



VOICES (Vasculitis Outcomes In relation to Care ExperienceS) Survey Part 1

The UK and Ireland Vasculitis Society (UKIVAS) and the Scottish Systemic Vasculitis Managed Clinical Network (SSVN) are conducting a mapping exercise of vasculitis services in the UK and Ireland. This work has been funded by Versus Arthritis as a priority to support care delivery for those with systemic vasculitis.

The survey will help us understand how services are delivered for people with vasculitis; the impact of the COVID-19 pandemic on care; and what is required to support future care delivery.

We would be grateful if you could answer the survey collaboratively amongst disciplines to encompass vasculitis services provided by your Health Board/ Trust where possible.

You will be provided with a summary of the collective de-identified results. This can be used to support local service restoration and improvements.

Using the UK Health Research Authority decision tool, this service mapping exercise is not classed as a research study and in line with the tool UK NHS ethics approval is NOT required. This project has been registered as a service evaluation on the NHS Grampian Audit and Service Evaluation database, Project ID 4960. The University of Oxford as UKIVAS Coordination Centre will process and prepare de-identified data for analysis. Data will be stored securely at the University of Aberdeen for 10 years. After this time it will be destroyed.

The survey should take around 30 minutes of your time to complete.

If you have any questions about the survey you can contact the study team at voices@abdn.ac.uk (<mailto:voices@abdn.ac.uk>).

Thank you for your time.

* Required

1. Please type in the site identifying code that was provided in your email invitation. *

This ensures that responses to Part 1 and 2 are linked and that responses are de-identified. Many thanks. If you haven't got the ID number, please contact rhollick@abdn.ac.uk (<mailto:rhollick@abdn.ac.uk>).

Number must be between 1020 ~ 1205

2. Please tell us the hospital(s) where you and your team manage patients with vasculitis?

The information would be really helpful in order to help us create a map of vasculitis services across the UK. This information will remain confidential and will not be disclosed to any other party. Results will be de-identified and presented anonymously. If you do not wish to identify yourself that is fine, but please continue to fill in the rest of the survey. Thank you.

3. Please tell us which specialty you work in?

We appreciate that in some cases you may not have all the information we are asking for in this form, so please feel free to send the survey to other colleagues who may be able to help. If you have any questions please contact rhollick@abdn.ac.uk (<mailto:rhollick@abdn.ac.uk>).

Service setting

4. What is/are the healthcare setting/s for your vasculitis service? *

☐ District General Hospital

☐ Teaching hospital

☐ Tertiary referral centre

☐

Other

5. What is the size of the vasculitis service catchment area? *

This is not necessarily the same as (and in many cases may be larger than) your hospital's catchment area

☐ Up to 100,000

☐ 100,000 to 199,999

☐ 200,000 to 499,999

☐ 500,000 to 999,999

☐ 1 Million to 1.499999 Million

☐ 1.5 to 1.999999 Million

☐ 2 Million or more

6. Which of the following best describes the geographical catchment area? *

☐ Inner city

☐ Rural

☐ Urban

☐ Mixed

7. Approximately how many patients are you responsible for as part of the vasculitis service you deliver? *

- ☐ 0-49
- ☐ 50-99
- ☐ 100-249
- ☐ 250-499
- ☐ 500-749
- ☐ 750-999
- ☐ more than 1000
- ☐ Don't know

Organisation and processes of care: service set-up

This section focuses on the set-up of vasculitis services pre-COVID-19.

8. In which clinical specialty does your vasculitis service exist? If it is a joint service please select all that apply. *

☐

ENT

☐

Gastroenterology

☐

Immunology

☐

Nephrology

☐

Neurology

☐

Ophthalmology

☐

Respiratory medicine

☐

Rheumatology

☐

Other

9. Is your service currently recognised by NHS England as a specialised centre? *

☐

Yes

☐

No

☐

Not applicable

10. In which type of clinics are vasculitis patients usually seen? *

Tick all that apply.

