What aspects of benefit, cost and need should NICE take into account when developing social care guidance?
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreword</td>
<td>2</td>
</tr>
<tr>
<td>Citizens Council</td>
<td>3</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>4</td>
</tr>
<tr>
<td>Full Report</td>
<td>8</td>
</tr>
<tr>
<td>1. Introduction</td>
<td>8</td>
</tr>
<tr>
<td>2. What we did and what we heard</td>
<td>10</td>
</tr>
<tr>
<td>Meeting Day One</td>
<td>10</td>
</tr>
<tr>
<td>Meeting Day Two</td>
<td>18</td>
</tr>
<tr>
<td>3. Conclusions</td>
<td>24</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>27</td>
</tr>
<tr>
<td>Appendices</td>
<td>28</td>
</tr>
<tr>
<td>Appendix 1: Keypad questions</td>
<td>28</td>
</tr>
<tr>
<td>Appendix 2: Citizens Council Members</td>
<td>31</td>
</tr>
<tr>
<td>Appendix 3: Briefing paper</td>
<td>32</td>
</tr>
<tr>
<td>Appendix 4: Presentation slides</td>
<td>38</td>
</tr>
<tr>
<td>Appendix 5: Visual minutes of meeting</td>
<td>71</td>
</tr>
<tr>
<td>Appendix 6: Measurement tools</td>
<td>75</td>
</tr>
<tr>
<td>Appendix 7: Tessa’s story (care pathway)</td>
<td>83</td>
</tr>
<tr>
<td>Appendix 8: Agenda for meeting</td>
<td>85</td>
</tr>
</tbody>
</table>
Welcome to the report for the 17th NICE Citizens Council meeting.

The Citizens Council is a group of 30 members of the British public, reflecting the diversity of our society. Every year the council provides us with advice on challenging social and moral issues that come up during the development of NICE’s quality standards and guidance.

The Council is a formal committee of the Institute, and its role is to debate broad social values and how NICE might apply them in preparing its guidance. Following each meeting the Council submits a report to NICE’s Board. The views expressed in the report are those of the Citizen Council members; they do not represent the views of the Institute. However, the Council’s advice and views are very important in helping to inform NICE’s work, and the work of the independent groups and experts who develop NICE guidelines and appraisals.

On 1 April 2013 NICE became responsible for the development of quality standards and guidance for social care, in addition to its responsibilities for health and public health. NICE is facing many new challenges and felt it was fitting that this year we should ask Citizens Council members the same question we have asked ourselves, namely:

“What aspects of benefit, cost and need should NICE take into account when developing social care guidance?”

The Citizens Council members spent two packed days listening to presentations by a range of social care professionals and academics and then debating this question. This report presents the journey they took, the learning they experienced, the conclusions they reached and the feedback they provided to NICE (see Executive Summary, pg 5).

While NICE does not provide front line services our crucial role in social care will be, with our partners, to guide and influence those that do by developing and producing quality standards and guidance based on the best evidence available and that will in time cover aspects of social care delivered in a range of settings.

Council members highlighted a number of challenges which we need to consider. Priorities include: ensuring that social care guidance is built around people’s individual needs and developing joint standards and guidance for health and social care. There are many more, but perhaps the most over-riding concern of council members was the need for NICE’s quality standards and guidance for social care to have ‘teeth’ and to ‘be enforceable’.

NICE now has to consider the feedback from the Citizens Council. This report will be presented to NICE’s Board by members of the Council and the Board will discuss their findings and recommendations.

I want to thank the Council members for their time, insights and the way they responded to the challenge we set them. The work of the Citizens Council is important and helpful and will certainly inform our thinking as we move into the world of social care.

Professor Carole Longson

NICE Executive Director responsible for Citizens Council

April 2013
What is the Citizens Council?
The Citizens Council is a panel of 30 members of the public that reflect the demographic characteristics of the British public. Members of the Citizens Council serve for three years.

What is the role of the Citizens Council?
The Citizens Council provides NICE with a public perspective on challenging social and moral issues that NICE has to take account of when producing guidance. The council’s recommendations and conclusions are incorporated into a document called “Social Value Judgements: Principles for the Development of NICE Guidance” and, where appropriate, into NICE’s methodology. The Social Value Judgements document can be accessed here: www.nice.org.uk/aboutnice/howwework/socialvaluejudgements/socialvaluejudgements.jsp.

The Citizens Council does not produce NICE’s guidance, nor does it input directly into any individual pieces of guidance that NICE produces; there are other mechanisms NICE uses for doing this.

How does the Citizens Council operate?
Members meet once a year for two days at a time to discuss a topic that has been chosen for discussion. During the meetings, council members listen to different views from experts on a topic and undertake exercises which allow them to examine the issues in detail and thoroughly discuss their own views. The meetings are open to public observers. The members’ views and conclusions are captured in a report by an independent report writer and this report is circulated to the members for comment and amendment before finalising. After a meeting, the report is made available for public comment. The report, as well as a summary of the public comments, are then presented to NICE’s board.

How are topics chosen?
Potential topics usually arise as a result of the activities of NICE’s advisory bodies during the guidance development process, as they explore issues that require value judgements to be made.
Thirty Citizens Council members attended the Citizens Council meeting in January 2013.

Over the two days of the meeting we began to appreciate that what makes good social care is very different from what makes good health care. While a doctor might prescribe treatment that will cure an infection, social care does not provide cures but aims to help people live their lives as normally as possible. No two people’s needs are the same. Health care is often provided in the short term and usually focused on recovery. Social care provision is often long term and will not usually lead to recovery.

We listened to a wide range of presentations and had many opportunities to give our views on what we heard informally, as individuals, in small groups and as one large group. We were also asked to vote on questions put to us throughout the event using electronic keypads (see Appendix 1). While the keypads were presented as ‘a bit of fun’ the answers we gave did reflect our views as a whole and provided a way for us to track how our views were changing. For example, on day 1 we were asked about what NICE needs to do to produce good social care guidance and whether it is possible for NICE to produce social care guidance in the same way it produces health guidance. The question was asked on day 1 and again towards the end of day 2; we were asked to select one response (1-4) shown in Table 1 that reflected our individual thoughts the best.

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<thead>
<tr>
<th>Results</th>
<th>Response 1</th>
<th>Response 2</th>
<th>Response 3</th>
<th>Response 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1 (n=29)</td>
<td>3.5% (n=1)</td>
<td>24.1% (n=7)</td>
<td>37.9% (n=11)</td>
<td>34.5% (n=10)</td>
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<tr>
<td>Day 2 (n=26)</td>
<td>7.7% (n=2)</td>
<td>23.2% (n=6)</td>
<td>69.2% (n=18)</td>
<td>0.0% (n=0)</td>
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Response 1. NICE’s existing methods for developing healthcare guidance are sufficient for developing guidance on social care

Response 2. NICE’s existing methods for developing healthcare guidance are not sufficient for developing guidance on social care but only require minor changes to make them sufficient

Response 3. NICE’s existing methods for developing healthcare guidance are not sufficient for developing guidance on social care and new methods need to be developed.

Response 4. Don’t know

The change in opinions shown in Table 1 reflects the deepened learning and understanding about social care we gained over the two days. On day 2, almost 70% of us selected response 3: ‘NICE’s existing methods for developing healthcare guidance are not sufficient for developing guidance on social care and new methods need to be developed’. Agreement with response 4: “Don’t know” reduced from 34.5% on day 1 to 0.0% on day 2.

By the end of the two days we were able to reach further conclusions in response to each aspect of the question:

“What aspects of benefit, cost and need should NICE take into account when developing social care guidance?”
Benefit

While we understood that there are limited resources to fund social care we felt that the more personalised care is, the better quality it will be. We also thought that there are elements of care that provide huge benefit but cost nothing to provide, compassion for example, but that can get forgotten in the continuous discussion about resources and cost of care.

Our overall conclusions were, in the words of one of our members: “The client is king”. Everyone who needs it should have care built around his or her needs. He or she should have control over the care he or she receives and that care should enable him or her to live their life as they wish as far as possible. We felt that people receiving social care need to feel they have choice and control in the care they receive and not have things done to them over which they have no control.

A powerful presentation by carer ambassador Barbara Pointon on day two spoke volumes about the value of informal and family carers - not just in terms of the quality of care they provide to loved ones, but how much money they save the social care services and the NHS every year.

We discussed this and thought that when developing social care guidance NICE should do everything in its power to make sure that there should be more emphasis on prevention and early intervention. Guidance and standards should take carers into account and ensure support for carers in the vital job they do – from day one. We agreed that someone who knows, or takes the trouble to get to know, the person receiving care probably provides the best care.

While we were not asked to consider who funds social care because this is not the job NICE is being asked to do, most speakers talked about cost in one way or another - whether it was the cost of social care, the shortage of money to pay for social care or how to get the best value in social care. We learnt that need in social care cannot be confined to what local authorities fund and that many people self-fund and do not ask for social care even when they may be entitled to it. A few members suggested that if local authorities commissioned social care directly, rather than contracting for-profit private agencies to provide different aspects of care (including residential care), they would have more control over the quality of care and care would not cost so much. The incentive mechanisms should be for any efficiency savings to be put back into the provision of care rather than taken off as profits.

In the group discussions the cost of residential care came up repeatedly and many of us recounted stories where the quality of residential care had been poor and the costs demanded for it too high. We were however; really impressed with the way care home proprietor (and speaker) Anne Fretwell ran her residential home and wondered why the model of care she advocates is so rare. Her talk demonstrated that excellence is possible. We wondered about whether excellence is due to strong leadership and how such innovation could be encouraged.

We also appreciated the value of unpaid carers - both in terms of cost effectiveness and the quality of care they provide. We thought it was important that their value in financial terms should be made more explicit and included in cost-effectiveness calculations. We discussed the potential of local communities and volunteers to provide care where there is no immediate family or where the family chooses not to care.

Overall, we felt that NICE’s quality standards and guidance must stipulate better support for informal and unpaid carers from the start of their caring journey. We also concluded that if health and social care were better integrated then social care must cost less and function more smoothly, and we thought more resources should be put into training the social care workforce and into treating them as professionals.
Need

We concluded from listening to presentations that the concept of need in social care is different to need in health care, where the health professional determines it. In social care need is determined and defined by the service user and is much broader. So for example, we learnt that in social care not all need can be confined to what local authorities fund, there are those who have needs but self-fund and others whose needs are met by carers who are unpaid and whose work goes unrecognised.

The question of need was perhaps the most difficult to define and we did not have enough time to fully learn about the different mechanisms used to estimate need. However, we didn’t like the clinical way social care need is currently defined (low, moderate, substantial, critical) but wondered in group discussions over the two days how you can measure need when it varies from person to person. We agreed with the speakers from research and economics backgrounds that there has to be more emphasis and research into how need is measured because otherwise how do you know what services to provide?

Summary

On day one Sarah Garner, NICE’s Associate Director for Research and Development asked us: “Can the methodology used for assessing health care intervention costs be transported into social care?” Our eventual response to this and final conclusion was, broadly, ‘No’ - current ways of measuring health and aspects of social care will not suffice. NICE needs to develop new methods and processes for social care because there are more differences than similarities.

Over the two days and as the result of the group discussions we came up with a range of ‘challenges’ or ‘recommendations’ that we hope will inform the way that NICE approaches the development of standards and guidance for social care. While we did not list these formally or in any particular order during the meeting there are some clear priorities for NICE to address and these are listed first under “Priorities for guidance and quality standards” (below).

In particular, we felt that existing models used for health care cannot be adapted to ‘fit’ social care and NICE, with their collaborators - the Social Care Institute for Excellence (SCIE), must approach social care with fresh eyes.

Conclusions and challenges

Priorities for guidance and quality standards

★ NICE should approach the development of quality standards and guidance for social care with ‘fresh eyes’ – those of the service user.

★ NICE should produce new and original quality standards for social care that are authoritative and they must have ‘teeth’.

★ NICE standards and guidance should enable care to be built around each person’s individual needs.

★ NICE should consider integrating health and social care better to the point of producing joint health and social care guidance, and

★ NICE standards and guidance should advocate that unpaid and informal carers are properly supported from an early stage and that these costs and benefits are taken account of in any calculations.
Other recommendations for guidance and quality standards

- advocate social care that is tailored to individual need including cultural needs.
- be flexible and adaptable as clients’ needs change.
- advocate that clients have choice and control over their care and how they live their lives.
- enable a culture of carers getting to know their client.
- make sure the importance of meaningful activity, and paid and unpaid carers understand stimulating interaction with others.
- advocate that the physical and mental health needs (the wellbeing) of clients is equally important, and
- make sure that the vital role played by partners and families is recognised and valued.
- be recognised and seen as authoritative.
- be constantly monitored, audited and reviewed to make sure that care is benefitting the client and provides value for money.
- should address communication issues between staff and between staff and service users - the needs of individuals who have particular communication needs must be recognised and resourced, and
- make sure there is less duplication of care provision and better co-ordination of care.

Staffing

- work to raise the status of social care so that a career in social care equates better with a career in health care
- work to ensure that staff are well trained and better rewarded with increased opportunities to progress, and
- emphasise the importance of on-going staff assessments

Whilst the meeting focused on adult social care, over the two days we heard a number of examples of social care that was provided for older people in particular. Whilst we realised we were not producing recommendations about that group, and there were other case studies that could be explored, this was a recurring topic and we wanted to highlight a general need for NICE to:

- advocate early support for carers and families particularly those of older people.
- work to change public attitudes towards older people.
- advocate and encourage earlier support for older people who are lonely and isolated, and
- produce guidance for schools to educate children that older people are an asset. One member suggested that schools should find ways for young people to spend time with older members of the community.
1. Introduction

This report has been written by an independent writer commissioned on behalf of the Citizens Council members by NICE. The writer attended all sessions of the Council members’ meeting held on 24th and 25th January 2013 in Manchester.

What NICE does

The National Institute for Health and Clinical Excellence (NICE) was created in April 1999. It is the independent organisation responsible for providing national guidance on health and public health to support the NHS, local government and others improve health and wellbeing of all - as well as provide the best quality and value for money in clinical and public health interventions.

On 1 April 2013, NICE was renamed as the National Institute for Health and Care Excellence and also became responsible for developing quality standards and guidelines for social care.

NICE’s quality standards and guidance are developed by independent groups of experts, including clinicians, health care professionals, local authority professionals, researchers, economists, service users and carers.

NICE Citizens’ Council

The Citizens Council is made up of 30 people who (broadly) represent a cross section of the adult British population. A list of members that attended the January 2013 meeting and whose collective views are captured in this report can be found in Appendix 2. We come from all over the UK and meet (usually) once a year to discuss a question put to us by NICE. The Citizens Council provides NICE with advice on what can be challenging social and moral issues raised during the development of guidance. This advice helps NICE’s expert groups to take decisions on NICE recommendations.

This year our thoughts and perspectives will feed into the development of the methods and processes NICE will use to develop quality standards and guidance for social care. Please note that while individual member experiences have not been included in the report, members did share some very personal experiences and the group as a whole appreciated these.
What we were asked to consider

As NICE moves into developing quality standards and social care guidance for the first time, the question we were asked to consider this year was:

“What aspects of benefit, cost and need should NICE take into account when developing social care guidance?”

This question is broad but reflects the instructions given by the Government to NICE in the Health and Social Care Act 2012. NICE has asked for our help in considering what is important to include from society’s point of view.

It would be fair to say that at first the question seemed overly technical and complex to us and we were not sure what was meant by cost, benefit and need in the context of social care. However, the meaning became clearer as the meeting progressed. We realised that whilst we are a lay group composed of members of the public, between us we have experience of social care, of caring and all of us are potential users of social care.

