COMFORTage CCF webinar. Analysing Patient and Caregiver Needs

POLLS RESULTS

The poll gathered insights from stakeholders regarding key issues in dementia care, revealing widespread consensus on several critical challenges and opportunities for improvement.

Delayed diagnosis is perceived as a consequence of individual hesitancy to seek early medical checks, reinforced by a general aversion to invasive tests until symptoms become severe. These behavioural barriers are seen as major obstacles to timely intervention.

There was overwhelming agreement that predicting the progression of dementia and frailty remains highly challenging, highlighting the need for improved prognostic tools and personalized care strategies. Likewise, rural-urban disparities in access to dementia services were noted, with most participants recognizing that rural areas suffer from a lack of specialists and resources.

A significant proportion of respondents acknowledged that healthcare professionals and care home staff often lack adequate training in dementia care, which affects care quality and confidence in caregiving. Moreover, the financial burden of dementia care is widely seen as underestimated and insufficiently supported, placing further strain on families and care systems.

While support groups are generally available, many respondents noted that carers frequently experience stress and burnout, suggesting that these supports fall short without sufficient mental health services and structured well-being interventions.

Participants expressed concern that public health campaigns, despite improving awareness and reducing stigma, do not sufficiently promote prevention through modifiable risk factors. There was also agreement that current dementia care in many countries is limited to monitoring and medication, lacking comprehensive and individualized support.

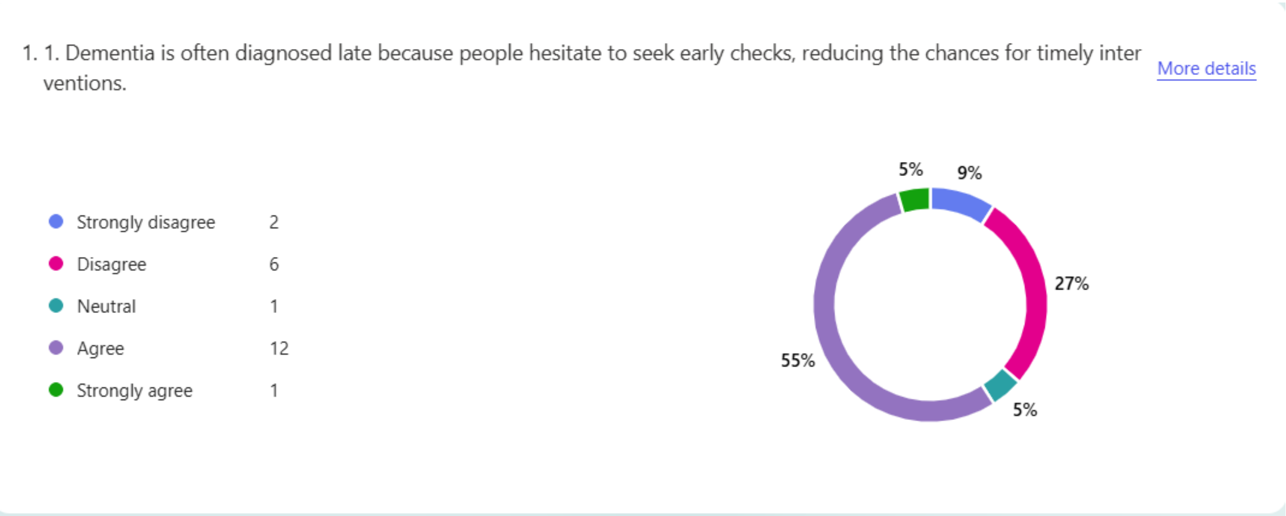
Coordination failures between clinical and social care services were also flagged as a major systemic weakness, underlining the need for integrated approaches. On a more hopeful note, strong support was expressed for empowering caregivers through education, community networks, and citizen science—with many seeing caregivers as active contributors to both real-world data and policy change.

There was near-universal agreement that people with dementia face difficulties in using digital tools, calling for more inclusive design and caregiver support. Similarly, respondents highlighted the challenge of balancing independence with safety, emphasizing the ethical tensions in caregiving.

Respondents were broadly optimistic about the role of AI in tracking behavioural changes and supporting caregivers, while also stressing the importance of responsible, user-friendly implementation. Finally, the importance of addressing patients’ dependency needs while upholding their dignity and freedom was emphasized as a foundational value in quality dementia care.

Dementia is often diagnosed late because people hesitate to seek early checks, reducing the chances for timely interventions.

22 responses



1. 1. Dementia is often diagnosed late because people hesitate to seek early checks, reducing the chances for timely interventions.

More details

●	Strongly disagree	2
●	Disagree	6
●	Neutral	1
●	Agree	12
●	Strongly agree	1

The statement, *"Dementia is often diagnosed late because people hesitate to seek early checks, reducing the chances for timely interventions,"* received 22 responses, offering insight into perceptions surrounding early dementia diagnosis.

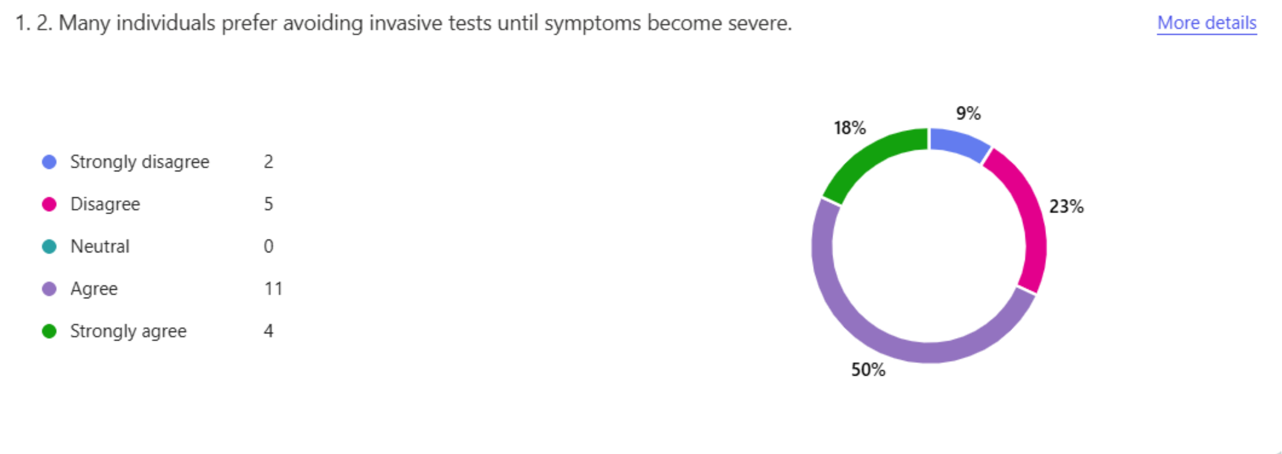
The majority of respondents (55%) agreed with the statement, indicating a shared belief that delayed diagnosis is largely due to reluctance in seeking early medical evaluation. This suggests an awareness of the behavioural and psychological barriers individuals face, such as fear, stigma, or denial, which hinder timely action. Additionally, 27% of participants disagreed, which could reflect either confidence in current diagnostic practices or a belief that other factors—such as systemic inefficiencies or lack of access—may play a more prominent role in delayed diagnoses.

