Boundaries of roles and responsibilities in housing with care schemes

Viewpoint
Informing debate

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Commissioning and delivering housing with care (HWC) services can be complex. Different organisations provide a range of services while external agencies guide, regulate and inspect what they do. Since residents' quality of life can be affected by the way in which these diverse organisations work together, clarity over boundaries, roles and responsibilities is likely to be crucial.

Key points

- There is no single model of HWC. Individual dwellings and schemes vary enormously in size and scale, location, services and cost; they are run by private companies and not-for-profit housing associations and charities; and there are significant variations in provision and policy context across the UK.

- Contested roles and responsibilities in HWC concern issues around:
  - decisions to move in and allocations (and the different perspectives of older people, their families and external agencies, especially those with nomination rights);
  - the different expectations residents, families, providers and professionals have of HWC;
  - buildings and facilities provision, management and maintenance, health and safety;
  - promoting well-being and preventing exclusion of frailer residents;
  - safeguarding and duty of care;
  - managing increasing care and support needs;
  - whether HWC offers a 'home for life'.

- There may be contests between key players over these issues. The interactions between two, three or more of these areas can also create challenges, grey areas and the need for balancing acts.

- Contested roles and responsibilities also link to a number of cross-cutting themes, which include:
  - regulation, complaints, user consultation and involvement;
  - rights, mediation and advocacy;
  - equality and diversity;
  - costs and affordability.

- Further research in 2011 is expected to produce a final report and Findings, and a Guide with examples to inform providers and others, all in 2012.

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An introduction to housing with care

HWC schemes include:

- extra care or very sheltered housing;
- retirement villages;
- assisted living and close care models;
- rented, shared ownership and leasehold tenure;
- private, housing association and charitable providers.

HWC aims to combine the best of both worlds for older people, offering them:

- the privacy and independence of their own front door and home within a safe and secure setting with a range of facilities;
- help and support, personal care, companionship and social activities as and when they are needed (with security and care usually available round the clock).

HWC is quite distinct from other forms of housing (including sheltered housing) because of the care provision, but it is also different from residential care. It is 'housing first'. Older people have legal rights as tenants or owners. Housing rights give tenants and owners security of tenure (within the terms of their tenancy agreement or lease) and the right to control who enters their property. In contrast, people in residential care and nursing homes are legally licensees so can be asked to leave at short notice.

The idea is that HWC should be 'my own home', not a care home.

Whilst the concept of 'home' is important to people of all ages, research on older people and housing show that in later life, memories and possessions accumulated over many years may become even more important (Sherman and Dacher, 2005; Heywood, *et al*., 2002; Benjamin, 1995). Going into 'care' can mean a loss of that sense of 'home'; HWC offers an attractive alternative.

> 'I do like the fact that we've got our own front door, and you can shut it, if you want to.'
> Very sheltered housing resident in Evans (2007)

There is no single model of HWC. Both individual dwellings and schemes vary enormously: in size and scale, location, services and cost (rent level, purchase price, charges). Providers may be private companies or not-for-profit housing associations and charities. There are significant variations in provision and policy context between the four nations of the UK.

An essential early task of the project was to establish a working definition of HWC in order to select a range of schemes for our study. The Elderly Accommodation Counsel (EAC) provides details of a total of 1,257 extra care and assisted living schemes on its HousingCare website across the UK. However, providers choose their own categories and a closer look at individual scheme details reveals that only around half provide the facilities and activities necessary to meet the criteria for our research:

- on-site care team;
- 24/7 staff cover (i.e. more than community alarm service);
- availability of some meals, usually in an on-site restaurant;
- social and leisure activities and facilities.

The Joseph Rowntree Foundation (JRF) *Better Life* programme has identified the key role of HWC in supporting and sustaining older people with high or increasing support and care needs. This is one of three current JRF research projects on HWC (http://www.jrf.org.uk/work/workarea/housing-with-care-older-people).

This *Viewpoint* introduces and explores some initial findings from the first few months of a new study into HWC schemes. It considers the roles and responsibilities of different organisations involved in HWC schemes, and their impact on quality of life.

Introduction to roles, responsibilities and boundaries in housing with care

Commissioning and delivering this mixture of housing and care can be complex. Often there are different organisations providing a range of services: care, support, leisure, meals, housing (management and maintenance) and other services. External agencies (local authority social care, housing and other departments; health services; other regulatory authorities) are also likely to have different roles: strategically, commissioning, safeguarding, or inspecting.

Who are the key players with roles and responsibilities within housing with care?

- older person (and partner/spouse);
- family/friends/professional advisers (involvement may be informal; or formal via Enduring or Lasting Power of Attorney (EPA or LPA), or Independent Mental Capacity Advocate);
- housing provider (landlord/freeholder);
- housing management provider;
- housing maintenance provider;
- care provider;
- support provider;
- catering provider;
- other providers (e.g. voluntary agency coming into scheme);
- commissioners and funders: local authority (Housing; Social Services; Supporting People); health;
- health services (e.g. GPs, community health services, hospital discharge or end-of-life);
- DWP (because of effect of changes to resident income via benefits);
- organisations with regulatory role (because of statutory responsibilities e.g. local authority for safeguarding and some buildings matters; Fire Service) and for complaints (e.g. ombudsman);
- advice organisations and advocates (e.g. Age UK, FirstStop, IMCAs).

