions, there is a significant lack of research investment relative to other health conditions (2, 3). Funding is highly competitive and this has an impact on vascular clinical practice, as service commissioners have been reluctant to commit resources for procedures and pathways that they perceive to have an insufficient evidence base (4).

Why Set Priorities for Vascular Research?

Evidenced based practice is essential to direct and underpin the delivery of care, it can change the way clinicians work and how healthcare is delivered to improve patient outcomes. However, it is reported that clinical practice guidelines are often based on a poor levels of evidence, and that many trials address low-priority questions that are poorly related to the burden of disease (5, 6). Prior to the Vascular PSP, there was no agreement over research priorities within the vascular specialty (7), which results in individual units or researchers focussing on their own interests, that is not necessarily the research that delivers the greatest impact.

85% of research investment is wasted when the needs of users of research are ignored (8).

Prioritizing research that generates maximum impact on health outcomes is a key criterion for funding panels and policymakers in deciding where best to target their investments. Traditionally, medical research has largely been conducted by academics, in isolation from patients and other healthcare professionals. It has focussed on the
Background

problems that research professionals think are the most important, which can often be different from what patients, their carer’s and their families think are important. It is estimated that up to 85% of research investment is wasted, and this happens in part when the needs of users of research are ignored (8).

What are the Benefits of a Priority Setting Process?

There is growing evidence that involving patients, carers and health professionals in setting research and funding agendas can improve the quality, relevance and implementation of the research conducted and ensure that research resources address the issues which are most important to those people affected by a particular health care problem (9).

Patients and carers across the UK are closest to the conditions and living with the effects every day. They have valuable insight to share.

Researchers may become more aware of the lived experiences of the conditions they research and be alerted to areas previously under-researched, or ignored. Service users and members of the public may in turn gain a new perspective on their situation and be encouraged to think about their personal experience more widely (10). It is therefore recommended that research into clinical practice and national health services should identify and address the questions and uncertainties that are of most practical importance to patients, their carers and clinicians (11, 12).

It was nice to be able to hear the thoughts of some of the professionals.

Absolutely fantastic opportunity to learn from patients.

Feedback from the Vascular PSP Final Workshops.
Background

How did the Vascular Priority Setting Partnership agree the priorities?

The Vascular PSP was undertaken in three main phases;

1. Delphi Survey: an initial Delphi survey to gather the opinions of vascular health care professionals about their research priorities.

2. A James Lind Alliance (JLA) survey to gather the opinions of vascular patients and carers about their research priorities.

3. Final workshops to bring together patient and healthcare professional priorities to jointly agree research priorities.

The Delphi Methodology and James Lind Alliance are two popular approaches for conducting priority setting and both methods were applied to the Vascular PSP. Following successful implementation of the clinician Delphi survey, funding was secured with the Vascular Society to engage the James Lind Alliance to oversee phase two and three above.

Delphi Background
The Delphi method is regarded as a flexible research technique, often used in priority setting processes that focuses on the identification of expert opinion (14). It is an iterative process to collect opinions of experts who respond to several rounds of questionnaires. The responses are aggregated and shared with the group, there are multiple rounds until a consensus is reached. The full methodology of the Delphi phase of the project has been published in "Identifying the research priorities of healthcare professionals in UK vascular surgery: modified Delphi approach" (7).

JLA Background
The James Lind Alliance (JLA) was established in the UK in 2004 and is funded by the National Institute for Health Research (NIHR) and to date, over 100 JLA PSPs have been conducted across a range of settings and conditions. The JLA encourages patients, carers and clinicians to work together in PSPs to identify and prioritise shared uncertainties. It provides a transparent and structured framework that emphasises patient participation in PSPs, whereby patients have an equal voice to clinicians in influencing the research agenda (13, 15).
Timeline

How did the Vascular Priority Setting Partnership agree the priorities?

