



Vasculitis Outcomes In relation to Care Experiences Study

November 2021

Welcome

Hello, and welcome to our VOICES of Vasculitis newsletter.

In this issue, we will introduce you to our newest team member, Dr Warren James, and give you an update on what the team have been up to. We also have a very interesting article from Steve Chinn, who tells us what being part of the VOICES Study has meant to him.

We always welcome any feedback or suggestions you may have, please email us at voices@abdn.ac.uk

Kind regards,

The VOICES Study Team



**VERSUS
ARTHRITIS**



VOICES is a research study funded by Versus Arthritis and sponsored by the University of Aberdeen in collaboration with the University of Oxford.

People with vasculitis report an uphill struggle to navigate healthcare systems not designed to manage complex conditions. Services are delivered in many ways, with different health outcomes even among specialist centres, and it is unclear what works best.

Our study aims to understand which key elements of care delivery are associated with health outcomes of prime importance to people with vasculitis. The findings will help to design better services and ensure equitable access to effective, coordinated care.

Study Update



Routinely Collected Healthcare Data

(Using anonymised data to understand the use of healthcare services, and the healthcare outcomes of people with systemic vasculitis)

Enock Havyarimana and Matthew Rutherford, PhD students working with Prof Neil Basu, and our study research fellow Warren James have looked the number of people identified as having systemic vasculitis in routinely collected healthcare data in Scotland. We have looked at important health outcomes such as serious infections, heart disease and cancers across regional health boards in Scotland. We are now going to look at people's healthcare journey, including hospital stays, clinic appointments and use of out of hours GP services and emergency care. This will help us understand how people with vasculitis use services and move around the healthcare system.

Healthtalk Interviews

Our 32 in-depth interviews have given us a real insight into people's experiences of vasculitis and healthcare across the UK. The forthcoming vasculitis section on www.healthtalk.org is based on analysis of these interviews and includes video or audio clips so you can hear directly from those who took part.

We hope the website will go live early next year; however, we do have a short film available to view now on our website:

<https://www.abdn.ac.uk/iahs/research/epidemiology/vasculitis-1616.php>.

This is from our interviews with people across the UK who live with systemic vasculitis. We hope it will help staff and patients think about how they could improve care locally.

Case Studies

Our service case studies are underway. Our research fellow Avril Nicoll has started interviews with staff at the first of six NHS sites to understand how care for people with systemic vasculitis is organised and delivered. She says, "I'm already learning a lot about work that goes on behind the scenes to coordinate appointments and the kind of service developments that are intended to give patients access to care when they need it. I'm also getting an understanding of the challenges that services face and how these shape decisions about how care is delivered."

Survey of Vasculitis Services across UK and Ireland

We invited all UKIVAS sites across the UK and Ireland, and health boards in Scotland to complete two online surveys detailing how services are delivered for people with vasculitis and the changes resulting from the COVID-19 pandemic. This is now complete, and the data is being analysed. Initial findings were presented at the Royal Society of Medicine Webinar: Vasculitis: From cell to service, more details here: <https://www.rsm.ac.uk/events/nephrology/2021-22/neq51/> .

A Patient's Perspective: The value of research and being a patient advisor

Steve Chinn is a patient partner on our VOICES Study. Below he describes why patient and public involvement is important to him.

You can find out more about the VOICES Study [here](#)

Steve Chinn



"I was diagnosed with ANCA Vasculitis with MPO Antibodies, also known as Microscopic Polyangiitis, in December 2018. I try to give something back by acting as a patient advisor on research projects. This involves working with the research team to build a patient perspective into the way research needs are identified, and the research itself is designed and carried out. In the end, I always want to help ensure that a study gets at the real issues and produces relevant information.

Sometimes, there are questions of wording too. A patient advisor keeps a watching eye out for this. I think it is very important, as a patient advisor, to represent all patients, and not just one's own views. So, I talk to fellow patients a lot. I've learnt a few things from this.

