

Measuring Outcomes in Dementia Services

December 2016

Acknowledgements

In developing this measurement tool the Health Innovation Network (HIN) worked in partnership with a number of health and social care services in South London, both staff and service users have been central to the development of this tool.

Beth Ezra Care Home

Young Onset Peer Support Group run by Dementia Pathfinders

Healthy Living Club

Kingston Hospital NHS Foundation Trust

Oasis Peer Support Group run by Merton Dementia Hub

Special thanks to Nada Savitch from Innovations in Dementia who advised throughout on engaging with people with dementia.

Project Team

Polly Sinclair,

HIN Project Manager and Project Lead

Rebecca Jarvis,

HIN Programme Director for Dementia

Nada Savitch,

Innovations in Dementia

Amy Semple,

HIN Project Manager

Dr Hugo de Waal,

HIN Clinical Director for Dementia

Zoë Zambelli,

HIN Project Support Officer

This report was written by Polly Sinclair.

Contents

Executive Summary	4	Appendix A: Good practice principles in using the dementia outcomes tool	11
1 Background	5	Encouraging people with dementia to respond	11
1.1 Dementia i-statements	5	Involving family members/carers	11
1.2 Outcome-Based Commissioning	5	People who are not aware they have dementia	11
2 Aims and objectives	6	People with verbal communication difficulties	11
3 How we developed the tool	7	Face-to-face and one-to-one methodology	12
3.1 Review of existing measurement tools	7	Independent but familiar	12
3.2 Developing and testing the draft tools	7	Confidentiality	12
3.3 Gaining feedback on the usability of outputs	8	Encouraging honest feedback	12
4 Perspectives on using the tool	8	Consent	12
4.1 People with dementia	8	Services that are present	13
4.2 Providers and service managers	8	Different service contexts	13
4.3 Commissioners	8		
5 Discussion	9	Appendix B: Data capture tool for dementia outcomes	14
5.1 Strengths	9	Community groups	15
5.2 Limitations	9	Hospital wards	16
6 Conclusion	10	Care homes	17
7 References	10	Dementia advisor/navigator	18

Executive Summary

Background:

- In October 2010 the National Dementia Declaration was launched which describes the seven outcomes that matter most to people with dementia, known as the dementia i-statements. Further work was identified to understand how to measure these outcomes
- Since 2011 the UK has been moving towards Outcomes Based Commissioning which requires the collation of meaningful data on whether patient or service users' outcomes have been met

Aims and Objectives:

- The primary objectives of this project were to aid dementia services to:
 - » obtain meaningful feedback from people with dementia on how the service is meeting their needs to inform service improvement
 - » demonstrate how the service contributes towards achieving outcomes that matter to the person with dementia and their carers.

How we developed the tool:

- A scoping exercise was carried out to review a range of tools that dementia services use to collate feedback on their service and found that existing feedback tools are often not user-friendly for people with dementia
- We developed four sets of questions (see appendix B), all based on the outcomes described in the i-statements but each set is specifically tailored to different types of dementia services: care homes, community groups, hospital wards and dementia advisor or navigator services.
- We tested the resulting tools in all four dementia service types and changed wording in response to feedback.
- We followed up with service managers to gauge if the feedback produced by the tool is useful to collate in future. We also spoke to a wide range of London based commissioners from Clinical Commissioning Groups and Councils via the London Dementia Commissioners Network to seek their views.

Perspectives on using the tool:

- On the whole people with dementia welcomed the opportunity to give their views on their experience of the service.
- Service managers at the services which participated in the design and testing project felt that the tool was helpful, not too onerous and provided useful information which was not already collected.
- There was strong support from commissioners, who informed us that this type of tool would be useful to fill the gap in evidence regarding the efficacy of services, which Outcomes Based Commissioning has uncovered.

Discussion:

- The tool has a number of strengths, including being quick and easy to use, being inclusive of different types and stages of dementia and focusing on emotions and perceptions.
- The tool has its limitations, in particular it doesn't measure improvement over time and a small group of people with dementia will not have capacity to understand and answer the questions. In addition a pragmatic approach was used to develop and test the tool but it would benefit from a study to validate more extensively.

Other outcomes/patient feedback:

- This tool does not collate information on all outcomes. There are a number of additional outcomes and measures that would be worth collecting through alternative processes and information systems. The information provided by this tool can be combined with other service specific information such as activity data.

