

NEURO VOICE/ LLAIS NIWRO PROJECT EVALUATION FINAL REPORT



Dr Naomi Tyrrell
June 2022

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1. Introduction

Neuro Voice/Llais Niwro was a pilot project that ran across Wales in 2021-2022, with a strategic and sustainable volunteer-led infrastructure aimed at amplifying the voices of people with neurological conditions (pwNC), with the desired outcome of improving health and care services. It was developed by the Wales Neurological Alliance (WNA), with the MS Society, and funded by WCVA.

WNA is a coalition of 23 Welsh charities, large and small, working to ensure that neurological services are given priority at all levels of health and social care planning. WNA's carried out a survey in May 2020 which showed how the pwNC had been impacted by the pandemic:

- 42% had health appointments cancelled, leading to a deterioration in health;
- 29% experienced worsened physical health;
- 18% poorer mental health.

In September 2020, WNA recruited a new Advisory Group of twelve pwNC as volunteers to represent the wider pwNC community and inform their work. The group were instrumental in influencing the WNA's manifesto in the run-up to the Senedd elections, coordinating hustling sessions with prospective Senedd members, and bringing together pwNC to share their views and experiences. Building on this success, the Advisory Group suggested that WNA recruited more pwNC, working with existing/ new partnerships with local health and care services, to identify and embed best practice. The project that is evaluated in this report set out to achieve this, as a pilot project to inform a longer-term strategic initiative.

1.1. Aims of the project

The overarching aims of the project were to:

- 1) Work with the Advisory Group to identify the pwNC community's knowledge gaps, service access issues and priority stakeholders to target.
- 2) Create local campaigning groups, empowering pwNC as campaigners to improve policy and practice within Powys, Cardiff and Vale, and North Wales (Betsi LHB).
- 3) Create an online hub for pwNC to access trusted, quality information about self-management / upcoming campaigns and make new connections with peers.
- 4) Facilitate an online community, alongside three new local support groups for mutual support / experience sharing.
- 5) Reactive and planned social media campaigns, informed and led by volunteers on a range of platforms.

- 6) Coordinate national campaigns by training and supporting pwNC as individual campaigners, helping them to engage with the political process within national campaigns informed by issues raised by local campaigners.
- 7) Co-create a campaign toolkit with standard letters / key contacts, and co-delivering campaigns targeting key stakeholders.

1.2. Outcomes of the Project

The project's anticipated project outcomes are to:

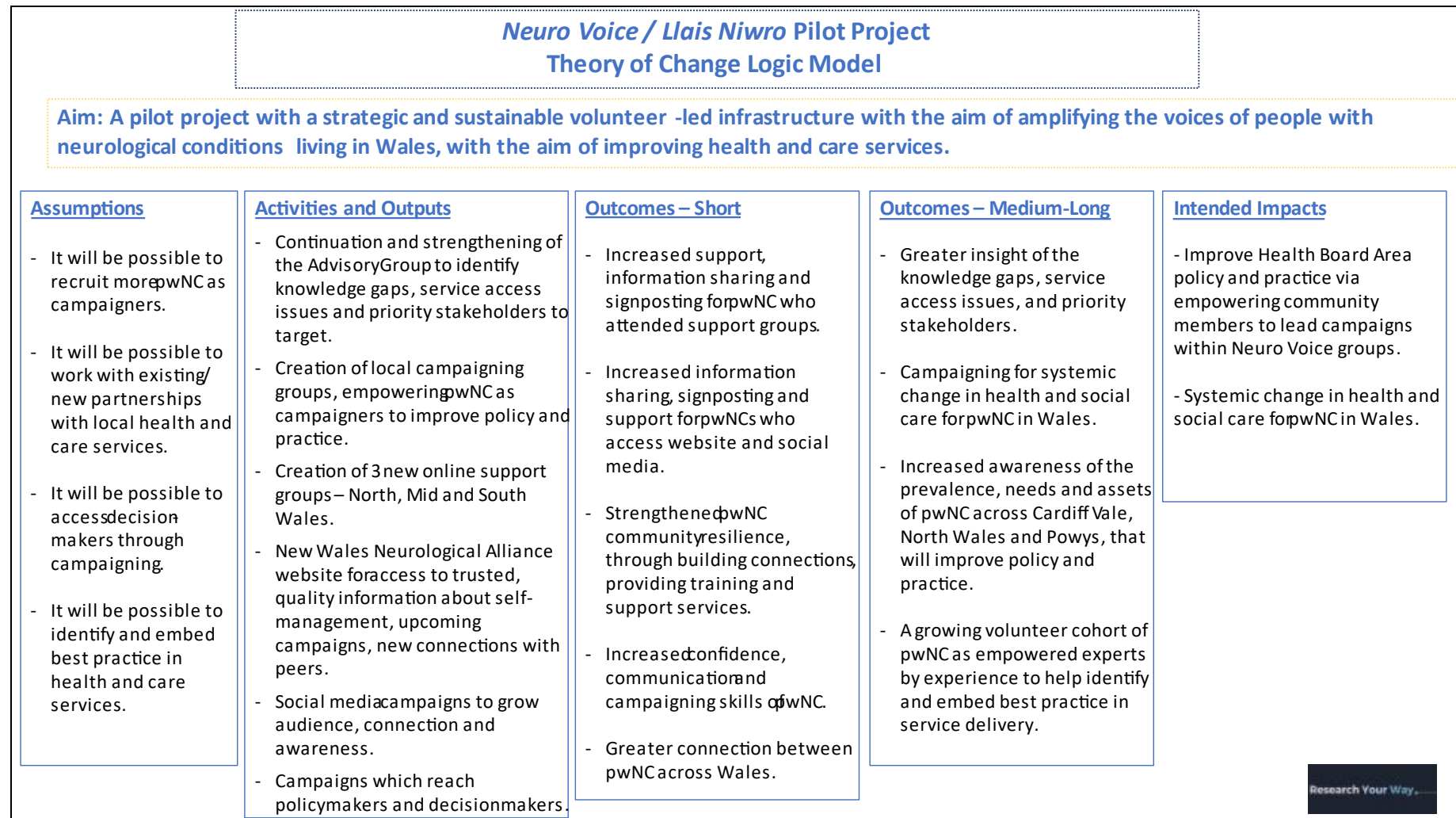
- 1) Strengthen our community's resilience to recover from/cope better with future crises via – creating an online hub, enabling peer connections and providing training.
- 2) Improve the confidence, communication, social media and campaigning skills of community members via enabling them as individual campaigners.
- 3) Improve Health Board Area policy/practice via empowering community members to lead campaigns within Llais Niwro groups.

