

Catalyst Event Report on

***Identifying the gaps in dementia research;
Opportunities for novel approaches through
collaborations***

Aintree Race Course, Wednesday 22nd January 2014

CONTENTS PAGE

<i>Purpose of the day</i>	4
<i>Presentations from Alistair Burns and Ann Johnson</i>	5-6
<i>Visual Minute start of the day</i>	7
<i>Convenor Reports:</i>	
Group 1 - How can research make a difference to the loss of friendships that people with dementia currently experience possibly resulting in social isolation.	8
Group 2 - Post diagnostic support for people living with dementia and their families	9
Group 3 - Changing the name of dementia	10
Group 4 - How can we actively involve people with dementia and their families in research and let them know about research findings? Any examples? What has been the result/impact?	11
Group 5 - How do we evaluate the impact of staff training on the care/experience of people with dementia	12
Group 6 - Involving people with a learning disability and their families/carers in research	13
Visual minute session 1	14
Group 7 - The impact of the barriers of language, culture and faith to early diagnosis and post diagnostic support for BME populations.	15
Group 8 - Early diagnosis of the dementias – molecular markers / brain imaging	16
Group 9 - Sharing data and information – How can we improve overall data sharing and levels of inflation?	17
Group 10 - How do we create a more patient society, frustration with repetition?	18
Group 11 -How to inspire and inform young people about dementia and encourage them to think about working with people with dementia as a career option.	19
Group 12 - How can technology (e.g. mobile technology, electronic data) support people with dementia and their carers.	19
Group 13 - How can research result in reducing the fear that people living with dementia experience every day (Ann Johnsons word terror)	20



Continued...

Group 14 - Dementia and criminal justice	21
Visual minute session 2	23
Group 15 - Keeping dignity as dementia progress's	24
Group 16 - Support for family members – Problems and what is needed	25
Group 17 - What is the evidence for the effectiveness of interventions in dementia	25
Group 18 - Individualisation of solutions for people with dementia and support	26
Group 19 - Potential for continued employment for people with dementia	27
Group 20 - Do we have an evidence base for understanding whether staff delivering care to residential elderly have sufficient training knowledge of dementia	28
Group 21- Family and friends, changes in relationships, roles, continuity and discontinuity of wider social relationships.	28
Group 22 - The barriers between general community services and mental health services e.g. training of front line carers	29
Visual Minute session 3	31
Group 23 - Dementia – Dementias, disease sub types within 'dementia' individual care for dementia subtypes	32
Group 24 - Sensory life day, work and development/ measurement	33
Group 25 - Remote, mobile, personalised technologies	34
Group 26 - Adapting mindfulness based practice for people with dementia and measuring clinical efficacy in terms of quality of life - Emotional - Regulation	35
Summary / Next Steps	36
Visual minute—As a result of today	37
Feedback from Survey Monkey	38
Poster Feedback	40
Postcard Feedback	41





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Identifying the gaps in dementia research; opportunities for novel approaches through collaborations

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Purpose

The event brought together prominent people from diverse backgrounds across the North West of England who have an interest in dementia research. It is hoped the event allowed attendees to begin collaborative work across their organizations, with a view to developing innovative bids for National Institute for Health Research (NIHR) / EU funding.

The event was conducted using a forum known as 'Open Space'. The method is designed to enable people with mutual interests to meet and progress ideas in a short period of time. Participants have control over what is discussed and can choose to include themselves in various forums generated on the day. At the conclusion of the various forums, decisions are made about outcomes and further steps to progress them. Participants are expected to contribute further via the networks developed on the day.

A summary of the Open Space discussions, including the names of participants and those expressing an interest in being contacted at a later date, form the basis of this workshop summary.

The discussions are not presented in any particular order and do not reflect the popularity or the merit of the research themes. Some themes are closely interlinked and could be collated.

Visual minutes were made during the event by a team of artists and those minutes are also included in this report.

Workshop Summary

Presentations

Dr Stuart Eglin, Director of NHS Research and Development North West, introduced the day and went through the concept of the Catalyst event and how it was a highly participatory event. He stated that everybody attending the event had an interest in dementia and all would have something to contribute. Stuart introduced the next speakers, Professor Alistair Burns National Director for Dementia at NHS England and Ann Johnson who is living with dementia.

Alistair Burns National Direction for Dementia at NHS England

(Summary)

Awareness of dementia has never been higher than it is currently and a lot of interest has been generated that wasn't happening 5 out of 10 years ago. There has been interest from the general public and the main point, now, is to change awareness into action.

The National Dementia strategy from 2009 has been running for 5 years.

The prime ministers challenge on dementia includes 2 important points:

1. For people over 55, dementia is the most feared illness. It is important to create a dementia friendly community and the issue of awareness.
2. Diagnosis and the support people receive after diagnosis

It is important to try to raise the amount of money to enable research into dementia to take place. For every £1.30 spent on research only 5p is spent on dementia research. We need to double it by 2015 and we are well on the way for that to happen.

We need to look at how we manage research in dementia and how to raise the profile. Money, alone wouldn't make much difference. The key thing is to get younger researchers to think of dementia research as a career, (it's as good as cancer research!) and to engage more mature researcher's as well.

There is lots of money for dementia right now, and it has never been a better time to do research.

There was the G8 Summit (December 2013) focusing on the social impact of dementia and remembering that prevention is also important with regular exercise, a healthy diet and social interaction playing a role.

We need to think of Dementia as a long term health condition.





Ann Johnson – Living with Dementia

' I have dementia but I have a life!'

(Summary)

Ann was a trained nurse and was diagnosed with dementia 8 years ago when she was 52 years old. She now lives in a care home in Altrincham. She first went to see her GP about her symptoms in the December, and was diagnosed in October.

Anne talked through the strategies she uses that help her to deal with dementia on a daily basis, which aren't hi-tech, just simple things such as a talking watch, dictaphone and a tag that is worn with address details in case she gets lost.

3 main things that keep her going:

-  Friends
-  Faith
-  Speaking/ talks to groups of people

Without these she would be lost. The talks give a purpose for living and she enjoys travelling all over the country.

Anne is involved in part of the Dementia Strategy which was launched in 2009. She is also part of the Prime Ministers dementia friendly group which enables her to meet many different people and connect with people from different organisations. From this she has joined the Sainsbury's retail group to help them look at how they can help people with dementia. Lots of business's are on board with this.