Conclusion:

- Through developing and testing some tools for exploring whether certain types of services are meeting the outcomes that matter most to people with dementia, we have found these tools to be dementia friendly, fill a gap in information for providers and commissioners. The tools themselves can be found in appendix B, and some guidance for using these is included in appendix A.

1 Background

1.1 Dementia i-statements

In October 2010, 45 organisations united to form the Dementia Action Alliance with the aim to bring about radical changes in the way society responds to dementia.

As a way of achieving this change, the Alliance launched the National Dementia Declaration; a charter that spells out exactly what each Alliance member plans to do to improve the quality of life for people with dementia in England. Created in partnership with people with dementia and their carers, the declaration explains the challenges dementia presents to society and some of the outcomes being sought for people with dementia and their carers. Organisations and services that chose to sign up to this declaration are required to publish their own action plans setting out what they will do to secure these outcomes and improve the quality of life of people with dementia. The Alliance has gone from strength to strength and as of August 2016 over 4,500 organisations/services are taking action to meet the outcomes that matter most to people with dementia.

The outcomes that were drawn up as part of the National Dementia Declaration are more commonly known as the 'dementia i-statements' and are listed below:

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

Whilst these are the outcomes that people with dementia and their family carers would like to see in their lives, it was acknowledged that further work was needed to understand how to measure these outcomes (National Dementia Declaration for England).

1.2 Outcome-Based Commissioning

Outcome Based Commissioning (OBC) is a relatively new approach to commissioning health and social care services in the UK. It rewards both value for money and delivery of better outcomes that are important to patients.

A move towards Outcomes Based Commissioning means there would be a change in emphasis from rewarding volumes of activity delivered to rewarding providers for delivering outcomes people need and want, leading to better joined up care that is focused on the patient or service user's needs.

Whilst the rationale behind Outcome Based Commissioning is clear, it is much harder to collate meaningful data on whether patient or service users' outcomes have been met, than it is to collate information on the number of hospital beds occupied or the number of hours of home care that has been delivered. Collating this information is harder still amongst people with dementia who are not always able to answer complex questions about their care.

Since the first Outcome Based Commissioning scheme started in 2011 there has been rapid progression in this area with many commissioning organisations moving towards this model, asking providers to submit information on how they are meeting their patients' and service users' outcomes in order to influence decisions around the recommissioning and decommissioning of health and social care services.

2 Aims and objectives

The primary objective of this project was to aid dementia services to demonstrate how they contribute towards the outcomes that matter to the person with dementia and their carers. Specifically, this project sets out to:

- develop a tool which can be used to measure the extent to which services are delivering specific outcomes for people with dementia
- Test this tool in different service settings
- Seek feedback from provider organisations and commissioners on the usefulness of the information provided by this approach



3 How we developed the tool

3.1 Review of existing measurement tools

A scoping exercise was carried out to review a range of tools that dementia services use to collate feedback on their service as well as to identify the most meaningful outcomes to be measured. There are a lot of service specific tools that focus on the quality of services and/or the patient/service user experience but few that collate information on meeting outcomes. Those that do are not always user-friendly and are particularly difficult for people with dementia who may have communication difficulties: tools have long rating scales and consist of pages of questions, resulting in a significant amount of time needed both by staff asking the questions or observing care and by people with dementia answering them.

3.2 Developing and testing the draft tools

Health Innovation Network (HIN) Dementia Team decided to use a set of outcomes that had already been developed with people with dementia and their carers and had already achieved national recognition, i.e. the dementia i-statements as validated by the Dementia Action Alliance. We developed four sets of questions, all based on the outcomes described in the i-statements but each set is specifically tailored to different types of dementia services: care homes, community groups, hospital wards and dementia advisor or navigator services. In order to keep questionnaires as simple as possible we gave respondents only the options 'yes', 'sometimes' and 'no'. In addition we provided space for narrative comments to be captured.

We tested the resulting tools in all four dementia service types and changed wording when needed. The dementia advisor/navigator tool was tested in a community group setting for those who had recently been diagnosed with dementia and were being provided with information and advice as well as peer support. This series of outcomes explore information provision and knowledge of local services that are most commonly delivered by dementia advisors or navigators. Two to three members of the HIN team spoke to people with dementia one-to-one in each of the targeted services and asked them the questions contained within the tool, recording their answers. The testing was done between March and October 2016 and questions were refined until we were confident that the tools were well understood and the approach

was dementia friendly. The final tools can be seen in appendix B. Whilst each service had given consent for us to speak with their service users, additional consent was sought from the person with dementia to ensure they were happy to answer questions about the service. More information on consent can be found in the guidance in appendix A.

