

WESTMINSTER
HEALTH FORUM

Next steps for improving dementia care: funding, reducing variations and implementing the 2020 Challenge 30th January 2017

CONDITIONS FOR USE OF TRANSCRIPTS:

This document is intended to provide a timely reference for interested parties who are unable to attend the event to which it refers. Some portions are based on transcripts of proceedings and others consist of text submitted by speakers or authors, and are clearly marked as such. As such, apart from where it is indicated that the text was supplied by the speaker, it has not been possible for the transcript to be checked by speakers and so this portion of the document does not represent a formal record of proceedings. Despite best endeavours by Westminster Forum Projects and its suppliers to ensure accuracy, text based on transcription may contain errors which could alter the intended meaning of any portion of the reported content. Anyone who intends to publicly use or refer to any text based on the transcript should make clear that speakers have not had the opportunity for any corrections, or check first with the speaker in question. If in doubt, please contact the forum first.

Contents

| | |
|--|-----------|
| <u>About this Publication</u> | 3 |
| <u>Agenda</u> | 4 |
| <u>Session Chair's opening remarks</u> | |
| Baroness Greengross , Co-Chair, All-Party Parliamentary Group on Dementia (<i>transcript</i>) | 6 |
| <u>Risk reduction, raising awareness and early indications from the Dementia Intelligence Network</u> | |
| Duncan Selbie , Chief Executive, Public Health England (<i>transcript</i>) | 7 |
| Questions and comments from the floor (<i>transcript</i>) | 9 |
| <u>The role of Health Education England in implementing the 2020 Challenge</u> | |
| Lisa Bayliss-Pratt , Director of Nursing, Health Education England (<i>transcript</i>) | 14 |
| Questions and comments from the floor (<i>transcript</i>) | 18 |
| <u>Priorities for building dementia-friendly communities, reducing variations and increasing participation in research</u> | |
| George McNamara , Head of Policy and Public Affairs, Alzheimer's Society (<i>transcript</i>) | 22 |
| Andrew Cornwall , Carer and Research Network Volunteer, Alzheimer's Society (<i>transcript</i>) | 24 |
| Professor Louise Robinson , Professor of Primary Care and Ageing, Newcastle University (<i>transcript</i>) | 26 |
| Professor John Gallacher , Professor of Cognitive Health, University of Oxford and PI and Director, MRC Dementias Platform UK (<i>transcript</i>) | 28 |
| Questions and comments from the floor (<i>transcript</i>) | 30 |
| <u>Session Chair's closing remarks</u> | |
| Baroness Greengross , Co-Chair, All-Party Parliamentary Group on Dementia (<i>transcript</i>) | 35 |
| <u>Session Chair's opening remarks</u> | |
| Baroness Finlay of Llandaff , Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum (<i>transcript</i>) | 36 |
| <u>Priorities for regulating and inspecting dementia services</u> | |
| Alison Murray , Head of Inspection for Adult Social Care, CQC (<i>transcript</i>) | 37 |
| Questions and comments from the floor (<i>transcript</i>) | 40 |
| <u>Key issues for social care: enhanced health in care homes, financial sustainability and workforce challenges</u> | |
| Simon Williams , Director of Community and Housing, Merton Council (<i>transcript</i>) | 43 |
| Professor Martin Knapp , Professor of Social Policy and Director of the Personal Social Services Research Unit, London School of Economics and Political Science and Director, NIHR School for Social Care Research (<i>transcript</i>) | 45 |
| Hilda Hayo , Chief Executive and Chief Admiral Nurse, Dementia UK (<i>transcript</i>) | 48 |
| Questions and comments from the floor (<i>transcript</i>) | 50 |
| <u>Next steps for dementia care and implementing the 2020 Challenge</u> | |
| Professor Alistair Burns , Professor of Old Age Psychiatry, University of Manchester and National Clinical Director for Dementia, NHS England (<i>transcript</i>) | 56 |
| Questions and comments from the floor (<i>transcript</i>) | 57 |
| <u>Session Chair's and Westminster Health Forum closing remarks</u> | |
| Baroness Finlay of Llandaff , Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum (<i>transcript</i>) | 59 |
| Sam Dolton , Producer, Westminster Health Forum (<i>transcript</i>) | 60 |
| <u>Comments</u> | 61 |
| <u>List of Delegates Registered for Seminar</u> | 62 |
| <u>Contributor Biographies</u> | 65 |
| <u>About the Core Sponsors of the Westminster Health Forum</u> | 68 |

Please be advised that speakers' PowerPoint presentations are included within the transcript itself, just beneath the relevant speaker's text. Please note that not all speakers are able to grant permission for us to include their slides.

About this Publication

This publication reflects proceedings at the Westminster Health Forum Keynote Seminar: Next steps for improving dementia care: funding, reducing variations and implementing the 2020 Challenge held on 30th January 2017. The views expressed in the articles are those of the named authors, not those of the Forum or the sponsors, apart from their own articles.

Although Westminster Health Forum is grateful to all sponsors for the funding on which we depend, participation in events and publications is never conditional on being a sponsor. As well as funding ongoing operations, sponsorship enables the Forum to distribute complimentary copies of publications, and offer complimentary tickets for events, to Government ministers, parliamentarians and officials most involved in policy.

This publication is copyright. Its copying, in whole or in part, is not permitted without the prior written consent of the publishers. However, extracts of the text may be reproduced for academic or review purposes, subject to the conditions of use outlined in the previous page, providing they are accurate, are not used in a misleading context and the author, their organisation and the Westminster Health Forum are acknowledged. We would also appreciate being informed.

Westminster Health Forum

UK Headquarters
4 Bracknell Beeches
Old Bracknell Lane West
Bracknell
Berkshire RG12 7BW

T: 01344 864796
F: 01344 420121
publications@westminsterforumprojects.co.uk

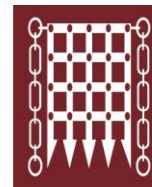
Directors

Peter van Gelder
Chris Whitehouse

**Westminster Health Forum Keynote Seminar:
Next steps for improving dementia care: funding, reducing variations
and implementing the 2020 Challenge**

Timing: Morning, Monday, 30th January 2017

Venue: Royal Over-Seas League, Over-Seas House, Park Place, St James's Street, London SW1A 1LR



**WESTMINSTER
HEALTH FORUM**

- 8.30 - 9.00 Registration and coffee
- 9.00 - 9.05 **Session Chair's opening remarks**
Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia
- 9.05 - 9.35 **Risk reduction, raising awareness and early indications from the Dementia Intelligence Network**
Duncan Selbie, Chief Executive, Public Health England
Questions and comments from the floor
- 9.35 - 10.00 **The role of Health Education England in implementing the 2020 Challenge**
Lisa Bayliss-Pratt, Director of Nursing, Health Education England
Questions and comments from the floor
- 10.00 - 10.45 **Priorities for building dementia-friendly communities, reducing variations and increasing participation in research**
How successful have initiatives such as Dementia Friends Programme, Dementia Friendly Charters and the Citizens Panel been in changing perceptions of dementia, and what are the next steps for building dementia-friendly communities? Following publication of the Government's Dementia Atlas, which indicates disparity in dementia services across the country, what more should be done to reduce local variations in care and disseminate best practice? How can health professionals effectively utilise linguistically and culturally appropriate diagnostic tools to improve diagnosis rates for people from BAME and other hard to reach groups? What impact has the introduction of named GPs had on personalising care for people with dementia, and what more needs to be done to improve post-diagnosis support? With the UK Government and other G8 nations committing to developing a cure or treatment for dementia by 2025, how is this likely to be affected by the outcome of the EU referendum, and what are the next steps for increasing participation in research?
George McNamara, Head of Policy and Public Affairs, Alzheimer's Society
Andrew Cornwall, Carer and Research Network Volunteer, Alzheimer's Society
Professor Louise Robinson, Professor of Primary Care and Ageing, Newcastle University
Professor John Gallacher, Professor of Cognitive Health, University of Oxford and PI and Director, MRC Dementias Platform UK
Questions and comments from the floor
- 10.45 - 10.50 **Session Chair's closing remarks**
Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia
- 10.50 - 11.20 Coffee
- 11.20 - 11.25 **Session Chair's opening remarks**
Baroness Finlay of Llandaff, Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum
- 11.25 - 11.45 **Priorities for regulating and inspecting dementia services**
Alison Murray, Head of Inspection for Adult Social Care, CQC
Questions and comments from the floor
- 11.45 - 12.30 **Key issues for social care: enhanced health in care homes, financial sustainability and workforce challenges**
What lessons can be learnt from the enhanced health in care homes vanguard sites in joining up services for people with dementia in residential care, and what are the early indications of how effectively multidisciplinary teams - including carers, nurses, therapists and the voluntary sector - and telemedicine are collaborating to reduce pressure on primary and secondary care services? What more needs to be done to ensure fewer people with dementia are being inappropriately admitted to hospital and to what extent can utilising and building capacity in care homes improve the discharge process? How has the introduction of the council tax adult social care precept eased pressure on dementia services, and what other options exist going forward for funding care? How can challenges around retaining staff, ensuring continuity of care and implementing the living wage be overcome, and what impact will Britain's withdrawal from the EU have on the social care workforce in delivering dementia care?
Simon Williams, Director of Community and Housing, Merton Council
Professor Martin Knapp, Professor of Social Policy and Director of the Personal Social Services Research Unit, London School of Economics and Political Science and Director, NIHR School for Social Care Research
Hilda Hayo, Chief Executive and Chief Admiral Nurse, Dementia UK
Questions and comments from the floor
- 12.30 - 12.55 **Next steps for dementia care and implementing the 2020 Challenge**
Professor Alistair Burns, Professor of Old Age Psychiatry, University of Manchester and National Clinical Director for Dementia, NHS England
Questions and comments from the floor
- 12.55 - 13.00 **Session Chair's and Westminster Health Forum closing remarks**
Baroness Finlay of Llandaff, Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum
Sam Dolton, Producer, Westminster Health Forum

Westminster Health Forum opening remarks

Sam Dolton, Producer

Good morning everyone. Good morning. I'm Sam Dolton, Producer of the Westminster Health Forum and it's a pleasure to welcome you all to today's seminar.

Just a couple of very quick housekeeping points from me before we can get started.

You will see from the agenda in your delegate packs a number of opportunities throughout the day for questions and comments to be taken from the floor. If you would like to ask a question during one of these sessions, we would just ask you to catch the attention of the Chair by raising your hand, and please start your question by giving your name and organisation for the purpose of the transcript.

We are still waiting for a few late delegates to trickle in throughout the morning, probably in the next half an hour or so, so please do make room for them as they arrive.

We are tweeting today's event as hashtag WHFEvents, so please do feel free to use that throughout the day.

Could I just ask everyone to turn their phones to silent to avoid disrupting proceedings at the front, and now I will pass you over to our Chair for the first session.

Session Chair's opening remarks Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia

Good morning.

So it's great to be here and my name is Sally Greengross, I'm really pleased to be here because for me... shall I use the hand one, is that better? Yes.

I spend a lot of my time on issues relating to dementia, all the different types of dementia, and it's now very much in the news and I suppose you could say that dementia is the plague of this century, it's like the plague was in middle ages, it's something we still are very worried about because various attempts to find a cure or really sound prevention seem not to be succeeding, we've had a lot of very sad results recently, masses of work being done, but a great deal of hope as well, because so many people are now involved in seeking either a cure or a way of preventing dementia in all its forms, or in some of them, and also perhaps a way of slowing down the progress of these diseases, and there are so many different ones, and so I do a huge amount of work with the two organisations in this country who specialise in dementia, that's Alzheimer's UK and Alzheimer's Research UK, and I was delighted that David Cameron, the former Prime Minister, agreed to be President of Alzheimer's Research because he did do an enormous amount globally to really increase awareness and get more people committed to getting us out of the sort of impasse we are in where it's difficult to go further at the moment and we have these disappointing results over some new drugs that are great hopes.

And I just feel this is priority number one, to get this right, and I'm really keen to hear from the experts involved in these issues this morning and very privileged to be your Chair therefore.

I'm delighted to introduce our first speaker, and he is Duncan Selbie, Chief Executive of Public Health England and he is going to speak to us, and as I think our colleague said, you will have time for questions as soon as he has finished. Over to you Duncan.

Duncan Selbie: Thank you. May I?

Baroness Greengross: Of course you may.

Risk reduction, raising awareness and early indications from the Dementia Intelligence Network

Duncan Selbie, Chief Executive, Public Health England

Thank you very much, good morning everyone.

I'm delighted to be here, thank you for having me to kick off the day. We're now talking a lot more about dementia, it's covered in *The Times* today, but actually there's not a day that passes where there isn't some debate or conversation on dementia and about how it has affected people and their families. There are also some quite striking statistics about how the number of people with dementia may increase over the next 10, 20 years.

This morning, I won't repeat the statistics that you are already aware of or try to tell you what you already understand. Instead I want to highlight a couple of key points and then invite you to ask me questions.

At Public Health England, we have seven priorities. One of those priorities is 'the best start in life' because that start has important bearing on the whole of a person's life; and one of them is dementia, which isn't just an issue affecting older people. Dementia is very much something we can tackle, and we think we can make a difference in helping to change it. Our research shows that, if you're over 50, dementia is the thing that scares you the most, but it is not inevitable.

If dementia can't be stopped in its tracks, we can at least slow it down and for some we might be able to take it away as a risk altogether. So it is a priority for Public Health England.

And almost the most important thing I think we've been involved in, in our first four years at Public Health England, is raising awareness that there is so much we can all do individually and as families to reduce our risk of most long term conditions, whether that's diabetes, heart disease, many of the cancers and dementia; and in many cases these conditions have the same risk factors.

Put simply, we know that what is good for your heart is good for your brain.

In the past as a society we've thought of long term conditions as an inevitable part of aging, and that they are an issue for the health care system to sort out, and we have thought less about the actions that we can take as individuals and the difference we might make to our health.

Whether someone smokes or not makes a huge difference. If we look at the wider health profile of the nation and the health gaps and inequalities that exist, tobacco still accounts for half of the difference between the health outcomes of those that enjoy the best and the poorest health despite 50 years of tobacco control. It's also about how much you drink, your diet, whether you exercise or not and the issues that we're particularly grappling with at the moment about sugar and about sugar in children's food. Other risk factors can involve loneliness and isolation and not being connected; there are different words that we use but it underlines the importance of having someone to care for and about, of having affection in your life.

And those risk factors are more important to improving health than simply the treatment of illness. So the biggest part of my message to the nation is that if you pay attention to those risk factors throughout life, but particularly in mid-life, you can double your chances of being in good health at 70. It's quite extraordinary and doesn't mean you have to give everything up.

The media are playing an important role in this conversation, and I think they've doing a great job because every day, every paper, in social media and in the conventional media, they are talking about these risk factors and increasingly joining them up. It's raising awareness and getting the message out to people that there are things that you can do to improve your health now and in later life.

So as Public Health England, we work as part of a wider family of concerns, and I'm very grateful for the work that the various charitable organisations and research bodies do. We've heard about the Alzheimer's Society and Alzheimer's Research UK, we have got Dementia UK, and this provides great strength and richness for this country. Joining that up with statutory bodies and with Government gives us the best shot at success and that's what the Prime Minister was starting to do in highlighting dementia as an issue that really matters. It matters for a whole series of reasons, not just for the individual and the impact on family, although that is hugely important, but also for the economic wealth and productivity and growth of this nation that we need to be concerned with in order to keep people well for longer.

So Public Health England has been investing in the Dementia Intelligence Network – are people in the room familiar with this? The Fingertips tool, the Dementia Atlas, there are a range of different resources. The National Institute for Health and Care Excellence have got very involved in this work and there's a whole lot to come that will get us ever closer to understanding the actual impact of dementia and what can be done. Research into new treatments really matters and let's hope that we get a breakthrough. You know, we've all been in search of this for years. I think we can see the prospect of new treatments, but what can really make a difference is dementia risk reduction.

Dementia risk reduction, this term captures what I'm trying to say; that if we can raise awareness and get people more engaged and services more aware that there are things we can do to reduce our risk throughout life, the benefit won't just be felt with dementia but across all of life.

As the expert public health agency for the country, we see dementia as one of our seven most important objectives and it speaks absolutely to what can be done now as well as what we all hope might happen around treatment.

I'd like to be open to questions from you, so please ask anything of me. It could or might not be related to dementia and that's okay too.

Thank you.

Risk reduction, raising awareness and early indications from the Dementia Intelligence Network

Questions and comments from the floor

- Duncan Selbie: Yes, first question?
- Sara Livadeas: From The Orders of St John Care Trust.
Duncan I want to ask you if you're scared of dying?
- Duncan Selbie: Sorry?
- Sara Livadeas: Maybe, not today.
- Duncan Selbie: I don't know because I don't think about it. Before I came to Public Health England, I was leading an acute hospital and the average age of admission was 84 after 8:00 at night and the single biggest reason for being admitted after 8:00 at night, the most important prevalent reason, was did you have someone at home. It wasn't the presenting illness, it was not really about what the hospital could do. The presenting illness might be various long-term effects of antibiotics, someone who'd had a fall, and maybe he hadn't been able to go to the loo for a while, or it was more common things. Our job if we could was to get them home because many older people who were in hospital more than 28 days never went home. About half of people say they don't want to die in a hospital and less than half get that, not yet. I think I fear that more than dying. It's about how you maintain some sense of control over what happens to you.
- Calin Adrian Puia: I'm an Independent Researcher and Consultant.
My question is how much you consider that technology and assistive devices will help you and help dementia, in fact, or improve; and I think bring to the table a big, I think partner, in fixing dementia in... and public health? Sorry, I have some emotions but I'm trying to find out that technology these days, and assistive technology, is yet to be seen as not so objective, which from my point of view is the one that is objective right now, and we need data, how much do you consider that we need to introduce as soon as possible technology and assistive devices for each person that has dementia, entire England, a standard package?
- Duncan Selbie: Data, and knowing what's really happening, is at the heart of any strategy, plan or decision making and I would be very happy to talk with you further about the data as it exists and where that might be improved.
- I've got two thoughts, I want people to stay well for longer it was only for fun saying so you could work longer, although as I look at the young ones in the room that's probably true; but because if you become unwell, that you stay at home or where home is for you, and it's not about going into hospital. Because we have a binary arrangement at the moment in the main that you become unwell and you go into the NHS, and if you're of a particular age and a particular that involves being admitted and it's not a great outcome. So staying well for longer and when you're unwell to stay at home for longer

and how does assistive technology help with that I think is a big part of how we do that better.

The other thought I had was with the new housing that's going to be built over the next, 10, 20 and 30 years, that we build in ageing and dementia, so people don't have to move as their needs change. Now it's not just about new housing but I mention that because we will have to be building thousands and thousands and thousands of new developments but existing property as well and about how we can help adapt the property; and there are programmes going on about this as we speak and I'm certainly aware of conversations and discussions that Public Health England is involved. So that the new planning guidance for example, that has just gone out to all local authorities, from National Planning Guidance, for the first time has a chapter on health and wellbeing and you might want to look at that, it's a door that's opened.