Anne has also received an honorary doctorate from the University of Bolton and also an MBE.

She challenged the group with "What can you do for me??"



Convenor reports

Group 1 - How can research make a difference to the loss of friendships that people with dementia currently experience possibly resulting in social isolation.

Convenor – Sue Clarke and Ann Johnson

Participants -

Pauline Banks -University of West Scotland,

Michelle Collins – Person Shaped Support

Sally Spencer - Editor for the Cochrane Group

Tony Gatrell – Dean Lancaster University

Tracy Collins – Occupational Therapist – University of Salford

Christine Milligan – Lecturer University of Lancaster

Stephanie Tierney – Manchester University



Key points from the discussion:

- Why it is that friends disappear, what causes them to withdraw? Is it fear? Perhaps people don't know what to say, similar to bereavement/divorce?
- Is this the case for other disease/conditions?
- We all need social contact/networks/friendships'
- People who have had the worst quality of life are the most socially isolated.
- Befriending services extremely helpful volunteers are matched up with a person with dementia with similar interests.
- People's self-awareness in conversation with people with dementia is key – not to be embarrassed if there is no answer/inappropriate answer. Don't jump in if a person is struggling for words.
- Loss of friendships impact on carers and families as well.
- If anything is wrong you find out who your friends are
- People in the public eye need to speak out when they have dementia
- Social activity needs to be meaningful. That also maintains respect and dignity of the person



Next steps:

- ⇒ Research into importance of not becoming socially isolated.
- ⇒ Different levels of friendships
- ⇒ Research into befriending
- ⇒ Continue the conversation about dementia, open and honest to dispel the myths and the stigma to help reduce the fear.
- ⇒ Social networks may need to be maintained differently – virtual links and technology

Group 2 - Post diagnostic support for people living with dementia and their families

Convenor – Hilda Hayo

Participants

Gill Drummond -Caroline Hampson (OT) - Nicola Jarvis (L.D –Psychologist) - Joanne Singleton—
Damien Mentali – (Neuro Science) - Rumona Dixone

Key points from the discussion:

- What about people who do not want a diagnosis?
- What happens after diagnosis – Timely? – Ongoing?
- How can we support families? – Top Tips, Lists/Sheets (under evaluation)
- Nursing Home and Day Service Support
- Working group – MDT with dementia
- Individual tips
- Up to date information – should be communicated through talking, explaining rather than depending on papers and people finding out for themselves.
- Interactive and applied
- Positive role models – paid person living with dementia to share his experience with others.
- Research needed about peer support
- Best practice models of post diagnostic support needed
- Hearing people synthesise evidence (CLAHRC Research)
- Pre- diagnostic support - what happens immediately before?
- What are the triggers for seeking diagnosis
- What about genetic disorders
- Scotland – 12 month post diagnostic support
- Are outcomes better if the diagnosis is accepted and worked with



- Inundated with written information but lacking in support– consistency can be difficult
- Finances play a part in decisions
- Respite care – model in Australia - family member and friend both attend
- Who is going to fund it?

Next steps:

- ⇒ Explore models of best practice for post diagnostic support
- ⇒ Ask families what they need and people living with dementia and how their situation could be improved?



Group 3 - Changing the name of dementia

Convenor – Alistair Burns

Participants

Pauline Parker - Pamela Duffy - Andrew Garrity - Rebecca Jones - Sarah Butchard -
Ricky Wallace - Lorraine Trainer - Gillian Southgate

Key points from the discussion:

- It is more about stigma than about the name - you can call it what you want
- Promote living well with dementia
- Education –children – shops –clinicians – to reduce the fear and exclusion
- Negative association with treatment/decline
- Billboard campaign in Liverpool was very positive
- Carers can see/experience more stigma than the person living with dementia
- Biggest fear is the fear of going into a care home
- Change the underlying issues/views of dementia rather than change the name
- Ability of people to associate themselves / their loved ones with people with dementia
- Possibly early in the journey to changing attitudes
- Lots of awareness raising but yet to change attitudes
- Dementia is brain failure
- In the USA name changed to neuro- cognitive disorder

Next steps:

- ⇒ Education for many but specifically for young people
- ⇒ JK Rowling to get involved with younger people
- ⇒ Work with businesses to encourage them to be more dementia friendly e.g supermarkets



Group 4 - How can we actively involve people with dementia and their families in research and let them know about research findings? Are there any examples? What has been the result/impact of involving people in research?

Convenor – Melanie Chapman

Participants

Pauline Banks - Gav Cross - Lisa Woods - Chris Edwards - Christine Milligan -
Katrina Forsyth - Lorraine Trainer - Carol Taylor - John Keady - Dave Jones - Ricky Wallace
Stephanie Tierney - Chris Sew



Key points from the discussion:

Examples of involving people with dementia:

- The Scottish Dementia Working Group - people with dementia are involved when starting research and developing projects. This has led to changes in design. Sue Burn is to do research on people who develop dementia when working.
- Researchers at Manchester University have received ESRC funding to look at how to involve people in research. They have not been able to find courses or anything to empower people with dementia to take part. Creative methods may be useful.
- Christine Milligan gave examples of co-research with older people; however, the 'dementia nut still has to be cracked'. She has worked with older people to design and to carry out research. There are issues around training –if people receive a lot of training they are no longer just members of public/naive researchers. Can people only be naive researchers once?
- Model of older people as researchers looking at gaps in services and designing services and people with dementia have been included.
- Does the North West People in Research Forum include people with dementia?
- Gav Cross – it feels like being on a journey. As a commercial entity his company, Immersive Spaces, has access to development money. He is thinking about how to support people with dementia to be part of product development. They are using projection lights and sound to change the environment (for example, with Mersey care exploring how immersive experience can contribute to wellbeing, memory, conversation etc. They are holding group sessions to see if it has impact on evening experience (sun-downing) and whether it will reduce the medication needed.
- Lisa Woods –product development has been significantly changed by involving people at the beginning of development process up to the end.
- Dave Jones – would aspire to involve people in research. Areas for research would be carer support, measuring outcomes for families, people using offender services who have dementia.

Issues around involving people with dementia

Ethical issues and gatekeeping issues may be challenging

- The length of time it takes to gain funding and carry out research projects can take can be a particular problem when involving people with dementia.