Smaller groups of respondents held more polarized views: 9% strongly disagreed, and 5% strongly agreed. These outlier positions show that while the general consensus leans toward recognizing hesitation as a key issue, there is some divergence in opinion. Only one person selected a neutral response, highlighting that most respondents have a clear stance on this issue.

Overall, the responses indicate a prevalent concern that individual behaviour significantly impacts the timeliness of dementia diagnosis, underscoring the need for more effective public education, destigmatization efforts, and accessible screening campaigns.

Many individuals prefer avoiding invasive tests until symptoms become severe.

22 responses



1. 2. Many individuals prefer avoiding invasive tests until symptoms become severe.

More details

●	Strongly disagree	2
●	Disagree	5
●	Neutral	0
●	Agree	11
●	Strongly agree	4

The statement, *"Many individuals prefer avoiding invasive tests until symptoms become severe,"* also received 22 responses and illustrates prevailing attitudes towards diagnostic procedures.

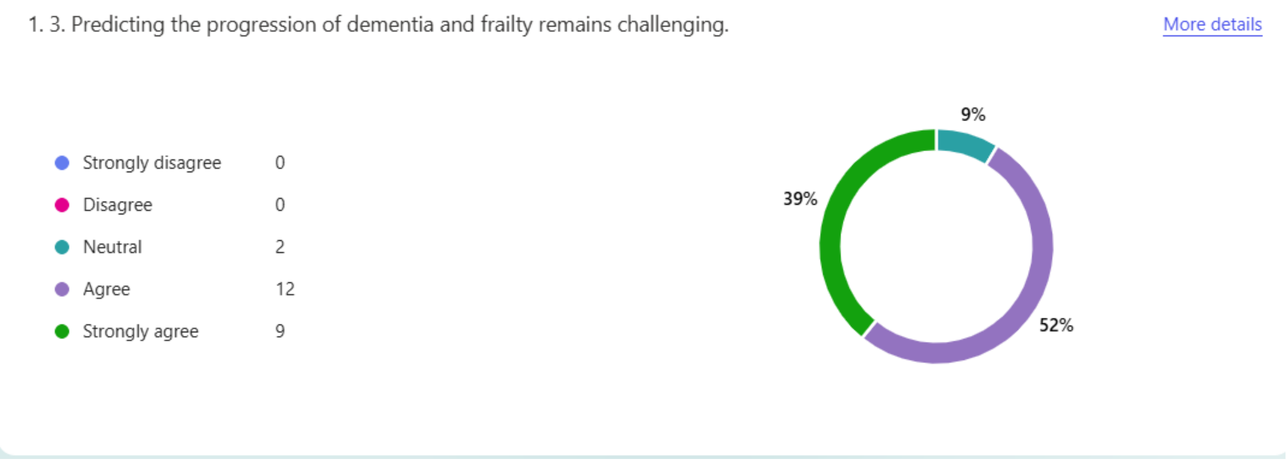
Half of the respondents (50%) agreed with the statement, and an additional 18% strongly agreed, showing that a significant majority perceive a general reluctance among individuals to undergo invasive medical testing in the early stages of cognitive or health concerns. This reflects a common apprehension related to discomfort, fear of results, or mistrust in medical interventions, which can delay early detection and timely treatment, particularly in conditions like dementia or frailty.

Conversely, 23% of respondents disagreed and 9% strongly disagreed, suggesting that a notable minority believes this hesitation is either overstated or not representative of the broader population.

Overall, the results underscore a trend where invasive diagnostic approaches may be perceived as barriers rather than enablers of early intervention, reinforcing the need to promote less intrusive screening options, increase public understanding of diagnostic benefits, and reduce fear surrounding testing procedures.

Predicting the progression of dementia and frailty remains challenging.

23 responses



1. 3. Predicting the progression of dementia and frailty remains challenging.

● Strongly disagree	0
● Disagree	0
● Neutral	2
● Agree	12
● Strongly agree	9

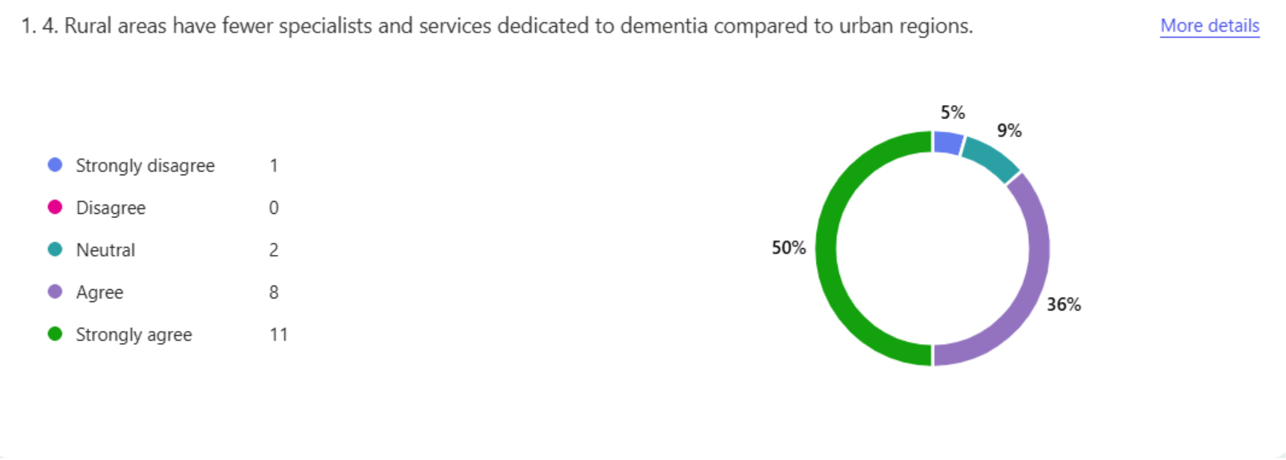
The statement, *"Predicting the progression of dementia and frailty remains challenging,"* elicited 23 responses and revealed a strong consensus on the complexity of forecasting these conditions.

