

Measuring
the
experience
of people
with
dementia



It Takes a Village

Dementia
Experience
Toolkit



The team



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...

#WeAreUnited

They ALL shaped the development of this resource. Alzheimer's Society



NEED FOR
THIS
RESOURCE



#WeGetIt

Changing times

Desktop research

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**

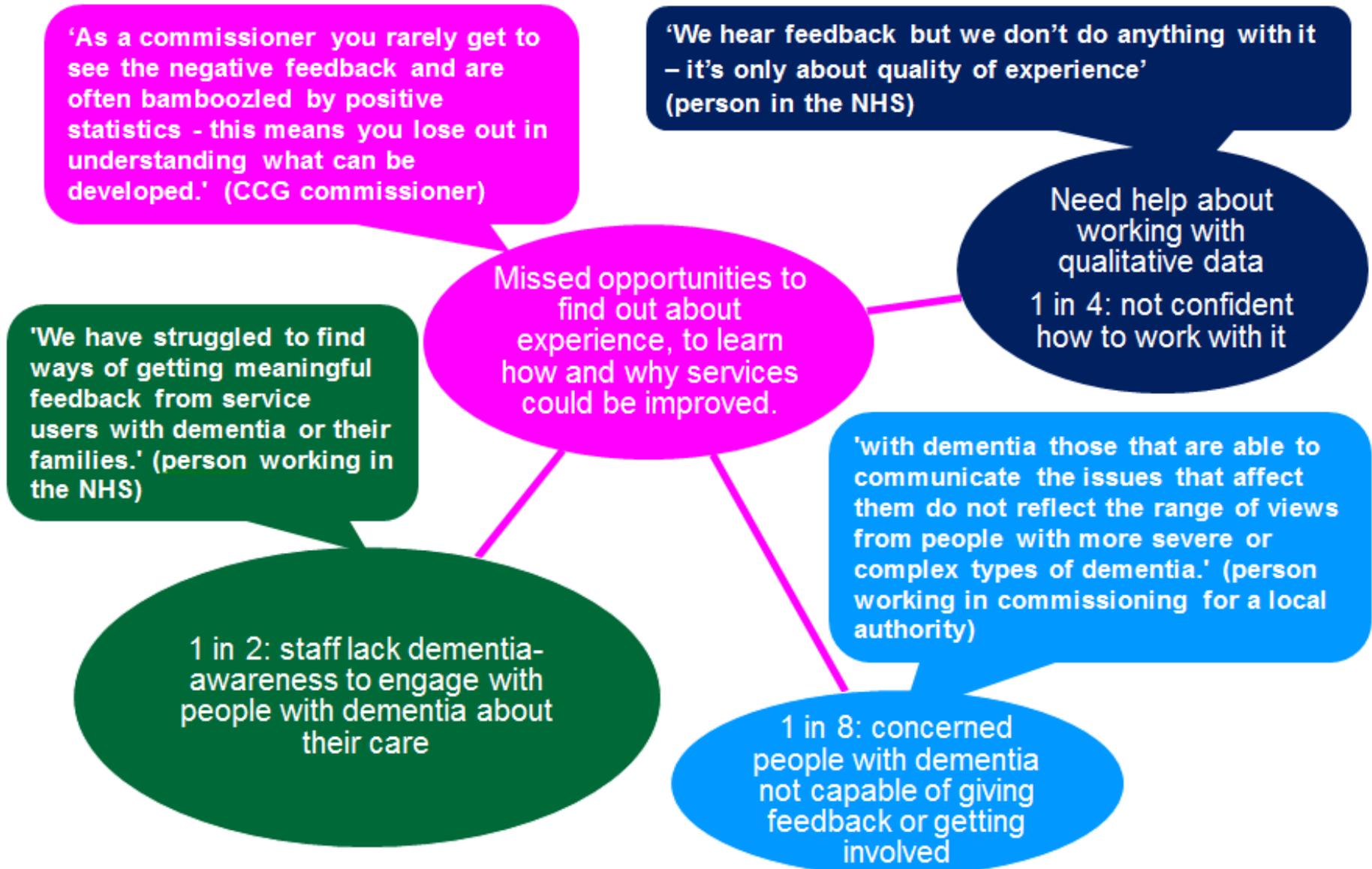
Healthwatch findings: care homes

- 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.

Key themes about issues: 30 people affected by dementia (25 of whom were people living with dementia). Our survey December 2018.



Key themes about issues: 37 commissioners, regulators and people working in health and care services. Our survey December 2018.