2. Theory of Change

The pilot project has enabled the development of a Theory of Change, shown in Figure 1, which can be used to:

- provide evidence of the efficacy of the delivery model in removing barriers to volunteering and enabling pwNC to support each other to develop partnerships with and improve services that matter to them most;
- test an approach to enable pwNC to identify, self-advocate and lead local campaigns in conjunction with higher level, strategic national campaigns, to improve services that matter most to them;
- provide an impartial evidence base to use to leverage further funding to continue the programme pan-Wales.

Figure 1. Theory of Change Logic Model



3. Evaluation Methods

An online survey was developed and distributed to people who attended the online support groups. The link was also in a 'pop-up' on the new WNA website. Interviews were carried out with 3 pwNC who had attended the support groups and the project coordinator. Website and social media analytics were recorded.

3.1. Survey

13 people completed the online survey. 9 people had neurological conditions, 2 did not, 2 did not say. 3 people attended the North Wales support group, 8 people attended the South Wales support group and 2 people did not say. 6 were female, 5 were male and two did not say. 1 person was aged 25-34, 2 people were aged 35-44, 2 people were aged 45-54, 4 people were aged 55-64, and 2 people were aged 65-74.

3.2. Interviews

The project co-ordinator put out a call for people who were willing to be interviewed about their involvement in the project. 4 pwNC agreed to be interviewed but only 3 were available during the project timeframe. All 3 interviewees were male. The project coordinator also was interviewed. Although only a small amount of project evaluation data was collected, survey respondents and interviewees gave a lot of helpful information. This has been used to assess the aims and three core outcomes of the project in the following section.

4. Project Findings

Table 1 shows the progress that the project has made, measured against its core aims. Good progress has been made in all areas, with strong connections being made within the pwNC community and campaigning being strengthened.

Table 1. Project Progress

Project Aim	Progress
1) Work with the Advisory Group to identify the pwNC community's knowledge gaps, service access issues and priority stakeholders to target.	Achieved.
2) Create local campaigning groups, empowering pwNC as campaigners to improve policy and practice within Powys, Cardiff and Vale, and North Wales (Betsi LHB).	Achieved; need to try to encourage more volunteers.
3) Create an online hub for pwNC to access trusted, quality information about self-management / upcoming campaigns and make new connections with peers.	Achieved; new website launched.
4) Facilitate an online community, alongside three new local support groups for mutual support / experience sharing.	Achieved; Facebook Group, online support groups in the 3 areas.
5) Reactive and planned social media campaigns, informed and led by volunteers on a range of platforms.	Partially achieved; need for some more social media training and volunteers.
6) Coordinate national campaigns by training and supporting pwNC as individual campaigners, helping them to engage with the political process within national campaigns informed by issues raised by local campaigners.	Achieved; good level of engagement with volunteers campaigning and raising issues with decision-makers.
7) Co-create a campaign toolkit with standard letters / key contacts, and co-delivering campaigns targeting key stakeholders.	Achieved and in progress.

