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CLAHRC Care Homes Research: National Work Stream November 2019 Summary Report

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1. Executive Summary 3
2. Introduction 5
3. Delegates and programme 5
4. Group work and facilitated discussion 6
4.1. Priority Setting 6
4.2. Themed Table Discussions 7
4.3. Data Integration and Technology 7
4.4. Volunteering 7
4.5. Dementia Care 7
4.6. Staff Development 8
4.7. Outcome Measures 8
4.8. Continence and Infection 8
4.9. Quality Improvement (QI) 9
4.10. End of Life Care 9
5. Event Feedback 9
6. Summary 10
7. Next Steps for the ARC Care Homes Network 11
7.1. Next steps 11
8. Appendices 12
Appendix 1 Event Attendance 12
Appendix 2 Cross-CLAHRC Care Homes Event Programme 14
Appendix 3 Notes from Priority Setting Discussion 15
Appendix 4 Table Discussion Notes 15
Appendix 4 Event Feedback 21
Appendix 5 Potential for Future Involvement 28

1. Executive Summary

The National Institute for Health Research (NIHR) funded thirteen regional Collaborations for Leadership in Applied Health and Care (CLAHRC's) up to the end of September 2019. The next step in these combined research efforts is the establishment of NIHR Applied Research Collaboratives (ARCs). These started in October 2019 and have been funded for five years. While there are changes to the ARCs, there are many continuities; and this includes interest in promoting research in care homes. Building on the national Cross-CLAHRC Care Homes' work in 2017, the CLAHRC / ARC care home collaboration brought together a network of health and care professionals, researchers and members of the public for a second Cross-CLAHRC research event just before the ARCs were announced. The event was held at King's College London on the 23rd July 2019. A total of 67 people attended, including researchers, practitioners and patient/care users and carer representatives. Five different CLAHRCs were represented on the day; many of them will take forward their work into the new ARCs but they will also be newly energised by the ARCs' additional social care research commitments.

Discussions on the day highlighted key areas for priority and research focus:

- Defining a mutual understanding of quality in care homes and care and developing methods of measurement.
- Workforce, leadership and the role of families and volunteers.
- Standardised training approaches, including topics such as QI and methods for implementing and de-implementing training.
- Multi-morbidities and the complexities this brings in relation to care delivery.
- Evaluation of existing technology to support care e.g. iPads to aid communication.
- Increase understanding of the care home environment and its role in supporting health and well-being of residents.

Barriers and complexities involved in conducting research in care homes were identified:

- Capacity, both in terms of staff and funding, both to the care home sector itself and the research environment.
- Keeping pace with industry developments.
- Implementation challenges, including lack of buy-in and unintended consequences.

The opportunity to continue with this important work by capitalising on the rich and varied expertise created by the Cross-CLAHRC / ARC Care Homes network has the potential to increase capacity for care homes research and influence how care provision in care homes can best meet the needs of those it is designed to support. The ARC network is also well placed to work with Academic Science Networks (AHSN's) who have recently published examples of care, safety and quality improvement projects in care homes supported by the AHSN network.[1]

Next Steps for the ARC Care Homes Network:

- The care homes research summary has been updated: https://bit.ly/2jWtEds.
- A discussion paper will be written for publication.
- Key people have been identified from ARC's to take forward work
  - Capacity building for care home research especially in under represented priority areas (e.g. continence and infection control).

[1] https://www.ahsnnetwork.com/care-homes-report

- Delivering a cross-ARC review of capacity building models that foster research in care homes (e.g. researcher in residence, Huddles approach for building relationships among frontline staff, NICHE model) to provide recommendations for practice and resource requirements.
- Holding workshops with care home organisations working with ENRICH and care home representative organisations to foster closer working on priority setting, implementation projects and identification of new research projects.
- Cross-ARC updates on funded and planned bids (co-ordinated by ARC East of England).
- Linking with national social care, ageing and frailty and palliative and end of life care themes to work to reduce duplication and fragmentation of ARC work and align with national theme priorities and projects.
- Regional events to develop topic specific review of implementation ready evidence and new projects.
- Holding a summit with funders and care home representative organisations to discuss how care home research priorities are included in upcoming calls and priority setting exercises.
- International collaboration on trials.

2. Introduction

The National Institute for Health Research (NIHR) funded thirteen regional Collaborations for Leadership in Applied Health and Care (CLAHRC's) up to the end of September 2019. The next step in these combined research efforts is the establishment of NIHR Applied Research Collaboratives (ARCs). These started in October 2019 and have been funded for five years. While there are changes to the ARCs, there are many continuities; and this includes interest in promoting research in care homes. Building on the national Cross-CLAHRC Care Homes' work in 2017, the CLAHRC / ARC care home collaboration brought together a network of health and care professionals, researchers and members of the public for a second Cross-CLAHRC research event just before the ARCs were announced. The event was held at King's College London on the 23rd July 2019.

The aims of the day were to:

- Recognise and learn from the expertise in the room
- Inform a strategy for research and implementation for working in and with care homes, to inform:
  - Implementation of best evidence
  - Development of genuinely collaborative research including residents, their representatives and care home staff
  - How we work with the new national ARC themes
  - Build capacity in using and doing research
  - How to keep connected with each other and other networks
- Identify research topics of national and international relevance that people want to influence, lead and collaborate on.

Prior to the event a summary document, originally created in 2017, comprising brief synopses of each of CLAHRCs' care homes projects, was updated. The summary included examples of 42 CLAHRC projects and 8 systematic reviews from 11 CLAHRCs. The document was sent to delegates prior to the event and made available on the day. Following the event, this was updated with further examples identified. This summary can be found here: https://bit.ly/2jWtEds.

3. Delegates and programme

67 people attended the event, including researchers, practitioners and patient/care user and carer and public and representatives. Five different CLAHRCs were represented on the day. (A list of those who attended can be found in appendix 1). Table 1 below shows the programme outline for the day (a more detailed programme is in appendix 2).

Table 1 – Programme outline for the 23rd July 2019 Cross-CLAHRC Care Homes Event

Time	Session
10:00	**Welcome** **Overview of CLAHRCs, their priorities, themes and research relevant to care homes**
10:10	**Social care research myths and misconceptions**
10.25	**Routine data use**
10.40	**Joint priority setting exercise with researchers, care home providers, commissioners, residents and their representatives** • Table discussion and responses
11.15	*Break*
11.40	**Current examples of working in and with care homes and CLAHRCs:** • **NICHE-Nurturing Innovation in Care Home Excellence** • **Leveraging external research funding** • **Care home concerns** • **Quality improvement and teaching care homes**
12:45	*Lunch and networking*
13:30	**Table discussion of current and future research interests**
14:40	**Skills for Care and the changing landscape of long term care**
15:00	**Future work** • Cross-CLAHRC strategy briefing, and network of alerts • Capacity building • Coordinating collaboration with ARC themes, NIHR schools, care home networks and research interest groups
15:15	**Panel discussion: research funding** Q&A panel with representatives from research funders and provider organisations
16.00	*Close*

The morning speakers were selected to give a range of different perspectives and current examples of working with care homes in order to set the scene for later discussion about priorities for research and potential areas for future work and collaboration.

Copies of the presentations from the day can be found here: https://bit.ly/2lxI6cw

4. Group work and facilitated discussion

4.1. Priority Setting

Delegates were asked to discuss priorities for care homes research across the sectors. Each table fed back with the summary from these discussions focusing on four broad areas: (further notes from this discussion can be found in appendix 3):

Quality of care: Defining what this means and then implementing and measuring quality and outcomes.

Workforce and leadership: Defining good leadership, and how to support managers to lead care homes and career development for staff.