Residents' quality of life can be affected by the way in which these diverse organisations manage to work with them, their families and advisers to tackle the inevitable problems that arise. For all parties, clarity over boundaries, roles and responsibilities is likely to be crucial. Local authority commissioners and not-for-profit providers tell us that partnership agreements should ideally be established at the commissioning stage, and again as services are tendered and perhaps re-tendered. There should be an evolutionary process with commissioners and providers working together to ask the right questions, establishing an 'audit trail' of decision-making, clarifying issues and developing strong partnerships and mechanisms such as operational procedures.

The impact on people with high support needs is likely to be even greater than for other residents. At risk of sudden or undesired moves to residential or nursing care, seamless care and support are essential to their well-being. Without help they may fall into the gaps between services; have to repeat their story or request to lots of different professionals; and not know what to expect and how to complain, a risk which becomes more difficult and more stressful for those residents who have a sensory, cognitive or learning disability. This is particularly so for those who do not have people to co-ordinate and advocate on their behalf or those who do not speak or read English well.

We have reflected on the perspectives of older people living in – or considering a move into – HWC (and their families and friends). Previous research and our early findings suggest that most will expect HWC to offer quality of life, and to meet their needs until the end of their lives. We have identified a number of possible uncertainties around going into and remaining in HWC.

The older person's perspective: key uncertainties about housing with care

Can I afford to stay here?

What happens if…..

- …my care needs increase?
- …my income goes down, through changes to benefits, occupational pensions or interest rates?
- …the costs go up more than my income (housing costs, care and support, other costs such as council tax …)?
- …my savings run out?

Will I be able to get the care I need?

What happens if…..

- …I do not agree with the assessment of my care needs?
- …I want different types of care and support?
- …I cannot afford to pay for my own care?
- …I want to choose a different care provider?

Will the scheme stay the same?

What happens if…..

- …the provider does not maintain the same standards and facilities?
- …the provider does not maintain the same level of support?
- …the provider changes?
- …the mix of residents changes?

Will I be able to stay here until the end of my life?

What happens if…..

- …I need to move to hospital or a care/nursing home?
- …I want to stay but others say I need to move?

What are the contested 'roles and responsibilities' in housing with care?

In the remainder of this paper, we identify some of the key contested roles and responsibilities that have emerged so far. The points made here are exploratory and will be developed further in the final report and to inform a Guide for providers.

Scenarios

First, we present three short scenarios which illustrate some of the contested roles and responsibilities in HWC and their impact on older people (especially those with high or increasing support needs). These include care and support issues, as well as more practical matters concerning HWC facilities.

We will then link these scenarios to some of the key contested roles and responsibilities we have identified.

Scenario 1: Facilities at housing with care schemes: car parking

Both previous research and our own knowledge of HWC confirm that car parking can be a contentious issue at schemes (Croucher, *et al*., 2007, Croucher and Bevan, 2010) and an important issue for older people (NHF, 2010b). If a scheme is designed with insufficient car parking spaces, whose responsibility is it to resolve matters?

Parking problems can result in:

- tensions between residents and their visitors;
- difficulties for paid carers and support staff coming on-site (especially if visiting staff numbers increase where residents are using individual budgets for external agencies);
- challenges for those working at or delivering to on-site facilities, such as restaurants, gym/spa, hairdressers, shops, etc.;
- concerns from residents about too many 'outsiders' taking up parking spaces, and perhaps exacerbating opposition to external use (examples in the literature include attendees at a day centre, a GP surgery, and social events or facilities open to older people in the wider community, and community health staff based at a HWC scheme). This can then lead to tensions between partner agencies, especially if wider use of the scheme is part of the local or health authority strategy;
- disputes between the housing/other providers and the planning authority; leaseholders are especially reluctant to give up their cars, even though planners expect less demand for car parking spaces amongst older people;
- arguments about how costs should be met if more car spaces have to be provided later: possibilities include the housing provider using their own funds; other partners contributing if there is excess demand from another facility on the site; residents paying, but this will depend on the detail of the tenancy agreement or lease (for example, some providers charge a rent or capital charge for a designated car parking space at the outset when a flat is purchased).

Older people with increasing or high support needs may be especially affected even if they are no longer driving themselves. They may be more reliant on visitors and care staff. Wheelchair users will find it more difficult (especially on a large site) if a shortage of spaces causes careless parking which impedes access to their home or to on-site facilities such as the restaurant.

Scenario 2: Moving on and end-of-life

Initial findings suggest that there may be particular challenges for boundaries, roles and responsibilities with respect to residents with increasing care needs and/or decreasing mental capacity. The following scenario is adapted and abridged from Vallelly, *et al*. (2006).

Moving on and end-of-life

An 87-year-old woman, who had been diagnosed with dementia, moved into a part sheltered and part extra care scheme. She had been referred by social services and moved in due to health reasons and so she could be closer to and receive support from her family.

She was subsequently diagnosed as terminally ill from cancer, and thought to have only a few weeks to live. The local authority which funded her care was now keen to refer her to a hospice so that she would no longer be funded from social care budgets but would transfer to 'continuing care'. Continuing care funding should be available in any living environment and is not limited to care homes or hospices so there had been some confusion about the application of this policy.

The resident's family, her GP and the HWC scheme manager all felt that an enforced move was against her best interests and were fighting to maintain her in the scheme, which she considered her home, until her death. Though her physical health had declined rapidly, her care plan had recently been reviewed and increased from 11 to 14 hours of care per week. Palliative care was on standby from Macmillan nurses. Her mental state and quality of life had improved since she had moved in and she preferred to be at home as much as possible.

