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New approach to measuring the outcomes that matter most to people with dementia

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About us...

The Health Innovation Network is the Academic Health Science Network (AHSN) for South London, one of 15 AHSNs across England.

We connect academics, NHS commissioners and providers, local authorities, patients and patient groups, and industry in order to accelerate the spread and adoption of innovations and best practice, using evidence-based research across large populations.

Working as catalysts of change across health and social care economies, we enable health improvements and economic growth.



Population
3 Million



Healthcare
Workforce of
60,000+



55
Member
Organisations



12
South London
Boroughs

Background

- National drive to commission for outcomes – assumption that outcomes can be evidenced
- National Dementia Declaration engaged with people with dementia and carers to develop the outcomes most important to people with dementia – the Dementia I-Statements
- Outcomes tools do exist but often lengthy and time-consuming

What we know about engaging with people with dementia



- Keep it simple
- Keep it short
- Adapt methods to the abilities of the person with dementia
- Work with people in an environment that people are familiar with
- Don't overwhelm people with too much information
- Give people enough time
- Don't rely solely on written information

Dementia I-Statements

- I have personal choice and control or influence over decisions about me.
- I know that services are designed around me and my needs
- I have support that helps me live my life.
- I have the knowledge and know-how to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I know there is research going on which delivers a better life for me now and hope for the future.

Approach/Methodology

Develop set of questions based on I-statements

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graph TD; A[Develop set of questions based on I-statements] --> B[Test these questions on people with dementia in a range of settings/services]; B --> C[Send feedback to organisation]; C --> D[Discussion with staff regarding usefulness of outputs]; D --> E[Final report highlighting settings this approach can be used in a final set of questions];
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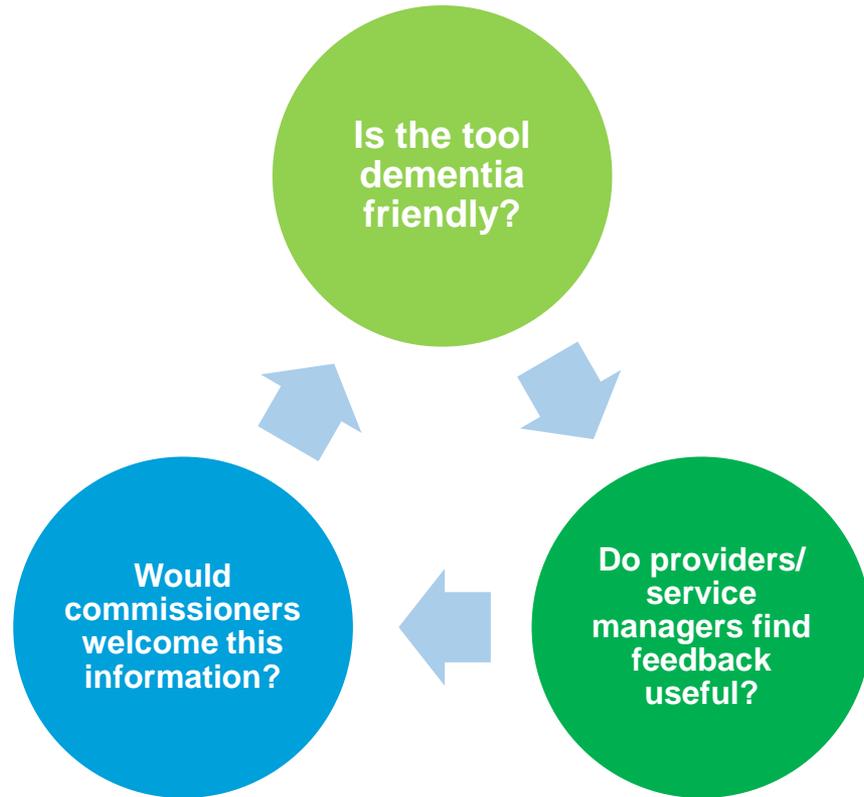
Test these questions on people with dementia in a range of settings/services

Send feedback to organisation

Discussion with staff regarding usefulness of outputs

Final report highlighting settings this approach can be used in a final set of questions

Project Objectives



Testing in different dementia services

Type of service	Service name	No. of people with dementia who participated
Community Group	Dementia Friendly Community	11
	Young onset peer support group	5
	Peer support group (for early diagnosis)	6
Care Home	Older adult Care Home	3
Hospital Ward	3 elderly care wards	7
Extra Care Housing	Extra Care Housing Scheme	5

Recommended Approach

Face-to-face

One-to-one

Independent
facilitator

Verbal
consent

Service
setting

What we found

- Most (but not all) people with dementia could respond to questions in a meaningful way
- Most people with dementia were happy to give feedback and were very honest in feeding back
- The tools are time-efficient and user/ dementia friendly
- They do not duplicate/ replace other feedback processes for these services

Community Groups

	Yes	Sometimes	No	Comment
Do you choose what you do when at the group?				
Do you get what you want out of going to the group?				
Does the group help you?				
Does the group offer advice and information about dementia?				
Have people at the group got to know you ?				
Do you feel a sense of community ?				

