

Catalyst Event Report on

How do we ensure dementia research improves lives?

Aintree Racecourse, Liverpool Thursday 5th May 2016



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Purpose



This Catalyst event was a collaboration between Alzheimer's Society and NHS Research & Development North West. It was designed to bring together prominent people from diverse backgrounds across the country who have an interest in dementia research and its subsequent implementation.

It is hoped the event allowed attendees to begin collaborative work across their organizations, with a view to develop innovative bids for grant schemes including Care and Public Health Programme Grants offered by Alzheimer's Society and other National Institute for Health Research/ 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.



Presentations

Dr Stuart Eglin, Director of NHS Research and Development North West



Dr Stuart Eglin, introduced the day and went through the concept of the Catalyst event and how it was highly participatory. He stated that everybody attending the event had an interest in dementia and all would have something to contribute. Stuart introduced the next speakers



Dr Bob Kahn, Research Network Volunteer, Alzheimer's Society

Dr Bob Kahn cares for his wife Sylvia who was diagnosed with dementia seven years ago. Bob talked about his experience of caring for Sylvia and described her as a time traveler, bringing the past into the present.



He explained the importance of circadian rhythms and how Sylvia became confused as the sun rose, began to go down and finally set. It is not helpful to do research at these times because many people with dementia become confused.

Bob emphasized the importance of love and loving for a person with dementia and how this can relax a person and keep them calm. Also, sometimes both the person with dementia and the carer need to keep calm and "bin it" as it is not possible to do everything they want to do.

Bob concluded his talk with the advice to keep focused, maintain your position and prepare for the long game.

Presentations

Professor Alistair Burns National Director for Dementia at NHS England



Professor Burns started his talk by applauding the Open Space format of the day which provides a fantastic and safe environment for conversation and collaboration around dementia research. He emphasized the need to get people interested in research and raise the awareness of dementia. He said the secret is for people to keep talking about dementia after he has left the room.

Professor Burns reflected on the progress in dementia research in recent years. He quoted the fact that for every £1 spent on health and social care in cancer £1.30 was spent on cancer research and yet for every pound spent on health and social care in dementia only 5p was spent on research.

Also 12% of people with cancer were involved in a clinical trial compared to only 1% of people with dementia.

There is evidence that the funding in dementia is now growing and research projects that previously would not have been funded are now going ahead.

This year £250 million of funding will be made available to the dementia research Institute.

Five things are important in dementia:

- Preventing well
- Diagnosing well
- Supporting well
- Living well
- Dying well

'Reflections on clinical and research issues, national concept, future collaborations, Open Space approach was very effective and relaxing!'

Presentations

Colin Capper, Head of Research Development and Evaluation,

Alzheimer's Society

Colin talked about motivating and encouraging conversations for the day. He said that we are now in a time of real significant advances in dementia research.

In the past there have been too few researchers and too few people with dementia involved in research and not enough evidence from research.

Now the UK is second in the world with regard to impact in dementia research.

Alzheimer's Society will invest £100million over the next ten years in dementia research.

Today is about bringing researchers together with others to explore how we care, how we share ideas, igniting old partnerships and developing new ones.

An incentive for the day are two new funding scheme's from Alzheimer's society

1. The Implementation Grant Scheme
2. Care and Public Health Programme Grants





Convenor Reports

Group 1 – Innovative methods of involvement

Convenor – Tracey Williamson

Participants – Ann Johnson, Caroline Hampson, Sue Clarke, Catrin Hedd Jones, Andrea Voger, Kathryn Harney, Nigel Hooper, Adelina Commas Herrera, Beth Luxmoore, Siobhan Reilly

Key points from discussion:

- Young onset dementia study at Salford University is currently underway – Ann Johnson involved. Looking at meaningful ways of involving people with dementia
- With cancer, people are more likely to be involved in research
- Ethics can be overwhelming for people. Want people to be involved but need to make it simpler
- You may not get a comprehensive answer but using music is a brilliant way to get people involved E.g. Manchester Camerata projects. Using the arts in general to involve people is the key
- How do we involve people right from the beginning?
- Camerata bringing people from care homes to a garden centre for example
- Social side is really important as well as medical. Salford University is involving people in baking. Alzheimer's Society has volunteers who have dementia reading research proposals
- LSE working with different groups of people as research progresses as people may deteriorate
- Difficulty with reference groups as people cannot always recall previous discussions
- Having simple visual materials regarding ethics but not always acceptable to ethics committees. NHS ethics can block people out. A lot of work to be done
- Do we need to capture all the work that have been done previously?
- John Keady referred a piece of work in 1995. Innovation is great but needs to be fit for purpose