It is important to:

- Listen effectively
- Make sure the person has support (e.g. family/professional/carer)
- Consider when people would be happy to take part. It may be that people with dementia can be part of a project but not involved in all of it, dipping in and out of a research project as their needs change

Group 5 - How do we evaluate the impact of staff training on the care/experience of people with dementia

Convenor – Claire Surr

Participants

Dave Jones - John Keady - Graham Smith - David Powell - Andy Pownall

Key points from the discussion:

- Sustainability and staff turnover – impact on outcomes.
- Many areas have dementia strategies and dementia training – many providers asking is it effective and cost effective training? How do I choose what I purchase?
- How do people respond to particular scenarios? Might lead to more insight into how people might change their behaviour?
- What can you train? E.g. compassion select for it, can you train people to be compassionate?
- Seeing training as continual development –organisations that support supervision and reflective practice.
- Things get in the way of implementing training.
- Lack of validated measures
- What do people with dementia want? What is their view on the service they receive? How do we capture this?
- Consensus on measures being used would be helpful - sharing of what is being used.
- Evaluation – or lack of evaluation is common place. Many things occur without proper evaluation.
- People can fear evaluation in case it is not shown to be effective.
- Evaluation needs to be meaningful
- What do we expect to achieve? Are we being over ambitious, should we expect less?
- Is it possible to do something meaningful/valid? Too many other things that impact on care.
- Being clear about what we expect the training to achieve. E.g. better care plans not necessarily better care.



Next steps:

- ⇒ Be honest about what training might be able to achieve and what not – what can we measure?
- ⇒ Sharing of existing tools, measures and approaches – consensus or recommended approaches.
- ⇒ Explore funding and resources to support evaluation of impact of training
- ⇒ Develop some scenario based measures to assess potential changes to behaviour

Group 6 - Involving people with a learning disability and their families/carers in research

Convenor – Nicola Jervis

Participants

Melanie Chapman - Chris Sowards - Noreen O'Sullivan - David Alsop

Key points from the discussion:

- Ethics around testing people with Downs Syndrome – consent e.g. drug trials around dementia trails
- Challenge = adapting materials
- Challenge getting funding and consent
- Smaller populations
- Could we do some research with carers just what they would like?
- What about research with friends of people with dementia, people with a learning difficulty who live with them?
- People combining together

Next steps:

- ⇒ Speak to carers to see if they would be interested – pilot data
- ⇒ Service evaluations
- ⇒ Speak to people with a learning disability.



Visual Minute—Session 1



Group 7 - The impact of the barriers of language, culture and faith to early diagnosis and post diagnostic support for BME populations.

Convenor - Dee Abimbola

Participants

Sue Clarke - Ann Johnson - Di Burbridge - Jill Drummond - Colin Ling - Nick Ponsillo

Key points from the discussion:

- Stigma is a big issue in many discussions around dementia and others
- Improved awareness of dementia now in China and other countries
- No word for dementia in many cultures, hence this promotes the stigma as it gets ignored
- Question: is there a carry-over effect from situations in countries of origin?
- Expectations of culture around care giving?
- Expectations are not the same in different cultures
- Can cultural awareness sessions improve care giving?
- People whose memories are fading take themselves out of social settings/situations to save family members the embarrassment
- What is the best way to ensure early diagnosis? –Information programmes? – Translations?- Education/awareness?
- Providers need to work more closely with 3rd sector BME organisations
- Insufficient BME representation among health care professionals
- Some communities perceive caring roles as low level jobs

Next steps:

- ⇒ Stigma should be out
- ⇒ People will feel more confident to come forward and express their concerns around dementia

**“Worthwhile event – time used effectively
with positive results – thanks!”**

**“Enjoyed the day very much and
excellent facilitation. Its heart was in the
right place and the facilitator was very
good, excellent. Thank you for the
opportunity”**



Group 8 - Early Diagnosis of the dementias – molecular markers / brain imaging

Convenor - David Allsop

Participants

Richard Jagger - Claire Surr - Dee - Stephanie Tierney - Gillian Drummond

Key points from the discussion:

- Moving towards early diagnosis based on molecular markers, brain imaging etc (MCI – Converters)
- EEG might be useful (Richard Jagger) Mobile EEG unit, cheaper than brain imaging.
- Who would you test? At risk groups? Could you repeat a test?
- Would you want to know?
- Would you really want to know if you were going to develop dementia in 10 years time?
- What would you do? Life style changes, repositioning of drugs, diet and exercise.
- Different type of drug trial – test on MCI people

Next steps:

- ⇒ Form 'bio marker interest group'
- ⇒ EEG Studies on dementia?



Group 9 - Sharing data and information – How can we improve overall data sharing and levels of inflation?

Convenor - Andy Pownell

Participants

Lynne Goodacre - Nicola Fletcher - Chris Stewarts - Carmel Dickinson

Key points from the discussion:

- Better system of referral for different groups of people
- Using technology – how we handle data sharing patient's needs – how we access data
- Inflation on carers of dementia
- Simple problem, simple solution
- Developing the technologies awareness campaign, GP NHS emergency services
- So many different data storage systems
- A consistent informed approach to sharing data
- Easy participant access
- Do not want to hide behind 'data protection'
- Create a data hub all agencies can access
- Understand each agencies constraint
- Sharing data is the way forward
- Individuals make a difference not agencies and that very often an individual will share data/ inform to achieve a common goal
- Need to share data to 'save lives'
- Easy to see why different agencies have data
- No one has died because we shared data but people have died because we have not

"Good day, well run, lots of opportunities to contribute. Hope it leads to great studies"

"A fantastic day; well put together and thought through. Excellent mix of people with a range of knowledge and expertise. I have learnt an awful lot and feel more informed and provoked into action than when I walked through the door, very important to have both Anne and Daphne here to ground our discussions in reality and give a more informed perspective."

Next steps:

- ⇒ The development of a project amongst different agencies to look at how we can share data and access different groups of individuals as well as safeguarding staff



Group 10 - How do we create a more patient society, frustration with repetition?

