

# Buckinghamshire County Council

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## Shadow Health and Wellbeing Board 13 October 2011

### Citizens' Jury Outcome Report



INVESTOR IN PEOPLE





# Buckinghamshire Citizen's Jury Learning and Outcomes Report

## Dementia Services

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Friday 16<sup>th</sup> to Sunday 18<sup>th</sup>  
September 2011

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## 1. Executive Summary

At the beginning of 2011 The Department of Health allocated resources to encourage new commissioning consortia to pilot approaches to public involvement in their local areas. Buckinghamshire Commissioning Consortia were awarded a grant of £50k and chose to set up a six month project to demonstrate local participation in a Citizen's Jury, as a method for public engagement and as a tool for influencing future commissioning plans/priorities. The project was sponsored and led by The Transformation Team, set up by the Clinical Commissioning Groups in Bucks involving other partners.

A project manager with experience of running a Citizen's Jury was commissioned to work with an Advisory Board for six months to plan and run the Citizen's Jury. The Advisory Board included representatives from health, including GPs and commissioning managers, social services, overview & scrutiny and lay representation.

Evidence indicates that Citizen's Juries are most effective when prioritisation is required. The Advisory Board were very aware that the subject matter chosen needed to be one in which a forth-coming decision would need to be made. After an initial ideas session and with reference to local priorities as well as on-going work, discussions took place with local commissioners across health and social services.

Time was then taken to craft the questions that would be put to the Jury. A draft of these was sent to the Buckinghamshire Dementia Strategy Board to ensure that these were questions that would add value to local decision-making. The final questions put to the Jury are set out below.

### Core question

- We want dementia patients and their families to receive the best care possible. Considering the services we currently have in Buckinghamshire, and what we know is 'good practice', which services does the Jury believe should be prioritised over the next 18 months for development?

### Supplementary questions

- What are the most effective ways of providing information to people with dementia and those who care for others with dementia?
- What would be effective ways of encouraging individuals to seek help at an early stage of the disease?
- How can dementia patients best be supported in health and social care settings such as residential care homes and hospitals?

An advert seeking volunteers to sit on the Jury was distributed across Buckinghamshire through community groups, GP surgeries and via a number of mailing lists. The invitation to apply was open for three weeks. More than 80 people applied for the 12 places and it was agreed that a ballot should be drawn to pick the 12. In order to ensure a cross section of the population the ballot was divided into groups and drawn to ensure a selection of ages, geographical location, gender, ethnicity and educational attainment.

The Jury sat from Friday evening until Sunday afternoon and listened to evidence from a variety of clinical experts, carers and voluntary sector representatives and joint commissioners as well as a national lead for Dementia. Having listened to the evidence the Jury identified what they considered to be most important in terms of the development of dementia services in Buckinghamshire and they were asked to put these into priority order. The top four priorities under each question are outlined below.

### **What are the most effective ways of providing information to people with dementia and those who care for others with dementia?**

#### **Priority**

##### **1. Key advisory for point of contact**

*What:* named contact/support with service knowledge

*Why:* to reduce stress and confusion

##### **2. At initial diagnosis provide information on a variety of services available**

*What:* no jargon 'one pack'

*Why:* reduce stress, confusion and give a pathway

##### **3. National advertising and local promotion**

*What:* TV, press plus local school visits, campaign bus etc

*Why:* to reduce taboo, encourage early help

##### **4. Taboo**

*What:* change attitudes; change name? Provide info

*Why:* to make it more socially acceptable

### **What would be effective ways of encouraging individuals to seek help at an early stage of the disease?**

#### **Priority**

##### **1. GPs should act earlier**

*What:* be pro-active and reactive

*Why:* To ensure appropriate referrals are made in a timely manner

##### **2. Screening**

*What:* regular cognitive/memory testing for age 60 plus and high risk/symptomatic

*Why:* to identify those with dementia early

##### **3. Public awareness**

*What:* to educate the public re: dementia

*Why:* to make it clear what help is available and the implications of not seeking help

##### **4. Listen to carers**

*What:* GPs and other respond to carer/family concerns

*Why:* To help ensure people who need support/help receive it /support carers

### **How can dementia patients best be supported in health and social care settings such as residential care homes and hospitals?**

#### **Priority**

##### **1. Work in partnership with families**

*What:* every decisions families to be consulted and listened to

*Why:* feeling of being part of decision making/supported

##### **2. Big society centres to support families**

*What:* community organisations doing their part

*Why:* cost productive and accessible to enable people to live at home longer

##### **3. Specialist training and education**

**What:** dementia training for all staff

**Why:** raise awareness, encourages early diagnosis

**4. One provider – over-all**

**What:** one gateway

**Why:** avoids confusions, relieves stress, efficient

A key learning point from the exercise was that the Jury were very well able to prioritise what they felt were the most important service developments whilst understanding that there are limited resources.

At the end of the event the Jury were asked to reflect on:

- what went well
- what would have been even better if....
- what I will tell others

In summary the Jury felt in terms of what went well: the organisation and planning; learning about dementia; respect of jurors for each other; guest speakers (witnesses) and good interaction.

In terms of what would have been even better if: we had more time; personal stories more balanced?; pre-jury reading material; we get to follow up on this; tone down the pace and stay over-night to allow more discussion time.

The Jurors suggest what they would tell others might include: I will encourage others to volunteer; I have the confidence to talk about dementia; that there is help out there; very good process and fantastic to be asked; intense but worthwhile; local community should develop its own support; there is a need for more awareness.