Next steps:

- How do we reach hidden people? Use of social media is not always the answer. We tend to ask the same people and they are usually using the services
- MICRA do a lot of research involving people. They are involved at research proposal stage. We need to be involving people without dementia as well as some sort of control.
- Join dementia research – is having a great success in involving people
- Ann Johnson is involved in the neighborhood and dementia work with Caroline Swarbrick at Manchester University

- Involvement doesn't have to be formal – need to be more creative
- It is hard to just involve the 'usual suspects' DENDRON carry out clinical trials
- We need to take learning from learning disability research – so much to share. Access seldom-heard groups. Need to reach out across professions and clinical fields
- Dementia research is still in its early days – niche market
- People tend to join research because they think they will get better care
- Also research can be fun, not dry and boring! We have a lot to learn!
- Six Degrees social enterprise in Salford has developed empowered conversation, difficult to measure the 'softer' outcomes. Need to use a broad range of methods

Group 2 – Elements of service user involvement that are beneficial

Convenor – Sarah Butchard

Participants – Liz Fisher, Ann Johnson, Sure Clarke, John Keady, Colin Capper

Key points from discussion:

- There are recognised people living with dementia being involved in service delivery research E.g. feeling valued/appreciated/empowered
- There is a lack of knowledge base related to this topic – anecdotally we know it is a good thing but this isn't evidenced
- Talking circles of support/friendship require money and investment and providing opportunities for people
- Links to dementia friendly communities and public health
- Need innovative methodologies to fully investigate these and may include things such as blogs/ Twitter/photographs
- Do people who get involved do better (cognitively and emotionally) and why? Is it personal factors/social factors or both?
- Local community measures of change are vitally important. We are talking about social change
- Key is 'being able to be me' – may be important to look at self identity e.g. biological continuity and personal construct theory



Next steps:

- Review of current literature
- May require a specific research call to allow researchers to take risks will innovative methodologies.

Group 3 – Care pathway – pre and post diagnosis

Convenor – Brenda Gannon

Participants – Denise Taylor, Stephen Green, Ruth Boaden, Murna Downs, Rita Newton, Daz Greenop

Key points from discussion:

- Evaluations of care pathways for post diagnosis. Use of services starting with GP, hospital, community care
- Incorporation of medication in care pathway
- Service delivery – use of qualitative, lived experience views
- Medium term and longer term diagnosis are important
- Use of health and social care inputs current and future use of services.
- Heavy users and low users
- Include information on dementia friendly communities
- Integrated health and social care
- State funding social care who pay for care and how can we pick that up in data?
- Pre diagnosis?
- How to predict diagnosis based on early onset of cognitive decline?

Next steps:

- Follow up on proposal (summary) sent to Colin Capper to find out remit and themes for funding
- Follow up on quantitative aspects



Group 4 – Building relationships between person with dementia, the nursing home and the family

Convenor – Jackie Samuel

Participants – Murna Downs, Daz Greenop

Key points from discussion:

- Feeling that families get shot out of the role of care once a person with dementia is in a nursing home
- Couldn't tell who were family and who were carers (model to aim for)
- Assumption that people don't understand what is being said so we don't engage – engagement is the key or even include in conversation
- Skill of successful interaction – find a harmony in conversation not a purpose



Next steps:

None recorded

Group 5 – Technology and built environment

Convenor – Pete Sawyer

Participants – Claire Surr, John Woolham, Mark Hawley, Ruth Newton, Katie Bolton, George Kernohan, Allison Jackaman, Eneida Mioshi

Key points from discussion:

- Technology often situated, so slowly link to the built environment
- Technology being developed for a range of functions from early diagnosis through ambient monitoring to telecare
- Evidence suggests chores currently a problem with technology prescription and that affects links to outcomes
- There's a need for: understanding how and what to prioritise, understand what works for who, understanding the downsides (e.g. increases social isolation)
- How to make effective technologies acceptable? Who wants an early diagnosis? Aesthetics of 'medical' devices – consumer tech (Fitbits etc) Privacy preservation and social attitude change
- Pig backing on tech we already have/are getting (smartphones, Fit bits and smart energy monitors)
- Policy and commissioning systems seem wrong – does tech providers face real competition, is the NHS getting the best value?



