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HEALTH ECONOMICS
ALBERTA CANADA

MEETING THE CHALLENGE: DEMETIA AND CONTINUING CARE

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Event Proceedings

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Forum XI**

About the IHE

The Institute of Health Economics (IHE) is a not-for-profit organization committed to producing, gathering, and disseminating health research findings relating to health economics, health policy, health technology assessment, and comparative effectiveness. This work supports and informs efforts to improve public health and develop sustainable health systems. Founded in 1995, the IHE provides services for a range of health-sector stakeholders, and is governed by a Board that includes representatives from government, academia, health-service delivery organizations, and industry:

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Preface

In December 2008, the Institute of Health Economics launched a series of semi-annual Innovation Forums whose goal is to bring together senior public and private sector decision-makers to address policy issues of importance in the health care system, not just in Alberta, but to all of Canada and the international community, as well.

Meeting the Challenge: Dementia and Continuing Care was the eleventh in the series of Innovation Forums. The keynote speakers, Dr. Sube Banerjee, Professor and Associate Dean for Strategy at Brighton and Sussex Medical School, and Dr. David C. Grabowski, Professor of Health Care Policy at Harvard Medical School, presented on *Quality of Life and Quality of Care in Dementia* and *Coordinating Care for Vulnerable Elders*, respectively.

Dr. Sube Banerjee's and Dr. David C. Grabowski's presentations, as well as the panel discussion on Alberta's Seniors' Health Strategic Clinical Network, can be found on the IHE website at <http://www.ihe.ca/research-programs/knowledge-transfer-dissemination/innovation-forum/if-xi/if-xi-pres>.

IHE Innovation Forums

Forum I: Paying for What Works. Comparative Effectiveness of Health Technologies and Programs
- December 2, 2008

Forum II: Making Difficult Decisions - May 25, 2009

Forum III: Maximizing Health System Performance. Cost Containment and Improved Efficiency -
December 1, 2009

Forum IV: Innovation and Economics. Investing in the Future Health System - April 22, 2010

Forum V: Innovation and Sustainability in Health Systems - October 14, 2010

Forum VI: Maximizing Health System Performance - Assisted by Evidence, Science, and Information
Systems - November 29, 2012

Forum VII: Social Determinants of Health - May 31, 2012

Forum VIII: Value for Money in the Health System - December 6, 2012

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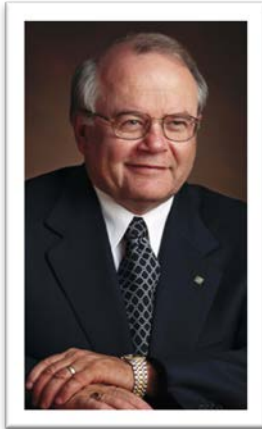
Forum X: Choosing Wisely® in Health Care: A Canadian Perspective - November 28, 2013

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MEETING THE CHALLENGE: DEMETIA AND CONTINUING CARE

Welcome and Opening Remarks



Master of Ceremonies: Dr. Lorne Tyrrell, Chair, Institute of Health Economics

Welcome, everyone, here today. My name is Lorne Tyrrell, and I have the honour of serving as the Chair of the Institute of Health Economics. On behalf of the Board, our CEO, Egon Jonsson, and the whole IHE team, it gives me great pleasure to welcome you here to the eleventh Innovation Forum. You'll see the titles on your program of the previous 10 forums, and as you go through that list you'll see that a number of the key issues of health care have been addressed, and continue to be addressed, by the Forum.

Since December of 2008, we've had these Forums in conjunction with our semi-annual board meetings. I'm very pleased that we've been able to do so

successfully, and I think they became a very important fixture for our board meetings. I attend a lot of board meetings, and I think this is the only one that really puts a forum with the meeting, gives a lot of meat, and it gives a lot for the board members to come and attend.

The Forums are an opportunity for Alberta Health system leaders to learn about international thought leaders and experts and key issues in health. They also provide us a chance for all of us in Alberta Health systems to talk informally about those lessons that might apply here. "Good things happen when people get together." It's a tagline that we use for all of these Innovation Forums. We need more opportunities to get together and to talk, and we at IHE are very pleased to provide one of these opportunities.

Before moving to the program, I wanted to say a few thanks to a number of people and introduce some of our board members. First, our Board. The IHE Board is a unique partnership, because it includes academia, government, and industry. A group like this is a critical asset, because the problems we face in improving the health care of Albertans are so challenging and complex, they'll be solved only through partnerships.

The Board members may stand as I call their names, but we are expecting: Doug Gilpin, from our chair of our Audit Committee; Keith Gilchrist, from GlaxoSmithKlein; Ghislain Boudreau from Pfizer; Jennifer Chan from Merck; Lauren Fischer from Eli Lilly; Doug West, James Kehrer, and Walter Dixon from the University of Alberta; Braden Manns from the University of Calgary; Cy Frank from the Alberta Innovates - Health Solutions; Egon Jonsson, our CEO, and Allison Hagen are here as well. And I believe Steve MacDonald, our Deputy Minister of Alberta Innovation and Advanced Education is here as well. And Jon Meddings from the University of Calgary, I think, will be joining us later.

And last but certainly not least, Janet Davidson, our Deputy Minister of Health. And I left Janet at the end, because I want to mention that she will be hosting the second half of our program today and moderating the panel discussion.

I also want to acknowledge the board and management team at Alberta Health Services, who have been such great partners over the years in these forums. Thanks to Rick Trimp who has represented Alberta Health Services board as an interim CEO, and Kathryn Todd, VP Research, I believe, is here as well. I'm delighted to welcome Vickie Kaminski, our new CEO who will be joining the IHE board on June the 1st. Welcome, and all of us in this room are looking forward to working with you, Vicky.

Finally, the government of Alberta: we'll be joined today by the Honourable Fred Horne, Minister of Health, who, I think, has been at at least half of these Forums, haven't you, Fred? Or almost all of them? Fred has been a friend and a colleague of the Institute for many years. He's been a leader in health care, long before he became a minister, and before he was an MLA. And he continues to serve the system with great distinction. Other key government partners are Alberta Enterprise and Advanced Education, and I mentioned we are pleased to have the Deputy Minister, Steve MacDonald, here with us today as well.

The theme today is: *Meeting the Challenge - Dementia and Continuing Care*. The challenge of dementia is not new, but it is of particular interest right now to the Minister and to his department, and to AHS. So I'm very pleased to be able to continue this discussion today.

Today's *Edmonton Journal*, and I see many people are referring to it, had on the front page an article entitled "Doctors sound alarm over dementia." We asked them to specifically do this to bring publicity to this meeting today. [audience laughter] Dementia, as it points out in this article, is the commonest cause of surgery delays and probably emergency room back-ups. Seventy percent of the patients with Alzheimer's are women. Canada currently has 700,000 people with dementia, and that'll double to 1.4 million in 20 years.

This raises a number of questions. But I would point out that we have about 100,000 acute care beds in the country, and we have 700,000 patients with dementia. It may not be surprising that some of those patients are in acute care beds, and this is an issue that needs to be addressed.

So, how do we care for patients with dementia? What is the effect on the health care delivery system and the cost? However, I really believe through basic research in neurosciences, we will change the rate of the development of dementia, and even the outcomes of dementia, maybe completely preventing it. Maybe we won't see the 1.4 million, if we can get key discoveries in basic research lead to events that transform our health care system.

As I mentioned before, the classic examples of doing 1% of the ulcer surgery today that we did in 1975 because of the discovery of the bacteria that causes ulcers. Or the treatment of AIDS: in 1995, 1996, I worked in a hospital, in a ward that was full of AIDS patients; today, there is none in hospital. And that is attributed to discoveries of basic science: the structures of the enzymes that replicate the virus, and development of drugs to inhibit it. And I want to bring a very relevant example that is just happening as we sit here today: that's hepatitis C, discovered in 1989, but today we're at the point of curing hepatitis C, and it can be eliminated in a province like this.

So I hope that discovery will prevent or treat dementia, and I believe that the health care system should do everything possible to ensure people live their lives to the fullest, until their biological clock runs out. And we have to deal one day with end of life issues around the time that our biological clocks run out.

We have five expert speakers here today, and I want to thank all of them, especially, of course, our keynote speakers, who have travelled from England and attempted to travel from the US. I will point out that one of our speakers was bumped from the plane in Chicago last night, and got put onto a plane that would arrive here shortly after this meeting was over. So he will be, I think, hooking up with us by teleconference, and his slides are here.

These experts are from countries that have developed dementia strategies on a national level: the US, the UK. Other countries have done so, in Norway, France, Netherlands, and Australia. I believe we need such a strategy in Canada. Sometimes it is more difficult to develop these strategies in health care in Canada, because we do have two jurisdictions, both federal and provincial. And possibly the Honourable Minister Fred Horne can address how that health care delivery, by provincial and the national policy, how we can develop national policies in this setting.

I want to get right to it, and I just want to point out that your program has a quick bio on each of the speakers. So we won't spend a lot of time through the introductions, and we'll wrap up around 5:50. But please remember, you're welcome to stay for the reception that follows the program. So if there's a topic that we don't cover in the program, you'll have an opportunity for discussion, or in the question period.

Now, I'm going to introduce the Honourable Fred Horne. It's my pleasure to introduce Fred Horne, the Minister of Health. I mentioned earlier that Fred is a long-time friend and colleague of the Institute. And I think he uttered that he's been to all of our Innovation Forums, and I'm sure that's probably true. We've been fortunate over the years to have him participate in many of our events, and all of us in health care systems are fortunate to have him representing us at the Cabinet table. We all know Fred, so I won't delay except to say, thank you, Minister, for joining us again, at this Innovation Forum, number eleven. Please join me in welcoming Fred Horne.

Honourable Fred Horne, Minister of Health, Government of Alberta

Thank you very much, Lorne. And good afternoon, everyone, and, in particular, good afternoon to those of you who are coming to us from other places in Canada, or from beyond. It's a great pleasure to have you here and again to participate in an IHE Innovation Forum. As Lorne said, these events have long been highly valued learning opportunities for those of us that have the privilege of working in the health care system in Alberta; increasingly, as well, for people from outside our borders.



They provide us with an opportunity to hear from leading thinkers on key issues, such as the one we're going to hear about today. But more importantly, they're designed in such a way that there's an opportunity for dialogue and discussion and exchange of ideas. That, in my experience, at least since I came to Alberta, is really unparalleled anywhere else in Canada.

So, Lorne, I want to thank you for not only inviting me, but I'd like to thank you for the opportunity that you and the Institute consistently give all of us: to really take an in-depth look at issues; to think about not

only the subject matter at hand, but to reflect on our own roles, whether we're providers of care, whether we are involved in running the health care system at an administrative level, whether we're a regulator, or a researcher, whether we're a partner in industry, or any other one of those roles.

These Forums do give us an opportunity, I think, to think and to talk about what we can do and what we need to do, to address the needs of Albertans. So it's with that in mind I'll make a few opening remarks. And I know we're running just a bit behind time, so I won't take a lot of the program. But I believe we've rearranged things so that I can keep my record up and stay for most of the program this afternoon, and be here for the panel at the end.

But I do want to reflect on a couple of things. And this is from my perspective as the Health Minister, but it's also from the perspective of someone who started his career as a health planner well over 30 years ago, a community health planner in Ontario. And looking at, reflecting a bit on how things have changed in the last 30 years.

I'll start with the near present. I had the opportunity at the end of last year to attend the G8 Health Summit – now the G7, of course, but the G8 Health Summit at the time – which was focused on dementia, was held in London. And for those of you that were there or followed the proceedings, you'll know it was important for a number of reasons. First of all, the fact that we had a, I think for only the second time in the history of the G8, we actually had a health event, which all the Ministers attended. Because of the nature of our system in Canada, I was invited to attend as well. So I was the ninth Minister at the G8, and had an opportunity really to talk to Ministers from a number of countries about how they're tackling this issue.

And I can tell you what I heard really at the outset of the conference began to change the way I've been thinking about this in recent years. The opening speaker, who was the Minister of Health in the UK, Jeremy Hunt, who you should know, the Secretary of State for Health, began by telling the audience that we need to think about dementia as the new cancer. And by that, he meant that we needed to recognize the fact that we're dealing with a health issue on a scale that we would have experienced cancer 25 or 30 years ago in most of the countries that make up the G8.

And you heard Lorne talk about some of the statistics, the numbers of people involved, the rate of growth at which dementia is increasing. But it also got me thinking a lot about some of my early years as a health planner, when I used to go to conferences that would debate what caused dementia or Alzheimer's disease. So, you know, spend two hours in the afternoon 30 years ago talking about aluminum and the theory around aluminum at the time, and you don't really walk away with a sense of the true nature of this issue, which I think we need to increasingly regard as a public health issue, as opposed to a health care problem that we need to solve.

The UK has taken a very interesting stance, and Lorne talked about the need for a national or a pan-Canadian dementia strategy, which I tend to agree with. The practicality of that I'll maybe get to later, or we can talk about during the panel. But I think, increasingly, all the countries that are involved recognize that the prime directive, so to speak, in addressing this problem is to find a way to, first of all, delay the onset of the disease, and then, for people that actually develop the disease, to find ways – strategic ways – of delaying the need for institutional care for these patients for as long as possible.

Now, there are many economic reasons for making a statement like that, when you look about, when you look at other demands that we have in the system that we have to be able to continue to meet. But the argument also makes a lot of sense when you start to think as a family member, as I am, of someone who is

living with Alzheimer's Disease, when you start to think about the quality of life that we would hope to achieve for our fellow citizens that are living with Alzheimer's and dementia.

So my point is: I think our approach to this needs to be guided, first of all, in our values with respect to the people and the families that are involved. And secondly, I think we need to make a conscious choice with respect to as how we want to frame this problem. In my view, if we only look at the issue from the point of view of how we're going to manage increasing numbers of alternate level of care patients and hospitals, or how we're going to segment or parcel out care in the traditional acute care focus that we still tend to have in our system, we're not going to successfully deal with the issue. We're not going to manage the patient load, and we're not going to achieve the quality of life that people want.

And so I would submit to you that we need to begin to look at this problem as a public health issue. We need to look at it as something that has a very strong social or cultural dimension to it. For those of you that are, again, to use the UK as just one example, if you're familiar with the UK, they have stopped distinguishing between Alzheimer's disease and dementia – they call it “Aldementia” now. And they've begun a very aggressive social movement in the country called Dementia Friends, which aims to train, I believe, 1 million people over a three-year period in how to do the kind of things that we talked about in Alberta when we developed mental health first aid: how to recognize an individual who may be showing signs of dementia; how to approach that person and their family; how to approach the spouse or a family member of someone who is living with dementia and to offer them appropriate support; how to manage or navigate the health care system when you need clinical help, or when you need other supports.

All of these are, increasingly, at least from the presentation at the conference, these are aspects of a social movement that I think we really need to wake up to globally. And so I submit that to you as an opening thought. I know we're going to hear from much wiser minds than mine this afternoon. But to simply segment this problem out as another disease that must be managed in terms of the traditional disease management model, I think it's going to be ineffective.

The final point I'll make, and perhaps some of the speakers will raise this, is just to try to connect this problem with a broader concept of health care sustainability, or system sustainability, which I think was the subject of the last Forum, if I remember right. And so we spent a lot of time at the last Forum, or I did anyway, talking about the role of evidence in decision-making, and the need for us to make a clear commitment as a health care system, not just in Alberta but in Canada, to being guided by the evidence.

And we talked about things like decisions regarding drugs to vices, procedures, clinical protocols – a lot of the problems that our strategic clinical networks are working on today. So I'd suggest to you that the same needs to be true in this discussion about dementia and continuing care today. We do need to be guided by evidence. We do need to have better access to data; we need to share that data. And we need to think about strategies that are focused on home and community that will, as I said, try to offer the quality of life that we all of us would expect for our father or mother or another loved one.

So I hope that lends perhaps some perspective from me as Minister to how we're looking at this problem in Alberta. I'm very pleased to be here with our Deputy Minister Janet Davidson today. Really really look forward to the discussion, and thank you again for the kind invitation and for having us here today. Thank you.

Dr. Tyrrell: Thank you very much, Fred. We'll move onto our first invited speaker.

Keynote Presentation #1

Quality of Life and Quality of Care in Dementia

Introduction: Dr. Lorne Tyrrell

Dr. Sube Banerjee is from University of Brighton and Sussex Medical School. He's an Associate Dean for the strategy and direction of the Centre for Dementia Studies. And he was in the Department of Health for England's senior professional advisor on dementia that led to the development of the National Dementia Strategy. Without further ado, I'll welcome Dr. Banerjee.

Keynote Speaker: Dr. Sube Banerjee, Professor & Associate Dean, Brighton and Sussex Medical School

Thank you very much. It's a great pleasure to be here. What I'd like to do in the next three quarters of an hour is to give some idea about why the next 10 years are the most important 10 years for dementia ever. They will be the most important 10 years. What we do and what we don't do in the next 10 years will make a gigantic difference to the quality of life of people with dementia.



But I'm going to try and make a case here that it's not just people with dementia and their families that are affected by dementia. It is society as a whole. It is health systems as a whole. It is the whole of our social care system. Dementia is one of the major unmet challenges that we have. It's the thing that we haven't done yet that is causing immense difficulties and problems throughout our system. And that's a fantastic opportunity, because this is something that we haven't dealt with, but, if we do deal with it, and the reason why this slide says that there are "reasons to be cheerful," is that there are already things that we can do that can enable people to live well with dementia, that can enable families to care well with dementia, and that can enable health systems to function more efficiently and effectively by managing dementia well.

There's a win win win here. Doing it better costs less than doing it badly, and we're doing it badly at the moment, almost no matter where you go in the world. But there are glimmers. There are exciting examples all over the place of how to do various bits of it well. So, for me, there's a message of hope and of opportunity here.