Summary Timeline of Activities

- **Jun 2016**: Vascular Research Collaborative Established
  Oversight for Delphi survey of healthcare professionals.

- **Jan-Mar 2017**: Clinician Delphi Round 1 Survey
  Gathering Priorities.

- **Aug-Oct 2017**: Clinician Delphi Round 2 Survey
  Scoring Priorities.

- **Sept 2018**: Engagement with the James Lind Alliance
  JLA Advisor appointed.

- **Jan 2019**: Vascular PSP Steering Group Established
  Protocol and scope of Vascular PSP agreed.

- **Aug 19-Mar 20**: Patient JLA Round 1 Survey
  Gathering Priorities.

- **Nov 2019**: Special Interest Group Chairs Appointed
  Oversight to ensure representation for vascular conditions.

- **Nov 20-Feb 21**: Patient JLA Round 2 Survey
  Scoring Priorities.

- **Jan-Sept 2021**: Final SIG Prioritisation workshops
  Clinician and patient priorities amalgamated. A ranked top 10 list of research priorities for each SIG sub-specialty area.
Following the responses of the Delphi Survey, recognising the importance for planning and continuity to take the priorities forward for research (13), Special Interest Groups (SIGs) were appointed to support the Vascular PSP process. Their role is:

- To identify, recruit and appoint appropriate SIG members.
- To support the James Lind Alliance (JLA) Vascular Priority Setting Process.
- To establish research based on both the clinician and patient priorities.
- To develop a portfolio of funded research studies in area of special interest.
- To promote and facilitate trainee involvement in vascular surgical research.

### Special Interest Groups (SIGs)

<table>
<thead>
<tr>
<th>Specialist Area</th>
<th>Chair/Co-Chair</th>
<th>Deputy Chair</th>
</tr>
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<tbody>
<tr>
<td>Access</td>
<td>George Smith</td>
<td>Jonathan De Siqueira</td>
</tr>
<tr>
<td>Amputation</td>
<td>Rob Hinchliffe</td>
<td>Dave Bosanquet</td>
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<tr>
<td>Aortic</td>
<td>Matt Bown</td>
<td></td>
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<tr>
<td></td>
<td>Colin Bicknell</td>
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<tr>
<td>Carotid</td>
<td>Alison Halliday</td>
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<td></td>
<td>Dominic Howard</td>
<td></td>
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<td></td>
<td>Richard Bulbulia</td>
<td></td>
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<tr>
<td>Diabetic Foot</td>
<td>David Russell</td>
<td>Joe Shalhoub</td>
</tr>
<tr>
<td>PAD</td>
<td>Patrick Coughlin</td>
<td>Athanasios Saratzis</td>
</tr>
<tr>
<td>Service Organisation</td>
<td>Jonathan Michaels</td>
<td></td>
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<tr>
<td>Venous</td>
<td>Dan Carradice</td>
<td></td>
</tr>
<tr>
<td>Wounds</td>
<td>Ian Chetter</td>
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</tbody>
</table>
Summary of PSP Process

Clinician Delphi
Priority Setting Process

Priority Gathering. Survey inviting clinicians to submit research priorities.

Sorting. Priorities gathered were sorted and grouped into vascular condition areas (SIGs) and overarching summary priorities agreed.

Prioritising. Clinicians scored the importance of priorities, generating a final list of clinician ranked priorities.

Patient JLA
Priority Setting Process

Priority Gathering. Survey inviting patients and carers to submit research priorities.

Sorting. Priorities gathered were sorted and grouped into vascular condition areas (SIGs) and overarching summary priorities agreed.

Prioritising. Patients and carers scored the importance of priorities, generating a final list of patients ranked priorities.

SIG Amalgamation Workshops
Clinician AND Patient priorities were amalgamated to create final list of joint priorities for discussion at final workshops.

SIG PRIORITISATION WORKSHOP
Each SIG held final workshops with patients and clinicians to agree a ranked top 10 list of research priorities for each SIG sub-specialty area.
Phase One; Clinician Delphi Survey Summary.