One is that what's important to patients often isn't what's treated as important in medicine. Another is that there's a reason we're called patients – it's that we have to be infinitely patient. Another is that what counts as quality of life in medical research can still leave patients with sizeable day to day challenges.

Research is crucially important in a number of ways. It produces the information that helps to achieve two goals:

- 1. Better understanding of our needs as patients and carers, so services can better meet them.*
- 2. Develop and trial new treatments, behaviours, and devices (including both brand new meds, and new ways to use existing meds) - so that genuine progress will be made in how medicine can treat vasculitis and all the knock-on problems that come with it.*

I think the most important thing to know about research is this:

Research is how medicine and healthcare move forward. We, the patients, are the partners of the scientists, medical professionals and other researchers who make it happen. Our role is crucial. Without us, there is no research. Without research, there is no progress.

The patient advisor is there to help this all happen, and that's very rewarding."

Meet the Team: Dr Warren James



1. Tell us about your role on the VOICES Study

"My main role is handling data, so I spend my time cleaning and processing data to put it into a format that can answer the questions we're interested in answering. In particular, I'm responsible for looking into how different services in Scotland are used by examining various factors such as when and how often patients visit health services, and what their outcomes are."

2. How do you usually start your day?

"On the days I come into the office, I have to walk through the park between where I live and the office. It's a bit unfortunate that the office has opened up just as it's getting colder, but the walk's still nice regardless. Then I catch up on any emails I may have missed the previous evening and look through the notes I made the day before for any outstanding problems."

3. What brought you to the University of Aberdeen?

"Back in 2012, I came to Aberdeen to start my undergraduate degree in Psychology. I decided on coming to Scotland as I spent plenty of my childhood holidays coming north of the border to see family and going to some smaller music festivals. Fortunately, my adolescent self managed to make a good decision without being particularly well informed as Aberdeen university has consistently performed well in university performance tables."

4. What's the favourite thing about your job?

"Probably sounds quite 'nerdy', but I've always enjoyed working with data and using it to explain something that is happening. It's very satisfying to clean a dataset to produce a clear and informative set of analyses and graphs. Data itself can be quite daunting, so I very much enjoy taking something complicated and finding ways to make it more comprehensible."

5. What are your priorities at the moment?

"Currently I'm focussed on producing figures and tables for a presentation on the different services available to people with vasculitis across the UK. I'm also working on a large dataset looking at health care outcomes across Scotland for patients with vasculitis. Just now, I'm working on recreating some analysis produced by another researcher on the study as the dataset has been updated."

6. How do you relax outside of work?

"I'm very keen on music. I've been playing guitar for a fair while and am slowly trying to teach myself piano when I get the time. Apart from music, I enjoy also visiting some of the nature walks around Aberdeenshire (weather permitting)."

Other Exciting News



Conference News

Our qualitative team presented a poster at the Royal College of Speech & Language Therapists' conference (5-7 October 2021). 'So many limits': Living with subglottic stenosis as a result of vasculitis focuses on the experiences of co-author Charlie and is illustrated with excerpts from his interview. Subglottic stenosis is a narrowing of the airway just below the vocal cords and – although it is rare – is an example of the kind of damage that vasculitis can do to the body.

You can view the poster [here](#)

Patient and Public Involvement

We are very grateful to our patient partners who continue to support the VOICES research in a number of ways. Eight of them read topic summaries for the healthtalk.org website to check that they made sense and were worded sensitively, and we used their feedback to make improvements. In addition our core group – Steve Chinn, Lynn Laidlaw and Mo McBain – take part in the study management team meetings on a rotational basis and are co-authors on a planned paper about what good care looks like for people with systemic vasculitis.

You can find out more about our study and how to get involved here:

<https://www.abdn.ac.uk/iahs/research/epidemiology/vasculitis-1616.php>

**Thank
You**

Thank you for taking the time to read this newsletter, we would welcome your feedback. All feedback will be used to improve future communications, please email any feedback to voices@abdn.ac.uk