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REPORT

AFFORDABILITY, CHOICES AND QUALITY OF LIFE IN HOUSING WITH CARE

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This UK-wide study focuses on the views of tenants and leaseholders who pay some or all of their own costs in private and not-for-profit housing with care.

Research on affordability of housing with care has so far focused on costs and savings to local authority budgets. There has been little research on affordability for residents, especially self-funders. Proposed changes to benefits will potentially impact on all residents, especially on people under state pension age.

This qualitative study analyses resident choices and decision-making, and examines how affordability affects choice, and the consequences for quality of life, particularly for residents with high or increasing support needs. Its key, interlinked concepts (affordability, quality of life and value for money) are explored by following the 'journey' of 78 residents through:

- looking back at their decision to move into housing with care;
- their views on their current position; and
- their hopes and fears for the future.

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EXECUTIVE SUMMARY

This is the first study to focus on the views of older people who are self-funding, and living in not-for-profit and private sector 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.

The study is important because individuals face so many uncertainties 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 happens if standards, facilities or the resident mix changes?
- **Will I be able to stay here until the end of my life?**

Self-funders are tenants and owner-occupiers who pay some or all of the costs of their housing, care and support, including people with a personal budget. People with high (or increasing) support needs are mainly, but not exclusively, aged 85 and over.

This 18-month UK-wide study involved 21 schemes (for rent and sale), developed and managed by private and not-for-profit providers. We interviewed 78 residents (54 tenants and 24 leaseholders), 4 family carers and 47 professionals. We worked alongside a consultative group of older residents and held four stakeholder meetings, and a final conference with HWC residents, family carers and professionals to test findings.

Context and concepts

There is no single model of HWC. Both individual dwellings and schemes vary in size and scale, location, services and costs (rent levels, purchase prices, charges). There are significant variations across the UK. As found in other studies of HWC, nearly all respondents (85%) were very happy overall and reported a good quality of life.

Housing costs include purchase price (leaseholders), rents (social/private tenants), service charges (all tenures): these are usually higher than mainstream housing because of paying for communal facilities (e.g. gardens, common rooms, restaurant). Benefits take-up is important in boosting income for HWC residents. Help for housing costs can come from entitlement to Housing Benefit (tenants) and Pension Credit (leaseholders). People over state pension age who become entitled to disability benefits can find that this also gives them higher amounts of means-tested Pension Credit, Housing Benefit and Council Tax Benefit, or a new entitlement that they did not have before.

It is impossible to generalise about costs, charges and state help for support and care in HWC. Key issues for HWC self-funders include the effects of:

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

Support and care costs will also depend on how the scheme is commissioned and funded. Private leaseholders are the least likely to get help with costs.

Three key concepts underpin our analysis: 'affordability', 'quality of life' and 'value for money'. These concepts are interlinked: decisions about whether we can afford something are partly shaped by our judgement of whether or not we think it represents good value for money, compared with the alternatives; and partly by what impact we expect from buying it (compared with not buying it) on our quality of life.

The older person's journey

Older people's views are explored by following the 'journey' of 78 HWC residents:

- looking back at their decision to move into HWC;
- views on their current position (at the time of their research interviews);
- hopes and fears for the future.

At all stages, there were two key issues. Family involvement was important for most participants: initially, and continuing in most cases. HWC was especially suitable for couples and provided a better quality of life than other settings: they could stay together, and partner carers received support. The effect of changing circumstances for couples had important consequences for affordability; there were also four newly formed couples in our study.

Deciding to move in

We identified various groups among HWC residents:

- 'planners', including 'careful self-funders' who made an informed decision;
- 12 unplanned 'crisis movers';
- 25 'tenure-swappers': 24 former owner-occupiers who moved into HWC for social rent, and one tenant renting privately and letting his house.

Planners had more opportunity to consider costs than crisis movers. Tenure-swappers were happy to be renting: for most, there was no option of moving

into owner-occupied HWC in their area. Many interviewees took the decision to move in as a couple; some were later widowed, with implications for affordability (e.g. needing more paid-for care if the carer partner had died; similar housing costs but reduced income, especially for widows).

Views at the time of the interviews
Most participants reported mainly positive views on different aspects of quality of life in HWC, including:

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

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

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

Hopes and fears for the future
Residents overwhelmingly wanted to stay in HWC to the end of life. No-one talked about having to move out of HWC to another setting for affordability reasons, although some were worried about what they would do as their capital decreased. The more relevant question was whether their care needs would become too high for services on offer in their HWC scheme.

Value for money, overall affordability
Over half of our respondents commented specifically that their HWC was good value for money: one leaseholder summed up her upmarket HWC as "extravagant value for money". Ten thought it poor value because of dissatisfaction with services, charging practices or overall management; others had mixed feelings or no comment.

The majority of participants (especially leaseholders and 'tenure-swappers') were fully self-funding; most (but not all) were managing because of good occupational pensions and/or significant savings. Age and health mattered: most older residents thought their money would probably last even if care needs increased; younger residents were more concerned about whether savings would last. Unexpected/unplanned changes of circumstances also caused concern, especially for couples (e.g. paying for a partner in a nursing home; or following bereavement).

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 HWC residents. There was little evidence of local authorities and providers

'modelling' affordability of HWC against the profile of their local population (income/demography).

There appeared to be a lack of benefits advice and information in many (but not all) HWC schemes. Claiming benefits helps residents to afford HWC. Residents and staff mostly understood disability benefits, but not always links to Pension Credit and other help (with housing/support costs, Council Tax). There was confusion about different capital limits. Future changes (especially to Pension Credit, Housing Benefit, service charges and the 'bedroom tax') will impact especially on affordability for people under state pension age.

A third of our interviewees were 'tenure-swappers': former owner-occupiers happily renting (including the tenant renting privately). Even when HWC for sale was available, some had made a clear decision to rent in preference to full/shared ownership, 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 a good quality of life. Increasing housing and care costs made it less affordable over time for some of those not entitled to (or not claiming) state help. For the less well off, claiming benefits and state help was 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 of affordability problems. So this qualitative study confirms findings from parallel quantitative analysis on affordability (Aldridge, *et al*., 2012).

For the less well off, claiming benefits and state help was what made housing with care affordable. Lower-income private leaseholders with high care/support needs were most at risk of affordability problems.

Final reflections

If we return to the residents' key uncertainties, what did we find?

Can I afford to stay here? That depends ... on income and savings, and on changes for couples when one dies; on getting benefits advice; on where I live and 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 if I need it, paying for personal care could be a problem, especially in England; (for couples) HWC helps us to live together, and maybe my partner can continue caring ... depending on health.

Will my HWC scheme stay the same? That's more difficult to predict ... and depends on wider commissioning and funding decisions (if publicly funded) or change of provider (all sectors) ... , ... and whether as residents we will have any control (or even be consulted).

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.

1 INTRODUCTION

This chapter summarises the key uncertainties concerning affordability, choice and decision-making in housing with care from the perspective of older people. It provides an overview of the study, discussing the research questions, defining housing with care and introducing the research participants.

This is the first UK-wide study to focus on the views of older people who are self-funding and living in not-for-profit and private sector housing with care (HWC). Self-funders are defined as tenants and owner-occupiers who are paying some or all of the costs of their housing, care and support.

Extensive previous research on HWC includes evaluations and reports that include resident views, but there are gaps. Most research has been in England, in HWC provided by housing associations and charitable trusts, not private sector HWC. Costs to public bodies (especially potential cost savings) have featured in previous studies. However, as a recent report on HWC for owner-occupiers in Scotland pointed out:

> There have been many insightful research studies on the issue of housing with care in England ... but the question of affordability has been given scant attention.
> – Newhaven Research, *et al*., 2011

The Joseph Rowntree Foundation (JRF) A Better Life programme identified the key role of HWC in supporting and sustaining older people with high or increasing support and care needs, defined as:

> Older people of any age who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle, etc. Some of the very oldest people may never come into this category.

This report complements other JRF research and practice-oriented work by member/s of the same research team. Links are made where relevant:

- *Whose Responsibility?* on the boundaries of roles and responsibilities in HWC, supported by JRF (Blood, *et al*., 2012a, and Findings (c)), referred to subsequently as the *Whose Responsibility?* study;
- *Affordability of Retirement Housing* (including HWC), supported jointly by JRF and Age UK (mainly quantitative data analysis) by the New Policy Institute (Aldridge, *et al*., 2012 and *Findings* (b)), referred to as the *NPI Affordability* study;
- *Findings from Housing with Care Research: Practice Examples* (Blood, *et al*., 2012b), referred to as *Practice Examples*;
- *Can Self-funders Afford Housing with Care? A guide for providers and commissioners* (Copeman and Pannell, 2012), referred to as the *HWC Affordability Guide*.

Affordability, choice, decisions and quality of life

Our main research question asks how affordability affects choice and decisions on whether or not to purchase care and other services, and consequences for residents' quality of life. 'Affordability' is a contested concept and there will be different views both within and between:

- older people themselves;
- older people's families;
- providers of HWC housing, care and support services;
- statutory and voluntary organisations.

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.

An introduction to housing with care

There are approximately 1,200 housing developments across the UK offering care services (Housing LIN/EAC, 2012).

Table 1: Housing with care across the UK: 2012

Country	No. of dwellings	No. of schemes	Main providers	Sources
England	Over 55,000 (40,000+ for social rent; 15,000+ for sale)	1,100+	HA: 770+ LA: 150+ Other charities: 60 Private companies: 200+	EAC (2012a) and Housing LIN/ EAC (2012)
Northern Ireland	700	21	HA only	Housing LIN/ EAC (2012)
Scotland	3,800	92	HA: 72 LA: 12 Private companies: 7	Housing LIN/ EAC (2012) and Scottish Government (2012)
Wales	2,500 (including 300 private leasehold)	49	HA: 42 LA: 2 Private companies: 5	Housing LIN/ EAC (2012)
Total	Over 62,000	Over 1,200		

Abbreviations: EAC = Elderly Accommodation Counsel; HA = housing association; LA = local authority; LIN = Learning and Improvement Network

The older person's perspective: key uncertainties about affordability, choice and decision-making in HWC

Can I afford to stay here?
What happens if ...

- ... my housing costs (rent, service charges) go up?
- ... my need for paid care and support increases?
- ... my income goes down through changes to my state pension and benefits, occupational or private pensions, interest on my savings?
- ... my income goes down because of the death of my partner, or separation or divorce?
- ... my income goes up but not as much as the cost of living here (e.g. housing costs, care and support charges, utility bills, Council Tax etc. ...)?
- ... my savings run out?

Can I get the care and support I need?
What happens if ...

- ... I can no longer afford to pay for (as much/enough) care and support?
- ... I don't agree with how my care and support needs have been assessed (e.g. by the care manager or social services)?
- ... I want to change things about my care and support (e.g. care at different times)?
- ... I want to choose a different care or support provider?
- ... my partner/family can no longer give me as much unpaid help as before?

Will the HWC scheme stay the same?
What happens if ...

- ... the provider/s do not maintain the same standards and facilities (e.g. closing the restaurant and replacing it with a meals delivery service)?
- ... the provider/s do not maintain the same levels and availability of care and support (e.g. changing night cover from waking staff to sleep-in)?
- ... the provider/s change (e.g. the company or housing association goes bust, merges or is taken over; the council gives the care or support contract to someone else)?
- ... the mix of residents changes (e.g. there are more very frail people moving in)?

If I don't like these changes, can I afford to move out and live somewhere else?

Will I be able to stay here until the end of my life?
What happens if ...

- I have to go into hospital, or a care/nursing home?
- I want to stay in my HWC property, but others (e.g. GP, social services, family) say I need to move?

Does this depend on whether/how much I can afford to pay for more care coming into my HWC property (perhaps a live-in carer if a two-bedroom property)? Or being able to afford to move to a care/nursing home of my choice, if that becomes necessary?

There is no single model of HWC. Both individual dwellings and schemes vary enormously: in size and scale, location, services and costs (rent levels, purchase prices, charges). There are significant variations in provision and policy context across the UK. The HWC schemes visited for this study included:

- extra-care and very sheltered housing (mostly smaller schemes of between 20 and 50 flats);
- retirement villages (mostly larger, with a range of accommodation types and care provision, sometimes mixed-tenure and/or with a care/nursing home on site);
- assisted living developments (a term used for private sector HWC);
- housing for social rent, full and shared ownership (leasehold), market rent;
- private, housing association and charitable providers.

HWC is quite distinct from other retirement/sheltered housing because of the greater extent of on-site support and care. It is also different from residential care: HWC is 'housing first'. Older people have legal rights as tenants or owners (through a tenancy agreement or lease), which give them security of tenure, the right to control who enters their property, and the legal basis for charges. The concept of 'home' is especially important to older people: going into institutional care can mean a loss of that sense of 'home'. HWC offers an attractive alternative, usually at lower cost.

Terms used in this report

HWC – housing with care

Care – personal care and health care

Support – practical and social support, including the community alarm service, part of the scheme manager costs, and sometimes 24/7 staffing and activities co-ordinators. 'Support' is the usual term in the not-for-profit sector; some providers (especially private sector) may use other terms.

Residents – includes HWC tenants, owners and shared owners; where relevant, tenure is specified.

Care worker – means paid staff. However, where interviewees refer to 'carers', this term has been left unchanged.