More than half of the respondents (52%) agreed, and 39% strongly agreed, illustrating that 91% of participants acknowledge the difficulty in accurately anticipating how dementia and frailty will develop over time. This reflects the widespread understanding that despite advances in diagnostics and data analytics, the trajectory of such conditions is still influenced by numerous unpredictable factors including comorbidities, individual variability, and environmental influences.

Only two participants (9%) selected a neutral position, and notably, no one disagreed or strongly disagreed with the statement. The unanimity of agreement reinforces the urgency for further research and innovation in predictive tools, suggesting that enhancing early detection and individualised care planning remains a shared priority among stakeholders.

Rural areas have fewer specialists and services dedicated to dementia compared to urban regions.

22 responses



1. 4. Rural areas have fewer specialists and services dedicated to dementia compared to urban regions.

● Strongly disagree	1
● Disagree	0
● Neutral	2
● Agree	8
● Strongly agree	11

The statement, *"Rural areas have fewer specialists and services dedicated to dementia compared to urban regions,"* received 22 responses and highlights a widely recognized disparity in healthcare accessibility.

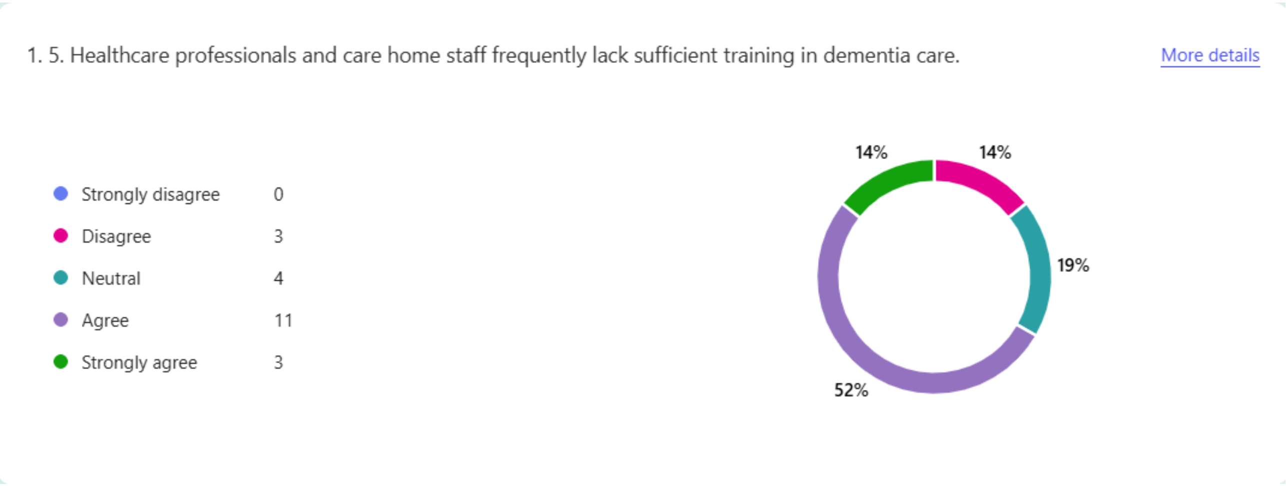
Half of the respondents (50%) strongly agreed and 36% agreed, revealing that 86% of participants believe rural regions are significantly underserved when it comes to dementia-specific services and specialist care. This indicates a strong awareness of geographical inequities that can hinder early diagnosis, treatment, and ongoing support for people living with dementia in non-urban areas.

Only one respondent strongly disagreed with the statement, and two selected a neutral stance, suggesting that while a small minority may perceive more balanced access or may not have sufficient experience to judge, the overwhelming consensus affirms a systemic gap in service distribution.

The responses underline the necessity for targeted policies and investment to strengthen rural health infrastructure, deploy mobile or digital health solutions, and ensure equitable care delivery across regions.

Healthcare professionals and care home staff frequently lack sufficient training in dementia care.

21 responses



1. 5. Healthcare professionals and care home staff frequently lack sufficient training in dementia care.

● Strongly disagree	0
● Disagree	3
● Neutral	4
● Agree	11
● Strongly agree	3

The statement, *"Healthcare professionals and care home staff frequently lack sufficient training in dementia care,"* was answered by 21 participants and reveals a prevalent concern regarding workforce preparedness in this area.

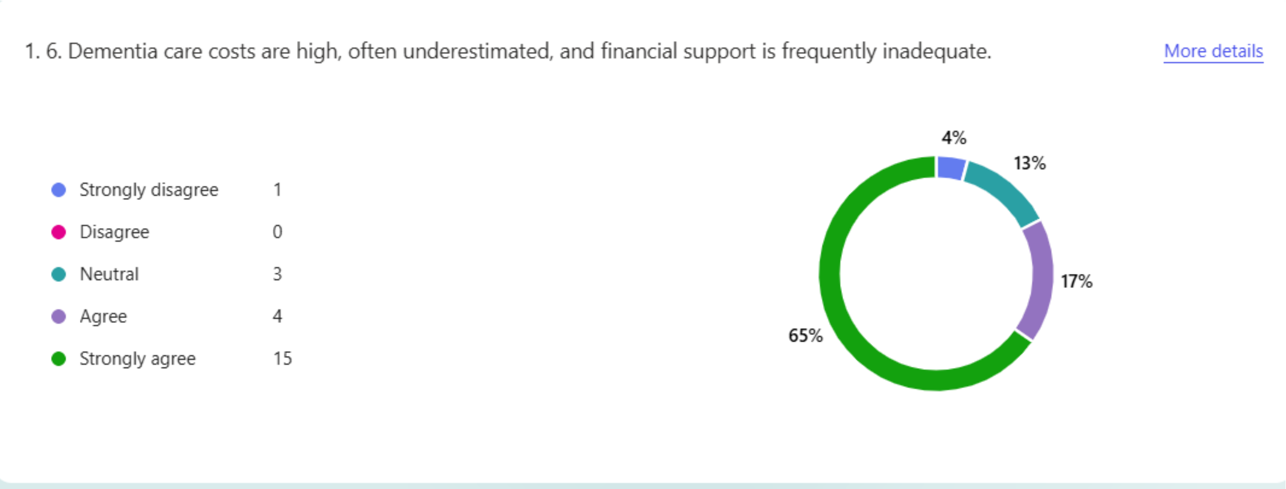
A majority of respondents, 52% agreeing and 14% strongly agreeing, indicate that two-thirds of participants perceive a notable training gap among those responsible for dementia care. This consensus points to a widespread recognition that current education and professional development programs may not adequately equip healthcare providers or care home staff to address the complex needs of people living with dementia.