So I thought I'd start with some weather because I think you have weather here in Alberta, don't you? We have weather in England as well. [audience laughter] So the question is: if you look at those clouds there, is there better weather coming or is there worse weather coming? And the great thing is that we can make the weather here, no matter what we're working in with dementia, because it affects so many different areas, whether we're working in a health system, in a general hospital, or in a community service, in primary care, or in mental health; whether we're working in a drug company, or in the Alzheimer Society; or whether we're working with members of our families that will be affected. There are things that we can do that can make the difference. We can make the weather; we can make the weather better for dementia.

So, I suppose, I'm going to take as my theme, as the text for my talk today, the remarkably brilliant song written by Ian Dury and published and released in 1979, 30 years ago, "Reasons to Be Cheerful," and there are three reasons to be cheerful within that.

So our first reason to be cheerful, our first reason why we can do things about dementia, is we *do* know much more about dementia than we used to know. We're building on foundations that have been being built over the last 10, 20 years, and that means there's a solid foundation of knowledge that we have. We know much more about dementia, and what we know is much more likely to be true. So these are the numbers of papers on Alzheimer's disease by decade.

If you go back to the 1960s, there were less than 100 papers published on dementia. In the 1970s, it was only 290 papers. It's remarkable how small the evidence base has been, and it's also remarkable how quickly that evidence base is growing. We are starting from a low base in the 60s and the 70s, but there's a gigantic amount of activity now. In the 2000s, there was something like 40,000 papers on dementia, and there'll be at least double that in this decade.

So we know a lot more about dementia. We know a lot more about dementia right through from causes, from basic biology, right through to treatments for dementia. And while we don't have the magic bullet that makes it go away – and we would like to have the magic bullet that makes it go away – we're a lot closer to approaches that will slow or stop the process of the disease than we were before. But not only are we interested in that cure element of it, we're interested in the evidence base for care, for good quality care.

So what are some of the things that we know about dementia? Well, we know that the numbers are big. Those have already been mentioned. If we look worldwide, there are 36 million people with dementia, and that, in technical terms, is a lot. Yes? So there we are; it's the first fact that you have here. There are a lot of people with dementia, and it's not just an issue for the developed world, it's an issue for the developing world as well.

These are data from Alzheimer's Disease International, and what they show is, by 2050, we will have over a 150 million people with dementia. And those people will develop that dementia because those people who will develop dementia in the next 20 or 30 years already have the dementia pathology in their brains, and we can predict how many people there will be in the world. So this is a predictable challenge for the world, which is why I think it is so important that the G8, now G7, identified this as a strategic challenge for the world as a whole. And the nature of the problem means that it is the world as a whole that needs to be able to deal with this. We need to approach it at an international as well as a national, a regional, and a local, and an individual level.

So, a gigantic increase in numbers – a predictable challenge. And the thing about big numbers is that it's difficult to visualize them, and there are already as many people in the world with dementia as have HIV/AIDS. And you have to ask whether the policy priority is the same as that?

This slide from the UK Alzheimer's Society I think is very helpful, because it shows the 800,000 people that we have in the UK at the moment and how that will grow to 1.7 million people by 2051, which is, I think, a very similar sort of figure that you have for Canada also. But what I like about this is it reminds you that those numbers are made up of individuals, of people with dementia, of men and women with dementia, and of families, each of which everyday performs countless kind of everyday miracles in terms of dealing with what is an appalling and an devastating illness.

I've said there are reasons to be cheerful, but having dementia is a bad thing. It's a bad illness. It causes inevitable decline of your ability to think, to speak, to plan, to do the things that we do. It's the single illness that is most feared by people over the age of 65. Dementia is the new cancer in many ways. One way is

because it is now feared more than cancer. We can do a gigantic amount of things for many people with cancer, whereas dementia, people fear tremendously.

So, every day, families are dealing with this complicated and difficult disorder, and every day people are coming up with solutions, solutions that are as simple as focusing on what people can do rather than what people can't do. Our health services do remarkable things to help people with dementia, but sometimes do things that harm people with dementia without meaning to. Our systems are not set up to work for people with dementia and so, however well-meaning they may be, what works for people without dementia may not work for people with dementia. But we can turn that around.

So, if we create systems that work for people with dementia, they will also work for the vast numbers of old people with complex problems with more than one thing going on. If it works for people with dementia, it will work for all older people, all people who need health services. And this slide reminds me of the individuals who are involved in that.

The other thing that we know is dementia is tremendously costly. Dementia costs the world \$600 billion per year. And that, in technical terms again, is a very great deal in deed. Dementia is a very expensive illness already. Now, half of that money is the cost of family care, as costed at the minimum wage in whichever country we're looking at there. But half of it is real money spent on health services, but increasingly on long-term care. We spend a lot of money on a lot of facilities, some of which are not a very good quality, late in the illness. And there has to be questions about whether the \$300 billion that is spent – most of it in the developed world, most of which is on long-term care – whether we're spending that well.

And the \$300 billion is an immense opportunity that we have, because we've got to be able to re-engineer that in order to be able to make it work better. As an illness, dementia is different from heart disease and cancer and stroke, in that it is bigger than heart disease and stroke and cancer put together, in terms of its impact. What is remarkable is that we haven't noticed that spend because it's distributed.

Dementia is an incredibly disrespectful illness. It doesn't respect the kind of boundaries that we've set up between health services and social services, between what families do and what the voluntary sector does, between what the care home sector does and what happens in people's own homes. And so, the cost of dementia is distributed in a way that we cannot identify readily, but the minute we start to look for it, we start to find it.

Dementia, if it were a company, would be the largest company by turnover in the world – bigger than Wal-Mart and bigger than ExxonMobil. If it were a country, it would be the world's eighteenth largest economy – not as big as Canada, but almost. And that's remarkable if you think about that. If dementia were a country, it would be part of the G20, wouldn't it? Deciding on world events and how we should respond, and probably making more sense than some countries. Not Canada, obviously [laughter from the audience], and certainly not Alberta, but making more sense.

So we have a challenge that is of a different magnitude than the challenges we've dealt with before. And here we have data from the UK looking at the cost of illness. Just showing, what I said before, that dementia costs more than cancer and heart disease and stroke put together. And we have to ask ourselves: are we paying dementia as much attention as we pay in policy terms and service terms as we do to cancer and heart disease and stroke put together? And the answer in UK is certainly 'no', and I imagine the answer in Canada is also 'no'.

And noticing these things has led to the development of national dementia strategies. I was involved in the development at the strategy in the United Kingdom. But all over the world, people are waking up to the fact that actually this is an issue, for almost all families are affected by dementia. So in France, Nicholas Sarkozy, when he was running for the Élysée Palace the first time around the presidency, he made creating a *plan Alzheimer* one of the tenets, one of the pillars of his manifesto, and he ran on that ticket and he won, on that occasion.

Actually the second time around, he didn't put dementia in there, and he lost. So maybe there's something in there for the politicians in the audience: there's votes in dementia, and all over the world. Australia, I think, is a very good example; it's a relatively young country. I was working with the Australian government some time ago, and you kind of knew they got it when you walked through the doors of the big office in Canberra: there's a great big sort of a coat of arms with an emu and a kangaroo and stuff, and it's the 'Department of Health *and* Aging', because that's who's ill now.

We have all sorts of systems that we've set up that are brilliant at dealing with people in their 50s with single illnesses. But they're not the people who really need more, because we can do that, and we do that well. And it's brilliant that we're able to deal very well with people in middle age with single illnesses. But it's older people with complex problems that actually are the people who are in the acute hospital beds, and are the people who stay in those hospital beds longer, use more resources. They are the people who are in care homes using long-term care. So that is the population of people that we need to generate information and understanding about how to deal with.

And that population has very high levels of dementia, and dementia is the bit that we know least about. So all over the world, there are countries developing dementia strategies. Japan has its Orange Plan, and I'll show you something from that in a minute. South Korea not only has a national dementia strategy, it's declared war on dementia, which is very good. It's still at war with North Korea as well [laughter from the audience], so there's fighting on many fronts there, which is all very good.

And India is thinking seriously about its dementia strategies. Because the assumptions that in the developing world people will look after their own in multi-generational households, it's just remarkable how quickly those things break down, as people move from villages into towns, towns into cities, cities to all over the world – the generations that will look after you may not be there. As countries industrialize, the unit cost of labour increases, so that it's not so easy to get someone in to help look after your relative. And this is an issue in India.

In China, it's remarkable, because one of the unforeseen consequences of the one-child policy is that, for a whole generation, there is a missing group of carers. Who will care for the elderly? When you have so few people in that generation, where will those carers come from? And this has macro-economic impacts, because, if you look at the number one concern of people in China, it's about their health care, about long-term care, about who's going to look after them, how it's going to be afforded. And that makes China save so many dollars, and it affects money markets world-wide, the concern about what will happen with long-term care.

And in England, we developed our National Dementia Strategy and I've worked with other countries, I've worked with other places, and they all have three things in common: they say that it's very important to improve public and professional attitudes and understanding, and I'll show you some data on that; that it's very important to enable early identification, an early treatment of dementia, because that unlocks the door

to quality, and I'll say something about that; and the third thing is, it's really important to improve the quality of care from diagnosis right through to the end of life. And that means, that's a complicated journey which involves being in your own home, involves being in general hospitals, receiving home care, coming into your own home. It involves care homes right through to end of life care.

And there are great examples of doing all of those things well. It's just that nowhere puts it all together at the moment. And that's what a strategy can help you to do. It can help you try and chunk up what the issues are, and enable you to work out what you need to do and when you need to do it. This is an example, the Minister mentioned Dementia Friends in the UK, and the Dementia Friends in the UK was an idea that was taken from Japan. Because, in Japan, there was a problem with dementia, and the problem was that the word for dementia, *chihō*, is essentially very close to being a swear word in Japanese. And if you have a population whereby there is respect for older people, and we have in Japan, of course, the country which has the oldest population in the world per unit of population, it was slightly bizarre that Japan had such poor care of people with dementia. They had the highest levels of physical restraint, for example, of any country. And nobody spoke about dementia. But they didn't speak about dementia, because it was very difficult to speak about dementia; because, if you were a nice politician standing up in the Japanese parliament, you didn't want to swear about old people, because you do have a certain degree of filial piety.

And what Japan did – and I don't think we need to do this in English, this is a symbol of how doing simple things can sometimes yield great benefit to society – they changed the name of dementia from *chihō* to *ninchishō*, which is a neutral word which means 'neurodegenerative disorder'. And now they have recruited, I think, 3 million people to be Dementia Friends in Japan. And they published their Orange Plan, called the 'Orange Plan' because orange is the colour of autumn, as a positive image of aging. They published their Orange Plan last year, which involves generating a national network of services to be able to diagnose people with dementia, and to diagnosis them well, and to diagnosis them early, and to be able to help health services manage those people better.

These are the objectives of the National Dementia Strategy in England, and it's complicated. That's the point that I'm trying to make here. One of the reasons why we haven't sorted dementia out is because it's not simple. We've done the simple stuff, we've done the simple stuff like cancer and heart disease and stroke and diabetes and those bits. And that's brilliant; we should celebrate the wonderful things that we have done, but we know how to do those things now. What we haven't done is the complicated things like dementia, which transgress these boundaries. So it is a public health issue, but it's also a social care issue, it's an acute health issue, it's a specialist health care issue, it's an issue for people in care homes. And so that presents more of a challenge. And what a strategy can do is help chunk things up, help work out things on each so you can get on with it.

And, again, worldwide, there's an increasing understanding of this. So the World Health Organization and a quote from Margaret Chan the Director General: "I call upon all the stakeholders to make health and social care systems informed and responsive to this impending threat." So, a worldwide issue here. We have a picture of, not the Minister, but of David Cameron at the G8 meeting, and with his challenge asking us to go forward further and faster.

And there is a real movement here. And there is real value, I think, in thinking strategically about dementia, because the cunning plan that we've had to date to, kind of, waiting for the magic thing to happen, so that it all goes away, hasn't worked. So we need to try something different. And if it is big and complicated – and it is big and complicated – then we need to be able to coordinate that. And strategies are all very well and

good, they're a kind of shiny piece of paper. It's how you execute those strategies that makes a difference for individuals. But it is very difficult to kind of work out what you should do without having a kind of road map ahead of where to go.

So, in terms of the first theme of all these strategies, which is about improving public and professional attitudes and understanding, because there are things that people believe that are wrong about dementia. There's a stigma that attaches itself to dementia so that people don't like to talk about it. And that's people with dementia themselves and families, but also health care providers, find it difficult to talk about dementia. But that stigma is changing as you have the work of Alzheimer's associations and Alzheimer's societies throughout the world that have done remarkable things in terms of changing stigma. But I think the thing that really has made a vast difference is people being willing to come forward and talk about having dementia.

In the United Kingdom, we had someone called Terry Pratchett – do you know him? He's an author, he writes fantasy novels, very popular novelist. And he was brave enough to come forward and say that he has dementia and he does have a dementia. But he was also well enough in his dementia to make an entertaining and informative program about having dementia, and was well enough to go and be knighted for his services to literature.

And that starts to give a different image of what dementia is. It's not just the state of total dependency, when you can't eat for yourself and you need to be helped in every way, that you can't communicate – that's the end of dementia. But there are vastly more people with dementia in that mild and moderate stage where they are able to talk and interact, and they are able to function in society, and they are part of our society. And so it starts making one think about ones aunt who is asking the same question over and over again, who is distressed by that – maybe that's not just normal aging, maybe that's an illness. And if there are treatments that are clinically and cost-effective – maybe not treatments that make the illness go away but treatments that enable the person to live well with that dementia – you start asking the question: 'Why is my relative not getting those health care, those social care, those psychological interventions to enable them to live well? Why are we not getting support to look after this person so that she can stay in her own home rather than go into an expensive care home, which maybe of less good quality than staying in her own home?'

And so, the false beliefs that dementia is a normal part of aging; that needs to be dealt with. Again, if you get to the age of 85, it's still only about 30% of people that have dementia. So at any age, you're much more likely not to have it than to have it. But it is associated with age – doesn't mean that it's *caused* by age. And in fact, most of the illnesses that we deal with get more as you get older.

And the false belief that nothing can be done, the idea that, because we don't have a magic bullet, there's nothing we can do. Well, you know, there are very few illnesses now. Of all of the long-term conditions that are the illnesses of the 21st-century, they're all about managing illnesses rather than necessarily giving it something and making it go away. The paradigm of infectious diseases doesn't necessarily work with long-term and complex disorders, and it certainly doesn't work with dementia.

That doesn't mean to say that...we certainly *do* need good quality research. We need better treatments and compounds. But we already have things that we can do that can make big differences to people with dementia. So there's some good data to suggest that just four sessions of good quality information given to people with dementia at the time of diagnosis, particularly given to the carers of the people with dementia, can decrease institutionalization by 28%. So that's something that costs a couple of hundred dollars saving

something that costs hundreds of thousands of dollars, decreasing the median stay length by 558 days. And those are US data, where there may be some read across. But what we're seeing there is a small investment in something upstream kind of changing the direction of the river of dementia, changes the path that people are on to one where these harms are potentially prevented in people's lives. Little things done early, saving big things that happen late.

And here's an example from the UK about our health promotion. The great news about this, of course, is that it's about using resources that are out there. And we can change people's minds and change people's behaviour. We've changed people's minds with respect to wearing seat belts, and to drunk driving, and to even complex things like sexual behaviour with HIV. And this is the Worried About Your Memory campaign, which was written by the Alzheimer's Society but funded by the Department of Health in England, with a simple message, that: "Many people suffer from memory loss as they get older. But if it starts to happen on a regular basis, it could be the early signs of dementia. If you're worried see your doctor." A simple message to the public, but a simple message to the profession as well, in terms of what is expected.

So the second reason to be cheerful is better diagnosis of dementia. We can diagnosis dementia well, we can diagnosis dementia well in life. It's just that it is a bit complicated, particularly if you're diagnosing people early. But the problem that we have, the fundamental problem – and these are data taken from the UK, but I imagine there are similarities in Canada – that only about 44% of people with dementia ever get a diagnosis at any stage of their illness. And when they do, it tends to be late in the illness, at a time of crisis when it's too late to prevent harm. There's a gigantic preventative agenda in dementia, and it is about the prevention of harm and cost. But mainly, these diagnoses are often made when people go into hospitals, or when a crisis happens.

And why is there an inaction? Well, you know, again, it's complicated, because dementia is not something that happens on a Tuesday. There's an insidious onset; people may not be aware of it. There is no simple test, and anybody who says that there is a simple test is trying to sell you that simple test.

There are public misconceptions that we've talked about and professional misconceptions; it can be difficult to offer help as well as to seek help. There's role uncertainty. One of the things that characterizes dementia is a lack of role clarity. If we can get roles clear, then can start to deliver quality. And that leads to inaction.

And our goal, of course, isn't that everybody gets a diagnosis of dementia, because there are some people who don't want it. It's not about forcing people who don't want to know whether they've got dementia that they have dementia. It's not about screening populations. It's about finding people who have symptoms who are concerned about those symptoms and giving them accurate information that enables them to make choices about their life.

And one of the things that is true about dementia is that, the later you are diagnosed, the more severe your dementia, the less your capacity to make those choices and to make your own wishes clear. And that predicts poor outcomes for people with dementia, for families, and for services and society.

So, by early diagnosis here, I'm not talking about the world of mild cognitive impairment and finding people with dementia before they have any symptoms at all – that's the world of research. It's tremendously important that we do that research; it's tremendously important that we work in that area. But I'm talking about the clinical diagnosis of dementia and being able to make that when people have a mild dementia, rather than when they have a severe dementia and they're admitted to hospital.