Testing showed that people with varying stages of dementia (including those with difficulty communicating verbally) could respond in a meaningful way to most of the questions. However, a question about being involved in dementia research was not well understood, so this question had to be excluded from the tool. The team recognises the importance of people being invited to take part in research, but from our work it has become clear that other avenues to engage will have to be used and further developed, for instance through the nationwide programme of 'Joining Dementia Research'.

The below table sets out the number of people with dementia that were involved in the development of the tool by the type of service being evaluated:

Type of service	Service name	No. of people with dementia who participated
Community Group	The Health Living Club	11
	Young onset peer support group	5
	Oasis peer support group (for early diagnosis)	6
Care Home	Beth Ezra Care Home	3
Hospital Ward	3 elderly care wards at Kingston Hospital	7

3.3 Gaining feedback on the usability of outputs

In addition to ensuring questions were relevant to people with dementia and their carers and user friendly, we were also keen to work with staff at provider organisations to ensure that the feedback produced by this tool yielded useful information that would complement (and not duplicate) information already obtained by providers. The HIN produced a short report for each participating service which sets out the feedback from respondents. An example of the type of information that can be reported back can be found in an example report in appendix C. We then followed up with service managers to gauge if the feedback would be useful to collate in future. Feedback from service managers was positive with many seeing the benefit of collating information on outcomes in this way and welcoming the use of the tool.

Finally we spoke to a wide range of London based commissioners from Clinical Commissioning Groups and Councils via the London Dementia Commissioners Network to seek their views. They viewed the information produced by the tool as filling a real gap in the way that dementia services are commissioned and were very interested to include these outcomes in their service specs and contact monitoring processes, so they could review better to what extent relevant outcomes are being achieved for people with dementia.

4 Perspectives on using the tool

4.1 People with dementia

Feedback on whether services are meeting the outcomes people with dementia want, provides useful information about the responsiveness of services to the needs of people with dementia. The tool also gives people with dementia a voice and an opportunity to flag up any of their unmet needs. When testing the tool people with dementia welcomed the opportunity to give their views on their experience of the service.

4.2 Providers and service managers

Service managers at the services which participated in the design and testing project felt that the tool was helpful. Most services had some form of feedback process in place, but nevertheless felt that the tool would complement the information they already collate. They also did not think it would be an onerous exercise to carry out regularly, i.e. in the way we propose the tool should be used. From the summary report produced some were able to identify areas where there was room for improvement and they put actions in place to ensure that these outcomes would be met in future.

4.3 Commissioners

We presented the tool to the London Dementia Commissioners Network and it was clear there was strong support from commissioners, who informed us that this type of tool would be helpful for commissioners in a number of ways:

- by including the outcomes in service specifications
- as a test to use in contract monitoring processes, e.g. by requiring providers to use the tool to evidence whether they are meeting the relevant outcomes
- to fill the gap in evidence regarding the efficacy of services, which Outcomes Based Commissioning has uncovered.



“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

5 Discussion

A full set of guidance on using these tools can be found in appendix A, but here we discuss some of the strengths, in comparison to other dementia outcome tools as well as some limitations we identified.

5.1 Strengths

The tool is quick and easy to use. Asking the questions should take no more than 10 minutes, even when people want to talk in-depth about the service. The number of questions is kept short and focused and the response options are succinct and focused solely on whether or not an outcome is being met, so little or no prompting is needed.

Care has been taken to focus the questions on emotions rather than facts and explore people's perceptions of the services they use. Therefore:

- The questions don't talk about diagnosis or symptoms.
- The questions deliberately don't mention specific aspects of the service.
- The questions deliberately don't mention the type of service (the person with dementia may not know the exact designation of the service they are receiving).
- The questions are as short as possible and emphasis is given to key words that people can understand.
- The questions are not reliant on memory in order to answer them.

We were careful not to duplicate other outcome tools that already exist. We feel the purpose of this tool is different from others that focus more on specific aspects of a service and service user experience or are more comprehensive or try to capture a broader range of outcomes, often at the risk of being less user friendly. We took a pragmatic approach in order to produce a tool that services can easily use and work with, whilst still yielding relevant information.