However, 19% of respondents selected a neutral position, and 14% disagreed, suggesting that while most see a need for improvement, some participants either have observed satisfactory levels of training or feel the issue varies significantly across institutions or regions.

Overall, the responses suggest an urgent need to strengthen and standardize dementia-specific training across care settings to ensure quality, person-centred support and to reduce the emotional and practical burden on both staff and families.

Dementia care costs are high, often underestimated, and financial support is frequently inadequate.

23 responses



1. 6. Dementia care costs are high, often underestimated, and financial support is frequently inadequate.

● Strongly disagree	1
● Disagree	0
● Neutral	3
● Agree	4
● Strongly agree	15

The statement, *"Dementia care costs are high, often underestimated, and financial support is frequently inadequate,"* received 23 responses and strongly reflects the economic concerns tied to dementia care.

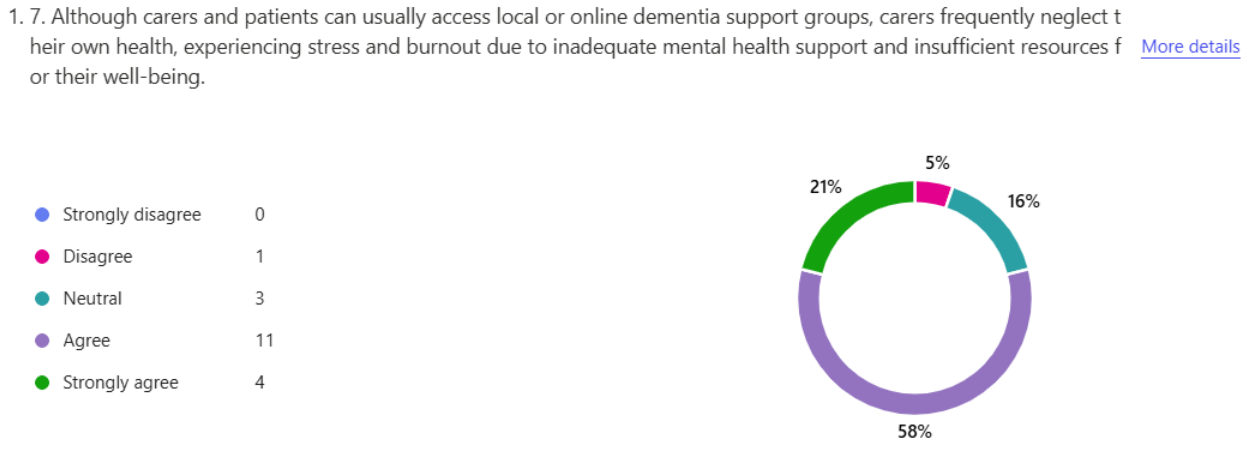
An overwhelming 65% of respondents strongly agreed, and an additional 17% agreed, indicating that over 80% of participants recognize the significant financial burden associated with dementia. This consensus underlines the common experience or awareness that the real costs—encompassing medical treatment, long-term care, and informal caregiving—are often underestimated, both by families and policymakers.

Only one participant strongly disagreed, and three chose a neutral stance, suggesting limited dissent or uncertainty about the issue.

Overall, the data clearly convey that cost is perceived as a major barrier to quality dementia care, pointing to the need for enhanced financial support systems, greater public funding, and policies that better account for the long-term economic implications of dementia on families and health systems.

Although carers and patients can usually access local or online dementia support groups, carers frequently neglect their own health, experiencing stress and burnout due to inadequate mental health support and insufficient resources for their well-being.

19 responses



1. 7. Although carers and patients can usually access local or online dementia support groups, carers frequently neglect their own health, experiencing stress and burnout due to inadequate mental health support and insufficient resources for their well-being.

● Strongly disagree	0
● Disagree	1
● Neutral	3
● Agree	11
● Strongly agree	4

The statement, *"Although carers and patients can usually access local or online dementia support groups, carers frequently neglect their own health, experiencing stress and burnout due to inadequate mental health support and insufficient resources for their well-being,"* was answered by 19 participants and highlights the emotional and psychological toll of caregiving.

A strong majority—58% agreeing and 21% strongly agreeing—affirm that while support groups are generally accessible, these alone are not sufficient to address the deeper mental health needs of carers.

