



VOICES (Vasculitis Outcomes In relation to Care ExperienceS) Survey Part 2

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

Site identification

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

We apologise for asking for this again, but 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

Day unit facilities

2. Do you have the ability to provide biologic and cytotoxic infusions? *

☐ Yes

☐ No

3. How do you usually provide biologic and cytotoxic infusions? *

Tick all that apply.

☐ Within own specialty day unit

☐ Within another day unit facility

☐ Use of inpatient beds

4. What is the average wait time (days) for patients requiring urgent IV treatment for active systemic vasculitis? *

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 11
- ☐ 12
- ☐ 13
- ☐ 14
- ☐ >14

5. Are staff specifically trained to administer cytotoxic therapy? *

- ☐ Yes
- ☐ No
- ☐ Don't know

6. Would a regional or national training module be helpful to support administration of cytotoxic therapy? *

☐ Yes

☐ No

7. Do you have any other specific comments regarding training and delivery of cytotoxic therapy?

For example, do you have a module already that you could offer to others, any other specific challenges.

Registries and databases

8. Do you enter data into any national registries? *

For example, RaDaR, SSVN, UK GCA Consortium, UKIVAS

☐ Yes

☐ No

9. Which of the following national registries do you enter data into? *

Tick all that apply.

☐ RaDaR

☐ Scottish Systemic Vasculitis Network

☐ UK GCA Consortium

☐ UKIVAS

☐

Other

10. What proportion of patients with vasculitis in your service have data in one or more registries? *

We simply want to know if patients are being included in at least one registry.

☐ All

☐ >75%

☐ 50-74%

☐ 25-49%

☐ 1-24%

☐ None

☐ I don't know

11. Do you know who enters data into the registries? *

☐ Yes

☐ No

12. Who enters data into the registries? *

Tick all that apply

☐ Administrator

☐ Research assistant

☐ Research nurse

☐ Senior clinician

☐ Specialist nurse

☐ Trainee/research fellow

☐

Other

13. Do you find that there are the barriers to registering patients into registries? *

☐ Yes

☐ No

14. What are the barriers to registering patients into registries? *

- ☐ Asks for too much information
- ☐ Concern about data governance
- ☐ Lack of staff to enter data
- ☐ Lack of time to enter data
- ☐ Unclear of purpose of data collection
- ☐ Unaware of registry

☐

Other

15. Do you have a local database of vasculitis patients? *

- ☐ Yes
- ☐ No

16. How often is the database updated? *

- ☐ Immediately on seeing the patient
- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ Less frequently than monthly

☐

Other

17. What data is collected? *

- ☐ Cross sectional only
- ☐ Longitudinal

18. Who enters data into the database? *

Tick all that apply

- ☐ Administrator
- ☐ Research assistant
- ☐ Research nurse
- ☐ Senior clinician
- ☐ Specialist nurse
- ☐ Trainee/research fellow

☐

Other

Information and support for patients

19. Do you engage with local or national support groups for patients with vasculitis? *

For example, attend local group meeting, consult them about local service changes

☐ Yes

☐ No

20. In what ways does your service and support groups (local or national) for patients with vasculitis engage with each other? *

Tick all that apply.

☐ Support group(s) directly or indirectly approach you about new/exisiting patients

☐ Support group(s) ask your opinion about new developments e.g. Covid-19 pandemic, new drugs

☐ Service representative attends support group meeting

☐ Service requests help from local group in plans for service improvement

☐ Involvement in research - study participant

☐ Involvement in research - development of protocols, review of results

☐

Other

Changes to care delivery during COVID-19 pandemic

In this section we would like to understand the way care delivery for vasculitis patients has changed during the COVID-19 pandemic and subsequent restoration of services.

21. Do you think patients have delayed presenting to medical services because of the COVID-19 pandemic?

☐ Yes

☐ No

22. In your opinion, what factors have contributed to this delay? *

Please select all that apply.

☐ Patient anxiety about COVID-19

☐ Patients not wishing to burden NHS services

☐ Difficulty accessing primary care

☐ Difficulty accessing specialist services

☐

Other

23. During lockdown, how much vasculitis work was being done in relation to other specialty work/general medicine? *

☐ A lot less

☐ Somewhat less

☐ Same as before

☐ Somewhat more

☐ A lot more

24. During lockdown what was the average wait times for new patients with suspected vasculitis from referral to local specialist evaluation? *

☐ On the same working day

☐ Within 3 working days

☐ Within 1 week

☐ < 1 month

☐ up to 3 months

☐ 3-6 months

☐ >6 months

☐

Other

25. What impact did lockdown have on the frequency of clinics (either face to face or remotely by video or telephone) where patients with vasculitis were usually seen? *

☐ All regular clinics were cancelled

☐ Regular clinics were held but less frequently than before

☐ Regular clinics held but less frequently than before and some replaced by urgent clinics

☐ Same number of clinics as before

☐ More clinics than before

26. In which type of clinics were patients with vasculitis usually seen during lockdown? *

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
- ☐ Specialist clinic with only vasculitis patients
- ☐ Urgent access/flare clinic

☐

Other

27. Did you triage existing patients with vasculitis to determine who needed to be seen, either by via face to face or remote consultation? *

☐ Yes

☐ No

28. How did you triage existing patients with vasculitis? *

We would like to know how you went about triaging patients, for example, contacting all patients to identify if they had any problems, reviewing clinical notes and identifying those at high risk of flare/complications, or using a patient triggered approach. Tick all that apply.