Research approaches: Consideration of the Maastricht model of the embedded researcher and potential pitfalls of this approach; and methodological challenges to data collation.

Multi-morbidities: Challenges in supporting people with several health problems or co-morbidities in care homes (e.g. cancer and dementia).

4.2. Themed Table Discussions

Following lunch, themed table discussions took place focusing on current and future areas of research interest. Tables were organised across eight themes which were selected by delegates upon registration for the event:

1. Data integration and technology
2. Volunteering
3. Dementia care
4. Staff development
5. Outcome measures
6. Continence and infection
7. Quality improvement
8. End of life care

The discussions are summarised below (detailed notes from each table can be found in appendix 4)

4.3. Data Integration and Technology

The need to standardise data collection was identified as a priority, although capacity and resources to explore a standardised data-set were identified as potential barriers. The use of existing technology that can be used for different purposes (e.g. iPads to potentially improve communication) is an additional area for further research focus.

Evaluating effective technology was also highlighted as a priority. The disconnect between industry development without an evidence base and the capacity to evaluate at industry pace was identified as an challenge with the suggestion of an independent body to provide a stamp of approval raised as a potential solution.

4.4. Volunteering

Although ambitions for volunteering have been widely stated throughout NHS 5-year plan, the role of volunteering is not widely recognised, and volunteers sometimes face barriers across different settings. The need to understand the complexity of volunteering across a fragmented health and social care landscape was highlighted as a priority. Tensions between a positive risk-taking approach and the duty of care for vulnerable people were identified as sometimes giving rise to implementing volunteer support. Understanding how organisations better work together to remove some of these barriers e.g. recognising training given by another organisation or supporting volunteers through mentorship schemes, were suggested as ways to encourage recruitment and retention of volunteers. Framing volunteering as teaching life-skills or a possible route into a social care career was suggested as a way to help attract volunteers. The development of a “volunteering passport” to record volunteer hours to increase recognition by employers was a further suggestion to improve recognition of the role.

4.5. Dementia Care

As the largest of the discussion groups, this group not surprisingly discussed a wider range of opportunities and barriers. Variability between care home options in terms of permanent or respite care available to people with dementia was discussed, together with the role of Admiral Nurses in relation to moving from community to care homes and variability of the support across regions.

The care home environment was highlighted as an area for exploration particularly in relation to the impact this has on health and well-being; how space is used within care homes; tensions between personalisation and ownership of environment; dementia friendly

environments and how to encourage use of the environment in a meaningful way. The need for increased staff resource and therefore costs, to facilitate better use of care home environments, was highlighted as a potential barrier and therefore something that could be further explored.

Examples of different pharmacy models within community care were discussed and the role of involving family members and care home staff to support medication reviews and policy development within homes. Medication compliance and solutions to support this were also suggested as areas for research focus.

The group also discussed the role of volunteers to support residents with dementia and unintended consequences that need to be considered such as professionalisation of volunteers; the risk of paid staff roles becoming very task focused if volunteers are focused mainly on activities. Also there may be spikes in workload for staff in preparing residents for time with volunteers.

4.6. Staff Development

The need for a framework for implementation and de-implementation of staff training was discussed. Researchers need confidence to ask and engage family, residents and those who are hard to reach in relation to research around workforce development. Areas for further exploration include how leadership and management influence workforce development. There are also opportunities for creating lay summaries to demonstrate how research can be impactful.

4.7. Outcome Measures

Potential opportunities for implementation include using Adult Social Care Outcomes Toolkit (ASCOT) Mixed Methods Care Homes tools in care planning to improve quality of care and quality of life.

Measures for implementation and measures suitable for social care are national priorities for research however clinical measures are often prioritised over social care measures. Understanding what to measure in care homes from the perspectives of residents and people managing homes; identifying gaps in measures available; and adapting existing measures and/or developing new measures were suggested as opportunities. The take-up of measurements after the development however is an implementation barrier, requiring buy-in from providers was highlighted as key to success.

4.8. Continence and Infection

This was the smallest of the discussion groups which potentially reflects the challenge of carrying out research in this area. The group highlighted the barrier of researcher capacity and recommended that engagement of researchers in the area of fundamental care delivery needs to be encouraged. Availability of research funding is also a challenge.

Hydration, constipation, incontinence and infection are linked and there is a need to understand the complexity of these for implementation and evaluation of interventions to address these conditions. The group felt that this should be part of the quality agenda and therefore adequately resourced.

There is tension between resident autonomy i.e. resident/family choice and standardisation / routinisation / institutionalisation in care delivery. Co-design of interventions with residents and families is an important approach that could help in overcoming this. The influence of Care Quality Commission on the care delivery priorities of care homes is also an important factor to consider.

4.9. Quality Improvement (QI)

The group agreed that there is an accumulative body of expertise that could be harnessed although it was acknowledged that methods and approaches to support care homes approaches to QI are yet to be developed. There is a need and opportunity for a minimum data-set and outcome measures to be developed that could drive QI.

Capacity was identified as a barrier for QI initiatives coupled with the need to be able to sustain initiatives for these to be successful. Developing a consistent and generalisable approach to QI in care homes and educating the workforce on both QI and topic specific areas of QI expertise could help to mitigate the problems of high staff turnover and competing priorities within care homes. The challenge of ensuring new skills are maintained and implemented however were highlighted.

The problem of sensory deprivation in care homes and how hearing and visual loss represent opportunities to intervene and could potentially be fruitful test cases for QI in care homes was discussed. It was felt that there is much ground to be made up because they represent matters that both care home staff and residents often feel strongly about.

4.10. End of Life Care

The process of capturing advanced care planning including appropriate documentation and responsibilities for starting this process were identified as areas for focus; RESPECT (Recommended Summary Plans for Emergency Care and Treatment) documentation for example may need further evaluation.

The group discussed capacity for end of life care planning and the need for conversations relating to advanced care planning to begin ideally prior to care home moves. Care home staff's knowledge of residents and how medical staff do not always acknowledge this input in health treatment were discussed. Further exploration of services for people with frailty was also highlighted as an area for further research.

Outcome measures were highlighted as an area for further exploration, with current studies often considering advanced care planning documentation as an outcome and a need for research focusing on the impact of this documentation on care outcomes.

5. Event Feedback

Following the event an online survey was circulated. 37% (25) of those who attended took part in the questionnaire. Generally, people enjoyed the event with almost all of those who responded rating it as good or excellent. There had been some problems with the audio quality, which appeared to be in part caused by the audio system itself and the use of microphones which did not appear to be overly sensitive, this was reflected within the feedback.

Both morning and afternoon sessions were well received by participants with almost everyone (96%) rating the morning session as good or excellent and very near the same (92%) for the afternoon session. The day was useful to those who attended with 20 people (86%) reporting they had learnt from expertise in the room; 18 (78%) had found new networking opportunities; and 12 (52%) opportunities to collaborate. Suggestions to improve the event included allowing time for Q&A following speakers presentations and the option to submit questions in advance to the Q&A panel. Although care home representatives were invited to attend, representation was noted as lacking on the day. Further thought is needed on how to enable care home staff to attend / contribute to any future events.

6. Summary

The CLAHRC outputs and discussion from the day highlight how CLAHRC research is focusing on subjects that we hope are important to residents and care home staff.

Discussions highlighted areas for priority and research focus. Defining a mutual understanding of quality in care homes and what this entails is key in developing services that meet the needs of those they are intended to support. Developing care home specific outcome measures; a standardised minimum-data set; and methods for collating data are required to drive quality improvement approaches. Increased understanding of the care home environment and how this can support the health and well-being of residents was also discussed as an area for exploration.