Next steps:

- Keep talking
- Very wide range of ways forward

Group 6 - End of life discussions

Convenor – Kirsten Moore, Karen Harrison Dening

Participants – Nick Ponsillo, Caroline Hampson, Eneida Mioshi, Barbara Woodward -Carlton, Karen Watchman, Jackie Samuel



Key points from discussions:

- Sometimes a long trajectory – when do we talk about death and dying?
- Discussions need to be individual but within a relational context
- How early do we start to discuss prognosis, end of life, is there a place for advance care planning
- Who is to have these difficult conversations and at what stage are they to happen?
- Importance of continuity of care and information over the trajectory of dementia—how so we ensure that care episodes are not disjointed?
- Impact on those left behind if care not as good as it can be
- End of life care in dementia is often about managing uncertainty. How do we develop healthcare professionals skills in helping carers cope with and manage certainty?
- How do ACP and discussions about future care actually impact on what happens at end of life? Are these care plans followed?

Next Steps:

- Studies in ACP – more flexibility with new grant schemes – naturalistic methods
- Compare across UK counties
- Who does it?

*'Great concept (Open Space)
– loved live drawing minutes,
met some interesting people I
will keep in contact with.
Want to take ideas forward'*

*'Great day, democratic
process, invigorating and
creative, looking forward
to next steps'*

Visual Minute 2



Group 7 – Support older carers

Convenor – Deborah Oliveria

Participants – Karen Watchman, Emma Oughton, Karen Harrison Denning, Kirsten Moore,

Key points from discussion:

- Ask what carers want (and if they want it)
- Recognize different family configurations
- More reciprocity in caring
- People ageing with a learning disability and dementia often living with older parent who may also have dementia and increased role for siblings
- Carer benefits – information needed, financial disadvantage
- More family research – family-centred approach relationship-centred care
- Whose best interests do we look at? Carer or person with dementia – especially if needs/ wants differ
- The 'don't put me in a care home' dilemma. The additional pressures and guilt placed on family carers when trying to meet the person with dementia's request of not going into a care
- There needs to be greater recognition on the ageing carer's own health needs
- Care home residency doesn't mean person doesn't experience isolation
- Discussion around peer support – when/how often/how appropriate
- Less support available for advanced dementia
- Increased emphasis on carer health needs



Next steps:

- Relationship focused research to better support family systems
- Consider care home environment for older carer visitors
- Flexible and appropriate options for carers, who is respite for? Are programmes adequately meeting the social needs of people with dementia and offering a real break for carers?
- Older carers overloaded; their contribution to society is not measured



'A very stimulating, useful day maximised the chances of networking – the Open Space process worked well. It will be great to continue some of the conversations!'

Group 8 – Volunteers /volunteering

Convenor – Josie Tetley

Participants – Liz Taylor, George Kernohan, Nan Greenwood, Colin Capper



Key points from discussion:

- Evaluating new service to be run by volunteers, perhaps there are challenges in recruiting and supporting large numbers of volunteers for organisations including Alzheimer’s Society. Have to go through formal checks e.g. DBS which can take weeks and put people off
- Volunteers unpack their initial motivation e.g. some might have had relatives with dementia, research what motivates volunteers
- Change name of project
- Look at other areas where volunteering schemes work well, capture positive aspects and how they transfer
- Technology to match the volunteer with the person requiring support
- How to keep volunteers ‘warm’ whilst waiting
- Do bureaucratic systems put people off?
- What do organisations see as the purpose of volunteers
- Is there an expectation that volunteers can fill voids where health and social care services cannot meet needs
- Issues of matching volunteers with people who need support
- Changing nature of volunteering – becoming more job like
- What are volunteers expectations?
- Volunteering needs to be flexible
- Is there an expectation that volunteers have to be ‘relied’ on?



Next Steps:

- Need more work to explore volunteering in current contexts



Group 9 – Empowerment of people with more advanced dementia to be more involved in research and development.

