Healthcare Improvement Scotland

Voices that matter: putting people at the centre of SIGN guidelines webinar

Leading quality health and care for Scotland

NHS SCOTLAND

What is SIGN?

The Scottish Intercollegiate Guidelines Network (SIGN) was formed in 1993. Our objective is to improve the quality of healthcare for patients in Scotland by reducing variation in practice and outcomes, through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence.

We collaborate with a network of clinicians, other health and social care professionals, patient organisations and individuals to develop evidence-based guidelines.

AGREE criteria/SIGN methodology

APPRAISAL OF GUIDELINES RESEARCH & EVALUATION

AGREE

www.agreetrust.org

- Clearly defined remit
- Developed by multidisciplinary nationally representative groups
- Patient/carers are represented
- A systematic review is undertaken to identify and critically appraise the literature
- Recommendations are explicitly linked to the supporting evidence.

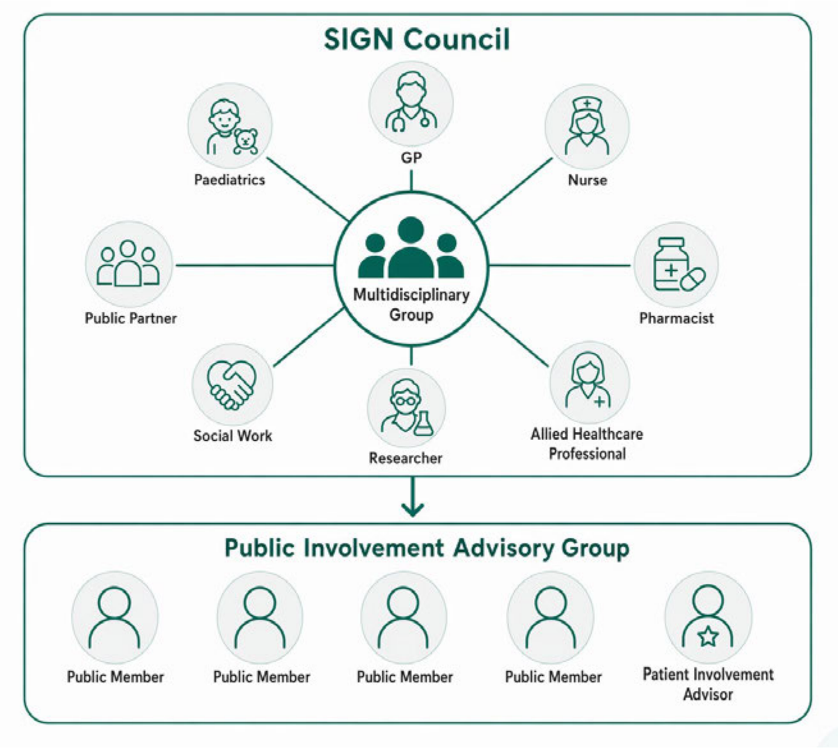
From methodology to meaningful involvement

Why lived experience, public and third sector voices matter in SIGN guideline development:

- Complements clinical and academic evidence with real-world priorities and outcomes
- Supports recommendations that are relevant, acceptable, and implementable
- Surfaces barriers, inequalities, and unintended consequences early
- Strengthens transparency, credibility, and public trust in the guideline process

Involving the public in our work

Public partners sit on SIGN Council to help set SIGN's direction.



Including the lived experience perspective in our work

- Group membership
- Involvement of third sector organisations
- Literature search to highlight equality issues
- Focus groups and workshops to discuss guideline topic and share views
- Participation in discussions about recommendations for inclusion in our guidelines
- Involving people with lived experience in peer review

Role of people with lived experience on groups

Ensuring that questions about treatment take into account issues that matter to people living with the condition

Identifying areas where people feel care could be improved

Consider how recommendations reflect the concerns of people living with the condition

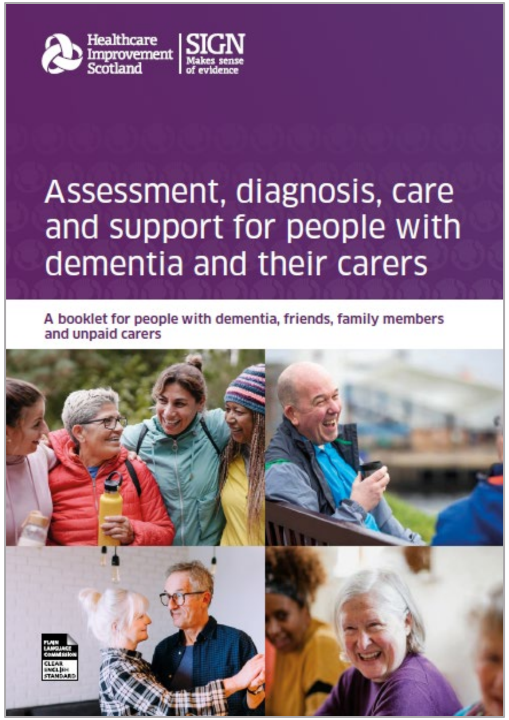
Helping to ensure that the guideline is sensitively worded