Support workers (the usual term in the not-for-profit sector) – some providers (especially private sector) may use other terms, such as concierge staff, porters or stewards.

Family member/relative – describes providers of informal, unpaid care and support.

Participants, interviewees, respondents – interchangeable terms for those we interviewed.

Residents – used when describing general reported observations, stories told to us by professionals, and when making reflections or drawing conclusions.

Housing provider – a term used generally, across both social and private HWC.

Landlord – organisations providing social housing for rent (and mixed tenure).

Freeholder – the organisation that owns the site and buildings for private leasehold HWC that is for sale.

Adult social services – local authorities with adult social services responsibilities in England, Scotland and Wales, and Health and Social Care Board in Northern Ireland.

Commissioners – such as local authority or, in some cases, health staff who have responsibility for determining the level of resources and funding available to ensure that publicly funded HWC services are provided effectively and meet the needs of older people.

An overview of the study

The main research question examines how affordability affects choice (and decisions on whether or not to purchase care and other services) and the consequences for quality of life, with a focus on those with high (or increasing) support needs.

In addition, JRF's research brief outlined a range of more specific issues, which fall into three broad areas:

- decision-making: timing, processes, who decides?
- quality of life: for the individual, for the scheme (i.e. all residents) and the perspective of HWC providers and commissioners;
- value for money: different perceptions by individuals, family, providers and commissioners; how HWC costs compare with other options (staying put, other housing, residential/nursing care).

An essential early task was to establish a working definition of HWC to select schemes for this study:

- 24/7 staff cover (i.e. more than community alarm service);
- availability of some meals (usually an on-site restaurant);
- social and leisure activities and facilities;
- on-site care team (at most schemes): a few private sector schemes no longer provided care (e.g. from a care/nursing home on site) because of regulation and registration issues (discussed in *Whose Responsibility?*): residents now have to buy in care from outside providers.

The research took place between January 2011 and August 2012 across the UK and included:

- a consultative group with older HWC residents;
- consultative groups with commissioners, providers and other stakeholders in all four nations;
- a focused literature review;

- visits to 15 not-for-profit and 6 private schemes across the UK, in rural and urban areas, and most English regions from a cross-section of providers: England (14, including 5 private sector), Northern Ireland (2), Scotland (2) and Wales (3, including 1 private sector);

- semi-structured interviews using a topic guide and a data collection tool with 78 residents (24 leaseholders, 54 tenants), 4 family members and 7 frontline staff;
- 40 interviews with providers, statutory and other organisations and experts;
- a final conference with residents, providers and other stakeholders to test findings.

The team sought advice and guidance on research ethics. It was agreed that the research could address the key research questions by including all residents who could be supported both to take part and to give informed consent.

We analysed the qualitative data using QSR NVivo software. This helped us to organise the data into over 100 themes and to cross-reference what participants said with information about them (e.g. age/ethnicity/health, HWC scheme type).

Resident profiles

Interviewees were invited to take part by HWC staff who selected residents with high/increasing support needs who were paying some of/all their costs, or (England only) had personal budgets:

- 64% were women;
- ages ranged from 51 to 101 years old: the average age was 84, and 62% were aged 85+;
- 13% were from black or minority ethnic backgrounds;
- 68% were social renting, 31% were leaseholders;
- 60% had previously been owner-occupiers, 26% had previously been social tenants;
- interviewees had up to five health conditions each (average: two conditions): physical, sensory and cognitive impairment and progressive conditions; we did not use formal tools but relied on respondents (or relatives/HWC staff where they had difficulty with this) to tell us about health conditions and care/support provision.

Half the private leaseholders, and nearly three-quarters of social tenants and leaseholders in not-for-profit HWC, were receiving disability benefits (Attendance Allowance/Disability Living Allowance).

Fewer private leaseholders (17%) were getting Pension Credit than not-for-profit HWC tenants (29%) and leaseholders (25%). Of 51 tenant participants, 19 (37%) were claiming Housing Benefit.

Three participants (4%) did not know what benefits they were getting because this was dealt with by someone else. Our findings for benefit take-up amongst private leaseholders are similar to the only other study with such information (Kneale, 2011).

In private and not-for-profit leasehold HWC, everyone was fully self-funding their housing (purchase and service charges), except for those receiving Pension Credit, which includes some help with service charges (see Chapter 2). Two-thirds of tenants were fully self-funding, including many

Half the private leaseholders, and nearly three-quarters of social tenants and leaseholders in not-for-profit HWC were receiving disability benefits. Fewer private leaseholders were getting Pension Credit than not-for-profit HWC tenants and leaseholders.

'tenure-swappers' (i.e. previous owner-occupiers) who had savings (including from house sale) and/or higher incomes.

In private sector leasehold HWC, everyone was paying in full for their care and support; in not-for-profit HWC, this depended on the model (see Chapter 2). Permutations of care and support purchase (see Chapters 3–5) included:

- all care/support needed included in basic package (see Chapter 2), so paying no extra;
- most care/support from partner/other relative/private outside help, so buying little or no extra services from HWC provider/s;
- paying (sometimes substantial sums) for care/support.

We asked respondents how much care/support they received: 35 (45%) were receiving personal care at least once a day and/or regular night time assistance; all needed support.

Structure of the report

The report considers what 'affordable' means to residents with high support needs in HWC, how they make decisions about what they can and cannot afford, and the strategies they adopt:

- Chapter 2 outlines the context and key concepts;
- Chapter 3 is the first of three chapters following the 'journey' of older people, looking back at their decision to move into HWC (i.e. reflecting on the past);
- Chapter 4 considers their current position (at the time of our interviews);
- Chapter 5 looks forward to hopes and fears for the future;
- Chapter 6 draws out key messages and reflections.

2 CONTEXT AND CONCEPTS

This chapter sets the context of affordability in housing with care. It summarises costs to residents, the availability of help from public funds, comparisons across the UK, and equality and diversity issues. The key concepts that underpin our analysis of the 'resident journey' in later chapters are outlined: affordability, quality of life and value for money.

The costs of different HWC and help to meet them

Chapter 1 outlined different models of HWC (tenure, provider type, etc.). Costs in HWC fall under three headings:

- **housing costs:** rent and service charges for tenants, and purchase costs, service charges, ground rent (in some retirement housing) and (perhaps) mortgage interest for owner-occupiers (housing costs may be higher than in mainstream housing: see Table 2);
- **support costs:** some HWC scheme costs (obligatory, may be classed as 'housing-related support' or 'well-being charge', e.g. for 24/7 cover); sometimes one-to-one support (that is not personal care);
- **care costs:** not all residents in HWC have care needs; even if they do, not all will have to pay for care (e.g. because of low income or savings/ receiving free personal care in Scotland); HWC schemes may or may not impose charges for some care services that are obligatory, e.g. minimum amount, or for 24/7 cover.

The HWC Affordability Guide provides indicative weekly costs of HWC in England, mainly from the *NPI Affordability study* detailed analysis. Note that this includes rent (tenants) and service and support charges (tenants/ owners), but excludes most personal care and one-to-one support. Leaseholders will also have paid the purchase cost. Because of differences

between models/providers in what is included (or not) in service/support charges, and how care and 24/7 support is commissioned, the costs are indicative:

- social rent HWC (England) £95–170 per week;
- not-for-profit owners (mixed tenure HWC) £30–90 per week;
- private owners (England) (Newhaven, *et al*., 2011) £65–112+ per week.

Costs at our fieldwork sites were higher than those above: in more expensive private sector leasehold HWC, costs ranged from £120 to £180 per week, and for most housing association/charitable HWC, weekly costs were towards the upper end of the amounts above.

Table 2 shows how costs in HWC compare with mainstream housing.

Table 2: Variations of housing costs in HWC, compared with mainstream housing

Item	Type of housing	Variation for HWC
Initial purchase price	Owner-occupied HWC	Purchase price of new-build HWC usually higher than similar size non-retirement dwellings; re-sale prices can be lower because of market conditions, lease restrictions (age, renting out), exit fees.
Rent	Rented (social and private) HWC	Rents may be higher than in similar size all-age housing.
Service charge	All HWC	Service charge will be higher than equivalent all-age housing because of extent/range of communal areas/facilities and 24/7 staff cover; for owner-occupiers it also replaces some costs in previous housing (e.g. repairs/ maintenance, buildings insurance, gardening).
Council Tax (except NI)	All HWC	Some providers report that Council Tax can be significantly higher than for similar all-age dwellings.
Utilities	All HWC	Sometimes included in service charge: comparison will depend on size/efficiency of previous housing (so HWC utilities may cost less).
Food costs	All HWC	Most HWC provides a restaurant: charges vary: 'pay as you go'/included in service charge/fixed amount per month (flexi-dining). Meal costs vary. May save money if would otherwise need paid staff to prepare meals at home.

Sources: *NPI Affordability* study; Age UK, 2010; Pannell, *et al.* 2012.

Table 3 indicates help available for pensioners (i.e. single people, or couples with one person over state pension age) to meet housing and support costs. Weekly amounts are for April 2012–March 2013. Note that people under state pension age get much less help: under current proposals (September 2012), couples with one person above and one below pension age will lose their entitlement to pensioner benefits.

Table 3: State benefits/help for pensioners

Name of benefit	Means tested?	Purpose	Age? Tenure?	Amounts (£ per week)	Notes
Pension Credit (PC):					
Guarantee Credit	YES	Minimum income guarantee	State Pension Age (SPA)	£142.70/ 217.90	To bring income to these levels (single/ couple)
Savings Credit	YES	Additional/ alternative help for those with savings/ occupational pension	65+	Up to £18.54/ 23.73	Maximum for single/couple
PC housing costs	YES	For eligible service charges, ground rent	SPA Owner-occupiers	£0–80	Wide variation in amounts awarded
Disability Premium	YES	Extra costs of disability	SPA	£58.20	If getting AA/DLA
Attendance Allowance (AA)	NO	Extra costs of disability	65+	£51.85/ 77.45	Lower/higher care components
Disability Living Allowance (DLA)	NO	Extra costs of disability	Birth–65 or older (if awarded before age 65)	Care: £20.55/ 51.85/ 77.45 Mobility: £20.55/ 54.05	Includes care component (three levels) and mobility component (two levels)
Housing Benefit (HB) (social tenants)	YES	Rent, eligible service charges	Adults Tenants	Varies	100% for those on PC Guarantee Credit
HB Local Housing Allowance (LHA) (private tenants)	YES	Rent	Adults Tenants	Varies and upper limit	Upper limit for LHA: 30% of local market rents
Housing-related support costs	YES	Elements of service charge excluded from HB/PC (e.g. scheme manager, alarm)	Adults	Varies	Tenants may get this (sometimes passported 100% if on HB); owners probably will not

Source: adapted from *NPI Affordability* study

Paying for support and care, self-funders and personalisation

It is impossible to generalise about costs and charges for support and care in HWC. For residents, there are differences in costs, charges and entitlement (or not) to help through benefits and local authority charging policies, and some costs will be ineligible for state help (see also *HWC Affordability Guide*). For providers, there are different regulation and funding mechanisms. It is important to distinguish between 'support' and 'care' (see Garwood, 2010). The distinction is complex, not always clear-cut and there are significant

'grey areas' explored in *Whose Responsibility?* In summary, care is 'doing *for*' and support is 'doing *with*' someone.

Some level of support is usually included in the basic cost for all HWC residents. Additional one-to-one support may be provided, sometimes at extra cost. Support and care costs will also depend on how the scheme is commissioned and funded. This charge may be covered (in full or part) for those receiving different benefits. Private leaseholders are the least likely to get help. Benefits take-up is as important as eligibility when considering affordability.

Many HWC residents need no paid-for personal care, even if they have high support needs. Some will have to pay no extra because their support needs are met informally (e.g. through social interaction), and through services provided within the basic charges. Personal care is likely to involve additional charges, although in some HWC a low level of care is included. As for support, whether or not residents have to pay or get these charges covered will depend on many factors (too complex to detail here). HWC residents may also receive care and/or support from partner/family members at no cost.

State help with care costs is different across the four nations, as discussed in detail in the *NPI Affordability* study. To summarise:

- in Scotland, personal care (tightly defined) is free for over-65s (Wiseman, 2011);
- in England and Northern Ireland, personal care is means-tested and anyone receiving care in their own home (including HWC) with over £23,250 savings (excluding their home) gets no help;
- in Wales, there is a similar capital limit but a cap of £50 a week (SSIA, 2011).

There are three key issues for HWC self-funders:

- different charging rules 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);
- different methods of charging for care in HWC.

Charging in Extra Care Housing (Institute of Public Care, 2010) discusses different approaches to charging in HWC, with a focus on care charges. Out of many potential combinations, there are three main charging models in publicly funded, local authority-commissioned HWC:

- charges related to banding (typically low, medium, high care needs), also discussed in Garwood 2008a,b;
- core and top-up: typically the core element includes night cover, with a top-up based on individual assessment;
- individualised: the charge is based on the actual number of hours of care per resident (this is also the usual model in private HWC).

There has been extensive discussion of the cost of domiciliary and residential/nursing care charges, especially in England, most recently in the Dilnot Commission (Commission on Funding of Care and Support, 2011). Recent interest in those who self-fund care (ADASS, 2011: Henwood and Hudson, 2009; NAO, 2011; EHRC, 2011) has been driven by concerns not only about quality but also about the cost to the public purse if self-funders

run out of money. This was also raised in interviews and consultations for this project. The National Audit Office report (NAO, 2011) estimated the annual aggregate cost to local authorities of 'run-outs' as £0.5 billion, increasing to £1 billion by 2035.

