



# Working together to support people living at home with neurological conditions

Organisation/NHS Board: Ayrshire and Arran

Project Lead: Care Inspectorate and NHS Ayrshire & Arran

Funded via the Framework for Neurological Care 2020-2025

## 1. Project background

The Care Inspectorate and NHS Ayrshire and Arran were successful in a joint bid for funding as part of Round 4 of the [Neurological Care and Support in Scotland: A Framework for Action 2020-2025](#). The project brought together expertise from both the Care and Health sectors, with a focus on care at home services.

This innovative project brought people living with a neurological condition into the heart of a new network, working together with the care and health professionals who support them to live at home. The approach reinforces the importance of co-operation and communication between those providing a care or health service and those receiving it. This reflects the key findings of [Christie's Commission on the Future Delivery of Public Services](#), which urges empowering individuals and communities receiving public services by involving them in the design and delivery of the services they use. It also echoes the Scottish Government's '[Scottish Approach to Service Design](#)' which promotes exploring the problem space openly, collaboratively and with users, before a solution or service is decided.

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## 2. Overall Aims

The overall aims of the project were

- to prototype a care network to create structured opportunities for multi-agencies and those accessing care at home services to learn with and from each other
- for the network to develop a shared understanding of how the person's holistic needs and outcomes are best met
- for the network to contribute to improvements in the care and support, and quality of life, for people living with neurological conditions and their families.

## 3. Project Overview: Our six-stage approach

Our project took a Service Design Approach (see Figure 1). The steering group therefore took time to understand the problem through a discovery phase, before defining the issues. The results from this first phase of understanding the problem would then be passed to a network established as part of this project. The network would be tasked with designing and delivering the solutions based on the results obtained. The project followed a six-stage approach. Each stage is outlined in further detail in the following sections.



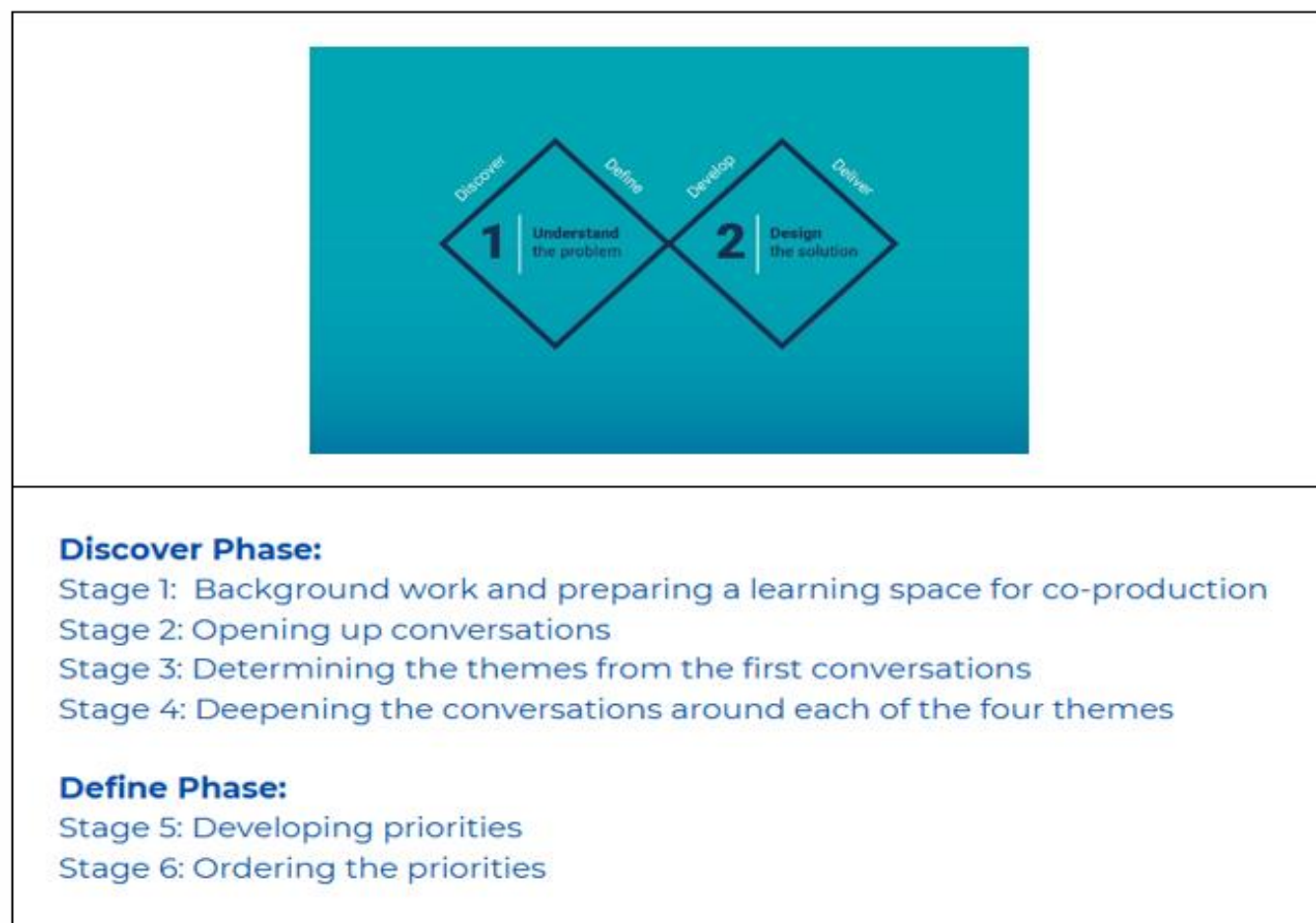
Image from project event: deciding priorities



