

Involving unpaid carers in improving care co-ordination for people with dementia in Inverclyde

January 2023

Focus on Dementia, part of the Improvement Hub (ihub) at Healthcare Improvement Scotland, were commissioned by the Scottish Government to run the [Care Co-ordination in the Community Improvement Programme](#) on their behalf, improving access to high quality care co-ordination for people with dementia and carers in the community.

This case study shares examples of how the programme engaged with a group of carers in the implementation site of Inverclyde.



“

“Thanks to this engagement we have been able to ensure the carer perspective is heard and it has kept our work on care-coordination firmly rooted in what is important to people with dementia and those who care for them.”

Focus on Dementia

Background

Inverclyde were chosen as the dementia care co-ordination programme implementation site after an application and selection process.

The Inverclyde Dementia Care Co-ordination Programme considered the whole systems and pathway approach for people with dementia, from diagnosis to end of life. The programme aimed to:

- improve care co-ordination for people with dementia and their carers
- develop and evaluate a model of effective care co-ordination for people with dementia and their carers, and
- share learning across NHS Greater Glasgow and Clyde, Scotland and further afield.

The programme concluded in March 2022. For more information on the programme, visit the [ihub website](#).

Working with carers

The programme aimed to meaningfully engage people with dementia and their carers throughout each stage of an improvement programme journey. The programme engaged with carers at both a national and local level.

A key method of engaging with carers was through collaborating with the Inverclyde Dementia Reference Group. The Dementia Reference Group is a forum for people living with dementia and their carers “to share stories, ideas and help identify areas for improvement”.

In this impact story, we share examples of how the programme engaged with the Dementia Reference Group.



Approach

The Inverclyde Dementia Care Co-ordination Programme engaged with carers in a number of ways. Some examples are listed below.

- **Contribution to programme planning activities**

Members of the Dementia Reference Group attended an initial stakeholder event and contributed to focus groups which informed the design of the programme. As part of these activities, attendees were involved in mapping exercises and discussions to identify improvement themes to inform this work.

- **Ongoing engagement**

The team considered how to meaningfully engagement with the group during the programme. The group opted not to attend the large steering group meeting. Instead, key members of the project team attended meetings of the reference group to provide updates and consult with members.

- **Involvement in improvement activities**

Through the ongoing engagement with the Dementia Reference Group, a number of improvement projects that the group wished to contribute to were identified and actioned. Some examples of the activities the group contributed to are shown in the table below.

Project	Involvement
Development of a single quality question	Every person diagnosed with dementia is entitled to one year's post-diagnostic support (PDS). The group were involved in a national initiative to test a PDS "single quality question" to support the evaluation of PDS service provision. Inverclyde have now incorporated the single quality question as part of their PDS service. Read more about this work on the ihub website .
Dementia self-management leaflet	The group contributed to the development of a leaflet detailing support and services for people with dementia. They provided information and feedback on the development of the leaflet. The leaflet is available on the Inverclyde Council webpages .
Living Well in Dementia app	The Dementia Reference Group helped design an app to support people with dementia and their carers live well with dementia. This work is continuing beyond the timescales of the programme.

To learn more about carer's involvement in this programme, [watch this video](#) where a carer shares their experiences as part of the Dementia Reference Group contributing to the improvement programme.

Impact

Consulting and involving carers has positively impacted on the work of the programme. Below are some examples their impact.

- **Shaping the design of the improvement work**
The early involvement of carers has helped inform the overall commission of the work, and to help design a meaningful programme of work.
- **Bring new expertise and perspectives to the improvement work**
The voice of lived experience provides expertise.

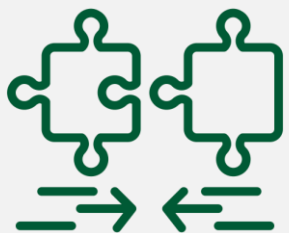
The Focus on Dementia team have identified enablers which have supported their engagement with carers. The enablers are shown here.

“

“There has been great engagement and information sharing between organisations, agencies, people with dementia and carers. This is more obvious now than before the programme.”

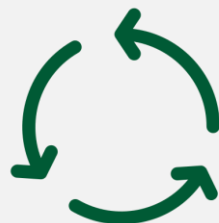
Inverclyde Dementia Reference Group

Enabler 1: Building involvement into the design



Engage with people before the commission to learn what is needed and to help design a meaningful programme of work.

Enabler 2: Continue engagement throughout the programme



Continue to engage with carers and individuals as the programme of work develops. Work to remove assumptions and ensure issues remain current.

Enabler 3: Ensure engagement is meaningful



Ask people how they want to work. For example for this work, the carers preferred not to attend the large steering group, and preferred to engage as part of their reference group meetings.

Enabler 4: Seek to understand



Continue to engage with carers and individuals as the programme of work develops. Work to remove assumptions and ensure issues remain current.

Further information



The Inverclyde Dementia Care Co-ordination Programme work has now completed. Read more about the programme on the Focus on Dementia [webpages](#). The team will continue to work with carers in their future projects.

The Unpaid Carers Improvement Programme is part of Healthcare Improvement Scotland's Improvement Hub ([ihub](#)). Visit our webpages to read more about our improvement work, including further impact stories, on our [webpages](#).

© Healthcare Improvement Scotland 2023
Published January 2023

This document is licensed under the Creative Commons Attribution-Noncommercial-NoDerivatives 4.0 International Licence. This allows for the copy and redistribution of this document as long as Healthcare Improvement Scotland is fully acknowledged and given credit. The material must not be remixed, transformed or built upon in any way. To view a copy of this licence, visit <https://creativecommons.org/licenses/by-nc-nd/4.0/>

Published January 2023

You can read and download this document from our website. We are happy to consider requests for other languages or formats. Please contact our Equality and Diversity Advisor on 0141 225 6999 or email his.contactpublicinvolvement@nhs.scot