- ☐ General clinics (unselected patients)
- ☐ Sub-specialty clinics (e.g. connective tissue disease) with < 50% vasculitis patients
- ☐ Sub-specialty clinics with > 50% vasculitis patients
- ☐ Dedicated specialist clinic with only vasculitis patients
- ☐ Urgent access/flare clinic
- ☐
- Other

11. How often are dedicated/enriched vasculitis clinics held? *

- ☐ More than twice a week
- ☐ Twice a week
- ☐ Once a week
- ☐ Once a fortnight
- ☐ Once a month
- ☐ Ad hoc
- ☐
- Other

12. Do you hold joint vasculitis clinics with other specialties? *

- ☐ Yes
- ☐ No

13. Please state which specialties? *

☐ Dermatology

☐ ENT

☐ Gastroenterology

☐ Immunology

☐ Nephrology

☐ Neurology

☐ Ophthalmology

☐ Respiratory medicine

☐ Rheumatology

☐

Other

14. Do you hold parallel clinics for patients with vasculitis with other specialties? *

☐ Yes

☐ No

15. Please state which specialties? *

☐ Dermatology

☐ ENT

☐ Gastroenterology

☐ Immunology

☐ Nephrology

☐ Neurology

☐ Ophthalmology

☐ Respiratory medicine

☐ Rheumatology

☐

Other

Organisation and processes of care: staffing

This section focuses upon vasculitis service staffing.

16. How many programmed activities in total do you as an individual have for your vasculitis service per week? *

Please include direct clinical care and administration. Please think about this pre-Covid, how it has changed during the Covid pandemic and what you would ideally like in order to deliver your service in the future to your satisfaction.

	1-3	4-5	6-7	8-9	10-15	16-20	>=21
Pre Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ideal scenario	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. How many programmed activities are available per week across the whole vasculitis service in your Trust/Health Board?

Please think about this pre-Covid, how it has changed during the Covid pandemic and what you would ideally like in order to deliver your service in the future to your satisfaction.

	1-3	4-5	6-7	8-9	10-15	16-20	>=21
Pre Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ideal scenario	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Do you have specialty trainees and/or clinical research fellows working directly within the vasculitis service? *

	Yes	No
Pre-Covid	<input type="radio"/>	<input type="radio"/>
During Covid	<input type="radio"/>	<input type="radio"/>

19. Do you have specialist nurses working directly within the vasculitis service? *

	Yes	No
Pre-Covid	<input type="radio"/>	<input type="radio"/>
During Covid	<input type="radio"/>	<input type="radio"/>

20. Do specialist nurses undertake any of the following activities within the vasculitis service? *

Infusion delivery, nurse-led clinics, provision of a patient advice line.

☐ Yes

☐ No

21. Which of the following activities do specialist nurses undertake within the vasculitis service? *

Tick all that apply.

☐ Infusion delivery

☐ Nurse-led clinics

☐ Patient advice line

22. Does your service have input from any of the following healthcare professionals ? *

Clinical psychology, dietician, occupational therapy, pharmacy, physiotherapy, social workers, speech and language therapists

☐ Yes

☐ No

23. Which of the following healthcare professionals can you access for your patients with vasculitis? *

- ☐ Clinical psychologist
- ☐ Dietician
- ☐ Occupational therapist
- ☐ Pharmacist
- ☐ Physiotherapist
- ☐ Social worker
- ☐ Speech and language therapist

Organisation and processes of care: service activity

This section focuses upon the vasculitis service case load.

24. How many new cases does the service typically see per month?

	0-5	6-10	11-15	16-20	21-30	31-50	>50
Patient with vasculitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients with suspected vasculitis (but subsequently proven not to have vasculitis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. What type of new cases do you most commonly see? *

Please put these in order of how commonly you see these patients. Click of any on these groups of conditions and move them up or down the scale (click and drag). In order to answer this question you need to make at least one change in the order of conditions, even if you change it back again before submitting the question.

If there are any conditions that you do not see at all, please put them at the bottom and make a note in the comments section below.

Giant cell arteritis

Takayasu arteritis

Polyarteritis nodosa

ANCA-associated vasculitis

IgA vasculitis

Anti-GBM disease

Behcet's

Other large vessel vasculitis

Other medium vessel vasculitis

Other small vessel vasculitis

26. Do you have any comments about the conditions you commonly see?

For example, if you don't see a particular type of condition, or if you would like to give us an estimate of the proportion of the types of cases that you see please do so here e.g. 50% are GCA or ANCA vasculitis etc.

27. What type of follow up cases do you most commonly see? *

Please put these in order of how commonly you see these patients. Click on any of these groups of conditions and move them up or down the scale (click and drag). In order to answer this question you need to make at least one change in the order of conditions, even if you change it back again before submitting the question.