Workforce and leadership are crucial areas for research focus. Standardised yet relevant training approaches for new areas such as QI and topic specific areas need to be developed together with methods for implementing and de-implementing training. The role of families and volunteers are also key areas to explore in order to support workforce capacity. Developing formalised recognition methods for volunteers such as 'volunteer passports' could be approaches to increase capacity and the recognition of these roles. The involvement of family members to support some aspects of care such as medication reviews among people living with dementia for example is a further area for potential focus.

The impact of several health problems or multi-morbidities and the complexities this brings in relation to care delivery and research are challenging areas for the sector. There are potential opportunities particularly in areas that care home staff and residents feel strongly about, such as sensory deprivation. Working with residents, families and care home staff to co-design research should help in the development of research and services that will better serve the needs and wishes of those they are designed to support.

The discussions highlighted opportunities and approaches that could be harnessed to improve care for residents. The evaluation of existing technology to support care, such as iPads, to potentially aid communication was one for example.

Each of the discussions highlighted barriers and complexities involved in conducting research in care homes. Capacity, both in terms of staff and funding were part of every discussion. This applies both to the care home sector itself and the research environment, with research expertise, time, and funding lacking, particularly in some of the more complex and less understood areas, such as continence and infection care. Keeping pace with industry developments, particularly in relation to new technologies, was highlighted as a challenge, with suggestions of an independent kite-mark system to provide a level of endorsement. Implementation challenges, such as lack of buy-in and unintended consequences of new interventions, were also identified as potential barriers.

The opportunity to continue with this important work by capitalising on the rich and varied expertise created by the Cross-CLAHRC / ARC Care Homes network has the potential to increase capacity for care homes research and influence how care provision in care homes can best meet the needs of those it is designed to support. The ARC network is also well placed to work with Academic Science Networks (AHSN's) for which improving quality, safety and consistency in care homes is part of their quality improvement and patient safety agenda.[2]

[2] https://www.ahsnnetwork.com/care-homes-report

7. Next Steps for the ARC Care Homes Network

Delegates were asked to indicate potential for future involvement in ARC care homes research and areas which they may be interested in leading and/or collaboration. Just over half (78%,52) of those who attended indicated their interest in further collaboration, of whom a quarter (46%,24) are interested in leading work. A summary of future involvement interest can be found in appendix 5. This list can be used by the network for collaborative opportunities.

7.1. Next steps

- The care homes research summary has been updated following feedback. The summary document can be found here: https://bit.ly/2jWtEds.
- Discussion paper for publication
- Key people identified from ARCs to take forward work on:
  - Capacity building for care home research especially in under represented care priority areas (e.g. continence and infection control).
  - Delivering a cross-ARC review of capacity building models that foster research in care homes (e.g. researcher in residence, Huddles approach for building relationships among frontline staff, NICHE model) to provide recommendations for practice and resource requirements.
  - Holding workshops with care home organisations working with ENRICH and care home representative organisations to foster closer working on priority setting, implementation projects and identification of new research projects.
  - Cross-ARC updates on funded and planned bids (co-ordinated by ARC East of England).
  - Linking with national social care, ageing and frailty and palliative and end of life care themes to work to reduce duplication and fragmentation of ARC work and align with national theme priorities and projects.
  - Regional events to develop topic specific review of implementation ready evidence and new projects.
  - Holding a summit with funders and care home representative organisations to discuss how care home research priorities are included in upcoming calls and priority setting exercises.
  - International collaboration on trials.

8. Appendices

Appendix 1 Event Attendance

Name	Organisation	Region
Chris Albertyn	King's College London	London
Kerry Allen	University of Birmingham	West Midlands
Wendy Andrusjak	University of Bradford	Yorkshire and Humber
Fiona Aspinal	NIHR CLAHRC North Thames / University College London	London
Paul Bird	NIHR CLAHRC/ARC West Midlands	West Midlands
Yvonne Birks	University of York	Yorkshire and Humber
Katie Brittain	Northumbria University	North East
Angela Browne	NIHR CLAHRC East of England	East of England
Diane Bunn	University of East Anglia	East of England
Frances Bunn	University of Hertfordshire	East of England
Jenni Burton	University of Glasgow	North West
Louise Butler	Salford Royal NHS Foundation Trust	North West
Neil Chadborn	NIHR CLAHRC East Midlands /University of Nottingham	East Midlands
Laura Cole	NIHR Health & Social Care Workforce Research Unit / King's College London	London
Anna Cox	University of Surrey	South East
Miguel Da Silva	King’s College London	London
Nicole Darlington	University of Hertfordshire	East of England
Jo Day	NIHR CLAHRC South West Peninsula	South West
Emma Dickerson	NIHR CLAHRC East of England	East of England
Val Dunn	N/A	East of England
Joanne Fitzpatrick	King's College London	London
Anne Forster	University of Leeds Bradford Teaching Hospitals NHS Foundation Trust	Yorkshire and Humber
Jane Fossey	Oxford Health NHS FT / Oxford University	South East
Clarissa Giebel	University of Liverpool	North West
Claire Goodman	NIHR CLAHRC East of England / University of Hertfordshire	North East
Sally Gordon	NIHR ENRiCH	Yorkshire and Humber
Adam Gordon	University of Nottingham	East Midlands
Liz Graham	Bradford Teaching Hospitals NHS Foundation Trust	Yorkshire and Humber
Melanie Handley	University of Hertfordshire	East of England
Barbara Hanratty	Newcastle University / ARC North East and North Cumbria	National
Ruth Harris	King's College London	London
Deborah Harrop	Sheffield Hallam University / University of Sheffield	Yorkshire and Humber
Nicola Hart	Alzheimer's Society	London

Name	Organisation	Region
Jane Horne	University of Nottingham	East Midlands
Lisa Irvine	University of East Anglia	East of England
Mary James	Central London Community Healthcare Trust	London
John Kelley	Sheffield Hallam University	Yorkshire and Humber
Anne Killett	University of East Anglia	East of England
Maria Lagos	Skills for Care	Yorkshire and Humber
Jill Manthorpe	King's College London	London
Andrea Mayrhofer	University of Hertfordshire	East of England
Serap Mert	NIHR CLAHRC East of England	East of England
Julienne Meyer	City, University of London	London
Katharine Orellana	King's College London	London
Noreen Orr	NIHR CLAHRC South West Peninsula	South West
Professor Paul O'Brien	Elaros	Yorkshire and Humber
Guy Peryer	University of East Anglia	East of England
Kritika Samsi	King's College London	London
Filipe Santos	Improvement Analytics Unit (NHSE & NHSI)	London
Victoria Shepherd	Cardiff University	South West
Kate Spence	East Coast Community Health Care CIC	East of England
Karen Spilsbury	University of Leeds	London
Jane Stafford	King's College London	London
Jack Stancel-Lewis	NHS England	London
Jean Straus	Patient advocate	London
Claire Surr	Leeds Beckett University	Yorkshire and Humber
Alison Tingle	University of West London	London
Ann-Marie Towers	University of Kent	South East
Tushna Vandrevala	Kingston University	South East, London
Michael Varrow	The Health Foundation	
Oluwafunmilayo Vaughn	University of East Anglia	East of England
Louise Wallace	The Open University	South East
Andrea Whitfield	University of West London	London
Jill Will	Robert Gordon University	North East
Jennie Wilson	University of West London	London
Arne Wolters	The Health Foundation	East Midlands
Laura Wood	Freemantle Trust	