Aims: To survey the opinions of vascular clinicians, to identify and score research priorities using a modified Delphi methodology.

Methods
A full description of this phase of the project has been published (7) however, for the purpose of this report, the methodology and results are summarized below.

1) Gathering priorities. An open-ended survey was designed and piloted with a steering group and produced in electronic and paper format. The survey invited vascular clinicians to submit research priorities or uncertainties that could be about anything. The survey also asked basic demographic information to enable the steering group to monitor who was responding to the survey.

The survey was open from January - March 2017. It was disseminated via email to the members of UK societies involved in the care of vascular patients and via letters of invitation sent to each vascular unit registered on the National Vascular Registry (NVR), and included the survey link.

Results from round one
There were 1231 potential research priorities submitted by 481 participants, 61% identified as male and 39% female. A combined total of 1577 members of UK societies were emailed a survey link with a 31% response rate (n=481). There was representation from 90% UK Vascular Units (as identified by NVR 2016 database).
Phase One; Clinician Delphi Survey Summary.

2) Sorting responses. A sub-group of the steering group collated and reviewed responses from the first round of survey. There were 366 suggestions considered to be out of scope and excluded e.g. comments which did not appear to contain a question, suggestions already answered by existing evidence, requests for information or advice, suggestions that were too broad or unclear and non-sensical.

ii. Summarizing responses; Similar responses were grouped and an overarching summary priority agreed. Priorities were assigned to a vascular category, and these categories formed the basis of the Special Interest Groups (SIGs). A service organisation category was introduced to encompass the general questions that could be applied regardless of a specific vascular condition, for example questions about access to services, communication, lifestyle and education.

3) Scoring Priorities; a second survey was designed and piloted with the steering group and made available in electronic and paper format. The survey invited vascular clinicians to score the summary priorities on a scale of importance between one and ten (ten being the most important and one the least).

The survey was open from August 2017 – October 2017. The rationalised list of research priorities was recirculated to all invited participants from the first round of survey, as well as being open to new participants.

Results from Round Two
A combined total of 1179 vascular society members were emailed a survey link, 323 responded, achieving a 27% overall response rate. A final list of priorities was determined using sum scores, producing an overall top 10 list of research priorities for vascular clinicians.
### Overall Clinician Top 10 Priorities

This priority list reflects the opinions of vascular clinicians in vascular surgery and does not include input from service users.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>What can be done to improve outcomes in critical limb ischaemia (including how best to identify those who would benefit from revascularisation and those who would be best managed with primary amputation or palliation)?</td>
</tr>
<tr>
<td>02</td>
<td>What is the optimal revascularisation strategy in diabetic patients?</td>
</tr>
<tr>
<td>03</td>
<td>How can we reduce the rates of major lower limb amputations?</td>
</tr>
<tr>
<td>04</td>
<td>How can we improve outcomes in diabetic patients with foot sepsis?</td>
</tr>
<tr>
<td>05</td>
<td>How can we improve clinical outcomes for patients following major limb amputation?</td>
</tr>
<tr>
<td>06</td>
<td>What is the most effective way to manage mixed aetiology / hard to heal complex leg ulcers?</td>
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<tr>
<td>07</td>
<td>Can we characterise carotid plaque to identify patients at high risk of events and target interventions?</td>
</tr>
<tr>
<td>08</td>
<td>How can we best organise regional vascular services to facilitate optimal management and outcomes for vascular patients?</td>
</tr>
<tr>
<td>09</td>
<td>How do we optimise delivery of vascular services to improve patient experience and outcomes?</td>
</tr>
<tr>
<td>10</td>
<td>Can we optimise wound healing in vascular patients?</td>
</tr>
</tbody>
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Phase Two; Patient and Carer Survey with the James Lind Alliance (JLA).

