HDRC membership workshop: The HDRC what next? Shaping research and informing decisions.

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Acknowledgements

The HDRC steering group would like to thank all of the people who took part in the membership event reported in this document (1st May 2014) for giving up their time and sharing their views, knowledge and learning.

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For contact details see the HDRC website as these will change on 1st September.

http://housingdementiaresearch.wordpress.com/
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1. Introduction

On 1st May 2014 the HDRC steering group organised a workshop for HDRC members, chaired by Jeremy Porteus (Director, Housing Learning and Improvement Network), the aims of which were to raise awareness of the HDRC, to gain an understanding of how best to engage the membership and to set the future research agenda. Key priorities were the sharing and understanding of the issues that members currently face in relation to accommodation and care for people with dementia and the development of research goals that address these issues. In March 2012, the Prime Minister launched his “Challenge on Dementia”, announcing plans to tackle a “national crisis” posed by dementia including a doubling of research funding into dementia to £66 million per annum by 2015; the current attention to Dementia provides a good opportunity for the HDRC to carry forward research proposals based in the identified research goals.

In addition to the eight steering group members and two guest speakers, 19 members of the HDRC attended, representing 17 different organisations, including: housing providers and commissioners, academics, architects and the third sector. Attendees had a broad spectrum of experience, expertise and interest relating to accommodation and care for people with dementia.

1.1 New research remit and home for the HDRC

When the HDRC was set up in 2008 the original research remit focused on what works for people with dementia living in Housing with Care settings. In order to reflect the range of accommodation and care choices now available to people with dementia, in Summer 2013 the steering group took the decision to broaden the research remit to include other types of accommodation and care arrangements available to people with dementia (e.g. care homes, retirement housing and villages, sheltered housing, Housing with Care / Extra Care schemes / assisted living schemes, close care housing, continuing care retirement communities, general needs housing, domiciliary care, hybrid approaches combining a number of different provisions). This also made HDRC membership more attractive to housing providers who offered a broad range of housing choices.

The HDRC core / steering group had felt for some time that it was not ideal to have the research coordinator employed by one of the core housing provider members (Housing and Care 21), particularly in terms of attracting new members who may perceive Housing and Care 21 as having an unfair advantage in terms of influence over the HDRC’s direction of travel. The steering group concluded that another “home” was needed for the HDRC, preferably a trade body or University, and pursued a number of options. The HDRC is due to transfer to The Association for Dementia Studies at the University of Worcester in early September 2014.
2. Workshop

At the 2014 membership event, delegates were given a presentation on the genesis, history and progress of the HDRC, an overview of relevant research and a presentation on the research priorities resulting from the 2009 HDRC event. Information on these aspects of the HDRC can be found on the HDRC’s website:

http://housingdementiaresearch.wordpress.com/

The presentation slides from the event are also available on the website.

2.1 Reviewing the research priorities

Delegates were asked to consider and discuss, in their table groups, what their / their organisation’s research priorities were, bearing in mind the HDRC’s new research remit. There were six table groups with a member of the steering group acting as discussion facilitator / note taker. The aim was to generate the group’s top five research themes (although this was flexible), which could also have some associated key research questions.

Each delegate was provided with a handout of the existing research priorities (see 2.1.1, below), the “oven-ready” research proposals (see 2.1.3, below) and questions that they might like to consider while discussing their research priorities (see 2.1.4, below).

2.1.1 Research priorities from the 2009 membership event

In September 2009, an HDRC event, involving 33 member organisations, was held in order to generate the HDRC’s research priorities and an action plan. Of the key research gap areas that had been identified by an HDRC scoping review of the literature (Dutton, 2009), those which were given the highest priorities by attendees are given below, together with associated key research questions (in no particular order).

1. The effect of building and environment on outcomes for people with dementia.
   - What are the effects of key differences in building and environmental design on outcomes for people with dementia in housing with care, and on the ability to support them successfully?
   - What is the impact of interaction with the outside world on the health and wellbeing of people with dementia living in Housing with Care?

2. Assistive technology in Housing with Care.
   - How useful, acceptable and effective are various assistive technology devices in Housing with Care, a) for occupants with dementia, b) for families, staff and management?
3. **Care and support in Housing with Care and the effect of personal budgets.**
   - In the context of personal budgets, what will be the impact of care and support procurement models, and service configuration and delivery, on the wellbeing of people with dementia in housing with care?
   - What are the barriers and enablers to providing the necessary levels and flexibility of care in response to increasing care and support needs?
   - For occupants with dementia, to what extent are these mechanisms maximising choice and control within the context of the individual’s capacity and wish to exercise them, and what are the outcomes for the individual?