Baroness Greengross:

Duncan, can I follow up on that, taking Chairman's if I may. There is some legislation now, I'm going from here to Parliament and taking part in it, and in the Neighbourhood Plans it seems to me two things are important, one is that we build more housing with care, retirement housing with care because if people are in that sort of housing then they can stay there and that helps not to get hospitals full of people who shouldn't be there but this sort of care that people need, they can get so it saves the health service. But it has to be retirement housing with extra care so that people can stay there for much, much longer. And I am trying to get that built in to the neighbourhood planning stuff and also into the new plans that are being put into a White Paper shortly. So I think housing is extremely important and perhaps you do; but the other thing about older people's housing that if somebody moves into extra care retirement housing then they've usually moved down-sizing and that makes housing available for young people, so it's got three different aspects to it, is that not right that it's good for everyone?

Duncan Selbie:

Yes, I've talked about the risk factors that account for about 40% of what matters to the two things that get measured internationally - how long you live and how long you live in good health. The rest of it is to do with wider determinants, and we all use different language for this, but the Baroness has just touched on one of the main determinants.

The most important thing is to have a job and to have one that is good for your health; and not to have a job is not good for your health. If you're not in work your health will not be as good as those who are in work.

The second most important factor is to have a home somewhere warm where you feel safe and that is relevant to all of life.

And the third is affection. In a clinical setting, one might talk about isolation in the elderly, but actually it's issue throughout life, it's about having someone to care for and about.

Those three things, alongside some genetic pre-disposition, are important risk factors that we must pay attention to. We need a strong NHS but we must use the NHS for what only it can do and think more about investment in other areas such as helping people stay where they as their needs change. And although there are really great examples of that we are not yet doing it at scale and in a joined up way. So, Baroness if you get the chance to say Public Health England says this is really, really important for health, it would be very helpful.

Baroness Greengross:

I will. I think next to you yes?

Professor Louise Robinson:

I'm a part time GP in Newcastle and work at the University. Just a comment about assistive technology, I think there are several things I want to reply to that really. I think there's a responsibility there that's outside of the healthcare sector, certainly terms of engaging with industry and business about the importance of the current population and the silver economy, and the way our population is going, and whose needs need to be met most. I find it fascinating that a new Apple iPhone comes out every six months but the people I care for at home are still living with technology and gadgets that are absolutely ugly to look at and they don't use them. So there's a real responsibility about engaging with industry and business around who's the market really. And it's not just the responsibility of healthcare, technology is part of a whole package that involves the family and carers and healthcare and I think certainly at Newcastle we're hoping to work closely with industry and we're setting up a National Innovation Centre on AG where we hope to engage with industry and the public to make products that actually will make a difference, will be used. But I think it's not just about health and we've got to make where the money is in terms of some of these really big businesses realise where the market is in the future.

Duncan Selbie:

What I'm trying to say and what you know from your practice is that health is about much more than healthcare. I think there was a gentleman just here in the middle.

Jonathan Papworth:

Person Centred Software.

We provide software for residential care homes and I want to pick up a few things, one is about housing, there is an increasing number of village based care settings which in my mind provide a very sensible home for people who would otherwise be living alone, would be suffering from loneliness and have no access to care resources. A care village can be called a care home and all of a sudden we've turned into a stigma of going to an old age home. One of my concerns is there is a growing perception that frail elderly care homes are best avoided; people are being encouraged to stay in their own home, community care and that leads to loneliness and isolation. And I believe that policy may well be increasing the rate of dementia and I believe that a well-managed, a caring environment with lots of activities can be for many older people the best place for them to be and will reduce the burden on the NHS because they're receiving secondary care rather than primary care. I'm not sure if I have a

question but I'm just really interested what your thoughts would be on that?

Duncan Selbie: Well I think it's about people being where they most want to be, and not excluding any particular model.

Jonathan Papworth: Sorry to butt in, being where they most want to be depends on them having the choice and they only have that choice if they have information and at the moment the information people are receiving is avoid the care home like the plague, the policy is doing community care.

Duncan Selbie: What we have is a model where the default, particularly for the very elderly, is a hospital and that's not always what they want or what the hospital is best at doing. It's about how we choose and having a range of different possibilities for people. I think we have time for one more, yes?

Dr Deborah Roebuck From Otsuka Pharmaceuticals Europe.
You touched briefly on the media and their sort of awareness and the positive messages that they're implementing regarding risk factors, possibly linked to the stigma of care homes, is there anything you think that we can do to encourage the media to report more positively and give hope regarding treatment and holistic care rather than just promoting the risk factors and raising the awareness in that way?

Duncan Selbie: I was praising the willingness of the media to engage in a wider set of understandings about dementia in all of its different forms; and I was drawing together the conversations that go on about cardiovascular disease or about diabetes and saying actually it's all about those risk factors and about how we mitigate them individually and as a society. I'm not limited to thinking about risk reduction, and I am seriously keen and interested in wider work, particularly new drug discovery, but even more about the wider societal agenda that we've just been touching on. I think the media are massively important in taking the opportunity to talk positively about dementia and what can be done to help people to manage it when it happens, so we should say thank you to them. What *The Times* is reporting this week will bring lots of attention to this and I think that's a great thing.

Baroness Greengross: Perhaps then I can thank you very much indeed Andrew... Duncan I mean, sorry.

Duncan Selbie: I have a twin called Andrew.

Baroness Greengross: Why does that happen, I must have known someone.

Duncan Selbie: You've met my twin.

Baroness Greengross: Can I thank you very much indeed, I think if we all knew how to keep healthy and above all to prevent some of these, well we do know some forms of dementia, we do know that if we can do something about vascular dementia obviously in keeping healthy. And I think the more people, and indeed it's your responsibility and you do it

wonderfully, the more we can learn about the other sorts of risks that we can avoid then the better. And the press, I hope they go on reporting all of these things because although some of those articles are very scary, it's better to be scared and do something than to continue without doing anything to avoid anything in this sort of illness which is avoidable; and where we live and how we live are so important, so may I thank you very much indeed. Thank you so much.

Duncan Selbie:

Thank you everyone, thank you.

Baroness Greengross:

And now, looking for her, oh there she is, somebody who is a friend of mine and a colleague, I'm delighted that she is with us, this is the Director of Nursing for Health Education England, Lisa Bayliss-Pratt, and she is going to speak to us, and I know you will be very interested in what she has to say, and I'm delighted you made it.

Lisa Bayliss-Pratt:

I did yes.

Baroness Greengross:

You made it in time.

Lisa Bayliss-Pratt:

A bit of a challenge this morning.

Baroness Greengross:

Thank you so much.

Lisa Bayliss-Pratt:

Thank you, thank you Sally.

The role of Health Education England in implementing the 2020 Challenge

Lisa Bayliss-Pratt, Director of Nursing, Health Education England

Good morning, everybody, and it's great to be here. And really enjoyed Duncan's talk, actually just earlier now and it was great to have the, you know the question time to really think about all the issues that we're faced with.

I've been in this role since 2012, October 2012, and one of my first challenges was around how we get dementia education and training into the predominant NHS workforce, but work with social colleagues to make that happen. And I think we've made amazing progress, over the last four years, there's still an awful lot more to do. But when I think about people's awareness of dementia, back in 2012, to where it is now we've come an awful long way, and that's thanks to many of you in the room.

So I think everybody knows what Health Education England is here to do. Does anybody not know the term Health Education England or not heard of us? No, that's good. This is only a couple of years old, as I say, we're, sort of, four years, going into our fifth year now but it's took some time really, for people to understand what Health Education England is here to do.

And we're about creating a workforce, with the right knowledge, skills and behaviours, to support a range of conditions, identified with our Department of Health Mandate, and to support the workforce transformation set out in the Five Year Forward View, which, again, really speaks to the things that Duncan was talking to earlier, around the importance of prevention, how do we get on the front foot, how do we look and think differently about the people that we care for.

And I think, that point about the hospital and the care home not being the default position, is really incredibly important. And what we've been trying to do at Health Education England as we've progressed on this journey, is bring together dementia, end of life, mental health and learning disabilities, and identify the core competencies and behaviours, that the staff are requiring.

And as we're maturing as an organisation, we want to move into the space of saying, actually it isn't about particular roles, or professions, or groups, it's around, what are the competencies that your teams need to have, and the knowledge and expertise in to care for people. So we're trying to shift the paradigm, and say, it isn't about more doctors, or more nurses, or more carers, it's about how the teams have the right competencies. And to do some really exciting work around, what is the impact of upskilling carers, you know how do we get more care navigators into the system.

So for us, our HE Mandate in the Prime Minister's Challenge, which was incredibly helpful in raising the profile of this agenda, has enabled us to achieve quite a lot, I would say, over the last few years. So one of our early things, that was really important for us to do, and very much supported by Sally and Professor Alistair Burns, was how do we come up with exciting, innovative awareness tools for all NHS staff, by the end of 2018.

And we've been measuring that on a biannual data, and I'm really pleased to say, we've got over half a million people trained in dementia awareness, that we count. And you know numbers are only good as the information you've received, but the fact of doing the audit is telling us that, shows that we've got traction across the system.

We also wanted to think about not just typical people that you might expect with dementia, but also those that are younger, those from a BME background. And we developed two short films, to raise awareness of dementia, and that was finding patients, and finding patients in the later years. And it was really interesting, when we undertook this work, the assumptions and misunderstandings between people with dementia from different backgrounds, and that's been really popularly utilised across the system, which is fantastic.

We also want to ensure that staff working regularly with dementia, undertake more in-depth training. So we've now moved on to developing tier two and tier three levels, which actually enable people to become

expert in the field of dementia. And we've worked very hard with the higher education institutions, and the medical Royal Colleges, to ensure that the undergraduate courses for all healthcare professionals include education and training in the field of dementia, which is brilliant.

And we're also delighted to support Public Health England to raise awareness of the dementia risk reduction, and contributing to the review of dementia components on the NHS Health Check. And I have to say, Public Health England are fantastic partners, and we really work well together.

So Health Education England's aims, what we want to do is, we want to work... although we're funded, and this is a dilemma, and there is so much in the news all the time, about the integration of health and social care. And I think, most of us want it to happen, but how do you make it happen. But we're trying to work across the health and care systems, to support service change, and improve outcomes.

Sally, I might just need some water.

So we were doing that, as I just have a drink, apologies, so yes, as I said, we want to work across health and care systems, to really support outcomes, and improve experiences for people with dementia. We've developed and promoted awareness of the core skill training that is required, and that's been the production of a Dementia Core Skills Education and Training Framework. And this really speaks to what I said earlier, about getting away from professional siloes and saying, actually what are the competencies that you need across your teams, to care for people effectively.

We're also looking to develop high quality training resources, and we've recently introduced a quality framework, which benchmarks the tools that are out there. And we're looking to improve on that, with a good practice guide and research to follow. We always get asked questions about kite marking, and looking at excellence, in terms of education and training tools, but it's something that can be quite expensive, and often doesn't last very long.

And I talked about engaging with the HEIs, the medical schools, to make sure that all people have the awareness of dementia, underpinned, of course, by person centred care. And I'll never forget Alistair Burns that said, actually you know Lisa, the trick is, if people can look after individuals with dementia well then, actually other brilliant care will flow. So it's important not to see this just as within an isolated condition, but actually how do I give brilliant person centred care to those that have entrusted me to look after them.

And the key achievements in dementia, that we have, just to sum up, have achieved, are we do have the publicised core skills education and training framework. Again, trying to nudge the system to think differently about how you get great care with teams. We have updated e-learning programmes, which are available on our website. These are available to all people in the NHS, and social care colleagues, if they so wish.

We've talked about the biannual census of dementia training, and you can see there how impressive those numbers are. So for tier one, we're just shy of 800,000 people that have actually reported to undergo the tier one awareness training. Delighted that over 55,000 are becoming more expert at it, and 17,597 are actually at the level three, which is absolutely cutting edge, expert research development innovation around dementia. So as you can see, we're doing great, still more to do, but there's lots of interest in this, that continues to grow.

And this just points out the Dementia Core Skills Education and Training Framework. And again, I do keep repeating it, because I think it is important to see the compact together, around the competencies, and around the tools, that people need to work effectively. Because you don't need to train everybody in everything, you know we do need to be efficient, we need to be effective, and we need to work with that, and this framework enables you to do it.

And the current activities, and this is a really exciting one, and if anybody would like to come along and see this, I'd be delighted to enable that to happen. But we've started to roll out a simulation training, that actually

works in real time, with people with dementia, with support and family, people involved. And this is proving to be brilliant with Bournemouth University.

Also in that neck of the woods, they've got this fantastic programme, whereby student nurses are linked to people, and families with dementia, as part of their training. Again, getting that real-life experience, and developing a long-term relationship with people and families that have dementia. And it's proving absolutely fantastic.

We've talked about the ongoing promotion of the training resources. We will keep refining and developing training resources, that people can utilise. And the important thing that came home here, to me, and I am embarrassed about it, is that we didn't take into account the cultural differences, until we really started to look at what the African Caribbean community, for example, requires in terms of dementia awareness education and training.

We've talked about the quality assurance checklist, and will continue to do that. The University of Manchester, are working with us around the mental capacity assessment resources which, again, is really helpful. When we've got ongoing collections of good practice, and we're developing a bespoke website. And these are just some good practices, that we've identified.

So we've talked about the film, very powerful, gone down very well. Have to give lots of credit to Dame Eileen Sills, because actually it was Barbara's story that really got us into the mode of thinking how powerful films can be, in terms of training. We've got another story around a patient, a person called Fred, and how you help to manage people that have wandering tendencies.

We've got a dementia guide for carers. We've got the appointment, how do you help people cope with appointments in a dentistry environment. It sounds quite simple, but actually it's really challenging. We've got Dementia Care Champions, that we're absolutely delighted with. The University of Worcester, are working with us on the cultural competencies in dementia, in domiciliary care, which is fabulous.

The Liverpool House of Memories, I don't know if all of you have been there. Oh, some of you. But again, very powerful resource to utilise. Manchester Met are doing a university dementia toolkit. And the importance of dementia in delirium and again, moving into that territory of, how do we ensure we get the diagnosis right, and how do we make sure that we support people that might have both dementia and delirium. And then, we've got the Thames Valley Academic Action Group which, actually is looking to create more and more evidence base as we go through.

We've talked about the undergraduate curriculum, but this is a major feat, because people will know that, every university likes their own USP. They like to be able to say, our curriculum is the best in this, because x, y, and z. And then, you know they're not necessarily keen on saying, yes, we'll put things in, because they like it to be developed by themselves. But the fact that we have got that, into the undergraduate curriculum, puts us on the right step, from day one, with our healthcare professionals, and we're delighted about that. And you can see the evidence of that there.

We are looking, as well, at what works, a longitudinal research project. And back about three years ago, we had the opportunity to bid into an NIHR funded pot of money, that looks at the longer-term benefits objective from health Education England. And we're delighted that Leeds Beckett was successful within that, and they're trying to come up with, actually what is the most efficient and effective way of training people for all tiers of dementia. And that will be a robust longitudinal piece, to look at the impact on the individual's they care for, look at the workforce that are delivering and actually what are the optimum tools to capture people's imagination.

And I, kind of, go back to Barbara's story, Sally, because people were frightened of dementia, many people shied away from it. And I'm a nurse, I can speak, you know I can speak to truth on that, because I've been in the environment. But you put something out like Barbara's study, you get the Chief Nurse to sponsor it, you put it as part of mandatory training. And all of a sudden, you start to really enthuse, energise.

And Sally, do you remember the word that Dame Eileen uses, prick people's consciences, didn't she? She said, it's actually about sometimes pricking people's conscience, to get them to think, it is no good ignoring this, I need to be educated in order to look after people appropriately. So I think this work will give us more of that.

And I think my, probably, ten minutes is up now so very happy to take questions. I'm sorry for coughing half way through. Thank you.

Lisa Bayliss-Pratt's PowerPoint presentation can be downloaded from the following link:

http://www.westminsterforumprojects.co.uk/forums/slides/Lisa_Bayliss_Pratt_Dementia17.pdf

The role of Health Education England in implementing the 2020 Challenge

Questions and comments from the floor

- Baroness Greengross: Thank you so much. I think the work you're doing is fantastic. Can I say that, I'm somebody who's seen quite a few of these films, and Barbara's story is one, probably the first that I saw, and I recommend it to everyone. Because whenever this is shown, and it's shown from people from the Chief Execs, to the most junior porter, who wheels patients around in a hospital setting, and there's always at least one person who breaks down in tears, and has to go outside. And it changes your view completely, about what it's like to have dementia, and the confusion and the worry. And it just changes your life. So please, anybody, do try and see some of these, whether you're working directly or indirectly, and I think we've spoken about this before, Lisa, haven't we? And it's all of us, you have no idea how this transforms your understanding. And having been a student, if you like, on some of those courses, it is just amazing. So I do recommend that you... and Lisa, I'm sure you can say to people how they can get hold of them.
- Lisa Bayliss-Pratt: Absolutely. Absolutely. Yes. Yes.
- Baroness Greengross: So they're my most valuable possessions in many ways.
- Lisa Bayliss-Pratt: I think the power of them is that they don't take too long to undertake, actually you can do them whilst you're moving around. You can watch them more than once, I think, it's all of that that really helps to give people the impact.
- Baroness Greengross: Yes. I mean, just imagine now that you're confused, and you go into a hospital, a nice person at the desk says, you know go down the corridor and turn left, and the lift's on your right, and you've got early stage dementia. And that throws you completely, and so that member of staff needs to know that that throws somebody completely, we don't think about it. Or, if you're in a trolley, and you're pushed backwards, what it does to you if you're confused, and you've got dementia, the early stages. It really is dramatic.
- Lisa Bayliss-Pratt: It is. And I think the more stoic people are as individuals, especially the era, probably, was, I can do it myself, I don't need to tell my daughter, I don't need to tell anybody, I'll be fine. And then, it's only, actually when they get into the environment, and think, oh, my goodness. And that's the heart rendering thing, actually is that it's because of their tenacity and stoic nature, and they don't ask for help, but yet they so need it. And especially when faced with, you know a dental appointment, the dental video, again, is really, really powerful.
- Baroness Greengross: It is indeed. So I'm sure people want to ask you questions. Yes, please, say who you are.
- Eileen Harrington: From DonMentia, which is a specifically Doncaster based charity. I'm a lay person here, I'm not in the professional field at all, so I've got a very simplistic question. You've mentioned constantly about

the competencies that you have, and I know it's an investigation, and you're going to look into it, but have you got some steps, have you got a checklist of the competencies?

Lisa Bayliss-Pratt:

Yes, absolutely. And what I can do is make sure we can connect, and that you can get the link to the document, the dementia education training. And that actually identifies the competencies, what the learning outcomes are, how you would achieve them, and then how you might want to progress across your workforce with that. So it does... it should all explain it in there. Do you have a particular challenge, Eileen, with it?

Eileen Harrington:

Well, I haven't got a workforce, it's me. I just deal with people with dementia, I raise money, and then I do activities and events, and excursions and trips with them. So I just want to know what you mean, I do get involved in several different meetings, the Action Alliance, and Strategic Partnership, and steering groups, and so on, because I always have a lot to say. But I don't know what you're talking about.

