VOICES of Vasculitis

Vasculitis Outcomes In relation to Care Experiences Study

Delivering Effective Care Services for People with Vasculitis in the UK

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What is the background to this research?

Getting access to care and support can be challenging for people living with rare conditions, such as vasculitis.

Vasculitis is a group of rare autoimmune conditions that cause inflammation of the blood vessels. There are different types of vasculitis, and the problems that result can range from mild to very severe and life-threatening.

It can affect many different parts of the body, and even people with the same type of vasculitis can be affected in different ways and need different care from several different specialists. While vasculitis is not curable, it can be controlled using medicines to suppress the immune system.

Early diagnosis and effective and timely treatments are important to prevent permanent damage to the body.

What did we want to find out?

Care for people with vasculitis is organised in different ways across the UK and currently there are no standards to guide what services should be in place for rare autoimmune conditions.

The VOICES study set out to provide evidence of how best to deliver effective services that will improve health outcomes and experiences of care for people living with vasculitis.

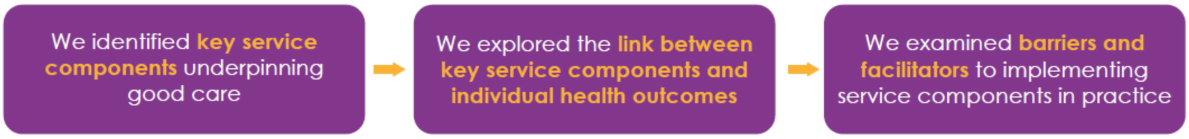
In particular, we wanted to understand:

- How is healthcare currently planned, carried out, and sustained for people with vasculitis?
- What do both patients and healthcare providers think good care for people with vasculitis looks like?
- What are the key parts of services that enable good care, and if and how these relate to improved health outcomes (such as fewer serious infections, emergency admissions to hospitals and deaths)?

What did we do?

In this study, we looked at numerical data and non-numerical data such as interviews. This is called a 'mixed-methods study.'

- We spoke to people living with vasculitis and healthcare professionals about their healthcare experiences.
- We looked at how vasculitis care is delivered across the UK and Ireland.
- We analysed national health data that is routinely collected in Scotland, for example, when you stay in hospital, to identify people with vasculitis and their health outcomes e.g., serious infections, emergency admissions to hospital and deaths.



We identified **key service components** underpinning good care → We explored the **link between key service components and individual health outcomes** → We examined **barriers and facilitators** to implementing service components in practice

To gather information for our research, we carried out four key activities:

1. We carried out a series of interviews, including with people living with vasculitis and healthcare staff.

Patient experience of care

32 interviews with people across the UK with systemic vasculitis

Case studies

67 interviews with range of healthcare professionals looking after people with vasculitis

2. We conducted a survey of vasculitis service providers across the UK and Ireland

Vasculitis provider survey

59 responses from **51** Trusts and Health Boards across UK and Ireland

3. From the interviews and surveys we identified the key service parts (components) that enable good care.

4. We linked routinely collected healthcare data for vasculitis patients in Scotland and survey data to understand if people looked after in a service that had these key service components in place had better health outcomes.

What did we find?

What does good care look like for people living with vasculitis?

We found that good care for people with vasculitis is realised when healthcare teams:

- Respond to illness quickly (including getting a diagnosis, providing urgent treatment and managing any flare-ups of the condition)
- Provide continuity of care (for example, seeing the same clinician or clinical team throughout the patient journey, and effective sharing of information across different teams)
- Support people to make decisions about their own care (encouraging shared decision making).

Combining and connecting care

Being in the loop

Feeling safe

What are the key components of service that facilitate good care?
From our interviews, case studies and surveys we identified components of service which are key to facilitating good
care:

Timely access to services
Wait time <1 week for new patients
Vasculitis specialist nurse
Nurse advice line