Appendix 2 Cross-CLAHRC Care Homes Event Programme

09.30	**Registration and refreshments**
10:00	**Welcome** **Overview of CLAHRCs, their priorities, themes and research relevant to care homes** *Prof Claire Goodman, CLAHRC East of England*
10:10	**Social care research myths and misconceptions** *Prof Jill Manthorpe, King's College London – NIHR School for Social Care Research*
10.25	**Routine data use** *Arne Wolters, The Health Foundation*
10.40	**Joint priority setting exercise with academics, care home providers, commissioners, residents and their representatives** *Prof Barbara Hanratty, CLAHRC Yorkshire and Humber / Newcastle University* **Table discussion and responses**
11.15	**Refreshments**
11.40	**Current examples of working in and with care homes and CLAHRCs:** • **NICHE-Nurturing Innovation in Care Home Excellence** *Prof Karen Spilsbury, CLAHRC Yorkshire and Humber* • **Leveraging external research funding** *Prof Claire Goodman, CLAHRC East of England* • **Care home concerns** *Dr Kritika Samsi and Dr Laura Cole, ARC South London* • **Quality improvement and teaching care homes** *Prof Adam Gordon, CLAHRC East Midlands*
12:45	**Lunch and networking**
13:30	**Table discussion of current and future research interests**
14:40	**Skills for Care and the changing landscape of long-term care** *Maria Lagos, Skills for Care*
15:00	**Future work** • Cross-CLAHRC strategy briefing, and network of alerts • Capacity building • Coordinating collaboration with ARC themes, NIHR Schools, care home networks and research interest groups
15:15	**Panel discussion: research funding** *Q&A panel with representatives from research funders and provider organisations*
16.00	**Close**

Appendix 3 Notes from Priority Setting Discussion

- Everything fits under quality of care – this is a very broad heading, need to be more specific
- How do we measure quality?
- What does good leadership look like? We know it is important but not clear what aspects are most important
- Workforce – important to have incentives, perhaps in the form of better career paths
- Discussion about the Mastricht model of embedded researcher
    - This is an intervention in itself
    - Working with 'good' care homes so maybe not typical
    - Does it reinforce inequalities?
- Comorbidities for people in care homes, e.g. cancer and dementia. Access to cancer treatment may be worse. Lack of awareness amongst staff that people have a diagnosis of cancer
- What does good look like in different circumstances – e.g. what might be realistic for residents with high levels of physical frailty?
- Leadership – training and opportunities better for staff in NHS than social care. What support do managers need to lead care home?

Outcome measures – need to develop outcome measures that are suitable for care home residents

- Methodological challenges of data where lots of participants may be lost to follow up (e.g. through death)

Appendix 4 Table Discussion Notes

Theme: Data Integration and Technology	**Table Lead: Chris Albertyn**

- Need to standardise across data collection source
- So many small tech start-ups, how do we know when they are effective?
- Capacity to evaluate effective technology. Industry is driving ahead without evidence to back it up. Could an independent body to provide a stamp of approval be the answer?
- Existing technology can be used for different purposes (e.g. iPad to improve communication)
- It is positive to have a Minimum Data Set in place but who will explore the data and where will the funding and capacity come from?

Theme: Volunteering	**Table Lead: Kritika Samsi**

- We discussed the need for a workforce of 1.3 million people in social care sector in next few years – could volunteering be a route to a social care career? The NHS 5 year plan has set out wide-ranging ambitions for volunteering. For this to work and volunteering to be encouraged, there is need for less rigid boundaries between sectors and greater recognition of what volunteers do – such as accreditation schemes, time banks etc.
- A delegate discussed his experience with volunteers facing barriers in the different settings they worked in. A volunteer sitter in a hospice could not always become a volunteer at home. His experience had been that patients' discharge from hospital

was being delayed as they couldn't find the right care support package at home – in some cases, this was something a volunteer could easily have done.

- We wondered whether there were a lot of myths around what volunteers could and couldn't do and whether we need to make people more positive risk-takers. However, we all consolidated the idea that duty of care should remain paramount, and safeguarding vulnerable people should remain a priority, alongside positive risk-taking; because there is always the possibility of a volunteer deliberately harming a vulnerable lonely person, through physical, emotional, or emotional abuse.

Implementation Issues:

- How can we make care home managers more volunteering-ready and positive risk-takers when it comes to accepting volunteers and engaging with other local services? We are mindful that volunteers should not replace care staff.
- Who is a volunteer working for? What models of volunteering work in practice? – the care home manager, voluntary organisation, residents?

Capacity Issues:

- Crucial to frame volunteering as teaching individuals' life-long skills. And that it could be a possible route into a social care career. Discussed the need for something like a "volunteering passport" to encourage volunteers to record hours volunteer and make it recognisable by employers.
- Public health approach to volunteering.
- Issue 1: Need to understand the complexity of volunteering and what it means in the context of fragmented, disjointed health and social care sectors? Should we contextualise volunteering more in terms of community engagement – i.e. less about a visitor going to a care home weekly for 1 hour, and more about local companies offering services free of charge to a care home (i.e. baker baking a cake for a resident's birthday).
- Issue 2: How can organisations better work together to remove some of these barriers to volunteering – by recognising the training another voluntary organisation has provided, by supporting volunteers through mentorship schemes to encourage into related careers, and encourage recruitment and retention of volunteers?

Theme: Dementia Care **Table Lead: Melanie Handley**

- Discussions around choosing when is the best time for moving into a care home. How some people use respite care as an option for trying out a care home they will eventually move into. But there is wide variation between local authorities, some do not fund respite care while others have funded spaces in local care homes.
- General literacy about the services is variable. Admiral Nurses can help navigation and offer advice around self-funding but there is a lack of Admiral Nurses. Where people have access to them, they are beneficial and help support choices. Also, variable is what happens between carer and Admiral Nurse when person with dementia moves into the care home. Some continue with their contact, dependent upon the funding, for example if through British Red Cross.
- Care homes with community links. Some have day care facilities and are an option for testing out a care home, but again funding issues.
- Role of Pharmacist in care. SW London looking at different models, either referral or case finding. Current case finding role is one month in place. Looking at use of antipsychotics and other medications review. Involving staff and families in review

process and supporting care homes with their policies so attempting to streamline services.
- Discussion of community dwelling project on polypharmacy and medicine regimen adherence. Discussion of how in care homes time restrictions on drugs rounds might lead to non-compliance and looking at ways could support i.e. knowing something about the resident that could be built into supporting them to take their medication (e.g. like a drink and so chinking glasses to help swallow tablets). Medication formulation also important.
- Quality Improvement discussion, not dementia linked to dementia, but around the role of the Comprehensive Geriatric Assessment (CGA) and whether dementia is being picked up. Is there a benefit to the resident having that picked up? Is it better that access to services is needs driven rather than linked to diagnosis?
- Getting professionals working together, and is there a role for technology?
- Policy drivers and problems with not taking a holistic view. Example of dentists removing teeth, then residents needing a puree diet and losing weight. Also question of how often care home residents have access to dentists. Other specialists often missing including podiatrists and speech and language therapists.
- Mention of a study by Shepherd looking at CGA addressing the focus of resident access to care plans using technology. Also what is the access to technology in care homes for staff?
- Looking at the physical environment, the use of outside spaces and how to measure the impact on health and wellbeing.
- Considering who the care home is marketed at should be acknowledged. Lisa Trigg's doctoral study of UK and Australian care homes compared the importance of elements of the environment to the relative and to the resident.
- Questions around environmental fixtures that are tagged as dementia friendly, for example images of bookcases or landscapes, these may look nice but is there an element of deception and how are residents with dementia interacting with these images?
- Using the environment to support Activities of Daily Living (ADLs), for example getting residents to help lay the table, to put out washing, to be involved in care home life. Using the environment in a meaningful way, not expecting people to make use of, for example, access to the outside, without context. But this can be labour intensive and therefore have cost implications.
- Role of volunteers in care homes to support meaningful activities. North Thames study of volunteering in care homes is underway. Examples from the Netherlands where students and school children spend time in care homes were given This was said to be common practice in Germany but not in the UK.
- However, also need to consider that the care home is someone's home and they may not want it open to the public. Is it fair to say to a resident their lounge will be used by schoolchildren at set times of the week? What are the expectations of different stakeholders on the use of the space?
- Staff value spending time with residents but are conflicted by their role and what they are paid to do. Some consideration needed on the use of volunteers so that there is not a separation of roles; that the volunteers take the roles that staff value and that the value of staff roles, in monetary terms, is not focused on task-based activities. Also is there a spike of caring activities for staff in preparing residents for time with volunteers such as helping with personal care such as dressing? Some evidence for this was provided in a study of reminiscence arts groups where staff activities

focused around preparing the residents for the activity rather than balancing contact throughout the day.
- Concern that volunteering may become professionalised.

