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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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 Summer 2013 the steering group took the decision to broaden the HDRC’s original research remit (what works for people with dementia living in Housing with Care settings) to include other types of accommodation and care arrangements available to people with dementia.

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.

2. The workshop

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. 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.

2.2 “Next steps” survey

Attendees 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.
3. Results

3.1 Reviewing the research priorities

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. 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”. Table 1, below, lists the 2009 priority research themes in order of popularity as a result of the group discussions at the May 2014 event.

Table 1: Research priorities popularity (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>

The steering group also presented their plan to expand the HDRC’s in-house small-scale case study, “Provision for people with dementia within Housing with Care: Case studies from HDRC Steering Group Providers”, by applying the research at a larger scale across a broader range of accommodation and care models. The aims being to 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 received favorably by the workshop delegates.

3.2 “Next steps” survey

Seventeen questionnaires were completed; representatives from housing associations formed the largest portion of the respondents.
3.2.1 Research into housing and support for people with dementia

Eleven of the attendees that completed the questionnaire stated that their organisation carried out research into housing and care models for people with dementia. The types of research being carried out 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.
- 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’. The most common aspiration for carrying out research on accommodation and care for people with dementia 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.

3.2.2 Involving the broader membership

The most popular means of involving the broader membership were (in order of popularity):

- “Attending an annual HDRC event to share learning and set research priorities”
- Sharing learning from my organisation with the wider HDRC network” and “receiving regular newsletters by email”
- “Receiving general updates on relevant research findings”
- “Being involved in future HDRC research through offering case study sites or similar”.

The least popular methods of involvement were those that required a financial commitment: “becoming a core steering group member” and “funding key pieces of work carried out by the HDRC” (4 attendees each).

Additional ideas 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?” It can be seen from Table 2 that, as with the small group discussions,
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”.

Table 2: Which of today’s research priorities would be most important to your organisation?

<table>
<thead>
<tr>
<th>Research priority</th>
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<tr>
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</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.

4. Conclusions

4.1 Research Priorities

It is clear that, for the delegates at this membership event, the top priority research theme was “Advantages and disadvantages of different models of Housing with Care schemes for people with dementia”, closely followed by “The effect of building and environment on outcomes for people with dementia”. Taking into consideration the findings of both the small group discussions and the “next steps questionnaire”, for the remaining 2009 priority research themes, there was no clear order of priority, except it can be concluded that staff skills and training no longer appears to be a priority theme.
Based on the findings of this membership event and taking into consideration the broadened HDRC research remit to include not only Housing with care but other forms of accommodation and care available to people with dementia the HDRC’s priority research themes, with associated key research questions, are listed below. 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?

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.
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.

- 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 will be given to sending out regular reminders to members to check the website and / or to emailing a quarterly newsletter to members.

- 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.