4. **Suitability of Housing with Care for people with dementia and home-for-life issues.**
   - At the point of entry to Housing with Care, is Housing with Care a suitable option to move to for everyone, at all stages of dementia, and if not, what are the criteria for determining that Housing with Care is an unsuitable option?
   - For people already living there, as the dementia progresses, what is the continued suitability of Housing with Care? Under what circumstances does Housing with Care become unsuitable for an occupant with dementia? What criteria are, and should be, used to determine when this point has been reached, and what can be done to minimise the number of avoidable moves to alternative settings?

5. **Advantages and disadvantages of different models of Housing with Care schemes for people with dementia.**
   - Do any of the models (integrated, separated, specialist and hybrid) offer a better quality of life to people with dementia and their carers than others? If so, what are the factors which contribute to this outcome?

6. **Cost effectiveness of housing with care for people with dementia compared to residential care and own homes in the wider community.**
   - Is Housing with Care a cost-effective accommodation and care option for people with dementia and how does it compare with residential care in terms of costs to all stakeholders and quality of life outcomes?

7. **Communicating with people at all stages of dementia and assessing quality of life.**
   - What are the most effective methods and tools for understanding and communicating with people at various stages of dementia, and various backgrounds, in Housing with Care settings?
   - What are the best methods and tools for assessing the quality of life of people with dementia in Housing with Care settings?
8. **Maximising wellbeing – voice, choice and control for people with dementia in Housing with Care.**
   - How do staff in Housing with Care ensure that people with dementia have their voices heard and are empowered to engage with the community and exercise choice and control as far as possible so that they feel they belong and experience high levels of wellbeing?

9. **Views of people with dementia living in Housing with Care.**
   - How do people with dementia feel about living in Housing with Care?

10. **Staff skills and training.**
    - Which configurations of management, staffing, staff skills, training, leadership, supervision and mentoring are most effective for occupants in Housing with Care with varying severities of dementia?

2.1.2 **Providing a baseline – what is being done by housing providers now?**
During September to November 2011, the HDRC Research Coordinator visited several Housing with Care schemes belonging to core / steering group members in order to assess the provision for people with dementia. The case study schemes consisted of six integrated model schemes (people with dementia living alongside other tenants) and one specialist / dedicated dementia scheme (specifically designed for people with dementia). The report of this small-scale study, “*Provision for people with dementia within Housing with Care: Case studies from HDRC Steering Group Providers*” (Barrett, 2012), can be found on the HDRC website.

The report highlighted some of the differences in how schemes are tailored to support people with dementia and the need for more comprehensive information on how the needs of people with dementia are being met in Housing with Care. The HDRC steering group feels strongly that there is a need to expand this research and apply it at a larger scale across a broader range of accommodation and care models. This will provide: a more comprehensive picture of what providers are doing to support people with dementia; a valuable baseline for future research activities and supporting evidence for research proposals. This plan was presented to the delegates at the 2014 event.

2.1.3 **Research proposals**
The current HDRC research coordinator has initiated and contributed to five funding bids and has been included as a collaborator on five other bids. Funding was successfully secured from the NIHR School of Social Care Research for a 21 month project, which started in July
2012, concerned with developing best practice in social care and support for adults with concurrent dementia and sight loss within different housing settings.

Three project proposals which were not successful in securing funding but are nevertheless still considered important and topical areas of research by both the project development teams involved and the HDRC steering group are:

- **Interaction with the outside community**: evaluating the impact of interaction with the outside local community on the health and wellbeing of residents with dementia in extra care / continuing care settings and on the attitude of the local community.
- **Dementia Friendly Housing**: three projects tackling different aspects of this research theme
  - analysis of the issues influencing decisions of people with dementia and their carers to move into Housing with Care;
  - the advantages and disadvantages of different models of Housing with Care;
  - the effect of building and environment design on outcomes for people with dementia.
- **Green Dementia Care**: examining the impact of interaction with nature on multiple health and wellbeing dimensions for people with mild cognitive impairment / early stage dementia living in different accommodation settings.

These “oven ready” proposals fell within the HDRC’s research priorities.

