Research Into Ageing: Highlighting Our Strengths

Over 100 participants came together at the ‘Research into Ageing: Highlighting Our Strengths’ workshop event held on 28 April 2014.

The workshop was jointly hosted by the Yorkshire Comprehensive Network - Ageing Priority Group and the White Rose Network, which includes the Universities of Leeds, Sheffield, and York.

The event brought together the latest research ideas and developments from across the region and also involved delegates in considering what are the regional priorities for ageing research and how best to involve the whole community in the research agenda.

Key messages from the day

There have been significant achievements in ageing research across Yorkshire. There is a legacy of successful projects and a variety of studies are currently taking place.

However delegates also identified important and sometimes neglected priorities going forwards. The need for innovative research projects and methodologies was highlighted. Meaningful ways of assessing outcomes and the importance of taking ethical issues into consideration were also raised.

Suggested topics/ issues for future research included;

- achieving patient-centred care
- impact of retirement and opportunities for community participation
- how we engage with people towards the end of life
- effectively joining up services
- occupation in care homes
- development of volunteering

Other suggested areas for research included: mental health, podiatry, delirium, loneliness, frailty and community based rehabilitation.
There was an emphasis throughout the day upon ensuring the appropriate and inclusive involvement of a whole range of important groups and individuals, and in particular patients and the public. It was agreed that such involvement should extend to all stages of research process including question identification, proposal development, the research itself and implementation of the findings.

The value of involving different groups and collaborations for creating research ideas and for sustaining and implementing subsequent research activity was discussed and examples provided of how this has been achieved.

There were calls for innovative research methodologies that directly involve people with dementia. Research methods for use with this group are under-developed particularly for assessing ‘in the moment wellbeing’ and evaluating cost-effectiveness of interventions.

It was agreed that there is a need to challenge society’s perceptions of older people. This should entail shifting from a deficits model to one which values the contribution of people at all stages of the lifecourse and encourages the fullest participation of all.

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Setting the scene
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Research into later life: the road less travelled
Professor John Young, Geriatrician, Leeds University and Bradford NHS Hospital, Yorkshire

John Young’s session provided an overview of some of the achievements of ageing research. Some of the challenges were also highlighted. For example ageing research is rarely condition specific and mostly involves looking at older people ‘in the round’ which is complicated. Most research is of multi-component interventions which can be difficult to establish, to implement and to evaluate. This complexity requires working with large teams and can be expensive. Additionally, there are often challenges to recruitment to studies such as encouraging different services to get involved, getting older people to sign up and managing the many ethical issues that can arise.

John talked about how challenges can be overcome and how we can move ahead with confidence, providing several illustrations of research into complex topics where progress has been made and further questions subsequently identified.
The first example was **provision of specialist care for older people.** John showed how we know, based on evidence from randomised controlled trials that specialist medical care for older people delivers better outcomes. This is now the gold standard that we should be aiming for. Work is currently in progress to look at whether good hospital practice can be transferred into the community. John indicated that this is an area that we need to know more about.

The second example provided was **falls prevention.** Drawing upon the extensive work undertaken by J.H. Sheldon in 1960 who began to classify falls and whose work still forms the basis of current practice. John described how research into falls prevention spans over fifty years. There has been considerable research investment into falls prevention for older people living at home. Over 50,000 people have participated in such studies and we can be confident about what works well and what is less effective. Examples provided to illustrate this point included the value of exercise and in particular tai chi, snow shoes and cataract surgery. Alternatively certain interventions are known to be less effective; examples given included taking Vitamin D and home safety. However we are still left with some uncertainty regarding how to prevent falls in nursing home residents and in those who are hospitalised. Furthermore a study carried out in care homes in Finland in 2002 indicated that falls in care homes are more injurious.

Reference was made to one of the pioneers of geriatric medicine, Dr. Trevor Howell (1908 – 1988) who identified what he termed the ‘Dragons of Old Age.’ These were pressure ulcers, contractures, falls, incontinence and confusion. John expressed the view that although progress has been made with identifying best practice through research in some of these areas, for example pressure ulcers, contractures and falls, issues remain in implementing best practice.

Participants were challenged to identify their own ‘dragons’ – the big topics that matter to older people. It was suggested that these might now include, loneliness, podiatry for older people and confusion.

John then turned our attention towards one of the new dragons – confusion. The Prime Minister’s Challenge has prioritised dementia, highlighting the need for improved diagnosis, post-diagnosis support, dementia friendly cities, dementia in care homes and appropriate prescribing of antipsychotics and research into both cure and care.

John spoke about one of the dementia projects that he has been involved with – P.I.E which is a ward-based observational tool. P.I.E stands for Person, Interactions, Environment. The tool is for ward nurses to use to determine to what extent person-centred care is being carried out by colleagues. This work was carried out as part of a national audit of dementia across 105 hospitals. Results showed that it was almost impossible to find any wards which were consistently practicing person-centred care. The study team then developed
the observation tool into a practical tool to help practitioners deliver person-centred care. A number of sites across the country, including Sheffield are now using this tool to improve the delivery of person-centred care.

He also talked about how delirium (otherwise known as acute confusion) has not been significantly researched and yet it is prevalent in older age. The impact of delirium is wide-ranging and can it can be life threatening. Along with other colleagues, John has been involved in developing guidance on delirium for the National Institute of Clinical and Care Excellence. John emphasized a major aspect of the guidance - **there is an imbalance between treating someone with delirium and trying to stop the onset of delirium.** Research evidence confirms that complex, multi-component interventions for delirium prevention can change outcomes.

