

## AFFORDABILITY, CHOICES AND QUALITY OF LIFE IN HOUSING WITH CARE

This is the first study of tenants and leaseholders who are paying some or all their own costs in private and not-for-profit housing with care (HWC). It examines how affordability affects choice, and the consequences for quality of life - particularly for those with high or increasing support needs.

#### **Key points**

- Older people face many uncertainties when making decisions about moving into and remaining in HWC. Is it affordable at the outset? What if charges and care needs increase, but savings (and perhaps income) decrease? What state help is available?
- Overall, 85% (of 78 residents interviewed) were very happy in HWC. Most reported positive views across different aspects of quality of life. This was especially the case for couples: they could stay together, and partner carers received support.
- The majority of people saw HWC as good value for money, despite higher costs than mainstream housing. Some had mixed feelings and a small minority thought it poor value; residents wanted more transparency over charges and better consultation overall.
- Age and health influenced whether HWC was (and would remain) affordable: residents who were very old or in poor health thought their money would probably last (even if care needs increased); younger residents had to plan over a much longer timeframe so were more anxious. Unexpected/ unplanned changes of circumstances caused concern, especially for couples.
- Commissioning decisions by local authorities have important implications for affordability, but their main focus has been on their budgets, rather than affordability for self-funding residents.
- Claiming disability and means-tested benefits helps residents afford HWC, but more advice is needed. Proposed changes to benefits will impact on affordability of HWC, especially for people under state pension age.
- Home ownership is not necessarily the preferred option: a third of interviewees were former homeowners who were now happily renting.

#### The research

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DECEMBER 2012

# BACKGROUND

This is the first UK-wide study of the views of self funders living in not-for-profit and private HWC. Self funders are tenants and owner occupiers paying some or all the costs of their housing/care/support, including people with a personal budget.

This qualitative study examines how affordability affects choice (of care and other services) and the consequences for quality of life, especially for those with high (or increasing) support needs (i.e. mainly, but not exclusively, those aged 85+). The study is important because there are so many uncertainties faced by individuals when making choices and decisions around affordability, quality of life and value for money in HWC:

- **Can I afford to stay here?** What happens if my circumstances change (e.g. increasing costs, reduced income or savings)?
- Can I get the care and support I need? What happens if my care needs increase?
- Will my HWC scheme stay the same? What if standards, facilities or the resident mix change?
- Will I be able to stay here until the end of my life?

## What is housing with care?

HWC offers older people the privacy of their own self-contained home within a community setting, with access to care and support (usually with staff on site 24/7), company and social activities, and other facilities (e.g. restaurant). Models from not-for-profit and private providers vary greatly and have different costs. Some HWC is run independently by private companies or charities, many schemes are publicly funded.

## Paying for housing with care: costs and help

Housing costs include purchase price (leaseholders), rents (social/private tenants), service charges (all tenures) and are usually higher than mainstream housing because of the additional communal facilities. Benefits take up is important in boosting income for residents. Help for housing costs can come from means-tested Housing Benefit (tenants), Pension Credit (leaseholders) or disability benefits (Attendance Allowance, Disability Living Allowance, not means-tested). A successful claim for disability benefits can result in new (or increased) entitlement to Pension Credit, Housing Benefit, help with council tax and sometimes support costs. Private leaseholders are the least likely to get help with housing and support costs.

Turning to the additional costs in HWC (on top of housing costs) for care and support, it is impossible to generalise about charges and state help for support and care. Key issues for self funders include:

- different arrangements across the UK and whether care is free, means-tested, or a mixture;
- care and support needs assessment methods (e.g. in England under local authority guidelines); and
- different methods of charging for support and care in HWC.

## Choice and decision making: the resident journey

The study analyses resident choices and decision making, and their views on affordability, quality of life and value for money. These concepts are interlinked: decisions about whether something is affordable are partly shaped by a judgement of whether or not it represents good value for money compared to the alternatives; and partly by the impact of buying it (compared to not buying it) on quality of life.

The full report follows the 'journey' of 24 leaseholders and 54 tenants. At all stages, there were two key issues. **Family involvement** was important for most participants: initially, and continuing in most cases. The effect of **changing circumstances** for couples had important consequences for affordability. HWC was especially suitable for couples and provided a better quality of life than other settings: couples could stay together, and partner carers received support. Many interviewees took the decision to move in as a

couple; changes of circumstances (including increased care needs or being widowed) had implications for affordability.

#### Deciding to move in

The study identified various groups:

- planners, including 'careful self-funders' who made an informed decision and had more opportunity to consider costs;
- 12 unplanned 'crisis movers';
- 25 'tenure-swappers': 24 former owner occupiers who moved into HWC for social rent (and one private tenant who was letting his house).