- ☐ Contacted all patients by telephone
- ☐ Contacted all patients by letter or email
- ☐ Review of clinical notes, patient provided information, blood tests to identify those at high risk
- ☐ Patient-triggered e.g. following contact with advice line, GP

☐

Other

29. Did you triage new referrals to determine who needed to be seen, either by via face to face or remote consultation? *

In other words did you avoid seeing some patients face to face

☐ Yes

☐ No

30. How did you triage new referrals?

This may vary depending on where cases are referred from (e.g. primary or secondary care) and the condition.

31. What proportion of clinical encounters with vasculitis patients were conducted *

Pre Covid 19

	None	1-24%	25-49%	50-74%	75-100%
Face to face	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telephone consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asynchronous consultation (e.g. review of patient provided information, blood tests) and advice to patient/GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

32. What proportion of clinical encounters with patients with vasculitis were conducted *
During lockdown

	None	1-24%	25-49%	50-74%	75-100%
Face to face	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telephone consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asynchronous consultation (e.g. review of patient provided information, blood tests) and advice to patient/GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

33. During lockdown, please estimate what proportion of patients were seen in virtual consultations (video or telephone rather than face to face) *

	None	1-24%	25-49%	50-74%	75% or more
Patients with an existing diagnosis of vasculitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New patients with suspected vasculitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. Did you undertake face to face consultations for patients with vasculitis during lockdown? *

- ☐ Yes
- ☐ No

35. What were the indications for a face to face consultation during lockdown? *

Tick all that apply.

- ☐ Assessment of disease activity
- ☐ Change of immunomodulatory therapy
- ☐ Co-morbidities
- ☐ Diagnosis
- ☐ Flare of vasculitis
- ☐ Infection
- ☐ Other

36. Approximately what percentage of remote consultations for patients with vasculitis were subsequently converted to a face to face consultation? *

This is to determine how often the remote consultation was not sufficient to manage the patient for that episode of care

- ☐ None
- ☐ 1-24%
- ☐ 25-49%
- ☐ 50-74%
- ☐ 75-100%

37. Regarding remote (video or telephone) consultations, to what extent do you agree or disagree with these statements? *

	Significant problem	Sometimes a problem	Neutral	Not usually a problem	Never a problem
Digital/IT literacy of patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hearing difficulties	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Language barrier	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reliable assessment of disease activity or damage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical examination of patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Investigations - blood and urine testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Investigations - imaging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Technical quality of consultations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IT support for remote consultations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

38. In what way did access to day unit facilities for biologic/cytotoxic drug administration change during lockdown? *

- ☐ No access
- ☐ Limited access for urgent cases only
- ☐ Same access as before

39. How often did the following activities occur during lockdown compared to usual? *

	Did not happen at all	A lot less	Somewhat less	Same as before	Somewhat more	A lot more
Advice line	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse-led clinics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient education sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-management support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Monitoring of immunosuppressant therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Infusion delivery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

40. During lockdown did the frequency of MDT meetings change? *

- ☐ All MDT meetings were cancelled
- ☐ Less frequently than before
- ☐ No change to frequency of meetings
- ☐ More frequently than before
- ☐ Not applicable (no MDT to discuss vasculitis patients pre-COVID)

41. Have local/regional networks provided support for patient management either before or during COVID-19? *

- ☐ Yes - local network only
- ☐ Yes - regional network only
- ☐ Yes - both local and regional network
- ☐ No

42. How has this changed during the COVID-19 pandemic? *

- ☐ Did not happen at all
- ☐ Less than before
- ☐ Same as before
- ☐ More than before

43. What role(s) have local/regional networks played during the COVID-19 pandemic? *

Tick all that apply.

- ☐ Education and updates for health care professionals
- ☐ Enabling patients to access biologic therapies
- ☐ Forum to conduct COVID-19 related research
- ☐ Forum to discuss patients
- ☐ Peer support

☐

Other

44. What role(s) have local dedicated vasculitis services played during the COVID-19 pandemic? *

Tick all that apply.

☐ Education and updates for health care professionals

☐ Enabling patients to access biologic therapies

☐ Forum to conduct COVID-19 related research

☐ Forum to discuss patients

☐ Peer support

☐ Does not apply

☐

Other

Organisation and process of care: Future service requirements

45. In one year's time what proportion of clinical encounters in patients with vasculitis do you think will be conducted *

	None	1-24%	25-49%	50-74%	75-100%
Face to face	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telephone consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asynchronous consultation (e.g. review of patient provided information, blood tests) and advice to patient/GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

46. What are your priorities to enable you to meet future vasculitis service needs? *

Please rank in order of priority (click and drag). In order to answer this question you need to make at least one change in the order of priorities, even if you change it back again before submitting the question.

Specialist nurse led care

IT support for remotely delivered care

Community-based services e.g blood tests to support remote consultations

Delivery of timely biologic/cytotoxic infusions

Support for MDT meetings

Effective ways to remotely assess vasculitis patients

Administrative pathways to support remote consultations

Development of new care pathways (e.g. hybrid of face to face and remote consultations)

More opportunities for specialty training in vasculitis

47. Additional comments

If you have any other comments about any aspect of care delivery for patients with vasculitis, please include them here.

48. Consent for future contact *

Results from this survey will be de-identified, however, we may wish to contact you and invite you to take part in other activities (for example, a service case study as part of the VOICES study). At the moment, you are only asked to provide consent for us to contact you again. If you agree, we will send you further details at a later date. You will be free to decide if you wish to take part or not. You are free to change your mind and withdraw your consent at any time.

If you give your consent to be contacted, please provide us with the address of your service and an email address with which we can contact you.

- ☐ I give my consent to be contacted with an invitation letter
- ☐ I do not give my consent to be contacted with an invitation letter.

49. Contact details

Please enter your hospital and email address

Thank you for completing the second part of this survey

If you did not complete the first part of the survey, the link to Part 1 can be found in the email we sent you and in the message you will see after you submit this part of the survey. Many thanks.

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