Personal budget-holders were within the scope of this study because the intention is that although they are funded by the state, they will make their own choices in the same way as self-funders. The personalisation agenda aims to develop self-directed support, direct payments and personal budgets for social care and other needs, including housing support (Housing 21, 2008, 2009; Garwood, 2009; NAO, 2011; ADASS, 2012). The main increase has been in 'managed budgets' (through provider or local authority) rather than direct payments to individuals or their carers. Despite considerable efforts, we had difficulties finding residents with personal budgets. None had direct payments and all had managed budgets.

Comparisons across the UK

Following devolution, the variation across the four UK countries was even more significant than we initially expected (see Viewpoint (2011) for further discussion), including:

- housing law (fundamentally different in Scotland, and no leasehold);
- housing tenure, equity (e.g. more social rent in Scotland; lower equity in Scotland, Northern Ireland);
- help with care charges (see above);
- income, capital, benefits (e.g. more people on means-tested benefits in Northern Ireland);
- disability and long-term ill health (e.g. higher levels in Scotland, Northern Ireland);
- HWC costs and charges (e.g. different charging arrangements in Northern Ireland);
- funding arrangements (e.g. Department of Health HWC capital funding only for England);
- impact of personalisation (personal budgets less developed in devolved nations);
- type of HWC provision (e.g. very little private sector HWC in Scotland, none in Northern Ireland).

There are also significant differences within countries (including English regions/sub-regions) and between urban, coastal and rural areas. For example, private HWC in Wales is concentrated in traditional retirement areas (especially the North Wales coast); and in England mainly in the South, the Midlands and in wealthier areas with high house prices (Housing LIN/EAC, 2012). These factors impact on availability, affordability and choice. For example, should older people want to stay local or move to be near family, there may be no available or affordable HWC. It was clear that many of our respondents had only moved into HWC because it was available near where they (or their relatives) lived. Conversely, most residents in a specialist scheme for a minority community had needed to choose between staying near friends/family or moving a long way to the specialist scheme.

Should older people want to stay local or move to be near family, there may be no available or affordable HWC; it was clear that many of our respondents had only moved into HWC because it was available near where they (or their relatives) lived.

Equality and diversity

Equality and diversity issues run through this study in a number of ways and are discussed in more depth in King and Pannell (2010) and Blood and

Bamford (2010). An individual's financial, family and other resources are shaped by what the Equality Act 2010 terms their 'protected characteristics' (disability, ethnicity, gender, marital status, etc.). Economic inequalities cumulate through the life cycle, reinforced by unequal pay, limited opportunities and systematic discrimination. These factors generate different resources in retirement, and inequalities in health and mortality in later life (NEP, 2010).

Of particular relevance to this study are:

- the impact of social class, wealth or poverty on options in later life;
- the unequal financial position of older women (parenting/caring responsibilities; lower income and other resources following widowhood);
- economic differences between those with a lifelong disability/early retirees (due to illness/disability) and those who first develop health problems when much older;
- the impact of ethnicity/faith on shaping preferences (e.g. moving to specialist HWC that meets social/cultural/religious needs);
- the impact of current/former marital status, sexual orientation and family structure on support needs and resources;
- the social model of disability, which recognises that support needs result from environmental and social barriers as much as from medical conditions.

Economic inequalities cumulate through the life cycle, reinforced by unequal pay, limited opportunities and systematic discrimination. These factors generate different resources in retirement, and inequalities in health and mortality in later life.

Key concepts

We carried out an extensive literature review on the three key concepts which underlie this study (our conceptual framework): 'affordability', 'quality of life' and 'value for money'. These concepts are interlinked: decisions about whether we can afford something are partly shaped by our judgement on whether or not we think it represents good value for money, compared with the alternatives and, partly, by the impact we expect that buying it (compared with not buying it) will have on our quality of life. Space precludes detailed discussion of our findings or a full bibliography but a summary follows under the three headings.

Affordability

Our extensive literature review included research on:

- poverty measures (e.g. McKay, 2004; Price, 2008);
- affordability (e.g. Hancock, 1993);
- affordability of housing (e.g. Fenton, *et al.*, 2011);
- affordability of care (e.g. Commission on Funding of Care and Support, 2011; NAO, 2011;
- qualitative studies on attitudes to money, spending and benefit take-up (e.g. Dominy and Kempson, 2006; Finch and Kemp, 2006);
- choices and attitudes to risk (e.g. Faulkner, 2012).

As in the *NPI Affordability* study, we rejected the idea of setting a quantitative measure of affordability (such as percentage of income/residual amount left after paying for housing) like those developed in studies for working-age households (e.g. Fenton, *et al.*, 2011). This makes no sense in HWC, given the complex interplay of HWC costs (for housing, support and care), and uncertainties and inconsistencies around entitlement to public funding. Instead, we followed the *NPI Affordability* study which concluded:

> This study should dispel any idea that the affordability of retirement housing is a straightforward, albeit somewhat subjective, question. The problem is not just that it turns out, on close inspection, to be complicated. Rather it is that so many aspects of the matter are both bedevilled with uncertainty and, in the way the state treats the matter, riddled with inconsistency
> – Aldridge, *et al*., 2012, p. 6

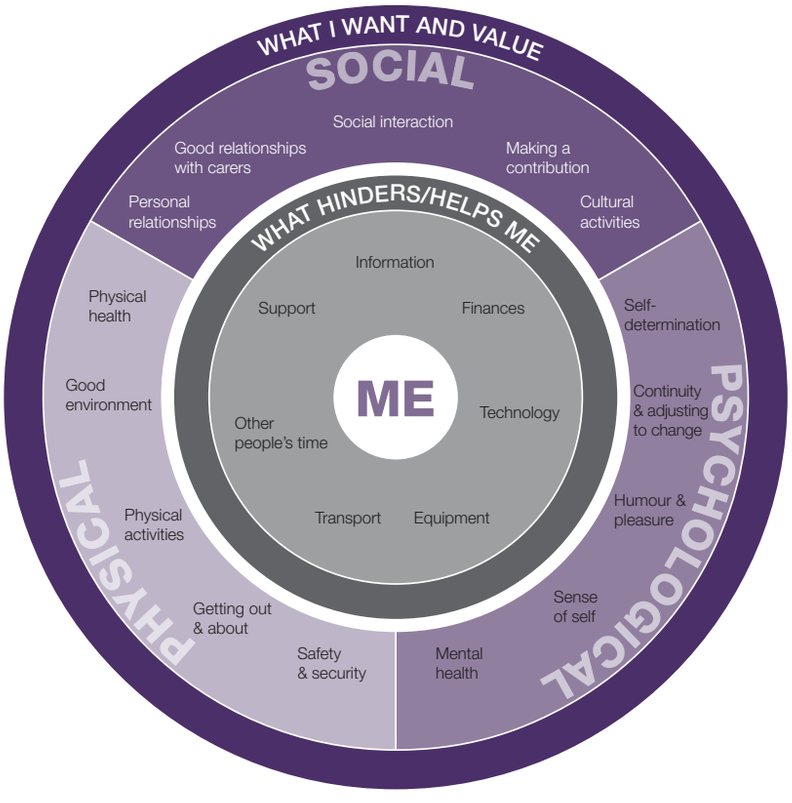
Bearing these factors in mind, we were primarily guided by residents' perceptions of what was 'affordable', which we interpreted within our conceptual framework (below).

We look more closely at affordability, benefits, state help and commissioning decisions in our *HWC Affordability Guide*. This is because the way that HWC is planned, developed, funded (if commissioned by public bodies) and managed has a significant effect on costs for residents and entitlement to state help, as discussed briefly above.

Quality of life

To inform the A Better Life programme, JRF commissioned a study to review literature and seek the views of older people with high support needs about what they value in their lives (Katz, *et al*., 2011). The resulting model is presented below.

Figure 1: What older people with high support needs value



We incorporated the 15 themes from the outer circle into our data analysis to explore the impact of living in and paying for HWC on residents. Also note that 'finances' are one of six items that can help or hinder, and that this inner circle also includes other resources that impact on affordability.

We reviewed other quality-of-life literature and found the models in Godfrey, *et al*. (2004) especially helpful in understanding the adjustments that older people make when leaving their previous homes and moving into HWC, which we return to in our reflections in Chapter 6.

Value for money

We found very little discussion of value for money from the perspective of residents in previous research on HWC, although some refer to this (e.g. Evans and Means, 2007; Garwood, 2008b). The main emphasis was on value for money and savings for commissioners (especially health and social services) and related issues for providers (e.g. Baumker, *et al*., 2008; Netten, *et al*., 2011). There was some discussion of value for money from the older person's perspective in the broader affordability literature summarised above, especially in the JRF *Resources In Later Life* study (Hill, *et al*., 2009). Their section on value for money from the perspective of older people resonates with our findings in Chapters 3, 4 and 5:

> Participants sometimes resisted paying for formal help or services despite having ample funds – the issue here was not affordability, but justification of cost ... [and] the thought that the organisation was making ... excessive money from them ... Cutbacks had also been made where services were no longer seen as justifying the cost ... One advantage to paying privately for help was that participants could ensure that their money went directly to the person performing the service, which provided reassurance and an element of control. (p. 16)

Their overriding conclusion, used in our analysis, was that the value of money for older people rests in what it enables them to do, and in the sense of control over personal circumstances that it gives.

3 REFLECTING ON THE PAST: DECIDING TO MOVE TO HOUSING WITH CARE

This chapter explores affordability through the voices of residents looking back on their decision to move. Why did they move? How much did they know about costs at the outset? Did they have any initial concerns about affordability? We analyse the factors and priorities that influenced their decision-making, as well as the roles of families, providers and other agencies.

Older people's decision-making and priorities

Why did they move into HWC? Differences between 'planned' and 'crisis' moves

We mapped out 78 participants' routes into HWC, including precipitating factors, alternatives considered and key players. All moves sit somewhere on a continuum between crisis and planned, with some more clearly at each end of the spectrum.

Many 'planners' fall into a distinctive group of 'careful self-funders' who recognised the need to move and made an informed decision about when, where and how. 'Push' and 'pull' factors echoed other HWC research (e.g. Baumker, 2007; Croucher, 2008), especially:

- being able to sell an often valuable property (especially before the recent housing market downturn);

- increasing health problems/diagnosis (usually chronic conditions) that made their situation unsustainable because of factors including existing housing, caring responsibilities, social isolation, distance from family, living abroad.

Planners tended to 'try out' the scheme: for example, visiting with family/friends or for respite. A few people had planned years before to move to HWC when needed, especially to an ethnic minority community HWC scheme.

There were also a few planned moves with ongoing social worker input (especially around mental health and/or learning difficulty).

Twelve were clearly crisis or unplanned moves: nine from hospital or in-patient units, or via intermediate care or a nursing home, and three for safeguarding reasons.

For other unplanned moves, the crisis came when a sudden change in health/mobility made their current situation untenable. Overall, planners had more opportunity than crisis movers to consider costs, alternative HWC schemes and other provision (e.g. retirement housing or care homes).

Differences in affordability considerations for couples

Many had made a planned move into HWC as a couple: seven couples with one carer and one partner with high/increasing support needs, two couples where both had high care needs, one couple living separately in the community and newly formed couples.

Couples usually calculated income based on both partners, and full occupational pension/s. They did not factor in future additional care costs if one partner was the carer. Couples also chose larger properties (often two-bedroom, with larger purchase costs/rent/service charges).

The effects of later changes (e.g. newly formed couples, or increased care needs) are explored in Chapters 4 and 5.

Financial decision-making: sufficient information about HWC costs?

Overall costs

A very small number of participants were not aware of costs because others had dealt with financial decision-making for them. However, several (especially crisis movers/those with cognitive impairment) were in a state of upheaval at move-in and so did not understand charges until later (if at all):

> No, I think they didn't discuss the financial side of things with me at all because they felt at that time that I couldn't have understood. ... Since then I've found out how much it costs but my daughter has power of attorney now.

However, most respondents were well informed (often with help from family). The most frequent source of detailed cost information (mentioned by a dozen of our respondents) was a meeting with HWC scheme staff.

Some had little choice but to move because of their deteriorating situation at home, even if they were worried about the cost. One 'crisis move' leaseholder was calling emergency services frequently because of falls and breathing problems:

> One of my daughters worked it all out, when I realised how much it cost I said "Bloody hell!" but I came anyway. My pension is rubbish – I worked from the age of 14, fifty years, and because of Robert Maxwell, I get £28 a month.

Care costs

Some participants were clear about housing-related charges but less clear about care charges because they did not need care when they moved in.

Some not-for-profit HWC self-funders had to pay care charges to the local authority rather than to the HWC care provider. Some partial self-funders did not know the care charges until (much) later: both residents and family members found this stressful. A provider told us about a self-funder whose daughter had received the first very large bill two years after she moved in (as a crisis move direct from hospital). When the scheme manager checked her copy of the original care plan, all that was entered in the funding section was 'TBC' (to be confirmed); it had never been updated, so neither resident nor relative had known what the care costs would be.

Assessing value for money

Residents made different comparisons, which depended on why they moved.