The tool is inclusive: we found that the vast majority of people with different types and stages of dementia (including those with verbal communication difficulties) could give feedback using this tool.

5.2 Limitations

It is difficult to measure whether outcomes have improved over time as the tool does not use a four or five point rating scale whereby people can move from e.g. 'good' to 'very good' when asked the same questions some time later. Following discouraging experiences using a six point rating scale in a previous HIN project involving people with dementia, we decided that it was more important for the tool to be as simple and inclusive as possible and that simple 'yes' and 'no' responses was the best approach to get as many people as possible to give their views. The tool is therefore much more about considering whether outcomes are being met and understanding where and why some are not being met and less about monitoring improvement over time. Nevertheless, we do suggest that the tool is deployed regularly: different people will be using the service at different times and longitudinal snapshots will still provide information on how a service is being developed and improved. Obviously it would be prudent to follow up on any results by putting in place specific action plans to address identified shortcomings and repeated usage of the tool may serve to illustrate the efficacy of such action plans.

There was a small number of people who did not have capacity to understand and answer the questions: most of these were in a care home. In these cases any questionnaire will prove to be inappropriate and it would be better to resort to observational methods, such as Dementia Care Mapping.

The resources available to the HIN to carry out this project were limited. We therefore adopted a pragmatic approach to the development and testing of this tool to ensure it works in an easy and practical way, but this meant we were not able to undertake a study to validate more extensively. We obviously will be very interested to be involved if any third party would be interested in undertaking that type of more intensive evaluation.

Whilst these tools have been designed to understand whether services are meeting the needs of people with dementia, based on the outcomes that matter most to people with dementia (the dementia i-statements), the tool does not collect information on all dementia outcomes, there are a number of national outcomes such as the estimated diagnosis rate for people with dementia (Public Health Outcomes Framework) whereby data would be gathered in a different way such as through performance information systems holding patient-level data.

6 Conclusion

The Health Innovation Network has produced four short questionnaires/tools (see appendix B) which can be used to determine whether certain types of services are meeting the outcomes that matter most to people with dementia, based on the dementia i-statements. A number of people with dementia have given feedback using these tools, ensuring the result is dementia friendly and ascertaining the relevance of the questions asked.

Feedback from service managers indicates that this type of information is not usually routinely gathered at the moment and we have found that commissioners are enthusiastic to include these outcomes in their service specifications and contract monitoring processes.

Whilst this tool has some limitations it has been found to be particularly user friendly both for the person with dementia as well as members of staff, as it is very simple, easy to use and time efficient. Further guidance on how to use it effectively can be found in appendix A.

7 References

Bradford Dementia Group. (1997). Evaluating dementia care: The DCM Method (7th ed.). Bradford, U.K.: University of Bradford

Dementia Action Alliance, National Dementia Declaration for England, Retrieved on 10th May, 2016, from http://www.dementiaaction.org.uk/assets/0001/1915/National_Dementia_Declaration_for_England.pdf

Department of Health. (2013). Improving Outcomes and Supporting Transparency: Part 1A: A Public Health Outcomes Framework for England, 2013-2016. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/263658/2901502_PHOF_Improving_Outcomes_PT1A_v1_1.pdf. (Accessed 24th November 2016).

National Institute for Health Research, Join Dementia Research, Retrieved on 24th November, 2016, from <https://www.joindementiaresearch.nihr.ac.uk/>

The Health Foundation. (2015). Need to nurture: Outcomes-based commissioning in the NHS. Available from: http://www.health.org.uk/sites/health/files/NeedToNurture_1.pdf (Accessed 6th October 2016).

Appendix A:

Good practice principles in using the dementia outcomes tool

We have developed a number of good practice principles in using the dementia outcomes tool. This guidance is based on our observations and the feedback we received when developing this tool with people with dementia, as well as a wealth of experience Innovations in Dementia have brought to this project based on their wider work engaging effectively with people with dementia.

Encouraging people with dementia to respond

There may be resistance from staff, volunteers and families to asking people with dementia for their opinions as they might think that the person with dementia will not be able to understand, will not be able to respond or would be distressed or confused by the questions. We have found that the vast majority of people with dementia in different care settings have been able to understand the questions and give a view. The questions have been adapted to help people with dementia to understand them. It is important that the questions are not represented as a challenge or a test for the person with dementia.