### 2.1.4 Questions

- Are the current research priorities still applicable to you / your organisation? Are there any changes you would like to make to these?
- What research would you / your organisation like to see being done?
- What issues are you / your organisation grappling with in relation to accommodation and care for people with dementia?
- What questions would you / your organisation like answered?
- What research would help you / your organisation with these issues and questions?
- What research would help you / your organisation to make decisions relating to accommodation and care for people with dementia?

### 2.2 “Next steps” survey

The 19 attendees at the 2014 membership event were given a questionnaire to complete, to enable the steering group to find out: what membership organisations are doing in terms of accommodation and care for people with dementia; how the HDRC could more effectively work with member organisations and involve members more actively in the future research programme. The questionnaire is given in Appendix A.
3. Results

3.1 Reviewing the research priorities

Of the six table groups four produced a list of five top research priorities, one listed eight and another discussed three in depth, coming up with a number of associated key research questions.

All of the discussion groups agreed that the 2009 list of priority research themes were still priorities and selected those that they felt were most important, adding further key research questions. A few new research themes also emerged that tended to reflect the particular expertise / interests of the members of a group.

The most popular priority research theme, selected by all six groups was “Advantages and disadvantages of different models of housing with care schemes for people with dementia”, followed by “The effect of building and environment on outcomes for people with dementia”. Two of the “oven ready” research proposals (evaluating the impact of interaction with the outside local community; examining the impact of interaction with nature) were originally considered to fit into the building and environment theme. However, some of the groups felt that these were important enough to be top research priorities in themselves.

Table 1, below, lists the 2009 priority research themes, including the “oven ready” research proposals, in order of popularity as a result of the group discussions.

<table>
<thead>
<tr>
<th>Research priority</th>
<th>Number of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advantages and disadvantages of different models of Housing with Care schemes for people with dementia.</td>
<td>6</td>
</tr>
<tr>
<td>The effect of building and environment on outcomes for people with dementia.</td>
<td>4</td>
</tr>
<tr>
<td>Care and support in Housing with Care and the effect of personal budgets.</td>
<td>3</td>
</tr>
<tr>
<td>Evaluating the impact of interaction with the outside local community.</td>
<td>3</td>
</tr>
<tr>
<td>Assistive technology in Housing with Care.</td>
<td>2</td>
</tr>
<tr>
<td>Suitability of Housing with Care for people with dementia and home-for-life issues.</td>
<td>2</td>
</tr>
<tr>
<td>Cost effectiveness of housing with care for people with dementia compared to residential care and own homes in the wider community.</td>
<td>2</td>
</tr>
<tr>
<td>Views of people with dementia living in Housing with Care.</td>
<td>2</td>
</tr>
<tr>
<td>Examining the impact of interaction with nature</td>
<td>2</td>
</tr>
<tr>
<td>Communicating with people at all stages of dementia and assessing quality of life.</td>
<td>1</td>
</tr>
<tr>
<td>Maximising wellbeing – voice, choice and control for people with dementia in Housing with Care.</td>
<td>1</td>
</tr>
</tbody>
</table>
Additional research themes proposed by individual groups were:

- Learning disabilities and dementia.
  - What is the impact of deinstitutionalisation and integration into the community – do such people return to an institution and / or additional care?
- The role of family carers in supporting people with dementia living in different settings.
- The benefits of diagnosis.
  - Is early diagnosis always the best thing for individuals?
- Outcomes for couples in Housing with Care where one is living with dementia.
  - What are the effects of splitting couples and what are the associated costs?
  - How does this compare in different Housing with Care models?

The steering groups’ plan to expand the in-house small-scale case study by applying the research at a larger scale across a broader range of accommodation and care models was received favorably by the delegates at the May 2014 membership event.

### 3.2 “Next steps” survey

Seventeen questionnaires were completed. It can be seen in Table 2, below, that representatives from housing associations formed the largest portion of the respondents.