Lisa Bayliss-Pratt:

Okay. Well, let's connect and I'll give you the link to the document, and then you can, kind of, see it on there, as to how you demonstrate the competencies, and what the activities are for you to be able to achieve them. And I guess, probably, in our situation, you would self-assess yourself, would that be what you'd want to do?

Eileen Harrington:

Yes. Yes. Yes. I think I'm fairly competent enough to do it.

Lisa Bayliss-Pratt:

I'm sure you are.

Eileen Harrington:

But I'm sure... I know the more I know the more I know there is to know and the more I know I don't know...

Lisa Bayliss-Pratt:

That's the curiosity about this, isn't it, absolutely. Well, Eileen, let's connect, and I'll get you the link.

Eileen Harrington:

Thank you.

Baroness Greengross:

Does somebody else want to put a question to Lisa? Yes.

Jacqueline Cannon:

From The Lewy Body Society.

We've just been talking about competencies, I think we probably need to connect. Does that competency list go to a level of helping staff understand the characteristics of different types of dementia? Because Lewy Body, for example, is not about memory, you say dementia, and people think, memory, and Lewy Body is totally not about that. My dad was in a hospital, and I was called at 12 o'clock at night by nurses who couldn't deal with him, to come to the hospital, and we couldn't leave him in the hospital by himself.

Lisa Bayliss-Pratt:

Yes. I mean, again, let's connect, and I'd like your feedback on the framework. We did do a lot of work on it, but I would say that sort of dementia is around level tiers two and three. So we did a big push on level one, so the point there is, spot it, and signpost, and help to relax somebody and feel confident that you can deal with that. I think,

what you're talking about, is in the tier two and three territory, and I think the numbers reflect the amount of work we've still got to achieve on that, because they're a long way away from where we are on the awareness. But it is our next big push, yes.

Jacqueline Cannon:

Okay. Thank you.

Baroness Greengross:

One more question? Yes, the lady at the back. Well, Lisa, am I right in thinking that there's over 100 different types of dementia?

Lisa Bayliss-Pratt:

Yes.

Baroness Greengross:

Some are very rare, but even so we can't all learn everything.

Lisa Bayliss-Pratt:

Yes.

From the floor:

I appreciate that.

Baroness Greengross:

Absolutely.

Lisa Bayliss-Pratt:

Yes. Yes.

Baroness Greengross:

So lady there.

Dr Diana Hilliard:

Argue to Think.

I'm part of a research group, we're looking at dialogue approaches to improving social care and communication between carers and cared for. I would really like to connect, please, and have a look at your framework, and work out whether we can actually be beneficial, and work across the whole, sort of, health and social care framework. If that's okay.

Lisa Bayliss-Pratt:

I would be absolutely delighted, yes. Yes.

Dr Diana Hilliard:

Thank you very much indeed.

Baroness Greengross:

One very quick last question, if there is one. Yes. If you could make it brief, please.

Maureen Hume:

From the Camberley Alzheimer Café.

Yes, I will, it's just a query. Can we all be sent the link to this connect please about the competencies?

Lisa Bayliss-Pratt:

Yes. Yes. I mean, it might be with Westminster Forum colleagues, we can actually send you the link. And then, if you would like, we could have a follow up telephone call, with myself and the team, to see, you know to see where we want to go with next steps, because it's not fixed in stone, we can iterate and develop it. So shall I speak to yourselves, and we'll work out the link, my contact, and a follow up conversation about this, and then, people that don't need it, fine, but you can have a look at decide for yourself.

Sam Dolton:

Yes. If there's any material you wanted to include in the transcript, then please do feel free to, because it will go to everyone here today, and a wider range of stakeholders as well.

Lisa Bayliss-Pratt: Great. We will definitely do that, that would be wonderful, thank you.

Baroness Greengross: Lisa, as always, thank you so much, wonderful presentation.

Lisa Bayliss-Pratt: Thank you.

Baroness Greengross: And may I ask our next speakers to come and join me.

Well I'm delighted now to welcome George McNamara, Head of Policy and Public Affairs at the Alzheimer's Society, and I was thrilled this week because there's a whole new design and stress now on the word dementia as well as Alzheimer's, bearing in mind what we've just said, and George, fantastic, somebody I work with very closely, it's lovely to see you George. So now Andrew Cornwall, who is a Carer and Research Network Volunteer for the Alzheimer's Society, a very important person, thank you so much for being with us. And Professor Louise Robinson, who I know well as well, it's lovely to see you here Louise, and who has come down from Newcastle University, and is Professor of Primary Care and Ageing at Newcastle. And Professor John Gallacher, Professor of Cognitive Health at the University of Oxford and Director of the MRC Dementias Platform UK. It's great that you're here everyone. Thank you.

So if I may, in that order I think, we will ask you to say a few words. Over to you George.

Priorities for building dementia-friendly communities, reducing variations and increasing participation in research

George McNamara, Head of Policy and Public Affairs, Alzheimer's Society

Thank you very much, Sally, and good morning everyone.

I'd just like to, firstly, just say that the Alzheimer's Society hasn't changed, but our branding has just changed, so the sign at the bottom is our new logo. But I think what it really represents, and it is a process which we went through, over a long period of time, over the last 18 months, speaking to people living with dementia, speaking to all those supporters of the charity.

And I think that, today, talking about dementia around the communities, and that journey to which the organisation has embarked on, working with all parts of society, really reflects the tone and the direction of the charity. That we're responding to the changing needs of people with dementia. And I think, the strapline underneath, really reiterates the central tenement, of our drive to have a dementia friendly society and indeed, a dementia friendly world, and that's united against dementia. And that, together, we can actually deliver what we all want for people with dementia.

So where are we? Five years ago, we very rarely heard about dementia friendly communities. We didn't even hear about Dementia Friends. And I think, the tribute of the change that we are starting to make, and it is still a start of that journey, is really down to people in this room, people right the way across society, the fire service, the local swimming centres, who are becoming dementia friendly, the football clubs, the workplaces and indeed, people living with the condition.

What we've started, I believe, is really a movement for change, a change across society for people with dementia. And at the very heart of it, central to any of those decisions, central to any of those actions, be they national, international or, more importantly, on a day to day basis local in our community, we're driven by what matters to people with dementia in that particular community, and at that particular time.

And as you can see, this is just some of the highlights on Dementia Friends. This is really about the tier one aspect, that we're on 1.8 million Dementia Friends, over 1,000 new Dementia Friends every day. In essence, it's now generating its own awareness, through the programme. And indeed, I'm pretty certain that, within a couple of months, there months, we'll be over two million Dementia Friends, and that's a great tribute to people with dementia, carers, families. But importantly, communities, who recognise that they need to learn more about dementia, but also the benefits of doing that, to them personally, to their work, to their environment and importantly, to their community, and people living with the conditions.

But what really strikes me, as a real opportunity, is that figure in the middle of the slide, 79%. And this is where I believe that we can transform and translate the awareness, increasing awareness of people of dementia, to actually action, social action, in our communities. The idea that four out of five people, who have done a Dementia Friends session, want to feel motivated, and want to do something more for dementia in the community, is a real opportunity to take forward and harness. And that's something which we'll need to do, and I'll talk about a bit later, going forward.

The other aspects here are really important as well, because Dementia Friends, and dementia friendly communities, fundamentally, are about reducing social isolation and loneliness and importantly, eliminating stigma.

Can someone put it on, please?

So in terms of dementia friendly communities, back in 2012, the Prime Minister's Challenge had a commitment to have, I think it was just about 15 communities, committed to become dementia friendly.

Whereas, you can see today, that has been far outstripped, not only are there more than 15, there are 220 communities across England alone, which are committed to becoming dementia friendly. And I think that's a great

tribute, that the fact that the communities want to act, and want to make change. We have annual dementia friendly awards, and this was the third year of it, and over 400 applicants for these awards.

We're giving just a little example, a little taste of the innovation, the excitement and the changes that are happening in our communities, going forward. You can see there, some of the pictures showed, some of the really small examples, dementia friendly cinemas showings. Dementia friendly swimming, you know what a great opportunity there to have enjoyment, but also have exercise as well.

So how are we doing, and what are we doing going forward? Well, at the Alzheimer's Society, our role is really to support the community, support people with dementia, support the leaders in those communities who want to make their community more dementia friendly. So there are a number of materials, that we've been working with, different sectors, where people in dementia have told us are important to them, in terms of their quality of life. Like, the financial services sector, you know the high street. Dementia friendly churches guide as well, very important to many people living with dementia, their faith. So there's a range of these support materials, which are coming forward, and will continue to do so.

So what's next? Well, we've got a huge challenge really our ambition is to have four million Dementia Friends by 2020. But actually the success of Dementia Friends isn't the number, and I'm absolutely convinced we will reach that four million. The success of Dementia Friends will be what it does in terms of the action and the change. And this is why, for example, we're looking at some really interesting ways of developing that, and harnessing that support.

Some people will volunteer. Some people will do things on social media to support dementia. But actually is there a role of getting some, for example, public health messages around risk reduction, really motivating through those routes, in terms of supporting people with dementia, but also reducing the risk of people getting dementia, particularly in mid-life.

We're also going to continue to work and support the communities, who are committed to become dementia friendly. And really, to go into some real depth, and understanding, about what that actually means. So getting some evaluative, getting some learnings from the communities, but also sharing best practice, will be one of the key priorities going forward, and something we're working on.

And finally, it's really just notifying that, something which was started in the communities up and down the country, is now a concept which has gone global. There are over 18 countries now who adopted, in one shape or form, the Dementia Friends programme, around awareness, and we are supporting them to do that, from the very developed countries, to the much less developed countries. There's a real interest, because we recognise the global challenge of dementia.

But also secondly, it's about, how do we embed dementia friendly communities, not just to be an initiative or concept, but actually into something which is fully integrated into the decision makings within communities, Whether you're in a local authority town hall, whether you're in the emergency services, whether you're in the private sector, the voluntary sector, it shouldn't matter whatever, what we want to do is make sure that people are making decisions that can affect the lives of people with dementia, and recognising the impact that they can have on their lives.

Thank you very much.

George McNamara's PowerPoint presentation can be downloaded from the following link:

http://www.westminsterforumprojects.co.uk/forums/slides/George_McNamara_Dementia17.pdf

Baroness Greengross:

Thank you very much George, there's masses going on and it's wonderful news and we are going to hear now from somebody who is a carer and a volunteer and I think will expand very much on the knowledge of what George has introduced us to. Over to you.

Priorities for building dementia-friendly communities, reducing variations and increasing participation in research

Andrew Cornwall, Carer and Research Network Volunteer, Alzheimer's Society

I decided last week, and I told the organisers, that I wasn't going to use a PowerPoint presentation and that's largely because I've been thinking about what I was going to say today for about three months, since I was invited by the Alzheimer's Society to come along today and make sure that the carers' point of view is put forward, and that's always important and I will come back to that at the end. But it is really, really important and I was really glad to hear Lisa say the word carer several times, and there were lots of bits on the slides, carers resources, very, very important.

I think I will now write an article or maybe a PowerPoint presentation, I haven't quite got my head around what to do, but to go in to the transcription document afterwards.

So I'm going to try and limit myself to a few remarks, I've been warned there are yellow and red cards that will be shown to me, I'm likely to go over time, so I will just check when I'm starting.

You will have seen, and I was a bit daunted when I got the agenda, there's a huge slab of text and as you read it there are lots and lots of questions there that the speakers were asked to consider and lots and lots of parts of each question. So when I sat down at the end of last week to write bullet points and key things that I wanted to get over to you, then that's when I realised, well maybe I should have said that I would do a PowerPoint presentation.

I just want to give you a few things, more than a few things, to think about.

The first question is priorities for building dementia friendly communities, reducing variations and increasing participation in research, going on how successful have initiatives such as Dementia Friends been? I was in the very first cohort of Dementia Friends Champions trained by the Alzheimer's Society, and that was many years ago now, and I have sort of run out of steam, I have to admit I'm continuing to do Dementia Friends sessions at work, I just don't have time to go out and contact organisations and arrange sessions and do it, and I find many, many people like that who are running out of steam, so we need to refresh some of the champions. We also need to give them more resources and maybe linking in to some of the Health Education England resources is a way of doing that.

I'm also concerned that some of the first people I trained and talked to about dementia to, that's some years ago and I'm not sure how long lasting the effect of Dementia Friends is. As one of the lay reviewers of lots of grants, I see occasionally applications put in to assessed Dementia Friends programmes, not just here but in the Netherlands and in Japan; none of the ones that I've seen have been funded, and I think we do need some academic research in Dementia Friends.

We also need to make sure that we have whole organisations changed, we need cultural change in organisations, it's not just enough to go in and train a few health workers in a care home, you need to train everyone and I'm delighted that my local hospital is part of becoming an NHS Foundation Trust embrace that, so that everyone gets Tier 1 training and there's lots of chances to go on, and it's embedded in their annual performance assessments.

The next question was, following the publication of the Government's Dementia Atlas, what more should be done to reduce local variation? This is where I get a bit emotional because the last 18 months in Surrey have been hell on earth, and that's because Surrey County Council withdrew funding for dementia, just gone, almost entirely. On the west side of Surrey, the Clinical Commissioning Groups give more than they do on the East, there is so much inconsistency and it's all short-term. As a charity, we have to respond to that and

various day centres have had to close because the funding just isn't there any longer and that affects a lot of people I know, fellow carers, people with dementia.

So if you ask me what we should do to reduce local variants, it's stop the short-termism, however difficult that is, and make sure that the funding bodies treat it equally.

Within Surrey we activated a lot of very key people... there's the yellow card... a lot of very key people to talk to the funders but there's lots of parts of the country where we might not be strong enough on the ground to do that as effectively, so we need to affect the short-termism.

I have lots of other bits on this, but I think I will just finish with dementia awareness has increased, I'm on my third time as carer for a family member with a dementia and lots and lots of comorbidities. Things have improved, people are more aware of dementia, it's almost an afterthought though, with some people, that these are real people, this isn't a condition, these are people living with a condition and almost always their support network are forgotten, their carers, their families, their dependent children, or the fact that something like 40% of people with dementia have no carers, have no immediate carers, no family.

And the thing that I really would like to get across I think I've spoken to Sally about this before, but I really want to get across, is the carer's journey with dementia does not stop when the person that you love, that you are supporting, caring for, dies. The carer's journey with dementia goes on to the end of that carer's life.

Since being asked to talk today and since joining one of the NIHR public panels last year, it's given me a chance to just think about my journey with dementia and progressively giving up work, over 10 years ago now, to help my mother look after my father, and then going and looking after my oldest brother, and now my mother. All sorts of things have gone on there, the ability to grieve, I've struggled with absolute crippling guilt that I was so glad that my father had died, and I will say that openly, I was very glad that he died because the last two weeks he was in such pain, he was in a place in hospital with staff who did not understand his condition, and I was just overwhelmingly relieved that his struggle was over. And then I became aware that I wasn't grieving for him as I had for various elderly relatives and therefore I felt guilt for not, and it took me a long time to thoroughly understand I had lost him years before, the man who was my father, I had been grieving for years, and it's affecting me now, every time I come back to that, it affects me.

So please remember the carers, please remember their journey goes on. I have absolutely no regrets, and I don't want you to get the idea that I've got any regrets about being a carer, and I have spent over a decade now caring, at best working part-time, so I am going to have to rely on the State Pension, through no recklessness of myself, but I have not been able to contribute to a personal pension.

So that's one affect, but there are many, many others.

Before I get a red card, thank you very much.

Andrew Cornwall's additional comments can be accessed from the following link:

http://www.westminsterforumprojects.co.uk/forums/slides/Andrew_Cornwall_additional_comments.pdf

Baroness Greengross:

I actually don't think anybody who heard you is going to forget carers after listening to you. Thank you very much indeed Andrew. And I mean there is a law that we involve carers, but how they need to be involved is the question, and how long caring continues is another huge subject. Thank you for bringing so many important issues to our attention, it's very, very important. And now I'm absolutely delighted to welcome Professor Louise Robinson, who is Professor of Primary Care and Ageing at Newcastle University, very dear to my heart, it's lovely that you're here. Over to you Louise.

Priorities for building dementia-friendly communities, reducing variations and increasing participation in research

Professor Louise Robinson, Professor of Primary Care and Ageing, Newcastle University

Thank you Sally, and thanks for inviting me.

Obviously, I must apologise for the tongue in cheek title. I'm really not wanting us to forget about finding a cure and it's absolutely fabulous that there's huge amounts of money going into setting up a national dementia research institute. But I want to take my five minutes to really focus our minds on the here and now, because a cure may be a very long time away and as a part-time GP I'm conscious that really things, I don't feel, have moved on a great deal and as, Andrew, said, in fact it might even be getting worse I feel.

I had the great privilege and pleasure to be at the Live Theatre in Newcastle on Saturday night, watching a performance of a play called Each Piece, which was written by the director of the Live Theatre, who also works at Northumbria University. And what Steve Gilroy does, is he writes narrative plays and by that he means he takes the words of people and doesn't alter them but puts them together into a storyline to make a play.

And he had spent six to 12 months immersing himself with people and their families living with dementia in Sunderland and some of the voluntary and healthcare services in Sunderland, and then put this together to make this play, which was previewed in Newcastle last week.

And the thing that it really brought home to me was that the voices of people with dementia and their carers, because that's all he was doing really, he was conveying their voices, and what came over was the strong message about the inequalities in care, which appear to be growing, the inadequacies in care, which are persisting and I think the worrying fact that nobody seems to be taking responsibility for this at a systems level.

And, of course, we all know about the inadequacies, it's a decade ago that the National Audit Office actually produced its report on dementia care, being very concerned about the quality of care. And I remember reading that and was actually embarrassed to think that I was sitting listening to that play on Saturday night and much of the things that were said in the report were being said in this play on Saturday.

The other thing of course, apart from the inequalities and the inadequacies, is the inefficiencies, and of course dementia is a costly illness. But it's now the most common cause of death in women over 85, so it's on the increase and we know that. We know from the All-Party Parliamentary Group that we need to try and look at more efficient and integrated ways of actually delivering better care for people with dementia. And so I mean there's a whole range of challenges there to us, not just about improving quality, but looking at more efficient and person centred methods of care. And, of course, we've had a brilliant chance over the last 10 years with the national dementia strategy, the work of the Alzheimer's Society, David Cameron's Prime Minister's dementia challenge, but it seems to me that there's something still not quite right that we're not really getting this at a very fundamental care level. And the people on the ground who are suffering are the families and the people with the illness.

This was in David Cameron's second national challenge, it's interesting to look at putting GPs at the centre of dementia care and of course that's a complete change from the last national guidance we had from NICE which was over a decade ago now, which was very much about dementia being a specialist illness that should be diagnosed and initial care coordinated by specialists such as old age psychiatrists, neurologists and geriatricians. But actually, over the last decade, there has been a change in how we look at dementia care and it'll be interesting to see what the new NICE guidelines, which are apparently due out later this year or early 2018, say about this. But it certainly seems that we really do need to think about a fundamental shift in dementia care.