Comparison with residential care or nursing homes

Costs in HWC – even with a high care package – can compare favourably with residential care for a self-funder (see *NPI Affordability* study). A former home-owner moved to rented HWC from a nursing home. As this was in Northern Ireland she had no option to move to owner-occupied HWC:

> Yes, the staff explained [HWC costs] – it's all done by direct debit – when I was in the nursing home it was by cheque and it cost more than here.

A recent widow (and leaseholder) had been in hospital, then rehabilitation after a fall, so her support needs had increased – both physically and socially – very quickly:

> I managed to sell the bungalow and at that point we had already had a look round this scheme ... up until that point I had no idea what I would do if I could no longer live in my own home. I knew that nursing care is expensive, about £900 per week, and I couldn't have gone on like that ... I realised that the choice for me was to carry on living in my bungalow with carers visiting but with life being a struggle, or moving here to a nice flat with no upkeep worries, with staff available and with a social life; but I know that I'm fortunate because I am in a position to be able to afford to make that choice.

Comparison with their previous housing

Several respondents had previously been living alone in four- or five-bedroom houses. Because of declining health, they had been paying people to do maintenance, cleaning and gardening: one man told us that he had paid several hundred pounds to have the hedge cut. Heating was another problem: an affluent respondent had been carrying a portable heater around his previous house. Compared with this, HWC can seem financially viable and less stressful. As one leaseholder put it:

> I worked out that the costs of running and maintaining my old house were pretty much the same as the service charge for living here in a brand new flat with all the facilities and none of the upkeep.

Change of tenure

We have identified 25 tenure-swappers (15 single/widowed and 5 couples):

- 23 from owner-occupation to social renting;
- the person renting privately in a leasehold scheme, who rented out his own home;
- other two-/three-stage tenure swaps: from owner-occupation to HWC via private rent, a 'granny flat', or buying a larger property with family members (sometimes losing their housing equity on the way).

Many tenure-swappers could not buy because equivalent HWC for sale did not exist (see also Pannell, *et al*., 2012 and *Findings* (a)); this applied especially for residents in a minority ethnic scheme, and in Northern Ireland and Scotland (see also *NPI Affordability* study).

Recurring characteristics amongst tenure-swappers included:

- couple, one partner with high support needs, other partner struggling to care (10 of 25 tenure-swappers were currently living as couples; for others, some partners had since died or moved into care homes);
- crisis moves from intermediate care-type placement (4) or vulnerable/isolated before moving to HWC (10);
- previous connection so already knew HWC scheme/provider;
- younger people (in their 50s) with high support needs (stroke, serious accident) or without sufficient capacity (stroke, dementia) to decide to sell, so decision led by others;
- renting because previous property not yet sold (one had tried to buy at a different HWC, lost the deposit and moved in crisis to social rented HWC).

Many tenure-swappers could not buy because equivalent HWC for sale did not exist.
One tenant, offered a choice between shared ownership and social rent in the same scheme, chose to rent, after previously having to sell her house to pay for care.

One tenant, offered a choice between shared ownership and social rent in the same scheme, chose to rent, after previously having to sell her house to pay for care:

> I do feel a bit grieved that I was paying a mortgage for all those years and they wouldn't let me keep the money from my house sale. That's the reason I didn't want to buy again. I felt like I'd already had one property taken from under me and I thought, if I rent, they can't turn me out and force me to sell it. Now I understand the way they work, I feel happier renting. I can control what to do next without being penalised for owning my own home.

A couple explained that:

> We thought we may have had too much money to be allowed to live here but that's not the case. There is a mixture of people here, some who get benefits and some who don't. We are selling our flat and we are renting here but that is fine because this is where we want to live and it suits us perfectly; it's a very good flat, close to the town and the help we need is here.

Considering their age and health, and without the option of renting, would this couple have gone through the stress of selling up and buying HWC? Would they have 'under-consumed' care and struggled on, or ended up (perhaps separated) in residential care?

Role of family

Over a third of all respondents spoke (without prompting) about help from families: researching availability, visiting prospective HWC schemes, looking at affordability, sourcing furniture, doing DIY, selling a previous house and, perhaps most importantly, providing emotional support. Most frequently it was the daughter/daughter-in-law, although others were also involved. But although relatives had an important supporting role, the older people were clear that it was *their* decision to move: it was important that they had been agents in their own lives and taken the plunge.

Older people often moved to HWC nearer their family, especially middle-class professional families who were more likely to be geographically dispersed and busy with their own careers. Many (especially women) did not want to impose on their adult children. One participant's daughters had moved away, after her husband died:

> She said "do you want to come with me? You looked after your mother" but although we have a great time together, we're like sisters, if I came now we'd have a great time, but in five or ten years time ... I don't want them to be burdened with it.

In another case, the daughter and husband had moved to live next door to give support:

> But I was worried about being too dependent on them – they could move away again at the drop of a hat and I wouldn't be able to cope then. It also takes the stress off my daughter ... It was a full-time job for me looking after my mother and I'm sure that the stress of doing all that, and working and everything, was what led to me becoming ill in the first place. I really didn't want the same thing to happen to her.

In other cases, HWC was first suggested by adult children or siblings. Reasons included:

- encouraging the older person to move nearer, but not to live with them;
- problems trying to deliver care in their previous home (through domiciliary care agencies and/or delivering care themselves);
- relatives wanting peace of mind, especially with deteriorating conditions/ problems maintaining independence in previous housing (examples included frequent falls; forgetfulness; social isolation; depression).

Three family members talked about the difficulty of providing care at a distance: in one case their relative was at the other end of the country, going in and out of hospital; in the other two cases they only lived 15–20 miles away, but this was still an hour or more each day, and especially difficult in winter weather. Older people also expressed concerns, for example the resident who told us:

> My eldest daughter was coming round to care for me after she had finished work but she was wearing herself out.

In a few cases, family pressure seems to have been paramount and links to literature on risk and independence (e.g. Faulkner, 2012):

Although relatives had an important supporting role, the older people were clear that it was *their* decision to move: it was important that they had been agents in their own lives and taken the plunge.

> I really didn't want to leave but my daughter-in-law and son tried to persuade me to move to [HWC]. They wanted me to think about what would happen if I needed some help when I was living at home or I had an accident and there would be nobody there to help me. I thought that it would be OK where I was living but they [daughter-in-law, son] got my GP to talk to me about moving.

Financing the move

Wherever the initial idea came from, families played an important role in working out whether HWC was affordable:

> My son-in-law is an accountant and he calculated the costs of me living here on a spreadsheet and he showed it to me. This convinced me that I could afford to live here and I am reassured because my family have been so thorough in helping me.

Families were also looked on as a potential source of financial help in case of difficulty:

> My family were really supportive and said if I couldn't afford it any stage they would pay for me.

In a few cases, family members contributed financially towards costs:

- buying the HWC property;
- contributing capital for the purchase;
- helping with service charges/care costs.

Families were also an important non-financial resource; Chapter 5 gives examples of families contributing in kind to reduce the cost of care, support and domestic tasks. Where the older person/couple moved to be nearer to family, this was sometimes factored into the initial financial planning.

Role of provider

Most participants said they understood HWC costs at the outset: we found no evidence that the opportunity was not there to find out about most costs in advance. What is less clear is how proactive providers were in offering a benefits check, and we return to this in our final chapter.

Although many interviewees (especially leaseholders in private HWC) were very well off, it is unclear whether everyone was made aware of both disability and means-tested benefits described in Table 3, Chapter 2. This was more likely if they also had social services involvement (see below).

Information to leaseholders

Those buying leasehold properties described getting information and support from providers as part of the sales process:

> Before you buy you have an 'interview' when all the costs of living here are explained so you can check that you will be able to afford to live here as well as buy a flat or bungalow.

As well as/instead of family, some had support from a solicitor/financial adviser:

> My solicitor made a point of checking that I did understand what the costs would be. He thought it was dreadfully expensive and he asked me if I could afford it – he was concerned about whether I could afford the charges to live here once I had bought a bungalow.

Leasehold providers held varied views on the extent of their responsibility to ensure whether or not people can afford to buy. This applied to not-for-profit providers with mixed-tenure developments, as well as to private providers.

Different perspectives from private providers on advice and affordability

"If we were acting as estate agents we would need to make sure that someone could afford to pay but we generally take the view that 'we've told you what the costs are and if you buy a lease, you have presumably worked out that you can afford the costs'."

"Very occasionally we have had people wanting to buy a leasehold property that is dearer than their current property and yes, we will have a long discussion with them about the implications of this, because it is unfair to sell to someone who is older and possibly vulnerable, and might end up in a difficult position as a result."

"The tension here is that whilst the sales team look at affordability obviously from a financial perspective, we can also look at the person's requirements from a care and support perspective; for example, in some cases we have seen people move into our scheme and the amount of domiciliary care that they were receiving in their own home has reduced, due to the supportive environment that we create here."

It is unclear how far private providers advise on benefits, and practice varies even amongst not-for-profit providers (see our *Practice Examples*, which include one large private provider which employs a specialist benefits adviser). For others, the main emphasis in their marketing literature is the suggestion to seek advice from a specialist financial adviser (for advice on equity release and annuities for future care costs): it is a requirement that the financial adviser also does a benefit assessment. Some providers also have their own schemes for leaseholders to access capital/equity for future care costs.

A housing association respondent told us:

> When a vacancy comes up, the manager will generally go out and visit and they will discuss income at this visit. In particular, they will look at starting discussions about any benefits that the older person and their family may not be aware of and that may assist them to be able to afford very sheltered accommodation.

Role of other agencies/professionals

Adult social services were most likely to be involved for crisis moves if no family was available or (in very few cases) because of safeguarding issues linked with family relationships.

Most self-funders did not mention social workers/social services as sources of advice. Some perceived them to be purely about financial help, and may have confused them with social security/benefits:

> I don't want social services involved now – I've never been one for hand-outs.

Some reported negative experiences, such as a couple who were very unhappy with the assessment process and the intrusive questions on the financial questionnaire they received.

Others reported positive experiences of involvement:

- in cases of crisis, complexity or previous involvement because of long-standing disability;
- because of safeguarding/mental capacity issues (at the time of the move);
- if receiving social services part-funding care and/or being a self-funder with high support needs approaching the capital limit for entitlement to local authority care funding;
- in the case of former council tenants (so more likely to be 'in the system', and likely to be eligible for at least part-funding if they had high care and support needs).

Social worker involvement also provided access to additional sources of advice. For two residents, benefits advice was vital to understanding charges and working out affordability. One resident (mentioned previously) had been living at a private residential home for people with mental health problems, following the death of parents: the social worker (and a relative) helped to find the right HWC scheme:

Social worker involvement also provided access to additional sources of advice. For two residents, benefits advice was vital to understanding charges and working out affordability.

> Once I had decided that I was going to move in here, we met with something called the 'FAB' team (Financial Assessment and Benefits team) from [name] Council and they helped me to work out what it would actually cost me to live here.

A few partial self-funders had received benefits advice, as well as care assessment:

> When we decided to take it we went into it [the finances] then – a couple of ladies from the council came to see me and we decided that I could just about afford it. The rent is high here, and care is very expensive if you have to pay it all – I couldn't do it. It's £27 a week more here than the rent in my council bungalow.

However, other partial self-funders described a stressful delay (after moving in) while waiting to find out how much Housing Benefit and help with care costs from social services there would be. This was echoed by a commissioner, who explained that:

> Another affordability impact for older people is in relation to not knowing whether they will get financial assistance from the local authority.

4 LIVING IN HOUSING WITH CARE: THE CURRENT POSITION ON AFFORDABILITY

This chapter analyses residents' views about affordability, quality of life and value for money at the time of the interviews for this study; in the previous chapter, they were looking back on their decision to move. Have their circumstances now changed? How are they coping? And what trade-offs are they making to manage affordability?

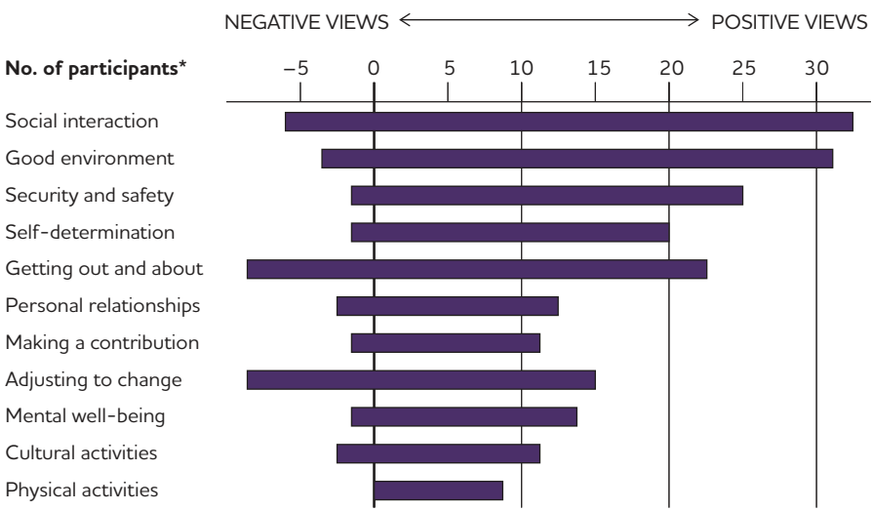
Views about quality of life and value for money

The vast majority (around 85%) of respondents were very satisfied and positive about their quality of life within HWC. This reflects the findings of previous research, for example, Garwood (2008b), Croucher, *et al.* (2006, 2007, 2010), the PSSRU evaluation (Netten, *et al.*, (2011) of 19 not-for-profit schemes, and the ILC-UK study of three providers, mainly for leasehold ownership (Kneale, 2011).