Helping to identify people to take part in the consultation process

Contributing to plain language version of guideline

Participating in dissemination activities

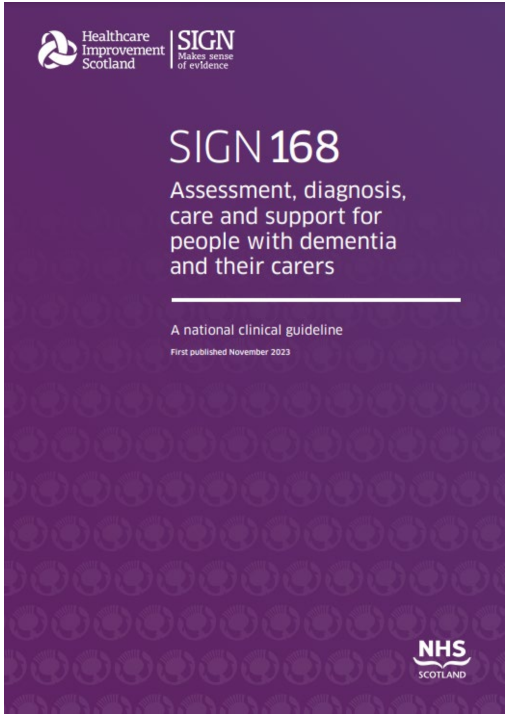
Case Example - Dementia



Healthcare Improvement Scotland | SIGN Makes sense of evidence

Assessment, diagnosis, care and support for people with dementia and their carers

A booklet for people with dementia, friends, family members and unpaid carers



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SIGN 168

Assessment, diagnosis, care and support for people with dementia and their carers

A national clinical guideline

First published November 2023

NHS SCOTLAND

Organisations we engaged with

ndcan
National Dementia Carers
Action Network

carerstrust
Scotland
action · help · advice

carers
SCOTLAND

Alzheimer
Scotland
Action on Dementia

Carer Voices

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

aboutDementia
Shaping our worlds together

life
changes
trust
Creating better lives.

the scottish
dementia
working group

tide™
together in dementia everyday

age Scotland
Love later life

MECOPP

Alzheimer's
Society
United
Against
Dementia

YoungDementia uk

Involving people with lived experience and organisations that represent them

Stage	How people were involved
Scoping/KQ setting	• Meeting with people with dementia to discuss what matters most to people • Patient organisation submissions • Consulted on KQs with third sector organisations, including equality and diversity organisations
Evidence review	• Lived experience reps assigned to KQs • Provided lived experience perspectives during discussions and contributed to considered judgement process • Developed ‘Provision of information’ section of guideline
Consultation	• Organised a consultation meeting “pre meet” to support people to participate on the day • Participation in consultation meeting • Peer review • Discussed preferences for plain language version

Involving people with lived experience at different stages of dementia guideline

“Because there were just two lived experience representatives [on the guideline development group], I am so glad that there was a variety of consultations with people living with dementia and carers throughout various stages of development, and in the final stages before publication.”

(Carer on guideline group)

From generously sharing their unique, personal experiences of living with dementia or supporting someone living with dementia to offering practical advice and guidance to ensure that the guideline is truly accessible to non-professionals, our members have been influential in the development of the guideline.

(Representative, Alzheimer's Scotland)

How patient group submissions impacted KQs for dementia guideline

Suggestions	KQ
At the time of diagnosis, where possible the person with dementia’s loved one or carer should be involved and given advice and training on how to deal with the person	When, where and how should a diagnosis of dementia be discussed and who should be involved?
Families should be seen as equal partners in care	What post diagnostic support do people with dementia and their families and carers need after dementia is diagnosed?
Impact of grief in carers and families of people with dementia	What are people with dementia, their families, carers and Health Care Professionals views and experiences of grief management approaches throughout all stages of dementia and after death?

How patient group submissions impacted KQs for dementia guideline

"I felt strongly, as did many of my National Dementia Carers Action Network fellow carers and former carers, that grief needed to be looked into at various stages, from pre diagnosis, at diagnosis, post diagnosis and during the advancing stages of the illness. I also felt that we introduced the link between guilt and grief experienced by carers, throughout the patient's journey, and after death. This changed the direction of the guideline to include a specific section on the different kinds of grief and how these might be recognised and treated."

(Carer on guideline development group)

Overcoming challenges in PPI

- Inclusive communication strategies for involving people with cognitive impairments
- Allowing carers to accompany person with dementia
- Balancing power dynamics within the group was crucial

> “Having carers on the guideline [development] group certainly enhanced the guideline and ensured their views were taken into account. There were tensions between those with lived experience and experience from clinical practice as these experiences were based on different knowledge bases. I think involving lived experience in the group may have challenged some individual's thinking which is a positive” (Representative, About Dementia, Age Scotland)

Person-centred guidance for dementia

- Issues from third sector organisations reflected in KQs
- KQs changed/added to reflect concerns of carers on guideline group
- Provision of information section changed to include issues of importance to people with dementia and carers
- Infographic in guideline on post-diagnostic support changed to reflect views of people with dementia
- Post consultation guideline updated top highlight good practice for regular Anticipatory Care Plan reviews
- Plain language versions available in various formats

Person-centred guidance for dementia

My main contribution was probably getting professionals to accept my feelings that depression is too often diagnosed when people living with dementia, their unpaid carers and family are all suffering from a form of grief—pre death or anticipatory grief from diagnosis through to death.

(Carer on guideline group)

Beyond guideline development

- Media releases
- Involvement in development of digital tools such as websites and apps based on guideline recommendations
- Community champions
- Patient organisations and networks of patients can promote the guideline and its public version
- Public awareness campaigns

Find out more

Libraryhttps://onlinelibrary.wiley.com/doi/full/10.1002/gin2.70054?msockid=1d0f73b1a1f860e72aca66a0a04361e8

https://www.sign.ac.uk/patient-public-involvement/sign-100-training/