Sorry, are you changing it for me? Thank you.

So it's interesting to look at what the world Alzheimer's report said last year and they were looking at improving healthcare for people living with dementia and their families and basically they said that the current model, which would be delightful if we could have experts providing on the spot care all through the dementia journey, it would be a fabulous model to have, but it's unaffordable and it's unsustainable. And not just in lower middle income countries, but in western countries with very equipped and sophisticated healthcare systems. And what they're suggesting is that we do need to urgently think about a more task shared and task shifted model where some of the basic aspects of care such as support, information provision, continuous care, could be provided by, if you like, less specialist professionals within the health and social care sector. The next slide please.

So the first thing we need to think about, well why primary care? Well primary care because actually 90% of people with dementia will spend their time in the community, either living at home with their families or in a care home in the current UK model. Who will provide their care? The majority of their care, unless they go into hospital or into a hospice, will be provided by the GP and the primary care team and the community care teams supporting them. So it's a fact that they are the people who will provide most of the care most of the time. It's also a long-term condition.

So over the last decade, primary care has evolved considerably and most of the chronic illnesses such as asthma, epilepsy, high blood pressure, are now cared for largely by GPs and primary care teams, usually with expert nurses, with only the very complicated cases going to hospital. This is a list of roles that Steve Iliffe and myself and a few others, thought that the GP could actually contribute to dementia care and if you look at that, most of those issues you could actually say would be the same for diabetes or for hypertension or for asthma. It's no different, it's about providing care for a long-term illness from the start of the journey, from diagnosis until the end.

The next slide please. So, if people say, and most of my GP colleagues say, well is there any point in making a diagnosis because there's nothing that can be done, there's no treatment or cure, well actually the evidence tells us that there is quite a lot that can be done. We can now increasingly make a more accurate diagnostic assessment with all of the scanning techniques that my specialist colleagues have. We can hopefully more timely diagnose the illness and put in early support. For some, with Alzheimer's disease and mixed dementias, this will be in the form of drugs, but for others there's still key things we can do in the term of carer support, family support, information provision, non-drug interventions such as reminiscence therapy and cognitive stimulation therapy, and also getting people to plan for the future and think about not just living well with dementia but dying well with dementia.

Oh and of course there's that little bit about all the other co-morbidities and health problems that people with dementia tend to have at the same time, which require the GP and their team to look after.

So, how can we bring this into reality? I think we've got to listen to the people with dementia and their families first and I certainly hope that there's a way I can promote, Steve Gilroy's work more widely than the north-east.

I don't want us to forget about finding a cure and, John, is probably going to talk a lot about that and I'm really encouraging to help people join in dementia research. But it seems to that we have a fundamental issue about how we provide dementia care, about making it better quality, more joined up and somebody taking responsibility for this and trying to deliver a shared care pathway that brings together not just healthcare but also the more important aspects such as social care and voluntary care, which can provide support.

Thank you very much.

Professor Louise Robinson's PowerPoint presentation can be downloaded from the following link:

http://www.westminsterforumprojects.co.uk/forums/slides/Louise_Robinson_Dementia17.pdf

Baroness Greengross:

Thank you very much indeed Louise, that was so packed with information. And our last speaker this morning is Professor John Gallacher, Professor of Cognitive Health at the University of Oxford and Director of the MRC Dementias Platform UK. Over to you.

Priorities for building dementia-friendly communities, reducing variations and increasing participation in research

Professor John Gallacher, Professor of Cognitive Health, University of Oxford and PI and Director, MRC Dementias Platform UK

Well it's very kind of you to invite me, and to come and listen. I will not keep you long.

The purpose of the Dementias Platform is to create the context for a new generation of highly targeted and highly informative clinical trials. The importance of this has only just recently been re-emphasised with the unfortunate failure of the Solanezumab trial. MRC were prescient when they proposed this initiative.

So let's look at the problem. The majority of clinical trials up until now have been conducted in the MCI early dementia space. If we consider this illustrative curve of cognitive decline, this space is described by the green slope. You will notice that slope is quite steep.

The trouble is that the brain is fairly well into the degenerative process by this time, so there is not really very much to save, even if you can slow or stop further neurodegeneration. Where we would like to go is to conduct trials before the majority of the neurodegeneration occurs; what is called the pre-clinical disease stage. Now the problem with doing this is that in the preclinical disease stage you do not realise there is a problem as you don't have any symptoms. So if I was to recruit you for a trial and you said, "Well, John, that's very kind of you, I'm really pleased to help, why have you talked to me?" and I replied "it's because you have early stage Alzheimer's disease," It could ruin your whole day.

Nevertheless, it's something we have to find ways of doing. And we need to have a public conversation to find ways of doing it which are widely socially acceptable. The solutions will not be without risk, but only by learning how to do early disease stage trials will we be able to identify treatments which will prevent us getting dementia. And I'd like to think that everybody in this room would agree with that goal, even though we don't necessarily yet know how we're going to achieve it.

So, achieving the goal of developing early interventions, is really quite challenging. A first step is identifying people who are at higher risk of getting dementia. We can do this by recruiting volunteers and following their progress for 20 years or so until they show signs of higher risk and then, in 20 years' time, do the trial. Alternatively, we can identify people who have already been followed for 20 years and do the trial now. The Dementias Platform has adopted the second strategy and is working with over 30 established cohorts to work out ways of doing early disease stage trials now.

To identify those at higher risk, with increasing degrees of accuracy, we use a staged approach with each stage providing more detailed information. In our informatics platform we have 30 cohorts with two million individuals in and these are people who've been followed for various periods of time and to various degrees of detail. Within this there is UK Biobank which has baseline data, including genetics on half a million individuals. And within the UK Biobank, brain and body imaging 100,000 individuals is ongoing. This is an extraordinarily large number of individuals that will have detailed imaging. From that group the Dementias Platform is funded to conduct repeat brain imaging in 10,000 individuals. So you have 10,000 people for whom we have a full medical background including a genetics screen, but we will also have repeated brain scans. These detailed measurements will allow us to detect early changes very precisely. This is an absolutely unique resource for dementia research.

So essentially what the Dementias Platform intends to do, is to de-risk the trials in the environment by identifying people at higher risk for different dementias, so we can recruit very specifically the right individual for the right intervention, at the right stage of the disease. The Dementias Platform is a public private partnership and it's been very helpful to engage with industry to get the best out of industry and academic approached in order to accelerate the development of new treatments.

Thank you.

Professor John Gallacher's PowerPoint presentation can be downloaded from the following link:
http://www.westminsterforumprojects.co.uk/forums/slides/Professor_John_Gallacher_Dementia17.pdf

Priorities for building dementia-friendly communities, reducing variations and increasing participation in research

Questions and comments from the floor

Baroness Greengross:

Thank you so much. And it is a wonderful establishment and probably the intervention today that gives us the greatest hope for the future, and I wish you every success in what you're doing because I think that affects all of us, whatever our age here. So, just time for probably one or two questions and then I'll ask the panel to respond to them. Yes, the person over there.

Sara Wilcox:

I actually work for a charity called Pathways Through Dementia, but I also work the Alzheimer's Society as a Dementia Action Alliance Coordinator and it's really with that hat on that I'd like to make a comment.

I couldn't agree more really with what, Andrew, said about short-termism, so in the office where I work, you have people on these short-term contracts, sometimes 12 months and then of course what happens is, nine months into their 12 month contract they start to get nervous and these are people like dementia advisors and dementia support workers. So then they look for another job and then they get another job and then we can't advertise the job then of course because there's only one or two months left on the contract. So then you wait until the contract is renewed, which invariably it is, and then you recruit and then you interview and then you appoint. But in that time people who are living with dementia have got a huge gap in service provision, they've lost the person that they built up a good relationship with and they don't know when someone else is going to come into the role and I think that's really an important fact that we need to address.

Baroness Greengross:

I think you're absolutely right. Is there somebody else who'd like to make a point and ask a question? Yes, the lady here.

Jacqueline Cannon:

From the Lewy Body Society.

I just wanted to first of all say thank you to, Andrew, for your comments. I myself was a carer for 10 years and I totally applaud everything that you've said, thank you. A question about diagnosis. We speak to people on a daily basis who are struggling to get a correct diagnosis, one year, two year, up to three years. We're now getting contacted more and more about people who are being turned away from care homes because the care homes don't know about other types of dementia and they don't feel able to deal with the person with that type of dementia and help them on the journey. So I'd just like to understand from the panel what their view is about getting a correct diagnosis so that people get the right care, the right support and the right medication?

Baroness Greengross:

Thank you very much for that. Yes, is there anybody else who would like to put a question and then I'll go to the speakers? Yes the lady in the front.

Delegate:

Thank you, I thought all four presentations were really, really interesting. But it's question probably for, John, about what to what

extent... it's about the prevalence of dementia and to what extent education is a protective factor. I know the total numbers are going to increase as older people continue to live longer, but I have read some research about education, the number of years of education reducing the incidents later on.

Baroness Greengross:

Thank you. And the last person near the back.

Delegate:

Hello, I thought all the speakers were very helpful. I don't know if you can answer this because it hasn't been covered, but I was thinking about how to get young people involved and I was wondering what the panel's view was of the kind of use of technology in helping people with dementia. I know there's a move now to get young people using things like virtual reality and augmented reality and I know there have been some pioneer research in this area with people with dementia in care homes. And I'm involved in this area as well. So I'd be quite interested to hear a bit about that.

Baroness Greengross:

Thank you very much everyone. So I think if we start with you, John. If we can come across with everybody answering what they feel they can and making a final comment.

Professor John Gallacher:

I know little about care or augmented reality so I can't help you there. When it comes to the incidence of dementia, yes it is going down, relative to our expected levels and I think, Carol Brain's, research has demonstrated this convincingly. However, because of the ageing population, although the risk may be going down, the overall prevalence i.e. the number of people with dementia will continue to rise. Your question then focuses on the impact of education. Well the point here, to take it a bit deeper, is what are the likely mechanisms involved which would make the impact of education a plausible causal factor. Now the mechanism which is most relevant would be synaptic plasticity. As you are educated, as you learn how to learn, as you continue to learn throughout life because you've learnt how to learn, so you're exercising your brain more intensively which encourage synaptic development, which in turn slows cognitive decline. I think this is a plausible explanation. Now whether it slows down neurodegeneration per-se, or offsets neurodegeneration through other factors is a matter for research. So I think education is a great idea. I think we should all continue to learn and it will only do your brain good. It's the 'use it or lose it' approach.

Baroness Greengross:

Thank you very much indeed. Louise.

Professor Louise Robinson:

Yes I mean I think it's really important, it's not just about education as well, it's about, you know, social networks and reducing social isolation and the healthy hearts, healthy minds is a great... you know, is a great phrase if you like, but I think we know increasingly that there are other factors as well, such as education, but also the importance of social networks and keeping socially engaged for our health, which is becoming increasingly important. Technology as I said before, I think there's huge, huge leaps to be made there in lots of ways... in many ways. But I think it's about... well, certainly

thinking about the role of technology in terms of looking at how, you know, we can increasingly help the public health aspect so younger people today... ensuring that they do their 10,000 steps a day, ensuring that they stick to healthy diets. All of that aspect is helping the prevention aspect. But also I think there's a huge role for looking at how technology can be more integrated into our lives if you like in terms of helping, not just our social networks, but actually helping us age in place and I think there's huge work to be done there which is particularly valuable, perhaps to the middle aged generation who will be the next generation to start developing dementia and other morbidities with later life where technology might be able to play a bigger role in their care because they've sort of grown up with it.

Baroness Greengross:

Thank you very much indeed, Louise. Andrew.

Andrew Cornwall:

To start with dementia navigators as we call them in Surrey, or dementia support workers, yes I do a lot of my volunteering with the Alzheimer's Society and various other organisations, but most of it with the Alzheimer's Society, because it's not a tokenism, PPI, patient and public involvement is absolutely at the core of everything. So I think this is the first time I've met, George, but I know all of the board members, I've met lots of them and I have discussed with virtually all of them, the problems that we've had in Surrey. I chair a fund raising group in Surrey, so I'm very well aware. And I was involved very early on... I was asked for advice and input and spread that to the other members of my team, when we realised we were losing funding. All I can say is I've mentioned this to the chief exec and the board level and they're very, very well aware of this, and hopefully we will see in the strategy, something going on with that. Diagnosis, yes I've noticed enormous changes. My mother got to diagnosis last year. With my father, I had to battle to be in the room, the GPs didn't want me there, the consultants didn't want me there. Well, by the time I started giving up work to help my mother look after my father, and then largely took the lion's share of caring, my mother wasn't in a position to think of questions, she was just absolutely physically, emotionally and mentally exhausted. I didn't have that problem with my mother but basically once we got the diagnosis we were just left with, that's it, there was no follow on. And I still hear... because I'm part of the research network with the Alzheimer's Society, I still hear so often of loved ones going down the road and getting sectioned and just we should be so far beyond that now. People should... you know. But then I work with Brains for Dementia, the scientists will still say to me, however good they're getting with scanning, you can only actually diagnose post-mortem, so we need more science.

Young people, just very quickly, I didn't go into this, but one of the questions was how we increase the effectiveness, the Alzheimer's Society as you may know, do a programme with the Scouts where they can earn a badge and I did a lot of work with the Alzheimer's Society, two, three, four years ago, looking at how we tackle stigma around dementia and I had the pleasure of being invited to a dinner and a debate at the House of Lords, thanks to Sally, where we had speakers from various cancer charities and from the Terrence Higgins Trust and various things and I dealt with them, and they all said to me, it's a generational thing. Don't expect to have a big launch and

tackle this overnight, you've got to get them young, you've got to keep them engaged and you've got to keep going. So more with that. I've also been involved a little bit with AR UK and the launch of their sea quest project which you've probably heard about, the virtual reality testing. I was involved in some of the trials and then the public launch of that, so we need more of that sort of thing, absolutely. We need to get them young, keep them engaged and effectively as they grow older than we will have the whole community much more dementia friendly. Thank you.

Baroness Greengross:

Thank you very much. George.

George McNamara:

Thank you, Sally. I think just on the question around short-term contracts, I think this goes to the heart of actually good quality care for people with dementia, because what they value the most is that stable relationship, and short-term contracts in any shape or form, whether they be commissioned or other, are contrary to that. So maintaining the relationship and particularly for carers as well, is so important as the condition progresses. And that's something for us at the Alzheimer's Society which we are actively looking at how do we respond to that because it's a societal, it's a governmental decision, the care navigators, dementia advisors are predominantly commissioned by local government or CCGs, and it's not in their long-term interests in terms of the outcomes, to have short-term contracts, any more than it is for the people who are receiving the services. But we have to say that, you know, this is the result of very much a system of social care which has been skinned to the bone and we have to really address the causes, the core causes of the challenges that the commissioners are having to face first and then look at how we can resolve that. And I think as well, we can look at, you know, innovative ways, new ways of redesigning services. The role of technology, the role of the internet, to maintain a communication. The role of different modes of communication to actually get the answers or seek the information that people want. It doesn't always have to be one to one support. But importantly that one to one support should not be withdrawn when it is absolutely necessary and needed.

And just finally to add to the points around young people, absolutely right around the public health messages potentially and the challenge of overcoming stigma. But I think it goes a little bit further than that, and the fact is that dementia isn't just a disease which affects adults or older people, it affects young people as well. And we did a bit of research a while back with a number of secondary schools and a third of pupils had heard about dementia within their families, in the survey. And they're living alongside their grandparents, their relatives, their parents even, with the condition. So we need to make sure the support is available there. And we're seeing some really innovative work in schools particularly. For example, in Gloucester where they've integrated the importance of dementia into their curriculum and other parts of the country as well. But it's absolutely right and the benefits are huge. You know, increasingly we're actually seeing that as a result of an interest taken around dementia, that young people want to build up relationships and have intergenerational projects with care homes, which obviously...

nearly... well, very much closely located to schools. But increasingly as well, we're seeing actually, young people wanting to go to social care as a result of their experience and a drive towards that. And that can only be a good thing going forward.

Baroness Greengross:

Thank you very much. A quick point.

Professor John Gallacher:

I'd just very briefly like to add to that. This is not just a matter of having conversations between generations. The issue of dementia is neuropathology, which starts decades before symptoms occur. with risk factors start decades before the neuropathology. And if we could move away from talking about dementia to talking about brain health, if we could remove the stigma of going to the memory clinic, replacing it with going to a brain health centre for a cognitive check-up, where you are routinely monitoring your mental capacity, years before symptoms occur in exactly the same way that you measure your blood pressure, at that point you have engaged the younger generation and at that point you can intervene at the earliest opportunity.

Session Chair's closing remarks

Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia

I think that's a very, very good note to end on and can I say that I think we've all learned a great deal from this morning and it's been very moving as well.

I was very fortunate to Chair an awards scheme for the Design Council some time ago, and the amazing things I learned that technology can do to help people with dementia. I shan't forget, and one of the most moving was actually not about design it was about dementia dogs who can give people company, but also remind them to turn the oven off, or whatever it might be. They are brilliant, but of course not everybody can cope with a dementia dog and they are very difficult to train, but a lot of IT can actually do all of those reminder jobs, and there's much that we can introduce to help people who do have some form of dementia if we develop the technology, including virtual reality in fact, and I have seen some wonderful examples of what can be done and what will be done as we go forward.

So there's lots to be hopeful about, and I think our speakers this morning because there's many more to come, have given us a huge amount of information and knowledge on which we can build. So I would like to thank them all, as well as our earlier speakers, thank you all very much for being here.

Session Chair's opening remarks

Baroness Finlay of Llandaff, Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum

And if anyone is the proud possessor of a roving microphone, could they hold it up and we will have it. No? Oh yes, Sam you've got it. Thank you.

Thank you can I take it, I don't like being stuck behind this.

Thank you, that's much better. I'm Ilora Finlay, and I, like Sally Greengross who was Chairing before, am a Cross-Bench in the House of Lords. I also Chair the National Mental Capacity Forum and the National Council for Palliative Care. I gather in the last session there was a good debate; I'm sorry I wasn't here because I was on the train coming up from very cold Wales, where it was cold and foggy and it's boiling in here.

I gather there was a very interesting question in the last session about whether people are scared of dying, of death. So hands up, how many of you have made a Will? Okay, the rest of you where did you buy your ticket to immortality, because I would love to have it? Have you ever been an Executor or had somebody die and try to sort out their estate without a Will? It is a complete nightmare, even if all you own is a bicycle, out of kindness to any relatives you might have, please make a Will this afternoon.

How many of you have done an organ donation card, or made your decision? Great. And how many of you have done an LPA, Lasting Power of Attorney for health and welfare? Right, okay, a few of you.

Well how many of you can tell me the principles of the Mental Capacity Act too, because this is really what we are all about here? Okay. Those of you that can, bear with me, everybody else you've got 2 minutes, raise your left hand. Okay, wriggle your little finger, okay, that is that you presume somebody has capacity for that decision at that time in front of you until you can demonstrate that they don't. It is 'that decision at that time'.