Using scientists from the past to illustrate the point, John drew our attention towards the work of Professor Bernard Isaacs (1924 – 1995) who highlighted the so-called frailty syndromes in later life – incontinence, falls, confusion and immobility, popularising them the ‘Geriatric Giants’. This has tended to draw us into a crisis response service for frailty. In the future, we need to move towards an earlier more proactive approach which includes a systematic diagnosis of frailty and early forms of care. John made reference to the ‘4m walking speed test to detect frailty’. There is evidence that taking more than 5 seconds to walk more than 4m can help to predict future likelihood of disability, long-term care needs, falls and mortality.

This great key note presentation was summed up by the observation that while there have been successes in ageing research there are significant areas for further development. These include: care home medicine, community based rehabilitation, dementia care, preventing delirium and frailty programmes.

John stated that older people are inspiring people to work with, tremendously resourceful and have much to contribute and that we need to include older people as partners in research programmes.

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**Involving the public and patients in research**

**Patient and Public Involvement in Motor Neurone Disease Research**

Dr Emily Goodall, University of Sheffield

Emily spoke about work of the Patient and Public Involvement (PPI) in Motor Neurone Disease (MND) Research Advisory Group. MND is a rapidly progressive neurodegenerative disease. It affects people who are mostly over 55. There are around 5,000 people affected by MND in the UK.
The PPI group Emily is hosted by a research centre in Sheffield called SI TraN – the Sheffield Institute for Translational Neuroscience.

The MND research advisory group was set up in 2009 and aim to include patient and carer perspectives into research programmes. The group meets quarterly with regular email contact in between where members are invited to comment on research documents. The group has developed a feedback form, which provides two-way feedback between researchers and members of the group. The form covers a number of areas including: relevance and importance of the research, clarity of the written document and implications for potential participants (e.g. burden).

Emily described some of the specific challenges of involving people who are living within MND, particularly as the disease progresses rapidly. To enable involvement, email and hard copy documents are sent out to members so that face-to-face meetings are not always required. Membership also extends to carers and family members. Guidance has been provided to help explain research terms and the research process and also to provide technical support and training.

Some of the stated benefits of the group for patients and carers include meeting and engaging with researchers, finding out about the disease and learning about the research process. Feeling valued and being able to make a difference to influence research are reportedly crucial aspects of involvement.

Researchers have benefited from the process through learning about communicating and disseminating research to wider audiences, production of lay documents about research and identifying barriers to effective PPI involvement of research.

To date, the group have reviewed numerous research proposals, helped to improve recruitment to studies, helped to increase awareness of MND and research taking place and helped to direct researchers to focus their results on improving standards of care. A core panel to represent those affected by MND has been set up with developments including submissions of members as co-applicants on grant proposals.

Future aspirations include becoming a specialist PPI resource for pharmaceutical companies and expanding web presence and use of social media. The group hopes to act as a model for other such groups. Emily acknowledged and thanked colleagues and participants involved in the work of the group. She concluded with a thought from one of the members;

‘my hope is that we can add value by providing the patient’s perspective in a way which complements the fantastic work of the professional researchers, nurses and doctors’.
Anne recounted the work of the Patient and Public Involvement (PPI) group in stroke. The group was set up in 2005 with volunteers from local stroke groups. Initially, the group met in a hospital Trust but now meets bi-monthly in Leeds Centre for Integrated Living. One of the first tasks of the group was to decide upon its name and it became the Stroke Consumer Research Advisory Group (CRAG). Initially the group reviewed research from the Academic Unit of Elderly Care and Rehabilitation at the University of Leeds. They were an integral component of a bid to set up the Yorkshire Stroke Research Network (YSRN) and helped to play an important part in the delivery of the work that followed. CRAG also participated in the Stroke theme of the Leeds Collaboration for Leadership in Applied Health Research and Care (CLARHC).

Some of the activities of the group have included advising on strategy for the stroke network (YSRN), reviewing and approving the YSRN annual report and commenting and inputting into the development of grant applications. Representatives of CRAG have been included on grant applications and on Trial Steering Committees (for randomised controlled research studies). The group has helped in the production of lay summaries, ethics applications, information sheets and in the identification of appropriate outcome measures for research.

One of the big successes of the group is an Annual Conference, which is centred around World Stroke Day and has been running for six years. It attracts over 80+ participants and brings together invited speakers, showcases achievements and provides an opportunity for discussion of key themes.

Anne paid tribute to the members of the CRAG for all their support and contributions.

Key points from open mic session – how can we promote patient and public involvement?

A lively exchange followed, stimulated by the speakers and involving delegates from a range of backgrounds as illustrated below;

My main interest is in trying to encourage my academic colleagues to engage with older people in participatory action research and what we’ve heard so far
this morning is not this. It is about older people and patients advising the ‘great and the good’ on their research projects. There is a need for greater co-production of research and getting older people to put in their own ideas about what’s important. They are the experts on their lives.

I have recently been involved in a James Lind Alliance funded project looking at pressure ulcers, in which there was a close partnership between the researchers and the patients, carers and professionals. Based on this, I agree that there is a big difference between joining in on a research agenda that has already been established and taking the ideas from the bottom up (from users themselves). There isn’t much research on pressure ulcers and the group worked together to set research priorities and trying to overcome some of the problems experienced by those loving with the condition.

I am dismayed by the deal given to older people in terms of their mental health – this is as important as their physical health and we need to think more about early intervention and prevention. We don’t readily ask older people what they want to be researched, which is an issue. I would also just like to make a plea for more research on older people’s mental health.

As an occupational therapist by background, I agree that older people’s mental health is an under-researched area. In addition, there is an absence of evidence for how to get older people more involved in leisure activities.

It is also difficult to get funding for activities to keep older people active within my community because we are classed as an ‘affluent’ area, which is frustrating.