And here's data that show that we can do it, that we can do it at a reasonable cost. These are data from the Croydon Memory Service, which was a service model that I was involved in developing. What it does is shows what 'good' looks like. What 'good' looks like is a service that makes the diagnosis well, so it makes that diagnosis of dementia accurately, but, very importantly, makes the subtyping of dementia – whether it's Alzheimer's disease, or Lewy Body Dementia, or frontotemporal dementia – so that people have accurate and useful information on what's happening with them. That makes that diagnosis well, but then communicates it well. That gives it to the family and gives the information to the family and to the person with dementia in such a way that they can use it, in such a way that knowledge is power.

People sometimes say ignorance is bliss, but it's not bliss in dementia – it's not good not to know. Bad things happen to you if you don't know. And if you do know and if you're told well, then there are good studies out there that levels of depression and anxiety decrease when you're given the diagnosis, if you're given it well.

So that's part of the therapy: how you enable people to do well. And then, of course, providing the immediate care and support that people need. And these are services that can work for diverse groups, for people for all ages, services that improve quality of life and decrease behavioural disturbances in dementia.

One of the measures that we have is the measure of quality of life. This is the DEMQOL system that we developed, which was funded by the UK government, by the Department of Health and its Research Development Division. This was funded because it was important to have a patient-reported outcome in dementia. What this work did was show that people with mild and moderate dementia were able to give a proper and clear account of their quality of life. And that for people at all stages of dementia, it was possible to get a proxy report from a family carer that enables you to work out whether or not people are improving with dementia.

Tremendously important to be able to demonstrate the impact of your services, and here's the impact of the dementia services that we mentioned here. So it's six months and maintaining at 12 months. If you look at those people with the lowest quality of life scores, you're seeing effect sizes that are about twice what you get from anti-dementia medication. And there are limits to these studies; there are control groups and various things. But what this shows is that, individuals that receive these services, their quality of life improves. And it's not necessarily that their cognition improves, or their activities of daily living improve, but their quality of life does improve through these services.

And here we have some economic modeling that contributed to the National Dementia Strategy in England. And what it shows is that, if we were to generate a national network of such services and delivered them, and if they prevented just 10% of admission to care homes, then that would break even. And if they prevented 20% of admissions, which is perfectly possible, then they would start releasing substantial amounts of money back into the system.

The trouble is that you're doing something now that has a benefit in five to seven years' time; you're doing something now in health that has a benefit in social care and in families. And so the systems that we generate that want to account within a single year and that want to account within different silos kind of lose the point of doing things for dementia.

In fact, when we were developing these arguments for dementia, when we were developing the National Dementia Strategy, it was quite difficult to get different bits of different departments interested in something you had to do now in order to save somebody else money seven years later – until I went to the Treasury,

HM Treasury, because they believe they own everybody's money anyway. [laughter from the audience] And so they could see the value of this, and we had less problem getting this past the Treasury than we did through anyone else.

If you take a view that is big enough, then it starts to make sense. And here the cost-effectiveness argument is essentially saying that, if we achieved just a quarter of the quality of life increase that we found in the Croydon Memory Service and a 10% diversion – and these are the nastiest models that you can possibly generate that are of economics – these services are worth it.

And here we see data from the Croydon Memory Service model. But actually, what this shows here is, this is on about 4,000 people showing an improvement at six months and it's being maintained at 12 months. I apologize for these being a little unclear, let me just talk you through them. The top one here is, the green line here, of people who have moderately severe dementia, and this is the group of people that have mild dementia at first, at first contact.

And what we see is that there's more benefit that accrues to individuals with mild dementia than moderate dementia. So it's more useful for families to know earlier rather than late. And here we have a difference between men and women: the blue line is women, the green line is men. So men seem to do better than women. And we tried to work out why that was, and what it's probably a function of is the fact that most men have got a co-resident female carer who the team is able to work through and can deliver those quality of life improvements, whereas many of the women were alone because their husbands had died. And so, you can kind of draw a little conclusion from this if you're a woman, which is that, at about the age of 50, you'll probably need to trade in your husband for something about 20 years younger. [laughter from the audience] And that will see you through to the end there. So there we are – some advice, from a doctor. [laughter from the audience]

You start to see how the value of looking and to being able to measure quality of life and being able to investigate what happens with that.

How are things changing? So here are data in the UK, and slowly but surely we're improving the numbers of people that are diagnosed with dementia. You can change the system, you can modify the system, you can make a difference in the system.

And then what you have is memory services in the United Kingdom – you might have a different system here in Canada. But you have a system that enables you to turn worrying symptoms into people who know what's going on, to turn the toxicity of uncertainty into the empowerment of understanding, and enable choice, quality, self-efficacy. This is how we produce health and well-being. And I really believe that early identification services for that are the things that unlock the system as a whole.

I have I think five minutes left. So this slide is the single most exciting and optimistic slide that I've got. [laughter from the audience] So I'll let you look at it for a while. [laughter from the audience] It's good isn't it? [laughter from the audience] Let me talk you through it.

What we have here is increasing severity of dementia – minimal, mild, moderate, and severe. And what we have here is increasing quality of life score. And what this shows – and why this is so important and why it is so hopeful – is that what it shows is that there is no association between severity of dementia and quality of life. It is perfectly possible to live a good life and have good life quality when you have severe dementia; it's also perfectly possible to have a miserable quality of life. And the same goes for people with mild dementia:

it's perfectly possible to live a good life quality, but it also is possible to have a poor life quality. And that's tremendously important. This is a testament to the things that happen in people's families, the quality of care that people receive. This is what health services do, but it is what families do.

It would be very depressing if your quality of life necessarily decreased with increasing severity of dementia, because there isn't anything we can do at the moment to stop that increasing. So what this does is helps us to understand what our services are for. We find people with poor quality of life and we drive up their life quality. We find people with good life quality in their dementia and we learn from them and help maintain that good life quality for them.

And the last part of the talk deals with the world, the seven to 12 years an individual may have following diagnosis right through to the end of life care. And there are some reasons to be cheerful in terms of prevention. So here's a paper and a commentary that we wrote in *The Lancet*, which basically shows our data from the cognitive functioning and aging study.

So there were a set of studies done nationally 20 years ago, and a set of studies that finished about five years ago. And the prevalence of dementia is lower now, not by very much, but by 5-7% lower now than it was before, 20 years before. And that's probably because of the fantastic work that we've done on cardiovascular health: what's good for your brain is good for your heart, what's good for your heart is good for your brain. And so the things that people have done in smoking cessation, in exercising, and eating green vegetables, and all those things that I don't do: they have decreased the numbers of people with dementia. And that's a really positive message. There are things that we can do that can make a difference.

There's another thing that we can do where we can make a difference; this is the use of anti-psychotic medication - a particular concern, concerns that were first surfaced, I think, in Canada. I know that you're doing useful work here in Alberta to be able to drive down anti-psychotic people with dementia. And so we found that maybe 25% of people in the UK with dementia were receiving these in any year, which meant that 1,800 deaths were attributable to these drugs in any year. And we generated an idea that wasn't about big new extra services, but was about using the quality improvement mechanisms that exists for clinical governments and helping those to make the changes that we needed to use.

And it's interesting that this is a simple measure, which can potentially lead to major quality improvements in all sorts of other areas. But it's simple enough for media to pick up on it. And here's *Panorama*, which is the largest investigative journalism program on television, and they were asking 'What have the drugs done to Dad?', and the drugs had killed Dad. And the Minister at the time, Paul Barstow, he came on the program and said 'We will change this'.

And you change it by using the instruments of government that exist, and for the management of health systems, and the management of primary care and hospitals, saying that 'this is the time to look at this bit', rather than the things that you were looking at last year. You make dementia the priority. So you use existing government mechanisms and you turn them to work on dementia. And that's led to a decrease in the number of people on these drugs, down to about 6% now. And that's a positive thing.

We've talked a little about the acute side of things, acute beds. And what is remarkable, if you look at the UK, 70% of hospital beds are occupied by older people. Maybe a half of those, up to a half of them have a degree of dementia because people with dementia are overrepresented in those beds. Dementia predicts longer stays, more readmissions, about outcomes of every sort.

The thing that I'm most concerned about in these data from the UK – it may be different in Canada – is that 30% of people with dementia who come into a general hospital from their own home leave the general hospital and go to a care home. Now, there are brilliant care homes and it's absolutely vital for some people that they are cared for in a care home and cared for well in those care homes. But it beggars belief that that number of individuals needs to be put into care homes. Essentially, this makes our general hospitals in the UK machines for institutionalizing older people with dementia. It makes them dementia care facilities that just aren't just very good at dementia care. And that's because they're fighting last century's battles. They're brilliant at doing all the cardiac angiograms and this and that and the other; they're not so good at dealing with the general medicine, and the complex cases that are on the wards, and they're not so good at dealing with dementia.

And here we have some data from a hospital in the midlands of England, at Birmingham, showing that making the hospital see dementia as its business – seeing dementia is not what other people do, but what we do – and also providing more specialist input into the hospital: they are able to save money, to close beds, to reduce stay lengths, to decrease readmissions. There were more home discharges. And it diverted more people in the accidents and emergency department. The return was four pounds for every pound spent, and the hospital was able to close beds and use that money for other things.

So this is a report by Standard & Poor's – if we take a step back and start thinking about what the future is – this is Standard & Poor's looking at the challenges ahead for developed economies. And what they found in this report was that the number one challenge for developed economies was the cost of health care for older people. And probably about 50% of that is driven by dementia. And actually, we don't do the dementia bit very well, but we do the other bits quite well. So where's the room for improvement? It's within that dementia.

So, what do we have here? We have a picture, yes? We've got a picture of the Great Wall of China from space. There's the saying that you can see the Great Wall of China from space. So here's the Great Wall of China from space. And dementia's like that. If you look at it in the right way, if you have the right sort of imaging – and this is a funny x-ray imaging thing from space – if you look in the right way, dementia is a big enough problem to be seen from space. It's the one thing that we haven't done. It's the challenge that we have ahead of us.

So, I saw that this was the Institute of Health Economics. So I thought I'd do an S-shape curve. [laughter from the audience] Because I did an MBA and there were lots of S-shaped curves – that's all I can remember, but I remember the S-shaped curves. [laughter from the audience]

So let's think of a timeline, let's think about now. The ideal in investment, the ideal thing that we want to look for, are things whereby you have low investment and you get high yield. We want as many bangs for our bucks as we can get, yes? Particularly at a time of constraint.

Now, for cancer and heart disease and stroke and all of those brilliant things we've done so well, that was the 1970s and 80s, we did brilliant work. Things that we did there gave high yields for relatively little investment, and that's brilliant. But now, in 2014, we have to spend quite a lot of money to get not very much in the way of return. But we might have really really good evidence on that. So we've got multiple randomized control trials showing the incremental benefit of the extraordinarily expensive drug.

Whereas, for dementia, the evidence base is not so good, because, actually, it's quite difficult to do those studies. And actually, it's quite difficult to do randomized control trials of memory services, for example.

And so you have a difference in the quality of evidence that's out there, but you've got a difference in the quality of yield. And we're not so good at doing that. Politicians are quite good at this sort of thing, but I think that the mechanisms of health economics aren't so good at dealing with that.

So our challenge in 2014, in a time of constraint: making strategy. The strategy is always about making a choice, it's about deciding what to do and what not to do. And so our choice now is whether we spend what little money we have on things that give low yield but require high investment. But where there may be high degrees of certainty or in areas like dementia, where we do a little but we get a lot, but there is more uncertainty – that's our challenge.

Thank you very much.

Questions from the audience for Dr. Banerjee

Dr. Tyrrell: We have a few minutes for questions and there are microphones here on the floor. So, I'd ask people to go to the microphone and ask their questions if they would. We have about five, 10 minutes for questions.

Gita Sharma: Thank you so much for such a really amazing talk and, by the way, welcome to the best place in Canada. This is not my area of research, but I'm interested to know – oh by the way, I'm sorry, I'm Gita Sharma, the Chair of Aboriginal Health of the University of Alberta – I'm interested to know, is there a test for genetics acceptability for dementia? And then, the second question is: are there, and if there is, is there any association between mutant gene interactions that you can actually mitigate against those who are genetically susceptible?

Dr. Banerjee: Right. So...it's complicated. [laughter from the audience]

Gita Sharma: Thought so.

Dr. Banerjee: There are some forms of dementia that are highly heritable; those tend to be young onset dementias, people who develop dementia in their 40s and 50s. There's single simple single gene mutations that you could find in those people, and that accounts for about .0005% of cases of dementia. The rest of dementia is a complex gene environment interaction, whereby we don't understand much of the genetics or much of the environment.

There are the ApoE4 allele, which accounts for 20 odd percent of risk, but which is very distributed throughout the population. There are many more people that have that configuration of genes who will never develop dementia than who have it and will develop dementia. So there's nothing that's simple, I'm afraid, in genetics. You can get some of these tests on the Internet, they just don't tell you anything useful or helpful. That's the problem that we have at the moment.

In terms of environment, we know there are some environmental risk factors that are very clear. If you repeatedly get hit on your head, you are more likely to develop dementia. So if you were a professional boxer or if you play soccer and you head footballs a lot, especially in the 1950s when there were great big soggy bags of leather, then you can be more likely to develop dementia.

People with Down Syndrome are much more likely to develop dementia, for example. But it's again a complicated set of interactions.

One of the failures, I think, that we've had in terms of the paradigm of treatment for Alzheimer's disease has been that we have assumed it is a single illness rather than a syndrome. And there are probably 20,000 gene-environment interactions that lead you to develop Alzheimer's disease. So it's perhaps not surprising because we are unable to stratify, at this point, those groups. It's unsurprising we haven't been able to find *the* drug that modifies dementia. So the drugs that we have work at the end of the cascade.

So that's sort of where we are. Again, there's a tremendous amount of work to be done, but we won't find a single gene that causes it.

Gita Sharma: Thank you.

Dr. Tyrrell: Other questions? Yes.

Unknown speaker: Hi, thank you very much for your excellent presentation. I'm a physician; I do a specialized geriatric program. And, as you mentioned, the time the patient coming to us is quite late. So my question is not that much research, I wanted to know if you guys have any strategy to enable primary care physicians in detecting early dementia, as we are having some reforms on our primary care network right now and we're moving ahead? And I want to know if there is any way we can actually enable the family physician for early detection so we can be more preventative and proactive rather than end of the road.

Dr. Banerjee: Tremendously important question, and primary care has a fundamental role in managing dementia and managing dementia well. It is to primary care the people will come with the first symptoms of dementia. It is primary care that will be looking after people with dementia for the seven to 12 years they may be in the community. So working out clearly what the role of primary care is really important.

Now, there are different systems that work in different places. And I think what's very important is to work out what happens when somebody is concerned that somebody might have dementia.

So I think there's a nice parallel with cancer here. So if you are in primary care and somebody comes to you with a lump in their neck, so you as a primary care doctor will feel that lump, you'll make sure that it's not a spot or something like that, but you won't necessarily do the biopsy and the histology of that lump in the general practice. What you will do is you will send them off to the lump-in-the-neck doctors, who do all the complicated heavy-lifting stuff, and who do it on hundreds of people a year so they're good at it, as opposed to doing it on a couple of people a year and being bad at it. You send them to the lump-in-the-neck doctor, and they make the diagnosis, they communicate it to the patient, because that's quite complicated as well, they also communicate to the primary care doctors. Then you can get on with the system of knowing what's going on.

And I think that's the model you need in dementia. I don't think it's entirely simple to make a diagnosis for dementia if you've known the patient for eight years and you've seen the deterioration. But if you're making the diagnosis early, it's more complicated.

And if you tell somebody that they got dementia, they got Alzheimer's disease, then you need to be really sure they've got dementia and that family needs to have confidence in it. And if you tell them they haven't got it, then you need to be absolutely sure that they haven't got it as well. And so, for me, there is a real quality issue about that diagnostic process. And seeking to do it by using, you know, 10 questions on a sheet, it doesn't work like that.

There is no simple way of doing it; it's a clinical assessment with multiple sources of information. And all sorts of doctors can do it, so it can be done by geriatricians or psychiatrists or by primary care doctors or whatever. But it takes quite a while, and it takes some resources. So I think what's important here is to identify how, within your system, dementia is diagnosed, and diagnosed early by whom, so that service can be held to account for doing it well. And then you can have clarity for them as your average primary care doctor about what the role of a primary care doctor is afterwards.

So I think that it's about role clarity and it's about being really clear about who does what. Because the problem that we have with systems at the moment with dementia is that it's almost that anybody can do it. And it's everybody's business, so it's nobody's responsibility. What you want to do is to bring some responsibility down to individual things.

And for most disorders in medicine, it's really easy. It's a cardiologist to deal with angiograms; it's the cancer doctors who deal with the lumps in the neck. With dementia, we just haven't set ourselves up to do this. We don't have to create lots of dementiaologists, we just have to decide which bit of our system does it. And in different countries, it's done in different ways. And you'll have a much better idea on how to do it in Canada than someone from England.

Unknown speaker: I just wanted to know if you have any specific strategies in England that we could adapt it here?

Dr. Banerjee: So the data I showed you there is from the Croydon Memory Service model, which is basically generating a specific generic team that is able to see high volumes of people, that works on a population of 48,000 people. But that's an urban response. And I know you have issues from having quite a big territory to deal with. So there's different ways you can do it rurally, probably.

Unknown speaker: Thank you.

Dr. Tyrrell: Thank you. One more question.

Sophie Surpurja: Hi Doctor Banerjee, thanks so much for a fantastic presentation. My name is Sophie Surpurja, I work with the Provincial Seniors Health Strategy Team for Alberta Health Services in a role called Lead for Cognitive Impairment. And I'm just wondering if you have any, perhaps one or two, key lessons learned that you can share around the process of developing and implementing the strategy in England?