Ring finger, keep your hands up, okay, people need support, some of you might have a wedding ring on that finger, you might think that's supportive.

What about the finger sticking up in the middle? That is that we all make unwise decisions at time, some of you might think that wedding ring was an unwise decision, but I think you probably had capacity to make it. We all make unwise decisions. But now all of you do this - pinch as hard as you can - that is the power in your hand when somebody lacks the capacity for that decision at that time, and you must take a best interests decision: you need to find out all about them, it is about them, it is not about you, and you must go for the least restrictive option. You do not keep them under your thumb.

Okay, that's the five principles of the Mental Capacity Act, if any of you can give me the names of 100 people that you have taught that to, I will buy you a bar of House of Lords chocolate, and it's very good chocolate and I will pay for it myself, and it's expensive.

Now on with the meeting. I hope you've all learnt something already.

So we are now going to go straight into priorities for regulating and inspecting and Alison Murray is going to address us, thank you Alison. And I'm not going to run through people's biogs because you can all read them, I think.

Priorities for regulating and inspecting dementia services

Alison Murray, Head of Inspection for Adult Social Care, CQC

Hello everybody.

I'm going to run through some of the priorities and challenges around regulating and inspecting dementia services, and am very happy to pick up questions afterwards.

Okay, so Care Quality Commission, I won't dwell on this because I'm hoping that by now you all know what we're about. And similarly, when our inspectors go out and do their inspections we're focusing on five key questions that we think are important for everybody who uses any form of health or care service. And that's, is it safe, is it effective, is it caring, is it responsive to people's needs, and is it well led.

Now, back in October we published our annual State of Care Report. It got an awful lot of media coverage at the time and we're delighted to see that actually over the subsequent months it has continued to get quite a lot of coverage. I'm going to pick up some of the themes and trends from that that are helping to drive the priorities for our inspection programme over the next few years.

My focus is very much around adult social care; and in adult social care the State of Care Report highlighted that there is some seriously good news, that many services are providing good quality care and that more than three-quarters of care services that we had previously assessed as inadequate, got better; that a very large percentage of community social care locations are seriously good or outstanding; and that within those five key questions, the question around caring achieves the highest score, and that's a really powerful statement for all of us I think. The people who work in care services are fundamentally, exceptionally caring people who really want to do a very good job for all of the people in those services.

And in the State of Care Report, and through our inspection reports, we've been able to highlight some fantastic examples of really good care. Through the reports that we publish with outstanding ratings, we're able to highlight the very, very best of those that we hope that other providers, other people who are working the sector can look at and think, ah actually yes, I can do a bit of that, I can learn from that.

And what we're doing around that is, in my region, (I work in London), every Friday afternoon we have an outstanding panel, and at that outstanding panel which we extend to our colleagues in the South as well, we go through and we assess those reports that inspectors think are outstanding, you know where the service is providing an outstanding level of care. And we see some absolutely amazing examples of dementia care services that are doing a fantastic job.

There was one last week that we were looking at, a big dementia care service in Bristol and what the inspector had written about that service actually reduced us hardened regulators to tears, it was just so lovely.

But, there is some worrying news in that State of Care Report as well, nearly a third of services that we inspect are either requires improvement or inadequate and that just simply isn't good enough. We see, although the caring domain gets rated very highly, the domains around safety and leadership are disappointingly lower rated and that nearly a quarter of the services that we've rated inadequate and we re-inspect, haven't got better. Even more worrying for us and one of our priorities that we're going to pick up on, is that half of the services that we rated requires improvement, didn't get better and in fact, 8% of them actually went on to get worse.

And people who live in care homes for older people, services for older people, are receiving a much worse service than those people with a learning disability. And these examples of poor care on the slide really speak for themselves. The one about Mental Capacity Act, understanding thereof is, that's a verbatim quote that somebody actually said to an inspector on an inspection.

And what we're looking for when it comes to good quality dementia care it really, really isn't rocket science. That care providers help people living with dementia maintain independence for as long as possible, they enable people to live life to the full, they make sure that families and carers feel cared for and supported, ensure that end of life care is as good as it could be and fundamentally, they see the person and not the diagnosis.

And as the State of Care Report showed, actually adult social care is at a tipping point. There's a real tension around volume, cost and quality, and maintaining quality whilst demand increases and budgets are under pressure, is challenging even for the most well led services.

Now, within CQC, as you can imagine, we are very, very keen to bang the quality gong and we see that there are five key influences on quality. We need to listen to what the public say and act on what they tell us. For example, Healthwatch have just produced a really helpful report giving some of the findings from their enter and view visits around what people with dementia are saying about their care services, both care homes and primary care services, some fascinating stuff in there.

I'm sure that we'll go on later on to think about the workforce, that we need to recruit and retain staff who are capable, confident and feel supported. We know that it's really difficult for providers out there, but we need to see providers who care, who learn, who want to improve, who are looking at integrating services and innovation. Commissioners, again, really tough climate out there, but please don't compromise on quality. And as far as the regulator is concerned, we need to be on the side of people using services.

So, we are now just finishing our first wave of inspections under our new approach, the last ones are happening at this very moment for adult social care. We've pulled together four strategic priorities for CQC over the next few years. These are encouraging improvement, innovation and sustainability in care, delivering intelligence-driven approach to regulation, promoting a single view of quality, and improving our own internal efficiency and effectiveness. And within the dementia care field, there are three areas that are our main priority over the coming months, because we won't be able to do it overnight. We are looking at domiciliary care. We know that yes, we've rated a significant proportion of supported living services, dom care establishments as either good or outstanding, but actually we're not completely convinced that our methodology really gets under the skin of those services and helps us to understand people's experiences.

So, we've got some pilots starting I think next week and running through February and March, looking at some tweaks to our methodology to see how we can involve people better in those inspections. We also want to focus more on services that are rated requires improvement. It's fantastic that services that we're rated inadequate have taken those messages on board and either, have chosen to exit the market, or perhaps we've nudged their arm to exit the market, or they've improved, that's great. But actually, if a service requires improvement it really, really does require improvement, it is not good enough. And we need to look, as an organisation, at again, how we can understand the themes and trends that make that service requires improvement, and what we can do to help lever that improvement. And that's where working with the academic institutions, working with colleagues in voluntary sector, the charitable organisations, we can really help influence that.

We're also internally looking at our inspector skills sets to make sure that actually when our inspectors go out and do the inspections they have the right knowledge and information at their fingertips. They can't be an expert about every single type of service, but we can make sure that when they're doing inspection planning, they're looking at the key features of that service and what it is that they need to look at and do they know enough about it, if they don't, where can they find that information, where can they get that support.

At the moment, we've got a couple of consultations running, they're open until 14th February and I really would encourage all of you please, have a look at them and put your two penneth worth in. You might not agree with some of the things that we're advocating, but actually you may do. If you don't agree, please tell us because these are genuine consultations, things aren't written in tablets of stone, they're not tied down completely yet.

And in a little bit more detail around those consultations, we're looking at cross-sector changes to the assessment framework which I'll come onto in just two ticks. Not perhaps so relevant for all of this audience, except to flag up the incidence of Downs Syndrome related dementias, we're doing some work around guidance for the registration of learning disability services, particularly around the size of establishments that we're saying we will or we won't register, and some NHS-specific stuff. So that's up until 14th February.

And then later on in March, we're going to start consulting more formally around changes to our assessment methodologies in adult social care. So, we're going to be doing a bit of work with our key lines of enquiry, the KLOEs, we're simplifying them significantly. At the moment, we've got 11 of them throughout CQC and as we're moving towards new models of care and we're trying to encourage innovation, it can be really difficult and confusing for providers to work out which of the KLOEs is particularly relevant to their service. And you know if somebody is doing some form of integrated care then actually, they're going to chop and change between about four different sets of KLOEs, which really doesn't do anybody any good.

So, we're honing those right down to two KLOEs, one for health and one for adult social care. The academics amongst you will be delighted to know that we're strengthening up the prompts under the key lines of enquiry to make it much more explicit that we expect care providers to take account of and make reference in their policies, in their training, to evidence-based practice and good practice guidance.

We're also, you'd be delighted to know, beefing up some of the KLOEs around capacity and consent, because although it's been out there for a long time, providers still aren't always getting it, so we're making that more explicit.

But this is all to strengthen and simplify, for the providers of you out there, please be assured this is evolution, not revolution. We're looking to make things simpler for you, we're not looking to increase the regulatory burden in fact, we're doing a lot of work with our colleagues in ADASS and within the CCGs to look at how we come to a shared view of quality, so that we ask you for one set of information and we all use that one set of information. Obviously, we'd like it if that shared view of quality was our view of quality, but hey we'll work on that gradually.

And that's some links and some guides about where you can find all of our consultations.

So that's all I've formally got to say, but very happy to pick up questions and queries.

Alison Murray's PowerPoint presentation can be downloaded from the following link:

http://www.westminsterforumprojects.co.uk/forums/slides/Alison_Murray_Dementia17.pdf

Priorities for regulating and inspecting dementia services

Questions and comments from the floor

- Baroness Finlay of Llandaff: That's great. Thank you very much indeed. And I would like to take questions from the floor, whilst you're just thinking of them, can I say I think you need to be congratulated in CQC for really having brought about change, because I have been very impressed at the speed with which improvement seems to have happened and that's down to those of you that have really driven it forwards. Of those organisations that you inspect and are failing though, I was wondering as you were talking, how much risk averse practices and protocol-type thinking is embedded in those organisations, rather than freeing up staff to do what their gut feeling tells them will be right for this or that person?
- Alison Murray: Yes, I think it's a very good challenging question. In the very best services, we see actually that staff are encouraged to look at the wider person and responsible risk-taking. In this outstanding service that I was talking about in Bristol, they asked their residents what they wanted to do and they said, do you know we haven't swum for ages, it's really good, the water makes us feel tonnes better, reduces aches and pains. So the manager of this service said, yes, fine, okay went down to the local leisure centre and has now got swimming classes for those people. And obviously massive risk involved there for people, but risk assess people love it, brilliant. But in the poorer services, we can know from what I was saying earlier, that the staff are fundamentally caring and want to do the right thing for people, but health and safety says no. And CQC doesn't say no, CQC says okay assess what the risk is, what can you do to mitigate that risk, that's fine on you go.
- Baroness Finlay of Llandaff: That's very interesting to hear. People from the floor. Thank you.
- Sara Livadeas: The Orders of St John Care Trust.
Can I ask you a question about housing with care, housing with care and supported living which falls somewhere in between residential care, and dom care and what your thoughts are on how that might evolve in terms of regulation? Thank you.
- Alison Murray: It's one of the things that we're looking at very closely and we're going to be addressing as part of the pilots that we're doing starting next week or so. We don't want regulation you know to be a barrier to innovation, we think that actually housing for care and all of these various different new models of care, are the way to go. And it's how, we as a regulator, can make sure that yes, we've got the safety and we've got the frameworks in place, but that people can live where they want to live in services that can meet their needs whatever those needs are.
- Baroness Finlay of Llandaff: Thank you. Lady here and then the lady with the white cardigan. Thank you.
- Jacqueline Cannon: From The Lewy Body Society.

You may have heard my question before, that we're constantly, well I say constantly, but more frequently being contacted by relatives saying that they're finding it difficult to find care homes that will actually take somebody with Lewy Body dementia, because there either seems to be a lack of knowledge, or kind of afraid, my dad was in a care home and it was an exceptionally good care home, you know so there are good stories out there, which we need to hear more of. But what's your view about people being turned away because they've got one particular type of dementia?

Alison Murray:

As a regulator we can't dictate what people care homes choose to admit or not admit to their services, but what we can and we do, do is that we insist that care homes when they take a person into their service that they're able to meet that person's needs. And one would hope that the forward-thinking care homes invest in training and developing their staff, so that when they have somebody knock on the door with for example, Lewy Body dementia, they can say actually, at the moment I'm not entirely certain that we can meet those specific needs, but let me find out what training is around, let me see how we can skill up our staff and we'll come back to you.

Baroness Finlay of Llandaff:

The lady here. Thank you.

Maureen Hume:

From Camberley Alzheimer Café.
Now we hear a lot about what happens in the community and many of the people tell me that they have sometimes a five minute visit or a 15 minute visit. Now how can that possibly care for somebody in the later stages of dementia?

Alison Murray:

Personally, I don't think it can. It's very interesting when we look at the reports of domiciliary care agencies that provide care packages to people with dementia, the ones that we're rating as outstanding tend to be the ones that say to commissioners, actually do you know we can't do it on less than 30 minutes visits.

Baroness Finlay of Llandaff:

That's interesting. Thank you. Other questions? Gentleman here and then down the front.

Simon Papworth:

From Person Centred Software.
As a regulator are there any plans to promote best practice and a national standard from that?

Alison Murray:

As a regulator, we have to be very careful about endorsing standards. What we do within our guidance and our key lines of enquiry is we try to signpost providers to frameworks that may assist things like skills for care, PH England etc. but we can't kitemark or endorse specific products. But within the new key lines of enquiry that we're putting out there for consultation, as I said before, we're making it much more explicit that we expect there to be an evidence base behind the service that a provider is giving to people. You know, so for example, if they're using person centred software, we would expect them to be able to demonstrate why they're doing that, why they choose to do that, and what the benefits are.

- Baroness Finlay of Llandaff: I'm just going to squeeze in one very short question with a very short answer in the closing seconds. Go on.
- Calin Adrian Puia: Alright, how do you consider to tackle the problem of inspecting more regularly the same house? So for example, are you going to make a report today and you're going to say it's inadequate, but for many occasions there will be six months until you are going to come back. And for them they're going to show you a red carpet, they will have time to prepare the red carpet and for you, you will not get the best results from that.
- Alison Murray: All of our adult social care inspections are unannounced.
- Same delegate: No I'm speaking about the second one, so for the first house you are going to say it's inadequate.
- Baroness Finlay of Llandaff: It's the follow-up.
- Alison Murray: The follow-ups, we say that we will definitely go back within six months, but we can enter and inspect at any time. And we use information that we get from the providers themselves, from commissioners, from data to help us assess that risk constantly. If we've rated a service inadequate, for example, and we're hearing rumours perhaps in safeguarding enquiries that things are deteriorating, we go straight back in.
- Baroness Finlay of Llandaff: Thank you so much, that was really interesting and you took a lot of questions in a short time. Thank you.
- Alison Murray: Thank you.
- Baroness Finlay of Llandaff: We now have three speakers coming one after the other, we are going to start off with Simon Williams who is Director of Community and Housing from Merton, and then we will follow straight on. Please think about your questions now, because it's easy to forget them when you've heard the third speaker, so even jot them down now so that when we get to discussion we have a broad range. Thank you.

Key issues for social care: enhanced health in care homes, financial sustainability and workforce challenges

Simon Williams, Director of Community and Housing, Merton Council

Thank you very much and I loved your introduction, I'm going to book you to come and train some of my social care staff because that was such a fantastically simple introduction to mental capacity and really gets back to the principles.

So I'm kind of here probably to talk quite a lot about the money, I think, when I looked at the italics. And so I'm here to answer three questions I think, in short order. And the first of the questions is, has the funding gap in social care been fixed by some of the recent announcements. My short answer is no, but I'll give you some short numbers just to say why, not just I, but ADASS don't believe it has, welcome though it is. And essentially from the kind of announcements about the social care precepts and a new Better Care Fund, over the next three years to 2019/20, that will raise about £3.3bn.

The very recent announcement about that extra 1% on the precept makes no difference because you can only do 6% over three years. All that changes is the phasing of it. So, hold that £3.3 billion in your head. Our calculation of the pressures in adult social care over the next three years are about 1.5 billion on demand pressures, 1.6 billion national living wage and other cost pressures on providers, about 0.2 billion on deprivation of liberty, the kind of amount of extra work that's come from doing the work on the Mental Capacity Act. And about 1 billion just to make our share of the savings that local authorities have to continue to make.

So when you total that up, that comes to about 4.4 billion, which leaves a recurrent gap of something over a billion. And actually next year it'll be higher than that, we reckon about 1½ billion because the new Better Care Fund won't have come in.

And actually, other organisations like the Nuffield or the King's Fund put it higher than that. They put it up to about 2.9 billion. So our view is, welcome though it is, we're still not out of the woods by a long way.

The second question is then what's the kind of mutual impact of that if we're looking at dementia. Because we would say it's imperative that providers can provide a good service, they can pay their staff properly, train their staff properly, quality assure properly, the reasons we've been hearing. And the fact is that if we look at a lot of the budget surveys we do with directors every year, frankly we're playing catch-up in the reasonable rate that we're paying to providers.

And so in a lot of places commissioners are facing an invidious choice of really three things. They can pay a reasonable rate to providers, but that's probably not affordable in the budgets that they're currently being set and having to make the savings. Or, providers will simply collapse or leave the market. Or in some places, providers don't have to leave the market but they can sell their capacity to other people, particularly self-funders or the NHS. And what we're seeing increasingly is commissioners trying to find a way through that.

So if I take southwest London where I happen to work, as an example, we've done some analysis recently on care homes across southwest London. And we reckon that for people with dementia we are now paying up to about 50% more than what we think is the going rate that we're offering to care homes. And for people with dementia and challenged behaviour it climbs to about 80%. So what we are frankly, we're kind of deluding ourselves increasingly in thinking that we can actually buy quality care for the kind of rates that we are trying to hold to.

We're taking some strategic kind of work to address that, but I suppose the point being that for people with dementia, the funding shortfall for social care bites even deeper, it has an even bigger impact because the cost is that we cut corners in terms of having trained staff and all the rest of it. And they are the most vulnerable group, least able to kind of speak up for themselves.

So our third question is, so is there any hope, are we all doomed? No, I don't think we're doomed, because I'm still conscious and looking to Alistair at the back, I remember saying this when I was doing a bit more work on dementia, I believe the loss of money is wasted getting things wrong for people with dementia. And I still believe that now I'm sort of more on the money side I can see it more than ever because if we get it wrong with people with dementia they are forced into ever more expensive, intrusive settings of care and that's essentially what happens.

So I would say really that getting the funding right is a necessary but not sufficient condition. We need to do that but we can't just sort of sit back because there are some other challenges we have to step up to. Firstly, commissioners have to get commissioning right and we know, and there's a question about time and task commissioning came a little bit earlier, we know we have to commission better and we know we have to commission for outcomes, we know we have to commission in ways that incentivise taking and promoting independence approach. We know we have to commission in ways which enable providers to really, really have an incentive to provide quality services.

Secondly, we know that providers have to be able to step up to that and that's variable, and we need to make sure that we are actually supporting providers, working with them transparently to get that right.

Thirdly, we have to make sure our processes work because we could get that right but some research we did last year from the local Government association on integration showed that actually a key process was as people coming out of hospital was to kind of get decision making right then to get people into the right setting of care, so we have to do that.

And then lastly, we have to make sure that dementia continues to be everyone's business, do dementia action alliances. And on that last point I'm hopeful. Little anecdote, I was seeing my physio who I happen to unfortunately have to see quite regularly at the moment, having a chat as one does. And he said have you got any old manual typewriters and I said no. He said well because my mother-in-law's in a nursing home and they're trying to get lots of typewriters for people with dementia who used to use typewriters like that.