The scenario above was set in social rented HWC provided by a housing association. We assume that the resident had limited capital and a low income and that her care costs were met in full by social services, so the tensions were between the provider, the resident's family and the GP (all arguing for her to stay) and the funding authority.

Assuming there was a question over mental capacity because of her dementia, would this have affected boundaries, roles and responsibilities, with family members formally involved through an EPA or LPA? What if there had been family disagreement, or no family? What if an Independent Mental Capacity Advocate (IMCA) had been involved?

Things might have been different again had she been fully or partially self-funding and her capital was already running down: maybe family members would have preferred a move to continuing care, paid in full by the NHS, to preserve her capital for their inheritance. What if she had been a leaseholder, perhaps in a private retirement village – would that have made a difference to the boundaries of roles and responsibilities, and the outcome? What if the continuing care funding was to have been available to pay for care in a nursing home on site, owned by the same provider – would that have influenced the decision-making process?

Scenario 3: Resident mix

The following scenario comes from an initial discussion with a provider and a commissioner. It also reflects research findings about male tenants being at risk of greater isolation, as well as more general discussion on the promotion of well-being and inclusion of more disabled residents (see, for example, Callaghan, *et al*., 2009; Evans and Vallelly, 2007). Tensions between the provider and the local authority over nomination arrangements and managing increasing care needs can affect all residents. In this scenario, we focus on the effect on male residents – which links to our cross-cutting theme of equality and diversity.

Resident mix

Five older men moved into a new HWC scheme. They enjoyed doing 'men things' together, like watching sport and doing small DIY tasks. Over time, nominations arrangements changed. As existing residents grew frail, new arrivals were more disabled. Eventually there was only one active older man left. He was frustrated about having no male company amongst residents, compounded by most of the staff being female. As a result of this and other complaints from residents, the housing provider is now negotiating with the local authority about the care needs of new nominations.

The challenges here were how to meet the needs of a minority group – in this case active males – whilst maintaining a constructive relationship between commissioner and providers (of housing, care and support).

This scenario is set in social rented housing, and the male resident appears to be active and (we might assume) in good health. But he might have had mental health problems, exacerbated by his isolation, which could bring him into the *Better Life* category of increasing support needs. As in the end of life scenario above, it is also possible that there is an EPA or LPA in place, or IMCA involvement. Any would have an effect on decisions to stay or to move elsewhere, and on boundaries of roles and responsibilities.

We can assume that the male resident, though unhappy, tried to change things through the complaints process – voice – rather than by leaving – exit (Hirschman, 1970). But again, as in the end of life scenario, what difference would it have made if he had been self-funding as a leaseholder (or indeed renting at a market rent)? Would he have preferred to take the exit option, moving to another HWC scheme where residents had lower dependency levels, or to leave HWC altogether for a different form of housing? Clearly his capital and income would affect his choices, an aspect that we will be exploring in more detail in our parallel study on affordability in housing with care. Any decision would also affect the boundaries of roles and responsibilities between the different parties.

Introducing our emerging variables and contested areas

Through our preliminary discussions, literature review and previous research on HWC, we have identified:

- variables likely to affect the boundaries between roles and responsibilities and the mechanisms for partnership;
- a number of areas around which roles and responsibilities tend to be contested.

We intend to explore these further through our fieldwork and analysis.

Variables affecting boundaries include factors relating to:

- the national external context;
- the local external context;
- the internal management context for HWC providers (and their partners);
- the characteristics of the residents.

Areas around which roles and responsibilities tend to be contested include:

- decisions to move in (residents and families), nominations and allocations (professionals);
- different expectations of HWC (residents, families, different professionals);
- buildings and facilities provision, management and maintenance, health and safety;
- promoting well-being, preventing exclusion of frailer residents;
- safeguarding and duty of care;
- managing increasing care and support needs;
- moving on and end-of-life: is HWC a 'home for life'?

We present some of our initial thoughts and findings on these variables and areas in a later section. There are also a number of cross-cutting themes, including regulation, rights, equality and affordability, which we set out below.

We are finding that it tends to be the interactions between two, three or more of these areas that create the challenges, grey areas and balancing acts. For example, in the 'Resident mix' scenario, there were tensions between nominations/allocations, promoting well-being and managing increasing care and support needs, and around the expectations of residents.

We are keen to ensure that the views and experiences of older people with high support needs (and their family and friends) are central within this project. For each issue, we will – in our fieldwork and, as far as we can, in this paper – be considering:

- How older people and their families/friends/carers view these contested roles and responsibilities?
- What their expectations are and whether and how they diverge from those of the professional stakeholders?
- How the contested responsibilities and good practice in establishing good partnerships impact on older people and the uncertainties we outlined earlier.

In the following table, we identify the key players and issues – the contested roles and responsibilities – in our three scenarios:

	Car Parking	End-of-life	Resident mix
Housing: Landlord	✓ Lease/tenancy, land owner (e.g. finding site for additional car parking)	✓ Tenancy/lease, housing rights	✓ Nominations, relationship with commissioner/funder
Housing: Management/ Maintenance	✓ Resident disputes, complaints	✓ Supporting tenant and family	✓ Resident complaints, role of activities co-ordinator?
Support	✓ Affects visiting staff	✓ Supporting tenant and family	✓ Inclusion of male tenants
Care	✓ Affects visiting staff	✓ Increased care, assessment that tenant should stay	✓ Well-being of male tenants
Catering and other facilities	✓ Affects demand from customers (could even affect financial viability). Affects staff, and possibly deliveries		✓ Change of dependency levels could affect levels of demand (and even financial viability)
Other, e.g. voluntary agencies	✓ e.g. outside use for day centre, LA Planners	✓ Palliative care arranged from Macmillan nurses	✓ e.g. potential for voluntary agency to run men's group
Commissioners, funders	✓ If strategic objective for HWC e.g. outside use of facilities, day centre, GP surgery	✓ Cost-shunting to health	✓ Nominations
Health	✓ e.g. GP surgery, could affect visiting health staff	✓ Potential continuing care funding	

Cross-cutting themes

A number of themes are emerging which cut across the areas identified above:

- regulation, complaints, user consultation and involvement;
- rights, mediation and advocacy;
- equality and diversity;
- costs and affordability – both residents' personal finances and organisational budgets.

