

## **Alzheimer's Society online survey and actions taken for 'Measuring the Experience of People with Dementia': people affected by dementia**

### **Introduction**

Work on this resource began in late 2018 with desktop review of the findings of Department of Health and Social Care round-table events with around 100 commissioners, provider organisations and people affected by dementia in late 2017. Those events had recommended the creation of a resource about measuring the experience of people with dementia.

Two surveys were then undertaken in December 2018, one for commissioners, regulators and providers of health and care services, and one for people affected by dementia.

This survey opportunity was shared through Alzheimer's Society local services teams, the 3 Nations Dementia Working Group and attendees of Department of Health and Social Care round-table events in 2017.

This document provides summary highlights of what people said in the survey for people affected by dementia– and notes about action taken to respond to what people said.

Through the survey several people asked to stay involved in the development of the resource and are continuing to contribute to its development. More people with dementia, and carers, have become involved too, including people with rare types of dementia, and people not in involvement groups/networks.

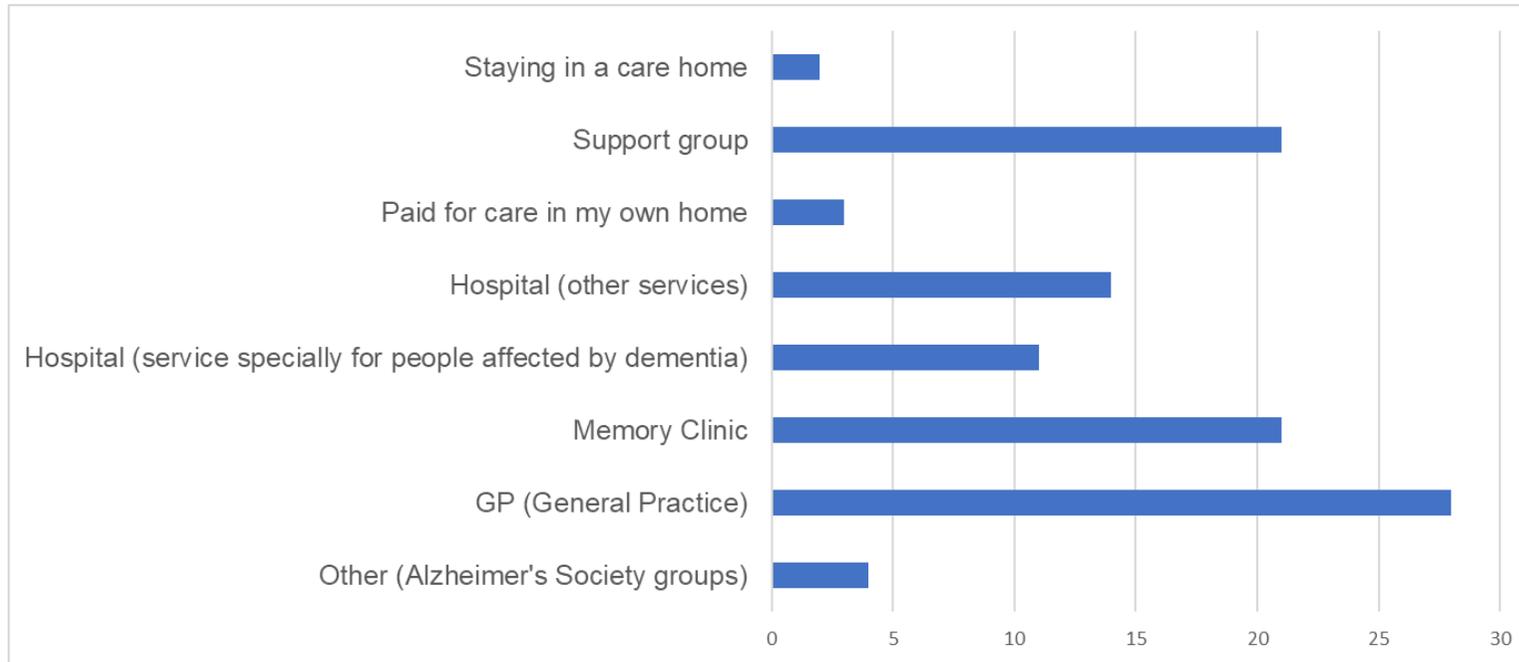
### **Who were the 30 survey respondents to this survey?**

25 people living with dementia (some with current or past experience of being carers too)