Immediately after the Jury the key priorities were put onto the Buckinghamshire Citizen's Jury web site [www.buckinghamshire.nhs.uk/have-your-say/citizens-jury/](http://www.buckinghamshire.nhs.uk/have-your-say/citizens-jury/) and emailed out to Jury members, witnesses and other interested parties. This Learning and Outcomes Report will then be discussed at:

- Dementia Strategy Board
- Clinical Commissioning Group
- Health and Well Being Board
- Overview and Scrutiny Committee
- Department of Health

These organisations' responses to the outcomes of the Jury will be put onto the website and the Jurors will be asked to continue to input into future work on this topic.

## 2. Background

At the beginning of 2011 The Department of Health allocated resources to encourage new commissioning consortia to pilot approaches to public involvement in their local areas. Buckinghamshire Commissioning Consortia was awarded a grant of £50k and chose to set up a six month project to demonstrate local participation in a Citizen's Jury, as a method for public engagement and as a tool for influencing future commissioning plans/priorities. The project was sponsored and led by The Transformation Team, set up by the Clinical Commissioning Groups in Bucks involving other partners.

## 3. Why a Citizen's Jury approach

Research conducted into deliberative models of participation indicates that, in circumstances where prioritisation is required, they offer advantages over many traditional approaches to consultation in that they:

- bring together a cross-section of the population so that deliberations reflect on a variety of experiences and viewpoints
- are run by independent organisations to ensure fairness
- produce outcomes that reflect citizens' considered judgements

Evidence suggests that if a diverse range of citizens are brought together they have the capacity and skills to deliberate and make recommendations on complex public policy issues.<sup>1</sup>

Commissioners were aware that a great deal of public involvement work already exists across the county but they were keen to experiment with a model that was different to the existing mechanisms. Never-the-less it was made clear that the learning needed to go beyond how to run a Citizen's Jury and be used to demonstrate good practice in involving local people. The process was intended to engage local commissioners and the learning from it influence future public involvement initiatives. Given the expense and time involved in running this type of event it is unlikely that the exact same model would be repeated on a regular basis it was therefore important that the knowledge gained be transferable to other work and that the conclusions drawn by the Jury would influence future commissioning decisions.

## 4. Project infrastructure

At the outset a project manager with experience of running a Citizen's Jury was commissioned to work with an Advisory Board for six months to plan and run the Citizen's Jury. The Advisory Board included representatives from health, including GPs and commissioning managers, social services, overview & scrutiny and lay representation. Membership of the Advisory Board is attached Appendix 1.

The Advisory Board established its terms of reference and met on a two weekly basis for the first two months and there-after monthly. The Board took the time to consider the learning from other Citizen's Juries that had been run in the UK and internationally. The Jefferson

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<sup>1</sup> **Beyond the Ballot 57 Democratic Innovations from Around the World** A report for the POWER Inquiry  
Graham Smith



Center work on Citizen's Juries was a specific source of guidance throughout the planning stages.<sup>2</sup>

Early discussions of the Advisory Board focused on the principles that should underpin the Citizen's Jury. It was agreed that:

- I. The topic chosen for the Jury's consideration must be one which Commissioners will need to make future decisions and therefore be of value and relevance
- II. Commissioners must be committed to listening to and responding to the Jury
- III. The learning from the Citizen's Jury needs to be applicable to future commissioners in terms of the principles for involving local people, i.e. not just the mechanics of running a Citizen's Jury

Throughout the planning stages of the Citizen's Jury detailed attention was paid to communications. This took the form of an initial communications plan that detailed the various channels of communication including when and how communication would take place. A web site was established on the NHS Bucks Health site but other web sites (for example GP practices) were encouraged to link to this. At the outset the web site was a key route to recruiting the Jury but was then developed to provide more information about Citizen's Juries and about how the Buckinghamshire event would work. In addition briefing update papers were produced for key stakeholders including the Department of Health and local MPs. A press release was issued to encourage people to volunteer to be on the Jury. The web site address is:

[www.buckinghamshire.nhs.uk/have-your-say/citizens-jury/](http://www.buckinghamshire.nhs.uk/have-your-say/citizens-jury/)

The web site is being used to communicate the outcomes from the Jury.

## **5. Deciding on the topic and questions to be addressed**

Evidence indicates that Citizen's Juries are most effective when prioritisation is required. The Advisory Board were very aware that the subject matter chosen needed to be one in which a forth-coming decision would need to be made, otherwise there was a danger that the Jury's deliberation would have no impact. Together the Board considered the key strategic priorities for Buckinghamshire and prioritised those areas that would require local decisions about the future shape of services.

After an initial ideas session and with reference to local priorities as well as on-going work, discussions took place with local commissioners across health and social services. Suitable topics were narrowed down to 'Where to go for Urgent Care' and 'Which dementia services should be a priority for development in Buckinghamshire'.

After full discussion and further advice it was decided the focus for the Jury would be dementia services. The Advisory Board felt that Dementia would be a topic that would have a broad appeal across all sectors of society and would be one that many people could relate

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<sup>2</sup> The Citizen's Jury Handbook. [www.jefferson-center.org](http://www.jefferson-center.org)

to and want to get engaged in. This work builds upon the work undertaken by the Buckinghamshire County Council Overview and Scrutiny Committee Review of Dementia Services and the Buckinghamshire Dementia Strategy. Both these reports set out good practice in terms of services required but it was felt that the Jury process would help prioritise which services should be developed over the next 18 months.

Time was then taken to craft the questions that would be put to the Jury. A draft of these was sent to the Buckinghamshire Dementia Strategy Board to ensure that these were questions that would add value to local decision-making. The final questions put to the Jury are set out below.