The following table identifies how the three scenarios link with these cross-cutting themes. We will then present our initial thoughts about each of these themes below.

Issue	Equalities	Cost and affordability	Residents' rights, regulation, complaints
Car parking	✓ Especially residents with high care needs and/or wheelchair users	✓ Cost to improve or to increase car parking	✓ Can lead to complaints. Cost issues may relate to tenancy/lease
End-of-life	✓ Cognitive impairment, terminal illness	✓ LA budget for care	✓ Security of tenure, right to care funding
Resident mix	✓ Needs of male tenants	✓ LA budget for care	✓ Did lead to complaints

Regulation, complaints and user consultation and involvement

The regulatory landscape is important and links to complaints and questions over where responsibility lies. This was also a problem for residents and their supporters in sheltered housing in our previous 'Nobody's Listening' project (King, *et al*., 2009). In England, housing association 'registered providers' are required to have a formal complaints process which ends with the housing ombudsman. This is also covered in the Ten Standards for accreditation by the Centre for Housing and Support Code of Practice (CHS, undated) which includes specific rented and mixed tenure housing with care (but not leasehold-only schemes). We are not aware of a similar requirement for private HWC providers, although a complaints process is advised by industry bodies: see ARHM (Association of Retirement Housing Managers) 2000, 2005, 2009 and 2010, and ARVO 2008. In this study, we also aim to explore how the new health and social care arrangements for joint working on complaints are working with respect to HWC, as well as the role of the housing ombudsman (Age UK, 2010).

We are also interested in positive mechanisms which older people and their supporters can access in order to effect change within HWC. This can be collectively, such as resident consultative mechanisms and resident management committees (see, for example, Hanover, 2009; Croucher, *et al*., 2003) and individually, through mediation, advice and advocacy schemes. We are conscious that since the election of the Coalition Government, changes are under way in England, such as the abolition of the Tenant Services Authority and the transfer of regulation to the Homes and Communities Agency (with a 'lighter touch') (NHF, 2010a). We will be interested to find out more about the impact of changes and cuts in this area. On a positive note, in response to the demise of the Tenant Services Authority, the Joseph Rowntree Housing Trust (JRHT) is in the process of developing 'resident inspectors' who will contribute to the process of continuous service improvement and service scrutiny within the organisation by providing evidence-based, objective assessments of service areas from the customer's perspective.

Rights, mediation and advocacy

JRF's *Better Life* Programme is underpinned by 'a commitment to sustainable, rights-based approaches'. However, the question arises as to how to balance a rights-based approach with a responsibility for protecting those who are unable to protect themselves, or whose capacity to exercise rights is limited due to frailty.

HWC residents (unlike those living in residential or nursing care) have housing rights, which clarify responsibilities, such as those relating to repairs and maintenance, and set out legal duties, such as that of housing providers to supply tenants and leaseholders with clear information on service charges, budgets and expenditure. All HWC providers should be working within the legal framework of housing rights. However, we believe that there are examples of poor as well as good practice, such as providers trying to increase service charges without following the terms set out in the lease agreement or questionable practice on hospital discharge, where tenants and their families have been persuaded to give up tenancies without understanding their housing rights (personal communication from advice agency, September 2010).

Older people often do not know their rights, or even which organisation is responsible for which aspect of their housing or care or support services. This was a key finding in recent research in sheltered housing, where residents had great difficulty in protesting about changes (King, *et al*., 2009), and led to new good practice materials (Hasler and Davis, 2010). Even when they know their rights, enforcing them can be emotionally draining and time consuming. This can be particularly difficult for older people with high support needs, for those without family support, for those with disabilities or communication issues and for those who are disadvantaged in other ways (King and Pannell, 2010; Blood, 2010; Pannell and Blood, 2008).

Much of the work done to support older people therefore relies on mediation and advocacy, looking at needs, conflict resolution and problem solving. Legal rights, formal complaints mechanisms and security of tenure can provide important leverage for mediators and advisers to negotiate solutions with housing providers. Without housing rights, it can be easier for providers to ask a resident to leave rather than put resources into resolving matters.

Equality and diversity

Older people from different social groups may encounter greater or different barriers as they seek to complain, enforce their housing rights, or argue for their increasing care and support needs to be met. In fact, 'equality and diversity' is likely to be relevant to each of our emerging themes. As we saw in the 'Resident mix' scenario, there can be particular issues for residents who represent a minority within a scheme, whether on account of their gender, race, religion, sexual orientation or social class.