Image from project event: deciding priorities

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Figure 1: Service Design Approach



## Discover Phase

### Stage 1: Background work and preparing a learning space for co-production

A four-person steering group was established. This included leads from the Care Inspectorate, NHS Ayrshire and Arran, a clinical information specialist with experience in participatory research and a skilled graphic facilitator (from [Envision](#)) to help shape the process and capture complex discussions to aid understanding.

During stage 1 a learning space was designed where disparate parts of care at home provision in Ayrshire and Arran (people experiencing care, informal carers, care professionals and health professionals) had equal status and opportunity to contribute while working together around a common goal.

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Conversations and data gathering sessions to inform this work were held with two people living with neurological conditions and receiving care at home in a different partnership area.

Different avenues (e.g. via the Care Inspectorate's Provider Updates to the care sector, NHS Patient Engagement forums, including social media) were used to communicate about the event and to invite participants.

Communications were designed to reflect a relaxed and informal air. This included reference to cakes and conversation at a community venue rather than a meeting/agenda/chair etc. The invite can be seen in Figure 2 below.

Figure 2: Invitation to the first event

### Supporting people to live well with a Neurological Condition

#### Do you have a story to share?

We are looking to start a network focussing on how Ayrshire and Arran can provide even better support at home for people to live well with a neurological condition.

**We aim to bring together:**

- ★ People living with neurological conditions who receive care at home
- ★ Care at home support staff
- ★ Members of the health team supporting people in their homes (e.g. physiotherapy; occupational therapy, district nursing).

**We will do this by:**

- ★ Starting a conversation
- ★ Giving everyone a chance to share knowledge and experiences
- ★ Decide on the best way to build a network of people who contribute to this work

**A small, informal event will be held to start this project:**  
**Where? Fullarton Connections, Irvine**  
**When? Tuesday 23rd July 2024**  
**What time? 1.00 pm to 3.00 pm**

This will be the first in a series of events where people can share experiences and challenges and think about developing some solutions.

If you receive care at home and can't come along to an event, we hope that we can still find a way to hear your thoughts and ideas. This might involve meeting with one of our team, either in person or virtually to share your story and join in the conversation.

**If you would like to join us or to find out more about this new initiative please contact us by Friday 28<sup>th</sup> June 2024 on:**  
**Telephone - 01294 323037**  
**Email - Jenny.Preston@aapct.scot.nhs.uk**

**Dr Jenny Preston**  
 Consultant Occupational Therapist  
 and Clinical Lead Neurological  
 Rehabilitation

**Louise Kelly**  
 Senior Improvement Advisor  
 Care Inspectorate





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### Stage 2: Opening up the conversation

The conversation was started at an event in a community venue. 18 people attended. This first event set the scene for the project reflecting an ethos where all involved were experts in their own right, and each person's response would contribute to a greater understanding of the issues. This was achieved by using a café style set-up with facilitators tasked with developing conversations at small tables. This enabled a rich picture to be built up that respected the variety of views. The steering group worked to ground discussions around our common humanity and experiences.