#### Table 2: Types of organisations

<table>
<thead>
<tr>
<th>Type of organisation</th>
<th>N</th>
<th>(%  )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing association</td>
<td>6</td>
<td>(35.3%)</td>
</tr>
<tr>
<td>Local Authority</td>
<td>2</td>
<td>(11.8%)</td>
</tr>
<tr>
<td>Academic institution</td>
<td>1</td>
<td>(5.9%)</td>
</tr>
<tr>
<td>Representative body</td>
<td>0</td>
<td>(0.0%)</td>
</tr>
<tr>
<td>Charity</td>
<td>4</td>
<td>(23.5%)</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>(23.5%)</td>
</tr>
</tbody>
</table>

#### 3.2.1 Research into housing and support for people with dementia

Eleven of the attendees (64.7%) that completed the questionnaire stated that their organisation carried out research into housing and care models for people with dementia. Those in an organisation that conducted research were asked to describe the types of research being carried out (e.g. service evaluations, action research, exploration of dementia friendly environments, customer surveys). The types of research described were:

- The importance of adaptations and other low level works to ensure older people with dementia can remain safe and well in their own homes.
- Collecting anecdotal evidence, e.g. walk around completed buildings and talk to people.
- All of the above (service evaluations, action research, exploration of dementia friendly environments, customer surveys).
- Evaluation of self help, peer support for people living with dementia in extra care and sheltered housing.
Comparing different extra care service models. Dementia friendly environments. (Doncaster & Cumbria).

Dementia Voice Nurses.

Researching and gathering data on specialist housing for older people including extra care and services for people with dementia.

Customer surveys, Enriched Opportunities Programme Random Cluster Controlled Trial, current research with Aston University and Keele University into Housing with Care.

Surveys, work with carers networks, etc.

Working with partners, e.g. National Housing Federation. Small scale evaluations rather than “research” e.g. evaluations of smarter homes & Gentoo.

For 11 of the organisations the issue of housing and support for people with dementia was considered ‘very important’; the remaining six considering it ‘quite important’.

Table 3, below, shows the attendees’ responses to the question: Which of these statements best matches the aspiration for carrying out research on accommodation and care for people with dementia for your organisation? It can be seen that the most common aspiration was that, due to a growing business need for evidence around ‘what works’ for people with dementia, the organisation was looking to collaborate and learn from other organisations rather than carry out its own ‘in-house’ research. Being a member of the HDRC fulfils this aspiration.

Table 3: Research aspirations

<table>
<thead>
<tr>
<th>Statement</th>
<th>No. of attendees (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a growing business need for evidence around ‘what works’ for people with dementia and we are looking to collaborate and learn from other organisations rather than carry out ‘in-house’ research</td>
<td>11 (64.7%)</td>
</tr>
<tr>
<td>There is a growing business need for my organisation to research the accommodation and care needs for people with dementia and we are planning to carry out our own programme of work</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>We already have an in-house programme of work but are exploring opportunities for collaboration and partnership</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>We have our own in-house projects on this topic and are not looking for broader collaborations at present</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>It is an interesting area but not a current priority, though this may change in future</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>None of the above</td>
<td>2 (11.8%)</td>
</tr>
</tbody>
</table>
3.2.2 Involving the broader membership

In order to establish the best ways to involve the broader membership in the HDRC's developing work programme, attendees were asked to indicate their level of agreement with a number of statements, shown in Table 4, below. It can been seen from Table 4 that the most popular means of involving the broader membership was “attending an annual HDRC event to share learning and set research priorities”, with 15 (94%) of attendees stating that they would be ‘very interested’ in attending such an event, followed by “sharing learning from my organisation with the wider HDRC network” and “receiving regular newsletters by email” (both 75%). The least popular methods of involvement were those that required a financial commitment (becoming a core steering group member and funding key research).

Table 4: Ways of involving the broader membership

<table>
<thead>
<tr>
<th>Number of attendees (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very interested</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td><strong>Attending an annual HDRC event to share learning and set research priorities</strong></td>
</tr>
<tr>
<td><strong>Sharing learning from my organisation with the wider HDRC network</strong></td>
</tr>
<tr>
<td><strong>Receiving regular newsletters by email on the HDRC's work</strong></td>
</tr>
<tr>
<td><strong>Receiving general updates on relevant research findings</strong></td>
</tr>
<tr>
<td><strong>Being involved in future HDRC research through offering case study sites or similar</strong></td>
</tr>
<tr>
<td><strong>Contributing to funding key pieces of work carried out by HDRC which fit with my organisation's priorities</strong></td>
</tr>
<tr>
<td><strong>Becoming a core steering group member (paying an annual membership fee)</strong></td>
</tr>
</tbody>
</table>

Other ideas for how the HDRC could more actively involve its wider membership suggested by attendees were:

- Regular events, newsletters, website.
- More frequent meetings – at least once a year.
- Webinars to share learning.
- A directory of learning amongst the wider sector and regular updates.
- Create a single membership group that elects the core group and charge everyone a membership fee. It will create an equal relationship and potentially increase funding and participation.
- Articles in membership organisations’ own newsletters, or on websites, etc.
• Hold ‘Best Practice’ sessions where members explain their approach and how they found that it worked.