I agree with John Young - we find that the fear of falling is a key problem for frail older people and we have started to use Cognitive Behavioural Therapy to help with prevention – a technique which isn’t often used with this population as it is assumed that this is for younger people. I also think that it’s important to look at the impact of retirement and opportunities for community participation at this transitional stage.

I have worked with the CRAG (Stroke user group) to get feedback on a research proposal and worked with CATCH (Centre for Assistive Technology and Connected Healthcare at Sheffield University) to get people involved with new technology, as well as the Dementia Advisory Group in Sheffield and these experiences were all really useful. I think that it has to be a two-way street between researchers and users.

I would just like to highlight the importance of having ethnically diverse communities involved in PPI. It is important to reach out and engage people from different ethnic groups.
I am married to a stroke survivor.....I have a good idea for stroke rehabilitation, which comes from the USA (injection of Intentisep into the base of the brain). The Stroke Association are interested but they need academic researchers to get involved, and when I have tried to get researchers involved, they are usually interested but explain that this isn’t on their research agenda which is frustrating. If anyone can advise on how to get this moving, I would like to know.

I would just like to say that we have done work which is more involved with users than I described during my presentation (Emily Goodall speaking). The neck brace idea actually came from within the user group and they were also co-applicants on the grant. More generally than that, it is difficult to have greater patient involvement within MND because the progression of the disease is so quick that patients pass away and are only members of the group for a short time. More family members and carers tend to be involved. You can look at advanced wishes and gain informed consent in advance, but I wonder if there are collective ways to do this? We have actually been debating this within the group recently. On the other side, the Nuffield Report on Dementia challenged us to get more people involved in research, so it’s a good question.

The approach that ethics committees take towards dementia is very cumbersome. For people with dementia, families and carers are constantly judging their capacity to consent and do things, and it would be useful to get ethics committees to appreciate this.

It’s also important to consider how we engage with people towards the end of life within the dementia journey. I have worked with people with dementia over the lifecourse and have seen how their perspectives change, relative to that of their carers and family members.

Highlighting our strengths: developing our capacity
Tour of PhD funded study from the White Rose initiative.

Service Change and Older People’s Access: Does Rurality Matter?
Charlotte Hamilton, University of York

Charlotte provided an overview of her research study which is concerned with older people living in rural locations. She is looking at changes in everyday services, finding out what is available and where those services are, examining the impact of service changes on older people (those aged 65 and over) and exploring where social services could help mitigate any impact.
She is using a mixed methods approach, drawing together quantitative and qualitative findings. Tentative and preliminary findings include:

- Rural services are vulnerable to change
- Different services present different challenges
- Attitudes towards age is important
- Individuals have different expectations of services
- Impact of different changes is cumulative

**Exploring enjoyable activities using touch screen computer technology with people with dementia living independently**
Sarah Smith, University of Sheffield

Sarah outlined the rationale for the study highlighting that 63% of people living with dementia are also living with depression. The most frequently identified unmet need is having something enjoyable to do during the day. In addition, the focus of much current research remains on deficits and losses associated with dementia and can neglect all that is retained, enjoyed and done well.

Touch-screen technology was chosen for it’s contemporary and popular appeal. It is also intuitive to use and is holistic, adaptable and flexible – a particularly important aspect for people living with the changing impact of dementia.

The first research study was carried out with members of the Darnall Dementia Group, a charity based in Sheffield providing a meeting place for people with dementia living in the community and respite for carers. Twelve participants in the moderate to later stages of dementia took part with sessions video-recorded over a four-week period. The main findings from study one were that the majority of participants enjoyed interacting with the technology and with each other in a group context. Some preferred not to engage for extended periods of time. Familiarity of the technology and applications was observed within sessions but was limited between sessions. Study two has involved members of Sheffield Memory Services. Twelve participants in the earlier stages of dementia took part. The technology was personalized based on individual requirements. Preliminary results from study two suggest that technology can facilitate enjoyable activity. A key finding from study two is that social contact is paramount.

**Modelling Health and Healthcare Demand for an Ageing Population**
Ji-Hee Youn, University of Sheffield

Ji-Hee’s research project is estimating the impact of population ageing on healthcare demand. She is developing a flexible modeling framework, which incorporates all the potential influences upon demand. Research findings will
inform the efficient planning of healthcare resources and the evaluation of interventions and policy changes.

Ji-Hee provided an overview of the literature search strategy she has used and how she used the results to identify key themes. The diseases she is using for the model are those which are most costly; heart disease, dementia, osteoporosis and chronic obstructive pulmonary disease. The study will also provide examples of the economic impact of multiple diseases.

**Alternative ways of supporting the voice of people with dementia in research: a systematic review**

Katie Sworn, University of York

Katie’s research study involves a systematic review of the literature on alternative ways of supporting the voice of people with dementia. Most recent policy is emphasising the importance of ensuring that the voices of people with dementia are included within research and development and in services. Alongside verbal communication there are a range of other forms of communication which include; non-fluent/augmented communication; body language and non-verbal communication; communicating through the arts and sensory stimulation. These forms of communication may become increasingly important as verbal communication is compromised through the disease process.

Methods which support augmentative and alternative (AAC) forms of communication include:

- Augmenting communication; for example low tech word boards, photo elicitation, writing.
- Alternative communication; for example high tech speech, speech synthesis devices, gesture, arts-based methodologies.

The research is comprised of four reviews. The first focused on mapping the use of AAC methods. Over 11,500 studies were screened, identifying 85 studies which were considered relevant; with 6 studies having a narrower focus on dementia, AAC or voice.