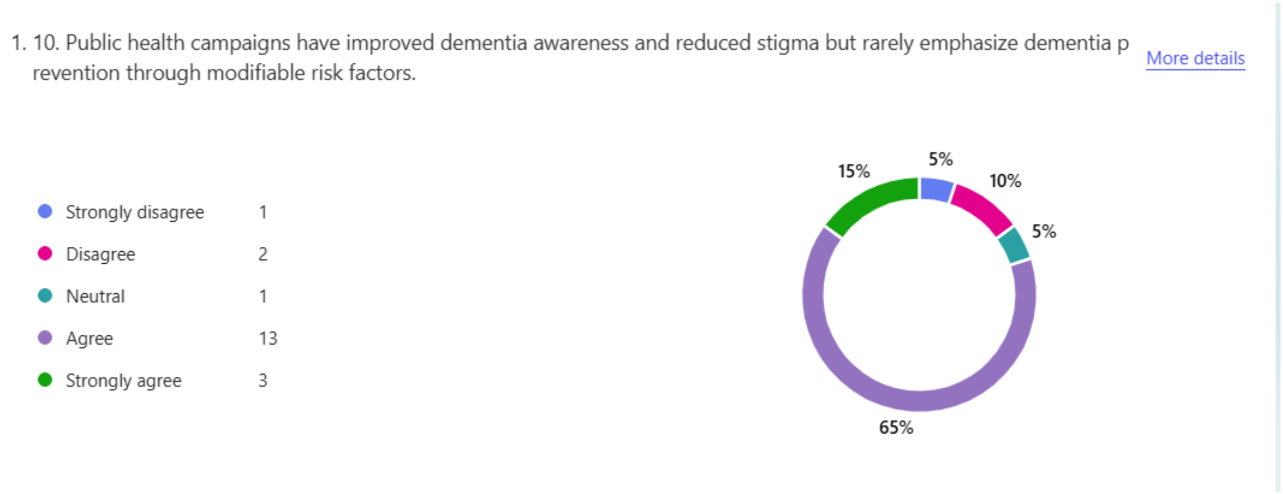
The responses indicate that most participants recognize a gap between the availability of basic support networks and the actual resources required to safeguard caregivers' health and resilience.

Three respondents (16%) remained neutral, and only one person disagreed, showing that disagreement is minimal and the consensus is clear: caregiver burnout remains a major and under-addressed issue in dementia care systems.

This response pattern suggests that there is a pressing need to complement informational and peer-based support with structured psychological, emotional, and respite interventions tailored specifically to carers' well-being.

Public health campaigns have improved dementia awareness and reduced stigma but rarely emphasize dementia prevention through modifiable risk factors.

20 responses



1. 10. Public health campaigns have improved dementia awareness and reduced stigma but rarely emphasize dementia p
revention through modifiable risk factors.

More details

●	Strongly disagree	1
●	Disagree	2
●	Neutral	1
●	Agree	13
●	Strongly agree	3

The statement, *"Public health campaigns have improved dementia awareness and reduced stigma but rarely emphasize dementia prevention through modifiable risk factors,"* garnered 20 responses and highlights a critical gap in current public health messaging.

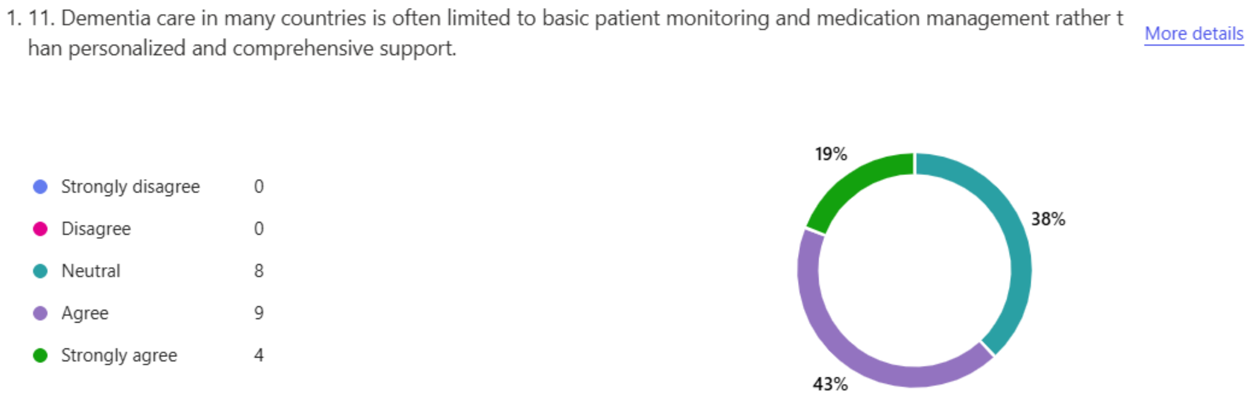
A majority of respondents—65% agreeing and 15% strongly agreeing—support the view that while awareness and destigmatization efforts have made progress, they often fall short in promoting prevention strategies related to lifestyle and other modifiable factors. This consensus points to a missed opportunity in public health communication to empower individuals with actionable knowledge for reducing dementia risk.

A small portion of respondents—5% strongly disagreed, 10% disagreed, and 5% remained neutral—suggests that some participants either view prevention messaging as more present than described or have differing experiences with public health campaigns.

Overall, the responses indicate strong support for enhancing educational outreach that goes beyond awareness to actively promote risk reduction, such as through cardiovascular health, nutrition, cognitive engagement, and physical activity, aligning dementia prevention with broader health promotion goals.

Dementia care in many countries is often limited to basic patient monitoring and medication management rather than personalized and comprehensive support.

21 responses



1. 11. Dementia care in many countries is often limited to basic patient monitoring and medication management rather than personalized and comprehensive support.

● Strongly disagree	0
● Disagree	0
● Neutral	8
● Agree	9
● Strongly agree	4

The statement, *"Dementia care in many countries is often limited to basic patient monitoring and medication management rather than personalized and comprehensive support,"* received 21 responses and sheds light on the perceived limitations of current care models.

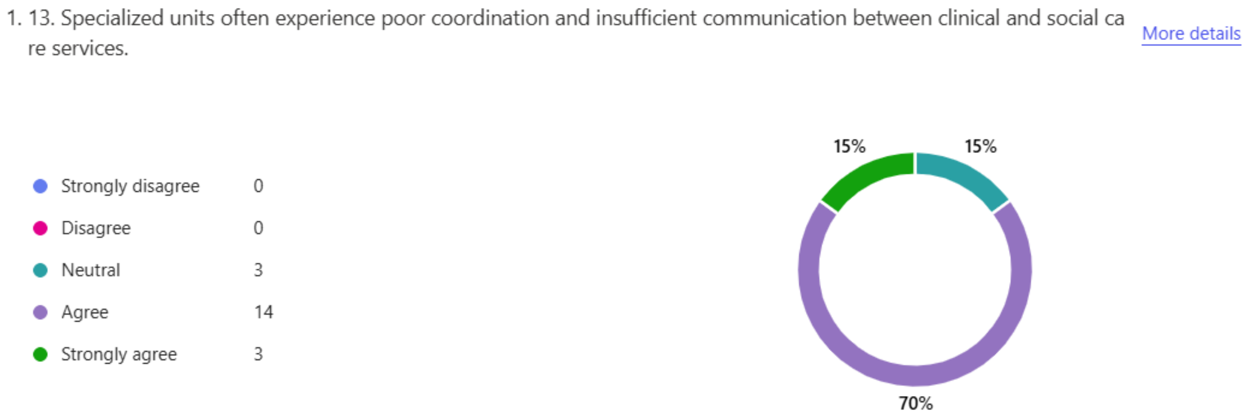
A combined 62% of respondents (43% agreeing and 19% strongly agreeing) affirmed that dementia care frequently falls short of offering holistic, tailored support to individuals. This suggests a general concern that care systems prioritize routine clinical management over individualized approaches that consider emotional, social, and lifestyle dimensions of the condition.