And I was thinking to myself after I left, I'm sure five years ago I don't believe that sort of conversation would have been... we wouldn't necessarily have been thinking that way. So I just feel that's so encouraging that that kind of practice and that thoughtfulness is spreading.

So a lot of challenge, but a lot of reasons for hope.

Thank you very much.

Baroness Greengross:

Thank you Simon, and our next speaker is Martin Knapp who is Professor at the LSE and takes an academic, perhaps, perspective on it. Thank you Martin.

Key issues for social care: enhanced health in care homes, financial sustainability and workforce challenges

Professor Martin Knapp, Professor of Social Policy and Director of the Personal Social Services Research Unit, London School of Economics and Political Science and Director, NIHR School for Social Care Research

Thank you.

I am going to give us some numbers, focus on some economic issues and then finish with a slide that suggests things that need to be done. I am very pleased that Simon covered what I hoped he would cover, because that saves me a lot of hassle.

Some of the slides I will show you come from two studies we finished in 2014 and apologies if you've seen them before, but they offer the best evidence we have available at the moment, and I will use them as a platform for what we want to be discussing.

So, this first slide is just an indication of the total costs of dementia in the UK today. The total is less important than the proportions: quite a large cost falling to the NHS, an even larger cost to the social care sector, and a very substantial amount of unpaid care (on which we put a monetary value). I am going to come back to that in a moment.

One part of that social care element is very difficult to get it from national statistics, but our estimate is that 22 percentage points of that 39% is self-funded, mainly self-funded residential or nursing home care. So what you have is a substantial contribution to the total cost of dementia coming from people with dementia themselves and their families.

This next slide just tells you what you know: the projected substantial increase in the number of people with dementia over the coming years. The challenge is clearly considerable. There are studies that suggest that the age-specific prevalence rate is falling, but the total number is not going to fall noticeably. Anyway, that age-specific prevalence rate only seems to be falling for people with high education. The question is, how can we best support people in a good way, people with dementia and their families over that period, and that is what I want to speculate on in this presentation.

I am going to just show you some results from another study that we did for the Department of Health for the Dementia Legacy event in London when David Cameron was Prime Minister in 2014. We were asked to look at current and future scenarios for dementia care.

Five things we were asked to look at: (1) what is current care and support, and I will show you the slide which repeats the figure that I showed you before from the Alzheimer's Society study; (2) what happens if there's no diagnosis or treatment; (3) diagnosis is carried out but then no treatment; (4) what happens if we take what we know about what care works and give it to people with dementia who may not currently be getting it; and (5) and then, fifthly, what about prevention or disease modifying treatments.

I always say that this first slide of results is 'boring' because the heights of the columns change very little when we offer evidence-based interventions to everyone. The left-hand column represents current care for people with dementia. The second column shows what would happen if everybody with Alzheimer's Disease who would be eligible by NICE guidelines gets donepezil. Cognitive stimulation therapy is available to people with mild to moderate dementia in the third column. In the fourth column, case management is delivered. In the final column, carer support based on the START model, which has been shown to be very effective and very cost-effective.

What those interventions do, if we roll them out to everybody who is eligible in the population, is not to change the total cost of dementia care very much at all. What it does do is change some of the balances, often

to put more burden or responsibility onto family carers. There were improvements to quality of life, but those were modest.

Now, if we go to the second set of analyses that we undertook, they show what happens to cost if you have better prevention, or you have a cure or disease-modifying treatment available. Now the slide is less boring because the column heights change quite a lot. There are various things we have modelled there: I am not going to go through the details of them, but I will explain briefly. The left-hand column is what we do currently. The next three columns are showing what happens if you slow down the progression of the disease, i.e. you are able to slow down the transition from mild to moderate dementia, and from moderate to severe dementia. The final two columns on the right-hand side show what happens if you delay the time of onset, initially by one year, and then by three years.

Now, these are all hypothetical scenarios, but what you can see is you get quite a substantial change in the cost pattern. So it suggests that if affordability is a challenge for us, which I think it will be if we don't change our care and support arrangements, then maybe those prevention and/or disease-modifying strategies would help to make the system more manageable.

Now, if I take that same slide and then add on (in black and grey) some hypothetical costs for this new disease-modifying treatment, or for a successful prevention strategy. I have shown costs at today's prices of either £1,000 or £10,000 per person per year. When you add in intervention costs of that size you completely wipe out the savings, so although, for example, the delayed onset scenarios look pretty attractive from an economic point of view, actually we have got to find a way of paying for them, and if the cost is even quite modest it might mean that they are not seen as very affordable.

Those figures that I have just shown you come from some what I would call 'fairly clunky' modelling. What we are doing now is a much more sophisticated and ambitious study, with much more careful modelling of the costs of dementia and the outcomes from treatments for dementia, both in the current period and over a 25-year period going forward.

This is the MODEM Study. It doesn't finish until March next year, so we have not got the results of any new modelling yet, although we are making very good progress. What I can tell you about now is the MODEM Evidence Toolkit: it will help you find out what works in dementia from the published research literature. This is an interactive website which has got more than 1,000 studies on it, reporting what works in dementia care and treatment and support, and (if available) what is cost-effective. It is a very useful searchable website.

Let me then go to my final slide, which is what then do we learn from this economic evidence and what is needed if we think about the future planning and delivery of good dementia care? The first point is - to state the obvious - that today's care and support arrangements projected forward look unaffordable and/or infeasible. I say 'infeasible' in the sense that we are not going to have enough family or other unpaid carers to deliver the level of support that we see today.

Secondly, the contribution from the NHS is substantial without any doubt, but it is actually the smallest of my three segments of the total cost 'pie'. It is still a substantial cost, and it will increase. One question is then whether that is appropriate: how much of that increase is appropriate in the sense that are there people in hospital with dementia who do not need to be there, for example, as we have discussed already today.

Thirdly, there is a huge social care contribution. A large proportion of that (two-thirds or so) is coming from self-funding. That self-funded proportion is undoubtedly going to grow, as I cannot see any Government voting for it not to grow, if you understand my meaning. We desperately need to sort out the funding arrangements for social care in England.

Fourthly, there is heavy reliance on unpaid family and other carers. We need to support them, but even if we support them in the best ways that we know today, our projections from another study that we have recently finished for the Department of Health (and which should be public in a month or so) suggests that there will be

nowhere near enough unpaid family and other carers available over the next 25 years unless we can find some way to increase the supply somehow.

My fifth point is the growth in self-funding, which I have talked about already.

Sixthly, we need investment in risk reduction. We heard this message from Duncan Selbie earlier this morning: clearly, we must invest in that way, but the impact in terms of the affordability of dementia care is going to be relatively slow to materialise. It does not mean we should not do it, but it does mean that it is not going to solve the economic challenge of the next couple of decades.

My seventh point is, of course, that we need a cure. But then the question is: how affordable would those treatments be? It was great to hear John Gallacher's talk about what is happening in the basic science world. There is a lot of interaction now between industry and academia, people in the sector, families and carers. We need that interaction to make sure that when something is developed and delivered it is affordable and gets purchased.

Finally, and here I am repeating what Louise said earlier this morning, we cannot wait for the prevention strategy to work its way through, nor can we keep hoping that a cure will be discovered in the next month or so. Consequently, we do have to put a lot of emphasis on care and support today. We need to explore new approaches to care, and I am glad that in this country we invest a lot in dementia research, particularly on services research, to help us move things forward. I am sure Alistair will tell us more about that later on. But then we need to check for effectiveness and cost-effectiveness of any new service ideas.

My final message is that we need to implement what we know works today and that is one of the worrying things: a lot of what we do today across the country is simply not evidence-based. When there are evidence-based interventions, why aren't we delivering them?

Thank you very much.

Baroness Finlay of Llandaff:

Thank you. You've given us a bit of a reality check and our next speaker is Hilda Hayo who is the Chief Executive and the Chief Admiral Nurse from Dementia UK. Hilda.

Key issues for social care: enhanced health in care homes, financial sustainability and workforce challenges

Hilda Hayo, Chief Executive and Chief Admiral Nurse, Dementia UK

Hello everybody.

The room is still very, very hot so if I expire with the heat you'll understand why.

The topic area that I'm going to be looking at is a model of how Admiral Nurses can actually work within the care home setting. I'm looking at the guidelines in italics on your agenda, the ones that we're going to address are working as part of a multi-disciplinary team, or working in collaboration. Reduction of inappropriate admissions both to acute care and also inappropriate admissions to long-term care before the person is ready and before the family is ready.

And I'll also be looking at the improvement in the evidence base as well around the quality of care that's received by people that's living with the diagnosis and their family, but also for cost effectiveness too. I take on board what the other two speakers were saying about there's going to be no extra money into the system that we can envisage for the foreseeable future, so we have to use that money in a different way.

How many of you in the room have actually heard of Admiral Nurses? Oh, that's good, well done. Admiral Nurses, for those of you that don't know, we have been called the Macmillan Nurse equivalent for dementia. So we are specialist dementia nurses that work with the whole family, not just the person living with the diagnosis, not just the carer or the family member., we work with the whole family.

Some families as we know can consist of two people, some families can be as many as 14 people. We work with the whole family particularly when there's complexity.

Why are we called Admiral Nurses? A family realised back 25 years ago that there was care and support for the person with the diagnosis but the family felt there wasn't the care and support for themselves. So they wanted to make a difference to the family's experience. They didn't know quite what to call these nurses, but because of their family member, Joseph Levy (whose nickname was Admiral Joe) they decided to call the nurses Admiral Nurses. So that's why we're called Admiral Nurses. Which can cause us a bit of a problem when I'm on the helpline and when my staff are on the national helpline, when people are phoning up for insurance! I had three calls last Thursday when I was on the helpline!

Now, the working partnership isn't just with the family, we work in partnership with all other organisations, whether that's statutory services, the NHS and social care, whether it's other organisations like Alzheimer's Research, Alzheimer's Society, CQC, Order of St John's, care home providers; we work across the range. We've got Admiral Nurses in acute hospitals, hospice settings, working out in the community with GPs, or working out with secondary services, so we have nurses all over. We also have nurses working in the care home sector. We have 20 nurses in total working in the care home sector, out of 184 and numbers are growing.

What we also do is provide a family and relationship centred approach. Not everybody that's living with a diagnosis of dementia and their families need access to an Admiral Nurse. We cope with the complex end of dementia care. So we're working with families that are having difficulty with relationships. We're having families that are having difficulty with changes in behaviour, in adapting to the diagnosis, in the fact that they might have a genetic form of the disease process.

So a lot of our work is actually working alongside that family to enable them to build resilience and to get the skills to be able to proceed further forward in an enlightened way so that they can actually work positively as a family and live as well as is possible with dementia.

Also, on top of that we do specialist assessment and evidence based interventions. Nationally the evidence based interventions for dementia, as we heard from Martin, are pretty few and far between. We do need to

have a greater evidence base and with a view to that at Dementia UK we're building up the evidence base for the effectiveness of specialist dementia nurses.

We work with the whole family, as I said before, but we don't just concentrate on the dementia, we have to look at the whole of that family's make-up. We have to look at the biopsychosocial aspects that are affecting the way that family is living and breathing with dementia.

We also provide supportive education, whether that's with our other clinical colleagues, our other social care colleagues, or whether that's with the family themselves.

So what do we do specifically with care homes? What do we do specifically to help with the retention of staff, with the development of staff? Each one of our Admiral Nurses that are linked with care home providers have between four to eight care homes that they work with, so you don't have an Admiral Nurse per care home. And with those homes that they work with, they're doing a lot of staff support and training. Not the dementia awareness training, they're doing the higher level, this is how you deal with somebody that has a particular set of behaviours. This is how you work with a family who are having a difficulty coming to terms with mum, dad, husband, wife, coming into a long-term care setting.

We also help to prevent complex situations because a lot of the complex situations that occur and the distressed behaviours are because of the environment. So it's about working with the people within that environment to make that the best environment possible. This morning somebody was mentioning about activities within the care home settings. It's really important to have appropriate activities and I would say meaningful activities within care home settings because that will enable people to live as well as possible, whatever setting the person lives in.

We also are able to model techniques and approaches. So, as an Admiral Nurse, we are specialist nurses that have been working with dementia for a prolonged period of time. We've come across most things so we will be able to model the most effective behaviours because it's no good just reading it from a piece of paper. It's a different thing when you've got the person that's actually sitting in front of you, or a family that are coming in, and you want to know the best approach with that family and with that individual.

What we're finding is where we've got Admiral Nurses working with other care teams or social care teams, we can increase staff morale and skills. If people feel that they have a difficulty coping in the environment they're in as an employee, they are more likely to seek alternative places to work. What we're doing is trying to encourage that person to be able to have the skills and the knowledge and the attitudes and the values that they need to be working effectively in those settings.

And as we were saying before, we've give a lot of advice and support about the environment and activities that are appropriate for the person that's living with the dementia within the setting.

So, as I said before, we're looking really at cost effectiveness because that's the real world that we're working in. However, what's more important to me is quality. So the quality of experience that families are getting, that the person that's living with the diagnosis is getting, is very, very important. And we deal with the sorts of dementias that are not as common, like for instance Lewy body, like for instance my specialism is people under the age of 65 living with dementia and people with frontal damage.

So across the board and because we're specialist nurses we are more likely to have those skills and we are the ones that can go in and actually work with those care staff, so you don't get the phone call 10 o'clock at night saying can you please remove your mum, dad, husband, wife, and find another placement. Which, as a practitioner and as a family member, I've also received.

So, thank you very much.

Hilda Hayo's PowerPoint presentation can be downloaded from the following link:

http://www.westminsterforumprojects.co.uk/forums/slides/Hilda_Hayo_Dementia17.pdf

Key issues for social care: enhanced health in care homes, financial sustainability and workforce challenges

Questions and comments from the floor

- Baroness Finlay of Llandaff: Can I invite our three speakers to come up here to form a little panel for us now? Thank you. And as they're sitting down, hands up for those who'd like to ask a question. Three very different presentations in many ways ... yes, lady here again. Thank you.
- Jacqueline Cannon: This is a question I think for Hilda. If another charity for example, or another organisation came to you to say okay we want to sponsor an Admiral Nurse, what would be the procedure to say and identify the best area for that Admiral Nurse to operate in? So whether it's to go into a hospice, or to go into a group of care homes, what part of the country, how would that work?
- Hilda Hayo: We have a business development team so we know each of the regions of the country which areas we still need Admiral Nurses in, which areas we've got Admiral Nurses, and what are the range of settings. So, for instance, if we've got a county where we've got Admiral Nurses that are working predominantly in acute care at acute hospitals, then we know we're going to be looking for providers that provide care in the community, hospice settings, or within the care home setting. We have a member of our business development team here somewhere, Claire stand yourself up.
- Claire Ferris: Hello.
- Hilda Hayo: If you speak to Claire, Claire will be able to give you some details if you're interested in that. Thank you.
- Baroness Finlay of Llandaff: Great, thank you. Can I just then ask Simon a question because you spoke about the different budgetary pressures on local authorities including DoLS. As you're probably aware I feel fairly passionately that that has gone out of control, but I'm trying to do something about it; I have got State detention re-defined, thank goodness, but other things are coming along. But I was just wondering as you were speaking whether there it'd be actually helpful to have a stipulation or a guidance that the budgets for different pockets need to be ring-fenced so that you don't get corrosion out of some which are much more administrative into frontline care which somehow I have a sense often is the one that suffers, because you can look at the forms that haven't been filled out, but it's much more difficult to add up the bits of care that never happened.
- Simon Williams: The view of local Government as a whole is we don't like ring-fencing...
- Baroness Finlay of Llandaff: Oh, I know that...
- Simon Williams: ...so I've got to take the party line...
- Baroness Finlay of Llandaff: ...I want your view.

- Simon Williams: I suppose I would say I would prefer benchmarking. I think it's right that we should make every pound get to the front line that we can. I think the way in which to encourage us to do that is essentially to be transparent about how we use our money. How many people have heard of local accounts? That's interesting you see, so that came in what three or four years ago, it was kind of the deal when we weren't inspected so heavily, we were all encouraged to publish a local account every year that sets out for local people how we spend the money, how we perform basically. And I think certainly I locally feel really strongly your challenge is absolutely right, how do I sort of demonstrate to local people that I'm using the money wisely and that sort of benchmarking about how much of the money goes into care management costs, if you like, and admin, and how much reaches the frontline is exactly right. So I would probably go for that sort of transparency challenge rather than it being kind of if you like hypothecated before. Because I sometimes think that can have unintended consequences.
- Baroness Finlay of Llandaff: Other questions, because I have another one for Hilda if nobody... does anybody, yes, come on, I'll let you in.
- Sara Livadeas None of you have mentioned workforce particularly, which is so crucial in terms of delivery.
- Baroness Finlay of Llandaff: Hilda?
- Hilda Hayo: I think I mentioned workforce and actually retention and staff development. I agree with you, I think the workforce is often a neglected area, particularly in care home provision and I think the retention of staff within the care home provision. I know myself if I go into a care home, some care homes have staff that I can see time after time and they're there for a longer period of time. There are other care homes that every six months I go and I see more or less a 70% kind of lack of retention, so I see different staff each time. So yes, the good providers I have to say, and I'm not just saying because you are Order of St John, like Order of St John you have an excellent support of your staff.
- Sara Livadeas We have a massive workforce challenge, we can't do the services because we can't get enough employees.
- Hilda Hayo: Exactly, you can't recruit, but the people you've got, you keep for a considerable length of time, yes.
- Baroness Finlay of Llandaff: There's a lady here.
- Delegate: I'm just interested, I was quite interested in what Hilda was saying about having an interest in the under 65s. I think they do actually get neglected and I wondered in care homes if there are specific care homes for under 65s, if they get specific kind of financial allowances and if there aren't those kind of facilities, what kind of financial facilities are available within the kind of generic dementia care homes, but under 65s. So it's really about the finance for that particular cohort which I feel somehow has been neglected.

