Measuring the experience of people with dementia

Dementia Experience Toolkit

It Takes a Village
Late in 2018, Dementia Voice team united with

- People with dementia
- Carers
- Commissioners
- Regulators
- Providers of health and care services
- Researchers
- dementia organisations and
- other teams at Alzheimer’s Society: Evaluation, Policy, Innovation, Local Services, Digital...

They ALL shaped the development of this resource.
NEED FOR THIS RESOURCE
2017 round-table Department of Health-led events with commissioners, regulators, providers and people affected by dementia.

2018 more than 1 in 5 services providing dementia care rated as failing by CQC: a higher proportion than non-dementia services.

Supporting self-management and community living
- Royal College of GPs survey 2018: 59% of GPs said social prescribing helped patients and reduced their workload (by an average of 28%).
- Gateshead and Shropshire Dementia Navigators and Companions reduced unplanned hospital admissions, improved well-being and patient experience.

Co-produced care plans and shared decision-making
- should include goals or actions to enable the person with dementia to live well, to maintain their well-being, including through pursuing interests and social functioning

Healthwatch findings: care homes
- conversations and observations: residents, carers and staff: almost 200 site visits, 63 local authorities. Key factor for good care services: continually seek views from, and be influenced by, service users.
- Around 75% of 93 care homes in Surrey significantly improved care offers (following 'My way, every day' report) by using qualitative approaches to improve user experience.

NHS Long Term Plan: Universal Personalised Care
Key themes about issues: 30 people affected by dementia (25 of whom were people living with dementia). Our survey December 2018.

'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.'

'I attended a meeting...so clearly a tick boxing exercise it was insulting. Nothing was done to put the attendees at ease or...to look to their comfort; no water offered, toilets not indicated. The person... took no notes...'

'Missed opportunities to find out experience, to learn how and why services could be improved.'

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

'People want to help service providers and commissioners learn from lived experience'

'Staff lack dementia-awareness to engage with people with dementia about their care'

'Staff think they know better so don't value lived experience'

'Their response was they were the professional so knew more about it (my condition) than I did.'
Key themes about issues: 37 commissioners, regulators and people working in health and care services. Our survey December 2018.

Missed opportunities to find out about experience, to learn how and why services could be improved.

- ‘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.’ (CCG commissioner)

- ‘We have struggled to find ways of getting meaningful feedback from service users with dementia or their families.’ (person working in the NHS)

- ‘We hear feedback but we don’t do anything with it – it’s only about quality of experience’ (person in the NHS)

- Need help about working with qualitative data
  1 in 4: not confident how to work with it

- ‘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)

- 1 in 2: staff lack dementia-awareness to engage with people with dementia about their care

- 1 in 8: concerned people with dementia not capable of giving feedback or getting involved
Identifying what to include in site build January to mid-March 2019

#WeWillDolt
What commissioners and organisations said they want in this resource

84% pros and cons of different methods of getting feedback/ideas

84% tips to make involvement/feedback methods dementia-friendly

75% templates to make it easy to use methods described

73% tips to involve people with dementia in commissioning

68% how to get broader information than just one person's story

60% how to work with qualitative data

60% contacts to find out more about involving people with dementia

49% contacts to help recruit people with dementia and carers

... how to measure experience of people with advanced dementia.

'encourage and 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.'
How people affected by dementia said they want to give feedback

- Giving feedback online - such as using forms on websites
- Talking with professionals as a routine part of care and support
- Meetings with people who plan/manage health/care services
- Discussion groups: people living with dementia and carers
- Discussion groups: people living with dementia
- Surveys
- Other (video diaries, 121 interviews, email)
DEVELOPING THE SITE AND CONTENT

We are now working together with more people with dementia, carers, commissioners and organisations.
Words people used most in their feedback of what they like about the site.
“It’s got to be easy to go straight to the parts you really want. It should say why this is important, but we are busy people, so it needs to be possible to skip reading through all that introductory information, to go straight to, say, how to work with qualitative data or ways to involve people.”

(NHS Clinical Commissioning Group manager)

You said, we did

‘It’s quick and easy to read. I like that you can dip – so many resources you have to wade through lots of other stuff first.’

‘I think the National DAA will love this and I like what you’ve done with the Dementia Statements.’
You said, we did

Screenshot from our test site.

‘...include: use of observational tools such as Dementia Care Mapping to capture experience for the person with dementia who may not be able to respond to… forms of questioning’

‘[include] Tips on how to plan involvement … with people with dementia and their carers … managing time’

‘I would like to share this with commissioners’

‘I’d like to share this with British Psychological Society Faculty for the UK’
You said, we did

Screenshot from our test site.

Each method is described in clear and simple format
- Might this be the method for you?
  - Yes
  - Maybe not
  - No
- Ethical considerations (consent, safeguarding, proxies...)
- Step-by-step:
  - Useful for/Disadvantages and risks
  - Preparation
  - On the day
  - Afterwards
- Tips developed with people with dementia and carers

‘I would like a see a simple guide to support consultation with people with dementia from simple hints and tips through to models for working with a variety of situations.’

‘We need... practice for engagement with people with dementia at all levels’

‘It will be really useful to us - so clear and easy to read and exactly the sort of thing people are desperate for.’
You said, we did

Screen snips from our test site.