- Each small group comprised people living with a neurological condition, care professionals and health professionals.
- Some of these care and health professionals also had experience of living with a condition themselves or had a relative who had a neurological condition which added to the richness of experience in the room.
- These small groups discussed what matters to them, what makes their hearts sing, what the small moments are that add to people's lives. This helped keep the group focused on participants living their best lives, on their own terms, rather than focusing on illness alone.
- Each group then looked at what is working well at the moment to support people living with neurological conditions to live well at home.
- Finally, the groups spent time being curious about what could be improved and discussing changes that could improve the current situation.
- The results were captured graphically and can be seen in the short video shown in Figure 3 below.



"There was a good combination of experiences to gain a balanced representation"

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### Stage 3: Determining the themes from first conversations

The steering group took the findings from Stage 2 and used the information to develop a rich thematic description of the collective views of the participants. This work resulted in four themes which were identified as follows:

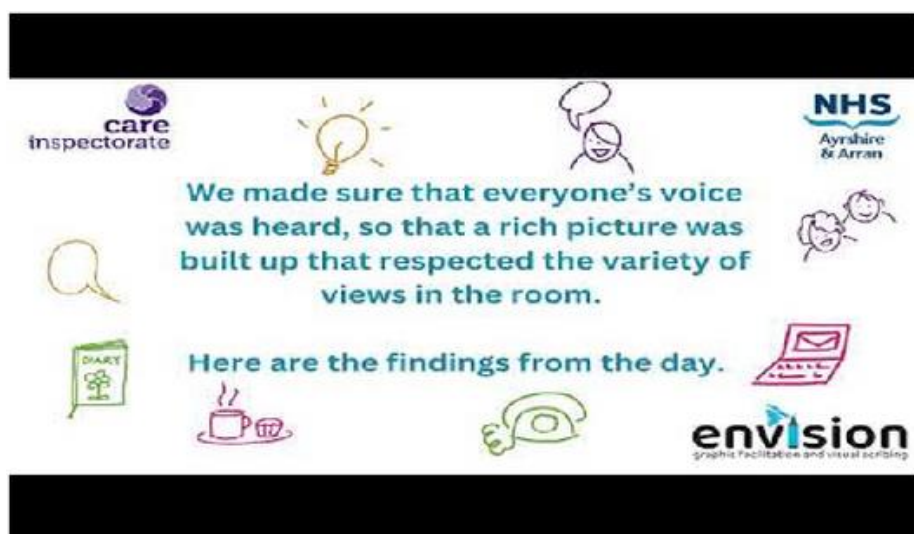
- Theme 1: Being person-centred
- Theme 2: Continuity of provision
- Theme 3: Signposting
- Theme 4: Communication



**Figure 3: Video outcome of the Stage 2 Cakes and Conversation July event**

[www.youtube.com/watch?v=ht-eejoO3KM](https://www.youtube.com/watch?v=ht-eejoO3KM)

Image from project event: session 1



### Stage 4: Deepening the conversations around each of the four themes

Two further events were held in October and November 2024. People were invited to attend either or both events, with two themes to be discussed at each. To ensure equitable access, we also offered phone or video conversations or a visit to the person's home to hear their thoughts.

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Each event followed a similar agenda, discussing what was meaningful about each of the themes in terms of supporting people with neurological conditions to live well at home. This built on and deepened the conversations about the themes as identified in Stage 3.

Key areas of concern about care and health services at home for people with neurological conditions emerged through in-depth discussions during this stage. A total of 90 individual issues were identified as a result of this, and informed the four broader, overarching themes (see Figures 4, 5, 6 and 7).

“What worked well was the valuable conversations shared between service users and professionals”



Image from project event: Dr Hannah Spring with graphic boards outlining outcomes of the final priority setting event



Image from project event: deciding priorities



Image from project event: Helen Wilson from Envision developing graphic representation of in-depth discussions

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## Results of deeper discussions of the four themes produced by Envision

Figure 4: Theme 1 - Being Person-Centred



Figure 5: Theme 2 - Continuity of Provision





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Figure 6: Theme 3 - Signposting



Figure 7: Theme 4 - Communication



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## Define Phase

### Stage 5: Developing priorities

The 90 individual issues informing these themes were then coded using principles of thematic analysis. Coding was applied to explore and derive meaning in the data which then informed the development of 18 individual statements of priority.