We analysed our interviews with older people using the quality of life headings proposed by Katz, *et al.*, (2011, see Figure 1, p. 20). Although there were many comments about physical health, it was difficult to determine a link between them and living in HWC. We have also omitted several other Katz headings where there was less data.

Figure 2 shows the number of individual respondents who described positive gains and negative issues linked to HWC under specific Katz quality-of-life headings. Bars mainly to the right of the centre line indicate positive responses: this applies to all the headings, although 'Getting out and about' and 'Adjusting to change' had more negative responses than other headings.

Figure 2: Number of research participants reporting positive and negative aspects of their quality of life in their HWC scheme



*For example, 6 people gave negative views about the impact that living in HWC has had on their social interaction; 32 spoke positively about this.

There were several themes that we found striking, which follow.

Social interaction/personal relationships

Many who reported substantial improvements in their social lives since moving to HWC had high care or support needs. Often this was in contrast to isolation in their previous homes; some described how staff or other residents had supported them to mix and participate in activities.

> The scheme manager provides practical help and advice, and she is really good at helping people have a social life here. She realised that some of us would like to have more social events so she has been putting on coffee mornings and 'sherry mornings' on Sundays. She has also made it easier for those of us who are deaf (I am very hard of hearing) to come along and join in. I have needed that kind of help to make me more confident.

Negative comments often related to the changing age, disability and gender profile of residents, and the impact this had had on structured social activities.

HWC also seemed to be particularly good at supporting people's personal and intimate relationships. We met couples who had been enabled to live together, despite care needs of one or both that might otherwise have necessitated a move to a care home. One woman told us:

> We have been married for 67 years and we can carry on living together here even though my husband does need quite a lot of care now.

We were also struck by the number of newly formed couples we met, and how they had been accepted and supported by the HWC community: one couple who met since moving in told us about their engagement party at the scheme.

Getting out and about

This aspect was particularly complex in terms of barriers and enablers: some but not all were directly related to living in HWC. Participants were hindered or helped to get out and about by:

- private and public transport (availability, accessibility and affordability);
- other people's time (family, friends, neighbours, scheme staff and private carers);
- scheme location (especially in relation to shops, public transport and other services);
- design and accessibility of their flat, the scheme and the surrounding local area;
- mobility equipment;
- provision (or lack of provision) and affordability of shopping trips/outings run by the scheme.

Adjusting to change

Most participants seemed philosophical about needing to move from their previous homes, despite the losses and need to adapt resulting from the move. The majority felt they had now made the transition successfully (Godfrey's 'compensation', referred to in Chapters 2 and 6), though they still missed homes, friends, pets and possessions. Although people told us about things others had done (or not done) to help this process, personal attitudes and resources seemed the main driver. One couple described moving to HWC as "quite difficult to start with – it's another phase in your life and you just have to adapt to it". Another woman told us:

> It's difficult to explain how I feel about living here – you can't compare it to living in your own home – but I had just lost my husband and everything then is different.

Participants who felt less positive about HWC

Of the eleven less positive respondents, five had 'internal' or family issues, so although they felt low, this was not necessarily linked to living in HWC. Some voiced concerns about some aspects (e.g. the mix of residents, reductions in social activities) but these problems were balanced out by positive things so did not seem to be ruining their overall experience. Two people (both social tenants) talked about problems in the scheme that had a major impact on their quality of life, although they were both satisfied with their flats.

For some participants, negative perceptions of some or all aspects of quality of life in their HWC scheme echoed their negative views on value for money. The two very dissatisfied social tenants also felt the service charge was high and poor value; as former council tenants, they had no experience of paying a service charge in addition to rent. One commented on the 'brilliant' care staff, but had other criticisms about the HWC scheme. The other was fiercely independent, critical of both quality and cost of all the staff and services, and worried because her savings were running out:

For some participants, negative perceptions of some or all aspects of quality of life in their HWC scheme echoed their negative views on value for money.

> For me it was a shock having to pay extra – having a service charge – and it has gone up from £4 a week to £10 a week. I knew about the basic rent – that was about 10% more than with the council. It goes up more too – it was £34, now its £64. And it's ridiculous the things we have to pay for in the service charge – the gardens, snow clearance last winter that they did not do ...

Four private leaseholders had some criticisms related to value for money: three commented on the "money-making ethos", and the HWC provider "robbing residents". A self-funding tenant thought her HWC scheme was poor value, but her daughter was pleased and felt her mother's expectations were too high.

A number of participants had been reluctant to move, thinking HWC would be like living in a care home but had been pleasantly surprised by the balance between privacy and community: another woman with very high care needs had expected more privacy and been disappointed by the fact that care staff were in and out of her flat all the time.

Value for money

Figures 3 and 4 explore different aspects of value for money. Figure 3 shows the number of participants who felt that, overall, their scheme represented good value for money; those who did not; those who were ambivalent (expressing a mixture of positive and negative views); and those who did not or could not express a view (perhaps because of learning difficulty, confusion and/or the fact that someone else dealt with their finances).

Figure 3: Participants' overall views about value for money at their scheme

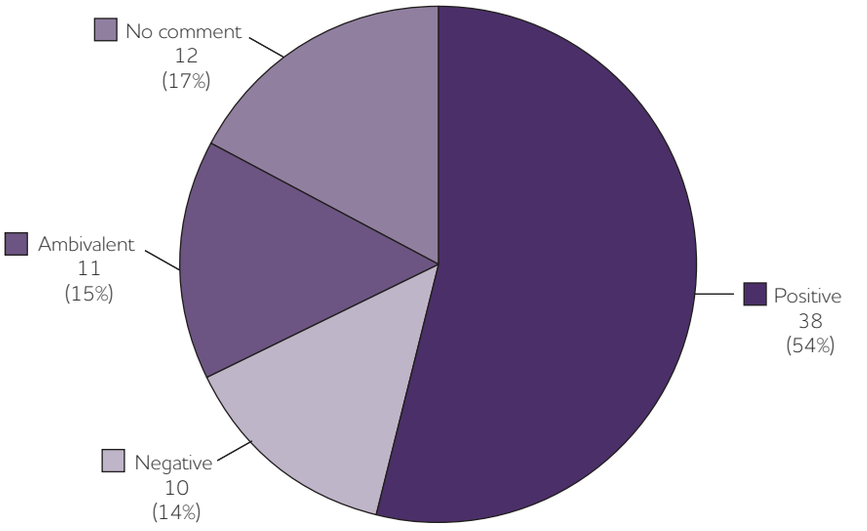
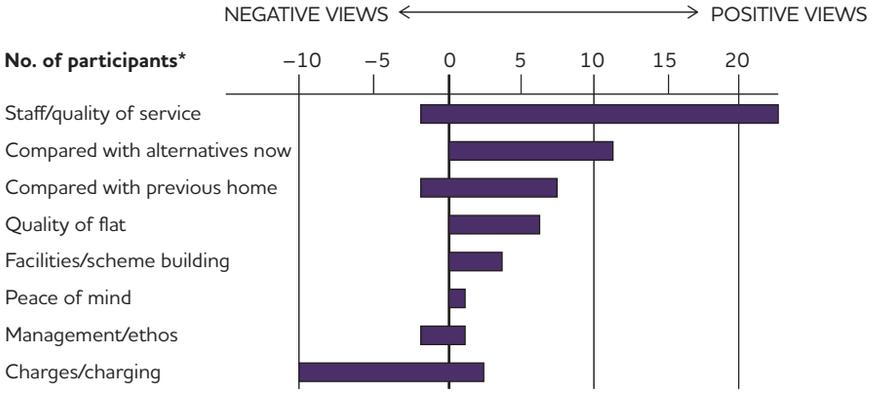


Figure 4: Number of research participants reporting positive and negative judgements about value for money on different aspects of their HWC scheme



*For example, when explaining why they felt their scheme did (or did not) represent good value for money, 22 respondents spoke positively about the staff and/or quality of service; 2 spoke negatively about this. Ten spoke negatively of the amount of charges and/or the way in which charges were calculated or administered.

Below, we highlight the most interesting themes from our analysis of value for money.

Justification of cost

Our findings resonate with Hill, *et al.* (2009), presented in Chapter 2: justification of cost was central to the value for money judgements of many of our respondents. As one said: "The quality needs to be commensurate with the price". It mostly was: the staff, services, flats, facilities were generally felt to be good so HWC did offer value for money:

> I think it is good value for money when you weigh up what you get for the money you have to pay; it's a very nice, comfortable place to live, there are staff available all the time and they are very good, and there is companionship.

Another private leaseholder described her scheme as 'extravagant value for money': very good but very expensive. As the Hill study points out, trust in the ethos and motives of the provider can inform judgements about whether or not costs can be justified. We met several private leaseholders who felt that costs were inflated by their provider's desire to make a profit:

> They [private HWC provider] know how to get the last penny out of you. I feel very angry about it; it rankles about the high cost of living here.

Trust in the ethos and motives of the provider can inform judgements about whether or not costs can be justified. We met several private leaseholders who felt that costs were inflated by their provider's desire to make a profit.

One couple (former owner-occupiers) were renting from a small not-for-profit organisation and felt their scheme represented very good value for money since there were "no directors being paid thousands of pounds in salaries".

Comparisons

As when deciding to move in (see Chapter 3), many participants judged value for money of HWC by comparing costs with running their former home; living in a care home; or paying for outside domiciliary care. For most respondents, these comparisons worked out in HWC's favour:

> It costs a minimum of £600 per month to live here, which I think is quite a lot of money but still I think it is a much better deal than moving into a nursing or residential home. A very nice nursing home near here I know costs £1,400 per week.

The exceptions were the former council tenants mentioned earlier, with higher rent and an additional service charge.

Method of charging

In general, participants felt that all-inclusive charging provided better value for money than itemised billing. Those who paid all-inclusive charges were pleased that there were 'no hidden costs' (private leaseholder) or extras except Council Tax (social renter); whereas a number of people receiving itemised bills seemed to resent being charged for 'every little thing'. One person renting within a private scheme told us:

> The previous place was expensive (£1,700 per month) but that included everything – food, energy costs, the lot. Here, everything is individually costed and it seems more expensive.

Changed circumstances impacting on affordability

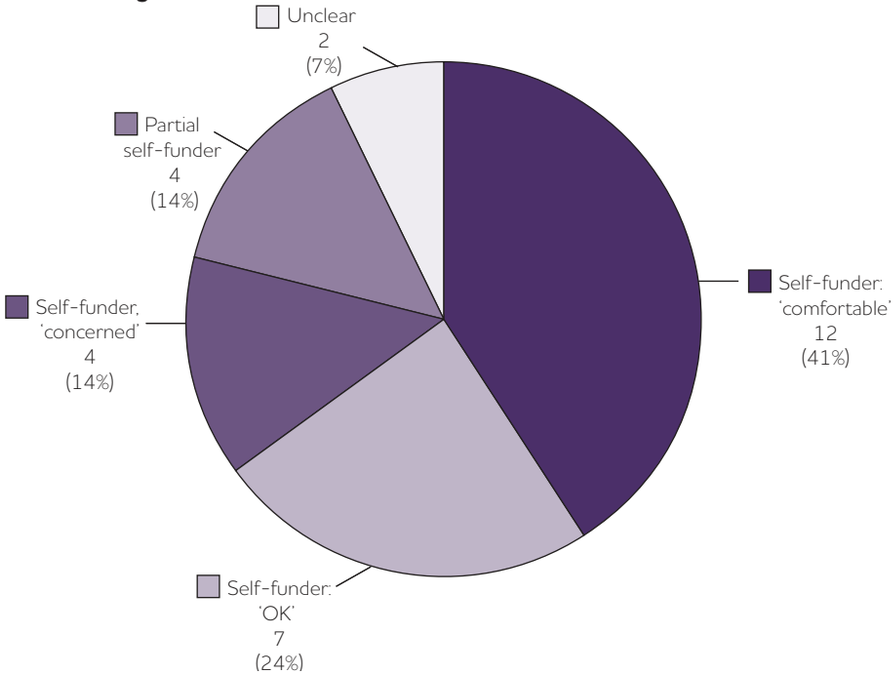
Various factors had impacted on affordability and quality of life. For some participants, factors combined to have a bigger impact:

- a need for more care or other services;
- changes in relation to partner;
- increased charges (in excess of increases in income);
- reduced income (especially for the surviving spouse after bereavement).

Increased needs

For 29 (nearly 40%) of our interviewees, care and support needs had increased significantly since moving into HWC. We have categorised the financial status of this group in Figure 5, based on how they described their financial position. There were 4 partial self-funders, 23 full self-funders and 2 where the position was unclear. The 23 full self-funders can be divided into those who felt they were financially 'comfortable', those who were 'OK' (i.e. they could just about manage but had to be quite careful), and those who were 'concerned', usually about rapidly depleting levels of capital. The partial self-funders were already getting some help with costs so were less worried because of becoming entitled to more help if their income/savings decreased further, or care needs/costs increased. To take two examples, one had needed an extra three hours of care a week but this had been agreed promptly with no increase in costs; another's needs increased but she remained within the same care band, so charges remained the same, but she said she could not have afforded paid care without help.