Aims: To survey the opinions of patients with lived experience of vascular conditions (and their families and carers), to identify and score research priorities using the JLA framework.

In association with

James Lind Alliance
Priority Setting Partnerships

Methods

Following the success of the vascular health care professional Delphi survey, the Vascular PSP worked in collaboration with the James Lind Alliance to identify and score patients and carers research priorities.

1) Gathering priorities. An open-ended online and paper-based survey was designed and piloted with the steering group that also included patient representatives. The survey invited participants to submit suggested priorities or topics and provided guidance that questions could be about anything (e.g., treatment, prevention, access to services, anything that was important to participants). The survey also asked basic demographic information to enable the steering group to monitor who was responding to try and ensure the opinions were representative across the range of vascular conditions.

People with experience of vascular conditions helping to set the research agenda.

The survey was open from August 2019 – March 2020. The electronic link was disseminated via email to UK societies whose members care for vascular patients, encouraging them to involve their patients and to make sure vascular patients were represented.

Participant packs were also sent out to vascular units and contained paper copies of the survey with a freepost return address, and promotional materials such as postcards and posters that could be left in outpatient waiting areas. The survey was promoted via social media (twitter) and advertised via affiliated websites and newsletters such as the Circulation Foundation.
Phase Two; Patient and Carer Survey with the James Lind Alliance (JLA).

Results from Round One
There were 582 potential research priorities suggested by 373 participants. From the 373 participants who opted to complete the demographics section, 48% were male, 47% female and 5% preferred not to answer. Participant age range was 20 years to 94 years, with an average age of 61 years.

When participants were asked “Which of these categories best describes you?” 81% had a vascular condition, 15% were carers and 4% preferred not to say. Most surveys (70%) were completed electronically compared to 30% completed in paper format.

2)i. Sorting suggestions; a core working sub-group of the steering group collated and reviewed the suggestions from the first round of survey. There were 143 considered to be out of scope and excluded e.g. suggestions which did not appear to contain a question, suggestions that are already answered by existing evidence, requests for information or advice, suggestions that were too broad or unclear and non-sensical. Following this initial review, priorities were assigned to the relevant Special Interest Groups (SIGs) for summarising.

ii. Summarizing responses; the SIGs were tasked with reviewing the responses assigned to their special interest area, combining duplicates, formulating overarching summary priorities, and checking the priorities against current evidence, before these were sent to the next round of survey for scoring.
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3) Scoring priorities; an online and paper-based survey was designed and piloted with the steering group that also included patient representatives.

The survey invited patients to select their vascular area/s of interest and to score the priorities within this area using a likert scale (Extremely Important to Not at all Important or Don’t know). The survey requested to score the service organisation priorities since these were considered to be general and relevant across all vascular conditions.

Participants were also invited to submit their interest in participating in final SIG workshops.

The survey was open from November 2020 - February 2021. Dissemination activities followed those outlined in the first round.

Results from Round Two

A total of 273 responses were received. From the participants who opted to complete the demographics section, 60% were male and 37% female and 3% preferred not to answer. Participant age range was 25 years to 93 years, with an average age of 61 years. When participants were asked ‘Which of these categories best describes you?’ 84% had a vascular condition and 15% were carers.

A final list of priorities within each Special Interest Group was determined using mean likert scores.
Overall Patient and Carer Priorities

This priority list reflects the opinions of vascular patients and carers. The highest scoring priority for each Special Interest Group is shown below:

**ACCESS**
What can be done to make fistulas or grafts last as long as possible?

**AMPUTATION**
In a person who has undergone amputation, how do you reduce the chances of amputation in the other limb?

**AORTIC**
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?

**CAROTID**
Can doctors predict which people with carotid artery disease are most at risk of a stroke accurately?

**DIABETIC FOOT**
What is the most effective way of preventing further amputation after toe amputation for diabetic foot disease?

**PAD**
How can we diagnose patients with poor circulation to their legs earlier and better? Would this make a difference in the long term?