Theme: Staff Development **Table Lead: Karen Spilsbury**

- A framework is needed for implementation and de-implementation of staff training.
- There is a good opportunity for creating lay summaries to demonstrate how research can be impactful.
- Researchers need confidence to ask and engage family, residents and those who are hard to reach in relation to research around workforce development.
- Leadership and management and how they influences the development of staff are unanswered questions in the main.

Theme: Outcome Measures **Table Lead: Katharine Orellana**

Potential opportunity for implementation:
- Using Adult Social Care Outcomes Toolkit (ASCOT) Mixed Methods Care Homes tools in care planning to improve quality of care and quality of life. Implementation issues: needs buy-in by several providers in order not to fail; take-up post-development of measure(s).

National priorities for research
Measures for implementation and measures suitable for social care are needed, but clinical measures are often prioritised over social care measures.
a) Understand what we want to measure in care homes – from the perspectives of residents and people managing homes.
b) Identify gaps in measures available.
c) Adapt existing measures and/or develop new measures.
d) Implementation issues: take-up post-development of measure(s).

Theme: Continence and Infection **Table Lead: Ruth Harris**
- This was the smallest of the discussion groups which is significant and potentially reflects the challenge of doing research in this area. Capacity is a barrier. Engaging researchers in the area of fundamental care delivery needs to be encouraged. Availability of research funding is a challenge.
- Hydration, constipation, incontinence and infection are linked and there is a need to understand the complexity of these for implementation and evaluation of interventions to address these conditions. This should be part of the quality agenda and adequately resourced.
- There is a tension between resident autonomy i.e. resident/family choice and standardisation/routinisation/'institutionalisation' in care delivery
- Co-design of interventions with residents and families is an important approach.
- The influence of CQC on the care delivery priorities of care homes is important.

Theme: Quality Improvement **Table Lead: Adam Gordon**
- There is an accumulative body of expertise that could be harnessed to make sense of what we know
- Capacity and sustainability can be barriers, as QI initiatives need to need to be sustained to be successful

- The language of measurement and improvement can be challenging for care homes. Quality improvement comes with implicit assertions of deficiency in current practice, whilst data and metrics are seen to be high level service design approaches of the sort used by the NHS.
- There was also a recognition that both improvements and metrics take dedicated time and resource, and care homes might not always see these as a priority given their very broad agenda and very limited excess capacity to take on additional tasks. There was a recognition that most care homes can explain some of the variation in processes and outcomes – this is legitimate but the metrics, and the methodology required to generate the metrics, to case-adjust current service level process and outcome metrics have not been developed.
- The issue of sensory deprivation in care homes and how hearing and visual loss represent opportunities to intervene and could, perhaps, be very fruitful test targets for quality improvement in care homes – because there is much ground to be made up (current practice is often suboptimal) and because they are subjects that both care home staff and residents feel strongly about.
- Research areas to prioritise:
    a) Moving towards a minimum dataset for long-term care homes that would be gathered at an individual care home level and could drive QI whilst also acting as a balancing metric/case-mix adjuster for the for the high level stuff presented by the Health Foundation.
    a) Developing a consistent and generalisable approach to "How to do QI in care homes" that could take account of the variability between institutions. This would need to take account of organisational culture within care homes and how this varies between care homes.
    b) Education for the care home workforce – both around QI, and on topic specific areas of expertise needed to support QI – how can sustainable models be developed so that staff turnover and changes in organisational thrust can be accounted for. Education is often seen as a panacea but how do we balance generic skills (e.g. improvement and working with data) against topic specific skills (pressure ulcers, falls, etc) and how do we ensure that what is learned in maintained and used (knows, knows how, shows how, does)?

Theme: End of Life Care **Table Lead: Frances Bunn**

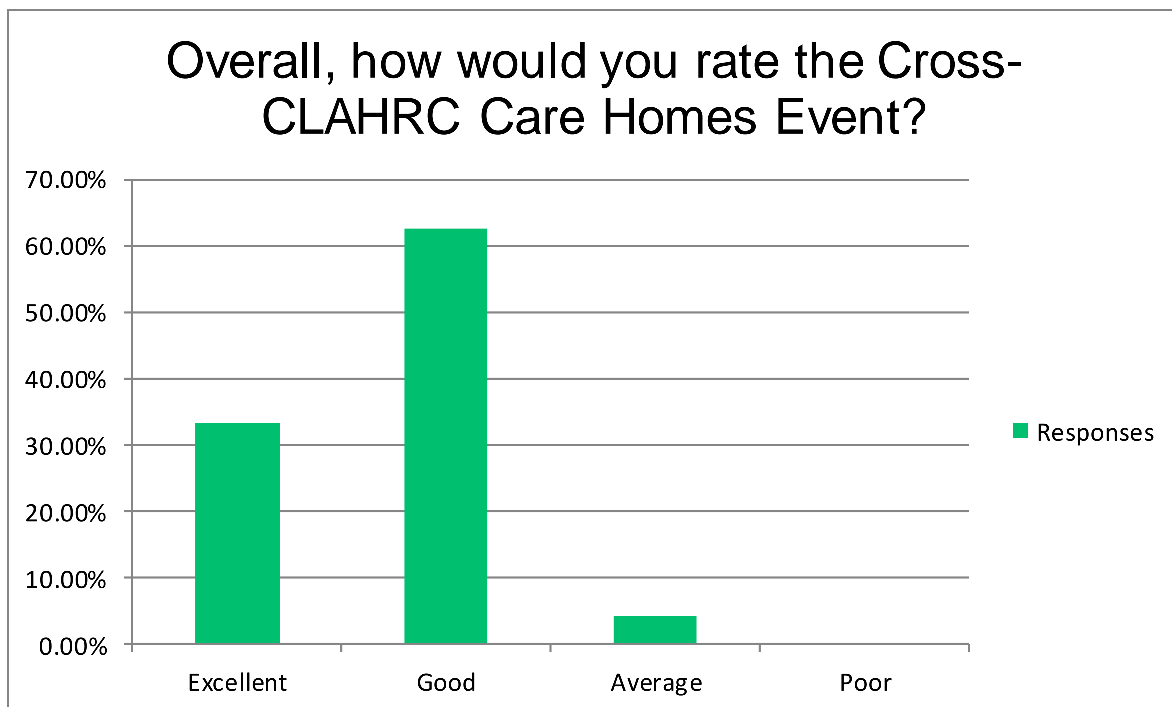
- Discussion around advanced care planning (ACP) in care homes. Needs to be done when someone has capacity so should be thinking about it before someone moves to a care home. Several people were interested in this topic.
    a) ACP needs to be an ongoing process but not always clear whose responsibility it is to have that conversation
    b) Current documentation may not be suitable for recording ACP conversations and preferences
    c) RESPECT documentation – not properly evaluated? May not be that useful
    d) Lack of good outcome data – studies tend to look at having ACP documentation as an outcome rather than whether it impacts on other outcomes
- Palliative care services for people with frailty was also a topic of interest. Barbara Hanratty has done some qualitative reviews on end of life care and frailty. Need to know more about the needs of this group

- Discussion around care home staff and their knowledge of residents – how they may be aware when something is wrong with a resident but are not taken seriously by medical staff.
- ‘Huddles’ for care homes.