In evaluating the progress that the project has made in relation to its aims, and areas for further development, it is helpful to assess its outcomes.

4.1. Outcome 1:

Strengthen our community's resilience to recover from/cope better with future crises via creating an online hub, enabling peer connections and providing training.

Evaluation data show that this intended outcome of the pilot project has been achieved. Three online support groups were set-up in North, Mid and South Wales and met regularly during the project. These groups provided new peer connections for participants, information about their specific conditions and more general information, and also signposted people to resources. The groups also encouraged pwNCs to become involved in the campaigning aspects of the project, aimed at increasing decision-makers awareness of the needs of pwNCs.

Survey respondents said that they had joined the online support groups for the following reasons:

- 6 people said it was to learn more about WNA.
- 5 people said it was to meet other pwNCs.
- 5 people said it was to become part of a community of support for pwNCs.
- 4 people said it was to learn more about neurological conditions.
- 4 people said it was to get support for their neurological condition.
- 1 person said it was so that they felt less isolated.
- 1 person said it was to become more optimistic about the neurological condition.

Evaluation participants felt that their needs had been met through joining the groups, that they had learned new information and made new connections.

'The groups are very useful, especially when you have neurological conditions, and especially during the pandemic. It's important that people who maybe feel lonely, or isolated, you know, they can reach out to other people'. (Interviewee 1)

One of the benefits of the project was that people could gain advice and support from each other about their conditions, and also gain support with navigating the health system. Some interviewees felt that this support was vitally important because neurological conditions can have many aspects to them so their treatment can lack a coordinated approach.

'Neuro Voice is important because [when you are diagnosed] you find nothing is linked up, you get that initial diagnosis and then you get branched off to various areas of specialism where you need treatment. So, it's just physiotherapy, mental health, whether it be bladder and bowel problems,

various things, is, sort of, there's no coordinator. I do feel that the neurologist should be the coordinator and pass you on to these places.' (Interviewee 2)

The resilience-building and information sharing aspects of the groups was welcomed by the participants. Some of them shared the information that they had learned from the groups to people in their networks who could not attend themselves.

'Some of the people in my [name of condition] Support Group haven't been involved with online events, but found the information I've shared very useful in knowing these help out there.'
(Interviewee 1)

The general lack of information from healthcare providers for pwNC about their conditions was commented upon.

'There is huge need for improvement in neurological care within Wales. There is staggering difference between the care in Wales and England, which is far superior from my personal experience although I believe both could be improved.' (Survey respondent, attended Cardiff and the Vale Group)

The lack of joined-up service provision was felt to be a problematic for pwNCs. PwNCs may be under the care of different medical teams for their conditions so support in navigating these systems was felt to be crucial. A joined-up information system was felt to be needed, and the project could help with that.

'I think there are a lot of people who just at the moment, they're in the dark of who they can contact. You know, if you go into a doctor's surgery now and say, 'Well, I've just been diagnosed with it'. And the doctor would say, 'Oh, hold on, you know, I'll put you on to these people' that would be great.'
(Interviewee 3)

'Another thing that I found personally is because like, you don't see the neurologist that often when these new problems do develop, and it's delays, delays and getting these specific treatments and or seeing specific specialists.' (Interviewee 2)

'We've just done a survey, a minor survey across the whole of the UK. And it's come to light that people are still being diagnosed and given like a scrappy bit of paper with Parkinson's UK on it, and told to look up their own condition. So, if we could make this website a starting point for resources [and] get people a leaflet at diagnosis we can at least signpost you to the appropriate agency and

making sure you only get an information that is properly standardised and appropriate.’ (Project Coordinator)

Evaluation participants felt that there was potential for the project to continue to deliver the support that pwNC need and raise awareness about neurological condition if it was funded for longer. The knowledge that was shared by pwNCs in the groups about what had helped them in navigating health and social care systems was recorded by the project coordinator so that the information could be shared more widely both during and beyond the project.