How we worked

Prior to the meeting we were given a briefing paper (Appendix 3) which gave us some background to why the question we were asked to discuss had been chosen.

Over the two days we listened to presentations from 15 speakers, these included representatives from NICE, a director of social care, a social care commissioner, academics, social care service users, a carer and a proprietor of a private care home. Copies of the speaker presentations can be found in Appendix 4.

We considered different aspects of cost, benefit and need and looked at ways of measuring quality, assessing value and examining evidence. We completed questionnaires and tools used to measure health, social care and capability and considered how we feel about our own quality of life. All background information referred to in the report, and other supporting material, is listed in the Contents page and can be found at the back of this report in the Appendices section.

Throughout the two days, working at the back of the room, two animators were producing visual minutes of the meeting. They captured everything that was said, interpreted it with humour and perception and produced an accurate and empathetic record of this meeting. Excerpts from those minutes can be found throughout this report and the complete set of the visual minutes can be found in Appendix 5.
Whilst we were not asked to consider who should fund the cost of social care, we were asked to consider value for money. We looked at the question and began to break it down into definitions of benefit, cost and need.

What do we mean when we talk about benefit? What is value for money when it comes to providing care? How do you measure the needs of individuals who all need different things?

We asked: “When we talk about needs, is it a social worker who defines it or are you asking us to define a general view of what need is?”

Gill responded that we needed to look at need from our own perspective - at the things that are important to us, our family or people we care for.

We learnt that there are a number of challenges facing NICE as it moves into social care. We heard that the evidence base is less well developed for social care than for health and the culture of evidence-based practice is also less well developed.

Our role as Council members then was to consider, discuss and debate, to ask questions, to test current measurement tools and ultimately to give NICE our view of what it needs to do to develop social care guidelines.

First, we had to consider what social care looks like now and we discovered that care looks very different depending on whether you are developing guidelines, providing services, measuring or evaluating the quality of care, if you are caring for someone or receiving care yourself.

As a group, we wanted to know if the fact that NICE’s quality standards, referenced in the Health and Social Care Act 2012, will give them more weight. Specifically, one member asked for reassurance that the new quality standards will have ‘teeth’. We were reassured that the NHS England (formerly the NHS Commissioning Board) and the Government must pay ‘due regard’ to NICE’s output.
What does social care look like in practice?

Tina Coldham, mental health user consultant, Trustee for Social Care Institute for Excellence (SCIE) presented a user perspective of social care and delivery.

Over the two days we heard from service users and from a carer. Their perspectives taught us about the enormous diversity of need that exists and how social care sometimes, perhaps unsurprisingly, struggles to meet it.

Tina Coldham is a mental health service user who is also a Trustee for the Social Care Institute for Excellence (SCIE), which is collaborating with NICE to produce social care guidance.

Tina looked at what she called “the conundrum” that exists between benefit, cost and need and she immediately honed in on why it is that social care is more complex to understand than health care.

She said: “I think of myself as a person and not a care group. I can walk into Accident and Emergency and it is free at the point of delivery – that is a key principle of the NHS. But if I need social care I can ask for an assessment, if I know how to get one - it's not all that accessible. People don’t know how to access care and so immediately you are into navigating a system that can be difficult.” Tina mentioned that too often the point that people ask for social care help is when they are at crisis point.

Tina looked at what is meant by ‘need’ rather than ‘crisis’ and she was the first of several speakers to comment that social care needs to be provided at an early or even as a prevention before things get to crisis point. She said: “If we don’t invest in preventative measures people get ill and go into crisis and it costs more. If we can’t give someone a bath what kind of society are we living in?”

Tina talked openly about her own experiences of social care: “When you are on the receiving end it can feel to you like things aren’t joined up. It can feel very messy as you are pushed from one service to another, social care might say.. ‘umm not sure we can pay for that’ or ‘Is that a health bath or a social care bath?’, when all I am interested in is who will pay to help me to have that bath safely.”

Tina talked about how the person receiving services should be at the centre of the system because then care can be coordinated around him or her. Health and social services should be integrated and built around someone’s needs and might be provided in a variety of ways – using personal budgets for example.

We asked: “if you had a magic wand would things come under a centralised banner?”

Tina said she would provide integrated services, where care was coordinated. “In a sense it doesn’t matter if a nurse or social worker comes - I just need someone to talk about my life to and what I need to do to stay on track and how we can bring in things to help me.”

Several members commented in discussions following this and after other presentations that NICE should strongly advocate integration of health and social care - to the point of producing joint social care and health guidance.
What defines excellence in social care?

The Social Care Institute for Excellence (SCIE) produces videos on a range of different topics related to social care. We watched one: 'Defining Excellence – What is Excellence?' www.scie.org.uk/socialcaretv/video-player.asp?v=whatisexcellence which was the springboard for a group discussion. The video focused on a number of service users in different settings with particular issues and looked at how care professionals resolved these issues. A panel of experts in social care then analysed what had been done and what the benefits to the service user were.

One example shown was that of an elderly man with dementia living in residential care who repeatedly piled furniture in the middle of the room. This alarmed the carers and other residents alike because they thought he was going to start a fire. Care workers investigated the man’s past to find he had been a painter and decorator whose habit was to move all furniture into the centre of the room before painting. His dementia meant that he thought he was still working. He was provided with a paint tin filled with water, brushes and some ‘decorating’ to do and because he had meaningful activity in his life it distracted him from furniture piling.

What we learned from this video is that excellence in care is about knowing who someone is, because this enables the service provider to develop personalised care. Once excellent personal care is in place regard must be taken to maintain it by all involved in the person’s care for example where there are handovers of care between staff in a residential setting, or where a team of carers care for someone at home.

Excellence is also about giving service users control to do what they would like to do so they can feel, as one man in the video put it, “I am still part of the world to which I once belonged.”

What is missing from social care?

We were then asked to consider what good social care looks like, and to focus on values, quality standards and need. We broke into groups and found that we needed to talk about what we think is wrong with or missing from social care at the moment, before we could then draw up lists of what we thought would make social care excellent.

While we were impressed by the standard of excellence shown in the SCIE video, one member thought the video showed a dream world where service users are provided with a 10/10 service – when in reality social care can only be rated as scoring 2 to 3 out of 10.

We wondered if social care could be better and more cost-effective if local authorities provided care directly rather than contracting out to for-profit private agencies. One member thought that care homes as represented in the SCIE video “don’t really exist” and others agreed. The member thought it would be possible to reduce costs dramatically if local authorities were responsible for the commissioning and provision of social care.

As an aside to that, we wondered why it is that when someone’s needs come under ‘health’ costs these are paid for by the NHS but if he or she has ‘social care’ “those costs are not met”. We wondered if this was a further argument for better integration of health and social care given that many older people need support from both health and social care.
The role of paid and unpaid carers

We discussed the fact that while nursing is seen as a career, working in social care has a lower status and acknowledged that many carers do it for love and are not paid at all. We talked about the role that these unpaid carers play and the money they save the NHS in supporting and caring for relatives and loved ones. We thought that the more the family was involved and the better the carers know the person they care for, the better care will be. One member reminded us all that “not everyone has family or someone who can help”. We discussed how care could be seen as more of a community issue and better use made of volunteers, time banks and other community resources.

We thought that older people were becoming more distant from younger people as the population gets older and wondered whether work could be done in schools with young people to make their attitudes to older people more positive. We also considered how difficult it can be for people to access services and thought that local authorities should make it easier for people to find out about and access care.

Our discussion showed us more clearly the complexities of providing personal social care and how difficult it is to find consensus on what makes good care given that each individual case is different.

What makes for joined up social care?

The above comments were our criticisms of the quality of social care as it currently is. In the “Conclusions” section of this report we list the points we thought to be essential in providing good social care and present them for NICE to consider when drafting its standards and guidance. The points represent the views of small groups pulled together and arranged thematically under the headings. The points we prioritised as a group are at the top of the list under ‘Priorities for guidance and quality standards’.

Joint working in ‘care’ from my/our perspective

Dr Ian Basnett is both a service user and Director of Public Health in East London. He explained that he looks at disability from a social rather than a disability perspective. He said: “If I get one thing over today then it’s to see social care from the perspective that enables people to be equal.”

Ian explained that his view of social care was very distinct from the medical view, which is about things that ‘people can’t do’. He said: “Choice and control for disabled people works best. There is an old slogan but it’s a good one and it is ‘Nothing about us without us’.”

He commented that the current NHS focus is about cure and alleviating symptoms. He said: “The first question is always going to be: ‘Does it work? And if it does work how much does it work?’ And so we set about measuring that in various ways.’ But he said, “Social care cannot be measured in the same way and therefore mustn’t be reduced to a tick box exercise.”

Ian explained that there needs to be a greater focus on things that work. There needs to be better communication and co-ordination between services. He felt that there is much that could be done around assessment of needs. He was particularly concerned that assessment should not be a ‘tick box exercise’, a point that resonated with council members and was a phrase used in many of the discussion groups. He said: “The standardised approach doesn’t work when people’s needs vary so much and trying to measure it like that takes a rather task based approach. For example allowing 15 mins for hair wash.”
Challenging issues: what are the wider issues that impact on social care?

Sue Lightup, strategic director of community health and social care in Salford City Council and Chair of the North West Association of Directors of Adult Social Services (NW ADASS) region and Jennifer McGovern, assistant director for joint commissioning, Salford City Council presented a provider and commissioner perspective of social care.

Salford local authority provides and commissions social care. Sue Lightup, its strategic director of community health and social care, explained that: “Social care is about people living their lives. We should only be there when people are struggling a bit and need help and then we should get out and help people to carry on living their lives.”

In relation to need, Sue commented that getting evidence of what works is helpful but difficult to get and there is a greater need to focus on prevention and early intervention, to support people but not to create a dependence on social care. Salford’s vision she said is that people receiving social care deserve to “Get a life and not a service. What do you want and how do you want to live? The aim is to provide people with just enough support to help you get on with life.”

Jennifer McGovern advocated joint funding to pool resources and resolve the conundrum of “When is it social care, when is it health?” because so often, she said, a service user needs support from both systems.

A perspective of benefit, cost and need in developing social care guidance

From considering care that the local authority provides, we moved to the views of a private care home provider. Anne Fretwell is owner/manager of Merevale House in Warwickshire, an innovative residential home for older people with dementia. Her presentation encapsulated what CAN be done rather than what can’t be done to support people with dementia.

Anne explained that her home has no designated staff areas, no uniforms or badges. The staff use the same facilities as the residents and residents help with the cleaning. Anne said: “We want to know everything about a person; who they were, who they are, what will work for them. We encourage people to live and not just exist and that gives people a purpose again.”

Anne and the staff work to make people feel at home and to feel safe. Her motto is “look for the person, understand the meaning”.
Anne talked about the benefits of the way she runs the home. Their research showed it has lower acute admissions and psychiatric intervention, reduced ‘behavioural’ problems, reduced numbers of drugs prescribed than many care homes and operates in a culture of hope and happiness. She explained the cost benefits – no massive training costs as staff retention is excellent, no uniforms and no high drug costs. She talked of the importance of getting the right staff, and said: “I’d rather have someone with no experience who can connect with people. People with dementia help me interview.”

The key to it all Anne said, is to look at the person not the dementia and to encourage people to live and not just exist.

We asked: “How would you get other homes running like yours?” Anne said: ‘It’s a passion and I wish people wouldn’t see care workers as low in motivation. It’s about changing the culture and that looks easy but needs to be run like that from top down. We are not part of a big group (of care homes) so we don’t have those kind of politics or money issues.’

Anne’s presentation helped us to see what is possible and we saw again the benefits there are in knowing someone’s history, recognising individuality, providing meaningful activity and building care around them.

Translating values into ‘value’

Sarah Garner, Associate Director for Research and Development at NICE got us thinking about how to measure social care.

While as a group we were asked to consider value for money, Sarah asked us to think about getting value for values! She explained how values represent our underlying beliefs and drive our behaviours – for example we wave flags to demonstrate our patriotism. NICE strives to identify our underlying values and take them into account when making decisions. When looking at value for money in healthcare the questions are: ‘How well do the drugs work?’ ‘How much more does the better option cost?’ With the conclusion that there is no benefit to anyone in funding drugs that have not been proven to provide additional benefits over existing care, particularly if they come at an extra cost that has to be taken from elsewhere in the health service.

We learnt about some of the different ways that the benefits of interventions are measured. As a universal unit of health measurement NICE uses Quality Adjusted Life Years (QALYs) as a measuring stick to compare interventions for different diseases. QALYs take into account the impact on both quality and quantity of life. While different diseases all impact on different parts of the body, for example by raising blood pressure or causing an infection, they all impact on the length of life and the quality of life for example by causing depression and anxiety or preventing people from being mobile or doing their usual activities. By looking at the impact on quality and length of life you can measure the impact of different diseases or treatments on the
To capture quality of life NICE uses a health assessment tool called European Quality of Life - Five Dimensions (EQ5D). However, this method has been criticised and other options suggested - all have their advantages and disadvantages.

In recognition that quality of life in relation to social care may differ from that for health care economists have developed new methods for social care. One tool is the Adult Social Care Outcomes Framework (ASCOT). But there are others, for example, the Index of CAPability - Adults (ICECAP-A), is used for measuring capability and wellbeing. There are professional concerns that none of these tools are capturing all the information that is needed, so as part of a group exercise we were asked to trial them and come to our own conclusions. (See Appendix 6 for copies of all the measurement tools).

**Adult Social Care Outcomes Framework (ASCOT)**

ASCOT was developed over a period of ten years by Ann Netten, a professor at the University of Kent, and was designed to reflect the benefits of social care. It is used in policy and practice. The measure looks at different aspects of someone’s life and covers areas such as dignity and self-esteem. Professor Netten compared the differences in measuring health and social care:

**HEALTH**
- Treating and reducing impairment
- Health related quality of life (HRQol)
- Ability to undertake activities, pain, etc.
- Prevention

**SOCIAL CARE**
- Compensation for impairment
- Social care related quality of life (SCRQol)
- Personally clean, fed, socially engaged
- Prevention

**Index of CAPability for Adults (ICECAP-A)**

ICECAP-A (Index of CAPability - Adults) measures social care benefits in terms of capability wellbeing in adults. Professor Joanna Coast, Professor of Health Economics, University of Birmingham defined ‘capability’ as "what a person is able to do or be in their lives”. So ICECAP-A includes things like quality of life, feeling settled and secure, love, friendship, being independent, assessment and progress.

Joanna explained that if you talk to older people about what is important they will often talk about loss of capability. For example, not being able to read for enjoyment because of poor eyesight or not being able to help out with the grandchildren because of pain from arthritis.

Focusing on one element of our question for the day and looking specifically at benefit, Joanna considered that benefit is what people feel is important that they are able to do and be in their lives.

Our group work was to look at and evaluate these different tools for collecting information quality of life, capability and well-being. We were divided into groups and asked to complete the EQ5D, ASCOT and ICECAP-A assessment tools for ourselves.

While the purpose of EQ5D was clear as a health assessment tool, we weren’t clear who the ASCOT questionnaire was aimed at. One member said she was “not sure if I would
answer if I were having a bad day”. Someone else commented that “I might be scared to fill it in’ with the implication being that care home residents might be apprehensive about reporting criticisms to those directly responsible for their care. Another commented, “It might feel intrusive”. A few of us thought we might answer questions differently on different days depending how we were feeling. Some of us thought ASCOT might be used as an assessment tool (but later learnt it is not).