Convenor – Beth Luxmoore

Participants – Emma Oughton, Nan Greenwood, Linda Clare, Daz Greenop, Mark Hall, Tracey Williamson, Josie Tetley, Pete Sawyer, Arwen Wilcock

Key points from discussion:

- Observational approaches – how can we make these empowering for people with dementia
 - ⇒ Taking on board one’s own experiences and how these may relate to the experience of others
 - ⇒ Being discreet in observations
 - ⇒ Being natural in a situation
 - ⇒ Takes a long time
- Being willing to listen to negative feedback – understanding how peoples reactions may be impacted by their dementia symptoms
- Educating ethics committees around issues of consent
- Interpreting findings – conversational transcripts may not be linear
- Some stigma can still exist around the capabilities of people with more advanced dementia. Often, people with more advanced dementia can be assumed to be globally confused and therefore not worth listening to
- Studies should be structured to account for unexpected outcomes as well as both positive and negative aspects of dementia care
- Having time to try different engagement approaches/times/settings – being flexible in approaches
- It is important to develop trusting relationships when working with people with more advanced dementia. This does not necessarily make methods restrictive but the impact of these relationships should be considered during data analysis
- Carers are not proxy but can be extremely useful – interpretation needs to be careful. not only listen to the carer, have separate and combine conversations with the person with dementia and carer
- Using talking mats as a tool for research
- We can learn from talking about things that haven’t gone well
- We can learn from work in learning difficulties

'Enthusiasm was great!'

Next steps:

- Bring together tools for involving people with more advanced dementia in research
- Start more honest conversations

Group 10 – Appropriateness of current measurement in dementia care and how to implement this

Convenor : Sarah Butchard / Arwen Wilcock

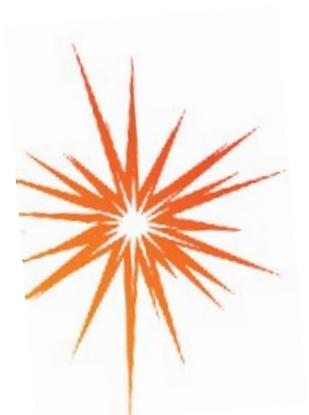
Participants: Denise Taylor, Rachel Volland, Nick Ponsillo, Daksa Trivedi, Linda Clare, Beth Luxmoore, Ruth Boaden

Key points from discussion:

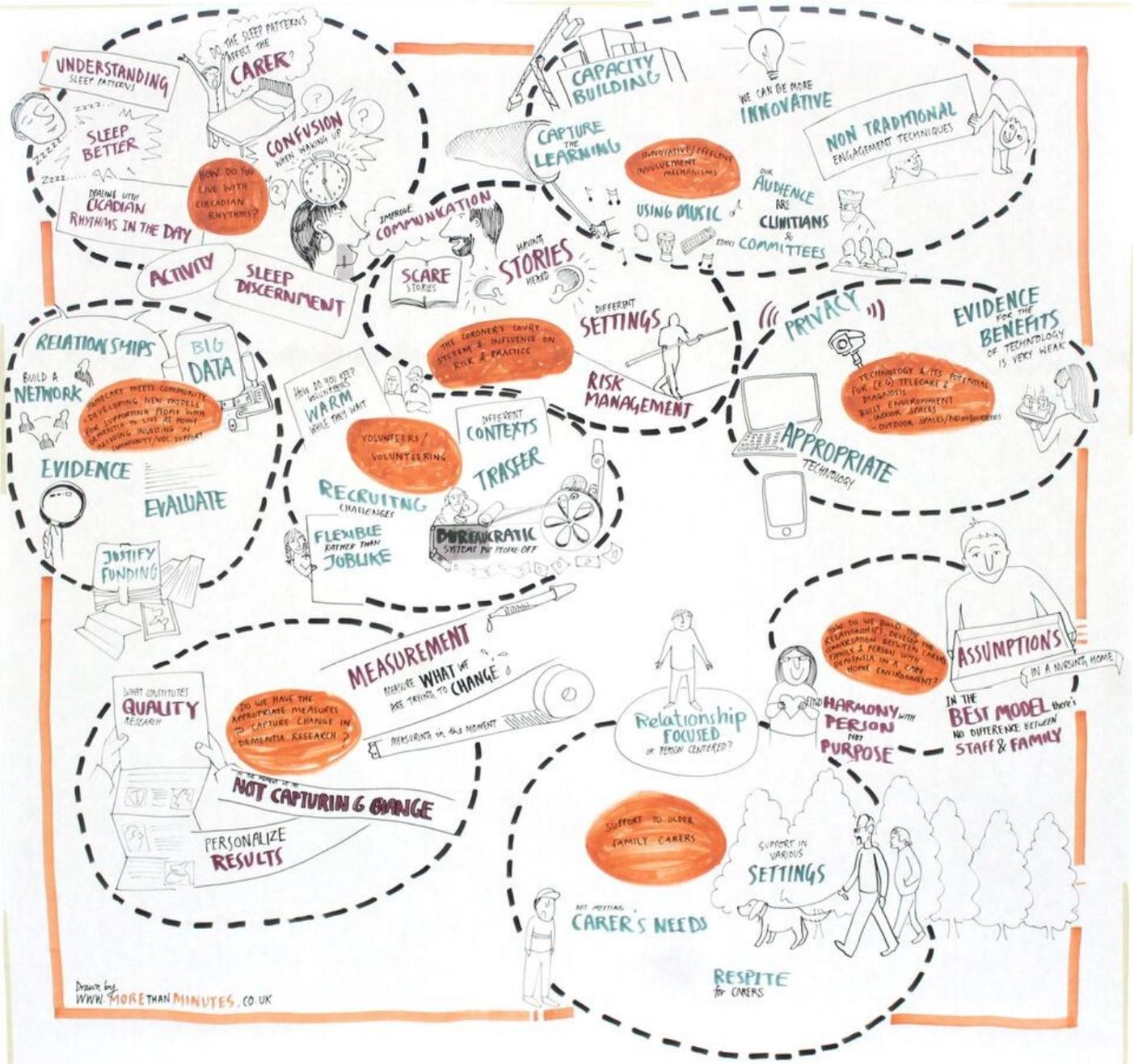
- Acknowledgement that current standardized measures are not always capturing what we hope to measure
- It is important we evidence what we are doing is effective and also how we implement this in practice.
- Randomized controlled trials may be appropriate in some situations but not in every situation. Need flexibility to undertake other types of studies too and the importance/appropriateness of other types of studies needs recognising. Also at implementation level.
- Mixed measure designs can provide context to the data obtained from quantitative measures
- Robust process measurement is essential in order to demonstrate why an intervention may be appropriate for one person
- There is also a need to capture the economic impact of interventions. This may require us making new partnerships to capture the skills necessary to undertake this.
- Some of the things we try to measure are 'soft' but vitally important. Essential measures are personalized
- May be more important to evaluate the relationship rather than the intervention per se. ●
- Essential to measure what you are trying to change e.g. individual goal setting ●
- If people with dementia are living in the moment then how so we measure what is happening in the moment. ●
- How do you measure change in the context of decline

Next steps:

- Agreement on what constitutes good quality/appropriate measurement in this context
- Educate policy makers/funders/researchers about how things should be measured. Political pressure for change
- Statement on the right kind of measurements for the right issue
- More consideration of the economic impact of interventions to convince commissioners



Visual Minute 3



**Group 11 – Community care, home care and voluntary sector –
demonstrating benefits and outcomes for investment**

Convenor – Nick Andrews, Neil Chadborn

Participants – Kathryn Lloyd, Katherine Gray, Brenda Gannon, Karen Harrison Dening, Nick Ponsillo, Jill Manthorpe, Catrin Hedd- Jones, Rachel Volland

Key point from discussion:

- Blending community/voluntary services with statutory care. Need for relationships in managing care, rather than bureaucratic/corporate approach
- Manchester devolution – how to involve third sector – what evidence can be applied in improving evaluation – need to be cost effective
- Start trial of implementing evidence of clinical and cost effectiveness
- Assessment from social worker and providers do own assessment – duplication
- Meaningful outcomes/measures for people / person-centred
- Research of evaluation should be proportionate to service being delivered
- Drawing together anecdote evidence and narrative
- Researchers may work for years on a topic, then politicians bring in intervention without evidence
- How can researchers be better advocates – to include implementation from the start
- Are the right people engaged in the research
- Use big data to evaluate
- Manchester camerata orchestra – relationships are important – relationship between care home and community
- Show quality of life and wellbeing

Next Steps:

- Divide between community assets, carers, relationships and services
- Very different types of evidence but we need evaluation to justify funding
- Potential big data analysis
- Development of narrative evidence, acknowledging importance of relationships not just task
- Build network



Group 12 – Coroner’s Court – Systems, practice and risk in dementia Care

Convenor – Jill Manthorpe

Participants – John Keady, Ruth Barlett, Stephen Green

Key points from discussion:

- Familiarity with system – practice and personally related
- Consideration of importance of socio legal aspects to care in many settings and practice
- Different dimensions – frame as positive – used as ‘scare’
- Potential of research to improve communications, risk management, professional support, info for families

Next steps:

- Further engagement
- Links to human resource dimensions
- Consideration of user systems



**'How do we involve
the front line and
leaders implementing
research?'**

Group 13 – Implementing research in practice – research culture in health and social care

Convenor – Rachel Volland

Participants – Neil Chadborn, Catrin Hedin- Jones, Claire Surr, Jill Manthorpe, Nigel Hooper, Arwen Wilcock, Siobhan Reilly, Adelina Comas- Herrera, Kathryn Lloyd, Deborah Oliveria, Kathryn Harney, Daksha Trivedi

Key points from discussion:

- How to engage the right people to close the 'implementation gap'
- Organization's exist to promote 'research into practice' however more than promotion is needed and actual activity is required
- Maybe social care is less engaged in research
- Need regulators to pull levers to help make it happen
- Research is on agenda for memory clinics
- Relationship between researchers and service users can be strong during research, however, the research often struggles to then drive into practice using these channels
- Ownership
- Can Alzheimer's Society or other charities act as a broker to help getting research into practice
- Tailor messages from peer colleagues
- Is it a barrier to label as research
- Real problem of headlines announcing 'breakthroughs' – Alzheimer's Society use similar messaging at times?
- Problems of leadership not understanding research projects
- Do we need to attend/be more involved in health and well being boards etc
- Clinical researchers may feel unable to continue in clinical role



Next steps:

- Partnership working – from the outset
- Clinical research posts
- Doctoral route for clinical researchers to build researcher
- Academics tied to one organization – need broader footprint of ownership

Group 14 – Resilience in people with dementia (positive outcomes)

Convenor – Deborah Oliveira

Participants – George Kernohan, Pete Sawyer, Katherine Gray

Key points from discussion:

- Speaking to other people promotes resilience
- Meaningful group activities
- Communication
- Regular routine
- Feeling safe
- No pressure, flexibility through environment
- Continuing of care and support



Next steps:

- Long term projects
- Enough budget to maintain a continuity of activities
- Keep names of staff members
- Life span evaluation
- Evaluation of capacity to cope on a regular health/ social check



Group 15 – How can we live with circadian rhythms?

Convenor – Bob Kahn

Participants – Penny Rapaport, Stephen Green, Katie Bolton, Barbara Woodward- Carlton,
Jackie Samuell

Key points from discussion:

- You can try to manage sleep better – being studied as a new project at University College of London
- Do the sleep patterns of the person with dementia affect the carer?
- Two Key issues emerge
- How do people with dementia sleep at night?
- How do you deal with circadian rhythms during the day?
- How do sleep patterns link to mini mental state exam scores?
- How darkness and light affect sleep and confusion on waking up?
- Seasonal affective disorder happens to some people during winter
- The amount of sleep needed might be linked to the amount of activity in which the person with dementia engages
- People often do not actually understand sleep patterns

Next steps:

- Try to understand what the difficulties are in sleep discernment
- Consider how circadian rhythms affect people with dementia
- How does sleep affect personal resilience to face dementia– both for carer and person with dementia?
- Share personal experiences – everyone is different



Group 16 – Transition – support (to nursing homes) and resilience

Convenor – George Kernohan

Participants – Pete Sawyer, Katherine Gray, Deborah Oliveira

Key points from discussion:

- Can combine the two groups – transition and resilience
- Define the concepts and base line work – lit review and existing evidence
- Find an active intervention (like dance)
- Could we use Skype possibility of missing subtle signs
- Time needed – minimum eight or nine weeks to achieve outcomes
- Need to bridge activity before and after transition
- Need right time and some routine elements
- Familiar elements need to include creativity
- Can use resilience as core concept with researcher after outcomes
- Impact of context/environment/light etc



Next steps:

- Long term approach – integrate into service
- Clarify research question – to tailor and optimise resilience



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.

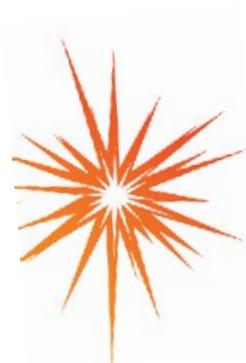
It is also suggested, to further increase the success of the event, that those who want to lead research provides a short summary to be sent to attendees of the event.