Convenor - Helen Morris

Participants

Ruth Eley - Dee Abimbola - Daniella Montaldi

Key points from the discussion:

Research Supermarkets

- Speak of life and coercion towards self-service. Development of slow lanes in super markets is not just about disability – Social till.
- Speed and access society from the internet. The young exercise memories in different ways – passwords etc.
- IT intergenerational work- bridge across generations that build skill of patience and understanding of dementia challenges (memory from one week to the next)
- Could the inverse be true? Because children do not need and use memory much (access to the internet etc.) that they may not be so hung up on it.
- Research across generations, finding trigger points for frustration and analysis – causation / cooperation v responsibility.
- Then research strategies to negotiate the stress.
- Research suggests longitudinal
- Primary – Families/ care workers/ social worker/ nurses/ care home workers (intense experience)
- Secondary – Police/ fire/ superstores/ banks/ transport etc (sporadic experience)
- Research into volunteering as a pathway to improved patience and capacity to work with people and cascade attitude to families etc.
- Research through life story network – people who have been through the process and produced life story books
- People from cultures where pace of life is slower and then dropped into society that allows no time.
- Research into psychology:
- Brains tend to look novelty – survival and evolution, so frustrated that we cannot move on but we all have a favourite work programmes, poetry , children’s games – we like predictability to be in control
- Why can’t we translate these into patience??

Next steps:

- ⇒ Research with young people, cross generalisation / different cultures
- ⇒ Why some repetition is therapeutic and some frustrating.
- ⇒ Research into volunteering / life story as a way of developing patience
- ⇒ Research into alternative sound spaces to allow for time, slow lanes in supermarkets?
- ⇒ Research into ways of learning and how then affect our attitudes towards memory loss



Group 11 -How to inspire and inform young people about dementia and encourage them to think about working with people with dementia as a career option.

Convenor - Ruth Eley

Participants

Michelle Collins



Key Points from the discussion

- Health champions, gone into Belvedere School. 10 pupils, now to whole sixth form group. 6 week course in Broad Green Comp PSS
- Do we need to start with top juniors? Use health champions, could organise around dementia.
- Using IT as a vehicle for engagement skills and expertise for younger people.
- Recruiting people with right values is challenging, especially when they are pushed into applying by job centres/ benefit challenges.
- Explore what children know about dementia in different year groups, different localities
- PM challenge – educational resource for schools about dementia
- Need for better information for children and young people about dementia, not much around?

Next steps

- ⇒ LSN and PSS to explore possibilities for joint work/ funding opportunities
- ⇒ Identify if anyone else is interested in this as a research topic?

Group 12 - How can technology (e.g. mobile technology, electronic data) support people with dementia and their carers.

Convenor - Carmel Dickinson

Participants

Gav Cross - Alicia Ridout - Tony Gatrell - Gillian Drummond - Rumona Dickson- Grahame Smith - Stephanie Tierney - Bill Ollier - Melanie Chapman

Key Points from discussion:

- For patient/ for carers – memory enabling technology for second person to use
- Is it ethical to monitor people or to use the aggregated data?
- Where is the technology? How can people know about it
- Anonymised GP data is beginning to be available
- Need for agile prototyping and iterative trials
- Can't be technology led, what do dementia patients feel they need? Also families and health carer needs
- Who pays for technology? 'Mood Lighting'



- Inventions can't be technology led, must be based on need of patients/ families / carers
- Technology as 'scaffolding' to support activities and social networks – avoiding social isolation for patients and carers. Choice and control is important in determining acceptability.
- The ethics of monitoring technologies and maintaining data ownership.

Some issues include:

- How do health and social care professionals know what technology is available?
- Where is the evidence?
- What is the business model?
- Need for agile prototyping and iterative trials
- Can technology used at home be transferred to care home? "Ghettos of technology"
- Where is the evidence? What is the business model?
- Technology to maintain and sustain friendships and social networks – Scaffolding/ choice/ control.
- Priorities for remembering – object recognition and enabling to maintain social links
- Successful interventions with patient and carer networks – keeping data ownership
- 'My Liverpool'
- Addressing social isolation for patients / carers. Prompts on TV, input from family. Addressing the individual's fears.
- Will there be 'ghettos of technology' e.g. care homes may not allow people to use technologies they are accustomed to



Group 13 - How can research result in reducing the fear that people living with dementia experience every day (Ann Johnsons word terror)

Convenor - Sue Clarke and Ann Johnson

Participants

Tracy Collins - Pauline Parker - David Powell - Rebecca Jones

Key points from discussion

- Finding a cure
- Education
- Having someone in your life makes all the difference?



- Psychological interventions help to develop coping strategies
- Social intervention – people with dementia and carers/ families should have someone who they can talk to.
- Looking at individual's and their history / background, this will determine their experience of dementia
- Can be re active depression to their situation psychological therapies not always effective as people with dementia might forget what was said or what coping strategies had been developed. Take notes or recording the session can help with this.
- Interactive technologies could help. Ways to reassure people/ reduce isolation. May help to slow progression of dementia
- Intergeneration understanding / support of families.
- Dementia friend's information sessions. Fear can be reduced through meaningful social engagement/ occupation
- Public figures / messages need to be about living more positively with dementia.

Next Steps

- Encouraging people to become dementia friends
- Make psychological interventions available to people with dementia earlier on
- Raise awareness and educate carers to be able to support / intergenerational understanding
- Have a range of coping mechanisms to choose from
- Develop services for younger people / appropriate environments
- Awareness raising in churches / faith groups on dementia friendly communities.

Group 14 - Dementia and criminal justice

Convenor -Katrina Forsyth

Participants

Dave Jones - Pauline Banks - Lynne Goodacre

Key points from discussion

- No screening in prison, not joined up for dementia.
- Prison culture v health care culture (human rights) managing security v providing health care.
- No mental health services in prison – old age psychiatry.
- No policy for identifying and managing dementia in prison
- No joined up / referral services – difficult to make referrals to specialised services in the community