Hospital wards

	Yes	Sometimes	No	Comment
Are you involved in decisions about your care? E.g. being asked your opinion?				
Does your care meets your needs ?				
Do you know how to get help to get what you need?				
Do the hospital staff understand and support you?				

Care homes

	Yes	Sometimes	No	Comment
Are you involved in decisions about your care? E.g. being asked your opinion?				
Does your care meet your needs ?				
Are you supported to do the things you enjoy?				
Do you know how to get help to get what you need?				
Have people at the care home got to know you ?				
Do you feel a sense of community ?				

Dementia advisor/navigator

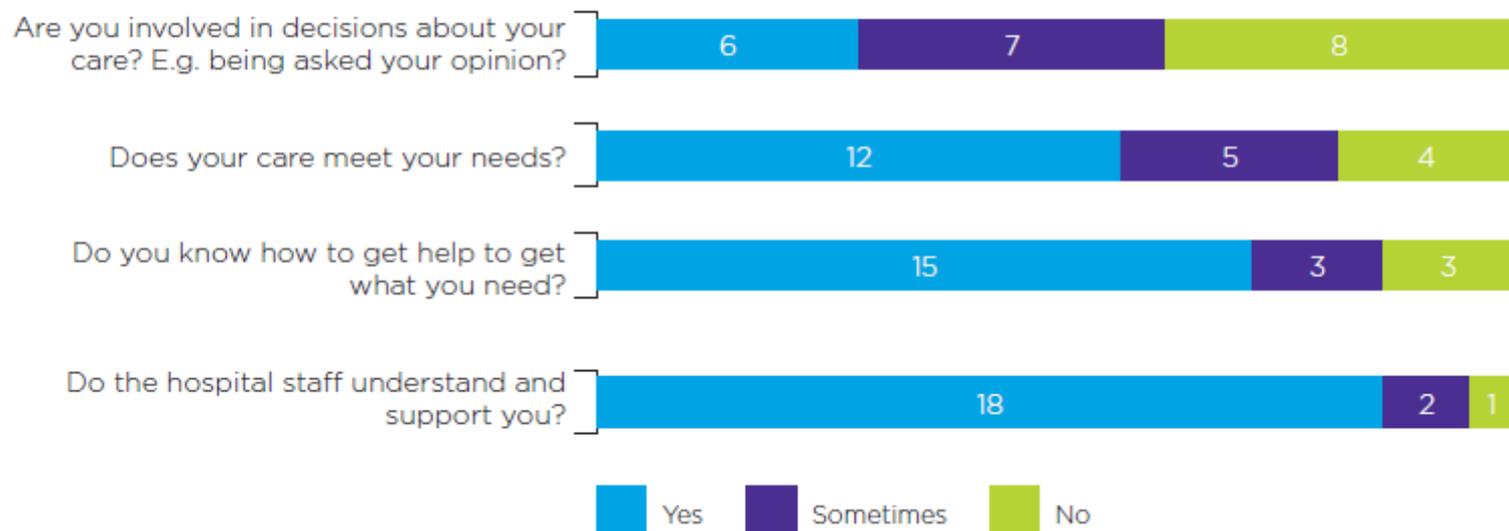
	Yes	Sometimes	No	Comment
Do staff tell you about a range of local services so you can choose what would be best for you?				
Do you get what you want from this service?				
Do you feel the service helps you?				
Do you know how to get more information when you need it?				
Have people at the service got to know you ?				

Extra Care Housing Schemes

	Yes	Sometimes	No	Comment
Are you involved in decisions about your care and support? E.g. being asked your opinion?				
Does your care and support meet your needs ?				
Are you supported to do the things you enjoy?				
Do you know how to get help if you need it?				
Have people at (name of extra care housing scheme) got to know you ?				
Do you feel a sense of community ?				

Using the results

Chart A: Patient responses to dementia outcomes questions



Feedback

Providers

- Complements information already collated
- Not onerous
- Provides opportunities to improve services

Commissioners

- include the outcomes in service specifications
- to use in contract monitoring processes
- to fill gap in evidence regarding outcomes

“In the past I have had business cases seeking funding for dementia services turned down as I have not been able to give supporting information about how a service has been meeting service user outcomes. This tool will give me the evidence I need to build a solid business case to secure more funding for dementia services in Lewisham”.

Karin Barthel, dementia commissioner from Lewisham CCG

Final Report

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