### **Core question**

- We want dementia patients and their families to receive the best care possible. Considering the services we currently have in Buckinghamshire, and what we know is 'good practice', which services does the Jury believe should be prioritised over the next 18 months for development?

### **Supplementary questions**

- What are the most effective ways of providing information to people with dementia and those who care for others with dementia?
- What would be effective ways of encouraging individuals to seek help at an early stage of the disease?
- How can dementia patients best be supported in health and social care settings such as residential care homes and hospitals?

## **6. Recruitment of the Jury and witnesses**

An advert for volunteers was distributed across Buckinghamshire through community groups, GP surgeries and via a number of mailing lists. Volunteers were invited to apply for a place on the Jury either via the web site or through completing a paper form. The advisory Board and their organisations and contacts were an important mechanism for advertising the Jury. The local paper also ran a small article on the Jury.

The invitation to apply was open for three weeks. More than 80 people applied for the 12 places and it was agreed that a ballot should be drawn to pick the 12. In order to ensure a cross section of the population the ballot was divided into groups and drawn to ensure a selection of ages, geographical location, gender, ethnicity and educational attainment.

Twelve people were invited to join the Jury and all twelve accepted.

Unsuccessful applicants were informed by email or post (where no email was available). They were invited to stay connected via the web site and send their views about the key areas for discussion to the project manager. A number of people took the time to write to say how disappointed they were not to have been selected to sit on the Jury. Three people subsequently wrote in with some comments they wanted the Jury to take into account. These comments, focussed on the need for information for patients and their carers and on advocacy, were addressed through the evidence given by the witnesses.

Witnesses were chosen on the advice of the Advisory Board, plus the experience of staff at Buckinghamshire County Council who had been involved in the Overview and Scrutiny Review of Dementia Services. Witnesses were chosen to reflect their knowledge and experience of dementia in four key areas:

1. As a provider of services for people with dementia
2. As a source of information and advice for people with dementia and their families
3. As people who had experienced dementia in their families
4. As commissioners of services for people with dementia

Appendix two: Outline of the Jury Agenda provides more information about the witnesses.

Witnesses and Jurors were fully briefed prior to the event about how the Jury would work. The Jury was not sent any reading material in advance of the Jury but they were alerted to the web site. This was a conscious decision by the Advisory Board as it was felt important not to 'overload' people with information prior to the event. It was also the case that the Advisory Board had sought to engage local people who did not necessarily have any prior knowledge of dementia and that the witnesses would provide the detail throughout the Jury. One Juror reflected at the end of the process that advance reading would have been useful.

## **7. Design of the Citizen's Jury and agenda**

The Jury sat from 6pm on Friday 16<sup>th</sup> to 4pm on Sunday 18<sup>th</sup> September at the Clare Foundation Saunderton. Eleven of the twelve Jurors recruited came to the event and all eleven participated for the full 2.5 days. The twelfth member was unexpectedly taken ill on the day the jury began. Expert facilitators were recruited to help design and run the event. They concentrated on designing each element of the Jury process in order to ensure maximum participation and the synthesis of complex information into the final recommendations. Appendix 2 provides an abridged version of the design of the event. This design could be used again for a future Citizen's Jury but the techniques used to encourage reflection and deliberation could also be used for other types of events.

In summary the 2.5 days addressed the following topics.

### **Friday**

Welcome session: introduction to Citizen's Juries and how they work; the purpose of this jury and how it will work together to achieve its aim.

### **Saturday**

An overview of dementia by a Consultant Psychiatrist

View-points from providers of dementia care: a Matron from an acute hospital; a GP and a manager of a care home specializing in dementia.

Perspectives from patients, carers and residents of Buckinghamshire including personal stories from spouses of people with dementia and representatives from The Alzheimer's Society and Carers Bucks.

## Sunday

A national perspective on best practice

Commissioning dementia services in Buckinghamshire. Joint Commissioners from Buckinghamshire County Council.

Jurors review the evidence, test ideas, form recommendations and give feedback to commissioners who are invited to this session

After each set of witnesses the Jury were reminded of the four questions they were being asked to address and were given the opportunity

1. To reflect on and describe their reactions to what they had heard
2. To discuss ideas and thoughts relating to the three supplementary questions

A 'graffiti' wall was used to capture their reflections and ideas. This wall was used as a way to map the jury's journey through all of the 'inputs provided over the course of the weekend. The facilitators then worked with the Jury on Sunday to distil their findings onto an 'output' graffiti wall, which was used to aid the feedback given by four volunteer jurors to the Commissioners and witnesses who attended on Sunday afternoon.



Jurors 'graffiti' wall

## 8. Outcomes from the Jury

Once the jurors had identified what they considered to be most important in terms of the development of dementia services in Buckinghamshire they were asked to put these into priority order. The top four priorities under each question are outlined below.

### **What are the most effective ways of providing information to people with dementia and those who care for others with dementia?**

#### **Priority**

##### **1. Key advisory for point of contact**

*What:* named contact/support with service knowledge

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##### **4. Taboo**

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### **What would be effective ways of encouraging individuals to seek help at an early stage of the disease?**

#### **Priority**

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##### **4. Listen to carers**

*What:* GPs and other respond to carer/family concerns

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### **How can dementia patients best be supported in health and social care settings such as residential care homes and hospitals?**

#### **Priority**

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*Why:* cost productive and accessible to enable people to live at home longer

##### **3. Specialist training and education**

*What:* dementia training for all staff

*Why:* raise awareness, encourages early diagnosis

#### **4. One provider – over-all**

**What:** one gateway

**Why:** avoids confusions, relieves stress, efficient

In addition, the Jurors considered the key actions from the current Dementia Strategy presented by the Joint Commissioners. The facilitators used a prioritisation method, to help the jury prioritise each of these using the criteria of: a) impact and b) ease of implementation. This raised important issues for the Jurors about the prioritisation of services and how difficult commissioning decisions are made. The top four initiatives the Jury felt should be prioritised are listed below.