Dr. Banerjee: Wow. Thank you. Thank you. [laughter from the audience]

You should never underestimate how difficult it is to get bureaucracies of whatever sort, however well-meaning they are, to take on doing a new thing. I think, the major achievement that we had in developing the strategy was getting the agreement to develop the strategy. And it was an immensely difficult thing to do because people were saying, 'Well we already got a strategy on older people, we got a strategy on cancer, we got a strategy on end of life care. We're not doing strategies anymore, because the center won't tell the periphery what to do anymore because it's a different world, until something happens.' And what we were able to do was to make the case that it's kind of a dumb not to have one, given the size of the problem. I mean who wouldn't want a strategy to be able to deal with something that costs the UK 23 billion pounds per year, and while we know we're probably not using that money very well, and when we know that almost everybody who experiences the services experiences them poorly.

It was helped by the fact that there were various people, including some people who had quite seen me in the NHS, who had recent experiences in trying to deal with the mother-in-law with dementia. And even if you were the kind of deputy chief executive of the NHS, you couldn't get anything done. And so those were helpful.

But when we were able to tell the story and, I think, that, a lesson: get a clear and simple story and tell it well. And get a clear and simple story and get other people telling that story, make it their story. So that they tell it and tell it well and other people will tell it, as well. So getting the thing started was probably the biggest thing to do.

Then once you got it started, then it really was a matter of inclusivity. You really really want this not to be something that's just done by the neurologists, or just done by the psychiatrists. It was absolutely vital to create a really big tent and to genuinely listen, so we carried out the largest listening exercise that has ever been carried out by the Department of Health. We spent a long time listening to people with dementia, and carers, and practitioners, as well as policy-makers and others. And that ended up with something that was robust enough to kind of transition from one government to the next government, and not go down in priority but go up in priority. It's only continued to go up in priority. Now that they've got the thing, they're really pleased that they've got it. So I think that once you've got that opportunity, then you need to make it as strong and real as possible.

And the final thing I'd say is, it is important, I think, to focus on dementia rather than to have a strategy that's about frailty, or about older people, or about general things. Because there are too many ways that becomes too unclear, you can't do it. What you want is a strategy for dementia that does 50% of that, and starts doing it really well. And that will then work with your other strategies for other things. So I think there is real value in promoting dementia as the focus strategy as well.

Dr. Tyrrell: Thank you very much. Just want to thank you once again, because, Dr. Banerjee, I just want to let you know that quite often these forums are such an attractive topic that my wife normally comes, but it's unfortunate today because she had a conflict, and she didn't come here to hear your advice about what older women should do. [audience laughter]

So thank you very very much. We're going to take a couple minutes, about five minutes I think, to get the hook-up for Dr. David Grabowski from Harvard. Just before we take that break, I want to say it always amazes me, to see the speakers and the quality of the speakers that come in. I got to thank Egon Jonsson and the whole team at IHE, and their work with the Alberta Health Services in putting together the speakers that come in here, because they really are the world experts in these different topics. So, Dr. Banerjee, you've done a great job at introducing this senior strategy in London. And we'll take a five minute break while we get hooked up, and we'll come back for David Grabowski.

Keynote Presentation #2 Coordinating Care for Vulnerable Elders

Introduction: Dr. Lorne Tyrrell

David Grabowski, as I mentioned, had the unfortunate thing happen that has happened to me once, where you get in a little bit, you come into the plane and they tell you your plane is full and you've been bumped,

and he could not get in here on time. So he's, through the magic of electronics, we're going to be hooking up David to speak to us, and his slides are all here.

David is a professor in the Department of Public Health Policy at Harvard Medical School, and his research focuses on the economics of aging, with particular interest in the area of long-term care. His research has considered issues of long-term care financing, organization, and delivery of services. Obviously, fits in very well with the first lecture that we had, and we'll start now and see if we can hook in with David.

Keynote Speaker:
Dr. David C. Grabowski, Professor of Health Care Policy, Harvard Medical School



Great, thank you, Lorne. Can everyone here me okay? Great. Hi everyone, good afternoon, and thanks to everyone at the Institute for this invitation. I would love to be there in person with you, but I didn't have, as it was just mentioned, very good travel karma today. I got as far as Chicago, but ultimately couldn't get to Edmonton, and so I'm back here in Boston. I was remarking to a colleague earlier, I had a really long commute: I only live seven miles from my office, but I'm back here at my desk via Chicago O'Hare Airport. [audience laughter] So, it's very inefficient way to get to work today, but I am delighted to join all of you, and I hope in a future date to be able to join you up there in person.

So the title of my talk today is *Coordinating Care for Vulnerable Elders*. Obviously, the vulnerable elders I'm thinking about in this talk are those individuals with dementia. What I would argue is, both here in US and up there in Canada, we have a real crisis in both how we're paying for the care, both health care and long-term care, of patients with dementia, and also how we're delivering and organizing services on the ground. And I would, once again, say that crisis is present both in the US and up there in Canada.

So with my time today, I'd like to make the point that, if we're going to improve the care of patients with dementia both in the US and Canada, we need to think about reforming both the payment and the delivery system. And we can't just do one or the other, and that's really going to be one of the punch lines of my talk: we really need a system-level reform.

So, next slide please. An overview of my talk today: I'd first like to make this point that, although the US and Canada have very different health care systems, we share some common features and some common problems when it comes to the care of individuals with dementia. And I'll talk a little bit about those commonalities and some of those issues.

I'd next like to say a few words about dementia care in the US, just give you some broad statistics. And next, then, talk more about this care coordination problem, why dementia care in the US is so lacking. And, as I said earlier, this relates to both about how we pay for services and ultimately how we deliver them. And I'll talk about some potential reforms that can improve how we pay and how we deliver services, and make this point, once again, that we have to reform the whole system. I then want to touch on an innovative program that just came online here in the US under our recent health care reform initiative, and I'll explain that program and how it might change the care for individuals with dementia.

Then finally, I want to talk about some of the challenges that we face going forward. And these challenges are present here in the US, and I think there's a lot of learning potential for those of you in the Canadian system.

So, next slide please. I'd like to start with an international perspective here. This is just the percent of gross domestic product that's spent on long-term care, data from the OECD. These are 2008 data and then projected out suspending in the year 2050: the blue part of the bar for each of the countries are public long-term care expenditures; the red part of the bar are private long-term care expenditures; and that little green triangle out to the right is the projection out in the year 2050.

First thing you'll notice about this is, this is one of few times you'll see health care standard rankings where the US isn't way ahead of everybody else. The US is actually an inlier when it comes to long-term care; so is Canada. Maybe that's good news, maybe not so much, in the sense that the countries that rank one and two here, Sweden and the Netherlands, are countries with universal coverage for long-term care. You can see it's all public spending there in blue. They spend almost 3.5% of their GDP on long-term care services.

If you look down a little bit further, Canada's about the middle of the distribution there, spending about 1.75% of their gross domestic product on long-term care. And see you some mainly blue, but some red as well. You go down even further, you can see the US there. And we have a little bit more as a percentage in red there, a little bit more reliance on the private side.

We're already beginning to see some of the commonalities that I'm referring to. The first commonality: both the US and Canada have a mix of public and private funding for long-term care. I think the more important point beyond that, I think the point there being that neither country has universal coverage of long-term care. I think the point that goes along with that is that long-term care in both countries is funded very differently than the rest of the health care system. Obviously, the health care system in Canada is funded and delivered and organized, and the delivery system is very different than the US. But when it comes to long-term care, both countries have this fragmentation, in that health care is paid for differently than long-term care services.

And that's a point we're going to come back to. I recently gave a talk to a group in Ontario, the same point resonated there. It resonates in Alberta. It resonates all over the US. This fragmentation, this disconnect in terms of payment for long-term care and payment for health care services, causes both programs to lack the incentive to invest in services that are going to manage overall costs and overall quality across the system. And this flows down to all the providers at the delivery level.

So, next slide please; I'm on the slide titled *Dementia in the US*. Just to give you a little bit of background about why dementia is such a good example of a condition that sort of fits this fragmentation model, this lack of care coordination. We have over 5 million Americans in the US with dementia. Over two thirds of those are women. And every year, nearly 500,000 individuals die because of dementia. And I think the key point from a care coordination perspective is that dementia patients require a strong mix of both health care services and long-term services.

Next slide please. This is a great study by Chris Callahan and colleagues, they published in the *Journal of the American Geriatrics Society* a couple of years ago. They took a cohort of elderly community-dwelling individuals, and followed them out over time. And roughly 1,000 of those individuals encountered dementia over the study period; almost 2,700 did not develop dementia over the study period. And they just looked at health care and long term-care utilization across the two groups. And you can see, whether it's hospital care, nursing home care, home health care, and ultimately mortality – all much higher in that group that experienced dementia relative to the group that, a very similar group at base line, that didn't experience dementia.

That's one way of looking at just the strong presence of dementia in the US, and just its importance in terms of driving health care spending. Another way to look at it is by setting. And next slide please. This next slide shows both percent of individuals with dementia – the darker shade of blue is dementia, the greenish shade is depression. And you can see across five different long-term care and end-of-life settings – adult day services centres, home health agencies, hospice, nursing homes, and residential care communities – we see a strong presence of dementia across all of those settings.

I wanted to draw your attention to one setting in particular, and that's the nursing home, where I done a lot of my research. Almost half of all nursing home residents in the US have dementia. So, you can't think about the nursing home population, you can't study nursing homes without thinking about dementia in the US. And you can see that it matches pretty well with depression and a lot of these settings as well, and obviously there's a lot of overlap in those populations.

So, next slide please. One final slide on a kind of background on dementia here. From an economic perspective, it's the most expensive condition in the US, accounting for an estimated \$214 billion in expenditures in this year alone. And that's just the direct costs that contribute to our national health accounts. It has a huge impact on families, and these sorts of expenditures often don't show up in our national health accounts: caregiver depression, lost work time, injuries to caregivers – there's all sorts of issues there, and just the high cost that this disease places on caregivers and families.

And in spite of all the resources we put towards dementia, both in terms of health and long-term spending and all the sort of contribution on the part of families, there's a big literature suggesting dementia care in the US is of fairly poor quality. And I can show you lots of different outcomes and lots of different data. But I wanted to point to one particular outcome, and that's the hospitalization, the avoidable hospitalization of patients with dementia.

I really like this measure for a couple of reasons: one, it's an indicator of quality; but, two, it's also an indicator of poor care coordination. If we could better manage for example, clinical care, we could keep individuals, for example, in a long-term care setting like a nursing home, out of the hospital. And so it contributes both to inefficient spending because these hospitalizations are avoidable. It's also a measure of poor quality, and ultimately a measure of poor care coordination.

And these hospitalizations are incredibly frequent. Lots of studies, but just to cite one study in particular by Lamberg and colleagues: they found in nearly one in four nursing home residents in the US with advanced dementia will have a hospitalization in the last six months of their life. Now, you might think this is a problem just in the US system. Once again, when I was meeting and working with the group in Ontario, we're trying to conceptualize a paper that actually compares rates of hospital transfers in Ontario for nursing home residents relative to comparable states like Pennsylvania, comfortably sized states, I should say, in the US, like Pennsylvania or Illinois. And at least our initial look at the data suggests the rates in Ontario are fairly high. I haven't seen any data, obviously, from Alberta, but I'd be really curious in the Q and A to hear a little bit about the experience there. But, based on the experience in Ontario, this hospitalization of chronically ill patients, those with dementia, is incredibly high in your system, it's incredibly high in our system.

Next slide please. So, why so many of these avoidable hospitalizations? I promise I'm going to answer that question in just a few moments. What I'd like to, kind of put a person behind this problem. It's easy to

throw a lot of numbers, but I'd like to give a quick patient vignette before turning to a little bit more background on why so many of these avoidable hospitalizations for residents with dementia.

So, next slide please. I want to tell you about "Miss B". As was suggested in the introduction, I'm a health economist, I'm not a clinician. But I work with lots of geriatricians, and one of those geriatricians is Joe Ouslander at Florida Atlantic University. And Joe and his colleague, Bob Berenson, published a really nice perspective in *NEJM*, back in 2011. And this was, they put forward as part of that perspective in *NEJM*, the case of "Miss B". She's a pretty typical nursing home resident here in the US, and I hope that she, at least from a clinical perspective, looks pretty similar to nursing home residences there in Alberta.

She's 90, she lives in a nursing home, and she's dually eligible for Medicare and Medicaid. What that means is that, because she's over age 65, she's qualified for Medicare; because she's poorer, she qualified for Medicaid. Medicare covers her health care; Medicaid covers her long-term care services. And that, I'm going to come back to that point: different funding streams, once again, for health care and long-term care. Very similar to Canada.

She has moderately advanced Alzheimer's, she has CHF with severe left ventricular dysfunction, and, finally, she has chronic pain from degenerative joint disease. Lots going on from a health perspective, but this is very typical for a US nursing home resident.

Next slide please. Under our traditional payment and delivery model here in the US, Miss B has three ID cards: Medicare covers her health care services; she has a separate benefiter card for her prescription drugs in Medicare part D; and then she has Medicaid to cover her long-term care services. So, three different sets of benefits that don't really fit together all that well.

At the delivery level, she has multiple providers she'll interact with on a daily, weekly, monthly basis: she obviously has a nursing home that she lives in; she has her clinicians; she potentially has a therapist; if she needs to be hospitalized, she has the hospital that she's interacting with. So, lots of health care providers all of them kind of working in their own silos, very rarely, under our traditional delivery model, communicating with one another.

So, as you can imagine, any sort of health or long-term care decisions aren't made from a coordinated, integrated perspective. They're not made with Miss B's best interests at heart; they're often made from a financial perspective. And so, we often, when Miss B, for example, gets sick, we often get perverse outcomes in our system.

Next slide please. So, let's say Miss B develops a changing condition here: she has a non-productive cough and a fever of a 100.4 degrees Fahrenheit. This condition, all of my clinical colleagues assure me, is very very treatable in the typical US nursing home. However, in the overwhelming majority of incidences, Miss B is going down the street to the emergency room, and then, once in the emergency room, emergency department, she is likely going to be admitted and have an inpatient hospital stay.

And the question is: 'Why?'. This is very treatable in the nursing home, yet in a lot of incidences she's going down the street to the hospital. Once again, this is an example from the US system, but I think this same example applies in the Canadian system. So the question is: 'Why?'. Once again, going back to my introduction, I think this is a failure of how we pay for services, and also how we deliver services.

Let's start with the payment failure. So, here in the US, Medicaid pays for Miss B's nursing home care, but Medicare pays for her hospital care and all of her other health care services. And so, Medicaid has very

little incentive to invest in services that are going to keep Miss B from using Medicare-covered services. They have very little incentive to – because they don't enjoy any of the savings associated with preventing a hospitalization – they have very little incentive to invest in infrastructure resources to keep her out of the hospital. That's the disconnect at the payment level.

We go down to the delivery level: that just flows downward. Nursing homes and other long-term care providers then, because they're covered by Medicaid largely, they will not invest in infrastructure expertise to treat patients with dementia like Miss B safely in a nursing home setting; they're more than happy to transition her down the street. That's not to say that they can't, that this is an impossible hurdle here. It's not like they couldn't invest in that infrastructure and that expertise. They don't because they're not incentivised; there's no real return here for them investing in it.

And so what I would argue is if we want to fix dementia care in the US, and similarly in Canada, we need to fix both of these failures: we need to fix how we pay for services, and how we deliver services.

Next slide please. So this two-by-two matrix helps sort of show why we can't just fix one – the payment, for example, or the delivery – without doing both. And I'd like to give a couple of quick examples from my own research, but you can see at least, we're currently, the status quo historically has been fee-for-service payment in the US. So that's the status quo. And then from a delivery level: very fragmented delivery. Every provider is sort of in their own little silo; they're not communicating or working as part of a team with other providers in that system. And then, from a payment perspective, each of those providers is paid on its own bottom, and there's no kind of global payment or sharing of risk and reward across providers.

So I would argue that we need to move where providers are paid globally. That is, they share in the risk and reward of investing in infrastructure and expertise to treat patients in lower cost settings. And then, from a delivery perspective, we need to move to a more coordinated system where providers are working together.

Why can't we just fix delivery or payment? Let me go through that upper left quadrant and that lower right quadrant before talking about that upper right quadrant.

So let's first think about fixing just the delivery. I want to give an example from a recent study we published on telemedicine. So this was an off-hour telemedicine intervention. Basically, if a medical issue arises off-hours during the evenings or during a weekend – think about the case of Miss B, that cough and that fever – what happens in a typical US nursing home?

Well, an on-call physician either comes to the facility – so this is a covering physician who may or may not know Miss B, gets this phone call. That physician has to either come out to the nursing home, or they can recommend a transfer to the emergency department, which will likely result in an inpatient admission. In the overwhelming majority of incidences in the US, once again, that on-call physician isn't coming out to the nursing home. Their call there over the phone isn't reimbursed, and so in all likelihood they're sending that patient to the emergency room.

Now, what we hypothesized is that, rather than having this covering physician model where it's over the phone, what would happen if, in the case of Miss B, that fever and cough, rather than calling a physician, we wheeled a two-way conferencing cart into the room? And now Miss B, the RN, the registered nurse in the room, the direct care worker in the room, maybe family members in the room, are all looking eye-to-eye with the physician who's sitting at a call centre. What happens? Does that sort of listening to that cough,

getting to talk to Miss B, talk to the staff at the nursing home and her family, are we able to prevent some unnecessary hospital transfers through this direct contact via telemedicine?

Well, we did a small randomized trial here in Massachusetts, where we paired up with a telemedicine company and a small nursing home chain with just eleven facilities here in the state. And we randomized six of the nursing homes to get this off-hour telemedicine coverage to better coordinate care for patients in those, clinical care for patients in those nursing homes off-hour. Then the control facilities would keep the standard on-call physician coverage model. And, it turned out, as you can see in the graph there on the right, that there was a much bigger decline in those treatment facilities in terms of hospital transfers, a 10% decline, whereas there was a downward trend in the control group, but only of 5%.