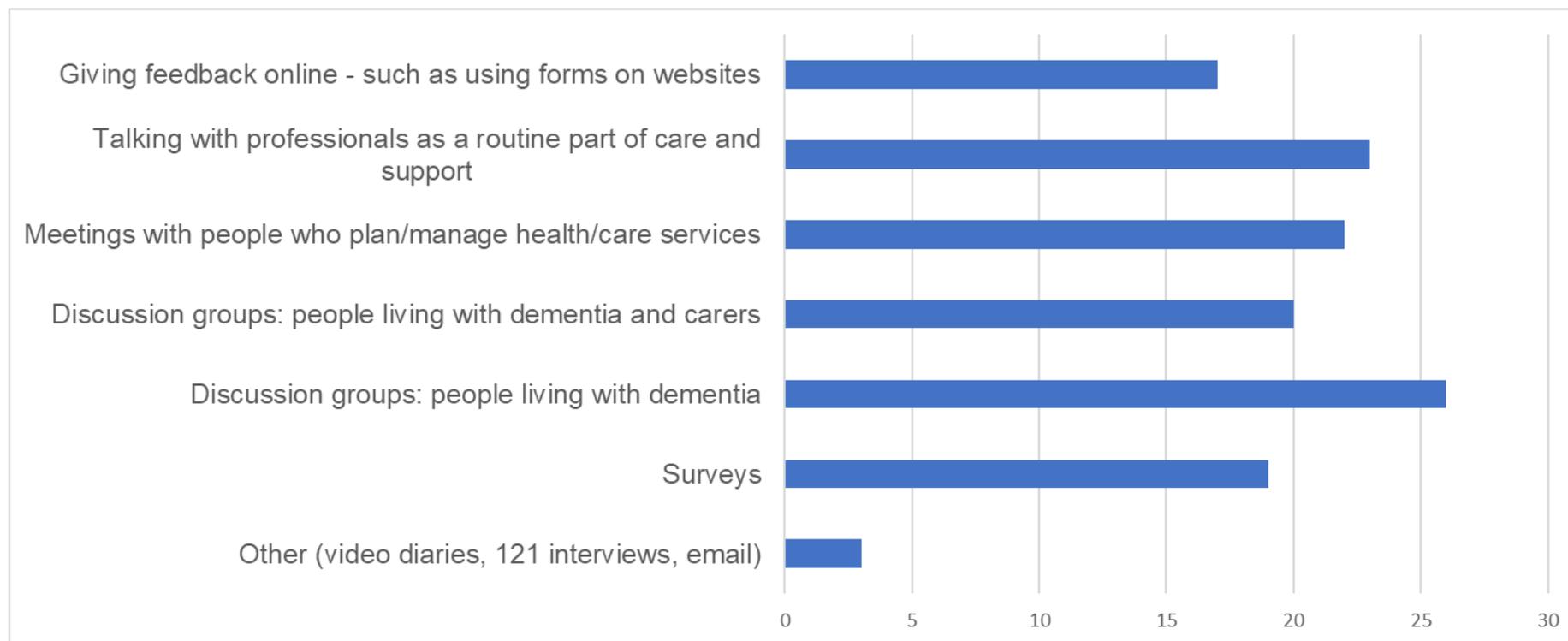
5 current carers

2 past carers

## What services had the respondents experienced as service users?



## How people who completed our survey would like to give feedback about health and care services



### Top tips for services suggested in the survey (now being tested with other people with dementia and carers)

‘Involve people with Dementia when health and social care services are being planned or commissioned. Commissioners in particular need to hear the Dementia voice.’

‘Talk to us don’t assume we can’t give any input.’

‘It is more about how we feel about the services, not just the nuts and bolts.’

‘Acknowledgement to always be given that each person is the main specialist of their own dementia. No other knows how that person feels/experiences their condition.’

‘Just ask – if you don’t ask, we can’t answer. Patience - give us time, to think, and to answer. Look for solution-based responses.’

## Free comment in the survey – grouped by emergent theme

Feedback theme	
<p><b>Current practice is leading to missed opportunities to learn from experience and improve value and effectiveness of services</b></p>	<ul style="list-style-type: none"> <li>• <b>Lack of dementia-awareness can make it difficult for people with dementia to share about their experience</b> <ul style="list-style-type: none"> <li>○ 'I have been rushed to supply answers to the medical professionals. Such pressure exacerbates my word finding difficulties.'</li> <li>○ 'It was appalling. Together with other people suffering from Dementia I attended a meeting with a [health service] representative which was so clearly a tick boxing exercise it was insulting. Nothing was done to put the attendees at ease or to make any attempt to look to their comfort; no water offered, toilets not indicated. The person conducting the exercise took no notes, and when asked if she had got what she wanted from us replied that we had told her nothing she had not already known. The slightest modicum of respect might have helped.'</li> <li>○ 'Giving feedback to staff at the care home where my mother was living we were told that the staff were professionals and knew her needs better than we did. This entailed getting her out of bed and dressed every day when at 94 and weighing only 5 stones she clearly needed at times to stay in bed. They did not help her to eat, or coax her to and her weight loss was alarming'</li> </ul> </li> <li>• <b>Feedback of people living with dementia is not valued</b> <ul style="list-style-type: none"> <li>○ 'My experience, and those of people I know, is that service providers and commissioners are not good at listening and following up later. We need to know that action has been taken to prevent things happening again, and I always offer, and want, to be involved in this.'</li> <li>○ 'I told the consultant I did not feel I was being taken seriously, as they did not believe me. Their response was they were the professional so knew more about it (my condition) than I did'</li> <li>○ 'Gave honest, frank and constructive feedback, however no response so far or indication my remarks had been taken on board.'</li> <li>○ 'Complaint to my GP: I got a letter eventually but no face to face discussion or apology.'</li> <li>○ 'Like pulling teeth to get answers to emails to other care entities.'</li> </ul> </li> </ul>

	<ul style="list-style-type: none"><li>• <b>Questions asked may not be relevant to what matters to people affected by dementia</b><ul style="list-style-type: none"><li>○ 'Had to complete some feedback for Local Authority. Found that it was very wordy and did not really cover all that applied to our particular circumstances.'</li></ul></li></ul>
<p><b>Wanting to help commissioners and services to learn from the experience of people with dementia</b></p>	<p>'I have been to many meetings to talk to professionals about living well with two terminal illness Alzheimer's disease and motor neuron'</p> <p>'I do public speaking to Medical students and other organisations with a Q AND A session at the end of the presentation.'</p> <p>'Not always easy for find out where/how to give feedback. Anonymity helps to give less than glowing feedback. Uncomfortable when complaining and speaking to a person who was justifying the unjust. But also want to give accolades when services have been great.'</p> <p>'Involve people with dementia when health and social care services are being planned or commissioned. Commissioners in particular need to hear the dementia voice.'</p> <p>'All planning for health/social care should be in full partnership with people living with dementia.'</p>