1. Training for general nurses in acute hospitals re: dementia care should be mandatory
2. In-reach by the multi-disciplinary team into care homes to support/train staff
3. Tool kit for GPs to support early diagnosis (one pack with a variety of information and support)
4. All care homes to sign up to 'Dignity in Care' 10 principles

Clearly there are synergies between what the Jury felt were priorities for the development of services in Buckinghamshire and the priorities outlined in the Dementia Strategy.

Commissioners have committed to taking into account the priorities outlined by the Jury and will be considering how these can now be incorporated into plans for the next 18 months.

Perhaps the most striking difference is the emphasis the Jury placed upon

1. Providing people with dementia and their carers (one pack) information at the point of contact with the GP
2. The need to 'de-stigmatise' dementia. This they felt would go a long way in terms of encouraging people to seek help at an early stage.

#### **9. Reflections on the process from the Jurors**

At various points in the process we the Jury were asked to reflect on what they had heard from witnesses and on the Citizen's Jury process itself. Some of their reflections are summarised below.

##### ***On the evidence presented by clinical staff and a care home manager:***

- 'Impressed by the Butterfly method and the 'This is Me' campaign
- 'Impressed by the knowledge of the staff who came along today'
- Worried by the mixing of patients on the wards
- Worried by the complexity of organisations that should be working together
- Worried by the fact that carers should be more central
- Surprised by how candid the staff who came were
- Worried that there is no 'dementia advisor' role funded

##### ***On the evidence presented by the voluntary sector and carers:***

- Worried that the voluntary agencies can't cope with all the demand for support
- Impressed by the Alzheimer's Society

- Worried by the difficulties experienced by carers in receiving appropriate help
- Impressed with the honesty of the people who told us their stories – thanks
- Surprised that it takes so long to diagnose dementia
- Impressed that carers manage for so long with poor support and advice
- Impressed with carers determination to look after their loved ones
- Worried about lack of support from social services
- Surprised that respite care is not working

***On the evidence presented by joint commissioners:***

- Surprised about the amount of money being spent but not achieving an effective result
- Impressed and reassured that there is a national strategy and a local strategy
- Impressed that locally we are getting lay people involved in decision-making
- Worried: I need more information about local services
- Surprised that the national strategy is 'new'
- Impressed by our joint commissioners and their commitment to this issue

At the end of the event the Jury were asked to reflect on:

- what went well
- what would have been even better if....
- what I will tell others

Here are some of their answers

***what went well:***

- Organisation and planning
- Learning about dementia
- Respect of jurors for each other
- Guest speakers (witnesses)
- Good interaction

***what would have been even better if....***

- We had more time
- Could the personal stories have been more balanced?
- Pre-jury reading material
- We get to follow up on this
- Tone down the pace
- Over-night to allow more discussion time

***What I will tell others***

- I will encourage others to volunteer
- I have the confidence to talk about dementia
- There is help out there

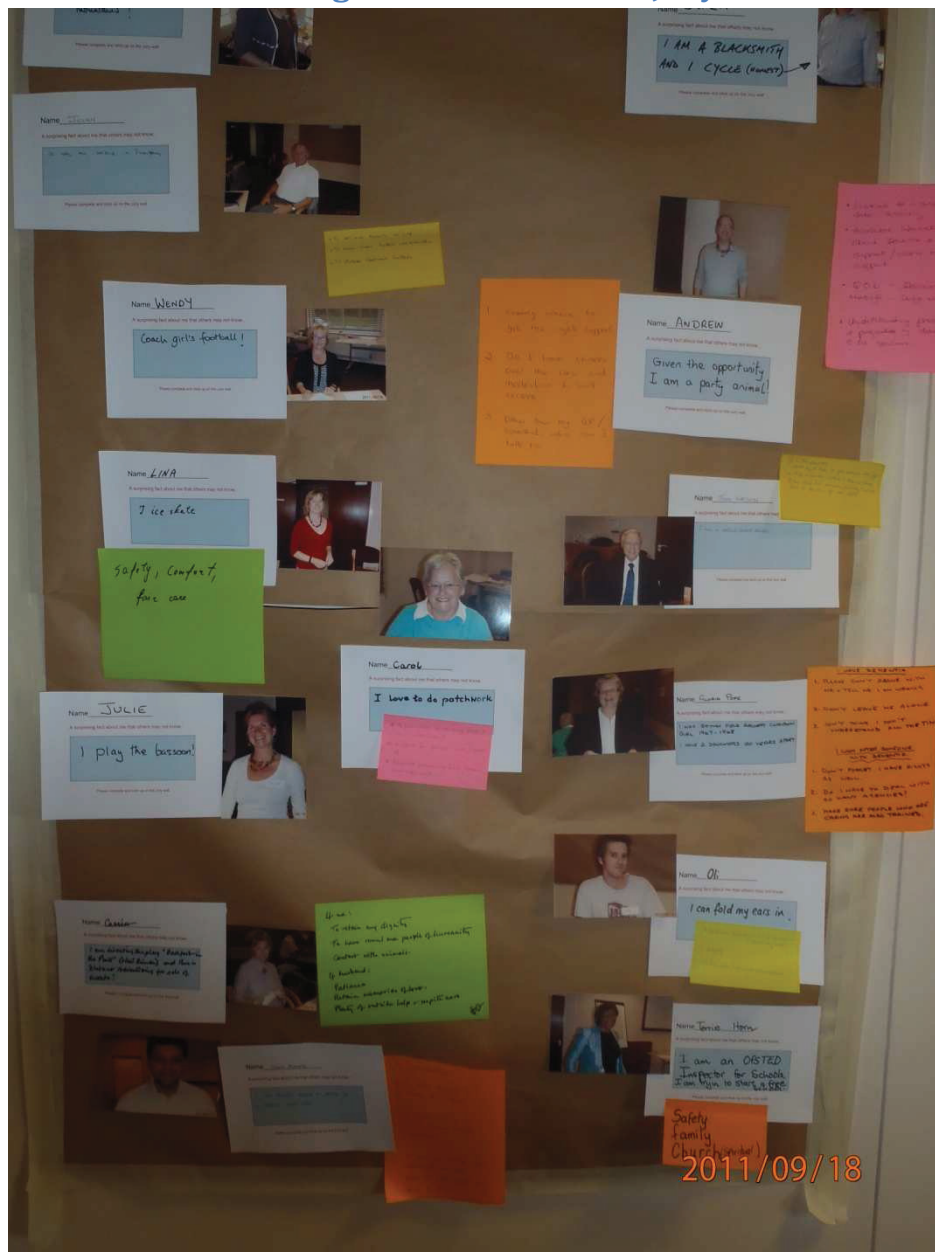
- Very good process and fantastic to be asked
- Intense but worthwhile
- Local community should develop its own support
- There is a need for more awareness

