

# iris



Stimulating Thinking on dementia policy and practice from the Dementia Services Development Centre at the University of Stirling

## 04. IdeasLab 2014

IdeasLab 2014 started with a world-wide, open call which simply asked 'Dementia in 2040 – what are the ideas today which will change the world of dementia tomorrow?' The special significance of this question is that this IdeasLab marked the start of celebrations for the 25th Anniversary of DSDC being at the forefront of dementia thinking and doing.

From submissions received from across the world, five very contrasting ideas were selected – from Australia, Canada, America, Denmark and the UK.

### The format

**Professor June Andrews and Mark Butler from DSDC** facilitated a process of exploration and exchange which involved both an expert Panel and a lively audience. Each idea was presented in turn to the Panel, drawn from the International Advisory Board for DSDC and representing in themselves a world-wide spread of knowledge and expertise. Also in the room were health and care professionals, policy experts, designers, inventors, technologists, researchers and members of the public.

The aim was to see where the exchange took everyone. There was no ranking or judgement made, but there was a lot of constructive and robust discussion and encouragement given to strengthen these ideas and to generate even more.

### The ideas

#### Idea 1 – Building life stories through social networks

*Harnessing the power of social networks such as Facebook offers exciting opportunities to improve the care of people with dementia.*

**Anders Moeller Jensen from VIA University College, Holstebro in Denmark** presented an idea based on building people's life stories through social media networks. This can be used in reminiscence work to stimulate memory and strengthen identity.

*In October 2014 DSDC hosted an international Ideas Lab to explore the next generation of ideas that will make a practical difference to people with dementia. This Iris captures the ideas explored at the one-day IdeasLab 2014 event held at the Iris Murdoch Centre at the University of Stirling. The Centre, like the IdeasLab itself, was made possible by the Dementia Services Development Trust which has generously supported DSDC for the last 25 years.*

Written by

Mark Butler and Bryan Christie

Life story work is valued by dementia care staff and carers but it is often left to the principal carer to collect the material needed to develop the life story. However, social media opens up the prospect of tapping in to the memories of a much wider range of individuals. Former school friends, work colleagues, neighbours and the wider family can all be encouraged to share their memories of the person with dementia to create a story that is more rich and complete.

Andres said a number of computer-based life story programs already exist which can allow photographs, text and video to be shared widely. Friends and family members can be invited to contribute content with the family having the final say on what gets posted for others to see and share.

Privacy is a key issue and the person with dementia has to remain in control and agree to what can be included in their life story.

Technology provides a way of building a person's life story that is more rich and diverse; it shares the work of doing this across more people and, by creating greater openness around dementia by involving more people, it can help to combat the stigmatisation that continues to exist about the condition.

## Idea 2 – The potential of cognitive stimulation

*A model of improved care based around one-to-one cognitive support could be adopted internationally to slow cognitive decline, reduce care costs and lessen family stress.*

**Alison Kennedy of Kennedy Cognitive Services in Winnipeg, Canada** said research is required to establish the benefits of such an approach but the work of her team has shown that it has considerable potential.

A methodology and toolkits have been developed through work with a group of nine clients over the past six years. This is based on gathering information about the client and his or her abilities and designing slightly challenging, fun activities for stimulating engagement. The client meets with the same trained worker for a one-hour session every one to two weeks.

Alison said the programme has brought joy and meaningful support to the clients and their families. It has helped to discover residual abilities and has improved both self-esteem and quality of life.

Too many people with dementia do not get any opportunity to benefit from cognitive stimulation and she suggested that care support or recreation workers could be trained to deliver this form of help. If it was shown that clients receiving the service were happier, more manageable, retained their cognitive abilities longer and perhaps needed less medication, such an approach may save rather than cost money.

Alison said such a model has the potential to reduce cognitive decline, long term care costs and family stress.

## Idea 3 – Learning from computer games

*The success of computer games has been the inspiration behind the creation of a virtual world that people with dementia can explore using a tablet computer.*

**Mandy Salomon of Swinburne University of Technology in Hawthorn, Australia** has developed AVED (Applied Virtual Environment for Dementia Care) to help promote enjoyable engagement among people with dementia.