Figure 5: Number of participants with increased care needs: views of those self-funding care



For nearly everyone else, their care and support needs had:

- increased slightly but were covered by their HWC package (e.g. still within the same price band – see discussion in Chapter 2);
- been relatively high on arrival and had remained constant (or even decreased slightly);

- been up and down (such as needing more care temporarily following a hospital admission, illness, fall. Again, this was sometimes allowed within the package, see Chapter 2).

Changes in relation to partner

As seen in Chapter 3, many respondents moved into HWC as a couple. A common pattern was a planned move together: one as the main carer, the other with high/increasing care needs. Some couple respondents were still in this position; others were at the next stage, as in Table 4 (see p. 38) in which:

- the person with high care needs had died;
- the carer spouse died before their partner with high care needs;
- the person with high care needs had to move into residential or nursing care.

Table 4 also shows different permutations and the effects of later changes (e.g. newly formed couples or increased care needs).

All of these scenarios had a significant impact on affordability. Where the surviving spouse was younger, fitter and with few or no care needs, this made them question the value for money of HWC. The shorter the time between moving in and the death of their spouse, the more they wondered whether they had done the right thing. Where carers die first, the person with high support needs is likely to need significant paid care input and may even find that their needs cannot be met long term within HWC.

Those with a partner in a care or nursing home were especially at risk of financial problems, having to pay high monthly charges to remain in HWC and the additional costs for a nursing home. This was an outcome that even careful planners had often not anticipated. One respondent had been finding things difficult but then applied for and received NHS Continuing Care Funding to pay his wife's nursing home fees in full, although he said there was no guarantee that this would continue indefinitely. Another respondent was very frank: the only reason she did not worry was because she still had some savings from a house sale, and her husband was not expected to live very long.

Those with a partner in a care or nursing home were especially at risk of financial problems, having to pay high monthly charges to remain in HWC and the additional costs for a nursing home. This was an outcome that even careful planners had often not anticipated.

Reduced income

For some widows their income almost halved once their husbands died. The situation also depended on their need for paid care, and whether they had been the carer or had been cared for by their husband. Some widowed leaseholders were still paying the same as before; another told us that her income was much reduced, but this was balanced out because for the time being she needed much less care. Other widows were helped by entitlement to more benefits than as a couple (e.g. getting Housing Benefit).

Increased charges

Several providers and commissioners told us there was concern amongst self-funding HWC residents about service charges increasing. A few leaseholder respondents said they, or their neighbours, were worried. As discussed above, some private leaseholder respondents resented the level of charges and the money-making ethos in their HWC. This is a concern expressed more generally across different models of retirement housing for sale: see, for example, Age UK (2010); Pannell, *et al.* (2012); Blood and Pannell (2012), with some private HWC leaseholders taking over or changing the management of their scheme through the Right to Manage.

Table 4: Care and support needs, changes for couples, financial implications

Original situation	Care/support needs	Change of circumstances	Current situation	Financial implications
Moved in as couple	One or both no/low needs	One or both with increasing care needs	Need more paid help	Increased costs of care
Moved in as couple	One as carer, one with significant care needs	Partner in nursing home	Living as single person in HWC	Cost of nursing home, as well as HWC
Moved in as couple	One as carer, one with significant care needs	Partner who was carer died	Living as widow/ widower with high care needs in HWC	Lower income, higher HWC costs because of need for more paid care; but some residents then became entitled to means-tested benefits (PC, HB, CTB) and help with social care costs
Moved in as couple	One as carer, one with significant care needs	Partner with high/higher care needs died	Living as widow/ widower low/ lower care needs in HWC	Lower income, same HWC costs; but some residents then became entitled to means-tested benefits (PC, HB, CTB)
Moved in as couple	Various as above	Partner died; formed new couple with another HWC resident	Living together as couple	Increased income, lower costs than as two single HWC residents, but would reduce/remove any entitlement to means-tested benefits and help with social care costs, and could affect pensions
Moved in as single person or widow/widower	Various as above	Formed new couple with another HWC resident	Living together as couple	Increased income, lower costs than as two single HWC residents, but would reduce/remove any entitlement to means-tested benefits and help with social care costs, and could affect pensions

Abbreviations: CTB = Council Tax Benefit; HB = Housing Benefit; HWC = housing with care; PC = Pension Credit

However, a leaseholder at one of our fieldwork sites told us that the annual review of service charges in their scheme seemed reasonable. One private provider told us that, in order to attract new sales, they had not increased their charges for the past four years. Another felt that such increases were almost inevitable in future.

Some social tenants described changes to their basic HWC package (e.g. inclusive levels of care, housework or meals) and how these had impacted on charges and affordability. Some partial self-funder interviewees were angry about changes to services 'eligible' for financial help (as a result of local authorities changing their rules on charging, e.g. support tasks such as food shopping, for which the interviewees now had to pay).

Another benefit for those on all-inclusive charges (pointed out by the provider of a scheme which included heating and meals) is that residents can be cushioned from increases in living costs, such as utilities, if a charitable organisation does not pass all these increases on to them.

Coping strategies and trade-offs

From detailed questions about help that residents were getting, from whom, and at what cost, we analysed the trade-offs in terms of affordability, value for money and quality of life. This section discusses how residents were managing increasing needs and costs from finite savings and fixed/reduced income. Approaches included:

- partner (or other unpaid) care input;
- claiming Attendance Allowance/Disability Living Allowance (initial claim, or higher rate);
- claiming NHS nursing care or Continuing Health Care funding;
- lifestyle changes/modest spending;
- financial contribution from family;
- aids and adaptations;
- doing more yourself/going without;
- reduced or no use of HWC restaurant;
- tenure swapping/downsizing;
- use of financial products.

Partners providing care input

We were surprised by the amount of care between partners. For example, a couple who both had serious and multiple physical disabilities had significantly increased the amount of mutual care they could provide, with the support of HWC staff and adaptations to their flat. One wife was providing all her husband's daily care, despite social services' assessment that he needed two care staff because of his loss of mobility. Around a third of participants whose needs had increased significantly since moving into HWC were receiving most/all their care from partners.

We were particularly struck by our four newly formed couples, with one partner providing considerable amounts of care to the other. Decisions to cohabit and/or provide care had been partly motivated by financial reasons. The male partner of one couple explained:

> We talked it over; the care that [woman's name] was having was costing a fortune which she was paying for herself ... I had started to look after her and we decided it would make more sense financially if we lived together rather than having the costs of two properties.

Another couple, who met whilst living in HWC, explained that the man was paying £500 per month care costs until his new partner took over caring for him. She told us:

> He said "I'll be bankrupt", so I said "I've done care work, I can do it – if I did it for a little while then we could put some money behind us ... We could use the money we save on care for treats and for travelling."

Unpaid care and support from others

Chapter 3 showed how sons and daughters had often played a key role in supporting the move to HWC; many continued to provide support around managing finances, as well as social and emotional support and ad hoc practical support. A significant number of respondents were also receiving regular practical care or support from a relative that otherwise would have been charged for, including:

- food shopping;
- transport to health appointments;
- laundry;
- help with bathing.

Whilst many reasons for such support related to the dynamics of the relationship and the familiarity and flexibility a relative could provide, some people were more explicit about the financial savings that resulted. One woman told us that, when the local authority changed the system and help with shopping was no longer 'free' (or at least included in the charges), instead of paying an outside agency, her grand-daughter took over this role (unpaid). Another woman explained that:

> ... living here I do have some flexibility to trim the costs if I need to – I can always ask my son to do more for me rather than paying for additional help from the staff here.

Several participants were receiving continuing financial support from their children, including contributions to ongoing charges or 'lumpy' expenditure, such as servicing the car.

Living cheaply or doing without

Previous researchers (e.g. Price, 2008; McKay, 2004) have identified that older people tend to say that they do not want something when actually they cannot afford it. For example, Dominy and Kempson (2006) found that older people often used phrases such as 'cut down' or 'pulling in a bit' rather than 'can't afford', perhaps so as to be seen to be managing or perhaps because economising is so entrenched they are hardly aware of it any more. We recognise the complexity of picking out 'the truth' here, but we certainly heard these sorts of comments and visited the flats of people who evidently lived very modest lives. Some people told us that they had cut out 'luxuries' such as having a shampoo and set or that they enjoyed 'doing things that don't cost a lot of money' such as reading library books. One veteran who is currently paying up to £1,800 a month for care (on top of housing costs) said:

> I haven't got a great deal of savings and I need to draw my horns in – I used to have a daily paper but I don't any more.

A woman with high care needs was fast approaching capital limits and was waiting to hear whether she would get her housing, care and support paid for. She explained that she buys from charity shops or just does without. She seemed philosophical about meeting her 'needs' rather than her 'wants'.

A voluntary organisation at the English stakeholders' meeting reported cases of older people cutting back on care costs because they needed money for other expenses, including food. In our examples of people going without or reducing their paid care, this was presented as a positive choice. One younger woman recovering from a stroke explained that, by starting to make her own breakfast recently, she had managed to reduce her morning call from one hour to half an hour:

> This has brought me down a care band, which saves a lot of money, but also it has been important to me to challenge myself to improve and get more independent.

This is clearly a positive step, but there were more 'grey areas': people were resisting accessing care because they were determined to remain as independent as possible for as long as possible and were also worried about their finances.

Overall, though, it seemed that those living in HWC may be at less risk of deciding to go without the care they need than older people living in the wider community. As we noted in Chapter 3, many participants had supportive families; several told us that relatives pressured them to spend their money on care. Others said that, because it was easy to access care in HWC and they knew the care staff, they were more likely to buy care, especially in response to fluctuating care needs. Although the scheme manager and staff may not have the power to insist that someone has care if they do not want it, they are in a strong position to monitor changing needs. They can exert considerable influence in persuading someone to access care and help to arrange benefits or social services assessments where appropriate. Because self-funders have chosen to move to HWC and, in many cases, buy leasehold properties, this suggests that they are, as a group, prepared to spend what is necessary to have their needs met.

Many participants had supportive families; several told us that relatives pressured them to spend their money on care. Others said that they were more likely to buy care because it was easy to access and they knew the staff.

Aids and adaptations

A number of respondents had invested significant amounts of their own capital in equipment (e.g. electric wheelchair, hoist), or had made substantial adaptations to their (in some cases rented) flats. They could enjoy greater independence as well as benefiting from lower costs of care and support. HWC staff had helped one man apply for Disability Living Allowance in order to get a mobility scooter. He could then go to the restaurant independently twice a day, reducing his need for support to shop, prepare food and get around the scheme. One woman had paid to install a fully accessible wet room in her leasehold flat and told us that:

> As I now have a standing hoist, I don't need to have two carers with me each time, so it does actually cost me less than before I had the hoist.

We met a couple who had recently married and had spent a lot of money from the sale of their previous homes on doubling the size of the woman's rented HWC end-of-terrace bedsit. The flat had been too small for both of them to live in but it occupied a good location on the scheme site. The

widened doorways mean that the man can move around in the battery-assisted wheelchair they bought and the new wet room enables his wife to assist him to shower without additional paid help. Using the HWC restaurant for all their meals (including regular takeaways) makes her workload more manageable: "It's a wonderful feeling that I don't have to do cooking!"

Boosting income/liquid assets

Most of those who had moved from owner-occupation to social renting were in a strong financial position. They seemed to feel more in control of their finances and less anxious about their ability to foot future care bills than others. None of our interviewees mentioned equity release products, although one 90-year-old leaseholder explained:

> I've still got my bungalow here to sell if I ever needed to live elsewhere – I can still release the equity in my property if I needed to.

One woman had effectively 'downsized' to a smaller leasehold flat to free up capital following the death of her first husband. She was planning to rent this flat out to increase her disposable income now she is living with and caring for her new fiancé.

However, the most common method of boosting income was to apply for benefits, especially non-means-tested disability benefits. As shown above, some had increased their income through benefits after widowhood or secured NHS funding when their partner had moved to a nursing home.

Managing risks and increasing control over costs

Several people described approaches to managing the risk of unexpected outlay or saving for lumpy items, using insurance policies, funeral plans and saving schemes. One woman explained:

> ... now I pay £20 a month so I don't have to worry that my family won't be able to afford to bury me and £11 a month property insurance ... because we're not a family that has a lot of money.

As already discussed, some residents have turned to relatives or private staff in response to rising charges or reduced value for money in HWC. This seems to have given them a sense of control over the service, as in Hill, *et al.*, 2009 (see Chapter 2). The leaseholder above (not at one of our fieldwork sites) who complained about rising charges from the freeholder and managing agent also described how residents at his scheme had collectively exerted their Right to Manage (RTM). Since establishing their own RTM Board and replacing the managing agent two years ago, the leaseholders have saved money through collectively buying water butts and negotiating new contracts for decorating and gardening. As the communal electricity is very expensive, the Board is now trying to install solar panels for longer-term savings.

Conclusions

Most participants described significant gains in their quality of life through moving to HWC. Using Hancock's (1993) framework, affordability problems can manifest themselves in several different ways for older people with high support needs. This might be in under-consumption of care, or of housing,

or in low post-housing/care cost residual incomes – in other words, having very little left to spend once you have paid for your housing and care. This was certainly an issue for some respondents. However, on balance most seemed to feel that trimming smaller pleasures is a price worth paying to secure high quality housing and reliable care and to retain independence, personal relationships and social interaction. A key question, however, is whether – and how – anxieties about the long-term affordability of HWC can be managed. This is considered in the next chapter.