We also asked jurors to complete a short questionnaire before and after the Jury. This enabled us to compare their views and perceptions before and after they had participated in the event. In summary this told us:

- That there were a variety of ways in which people heard about the Jury including: GP surgery, word of mouth, email and via the web.
- That people had a variety of reasons for getting involved in this Jury including: that they wanted to learn more, that they had personal experience in their family of Dementia and that they were in caring roles themselves.
- We asked people before and afterwards whether they felt local people could make a difference to how services are developed. Before the Jury six people said yes and four people were not sure. After the jury one person was not sure because of financial constraints, the reminder all said yes they felt local people could make a difference.
- We asked people before and afterwards whether they were confident that their input would be taken into account by decision-makers. Before the jury six people said yes and four were unsure. After the Jury seven people said yes and three were unsure.
- There was a strong message from the jurors that they wanted to stay engaged with this topic, that they were willing to get involved in other health issues and that they felt the Citizen's Jury had been useful.



## 10. The Buckinghamshire Citizen's Jury Members



We have not identified the Jurors by name in this report. The Jury were representative, in terms of their characteristics and where they live of residents of Buckinghamshire, but they were not representing Buckinghamshire residents. They did give permission for their photographs to be used in reports such as this but we did not ask their permission to divulge their names. The Advisory Board discussed this issue at their last meeting and decided that in the circumstances no names should be published.

## 11. Next steps

Immediately after the Jury the key priorities were put onto the Buckinghamshire Citizen's Jury web site and emailed out to Jury members, witnesses and other interested parties. This Learning and Outcomes Report will then be discussed at:

- Dementia Strategy Board

- Clinical Commissioning Group
- Health and Well Being Board
- Overview and Scrutiny Committee
- Department of Health

These organisations' responses to the outcomes of the Jury will be put onto the website and the data base of 80 people who expressed an interest in the work will be alerted to this information.

In addition, the Advisory Board were keen that the Jurors remain engaged with this topic as they now have a great deal of understanding on the topic of dementia. Ten of the eleven Jurors have expressed an interest in further involvement and they will be contacted by the Joint Commissioners of dementia services to discuss their further involvement.

## 12. Summary of key learning

Key learning from the Buckinghamshire Citizen's Jury has come from a number of sources including feedback from the Jury themselves and feedback from Advisory Board members.

### ***In summary: on the planning arrangements***

Over-all it was felt that the planning and organisation of the Jury had been instrumental in ensuring it worked well and as intended. The Advisory Board was chosen carefully to ensure that all interested parties were represented and that there was a mix of professional organisations and lay people. Advisory Board members took participation in the planning of the event seriously and gave a considerable amount of time (fortnightly meetings at the outset) to this work. Feedback from members of the Advisory Board included that:

“meeting schedules were established at outset, with specific goals identified for each meeting/stage. I think that the involvement of participants across health and social care worked particularly well and that the wide variety of skill sets brought by members were particularly useful at different periods during the process. Also it was very useful to hear views from social care.”

and,

“Focussing on an issue which is current (new strategy), and one in which investment decisions need to be made. Topic crossed social and health care, therefore engaging a wide audience. Good advertising of pilot through briefings, good use of web and stakeholder list.”

### ***In summary: on the Jury process***

The mechanisms used to recruit the Jury were varied and as such were successful in bringing the Jury to the attention of the public. Some jurors said they heard about the Jury from a variety of sources and that after they had come across it a few times they were more inclined to put their names forward. Effort was made to try and attract people who would not necessarily put them-selves forward for this type of event. Over-all this approach was successful and there were a range of people some of whom do participate in other forums but some who had never taken part in a venture such as this.