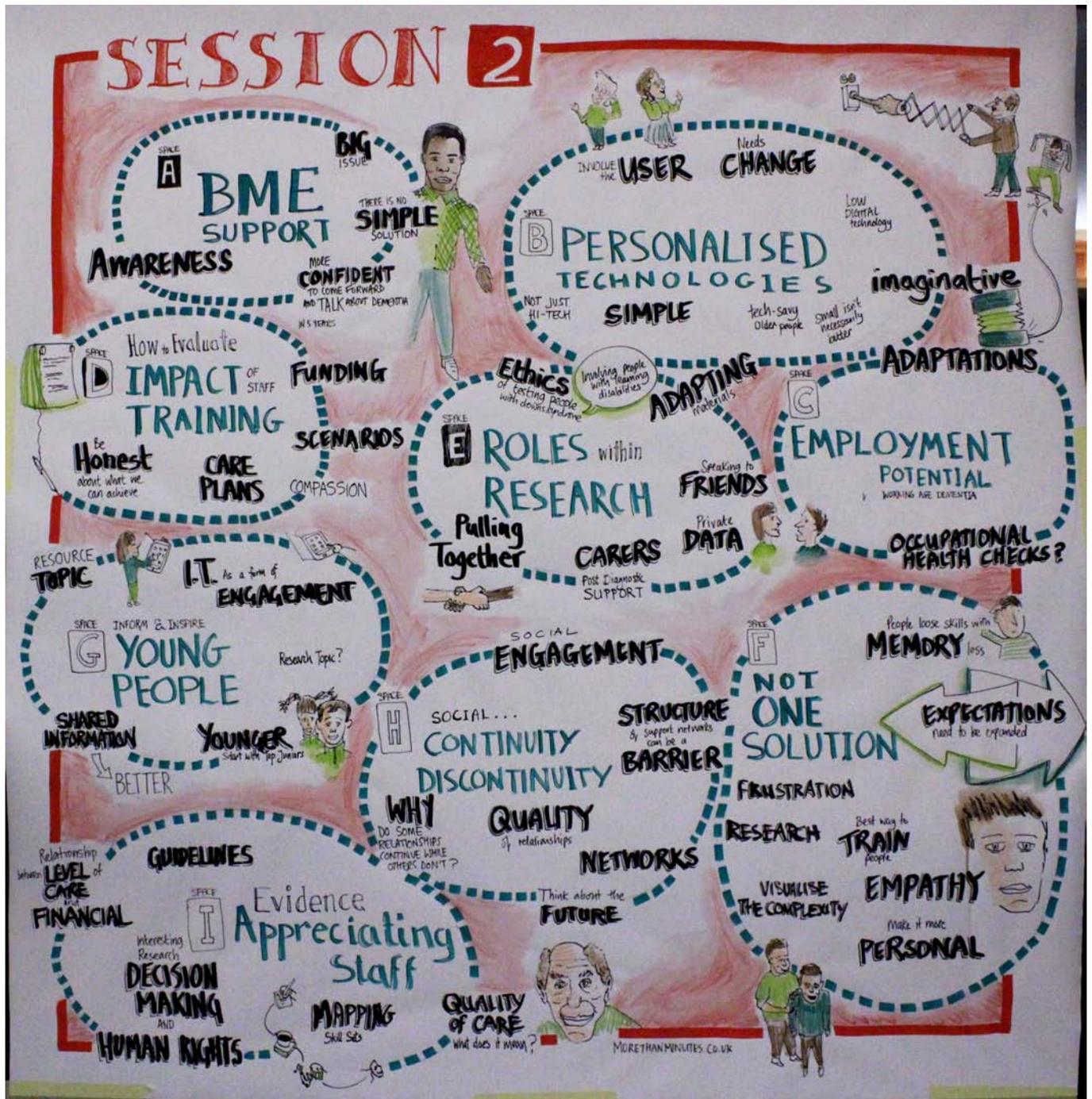
- Older person assessments need to be evidence based.
- Relying on staff to identify isn't ideal for training.
- Duty of care.
- Equivalence of care – dementia care in prison should be equivalent to the community.
- Ethical issues with dementia
- Grouping older prisoners together - pro's access specialised services v con's being away from family.
- Growing problem, older prisoners are the fastest growing group
- Challenges of frailty coupled with dementia
- Dementia in criminal justice system is an under researched area.

Next Steps

- ⇒ Understanding prevalence / scope of the problem
- ⇒ UK wide
- ⇒ Developing care pathways for dementia /networks
- ⇒ Access to specialised old age psychiatry



Visual Minute—Session 2



Group 15 - Keeping dignity as dementia progress's

Convenor-Joanne Singleton

Participants -

Nicola Fletcher - Dee - Sarah Butchard - Di Burbidge - Liz Postlethwaite

Key points from discussion

- Keeping dignity should not need to be discussed/ planned but automatic
- Managing both,
- Individually focused on each person to the standard of 'their norm'
- Information gathering for person/ family
- Acknowledging faith of person / specific needs to promote dignity e.g. wash/ showers
- Person centre care
- Personalisation not working – still task centered
- Detailed information of person needed
- Finances of local authorities
- Choice of what funding is spent on
- Choices not right
- Hospitalisation – losing mobility and control



Next steps

- ⇒ How do we understand and identify in the absence of memory - needs to be looked at.
- ⇒ How do 'we' and those with dementia identify themselves?
- ⇒ Need to create associations that is it something that affects us all.
- ⇒ 'Frameworks' need to be developed to support dignified decisions.
- ⇒ Person centred – changes needed from ground up to respect
- ⇒ How can empathy be captured and understood
- ⇒ Look at empowering care workers
- ⇒ Who supports dignity
- ⇒ Support network being respected for their decisions
- ⇒ Long term decision not being respected
- ⇒ Research and identify with dignity
- ⇒ Ability to remain engaged in society



- ⇒ Family not always respected
- ⇒ Dignity is different for each person



Group 16 - Support for family members – Problems and what is needed

Convenor Daniela Montaldi

Participants

Michelle Collins - Mike Taylor - Ruth Eley - Hilda Hayo - Andy Pownell- Lisa Woods

Key points from discussion

- Infrastructure limitations
- Good Memory clinic should include family but lack of standardisation means information is often out of date.
- 'I'm at my wits end, I don't know what to do or who to approach'
- Lack of knowledge in some areas of care provision and consistency
- Don't follow pathway through life as with other long term illness's. No clinical / social support
- Detailed discussion of current practice in Liverpool



Next Steps

- ⇒ Regional hubs – with national standards
Sharing best practice
- ⇒ Education
- ⇒ Delivery of information
- ⇒ Make information accessible
Clarity
- Consistency (consistency of content but individually selective)
- Availability
- One port of call for family members
- ⇒ No automated answer systems
- ⇒ Resources needed so NHS, local authorities and research bodies need to come together

Group 17 - What is the evidence for the effectiveness of interventions in dementia – where are the gaps in the evidence base?