We felt that ICECAP-A and EQ5D both missed questions on spirituality and social activity and thought there should be questions about sleep – which we felt impacted on both health and social care needs. We would have liked to see the forms ask something about:

- satisfaction of consumer
- happiness, and
- security/peace of mind

We felt that while each of forms contained some elements that were a good measure of certain things, we felt that NICE needed to consider extra elements when developing national guidance and standards. We concluded that NICE should not take any of these tools ‘off the shelf’ but rather develop a new tool that will capture everything relevant. We felt that the tools as they stand did not give an opportunity for respondents to explain their comments further and it wasn’t clear who should fill them in if the client were unable to. We thought that NICE needs to come up with a new template for measuring social care that would take in the unique context of each individual.
Meeting Day Two

The carer’s perspective

Barbara Pointon, former carer, ambassador for Alzheimer's Society and Dementia UK cared for her husband Malcolm for 16 years until he died. Malcolm was diagnosed with Alzheimer’s disease, a type of dementia, when he was 51. Barbara set the scene by saying that there are around 500,000 family carers in the UK and that when we talk about social care we need to think not just about the individual who needs care but their carers and the wider family and what support they need to care.

As a result of her experience of using social care, Barbara recommended the development of a new role. She said: “We need dementia advisors who are based in GP practices, who work between health and social care and who have clout...”

Barbara showed a slide showing the web of 16 professionals who were at one point providing different elements of care for her husband. She asked: “Why is care so expensive – why does nobody look at the books of providers. How can a care home cost £1,200 a week when food costs £2 a day per person?”

Barbara recognised the importance of NICE’s new role in producing social care quality standards and guidance. She said: “National guidance makes a difference. A little help earlier on is what is needed and we need a common, robust framework - guidance with clout. ‘Due regard’ must mean we cannot ignore it.”

One of the members said: “Your talk is the best reason of all why NICE needs teeth and a real way of enforcing guidelines. I can’t believe the amount of people you had to go through to get help.”

Barbara said that some things are improving. For example, GPs are now are supposed to offer carers assessments at the point of diagnosis. Barbara said. “They just need to say: ‘To get the support you need - fill in this form’”

We considered the implications of Barbara’s experience for NICE. Whilst we recognised that we were not producing guidance on the topic of dementia, and there were other equally important topics that we had not heard about - such as children in care, we incorporated what we had heard into our conclusions.
Professor Carole Longson, Director of the Centre for Health Technology Evaluation at NICE, gave her personal insights about how values are translated into decision-making. Carole explained that currently NICE must look at all the evidence before making decisions, for example where a drug that is efficacious for one particular patient group but is expensive NICE will consider implications for other patient groups. Carole went on to explain that decision makers need to be fair to everyone and that while people need to think about their own condition, decision makers need to think about the needs of everyone when there is a finite pot of money.

Carole said that NICE tries to give decision makers access to all views and values so they can make decisions. NICE then ensures that the decisions made and the technical work underpinning them is available for the public and all stakeholders to comment on. She said: “Not everyone can have their way but everyone can have their say”.

Carole explained that as the cost per QALY (quality adjusted life year) gets higher, what it means is that the NHS is being asked to pay more for the same unit of health care (QALY) than it could get by other options. So it’s likely other patient groups will be adversely impacted as money will be diverted. There is therefore an increasing chance that unless there is a good justification for doing so, decision makers will think the increased cost is not a good use of the NHS’s money. Therefore the chance of rejection, of a drug, device or service (for example) will increase.

We asked: “Who are the stakeholders in the decision making process?”
We heard they were ‘anyone with an interest can be a stakeholder - patient groups, commissioners (who decide what care services are contracted locally), health care professionals and drugs manufacturers’. NICE also puts all relevant information to the decision making process on its website so the public can view the process and comment on the outputs.

We also discussed corporate responsibility and whether society has a duty to do something for people who have been made ill through the nature of their work, for example people with asbestos related illnesses contracted at work.
Quality – what does it mean in reality?

Robin Burgess, Chief Executive, Healthcare Quality Improvement Partnership (HQIP) asked “What is quality in health care – you know it when you see it but how do you measure it?” He raised many questions around quality - who defines it? How do you measure it? He compared measuring quality in health care, where decisions are dominated by clinicians, to social care where it should be dominated by service users - but isn’t.

In health care, he explained, quality is about fitness for purpose and patient safety is the thing that matters. But in social care we are aiming for “aspirational versus minimum standards”. Current care quality he argued does not even show achievement of minimum quality standards. It measures process not outcomes, is not focused on the consumer and is riddled with errors. He said: “Quality has to be about people’s perceptions of what a good outcome should be….If you can’t measure stuff you can’t issue guidelines to improve quality. We are working with professionals to turn guidelines into measures of quality. But the challenge of social care is that if the evidence isn’t there then the standards aren’t there.”

We concluded that the learning from this presentation was that NICE needs to make sure that good outcomes are captured and assessed and that these form the basis for the quality standards and guidance it develops for social care.

Reviewing the evidence – but what evidence?

Ray Pawson, Professor of social research methodology, University of Leeds talked us through the ways that evidence is gathered. He commented that evidence gathering for social care will not be straightforward: “As the interventions, programmes, policies and services under review become more complex – so does the challenge of uncovering valid and reliable evidence.”
Ray set us a public health challenge. We had to consider collecting evidence to ban smoking in cars carrying children. Evidence gatherers were asked to find evidence to support or counter the proposal.

We worked in groups to consider the hazards (how significant is the risk?). We looked at public support (evidence base, surveys), asked if such a move would survive lobbying (for example by the tobacco industry) and if it would be enforceable by law. Despite overwhelming evidence (as we saw it) in favour of the proposal, Ray thought the evidence we collected was not overwhelming enough to be accepted at face value and there would need to be further delving into the data.

We looked at whether or not all aspects need to be captured and whether one piece of evidence (the health risks of smoking) might outweigh another (the individual’s right to smoke). We began to see how difficult it is to weigh up many and different considerations. We learnt that collecting evidence is not straightforward – even when the case seems cut and dried!

The implications for NICE then, given the complexities of social care provision, are that it will need to find new mechanisms for identifying, including, considering and weighing up evidence.

**Applying economics to social care**

Sarah Byford, Professor of Health Economics. Kings College London explained that we need to think about cost effectiveness or ‘value for money’ because we are constrained by the tax system. If you fund one service you deny someone else, so the demand is higher than we can afford.

She explained that in economics, “We take the resource we have then allocate it so as to get the most benefit we can. So, for example, if a surgeon has three slots – who gets the treatment? You might treat a younger person rather than a smoker, for example. Economics say you can’t make a decision without a rationale for doing it.”

Sarah explained that methods for health technology assessment in public health are different to those in health. She asked: “How much flexibility do we need in social care? Can we translate what is used for health into social care? We need to be more flexible in the approach to economic assessment.”

One of the problems we learnt is the difference between populations, between service users, carers, the wide range and overlap of providers and unpaid carers. We learnt that it helps to highlight gaps in the evidence and to highlight the methodological limitations. Sarah said: “We need to start with clear methodological guidelines and adapt these with experience. We need to consider research and training capacity.” She also said that even if we find good interventions they may not be cost effective to implement - because carers are already doing the work.
Developing guidance in health and social care

The Social Care Institute for Excellence (SCIE) produces guidance based on the best available evidence. Jennifer Francis and Deborah Rutter are both researchers for SCIE, they explained that SCIE has worked with NICE in the past and is going to be collaborating on the development of guidance and standards to cover England, Wales and Northern Ireland.

Jennifer and Deborah focused on the differences between health and social care, which they had narrowed down to:

- The aims of social care.
- The range of funders and providers.
- The role of families and unpaid carers.
- Personalisation and the importance of the individual.
- The social model of disability and focus on outcomes.
- Diversity and equality.

Broadly, health is about improving health and curing disease while social care doesn’t treat but aims for people to gain independence.

There is a big difference in how they are funded. Government funds social care but only 20% of people receive care in their own home while 45% are living in residential setting and pay for their own support. Unpaid and family carers save the NHS £billions. The value of all that care has to be considered. Most people who need social care are already disadvantaged in some way.

Deborah showed us the ‘Spot the difference’ slide (see slide 5 in their presentation in Appendix 4).

The slide showed two quality standards for dementia, one for the NHS and the other a draft quality standard for social care. They both set out advice for health or social care professionals advising people diagnosed with dementia on what to do. E.g. NHS text: “People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.” Social care text: “People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.”

As part of a group exercise we were asked:

(a) What’s different about the underlying approaches of these two quality standards?

(b) How does each reflect the needs of people living with dementia and their carers?

We discussed the fact that the text prepared for the NHS was very functional and referred only to the person with dementia and what he or she must do – while the text prepared for social care purposes was more gentle, referred to the person with dementia and carers and advised and suggested rather than directed. Because they were working from different perspectives, the two texts also differed in the advice that they gave. Neither was sufficient if taken in isolation. Some of us thought that health guidance and social care guidance such as this should be integrated and one over-arching version produced.

We thought that the text written for social care was more about the person not the disease. The social care text was also concerned with
supporting the person to continue to participate in things they like doing. They were offered choice. Carers were mentioned in the same sentence as the person with the diagnosis. The social care text advised support in the early stages while the NHS text prepared for the NHS suggested that assessment only comes at the end of life.

**Tessa’s Story**

As a group we then listened to Tessa’s story *(see Appendix 7 for full transcript)*, here is a summary:

Tessa was 91 and lived alone. Her daughter was her main carer but lived some distance away. Tessa had multiple physical, communications and mental health problems. Tessa was admitted to hospital after a sudden ‘crisis’ (she had an undiagnosed urinary tract infection). A paramedic was in attendance. Later, a hospital doctor diagnosed her with dementia, which meant she needed to be assessed.

We were asked as a group: What could have been done differently?

We thought there should have been more dialogue between GP, daughter, patient, social worker and that access to property should have happened earlier. We thought the fact that Tessa had a urinary tract infection would have made her more irrational and the doctor should have recognised that.

We thought other voluntary sector groups might have been able to support Tessa at an earlier stage for example the community wardens, library services, voluntary sector/charities.

As Tessa had been managing independently before admission perhaps she could have originally been offered sheltered rather than residential care.

Someone in the group had the innovative idea that older people over 80 be contacted every year by health/social care service to see if they are OK or even that there should be an older person version of Facebook.

We thought a lot of assumptions had been made about Tessa without people talking to each other and that there had been complete lack of communication between the different groups. There had been no early detection and the professionals didn’t work with the mother and daughter early enough. Some of us felt that Tessa was vulnerable. We thought there should have been a better link between hospital and social and mental health services. One member of the group suggested that perhaps a regular phone call could have helped “as you can work out on the phone if someone is disorientated or lost”.

Overall, we concluded that Tessa was only noticed at crisis point and that lots of opportunities for assessment had been missed. No one was thorough enough, except the paramedic, despite the whole panoply of people involved in Tessa’s care. In particular, a diagnosis of dementia was made with no reference to her history or ability to cope at home. The ward team was not effective at communicating with her daughter. The best support was the mental health social worker (who Tessa refused to see at first). We felt that NICE needs to ensure its guidance and standards address these basic failures of care and co-ordination across sectors.

We concluded that if Tessa had received support at an earlier stage she would not have ended up at crisis point. We thought that basic lack of communication between all involved as well as lack of care and co-ordination by the professional services, and Tessa’s capacity and wish to live alone was not taken account of – even when the reason for her confusion was established as a urinary tract infection and not dementia.

The penultimate slide in Deborah and Jennifer’s presentation linked to the question set us on day 1: “What aspects of benefit, cost and need should NICE take account of when developing social care guidance?” The slide asked:

- What resources & costs should be taken into account in the development of future guidance?
- What benefits should be considered?
- How should NICE deal with the notion of ‘need’ in social care guidance?
3. Conclusions

The final slide of the day, and of the Citizens Council meeting, encapsulated much of what we had discussed over the two days. The slide captured our conclusions; these are summarised in the three boxes below.

**Needs:**
- Capacity to deliver, capacity to benefit (not as clear as in health treatments)
- Social care has a wide remit: personalised service is very likely to improve quality of life for disadvantaged people

**Resources and costs:**
- Need in social care cannot be confined to what local authorities fund
- Funding complex. Self-funders also need NICE guidance
- The cost of informal, unpaid care must be explicit
- Workforce training always an issue/cost (skills base patchy)

**Benefits:**
- Better lives, personalised outcomes that matter to recipients
- Subjective experience, as well objective measures, is important.

We concluded from the presentations that the concept of need in social care is different to need in health care where the health professional determines it. In social care need is determined and defined by the service user and is much broader. For example, not all needs can be met by the services that local authorities fund.

NICE standards and guidance for social care need to address the broader range of services involved in delivering social care.

A few members went further and recommended that NICE should produce joint guidance and actively support the integration of health and social care working together as one unit with one budget and one set of guidelines.

We thought social care should be based around the person not the disease or disability and that it should do what it can to preserve people’s rights while supporting the person to continue to participate in the things they like doing and in making choices. We thought this was possible even within finite resources available. We felt that empathy and compassion shouldn’t get lost in the cost of things.

With reference to Alzheimer’s disease specifically, we liked the idea of local dementia advisors (based in GP practices) or a named coordinator with ‘clout’ across health and social care who can make things happen.

While in essence our perceptions of what is needed to provide excellent social care did not change over the two days our learning helped us to define better what NICE should take into account as it moves into social care. In particular, we felt that existing models used for health care cannot be used directly to ‘fit’ social care and NICE with collaborators SCIE must approach social care with fresh eyes.
Challenges for NICE

Priorities for guidance and quality standards

★ NICE should approach the development of quality standards and guidance for social care with ‘fresh eyes’ – those of the service user.

★ NICE should produce new and original quality standards for social care that are authoritative and they must have ‘teeth’.

★ NICE standards and guidance should enable care to be built around each person’s individual needs.

★ NICE should consider integrating health and social care better to the point of producing joint health and social care guidance, and

★ NICE standards and guidance should advocate that unpaid and informal carers are properly supported from an early stage and that these costs and benefits are taken account of in any calculations.

Other recommendations for guidance and quality standards

★ advocate social care that is tailored to individual need including cultural needs.

★ be flexible and adaptable as clients’ needs change.

★ advocate that clients have choice and control over their care and how they live their lives.

★ enable a culture of carers getting to know their client.

★ make sure the importance of meaningful activity and paid and unpaid carers understand stimulating interaction with others.

★ advocate that the physical and mental health needs (the wellbeing) of clients is equally important, and

★ make sure that the vital role played by partners and families is recognised and valued.

★ be recognised and seen as authoritative.

★ be constantly monitored, audited and reviewed to make sure that care is benefitting the client and provides value for money.