The second review took a broader focus, exploring how enhanced communication methods developed by people with specific needs (such as stroke) might be transferred to those with other needs (such as dementia). The review highlighted the ways that this might occur; these included which method was highly established (such as talking mats), where it appeared that the method might readily meet the needs of another group and where features of the communication technology might be readily adapted or enhanced.

Review three combined the knowledge from the different augmented communication methods which had been identified from the literature on different user groups and contexts.
Review four is in progress and seeks to bring together the wider knowledge of application of AAC methods to a dementia context.

The outcomes of this series of reviews will ensure that dementia research does not ‘re-invent the wheel’ in creating best practice of reporting and analysing alternative forms of communication.

**Exploring changes in personal relationships and health when older adults take on a caregiving role for their spouse or partner**

Cheryl Craigs, University of Leeds

Cheryl's study is exploring changes in personal relationships and health when older adults take on a caregiving role for their spouse or partner.

The background to this study noted those aspects which are already known, such as how caring can change the dynamics of personal relationships, caring can adversely affect health and that support can reduce the effect caring has on health. Cheryl’s study is adding to the existing knowledge by better understanding changes in personal relationship types from the caregivers’ perspectives, providing further understanding of how different personal relationships change and exploring connections between changes in personal relationship types and health effects.

The research is using a mixed methods approach with both qualitative and quantitative data collection methods. The qualitative aspect involved in-depth interviews with caregivers. Quantitative analysis used data from the five waves of the English Longitudinal Study of Ageing.

Preliminary findings include:

- **Health** – both negative and positive effects are highlighted. Negative health effects include stress, tiredness, weight change and susceptibility to infection. Positive health effects include increased awareness of own health needs.

- **Spousal relationships** appear to mirror the pre-carer relationship; whether this was previously difficult or close.

- **Friendships lost and gained**; friendships lost include as couples and mutual friends through shared activities. Friendships were also gained through support groups and with health professionals.
Jan outlined some of the research that is taking place at Bradford University’s Dementia Research Group, which is a multi-disciplinary applied research centre with two research themes: ‘Living well with dementia’ and ‘Improving the quality of care for people with dementia.’

**Living well with dementia**
This theme is focused on researching the lived experience of people with dementia, their friends and families, and researching the ways knowledge so gained can be applied to enable people with dementia, and those who support them, to maintain well-being. The stream includes research into a range of influences on subjective experience including social, cultural and family contexts; relational and personal history; cognitive changes in various dementias including Parkinson’s related, fronto-temporal and early onset; and user involvement and empowerment.

Various aspects of subjective experience are of interest including sense of self, self-narrative, inter-personal understanding, and general well-being. A range of creative methods is being developed for eliciting such experiences with people who have more severe dementia, including photo-, music- and film-elicitation. Innovative interventions being researched include cognitive rehabilitation and there is potential for many others. In addition experiences throughout the dementia journey from diagnosis to end of life are being researched and this offers opportunities for staff across the School.

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**Recruitment – examples from funded studies**

**Recruitment – Lessons learned from funded studies**
Kirsty Sprange, University of Sheffield

Kirsty’s presentation examined issues of recruitment and other lessons learned from three studies involving older people. These were:

- **Lifestyle Matters** – a multi-centre randomised controlled trial (RCT) to determine the population benefit of an occupational therapy based intervention for community living people aged 65 years or older.

- **Putting Life in Years (PLINY)** – a telephone friendship group research study. An RCT to determine whether telephone friendship groups can improve wellbeing in people aged 75 and over.

- **Journeying through Dementia (JtD)** – a small feasibility study to determine the feasibility of delivering of a manualised intervention for people aged 65 years and over with an early diagnosis of dementia.
For the Lifestyle Matters study which required people living in the community who did not have any particular health need but may have noticed their life contracting for various reasons, the most successful method of recruiting participants was through mail out to people from their GP. It was surprising and disappointing that there were very few enquiries received via other recruitment methods, which included health and social care workers, charities advocacy groups for older people. Of a total of 9379 letters sent out, 385 were from GP mailouts; there were only 25 enquiries from other sources.

Issues emerging from this study indicate that we need to clarify to health and social care workers. Whilst the GP mailout was the most successful method of recruitment to Lifestyle Matters this did introduce selection bias in that people self-identified to take part in the study and they were not necessarily who the study was looking for. The lesson from this is that we do need to engage services to understand what we are doing so that they are more likely to draw such studies to the attention of people that they work with whilst acknowledging that time and training are also key issues for services.

Recruiting older people to the telephone befriending (PLINY study) revealed similar patterns to Lifestyle Matters in that GP mailout was the successful strategy rather than referral through services. Also for his study volunteers had to be recruited to facilitate the befriending. The voluntary sector who were involved in recruiting and training volunteers experienced significant challenges in trying to meet the study needs and requirements.

The Journeying through Dementia study took a different approach to recruitment – there were no GP mailouts with recruitment being undertaken entirely through Memory Clinics where clinic staff initially identified those who met eligibility criteria for the study. Recruitment to this study highlighted that it is essential to have direct contact for people with dementia rather than relying upon mailouts.

In addition, although the study was for people with dementia, obtaining the support and buy-in of carers is a significant aspect. However carers of people with dementia can need reassurance before they feel able to support the person they care for. Therefore there were two recruitment targets for this small study; the person living with the condition and their family carer.

A third aspect in this study involved recruitment and retention of service providers to deliver the journeying through dementia intervention, with a number of staffing issues arising during the 12 weeks.