Each priority statement was written as an action to confirm the expectation that the new network will take practical steps to take this work forward. To maintain appropriate focus in alignment with the project, each priority statement referenced its relevance to neurological care at home. The resulting list of priorities captured the essence of the discussions during previous consultation meetings. The emergent list of priorities (in no particular order) was as follows:

- working on ways to offer a single point of contact and/or trusted faces to provide neurological care and health services to people at home
- working on ways to establish equity in provision of care and health services at home for people living with neurological conditions
- finding ways to bring together different care and health professionals to work together more effectively in providing the best care at home for people living with neurological conditions
- working on ways for computer systems to work better to support joined up care for people living at home with neurological conditions
- working on ways to help people with neurological conditions to receive the consistent and continuing care at home from care and health services that they need
- working on better processes to support people who are living at home with neurological conditions waiting for assessments or treatments to live well during this period
- establishing what training may be needed to develop and support care and health service provision for people living at home with a neurological condition

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- finding ways to overcome nervousness about General Data Protection Regulation (GDPR) restrictions to ensure it does not create barriers to service provision at home for people living with a neurological condition
- working on ways to simplify communication between services to support access to care and health services at home for people living with a neurological condition
- improving communication about referrals for people receiving care at home for a neurological condition to ensure they get to the right service and are not lost in the system
- finding ways to improve care and health professionals' systems and processes to support timely and efficient care at home for neurological conditions
- looking at what might support health and care professionals to develop confidence and communicate effectively with people who are receiving care at home for neurological conditions
- improving the ways in which information about care and health services are communicated to people receiving care at home for neurological conditions
- working with patient experience teams to hear individual voices and learn lessons from lived experience of people living at home with neurological conditions
- embedding person-centredness into all aspects of health and care at home services for people living with neurological conditions
- developing effective ways of giving and receiving feedback about care and health services at home for people with neurological conditions and communicating the outcomes
- working on ways for people with neurological conditions receiving care at home to have more control over their care by collaborating with health and care professionals
- working on better ways to embed kindness, compassion and the human touch within care and health services at home for people living with neurological conditions.

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### Stage 6: Placing the priorities in order

Participants were invited to a final event devoted to ranking the 18 priorities that emerged during Stage 5 into order of importance. It should be acknowledged that whilst all of the priorities are important, the aim of the project was to seek clarity about which priorities are considered most important for the new network to address first.

The process used during Stage 6 was informed by robust methodology developed by the James Lind Alliance (JLA). The JLA is a non-profit making initiative that brings patients, carers and clinicians together to identify and prioritise questions for research to identify what matters most to people using and providing health and care services. In this project, we used an adapted version of the JLA methodology to enable participants to ensure that the new network would be aware of the issues that matter most to the people involved.

As before, the experience was designed so that participants had the opportunity to consider and contribute to the final prioritisation exercise. We divided the participants into three small groups and provided each with a set of 18 cards. Each card had one of the priorities printed on one side of the card and the underlying information gathered from the discussions that contributed to it on the other (see Figure 8). This provided participants with a helpful reminder of the context and origin of the priority if needed. A descriptive graphic was also included on each card as a helpful prompt. The cards were printed on A4 laminate and were robust enough to pass around and place in different combinations while groups worked at tables to order and re-order them.

Participants were given time to familiarise themselves with each of the 18 individual priorities. Following this they were guided to sort the cards into three piles representing priorities they thought were the most important, less important, and least important. After doing this, the groups then worked to place the cards in each pile into priority order. This ultimately resulted in a long line of cards with the most important priority at the top, and the least important at the bottom.

Facilitators at separate tables involved everyone and kept discussions organic and interactive. Each table arrived at their order of priorities. These results were fed into a prepared spreadsheet with a ranking algorithm that took into consideration the priority order of all three groups to produce a final set.

This final list is therefore based on what the participants determined were the most important for the network to work on in the future.

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Figure 8: Sample card showing front and reverse detail