Involving family members/carers

Many dementia services are attended by people with dementia and their carers and carers may want to get involved in answering questions about the service. Whilst carers can provide some useful additional information to determine whether outcomes are being met, particularly for those with verbal communication difficulties, these questions have been designed for people with dementia to answer and it is important that the questions are directed to the person with dementia and they are given the opportunity to answer themselves. Some people with dementia will not have the capacity to understand these questions and in these cases carer responses may be helpful, however we found when trialling these questions that the perception by the carer of to what extent the person with dementia can contribute was not always correct so it is important to give the person with dementia the opportunity to give their views first and explain to the carer that you would like to hear from the person with dementia initially.

People who are not aware they have dementia

Not everyone you talk to will be aware that they have dementia, and some may only just have received a diagnosis of dementia so will still be coming to terms with what this diagnosis means for them. It is important to be aware of this when asking the questions. In most cases there is no need to mention the term 'dementia' if you are unsure of people's awareness of their diagnosis. Instead you can explain that you are interested in their views of the hospital/ care home/ community group etc.

People with verbal communication difficulties

Whilst testing the questions on people with dementia we spoke to a number of people with communication difficulties. The questions have been designed with very simple answer options (yes, sometimes, no) to allow as many people with dementia as possible to provide feedback. Where people have limited verbal communication they are sometimes able to indicate their answer non-verbally by nodding and shaking their head or indicating neither yes or no through non-verbal communication which can be recorded as 'sometimes'. When asking the questions to someone lacking in verbal communication skills it is advisable to repeat the answer they indicate back to them and wait for confirmation they are happy with this response.

Appendix A:

Good practice principles in using the dementia outcomes tool

Face-to-face and one-to-one methodology

It is recommended that these questions are asked to people with dementia by someone in person and ideally in a one-to-one situation rather than collectively in a group setting. Typically self-completion surveys sent out in the mail or given to people to complete themselves tend to get a low response rate and not everyone will be able to complete a survey themselves. By carrying this out face-to-face it allows the person facilitating the questions to build up a rapport with the person with dementia and allows the person with dementia to elaborate on their answers. For those who are not able to communicate verbally it gives them the opportunity to answer through non-verbal communication which cannot be done over the phone. Assumptions should never be made about the ability of a person with dementia to read or write. Face to face methodologies allow the facilitator to read out the questions as well as showing the written questions to the person with dementia.

Independent but familiar

It is recommended that whenever possible, the questions should be asked by someone who is independent of the service deliver team/staff. This person could be a volunteer or someone from a linked/partner service. By having someone independent it makes it easier to ask about the questions that relate to staff and it allows people with dementia to give more honest feedback. Ideally the person asking the questions would be relatively familiar to the person with dementia, or at least have experience of talking to people with dementia so they are able to put the person with dementia at ease and make the exercise more conversational rather than an interview.

Confidentiality

As it is recommended that this information is obtained face-to-face, it is not possible to conduct this exercise anonymously, however ensuring confidentiality can influence the quality of the feedback you receive, we have included an optional area to record the name of the participant if this is useful.

Thought should be given to where the conversation takes place. Some people with dementia might not like to discuss their experiences in ear-shot of the people who are providing the service or in front of other people (either people with dementia, families or professionals).

Encouraging honest feedback

Based on our experience of working with people with dementia, encouraging honest feedback tends not to be an issue, particularly those with more advanced stages of dementia. We would however recommend the facilitator introducing themselves and asking a bit about the service user to put them at ease and make sure the questions flow as part of a wider conversation. Facilitators can explain to the person with dementia why it is important to gain their views (see section 4). There may be people who are not used to giving their views, and so it is important to reflect back their answers and explore examples to ensure that the feedback is honest.

Consent

It is important when using this tool to first explain what you are doing and ask the person with dementia if they would be happy to answer a few questions about how they find the service. We found that most people are happy to participate but it is important to give people the choice and the option to opt out or to complete the questions at a time more convenient to them. This is even more important in a hospital ward setting where you may be talking to people in their hospital bed who are unable to move away from you if they do not wish to partake. Don't assume people are happy to talk to you about their care, always ask for their consent first. Even if someone has given consent verbally, be aware of body language that is telling you that the person is no longer interested or willing to take part.