'Promoting well-being' will mean different things to different people and the types of activities residents would like to do, the places they would like to visit, or the people they would like to mix with may be influenced by one or more of the above characteristics. 'Safeguarding' must include ensuring residents are safe from discrimination from other residents, their visitors, staff and members of the public. 'End-of-life' wishes will be shaped by religious and spiritual beliefs (or lack of them) and whether or not HWC or other alternatives, such as care or nursing homes, can meet these. If the woman in our case study was, say, Jewish and her current HWC scheme met her religious needs particularly well, the impact of a move at the end of her life might be even greater.

These issues are discussed in more depth in King and Pannell (2010) and in Blood and Bamford (2010), and we will be working to the recommendations of the latter report to ensure that our study promotes equality and diversity. For example, we will ensure that we seek the views of diverse older people (and monitor participants' social identity to ensure this); and will reflect in our analysis and final outputs on how different aspects of their diversity might affect their expectations, experiences and outcomes.

Costs and affordability

This links to the parallel study we are undertaking for JRF on 'Affordability, choices and quality of life in housing with care' (http://www.jrf.org.uk/sites/files/ jrf/better-life-2011-2012.pdf). This project will examine the affordability of HWC for residents and the impact on their quality of life. It will focus on residents who are fully or partially self-funding, or who hold personal budgets, and have increasing or high care and support needs. Costs and affordability in HWC are complex and significant (Institute of Public Care 2010): they will depend on contractual and financial arrangements with social services for care funding; liaison/partnership with NHS services; and assessment processes (if care needs change). Some of the resulting problems of cost-shunting were exemplified in the end of life scenario, and are also discussed in Baumker, *et al*. (2008).

Variables and areas of contest: our initial thoughts and questions

In this section, we return to consider briefly each of the areas of contested roles and responsibilities which we identified on page seven. In the following and penultimate section, we will begin to reflect on how our proposed variables (national, local and internal contexts and resident characteristics) might shape the type of contests, the impact they have on residents, and the potential solutions.

Decisions to move in, nominations and allocations, and different expectations of HWC

Differing (and perhaps conflicting) expectations about roles and responsibilities can create problems: from professional stakeholders (commissioners and providers) of each other; and from older people and their informal carers about facilities and services.

Those considering a move into HWC, and their family and friends, may have very different expectations regarding the level of care needs that could and would be met within the scheme. As Croucher and Bevan (2010) found in their study of the JRHT retirement village at Hartfields, 'some residents with care needs were given unrealistic expectations of what care services … would offer them'. As part of our research we will also be examining a case study where residents felt that their scheme was no longer 'their home' but was becoming like an institution due to the large number of older people with high support needs.

Conflicting roles and responsibilities are at work here, and these will differ by sector. In not-for-profit HWC, there is pressure on HWC providers from commissioners to house more people with high care needs (the 'frail') (Baumker, *et al*., 2008, and also raised with us by providers). If nominations are made regardless of overall care and support needs (including existing residents with increasing needs), there is a risk that HWC will 'feel like' an institution. Yet, is it right that allocations be determined by a care perspective, when HWC is supposed to be 'housing first'?

In contrast, for private HWC, there are no nominations. Local authorities encourage private developments at a strategic level but private providers have to sell a 'product' and in a difficult market (McCarthy, 2009). Older purchasers will have their own expectations: advertising focuses on active retirement for fit, healthy people. However, new purchasers may move in when fit and healthy but over time their needs will change. What happens then?

As Croucher and Bevan (2010) conclude, the different ethos and styles of housing management and care management 'need to be synthesised' and complemented by neighbourhood and community engagement skills if 'future expectations of the scheme' are to be successfully managed.

Buildings and facilities provision, management and maintenance, and health and safety

The housing provider has legal responsibility for physical safety through the tenancy or lease. Responsibilities include: repairs and maintenance, safety checks and servicing such as gas appliances and lifts. Scheme design is also a factor and because HWC is a relatively new concept, there has been less opportunity to learn what works and to design out problems, although the body of evidence is growing, especially through a range of publications by the Housing Learning and Improvement Network (LIN).

Managing and maintaining the buildings and site services in a HWC scheme is very different from either ordinary or sheltered housing. Some providers have built up this experience; for others they will be managing their first HWC scheme. Where residents have high support needs, the consequences of something going wrong are much greater. Facilities such as swimming and hydrotherapy pools and gyms will need specialist attention.

Managing access to facilities and balancing health and safety concerns against residents' needs and desires can be complex: we have already come across boundary issues in both previous research (as in Evans and Vallelly, 2007) and in discussions with providers. For example, on some schemes, gym equipment, spas or swimming pools are under-used or not used at all, because of concerns about insurance cover, risk and health and safety, yet elsewhere such problems have been overcome. There can be grey areas here between the housing provider and other players which we expect to explore further for the final report and in our guide for providers. Older people and their informal supporters may have different expectations of what should be provided, as discussed above. The tenancy agreement or lease may not be as clear as it should be on responsibilities (including who pays for what, and the potential effect on residents' service charges if, for example, alterations need to be made to a facility so it can be used more safely).

Promoting well-being, preventing exclusion of frailer residents

For the HWC provider, there are also broader questions of promoting well-being and balanced, active communities, and fears over exclusion of frailer residents. These issues are also being explored in other parts of the JRF *Better Life* programme, (http://www.jrf.org.uk/work/workarea/better-life) including 'Living together, getting along' and 'Not a one-way street'.

Resident and staff perceptions could either encourage or minimise the risk of marginalising residents with high support needs. This will depend on the steps taken to create thriving active communities (Callaghan, *et al*., 2009) including facilitating or encouraging 'communities of interest' (Evans and Means, 2007). Residents may also be more willing to accept neighbours who grow frailer after moving in, than new residents with high needs (e.g. Evans and Means, 2007; Percival, 2010).