To overcome recruitment issues within studies Kirsty identified that you need determine who you wish to recruit – volunteers, participants, carers. Buy-in is needed from a range of services and perceptions of randomisation, time and training all need to be considered
Engaging patients in research. Case studies from an Applied Dementia Care Research Programme

Professor (Hon) Esme Moniz-Cook, University of Hull and Humber NHS Trust

Professor Esme Moniz-Cook offered some reflections of recruitment based on experiences over the last twenty plus years and drew out some examples of what can help.

Esme located the importance of recruitment within the wider social environment. The methodology of ‘engagement’ – using social interactions and social contacts in recruitment to psychosocial research is hugely important.

Observations have come from experience in recruitment in a number of studies where we have had to use a variety of approaches to meet the changing landscape of health and social care contexts particularly in large, multi-site collaborative studies. Examples include:

- REMCARE: reminiscence groups for people with dementia and their family caregivers, a national 8-centre trial of joint reminiscence versus usual treatment
- PROMS: Using Patient Reported Outcome Measures to improve Dementia Care
- VALID: Valuing Active Life in Dementia. http://www.ucl.ac.uk/valid

Reflecting on what helps in engaging with people with dementia and their families and service providers in research, Esme identified the following key areas;

- The importance of clinical academic leadership and the role of the principal investigator. It helps where the principal investigator is a clinician / practitioner who is actively engaged in the research and can discuss this with every potential recruit. The principal investigator may also develop topic-specific local patient groups as these emerge through discussions. Patients are often willing to support studies if they appreciate the routine care / work of the principal investigator and the supporting team.

- through discussions. Patients are often willing to support studies if they appreciate the work of the principal investigator.
other staff involved in the research study also play key roles, in particular the role of an experienced topic specific research manager with local staff.

the development of a local NHS Centre and a research register where every patient is offered the opportunity to contribute – for example, Memory Clinics can also contribute to good practice.

External drivers to provide local support to stakeholders when possible example: INTERDEM: a pan-European network of researchers on early detection and psycho-social interventions in dementia. http://www.interdem.org

Esme also offered some cautionary notes

Resources

- Providing research funding to clinical teams can be helpful for some but does not necessarily guarantee recruitment.
- Offering incentives such as training is a good idea but clinical teams often do not have the time to attend.
- Support costs from local clinical research networks do not fully cover recruitment time (costs are only covered for those who actually enter the study) i.e. the level of research management costs i.e. for an experienced manager to support, coordinate and facilitate research staff jobs etc. is often hidden.

Methodology

- National initiatives can also have an undesirable impact upon the quality of real world research methodology; for example ‘research ready’ care homes may not be representative of all care homes and these initiatives run the risk of researchers missing the very homes that one may want to try and deliver good care to patients at.
- Local recruitment practices can also have an undesirable impact on the quality of real world research methodology; for example using the same ‘helpful’ participants to contribute to consecutive studies.

Esme commented on the need to consider serving the needs of all patients/older people; addressing individual needs as part of emerging research agendas.

For further information on initiatives to improve recruitment, see the Centre of Dementia Research and Practice which was officially launched in Jan 2014 by the Rt Hon Alan Johnson MP and Diana Johnson MP: http://www.humber.nhs.uk/news/Dementia-Research-Centre-launched-in-the-region.htm and http://www.challengedemcare.com re VALID study: patients and carers travel to London to join a consensus meeting
This took the form of an exchange between presenters and delegated which is recounted below.

<table>
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<tr>
<th>Name</th>
<th>Statement</th>
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<tbody>
<tr>
<td><strong>Kirsty Harkness, STH</strong></td>
<td>Reflecting on Esme Moniz-Cook’s talk, I agree on the importance of embedding research into clinical practice and has worked on 12 studies where this has been the case, and created follow-up appointments where the research nurse is also present so that they can explain about the research and recruit patients to those studies. I agree that having administrative and managerial support for research is essential. I am concerned about the push for more generic researchers – this is worrying because they often don’t have the confidence to work with the patients.</td>
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<tr>
<td><strong>Esme Moniz-Cook</strong></td>
<td>Having local, specialist teams is key but it is difficult to maintain staff and teams who have their day job and associated pressures to think about – the research process takes a long time and findings even longer.</td>
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<tr>
<td><strong>Gail Mountain</strong></td>
<td>But two of the studies that Kirsty Sprange has described did not involve patients; they involved citizens – so how can we better attract people within the community to participate in research?</td>
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<td><strong>Esme Moniz-Cook</strong></td>
<td>I have found that the media is wonderful for ensuring recruitment! Having a five minute slot on local TV or radio, perhaps with a patient advocate can help to recruit patients to clinical / care settings to support research.</td>
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<td><strong>Alison Laver-Fawcett, York St John University</strong></td>
<td>I have successfully used snowball sampling – by spending time in local libraries to recruit individuals who then recommend others within that community.</td>
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<td><strong>Gupreet Gill, Health for All Leeds</strong></td>
<td>I am working on empowering older people in Leeds and manage a network of groups of 25-30 people which are all run by volunteers with little support for these groups. I was wondering why Kirsty’s studies had received no recruits from the older people’s forum?</td>
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<tr>
<td><strong>Kirsty Sprange,</strong></td>
<td>We tried every route – local media, newsletters, libraries, GP, pharmacy – that we thought older people would be involved in.</td>
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<td><strong>University of Sheffield</strong></td>
<td>But despite lots of interest in the research, the need for randomization was very off-putting for individuals. We also found that this was a problem for health and social care professionals who were not keen to recommend their service users to a study involving randomization due to concern about the impact this could have on their relationship with the individual.</td>
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<tr>
<td><strong>Norma Whitfield, Billing View Community Group</strong></td>
<td>We find that a lot of people don’t seek help until they really need it and by then it is too late.</td>
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<tr>
<td><strong>Esme Moniz-Cook</strong></td>
<td>Perhaps we should change the research methodologies so that all participants receive the service!</td>
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<td><strong>Gillian Parker, SPRU</strong></td>
<td>We have experienced major difficulties in trying to recruit Health and Social Care staff to one of our current studies. We have paid admin staff to identify particular staff members responsible for life story work in their organisations, who could then be surveyed but this has been fruitless in most cases.</td>
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<td><strong>Ann Forster, Bradford Institute for Health Research</strong></td>
<td>We have always included project management in our bids and this is invaluable. I would also like to promote the good work of the CRN – they are undergoing a transition at the moment which is a little challenging but I would like to encourage everyone to engage with the CRN to aid recruitment.</td>
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<td><strong>Gail Mountain</strong></td>
<td>We found that some people who volunteered for our research were 'just' hoping to help the university and to help other people. What does this mean for the research?</td>
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<tr>
<td><strong>Kirsty Sprange</strong></td>
<td>This creates a self-selection bias when only those with an altruistic motivation take part in our research.</td>
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<tr>
<td><strong>Tony Maltby</strong></td>
<td>We also need to be careful not to just select the usual suspects. There is an useful report from Peter Beresford which cautions on this: <a href="http://www.shapingourlives.org.uk/documents/BTUSReport.pdf">http://www.shapingourlives.org.uk/documents/BTUSReport.pdf</a></td>
</tr>
<tr>
<td><strong>Gail Mountain</strong></td>
<td>People aren’t hard to reach for nothing and this is particularly difficult when you are trying to study social isolation.</td>
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Developing our ideas and working with practitioners from health and social care in different settings – examples of studies