Interestingly, 38% of participants selected a neutral stance, indicating either uncertainty, diverse experiences across countries, or recognition of emerging but uneven improvements in care practices. Notably, no one disagreed with the statement.

The results point to a shared desire for more comprehensive, person-centred dementia care models that integrate support services, community engagement, and personalized intervention plans—beyond the clinical framework of monitoring and medication.

Specialized units often experience poor coordination and insufficient communication between clinical and social care services.

20 responses


1. 13. Specialized units often experience poor coordination and insufficient communication between clinical and social care services.

● Strongly disagree	0
● Disagree	0
● Neutral	3
● Agree	14
● Strongly agree	3

The statement, *"Specialized units often experience poor coordination and insufficient communication between clinical and social care services,"* received 20 responses and highlights a widely perceived weakness in the integration of dementia care systems.

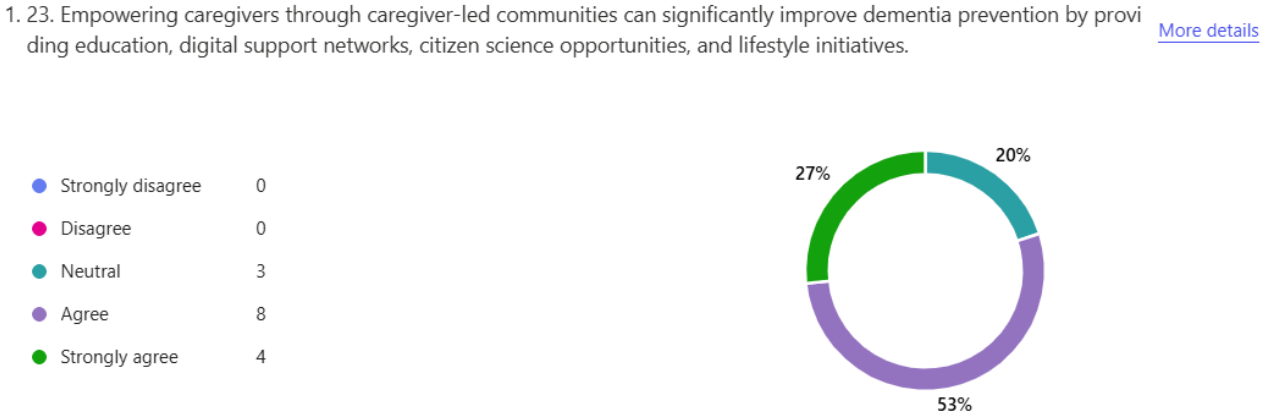
A strong majority of respondents—70% agreeing and 15% strongly agreeing—emphasized that communication and collaboration between medical and social care providers are frequently inadequate. This widespread agreement reflects concerns about fragmented care pathways, delays in service delivery, and missed opportunities for holistic support for individuals with dementia.

Only 15% of participants selected a neutral stance, and none disagreed, which suggests near-universal acknowledgment of coordination challenges in specialized dementia care settings.

These findings underline the urgent need for improved care integration strategies, such as shared information systems, interprofessional training, and more structured communication protocols, to ensure continuity and effectiveness in dementia care across sectors.

Empowering caregivers through caregiver-led communities can significantly improve dementia prevention by providing education, digital support networks, citizen science opportunities, and lifestyle initiatives.

15 responses



1. 23. Empowering caregivers through caregiver-led communities can significantly improve dementia prevention by providing education, digital support networks, citizen science opportunities, and lifestyle initiatives.

● Strongly disagree	0
● Disagree	0
● Neutral	3
● Agree	8
● Strongly agree	4

The statement, *"Empowering caregivers through caregiver-led communities can significantly improve dementia prevention by providing education, digital support networks, citizen science opportunities, and lifestyle initiatives,"* received 15 responses and reveals a largely positive outlook on the role of caregiver involvement in proactive dementia strategies.

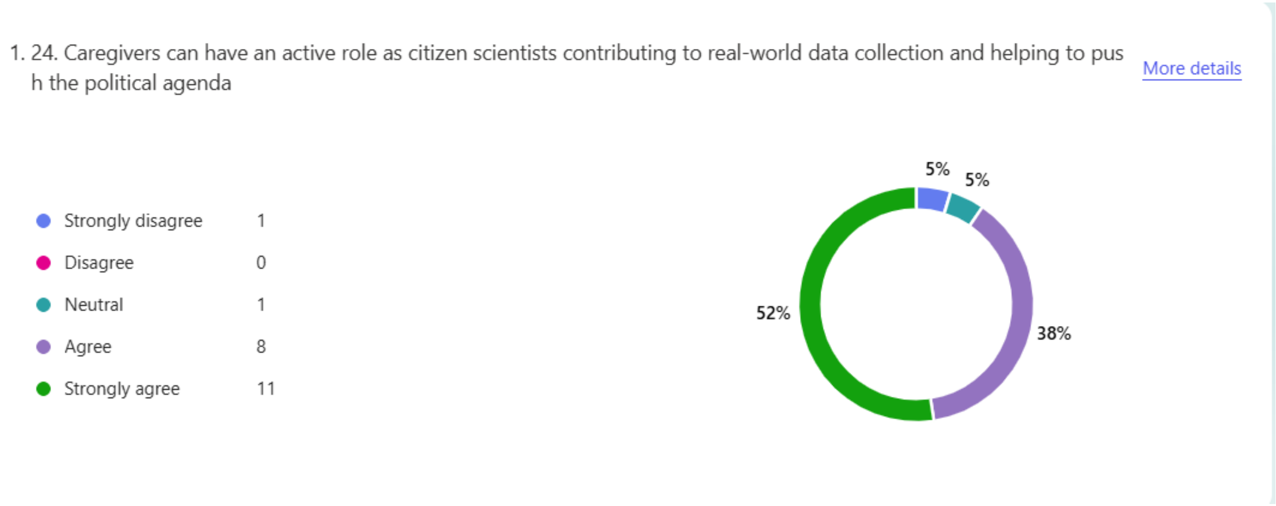
A total of 80% of respondents expressed agreement, with 53% agreeing and 27% strongly agreeing. This strong support reflects confidence in the potential of grassroots, community-driven approaches to enhance both preventative action and overall care ecosystems. Respondents recognize caregivers not just as care providers, but as valuable contributors to public health, innovation, and policy through active engagement in education and participatory research.