★ should address communication issues between staff and between staff and service users - the needs of individuals who have particular communication needs must be recognised and resourced, and

★ make sure there is less duplication of care provision and better co-ordination of care.
**Staffing**

- Work to raise the status of social care so that a career in social care equates better with a career in health care
- Work to ensure that staff are well trained and better rewarded with increased opportunities to progress, and
- Emphasise the importance of on-going staff assessments

Whilst the meeting focused on adult social care, over the two days we heard a number of examples of social care that was provided for older people in particular. Whilst we realised we were not producing recommendations about that group, and there were other case studies that could be explored, this was a recurring topic and we wanted to highlight a general need for NICE to:

- Advocate early support for carers and families particularly those of older people.
- Work to change public attitudes towards older people.
- Advocate and encourage earlier support for older people who are lonely and isolated, and
- Produce guidance for schools to educate children that older people are an asset. One member suggested that schools should find ways for young people to spend time with older members of the community.
ACKNOWLEDGEMENTS

The Citizens Council would like to acknowledge the following contributors to the January 2013 Citizens Council meeting

Speakers:    Ian Basnett  
             Robin Burgess  
             Sarah Byford  
             Joanna Coast  
             Tina Coldham  
             Jennifer Francis  
             Anne Fretwell  
             Sarah Garner  
             Gillian Leng CBE  
             Sue Lightup  
             Carole Longson  
             Jennifer McGovern  
             Ann Netten  
             Ray Pawson  
             Barbara Pointon  
             Deborah Rutter


Meeting facilitators: Word of Mouth  www.womresearch.org.uk

Visual minutes: More than Minutes  www.morethanminutes.co.uk
Appendix 1

Keypad questions

Q1a
I understand what NICE does as an organisation
(Select 1,2,3,4 or 5)
1. Strongly Agree
2. Agree
3. Neither agree or disagree
4. Disagree
5. Strongly Disagree

1 17.9% (5)
2 71.4% (20)
3 10.7% (3)
4 0.0% (0)
5 0.0% (0)
Total: 28

Q1b
The question the Citizens Council is being asked to discuss is "What aspects of "benefit", "cost" and "need" should NICE take into account when developing social care guidance". I understand the question that the Citizens Council is being asked to discuss.
(Select 1,2,3,4 or 5)
1. Strongly Agree
2. Agree
3. Neither agree or disagree
4. Disagree
5. Strongly Disagree

1 3.6% (1)
2 71.4% (20)
3 21.4% (6)
4 3.6% (1)
5 0.0% (0)
Total: 28
I think that it is possible to give a numerical "value" to concepts like dignity, respect and compassion and therefore be able to rank one over another

(Select 1,2,3,4 or 5)

1 Strongly Agree
2 Agree
3 Neither agree or disagree
4 Disagree
5 Strongly Disagree

1 0.0% (0)
2 31.0% (9)
3 10.3% (3)
4 41.4% (12)
5 17.2% (5)
Total: 29

I think it is possible to give a value to concepts like health, capability and integration within society, and by therefore be able to rank one over another

(Select 1,2,3,4 or 5)

1 Strongly Agree
2 Agree
3 Neither agree or disagree
4 Disagree
5 Strongly Disagree

1 3.3% (1)
2 40.0% (12)
3 13.3% (4)
4 36.7% (11)
5 6.7% (2)
Total: 30
Day 1

Q2. Based on what I have heard so far, I believe that:

1. NICE's existing methods for developing healthcare guidance are sufficient for developing guidance on social care
2. NICE's existing methods for developing healthcare guidance are not sufficient for developing guidance on social care but only require minor changes to make them sufficient
3. NICE's existing methods for developing healthcare guidance are not sufficient for developing guidance on social care and new methods need to be developed
4. I don’t know

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Total: 29

Day 2

Q2. Based on what I have heard so far, I believe that:

1. NICE's existing methods for developing healthcare guidance are sufficient for developing guidance on social care
2. NICE's existing methods for developing healthcare guidance are not sufficient for developing guidance on social care but only require minor changes to make them sufficient
3. NICE's existing methods for developing healthcare guidance are not sufficient for developing guidance on social care and new methods need to be developed
4. I don’t know

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Total: 26
Appendix 2
Citizens Council Members

The following Citizens Council members were in attendance at the meeting:

Rebecca Adewale
Fatima Ahmed
Ray Allen
Vance Ankrah
Alan Bacon
Calvin Beck
Sharon Bernard
Trevor Betts
Elizabeth Bodey
James Brown
John Corber
Arlette Fairclough
Ivan Gee
David Goronwy
Gay Hamilton
Cathal Harte
Andrea Josephs
Rachel Lawrence
Gary Mayall
Mary McGuinness
Karen McTaggart
Nirmala Parma-Hopkins
Ellie Perrott
Estelle Rose
Benjamin Smoldon
Robin Somerville
Pauline Turgoose
Gareth White
Matt Guy Wright
Samuel Wynter
CITIZENS COUNCIL 2013

What aspects of ‘benefit’, ‘cost’ and ‘need’ should NICE take account of when developing social care guidance?

NICE has been asked to develop guidance and quality standards on social care for adults and children. The legislation states that NICE must take into account, ‘the broad balance between the benefits and costs’ of care and people’s ‘degree of need’ for care.

Through the Citizens Council, NICE is seeking views on what are the important aspects of ‘benefit’, ‘cost’ and ‘need’ that it should consider. We are also seeking the Council’s views on which of NICE’s current methods and processes apply, which may need to be adapted and whether any new ones need to be developed.

This document provides some background to the question and the issues that will be discussed at the meeting. It is important to note that deciding how social care is paid for will not be part of NICE’s role and the Council will not be making recommendations about funding.

The role of the Citizens Council

1. The National Institute for Health and Clinical Excellence (NICE) was set up in 1999. NICE produces evidence-based guidance, quality standards, and other products to help the NHS, local government and other organisations (on how to improve health and wellbeing of local communities) identify the best quality and value for money in clinical and public health interventions.

2. All NICE guidance and quality standards are developed by independent groups of experts including, as appropriate, clinicians and other healthcare professionals, local authority professionals, patients and carers, and health researchers and economists.

3. NICE’s Citizens Council is made up of 30 people from a range of backgrounds, broadly similar to the population mix of the UK. The Council
provides NICE with advice on what are often challenging social and moral issues raised during the development of our guidance. This advice helps the independent groups of experts to make decisions on NICE’s recommendations.

4. The Citizens Council provides NICE with a public perspective on overarching moral and ethical issues that NICE has to take account of when producing guidance. The council's recommendations and conclusions are incorporated into the Social Value Judgements document. Values can be defined as “important and lasting beliefs or ideals shared by the members of a culture about what is good or bad and desirable or undesirable. Values have major influence on a person’s behaviour and attitude and serve as broad guidelines in all situations. Some common values are fairness, innovation and community involvement.”

**NICE’s new responsibility for social care guidance**

5. The government has asked NICE to develop guidance and quality standards on social care for adults and children. Potentially, this could cover many aspects of social care and would be relevant to a wide audience but, in particular, local authorities and other organisations that provide care.

6. The government has announced that NICE’s first social care quality standard will focus on personal care provided in people’s homes. NICE could also be asked to look at how:

- care is delivered in the community and in care homes
- people’s needs for care are assessed
- people are involved in planning their own care.

7. New legislation says that when NICE develops social care guidance it must take into account ‘the broad balance between the benefits and costs’ of care and people’s ‘degree of need’ for care. These instructions are similar to those given to NICE when it was asked to produce clinical and public health guidance. However, there are important differences between health and
social care and NICE needs to take these differences into account when developing social care guidance.

8. NICE has to identify which of its current processes and methods apply, and whether any need to be adapted or whether any new ones need to be developed. Through the Citizens Council, NICE is seeking views on which aspects of 'benefit', 'cost' and 'need' it should consider. It is important to note that it will not be part of NICE’s role to decide how social care is funded.

What is social care?

9. There is no agreed definition of social care. However, it generally refers to services provided (or arranged) by local authorities for children and adults who need extra support. This includes: vulnerable children (children who are at risk of, or who are already experiencing social and emotional problems), children and adults with learning or physical disabilities or mental health problems, people who misuse drugs and alcohol, and older people.

10. Social care services include the provision of: foster care, care homes, day centres, equipment and adaptations, meals and personal care at home, personal assistants and services to help carers (such as travel expenses and respite care). It can also extend to the provision of services such as gym membership, art therapy, life-coaching and other classes or courses to aid physical, mental and emotional wellbeing.

11. Social care also includes the mechanisms for delivering services, such as assessments and personal budgets, as well as information and advice about services.

12. There is an increasing focus on ‘personalisation’ within the social care agenda. This, says the Department of Health, means, ‘every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings’. Support is available to help with these choices.

13. Personalisation is often associated with direct payments and personal budgets to give service users the ability to choose the services they receive.
It also implies that services need to be tailored to the needs of every individual, rather than delivered in a ‘one-size-fits-all’ fashion.

**How does social care differ from healthcare?**

14. Healthcare is a national service funded centrally through a single budget drawn from general taxation and delivered throughout England. Everyone in need of medical care receives it more or less free of charge.

15. By contrast, there are 152 different adult social care systems in England – one for each local authority. Social care is paid for by a combination of central government grants to local authorities funded from taxation, the council tax, and from service users themselves. Many people arrange social care for themselves without support or funding from their local authority.

16. Entitlement to social care varies across the country, leading to what many people call a ‘postcode lottery’: different people, with similar care needs, can receive very different levels of support. Each local authority carries out a financial assessment to determine what someone can afford to pay.

17. NHS organisations provide most healthcare in England, whereas a multiplicity of private and voluntary sector organisations provide most social care services. These are commissioned by local authorities. (Local authorities provide a relatively small proportion of social services.)

18. Increasingly, local authorities are giving users a ‘personal budget’ to arrange social care services for themselves, in line with an agreed care plan and with the help of social care professionals.

**Need for social care**

19. The need for social care – and the nature of that need – varies, from place to place and from one person to another. Some areas, for example, have an older or poorer population than others. Some individuals also have better personal support networks than others (for example, families and friends and other trusted people).
20. Local authorities use a checklist (set out in national guidance) to assess someone’s needs as ‘low’, ‘moderate’, ‘substantial’ or ‘critical’.

**Benefits of social care**

21. Social care services seek to ensure people can live as normal a life as possible, despite their physical or mental impairments, by giving them choice, control, independence and dignity. They also aim, where possible, to prevent further physical or mental deterioration.

22. The government recently set out the ‘outcomes’, or benefits of social care from a user’s point of view. These cover health, capability (ability to do something) and integration within society and reflect societal values (see paragraph 4). Examples include:

- I am supported to become as independent as possible.
- I am treated with compassion, dignity and respect.
- I am involved in decisions about my care.
- I am protected from avoidable harm, but also have my own freedom to take risks.
- I have a positive experience of care that meets my needs.
- I have a personalised service that lets me keep control over my own life.
- I feel that I am part of a community and participate actively in it.
- The services I use represent value for money.

23. The metrics used to capture the benefits of healthcare are more directly related to the specific activities of the NHS. Healthcare aims to:

- improve people’s health and wellbeing
- support them to keep mentally and physically well
- help them get better when they are ill
- help them stay as well as they can, when they cannot fully recover.

24. NICE’s standard processes for judging the cost effectiveness of clinical and public health interventions use the quality-adjusted life year (QALY) to measure the ‘benefits’. This involves the use of standard questionnaires that
ask about a person's quality of life and level of health. Examples are the EuroQol-5 Dimensions (EQ5D) and the Short-form 36. Social care interventions aim to increase capability and function, in addition to health-related quality of life, and therefore a different approach may be needed. Two questionnaires which measure ‘capability’ have been proposed called the adult social care outcomes toolkit (‘ASCOT’) and the instrument of capability ‘ICECAP’.

25. Researchers are developing new methods for measuring whether new ways of providing services are benefiting users more, or whether the benefits they are gaining from standard services are increasing from year to year.

**Costs of social care**

26. Compared to healthcare, it is more complicated to find out how much social care costs. Partly because of the many different arrangements for commissioning, funding and delivery. Many services are ‘personalised’, in other words, tailored to an individual’s specific needs. Also, most people using social care services receive a significant amount of additional support from the community, friends, and family. Improvements in measuring costs mean that it may soon be possible to make better assessments of value for money.

27. Whether people get a service funded (or part-funded) by the local authority depends on its social care budget. There are concerns in some quarters that, increasingly, services will only be available for those with substantial or critical needs.

28. In 2010/11, an estimated £14.4 billion was spent on adult social care, accounting for 33% of spending which is under the direct control of local authorities (excluding education, fire and police).

29. It is difficult to balance the benefits and costs of social care due to the more limited evidence base when compared to clinical and public health. There has been increased investment in research into social care services in recent years, for example, through the National Institute for Health Research (NIHR) School for Social Care Research.
1. Introducing the question and NICE’s role
Prof Gillian Leng, Deputy Chief Executive, NICE

2. What is NICE
- The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance.
- Evidence-based guidance and other products from NICE help resolve uncertainty about best quality care and what represents value for money.

   www.nice.org.uk

3. Health and Social Care Act: what does it mean for NICE?

   “The Health Act makes NICE stronger than before”
   Rt Hon. Andrew Lansley MP
   Speaking at NICE Conference 2012

4. NICE becoming a Non Departmental Public Body
- No longer a Special Health Authority from 1 April 2013
- Will be renamed National Institute for Health and Care Excellence
- NICE will be enshrined in legislation
- Greater independence from government
- Remit expanded beyond the NHS to cover social care

5. Expanding our remit
- Formal role setting standards for social care from 2013
- Reflects new NDPB status – reaching out beyond NHS
- Guidance for every part of the patient pathway
- Working on two pilots to publish in April 2013
- Another wave announced by government

6. What it says in the Act
Quality standards

“The relevant commissioner may direct NICE to prepare statements of standards in relation to the provision of:
- NHS service
- Public health services, or

NICE must keep a quality standard under review and may revise it as it considers appropriate.

In discharging its duty, the Board/Secretary of State must have regard to the quality standards prepared by NICE.”
7. **Guidance and quality standards**

- **Evidence**
- **Guidance**
- **Quality Standards**

'Sentinel markers'
A prioritised set of concise, measurable statements designed to drive quality improvements across a pathway of care.

8. **Guidance and the Dementia QS**

The QS is based primarily on NICE clinical guidance 42 - Dementia: Supporting people with dementia and their carers in health and social care. Also SCIE guide 15 – Dignity in care

9. **Draft quality standard for Dementia**

A set of 13 statements

- Provide a clear focus on the priority areas for continuous improvement in quality and outcomes
- Associated with outcome and process measures

10. **Referred social care topics and timelines**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Quality Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental wellbeing in older people</td>
<td>Late 2013</td>
</tr>
<tr>
<td>Autism in adults and children</td>
<td>Late 2013</td>
</tr>
<tr>
<td>Medicines management in care homes</td>
<td>2015</td>
</tr>
<tr>
<td>Transition between health and social care</td>
<td>2016</td>
</tr>
<tr>
<td>Older people with multiple co-morbidities</td>
<td>2016</td>
</tr>
<tr>
<td>Domiciliary care</td>
<td>2016</td>
</tr>
<tr>
<td>Child maltreatment</td>
<td>2016</td>
</tr>
<tr>
<td>Transition between child adult services</td>
<td>2016</td>
</tr>
</tbody>
</table>

11. **Challenges for NICE social care work**

- **The evidence base**
  - Less well-developed than for health
- **Guidance**
  - Evidence-based practice less well established
- **Dissemination**
  - A broad range of diverse audiences, including the general public, in a range of different organisations and settings
- **Implementation**
  - Approaches for encouraging use of Standards will be different from those in health.

12. **The question**

"What aspects of ‘benefit’, ‘cost’ and ‘need’ should NICE take into account when developing social care guidance?"

13. **Definitions**

- What do we mean by:
  - ‘benefit’: health, capability (ability to do something), integration within society and reflect societal values.
  - ‘cost’: assessments of value for money.
  - ‘need’: local authorities use checklists to assess someone’s needs as ‘low’, ‘moderate’, ‘substantial’ or ‘critical’.

14. **Focus: Adult social care**

- You can work with people in:
  - Their own homes to enable them to live more independently. For many people, this will prevent them from needing to go into a care home.
  - The community to support them to live independently and use resources in the community such as libraries or leisure facilities
  - Residential and nursing homes to provide a safe and homely place where people can live in comfort and be treated with dignity and respect.
  - Supported housing to offer a range of services to help people live independently with the added security of having someone to call on in emergencies.
  - Day care to provide opportunities for people to take part in activities, meet others and learn skills that can lead to greater independence.
Tina Coldham – Social care from “my/our” perspective

1. User perspective of social care and delivery
   Tina Coldham
   Social Care Institute for Excellence
   NICE Citizens Council meeting
   24 January 2013

2. Who I am
   - Mental health service user.
   - Freelance user consultant.
   - SCIE Trustee.

   Mixture of two careers and perspectives.