People with cerebral palsy have responded positively to role playing in a virtual world where they can experience activities through an able-bodied avatar. This has been shown to improve their self-confidence.



*Technology provides a way of building a person's life story that is more rich and diverse.*

In the same way, virtual reality offers opportunities for people with dementia who may be missing the familiar and comforting surroundings of home. AVED has been designed as a 3D home environment with a sitting room, kitchen and garden to help users reconnect with their past.

Ten people with moderate to severe dementia helped to develop AVED by selecting the content and responding to updates. Observation of their use of the tablet helped to determine how engaged they were.

Mandy says experience of using AVED demonstrates that tablet based virtual worlds can be powerful tools for delivering non-pharmacological therapies. They are low in cost and maintenance and there is no need for extensive staff training, formal therapy sessions, dedicated activity rooms or travel.

The tablet is designed to be used with another person and becomes a conduit for interaction, not an end in itself.

#### Idea 4 – Monitoring quality of life

*Measuring the quality of life of people with dementia can help to monitor the status of their illness and influence their on-going and future care.*

A system for doing this has been developed by **Chengi Kuo, a retired professor and maritime safety expert from Glasgow**, who is the main carer for his wife who has dementia.

His Quality of Life indicator (QLI) is based on an assessment of the interests of a person with dementia. In his wife's case, that has been food and eating; drawing and shading; using an iPad; and resting and sleeping. A focus of these interests is helping her to lead a contented and happy life.

At the same time, regular monitoring of these interests can take place to assess her quality of life and any adjustments made to care, as appropriate. Trials with this approach are to be run with a day care centre to determine its wider applicability.

Chengi said the QLI approach has many potential benefits. It provides an important role for carers in identifying interests of the person with dementia that they can then support. It generates positive attitudes that something tangible can be done. It is low cost and can be used in countries that do not have many resources. It can be used with other activities and medical treatments while providing a measure for how well the person is responding to these interventions.

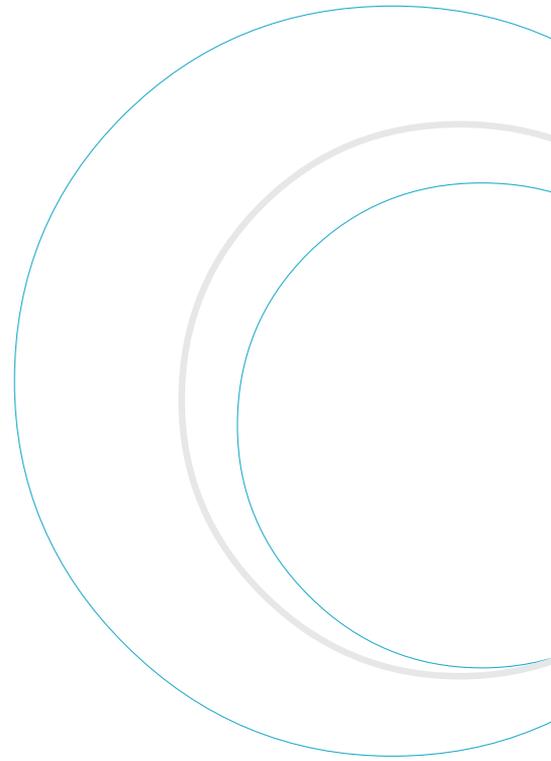
#### Idea 5 – International collaboration for dementia friendly communities

*Collaboration through shared resources is the key to supporting the development of dementia friendly communities around the world.*

**Olivia Mastry, Executive Lead at ACT on Alzheimer's from Minnesota in the United States**, proposed that an international online research portal be developed that every country could share to foster and evaluate the development of dementia friendly communities.

Her organisation has developed a model that is being used by 32 diverse communities in Minnesota to improve the care of people with dementia. It is based on a shared portal that uses research information, toolkits and other resources to help develop local action.