Appendix 4 Event Feedback

1. Overall, how would you rate the Cross-CLAHRC Care Homes Event?

Answer Choices	Responses	
Excellent	33%	8
Good	63%	15
Average	4%	1
Poor	0%	0
Other (please specify)		2
	Answered	**24**
	Skipped	**1**



- This is mainly because I felt as though the event did not cover practical aspects of research such as problems encountered and how they were managed. The booklet of research was very handy and I suppose this covered some of what I wanted to see at the event.
- I liked the examples of care home research that were presented and the overview booklet that was circulated.

2. How would you rate the following:

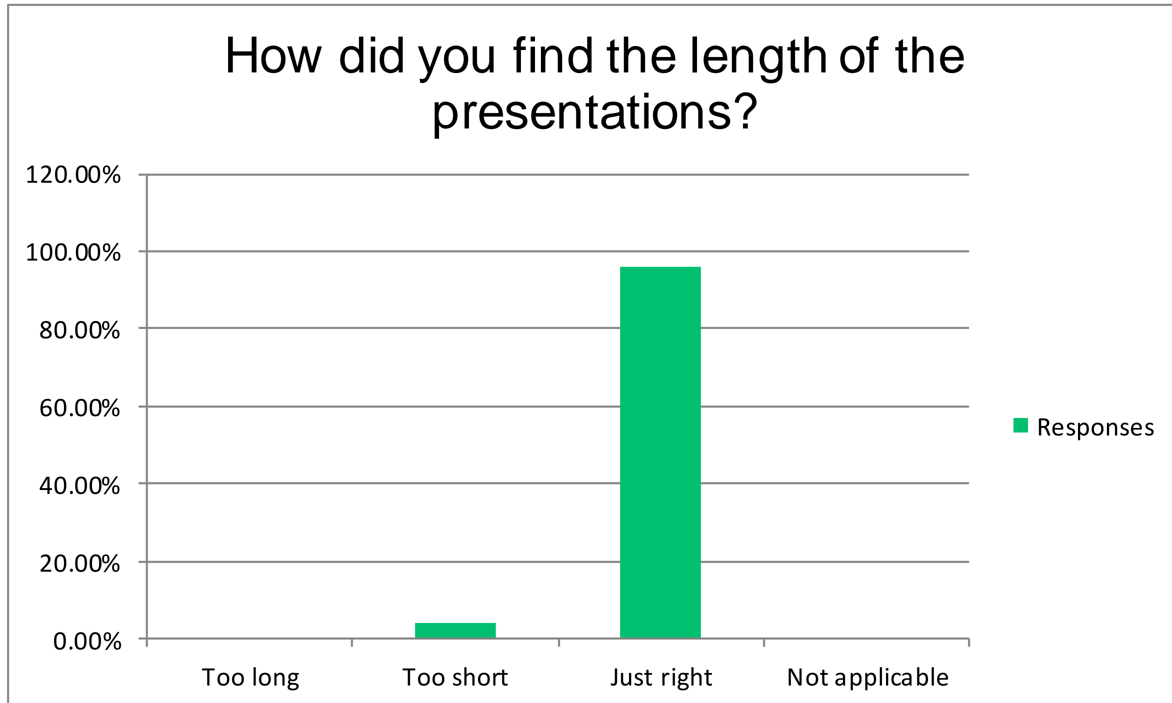
	Excellent		Good		Average		Poor		Not applicable		Total	Weighted Average
Organisation of the event	68%	17	32%	8	0%	0	0%	0	0%	0	25	1.32
Food and refreshments	48%	12	36%	9	16%	4	0%	0	0%	0	25	1.68
Getting to and from the venue	60%	15	32%	8	8%	2	0%	0	0%	0	25	1.48
Accessibility and layout	48%	12	52%	13	0%	0	0%	0	0%	0	25	1.52
Visual and audio system	24%	6	32%	8	32%	8	12%	3	0%	0	25	2.32
The morning session (which included guest speakers and discussion)	64%	16	32%	8	4%	1	0%	0	0%	0	25	1.4
The afternoon session (which included discussion by theme, speakers and Q&A panel)	44%	11	48%	12	8%	2	0%	0	0%	0	25	1.64
Comments (optional)											8	

Answered	**25**
Skipped	**0**

- I think the afternoon session purely suffered a little from us participants flagging in the heat.
- With the panel, it was a little difficult to pitch questions that weren't either far too general or too specific. Maybe some questions from the panel to the floor may have generated some discussion to get started.
- Speakers didn't use the microphones properly which made it hard to hear at times.
- Great venue - bit noisy with the builders outside and the windows open but couldn't be helped on a hot day!
- Found it hard to hear the speakers at times. The sound system wasn't great.
- Generally the day was informative and enjoyable.
- The mic and audio was a bit echo-ey. Not something organisers can help, but maybe something to feedback to the hosts.
- As you know, although the technical department said the hearing loop was working, it was not when I tried to tune in to it. The microphone seemed inadequate, and a few people with good hearing told me they struggled to hear at times. But how wonderful that you all banded together to enable me to hear, using my mini mic. That was a first, for which I'll forever be grateful.
- The sound system could have been clearer. Which is no fault of the organisers of the event, but perhaps a message that can be passed to King's as the venue is such an august one for KCL.

3. How did you find the length of the presentations?

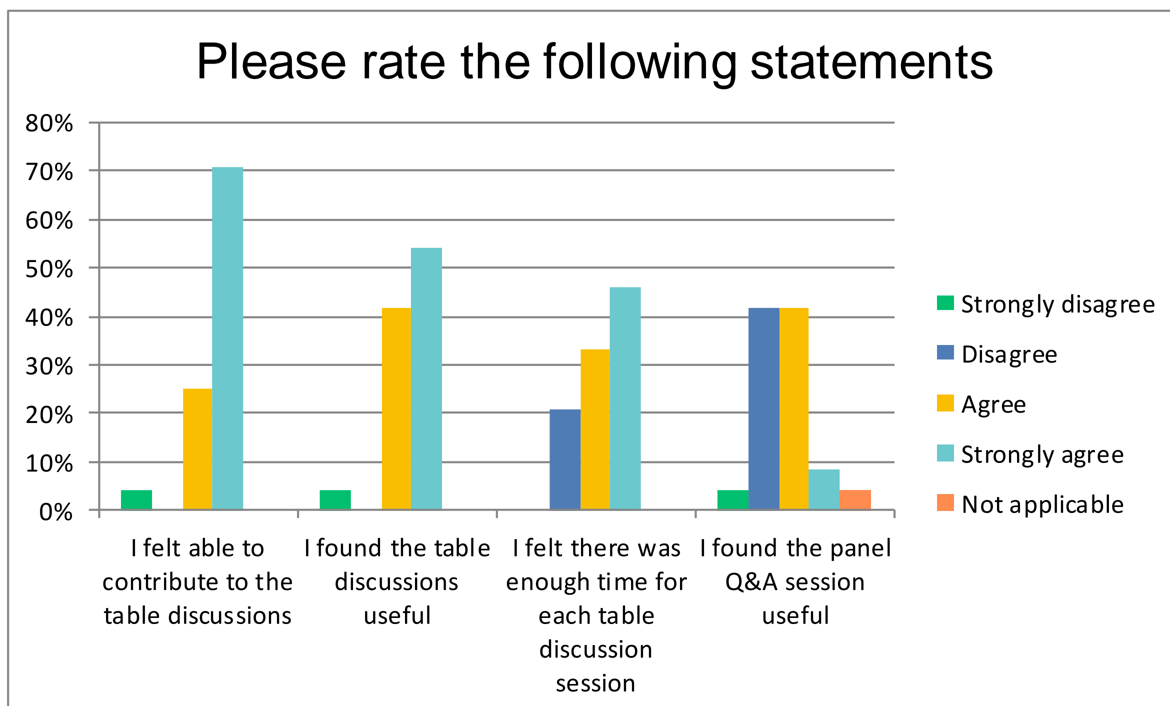
Answer Choices	Responses	
Too long	0.00%	0
Too short	4.00%	1
Just right	96.00%	24
Not applicable	0.00%	0
Comments (please specify)		3
	Answered	**25**
	Skipped	**0**



- Some of the speakers were not able to get to the nitty gritty of what they had done. Possibly giving 5 more minutes may have helped for examples.
- There could have been some time at the end of sessions for discussion/comments/questions.
- It would have been nice to have a quick Q&A after each of the speakers.