Having a dedicated activities co-ordinator helps to ensure a wide range of activities to appeal to everyone, including those with high support needs. However there can still be problems. Some residents insist on not participating because that is their informed choice. As in our 'Resident mix' scenario, if the resident profile changes over time, fewer active residents may mean that there are not enough people to maintain some types of activity (and the smaller the scheme the more likely this is to be a problem).

The initiative for activities may come from residents themselves. Whilst this is to be encouraged, it can throw up challenges and grey areas for providers. For example, how far do the provider's responsibilities extend if a self-organising resident group uses communal facilities, or excludes some residents from participating, or if one resident provides voluntary support to another?

Safeguarding and duty of care

If older people are not putting themselves in danger or causing nuisance to neighbours, then from the housing management perspective and interpretation of their tenancy agreement or lease, they can do what they like inside their own housing. One clear exception is if there are questions about mental health, mental capacity and links to safeguarding. Many HWC providers include a minimal level of service in the service charge (e.g. a small amount of weekly help with cleaning) in order to keep an eye on the situation and maintain a minimum standard (Evans and Means, 2007).

There are potential tensions between privacy and overall well-being for the wider community. In terms of balancing individual and community needs, one respondent commented that if the support needs of the individual are met properly then this will help the community, and where there are problems it may be because care and support needs are not being met. Literature on dementia and extra care housing also discusses this (Dutton, 2009; HDRC 2010). There are no easy answers and it can be difficult to balance the duty of care with an older person's freedom of choice. In both safeguarding and duty of care issues, if there is a question of mental capacity this further complicates things: in some cases an IMCA will need to be involved.

HWC providers are worried about the extent of their responsibilities if all sorts of agencies are coming into 'their' schemes to provide support/care: a situation which may increase if residents receive individual budgets and opt out of in-house provision. The housing provider may not have a strict legal responsibility (if for example another agency does not properly vet, train or manage their staff and there is abuse). However they are still concerned for the well-being of the resident, and they have a role as 'alerter' under safeguarding. There is also the potential for damage to their reputation if things go wrong: media interest in abuse cases and the desire to blame heightens the reputation risk for the housing provider.

We look forward to exploring these sensitive issues. Ideally, agencies will work constructively with the older person, their family (if any), the housing and support/care provider(s), and health professionals to achieve a solution. We know that this does not always happen: the housing provider may be caught in the middle; or there may be disagreements between the older person, family members and professionals over what to do, as in the end of life scenario above.

Managing increasing care and support needs

In HWC, housing and care are often provided by different agencies. In theory the input of different agencies wil be determined by contracts and funding (see for example Miller, *et al*., 2007). In practice (as so often with joint/multi-agency working) it will also depend on staff relationships at all levels – front-line, middle management, senior/strategic level. We will explore this further in interviews and our survey of HWC providers to identify the extent of this as a practice issue and how these tensions are managed and resolved.

Most HWC residents will have formal or informal agreements and arrangements concerning their support and care. However we expect that as we develop this research we will find that for support and care, the situation is less clear than it is for the housing element of HWC.

If a resident's increasing care needs are not being met then the housing provider can find themselves in a difficult position. If, from a housing rights perspective, this is likely to result in a potential breach of their tenancy or lease (for example causing serious noise nuisance to neighbours because of mental health issues), then it may well be within the housing provider's mandate to intervene. If there is no breach of the lease or tenancy agreement, it is less clear-cut and this is an 'unknown' that we will be interested to explore further. Vallelly (2006) points out that the hospital stays of those living in HWC are shorter than average. There may be questions here about the roles and responsibilities of housing staff in co-ordinating discharge and there can be a negative impact on the older person if unjustified assumptions are made by the hospital about the level of care occupants will automatically receive within the scheme. We will also be interested to see what protocols, processes and staff training our partner HWC providers and our survey respondents have in place to address these issues, and whether there is scope to share or develop good practice materials for our provider guide.

In the case of a breach, the HWC provider can argue that the person either needs more care and support or (if the situation still continues) they will have to work with health and social services to move the person to more appropriate accommodation and care. Depending on the comparative costs of a move, or staying in HWC, this may encourage the funding or provision of more care. The situation is more uncertain in the future because of severe budget pressures for public funding. In our experience, it is very rare for cases in social rented housing to get near to eviction proceedings or the Courts and in any case possession would not be granted unless suitable alternative accommodation is available. Another unknown is how this works in practice in leasehold housing, with both not-for-profit and private providers.

Moving on and end-of-life: is housing with care a 'home for life'?

Previous research suggests that HWC is not always a home for life and that residents may have to move on if their care needs increase, especially for those who develop dementia (Dutton, 2009). As the end of life scenario reveals, this may be a funding rather than a care issue.

The tenancy agreement, lease or other documentation may include information on moving on, so housing rights are of crucial importance. For example, some private and charitable providers state that the resident may have to leave if their care needs become too high to be met within a housing setting: we hope to explore how this is dealt with in practice. There are contrasts according to tenure and between providers, and for leaseholders there can be complex financial aspects of exit and sale.

Reflections

Initial discussions have confirmed that there are lots of grey areas and issues over balancing the needs of the individual, the HWC community of residents and wider demands. The initial stage of the research has also confirmed the complexity of issues and the likelihood of differences according to tenure (leasehold or rented), funding (state- or self-funded), provider type (private sector or not-for-profit) and the other variables we identified on page seven. In this section, we reflect on these variables and some of the ways in which they may relate to contested roles and responsibilities in HWC.