3. Where the money comes from?

   Community
   £ via taxation

   Government
   Funding to services

   Local Authority professionals

   Person in need via assessment and support

4. What it means to the person
   - Very often we don’t see the money, we only see the service or support.
   - Do people worry or understand where the money comes from?
   - Therefore is it a health or social care issue?

How you can help

- Discuss & debate
- Ask questions
- Test tools (EQ5D, ASCOT and ICECAP)
5. Health versus Social care

Health £  Social care £

6. Health and Social Care meeting need

Health  Social care

7. How do you get the money or service?

- LA’s set their own criteria for service entitlement
- Fairer Access to Care Services (FACS)
- Pressures on the system – £
- Demands on the system – aging population
- Devolution issues – Scotland 0 England £?
- Personalisation of services

8. Quality

- Who gets to say?
  - LA Commissioner
  - LA Councilors
  - Care manager
  - User/carer
  - Public
  - SCIE/NICE

9. The conundrum

 Benefit  Cost  Need

10. Conclusions

- It’s a complex arena
- Person centered/ person bewildered

Any questions?
Sue Lightup & Jennifer McGovern – Challenging issues: What are the wider issues that impact on social care?

1. NICE and Social Care

NICE and Social Care
Sue Lightup and Jennifer McGovern
Jan 2013

2. Social Care and the wider challenges in society

- Population Changes
  - Age profiles – baby boomers
  - Caring Responsibilities
  - Health and Wellbeing – improvements and long term condition management
  - Assets eg contribution to childcare
  - Grey power?
  - Housing for Life
  - JSNA – needs assessment

3. Social Care and the wider challenges in policy

- Care and support White Paper
- Vision for Adult Social Care - Think Local, Act Personal
- NHS White Paper – Liberating the NHS
- Public Health White Paper
- Dilnot Report – Long Term Care Commission
- Localities Act
- Big Society – community assets
- Role of Local Government
- Role re Social Care – promote access, secure coordination, protect the most vulnerable, managing market

4. Managing the Market

- Who are the providers?
  - 65% of organisations are privately owned. (Salford 92%)
  - 48% provide care for older people. (Salford 64%)
  - 37% provide care for adults with learning disabilities. (Salford 36%)
  - 23% provide care for adults with mental health needs. (Salford 36%)
  - 8% provide care for children, families and young people. (Salford 9%)
  - ~58% have achieved Investors in People (IIP) status with a further 8% working towards this (of the 65 members of SCTP in Salford 22 hold the IIP kitemark – 33.8%)
- In organisations in Salford
  - 31% were residential homes without nursing care.
  - 21% were residential homes with nursing provision.
  - 34% were Domiciliary Care Providers

5. Different models for delivery

- Prevention and early intervention
- Managing Demand
- Whole system approach
- Adult Social Care outcomes - improve
- Personalisation
- Co-production
- Asset rather than Deficit
- Equalities

6. City Council Vision

“Create the best possible quality of life for the people of Salford”.
Salford’s Proposed Integrated Care Model

An integrated Health and Social Care Contact Centre acts as a central hub, supporting Multi Disciplinary Groups, helping people to navigate services and support mechanisms, and coordinating telecare monitoring.

Local community assets enable older people to remain independent, with greater confidence to manage their own care.

Multi Disciplinary Groups provide targeted support to older people who are most at risk and have a population focus on screening, primary prevention and signposting to community support.

Promoting independence for older people
- Better health and social care outcomes
- Improved experience for services users and carers
- Reduced health and social care costs

Local community assets enable older people to remain independent, with greater confidence to manage their own care.

Multi Disciplinary Groups provide targeted support to older people who are most at risk and have a population focus on screening, primary prevention and signposting to community support.

Funding Challenge

- In excess of £81 million expenditure – Adult Social Care
  - £41 million on adults over 65year
  - 7,526 community support packages, including:
    - 2,774 home care, 2,998 major equipment
    - 682 residential placements, 242 nursing placements
    - 52,411 community health service contacts
    - 24,943 admissions and 16,749 A&E attendances

What drives need and demand

- 23,969 people aged 65+, 28% projected increase
- 1:14 have dementia and over-represented in acute beds
- Growth in people living alone: 12,542 in 2011 to 15,998 in 2030
- Disability-free life expectancy
- 2,130 falls related A&E attendances

Commissioning – a practical example – Intermediate Care

- Reduce unnecessarily prolonged hospital stays or inappropriate admission to acute inpatient care, long term residential care or continuing care NHS inpatient care
- Maximise independence and enable patients and service users to remain or resume living at home.
- Deliver a personalised respond to meet need.

Intermediate Care – Best Value

- 24 Medical Beds closures - £1.2m
- Reduction in social care packages - £580k
- Reduction in length of stay on acute wards
- Admission avoidance - £1.7m
- Total saving - £3.73m

Fit for the Future by:-

- Building Personalisation into the mainstream choice and control for citizens
- Focus on prevention and support in community – promoting wellbeing
- Ensure outcomes are owned by citizens and communities
- Develop the settlement for the future- incorporating the contribution of individuals and the public
Dr Ian Basnett – Joint working in ‘social care’

1. Dr Ian Basnett
   Reflections on benefit, costs and needs

2. My Perspective
   • Director of Public Health
   • Working closely with NHS Commissioners
   • User of Personal Assistants for over 20 years

3. Plan
   • Funding and who pays
   • Benefit, NHS and independent living perspective
   • Costs including wider costs
   • Needs and how defined

4. Exposure to the disability movement and independent living has taught me:
   • Social Model
   • Removing barriers

5. “Well, this certainly bugs our plan to conquer the Universe.”

6. • The goal of equal citizens
   • Choice and control for disabled people works best
   • “Nothing about us without us”
   • State moving from paternalistic to empowerment based approach
7. **Benefit and the NHS**
   - Focus on cure and alleviating symptoms
   - Does it “work”?  
   - How much – Measurement!
   - Who does it “work” in
   - Found ways of quantifying this across programs, e.g. QALYS, but last Rolo argument

8. **In practice**
   - Most is broad brush, e.g. 2/3 of £1.6 million
   - At a service level, will base more on population need
   - At an individual level

9. **In practice**
   - Most is broad brush, e.g. 2/3 of £1.6 million
   - At a service level, will base more on population need
   - At an individual level

10. **Where does this take us?**
    - Goals for life, not cure or treatment
    - Equality does not mean the same for everyone
    - Personal goals for independence and removing barriers
    - Prevention needs greater weighting

11. **Costs**
    - In practice, direct costs tend to dominate but shouldn’t
    - Costs to carers
    - Costs in terms of unemployment
    - Longer term costs, important for prevention

12. **Needs Assessment**
    Need
    Supply
    Demand

13. **Don’t**
    - Reduce it to a tick box exercise
    - Blindly use RAS
    - Ignore user defined needs
    - Reduce to tasks

14. **Do**
    - Build an assessment of needs around the individual
    - Focus on enablers to achieve equality
    - Be as holistic as possible
15. Communication and coordination between services

16. Conclusion - benefit

- Focus is quite different
- Therefore aims and benefits are
- Principles draw on Social Model
- But haven’t helped measurement

17. Conclusion – needs

- There is a great deal wrong with the current approach
- Inflexible, focus on critical and substantial
- Should draw on the earlier points I’ve made on benefit.
- There is much to be learnt at a population level about the assessment of needs

Anne Fretwell – Care home perspective

1. Merevale House: A Perspective of Benefit, Cost and Need in Developing Social Care Guidance

Anne Fretwell, Owner/Manager of Merevale House

2. How does what we do impact on a wider scale?

At Merevale House our approach is called Active Co-existence
Active-Co-existence is a free document
Document is available for others via our website
Others can follow guidance and use checklist as a self-assessment tool for a measurable indication of how much a community actively co-exists
Active-co-existence encourages people to develop their skills and create a passion for supporting people who live with dementia
Active-co-existence develops the potential for people to see the positives and embrace their experience of dementia, resulting incontentment and happiness
3. Developing Active Co-existence

- What do we mean by Co-existence?
- People living and working together
- Sharing emotions
- Learning about the way people choose to live
- Encouraging people to live and not just exist
- Fostering relationships that are built on trust and true friendship
- Showing emotional intelligence and understanding
- Listening to and understanding the real meaning of what people say

4. How do we achieve this?

- Create a community where people feel comfortable to live and work together
- Accept and encourage difference and diversity
- Breaking down and removing barriers, both emotional and physical
- Look for the person not the dementia or symptom
- Develop teamwork within the community, dissolve hierarchy and control
- Face challenges together

5. Recognize peoples strengths and ability, emotional and physical

- Encourage people to contribute to the community
- Encourage everyone to be themselves and live their own lives
- Embrace all emotions
- Include everyone through innovation and change to your approach
- Don’t be afraid to show your feelings

6. Need, Benefit and Cost

- Need: To provide opportunities for people living with Dementia to continue enjoying life
- Encourage opportunities for people to express their experiences, be heard and be free
- To change the understanding of Dementia and encourage people to embrace Dementia
- To reduce emotional and physical distress, which leads to acute emotional and physical distress

- Benefit: Reduced acute admissions and psychiatric interventions

- Active Co-existence reduces ‘behaviours’ due to its approach

- Incurred in the use of anti-psychotic medications, reducing the limiting side effects

- Change a culture is to use hope and happiness

- Cost: Active coexistence is cost effective – reduction in training costs, reduced hospital admissions, no return to hospital due to anti-psychotic medication and money to spend positively encouraging the concept of emotional autonomy and happiness within living with dementia

7. Merevale’s Take Home Message

- Look for the person and not the Dementia
- Active Co-existence is a change in culture and does not cost a lot of money
- Encourage people to live and not just exist
- Don’t be afraid to love
- The answer is often very simple, sometimes it is hard to find
- This takes innovation and courage
- Treat people with love and respect and you will be rewarded with the same
Dr Sarah Garner – Translating values into ‘value’

1. Measuring value for money

Dr Sarah Garner
Associate Director
R&D

2. The healthcare system perspective

New Health gain
Displaced Health forgone

3. What do we want to know?

• How well does the drug work compared to standard practice in the National Health Service
• How much does this course of action cost compared to standard practice in the NHS

i.e. Difference in costs
Difference in effects

4. Compare the costs...

Suppose B is more effective and more convenient

Average Acquisition cost
Average other treatment Costs
• Healthcare professionals
• hospital
• surgery
• other drugs
• tests
• ...

B A B

+ =

B A

* Disease and treatment related

5. The cost-effectiveness decision matrix

<table>
<thead>
<tr>
<th></th>
<th>Less effective</th>
<th>Equally effective</th>
<th>More effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less cost</td>
<td>?</td>
<td>NEW</td>
<td>NEW</td>
</tr>
<tr>
<td>Same cost</td>
<td>OLD</td>
<td>EITHER</td>
<td>NEW</td>
</tr>
<tr>
<td>More cost</td>
<td>OLD</td>
<td>OLD</td>
<td>?</td>
</tr>
</tbody>
</table>

6. How to measure the effects

- High blood pressure treated with a blood pressure lowering drug: Cost (£) per reduction in units of blood pressure (mm mercury)
- Rheumatoid arthritis – pain killer: Cost (£) per pain free hour
- Depression treated with a drug that improves mood: Cost (£) per reduction in units of a rating scale that scores depression
- Heart failure treated with a drug that improves cardiac performance: Cost (£) per unit increase in the output of the heart
- Breast cancer treated with a drug that prevents recurrence: Cost (£) per additional life year gained as a result of effective treatment
7. Quality-adjusted life years (QALY)
   • An effective treatment or intervention does one or both of the following:
     – Increase how long people live
     – Increase their quality of life

8. Measuring quality of life
   [Diagram showing a scale from worst to best health states]

9. For treatments that save life...

   If,
   Quality of Life = 0.7
   And,
   A treatment gives 10 extra years of life (0.7 per year)

   Then....
   People receiving the treatment gain
   Seven Quality-Adjusted Life Years
   (7 QALYs)

10. What would impact on your quality of life?

11. [Diagram with levels of disability and coding]

12. Broken arm
   no problems in walking about
   some problems washing or dressing
   some problems with performing usual activities
   no pain or discomfort
   not anxious or depressed

   The code: 12211

13. Some values
   • Broken hip
     • 22222
       – some problems in walking about
       – some problems washing or dressing
       – some problems with performing usual activities
       – moderate pain or discomfort
       – moderately anxious or depressed

14. [Diagram with code 12211]
15. **But...**

1. It’s public money
2. Different people give different answers
3. Patients get used to living with their conditions.
   - They therefore rate their quality of life BETTER than the public

16. **The societal perspective**

- Patients in clinical studies
- Health state
- Societal value

17. **Some values**

- Broken arm
- 12211
  - no problems in walking about
  - some problems washing or dressing
  - some problems with performing usual
  - no pain or discomfort
  - not anxious or depressed
- Societal value = 0.779

18. **Some values**

- Broken hip
- 22222
  - some problems in walking about
  - some problems washing or dressing
  - some problems with performing usual
  - moderate pain or discomfort
  - moderately anxious or depressed
- Societal value = 0.516

19. **Quality Adjusted Life Years (QALY)**

- Multiply life years with quality index
- Quality of life index
  - 1.0 = normal health
  - 0.0 = death (extremely bad health)
- Example
  - Losing sense of sight
  - Quality of life value is 0.5
  - Life = 80 years
  - 0.5 x 80 = 40 QALYs

20. **The cost-effectiveness of one thing compared to another... (INCREMENTAL)**

Cost treatment A – Cost treatment B
Effectiveness treatment A – Effectiveness treatment B

\[ \text{Cost per QALY} = \frac{\text{Cost treatment A} - \text{Cost treatment B}}{\text{Effectiveness treatment A} - \text{Effectiveness treatment B}} \]

21. **For example...**

<table>
<thead>
<tr>
<th>Cost</th>
<th>Life Expectancy</th>
<th>HRQoL</th>
<th>QALYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group A</td>
<td>£80,000</td>
<td>2 Year</td>
<td>X</td>
</tr>
<tr>
<td>Group B</td>
<td>£4,000</td>
<td>1 Year</td>
<td>X</td>
</tr>
</tbody>
</table>

Cost-effectiveness:

\[
\text{£80,000 - £4,000} = \frac{\text{£76,000}}{0.4} \Rightarrow \text{£190,000/QALY}
\]

22. **Consideration of cost effectiveness: threshold range**

Increasingly likely that the NHS could lose more health than it gains by funding a new drug/device
Ann Netten – ASCOT assessment tool

1. **ASCOT**
   - Measuring the outcomes of social care
   - Ann Netten
   - NICE Citizens Council meeting
   - 24 January 2013

2. **The role of social care**
   - Usually for people with long-term conditions
   - Often deteriorating over time
   - Often multiple
   - Which result in impairment in activities of daily living
   - Most social care is done by informal carers
   - Services:
     - Do what people would have done themselves
       - Home care/personal assistance/care homes etc.
     - Improve people’s abilities to do things
       - Equipment and adaptations
     - Prevent avoidable health problems
       - Through meeting needs (e.g. reducing isolation)

3. **Health and social care**
   - Health
     - Treating and reducing impairment
   - Health related quality of life (HRQoL)
     - Ability to undertake activities, pain etc
     - Prevention
   - Social care
     - Compensating for impairment
     - Social care related quality of life (SCRQoL)
       - Personally clean, fed, socially engaged etc
     - Prevention