There are plans to adopt this across the United States but Olivia said she would like to see the portal made available internationally to prevent duplication of effort and support the development of best practice.



The benefits would include sharing the burden of development and gaining from continuous collaborative learning. Some of the challenges include customising the portal for local use and issues around shared ownership.

She proposed that the best way forward is to establish a multi-country task force to examine the idea in more detail. This could examine securing shared funding, developing guidelines and shared measures for evaluation, and issues of technical assistance.

All this should be able to be done at relatively low cost as each country would be sharing one portal rather than developing its own.

## What does IdeasLab tell us about the future?

The ideas touched on many important themes but it would be wrong to paint a picture of the future on the basis of a single IdeasLab. However the event did raise a number of questions which went far beyond the specific ideas themselves.

These broader issues will now form the basis of further thinking and doing by DSDC and those it works with. A series of Master Classes is being hosted by DSDC during 2015 to explore these questions further. The full programme will advertised in December 2014.

Some of the questions which arose in discussion go to the heart of the future of dementia.

Social media and the online digital world will have an important role to play in the future of dementia. The true potential for making a real difference to the lives of people with dementia and their families is only now starting to be explored.

*What can now be expected from social media and how can it be supported?*

Training and development of flexible, skilled professional staff will continue to be important. Is knowledge being developed at the speed it needs to be? *How can the challenge be met for growing professional standards and expertise worldwide?*

Innovation is likely to come from many different places – reflection on practical experience, the application of methodology, conversation and sharing between different voices and expertise. Commercial designers and engineers need to be encouraged to share ideas on dementia innovation. *What does innovation mean for dementia and how can it best be supported?*

Having ideas is one thing but there still seem significant barriers to implementation. *What's holding us back and what can unlock the problems?*

Ideas look increasingly transferable between countries and cultures. This raises issues about sensitivity to cultural difference and has ethical implications for collaboration and exchange across borders and boundaries and between individuals and organisations. *What are the rights and wrongs of what we do which affects people with dementia?*

Involvement of people with dementia is emerging as a strong theme in making innovation relevant and vital. This is seen in everything from dementia friendly communities through research to standard setting and service review, but the underlying idea of a “voice” for people with dementia remains poorly defined and its value largely unquestioned. *What does “involving people with dementia” actually mean?*



*Social media and the online digital world will have an important role to play in the future of dementia.*

## Reflections and learning

The value of the IdeasLab itself was also reviewed as an integral part of the day. Presenters, panel members and participants identified several features which they said they valued:

- the opportunity to step back from day-to-day demands and have time to reflect
- the stimulation of new research ideas through informal discussion away from the programme for the day
- the ability to engage directly with worldwide experts face-to-face
- the focus just on exchange without pressure to come up with action plans or to drive things forward.

International exchange is increasing through social media, virtual exchange and events. DSDC hopes creative exchange similar to the IdeasLab will become more widespread. But what are the critical ingredients to consider in designing an event?

**Open call for ideas.** The world-wide call for ideas generated a range of ideas which would not have come from using existing channels of communication. It set the right tone for the whole event as an open, inclusive event of genuine international reach.

**Scale.** Numbers attending were deliberately restricted so that a genuine climate of participation and exchange could be generated – sometimes this can be lost in larger conferences where participation and access to experts is much more limited and the emphasis is more on presentation.

**Participants.** Some social engineering of who attends can make a huge difference to the climate in which ideas are received. The Ideas Lab included people with dementia, researchers, health and care professionals, policy experts, designers, inventors, technologists and members of the public. The different voices gave a richness and insight which helped provoke new lines of thought and action.