Whilst the methods of advertising the Jury were successful in terms of attracting a wide pool of people to volunteer this inevitably meant that many people were disappointed not to be taking part. Future exercises of this type may want to give more consideration to how to continue to engage those not chosen to participate on the specific event. This requires the web site to be designed in such a way as to encourage real time discussion etc. and mechanisms for emailing large numbers of people.

Other considerations for any future such exercise include:

- using internal (NHS/local) facilitators to enable the learning to be 'in house'.
- decide on decisions we need to involve the public in and then the most appropriate PPI model, not the other way around.
- if this were to be repeated then if the same format were used it could possibly be done more quickly if the group were presented with a specific topic, steering group members being invited accordingly.
- two jurors expressed the opinion that a '£250 payment' for their time over the weekend was unnecessary. This was not an issue the Advisory Board addressed in detail prior to the event as the Jury was based upon a model where a payment was made. Consideration might be given in future about whether an 'expenses only' reimbursement policy should be adopted.
- one juror questioned whether the personal stories from witnesses could have been more balanced. Consideration might be given in future to trying to ensure that where positive experiences have taken place in health and social care these too are represented. Having said that many Jurors commented on what a powerful impact the personal stories had had on them.

### ***In summary: on the Jury outcomes***

Running a Citizen's Jury is resource intensive in terms of time, people, money, and skills. It is a legitimate question to ask is this value for money? This will depend on a) how much difference the priorities drawn up by the Jury make to local commissioning decisions (this will not be known for some time) and b) whether the learning and principles of good public involvement can be transferred and used in other circumstances at a more economical cost.

What the Jury did demonstrate was that local people are willing to give up a substantial period of their time to participate in a dialogue that they feel is important. The Jury were able to work together and agree a set of priorities that were based on the evidence presented to them. Importantly the Jury became aware of the real issues involved in making decisions about healthcare priorities. The exercise where they needed to assess impact and ease of implementation and where they were asked to prioritise the initiatives they came up with provoked much discussion. On reflection the Advisory Board felt that introducing lay people to this type of commissioning 'dilemma' was an important outcome of the Jury.

A few members of the Jury felt that more time would have been helpful to them. The Advisory Board decided to run the Jury over a weekend in order to enable people who work

during the week to attend. Some Juries are run for 2 or 3 days with a gap and then another 2 or 3 days. This could be an option but adds to the resources required for such an exercise and is probably more suited to a national Jury than a local one.

***In summary: on the transferable learning***

There were a number of principles of good public engagement in this process that are transferable to other work, these include:

- use a variety of sources to engage people and clear communication
- use web sites to provide information and to encourage people to register their interest, but also use paper application forms for those who do not use the internet
- put time and effort into the design of the event and use skilled facilitators to ensure people understand what is expected of them and are supported to achieve the desired outcome
- ensure people are informed after an event about what happened to their input
- ensure those commissioning the event are willing to listen to the outputs and are clear about how these will be used.

## Appendix 1 Advisory Board Members

|                         |  |
|-------------------------|--|
| Andrew Walker           | Chairman of Local Involvement Network  |
| Sarah Jeffery           | Head of Communications – The Practice PLC  |
| Dr Jonathon Pryse       | GP Buckingham  |
| Rebecca Carley          | Locality Services Manager Bucks CC   |
| Elaine Young (sponsor)  | Executive Director United Commissioning (Leading transition to Clinical Community) |
| Dr Kevin Suddes         | GP Aylesbury   |
| Clare Blakeway-Phillips | Assistant Director -Partnership Development NHS Buckinghamshire                    |
| Deborah Sanders         | BCCP Lay Exec Member   |
| Helen Peggs             | Head of Communications, NHS Buckinghamshire  |
| Marion Lynch            | Associate Dean Primary Care Bucks and Oxford                                       |
| Noel Radcliffe          | Practice Manager   |
| Gareth Collings         | Practice Manager   |
| Cllr Mike Appleyard     | Chairman, Bucks CC Overview and Scrutiny Committee                                 |
| Julie Wells             | Project Manager  |

## Appendix 2 Design of the Jury

### Citizen's Jury on Dementia Services - September 2011

FRIDAY 16<sup>th</sup> September – Getting to know each other and clarifying the process

| TIME | TIMING  | ACTIVITY   | PURPOSE  | WHO                     |
|------|---------|--|--|-------------------------|
| 4.30 |         | PREPARATION – set up room / resources / graffiti walls   |  | JW/SG/DW                |
| 6.30 | 15 mins | Arrival & refreshments (choose menu options for Sat dinner)<br><br>- Instant photos + name labels<br>- Completion of “one thing about me...” card<br>– stick up photo and card against name on ‘Jury’ section of Graffiti Wall<br>- Folder for weekend | Facilitators / Jury ‘meet & greet’   | ALL                     |
| 6.45 | 15      | Housekeeping & Introductions<br><br>Welcome & Brief background of work and purpose of Citizen's Jury ('voice' not decisions)   | (CEO United Commissioning)   | SG<br><br>Louise Patten |
| 7.00 | 5       | Date on Coins – “ <i>what does that year mean to you?</i> ”<br>- quick chat with neighbour<br>- 2-3 people share with whole group  | Ice-breaker  | SG.                     |
| 7.05 | 25      | Speed Networking<br>- 2 circles of 6 chairs<br>Qu: “ <i>what made you want to be a part of this jury?</i> ” – 1 min each   | WARM UP<br><br>Getting to know each other & motivations                              | DW<br><br>ALL           |
| 7.30 | 10      | Briefing and outline for the weekend –<br>- purpose & process,<br>- core & supplementary questions<br>- expert witnesses<br>- use of graffiti wall (input & output)  | BRIEFING<br>Provide clarity re. aims, process and expectations for the next 48 hours | DW/SG                   |
| 7.40 | 10      | In Pairs – reflection on the briefing<br>a) <i>How am I feeling about the weekend ahead?</i><br>b) any ‘burning question’ / concerns about the next 24 hours – capture on cards & hand to facilitator  | Check people clear + bring up any issues /concerns that need addressing              | DW<br><br>ALL           |