Appendix A:

Good practice principles in using the dementia outcomes tool

Services that are present

Throughout our testing of these questions we always asked people with dementia to tell us about the service they were attending at that time. It is really important with people with dementia that they are not being asked questions that rely heavily on memory, e.g. about something that has happened earlier that day or week but what they think about what they are currently doing/ experiencing. In some of the community groups we attended people were going along to the group for the first time so would not have an opinion of it at the beginning of the session but were able to answer questions about the group towards the end of the session with great clarity.

Different service contexts


Having tested a similar approach and similar questions in a range of dementia services there are some fundamental differences in the way that people respond depending on the service they are receiving. This was most striking in a hospital ward setting as people in hospital did not choose to be there and some of the negative feedback about the wards was more of a reflection on the fact people would rather be in their own home and were not having an enjoyable experience. When comparing this to a community group service where people choose to go and take part in activities they may find fun, feedback on the same set of outcomes was generally very positive. For this reason it is important not to compare feedback from a hospital ward to that from a community group and to conclude that the hospital ward is not being as effective at meeting their service users outcomes. It is important in any setting to collate information (where possible) about why people are saying 'no' and to understand if any of the reasons can be mitigated or if they are to do with dissatisfaction with the circumstance. As the tool is being used more it may then be possible to compare feedback between different wards and between different hospitals to understand how the service compares with other similar services.

Appendix B:

Data capture tool for dementia outcomes

Below are the data capture tools/short surveys used to collate evidence that services are meeting the outcomes that matter most to people with dementia. Whilst there is similarity between these tools we have adapted the questions to make them relevant for different types of dementia services. The list of services is not exhaustive and more work is needed to further adapt the tool for use in other services such as home care and community nursing. We have avoided long sentences and highlighted key words that can be emphasised to aid comprehension.

Community Groups: Feedback on our service

Community groups
Feedback on our service



We would like you to tell us how you feel when you attend the [name of group]. There is no right or wrong answer and you don't need to give your name.

	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?				
Does the group support and understand you?				
Do you feel a sense of community ?				

Name (optional) _____

Measuring Outcomes in Dementia Services
December 2016
Page 15

Hospital Wards: Feedback on our service

Hospital wards
Feedback on our service



We would like you to tell us about your care whilst at [name of hospital ward]. There is no right or wrong answer and you don't need to give your name.

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

Name (optional) _____

Measuring Outcomes in Dementia Services
December 2016
Page 16

Care Homes: Feedback on our service

Care homes
Feedback on our service



We would like you to tell us how you feel about living at [name of care home]. There is no right or wrong answer and you don't need to give your name.

	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?				
Does the group support and understand you?				
Do you feel a sense of community ?				

Name (optional) _____

Measuring Outcomes in Dementia Services
December 2016
Page 17

Dementia advisor/navigator: Feedback on our service

Dementia advisor/navigator
Feedback on our service


We would like you to tell us how you feel about [NAME OF SERVICE]. There is no right or wrong answer and you don't need to give your name.

	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?				
Does the service support and understand you?				

Name (optional) _____

Measuring Outcomes in Dementia Services
December 2016
Page 18

We would like you to tell us how you feel when you attend the [name of group]. There is no right or wrong answer and you don't need to give your name.

	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?				
Does the group support and understand you?				
Do you feel a sense of community ?				

Name (optional)

.....

We would like you to tell us about your care whilst at [name of hospital ward]. There is no right or wrong answer and you don't need to give your name.

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

Name (optional)

.....

We would like you to tell us how you feel about living at [name of care home]. There is no right or wrong answer and you don't need to give your name.

	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?				
Does the group support and understand you?				
Do you feel a sense of community ?				

Name (optional)

.....

We would like you to tell us how you feel about [NAME OF SERVICE]. There is no right or wrong answer and you don't need to give your name.

	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?				
Does the service support and understand you?				

Name (optional)

.....

Appendix C:

Example of information produced from dementia outcomes tool

Below is an example of the type of information the dementia outcomes tool can produce. This example is based on data produced from the hospital ward outcome tool. The data itself is fictional and for a made up hospital 'St Clair's', however it should give an idea of how information gained by these tools can be used to monitor whether outcomes are being met for people with dementia.

Report for St Clair's Hospital

On the 15th October facilitators came to St Clair's Hospital to talk to inpatients with a diagnosis of dementia in order to measure the care received in hospital against a series of outcomes that matter most to people with dementia and their carers, based on the dementia i-statements. The questions can be seen in table A.