Using Robot Companions with People with Dementia
Claire Jepson, Occupational Therapist and Andrea Corso, Staff Nurse RMN, Sheffield Health and Social Care Trust

Claire and Andrea talked about their involvement in a research study evaluating the reactions of people with dementia to the PARO seal. Sheffield Health and Social Care Trust purchased two of these seal robots for use in clinical settings.

Andrea described the background to animal assisted therapy and pet therapy; a recognized intervention which has some benefits. Studies show that it can lead to a significant decrease in distressed behavior, can increase social interaction and can help to reduce loneliness. Disadvantages involve cost, dislike of animals, fear/negative experience and infection control.

Other associated interventions include doll therapy, which has been used with people who experience agitation, social withdrawal and communication difficulties. There is some support for the use of dolls in dementia care but the evidence is mainly anecdotal. Doll therapy also poses some ethical concerns, some view it as being demeaning and infantilizing and sometimes people have difficulty disengaging.

Robotic animals as companions are now emerging as a positive alternative to real pets. The PARO seal was originally designed by Dr Takinori Shibata for use with the increasing older population in Japan. Some of the features of the PARO seal include: it has sensors to interpret its environment; when a person interacts it interprets meaning and generates behavior in response; it will cry out if left untouched; it will cry if handled harshly; it responds to touch speed and light. Some of the considerations for using a PARO seal include: hygiene; size (it is big and heavy); noise (not always tolerated by everyone) and colour (it is white and prone to getting dirty).

Claire then shared some examples of using PARO seal with in-patients on a specialist unit for those with dementia and behavioural disturbance. Initially a cautious approach was used; one patient who was settled but withdrawn was selected. Initial observations seemed to show that her mood lifted and that the PARO seal helped to ‘unlock’ her. Further work has shown that PARO seal appeals to both sexes. Males tended to adopt a playful approach with females taking a nurturing approach. In many ways, play is an ideal vehicle to open the many closed doors experienced by people living with dementia. Lila, the Sanskrit word for play also means ‘delight and enjoyment of this moment’.
Claire described the joy and at times humbling experience of observing patients with the PARO seal. The robot increases socialisation, helps to create novel shared experiences between people, attracts attention resulting in group interactions, enables discussion and reminiscence and supports the expression of non-verbal communication.

Claire described how, as staff confidence with therapeutic use of the PARO seal grew, they began to use the robot for distraction purposes. Don, who was initially a very distressed person who constantly wandered around the ward started to use the PARO seal. Using the PARO seal enabled Don to sit peacefully for periods of up to an hour. Praising the seal also seemed to reassure Don.

However, the PARO seal is not for everyone. For example, two patients who initially had positive experiences with PARO were then unable to differentiate between the seal and their own pets. One became distressed because PARO could not perform like her dog (‘why won’t he walk, what’s wrong with him?’). Another patient became distressed shortly after disengaging with PARO (perceiving he had lost his own dog and would be in serious trouble).

Claire described some practical clinical applications of using PARO seal. The robot is currently being used to stimulate one patient who has deteriorated significantly both physically and cognitively but gains pleasure from the sensory experiences of PARO. On waking she is encouraged to touch the seal. This enables her to be alert enough to take diet, fluids and other medication.

The PARO seal intervention has been incorporated into the care plan for one patient, Maud, who finds instant relief when it is presented to her – ‘it’s ok it’s me Maud, I’m here you’re alright now’. Maud commented that:

‘He can change his eye lashes and makes things different. I think he’s beautiful, he gets you and looks at you.’

Delegates were fascinated by the live demonstration of the PARO seals as part of the presentation.

West Yorkshire Care Home Research Network
Professor Anne Forster, University of Leeds

Anne outlined the work of the West Yorkshire Care Home Research Network and talked about the value of a network approach in promoting the quality of research studies in care homes.

The network was created from research which highlighted the importance of increasing physical activity in care home settings. Anne was involved in meeting with a number of care homes interested in this research. A group
came together, assisted by considerable support from Bradford City Council and from primary care colleagues.