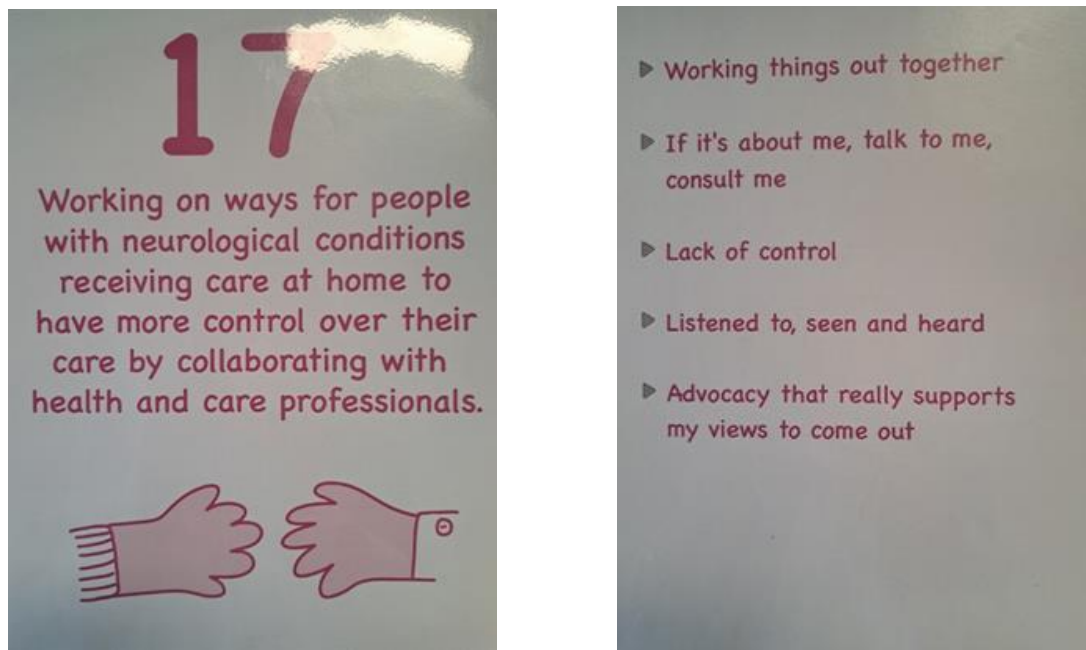


Table 1

The top four priorities for the network are:

- embedding person-centredness into all aspects of health and care at home services for people living with neurological conditions
- working on ways for people with neurological conditions receiving care at home to have more control over their care by collaborating with health and care professionals
- working on better ways to embed kindness, compassion and the human touch within care and health services at home for people living with neurological conditions
- working on ways for computer systems to work better to support joined up care for people living at home with neurological conditions.

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Pictures from the final event, where each group placed the priorities in order of importance



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### 4. Evaluation

Formative feedback was gathered at each event to seek input into what went well and what we could do to make it better for all participants. We used this as part of our project progress metrics. Summative feedback was sought from all those who participated in the project, giving a choice of paper and an online version. The quotes from this report were taken from formative and summative evaluation throughout the life of the project.

The summative evaluation sought both qualitative and quantitative feedback and was based on the Care Inspectorate's Quality Improvement Evaluation Framework. approach to evaluation (available on request), seeking information about the experiences of participants, the process followed, the project's impact and giving participants the opportunity to comment about the overall experience.

100% of those who completed evaluations either agreed or strongly agreed (chosen from a 5-point [Likert scale](#)) with the following statements.



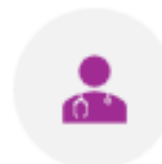
The events gave opportunities for discussion and shared learning



All participants were valued at the events



I felt engaged at any events I attended



This project created structured opportunities for care/health professionals and those accessing care at home services to learn with and from other people



All voices in the room were heard at the events



This project is helping to develop a shared understanding of how people living with neurological condition's holistic needs and outcomes are best met



People had the opportunity to share experiences and challenges at the events



The priorities we have chosen are those that are most important to work on

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### 5. What did not go so well and what we would do differently

- Initial exploration of best approaches and preparatory work to establish this network took longer than the target date in the original bid. It took time to develop a collaborative approach which would nurture, identify and increase connectedness and value for all those involved.
- It was difficult for the steering group to have time together due to conflicting work commitments and diaries.
- We did not manage to communicate with as many people with a neurological condition as we hoped. Next time, we would visit existing groups to spread word about the project and to generate interest.
- We offered diverse ways of connecting with people living with a neurological condition, for whom attending an event may not have been possible or easy. However, no-one took us up on this offer. We may not have advertised this possibility widely enough.

### 6. A breakdown of expenditure

Of the £35,000 committed to the project, £12,900 has been used to achieve the above. We are investigating if the remaining £22,100 can be used by the new network to progress the priorities.