4. **Social care related quality of life (SCRQoL)**
   - Personal cleanliness and comfort
   - Food and drink
   - Safety
   - Clean and comfortable accommodation
   - Social participation and involvement
   - Control over daily living
   - Occupation
   - Dignity
5. **Dignity**
   - Impact of care process on self-esteem
     - How you think and feel about yourself
     - Some people feel bad about needing help at all
     - In order to be clear about impact of care process two questions
       - How does having help make you feel?
       - How does the way you are helped make you feel?
     - Current study checking this works with large number of people

6. **What does social care do?**
   - Ensuring needs are met
   - More recently emphasis on..
     - Personalisation
     - Giving people control
     - Functionings
     - States of being e.g. clean, well-fed, safe
     - Capabilities
     - The freedom to be able to do something that is valued

7. **Response options**
   - Needs as functioning i.e. don’t do (enough) X
     - Some needs (no health implications)
     - High needs (health implications)
       - For some domains ultimately ‘being dead’
   - Absence of need as capabilities i.e. able to do X
     - No needs (mustn’t grumble, not as much as want)
     - Preferred situation (aspirations, as much as want)

8. **Occupation**
   - Which of the following statements best describes how you spend your time?
     - I’m able to spend my time as I want, doing things I value or enjoy
     - I’m able to do enough of the things I value or enjoy with my time
     - I do some of the things I value or enjoy with my time but not enough
     - I don’t do anything I value or enjoy with my time

9. **Scoring**
   - Aims...
     - Reflect relative importance of different aspects
     - Meaningful scale can link to measures like EQ-5D
   - Preference studies to get scores
     - General population and equipment service users
     - No difference – same things important
   - Scale
     - 0 = 'being dead' 1 = 'ideal' SCRQoL
     - Range = -0.17-1.00

10. **Relative importance of outcomes**

11. **Occupation**

12. **The toolkit**
   - Includes a range of ways of measuring outcomes
   - Self completion questionnaires
   - Interview schedules
     - Includes questions about impact of services
   - Care homes multi-method approach
     - Interviews – residents/staff/relatives
     - Observation
     - Rating scale
     - Training
     - Ongoing support and development
Social care surveys

- Important source of measures for national Adult Social Care Outcomes Framework
- Conducted by all local authorities
- Adult Social Care Survey (ASCS)
  - Annual survey since 2011
  - All service user groups
  - Includes ASCOT measure of SCRQoL
- Carer experience survey
  - Every 2 years from 2012
  - Includes carer ASCOT equivalent SCRQoL measure

Take home messages

- The ASCOT measure has been developed over 10 years to ensure it reflects the benefits of social care
  - Both basic and 'higher order' outcomes
- The scoring reflects the relative importance of benefits
  - Both general population and service users
  - '0' score links to 'being dead' as in EQ-5D
- It is already being used in policy and practice
  - The Adult Social Care Survey and national Outcomes Framework
  - Increasing demand by local councils and providers
- There is ongoing support and development for toolkit
  - Website, workshops, training and support for users
  - Projects on carers and extending methods for people hard to include

Translating values into 'value': What ASCOT does

- Includes the range of 'basic' and 'higher order' aspects of quality of life addressed by social care
- Includes levels within domains that demonstrate higher levels of control and personalisation
- Has a scoring system that reflects the preferences of service users and the general population
- Has a scoring system that is anchored to 'being dead' as does EQ-5D

The toolkit - online

ASCOT
http://www.pssru.ac.uk/ascot/

Instruments & data entry tools
Guidance & FAQ & References
Feedback
Registration

Joanna Coast – ICECAP-A assessment tool

Evaluating social care – ICECAP

Joanna Coast
NICE Citizens Council meeting - January 24th, 2013

Outline

- Measuring social care benefits in terms of improving capability wellbeing
  - What do we mean by capability wellbeing?
- Using ICECAP to measure capability wellbeing
  - What is ICECAP?
  - How can it be used?
- What are the advantages and disadvantages of this approach?
3. Measuring social care benefits in terms of capability wellbeing

4. Social care

5. Specific measure

6. Social care

7. Social care

8. Health

9. Beyond single sector measures

10. Beyond the individual

Beyond single sector measures

Wellbeing

Beyond the individual

Wellbeing

Family, Carers
Why capability wellbeing?

- What a person is able to do or be in their lives is what is important
  - Referred to as “capability”
- More important than what they actually do
  - E.g. Making cup of tea
- More important than happiness
  - People who have been in a poor situation for a long time may become ‘happy’ with what they have
  - Assessing happiness does not reflect what really matters if people ‘adapt’ like this

Evidence?

- Talking to older people about what was important to them in their daily lives (Grewal et al., 2006)
  - Loss of capability clearly important to people
  - E.g. not being able to read for enjoyment because of poor eyesight
  - E.g. not being able to feel secure because of worries about their partner’s health
  - E.g. not being able to help out with grandchildren because of pain from arthritis

Using ICECAP to measure capability wellbeing

- Measure based on talking to people (in-depth interviews)
  - About what is important and should be included
  - About wording of the measure
- Population values (method used called ‘Best-Worst Scaling’)
  - Top level of the measure is ‘full capability’ (1); bottom level is ‘no capability’ (0)

ICECAP-A

- 5 questions, each with 4 possible responses
- Aims to tap into what is important to the general adult population.

UK values

- Index values for ICECAP-A
  - Stability, Attachment, Autonomy, Achievement, Enjoyment
19. Using the measures (1)

- Increasing evidence that the measure ‘works’ in social care
  - Use of Dutch version of ICECAP to look at use of restraints in older people with dementia
    - ICECAP could pick up differences between restrained and unrestrained groups in a way that EQ-5D did not
    - Particularly around loss of independence from restraints
  - Use of ICECAP among participants in a falls prevention clinic in Canada
    - Found ICECAP measured more broadly than just health

20. Using the measures (2)

- ICECAP-A can be downloaded from website: www.birmingham.ac.uk/icecap
- Filled in by the person themselves (or someone close to them)
- Can be used to
  1. Get the most total wellbeing from the funds available; or
  2. Focus funds on those in greatest need, by giving priority to people under a set threshold

21. Using the measures (3)…

- … to get the most total wellbeing from the resources available: illustrative example
  - Joint replacement for arthritis:
    - Gain in index value on ICECAP-A = 0.78
    - Cost = £6,000
  - Wheelchair provision for COPD
    - Gain in index value on ICECAP-A = 0.21
    - Cost = £603
  - Cost-effectiveness
    - Joint replacement = £7,892/year of full capability gained
    - Wheelchair = £2,871/year of full capability gained
- Wheelchair provision is more cost-effective use of resources

22. What are the advantages and disadvantages of ICECAP?

23. Advantages

- A single measure can be used across funding sectors
  - Captures benefits from both health and social care
  - No need to ‘translate’ benefits from one measure to another
  - Can take account of benefits both to individuals and carers / people close to them
  - Highly important aspect of social care
- Based on what is important to people
  - What they want from life

24. Disadvantages

- May be less able to pick up differences than a measure that focuses just on social care
  - In same way as a measure for just one health condition will be better at measuring effects than a more general health measure like EQ-5D
- May not be what is most important to decision makers
  - Especially those spending budgets for a single department

25. Acknowledgements

Hareth Al-Janabi, Terry Flynn, Tom Kesley, Phil Kinghorn, Paul Mitchell, Rosanna Orlando, Eileen Sutton
Day 2

Carole Longson – Principles in practice: personal insights into translating values into value

1. **Value Frameworks: principles into practice**
   Personal insights into translating values into value
   
   Carole Longson
   Director
   Centre for Health Technology Evaluation
   NICE

2. **How NICE communicates important values**

3. **A process for understanding values**

4. **Increasing chance of rejection**

5. **Increasing cost per QALY**
7. **What do healthcare decision makers value highly**

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Detail</th>
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<tbody>
<tr>
<td>Significant development</td>
<td>Something that has not been done before</td>
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<td></td>
<td>Employs a new approach e.g. a new pathway, receptor or other chemical or biological target</td>
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<td>Not simply modification to an existing technology with no clear promise of significant patient benefit</td>
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<tr>
<td>Unmet need</td>
<td>Addresses a disease or condition which is life threatening or substantially reduces health-related quality of life</td>
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<tr>
<td>Substantial impact</td>
<td>Demonstrates substantial promise of delivering valuable, additional benefits to length or quality of life</td>
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8. **Factors influencing decisions**

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<thead>
<tr>
<th>Topic</th>
<th>Severity</th>
<th>Significant development</th>
<th>Unmet need</th>
<th>Substantial impact</th>
<th>Children</th>
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<td>Trastuzumab (breast cancer)</td>
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<td>Sunitinib (renal cancer)</td>
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<td>Human growth hormone</td>
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<td>Insulin pump</td>
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<td>Lenalidomide (myeloma)</td>
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9. **Translating values into value...?**

...it’s all about collective wisdom

10. **“Knowledge speaks, but wisdom listens”**

Jimi Hendrix

Robin Burgess – Quality - what does it mean in reality?

1. **Quality in health and social care**
Robin Burgess
Chief Executive, HQIP

2. **HQIP**
- A charity owned by the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices, but also works with other professions
- Cover all areas of quality improvement in health and social care but experts in clinician/profession led, data driven methods, including clinical audit in partnership with consumers
3. **What is ‘quality’ in care and how can it be measured?**

4. • I am not covering different methods of improving quality – for a full review, have a look at

5. **What is ‘quality’?**
   • The key aspects of quality set out by previous governments:
     • Clinical effectiveness, capacity, safety, patient centredness, equity, access and timeliness.
   • Does this help us set the bar for what quality is?

6. **Who defines what quality is?**
   • Is it the consumer, or professional, or both?
   • How many sets of measures or data we collect are equally defined by consumers as opposed to mostly by doctors and nurses?
   • NICE standards are amongst the best

7. **Is quality just about patient safety?**
   Some argue that quality in healthcare is just about patient safety, in acknowledgement that patient safety is internationally regarded as an essential marker of quality

8. **Is safety quality?**

9. **Minimum versus aspirational**
   • Is quality achieved in meeting minimum, or basic standards? –
     CQC say: By high quality care, we mean care that:
     – is safe
     – has the right outcomes, including clinical outcomes (for example do people get the right treatment and are they well cared for?)
     – is a good experience for the people who use it, their carers and their families

10. **CQC continued**
    • helps to prevent illness, and promotes healthy, independent living.
    • is available to those who need it when they need it, and
    • provides good value for money
11. Yet CQC accept that there is also a higher level of quality in care, above the level required to meet their standards – eg to meet NICE guidelines and Quality standards, and other processes.

12. A hierarchy of quality

   - Excellence: Achieves good outcomes
   - Aspirational: measures process and outcomes
   - Minimum standards: Safety/good processes

13. Quality is .......

   - Is not killing someone, quality?
   - Safety is fine, but quality is surely about exceeding the minimum

   - So how can quality be measured?

14. Measuring quality

   - Routine administrative data:
     - Often fails to measure the right things
     - Typically does not even show achievement of minimum standards
     - Measures process not outcome
     - Not focused on the consumer
     - Riddled with errors – 40% on HES

15. Specifically constructed data sets

   - Dashboards of essential process indicators
   - Key process ‘bundle’ measurements
   - Patient review mechanisms – including PROMS
   - Clinical audit
   - Registers
   - Accreditation system data

16. Hallmarks of good measurement systems

   By ‘good’, we mean:
   - Have ability to show suitable evidence for the purpose required but can also show excellence too

   But measurement alone is not enough:
   - Any process which includes measurement must be capable of driving quality improvement and engage professionals and consumers

17. The audit cycle

18. Why good clinical audit is so important

   - The best way to judge compliance with agreed clinical standards in detail
   - Addresses safety but measures quality from minimum to maximum
   - A proven, clinically led and run discipline of quality improvement
   - A whole cycle approach which includes action as well as measurement
   - Can measure patient and professionally defined outcomes
19. How HQIP helps organisations demonstrate quality

- HQIP helps organisations, professionals and consumers to conduct and use high quality clinical audits
- HQIP help to support good measurement which drives change through enabling organisations to be focused on quality relevant to consumer needs

20. Contacting us

Healthcare Quality Improvement Partnership
Holland House, 4 Bury Street, London, EC3A 5AW
0207 469 2500
www.hqip.org.uk
communications@hqip.org.uk

Promoting quality improvement for better healthcare

Ray Pawson – Public health - what NICE has already looked at with regards to types of evidence

1. Reviewing the Evidence (but what evidence?)
Ray Pawson
Presentation to the NICE Citizen’s Council
Jan 25 2013

2. 10 steps to NICE guidance
1. Topic selected
2. Stakeholders register interest
3. Scope prepared
4. Evidence reviewed
5. Call for Evidence
6. Draft guidance prepared
7. Consultation on the draft guidance
8. Fieldwork carried out
9. Final guidance produced
10. Guidance issued

3. NICE: The name stays – the remit grows

4. THE CHALLENGE:
As the interventions, programmes, policies and services under review become more complex – so does the challenge of uncovering valid and reliable evidence.

PRESENTATION:
1. An example of a potential public health intervention.
2. You (citizens) advise on what kind of evidence need to be considered.
3. I provide a glimpse of some of the evidence demonstrating its complexities.
Banning Smoking in Cars Carrying Children: Is there a case for legislation?

OVER TO YOU

What evidence would help you decide whether such legislation would be effective?
• You will have your own thoughts about whether such a ban would or would not work.
• Smokers, non-smokers, parents, medics, tobacco companies, police will also be able to come up with reasons why the ban might work and why it might fail

The EVIDENCE needs to test out these various ideas

HERE’S WHAT WE CHOSE TO STUDY AND THAT’S ONLY THE START

1. How significant is the risk? (Evidence base: Toxicology)
2. Is there public support? (Evidence base: Survey Research)
3. Will it survive lobbying? (Evidence base: Political Science)
4. Is it enforceable? (Evidence base: Policing Evaluation)

What is the evidence on risk?

Toxicity – small particulate levels per cigarette?
Ventilation – what difference does it make?
Relativities – comparisons with other risky environments?
Exposure – in-car time as compared to home, ... , etc?
Benchmarks – comparison with air quality standards?

What is the evidence on public support?

Magnitude of support?
Demographics of support?
Support from smokers?
Stability of support (words versus deeds)?
Reasons for support?

What is the evidence on tobacco company opposition?

Has the tobacco lobby opposed this particular ban?
Will they do so in future?
What is the broader strategy behind tobacco company opposition to smoking control?
How does the tobacco-control lobby interpret and respond to industry tactics?

What is the evidence on enforcement?

Is the law being enforced?
Will the police enforce the law (being a public health concern)?
Will the smoking public disregard the law?
What is the optimal enforcement strategy?

Evidence glimpses on public support.

Increasing support?
1994 – “Do you think it should be illegal to smoke in cars when travelling with children?” as follows: ‘of the 1461 adult responders, 72% agreed, 27% disagreed and 1% were undecided’ (Australia)
2009 ‘Do you think smoking should be allowed in cars with preschool children in them’ ... 95.9% disagreed and only 3.0% agreed with this question’. (New Zealand)

Support amongst smokers?
2007 ‘A smoking ban should be introduced ASAP’ 74.2% non-smokers agree, 61.7% smokers agree (Australia)
Uncertainties in the Evidence?

- Sensitivity to question wording. E.g. response patterns change if question refers to ‘banning’ or ‘allowing’; ‘children’ or ‘pre-school children’ etc.
- Social desirably effect. Conversations (or interviews) between strangers tend to reflect the ‘politically correct’.
- Gap between attitudes and behaviour. People don’t always practice what they preach.
- Sampling the committed. Surveys mainly conducted in Australia, New Zealand, Canada. Modest response rates reflect the views of the fervent.