National external context

Our preliminary research has highlighted a number of differences in the legal and policy context of the four nations of the UK, which are likely to be relevant to our research questions. We have summarised these in a table in the appendix to this paper. They include differences in housing law; the regulation of housing and social care; and legislation around mental capacity and vulnerable adults. As is well known, Scotland provides free personal care to older people (with some caveats); so we would expect this to affect decision-making by individual residents, their families, HWC providers and adult social care about accessing care, especially as care needs increase. It appears that personalisation is less developed outside England, so that issues such as the number of staff coming on to a scheme (as in our car parking scenario) may be less likely in the devolved nations.

It is our initial impression that the devolved governments of Wales and Scotland are more interested and involved in these debates and are tending to take a more directive approach to HWC, whereas in England the Coalition Government places more emphasis on localism. However there are also broader issues being considered by the Coalition Government: the recent Dilnot enquiry report and the Law Commission report on social care law.

Local external context

Our preliminary discussions with a range of stakeholders within HWC, including local authorities and HWC providers, have revealed a range of factors which can vary significantly at a local level and affect how HWC is provided and managed, with implications for boundaries between roles and responsibilities.

At HWC schemes where there are residents who are eligible for local authority funding, in full or part, towards the cost of care, the nature of the local authority's commissioning policies and practices can be significant. Local authorities with commissioning policies that require separation of housing and care provision will have a minimum of two different organisations involved in the management and delivery of housing and care services within a scheme. This can create tensions in terms of roles and responsibilities. Where local authorities have adopted a policy of promoting 'personal budgets' rather than commissioning and contracting for care services within HWC schemes, then a potentially different dynamic is likely to occur where residents may select from a larger number of potential care providers.

From our initial discussion with stakeholders there is evidence that some local authority commissioners are seeking to increase the numbers of people with higher care and support needs who gain access to HWC schemes, particularly as an alternative to residential care, with the aim of achieving some financial savings within local adult social care budgets. The implication of this policy is to shift the 'mix' and range of needs of individuals living within HWC towards people with higher care needs than has perhaps previously been the case, as highlighted in our 'Resident mix' scenario.

The nature of local partnerships, particularly between local authorities and health services, also varies considerably at a local level. The extent of, or lack of, partnership working arrangements at a local level can affect the experience of residents of HWC, particularly where there are very significant budget pressures, as there are currently, within local social care and health economies. In our end-of-life scenario, the process and outcome is likely to be shaped by, amongst other factors, partnership working and joint commissioning between health and social services; and the supply and availability of palliative care.

Internal management context

There is great diversity in the number and type of organisations involved in HWC schemes, across housing management, support, care, catering and other roles. Providers can be private businesses (large or small) or not-for-profit organisations (including social enterprises and charities). Some organisations have developed a group structure with separate companies for different roles. There may be differences in ethos, priorities, professional and organisational cultures, even amongst different sections of the same organisation. However, it is not necessarily the number and diversity of providers which determines whether roles and responsibilities are contested. We anticipate that what may matter more is how relationships are established (at the commissioning stage) and then managed, both formally (e.g. with protocols) and informally at all levels including – most vitally – on the frontline.

The skills, training and make-up of the workforce may reduce – or exacerbate – the incidence or impact of contested roles and responsibilities. Members of one staff group may have experience of working alongside another professional group: managers and organisational values may explicitly support a partnership approach. In-our 'Resident mix' scenario, the lack of male residents and staff may be less keenly felt if staff have had diversity training and are aware of the issues; if the organisation employs an activity co-ordinator; if an effort is made to encourage male staff recruitment; if there is sufficient vision, time and budget to link up those in the minority with others from the wider community.

The characteristics of the residents

Resident characteristics can include their tenure, financial position, the level and nature of care and support needs, a range of diversity factors, and the extent of their support networks (including whether they have a partner, or family who are involved in their care and support). Previous research on HWC identifies not only the potential for supportive communities, but also the risk of tensions between residents with different characteristics, and the knock-on effects on boundaries, roles and responsibilities and partnership working. These are generalisations and should be treated with caution but examples of tensions include:

- between leaseholders/self-funders and tenants/those supported by the State;
- between more active residents and those who are more disabled;
- between those with close family/couples and those who are more isolated/singles.

In our 'Resident mix' scenario, we saw how the diversity of residents, in terms of gender and care and support needs, can generate conflicts between key players and residents over allocations, support and activities. Tenure, financial position and diversity factors can also affect their power and influence over the way the scheme is run and the services they receive within it.

Next steps:

An overview of the study

The study focuses on the following research questions:

- What are the boundaries/fault lines of roles and responsibilities in HWC?
- What are the impacts on quality of life for older people (already living in HWC) whether they have high or increasing support needs, or no support needs?
- How far can clarity over boundaries ensure that for every resident, HWC remains 'my home' and not a 'care home'? What else is needed? What works, and what does not?
- Can a rights-based approach empower residents? Does this still work for those who have high support needs (and perhaps mental capacity issues) and how does it link to safeguarding issues?
- How do these issues change across different models/providers of HWC?
- How is quality of life affected by different expectations between residents, family, staff, providers, commissioners, regulators …?