THE INGREDIENTS

Identifying what
to include in site
build January to
mid-March 2019

#WeWillDolt

What commissioners and organisations said they want in this resource

'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.'

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

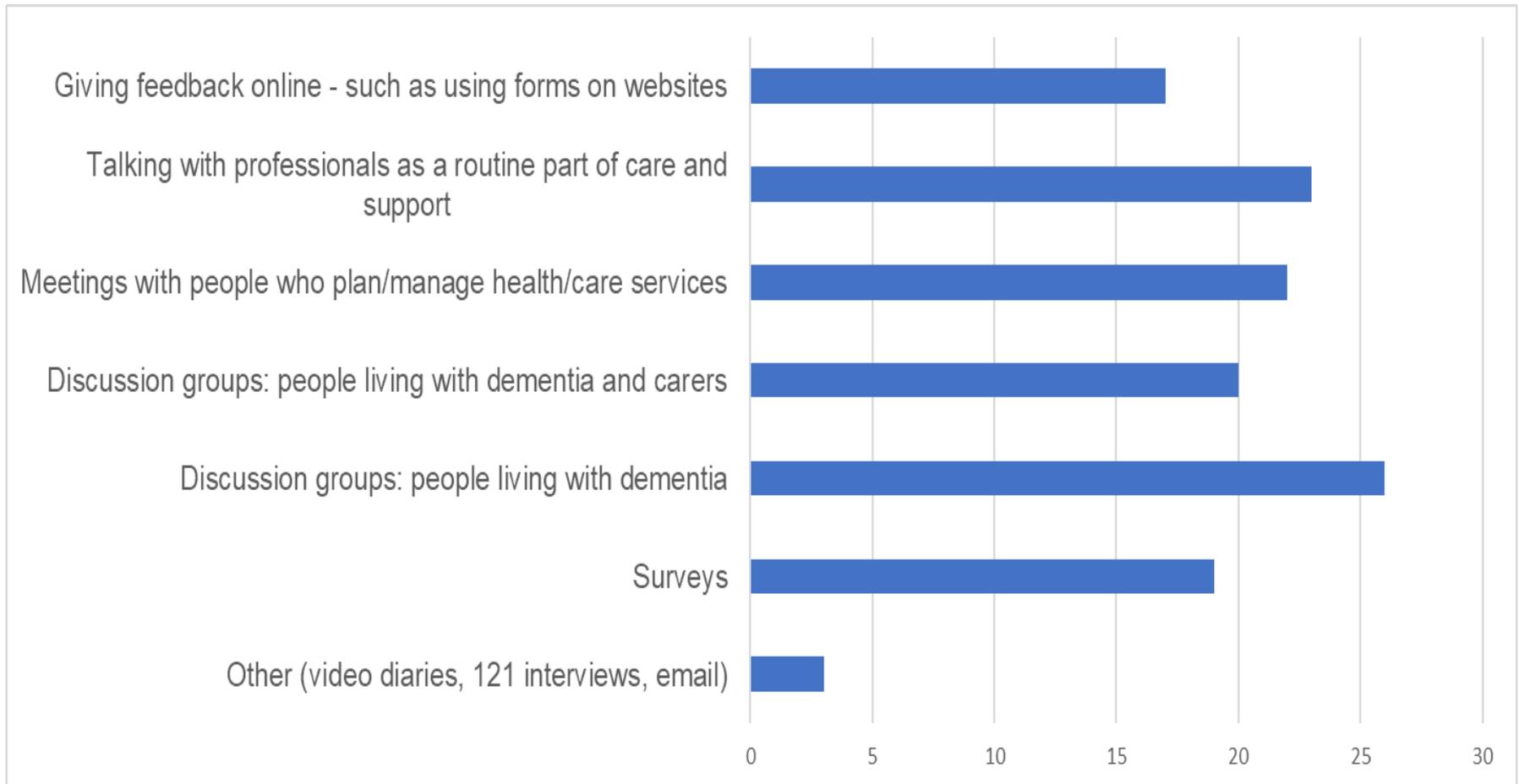
60% how to work with qualitative data

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.