#### Quality of life: views at the time of the interviews

Most participants reported mainly positive views on different aspects of quality of life in HWC, including:

- social interaction, getting out and about, cultural and physical activities;
- good environment, safety and security;
- self determination, making a contribution; and
- personal relationships, adjusting to change.

Respondents with high care needs explained coping strategies and trade-offs to manage increased needs and meeting costs (from finite savings, fixed/reduced income), such as:

- needing less paid-for care because of unpaid help from partner/family, or aids and adaptations (e.g. wet room; electric wheelchair);
- increasing income through claiming benefits/state help, or financial help from family;
- reducing spending by lifestyle changes including going without (eg. less use of on-site restaurant).

#### Hopes and fears for the future

Residents overwhelmingly wanted to stay in HWC to the end of life, rather than move to institutional care. No-one expected to have to leave for affordability reasons, although some were worried about what they would do as their capital decreased. More relevant was whether their care needs would become too high for services on offer in their scheme.

## Value for money, overall affordability

Nearly all respondents (85%) were very happy living in HWC overall. Over half of our respondents commented specifically that their HWC was good value for money: one leaseholder summed up her upmarket scheme as "extravagant value for money".

Ten thought it poor value because of dissatisfaction with services, charging practices, or overall management; others made no comment or had mixed feelings about quality and value for money. There were concerns about lack of transparency about charges, and a lack of consultation and involvement.

The majority of respondents (especially leaseholders, and 'tenure-swappers') were fully self funding; most (but not all) were managing financially because of good occupational pensions and/or significant savings. Age and health influenced whether housing with care was (and would remain) affordable. Residents who were very old or in poor health thought their money would probably last even if care needs increased. Younger residents had to plan over a much longer timeframe so were more anxious. Unexpected/ unplanned changes of circumstances also caused concern, especially for couples.

## **Policy/practice conclusions**

**Commissioning** of HWC schemes by local authorities has important implications for affordability, because commissioning decisions affect the way that services are charged for, and can affect entitlement to means-tested benefits or other help. Local authorities consider affordability in terms of costs to their budgets, and rarely in terms of affordability for self-funding residents. There was little evidence of local authorities and providers 'modelling' affordability of housing with care against the profile of their local population (income/demography).

In some schemes, there appeared to be a lack of **benefits advice** and information. Claiming benefits helps residents to afford HWC. Residents and staff mostly understood disability benefits, but there was confusion about different capital limits for benefits and charging for care. Proposed changes (to Pension Credit, Housing Benefit, treatment of service charges and the 'bedroom tax') will impact, especially for people under state pension age.

A third of interviewees were content to be **'tenure-swappers': former owner occupiers renting** (including one renting privately in a leasehold scheme). Even when HWC for sale was available, some had chosen to rent, challenging the assumption that home-ownership is always the preferred option.

So is HWC **affordable** for older people who have to self-fund? Many respondents (especially private leaseholders and tenure-swappers) were well off, and had chosen to spend income (and often savings) on HWC. For the less well off, claiming benefits and state help is what made HWC affordable, especially for those in social rented HWC, but future changes threaten this, especially for those under pension age. Lower-income private leaseholders with high care/support needs were most at risk. This qualitative study confirms findings from the quantative analysis on affordability.<sup>1</sup>.

## **Final reflections**

**Can I afford to stay here?** That depends ... on my income and savings, changes for couples when one dies, getting benefits advice, where I live, the way my HWC scheme is set up and managed, and what help (if any) I get from benefits (especially leaseholders).

Can I get the care and support I need? Probably... but paying for personal care could be a problem, especially in England. HWC helps me live with my partner, who can continue caring for me.
Will my HWC scheme stay the same? That depends on wider commissioning and funding decisions (if publicly funded) or change of provider (all sectors), and whether residents have any control.
Will I be able to stay here until the end of my life? As a self-funder I may have more choice... but it also depends on facilities and staffing models in my HWC.

## About the project

This 18-month study was UK-wide and involved 21 HWC schemes, interviews with 54 tenants, 24 leaseholders, 4 family carers and 47 professionals. Researchers worked alongside a consultative group of older residents and held stakeholder meetings, and a final conference with residents, family members and professionals. Practical examples identified in the study are presented in: Findings from Housing with Care Research: Practice Examples, Imogen Blood, Jenny Pannell & Ian Copeman, JRF (York) 2012

#### References

1. Aldridge, Kenway and Pannell 2012: Who can afford retirement housing?, JRF (York) 2012

## **ABOUT THE REPORT**

The full report **Affordability, Choices and Quality of Life in Housing with Care** by Jenny Pannell, Imogen Blood and Ian Copeman is published by the Joseph Rowntree Foundation and is available as a free PDF at www.jrf.org.uk

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