5 THE FUTURE: HOPES, FEARS, CHOICES, DECISIONS

In previous chapters, residents first looked back to the past and then considered their current position. This chapter discusses their uncertainties about the future and whether they can stay in HWC until the end of life. We return to themes explored earlier: help from the state, values and attitudes, changing circumstances and issues for couples.

The key issues discussed in this chapter reflect the uncertainties identified in Figure 1 (Chapter 1, p. 9) in relation to affordability, choice and decision-making in HWC, alongside themes from research literature:

- the desire to remain living in HWC until end-of-life: the issues of wanting to stay, being able to afford to stay, and getting care and support when needs increase;
- values and attitudes towards affordability: coping with anxiety and uncertainty, attitudes to inheritance and attitudes to saving versus spending, linking to research summarised in Chapter 2;
- expectations of what the state will (or will not) provide, as discussed in Chapter 2;
- how affordability concerns affect couples in HWC differently, as raised in Chapters 3 and 4.

HWC and end of life

Wanting to stay

Most participants were very keen to stay in HWC until the end of their lives. When asked about the future, the vast majority said they could not imagine moving elsewhere. Two respondents had specific circumstances: their mothers had moved or were in the process of moving into the same

HWC scheme, which committed them to staying. One woman in her late 50s was reassured to know that, if she had another stroke, she could come out of hospital back to her HWC flat. However, others did have concerns about being able to stay if costs and care needs increased:

> If you are used to being independent it is a good place to live ... (but) I wouldn't say I can easily afford to live here but I can manage at the moment.

Affording to stay

One of the uncertainties for self-funders is whether they will be able to afford to remain living in HWC if costs increase, income reduces or savings run out. Most of our respondents did not express concerns about being able to afford to stay. Ten people specifically said they did not anticipate any problems, for example:

> I don't feel I need to worry about the cost of living here as I am well off enough to be able to pay what it costs to live here. I can see this being my home for the rest of my life.

A few were confident that the local authority would pay (or continue to pay) for them. Two people had planned in detail for different scenarios:

- how many years they could afford if they needed to move to a residential/nursing care home;
- how long they could afford to stay in HWC with full care;
- implications for couples if one partner died/needed more care or could no longer care.

However, a smaller number of residents did express specific concerns about affording to stay in HWC. Five people were concerned about their capital running out and what would happen if it did; another four people were worried about the increasing costs of care, because of care needs increasing, and also inflation:

> [We are] ... both aware that we may need to pay for more help in future and it's difficult to be sure we will have enough to pay for everything.

A few explicitly considered age and health factors in their calculations and said, for example, that it would be a problem financially if they were 20 years younger, or if their partner lived much longer than was expected (given their health condition).

The evidence from our research is that very few local authority commissioners or other professionals have given significant consideration to the affordability of HWC from an older person's perspective. Several professionals pointed out that no-one had ever had to move out of their HWC schemes due to affordability issues or concerns. Commissioners tended to vary in terms of the extent to which they actively consider the position of (current) self-funders in their future planning:

> We have started to include additional top up funding for end-of-life care but we haven't really bottomed out how this will work for self-funders, i.e. what they would need to pay themselves in these circumstances.
> – Commissioner, London

Increasing care and support needs

Another uncertainty about living in HWC was the extent to which increasing care needs can be accommodated in HWC and, if not, what are the alternatives and the financial implications.

A number of people were explicit in stating that they did not want to 'end up' in a care home. This included our careful planners (Chapter 3): one respondent had calculated that he would need to draw down an extra £5,000 a year from capital to pay the on-site nursing home fees.

Another group were resigned to the fact that they and/or their partner might need to move into nursing or residential care if their care needs reached a certain level. However, there was evidence of some confusion about what such a move might cost and how it would be funded.

Where professionals recognised these concerns, they were characterised as a trade-off between spending money on meeting their care needs or retaining their capital and savings:

> Sometimes older people want to minimise their spending on care [earlier] to retain their capital in case they need it in the future to meet care or nursing home costs.
> – Stakeholder (England)

An issue for some HWC residents was the difficulty they found in getting information from staff at the scheme:

> A lady I know who had been living here for about six or seven years became very unwell and she moved to ... a nursing home I think, and then she died soon afterwards ... I wouldn't like that to happen to me – that is my main concern. I have tried to discuss this with the care staff here but I was told 'this is not my department' ... In my experience the care staff don't want to talk about it, staying here for the rest of your life if you become very ill ...

Values and attitudes

A key theme is the values and attitudes of older people (and others) about future affordability of HWC, attitudes toward inheritance, and the potential trade-off between spending and saving. As discussed previously, the desire to remain independent was a first-order value underpinning the desire to remain in HWC as long as possible. Here we concentrate on values and attitudes specifically linked to affordability considerations.

Anxiety and uncertainty

There was an approximately even split between respondents explicitly saying they were worried about affordability and those explicitly saying they were not. General or recurring reasons for worrying about affordability included:

- care needs increasing, needing to move into a care home, partner no longer being able to care as much/at all;
- rising fuel costs, utilities and service charges (also an issue that providers identified from feedback from their residents);
- changes to future income: income from pensions reducing, interest rates falling and/or remaining low;
- capital decreasing and benefit eligibility threshold levels.

> I want to stay here if I have the money, but I have to transfer £1,000 a month and you're allowed £16,000 and its coming down to that now. [scheme manager] would apply for Housing Benefit for me – I do worry a wee bit but I think that I don't need to – when the money is gone, I wouldn't want to be kicked out but I don't think it would come to that – I haven't asked but I'll wait and see what happens.

This was one of a number of participants who knew something about capital limits but may not have had a full enough understanding – benefits entitlement being an area (for both residents and many HWC staff) where 'a little knowledge is a dangerous thing'. As discussed in the *NPI Affordability* study and the *HWC Affordability Guide*, the resident quoted above may already have been entitled to Pension Credit Guarantee (which as of September 2012 has no upper capital limit). Even if capital still exceeds £16,000, significant help can be available: 100% help with Council Tax (tenants and leaseholders); and, for social tenants, help with housing-related support costs and full Housing Benefit (for an example of provider information to tenants and leaseholders, see Housing 21, 2012).

A number of participants knew something about capital limits but not a full enough understanding – benefits entitlement being an area where 'a little knowledge is a dangerous thing'.

Recurring reasons for not worrying about affordability included:

- having sufficient financial means to live in HWC; being 'financially OK';
- other members of the family already do/would if necessary provide financial support;
- another person dealt with the older person's finances (although in a case where we spoke to the relative, s/he was more worried than the older person about affordability);
- the age and/or health of the individual and/or their partner (some respondents did not expect to live much longer, so affordability was not a cause for concern);
- a few expected that social services would pay if they ran out of money;
- some had planned their finances carefully, often with family.

However, even for careful planners, anxiety and uncertainty about affordability did have an impact on their quality of life. Several participants wanted to stay living in HWC, and did not want to be dependent on their children financially, but identified that 'the worst is the uncertainty' about future costs, especially care costs. Even amongst careful planners, there was a desire for some kind of cap on care costs or more attractive financial 'products' to pay for care which would help remove or reduce uncertainty:

> If I needed a lot more care and help I think I could stand about six to eight years from my capital if my care needs increased dramatically. I did look at some care insurance type products but have been put off by the size of the up-front payments. If the costs could be met on death, that might be more attractive.

Inheritance

Tensions between passing on an inheritance and funding the costs of HWC, particularly paying for care, were raised by both older people and by professionals.

About a dozen participants raised inheritance and related issues, such as not wishing to be a financial burden on their family after death. For some, the desire to leave money for their children impacted on worries about spending/not spending money on themselves.

> I suppose I know that I can afford to live here because I have the money from my sister's house but I do worry about being able to leave this to my children rather than being forced to spend the money on living here.

However, others (one of whom had expressed such concerns) also said their relatives were urging them to spend now, rather than pass it on to them later. For example, one family had agreed to their widowed mother funding HWC from a trust fund left by her husband for them:

> Downsizing from our previous house has made it possible but I do feel like it's my children's inheritance so I don't like to be extravagant with it ... I have three children who are all very supportive and they all pushed us to come here. They tend to say 'don't think about us, we don't need the money' but you don't know what's in the future.

A few residents thought people should spend to meet needs, rather than save it for children's inheritance:

> A lot of people here, they've got money but they won't spend it, they want to leave it to their children. I'm of the opinion that my money is for me, my sons are doing OK, so I'm happy to spend what I need.

Professionals commented that although older people worried about inheritance, their families were usually much more concerned with them being comfortable now. They also identified more specific issues: for example, the deep resistance to selling the family farm for rural families. For leaseholders and inheritance, in the current market, those inheriting a leasehold HWC property may not be able to sell or be permitted under the lease to rent out. In addition, they usually have to pay the service charges until the property is sold. Even if allowed to rent it out privately, there may be additional charges and they still have to find a suitable tenant.

Saving versus spending

Chapter 4 included discussion of strategies residents used to help save money. Tensions between saving money for the future or spending it were raised by older people and professionals. One couple explained very clearly their dilemma when planning for the future:

> My family all lived into their 90s – a cousin lived to 102 – I'm only 76! If I knew I only had five years to live I'd probably go on a cruise, but what will I do when I have to pay for more help?

Expectations of future state support

We found differing attitudes towards the role of the state in funding the costs of HWC and a lack of clarity both amongst older people and professionals. Several participants were proud to be independent and were clear that they did not want 'hand-outs' (also reflected in previous research, e.g. Finch and Kemp, 2006):

> Supposing I live long enough that the money from the house goes; I'm told the government take over – is that right? I think that's what happens. I would like to die before that would happen; I wouldn't want to have money from the government.

Some were more accepting of state funding, and a few talked about their contributions (often for what they described as little or no money) to society generally: in the war, as a carer, doing manual labour for decades 'for peanuts'.

Reflecting the findings from some of the literature referred to in Chapter 2, several providers said that older residents tended to be proud and independent. In particular, they did not like to admit to financial problems or needing help unless they absolutely had to. Professionals from local authorities and providers said it was essential to get across to older people and their families the need to make some financial provision for themselves. They acknowledged the lack of clarity and information available to support informed planning and decision-making by older people and their families in relation to living and remaining in HWC, especially financing care needs.

Several providers said that older residents tended to be proud and independent. In particular, they did not like to admit to financial problems or needing help unless they absolutely had to.

Professional interviewees suggested (perhaps growing) differences between the four UK nations on expectations of what the state will provide:

- in Northern Ireland a deep resistance to accepting any help from the state (huge pride in independence);
- in Scotland a deep resistance to paying for social care;
- in England in particular, and to a lesser extent in Wales, wider acceptance that many people are already paying for their own care and the proportion of older people who self-fund is likely to increase.

Couples living in HWC

As noted in Chapters 3 and 4, an unexpected element of this research was the number of older people who were (or had entered HWC as) couples and the extent to which affordability concerns affected couples in particular.

Residents who were better off, and careful financial planners, had assessed affordability for the future:

> I have worked it all out that my wife would get half my pension, and her state pension and Attendance Allowance and she can still afford to stay here even if she needs full care, which would cost £700 to £800 a month on top of the housing costs of around £700 a month.

The private providers we interviewed seemed to be well aware of the affordability issues when one partner needs to move to a care home or dies.

> We know that another issue for our residents and some potential residents is where a couple move in and the main pension holder dies and therefore the pension income falls for the surviving partner.
> – Large, private retirement/HWC provider

A range of issues had an impact on individuals (and the state) in relation to affordability for couples if the main carer could no longer continue in that role. We found considerable variation in the amount or type of care that HWC schemes could provide in response to very high and increasing support needs – and whether the provider could, and would, act as an advocate for a resident who wanted to stay when social services or medical professionals were pressuring them to move on. Affordability is a factor in these circumstances, both in terms of whether or not self-funders can afford to stay but also whether professionals or family push for a move to institutional care because it will work out cheaper than very high levels of care input in HWC.

6 CONCLUSIONS AND REFLECTIONS

This chapter returns to the original research questions on decision-making, quality of life, value for money and affordability. We reflect on key messages, and consider implications for policy and practice. Finally, we see how far our study has answered the questions and uncertainties that self-funders face in housing with care.

Our reflections emphasise the things we found surprising or unexpected; our conclusions have a policy and practice focus. Practical implications concerning benefits advice are explored in the *Practice examples* linked to our parallel study, *Whose responsibility?*

We return to the concepts (in Godfrey, *et al*., 2004) on the stages of moving into, and remaining in, HWC, and link these to findings from and analyses of 'resident journeys'.

- **Selection:** HWC residents have made a decision to move from their previous housing, although this may also be a *loss*.
- **'Compensation' or Adjustment:** HWC residents *adjust* to living in a different setting, perhaps in a new area and probably in a smaller property.
- **Optimisation:** HWC residents can (hopefully) take advantage of the new *opportunities for personal development and growth* offered within HWC – for example, to meet new people and enjoy new activities.

Research questions

At the outset, we aimed to find out how affordability of HWC affects choice (of care and other services) by those who decide to move in, and the consequences for residents' quality of life.

