



# Alzheimer's Society online survey extract: concerns and free text comments for 'Measuring the Experience of People with Dementia': commissioners, regulators and providers of health and care services

## Introduction

This survey opportunity was shared through Alzheimer's Society local services teams, members of the National Dementia Action Alliance and attendees of Department of Health and Social Care round-table events in 2017.

## What services did the 37 respondents work in?

I work for the NHS 53%                      I commission services 36%                      I provide services 28%  
 I work for a local authority 14%    I work for a charity 8%                      I regulate services 6%  
 Other 14% (included integrated care manager and a nurse specialist in acute trust)

## Concerns about involving people with dementia in giving feedback about the experience of services

Feedback theme	What people told us
Lack of dementia-awareness	53% staff lacking skills or confidence in engaging people living with dementia about their care 15% lack of dementia-aware staff 12% lack of confidence personally in how to involve people living with dementia
Time constraints	41% time constraints
Working with qualitative data	26.5% lack of confidence about how to work effectively with qualitative feedback
Not convinced of value in learning from people with dementia	12% lack of confidence that people living with dementia are capable of giving feedback or being involved (such as in co-production or commissioning of services) 9% lack of compelling case for doing more to learn from the experience of people with dementia

## 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>	<p><b>Role of commissioners - missed opportunities to improve value of services</b></p> <ul style="list-style-type: none"> <li>• 'As a commissioner you rarely get to see the negative feedback and are often bamboozled by positive statistics - this means you lose out in understanding what can be developed.' (person working in commissioning for a local authority)</li> <li>• 'poor commissioning... unwillingness to hear any feedback that might necessitate spending more funds' (Consultant Clinical Psychologist in the NHS also involved in regulation of dementia services)</li> </ul> <p><b>How organisations work with information about experience</b></p> <ul style="list-style-type: none"> <li>• <b>services don't appreciate the value of what they hear.</b> <ul style="list-style-type: none"> <li>○ 'we only hear verbal feedback but then don't do anything with it to collate, other than feedback from people who have been discharged, but this is only around quality of experience' (person working in the NHS)</li> <li>○ 'our process has not been as systematic as we would have liked' (charity commissioner)</li> <li>○ 'process of noting feedback needs to be strengthened' (nurse specialist in acute trust)</li> </ul> </li> <li>• <b>services not finding out about a wider range of experience</b> <ul style="list-style-type: none"> <li>○ 'with dementia those that are able to communicate the issues that affect them do not reflect the range of views from people with more severe or complex types of dementia.' (person working in commissioning for a local authority)</li> </ul> </li> <li>• <b>service measures not helpful to improve care</b> <ul style="list-style-type: none"> <li>○ 'unwillingness of the wider system to produce outcome measures that would demonstrate the poor state of current care' (Consultant Clinical Psychologist in the NHS also involved in regulation of dementia services)</li> </ul> </li> </ul>

	<p><b>How commissioners and services find out about experience</b></p> <ul style="list-style-type: none"> <li>• <b>inconsistency of opportunity to share about experience meaningfully</b> <ul style="list-style-type: none"> <li>○ 'As a service we do not have any concerns about involving people living with dementia. We welcome feedback and this is actively sought, and acted upon. We regularly present qualitative feedback to commissioners which is well-received.' (person working in the NHS)</li> <li>○ 'people with dementia and their carers can often experience a difficult time/journey - being part of a consultation can add to that pressure' (Consultant Psychiatrist working in an NHS community team)</li> <li>○ 'We have struggled to find ways of getting meaningful feedback from service users with dementia or their families.' (person working in the NHS)</li> </ul> </li> <li>• <b>tools for finding out about experience are not dementia-friendly</b> <ul style="list-style-type: none"> <li>○ 'Directives from the Department of Health such as Family and Friends feedback interfere with effective feedback methods that have been developed locally with people who have used your organisation. In the organisation I work for we had developed really good feedback methods jointly with people using our services but corporate or Department of Health meant that these effective methods could no longer be used.' (Manager of an NHS memory assessment service)</li> </ul> </li> </ul>
<p><b>Wanting to learn from people with dementia</b></p>	<p>'feedback from people living with dementia is essential.'</p> <p>'encourage and the value the voice of the individual, however limited that might be. Feedback provided by carer/family on the individual's behalf is equally valued, but only provides part of the evaluation.'</p>
<p><b>Trying to apply quantitative data principles to qualitative data</b></p>	<p>'I do have some concerns about objectivity, the willingness to broach difficult feedback ( that could ultimately help improve)'</p> <p>'As everyone's experience of dementia is different, how do we include enough people to ensure that our service user and carer responses are as representative as possible for the local population?'</p>