If there are any conditions that you do not see at all, please put them at the bottom and make a note in the comments section below.

Giant cell arteritis

Takayasu arteritis

Polyarteritis nodosa

ANCA-associated vasculitis

IgA vasculitis

Anti-GBM disease

Behcet's

Other large vessel vasculitis

Other medium vessel vasculitis

Other small vessel vasculitis

28. Do you have any comments about the follow-up cases that you see?

For example, if you don't see a particular type of condition, or if you would like to give us an estimate of the proportion of the types of cases that you see please do so here e.g. 50% are GCA or ANCA vasculitis etc.

29. Approximately what percentage of patients receiving ongoing care have *

	None	0-24%	25-49%	50-74%	75-100%
Multi-system disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Single organ disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. What proportion of multi-system disease patients; *

	None	0-24%	25-49%	50-74%	75-100%
Are currently seen in combined clinics?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like to see in combined clinics?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. What was the average wait times for new patients with suspected vasculitis from referral to local specialist evaluation? *

	Same working day	<3 working days	within 1 week	<1 month	up to 3 months	3 - 6 months	> 6 months
Pre Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

32. How frequently are you able to see patients for follow-up if required? *

In other words how soon could you see a patient after initial evaluation

- ☐ Daily
- ☐ Twice weekly
- ☐ Weekly
- ☐ Monthly
- ☐ Three-four monthly
- ☐ Six monthly
- ☐ Other

33. How much time per week is required to complete non face-face patient management per week? *

For example, dealing with administration, investigation follow-up, queries from patients and GPs.

☐ up to 2 hours

☐ 2-4 hours

☐ 5-6 hours

☐ 7-8 hours

☐ 9-10 hours

☐

Other

34. How are in-patients with vasculitis managed? *

Tick all that apply.

☐ Under the care of individual specialty

☐ Dedicated in-patient vasculitis review team

☐ Under care of dedicated in-patient vasculitis team

☐

Other

Diagnosis and early management pathways

35. Do you have a local care pathway for ANCA associated vasculitis? *

- ☐ Yes
- ☐ Yes but I do not have any information on them
- ☐ No

36. Does your local laboratory offer ANCA testing? *

- ☐ Yes - ELISA and IIF
- ☐ Yes but only ELISA
- ☐ Yes but only IIF
- ☐ No but we can send it to a regional centre
- ☐ No but we can send it to a national centre
- ☐ No ANCA testing available

37. What is the standard turnaround time for ANCA testing? *

- ☐ up to 2 days
- ☐ 2-7 days
- ☐ >7 days

38. Are results of the ANCA test available within 24 hours if requested? *

- ☐ Yes
- ☐ No

39. With regards to access to renal biopsy, is this available *

- ☐ To all patients required
- ☐ Only in a limited number of cases
- ☐ Not available

40. Do you have access to specialist renal pathology? *

- ☐ Yes - a dedicated nephropathology service
- ☐ Yes - a general pathology service with special interest in nephropathology
- ☐ No

41. Do you have access to urgent CT-PET? *

- ☐ Yes
- ☐ No

42. What is the average wait time for urgent CT-PET for patients with vasculitis/suspected vasculitis? *

- ☐ Less than one week
- ☐ Up to 13 days
- ☐ Between 2 and 4 weeks
- ☐ More than 4 weeks

43. Do you have local care pathways for Giant Cell Arteritis (GCA)? *

- ☐ Yes
- ☐ Yes but I do not have any information on them
- ☐ No

44. Which specialty leads the GCA care pathway? *

☐ Immunology

☐ Nephrology

☐ Ophthalmology

☐ Rheumatology

☐

Other

45. Do you have a local fast-track referral pathway for initial diagnostic evaluation and treatment of patients with suspected GCA? *

☐ Yes

☐ No

46. What is the average wait time for someone with suspected GCA from referral to local specialist evaluation? *

	Same working day	Within 3 working days	Within 1 week	Within 2 weeks	Within 1 month	up to 3 months	3-6 months
Pre Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During Covid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