A bid was then put together to West Yorkshire Comprehensive Local Research Network to set up a Care Home Research Network (CHRN) with support from a Research Network Manager.

The objectives of the Care Home Research Network include:

- Increasing awareness and understanding of research among the care home community
- Co-ordinating regional care home research
- Supporting the development of care home research
- Development of resources

Current projects include:

- PiTStop, Stop Delirium! An Enhanced Educational Programme
- Development and testing strategies to enhance physical activity in care homes (REACH)
- Optimised food products for an ageing population
- Evaluating the effectiveness and cost effectiveness of dementia care mapping to enable person-centred care training for people with dementia and staff

To find out more information about the West Yorkshire CHRN, go to:

www.wychrn.co.uk

The feasibility of studying life story work in dementia care: report from the field
Kate Gridley, University of York

Kate presented emerging findings from a study that is looking at the feasibility, outcomes and costs of life story work in dementia care. The study began in July 2012 and is due to report in spring 2015.

Life story work involves recording aspects of past life, present interests, future plans and wishes. This record is then used to achieve a range of outcomes (not simply filed).

The research study is using a range of research methods including a systematic review of literature, qualitative interviews and focus groups, surveys of services and family carers.
The outcome measures were identified from work with people to establish what matters most to them. These were summarised as: wellbeing (quality of life), relationships, staff approach to care and identity. Kate talked about the quality of life outcomes available for use with people with dementia and how she had selected the QOL-AD and DEMQOL; both standardized outcome measurement tools for this purpose.

The study is involving six care homes with 10 residents with dementia from each being recruited to take part. Life story work was introduced at each home by the provider (through provider led training and templates). Data is being collected from residents, family carers and staff at baseline (before staff training) and 1 month, 2 months and 6 months afterwards.

At the time of the presentation, Kate described how 41 residents had been approached directly by researchers or by carers. Twenty nine had consented to take part in the study – Kate highlighted that there were 8 instances where the carer did not give consent to be contacted so they remain unknown to the research team.

Examples of the ways in which QOL-AD and DEMQOL have been used in the research were outlined. DEMQOL is more complicated and the research team found that fewer people were able to complete this measure. Of the 29 participants who took part, 20 were able to complete the QOL-AD at baseline; 12 completed the DEMQOL at baseline, 11 completed the Quality of Relationships scale at baseline (with support).

Reasons for non-completion included: person unable to answer the questions, person tired/does not want to answer any more questions, ran out of time, questions upsetting. In addition, for the Quality of Relationships Scale, reasons for non-completion include that the person does not have (or cannot bring to mind) any close relationships.

Kate’s concluding remarks noted that research in care homes is not straightforward and there are a range of barriers which are outside the control of the researcher. Also current outcome measures do not work for everyone; how do you measure in the moment benefit/pleasure? However overall it is worth pursuing. People with dementia residing in care homes are an under-researched group and potentially we can gain valuable insights.

To find out more information, go to: http://bit.ly/lsDem

Key points from the day– what are the priorities for ageing research?

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<tr>
<th>Name</th>
<th>Response</th>
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<tr>
<td><strong>Ann Heaven, Bradford District Care Team</strong></td>
<td>I have a question for Kate Gridley – did you use the proxy measure with carers? When I have used the DEMQOL with carers, this has been biased and everything has been reported as positive.</td>
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<tr>
<td><strong>Kate Gridley, SPRU</strong></td>
<td>We used the DEMQOL proxy with family members and some struggled with the requirement to answer as they thought the person would, I think because they felt they had insight that the person with dementia themselves didn’t have, and also because the person may not be able to communicate their feelings even to the family. It was also difficult to convey what the measures had to do with the research on life story work. There was some confusion initially but once they understood they were often happy to complete the questionnaire. Time is also an issue, especially with family members who may be routinely visiting their relatives for a short period of time. I recognise that this has some impact on the validity of our measurements.</td>
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<td><strong>Esme Moniz-Cook</strong></td>
<td>We are involved in the PROMS (patient reported outcome measures) study which has two sections – the DEMQOL for family caregivers and an adaptation of this for other caregivers – studies show the discrepancy between reporting from people with dementia and their proxies.</td>
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<td><strong>Gillian Parker</strong></td>
<td>Within the life story work study, we observed an improvement in quality of life assessment when we completed a follow-up just after a singing session in the home. This is questionable in terms of validity as this boost in reported quality of life had nothing to do with our intervention. I am also interested in measuring ‘in the moment wellbeing’ as this is often missed. Could greater use of photography help capture this, like in Sarah Smith’s work and the PARO seal work?</td>
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<tr>
<td><strong>Tim Gommersall, University of Sheffield</strong></td>
<td>In research, there is often a tendency to measure the measurable, and how often do we miss ‘in the moment wellbeing’ – methods are underdeveloped.</td>
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<tr>
<td><strong>Cook</strong></td>
<td>video methods to study emotion and joy and new ‘in the moment’ ways of capturing outcomes for people – such as during creative arts work - but how you would complete a cost-benefit analysis on this is questionable!</td>
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<tr>
<td><strong>Gillian Parker</strong></td>
<td>There is a lot of power in photography – Sarah Smith’s work uses photographs as data.</td>
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<td><strong>Sarah Smith</strong></td>
<td>I agree but what those images would say is lost when translated into words. This is one of the issues with innovative methods.</td>
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<tr>
<td><strong>Gail Mountain</strong></td>
<td>So, randomized controlled trials are still the method of choice?</td>
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<tr>
<td><strong>Esme Moniz-Cook</strong></td>
<td>In our couples group reminiscence therapy we noticed found that some family carers couldn’t cope with the discordance between how people behaved in public/social settings such as during the 2-3 hour group therapy (i.e ‘normally’) contrast to how they behave in everyday life at home where they could be withdrawn or always asking questions with conversation diminishing. Perhaps we need to do more longitudinal health economics studies?</td>
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<td><strong>Catriona McDaid, University of York</strong></td>
<td>There is an emphasis on the QALY and perhaps this isn’t always the right thing to use. The attractiveness of this is that it allows comparisons across different programmes but perhaps a more simple cost-benefit analysis would be more meaningful.</td>
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<td><strong>Ann Heaven</strong></td>
<td>Is there training for individuals to use PARO? I am a little concerned about the crying sound it makes when misused and the impact it might have on people.</td>
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<tr>
<td><strong>Andrea Corso, Sheffield Health and Social Care</strong></td>
<td>We provide training for all staff and limit the use of PARO with individuals who we feel that it may upset, e.g. those with psychosis would not use the robot. Occasionally PARO is left with individuals but only where we are confident that this will be okay.</td>
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<tr>
<td><strong>Gillian Parker</strong></td>
<td>I am just wondering what the seal can do that a human cannot?</td>
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<tr>
<td><strong>Andrea Corso</strong></td>
<td>We find that the robot is beneficial because it is tactile and is able to provide intimate affection to the individual as they can hug the seal and this isn’t routinely done with staff, for example.</td>
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<td>Name</td>
<td>Question/Comment</td>
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<tr>
<td>Gillian Parker</td>
<td>Is it also because they can look after the seal, and have a caring role, rather than just be cared for?</td>
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<tr>
<td>Mary Madden</td>
<td>Is the seal infantilizing people?</td>
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<tr>
<td>Andrea Corso</td>
<td>We have had some resistance from staff who struggle to lose their inhibitions and play with the seal, and some negativity because this isn’t a cat or a dog, for example.</td>
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<tr>
<td>Claire Jepson</td>
<td>Paro is well received by the relatives also.</td>
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<tr>
<td>Gail Mountain</td>
<td>Is anyone horrified by the seal? I know that some people can be.</td>
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<tr>
<td>Member of the audience – not named</td>
<td>I am a little – I want to know more about the crying.</td>
</tr>
<tr>
<td>Gail Mountain</td>
<td>In a care home environment, there is always a large expensive TV and do people in this environment always get benefit from this? So is PARO a more viable therapeutic option, relative to a TV?</td>
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Ideas and suggestions