The project runs from January 2011 to August 2012 across the UK and includes:

- Two small consultative groups, of older residents, and of providers and other stakeholders (June 2011 onwards);
- Limited and focused literature review (under way);
- A case study and visits to eight HWC schemes, to include interviews with residents, informal carers and staff (autumn 2011);
- An on-line survey of providers (autumn 2011);
- Interviews with providers, statutory organisations, experts and other relevant organisations (summer 2011-spring 2012); and
- A final conference (spring 2012).

We aim to obtain a variety of perspectives from:

- existing residents (with and without high support needs);
- their families/friends/informal carers;
- HWC providers (through the proposed survey and interviews).

and through interviews with a range of other agencies:

- care and support providers (when separate from housing provider);
- commissioners (housing, health, adult/social services);
- regulators;
- professional and provider bodies;
- older people's organisations, charities and advice organisations.

Further planned outputs, which we hope to publish in autumn 2012, include: a final report and *Findings*, and a *Guide* with examples to inform providers and others.

Our remit was to look at HWC across the United Kingdom and, since identifying key national differences through our literature review, we have developed our research design to allow greater consideration of these. We have added separate meetings with stakeholders in the four countries, and will aim to visit at least one scheme in each country.

The impact of personalisation and individual budgets (DH, 2008, 2010; Housing 21, 2008, 2009) and the different issues that arise for residents who are state-funded compared to those who are fully or partly self-funding (Henwood and Hudson, 2009a, 2009b; Henwood, 2011) are other factors of relevance to this project. We will draw from the findings of a parallel study that we are undertaking for JRF on affordability (http://www.jrf.org.uk/sites/files/jrf/better-life-2011-2012.pdf). This project will examine the affordability of HWC for residents who are fully or partially self-funding and the effect on quality of life for those with increasing or high care and support needs.

Since starting the project in January 2011, there has been great interest and willingness to take part from stakeholders (providers, commissioners, charities such as Age UK and Elderly Accommodation Counsel/ FirstStop) and agreement that the research questions are well-focused and relevant. Our consultation with a group of HWC residents is about to start.

In this paper, we have proposed what is effectively a draft framework for our forthcoming data collection and analysis. This has included variables which can affect the boundaries between roles and responsibilities (i.e. the national, regional and internal management context, and resident characteristics such as tenure and funding); areas within HWC where contests tend to be focused (e.g. safeguarding, nominations, end-of-life); and cross-cutting themes (such as equality and diversity and affordability).

In addition to exploring contested areas, we are also keen to uncover potential solutions. We hope to gather examples of good practice, particularly around the design, implementation and outcomes of protocols, formal agreements and partnership arrangements. We will review these and hope to present real examples, along with general principles, in our guide for providers. Please get in touch if you have examples to share.

The **Housing and Support Partnership** specialises in housing with a social care or health dimension. Most projects concern older people or those with disabilities. The research team consists of Ian Copeman, Jenny Pannell, Imogen Blood and Nigel King.

We would like to thank the residents, providers and other stakeholders who have already helped us with this study and those who have agreed to take part in the fieldwork phase. If you would like to contribute to the research in any way, please feel free to contact the team at: enquiries@housingandsupport.co.uk

Comparing the context in the UK – literature review summary

Theme	Key differences between the countries
Amount, type, tenure of HWC provision	Most provision in England No private provision in NI, only one private scheme in Scotland
Extent of relevant research and evaluations	Most research in England Useful study from NIHE (Boyle, 2008)
Tenancies and housing rights	Different legal system, housing law, organisations in Scotland (e.g. Land Tribunals in Scotland, Leasehold Valuation Tribunals in England & Wales for owner-occupied retirement housing)
Regulation (housing)	Different organisations and procedures
Regulation (care)	Different organisations and procedures
Recourse to independent complaints organisations	Different organisations and procedures Varies whether mandatory (housing associations or private providers)
Representative bodies, codes of practice	Different organisations for housing associations in four countries Association of Retirement Housing Managers UK-wide: separate ARHM Codes for leasehold retirement housing in England, Scotland, Wales to reflect differences in law etc
Can tenants or owners change the scheme manager, and if so, how?	Right to Manage (2002 Act) in England & Wales, or access to LVTs (owner-occupiers) Different arrangements in Scotland
Welfare Benefits and State Pensions	No differences: These are the same across all four countries (Department for Work and Pensions)
Delivering housing and social care for older people: policy, practice	NI has no clear policy on older people's housing
Personalisation: policy and implementation	Although the policy covers the UK, implementation is more advanced in England (though take-up in HWC still not widespread)
Charging for social care: arrangements	Free personal care in Scotland (though means-tested charges for other domiciliary help) Different means-tested charges in England, Wales, NI (because of different levels of the "buffer" i.e. the per cent above income support/pension credit before charges are made)
Numbers and health of older population, need for care	Significant differences between four countries
Older people's income, assets, tenure, value of owner-occupied property, per cent of population in social housing	Significant differences between four countries Note that there is also great variation within each country
Nursing care allowances	Different rates
Vulnerable Adults guidance/legislation	Law in Scotland, guidance in other three countries
Mental Capacity Legislation	AWISA 2000 Scotland; no legislation in NI; MCA 2005 England & Wales

Sources: Age Concern and Help the Aged in Scotland (2010), Bell, D. (2010), Boyle, F. (2008), Boyle, G (2010), Burholt, V. and Wandle, G. (2007), CLG (2008), Croucher, K. (2008), Counsel and Care (2010), EAC (2010), Garwood, S. (2010), Glendinning, C. and Bell, D. (2008), Welsh Assembly Government (2006), Wilcox, S. and Fitzpatrick, S. (2010)

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