Three participants (20%) selected a neutral position, and notably, no one disagreed or strongly disagreed. This suggests that while some may be unsure about the feasibility or impact of these initiatives, the overall sentiment strongly favors empowering caregivers as a strategy to boost dementia prevention and systemic responsiveness.

The findings point to broad support for integrating caregivers more formally into dementia care planning and innovation, emphasizing the importance of education, tech-enabled support, and collaborative models of care.

Caregivers can have an active role as citizen scientists contributing to real-world data collection and helping to push the political agenda

21 responses



1. 24. Caregivers can have an active role as citizen scientists contributing to real-world data collection and helping to push the political agenda

● Strongly disagree	1
● Disagree	0
● Neutral	1
● Agree	8
● Strongly agree	11

The statement, *"Caregivers can have an active role as citizen scientists contributing to real-world data collection and helping to push the political agenda,"* was answered by 21 participants and reflects strong support for engaging caregivers in research and advocacy efforts.

A majority of respondents—52% strongly agreeing and 38% agreeing—support the idea that caregivers hold valuable experiential knowledge that can meaningfully contribute to scientific understanding and influence health policy. This 90% agreement underscores the recognition of caregivers as active stakeholders, not only in care provision but also in shaping dementia-related data ecosystems and societal priorities.

Only one respondent selected a neutral stance and one strongly disagreed, suggesting minimal skepticism about this participatory approach.

Overall, the responses highlight enthusiasm for inclusive models of data generation and advocacy, positioning caregivers as empowered agents capable of driving change and contributing to evidence-based, people-centred dementia strategies.

Learning to use new digital tools is not easy for people affected by dementia or other cognitive impairments.

17 responses

1. 25. Learning to use new digital tools is not easy for people affected by dementia or other cognitive impairments.

● Strongly disagree	1
● Disagree	0
● Neutral	0
● Agree	8
● Strongly agree	8

The statement, *"Learning to use new digital tools is not easy for people affected by dementia or other cognitive impairments,"* received 17 responses and reveals strong agreement with the difficulties faced by this population in adapting to technological solutions.

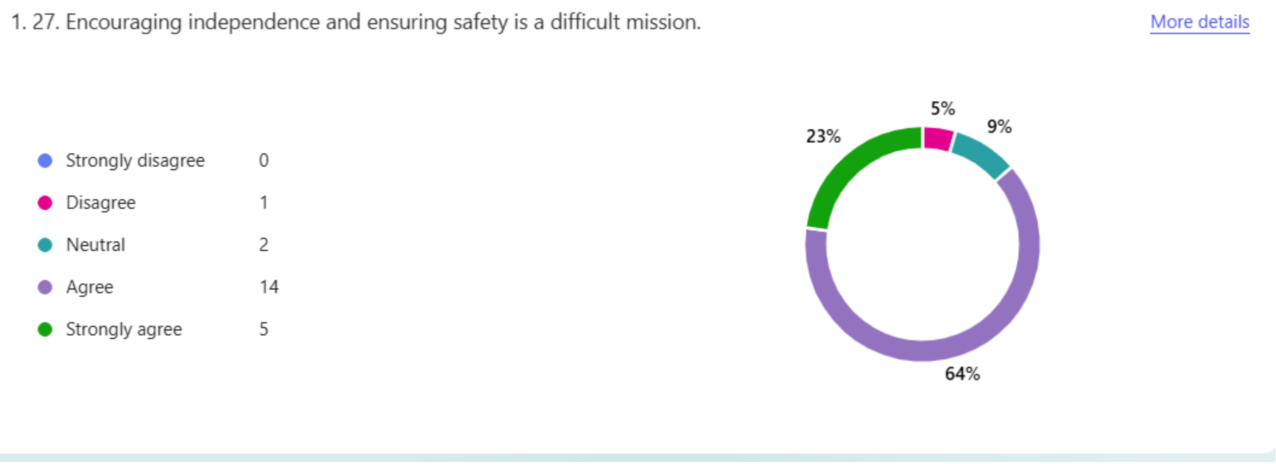
Nearly all respondents acknowledged these challenges, with 47% agreeing and another 47% strongly agreeing. This high level of consensus—94% overall—indicates broad recognition of the cognitive, emotional, and practical barriers that digital platforms can present for individuals with dementia or similar impairments.

Only one participant (6%) strongly disagreed, and no one selected a neutral or standard disagreement option, suggesting that contrary opinions are rare and the perception of difficulty is nearly universal.

The results emphasize the importance of designing inclusive, user-friendly digital tools tailored to the needs and limitations of people with cognitive impairments. It also highlights the value of supportive environments, caregiver assistance, and digital literacy training as essential components of any technology-based solution in dementia care.

Encouraging independence and ensuring safety is a difficult mission.

22 responses



1. 27. Encouraging independence and ensuring safety is a difficult mission.

● Strongly disagree	0
● Disagree	1
● Neutral	2
● Agree	14
● Strongly agree	5

The statement, *"Encouraging independence and ensuring safety is a difficult mission,"* received 22 responses and clearly resonates with the majority of participants as a key challenge in dementia care.