|      |    |   |  |               |
|------|----|---|--|---------------|
| 7.50 | 15 | Small group (or plenary?) discussion<br>- <i>If I or a loved one had dementia, the 3 most important things for me would be....</i><br>- <i>capture on cards and stick up on graffiti wall in Jury section</i> | VALUES<br><br>Surface different value bases / motivations / perspectives | SG<br><br>ALL |
| 8.10 | 10 | Work through burning questions  |  | SG/DW         |
| 8.20 | 5  | <i>How will we work together as a group over the next 48 hours?</i>   | Establish agreed ground rules for the weekend.                           | SG<br>ALL     |
| 8.25 | 5  | Reminder of timings and process for Saturday morning (incl outputs)   | Ensure all clear about start times and what to expect first thing        | DW            |
| 8.30 |    | CLOSE   |  | ALL           |

**SATURDAY 17<sup>th</sup> September: Hearing the evidence**  
(providers & receivers of care)

| TIME      | TIMING | ACTIVITY  | PURPOSE  | WHO   |
|-----------|--------|---|--|---|
| From 9.15 |        | Arrival & Coffee  | <i>Prepare flipchart – outline of day/ breaks</i>    | ALL   |
| 9.30      | 15     | Welcome<br>- Outline of the day<br>- Witnesses (put names on flipchart)<br>- Outputs<br>- Any outstanding queries about the day<br>- reminder of ground rules | PREPARATION<br>Ensure all clear about the day ahead. | DW/SG   |
| 9.45      | 30     | WITNESS: Dr Brian Murray – Consultant Psychiatrist<br><br><i>Dementia basics: lay person's description of dementia &amp; services</i><br><br>Q&A              | Deepen understanding of dementia                     | Fac – <i>intro (who, were from, why here)</i> |
| 10.15     | 5      | Introduction of WITNESS PANEL<br>- 3 witnesses from different perspectives in health and social care  |  | Fac   |
| 10.20     | 10     | WITNESS: – Toby Gillman GP<br><br><i>What's it like to be a GP and respond to / have early discussions about dementia?</i>                                    | Primary Care perspective                             |   |

|         |    |  |   |                         |
|---------|----|--|---|-------------------------|
|         | 5  | Clarification Q&A  |   |                         |
| 10.35   | 10 | WITNESS: Jo Birrill – Matron, Stoke Mandeville Hospital – SWAP with GP<br><br><i>What are the challenges of caring for people with dementia in an acute setting?</i>   | Acute Hospital perspective  |                         |
|         | 5  | Clarification Q&A  |   |                         |
| 10.50   | 10 | WITNESS: Mike Tullet – Manager, Chiltern View Care Home<br><br><i>What’s important for caring for people with dementia in a care home setting?</i>   | Care Home perspective   |                         |
|         | 5  | Clarification Q&A  |   |                         |
| 11.05   | 15 | <b>COFFEE BREAK</b>  |   | ALL                     |
| 11.20   | 25 | Panel Discussion<br><br>- facilitated Q&A session with panel plus Brian Murray (focused on 3 questions)  | Explore differences between the 3 perspectives<br>Deepen Jury’s understanding | Fac.                    |
| 11.45   | 40 | a) Reaction Cards:<br><i>What impressed you? surprised you? worried you?</i><br><br>b) Capture cards (3 questions)<br>- discussion in trios<br>- capture on cards<br>- stick up on graffiti wall in Witness section. | REFLECT & CAPTURE<br><br>- on input wall                                      | SG<br><br>DW<br><br>ALL |
| 12.25   | 5  | Overview of afternoon session  | Ensure clarity of process   | DW                      |
| 12.30   | 60 | <b>LUNCH</b>   |   |                         |
| 1.30 pm | 5  | Energiser – 123  | Counter after-lunch slump!  | SG.                     |
| 1.35    | 5  | Intro to witnesses   |   |                         |
| 1.40    | 10 | WITNESS: Nicole Palmer, support Services Manager, Alzheimer’s Society<br><i>An overview of the Alzheimer Society’s work</i>  | Third Sector perspective  |                         |
|         | 5  | Q&A  |   |                         |
| 1.55    | 15 | WITNESS: M J R, husband of wife with Alzheimer’s<br><br><i>“Our journey together”</i>  | Relative’s perspective  |                         |