‘how do we include enough people to ensure that our service user and carer responses are as representative as possible for the local population?’

‘It can be such an emotive and personal subject I do have some concerns about objectivity…’

Advice

Working with questions and data

How to develop questions to gather the type of data you want. Quality of Life scales. Guidance on data analysis, action-planning and reporting.

- If we only think of valuable data for health and care service-planning as a numbers game - we risk reinforcing assumptions and stereotypes about people with dementia and their needs. We risk continuing to provide poor care with continuing unmet needs.

When we consciously seek out more, individual stories, with open minds, we can build a richer picture of the experience of people with dementia. We give commissioners and healthcare services more chance to identify unmet needs and improve services for a wider range of people with dementia.

Here’s Sholagh Robinson giving a TedEX presentation in Staffordshire about the importance, for her, of people with dementia getting a diagnosis and using their experience to inform policy, strategy and services.

Why does one person’s story matter?

The answers to ‘how’ and ‘why’ things happen, can be found in people’s stories.

- Many of the problems commissioners and healthcare providers are trying to find solutions for, require looking for opportunities to innovate and make change. To do that, we need to consider human experience in rich detail.

There are many different types of dementia. They affect people in different ways. In the United Kingdom, one in six people aged over 80 will develop dementia, but over 40,000 people with dementia are younger than 65 years. Between 5% and 15% of people living with dementia receive a diagnosis of a young onset or rare dementia, such as fronto-temporal dementia or Posterior Cortical Atrophy (PCA).

Learning from a range of stories will give insights about experience of services and quality of life. These may be used to action plan for care and change.

‘It’s an AMAZING resource and fantastic piece of work! I like the cultural sensitivity page!’
You said, we did

Screenshot from our test site.

‘any resource that was not informed by lived experience would be invalid’

‘I would like to see best practice in health and social care reflected.’

Real-life examples
Case studies, published research studies, useful links, further reading, templates and tips - and contacts to find out more.

- Developing new services
  - Working together to close gaps, integrate services and prioritise what matters to people with dementia.

- Improving information and access to services
  - Films in community languages, guides, campaigns and self-help online.

- Enabling dementia-friendly practice
  - General Practice, care homes, hospitals, complex sites, and professional development.

- Commissioning, strategy and evaluation
  - Developing strategy. Monitoring and assessing progress.

- Templates: examples and tips

- Useful links and further reading
  - Articles, guides and published research studies.

‘it looks really interesting!’

‘Lots of good stuff in this! ... a fab collection!’
Real-life examples

Developing new services

Case study examples include:

- Programme adaptation: Live well with dementia – national
- Live well with dementia – transitioning groups, Essex
- Dementia Allies, Canterbury
- Setting up DEEP peer support groups, Shrops

Norfolk and Waveney STP Dementia Pathway development

This page is under construction. Work in Norfolk is ongoing.
Real-life examples

Commissioning and evaluation

Case study examples include:

- Dementia Strategy, Essex
- Dementia Strategy, Shropshire
- Priorities-setting survey, Shrops – Dementia Action Alliance
- Making evaluation count – national
- Use of observation: advanced dementia
Case study examples include:

- Time for dementia programme, Kent, Sussex and Surrey
- Public space in complex site – Colchester ‘meeting point’
- Turning up the volume – national
- Dementia-friendly signage and decoration in hospital, Shrops
- Managing involvement/volunteers with dementia progression, Glos.(tbc)
Case studies

Real-life examples

Improving access and information

Case study examples include:

• Bring Dementia Out: LGBT+ dementia awareness and inclusion

• Community language dementia awareness films in Bristol (and soon, Glos)

• Macintyre Dementia project: co-produced Easy Read Dementia Statements

• Easing hospital admissions: enhanced care ward, Southampton hospital

• Mapping the Dementia Diagnosis Journey to improve online self-guided support – national – Alzheimer’s Society

• Supporting self-management: improving the Dementia Guide – national
Site testing: 1-2-1 interviews

Quotes representing key themes

‘It’s a very impressive piece of work, a great collection. It deserves much support. It’s really easy to read. It will be really useful. It’s what people want. (Clinician, Older Adult Care, NHS)

‘…a cracking job! I like the tips – they will work in all of the different settings and are easy to read. Further reading – some brilliant stuff.’ (person with dementia)

‘I was rather excited it was there! The sort of information in it was useful and empowering for me… so quick and easy to read, I used it…’ (Dementia Friendly Communities Co-Ordinator)

‘what you’re doing here - it’s important as so many people think they know all about dementia, but they’ve only met one person. I like it.’ (person with dementia)

‘This looks good – something prestigious to be involved with – we’re pleased to feature in it. (CCG Commissioner)

‘… it looks very user friendly to me. Clearly laid out with good signposting.’ (Dementia Support Manager)
NEXT STEPS: SHARING GREAT PRACTICE AND IDEAS TO HELP ONE ANOTHER

There’s still time to get involved. Site build continues until 10 March 2019.
Thank you for looking through this presentation about the story so far of how so many people are helping to develop this resource.

There’s still time to get involved. We are continuing to test tips and other content, and to add content, especially real-life examples of great practice and useful links – so we’d love to hear from you if you’d like to contribute to this.

To find out more please contact:

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