How people affected by dementia said they want to give feedback

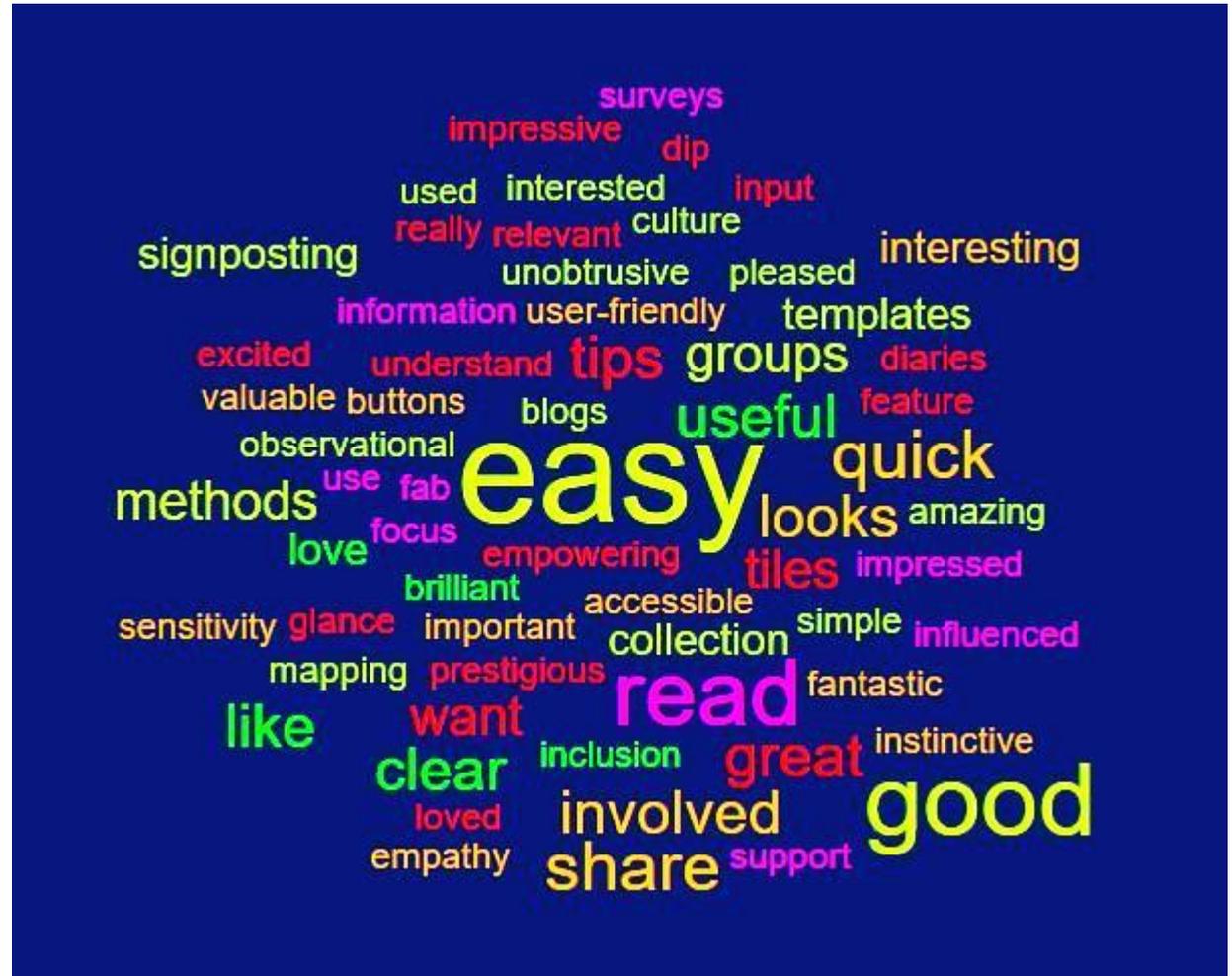


DEVELOPING THE SITE AND CONTENT

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.

Site testing: Wordle



You said,
we did

“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)

Information

The need to measure experience in dementia-friendly ways

Poor care and missed opportunities for services to improve. The role of commissioners, inclusive culture and dementia-awareness for staff.

Information

The Dementia Statements and rights-based approaches

The statements describe outcomes important to people affected by dementia. They can provide inspiration for measures of experience.

Advice

Guidance and ways of finding out about experience

Recruiting people affected by dementia. Ethical considerations. Gathering feedback and ideas.

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.

Real stories

Real-life examples

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

Information

Contents List

At-a-glance...

Screenshot from
our test site.

‘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'

Advice

How to recruit people affected by dementia

Representative samples. Ethical considerations: consent, proxies, confidentiality, remuneration, risk, safeguarding. Useful organisations.