- Hilda Hayo: Sure. Yes. There are specialist care homes for people under the age of 65. They're quite a costly environment. Frequently they're actually funded by continuing healthcare funding, so a particular set of healthcare funding. However, there are also care homes that claim that they can actually cater for the needs for somebody under the age of 65 when the average age is around 80, and I would hasten to argue against that as well. I think it is more appropriate to have the ideal setting for the individual. Some individuals might well be okay within older age settings, who are specialised in older age. But the majority of people that I've worked with, the best place is in the person's own home with support, with a care package. And if and when they do need to go into longer-term care, somewhere that's actually specialist for their needs is important.
- Baroness Finlay of Llandaff: Lady at the back, thank you.
- Priti Biswas: University of East Anglia.
Thank you very much. My question is to Professor Knapp, please. You mentioned one of the thing that one of your bullet points towards the end was to support and to increase the supply of unpaid carers. Now, my question is how do you think that can happen?
- Baroness Finlay of Llandaff: Thank you.
- Professor Martin Knapp: Okay, so it's sort of two questions in one. Let me just answer both of them. I mean the context for this is that we finished a piece of work for the Department of Health three weeks ago on economic aspects of unpaid care, supplies to feed into the discussions around the refreshed carer strategy. And part of that was to look at what evidence there is on what works in supporting carers. Part of it was also to project the number of people who will need care over the next 25 years and what the supply of carers might be. And you won't be surprised to learn that the gap between need and supply of carers is going to go like that over that period, I don't want everything off this table with my gestures. So we have this challenge. There are things that work. I mean in the dementia care area I mentioned in my quick presentation the start intervention, I was involved in evaluating that, so I have an interest to declare, but this is a very simple, affordable way to support family carers of people with dementia which not only improves the quality of life and health of the carers, but also reduces their use of health services and it looks like, though we're waiting to get the final results, that it might delay admission into care and nursing homes for people with dementia. So that's both... actually it's effective and cost saving. So that's one you can do. The key challenge however is then how do we increase the supply of new carers, if you like, people who might not have thought about being carers. And I don't have a simple solution to that and there isn't one we've found in any evidence from around the world. But we have to encourage people to see caring, unpaid caring, as something that they can do and that means, presumably, better flexibility in working patterns, maybe financial support although it's probably off agenda for this Government. Some way of getting more people, allowing more people to provide that unpaid care. Many of them want to do it but they don't feel they can take that decision

because they can't afford to, or they feel nervous about it perhaps, particularly for dementia.

Hilda Hayo:

I think I'd like to add to that. Look after the carers that you've actually got because people often give up caring at home because they simply can't do it anymore, they don't get the support that they actually need. And that isn't financial. That's about services, that's about respite, and yes that's got a little bit of a financial aspect to it, but even when people want to pay for their own respite they're not able to do so because the services simply aren't there. So I agree with you, but let's retain the carers we've got.

Professor Martin Knapp:

Oh no, for sure, for sure.

Baroness Finlay of Llandaff:

There's a question here. And whilst the microphone's coming through, it just strikes me too, Hilda, that one of the problems sometimes is that people worry that are they doing the right thing. And I think generally in health and social care, professionals are too slow to tell them you're going a great job, and really mean it, not just throw it out as a kind of thank you note.

Hilda Hayo:

Yes.

Delegate:

It's just a simple question. A lot is going to be expected of the volunteers in the future. But people are forgetting retirement age is going to be extended. So where are you going to get the people then?

Baroness Finlay of Llandaff:

Yes.

Hilda Hayo:

Good point.

Baroness Finlay of Llandaff:

Go on, yes.

Simon Williams:

Yes, I mean probably just to build on the points already made. Hopefully, we're not less inclined to want to support vulnerable people or people we see, it's just that our lives, family patterns, have changed and we have to change methods of support alongside it. So two things we're particularly interested in are one, basically carers who live a long way away from the people they care for, essentially using technology and there are all sorts of new technologies around that make it much easier if we can get it right for carers to have an appropriate level of say and kind of manage risks and all the rest of it for someone. And the second thing is, we're really looking hard at trying to rediscovering neighbourhood but particularly coming from London neighbourhood, we don't wander down the street and stop to chat to people. It's got to be much more virtual and there are some quite exciting new kind of platforms coming along which we believe would have a lot of potential to do that. So I just think we have... I don't believe fundamentally people are less caring, but all our lives are changing and we have to just make it possible for people.

Dr Roger Worthington:

Independent Researcher.

And my question probably is for you, Professor Knapp. What do you think will be the impact of Brexit? 80% of the carers who look after my mother are Romanian. What's going to happen to the sector in two or three years' time?

Professor Martin Knapp:

I can think of a facetious answer. I mean there are probably some very good carers who won't get into the States anymore so maybe we could have them here, that's the facetious answer. But I agree, I mean of course the day after the Brexit vote result, pound dropped dramatically and the send home money for many of those carers, many people work here to send money back to their families, the amount of money they were able to send back fell by what 20% overnight. So there's a big impact there so I'm sure there is... I mean even in those economic terms there's going to be an impact, so I agree it's a big challenge. And I'll say one quick thing about Telecare, because I just want to pick up on Simon's point. That just it's a new research finding we've got which actually I'm quite excited by. We did a study a few years ago on Telecare called the whole system demonstrator study. And it found that Telecare wasn't very effective or cost effective. A colleague of mine who's doing a PhD has re-analysed the results and found that actually Telecare works very well where you have a carer living with you. So where people live alone who might be seen as the best targets for Telecare, it doesn't work because the staff don't want to leave them on their own, that people don't want to resort to remote care. But for people who have a live-in carer it does work. So Telecare might also be a way of supporting the carers. Sorry, that was off the Brexit.

Baroness Finlay of Llandaff:

One more question here, thank you.

Gill Mobbs:

I'm Head of Integrated Community Services within Worcestershire Health and Care Trust.

So I manage integrated community services which includes older adult mental health and I was interested, thank you very much, for all your presentations, really interesting. And particularly with Martin and the challenges financially that we're facing. And I understand that you mentioned the contribution from the NHS is substantial but is it all appropriate. So just to say I've been tasked with...

Baroness Finlay of Llandaff:

I'm going to stop you there because we're into our next time. Can you just ask your question and then they can answer it.

Gill Mobbs:

Yes, I was just saying, I have to save a million pounds from our old age mental health services and so I just wondered any advice from the panel on where to start with that? Other than involving staff and patients, which we are doing, but it seems like a mammoth task. We are a high performing service and we want to stay that way. But how?

Baroness Finlay of Llandaff:

Who's going to take that one?

Professor Martin Knapp:

Very quick comment here, but my father was in hospital, he died recently, had dementia, he was there in hospital for six weeks. He didn't need to be there for all of that time, it wasn't possible to find a nursing home there. He died there. His care in hospital was

absolutely exemplary, it was very, very good indeed. I was very impressed with the staff. So I've no criticism of the care he was getting, he didn't need to be there for the level of skill that was being delivered, if you like.

Simon Williams:

Very quickly the only comment I would make is in community services probably the biggest opportunity is kind of more generic working that are one the big things that has driven cost in community services is the number of specialisms, the number of staff you have to deploy just to fix something, which is bewildering for the person and the family. So what I would strongly encourage anywhere, and it's not particular... I don't know who your Trust is, look for the opportunities to kind of make it simpler.

Hilda Hayo:

What I would say is that might be a false economy so you need to have a look at the cost effectiveness of the people that you've got in post and the services that you've got and then look at how much it's going to cost to actually replace those people. Because I've seen a lot of specialist posts across the board being cut and actually you end up paying even more money because the people who were receiving care don't receive it.

Baroness Finlay of Llandaff:

Thank you ...

Gill Mobbs:

And interestingly, sorry, but we have a very high performing in-reach to care home service and as far as senior managers and outward people looking in, they say well that's a small team, that's the first one to go. But actually ...

Baroness Finlay of Llandaff:

Okay.

Gill Mobbs:

...they're doing a really good job keeping people out.

Baroness Finlay of Llandaff:

Okay. We need to move on because we've got Alistair Burns...

Gill Mobbs:

Thank you.

Baroness Finlay of Llandaff:

...who's going to speak to us now, wherever he is. Thank you, he's right down the back that's why I couldn't see him. That's great. Can you join with me in thanking the panel very much.

And particularly with refreshingly honest answers from them all, that was great. Alistair Burns, fantastic that you are here today, Professor of Old Age Psychiatry from Manchester, over to you.

Next steps for dementia care and implementing the 2020 Challenge

Professor Alistair Burns, Professor of Old Age Psychiatry, University of Manchester and National Clinical Director for Dementia, NHS England

Text to be submitted by speaker

Next steps for dementia care and implementing the 2020 Challenge

Questions and comments from the floor

- Baroness Finlay of Llandaff: Thank you very much Alistair. And we do have time for a few questions to you. Eileen, thank you.
- Eileen Harrington: Thank you, just a quick one. I get asked a lot, I'm a volunteer but I work a lot with people with dementia. Why is the diagnosis rate so low, not so low necessarily, but why does it take so long. I get a lot of complaints, it took 3 years, it took such a long time, it was much longer, we all knew it but the doctor didn't diagnose. What is the problem?
- Professor Alistair Burns: Yes, it's a very interesting question. There's been a lot of debate and discussion about this and maybe colleagues and Hilda you might have a chance may be just to mention as well. There's a number of things. We know that dementia is the most feared illness for people over 50, we know that people still believe, a lot of professionals believe that it's part of normal ageing, and therefore people say you can't do anything about it, so it cuts off anything. That is changing and I would hope nowadays that people would not say it took 3 years to get a diagnosis. The only slight issue, just a couple of points. The diagnosis can be complex, particularly in younger people because a lot of younger people said, oh it took me 5 years to get a diagnosis. Well if someone of 50 comes complaining of, you know, depression and poor concentration, dementia is not the first thing you think of, it shouldn't be the first thing that you think of, and what tends to happen, when the diagnosis is made, people look back and say, oh that was 3 years ago and 2 years ago. So I have people at my clinic who I think have got mild cognitive impairment, I think they will develop dementia, and I know when I give them a diagnosis in a year or 18 months they'll say, oh he could have done that 3 years ago. So it's a complicated thing, it is changing. Another final thing, I will shut up in a minute, is the waiting lists at memory clinics which we are doing something about and we do have an aspiration of a 6 week waiting list from referral to a diagnosis. So it will change.
- Baroness Finlay of Llandaff: Hilda, did you want to add something to that, because you were given an opening there.
- Hilda Hayo: I will add to that. Certainly, when I did my doctorate I looked at the early recognition and diagnosis rates and very frequently it's the person that's living with the symptoms of dementia, particularly young onset dementia, that don't recognise that they have those symptoms and therefore will not seek an appointment with the GP, and when the family try to speak to the GP, basically the GP won't speak to them because of this cloak of confidentiality. So that has been a particular problem and I'm still getting calls on the helpline saying exactly that.
- Professor Alistair Burns: So when people say about the confidentiality aspect, I say well remember you can say things to your GP, you can't ask them. I phoned my GP recently about my dad and he was fine. So there are

ways of doing it, and as you know people are expert at coming up with excuses...

Hilda Hayo:

Exactly.

Professor Alistair Burns:

...not to do things they don't want to do.

Hilda Hayo:

I always advise people to write a little checklist for the GP and submit it beforehand, and it works.

Professor Alistair Burns:

That sounds like a bit of excuse, that's extremely good advice.

Baroness Finlay of Llandaff:

The lady here in the middle, thank you.

Caroline Price:

From Pulse magazine.

You mentioned the shift, perhaps to focus more on peri-diagnostic and post-diagnostic care and speaking to the GP expert who was on the panel earlier who mentioned that some of the progress that had been made had slipped back in terms of once people have been diagnosed actually getting the support they need and that they felt that GPs were ending up having to deal with that, but their view is that actually GPs should be part of the solution and caring for patients as they would care for other long-term conditions. Is that something that is a next step for NHS England to develop? Is that a plan for you to take on?

Professor Alistair Burns:

Great, well Caroline thank you for the question. As you know I'm a great fan of Pulse and Pulse and I have had lots of discussions over the years. I think the reality is, is that we are on quite a long journey of change. I use the example of diabetes. When I was a boy we used to admit people to hospital for 3 days to start them on insulin. Now much of diabetes is done in primary care.

I think the answer to your question is that I would like to work much more with colleagues in primary care. My own practice now is almost exclusively in primary care and that's supporting GPs when they feel they have the skills and they have the facilities to make a diagnosis and to manage people as part of the long-term condition, and I mentioned in the second slide, 80% of people with dementia have got another long-term condition, then that's quite appropriate. I think the issue of a specialist like myself, for example, is that we are there to be able to give rapid advice when there are particular challenges, and we would all know, we could describe very easily what those challenges would be, behavioural problems, complex care, whatever. So I think that is the secret. So it's not a sense in any way of dumping or putting something on primary care, it's working very closely with primary care, and I think that's what we're achieving.

Baroness Finlay of Llandaff:

Alistair thank you very much for a wonderfully lively presentation and for taking the questions as you did, that's great, and we will leave you to read both The Times and the Daily Mail and you can tell us afterwards which you prefer. So thank you.

Session Chair's closing remarks

Baroness Finlay of Llandaff, Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum

Well it's been very fast and very interesting, certainly the second half to the morning, and I just think, for the last couple of minutes, we should go back to the person themselves, the voice of the person who has got dementia, of some sort, whatever sort that is.

I correspond with someone who is an ex-colleague and he likes to email me; he has dementia and he sends me poems he writes and so on, and he has written a blog which is on the SCIE website of the National Mental Capacity Forum, under the name of Sydney, Sy, not Si, Sydney. It's really worth reading because he is talking about the joy and the quality that he gets out of every day, and it's easy for us to look at all the negative down side, the needing care, everything that's associated with dementia and to forget there is an intrinsic worth in everybody, and despite really severe progressive dementia, the sun can come up and you can have some wonderful meaningful days.

Just before Christmas he sent me a photograph of his pig which he had been rearing for the whole year and was taking to be slaughtered for their Christmas dinner, I have to say I felt quite sorry for the poor pig really, but he has actually taken to rearing pigs, amongst other things that he does.

But I think it is really important that we do remember that in the face of progression and what might seem to everybody else to be deterioration, people are transitioning, sometimes they are moving to be a different person to the one that they were before, but they can have quality of life and actually if we forget to value the person then we lower ourselves as well, because our role in society is interconnected and looking after other people.

After all, we're not robots, and I hope we're not all totally utilitarian. Lots of talk about money, but there's a whole lot of quality that you can't put a price on.

So thank you all for coming, I hope you enjoy Sydney's blog. Can you join me again in thanking all our speakers today.

Westminster Health Forum closing remarks

Sam Dolton, Producer

Many thanks Chair, I won't keep you all too long, just some final quick housekeeping points from me on behalf of the Forum.

Just to let you know the transcript from today's event will go out to you all in the next 10 working days. There are details in your delegate packs as to how you can have articles included in the transcript. If you would like to submit an article we just them to be no longer than 600 words long, and to be sent over in the next couple of days please.

The transcript will go to everyone here today as well as a wider range of policymakers, officials at the Department of Health and Parliamentarians with an interest in the subject matter.

If you could just drop off your badges and any completed feedback forms, either at the door or the front desk on your way out, that would be very kind.

I would like to thank our core sponsors, Boehringer Ingelheim and Optimity Advisors for their continuous support.

And finally, just to echo the words of our Chair, on behalf of all of us at the Westminster Health Forum, including my colleague, Steph, who helped produce today's seminar, I would like to thank all of our speakers and both Chairs involved in today's seminar. I hope you will join me in showing one last appreciation in the time honoured and traditional way.

Comments

Sara Livadeas
Strategy Director
The Orders of St John Care Trust

Mind the gap – the difference between rhetoric and reality in delivering dementia care.

The Westminster Health Forum 'Next steps for improving dementia care: funding, reducing the variations and implementing the 2020 challenge' was really uplifting. Knowledgeable speakers working at the cutting edge of dementia research and care talked about taking responsibility for your own health and wellbeing, least restrictive decision making, the value of dementia friends, the importance of recognising the needs of carers and the latest developments in care, cure and technology. However, I couldn't help coming away feeling uneasy and somewhat exasperated once again. The gap between the ambition for people living with dementia and what's happening on the ground is getting wider to the point where I fear it will become a chasm. And it's almost entirely down to workforce.

At the Orders of St John Care Trust (OSJCT) we support people to age well in 70 care homes and extra care housing services, providing a mixture of nursing and residential care to 3,800 people. Approximately 80% of residents have some form of cognitive impairment although only 50% have a formal diagnosis. We specialise in dementia, we deliver bespoke training, our homes are built to the Sterling Gold Dementia Standard and we deploy peripatetic Admiral Nurses. We know how to deliver dementia care in a person centred way. We pride ourselves on low use of anti-psychotic medication – less than 3%. We understand that families need on-going support at all stages of their caring journey, including at the point of diagnosis, when the individual is vulnerable to suicide, and long after the death of their loved one. Despite this, the major limiting factor stopping us from delivering more and better care is not money, it's not lack of expertise, it's workforce.

Nationally there is a shortage of nurses in health and social care. At OSJCT we increasingly struggle to recruit both nurses and carers. We currently have nearly a third of our nurse posts and around 10% of carer posts vacant. This is despite paying above the National Living Wage and enjoying a strong reputation for providing training. All our care workers complete the Care Certificate which is having a positive impact on retention. Our turnover has reduced to 23%, which is better than the sector average of 28% but some way off overall employee turnover of 13%. Behind these figures sit real workers who have decided to leave their job and real old people living with dementia who need familiarity and consistency in their care. Some of the employees we recruit discover they are not cut out for the job they thought they wanted. Not everyone can care for a person with dementia. Some people just want to come to work to do tasks and then go home. Deploying emotional intelligence, managing the power dynamic of care giving or working in a person centred way is simply beyond them. Whether it's just a job or a vocation we are expecting a lot from the lowest paid and often least valued members of our society – part time female carers.

I don't want to be defeatist. We are doing a lot to encourage people to work for us, recognising that we need to attract talent through a variety of channels including social media. We work hard to create a local presence in our communities. We participate in projects such as The Teaching Care Home initiative. We have sharpened up our recruitment process but unfortunately care providers are all fishing in the same pool, so trying to differentiate ourselves from other organisations will only help OSJCT. The health and care sector needs to collaborate and work with training providers and schools for example, so that 16 year olds can start thinking about working with people with dementia before they even chose their university degree. I really enjoyed the forum, but it's no good talking in concepts about independence, responsible risk taking and evidence best practice if we can't find enough good people with the right attitude to deliver the care that people with dementia need day to day (and night, and weekends, and holidays) in the places that they live. The workforce issue needs to be gripped and soon.