In addition to the workshop proceedings, participants were encouraged to add their thoughts and comments during the course of the day on sheets provided for comments. These are described below.

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<th>Ideas and suggestions</th>
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<tr>
<td>Find ways to bring together existing groups of health care clinicians, social care staff, people living with the conditions (and carers) plus groups of researchers to share existing research, ongoing research and influence future topics for research. These groups exist separately – just need someone to bring them together.</td>
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<tr>
<td>There is a new 'older people' group; for example those being offered early retirement. What are the needs of this group? What is the</td>
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impact of extended retirement; associated economics, physical and mental health.

- Develop more programmes of volunteering for older people and how to support new and existing volunteers.
- Remember: not for us – but with us!
- Involve local older people (like Sheffield 50+)
- Involve commissioners in research.
- Please use elderly friendly approach for research and use/think of how best you can involve BME elders too!!
- ‘Older people’ not the elderly.
- Involve the Alzheimer’s society developing and measuring the impact of dementia friendly committees rolling out initiative.
- Check out www.poetryandillness.co.uk. Join a poetry workshop.
- What are the studies looking at ‘pre-frailty’ and multi disciplinary team interventions?
- Occupation in care homes – seems to be missing.
- Patients, carers and clinicians working together on research priority setting and holding research community to account e.g. James Lind Alliance.

My dragons – big areas that can make a difference

- Society’s perception of older people: Why were we so shocked at the 80 year old lady doing the Salsa on Britain’s Got Talent? We need more of this.
- 3 F’s: Fear of Falling. Use of Cognitive Behavioural Techniques for older people at risk of falls.
• Patient Centred Care: lack of patient centred care on acute wards
• How to link what we do, with what our patients need us to do. For example how to link current services to prevent falls in community rather than treating post fall. Linking in charity / volunteering agencies to achieve patient outcomes.

Thanks

Professor Gail Mountain, Conference Chair, thanked all participants for their involvement and contributions during the day and to speakers for their presentations.

Thanks were also extended to members of the Alzheimer’s Society Sheffield: Singing for the Brain group for their endearing and enjoyable lunchtime participatory session.

Resources and further information

This summary together with presentation slides and audio recordings from the workshop event can be downloaded at: http://www.sheffield.ac.uk/scharr/sections/hsr/rrg/raay

Yorkshire Comprehensive Network - Ageing Priority Group: http://www.cm.nihr.ac.uk/homepage

White Rose Consortium: http://www.whiterose.ac.uk

White Rose Collaboration: Dementia, Cognition and Care:
http://www.whiterose.ac.uk/collaborationfunds/dementia-cognition-and-care/
http://php.york.ac.uk/inst/spru/research/summs/wrd.php

To receive occasional emails about the White Rose Collaboration: Dementia, Cognition and Care please contact: l.s.codd@sheffield.ac.uk or complete link: http://www.york.ac.uk/inst/spru/research/summs/wrd2.html
Centre of Dementia Research and Practice:  
http://www.challengedemcare.com

Sheffield Motor Neurone Disorders Research Advisory Group:  
http://smndrag.group.shef.ac.uk

Darnall Dementia Group: http://www.darnalldementiagroup.co.uk

James Lind Alliance: http://www.lindalliance.org

Beyond the Usual Suspects, Research Report by Peter Beresford:  