|      |    |   |   |  |
|------|----|---|---|--|
|      | 5  | Q&A   |   |  |
| 2.10 | 15 | WITNESS: M M O, wife of husband with Alzheimer's<br><br><i>'Caring for someone with Dementia'</i><br>Q&A  | Relative's perspective (incl early diagnosis)   |  |
|      | 5  |   |   |  |
| 2.30 | 10 | WITNESS: Ann Whitely, Carers Buckinghamshire  | Carer organisation perspective  |  |
|      | 5  | Q&A   |   |  |
| 2.45 | 25 | Facilitated discussion / Q&A session with all witnesses (focused on 3 questions)  | Deepen Jury understanding   | Fac.   |
| 3.10 | 20 | <b>TEA BREAK</b>  |   | ALL  |
| 3.30 | 10 | 2 x Alzheimer Society Film clips: experiences of people with dementia   | 'Patient' perspective   |  |
| 3.40 | 40 | Reaction + Capture cards<br>- discussion in trios ( <i>swap around</i> ) /whole group?<br>- capture on cards<br>- stick up on graffiti wall in Witness section.   | REFLECT & CAPTURE<br><br><i>- on input wall</i>   | ALL<br><br><i>SG/DW to theme from input wall</i> |
| 4.10 | 10 | Set up for session –<br>What does the story look like so far?<br>What needs to be considered next?  |   | Fac.   |
| 4.20 | 45 | 'Free Space'<br>- conversation / walk / tea<br>- discussion and working through supplementary questions (3)   | Space and time for Jury to digest and discuss the witness inputs and consider the supp. questions | ALL  |
| 5.05 | 20 | Feedback from exercise – 'what else?' ( <i>additional reactions / additional ideas on 3 Q / questions for Sunday witnesses</i> )<br>- synthesis of key themes / ideas<br>- capturing on graffiti wall – against 3 questions | Synthesis and capture of thinking so far<br><br><i>- use output wall</i>                          | Fac  |
| 5.25 | 5  | Next steps – tonight and tomorrow morning<br><br>- Give out M's story   | Ensure all clear about evening and start times for Sunday   | DW   |
| 5.30 |    | <b>CLOSE</b>  |   | SG/JW  |

## SUNDAY 18<sup>th</sup> September: Hearing evidence (commissioners) & Moving to recommendations

| TIME      | TIMING      | ACTIVITY   | PURPOSE   | WHO          |
|-----------|-------------|--|---|--------------|
| from 9.45 |             | Arrival & Coffee   | Flipchart outline / breaks  | ALL          |
| 10.00     | 10          | Welcome<br>- Outline of the day<br>- Witnesses<br>- Outputs<br>- Any queries about the day<br>- reminder of ground rules   | PREPARATION<br>Ensure all clear about the day ahead                                 | DW<br><br>SG |
| 10.10     | 20          | Review of Saturday's session<br>- <i>what from yesterday did you think about most last night?</i><br>- visit and review of Graffiti Wall   | Ensure work so far is fresh in people's minds<br><br>- focus on output wall         | SG<br><br>DW |
| 10.30     | 15<br><br>5 | WITNESS: National Lead:<br>Yve White-Smith<br><br><i>Challenges and national priorities for dementia services</i><br>Clarification Q&A   | National perspective  |              |
| 10.50     | 30          | WITNESS PANEL:<br>Joint Commissioners<br>- Ojalay Jenkins<br>- Jane Taptiklis<br><br><i>How do we currently buy services and decide on future services?</i><br>- <i>tricky issues for the system</i><br>- <i>current pathways &amp; strategy</i><br><br>(15 mins each) | Health & Social Care perspective<br><br>Focused on the core question re. priorities |              |
| 11.20     | 10          | Panel Q&A<br>Facilitated discussion<br>– focused on priorities   | Deepen Jury's understanding   | Fac.         |
| 11.30     | 20          | <b>COFFEE BREAK</b>  |   | ALL          |
| 11.50     | 40          | Reaction & Capture cards<br>- discussion in trios/pairs/<br>- capture on cards<br>- stick up on graffiti wall in Witness section.<br>- further work on supplementary questions   | REFLECT & CAPTURE<br><br>- use input wall   | ALL          |
| 12.30     | 45          | <b>LUNCH</b><br>– 4 volunteers for feedback  |   | ALL          |
| 1.15      | 5           | Energiser  |   | SG           |
| 1.20 pm   | 15          | Review of morning session<br>- visit and review graffiti wall  | REVIEW  | Fac.         |

|      |    |  |   |                                 |
|------|----|--|---|---------------------------------|
|      |    | - pull together work so far on supplementary questions   | - move to output wall                               |                                 |
| 1.35 | 65 | <p>Work on Core Question in light of all witness inputs</p> <p><i>1) list the key principles / services / 'things' that should be commissioned</i></p> <p><i>2) Agree criteria for prioritisation</i></p> <p><i>3) Apply criteria to list (prioritisation matrix)</i></p> <p>- Small group / whole group<br/>- capture "what if...?" ideas<br/>- use 6 hats to evaluate?</p> | Generate recommendations based on Core Question     | ALL<br><br>DW                   |
| 2.40 | 20 | <p>Synthesis and capture of outputs / recommendations / ideas</p> <p>Agreement of process for feedback to commissioners</p> <p>Support 4 Jury reps + tidy output wall for presentations</p>  | Clarify recommendations and feedback process        | ALL                             |
| 3.00 | 30 | <p>Feedback to Commissioners of Jury's recommendations</p> <p>-By Jury representatives (1 per Q)<br/>-Use graffiti wall<br/>-Q&amp;A</p> <p>Thank you to Jury – Chair of Bucks Primary Care Collaborative</p>  |   | 4 Jury reps<br><br>Annee Gamell |
| 3.30 | 10 | <b>TEA GRAB (commissioners leave)</b>  |   |                                 |
| 3.35 | 20 | <p>Review of Citizen's Jury process</p> <p>- <i>What went well?</i><br/>- <i>What would have made it better?</i><br/>- <i>What will I tell others?</i></p> <p>(capture on flipcharts or post its)<br/>Individual + group reflection<br/>- Completion of post-questionnaire</p>   | Reflection and review of the process and experience | ALL                             |
| 4.00 |    | <b>Goodbyes &amp; CLOSE</b>  |   | JW                              |