List of Delegates Registered for Seminar

| | | | |
|--------------------|--------------------|---|--|
| Rie | Adamson | Coach | Birch Tree Community |
| Angela | Baptiste | Volunteer | Phoenix |
| Lisa | Bayliss-Pratt | Director of Nursing | Health Education England |
| Priti | Biswas | Researcher | University of East Anglia |
| Angela | Bradford | Commissioning and Healthy Lifestyle Director | The ExtraCare Charitable Trust |
| Beth | Bradley | Statistician | DH |
| Professor Alistair | Burns | Professor of Old Age Psychiatry/National Clinical Director for Dementia | University of Manchester/NHS England |
| Allison | Butter | Quality Development Manager | Care UK |
| Jacqueline | Cannon | CEO | The Lewy Body Society |
| Julia | Chapman-Wright | Business Manager | Carebase |
| Michele | Clarke | Commissioning Manager | NHS Doncaster Clinical Commissioning Group |
| Janet | Collins | Home Manager | Carebase |
| Laura | Cook | Quality Improvement Lead Dementia Clinical Network, London Region | NHS England |
| Andrew | Cornwall | Carer and Research Network Volunteer | Alzheimer's Society |
| Rob | Craggy | Alzheimer's Disease Therapeutic Marketing | Eli Lilly and Company |
| Lesley | Cruickshank | Quality Innovation Manager | Essex County Council |
| Nicole | Darlington | Research Assistant | University of Hertfordshire |
| Gina | Dutton | Head of Association for Dementia Studies | University of Worcester |
| Sue | Eley | Development Manager | Shared Lives Plus |
| Tina | English | Director | Embracing Age |
| Claire | Ferris | Business Development Officer | Dementia UK |
| Baroness | Finlay of Llandaff | Chair of Trustees/Chair/National Council for Palliative Care/National Mental Capacity Forum | House of Lords |
| Colin | Freer | Medical Liaison | Eli Lilly and Company |
| Professor John | Gallacher | Professor of Cognitive Health/PI and Director | University of Oxford/MRC Dementias Platform UK |
| Joe | Gray | Web Editor | OmniaMed |
| Baroness | Greengross | Co-Chair, All-Party Parliamentary Group on Dementia | House of Lords |
| Eileen | Harrington | Founder | DonMentia Charity |

| | | | |
|------------------|--------------|--|---|
| Hilda | Hayo | Chief Executive and Chief Admiral Nurse | Dementia UK |
| Dr Diana | Hilliard | CEO | Argue To Think |
| U Hla | Htay | | |
| Maureen | Hume | Chair | Camberley Alzheimer Cafe |
| James | Humphreys | Policy & Communications Manager | MSD |
| Rachel | Hunter | Writer/Editor, Communications | Public Health England |
| Mark | Ivory | Editor | Journal of Dementia Care |
| Tracy | Jackson | Dementia Nurse Specialist | Heart of Kent Hospice |
| Rebecca | Jarvis | Programme Director, Dementia | Health Innovation Network |
| Pippa | Kelly | Writer | |
| Dr Juma | Khudonazarov | Health Advisor | HelpAge International |
| Dr Naoko | Kishita | Lecturer in Dementia and Complexity in Later Life | University of East Anglia |
| Professor Martin | Knapp | Professor of Social Policy and Director of the Personal Social Services Research Unit/Director | London School of Economics and Political Science/NIHR School for Social Care Research |
| Alan | Lenox-Smith | Senior Clinical Research Physician | Eli Lilly and Company |
| Dr Sabine | Lenton | Medical Assessor | MHRA |
| Sara | Livadeas | Strategy Director | The Orders of St John Care Trust |
| Chelliah | Lohendran | Vice Chair, Patient Engagement Group | NHS Merton Clinical Commissioning Group |
| Paul | Macken | Senior Area Manager | Sussex Healthcare |
| Jacque | Mallender | Partner | Optimity Advisors |
| Greg | Manuel | Account Manager | Incisive Health |
| George | McNamara | Head of Policy and Public Affairs | Alzheimer's Society |
| Gill | Mobbs | Head Of Integrated Community Services | Worcestershire Health & Care Trust |
| Dr Maria | Molinari | Medical Assessor | MHRA |
| Peter | Morton | Head of News | Public Health England |
| Alison | Murray | Head of Inspection for Adult Social Care | CQC |
| Anna | Myers | Senior Communications Officer | University of Oxford |
| Diane | Nicola | Deputy Chief Executive | Age UK Essex |
| David | Nuttall | Deputy Director, Dementia and Disabilities | DH |
| Gerry | O'Kello | Commissioner Social Care | London Borough of Newham |

| | | | |
|-------------------|--------------|--|--|
| Jonathan | Papworth | Director | Person Centred Software |
| Simon | Papworth | Director | Person Centred Software |
| Dr Simon | Parker | Healthcare Development Manager | Roche Diagnostics UK |
| Caroline | Price | Clinical Journalist | Pulse |
| Calin Adrian | Puia | | |
| Naseem | Ramjan | Audit Manager, Health Financial Audit | National Audit Office |
| Jacqueline | Rees Hordell | Assistant Director, Dementia Services | Birmingham Community Healthcare NHS Trust |
| Professor Louise | Robinson | Professor of Primary Care and Ageing | Newcastle University |
| Dr Deborah | Roebuck | Public Affairs and Patient Advocacy | Otsuka Pharmaceutical Europe |
| Councillor Sandra | Samuels | Cabinet Member for Adult Services | City of Wolverhampton Council |
| Duncan | Selbie | Chief Executive | Public Health England |
| Ian | Smith | Special Advisor | Four Seasons Health Care |
| Chris | Smyth | Health Editor | The Times |
| Ann | Sparks | Operations Manager | Age UK Essex |
| Professor Robert | Stewart | Professor of Psychiatric Epidemiology and Clinical Informatics | King's College London |
| Hal | Stockley | New Product Planning | MSD |
| Mary | Tagon | Dementia Lead | NHS Milton Keynes Clinical Commissioning Group |
| Ly | Tarday | Retired | |
| Agnes | Valdez | Registered Manager | Sussex Healthcare |
| Edward | Vidnes | Senior Associate | Royds Withy King |
| Sara | Wilcox | CEO | Pathways Through Dementia |
| Simon | Williams | Director of Community and Housing | Merton Council |
| Sandie | Woods | Senior Lecturer | London South Bank University |
| Dr Roger | Worthington | | |

Contributor Biographies

Lisa Bayliss-Pratt, Director of Nursing, Health Education England

Lisa was appointed as Director of Nursing at Health Education England (HEE) in 2012. In this role she has responsibility for leading national policy, workforce planning, and the commissioning of multi-professional education and training for the non-medical healthcare workforce. Her achievements include the establishment of the Shape of Caring Review, development and piloting of pre-degree care experience for aspirant nurses and leading the 'return to practice' initiative. Lisa's work also includes the creation of a three-tiered dementia education and training framework through which over 100,000 members of NHS personnel received dementia awareness training - achieving a key Government Mandate requirement. Lisa also led the development of the 'Fundamentals of Care' certificate for support/care workers across health and social care in England. Before joining HEE, Lisa led on strategic and operational work throughout a number of senior nursing roles at both regional and national levels. She led on preceptorship at the Department of Health and was Assistant Director of Nursing at Midlands and East Strategic Health Authority. Passionate about nurse improvement programmes, education and innovation and patient experience, Lisa was instrumental in the roll out of Flying Start, a national development programme for all newly qualified nurses, midwives and allied health professionals in England. Lisa also led on the creation of a Patient and Customer Revolution, which resulted in national implementation of the Friends and Family Test in all acute hospitals from January 2013.

Professor Alistair Burns, Professor of Old Age Psychiatry, University of Manchester and National Clinical Director for Dementia, NHS England

Professor Alistair Burns is Professor of Old Age Psychiatry at the University of Manchester. He is an Honorary Consultant Old Age Psychiatrist in the Manchester Mental Health and Social Care Trust (MMHSCT) and is the National Clinical Director for Dementia and National Clinical Director for Mental Health in Older People at NHS England. He graduated in medicine from Glasgow University in 1980 and trained in psychiatry at the Maudsley Hospital and Institute of Psychiatry in London. He became the Foundation Chair of Old Age Psychiatry in the University of Manchester in 1992, where he has been Head of the Division of Psychiatry and a Vice Dean in the Faculty of Medical and Human Sciences, with responsibility for liaison within the NHS. He set up the Memory Clinic in MMHSCT and helped establish the old age liaison psychiatry service in UHSMT. He is a Past President of the International Psychogeriatric Association. He is Editor of the International Journal of Geriatric Psychiatry and is on the Editorial Boards of the British Journal of Psychiatry and International Psychogeriatrics. His research and clinical interests are in mental health problems of older people, particularly dementia and Alzheimer's disease. He has published over 300 papers and 25 books.

Andrew Cornwall, Carer and Research Network Volunteer, Alzheimer's Society

Currently caring for a third family member with dementia and numerous co-morbidities. A wide range of dementias experienced, inc. Alzheimer's Disease, vascular dementia, fronto-temporal dementia, & Alcohol Related Dementia. Trained as a Historian & Environmental Archaeologist, currently working in science communication for several organisations, inc. the Natural History Museum, London. Member, Research Network, Alzheimer's Society (PPI scheme. Patient & Public Involvement). Lay committee member, Brains for Dementia Research. Alzheimer's Society & Alzheimer's Research UK joint funded brain banking project, supported by the Medical Research Council (MRC). Public Panel Member, Program Grants for Applied Research (PGfAR), National Institute of Health Research (NIHR). Lay Co-applicant of three on-going funded dementia research projects. Chairman, East Surrey Voluntary Fundraising Group, Alzheimer's Society & Registered Campaign Supporter, Alzheimer's Research UK. Member, of several ethics committees and service user advisory groups.

Baroness Finlay of Llandaff, Chair of Trustees, National Council for Palliative Care and Chair, National Mental Capacity Forum

Professor: Palliative Medicine, Cardiff University; Lead Palliative Care Clinician (Wales): established 7-day services with consultant advice 24/7, with patient/carer feedback & audit of end of life care. Chairs National Mental Capacity Forum for Ministry of Justice and Department of Health. Chairs National Council for Palliative Care. President Chartered Society for Physiotherapy. Co-Chair of Living & Dying Well. Past President British Medical Association; Royal Society of Medicine. Created Cardiff Diploma/MSc in Palliative Medicine. House of Lords: Crossbench Peer since 2001; member Assisted Dying for the Terminally Ill Committee. Currently: Access to Palliative Care Bill.

Professor John Gallacher, Professor of Cognitive Health, University of Oxford and PI and Director, MRC Dementias Platform UK

Professor John Gallacher is the PI and Director of the MRC funded Dementia Platform UK (DPUK), Professor of Cognitive Health at the University of Oxford and Honorary Professor at Cardiff University. Professor Gallacher is also PI for the Caerphilly Prospective Study and has developed the study's focus on ageing and dementia. As member of the UK Biobank Steering Group, he leads on cognitive and psychological assessment. He is a visiting Professor to Imperial College London and Honorary Professor at the University of Hong Kong. He is Chair of the Avon Longitudinal Study of Parents and Children (ALSPAC) Scientific Advisory Board.

Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia

Baroness Sally Greengross has been a crossbench (independent) member of the House of Lords since 2000 and co-chairs five All-Party Parliamentary Groups: Dementia, Corporate Social Responsibility, Intergenerational Futures, Continence Care and Ageing and Older People. She is the Vice Chair of the All-Party Parliamentary Group on Choice at the End of Life, and is Treasurer of the All-Party Parliamentary Group on Equalities. Sally is Chief Executive of the International Longevity Centre - UK; Co-President of the ILC Global Alliance; and was a Commissioner for the Equality and Human Rights Commission from 2006-12. Baroness Greengross was Director General of Age Concern England from 1987 until 2000. Until 2000, she was joint Chair of the Age Concern Institute of Gerontology at Kings College London, and Secretary General of Eurolink Age. She is an Ambassador for Alzheimer's Society, SilverLine and HelpAge International. Baroness Greengross is a Member of several advisory boards including Home Instead's Global Strategy Council; Fujitsu's Responsible Business Board; and BlackRock Retirement Institute's Advisory Council. She is President of the Pensions Policy Institute and the Association of Retirement Housing Managers; Honorary Vice President of the Royal Society for the Promotion of Health, a Vice President of the Local Government Association and Honorary Fellow of the Institute & Faculty of Actuaries. Sally is patron of several organisations including the National Association of Care Caterers; Care & Repair England; the Association of Retirement Community Operators; the National Network of Clinical Ethics Committees; Ransackers Association, the Association for Ageing & Education; and Age UK Westminster. Sally holds honorary doctorates from eight UK universities. Her work on ageing has been recognised by the UN Committee on Ageing and she received an outstanding achievement award from the British Society of Gerontology as well a British Geriatric Society Medal. Sally was UK Woman of Europe in 1990 and has been an Ambassador for the Prince of Wales supporting responsible business practice.

Hilda Hayo, Chief Executive and Chief Admiral Nurse, Dementia UK

Hilda Hayo has been the Chief Admiral Nurse/Chief Executive for Dementia UK since 2013, the charity who specialises in the provision and development of Admiral Nurses (specialist dementia nurses). A dual registered nurse, she has over 36 years' experience developing and leading dementia specialist teams. During this time, she has held senior positions in clinical services, hospital management and higher education. Hilda is particularly proud of setting up and leading a nurse led Younger People with Dementia service in Northamptonshire and still retains a small clinical caseload. She completed her doctorate in 2016 into How and why does social connectedness change in families living with the effects of behavioural variant frontotemporal dementia?

Professor Martin Knapp, Professor of Social Policy and Director of the Personal Social Services Research Unit, London School of Economics and Political Science and Director, NIHR School for Social Care Research

Martin Knapp is Professor of Social Policy and Director of the Personal Social Services Research Unit at the London School of Economics and Political Science (LSE). He is also Director of the School for Social Care Research, a position held since the School was established by the National Institute for Health Research in 2008. His research primarily focuses on dementia, social care, child and adult mental health, and autism. Much of his work has an economic focus. Many of his research findings have informed policy discussion and practice development in England and elsewhere.

George McNamara, Head of Policy and Public Affairs, Alzheimer's Society

George leads the policy development, government relations, campaigns and wider external engagement at the Society. George regularly comments on health and social care policy and sits on a number of government and sector wide health and social care advisory groups. Working with NHSE, he is leading new ways of delivering dementia care and support, particularly around diagnosis and post-diagnosis support. George played a leading role in the delivery of the Prime Minister's Challenge on dementia. He has been instrumental in the creation of

the Dementia Friends programme and dementia friendly communities, which is now the fastest growing social movement in England. Prior to joining Alzheimer's Society, George held senior positions at the British Red Cross and Action for Children. He specialises in organisational and cultural change and has written extensively on a variety of social policy issues, as well as leading a number of successful influencing campaigns. He spearheaded the development of family intervention projects across England and expansion of home from hospital services for the elderly. He has also worked in Parliament and Whitehall as a civil servant.

Alison Murray, Head of Inspection for Adult Social Care, CQC

Alison is a registered nurse, with many years' experience in both the NHS and private sector. She has specialist qualifications in the care of older people, and spent a number of years managing large nursing homes for a corporate provider organisation. Alison has worked in regulation since 2002. She was a member of the project team which worked with Bradford Dementia Group to devise the Short Observational Framework for Inspection (SOFI), and led its implementation within CSCI/CQC. Alison then moved to work with the CQC Provider Relationship team, before returning to frontline operations. Alison is currently Head of Inspection and takes the lead for dementia care within the CQC Adult Social Care Directorate.

Professor Louise Robinson, Professor of Primary Care and Ageing, Newcastle University

Louise Robinson is a GP and Professor of Primary Care and Ageing at the Institute for Ageing / Institute of Health and Society, Newcastle University. She is also the Royal College of General Practitioners National Clinical Champion for Dementia. She leads the Primary Care Clinical Studies Group for the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) and is part of the Ministerial Dementia Research Group. Her research programme is centred on Primary Care and Ageing, with a special interest in the care of people with dementia in primary care from diagnosis through to death. She is also primary care lead in several national cohort studies such as Newcastle 85+ study and MRC Cognitive Function and Ageing Study. In addition she was part of the expert multi-disciplinary team who worked with Department of Health to develop GP Commissioning Toolkits for dementia care.

Duncan Selbie, Chief Executive, Public Health England

Duncan Selbie took up post as Chief Executive Designate of Public Health England in July 2012 and as permanent Chief Executive on 1 April 2013. From 2007 to 2012 he was Chief Executive of Brighton and Sussex University Hospitals, the regional teaching hospital for the south east of England. From 2003 to 2007 he was the Director General of Programmes and Performance for the NHS and subsequently the first Director General of Commissioning. Prior to this he was Chief Executive of South East London Strategic Health Authority and before that South West London and St George's Mental Health NHS Trust. He joined the NHS on 1 January 1980.

Simon Williams, Director of Community and Housing, Merton Council

Simon did a first degree at Cambridge University in classics before training as a social worker. He then worked for 9 years in child care, before taking on more general social services senior management tasks in Berkshire and Hampshire. He then worked as a commissioning director for a health authority in the mid to late 1990s. He moved to the London Borough of Merton as head of community care 2000-2004. He then spent a further 2 years in the NHS as director of policy for a strategic health authority. From 2006 he has been back with Merton as Director of Community and Housing, a brief which includes adult social care, public health, housing, libraries and adult education. Simon has kept an interest in a non- executive role, including being a school governor and trustee for a national charity for people with sight impairment. He has held lead roles for the Association of Directors of Adult Services (ADASS) for dementia, and civil contingencies. He currently co-chairs the ADASS Resources network.

All biographies provided by speakers

About the Core Sponsors of the Westminster Health Forum

Boehringer Ingelheim



The Boehringer Ingelheim group is one of the world's 20 leading pharmaceutical companies. Headquartered in Ingelheim, Germany, Boehringer Ingelheim operates globally with 142 affiliates and a total of more than 47,400 employees. The focus of the family-owned company, founded in 1885, is researching, developing, manufacturing and marketing new medications of high therapeutic value for human and veterinary medicine.

Taking social responsibility is an important element of the corporate culture at Boehringer Ingelheim. This includes worldwide involvement in social projects, such as the initiative "Making more Health" and caring for the employees. Respect, equal opportunities and reconciling career and family form the foundation of the mutual cooperation. In everything it does, the company focuses on environmental protection and sustainability.

In 2013, Boehringer Ingelheim achieved net sales of about 14.1 billion euros. R&D expenditure corresponds to 19.5% of its net sales.

For more information please visit www.boehringer-ingelheim.com

Optimity Advisors



Optimity Advisors is an international consultancy based in Europeⁱ and the USA, providing policy advisory and strategy, service and technical transformation. For over 25 years, our health policy practice has carried out numerous evaluations and impact assessments, as well as economic analysis, data analytics and data visualisation assignments. We focus on engaging collaboratively with organisations to enable them to navigate change, mitigate risk and succeed in an industry that is re-inventing itself at its very core.

Our experienced healthcare team has a range of academic and professional backgrounds, combining international, national and local industry experience with postgraduate qualifications in fields including politics and social sciences, economics, law, health and public policy. Our professional experience results from working across all aspects of the NHS including policy, regulation, research knowledge, innovation, commissioning and providing.

We focus on the following healthcare areas:

- Influencing and translating policy into implementable, innovative service transformation and technology opportunities
- Realising the service quality and economic benefits of population-based health risk management
- Assessing the benefits and value of connected care, integrated care, new models of care, self-care and health systems reform
- Identifying and evaluating pricing and reimbursement systems for public services including outcomes-based contracting, social impact bonds and social investment

ⁱ Previously known as Matrix Knowledge

- Designing distributed data networks and connectivity across a range of health organisations
- Innovating and operationalising new health pathways

Our international portfolio includes working with clients such as Blue Cross Blue Shield Association and health plans, Medicaid and Medicare regional health programmes, and integrated mental health providers. In addition, we have worked with numerous European agencies such as DG Sante (formerly Sanco) and CHAFEA.

Our national portfolio includes, support for NHS England, Department of Health, Public Health England and NICE. Our local and regional portfolio includes support for NHS Clinical Commissioning Groups (CCGs), health and social care providers and local and regional authorities.

To find out more about us and the work we do please visit www.optimityadvisors.com