4. Please rate the following statements

	Strongly disagree		Disagree		Agree		Strongly agree		Not applicable		Total
I felt able to contribute to the table discussions	4%	1	0%	0	25%	6	71%	17	0%	0	24
I found the table discussions useful	4%	1	0%	0	42%	10	54%	13	0%	0	24
I felt there was enough time for each table discussion session	0%	0	21%	5	33%	8	46%	11	0%	0	24
I found the panel Q&A session useful	4%	1	42%	10	42%	10	8%	2	4%	1	24
Please comment											6
										Answered	**24**
										Skipped	**1**



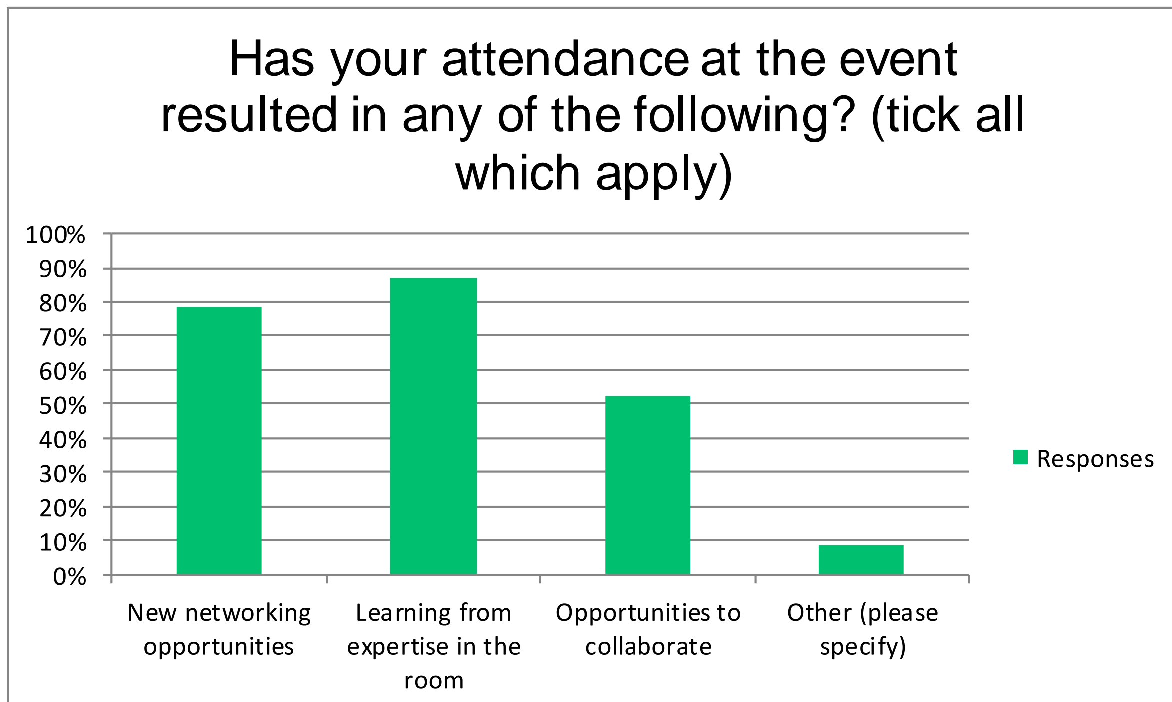
- It's a bit difficult to talk broadly and openly about funding. Where to start...? Almost all (my) questions would be about specifics, so it's difficult to find more generic topics to ask about.
- I would have liked to participate in more than one table discussion, so perhaps have a couple - choosing one was hard!
- Q&A session was more about timing in the day - just needed a break before to get brain going after the table discussion.
- I concur with comment about asking for questions in advance to ask the panel.
- What I found so wonderful was to what extent I was able to learn about research, current state of care homes, and care in such a short space, and the networking opportunities were marvellous.
- More time for people to ask questions of the speakers presenting, as well as the panel. Event got wrapped up a bit swiftly when no questions were asked in the first 3 minutes or so.

5. Are there other individuals who you think should be included / invited to future events? (please specify)

- Research on well-being initiatives in care homes.
- Would be good to actively engage with researchers from outside ARC too.
- Care home providers, residents and family carers.
- ENRiCH & JDR.
- Professor Pip Logan.
- There wasn't much representation of care homes themselves. Is there a way we can make the events more driven by the care homes rather than researchers?
- A care home manager.
- Not sure.

6. Has your attendance at the event resulted in any of the following? (tick all which apply)

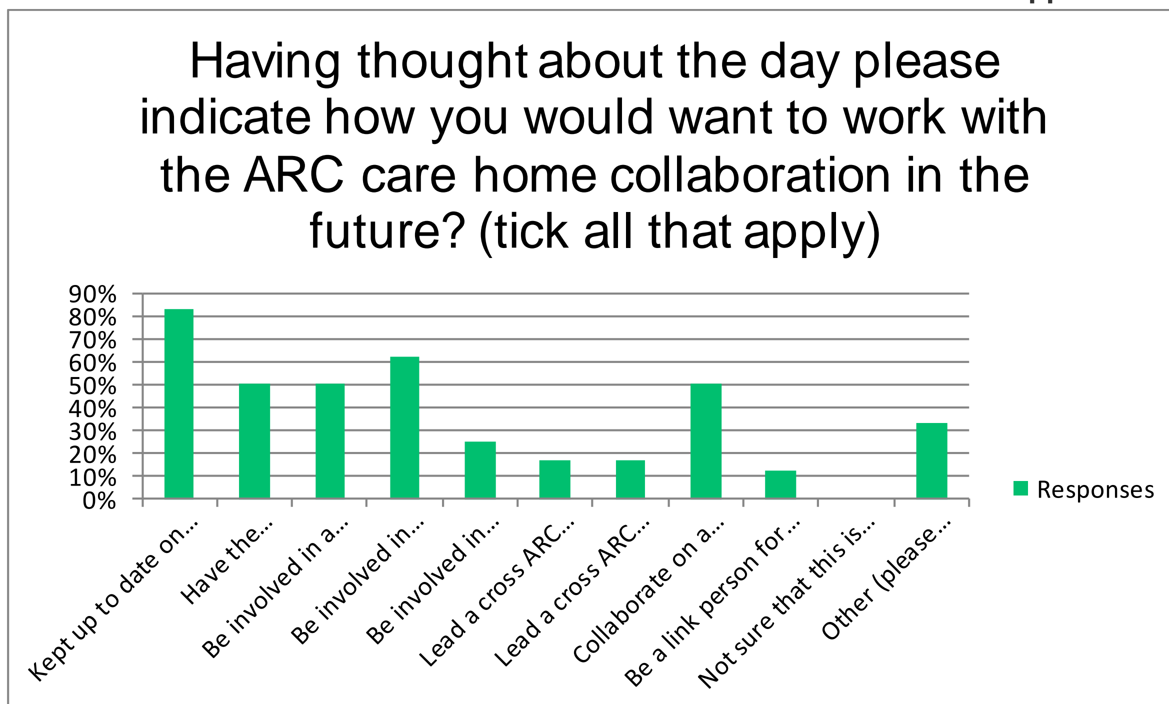
Answer Choices	Responses	
New networking opportunities	78%	18
Learning from expertise in the room	87%	20
Opportunities to collaborate	52%	12
Other (please specify)	9%	2
	Answered	**23**
	Skipped	**2**



- Via networking, I have a new idea of how to publicise some work I intend to do.
- Not enough time for these activities and felt that there were already networks in place.

