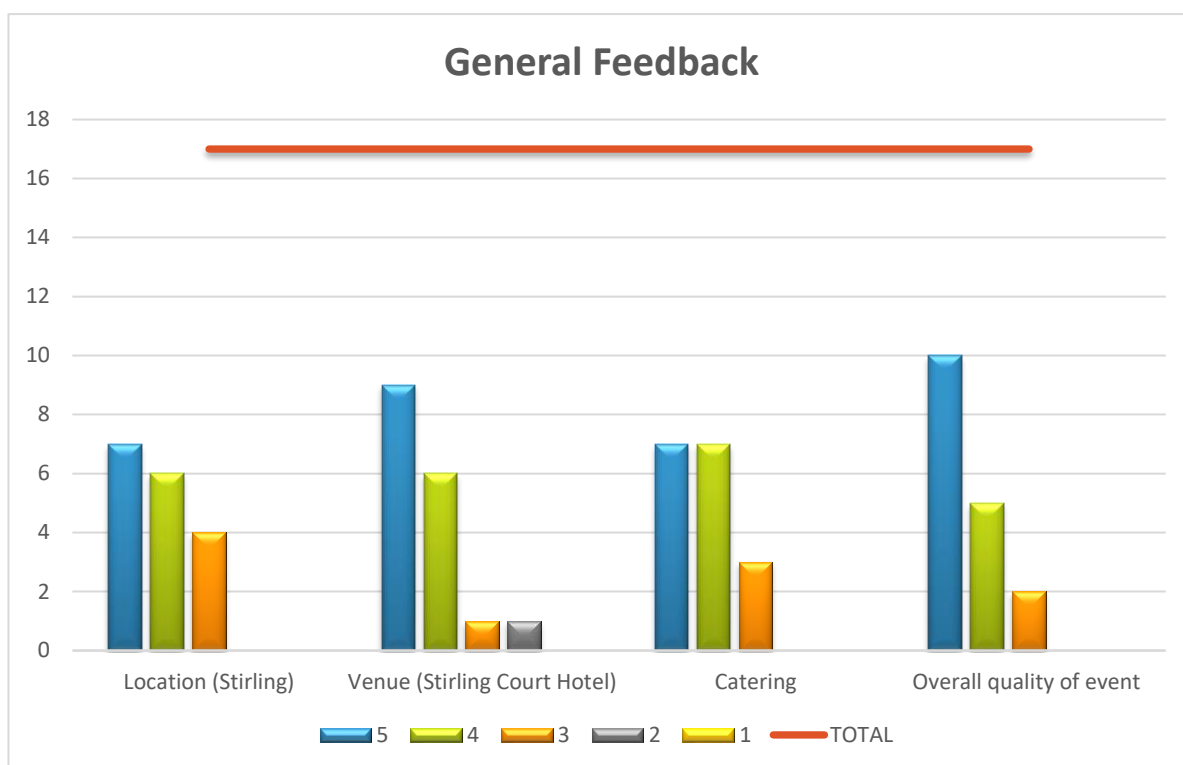


National Launch – 12th December 2019 – Evaluation Analysis

Of the 40 delegates in attendance, 25 returned the event evaluation, equating to a response rate of 63%. 14 of these returns completed the evaluation in full. NSS staff in attendance did not participate.

GENERAL FEEDBACK

Attendees were asked to rate the location, venue, catering and overall quality of event. (5 = Excellent, 4 = Very good, 3 = Good, 2 = Fair, 1 = Poor)



Any further comments?

A very informative day with good opportunities for multi-disciplinary discussions.

I enjoyed the launch event. I find this educational and enjoyed the testimonies from patients and current research in Scotland and across UK on vasculitis. I also felt I was contributing towards the future of the network and vasculitis service set-up in Scotland. I was a bit disappointed that we didn't get shown the network website/database and was told before the launch that there will be a demo presentation on it as this will help the clinicians when comes to using and keying data into the database.

It was sometimes difficult to hear some of the speakers at times

A venue closer to a station would be preferable but it was a very nice venue. Catering over lunch a bit slow but it was lovely to have a hot meal.

Excellent topics. Passionate speakers. Overall a wonderful meeting.

Very educational

Good start



What do you think worked well?

The mixture of presentations and workshops.

Range of talks

A partnership between the clinicians, scientist, NHS Scotland and patients with vasculitis.

Getting everyone in the same room to start with

The overviews in the morning were good. I thought the 2 patient speakers excellent too.