So that five-percentage point difference actually translated into about \$100,000 in savings to the Medicare program, that pays for hospital care here in the US, per nursing home per year. Now the telemedicine service only costs \$30,000 per facility annually. So you don't need a degree in finance to see that there's a big return on investment here: \$100,000 is a lot bigger than \$30,000. So why doesn't every facility in, why doesn't every nursing home in the US have off-hour telemedicine coverage? Next slide please.

Well, that's the real lesson for reform. There's just real disconnect on this return on investment. Here in the US currently, telemedicine has to be paid for by the nursing home. The nursing home has to make that investment, whereas all the savings go to the Medicare program. And so, whenever there's this disconnect, any sort of investment on the part of nursing homes is going to be limited and unsustainable.

And, indeed, we saw that in our study. The participating nursing home chain had hoped to roll out telemedicine to all the five control facilities at the end of the study. However, even in the context of our promising results, they couldn't justify cross-subsidizing this service anymore in the context of some big Medicare skilled-nursing facility payment cuts that occurred right as our study was ending. So, even in the context of these promising results, they had to scale back the program. They're never going to invest on a wide scale basis if those services aren't paid for and compensated at a broader policy level.

So, I think that story is pretty clear why you can't just fix delivery: it's not going to get the payment incentives right up top, and, ultimately, that's going to lead to something that's sort of small-scale and unsustainable. And there's a lot of nursing homes here in the US, and I imagine up there in Canada, and lots of other long-term care providers, they're doing really innovative things. But it's hard to sort of envision large-scale reform unless we get the payments right.

So, the second example I'd like to give you – and I'm an economist and I know there's lots of economists in the room up there: 'Can't we just get the payment incentives right and everything will work beneath that?' And I think that's been a longstanding belief that we just need to get incentives right, and everything will flow from there. And I was involved in a payment demonstration here in the US that actually tested exactly this idea.

So, next slide please. I'm on the *Nursing Home Value Based Purchasing Demonstration* slide. This was a classic pay-for-performance demonstration. It was a voluntary demonstration put on by our Medicare Centres for Medicare Medicaid services here in the US that ran from 2009 through 2012, and we were the evaluator of this program. It took place in three states: Arizona, New York, and Wisconsin. And basically, participating nursing homes in those states were incentivized to improve performance along four domains: nursing home staffing, so RNs, LPNs, and nurse aids; survey inspections or deficiencies; a series of

minimum data set based quality measures, like pain and pressure ulcers; and, finally, this measure of hospitalizations again – avoidable hospitalization.

And the idea in each of the states was those top-performing nursing homes would receive a reward payment, and the receipt of this reward payment was conditional on the fact that the state showed cost savings. So the program was ultimately set up to be budget neutral. So, for example, if the participating nursing homes in New York didn't generate savings to preventing hospitalizations relative to a set of control group, relative to a set of control nursing homes, then even the best nursing homes in New York didn't receive a payout from the Medicare program.

So what ended up happening? Once again, CMS said nothing about how you deliver care on the ground; they left that completely open, said: 'Here's this payment incentive, do with it what you will.' And what happened? Well, it turned out, when we looked at all these performance measures – staffing, survey inspections, MBS-based quality measures, hospitalizations: no real change in performance and quality across the treatment and control in nursing homes. When we looked at savings to see if there was a reward payment for those top-performing nursing homes, we had mixed results across states.

Next slide please. This is the slide titled *NHVPB: Medicare savings*. You can see here that, in a minority of states and years, we did see savings. So, for example, in Arizona and Wisconsin in year one, those top-performing nursing homes did get a reward payment, because collectively all the treatment facilities showed savings relative to the control facilities. However, that only occurred in Arizona in year one, and in Wisconsin in year one and two. So, in New York you could have been the top-performing nursing home in all three years and never received a reward payment, because collectively the treatment facilities never showed savings relative to the control group.

So, what do we make of this? We maybe saw some savings based on Arizona and Wisconsin. We definitely didn't see any improvement in performance. What do we conclude about this program? Well, what was really nice about our evaluation – next slide please – in terms of lessons for reform is that we didn't just do a quantitative analysis of the program, we actually went out and talked to a lot of the participating nursing homes. We asked them, especially in Arizona and Wisconsin, and especially those top-performing facilities that got a reward payment: 'How'd you do it? How did you prevent hospitalization?'

And the overwhelming response was that 'We didn't do anything'. It basically, a few of the facilities didn't even know they were participating in the demo anymore, there'd been so much turnover and leadership. Indeed, my favorite story, I'll tell quickly: we talked to one religiously-affiliated nursing home in Wisconsin that told us that, what they did every night was light a candle and pray that they would get a reward payment. Probably not what CMS had in mind when they designed the demonstration. [laughter from the audience]

It's interesting – there's this broader economic literature suggesting that incentives alone without any kind of education are unlikely to succeed in the context of a complicated task. Preventing a hospitalization is a really complicated task; preventing a pressure ulcer is a really complicated task. There's a series of these that we asked these nursing homes to undertake. The feedback we continued to get from the participating nursing homes is that: 'We don't know how to do this. We need some guidance.'

And, ultimately, that led us to then conclude that you just can't fix payments – you also have to something at the delivery level. And that led us to conclude that payment reform is necessary but not sufficient towards actually reforming the system.

So that leads us to this upper right quadrant. I hopefully have convinced you that you can't just fix delivery, you can't just fix payment – you ultimately need to do both. And there's a great example of this. I'm on the *Path to Reform* slide right now, and I just went forward one slide to the slide that introduces, in that upper right quadrant, the 'Integrated Care Demonstration' program.

This was a demonstration that was just introduced under the *Affordable Care Act* – 'ObamaCare' – here in the US, and it's quite new, but...next slide please. The Integrated Care demos have actually come online: 26 states received funding and approval to develop these models to coordinate care for duly eligible individuals. Once again, these are individuals where Medicare pays for their healthcare; Medicaid pays for their long-term care services.

Many of these individuals, as you saw earlier, have dementia. There's incredible variation across the states in the models of payment and delivery. But the basic idea: at the payment level, these states are blending Medicare financing for healthcare with Medicaid financing for long-term care. So they're sort of sharing in the risk and reward of investment at the payment or policy level.

Then on the ground, they're investing in incredibly innovative programs, whether it be medical care homes, whether it be case management programs. All sorts of, I think, really powerful innovations to try to better deliver and manage care for dementia patients and other chronically ill patients, other duly eligible patients – once again, these are individuals who are older and poorer, so the frailest sickest patients in our health care system here in the US – trying to reform the whole system of care for this population.

And quickly you can see that those programs are underway in a mix of states. The states in orange are the ones that are furthest along with the program. The states in blue, they are the states that have withdrawn their program. And the states in white, like Florida or Pennsylvania, are the states that haven't, that chose not to put forward programs.

Now it's obviously unfortunate here in the US that we have some of the usual suspects that are developing these programs and moving forward here, lots of states, both in the southeast and, I guess, in the Midwest there, that aren't. And that's something to think about with this kind of state-driven reform. Will we, will we end up with kind of the usual suspects in this real gulf between kind of the doers and the stayers, if you will, or the haves and the have-nots, whatever terms you want to use here. There's unfortunately a lot of states that aren't moving forward with these programs. Next slide please.

So, what are the challenges in terms of moving forward with this kind of reform, with these integrated care reforms for the duly eligible? Well, first, here in the States, we face this problem that you can't mandate that individuals join these programs, at least on the Medicare side. And so some of the states are being very innovative with nudging individuals into these programs. However, this is a very sensitive topic, obviously, when you have dementia patients, when you have patients that may lack the ability to make a really informed decision across multiple plans. We're now, in many of these states, having them opt out rather than opt in to these programs; basically, passively enrolling individuals into these Integrated Care Demonstrations. We could have a nice debate or discussion about whether we should be doing this kind of experimentation on this very frail, vulnerable population. Some might argue this is exactly the population we want to be kind of innovating on; others might argue this is exactly the population we want to be really cautious with.

I've already sort of highlighted this tension between federal versus state approaches. I don't know if that's an issue in Canada versus national versus some of the initiatives in the different provinces. But here in the

States, we have very different managed care penetration, very different health infrastructure from state to state. It's hard to imagine that there's a one-size fits all solution that would kind of work for every state. On the other hand, you saw that map on the last slide. There are a lot of parts of the country here that really aren't moving forward with any kind of program.

And the final point: historically, we have been very rooted here in the US in fee-for-service. Many of these state programs are thinking about capitated models using managed care. That's very exciting to me; I think there's a lot of potential there. But, once again, certain markets and certain states here in the US are much better positioned to move forward with that than others.

I just wanted to show you – next slide please – some data that we published last year in *JAMA Internal Medicine*. We looked at a cohort here in the Boston area with advanced dementia. These were individuals from 22 Boston-area nursing homes. And we looked at health and utilization outcomes, we compared individuals in traditional Medicare fee-for-service versus those in managed care.

And I won't have time here to talk through every line of this rather busy slide, but I did want to draw your attention to the second line there in terms of the outcome, "Hospital transfers for acute illness." You see there the percent was 15.7% for those in fee-for-service versus 3.8% for those in managed care. And there's a lot higher use of nurse practitioner visits in that managed care population. So clearly, some differences in terms of inputs there.

So maybe, hopefully they can distribute the slides. You can look through this or find the paper and work through this in more detail. The point is that managed care in our small sample in the Boston area seemed to do a lot better job for this dementia population than traditional fee-for-service.

So, final slide here, *Concluding Thoughts*. I wanted to go back to my patient vignette, Miss B, and suggest that, in an integrated model – maybe under the Integrated Care Demonstrations, maybe under other payment and delivery models here in the US and Canada – I can imagine her with one ID card; a comprehensive set of benefits that encompass primary care, acute care, medications, and long-term care; she would have a coordinated provider team and a comprehensive individualized care plan; and health care decisions wouldn't be made based on the financial interests of the different providers at play, but rather based on Miss B's needs and preferences.

Obviously, these are big goals. It's going to take time to get there. I think we're making progress here in the US. It'll be interesting to hear what's going on there in Alberta. But I certainly think we're making progress towards this end.

I'll stop on that point, and open it for any questions, or I don't know if we're going to move to the panel. But I very much once again thank everyone for their attention, and hope at a future date, to be able to join you in person. Thank you.

Questions from the audience for Dr. Grabowski

Dr. Tyrrell: Thank you very much, Dr. Grabowski. So we have time for a couple of questions, at least. And, are there some questions from the audience? And David can hear the mics you use with your questions, so it'll come through to him very clear. We have one question coming up here.

Yvette Dick: Hi, my name's Yvette Dick. I'm the Director with Alberta Health Services for North Zone, and in my portfolio I have a number of long-term care facilities. One of the things that we're doing here in

Alberta is using the RAI tool to do our funding. And it's not my favourite choice of funding, and I know that we're being told it's being used internationally. Is that what's being used in the States to dictate the funding, is the first question I have.

The second comment that I'd like to make is that it's been my experience the current RAI tool is tied to our staffing, which is often ineffective. And so our staffing is at unsafe levels, which increases the risks of injuries to our residents and staff, and then subsequently contributes to increased potential sick time and overtime. We do transfer residents to acute because the level of staffing precludes the ability to provide complex care.

Our staffing levels also increase due to wound issues, increased use of restraints, meds which are costly, and this of course contributes to lack of quality of life and our fiscal reality because of the meds we're using. And so, but I recognize we would need time to change our culture, because our staff are now so task-focused that, if they were to actually have the time to work with residents, that they could become more contracentric.

Because I said to our staff many many times, if you don't try to change the behaviours, if you try to work with them, you'll have more time at the end of the day. But it's really really difficult in a culture that's so ingrained with 'I got the next person, got to get the next person, got to get the next person', that it's really really tough to change that over to what we're trying to present to them. So I'm just wondering if you have any comments on any of that? Thanks.

Dr. Grabowski: I very much take to heart everything you just said. We see all of those issues here, here in the US. We also, I think, have struggled with kind of payment issues, especially with vulnerable populations like individuals with dementia. I think, historically, we relied on the minimum dataset to sort of code up and use the RAI to basically come up with a value in terms of payment, at least through Medicaid. And I think that payment rate has been completely inadequate in a lot of instances.

So how do we go about thinking about new models of staffing? As you were speaking, one of the big evaluations that I'm working on right now is a big cultural change initiative called 'Green House' here in the US, where it completely turned kind of a US nursing home on its head. Where these are small communities meant to resemble a home actually, and eight to 12 elders are living together with a universal worker. It's individuals of all sort of backgrounds and different payments sources, different health conditions, residents with dementia are living in these small homes or communities.

But I think they've taken a very different approach to staffing, where they've thought about universal workers, and it's much less about documentation and recording, and a lot of kind of classic sort of MBS-based measures that we've seen. It's much more about direct patient care. And so, like a lot of models here, it costs more. And so you can think about, it's very similar to telemedicine. And then nursing homes are investing in the Green House model, whereas other potential entities like Medicaid and Medicare might be enjoying the savings here.

And so, we haven't seen wide-scale adoption of that kind of model. But I'm very intrigued about it, because it, once again, it's an opportunity to really deliver better care. And if we want to think that at a more system-level about savings, this is an opportunity to incentivize those kinds of models, those delivery models that may offer kind of better staffing models and ultimately better performance around this population.

Dr. Tyrrell: Thank you David. Another question here.

Braden Manns: Thank you for the excellent talk. Braden Manns from Calgary. I commend you for doing, even if it was relatively small, this cluster-randomized trial of these different payment, or the telehealth model. Actually, we have this single health system where you can actually measure the impact of costs in the hospital, and you have lots of clusters of nursing homes in Alberta that you could test these sort of policy interventions. What barriers did you face in setting up that randomized trial with the nursing homes and things, and how did you overcome them?

Dr. Grabowski: Several barriers. One, I think a lot of providers here are relatively risk adverse about wanting to participate in research studies. Basically, they don't want to look bad, one. That's always a part of it. But I think, beyond that, I think they don't see the return directly to it, in terms of having to invest and having meetings with us and time spent with us.

The second barrier, and this was pretty interesting, is that – I showed you the overall results of the study, but if you have an opportunity to go look at the paper, you'll see that – out of the six nursing homes, two of the participating nursing homes that received the telemedicine intervention basically didn't use it. So the whole sort of effect there was from four nursing homes. I think a big part of the study was that even at the delivery level, even when a nursing home chain basically made this service available, the old model of care was so entrenched to a couple of these nursing homes. One of the facilities was just terribly run, it had, I think, a really bad administrator that didn't want to implement the intervention, and so it sat in a closet in his office rather than being used at the bedside. And then, in the other facility, there was a very kind of what I might term old school medical director. He just believed that this wasn't sort of helping him coordinate care, it was actually introducing another provider into the system and further fragmenting. And he thought sort of the classic on-call model was a better model. So he didn't want to use it in his nursing home.

So, that was the sort of resistance we faced, and that was really eye-opening. Going into it, I felt if you make this available, homes are going to love and they're going to use it. When we did the training for the different staffs, they were really excited about it and they wanted to use it. But that wasn't always the case with leadership at the different nursing home level. Even though the chain had bought in, the individual nursing homes didn't necessarily use it in all instances.

Dr. Tyrrell: Thank you David. I think we'll stop the questions now and there'll be a very short break, and then come back to the panel discussion.



Panel Discussion

Moderator: Janet M. Davidson, Deputy Minister, Alberta Health

Panel Members: Dr. Duncan Robertson, Dr. Carole Estabrooks, Corinne Schalm, Dr. Banerjee, Dr. Grabowski

Dr. Tyrrell: I would like to reconvene if we could for the panel discussion. And, as I mentioned before, the panel discussion is going to be chaired by Janet Davidson, who is the Deputy Minister of Health. And she is probably the most experienced person in health care around, with over 30 years in health care, that's varied from Deputy Minister of Health, to in the health care delivery systems, and to humanitarian work. Really a person – and, worked with industry. So, I just want to say, Janet, thank you very much for coming back to Alberta and, please, take over here today.

*Moderator: Janet M. Davidson, Deputy Minister,
Alberta Health*



Well thanks very much, Lorne. As Lorne mentioned, I'm going to be the moderator for this next part of the program. We've really been privileged, in my view, to hear two really excellent keynote presentations, so I do want to thank IHE for setting up the event and bringing them in, even if one of the presenters was a virtual presenter. But it was really quite something.

I would like to just take a moment though to recognize, we have some additional people who joined since the session started. And I won't pretend to be able to recognize all of them, but I see Steve MacDonald, who's the Deputy Minister of Innovation and Advanced Education, has joined us. We have Chris Couture, who is one of the assistant Deputy Ministers in my department, responsible for health policy; Dr. Tom Noseworthy, who is really leading a lot of the SCN work within Alberta Health Services; Shannon Spenceley, who is the president of CARNA; Linda Stanger, who is with CLPNA; Pam Valentine, who is the COO for Alberta Innovates – Health Solutions. I see Roger Palmer, a former Deputy Minister, is here. And there are a number of other leaders in the continuing care, long-term care sector, which I think is really a signal of the interest in this particular topic.

In fact, as I was listening to Dr. Banerjee's presentation, I started to think about, you know, 30 years ago or so, when I went into health care and nursing, the chances of ever sitting down and listening to a topic like this would have been non-existent. In fact, we were just starting, and it's probably...that would have probably been too early to actually sit down and talk about mental health. And I was struck about some of the things that, when he talked about professional and public attitudes, well, those were the sort of things that we were talking about, that just surfaced in mental health, really, in the 90s. Looking at early treatment, quality of care from diagnosis to end-of-life: these are things that, I think, are now much more on the agenda.

And, certainly, both speakers talked a lot about the importance of incentives, and how either the right ones or the wrongs will drive certain, whether it's institutional behaviour or individual behaviour. And they can really end up undermining what might be a serious intent to do something.

So, with that, I really want to move on, to the panel discussion. We've got three more great people that we're going to hear from. So I'm going to call on each of them in turn. And then they, along with Dr. Banerjee and Dr. Grabowski, if he's, I understand, still going to be available virtually, and perhaps the Minister would join us as well, and that we'll have kind of an open question and answer session. And not just question and answer, but more of a dialogue with the audience.