Next steps

The event report will be circulated to participants and other interested parties. It will also be available to the general public on the NHS Research and Development website and Alzheimer's Society website. Contact details will only be shared where someone has given permission for their details to be shared to help facilitate the further development of the proposals outlined. Alzheimer's Society may contact discussion convenors to ascertain what additional support is required to maintain momentum and track progress of bid development/successful application for funding.

Alzheimer's Society and NHS Research and Development 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 this report and a big thank you to all convenors for raising their question.



discussions detailed in

Alzheimer's Society next steps follow up to the catalyst event

1. We will contact all session convenors to discuss both their next steps and our next steps, and identify the potential role of the Alzheimer's Society
 - We will also contact Catalyst event participant who would like further discussion with us (please contact Arwen on Arwen.wilcock@alzheimers.org.uk)
2. We will review the 11 potential research themes identified, sharing this report with the grants team and Boards to inform future research funding considerations
3. We will support potential grant applicants with networking and developing collaborations

We have also identified a number of potential activities, to explore:

4. Supporting the development of a short (summary) guidance document that identifies a variety of potential research methodologies to support implementation research. Prioritised content is likely to include:
 - Summary methodologies
 - Outline of potential types of expertise to support implementation research
 - Outline of good practice in involving PPI within research
5. Enabling development of research collaborations through delivery of further networking events (e.g. WebEx events and face to face workshops/meetings)
6. Commissioning research/systematic reviews into niche areas of low evidence areas that were identified during the Catalyst event
7. We will aim to work with colleagues to influence perceptions and acceptance of research and different evidence types with commissioners and policy makers



Feedback (provided on cards during the event)

- Open space events always a positive experience and productive, professionally run and interesting thought provoking constitution that ends in action!
- Great concept (open space) – loved live drawing minutes, met some interesting people I will keep in contact with. Want to take ideas forward. New ideas, new people, new collaborations. Look forward to reading the report.
- Great programme however, focus on academics, need to invite more NHS health and social care professionals to implement the great ideas that have been generated practically
- Great workshop loved the open space idea! Thank you for putting implementation first!
- A very stimulating, useful day with maximized the chances of networking – the open space process worked well. It will be great to continue some of the conversations
- Reflections on clinical and research issues, national concept, future collaborations, open space approach was very effective and relaxing
- Inspirational
- Great event!
- Enthusiasm was great
- How do we involve the front line and leaders implementing research?



Feedback (provided in post event survey)

The catalyst event was attended by 53 people, 25 of these responded to the post event questionnaire.

The event aimed to identify important implementation research questions related to dementia care:

- Attendees identified 11 broad research themes and many sub themes

The event aimed to discuss and identify solutions relating to implementation of dementia care research:

- Through the meeting we identified many barriers to this form of research, and a number solutions or approaches to remove the barriers
- Alzheimer's Society will follow up with group convenors to solidify actions that contribute to solutions and tackle the barriers highlighted within the report
- Respondents stated that they would use their new contacts to develop research partnerships, funding opportunities, share research findings or to provide research advice and networking support

The event aimed to create new, exciting and innovative collaborations to develop future research project applications:

- We had a range of backgrounds represented at the event; of 25 survey respondents the majority, 15, were researchers (60%), other groups represented included commissioners, health care professionals, service delivery professionals, service development professionals, technology experts, quality improvement and transformation experts and research network volunteers and people affected by dementia
- All respondents said they had made useful contacts for future work. Most (21) stated they had made between three and five new contacts (21 people). While two respondents stated that they made over seven useful contacts

Overall, event feedback was generally positive; but also included some helpful suggestions for improvement which we will review and address before our next event. When asked what they liked about the event, respondents highlighted the benefits of the open space format and opportunities to discuss a range of topics with interesting people:

- "Energy passion and developing possible research ideas and networks"
- "There were a lot of opportunities for discussion"
- "Loved the open space format and the opportunity to meet new people"
- "Interesting range of people"
- "The freedom to select where you would benefit most from at the sessions"
- "The ability to network"

Next time the Alzheimer's Society run an event we will aim to:

- Apply the logistical lessons learned to ensure the event runs smoothly and is as accessible as possible
- Amend the structure of the event slightly to facilitate identification of next steps and take research translation ideas forward
- Include a greater number of people affected by dementia and a greater range of professional roles represented