‘The peer support has been amazing between individuals. [...] When it comes to groups, and people have shared experiences or issues that they’ve got there’s always someone that’s either been there done that, saying ‘I can give advice or support’ or ‘You need to ring these people’ or that kind of guidance or ‘This resource is really good.’ So, I’ve been furiously writing all that down and trying to share that more widely.’ (Project Coordinator)

This data ‘capture and cascade’ element of the group is important as not all pwNCs can attend the groups (or chose to). Interviewee 1 mentioned that people they knew could not attend the groups because they are at work during the day so it is important for information to be shared on social media and the website, as well as considering if evening or weekend group meetings would reach some more pwNCs who need support.

The new connections that pwNCs have made have been a very beneficial aspect of the project that participants commented on. The new connections have been made at the support groups and through social media. The increased emphasis on social media engagement throughout the timespan of the project had positive results. The number of Facebook Group members increased, as did the number of Twitter followers.

The reduced social media resource towards the end of the project and the short length of the project did limit its social media presence.

‘If someone engages and then asks a question about a link, or what this was to be involved in, we can’t reply in a timely manner. So, without that input, it’s a double-edged sword. You can’t have too much input engagement on social media because we can’t manage it without a dedicated resource.’ (Project Coordinator)

Social media requires updating and interaction so the next steps for the project will need to be considered carefully so that pwNCs are not left without knowing where to turn to for support and advice.

4.2. Outcome 2:

Improve the confidence, communication, social media and campaigning skills of community members via enabling them as individual campaigners.

The majority of the evaluation participants who had participated in the support groups felt that they were connected to other pwNC, although two people in the survey did not feel that they were. The online support groups and social media posts provided key ways of increasing connections between pwNCs and reducing social isolation and increasing confidence.

'Being part of Neuro Voice has helped me meet other people from different Neuro groups and build up friendships. It's helped me during the pandemic with my mental health and without it I feel I may have been isolated from information that would help me self-manage my condition. I would recommend Neuro Voice and the Welsh Neurological Alliance to other people living with Neurological conditions.' (Survey respondent, attended Cardiff and the Vale Group)

'The support group helped me with what's available in the community. The yoga classes and the digital technology classes helped me greatly during the pandemic. I also made friendship with other people living with Neurological conditions. I hope these groups continue to go one supporting people with Neurological conditions.' (Survey respondent, attended Cardiff and the Vale Group)

'The reason my confidence was better because I was helping other people [in the groups] (Interviewee 1)

The evaluation participants discussed the ways in which the project had helped build their confidence and communication skills, which then encouraged some of them to become active campaigners for pwNCs.

'I want to use my experiences to help others and I feel this would stop me feeling so isolated and also give me a purpose.' (Survey respondent, attended North Wales Group)

'Previous organisations haven't been backed up with the people who have the conditions. [...] you need the people who suffer to put their points of view across.' (Interviewee 3)

'I've made quite a few contacts through the groups. I'm looking to set up [name of condition] charity so I'm discussion with the Charity Commission and the UK government to try and put that together. It's been good meeting contacts, such as Rebecca Brown, and other people who've helped me to serve guides give me guidance along the way.' (Interviewee 2)

One of the barriers some evaluation participants felt that the project faced was encouraging enough volunteers to come forward for campaigning. Participants suggested some possible reasons for this that were related to the pwNC's circumstances, such as their condition, digital exclusion and/or not yet having enough widespread awareness of WNA.

'It's in the back of their mind and I don't think they feel the need to get involved until their condition gets worse. I think that's the biggest barrier. I feel this stops people getting involved.' (Interviewee 1)
'I just wish it would get more people to join too. I can't tell you the amount of people I know with neuro conditions I've met on my travels. I've tried to get them involved. But they said they're not they're not interested. Because they don't want to go on social media. I find that social media in itself is a barrier as well. It can be a barrier to certain people.' (Interviewee 2)

'I don't know whether that's an issue in terms of access to computers and things like that. In Wales, that sort of digital separation that there is, or it's more to do with, maybe we're just not getting into the NHS enough and spreading the word about us. I think it's probably a bit of both. But that's those are the kinds of barriers that we've has become against.' (Project Coordinator)

Building the campaigning skills of pwNC who have only just started to be active within the organisation is likely to take some time.

'We're not a new organisation, but in terms of trying to develop a volunteer sector, and people being aware that you can volunteer for us, we are brand new.' (Project Coordinator)

The evaluation data suggest that there is a core group of people who would like to continue campaigning for pwNC and the project has helped them gain confidence, skills and contacts to do so. Some evaluation participants were keen to learn from each other and then campaign collectively to raise their voices. The next steps were considered to be building on the project progress the project had made.