So, I think what I'll do right now – if I'm going to try to manage the session so we're pretty much over by six o'clock or around there – so I'd like to introduce our first panel speaker, who is Dr. Duncan Robertson. He's a practicing geriatrician, a senior medical director of the Seniors Health Strategic Clinical Network. He and I earlier were talking about the first time we met. And I was on the, there was a geriatric council within the city of Toronto, and Dr. Robertson was actually leading that work.

But he's one of the first physicians in Canada that's been recognized as a specialist in geriatric medicine. So, for most of us, myself included, the challenge of dementia is an important thing to talk about at a meeting like this; Duncan goes out and meets the challenges of dementia every day. And so I would say thank God for him, and for the SCN, and for anyone who cares about seniors in the province. It's a job that just gets

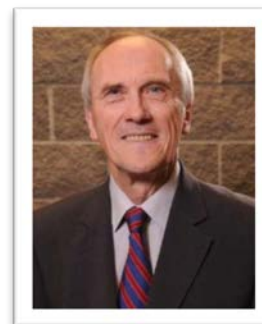
tougher, as we understand, but the rewards can be significant. And the progress we're able to make, I think, is due in large part to individuals like him and yourselves who really want to make a difference.

So, Dr. Robertson, I'll invite you to come forward.

Panelist: Dr. Duncan Robertson, Seniors Health Strategic Clinical Network, Alberta Health Services

So, thank you very kindly. After a kind introduction like that, I've really got to deliver. [audience laughter] And also within 10 minutes. And so, my first slide.

What I've tried to do is to answer two questions: what is Alberta's Seniors Health Strategic Clinical Network, and how are we trying to address emerging issues in an aging Alberta, and quite specifically the issues of dementia.



SCNs had their origin approximately two years ago, and two individuals, Cy Frank and Tom Noseworthy, were instrumental in developing these. And they were designed to improve all these issues here, which I won't read, through patient outcome satisfaction through to prevention and value for money.

Originally, there were six SCNs created in June of 2012, almost two years ago; seniors health is one of those. Some operational clinical networks have been added: respiratory and then, this month, primary care and chronic disease management has been added.

When you look at the titles of those SCNs, you'll see that most of them deal with issues that pertain to or are common and prevalent in older individuals. And so, when we created our SCN, we looked very carefully at our first meeting almost two years ago about what we should focus on.

This is our group, of the leadership of the SCN. On the left-hand side you'll see that we have a core committee of about 40 individuals, about half of whom are clinicians, and there's representation from all zones in the province, and many interest and representative groups. We have working groups and about 300 people in a community of practice, plus a researcher network that now runs, I think, about 70 individuals, from all parts of the province.

In our first meeting, we identified two of these platforms, which are the horizontal stripes in green, and more recently we've added the pillars beneath them. But let me just talk a little bit about the individual platforms, and the arrow indicates one of those platforms that I am going to be speaking about. Professor Banerjee in his discussion talked about use of antipsychotics, and that was our first project that we set up, approximately 18 months ago.

So, the lower of those platforms is 'Anticipating an Aging Alberta'. This is a non-clinical platform, and, to summarize briefly, we'll listen to anyone that talks and talk to anyone that'll listen about what it will be like 20, 30, 40 years from now. The one-liner on that that I use - I commute a lot by WestJet: 'What will it be like when everyone is a pre-board on WestJet?' [audience laughter]

So we're prepared to talk to anyone, and partnering with educational institutions, and look at the opportunities and the challenges that are posed by the changing demography of Alberta.

The second of those platforms is 'Healthy Aging and Seniors' care. And this is around preventing, anticipating, optimizing, and living with conditions that compromise health and functional abilities in old

life, later life. We've separated this one a little bit from dementia, recognizing that comorbidity, frailty, and dementia overlap significantly. But on this one, we're going to be talking about healthy aging and also the patient journey of individuals who survive to advanced years, with or without any cognitive impairment, and have complex comorbidity and frailty.

One of the other issues that we've just thought about in this is – and it resonates with self-efficacy and Professor Banerjee's – is the development of resilience in old age. Would developing resilience, or maintaining resilience in old age, improve quality of life? Can we learn it? Can it be taught?

The one I want to spend some time on is 'Aging Brain Care'. And again, this is preventing, anticipating, and living with conditions common in later life that result in cognitive changes. And Corinne will talk later, I think, about our work together on: a possible provincial framework and strategy and an action plan for dementia; every opportunity we get for public education; talking about dementia care in the community; and we've been liaising with the Alberta College of Family Physicians, who have an interest group in seniors care and particularly in dementia; and looking at the various technologies that may enable us to maintain older individuals with dementing illnesses in the community.

One of the deliverables is to develop an evidence-informed care pathway, from health promotion through to end of life care with dementia. And along that pathway, which I'll describe in a few moments, there'll be various modules, along with guidelines and protocols.

The journey from the earlier signs of perhaps mild cognitive impairment through to end of life may be a 15- or 20-year journey. And if individuals go to the United States to get amyloid scans, that may put that journey as a 40-year journey, from the first identification of some amyloid in the brain through to end of life with dementia.

So, here is a first attempt at a pathway, in that the middle section of the pathway is being deliberately left blank because we've used this to discuss with other people the kind of things that are going to be needed in that middle phase of the care pathway. Initially, it's around healthy aging: prevention, maintaining function and well-being. The issue of the 'worried well' – and I think some of the discussion we had about the utility and perhaps the damage that could be done by widespread screening for the worried well, as opposed to early identification of individuals who have beyond cognitive...memory impairment, who have other domains of cognition involved, and may be early in their journey of dementia – was well covered earlier.

Clearly, early on in this we're talking about safe driving and issues around financial management. And then also having discussions around goals of care and planning for the future. The area that's been highlighted is antipsychotic use, which was our first project that we've been working on. I'll spend just a few moments talking about that.

Clearly, in that long journey of the dementia, which is most often progressive, there are stages, and the early stages are as shown here. But it's in the middle stages that we often get a group of conditions that are being called BPSD – behavioural and psychological symptoms of dementia – or neuropsychological symptoms of dementia, and more recently we're calling them responsive behaviours. It's in that phase that many individuals are admitted to hospital, often with delirium, get started on antipsychotics, remain on them, and there's a high prevalence of use, not only in the community but more markedly in the long-term care sector.

So our first project was to reduce the use of antipsychotic medications in long-term care facilities. And we developed a clinical practice guideline and toolkit of resources that would enable staff in long-term care

facilities to better manage those responsive behaviours. And we used as a key performance indicator the RAI 2.0 indicator of the use of antipsychotics without an appropriate indication.

These numbers will look high to people from the UK, in that this looks at the prevalence of antipsychotic drug use across long-term care facilities in the absence of psychosis in facilities in various zones. You can see that the Canadian average is around one-third. There are some areas of Alberta that were lower than that, but some zones were quite high.

We set out a project to use some innovative learning methods in eleven early adopter sites. This was not the entire facility, but a unit or units within those facilities. And this was to demonstrate that this could be done. We're now in the phase of rolling it out to the remaining 160-some facilities in the province – I think it's 14,000 beds.

All zones were involved. There was a mixture of urban and rural, small and large sites, and a variety of ownership and operator models. You can see the sites on this slide.

This graph summarizes a pile of data that's been collected and an evaluation is currently underway. Essentially, the blue line shows medication reviews being done on a monthly basis in those 750 beds, in those 11 sites. And they went from just over 30% to almost 100% in the course of the period between June of last year and January. And the antipsychotic use, you can see, declines from about 40% to just over 20% in those sites. And the sites that were chosen were sites that had a high prevalence of use.

So we're now in the phase of a provincial roll-out. We're using a variety of techniques including: distributing the guideline and toolkit resources to all sites; there are e-learning modules; and there are multiple presentations and practice leads going out to these sites to enable them to implement.

There is a tailored intervention underway right now, that looks first at the sites that have an over-30% utilization, and then gradually, deals with those in a different way than those that have much lower utilization rates.

So, finally, we have a strategic clinical network transformational roadmap, which is both on the internal and external AHS website. And I'll conclude at that point, and hopefully I've kept within the 10 minutes.

Janet M. Davidson: Well thank you very much. I think we'll just go through all the speakers and then have everyone come up front to have some discussion.

But our next speaker is Dr. Carole Estabrooks. She's from the University of Alberta. She's another leader in this field whose name, I'm sure, is familiar to most if not everyone here. She's a Tier I Canada Research Chair, a leader in nursing research, a fellow of the American Academy of Nurses, and a past Vice Chair of the Canadian Institutes for Health Research, Institute of Aging. So please join me in welcoming Carole.

Panelist: Dr. Carole Estabrooks, Canada Research Chair in Knowledge Translation; Professor, University of Alberta

I'm here to try in the spirit of Sube to be optimistic, but make no mistake I'm talking about what my mother used to call the 'grim reaper'. And I wanted to talk for my five or six minutes about end of life care, because we have an



extraordinary death aversion in our culture. We don't like to talk about it, it's hard for us to talk about it. And failure to talk about end of life is as catastrophic, I'm going to submit, to older folks with dementia as is failing to diagnose dementia early, so that we can do some things that make things better.

I've put the end slide in first, in case I get hauled off the stage for going over my time. I think there's some really important policy issues in end of life care: managing transitions well is an important one; advanced care planning; education and training for the workforce; access to early palliation in the trajectory; support systems; and after death support for caregivers and staff including families and paid staff, which is something we often neglect. And I'll come back to these later.

This is a wonderful success story: Canada is a world leader in living a very long time. We've made extraordinary strides in our culture, and we are only outpaced by Japan. So we have lots to be proud of, but of course it's a bit of a double-edged swordness to the fact that we live so long.

Increasing numbers of Canadians are going to have dementia because age is the biggest risk factor. One in three Canadians over 85 now has an age-related dementia. And, as we sit here, the International Alzheimer's Society projects that they'll be a new case diagnosed every four seconds. So that's a lot of people who are going to have dementia.

Dementia is, I'm going to submit, a "wicked" problem. A "wicked" problem is the way that we characterize problems that are difficult if not impossible to solve. I don't think this is impossible, but it is difficult. It affects a lot of people, it costs a lot of money and it doesn't work like that "Mouse Trap" game where you let the marble down and everything just kind of goes until it plops in the little pail at the end. This is more like a squishy amoeba: you push it out in one place and it comes out in unintended ways and others. But if dementia is a wicked problem, then end of life care – appropriate end of life care – for those with dementia is an especially wicked problem, and one that demands more than the health system can offer. It demands health and social innovation and, quite likely, other forms of innovation.

So better community and supportive living arrangements are keeping people at home longer, in the community longer, in alternative kinds of facilities than we used to have. However, sooner or later, the care needs of the person with advanced dementia tend to overwhelm the caregivers.

The most common reason for admission to long-term care or nursing home – and I'll use those terms interchangeably – is the inability to cope with increased care demands, some of which you see on this slide. They consequently, these older adults, arrive late in their course of their dementia, much later than they used to, often with multiple other conditions. They are highly complex; they are highly vulnerable, largely due to the severe communication difficulties that are associated with late stage dementia; and with much heavier care demands than in the past. And they stay because they come later, much shorter periods of time in the past, making nursing homes and long-term care increasingly about end of life care. I'm going to argue that the goal, or at least a major goal, of care in these facilities is optimal end of life care.

About five years ago, Susan Mitchell in the United States published this paper in the New England Journal. And she argued – well, she didn't argue it, she just described something, it was first time that it had really been described – what symptom burden is in the person with severe dementia at the end of life. So this shows that, as you go from left to right across five really distressing symptoms and you get closer to death, the frequency of the symptoms increases. And these are not trivial symptoms; it's unpleasant to be short of breath, in severe pain, to have a pressure ulcer, to be choking on your own secretions, and to be agitated.

And it's not just uncomfortable and distressing for you the resident; it's incredibly distressing for the families and the caregivers.

There are no Canadian data published yet – I hope that soon we have Canadian data published. These are from data we have and some of the research we're doing in the three prairie provinces. And we took, we had about 1,000 people on the left hand part of the slide and about 500 on the right. And we divided them out into the people in nursing homes so that we could follow intact for a year, with dementia on the left and without dementia on the right.

So, and we took we close to the five symptoms as we had in the ride data as Dr. Mitchell had in her publication. And what you see is high symptom burden – and it gets higher as you get toward the end of life – but particularly in the group with dementia, the burden is higher. So these people are not only vulnerable and complex, they're experiencing far greater levels of distressing symptoms than people in nursing homes without dementia.

This is important information for us to have for two, for lots of reasons. It is, can be in some cases, less expensive if we treat these things appropriately or prevent them. But even more important than the cost savings you'll get, the reduction in human suffering is difficult to measure but important, I would submit to all of us.

So we have, we do applied research in the sector, and we focus on things like quality of care, and quality of life, and quality of end of life, and quality of work-life, and other things related to quality. One of the things that we're trying to do to deal with – and we have moved our work increasingly over the last five to seven years toward looking at the time that a resident spends in nursing home as the time at the end of life – is begun to look, especially as the trainees come on board, and try and address some of the burdensome symptoms like pain and depression and the consequences of poor oral health, and to begin to look at what these trajectories look like at the end of life in the Canadian system, and what can we do about the parts of those trajectories that are modifiable?

So, back to the policy issues. I'm hoping that we'll have some discussion when we get to the panel about how we address some of these issues, and how we prioritize them, and whether some of them, in fact, should be moved up in priority or, perhaps, removed from the list.

So, thank you very much for your patience, and I didn't get yanked off so that is always a good sign.

Janet M. Davidson: Wow, lots of food for thought in that presentation.

I'd now like to introduce our third panelist, and this is Corinne Schalm. Corinne is actually within the Ministry of Health, my own department. She's our Director of Access and Innovation in Continuing Care. She's got an MSc in gerontology and a Masters in public administration. She's a fellow of the Canadian College of Health service executives. She's part of the national network of people that are now looking – and quite passionate, actually – about improving life and care for seniors, whether it's a part of a research project, or in policy, or planning. So, Corinne, I'll ask you to come forward please.

Panelist: Corinne Schalm, Access & Innovation, Continuing Care, Alberta Health

So I've borrowed a slide from Carole, my co-panelist, to start off, because I



find it so compelling. Deaths – this is US data, so if we can find the Canadian data, that would be great – but deaths from chronic conditions, at least in the US, have been decreasing over the last decade with one exception, and that's deaths from Alzheimer's. It increased by 68% in the last decade, or between 2000 and 2010. Alzheimer's disease is the only cause of death among the top 10 in America that cannot be prevented, cured, or even significantly slowed.

I won't spend any time on this. Our other key note speakers did talk about the economic burden that's recognized in Alberta as well, the economic burden of dementia.

Most people with dementia are cared for in the community by family and other informal supports. The demand on family and informal caregivers will continue to increase. Dementia, of course, is a risk for admission to continuing care. In 2011-12 – our last available data – almost two-thirds of residents in long-term care facilities; 57% of clients in designated supported living; and 28% of home care clients had a diagnosis of dementia or Alzheimer's disease. And we know those numbers are likely underestimates, actually, of the prevalence rate.

Since 1999, seven provinces have released strategic policy documents to address dementia, BC and Quebec being the last or the most recent ones to release theirs. And there's a lot of common themes in each of those strategies. There's been calls for a national, pan-Canadian dementia strategy from the CMA, CNA, the Alzheimer's Society of Canada, CARP, and, most recently, yesterday at the BC Care Providers Association meeting that was reported on the front page of the *Edmonton Journal*, MP Claude Gravelle has introduced a private member bill calling for that national strategy. So far, the federal government is seeing its role in dementia as one of supporting research.

Dr. Banerjee talked about the national dementia strategies around the world. According to Alzheimer Australia, Australia was the first country to make dementia a national health priority. In 2005, it allocated \$320 million in funding, along with their strategy. Whether or not Australia was the first, the point is we see a significant amount of interest in these strategies over the past decade.

So why now? The need has been identified by our speakers this afternoon; it's not new, but there's a growing sense of urgency that we're seeing across the globe. Internationally, our Minister has spoken about the G8 Summit that brought together the national Ministers of Health, as well as our provincial Minister. And the key goals for this summit were just to start coordinate better the global action on dementia, to agree on a new international approach to dementia research, and to secure further international collaboration. And as a follow-up to that event, Canada, through CIHR, will be co-hosting with France an invitational event on dementia in Ottawa this fall, in September, to discuss new models of collaboration.

In Canada, I spoke just recently, or just earlier, about the interest in a pan-Canadian strategy. We also have the Health Ministers were working together, and the Premiers actually identified dementia as one of their priority areas for the Ministers of Health to work on. And Alberta is co-leading the senior's committee there, where we're looking at dementia.

And, in Alberta, we have the Seniors Clinical Network that Duncan just talked about. We have Campus Alberta Neuroscience, which is a province-wide network of about 250 professionals working in neuroscience and mental health. And their initial area of research focus is on the healthy brain, aging, and dementia. So the SCN had said that's their initial area, Campus Alberta Neuroscience, and we also have Behavioural Supports Alberta. And I see Suzette here today who's been organizing that. It's a provincial

network of service providers, caregivers, policy- and decision-makers – research, again, focusing on supporting individuals with challenging responsive behaviours, including those associated with dementia.

So the Government of Alberta and Alberta Health Services, working with our partners, are just in the very planning stages right now, looking at development of a dementia strategy. And some of the initial thoughts are: certainly, it would need to support other initiatives, not just in the health industry; it will need to be based on input from Albertans; it would identify where are the gaps right now; and build on some of the prior efforts and learning from other jurisdictions. It could address: the continuum we anticipate from prevention to the end of life care; impact on Albertans; the key issues and the programs and the services; as well as opportunity for more partnerships; and looking at a provincial research strategy.