#### Breakdown

- £4,900 : venue hire and subsistence
- £8,000 : professional fees and materials



# Ayrshire & Arran Neurological Project

## 7. Key project milestones

Table 2: Project timeline and milestones

Date	Milestone
Oct 2023	<ul style="list-style-type: none"> <li>• Funding announced</li> </ul>
Nov-Dec 2023	<ul style="list-style-type: none"> <li>• Project commences</li> <li>• Establishing a steering group</li> </ul>
Jan-June 2024	<ul style="list-style-type: none"> <li>• Stage 1</li> <li>• Design work by the steering group</li> <li>• Developing an agreed way of working</li> <li>• Designing events</li> <li>• Communicating with three groups</li> </ul>
July 2024	<ul style="list-style-type: none"> <li>• Stage 2 - Event 1</li> <li>• Opening up conversations</li> <li>• What makes our hearts sing?</li> <li>• What's working well in the provision of services for people living at home with neurological conditions?</li> <li>• What could be even better?</li> </ul>
Aug-Sept 2024	<ul style="list-style-type: none"> <li>• Stage 3</li> <li>• Development work by the steering group</li> <li>• Extracting themes from work at event 1</li> </ul>
Oct 2024	<ul style="list-style-type: none"> <li>• Stage 4 - Event 2</li> <li>• Deeper conversations</li> <li>• Investigating first 2 themes from initial network</li> </ul>
Nov 2024	<ul style="list-style-type: none"> <li>• Stage 4 - Event 3</li> <li>• Deeper conversations</li> <li>• Investigating last 2 themes from initial network</li> </ul>
Dec 2024	<ul style="list-style-type: none"> <li>• Stage 5</li> <li>• Development work by steering group</li> <li>• Analysis of conversations generated by discussion on themes</li> <li>• Developing a list of priorities to take to prioritisation event</li> </ul>
Jan 2025	<ul style="list-style-type: none"> <li>• Stage 6 - Event 4 (Final prioritisation event)</li> <li>• Three groups</li> <li>• Ordering of 18 priorities developed during previous events</li> </ul>

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**Table 3: Overview of participants**

Item	Details
Number of participants who attended events	42
Number of care professionals	16
Number of health professionals	20
Number of people experiencing care for neurological conditions	6
List of care and health professional roles who were involved.	<ul style="list-style-type: none"> <li>• Occupational therapy</li> <li>• Care worker</li> <li>• Physiotherapy</li> <li>• Care at home manager</li> <li>• Third sector representation</li> <li>• Nursing</li> <li>• Speech and language therapy</li> <li>• Care inspector</li> <li>• Care provider</li> <li>• Community brokerage Network</li> <li>• Community care manager</li> </ul>

## Ayrshire & Arran Neurological Project

### 8. Outcomes

A new neurological network has now been established in Ayrshire and Arran. An equal and reciprocal relationship between staff and people with lived experience where all contributions were recognised as valuable has successfully concluded. This democratic process has resulted in a list of authentic priorities that the new network can now focus on.



"We felt listened to and opinions were valued"

This network is comprised of people who have been involved in the project and who are committed to taking forward the top priorities as identified above.

The experience of the participants has been positive. This was identified via the formative and summative evaluation. A further positive output is the high number of those who were involved in the project who now seek to be involved in the network.



"People were enabled to talk openly..."

An unexpected outcome is that a woman living with a neurological condition told us that taking part in the project has had a profound effect on her life. She intends to continue as a member of the new network, and will come along without an advocate, which was not possible before taking part in this project. She told us that 'Being involved in the group has given me the confidence to advocate on my own behalf'. She also intends to use this new-found confidence and ability in other areas of her life.

### 9. Next steps

Now that the network has been established, it will continue to exist beyond the period of funding. This work is now subsumed into the work at NHS Ayrshire and Arran.

The network has a clear mandate to design the solution to the issues raised throughout this project. The network will develop and deliver (as per the service design approach graphic in figure 1) on the priorities that have been identified.

We anticipate that sharing this project report will foster interest with other Health and Social Care Partnerships/ Health Boards, who may wish to learn from this approach to social care and health staff co-producing better ways to work with people living with neurological conditions at home. The steering group may be able to assist at:

- webinars
- speaking at conferences and workshops
- suitable publications
- presentations to interested groups.

**Please contact:** [louise.kelly@careinspectorate.gov.scot](mailto:louise.kelly@careinspectorate.gov.scot) **or** [jennypreston@aapct.scot.nhs.uk](mailto:jennypreston@aapct.scot.nhs.uk) **for further information.** (COMMS-0225-541)