7. Having thought about the day please indicate how you would want to work with the ARC care home collaboration in the future? (tick all that apply)

Answer Choices	Responses	
Kept up to date on what is happening in care home research across the ARCs and related events	83%	20
Have the opportunity to promote my research and or interests to the ARC collaboration	50%	12
Be involved in a topic specific group within the ARC care home collaboration: please specify which topic	50%	12
Be involved in setting and discussing ARC care home research priorities and research questions	63%	15
Be involved in writing ARC led topic briefings to inform funders and commissioners	25%	6
Lead a cross ARC bid either as a responsive bid or as a research led bid	17%	4
Lead a cross ARC implementation project	17%	4
Collaborate on a cross ARC led project	50%	12
Be a link person for this collaboration with the National ARC themes (please specify which theme)	13%	3
Not sure that this is the right ARC collaboration for me	0%	0
Other (please specify)	33%	8
	Answered	**24**
	Skipped	**1**



- Dementia and diversity.
- Hydration and continence.
- Whilst we don't have huge experience in care homes we are keen to do more and to build on the Quality Improvement work we have done. Future opportunities around the implementation of QI initiatives would be of interest to us, as well as general interest in future opportunities.
- I am interested in working on the development of a core outcome set (and ultimately appropriate outcome measures) for residents.
- Staff development, improvement, implementing knowledge.

- As a NWL CLAHRC 2016 Fellow, there is no role I am obviously suited for as an advocate for residents' sensory well-being, and yet that should give others the possibility of considering me when my involvement could seem appropriate.
- Be involved in a topic specific group: volunteering, wider involvement of charities and third sector organisations;
- I joined the day from Scotland to learn more about the work being done in your area. I was really impressed with some of the work being done. I would welcome some exploration of nationwide studies or interest groups for example PEOLC in CH's for the UK.

Appendix 5 Potential for Future Involvement

Name	Organisation	Areas of interest	Interested in leading work	Interested in Collaborating
Chris Albertyn	King's College London	trials, data, sharing		Yes
Wendy Andrusjak	University of Bradford	sensory loss in care homes	Yes	Yes
Fiona Aspinal	NIHR CLAHRC North Thames / University College London	dementia, self-management, evaluation	Yes	Yes
Paul Bird	NIHR CLAHRC/ARC West Midlands	quality improvement, outcome measures		Yes
Yvonne Birks	University of York	dementia financing, funding, and information on care	Yes	Yes
Katie Brittain	Northumbria University	sharing data at end of life		Yes
Diane Bunn	University of East Anglia	hydration and continence care	Yes	Yes
Frances Bunn	University of Hertfordshire	end of life care for people with dementia / frailty	Yes	Yes
Jenni Burton	University of Glasgow	use of routine data pathways into care		Yes
Louise Butler	Salford Royal NHS Foundation Trust	advance care planning, end of life / community geriatrics		Yes
Neil Chadborn	NIHR CLAHRC East Midlands /University of Nottingham	dementia, quality improvement	Yes	Yes
Laura Cole	NIHR Health & Social Care Workforce Research Unit / King's College London	dementia care	Yes	Yes

Name	Organisation	Areas of interest	Interested in leading work	Interested in Collaborating
Anna Cox	University of Surrey	outcomes of importance to care home residents use of ASCOT in care planning		Yes
Miguel Da Silva	Kings College London	data sharing		Yes
Nicole Darlington	University of Hertfordshire	dementia care		Yes
Jo Day	NIHR CLAHRC South West Peninsula	implementation, workforce, collaboration		Yes
Joanne Fitzpatrick	King's College London	workforce quality	Yes	Yes
Jane Fossey	Oxford Health NHS FT / Oxford University	workforce, co-production, PPI, dementia		Yes
Clarissa Giebel	University of Liverpool	dementia, health inequalities	Yes	Yes
Sally Gordon	NIHR ENRiCH	getting more research into care homes	Yes	Yes
Adam Gordon	University of Nottingham	quality improvement, measurement for change, under-represented homes	Yes	Yes
Liz Graham	Bradford Teaching Hospitals NHS Foundation Trust	outcome domains of importance to residents - identifying these		Yes
Melanie Handley	University of Hertfordshire	dementia care, staff development, end of life, volunteers	Yes	Yes
Barbara Hanratty	Newcastle University / ARC North East and North Cumbria			Yes
Deborah Harrop	Sheffield Hallam University / University of Sheffield	physical environment	Yes	Yes

Name	Organisation	Areas of interest	Interested in leading work	Interested in Collaborating
Nicola Hart	Alzheimer's Society	dementia research	Yes	Yes
Jane Horne	University of Nottingham	implementation, co-production, continuous improvement		Yes
Lisa Irvine	University of East Anglia	trial repositories		Yes
Mary James	Central London Community Healthcare Trust	medication and dementia, end of life, infection control	Yes	Yes
John Kelley	Sheffield Hallam University	data mapping, intervention evaluation		Yes
Anne Killett	University of East Anglia	new community models		Yes
Jill Manthorpe	King's College London	workforce systems, policies and politics	Yes	Yes
Andrea Mayrhofer	University of Hertfordshire	community to care homes, volunteering	Yes	Yes
Julienne Meyer	City, University of London	community engagement		Yes
Noreen Orr	NIHR CLAHRC South West Peninsula	dementia care, living well with dementia	Yes	Yes
Guy Peryer	University of East Anglia	community engagement, palliative and end of life care		Yes
Kritika Samsi	King's College London	volunteering in care homes, making care home volunteering ready		Yes
Filipe Santos	Improvement Analytics Unit (NHSE & NHSI)	quality improvement and data		Yes

Name	Organisation	Areas of interest	Interested in leading work	Interested in Collaborating
Kate Spence	East Coast Community Health Care CIC	staff development, fundamental care		Yes
Karen Spilsbury	University of Leeds	workforce quality	Yes	Yes
Jane Stafford	King's College London	dementia, staff development		Yes
Jack Stancel-Lewis	NHS England	sensory health, access to sensory health	Yes	Yes
Jean Straus	Patient advocate			Yes
Alison Tingle	University of West London	staff development, fundamental care	Yes	Yes
Ann-Marie Towers	university of Kent	outcomes and how they can be used to improve quality of life	Yes	Yes
Tushna Vandrevala	Kingston University	end of life, diversity, staff development	Yes	Yes
Oluwafunmilayo Vaughn	University of East Anglia	well-being of staff, working in care (care homes / health settings)		Yes
Louise Wallace	The Open University	supporting / leading applied health research, dementia walks in parks.		Yes
Andrea Whitfield	University of West London	hydration, continence, long-term care, families		Yes
Jill Will	Robert Gordon University	advanced care planning		Yes
Jennie Wilson	University of West London	continence and infection in care home settings, hydration / continence	Yes	Yes
Arne Wolters	The Health Foundation	evaluation, data		Yes