

Testing the feasibility and usability of a post-diagnostic support single quality question

June 2021

Summary

For the full report or to ask questions contact:

his.focusondementia@nhs.scot

About this report

This summary provides key findings from a test to ask people with dementia and carers a single quality question (SQQ) to determine the difference post-diagnostic support (PDS) has made to them. This was a collaboration between Focus on Dementia, Sheila Inglis (ihub Associate), Alzheimer Scotland, Inverclyde Health and Social Care Partnership and Inverclyde Dementia Reference Group. The summary includes next steps for the PDS SQQ.

Background

The PDS SQQ was designed to provide important national information about how helpful PDS has been to people with dementia and their carers with the vision of it becoming a universal question that all PDS services build into their evaluation methods. If all services can ask the same question then we have the potential to complement the national PDS data, collected by Public Health Scotland, to demonstrate the difference PDS makes to people.

The PDS SQQ test project aimed to:

- assess the feasibility and usability of a PDS SQQ to establish the experience of the service and the difference it has made to the individual
- test the process for how PDS services might use the SQQ as part of their evaluation of their services.

In total, 28 people were interviewed by phone over the course of 2 weeks in February 2021



Here's the PDS SQQ we asked (and the follow on open-ended question):

Overall, how helpful or unhelpful has the support been to you? Please circle

Very unhelpful	Quite unhelpful	Neither helpful nor unhelpful	Quite helpful	Very helpful
1	2	3	4	5

Please tell us a bit more about the option you chose: If the support from your Link Worker made a difference to you, please tell us about the difference. If the support from your Link Worker did NOT make a difference, please tell us a bit more.

Key findings:

- 28 people were interviewed over the course of 2 weeks: 15 - 26 February 2021. All respondents were interviewed by phone (due to Covid-19).
- Although the majority (86%: 24) of respondents were carers, four people with dementia participated in the test - one jointly with their carer.
- The majority (89%: 25) of people said that “overall .. the post diagnostic support for dementia” had been “very helpful”.
- 2 people (8%) said that PDS had been unhelpful - this shows that the question can elicit important negative feedback as well as positive feedback. Furthermore, no respondents ‘sat on the fence’ by saying “neither helpful nor unhelpful”.
- When asked “whether you think this question is easy to answer”, all respondents said yes.
- All respondents answered the open-ended question “please tell us a bit more about the option you chose.....” (*see quote extracts on final page*).
- The person asking the SQQ must not be the person providing the PDS to ensure an anonymous and valid response.

Recommendations:

- The ordering of the answer choices should start with ‘Helpful’.
- The Likert scale should be reduced to 3 options rather than 5 i.e. a. Helpful, b. Neither helpful nor unhelpful, c. Unhelpful.
- Interviewers should be experienced and supported e.g. through training and guidance, and have appropriate dementia knowledge and skills.
- The method of asking the question is flexible, it can be asked by telephone, face to face, by post or digitally. People said they’d like a choice.
- Consideration should be given to also asking it at an interim point and not just at the end of the support, e.g. at 6 months to be able to address anything that is not going so well rather than finding out at the end.

Feedback received as a result of asking the PDS SQQ follow on open-ended question:

The Link Worker has been incredible. She is the place to go to for everything. She has helped with so many aspects for me and my wife.

What was particularly helpful was knowing we were not alone, and support was available.

Excellent support just wish it was for longer.

She had a real human touch to her support and that it never felt like a tick box exercise. It felt to my mum that it was just two people sitting down talking.

She has helped every step of the way. I could write a book about the ways we been supported by the Link Worker.

Since lockdown she has helped get me set up with a laptop which meant that I was able to continue to meet with her through NearMe. It has also allowed me to join a 6-week programme with Vision Care and other online groups.

Having someone I could contact and speak to gave me confidence to deal with my dementia.

She was given lots of help and that helped her and the family to understand dementia better. This reduced our worry about the diagnosis.

The Link Worker helped her to stay positive and anything she found difficult she tried to help. She arranged for aids and adaptations for my mum in her home to help her stay independent. She sorted out all the finances and benefits my mum was entitled to.

Overall the test project found that the PDS SQQ and the follow-on open-ended question “did its job”, it provides the qualitative feedback that is needed. Following adoption of the recommendations, no further testing of the question is required and its use can be promoted widely.

Next steps - call to action!

We are now asking for all PDS practitioners and PDS services to adopt the following updated question and the follow on open-ended question into their evaluation methods:

Please tell us, overall, how helpful or unhelpful the support has been to you? (Tick box)

Helpful	Neither helpful nor unhelpful	Unhelpful

Please tell us a bit more about the option you chose: If the support from your Link Worker made a difference to you, please tell us about the difference. If the support from your Link Worker did NOT make a difference, please tell us a bit more.

We will keep the SQQ and its use on the PDS Leads agenda and in our network newsletter to:

- Maintain momentum of its implementation
- Continue to promote its use
- Gauge its uptake
- Gather further feedback on the outcomes of asking it, and
- Consider how the qualitative data it yields can be captured and presented nationally.

Please let Focus on Dementia know if you will adopt the question and/or if you have any queries:

his.focusondementia@nhs.scot