47. With regards to access to temporal artery ultrasound for GCA, is this *

☐ Available to all patients with suspected GCA as part of a defined care pathway

☐ Available on a limited basis only

☐ Available but not within a time-frame to help with the diagnosis of GCA

☐ Not available

48. Who conducts temporal artery ultrasound for GCA? *

- ☐ Neurology/neurosurgery
- ☐ Ophthalmology
- ☐ Radiology
- ☐ Rheumatology
- ☐ Vascular surgery
- ☐ Vascular radiology

49. Does the scan routinely include axillary arteries? *

- ☐ Yes
- ☐ No

50. What is the average wait time for ultrasound of temporal arteries from initial referral? *

- ☐ <24 hours
- ☐ Within 72 hours
- ☐ Within one week
- ☐ Within 2 weeks
- ☐ Within 3 weeks
- ☐ Within 4 weeks

☐

Other

51. With regards to access to temporal artery biopsy (TAB) for GCA, is this *

- ☐ Available to all patients with suspected GCA as part of a defined care pathway
- ☐ Available on a limited basis only
- ☐ Available but not within a time-frame to help with the diagnosis of GCA
- ☐ Not available

52. Who conducts TABs? *

- ☐ General surgery
- ☐ Neurology/neurosurgery
- ☐ Ophthalmology
- ☐ Rheumatology
- ☐ Vascular surgery

53. What is the average wait time for TAB from initial referral? *

- ☐ <24 hours
- ☐ Within 72 hours
- ☐ Within one week
- ☐ Within 2 weeks
- ☐ Within 3 weeks
- ☐ Within 4 weeks

☐

Other

Multidisciplinary Team Meetings

54. Do you have the opportunity to discuss patients at an MDT meeting? *

☐ Yes

☐ No

55. Do any of your MDTs have multi-system clinical specialty input, including pathology and radiology?

☐ Yes

☐ No

56. As an outcome of MDT meetings, approximately what proportion of the time are you

	Never	Rarely	Sometimes	Often
Proposing changes to patient management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referring to another specialty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Requesting additional investigations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recommending prescription of biologics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Altering frequency of patient review	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recording and reporting on outcomes of the MDT to the Health board/Trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

57. What type of MDT meetings do you attend? *

Tick all that apply

- ☐ Local primary vasculitis MDT
- ☐ Local specialty meeting e.g. rheumatology, renal, respiratory
- ☐ Local organ specific meeting e.g. kidney, lung, liver
- ☐ Regional vasculitis MDT
- ☐
- Other

58. How often do the MDTs occur? *

	Once a week	Once a fortnight	Once a month	Ad hoc - as needed	Not applicable
Local primary vasculitis MDT	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local specialty meeting e.g. rheumatology, renal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local organ specific meeting e.g. kidney, lung, liver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regional vasculitis MDT	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

59. Which of the following apply to your MDT meetings?

Local primary vasculitis MDT

- ☐ Not applicable - I don't have a local primary vasculitis MDT
- ☐ Allocated protected time to attend
- ☐ Dedicated meeting coordinator
- ☐ Dedicated person to document outcomes
- ☐ Management recommendations documented for each patient

60. Which of the following apply to your MDT meetings?

Local specialty meeting e.g. rheumatology, renal

- ☐ Not applicable - I don't have a local specialty meeting
- ☐ Allocated protected time to attend
- ☐ Dedicated meeting coordinator
- ☐ Dedicated person to document outcomes
- ☐ Management recommendations documented for each patient

61. Which of the following apply to your MDT meetings?

Local organ specific meeting e.g. kidney, lung, liver

- ☐ Not applicable - I don't have a local organ specific meeting
- ☐ Allocated protected time to attend
- ☐ Dedicated meeting coordinator
- ☐ Dedicated person to document outcomes
- ☐ Management recommendations documented for each patient

62. Which of the following apply to your MDT meetings?

Regional vasculitis MDT

- ☐ Not applicable - I don't have a regional vasculitis MDT
- ☐ Allocated protected time to attend
- ☐ Dedicated meeting coordinator
- ☐ Dedicated person to document outcomes
- ☐ Management recommendations documented for each patient

63. Outside of formal MDTs, do you have rapid access to vasculitis expertise as required?

*

- ☐ Yes
- ☐ No

End of part 1

Thank you for completing this section - please ensure that you have submitted this part before proceeding to Part 2. Once you have submitted Part 1 you will see a link to Part 2 of the survey. The link to Part 2 is also available in your email.

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