Tips for a dementia-friendly welcome at your activity

A bad experience and good ideas from people affected by dementia.

1-2-1 conversations and interviews

Dementia-friendly approaches include semi-structured and unstructured interviews, photo elicitation, emotional touchpoints, and Talking Mats.

Information

Co-production and working together with people affected by dementia

Working in 'nothing about us, without us', dementia-friendly, ways.

Information

Digital user experience: website intercepts

Reach beyond 'the usual suspects'. Feedback can be immediate, No need for expensive software.

Information

Group discussions and activities

Dementia-friendly focus groups, service user groups, round-table workshops, electronic voting sessions, and customer insight activities.

Information

Observational methods

Dementia Care Mapping, controlled observation, observation in combination with other ways of finding out about experience.

Information

Surveys

How to use questionnaires in dementia-friendly ways including face-to-face, video, paper, telephone and online.

Information

Unobtrusive methods

Content analysis, empathy mapping, video, photo and solicited diaries.

'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

'I would like to 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'

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**

'It will be really useful to us - so clear and easy to read and exactly the sort of thing people are desperate for.'

Screenshot from
our test site.

You said,
we did

'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.

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.

- 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 Shelagh 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.



Are you planning on being 'neutral' when you research the experience of people with dementia? Remember however hard we try to be objective, we all have biases.

Screen snips from
our test site.

'It's an AMAZING resource and fantastic piece of work!
I like the cultural sensitivity page!

You said,
we did

'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.

Real stories

Developing new services

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

Real stories

Improving information and access to services

Films in community languages, guides, campaigns and self-help online.

Real stories

Enabling dementia-friendly practice

General Practice, care homes, hospitals, complex sites, and professional development.

Real stories

Commissioning, strategy and evaluation

Developing strategy. Monitoring and assessing progress.

Information

Templates: examples and tips

What people said works well. Tips for dementia-friendly documents.

Information

Useful links and further reading

Articles, guides and published research studies.

'it looks really interesting!'

'Lots of good stuff in this! ... a fab collection!'

Screenshot from
our test site.

Real-life examples

Developing new services

Norfolk and Waveney STP Dementia Pathway development

This page is under construction. Work in Norfolk is ongoing.

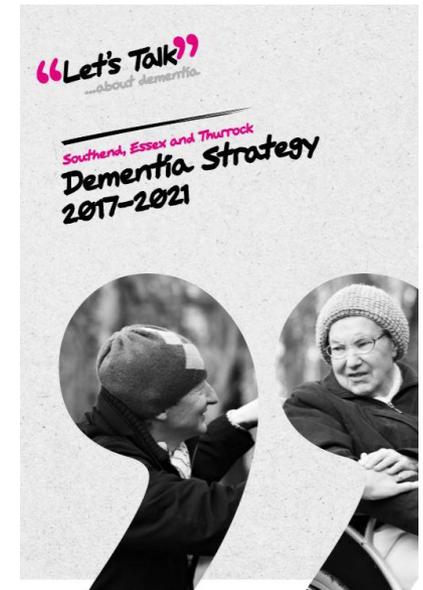
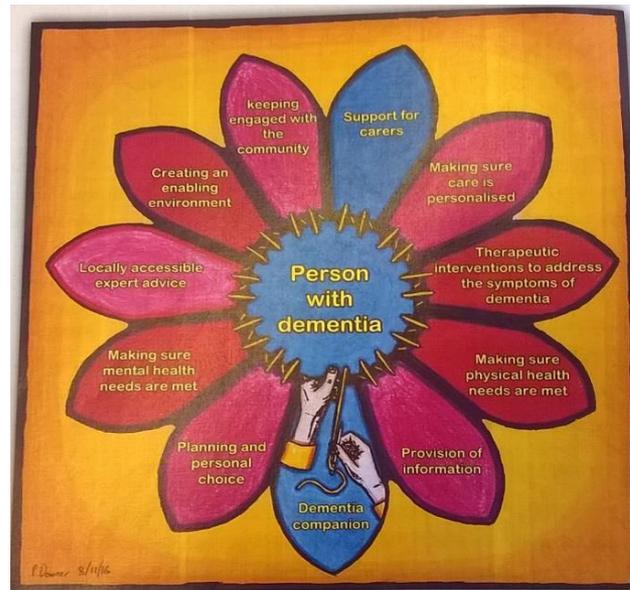


Case study examples include:

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

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

Real-life examples

Dementia-friendly practice

Lift the lid... on sex and intimacy in care homes: workshop in a box

This page is under construction.