More evidence to support the evidence

- The ‘near universal expression of regret’. 90% of respondents in a four country survey respond ‘agree / strongly agree’ to the following question: ‘If you had to do it over again, you would not have started smoking’.
- The ‘invincible sub-text’ of child vulnerability. Many (quantitative and qualitative) studies report that smokers already modify in their behaviour in the presence of children under the consideration that … ‘children were particularly at risk because they were still developing’.
- The steady march of ‘denormalisation’. Very high percentages of smokers agree with the statement that ‘there are fewer and fewer places I feel comfortable smoking’. An identical percentage agrees that ‘society disapproves of smoking’.

Sarah Byford – Social care - what is important in evaluation, what does the evidence say?

1. Social care – what is important in evaluation?
   Applying economics to social care

2. Background
   - NICE provides national guidance on the promotion of good health and the prevention and treatment of ill health
   - In making its recommendations, NICE is required to consider evidence of both effectiveness and cost-effectiveness
### Why cost-effectiveness?

- Health and social care systems are working within limited budgets determined by taxation
- Funding one service means forgoing the benefits that would have arisen by funding an alternative service
- Aim is to allocate funds available to services that generate the greatest benefit for users
- Economics is concerned with maximising societal wellbeing, given scarce resources

### Methods of economic evidence appraisal

- In health care, NICE has been assessing economic evidence for almost 15 years
- Methods for appraisal of evidence have been developed through expert consultation and have been adapted over time
- Different methods have developed for different aspects of NICE’s work
- Greater level of adaptation and greater flexibility in more complex areas such as public health

### Social care

- Differences between social care and health means health methodologies cannot simply be transferred
- Social care characterised by:
  - Highly variable populations
  - Complex interventions with complex impacts on users
  - Wide range of providers, funders and decision-makers
  - Predominance of unpaid care
  - Centrality of service users and carers
  - Relatively few trials, compared to health care
  - Even fewer economic evaluations

### SCIE’s approach to economic evaluation in social care

Economic evaluations in social care should...
- adopt a broad analytic perspective, including all relevant stakeholders and people who use services and their families
- value the cost of informal care associated with the intervention
- measure outcomes from the perspective of service users and their carers
- extract resource use data from relevant studies at the synthesis stage, even if not full or partial economic evaluations
- examine the costs and benefits of interventions for different sub groups of the population, to address issues of equity

### Cost perspective

- NICE HTA – NHS/PSS + justify any additions
- NICE PH – NHS/PSS + agreed relevant additions
- Social care – include all and justify any exclusions
- Captures the full impact of social care services
- Includes service users and carers
- Includes unpaid care
- Better grounding in economic theory
- Better grounding in the philosophy of social care
- Data and resource intensive
11. Outcomes perspective

- NICE HTA – Health effects on individuals
- NICE PH – Health effects on individuals
- SCIE – Well-being/capability effects

- Captures the full impact of social care services
- Better grounding in economic theory
- Better grounding in the philosophy of social care
- Uncertain how this should be measured (ASCOT, ICECAP?)
- Uncertain how results can be compared with QALYs

12. Discussion

- Attempts to capture full impact of social care will:
  - Be theoretically grounded
  - Help to highlight gaps in the evidence
  - Help to highlight methodological limitations
  - Help direct research funding and development of methods

- Need to balance consistency with flexibility
- Need to start with clear methodological guidelines
- Need to adapt these guidelines with experience
- Need to consider research and training capacity

Barbara Pointon – Case study of user/carer experience of care services

1. DEVELOPING NATIONAL SOCIAL CARE GUIDANCE

A Family Carer’s Perspective

Barbara Pointon MBE
Former carer
Ambassador for Alzheimer’s Society & Dementia UK
Member of Standing Commission on Carers
barbara@pointon.name

2. Malcolm in 1992, aged 51, just after he was diagnosed

3. Preamble

- Used range of different social care services over 16 years – talk based on personal experience in dementia.
- What makes for quality care at home in terms of outcomes, value for money and ability to meet our needs?
- NICE Guidance: a national yardstick by which to judge services on offer in our particular neck of the woods.
- Draft Bill for Care and Support applies to all adults including carers; compassion, dignity and respect.

4. Needs of client and carer are intertwined

- Two-thirds of people with dementia are cared for at home (half a million).
- Family carers form the largest dementia workforce
- Need for tailored information, advice, practical and emotional support – the right tools for the job.
- Overarching benefit of receiving quality care and support: A contented patient, regardless of their condition A contented family carer, enabled to offer enlightened care and support, individually tailored.
After diagnosis, we were dropped into thin air.

Staff given good training and updates.

Agency did not allow for travelling time between clients

Too rigid an application of ‘patient confidentiality’?

continuity is essential!

slightly increased, for but better value for money

Competencies and attitude equally important.

Job satisfaction, therefore

Loss of Malcolm always came back in a worse physical and

Continuity and reliability of personnel; getting to know

more likely to meet needs

(Years 4

A few realised that it’s not what you do, it’s the way you

A more confident, knowledgeable and capable carer, not

Better quality of life for cared-for and carer

Costs: minimal

Value for money – preventing more expensive crises in
care further down the line

Needs of both: met.

Using Services: Daycare (Years 4-6)

Social Worker a key player. Self-funders are often left to
fend for themselves and don’t know about services.

Daycare staff very kind, but inappropriate activities for Malcolm produced behaviours they misunderstood.

Lack of information flow (about deficits in his brain) between hospital and social care staff on a ‘need to know’ basis.

Too rigid an application of ‘patient confidentiality’?

Everyone has a basic human right to be helped to use the toilet. Issues of dignity in care.

Loss of daycare and therefore of benefit: needs not met

Using Services: Domiciliary Care (years 4-6)

Benefits of adequate time:

Careworker has time to do the job properly.

Dignity and independence of client preserved.

Job satisfaction, therefore carer likely to stay with it for longer (improving recruitment and retention of staff).

Continuity allows the carer to get to know the client and carer really well – more likely to meet needs

Cost slightly increased, for but better value for money

All needs met

Using Services: Respite Care (Years 5 - 7)

Important new dementia research : not the usual forgetfulness (i.e. ability to retrieve a memory)

The brain no longer converts an experience into a memory – so the memory is not there in the first place.

Respite care away from home – no memory of being there before. So each time, the staff were ‘strangers’.

Malcolm always came back in a worse physical and psychological state than when he went away.

Numerous times I was phoned to fetch him home.

Carers won’t take breaks if the respite care is not right for the client. Could become exhausted and give up caring early.

Using Services: quality domiciliary care

Staff given good training and updates.

Competencies and attitude equally important.

Time to do a good job.

Continuity and reliability of personnel; getting to know client and family really well.

Benefits: a contented client and carer

Cost – a slight increase in hourly-paid to allow for time. Poor quality domiciliary care causes the carer to give up and place the client prematurely in a carehome at greater expense (and that stresses the carer further!)

Needs –can be met by good care at home.

Using Services: Live-in Care (Year 7)

Malcolm losing more of his physical functions; perplexing behaviours, including aggression (which I only now know always have a reason).

Live-in carers from an Agency – two weeks at a time.

No-one was dementia-trained; tended to see care as a string of mechanical tasks; disengagement.

A few realised that it’s not what you do, it’s the way you do it that counts.

Personal qualities are as important as competencies.

14 different carers in 8 months – continuity is essential!

Totally exhausted, I placed him in a carehome for my sake. Guilt and a feeling of bereavement.
The dining room, turned into Malcolm’s room, with electrically-operated recliner chair, hospital bed, hoist and manual wheelchair.

December 1999

April 2000

Care at home in the advanced stage (Years 10-16)

- Received Direct Payments – after a battle!
- Benefits (1): choosing who worked in our home, greater continuity of staff, replacement care at home.
- Cost less than Agency or carehome care (i.e. no profit involved) and the carestaff were paid more.
- Grateful for support of the Rowan Organisation.
- Benefits (2): A more contented Malcolm.
- Tranquil environment; time to attend to details of care; familiarity of staff; meeting his needs beyond the physical. Feeling loved and cherished.
- Quality holistic care – physical, mental, psychological, social, sensory, emotional and spiritual needs fully met.

And what about the carer?

- Many carer’s assessments, few resulted in action
- Tedium form-filling. Social Worker’s solution – one blank piece of paper, one question: What one thing would make life better for you right now?
- Broken nights – lack of sleep making me impatient with Malcolm. Asked for a bit of night cover – and got it!
- Plea for less bureaucracy and paperwork.
- Carers find battles with officialdom (e.g. for equipment or NHS CHC) more stressful than the caring and they sap energy when there is none to spare. Carers Strategy: professionals should treat carers as partners in care.

Benefits, Costs and Needs

- Benefits to both the client and carer:
  - Better training of all paid staff: given time to do the job properly
  - Understanding the client and their needs from the inside looking out – empathy
  - Individuality – the person’s past history and their current likes and dislikes. Seeing the person, not the disabilities
  - Holistic assessments to meet physical, mental, psychological, emotional, sensory and spiritual needs
  - Care offered with compassion. Not measurable – either there or not!
  - Continuity of paid staff: reliability of home calls
  - Treating the family carer as a true partner in care – triangle of trust

Malcolm and Barbara

Memory Clinic
Neurologist & research
Dementia ward and NHS respite unit
Psycho-geriatrician & behavioural psychologist
Music therapist
Live-in carer for 8 months only
The Web of Care (First 9 yrs)

GPs
social worker
domiciliary care (daily visits)
Malcolm and Barbara
care agencies
respite care
dementia care advisor?
nenurologist & research
psychogeriatrician & behavioural psychologist
music therapist
live-in carer for 8 months only

GP
social worker
domiciliary care (daily visits)
malcolm and barbara
care agencies
respite care
dementia care advisor?
nenurologist & research
psychogeriatrician & behavioural psychologist
music therapist
live-in carer for 8 months only

Direct Payments Team, Rowan Org.
Consultant
District Nurses
Speech & Language Adviser
District
Community Dentist
Occupational Therapist
Physiotherapist
Equipment Service
Medical
Alzheimer’s Society
Out-of-hours doctors/paramedics
Dementia Advisory Nurse?
Dementia Adviser
Alzheimer’s Soc outreach worker
Care team
2 live-in carers (alternating weekly)
Replacement carer
Some night nursing
– Health
Emergency carers & Barbara
Sitting service
Caring Support worker

The Web of Care (Last 7 yrs)
Benefits, Costs and Needs

21. Benefits

- **Benefits** to both the client and carer:
  - Features of quality, tailored care:
    - The webs of care and the back-office lines of communication cry out for simplification and integration. Care is Care is Care
    - All carers are asking for a single point of contact for expert advice in caring for the condition that their loved one has and who will take the lead in co-ordinating the care
    - A single holistic assessment held by that person as the hub for any other assessments.
  - **Cost of this model**
    - Initially for setting up and training Dementia Advisers and dementia community or practice-based nurses, but more than offset by a reduction in the need for other professionals to be involved except when higher opinion is required.

22. Costs

- **Costs**
  - Invest in support for the family carer to enable them to carry on caring – for free
  - Poor domiciliary care can trigger premature admission to the more expensive option of the carehome
  - Value for money – why is care so expensive?
  - Why does nobody look at the books of providers – taxpayers’ money is being used – we should require greater transparency about size of profit.
  - Government incentives for more not-for-profit care.
  - Personal Budgets are changing the face of care

23. Determining level of need

- **Determining level of need** - fraught with difficulties
  - Depends on the individual and the size of budget.
  - Perceived unfairness of similar needs and situations treated differently – inevitable ‘postcode lottery’.
  - A little help earlier on will prevent crises and more expensive interventions later on.
  - People will not resent paying towards their care if it is of good quality, value for money, and genuinely meets their level of personal needs. But they resent being ripped-off.
  - Tendency to ignore needs beyond the physical; holistic assessments for holistic care.
  - Care is care is care.

24. Does National Guidance Make a Difference?

- Commissioners, providers, service users and members of the public need to have a common, robust framework of reference against which to determine what makes for quality care, whatever the setting, and wherever in the country the care is given.
  - Make sure that the guidance we are working on is given plenty of ‘clout’.
  - Then it will make a real difference to the quality of care for many vulnerable adults.
Developing guidance in health and social care
Jennifer Francis and Deborah Rutter
Social Care Institute for Excellence
NICE Citizens Council meeting
25 January 2013

Overview
- Health and social care – what’s the difference?
- Guidelines for dementia care.
- Exercise 1 ‘Spot the difference’.
- Exercise 2 ‘Mind the gap’.
- Concluding comments.

Health and social care: what’s the difference?
- Aims of social care.
- Range of funders and providers.
- The role of families and unpaid carers.
- Personalisation and the importance of the individual.
- The social model of disability and focus on outcomes.
- Diversity and equality.
- Workforce.

Guidelines for dementia care
- The NICE SCIE guideline on supporting people with dementia and their carers in health and social care (NICE, SCIE 2007)
- Quality standard on dementia (NICE, 2010)
- Pilot quality standard on social care of people with dementia (NICE, in progress)

Exercise 1 Spot the difference
For group discussion:
(a) What’s different about the underlying approaches of these two quality standards?
(b) How does each reflect the needs of people living with dementia and their carers?

Exercise 1 Spot the difference

<table>
<thead>
<tr>
<th>Q51 Dementia (for the NHS)</th>
<th>Draft Q5 Care of people with dementia (for social care)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with suspected dementia are referred to a memory assessment service specializing in diagnosis and initial management.</td>
<td>People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.</td>
</tr>
<tr>
<td>People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment &amp; support options.</td>
<td>PLwD and their carers are in contact with a local advisor who provides information about dementia &amp; how to access additional support.</td>
</tr>
<tr>
<td>People with dementia and their carers are in contact with a local advisor who provides information about dementia &amp; how to access additional support.</td>
<td>PLwD and their carers have choice and control in decisions affecting their care and support.</td>
</tr>
<tr>
<td>People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.</td>
<td>PLwD and carers participate in reviews when circumstances change, and at least once a year.</td>
</tr>
</tbody>
</table>
Living with dementia

I get frustrated, angry, depressed – not necessarily a symptom of the dementia but a response to living with it

We need to work out together what the best approach is

The only thing we have in common is the fact that we have a diagnosis of dementia

Exercise 2 Mind the gap (Tessa’s story)

Tessa, 91, lived alone. She has multiple physical, communication & mental health problems.

Sudden admission to hospital following ‘crisis’.

Diagnosis of dementia on ward: need for new assessment & planning.

Identified need for a new way of living.

Exercise 2 Mind the gap (Tessa’s story)

For group discussion:
What could have been done differently to improve Tessa’s experiences?

Exercise 2 feedback

Tessa’s needs only highlighted in crisis situation.

Opportunities for assessment neglected.

Division of medical & psychiatric services.

Little understanding of social care on OP ward.

Poor communication with the family, little information for them to work with.

The family’s need for an informed advocate:
  - With the whole person in mind
  - With understanding of services & ‘clout’ in system.

Conclusion

What resources & costs should be taken into account in the development of future guidance?

What benefits should be considered?

How should NICE deal with the notion of ‘need’ in social care guidance?