The numbers of people with dementia are increasing and will continue to do so for the immediate future, we heard today, the next 20 to 30 years. We need to do a better job with educating society; of de-stigmatizing this condition; of working together in our communities to assist those with dementia to remain at home as long as feasible; of supporting research that will one day lead to a cure or a significant delay in onset of symptoms; and, until that happens, of supporting research into best practices and caring for those with dementia; and of supporting caregivers – both informal and paid.

The strategy itself has to be bigger than Health Services, it has to be broader. This is a societal strategy. It cuts across government, across ministries, involves a multitude of partners outside of health care, outside of government. It has to be thoughtful and evidence-informed. The use of fear-laden, ageist language such as “grey tsunami,” “bankrupting our health care system,” serves only to pit groups in society against each other and misinform the conversation, and that’s not helpful.

Both our approaches to care as well as our policy around dementia need to be evidenced-informed. And we need to learn from other jurisdictions, both what they’ve done, and also what hasn’t worked; we need not just do the status quo and adopt it from elsewhere. So events such as today’s, where we bring together policy-makers, researchers, practitioners, are critical to the conversation, to bringing together “the tribes,” to quote my fellow panelist, Carole Estabrooks.

Although my first reaction to being on this panel was to emphatically suggest “just stick to the experts in the content area,” and I am not one, but as I reflected, as I was preparing for this, this panel is actually a good example of what we need to be doing in this province, and I think we’re beginning to do quite well. We have the Seniors Clinic Network focusing on clinical improvements, which includes representatives on it from the research world, as well as the policy world, to inform clinical improvements. We have the research world, in this case the Track Project, which just officially launched its second phase of work last week, and has been very intentional about including in its group, all of its structures, representatives from the direct care side of things and from the policy world to inform their research. And we have a policy rep coming from the perspective that it is our deliberations about provincial policy and where we can invest our limited resources in those, we need to involve those from the care community, and be involved with and informed by our research evidence.

So, with that, I will turn things back over to the chief of my tribe.

Questions from the audience for Panel

Janet M. Davidson: Thank you very much, Corinne.

I'd now like to invite the other speakers to come forward, and, Minister Horne, if you'd like to join the panel, that would be good. And I believe we still have our virtual panel member, maybe hooked up via Skype.

This has been a very valuable discussion we've had so far. We've had some very good presentations that give us perspective in, globally, on a number of the initiatives that are taking place, in particular in the UK and the United States. That's been followed up by some, I think, some very informed presentations on work that's occurring in Canada and, more particularly, right in our home province. Sometimes I think we can get lost in looking at all kinds of other things and not understand what we might be doing ourselves, so I think that's useful.

So I would now like to turn it over to you, the audience, and see if we can get some discussion going. I thought I might start by just saying, 'Okay, so we've heard all this, what's the next step?'

Don't all jump in at once. [audience laughter] Go ahead.

Unknown speaker 1: Well, I'll jump in. I think we need to increase our public conversation. I don't think we've created yet enough - we're starting - enough spaces to hear what it is the people with dementia and the families living with folks with dementia are facing in the kinds that - we think we know what all the challenges are, but I'm guessing that we only know some of them. So that's where I, one place I would start.

Dr. Robertson: The one area that I would add is that one of our areas of work at the moment is looking at a Dementia Link, to be a backup to Health Link, to give advice to some patients who might telephone, or particularly to caregivers and providers, around some of the issues in the caregivers' face in managing people with dementia in the community. We're working on that at the moment.

Janet M. Davidson: Any of you have, would you like to make any comments, or we'll just open it up for...? I see we have, well maybe we'll open it. Tom, Doctor Noseworthy?

Dr. Noseworthy: Hi, thanks very much. This has just been a great afternoon for me. I'm preoccupied by this subject. Every weekend I spend a lot of hours in long-term care facilities with my wonderful mother-in-law, who's only six months short of 100-years-old right now. And every time I go, there's a learning experience. I'm also preoccupied by it because I'm on the National Center of Excellence for the Elderly, and we're starting trying to get some traction on what we're doing right now. And it's from those discussions that I put this point to you.

I'm really troubled by the problem that we seem to have with growing prevalence and need for care provision, and the problem that we have with our geography in Canada. Yeah, we could learn some things from Japan, but the problem we have with our geography is that our cities are getting younger and our rural areas are getting older. And we are acting in our cities to squeeze old people out to the periphery because costs are going up, taxes are going up. If you look at the demography, most of the people that we are going to be trying to gain access to in the future are not going to be in our cities where all the care plans are and all the facilities are.

What's the suggestion? You know, we got one or two here, one or two there, they're going to be separated by long distance. Rural existence for seniors are coming, I know it, I'm starting to enjoy it myself. What are you going to do about care provision in this setting? Telehealth will take us probably some distance, but care provision at the individual level, what's the suggestion?

Hon. Fred Horne: I'll make a couple of comments from a health system perspective. I think, first, this discussion, which is about a very urgent problem, it begs a larger question about our whole attitude toward the provision of care to seniors. And like most provinces, Alberta, I would say, has had a preoccupation with building beds. We're just we're about to start to talk about a new approach to continuing care in the province that will see us actually reallocate resources that today are used for building and operating beds, reallocating a great portion of those to the community. We're currently targeting 1,000 beds a year, and, I don't know about others who are sitting on the panel, but I think that's a problem. Number one, because we know that we can provide a better quality of life for many people up to the point where they're approaching end of life care by not providing that care in an institution. And I think we have an obligation ethically to really question our present attitude. But, secondly, from a purely practical point of view, and particularly in a province as vast as Alberta, we are never going to be in a position where we can build enough beds, even if we decided that was the preferred locus of care. We'll never be able to build enough beds to meet the needs that people are going to have.

So that's kind of the foundation of the, some of the policy development work that Corinne is leading in my Ministry, along with many of the people in this room, to develop a new approach to continuing care.

I guess I will say as well that, from the people that I've talked to, how and when we use facility-based care, I think is something else that is very open to question. We don't have what I would call a robust discussion about end of life care in this province. It's actually, in some conversations I've been in, it carries more of a stigma today than mental health did even 10 years ago.

So I think we're going to have to kind of reignite that. We're going to have to look at the role of the institution in supporting end of life care. We're also going to have to look at dying at home. But, increasingly, we're going to have to regard our traditional mode of service delivery for seniors, the facility-based version, as a scarce resource, as an increasingly scarce resource, which is going to have to be reserved, in my view, for very specialized purposes. But that's just one opinion, I'm sure there's some others up here.

Janet M. Davidson: If I could just build on that and ask a number of the panelists though. I believe that, well, Dr. Banerjee started off by talking about professional and public attitudes that have to change, Dr. Estabrooks made the comments about public dialogue, and Dr. Grabowski and some of the experiential models that he gave us talked about that, despite there being certain incentives in place, that certain things didn't change. So how do you go about – it's not just the public – how do you actually go about working with the public and the professionals to say, for example, institutionalization is not the answer? Or, antipsychotics is not the answer? How, what sort of approach do you take in that regard?

Dr. Banerjee: There's no doubt that there are, there is an increasing demand that comes from people with dementia, and there's no doubt that the quality of we do at the moment isn't necessarily very good for people with dementia. So the answer to the question of what to do with this increasing problem is not to do more of the same; it's to do it better, and to do it differently.

So, for me, the challenge with long-term care for people with dementia is that people with dementia want to stay in their own homes. They have better quality of life in their own homes. But some of them do need to go into long-term care, but probably nowhere near the numbers that go in there at the moment, which are, for all sorts of administrative conveniences, often, in terms of, in the UK, for general hospitals.

So it's about changing things so that people are able to live in their own homes. And I think there are rural solutions to that in the same way as there are urban solutions to that. But it means doing things that would

normally be expected to be done in institutions, in people's own homes. I think that helps us to deal with the impossible challenge of, kind of, doubling the numbers of people with dementia, therefore doubling the numbers of beds. That's not the solution. So it is all about doing something differently rather than doing more of the same.

And I think that the opportunities that one has really do depend on the kind of capabilities and the capacities of particular areas. There are different things that will be done to maintain people in their own homes and different places. But if we can create communities that are friendly for dementia, communities whereby just having dementia doesn't necessarily mean that you can't use the local shop or the local bank, that people will enable them you to be safe within your own home, within your own community, because people are looking after each other.

And sometimes those things are easier in rural areas than they are in urban areas, as it may well be that there are capacities and resources that you have here that will enable you to go further and faster in supporting people in their own communities, because you have little communities, rather than in some other areas.

Dr. Grabowski: Quick, just to build on that answer. I'm very much also supportive of community-based alternatives. I think here in the US, we've seen way too much reliance on nursing homes. The big push here has been out of nursing homes into assisted living, but, unfortunately, assisted living, sort of residential care facilities, they haven't really, either from a quality perspective or from sort of a less restrictive model perspective, they haven't really measured up.

And so, if we want to think about this rural population: I talked a little bit about telehelp, and that can help on in a clinical side. But if we really want to pair that with long-term care services, which is a big part of the puzzle here, we need to think about services, whether they be community-based settings or home care settings, where even in a rural area there's the economies from a home care agency or a community-based setting where we can actually make that investment. Because, obviously, telehelp can get you some of the clinical side of this and that remote delivery, but you're not...it's not going to get you the long-term care.

And so, figuring out the right models, and it's certainly, I agree with the point, not more beds but rather rethinking or rebalancing our long-term care system toward more home and community-based services. Thanks.

Dr. Estabrooks: We have some barriers in the system that also make it difficult. We've got lots of barriers, I suppose. But families are different than they used to be, and so lots of our parents aren't where we are, and lots of our children aren't where we are. And it's not easy to move an aging parent across the country, because the rules are different in every province: the waiting periods are different, the cost of placing your parent or your, hopefully it's not, your child in a residential facility are different. So, if we could begin to think about how to remove those, that would help, but everybody can't and shouldn't move their parent across the country.

And it goes to issues of...I'm taken aback sometimes when I see the data about the importance of not being old, female, and alone to preventing bad things happening to you, especially around dementia. So that's social policy, that's not health policy, where we begin to think about how we begin to manage and talk about loneliness, and failure to engage socially, and isolation due to mobility or distance or whatever the cause might be.

And I think that's part of what I would see a large comprehensive dementia strategy would begin to help us talk about are some of those things, because we aren't going to change the things. It's like we talk about unpaid caregivers a lot, and how heavy our reliance is going to have to be on them. Except that will only work if we support the unpaid caregivers, so that we don't extract them from the workforce and have them themselves succumb to depression and a host of other things.

Janet M. Davidson: Thank you. I see we have a number of speakers. Yes.

Aruna Mitra: Thank you very much, it's been a wonderful afternoon. I think that has been a lot of very interesting things raised. My name is Aruna Mitra, I'm with Bethany Care Society. And I'm also an occupational therapist, and I bring that up because, when I think about dementia, when I think of myself as a clinician 30 years ago, we always talked about the environment and creating an environment that fostered optimal functioning. And I don't think you can actually talk about dementia, whether it's in the community or in long-term care or assisted living, without talking about creating a physical environment, a social and emotional environment that supports people's optimal functioning.

Doctor Banerjee started to talk about supporting people in the community and some of the changes that need to be made. We don't talk about things like accessibility. It's very very difficult to get any kind of funding to assist doing any home renovations and modifications to accommodate a wheelchair or any other kinds of things that people with dementia or other kinds of chronic illnesses require.

So it's not just about having support in the community with regards to things like home care. I think it's a broader conversation around a multi-ministerial approach to funding support that creates an environment, whether it's having the care providers that are needed in the right environment, but also having availability of resources so people can actually adapt to their environments to make them safe and accessible. I just wanted to raise that, because it hadn't been raised.

Dr. Robertson: If I could just come in on that one, because there is another environment that we could modify fairly quickly and have a major impact on the elderly, and that is the acute hospital environment. What we do know is that something like one-third of older individuals, and perhaps as many as half, of the over 85s, particularly those with dementia and frailty, develop functional disabilities as a result of their hospital stay, and not as a result of the condition that brought them in. And that has to do with the environment and care practices.

Our scientific director, Jayna Holroyd-Leduc, has been pioneering elder-friendly care. There is a proposal for a, there will be an elder-friendly surgical unit developed. I think widespread adoption of plans to maintain mobility and function during acute care would certainly defer, and perhaps avoid, some premature admissions to long-term care.

While it wouldn't deal with the demographic shift, it would have some immediate impacts on individuals who could go home. Along with that, we have to deal with the societal expectation that, in some parts of the province and maybe in places that you know, there's an expectation that the way into the long-term care system is through the acute care hospital. And I think that's something we have to discuss with patients and their caregivers, as well as with others working in the system.

Unknown speaker 1: Can I just jump in there a little bit too? I really support the speaker's comments about, again, that this needs to be broader than a health strategy. I look at initiatives such as age-friendly communities – that's not a health initiative, that's a societal thing. If the environment is better for elders to

walk around in, it's also going to be safer for moms and strollers and the rest of us who trip over our feet once in a while too. So, I mean, this is much broader that we're talking about here.

Shannon Spenceley: Hi, thank you. It's been a really really interesting afternoon. My name's Shannon Spenceley. I'm a registered nurse, I'm also a nurse researcher, and I'm also the president of CARNA. But, as I struggle to crystalize my question, I'm so tempted to ask it from the perspective of a daughter of a mother with dementia, rather than as a registered nurse and somebody passionate about primary health care reform.

So, I'll ask the researcher question first and that is, I hear precious little about connecting. We've got a, I think, a lot of energy and initiative that's gone into a primary health care strategy. And I see very little connection of it to a continuing care and a dementia strategy. And I also heard one of the earlier speakers say, you know, if we could do two things, if we get diagnosis happening earlier – and hopefully with research delay onset – if we could get diagnosis happening earlier, and then if we could extend that period of time between diagnosis and hospitalization or institutionalization, we could do a lot of great things for quality of life and also for saving the system money.

Now, I can tell you from a daughter of a mother with dementia, it's like every part of the system is doing their level best to get her the hell out of the department the minute she shows up. And that starts from...I live in a rural environment, and my brother and I both live in the same city. So we should have the perfect constellation of things: we live close by, I should be able to, you know, I'm there if Mom needs something. But trying to keep her out of institution and get the right supports in the home and have responsive primary care at moments when she really needed it...I know the system and I know most of the primary care docs in Lethbridge by their first name. But to try and get her in for responsive care, to intervene early in a delirium, was virtually impossible.

It was really easy to call the ambulance and get her to the emergency room – that was like drop dead easy. And then, once you get her in hospital, we really wanted to take Mom back home after multiple hospitalizations, we had the right family constellation to do it. But there was almost a...I think Dr. Banerjee talked about, you know, admission machines to long-term care – that's what hospitals have become, because they want to get them the heck out of hospital and, fair enough, and get them somewhere else. But that somewhere else isn't home, because the right supports are not in place to support a family who is working to try and support somebody in their home.

And now that she is finally in long-term care, to try and get the right supports in place so that she has a level chance of maintaining continence and maintaining mobility is virtually impossible. It's much easier to, the minute there's a bit of complexity, to get her in the ambulance and fire her back to the hospital and make it the hospital's problem. So there's this culture of avoidance and push it on to the next part of the system. That ends up costing the system a ton of money, and not doing much for the care and quality of life of people with dementia and families that are trying to care for folks with dementia.

So, to me, part of the answer – where do you tease apart this impossible knot? – part of it is authentically connecting the primary health care strategy to the continuing care strategy. And I'd like to hear some dialogue about that.

Hon. Fred Horne: Well, I'll make a couple of comments, because the release of the primary health care strategy is relatively recent event in our system. Number one, I agree, and I think your comment begs a number of questions. Number one, have we ignored primary health care as an important vehicle or as,

maybe as the key vehicle to delivering supports, including non-medical supports, that allow people to stay in the community in some form?

And I think the answer to that question is, absolutely, we have. But you can apply the same thesis to why we have such a high rate of hospital admission for patients with multiple morbidity, right? We learned last year, the year before, that about 5% of Albertans use about 65% of the health care resources. So I think you're correct in that the two need to be connected. And the policy work that we're involved in now, when you see it come out, you will see a very different orientation and you will see that linkage established.

But, if I could say candidly – and this obviously isn't from a research perspective – but one of the reasons that we are in this position, not just as a province, as a country, with respect to being ready for dementia, is that we just haven't paid attention to basic primary health care reforms that needed to occur. And, to a certain extent in Alberta, I think that's a function of all of the dollars that we've had to pour into health care. We have been able to indulge our focus on the hospital as the centre of everything. And that's resulted...and we still have more than anywhere else in Canada. We have more hospital beds per capita. So that would be my answer to that question.

The other thing that a few speakers have brought this up, and this is something I learned about in the UK, one of the ways to look at the big thing we haven't done yet is the question of the integration of health and social care. And I know that the UK is very much focused on this now. A lot of this problem is driven by government, because portfolios for Ministers and budgets and programs and services are not, in the planning stages, in the policy development stages, are not integrated. Therefore, budgets are segregated; therefore, program decisions are segregated; therefore, the needs of patients cannot be met, because we don't have that integrated focus.

So I think that's part of what we're trying to do in the Ministry now. I think the question is: can the patients and their families of today and tomorrow, can they wait for us to get that work done? Or do we need to be thinking about, as well, the things we can do right now, as you heard in the discussion about the SCN?

Dr. Banerjee: Yeah. To agree with that, really, I think that, I mean, there is nothing in the human genome that means that health care and social care spending should be in different pots. [laughter from the audience] These are constructs that we have generated for the administration of our countries or territories or whatever, and they don't work well for dementia – and dementia is simply an exemplar of many other conditions, also, the long-term conditions that are the true problems of the 21st-century. They just don't work when you have these siloed things, because you do end up with all these perverse incentives that we've been hearing about.