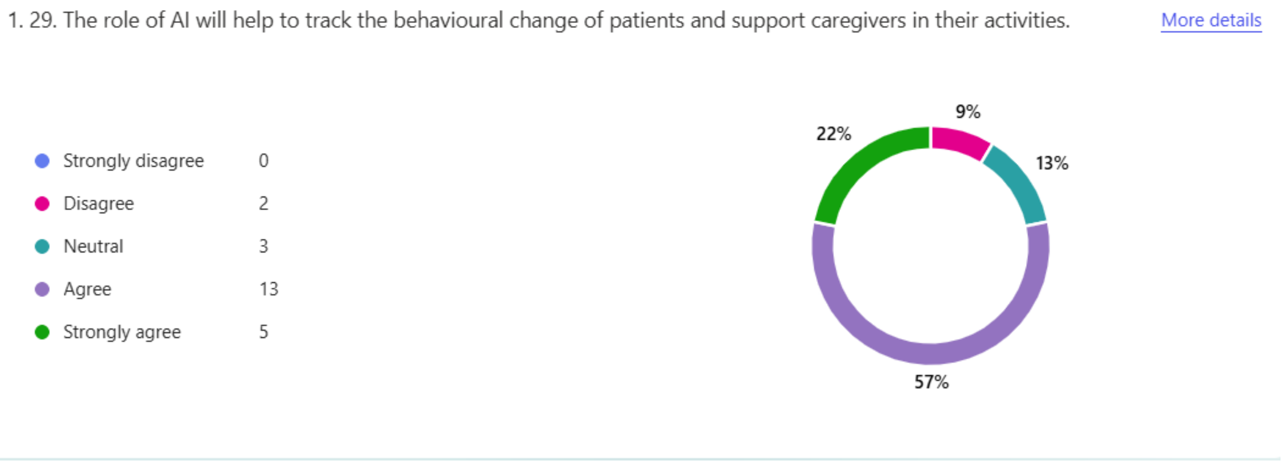
A significant 64% of respondents agreed, and 23% strongly agreed, illustrating that 87% acknowledge the inherent tension between promoting autonomy and maintaining safety for individuals with dementia or similar conditions. This reflects a widespread understanding of the ethical and practical complexities that caregivers and professionals face when balancing dignity, freedom, and protection.

Only two respondents (9%) selected a neutral stance, and one disagreed (5%), indicating minimal opposition and a strong collective agreement on the issue.

These results highlight the need for supportive tools, flexible care strategies, and ethical guidelines that can help caregivers and professionals navigate this delicate balance—respecting patients' independence while minimizing risk and vulnerability.

The role of AI will help to track the behavioural change of patients and support caregivers in their activities.

23 responses



1. 29. The role of AI will help to track the behavioural change of patients and support caregivers in their activities.

● Strongly disagree	0
● Disagree	2
● Neutral	3
● Agree	13
● Strongly agree	5

The statement, *"The role of AI will help to track the behavioural change of patients and support caregivers in their activities,"* received 23 responses and shows a strong level of optimism about the potential of artificial intelligence in dementia care.

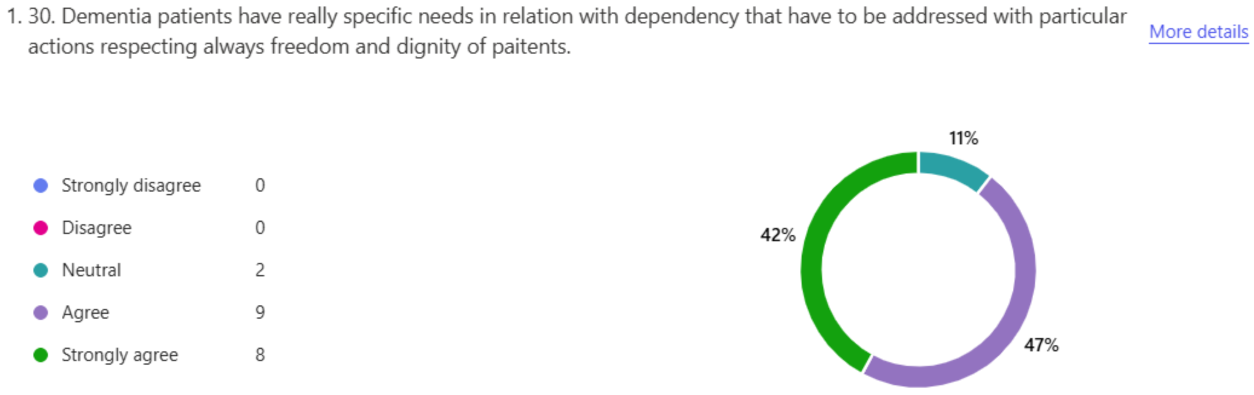
A majority of participants—57% agreeing and 22% strongly agreeing—expressed confidence in AI's capacity to monitor patient behaviour and ease the burden on caregivers. This 79% positive response rate reflects broad support for AI as a valuable tool in enhancing care quality, detecting early changes, and streamlining caregiving tasks.

A smaller group, 13%, selected neutral, possibly reflecting uncertainty or a need for more evidence, while only 9% (2 participants) disagreed, and none strongly disagreed.

Overall, the data indicate a forward-looking perspective, with most respondents viewing AI as a beneficial innovation for personalized and proactive dementia care, provided it is implemented ethically and with attention to usability and trust.

Dementia patients have really specific needs in relation with dependency that have to be addressed with particular actions respecting always freedom and dignity of patients.

19 responses



1. 30. Dementia patients have really specific needs in relation with dependency that have to be addressed with particular actions respecting always freedom and dignity of paitents.

More details

● Strongly disagree	0
● Disagree	0
● Neutral	2
● Agree	9
● Strongly agree	8

The statement, *"Dementia patients have really specific needs in relation with dependency that have to be addressed with particular actions respecting always freedom and dignity of patients,"* gathered 19 responses and reflects a strong ethical consensus.

A vast majority of respondents—47% agreeing and 42% strongly agreeing—affirm the importance of balancing dependency-related care with respect for the autonomy and dignity of individuals living with dementia. This 89% agreement highlights a shared understanding that quality dementia care must not only meet practical needs but also uphold patients' rights and humanity.

Only two participants (11%) selected a neutral response, and none disagreed, indicating near-unanimous recognition of this principle as foundational to compassionate and effective dementia support.

These results underscore the value placed on dignity-preserving care strategies and point to a collective commitment among stakeholders to ensure that dependency does not equate to disempowerment in care practices.