**SERVICE**
How can we make sure that people with vascular problems get to see the most appropriate professionals as quickly as possible?

**VENOUS**
How can we improve awareness and education of venous disease for healthcare professionals?

**WOUNDS**
How can we accelerate healing of open wounds?
Phase Three; Final SIG Workshops: A combined approach.

Final prioritisation workshops took place between January and September 2021. The nine special interest groups (SIGs) held individual workshops to agree on their ‘top ten’ list of research priorities.

1) Combining the survey results.
Following JLA recommendations, work was undertaken by each SIG in advance to agree on a final combined shortlist of priorities to be discussed at the workshops. Where clinician priorities and patient priorities overlapped, the patient priority was put forward. Clinician priorities were reviewed with patient input to reword any technical language to ensure that patient representatives attending the workshops could understand the priority, with care taken to ensure the original substance remained.

Online Workshops
Due to the ongoing risk of COVID-19, face to face workshops were not possible, however the JLA adapted their process to deliver the workshops online via zoom. The Vascular PSP sub-group worked with their JLA adviser to develop a template agenda, where online discussions and breakout sessions were conducted over a four-hour period (with plenty of breaks).

Each workshop was facilitated by the Vascular PSP lead JLA advisor and followed the JLA methodology, using a Nominal Group Technique to generate discussion, ranking, consensus and agreement. Each workshop aimed to include 18 participants to enable separate breakout groups that included a mixture of patients, carers, clinicians and representatives from affiliated organisations. SIG members acted as observers on the day and provided emotional support as required.
Phase Three; Final SIG Workshops: A combined approach.

Participants were sent an information pack in advance that contained a list of the priorities sheet in a random order, in which they were asked to identify their 3 most and 3 least important priorities. They were asked to bring this to the meeting to initiate discussions.

Small breakout groups were held to rank the research priorities (interim prioritisation), participants were encouraged to listen to each other’s perspectives and provided an opportunity to re-order priorities as discussions progressed.

A final session was held and aggregate ranking from the breakout sessions were presented and a consensus reached.

The Result: A ranked list of the top 10 most important research priorities for each Special Interest Group.

"I thought there was excellent discussion with very good agreement overall between the patients and healthcare professionals."

"I feel like we recognised that they are all important."

"I also better understand some of the challenges and limitations healthcare providers face. I would definitely do it again!"
Next Steps

Publishing Results
The agreed top 10s resulting from these workshops are presented earlier in this report. Each SIG is in the process of publishing the outcomes of the workshop, with further discussion about the overall process, relevance and implications of results with recommendations for next steps in translating the top 10s into funded research.

How to get involved
The priorities are freely available to be researched and we hope they will provide useful guidance to those who are considering funding applications, research strategies or campaign work.

If you have any queries or would like to get involved, please contact the project coordinator Judith.long3@nhs.net or one of the SIG leads.

Keep in touch
We encourage you to keep in touch and let us know how you intend to use these priorities. The SIGs have been involved throughout the Vascular PSP, they have a wealth of experience within their group memberships and are keen to work with others who might be interested in pursuing any of these priorities. For this process to continue to be a success we should work together and ultimately strengthen the approach for tackling these important research areas.

Call to Action
We encourage all vascular patients, carers and professionals to advocate the Vascular Research Priorities and to get involved in research to address these important questions.
References

5. Dechartres A, Ravaud P. Better prioritization to increase research value and decrease waste. BMC medicine. 2015;13(1):244-.
The work of the Vascular PSP was funded by the Vascular Society. This report was written on behalf of the Vascular PSP Steering Group by Judith Long (PSP Coordinator), Professor Ian Chetter (PSP Lead) and Toto Gronlund (JLA Lead Advisor and PSP Chair).

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Finally, a special thank you to Toto Gronlund, our lead JLA facilitator for all the support and guidance throughout and in helping to manage nine Vascular PSPs.