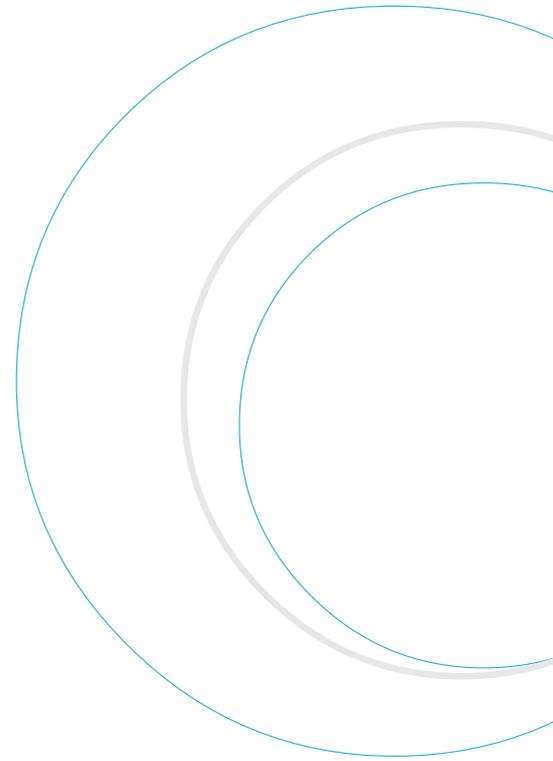
**Content.** The number of presentations was also deliberately restricted and sessions held in a single plenary setting. Ideas were therefore given room to breathe and everyone could participate directly in discussion.

**Format.** Each presentation was matched by the same amount of space for Panel comment and facilitated discussion.

**Face-to-face exchange.** In an age of electronic connection and access to information it was striking how being somewhere stimulating mattered to everyone at the IdeasLab. There seems to be something extra when people have made the effort to come together – a sense of occasion – which adds to the quality of the event.

**Setting.** The fact that the IdeasLab took place in the Iris Murdoch Centre allowed the audience to have access to resources which in themselves stimulated further discussion and exchange. This would not have been so effective elsewhere.

**Facilitation.** Critical challenge, as well as encouragement and support, is vital if real innovation is to be stimulated and ideas developed constructively. This requires expert facilitation involving sufficient authority, integrity and, what one Panel member called, the right “combination of intellect and common sense”. No one voice was or should be allowed to dominate.



## Next steps

### IdeasLab 2015

The Ideas Lab was a self-contained event, designed to give value to those who participated by being there. The DSDC website is hosting some short films drawing on the event [dementia.stir.ac.uk/ideaslab-2014](http://dementia.stir.ac.uk/ideaslab-2014). DSDC will also continue to work with presenters on their ideas.

A further IdeasLab is being planned for November 2015.

### 25th Anniversary Master Classes

DSDC will also be hosting a series of Master Classes in 2015 as part of its continuing celebration of its 25th Anniversary. Some of these will use the same format as the Ideas Lab and be small events, but the idea is that exchange will be opened out using social media to explore a different type of participation as well as the face-to-face approach used in October 2014.

For more information click [here](#)

## International panel members

DSDC would like to thank all their International Advisory Board Members for their support of DSDC and in particular to thank the following members who were so generous with their time, energy and contributions to the Panel and throughout the whole Ideas Lab.

### Jean Georges

*Executive Director, Alzheimer Europe*

### Prof Martin Green OBE FIAM: FRSA : FInstLM: FIPSM

*Chief Executive, Care England and Chair, International Longevity Centre UK*

### Prof Timothy Kwok

*Department of Medicine & Therapeutics, The Chinese University of Hong Kong and Director of Jockey Club Centre for Positive Ageing*

### Marie-Jo Guisset Martinez

*Independent consultant on dementia and old age*

### Cesar Rodriguez-Castello

*Consultant in Old Age Psychiatry, Clinical Lead, Older People and Dementia, NHS Tayside and Trustee of the Dementia Services Development Trust*

### Mary Schulz

*Director, Information, Support Services and Education, Alzheimer Society of Canada*

### Marion Villez

*Local Initiatives Department Manager, Fondation Mederic Alzheimer, Paris*

### Dr Ingrid Wuenning Tschol

*Senior Vice-President, Health and Science, Robert Bosch Stiftung GmbH*

The Dementia Services Development Centre (DSDC) exists to improve services for people with dementia and their carers throughout the UK and beyond. We do this through research and teaching and by supporting workers and organisations that provide care for people with dementia.

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