Good mix of specialties, patients, charities and support groups.

Nice to hear the potential plans for the network and to meet some new faces. Good patient involvement.

Particularly enjoyed the afternoon sessions. It was a great opportunity to brainstorm with other healthcare professionals as well as patients in tackling some of the burning issues within the community.

Informal relaxed atmosphere of collaboration

Presentations good. Glasgow data be useful to have included....we should have offered - apologies!

Venue and catering were good. Interest from a range of specialties is encouraging

How do you think future Network meetings could be improved?

More opportunity for feedback from group discussions bringing all the conclusions and ideas together.

Focused themes.

To have annual meetings on what's current and also how service could [be] evolved and improved. Funding for new services and MDT services in Scotland.

Ensure all HBs have someone there that will give feedback.

The round table discussions were difficult - partly because the patient reps seemed to not be engaged with the questions, and more interested in tapping into the expertise around the table in relation to their own conditions and/or wishing to bring very specific agendas to the discussion. However, that may not be common to all groups. The time keeping on those small group discussions could have been better.

More info on what the different charities can offer in terms of support to patients - one I had never heard of until a shared taxi ride back to the station but will be a good resource to direct patients to. As per round table discussion, some separate talks for patients and specialists but some shared.

Ensure all units were aware of the event / invited (became aware that Inverness nephrologists felt that they had not been invited after the event). Perhaps some example case discussions?

Perhaps aim for GP involvement. In an attempt to increase primary care awareness in terms of disease recognition to facilitate earlier referral to specialists. This could possibly partially address the issue of delayed diagnosis.

Further integration of MDT members e.g. Specialist Nurses

Think will evolve as becomes more apparent the full role with steering group and sub groups.

Patients and their reps helpful esp. Grant Currie. However whilst useful to always get their perspective I think for some of the group work there was a tendency to misunderstand in some cases and (naturally) want to discuss the details of their own experience without necessarily identifying wider issues. Maybe patients and reps to some but not all the meeting?

More time talking in groups

Will need to consider who the target audience is to continue to appeal to disparate specialty groups

NETWORK PRIORITIES AND THEMES FOR DEVELOPMENT

We asked people to identify the top three priorities for the Network in the future.

Apart from work already underway to:

- establish the network
- identify specialists to whom clinicians can refer patients
- identify the patients themselves

the following themes emerged:

Data	Pathways / Protocols	Education, Research and funding opportunities
Population based data registry	Establishing clear pathways / protocols to set national standard of care for vasculitis patients. Standardised care pathways Improving patient care and funding for a multidisciplinary service	Education for clinicians and GPs - specialities like ENT/ respiratory/ vascular as well as GPs- increase awareness and attempt to captivate their clinical interest for more holistic patient care
Robust data set	Outcome data on all vasculitis patients - not just those with an ICD code from hospital admission Ensuring equal access to labs/tests/service for whole country	Accurate diagnosis - education and information about referral pathways
Don't reinvent the wheel - tie into current systems	Involvement of the wider MDT e.g. Nurse Specialists	Research - (e.g. Scottish trial initiatives, national data linkage, national tissue biobanking)



We welcome your suggestions for future Network meeting and education day themes

More examples of good practice from other networks.
Focus on other kinds of vasculitis such as Behcet's.

Research

I will love to hear a talk or webinar on how to overcome chronic fatigue, depression and pain in vasculitis. This can be a talk given by patients about their journey, physiotherapist, clinical psychologist, pain specialist and rheumatologist with vasculitis interest.

Consider things like - fatigue management programmes/pain management/ mental health when living with chronic long term diseases

FUTURE ENGAGEMENT

We invited people to get involved and help us develop the Network with the following results:

- twelve expressions of interest in becoming an active member of SSVN
- eight expressions of interest in joining the Steering Group (meets quarterly)
- eleven expressions of interest in joining a Sub-group, along with any preference (e.g. Research, Data, Training and Education)

WEBSITE

We invited people to check out the SSVN website at <https://www.ssvn.scot.nhs.uk>

The top three things people would like to see included are:

Research and Funding opportunities	Protocols	Training and educational events for patients and clinicians
Current research and findings in Scotland and UK +/- available funding from NHS Scotland / charitable organisation	Ensure correct treatment protocols for all across Scotland	Signposting to patient charities
Information/contact details for those recruiting patients for trials or observational studies	Contacts for difficult cases	Patient forum and support for newly diagnosed patients