



Vasculitis Outcomes In relation to Care Experiences Study

March 2021

Welcome

Hello, and welcome to our first Voices of Vasculitis newsletter.

In this issue, we will introduce you to the various parts of our study and the progress we have made.

You will also meet a member of our team every issue; this time it is our Principal Investigator Dr Rosemary Hollick.

We welcome your feedback and suggestions by email to voices@abdn.ac.uk

Kind regards,

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

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The VOICES Study Team



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

Who we are: Dr Rosemary Hollick



VOICES is a multi-method project led by Dr Rosemary Hollick. Through working with patients, healthcare professionals and decision makers, we aim to develop recommendations that will improve healthcare for people with vasculitis.

Rosemary is a Senior Clinical Lecturer and Rheumatologist at the University of Aberdeen. Rosemary holds an Honorary Consultant Rheumatology post within NHS Grampian where she plays a key role in service development.

As principal investigator for VOICES, Rosemary is keen that it has as much impact as possible. She says, "VOICES will feed in to both the Scottish Systemic Vasculitis Network (SSVN) and the UK and Ireland Vasculitis Society (UKIVAS) to inform service reconfiguration. I was delighted to launch the service mapping survey at a Royal Society of Medicine Vasculitis meeting in November 2020, and to be part of a Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) roundtable discussion."

About the VOICES study

Background to the study

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.

How are we doing this?

1. Data Linkage

We are using anonymised data collected by the NHS in Scotland to understand healthcare outcomes and use of healthcare services by people with systemic vasculitis.

2. Healthtalk Interviews

We are interviewing a range of people living with different types of vasculitis to understand their experience of it and of healthcare. These will be used to create a resource for people with vasculitis on the www.healthtalk.org

3. Case Studies

We will interview healthcare professionals to find out how vasculitis care is organised and delivered at up to six case study sites. We will also interview up to eight people who help make decisions about vasculitis services at a national level.

4. Service Mapping Survey

We have invited all NHS health boards across the UK and Ireland to complete a survey detailing how services are delivered for people with vasculitis at their site, and the impact of COVID-19 on delivering these services.

How will this research benefit patients?

Our study will inform policy decisions and service improvement for patients with rare rheumatic diseases.

We will use the patient interviews to develop an online resource for people with vasculitis, their families, and healthcare professionals.

What does the VOICES study mean to me?

A patient's perspective: Mo McBain

As a patient with vasculitis, but also having worked as nurse and researcher, I knew how important this study would be and the difference it could make, so I was more than happy to have "my voice" heard.

Due to the fact that different groups' perspectives (professionals and patients) have been listened to, this study will for the first time give a clearer picture of what patients are experiencing regarding access to treatment and support services and more importantly suggestions on what and where improvements could be made.



For me, this project is proof that we (as patients) have been included and that our voices are being heard. Saying that, there is still much work to be done regarding awareness, research, education and support into vasculitis but hopefully this project will fill some of these gaps and I'm looking forward to seeing the outcomes.

Progress so far

Data Linkage: We are in the process of analysing our data to understand healthcare outcomes and patterns of healthcare usage of people with vasculitis in Scotland.

Healthtalk Interviews: We have completed 30 interviews with people who volunteered to talk about their experiences of living with vasculitis. Clips from the interviews will be available on www.healthtalk.org later this year.

Service Mapping: Our service mapping study has been live since November 2020 and to date 43 NHS sites have completed the survey. Thank you to everyone who has taken part. Analysis has started and we look forward to seeing the results soon.

Case studies: We recently submitted our proposal to the local ethics review board. Once they have approved it we will be able to start this part of the study.

Acknowledgements

We are grateful to the [Lauren Currie Twilight Foundation](#), [Vasculitis UK](#) and [Support for Polymyalgia and Giant Cell Arteritis Sufferers in Scotland \(PMR-GCA Scotland\)](#) for their support with study recruitment.

Many thanks also to our patient partners.

Peter Hall designed the VOICES logo, and Wendy Bryant, Steve Chinn, Lynn Laidlaw, Mo McBain, Claudia Miron Mirela and Karen Sinden helped us improve our plan for the case studies.

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