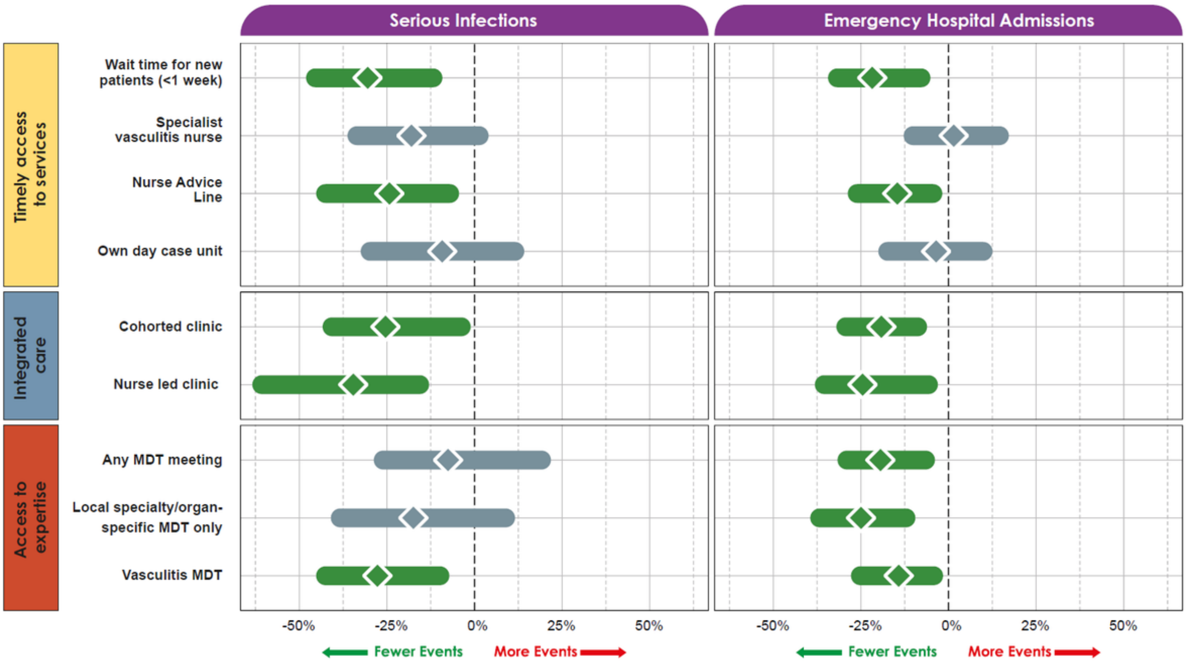
Integrated care delivery
Cohorted clinic
Nurse led clinic
Integrating local/regional and national vasculitis care

Access to expertise
Vasculitis multidisciplinary team meeting
Out-of-hours and unscheduled care

Which of these key service components are associated with improved health outcomes?
By analysing national data on hospital admissions and deaths, alongside available survey data, we were able to look at whether some of these key service components were associated with improved outcomes:

- **Timely access to services**: When a new patient with suspected vasculitis waited less than a week to see a vasculitis expert, and a nurse-led advice line for patients was available (i.e. a dedicated telephone line for patients to access advice about their condition), there were fewer serious infections and emergency admissions. Advice lines were an invaluable source of advice for patients when they experienced a flare of their condition and meant they could quickly access help.
- **Coordinated healthcare**: When a patient was treated alongside people with similar conditions or needs (in 'a cohorted clinic') and had access to nurse-led clinics there were fewer serious infections and emergency admissions to hospital. Nurse-led clinics offered patients more time to discuss issues that mattered to them and supported holistic care.
- **Access to the right expertise**: When a patient's healthcare included regular meetings of the different healthcare professionals involved in their care (multi-disciplinary team meetings), there were fewer serious infections and emergency hospital admissions to hospital. Multi-disciplinary team meetings can improve communication and co-operation between different healthcare teams and give patients the chance to be more involved in their care.

Key service components (rapid access, cohorted clinics, nurse advice line and vasculitis MDT meetings) were associated with fewer serious infections and hospital admissions*