I think that we've generated systems that are focused on what is good and what is easy for doctors, for hospitals, for those administering those systems, rather than for patients. Actually, if you turn the thing around and say that, you know, a health service, a social service, is for patients, and you work out what you need to actually give good quality patient care, and then you make the system work for that, that's the way you end up doing things better.

In the UK, we only spend 8% of our health budget on primary care. So we've got...and something like 90% of all activity is in primary care. Yeah, that's wrong, and that means, probably, doing slightly less of some of things that we do in hospital, but doing them better in the community. And there's immense resistance to that, but that's the only way forward in developed health systems, as far as I can see.

And if we do that properly, then we end up being able to deliver better care to people's mothers, who then will be allowed and enabled to stay in their own homes for as long as they can, with good quality care. And we will use long-term care facilities when they really need to be used, for those who really need them, rather than as a way of shifting costs from general hospitals, which is what happens in the UK, that you don't want the person in the hospital, because it costs you more money, so you just get rid of them into another bed somewhere where the cost falls differently.

And we can change that because, as I said, these are man-made conditions, and they can be changed by policy, they can be changed by restructuring systems. It's not simple, but it has a tremendous benefit, if we do it properly.

Janet M. Davidson: I would suggest that...actually, earlier today, I was reading Alberta's social policy framework. They actually have, the province has given thought to the fact that, if you're going to advance social policy, there are a number of things you have to do. I would say that, given the comments of the speakers, it's now translating that into a structure that can actually deliver on the sort of things that you all say are important.

One last question, I think, from Dr. Tyrrell, and then, so is it alright to continue? Okay, so these last two and then...

Dr. Tyrrell: Okay, just a quick question. We live in a multi-cultural province, and I can tell you that, from some of the people that work in the health care system, frequently they'll come back and say there's a big difference in how some cultures handle patients that need to go back home after dementia or problems like this. And that, often, the Asian cultures will take them back much sooner and look after them in their homes, rather than the non-Asian cultures that tend to say, 'We're both working, we can't do it, you got to keep them here.'

So a lot of the care in the acute care system is because families are not ready to take them home, and some families have a culture where taking them home and dealing with them in that extended family is much more common. Is anybody doing studies to looking at the multi-cultural differences on how we handle dementia in our society?

Dr. Banerjee: I don't know the Canadian literature, but it is very clear that there are cultural differences in how older people are managed, and there are differences between countries, depending upon how health and social care systems are built up.

I think what's also clear though, is that there is sometimes an assumption that Asian cultures will kind of look after their own. And the changes that we've been hearing about in terms of social structures of families no longer living in the same place, those apply to Asian cultures, as well as to white cultures. And so, some of those assumptions, actually, can't be followed through in the same way as they would have been in the generation before. And that can cause more stress and problems in those populations than in others.

Equally, as people with dementia grow old, sometimes they lose the second language that they've gained, and there can be particular problems in long-term care facilities that that will generate as well. So, services that one generates need to be culture-fair, in the same ways the ways that we assess people with dementia needs to be culture fair.

Dr. Grabowski: Yeah, I'm also not familiar with the Canadian literature, but the US literature definitely suggests big cultural differences, and I'll point to one example.

There's been a lot of research on Hispanics and how they potentially use the system very differently and rely on informal care very differently. It's very interesting. There's a really nice study of looking at sort of first-generation versus second- and third-generation Hispanics. And, it turns out, first-generation Hispanics very much, there's much more of a culture around caring for family members. But then, by second-, third-generation, they pretty much look like everyone else in the US, they're much closer to the norm here. I really found that a fascinating result, and kind of a lot to sort of chew on there.

But we still see some variations, certainly, as Dr. Banerjee just said, across countries and across cultures. I'll piggy back also on his comment. I recently met with a group from China – I'm very interested in sort of long-term care there, and the one-child policy, and lots of other things. Their actual age distribution is going to even be exaggerated relative to the US and other countries in terms of the distribution, so they're very much facing big problems, and I think they're very much building nursing homes. In talking to them, I'd joked with them that they're making a lot of the same mistakes that the US has made, and maybe they are sort of doomed to repeat a lot of our failures. But they are very much building beds there, and trying to deal with an aging population. Thanks.

Unknown speaker 2: Well, I would like to thank you for this wonderful conference, and all the speakers for their valid contributions. The question I have is around education. I think that...I've had family who have struggled with dementia, and I'm young but I will age, and I don't know if I will be one of the ones that is affected by this illness. And the one thing that really strikes me is what Dr. Banerjee mentioned, about how we can improve the quality of life for people in early stages, about prevention, about those things that we rarely ever hear – there is virtually no knowledge about those things, and I know there is a taboo around the topic.

But how do you think we can change this? We can educate the generations as young as me, younger generations, kind generations. So we can look at these people who might have dementia and help them improve or avoid the onset, that type of...

Dr. Estabrooks: I think one of the things we can do is learn from some of the things we know a lot about. We've have tremendous success over the last 60 or 70 years in reducing tobacco use. But it wasn't that long ago when people would say to you, 'well, I understand that smoking will cause cancer, but I don't know what it's got to do with heart disease, and how does it get it into your heart?' – literally, at that level. And I think that people don't understand today that if what's good for your heart is good for your brain is good for your heart is good for your brain. So I think, not simple – they're not simple – but straightforward public education campaigns are one piece of it.

So there's a big piece here around dissemination and discussion and exchange. And not just with wage-earning adults, but I think we need to put this into the public school system, the way we did with tobacco reduction and other major challenges that we face. So that's one place we could start that would be relatively straightforward.

Dr. Banerjee: Yeah, I think this is definitely something to be very optimistic about, because we can do this. You can change people's attitudes; you can change people's understanding. And you can do that right, as you say, from school right through to public education, right through to focused professional education, and then giving people good quality information, once they're affected by the illness, enabling patients and carers to make their own choices.

We haven't done it yet, and we haven't done it systematically. That doesn't mean that we can't do it now and do it systematically. And every national strategy for dementia, every local and regional strategy, shares the importance of improving both public and professional attitudes and understanding.

Closing Remarks

Janet M. Davidson: Well I'd like to, it's, I know we're running over now, but I'd like to on behalf of Alberta Health, I'd really like to congratulate the IHE for setting up another absolutely outstanding Innovation Forum. I think this continues a good tradition of not just not just stimulating talk, but very informative. And I'm confident this will actually help us advance our system in the province, which is really important.

So on behalf of Lorne Tyrrell and the Board of IHE, I'd like to thank our speakers for their obvious, not just the content of the presentations, but the obvious commitment and passion they have about the subject, which is really, from my point of view, it's remarkable. It gives you some hope that there's great opportunities ahead. So I'd like to thank them.

I'd also like to thank all of you for coming and participating. Now, I hope you'll take the opportunity to join us for a reception, and I'd be remiss if I didn't make a plug for attending any future Innovation Forums when they come up. So, thank you all very much.



INSTITUTE OF
HEALTH ECONOMICS
ALBERTA CANADA

IHE Innovation Forum XI

Meeting the Challenge: Dementia and Continuing Care

Tuesday, May 27, 2014

Sutton Place Hotel, Edmonton, Alberta

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| 2:30 - 2:45 p.m. | Welcome and Greetings from the Minister of Health <ul style="list-style-type: none">• Master of Ceremonies: Dr. Lorne Tyrrell, Chair, Institute of Health Economics• Honourable Fred Horne, Minister of Health |
| 2:45 - 3:35 p.m. | Quality of life and quality of care in dementia <ul style="list-style-type: none">• Keynote address: Dr. Sube Banerjee, Brighton and Sussex Medical School• Questions from the audience |
| 3:35 - 4:25 p.m. | Coordinating Care for Vulnerable Elders <ul style="list-style-type: none">• Keynote address: Dr. David C. Grabowski, Harvard Medical School• Questions from the audience |
| 4:25 - 4:45 p.m. | Break |
| 4:45 - 5:50 p.m. | Panel Discussion <ul style="list-style-type: none">• Moderator: Janet M. Davidson, Deputy Minister, Alberta Health• Dr. Duncan Robertson, Seniors Strategic Clinical Network, Alberta Health Services• Dr. Carole Estabrooks, University of Alberta• Corinne Schalm, Alberta Health• Dr. Banerjee and Dr. Grabowski• Questions from the audience |
| 5:50 - 7:00 p.m. | Reception |

Meeting the Challenge: Dementia and Continuing Care is the 11th IHE Innovation Forum, a semi-annual event bringing together senior public- and private-sector experts and decision-makers to address health care policy issues. Videotape of all Forum presentations is available at <http://www.ihe.ca/research/knowledge-transfer-initiatives/--innovation-forum-series/>

Previous Forums:

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|---|---|
| I Paying for What Works | II Making Difficult Decisions |
| III Maximizing Performance—Cost Containment & Improved Efficiency | IV Innovation & Economics |
| V Innovation & Sustainability in Health Systems | VI Maximizing Performance—Evidence, Science, & IS |
| VII Social Determinants of Health | VIII Value for Money in Health Systems |
| IX Early Childhood Development: Enhancing Children's Health | X Choosing Wisely® in Health Care: A Canadian Perspective |



Dr. Lorne Tyrrell, OC, AOE, MD, PhD, FRCP, FRSC
Chair, Institute of Health Economics
Professor and CIHR/ GSK Chair in Virology, University of Alberta

The former Dean of Medicine and Dentistry at the University of Alberta, Dr. Tyrrell is the Board Chair of the Institute of Health Economics. He is the CIHR/GlaxoSmithKline Chair in Virology at the University of Alberta. He is also Chair of the Gairdner Foundation and a member of the Research Council of the Canadian Institute of Academic Research. Dr. Tyrrell is a member of the Alberta Order of Excellence, an Officer of the Order of Canada, and a Fellow of the Royal Society of Canada. He received the F.N.G. Starr Award from the Canadian Medical Association (CMA) in 2004, and the Principal Award of the Manning Foundation in 2005 for his work on the development of oral antivirals for the treatment of HBV. He was inducted into the CMA Hall of Fame in 2011.

Honourable Fred Horne
Minister of Health

The Honourable Fred Horne is serving his second term as Member of the Legislative Assembly for Edmonton-Rutherford, and on May 8, 2012 he was appointed Minister of Health. He had previously served as Minister of Health and Wellness since October 2011. Previous appointments include serving as member of the Cabinet Policy Committee on Public Health & Safety, Treasury Board, Parliamentary Assistant to the Minister Health and Wellness, Parliamentary Assistant to the Minister of Seniors and Community Supports, Chair of the Standing Committee on Health, and Deputy Chair of the Premier's Council on the Status of Persons with Disabilities. Prior to his election to the Legislative Assembly, Mr. Horne worked as a health policy consultant for over 25 years. Mr. Horne holds a Master of Business Administration degree from Royal Roads University and post-graduate certification in Dispute Resolution from York University.



Dr. Sube Banerjee MB BS, MSc, MBA, MD, FRC Psych, MBE
Professor & Associate Dean, Brighton and Sussex Medical School

Sube Banerjee is Professor of Dementia and Associate Dean for Strategy at Brighton and Sussex Medical School, directing its Centre for Dementia Studies. Clinically he works as an old age psychiatrist in Sussex. He was the Department of Health for England's senior professional advisor on dementia and led the development of its National Dementia Strategy. He also conducted the national enquiry into the use of antipsychotics in dementia for the UK government. He developed the Croydon Memory Service Model and works with industry and governments on health systems, policy and strategies to improve health for older and those with complex needs in general and those with dementia and in long term care in particular. An active researcher, he focusses on measurement of quality of life in dementia, evaluation of new treatments and services, and the interface between policy, research and practice. He has published broadly and has been awarded national and international awards for his work in policy and research.

Dr. David C. Grabowski, PhD

Professor of Health Care Policy, Harvard Medical School

David C. Grabowski, PhD, is a professor of health care policy in the Department of Health Care Policy at Harvard Medical School. His research focuses on the economics of aging with a particular interest in the area of long-term care. His research has considered issues related to long-term care financing, organization and delivery of services.



Dr. Grabowski was the principal investigator on recent grants from the National Institute on Aging examining Medicare payment incentives and the implications for nursing home volume, patient acuity and quality of care; selection and the impact of ownership on nursing home quality; and, public policy and the demand for long-term care insurance. Other ongoing projects include an examination of the economic incentives associated with hospitalizations from the nursing home setting, research on post-acute care payment and delivery, work analyzing the relationship between Medicare and Medicaid in long-term care, and an analysis of the growth in potential substitutes for nursing home care, such as assisted living. Dr. Grabowski also led a team at Harvard in the evaluation of the CMS Nursing Home Value-Based Purchasing Demonstration.

Dr. Grabowski is a coeditor of the journals Health Services and Outcomes Research Methodology and the Forum for Health Economics & Policy and he is a member of several journal editorial boards. He was the 2004 recipient of the Thompson Prize for Young Investigators from the Association of University Programs in Health Administration.



Janet M. Davidson, O.C., BScN, MHSA, LLD (HON)

Deputy Minister, Alberta Health

Janet Davidson was appointed Deputy Minister of Alberta Health on September 10, 2013. She comes to this role with over 30 years of experience in healthcare in the government, voluntary and hospital/community sectors in a number of Canadian jurisdictions. She has also worked internationally in humanitarian relief and development. Until recently, she was the Official Administrator of Alberta Health Services. Prior to that, she was the Canadian Executive and Industry Specialist with KPMG's Global Healthcare Practice. From 2007 to 2011, Davidson was President and Chief Executive of Trillium Health Centre in Mississauga, where she led them through to the successful merger with the Credit Valley Hospital creating the largest community academic hospital in the country.

Janet has a wealth of experience in all aspects of health care policy and planning, management and operations. She has also been extensively involved in global humanitarian work and served for 10 years in a senior governance capacity with the International Red Cross and Red Crescent Movement in Geneva, first as a Vice President (Americas) and then as Vice Chair of the Standing Commission, its highest deliberative body.

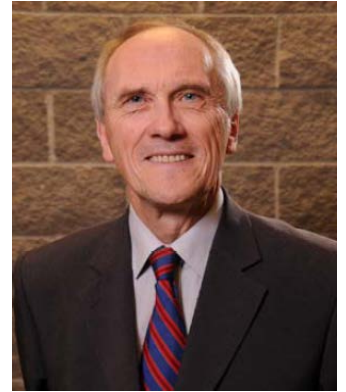
Janet trained as a nurse at Toronto East General Hospital. She received a Bachelor of Nursing Science from the University of Windsor and a Master's in Health Services Administration from the University of Alberta.

She is a graduate of the Institute of Corporate Directors' Education program, the UC Berkeley School of Public Health's Global Health Leadership program and has an Honorary Doctor of Laws Degree from the University of Windsor. She has received alumnae recognition awards from Branksome Hall School and the universities of Windsor and Alberta. She is an Officer of the Order of Canada and has been named twice to the list of Canada's Top 100 Most Powerful Women. In 2011 and 2012, Janet was also named as one of Canada's Top 25 Most Influential Women. She sits on the board of the Canadian Institute for Health Information, and chairs their Governance Committee. Other board experience includes service on the board of the Ontario Institute for Cancer Research and the immediate past chair of the Ontario Hospital Association.

Dr. Duncan Robertson, FRCP, FRCPE, FRCPC, FACP

Seniors Strategic Clinical Network, Alberta Health Services

Duncan Robertson is a practicing geriatrician and Senior Medical Director of the Seniors Health Strategic Clinical Network. He has a keen interest in policy and program development, having participated in development of Specialized Geriatric services in 11 cities in 4 provinces. In 1981 he was one of the first physicians in Canada recognized as a specialist in geriatric medicine and formerly held professorial appointments in Ontario and in three western provinces. As a clinician he continues to support specialized geriatric services in AHS Central Zone, in person and by video consultation. Duncan also has a long history of leadership positions in professional organizations including the Canadian Association on Gerontology, Canadian Geriatrics Society and the British Columbia Medical Association Geriatrics and Palliative Care Committee. He was awarded the Distinguished Service Award by the Canadian Geriatrics Society and the Queen Elizabeth II Diamond Jubilee Medal for services to Gerontology.



Dr. Carole Estabrooks, RN, PhD, FCAHS, FAAN

Canada Research Chair in Knowledge Translation

Professor, University of Alberta

Carole Estabrooks has been a member of the Faculty of Nursing and Director of the Knowledge Utilization Studies Program since 1997; she is cross appointed in the School of Public Health. She holds a Tier I Canada Research Chair in Knowledge Translation. Dr. Estabrooks is the Scientific Director of the Translating Research in Elder Care Program (TREC), a multi-province applied health services program in residential long term care. She has been the recipient of several awards and achievements among them, the CAFA Distinguished Academic Award (2010), the Alumni Award of Distinction, University of New Brunswick (2007), the Alumni Horizon Award (2002), and career scientist awards from CIHR/MRC and AHFMR. In 2007 Dr. Estabrooks was elected to Fellowship in the Canadian Academy of Health Sciences. In 2011 she was inducted as a Fellow into the American Academy of Nurses. She teaches in the graduate program and supervises undergraduate and graduate students and postdoctoral fellows.

Corinne Schalm

Access & Innovation, Continuing Care, Alberta Health

Corinne Schalm is the Acting Executive Director of Continuing Care with Alberta Health. She has a Master of Science in Gerontology degree and a Masters in Public Administration, and in 2008 was inducted as a Fellow of the Canadian College of Health Services Executives (FCCHSE). Corinne is passionate about improving the quality of life for seniors. She has over twenty five years of experience working in senior leadership roles in the field of gerontology in Alberta at the provincial policy level and with seniors service provider organizations. She has a strong interest in evidence informed practice in creating organizations of excellence, and is a frequent participant on research teams. Corinne is currently involved in research projects on improving quality in long term care facilities, workforce utilization in continuing care, knowledge translation interventions to support the implementation and sustainability of care innovations in assisted living and long term care, and improving care for long term care residents who are transferred to and from emergency departments and avoiding inappropriate transfers.