Table A: The questions asked of dementia patients based on the dementia i-statements

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

A total of 32 patients with dementia were identified, of which 21 completed the set of questions.

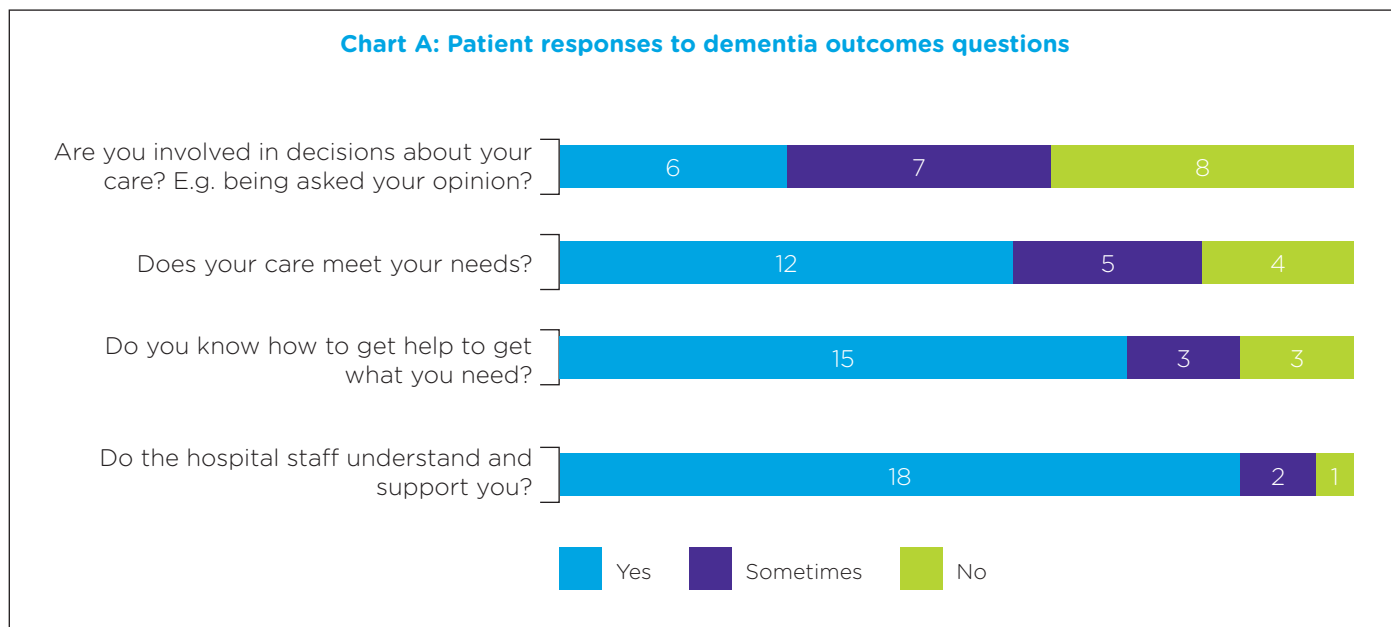
The remaining 11 patients were not interviewed for the reasons set out in table B:

Table B: Breakdown of non-responders

Reason for non-response	No. of patients
Hospital bay had been quarantined to prevent spread of infection	3
Patient does not speak English	3
Patient declined	2
Carer declined on behalf of patient	1
Patient was not in their bed	1
Patient had just received a diagnosis and not deemed appropriate	1

Results

Chart A below details the breakdown of responses to the 4 questions:



In some cases answers may have had more to do with general mood rather than specific care, in particular several patients did not want to be in hospital and were waiting to hear when they would be discharged so were feeling particularly negative about their experience.

One patient did not feel they wanted to be involved in decisions about their care and felt that clinical experts were better placed to make all decisions on their behalf. When prompted they did feel they made decisions about what to eat and how tilted their bed was.

Not all patients had a good understanding of what their needs are, particularly those awaiting a diagnosis. Some felt it would be hard for the hospital to meet their needs if their needs themselves were unclear.

Patients generally felt that they knew how to get help as they each had a buzzer and found staff on the whole to be responsive when they needed help.

Discussion points:

- How can patients feel more involved in their care?

Next Steps:

- Compare results to other hospitals using the same outcome measurement
- Share results with commissioners
- Put in place action plan for improvement