Convenor - Sally Spencer

Participants

Claire Surr - Allan Grogan - Noreen O Sullivan - Richard Jagger - Liz Postelthwaite - Nicola Jervis - David Allsop - Caroline Hampson - Carol Taylor



Key points from discussion



- Evidence should take into account the population and diversity
- Polypharmacy and adherence – why people do and don't adhere with medications?
- Trials should include adherence outcomes
- Adherence may be influenced by peer support
- No trials of memantine in learning disabilities and dementia – need to include co – morbidity in evaluation.
- Head to head trials to establish comparative efficiency, explanatory work prescribing practices.
- Look at complex interventions – core outcome set for inclusion in studies – evidence base to identify
- Overview on dementia research
- Need for social isolation evidence base
- Methodologically – Evidence base should take into account: population and diversity
- Identify core outcome set to inform future studies.

Next Steps

Need evidence on:

- ⇒ Complex interventions and identifying those components through the evidence base
- ⇒ Evidence for remediating poor adherence to interventions
- ⇒ What is evidence for effectiveness of medicines in relation to polypharmacy
- ⇒ Need evidence on comparison between interventions
- ⇒ Use current evidence base to develop a 'one stop' document on research i.e. an overview of dementia research

Group 18 - Individualisation of solutions for people with dementia and support

Convenor - Daphne Wallace

Participants

Mike Taylor - Helen Morris

Key points from discussion:

- Memory issues are different for different conditions, lost skills that work with memory, visually can be difficult.
- Loss of skill – when once gifted can lead to frustration. Not just about 'memory' registering new information but loss of memory based skills – knocking things over/ into things.
- Expectations need to be expanded to understand loss. The person is different and the disease process will be different.



- Research into developing support with continuity so that the person can be better understood by another person instead of a multiplicity of small tasks completed.
- Over lapping with the work of life, story work and understanding the background and life of the person concerned – understanding the importance of ritual.
- Some of the paradoxes of information sessions for dementia awareness, general findings, results of dementia but that each person is different.
- Parallels with people's response to pain and research into this aspect.

Next Steps

- ⇒ Research into the best way to train people about the complexities over and above general observations
- ⇒ Visualise the complexities first, then look at common themes/ occurrences, will this develop more empathy – make it more personal from the start?

Group 19 - Potential for continued employment for people with dementia

Convenor - Pauline Banks

Participants

Nicola Fletcher - Katrina Forsyth - Gillian Southgate - Stephanie Tierney

Key Points from the discussion

- Use of adaptations – need to be geared to specific roles
- Need to demonstrate tasks to businesses that is going to benefit them
- Challenge stigma – hindrance to seeking diagnosis
- Depends on job and level of responsibility
- Importance of driving
- Loss of identity
- Will companies want to commit to supporting people – resource implications
- Costs with increasing number of people
- People as an individual, might need to look at each case

Next Steps

- ⇒ Find people who are still in work – how many people are there
- ⇒ Include dementia in occupational health checks
- ⇒ Try to look at good practice
- ⇒ Awareness raising amongst employers/ HR that problems could be associated with dementia.



Group 20 - Do we have an evidence base for understanding whether staff delivering care to residential elderly have sufficient training knowledge of dementia

Convenor - Bill Ollier

Participants

Rhys Davies - Sarah Butchard - Liz Postlethwaite

Key points from discussion

- Staff decision making in nursing care NIHR human rights approach to care – working with DenDron and University of Liverpool.
- In difficult decision making in all types of staff – assessment of an intervention (training package)
- Are the instincts of people working in mental infrastructure different to those in nursing care – well-being of residents
- Health economy of this
- Use QUALD for outcome and dementia care and relatives intervention
- Has anyone done research to map / audit the skill sets / competencies for staff in different care homes/ settings – do we know level of qualifications? Knowledge of dementia/ awareness etc?
- Are there agreed minimum guidelines for what experience / knowledge/ qualifications for staff working in different care / dementia settings – if not why not?
- Interesting to investigate the relationship between level of care / training and financial basis for providing care
- Do we know what we mean by 'quality' for dementia care. Issue of delivering care for the same sex care for the elderly/ dementia.

Next steps

- ⇒ Focus groups?
- ⇒ Formulate research questions
- ⇒ Develop national guidelines
- ⇒ Define expected levels of care
- ⇒ What is the best model for people being looked after, should people with dementia be with dementia cases or in a home without dementia sufferers?

Group 21- Family and friends, changes in relationships, roles, continuity and discontinuity of wider social relationships.

Convenor - Tracey Collins

Participants

Andrew Garrity- Pam Duffy - Allan Grogan - Hilda Hayo

Key points from discussion:

- Person with dementia and carer perspectives, family, friends fall away
- Why do some social connections continue and others not?

- Quality of relationships
- Normalisation – life engagement important
- Flexibility of services to allow continuity
- Lose of control – structure of day
- Create new experiences
- Establish new networks
- Individualised support
- Balance risk management with choice and integrative engagement
- Do 'with' not 'for'

Next steps

- Why do some relationships continue and some not quality of relationships
- Does a flexible approach from support services etc allow a greater engagement with life/ social networks / continuity
- Explore the creation of new networks and experiences – living well with dementia – normalisation and life engagement – important future and here and now importance.

Group 22 - The barriers between general community services and mental health services e.g. training of front line carers

Convenor - Rhys Davies

Participants

Chris Ling - Di Burbidge - Allan Grogan - Nick Ponsillo - Daphne Wallace - David Rog Bill Ollier

Key Points from discussion

- 'Blocking' of time for staff to undertake tasks as a problem
- What they want – different individuals
- How to cope with low staff levels
- Aptitude test for staff?
- Induction process
- Funding
- Contracts
- Interpersonal Skills

Same people

- Training – Home carers/ general managers
- Research: Surveys / Intervention
- GP Interface – poor
- Diet nutritional – sales of nutrition in RH
- Delivery of medication



Currently barriers to 'specialist' medical or 'mental health' skills being brought to bear in general so-cial services

- Home care settings/ patients own homes
- Voluntary organisations
- General practice
- Care homes
- Acute general hospitals
- Timing, care, personal care, meals, activities (music etc)
- Deal with confrontational behaviour
- Individual v groups e.g in care home/ client list of care agency



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- Deal with confrontational behaviour
- Individual v groups e.g in care home/ client list of care agency
- Challenges –
- Contracts/ targets
- Induction days / aptitude tests
- Staff – keen on training in general, funding levels/ funding of staff

Time saving from good practice

Skill set in nursery nursing

- Use of microchip technology to monitor drug taking.
- Research questions at all levels



Visual Minute—Session 3



Potential Research questions:

- What is the current provision of dementia training in social services?
- What individual training provided?
- What interventions help?