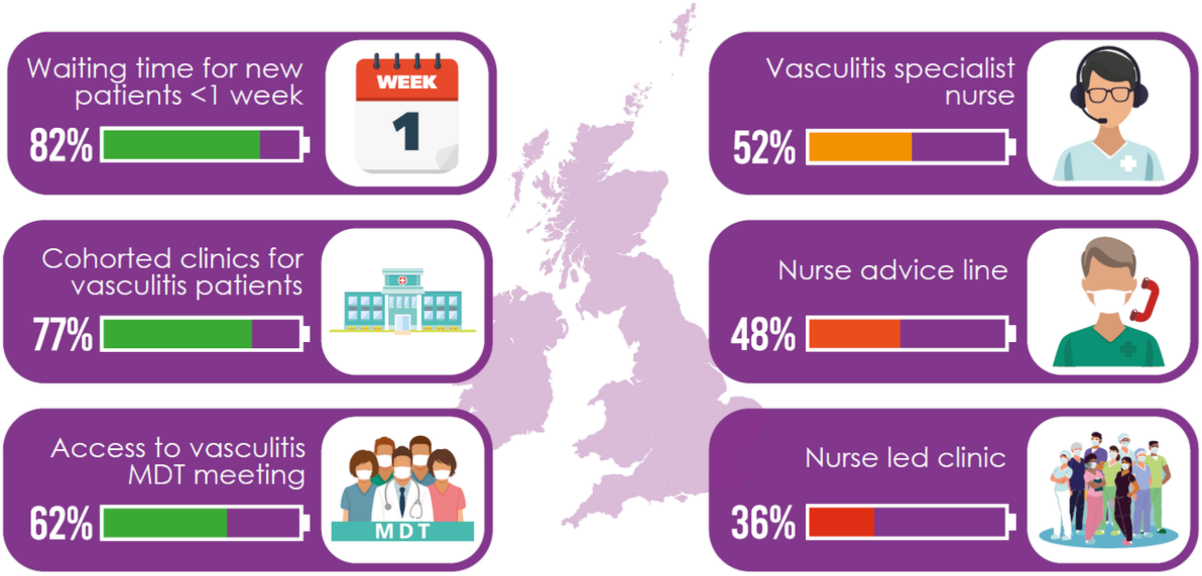
*Analysis of national linked administrative data for 1420 ANCA-vasculitis cases

What potential difficulties might be faced in delivering healthcare in this way?

Delivering healthcare in this way helps healthcare teams work better together and makes people living with vasculitis feel safer. However, access to the key service components identified varied across the UK and Ireland, particularly access to nurse-led care and the provision of vasculitis multi-disciplinary team meetings.

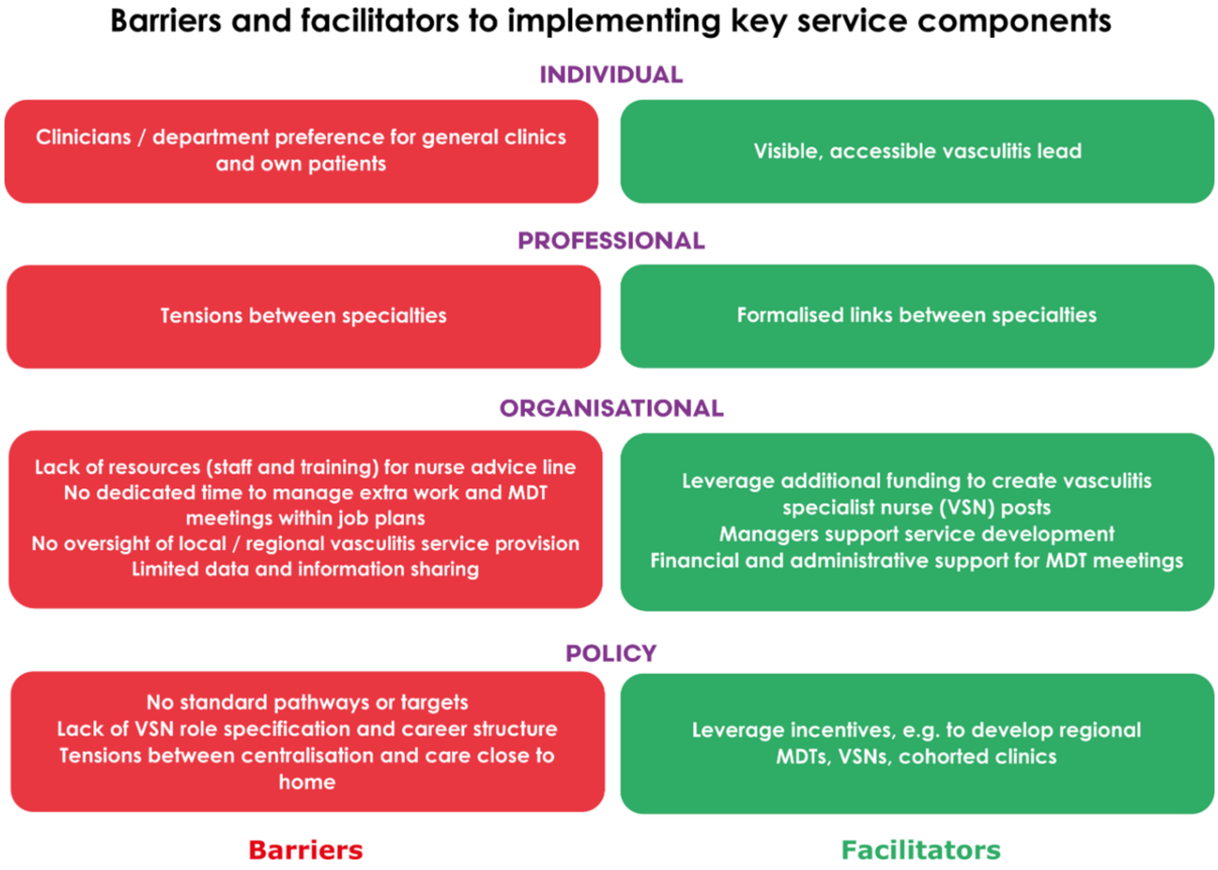
In our survey, for example:

- 52% of services reported having a specialist vasculitis nurse working within their service;
- 48% had a nurse-led advice line for patients;
- 36% held nurse-led clinics;
- 62% had access to a vasculitis multi-disciplinary team meeting.



We also discovered several key difficulties experienced when trying to put these healthcare suggestions in place:

- The different specialties involved in looking after people with vasculitis work in very different ways, and were sometimes not used to working together.
- Services providing care for people with vasculitis were often not aware of care offered by other specialties. This made it difficult to 'join up' care.
- There are no standards to guide what services should be in place, or measures (audits) of what services are available for rare conditions like there are for heart attacks and strokes.



Barriers and facilitators to implementing key service components

	Barriers	Facilitators
INDIVIDUAL	Clinicians / department preference for general clinics and own patients	Visible, accessible vasculitis lead
PROFESSIONAL	Tensions between specialties	Formalised links between specialties
ORGANISATIONAL	Lack of resources (staff and training) for nurse advice line No dedicated time to manage extra work and MDT meetings within job plans No oversight of local / regional vasculitis service provision Limited data and information sharing	Leverage additional funding to create vasculitis specialist nurse (VSN) posts Managers support service development Financial and administrative support for MDT meetings
POLICY	No standard pathways or targets Lack of VSN role specification and career structure Tensions between centralisation and care close to home	Leverage incentives, e.g. to develop regional MDTs, VSNs, cohorted clinics

Why does this research matter?

This is the first study to identify the key parts of health care services that can improve experiences of care and health outcomes for people living with vasculitis.

Findings from the study are already being used to inform changes to the way services for people with vasculitis are organised. For example, these recommendations are being used to develop clinical service standards and guidelines, and strategies to overcome the difficulties to making this happen in practice. The findings are also likely applicable to the many thousands of people living with other rare autoimmune conditions who share similar problems when accessing healthcare.

Who contributed to this study?

This work was conducted by the VOICES study team, which is led by Dr Rosemary Hollick in collaboration with Professor Corri Black (Aberdeen Centre for Health Data Science), Professor Louise Locock (Health Services Research Unit, University of Aberdeen), Professor Neil

Basu (University of Glasgow), Professor Mark Little (Trinity College, Dublin), Dr Warren James and Dr Avril Nicoll (University of Aberdeen), Lynn Laidlaw and Maureen McBain (public contributors), and the University of Oxford Healthtalk team (www.healthtalk.org).

We would like to thank all the patient contributors with lived experience of systemic vasculitis who have been involved in this study and members of the VOICES patient and public involvement group. These are groups of patients who act as 'partners' rather than participants in research. Our partners helped us to:

- Design the study, analysed the information collected, and reflected on the findings.
- Develop recommendations for healthcare practice.
- Create online resources for people with vasculitis, including filmed stories from people living with vasculitis .

We also wish to acknowledge our collaborators, the UK and Ireland Vasculitis Society, the Scottish Systemic Vasculitis Managed Clinical Network, the European Reference Network for rare immune disorders and the NHS Scotland electronic Data Research and Innovation Service Team (Public Health Scotland).

Who funded this work?

This study was funded by Versus Arthritis .

Where can I find out more?

You can read the full scientific paper in The Lancet Rheumatology here . A companion infographic detailing some of the study's key features and findings can be downloaded here . There is also an associated podcast you can listen to here , when Dr Rosemary Hollick discusses the study and its findings.
You can also read the press release which accompanies the publication of the scientific paper here .