Dementia-friendly general practice, Notts and Derbys

page under construction



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)

Real-life examples

Improving access and information

Case studies

Bring Dementia Out

Co-produced campaign to encourage dementia-awareness and inclusion.



The 5 Dementia Statements

Statement 2

We have the right to carry on with day-to-day and family life

We should **not** be judged

We should **not** have unfair costs

Page 8

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)

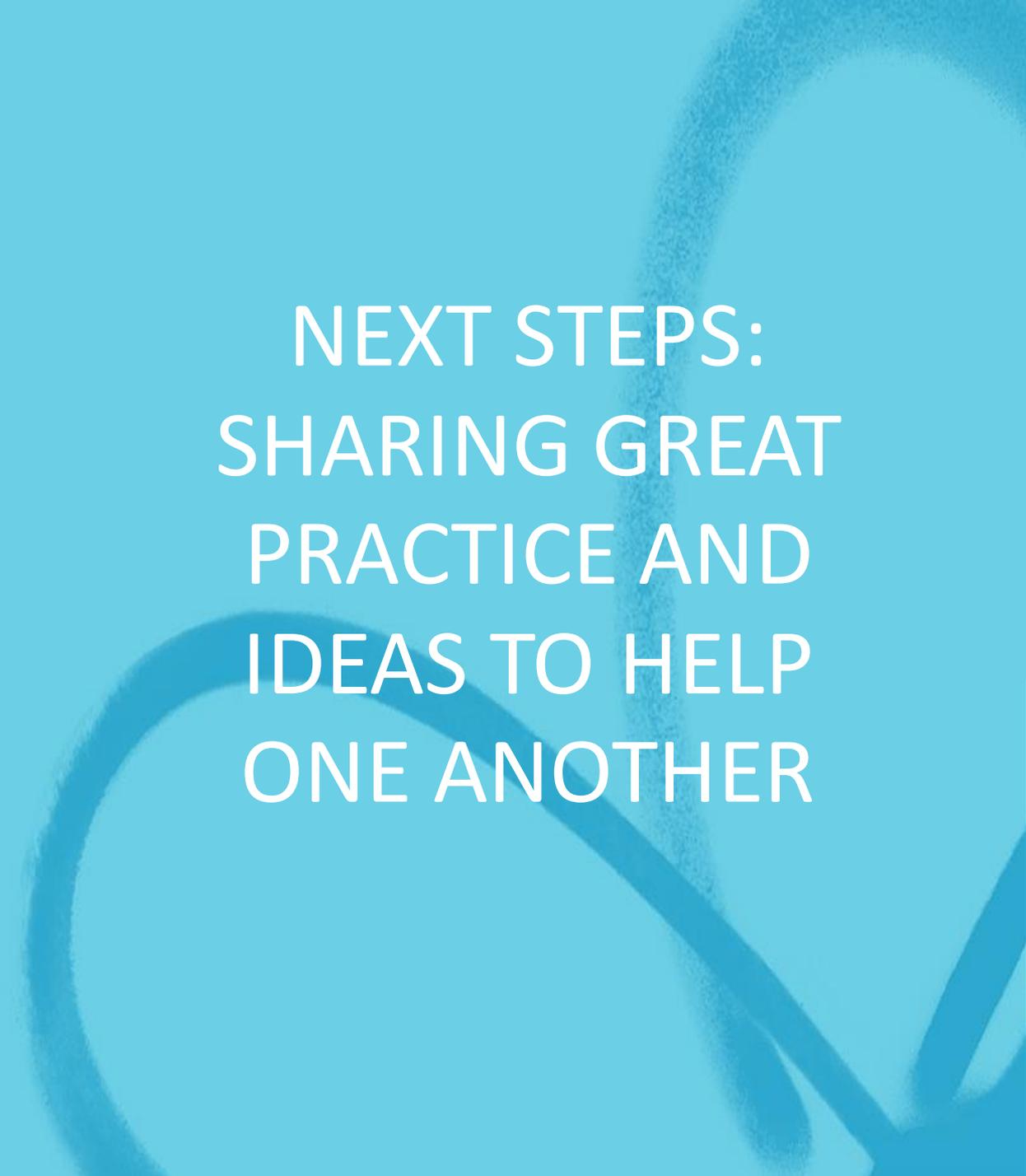
'...a cracking job! I like the tips – they will work in all of the different settings and are easy to read. Further reading – some brilliant stuff.' (person with dementia)

'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 and contact details

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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