To learn how best individuals like to be supported. To try to identify common themes in service navigation and provision challenges from individuals who are living with a neuromuscular condition. To try to identify how best I can offer support in my role, and be more effective. (Survey respondent, attended North Wales Group)

There was a strong feeling amongst the evaluation participants that pwNCs are the best people to campaign for pwNCs. The project has helped to bring pwNCs together, develop their campaigning skills and build their confidence in liaising with decision-makers.

'A lot of us have got neurological conditions and we're putting our things across [now]. It's all well and good having people working on your behalf but [...] most of the ways are led clinicians and we say 'Until you've had a neurological condition, you don't know what really what's happening'.' (Interviewee 3)

'We've had some really amazing new people come on board. [...] People that were there writing the original bids with us have obviously still kept with us and are really starting to take more of a leadership role in some ways. The people that have been with us for longer, sort of flourished with confidence.' (Project Coordinator)

4.3. Outcome 3:

Improve Health Board Area policy and practice via empowering community members to lead campaigns within Neuro Voice groups.

This aim of the project has been met in relation to empowering community members to lead campaigns within Neuro Voice groups and interact with Health Board are policymakers. Evaluation participants felt that their voices are now being heard by the right people and that this can be a motivator for carrying on campaigning and getting more pwNCs involved.

'I actually attended a few of the cross-party meetings when they were running. [...] I do think engaging with politicians and people who can improve things would get more pwNCs involved because they'd feel, like I do, I can see the progress happening. I can see things move. And that's so drives me to push things forward. I think that might drive other people as well.' (Interviewee 2)

'The further on we've gone, I think it's going to give us a voice to put our opinions across to politicians.' (Interviewee 3)

'The campaign group have been amazing. We've met with three separate members of the Senate with really good questions and had really in good engagement. They've been really upskilling them [policymakers] about neurology and why it's important, and they've asked tough questions and given them things to think about. I think we've really highlighted the issues facing people with neurological conditions in Wales, much more than maybe we did when we were doing sort of the more large-scale sort of campaigning work with the cross-party groups and things like that. It's been the individual engagement that has done amazingly well.' (Project Coordinator)

Evaluation participants recognised that policy change takes time and that it can be better for pwNCs to group together as part of WNA so that they can put their views across collectively, rather than have their voices separated into different smaller charity groups.

'I think because now we're getting together more as a group [Ms Wales, Parkinsons UK], everyone with a neuromuscular condition, we're all being grouped together so we're bigger force and I think that hopefully, then we'll get our things across.' (Interviewee 3)

Evaluation participants felt that they had been enabled to have their voices heard by policymakers because of the Neuro Voice project and its approach. This has resulted in some noticeable changes at Health Board Level already.

'It does take work behind the scenes, it's not just setting up a meeting [...] but I would say raising awareness of the campaigning, highlighting issues questions to the Health Minister gone up exponentially about neurology and we've noticed that they are suddenly they're very interested in patient engagement, which they weren't before. [...] We've had some great success with the campaign groups.' (Project Coordinator)

5. Conclusion and Recommendations

The project has been successful in meeting its stated aims and objectives. The amount of evaluation data that it was possible to gather has been small but the feedback was detailed and the people involved showed a strong commitment to the project.

The development of the Theory of Change for the project based, on this evaluation will be helpful in developing the project activities, if further funding is secured. The pwNC involved in the evaluation of the project felt that their voices had been heard, that they had gained support, new connections

and capacity to campaign for their needs with decision-makers. They felt that they had benefitted in a myriad of ways and were very keen for the project to be continued.

'I think that been the biggest success of Neuro Voice is that people have been listened to' (Project Coordinator)

Evaluation participants had some recommendations for future development of the project and campaigning, such as:

- Physiotherapy services in local communities for pwNCs;
- More support for pwNC's mental health;
- More help with the cost of living crisis and helping people know what they can get financial help with;
- Linking up with charities in other countries that support people with specific neurological conditions;
- Getting more neurological charities involved in the WNA;
- Information sharing for people who cannot attend the support groups;
- Information sharing for carers;
- Running 'How to live well' events in conjunction with local health boards to provide support for pwNCs;
- More linking-up with Community Neuro Rehabilitation Teams;
- Support for pwNCs in employment;
- Support and information for families with children living with Neurological conditions.

The pilot project supported pwNC across Wales during 2021-2022 and successfully raised the profile of their health and care needs with decision-makers. For this work to be strengthened and built upon, the recommendations put forward by evaluation participants could provide the foci of future funding bids.