• Come and talk to the North East Dementia Alliance, run workshops at NEDA dementia events.

• Improve links with the PM Challenge on Dementia Champion’s groups, especially the one on dementia-friendly environments

3.2.3 Membership event

With respect to the membership event itself, the key messages that the attendees would be taking back to their organisations were:

• Research priorities, learning from research papers, opportunities to be involved further.

• That we still have a way to go in the UK.

• The need for further research in a number of areas relevant to my organisation.

• Opportunity to obtain evidence to back up our ideas.

• Opportunities for research collaborations, ongoing importance of having research into housing, research priorities, focus on people living with dementia and impact on their lives.

• Research opportunities into Housing with Care models.

• Real interest in HDRC and buy in for future direction of travel. Great that other network members want to become more involved.

• Progress of the group and potential to engage and make a difference.

• Information on the development and changes of the HDRC.

• North East Dementia Alliance can influence and get learning from HDRC. The NEDA could help to source case study sites / participants.

Attendees were asked “Which of today's research priorities would be most important to your organisation?” Most gave more than one priority in answer to this question. Table 5 lists the research priorities set in 2009 in order of popularity, according to the attendees’ responses to this question.

It can be seen from Table 5 that “Advantages and disadvantages of different models of Housing with Care schemes for people with dementia” was cited most often as the most important research priority, followed by “The effect of building and environment on outcomes for people with dementia”.

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HDRC, July 2014
Table 5: Which of today’s research priorities would be most important to your organisation?

<table>
<thead>
<tr>
<th>Research priority</th>
<th>Number of attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advantages and disadvantages of different models of Housing with Care schemes for people with dementia.</td>
<td>6</td>
</tr>
<tr>
<td>The effect of building and environment on outcomes for people with dementia.</td>
<td>5</td>
</tr>
<tr>
<td>Suitability of Housing with Care for people with dementia and home-for-life issues.</td>
<td>4</td>
</tr>
<tr>
<td>Communicating with people at all stages of dementia and assessing quality of life.</td>
<td>3</td>
</tr>
<tr>
<td>Cost effectiveness of housing with care for people with dementia compared to residential care and own homes in the wider community.</td>
<td>3</td>
</tr>
<tr>
<td>Care and support in Housing with Care and the effect of personal budgets.</td>
<td>2</td>
</tr>
<tr>
<td>Maximising wellbeing – voice, choice and control for people with dementia in Housing with Care.</td>
<td>2</td>
</tr>
<tr>
<td>Views of people with dementia living in Housing with Care.</td>
<td>2</td>
</tr>
<tr>
<td>Assistive technology in Housing with Care.</td>
<td>1</td>
</tr>
<tr>
<td>Staff skills and training.</td>
<td>1</td>
</tr>
<tr>
<td>learning disabilities and dementia</td>
<td>1</td>
</tr>
</tbody>
</table>

Fourteen of the attendees who completed the questionnaire stated that the membership event had been ‘very useful’; the remaining three rating it as ‘quite useful’.

Seven of those who completed the questionnaire stated that it was very likely that their organisation would seek to become more involved with the HDRC’s work in the future, five stated that it was ‘fairly likely’ and five stated that it was ‘neither likely nor unlikely’. All 17 respondents stated that they were willing for the HDRC to contact them (or the lead person in their organisation for research / dementia services) to discuss further opportunities for engagement in the future.

### 3.3 Top research priorities

Looking at both Table 1 (popularity of the research priorities as a result of the small group discussions) and Table 5 (most important research priorities to the attendees’ organisation as stated in the “next steps” questionnaire) it can be clearly seen that, for the HDRC members attending the event, the most important priority research theme from the 2009 list was: “Advantages and disadvantages of different models of Housing with Care schemes for people with dementia”. The second most important theme was: “The effect of building and environment on outcomes for people with dementia”.

In terms of the living environment, three of the table discussion groups felt that evaluating the impact of interaction with the outside community was an important research theme and two of the groups felt that examining the impact of interaction with nature was important. One group felt that these two themes are linked in that they both involve some form of social activity. In fact, the “Green dementia care” proposal acknowledged the fact that many “green”

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activities in supported housing settings, such as rambling and gardening, will be group activities and therefore have a social interaction element and, in the case of gardening, a social therapeutic horticultural approach could be taken with people with dementia.