Needs, costs & benefits

Needs:
  - Capacity to deliver, capacity to benefit (not as clear as in health treatments)
  - Social care has a wide remit: personalised service is very likely to improve Quality of Life for disadvantaged people

Resources and costs:
  - Need in social care cannot be confined to what Local Authorities fund
  - Funding complex. Self funders also need NICE guidance
  - Cost of informal, unpaid care must be explicit
  - Workforce training always an issue/cost (skills base patchy)

Benefits:
  - Better lives, personalised outcomes that matter to recipients
  - Subjective experience, as well objective measures, are important.
Appendix 5- Visual Minutes
Appendix 6
Measurement tools

The following measurement tools were used:

- EQ-5D
- ASCOT (Adult Social Care Outcomes Toolkit)
- ICECAP-A
Health Questionnaire

*English version for the UK*
*(validated for Ireland)*
By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** (*e.g. work, study, housework, family or leisure activities*)
- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.
four-level self-completion questionnaire (SCT4)

1. Which of the following statements best describes how much control you have over your daily life?

   By ‘control over daily life’ we mean having the choice to do things or have things done for you as you like and when you want.

   Please tick (☐) one box

   - I have as much control over my daily life as I want
   - I have adequate control over my daily life
   - I have some control over my daily life but not enough
   - I have no control over my daily life

2. Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation?

   Please tick (☐) one box

   - I feel clean and am able to present myself the way I like
   - I feel adequately clean and presentable
   - I feel less than adequately clean or presentable
   - I don’t feel at all clean or presentable

3. Thinking about the food and drink you get, which of the following statements best describes your situation?

   Please tick (☐) one box

   - I get all the food and drink I like when I want
   - I get adequate food and drink at OK times
   - I don’t always get adequate or timely food and drink
   - I don’t always get adequate or timely food and drink, and I think there is a risk to my health
4. **Which of the following statements best describes how safe you feel?**

*By feeling safe we mean how safe you feel both inside and outside the home. This includes fear of abuse, falling or other physical harm.*

Please tick (☑) one box

- I feel as safe as I want
- Generally I feel adequately safe, but not as safe as I would like
- I feel less than adequately safe
- I don’t feel at all safe

5. **Thinking about how much contact you’ve had with people you like, which of the following statements best describes your social situation?**

Please tick (☑) one box

- I have as much social contact as I want with people I like
- I have adequate social contact with people
- I have some social contact with people, but not enough
- I have little social contact with people and feel socially isolated

6. **Which of the following statements best describes how you spend your time?**

*When you are thinking about how you spend your time, please include anything you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others.*

Please tick (☑) one box

- I’m able to spend my time as I want, doing things I value or enjoy
- I’m able to do enough of the things I value or enjoy with my time
- I do some of the things I value or enjoy with my time but not enough
- I don’t do anything I value or enjoy with my time
four-level self-completion questionnaire (SCT4)

7. Which of the following statements best describes how clean and comfortable your home is?

Please tick (☑) one box

- My home is as clean and comfortable as I want
- My home is adequately clean and comfortable
- My home is not quite clean or comfortable enough
- My home is not at all clean or comfortable

8. Which of these statements best describes how having help to do things makes you think and feel about yourself?

Please tick (☑) one box

- Having help makes me think and feel better about myself
- Having help does not affect the way I think or feel about myself
- Having help sometimes undermines the way I think and feel about myself
- Having help completely undermines the way I think and feel about myself

9. Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?

Please tick (☑) one box

- The way I'm helped and treated makes me think and feel better about myself
- The way I'm helped and treated does not affect the way I think or feel about myself
- The way I'm helped and treated sometimes undermines the way I think and feel about myself
- The way I'm helped and treated completely undermines the way I think and feel about myself

(c) PSSRU at the University of Kent

This questionnaire has been created by the Personal Social Services Research Unit (PSSRU) at the University of Kent with funding from HM Government, and the University of Kent is the sole owner of the copyright in those materials. The University of Kent authorises non-commercial use of this questionnaire on the condition that anyone who uses it contact the ASCOT team (ascot@kent.ac.uk) to discuss this use and enable the PSSRU at University of Kent to track authorised non-commercial use. The University of Kent does not authorise commercial use of the questionnaire. Anyone wishing to obtain a licence for commercial use of any of the ASCOT materials should contact the ASCOT team, who will put them in touch with Kent Innovation & Enterprise.
ABOUT YOUR OVERALL QUALITY OF LIFE

Please indicate which statements best describe your overall quality of life at the moment by placing a tick (✓) in ONE box for each of the five groups below.

1. Feeling settled and secure
   - I am able to feel settled and secure in **all** areas of my life
   - I am able to feel settled and secure in **many** areas of my life
   - I am able to feel settled and secure in **a few** areas of my life
   - I am **unable** to feel settled and secure in **any** areas of my life

2. Love, friendship and support
   - I can have **a lot** of love, friendship and support
   - I can have **quite a lot** of love, friendship and support
   - I can have **a little** love, friendship and support
   - I **cannot** have **any** love, friendship and support

3. Being independent
   - I am able to be **completely** independent
   - I am able to be independent in **many** things
   - I am able to be independent in **a few** things
   - I **unable** to be at all independent

4. Achievement and progress
   - I can achieve and progress in **all** aspects of my life
   - I can achieve and progress in **many** aspects of my life
   - I can achieve and progress in **a few** aspects of my life
   - I **cannot** achieve and progress in **any** aspects of my life

5. Enjoyment and pleasure
   - I can have **a lot** of enjoyment and pleasure
   - I can have **quite a lot** of enjoyment and pleasure
   - I can have **a little** enjoyment and pleasure
   - I **cannot** have **any** enjoyment and pleasure

Please ensure you have only ticked ONE box for each of the five groups.
Appendix 7
Tessa’s story (care pathway)

Overhead 8: Tessa’s care pathway (a family carer’s account)

Background:
Tessa, 91, lived alone. She has multiple physical, communication & mental health problems (depression, sometimes hears ‘command’ voices). She prized her independence, and resisted suggestions about getting help in the home. Her married daughter is her main carer but does not live with her.

Sudden admission to hospital:
Neighbours reported Tessa locked out of her house and wandering in the street, and the police contacted her daughter. The next day she saw a GP who diagnosed an infection and prescribed antibiotics. Tessa’s mental health social worker, who had never managed to gain entry, visited while her daughter was there to discuss a package of care to maintain Tessa at home. But Tessa became incoherent, dizzy and unable to stand or walk, and an ambulance was called. Paramedics took her to hospital for further tests, and she was admitted via A&E.

On the hospital wards – a new diagnosis to cope with:
Tessa was moved to a medical assessment ward and then to geriatric medicine. A junior doctor casually mentioned Tessa was suffering from dementia. Tessa’s daughter questioned the basis for this, and pointed out she could hardly hear, and whether this had affected this diagnosis. The doctor went to check the scan results, and returned to say they were consistent with a diagnosis of dementia. Meanwhile, Tessa’s daughter wrote a notice to staff, suggesting they should write messages on a notepad and allow time for her to read the message and reply. Staff cooperated, and the method worked well.

Where next?
When she first went into hospital, Tessa wanted to return home, but her views changed and she came to agree she did not want to go back to “that house” where she felt frightened and isolated. The social worker began gathering assessments and reports from the range of professionals in contact with Tessa, to assist the formulation of a discharge and care plan, and inform the choice of a care home for Tessa.

Tessa’s daughter knew that the value of her mother’s house and savings meant she would have to meet the full costs of social care. The social worker recommended still going through the local authority process, as then the local authority would assume financial responsibility when her funds ran out. The ward staff, informed of the care home proposal, placed a note on Tessa’s file saying “Has chosen private care”. The OT attached to the ward initially declined to assess Tessa’s abilities, assuming she was a private patient, so Tessa was almost denied an NHS service to which she was entitled. Tessa’s daughter was also keen to get a fuller psychiatric assessment. The geriatrician resisted seeking advice from psychiatric colleagues based on the floor
below: it took pressure from the social worker to obtain reports from the OT and a psychiatrist.

**Judgments and decisions:**
A small review meeting, chaired by the mental health social worker and involving a senior nurse from the ward and Tessa’s daughter, considered the information gathered. Tessa was medically fit for discharge, but did not feel safe at home. Finding the right care home would not only reduce her level of risk, but could offer her some independence, improved quality of life, and a wider range of choices than had been available for some time in her own home.
## Citizens Council Meeting

### Meeting Day 1: Thursday 24 January 2013

<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Speaker</th>
</tr>
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<tbody>
<tr>
<td>09.00 - 09.45</td>
<td>Day 1: Registration and refreshments on arrival</td>
<td></td>
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<tr>
<td>09.45 - 10.15</td>
<td>Day 1 opens/Welcome</td>
<td>Facilitators</td>
</tr>
<tr>
<td>10.15 - 10.30</td>
<td>Introduction to the question and NICE’s role</td>
<td>Dr Gill Leng, Deputy Chief Executive, NICE</td>
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<td></td>
<td>Question: What aspects of ‘benefit’, ‘cost’ and ‘need’ should NICE take account of when developing social care guidance?</td>
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<tr>
<td>Q1</td>
<td>See the slides for the question(s)</td>
<td>Facilitators</td>
</tr>
<tr>
<td>10.30 - 10.50</td>
<td>Presentation 1:</td>
<td>Speaker 1:</td>
</tr>
<tr>
<td></td>
<td>Setting the scene: Social care from “my/our” perspective.</td>
<td>• Tina Coldham, Mental Health User Consultant, Trustee SCIE</td>
</tr>
<tr>
<td>10.50 - 11.10</td>
<td>Presentation 2:</td>
<td>Speaker 2:</td>
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<td></td>
<td>Challenging issues: What are the wider issues that impact on social care?</td>
<td>Sue Lightup, Strategic Director of Community Health and Social Care at Salford City Council &amp; Chair of the NW ADASS region</td>
</tr>
<tr>
<td></td>
<td>Aspects from different perspectives/concepts covering compassion, dignity and respect</td>
<td>Commissioner’s perspective: Jennifer McGovern, Assistant Director for Joint Commissioning, Salford City Council</td>
</tr>
<tr>
<td>11.10 - 11.25</td>
<td>Refreshment and comfort break</td>
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<tr>
<td>11.25 - 11.45</td>
<td>What defines excellence in social care?</td>
<td>SCIE’s Social Care TV video on ‘Defining Excellence – What is Excellence?’</td>
</tr>
<tr>
<td>11.45 - 12.45</td>
<td>GROUP DISCUSSION:</td>
<td>Facilitators (with speakers 1-2)</td>
</tr>
<tr>
<td>Time</td>
<td>Item</td>
<td>Speaker</td>
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<tr>
<td>12.45 – 13.00</td>
<td>Feedback from group discussion</td>
<td>Council members with facilitators</td>
</tr>
<tr>
<td>13.00 – 14.00</td>
<td>Lunch in the restaurant</td>
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<tr>
<td>14.00 – 14.20</td>
<td>Presentation 3: Setting the scene: Joint working in ‘care’ from “my/our” perspective.</td>
<td>Speaker 3: Dr Ian Basnett, Director of Public Health, NHS East London</td>
</tr>
<tr>
<td>14.20 – 14.40</td>
<td>Presentation 4: Aspects from different perspectives/concepts covering compassion, dignity and respect</td>
<td>Speaker 4: Care home perspective: • Ann Fretwell, Owner/Manager of Merevale House</td>
</tr>
<tr>
<td>14.40 – 15.30</td>
<td>Presentations 5-7: Translating values into ‘value’. Re-introduce EQ5D and how it is used/considered at NICE ASCOT and ICECAP assessment tools</td>
<td>Speakers 5-7: • Dr Sarah Garner, Associate Director for Research and Development, NICE • ASCOT: Professor Ann Netten, Professor of Social Welfare, University of Kent • ICECAP: Professor Joanna Coast, Professor of Health Economics, University of Birmingham</td>
</tr>
<tr>
<td>15.30 – 15.40</td>
<td>Quick refreshment and comfort break leading into the exercise</td>
<td></td>
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<tr>
<td>15.40 – 16.30</td>
<td>GROUP EXERCISE 1: To explore the tools available for collecting data about social care quality of life and personal assessments of capability. This will be achieved by completing the ASCOT and ICECAP assessments forms, and also look at a health care assessment tool – EQ5D.</td>
<td>Facilitators with ASCOT and ICECAP representatives</td>
</tr>
<tr>
<td>16.30 – 17.00</td>
<td>Feedback from the group exercise</td>
<td>Council members with facilitators</td>
</tr>
<tr>
<td>Q2</td>
<td>See the slides for the question(s)</td>
<td>Facilitators</td>
</tr>
<tr>
<td>17.00</td>
<td>Day 1 closed</td>
<td>Jan Robinson, Project Manager, Research and Development, NICE</td>
</tr>
</tbody>
</table>
# National Institute for Health and Clinical Excellence

## Citizens Council Induction & Meeting

### Meeting Day 2: Friday 25 January 2013

<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.15 – 10.00</td>
<td>Day 2: Registration and refreshments on arrival</td>
<td></td>
</tr>
<tr>
<td>10.00 – 11.30</td>
<td>Day 2 opens</td>
<td>Facilitators</td>
</tr>
<tr>
<td></td>
<td>Presentations 8-11:</td>
<td>Speakers 8-11:</td>
</tr>
<tr>
<td></td>
<td>Principles in practice: personal insights into translating values into value.</td>
<td>• Professor Carole Longson, Director for the Centre for Health Technology Evaluation</td>
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<td></td>
<td>Quality – what does it mean in reality?</td>
<td>• Robin Burgess, Healthcare Quality Improvement Partnership</td>
</tr>
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<td></td>
<td>Public health – what NICE has already looked at with regards to types of evidence</td>
<td>• Professor Ray Pawson, University of Leeds</td>
</tr>
<tr>
<td></td>
<td>Social care – what is important in evaluation, what does the evidence say?</td>
<td>• Professor Sarah Byford, Professor of Health Economics, Kings College London</td>
</tr>
<tr>
<td>Q3</td>
<td>See the slides for the question(s)</td>
<td>Facilitators</td>
</tr>
<tr>
<td>11.30 – 11.45</td>
<td>Refreshment and comfort break</td>
<td></td>
</tr>
<tr>
<td>11.45 – 12.45</td>
<td>Group exercise 2:</td>
<td>Facilitators with speakers 12-13:</td>
</tr>
<tr>
<td></td>
<td>Health and social care dimension in day to day practice: Citizens Council members will have opportunity to explore real examples of new/existing services, challenges of service provision and how joint working leads to tangible outputs.</td>
<td>• Barbara Pointon</td>
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<tr>
<td></td>
<td>Example 1: Case study of user/carer experience of care services, followed by group discussion</td>
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<tr>
<td>12.45 – 13.45</td>
<td>Lunch in the restaurant</td>
<td></td>
</tr>
<tr>
<td>13.45 – 14.45</td>
<td>(See objective – noted under group exercise 2 above)</td>
<td>Facilitators with speakers:</td>
</tr>
<tr>
<td></td>
<td>Group exercise 2 continued:</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>Item</td>
<td>Speaker</td>
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<tr>
<td></td>
<td>Example 2: Joint guidance between NICE and SCIE, followed by group discussion</td>
<td>Speakers 13: Jennifer Francis, SCIE and Deborah Rutter, SCIE</td>
</tr>
<tr>
<td>14.45 – 15.15</td>
<td>Feedback from group exercise 2: examples 1 and 2</td>
<td>Council members with facilitators</td>
</tr>
<tr>
<td></td>
<td>Q4</td>
<td>Facilitators</td>
</tr>
<tr>
<td>15.15 – 15.45</td>
<td>Summary of the two days and next steps</td>
<td>Report writer &amp; animator/Facilitators</td>
</tr>
<tr>
<td>15.45 – 16.00</td>
<td>Questions from the floor</td>
<td>Facilitators</td>
</tr>
<tr>
<td>16.00</td>
<td>Day 2 closed</td>
<td>NICE</td>
</tr>
</tbody>
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