Mindfulness?

- Time management
- Altered targets for care quality
- Optional budgets
- Microchip to monitor drug intake
- What is cost saving of interventions to improve dementia skills in general service setting?
- Current models – can quality / cost aspects and in different regions to compared?



Group 23 - Dementia – Dementias, disease sub types within 'dementia' individual care for dementia subtypes

Convenor - Rhys Davies

Participants - Richard Jagger

Key points from discussion

How knowledge of disease types may be important for care

- Importance of biology of dementia
- Young onset dementia
- Training of practitioners in mental health teams
- MA treatment services
- Diagnosis framework
- Movement disorders – cannot tap into same services
- How many patients are diagnosed with one of the dementias
- Crucial for research selection.
- The right diagnosis for biological reactions and clinical trials and correct supportive treatment.
- Crucial for research selection.

Research questions:



- ⇒ What proportion of patients with a dementia diagnosis have a specific disease diagnosis?
- ⇒ Are diagnosis more delayed in unusual sub types of dementia
- ⇒ Does dementia training as it exists encompass information about different forms of dementia?
- ⇒ Issues of ensuring correct diagnosis in patients entering clinical trials
- ⇒ EEG as a biomarker for cognitive disorders
- ⇒ How can specialised forms of EEG (e.g event related potentials) be made to un harm biological diagnosis / subtyping?
- ⇒ Other biomarkers in differentiating sub types of dementia.

Group 24 - Sensory life day, work and development/ measurement

Convenor - John Keady

Participants

Nick Ponsillo - Daphne Wallace - Helen Morris - Christine Milligan - Chris Edwards

Key points from discussion

- Sense are very important, laughter as an example of engagement
- The emotional power of memories after sensory experiences such as touch, smell, hearing, texture etc.
- Arts bases measurements – singing and music
- Video and photo elicitation as evoking memories.
- The 'musical' memory tied into the life circle.
- Sensory work is complex but importance of being 'in the moment'; this should be the key to understanding evaluation. This could be a new active process based on multi-sensory experience built around individual / relational work.
- Currently, we don't know how to do this – new methodologies needed
- If you experience, you can understand, if you read and repeat you cannot.
- Eye contact, recognition, body movement, gestures are all important dimensions to the engagement of the human person living with dementia
- People with dementia need space for involvement and contribution.

“Excellent organisation and format which kept it interesting and offered something for everyone to engage in ”

“Talking to the Cochrane Dementia Group Editorial board in terms of setting future topic priorities as a consequence of output from the event. ”

Next Steps



- ⇒ Bottom up approach – visual methods/ participation
- ⇒ Innovative methodologies
- ⇒ Sensory experiences
- ⇒ Sensory forms of evacuation
- ⇒ Need to find out what is going on before we start: form a 'working group?'
- ⇒ The sensory tool should include elements of being:
 - 1) Audio/activity based;
 - 2) creative tapping into the senses and the person's 'musical memory';
 - 3) Innovative and use 'in the moment' visual methods to document engagement.
- ⇒ Potential PHD project

Group 25 - Remote, mobile, personalised technologies

Convenor - Tony Gatrell

Participant's

Daniella Montaldi - Carmel Dickinson - Pauline Parker - Joanne Singleton - Sally Spencer - Alicia Ridout - Carol Taylor - Lisa Woods - Caroline Hampson - Christine Milligan

Key points from discussion

- Intriguing mobile phone need to involve user as technology could be counterproductive – possibly frightening. Needs can change very quickly. Technology doesn't need to be 'high tech' expensive and plenty of experts are out there.
- New opportunities in wearable technologies (GPS enable wristbands) with high degree of intelligence
- Current issue of older people being not tech savvy but this will change so there are short term and long term issues.
- What are user preferences- for appropriate surveillance / getting lost?
- What is intrusive
- Personalisation matters – not everyone has identical needs
- Be imaginative e.g. embed new technologies in old devices and small isn't necessarily beautiful (eye, motor problems, co – morbidities)



Group 26 - Adapting mindfulness based practice for people with dementia and measuring clinical efficacy in terms of quality of life - Emotional - Regulation - Cognitive variables (e.g.memory) - Physiological variables (e.g. effect on brain structures e.g. hippocampus)

Convenor - David Powell

Participants

Noreen O Sullivan - Grahame Smith - Gillian Southgate - Alicia Ridout - Liz Postlethwaite

Key points from discussion

- Work done so far is fragmented, usefulness of review of published and un published work – possible publication
- Unpublished with survey of services and mindfulness networks
- Broad approach to thinking through how adaptations may be made – e.g. understanding practices from Buddhism not so far used in 'secular mindfulness'
- Tension around the intensiveness of research in this area, reductionism impoverishes capacity to really understand the impact for people.
- Problem of a consensual definition of mindfulness (some distinct) for research purposes
- Understanding 'good practice' re creative approaches that emphasis focussed purposeful activity 'in the moment' (something can be done in care homes)
- ? relevant outcome measures
- ?Qualitative and quantitative (mixed methods) 'hard' measures neuroimaging
- What range of outcome measures would an appropriate intervention be measured against?
- The challenge of helping people to maintain mindfulness practice? So what are the obstacles? What helps?
- How can mindfulness practice be more easily integrated into to day life.
- Relatively understanding how something like mindfulness practice can be integrated into activities in care homes etc and what effect this has
- Likely large variations in response to any mindfulness intervention
- ?focus on intervention on earlier stages

"More of this type of event please, structure, delivery, style, content, engagement, inside out agenda setting, short & sharp sessions, choice of where I invested my time - excellent event."

day

Next Steps

- Further re thinking involves others. Beginning to bring together the mindfulness and dementia communities.
- Locally small scale defined projects – some offered to students looking for research ideas in HEI's (e.g. clinical psychology trainees)
- Do we have experts for systematic review including survey data



Summary

This summary is for the purposes outlined at the outset; that is to make notes of the dialogue and to circulate this to the participants as a reminder of discussions and to locate individuals who were involved or who have since expressed an interest to be kept informed.

There are several themes common across different groups. These include: Support for family and carers, training for care staff, treatment interventions and evaluation of these interventions, stigma and maintaining dignity.

It is also suggested, to further increase the success of the event that those who want to lead research could provide a short summary to be sent to attendees of the event in case any of the research ideas were missed on the day.