As for the remaining 2009 research priorities, no clear order of priority resulted from the 2014 event, except it appeared that “staff skills and training” was no longer considered a priority research theme. These research themes were considered important by at least two of the small discussion groups and considered “most important to your organisation” by at least one of the attendees that completed the “next steps” survey questionnaire. “Staff skills and training” appeared to be the least important research theme, with none of the small groups considering it a top priority and only one attendee considering it important in the questionnaire. One discussion group commented that: “a lot of work has been done on this and it is now a matter of implementing what we know”. This particular group felt that this was also the case for design of the built environment, although this view is in conflict with the conclusions of the other discussion groups.

Any additional key research questions that the discussion groups wished to add are incorporated into the final list of priority research themes in the conclusions section, below.

4. Conclusions

4.1 Research Priorities

Based on the findings of this membership event and taking into consideration the broadened HDRC research remit the HDRC’s priority research themes, with associated key research questions, are listed below. The first two research themes were considered by the workshop attendees to be the highest priorities, the remaining themes are in no particular order. Any additional key research questions that the discussion groups wished to add are incorporated into this final list of priority research themes.

1. Advantages and disadvantages of different models of Housing with Care schemes for people with dementia.
   - What different models of Housing with Care (integrated, separated, specialist, hybrid, other) exist for people with dementia?
   - What, if any, are the differences between the different models in terms of quality of life and outcomes for people with dementia and their carers?
   - Integration vs segregation.
   - Does the stage of dementia on moving in affect the outcomes?
   - What is the role of background support?
   - What are the optimum staffing ratios for each model?
2. The effect of building and environment on outcomes for people with dementia.
   - There is a lot of anecdotal evidence, this needs to be formalised and the learning applied to different settings.
   - What really works; what are the key design features that impact on people with dementia and the ability to support them effectively?
   - What are the challenges of designing for people with dementia?
   - What does the Housing with Care building design specification offer as compared to sheltered housing, general needs housing and other types of accommodation?
   - What is the optimum size for a Housing with Care setting?
   - What are the effects of different building management systems (e.g. telecare, alarms) for residents with dementia?
   - Do the principles for dementia-friendly environments in care homes also apply to Housing with Care?
   - Could there be some form of kite-marking?

2a Impact of interaction with the outside community.
   - What is the impact of interaction with the outside local community on the health and wellbeing of residents with dementia in extra care / continuing care settings and on the attitude of the local community?
   - The impact of residents going out into the local community as well as the local community coming into the scheme.
   - What is the impact on members of the local community who use the shared facilities?
   - What are the benefits of a community hub and how best to make the most of the opportunities it affords?
   - What are the optimal arrangements around communal facilities inclusive of the needs of people with dementia?
   - The effect of location (urban, suburban, rural).

2b Green Dementia Care.
   - What is the impact of interaction with nature on multiple health and wellbeing dimensions for people with mild cognitive impairment / early stage dementia living in different accommodation settings?

3. Suitability of Housing with Care as compared to other forms of housing for people with dementia and home-for-life issues.
   - What are the issues influencing decisions of people with dementia and their carers to move into Housing with Care? How do people make the choice to move into Housing with Care, as opposed to other forms of housing or staying their own home? How is the decision made for people to move into, or from, Housing with Care? Who makes the
decisions? What role do factors such as capacity to give consent and deprivation of liberty play?

- Does moving to Housing with Care lead to positive outcomes, such as meeting expectations and previously unmet needs, improving health and wellbeing and enabling residents with dementia to lead active lives?
- When and why is Housing with Care indicated as opposed to residential care?
- At the point of entry to Housing with Care, is housing with care a suitable option for everyone, at all stages of dementia to move to, and if not, what are the criteria for determining that Housing with Care is an unsuitable option?
- For people already living there, as dementia progresses, does Housing with Care continue to be suitable? Under what circumstances does Housing with Care become unsuitable for an occupant with dementia? What criteria are, and should be, used to determine when this point has been reached, and what can be done to minimise the number of avoidable moves to alternative settings?
- What role does supported housing take in the journey of people from early to late stage dementia e.g. reduction of hospital admissions?

4. **Use of assistive technology.**

- How useful, acceptable and effective are various assistive technology devices in supported housing a) for occupants with dementia, b) for families, staff and management?
- Could we be smarter about how we use assistive technology (e.g. interaction with people through technology, flexible packages)?

5. **The effect of personal budgets.**

- In the context of personal budgets, what will be the impact of care and support procurement models, and service configuration and delivery, on the wellbeing of people with dementia living in Housing with Care?
- Changes from block funded schemes and contracts for those with dementia: what are the differences in contracting and what is the effect?
- What are the barriers and enablers to personalisation and to providing the necessary levels and flexibility of care in response to this group and increasing care and support needs?
- For occupants with dementia, to what extent are these mechanisms maximising choice and control within the context of the individual’s capacity and wish to exercise them, and what are the outcomes for the individual?
- Why have personal budgets not been taken up by people with dementia?
6. **Cost effectiveness of Housing with Care for people with dementia compared to other living situations.**
   - Is Housing with Care a cost-effective accommodation and care option for people with dementia and how does it compare with other living situations in terms of costs to all stakeholders, the older person’s journey and quality of life outcomes?
   - Are there opportunities to use data already collected by the NHS in terms of how often people are admitted to hospital and collate this with their living situation?

7. **Communicating with people at all stages of dementia and assessing quality of life.**
   - What are the most effective methods and tools for understanding and communicating with people at various stages of dementia, and various backgrounds, in different accommodation and care settings?
   - What are the best methods and tools for assessing the quality of life of people with dementia in different accommodation and care settings?

8. **Views of people with dementia living in different accommodation and care settings.**
   - What are the post occupancy views of people with dementia living in different accommodation and care settings?
   - How do residents who do not have dementia feel about those that do?

9. **Maximising wellbeing – voice, choice and control for people with dementia living in different accommodation settings.**
   - How do staff ensure that people with dementia have their voices heard and are empowered to engage with the community and exercise choice and control as far as possible so that they feel they belong and experience high levels of wellbeing?
   - How do staff balance risk taking, autonomy and self-determination with protecting individuals from harm, and if someone needs to be deprived of their liberty in their own best interests, what steps are being taken?

The “oven ready” project proposals fall within these research priorities (the effect of building and environment on outcomes for people with dementia), therefore the project teams will continue to seek funding for these research projects.

It was felt that priorities 7 and 8, being themes that would add value to a proposal, need to underpin all of the other research themes – seeking the views of people with dementia using appropriate methods of communication must be incorporated into every research project that the HDRC is involved in.
4.2 Expanding the in-house research

We would like to expand on the in-house small-scale case study and apply the research at a larger scale across a broader range of accommodation and care models from within the HDRC membership via an online survey. This will enable us to build a more comprehensive understanding of the current state of provision for people with dementia within Housing with Care and provide a valuable baseline for future research activities. A brief plan for a 4 month project was drawn up at the end of 2012 and emailed in a call to all HDRC members to contribute to the cost. The call was unsuccessful, yet this piece of work need not cost a lot and is ideal for funding from the HDRC membership. The steering group is now exploring ways to fund this valuable research.

4.3 Next steps for the HDRC

The issue of housing and support for people with dementia was clearly important to those HDRC members who attended the event. It appears that the primary incentive for belonging to the HDRC was that, due to a growing business need for evidence around ‘what works’ for people with dementia, organisations were looking to collaborate and learn from one another rather than carry out their own ‘in-house’ research.

For those HDRC members that attended the event, the most popular method for more effectively involving the broader membership in the HDRC’s developing work programme would be for the steering group to hold an annual event to share learning and set research priorities. Such an event would provide member organisations with an update of the HDRC’s research and other activities and also enable those organisations to share their learning with each other, with respect to housing and support for people with dementia. Judging from the success of the May 2014 event reported in this document, such events would be well-received and useful to member organisations. The “next steps” survey results showed that attendees certainly found the May 2014 event useful, were keen to become more involved with the HDRC’s work in the future and would take positive messages back to their organisations with respect to opportunities for research and learning. Receiving regular newsletters by email was also a popular means of engaging the broader membership among the event attendees. There is a members’ newsletter on the HDRC website, which is updated monthly; consideration should be given to sending out regular reminders to members to check the website and / or to emailing a quarterly newsletter to members.

After the membership event, the HDRC steering group met in order to follow up on all aspects of the event including considering all feedback from the day on the research priorities, ideas for more effectively engaging the broader membership and how best to pursue individual offers of involvement. The steering group made the following decisions:
• It would be useful and prudent to consult service users concerning their research priorities to determine the level of agreement with the priorities resulting from the membership workshop and whether they have any additional research themes that they would like to see addressed. Under the guidance of the Alzheimer’s Society (represented on the steering group) it may be possible to achieve this via a series of focus groups with people with dementia and their carers living in various housing settings.