Next steps

The Event Report will be circulated to participants and other interested parties. It will also be available to the general public on our website. Contact details will be circulated to Discussion Convenors on request to facilitate the further development of the proposals outlined. NHS R & D North West may contact Discussion Convenors to ascertain what additional support is required to maintain momentum and track progress of bid development / successful application for research funding.

NHS R&D North West would appreciate on going feedback with regards to the progress of any of the issues raised on the day from any of the people who attended the event even if they were not a convenor.

Thank you to everyone who attended on the day and contributed to all the discussions detailed in this report and a big thank you too all convenors for raising their question.

“The greatest value was in the fact that people had the opportunity to discuss issues that were important to them as well as listening to someone with a lived experience of dementia. ”

“Very productive event and great artwork! ”

“More of this type of event please, structure, delivery, style, content, engagement, inside out agenda setting, short & sharp sessions, choice of where I invested my time - excellent event.”

“Excellent organisation and format which kept it interesting and offered something for everyone to engage in ”

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Visual Minute—'As a result of today...'



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Feedback from Survey Monkey

Did you find the day useful, if so what?

- Very interesting to hear from Alistair and Anne, and to work with such a range of people
- The structure of the day was democratic and encourages participation - much better than being spoken to all day.
- Excellent day well planned and facilitated
- Yes by virtue of being able to both listen and talk
- The greatest value was in the fact that people had the opportunity to discuss issues that were important to them as well as listening to someone with a lived experience of dementia.
- Great to connect, reconnect and think. We don't get to do enough of those!
- Yes, good opportunity to compare ideas and discuss possibilities for further research.
- Networking & discussing thorny issues
- The day was very valuable. In particular it was great to meet with a wide variety of people who are all interested in the same topics.
- Really valuable use of time from a networking perspective and the sharing of knowledge from very different people
- Very useful in making new contacts and knowledge sharing

In terms of taking things forward, what plans have you got?

- Consider developing a sensory instrument for measuring effectiveness in dementia care
- developed partnership agreements with agencies directly engaged with dementia clients
- reconnecting with people I met to further aims of my project
- Raising concern about medication overload
- Wishing to run similar sessions with the community groups I work with at the moment
- Meeting 3 people I met on the day
- I am already involved in some research
- Talking to the Cochrane Dementia Group Editorial board in terms of setting future topic priorities as a consequence of output from the event.
- I plan to work with a wider range of NHS organisations
- one meeting re carer research
- Ideas for further research with collaborators but this needs facilitation from the organising group
- offer advice to people about submitting applications
- Continue to search for funding for raising awareness within the Chinese community and developing culturally appropriate dementia support services



Did you make any connections on the day and how will this assist you in your future work?

- Yes, I will email people re possible collaborations
- Yes, and was able to catch up with some existing contacts too.
- Yes many - research input for evaluation of the project, materials for Dementia Friends Sessions from ambassadors
- I made connections with the Alzheimer's Society from Manchester and I hope to keep communicating with them
- I met someone who wishes me to work with him on some work he is planning.
- Yes, with Carmel Dickinson and Rumona Dickson in particular. This will contribute to development of the evidence base for dementia therapies and interventions
- I made contacts with a number of local NHS organisations and at the University of Lancaster that I am contacting to arrange to work with them
- I made some good connections, which may help to inform my practice in the future.
- possible future connections
- Made connections in both academia but also in other sectors
- I have informed people about the role of the Research Design Service
- yes the mix and diversity of people attending really worked
- yes guest speaker has offered to deliver a talk to our Luncheon Club members

Any other comments

- If anything the title was misleading - it wasn't so much about identifying gaps, but in sharing knowledge and building connections
- Really powerful event format - so many ideas in such a short time. Hope some real research projects move forward as a result
- Meeting format was excellent, however perhaps less groups but one more session during day?
- Thank you for a well thought out and excellently run event
- Excellent event. Well facilitated - delighted to have been there.
- A very well organised day.
- Very productive event and great artwork!
- more service improvements than innovative research but good all the same
- Excellent idea to have Anne Johnson talking about living with dementia
- It would be nice to have more clinicians and commissioners present at these meetings. Some of the comments/discussions were a little removed from what actually happens in the real world. If we are to truly move forward, I feel that engaging with the people who deliver what the research finds and who commission services might mean that some of the work carried out in the academic world translates better to clinical practice.



Postcard Feedback

- Worthwhile event – time used effectively with positive results – thanks.
- Today has been a really enjoyable experience which provided opportunities to discuss important issues within the field of dementia care. There were some great ideas discussed and concerns raised and while it is fantastic to have these conversations and move forward with the research, I feel that the commissioners of services should be included as they need to provide the funding!
- Enjoyed the day very much and excellent facilitation. Its heart was in the right place and the facilitator was very good, excellent. Thank you for the opportunity
- An Informative and useful day, good venue, well organised
- An excellent way to hold an event. Interesting, stimulating and inspiring.
- Great event, well facilitated, good networking, great lunch, good ideas to take forwards, cold until lunch time in the room (not the best acoustics either!!)
- A fantastic day; well put together and thought through. Excellent mix of people with a range of knowledge and expertise. I have learnt an awful lot and feel more informed and provoked into action than when I walked through the door, very important to have both Anne and Daphne here to ground our discussions in reality and give a more informed perspective.
- Thanks for a really beneficial day. Well-structured and organised. Produced copious information. Can't wait to see the report
- Really worthwhile event Imaginatively organised with a good mix of interesting, engaged people. Excellent accessible venue(once room warmed up) good refreshments. The acid test will be whatever new grant applications emerge
- Very accessible, good opportunities. Art work an aid to memory, good sharing of knowledge, feedback on groups, too much choice – good, range of topics, could not have asked for more, venue chilly, people need teaching how to use a microphone, good size room.
- Inspiring and energised day, thank you
- Good day, well run, lots of opportunities to contribute. Hope it leads to great studies
- Great day, delighted it has included the creative and the imaginative. An exciting scope of possibility for people with dementia and their communities. Thank you
- Overall a very good day, would like to hear the outcomes of groups I could not get to. Worst thing was the extreme temperatures.
- Please add in:- research into identifying advance permission for research involvement to reduce barriers to inclusion for the important group of people with advanced dementia, incorporating ethics, very useful session and a lot of new thoughts and connections.