• Once the research themes that are priorities for both the HDRC membership and the service users have been established, the steering group will then discuss how much work each key research question requires and which projects the HDRC could feasibly do itself, with help from membership organisations.

• In terms of improving engagement of the broader membership, the steering group has decided to take on board the popular activity of holding an annual members’ learning and best practice exchange event. Such an event would be costly for the HDRC, but should be possible if the venue were provided by one of the member organisations.

• The steering group will also give serious consideration to other methods of involving the wider membership suggested by the events’ attendees, such as articles in membership organisations’ newsletters and websites.

References


Appendix A:
HDRC event - 'Next steps' survey

We'd like to find out how the HDRC can work with your organisation and involve you more actively in our future research programme. Please take a few moments to complete these questions before you leave today.

Q1 What type of organisation do you represent?
Housing association .......................................................... □
Local Authority .............................................................. □
Academic institution ....................................................... □
Representative body ........................................................ □
Charity ........................................................................... □
Other ............................................................................. □

Q2 Does your organisation already carry out its own research into housing and care models for people with dementia?
Yes .................................................................................. □
No ................................................................................... □

Q3 If YES, please tell us a bit about the type of research that your organisation is already carrying out or involved with? (e.g. service evaluations, action research, exploration of dementia friendly environments, customer surveys)

__________________________________________________________________________________________________________________

__________________________________________________________________________________________________________________

__________________________________________________________________________________________________________________

__________________________________________________________________________________________________________________

Q4 How important an issue is housing and support for people with dementia in your organisation now?
Very important ................................................................... □
Quite important ................................................................... □
Not really important .......................................................... □
Not at all important ........................................................... □

Q5 Which of these statements best matches the aspiration for carrying out research on accommodation and care for people with dementia for your organisation?
There is a growing business need for my organisation to research the accommodation and care needs for people with dementia and we are planning to carry out our own programme of work................. □
There is a growing business need for evidence around 'what works' for people with dementia and we are looking to collaborate and learn from other organisations rather than carry out 'in-house' research........ □
We already have an in-house programme of work but are exploring opportunities for collaboration and partnership .................................................. □
We have our own in-house projects on this topic and are not looking for broader collaborations at present.......................................................... □
It is an interesting area but not a current priority, though this may change in future ...................... □
None of the above ............................................................ □

Q6 We are keen to establish the best ways to involve our broader membership in the HDRC's developing work programme. Please indicate your level of agreement with each of the following statements. "I am interested in...."

Becoming a core steering group member (paying an annual membership fee)

Very interested □ Fairly interested □ Neither □ Not really interested □ Not at all interested □ Don't know / can't say □

Dr Julie Barrett
HDRC, May 2014
Contributing to funding key pieces of work carried out by HDRC which fit with my organisation's priorities
Attending an annual HDRC event to share learning and set research priorities
Being involved in future HDRC research through offering case study sites or similar
Sharing learning from my organisation with the wider HDRC network
Receiving regular newsletters by email on the HDRC's work
Receiving general updates on relevant research findings

Q7 What other ideas do you have for how the HDRC can actively involve its wider membership?
_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________

Q8 What key messages from today will you be taking back to your organisation?
_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________

Q9 Which of today's research priorities would be most important to your organisation?
_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________

Q10 How useful have you found today's event?
Very useful .......................................................................................................................... □
Quite useful ...................................................................................................................... □
Not really useful .............................................................................................................. □
Not at all useful .............................................................................................................. □

Q11 How likely is it that your organisation will seek to become more involved with the HDRC's work in future?
Very likely ....................................................................................................................... □
Fairly likely ..................................................................................................................... □
Neither likely nor unlikely ............................................................................................. □
Fairly unlikely ............................................................................................................... □
Very unlikely .............................................................................................................. □
Can't really say ............................................................................................................. □

Q12 May we contact you (or the lead person in your organisation for research / dementia services) to discuss further opportunities for engagement in future
Yes ................................................................................................................................. □
No ............................................................................................................................... □
Q13  Your name
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

Q14  Email / phone number
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

Q15  Who is the lead contact person on dementia services research and development in your organisation?
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

Many thanks for completing this questionnaire. Your feedback is a valued contribution to taking the work of the HDRC forward. Please hand the form to Julie or Sarah before you leave today.