In addition, the research brief included supplementary issues which fall into three broad areas:

- decision-making: timing, processes, who decides?
- quality of life: for the individual, for the scheme as a whole (i.e. all residents) and the perspective of HWC providers and commissioners;
- value for money: different perceptions by individuals, family, providers and commissioners, and how HWC costs compare with other options (staying put, other housing, residential/nursing care).

Decision-making

Most of the people we spoke to were very realistic, philosophical and positive – are these the sort of people who make a planned move to HWC? If so, HWC gives them the independence they crave and a new phase of life. Or is this only the case for people who were willing to speak to us? How do increasing support needs – or support needs that were expected to increase but have not – and affordability shape these reflections? Even where they felt some loss of their previous home, most had moved from the selection phase to the compensation phase and adjusted to their new life. Many were clearly well into the optimisation phase, even if they had significant health issues/support needs.

We found that there was a high degree of family involvement in the initial decision to move into HWC for most participants, with significant family support often continuing throughout their stay. There were gender issues here too: most support came from daughters/daughters-in-law. We wonder if there is a social exclusion issue: what happens to older people who do not have close family? Or to those who are estranged from their family and do not have a replacement such as the social workers who were involved with some residents who had learning difficulties, mental health issues or safeguarding concerns? Without close family/social care input, they may be less likely to know about, or be able to organise, a move to HWC. Is this a bigger exclusion factor than affordability or lack of money? From our relatively small number of interviewees, and the extent of family involvement, we suspect that older people without family are more likely to be excluded, but this study can only raise and not answer these questions.

What happens to older people who do not have close family, or a replacement such as a social worker? Is this a bigger exclusion factor than affordability or lack of money?

Most respondents were clear that they had exercised voice, choice and control over deciding to move into HWC even if family (or others) had also been involved. There were question marks around this at the outset for some of those who had been strongly influenced by relatives or those who had a cognitive impairment. However, most did later reflect that they were happy to have moved into HWC. This contrasts with research on care homes where a lot of people make a move in which they feel they have exercised little voice, choice and control, as discussed in Bowers, *et al.* (2009).

An unexpected finding was the relevance of making the decision to move in as a couple, and the many different outcomes from this later. Many of our respondents had since lost their partner (who was in some cases the main carer), and in a few cases the partner had moved into a care home). In such circumstances, residents were at risk of finding themselves in a difficult situation in terms of affordability.

Timing was tricky: careful planners had more chance to decide when to move, although sometimes their choice was restricted by availability (as for the man with dementia who had moved sooner than ideal to get a ground-floor flat suitable for his elderly cat). Crisis movers had less choice and were sometimes less involved in the decision than the 'careful planners'. They were also more likely to move to HWC as an alternative to a care home. This contrasted with planners, for whom it was more likely to be a lifestyle move

ahead of needing more care, or to enable a partner to carry on their caring role with the extra support available in HWC.

A surprising finding was the number of different strategies for managing higher care needs. A number of HWC residents were not using much of the care/support/domestic help provided in HWC, but instead relying on partner/family/private purchase (e.g. a private cleaner). These decisions were sometimes (but not always) linked to saving money. Other reasons included more control over availability or what a private help would do and, for some, a strong desire to remain independent at all costs. There were also lots of interesting trade-offs (often to reduce the need for paid care, such as buying a mobility scooter to get to the restaurant; paying to install a walk-in shower in an older HWC scheme).

Another unexpected finding was the willingness of former owner-occupiers to rent; this included market rent as well social rent. Sometimes this was because there was no alternative owner-occupied HWC. However, in other cases, the older person/couple made a clear decision to rent in preference to full or shared ownership, challenging the assumption that home-ownership is always the most desirable option for older people.

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Quality of life

Residents were overwhelmingly satisfied with their quality of life, and in this respect HWC is a good example of how finances can play an enabling role to achieve this (as discussed in Chapter 5 and the factors identified in Katz, *et al.*, 2011).

It was clear that HWC was especially suitable for couples. For our respondents, it provided a better quality of life than other settings: they could stay together, and if one was caring for the other the carer received support. We spoke to a number of couples where one partner had dementia, and the other was supported in their caring role by being in HWC. In at least one case, the carer partner died unexpectedly during the course of the research project, but the person with dementia was able to remain and be supported in HWC.

A surprising finding was the number of residents (both interviewed and observed in scheme visits) who had high support needs but no (or very low) personal care needs. Examples included people with a learning difficulty/mental health issues, or previous issues with loneliness/alcoholism/depression (sometimes following bereavement). Their needs could be met at fairly low cost by using the basic services available in HWC, but without a large (and potentially expensive) individualised personal care package. HWC appeared to be an especially attractive option for them, providing a very good quality of life and good value for money for self-funders, personal budget-holders and commissioners. Supporting factors included meals, social activities, the built environment, safety/security and informal interaction with other residents.

One delightful and unexpected finding was the number of new couples we met! In our parallel report, *Whose Responsibility?* we point out that HWC fulfils people's human rights, including to relationships in later life: this was evidenced by the newly formed couples. These were perhaps the most marked examples of optimisation and personal development and growth, but there were many other examples of new friendships and new interests, reflecting the Katz research that everyone, including people with high support needs, desires new interests, challenges and personal relationships.

Overall satisfaction with HWC was reflected in the large number of residents who were clear that they wanted to stay to the end of life if possible. However, there were some anxieties around this aspect, including its affordability, and it was not always dealt with well by HWC staff. This aspect of HWC is already explored extensively in guidance and reports, but perhaps these are not always reaching frontline staff. For example, see Crosbie, *et al.* (2008), Croucher (2009), Centre for Housing and Support (2010), Percival (2010), Housing 21 and NHS (2009) and NEoLCP/Housing LIN (2012).

No-one talked about having to move out of HWC to another setting for affordability reasons, although some were worried about what they would do as their capital decreased. The issues concerned whether their care needs would become too high for the particular services on offer in their HWC scheme.

Value for money, overall affordability

Although most residents and their families thought HWC was good value for money, there were some differences of opinion on this. Especially in the more upmarket private HWC, this was summed up by the resident who described it as "extravagant value for money". Some relatives felt it was better value for money than did their parents living in HWC; a few residents thought it poor value because of dissatisfaction with various aspects of services, charging practices and overall management. It also depended on whether residents were comparing HWC costs with institutional care or with their previous housing.

Many people we spoke to were fully self-funding and managing all right financially, usually because they had good occupational pensions and/or significant savings. This included those we classified as 'tenure-swappers' who often (though not always) had released significant equity from their house sale. Age and health were important factors here: for those who were older, their money was likely to last even if care needs increased, or at least they were not too worried because they were relying on family or the state to step in if needed.

Those who were more worried included where there had been unexpected and unplanned changes of circumstances, especially for couples (e.g. when one was in a care home and the other still in HWC or following bereavement). Some were more concerned because they were younger, and they did not know how long they had to make savings last; others reflected that they would have been more worried if they had been younger/if they (or their partners) were expected to live longer.

Good occupational pensions seemed to insulate people more from worry than big chunks of capital, unless people were very old/not likely to live very long. Also, the higher the husband's occupational pension, the higher the (usually half) pension for his widow if he died first. Few of the married women we interviewed had an occupational (or even state) pension in their own right. Some commented that they had only paid the married woman's 'stamp', even if they had worked; others had been carers for most or all their adult lives. In contrast, most single women had worked and some of these had an occupational pension (typically from nursing or teaching), but not at the same level as the better-off men who had been in senior public sector posts.

Good occupational pensions were more important than capital. Few married women had pensions in their own right. Most single women had worked and some had occupational pensions, but lower than the better-off men.

A few respondents had lower income/savings, and were already partial self-funders or on their way to being so. Some had received good advice at

the outset and were clearly receiving the benefits they were entitled to: this applied especially to social renters. Others seemed unclear about what help they would get from the state especially where capital was decreasing. In many cases there was no clear route through the HWC provider (especially in private schemes) to obtain such information, either when deciding to move in or as savings reduced. There was particular confusion over capital limits – this is not surprising because there are different limits for Pension Credit, Housing Benefit, support charges and care charges, and differences between the four nations.

We did not have many partial self-funders. Most respondents were paying in full for their housing (all the leaseholders and two-thirds of tenants). Of those (nearly half) receiving paid-for care, most were paying in full. The evidence is comparatively limited from our interviews of 'lower-income' self-funders because there is a gap in the HWC market for this income group. That is, people who are above benefit thresholds may not be eligible for publicly funded HWC, but do not see themselves as 'wealthy' enough to afford much of the private sector HWC provision, marketed at the 'luxury' end of the spectrum. This is discussed in Pannell, *et al.*, 2012.

We spoke with HWC residents from all four UK nations. Across the four nations, there were both similarities and differences in comments made by residents; to some extent this reflected the types of HWC and extent of self-funding across each nation. For example, we spoke only to social housing tenants in Northern Ireland and Scotland because there is very little private HWC, and the small number of personal budget-holders we interviewed were living in England. The two key factors where the differences between the devolved administrations amplified differences between residents' views about affordability were: whether they were social housing tenants or private leaseholders, and also which charges were or were not covered by help from the state. For social tenants, the different charging methods affected their views on affordability and value for money. For example, in Northern Ireland there were few affordability concerns where Supporting People funding covered more of the costs than elsewhere, and care charges were fully covered through claims for higher-rate Attendance Allowance for all residents, including self-funders.

There was evidence of more general resistance to self-funding in HWC amongst some residents from the devolved nations, which may reflect the different policies of the devolved governments (e.g. the Scottish system of free social care, compared with means-tested access to state-funded social care in England). Many of the commissioners and provider stakeholders we spoke to from Wales and Scotland were sceptical about the scope to expand significantly the private/self-funding HWC market because generally lower housing values made it unaffordable for many older people to buy into HWC.

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Policy/practice conclusions

Personal budgets/self-directed support

These were almost irrelevant in our study. As in *Whose Responsibility?* it seemed that it was the model of HWC that empowered residents, rather than the 'managed' budgets. However, where 'personalisation' and personal budgets have been introduced systematically by local authorities in relation to HWC (Staffordshire seems to be the only example we found of this),

they have had a significant effect on the HWC market. In effect, care providers are having a business relationship with the person with a personal budget, rather than a contract for care with a local authority. Some of our commissioner and provider participants also suggested that there was some evidence of local authorities moving away from contracting for care on a 24/7 basis, and seeking for providers to include overnight cover as part of 'well-being' charges that may be levied as an additional cost to residents. However, we did not find direct evidence of this at the schemes we visited.

Commissioning

There were lots of issues around how each HWC scheme is set up, and the implications for affordability. This links to our other report on boundaries, roles and responsibilities. There is little evidence that local authority commissioners are aware of affordability considerations and concerns from an older person's perspective or that they are looking at this issue across the whole population of older people in their area.

The evidence suggests that local authorities consider affordability in terms of their affordability of the costs of HWC. We found little evidence of local authorities and providers 'modelling' the affordability of either existing or planned HWC schemes in relation to the current or proposed costs against the local income/demography of the older population.

HWC scheme arrangements/Right to Manage

There are also issues about transparency of costs (especially service charges), consultation and control for residents, and the RTM (for private sector leaseholders only). These themes are also explored in *Whose Responsibility?* As discussed in Chapter 5, there are concerns in both owner-occupied and rented HWC about charges increasing ahead of income, and especially about these increases being outside residents' control. More generally, this relates back to the key uncertainties about affordability, choice and decision-making (see Chapter 1, p. 9).

Benefits issues

There appeared to be a lack of benefits advice and information in many HWC schemes, but with a range of practice from nothing/very little to very good. This is explored in more detail in the *Practice Guide*.

HWC staff and residents mostly appear to understand Attendance Allowance but it was less clear whether they understood the link with entitlement to Pension Credit, housing costs and 'passporting' to other help (especially Council Tax). There was also great confusion about capital limits; many of the residents we spoke to may be entitled (especially to Pension Credit Guarantee) but residents, staff and families probably do not know this. Even if not entitled yet, as capital reduces, some may become entitled in the future (and perhaps sooner than they think). This could then have a significant effect on affordability of HWC, especially for those with high or increasing care needs. It might have enabled them to avoid having to cut back on expenses, like the veteran from the Battle of Britain who could no longer afford a daily paper because of increasing care costs, or the couple worried about the cost of a taxi and hotel costs to attend a family wedding.

Future changes to the benefits system (especially the delay in accessing Pension Credit, and the 'bedroom tax') will impact especially on younger HWC residents and on couples with an age difference – because Pension Credit entitlement will only start when the youngest reaches state retirement age (whereas at present it is based on the age of the oldest). In addition, there is considerable uncertainty regarding future benefit funding

Future changes to the benefits system will impact especially on younger HWC residents and on couples with an age difference.

for supported housing (including HWC), specifically in relation to Housing Benefit, which may affect the affordability of HWC for residents reliant on Housing Benefit to cover rent and service charges.

Final reflections

If we return to the residents' key uncertainties, what have we found?

Can I afford to stay here? That depends ... on income and savings, of course, and on changes for couples when one dies, but also on whether or not anyone advises me properly about my entitlement to benefits; and which UK country I live in; and the way my HWC is set up and managed; and, if I am a leaseholder, whether I get the help with support costs, ground rent and service charges that I should be entitled to.

Can I get the care and support I need? Probably ... and maybe I won't need much paid personal care because HWC will meet most of my needs in other ways ... but if I do need it, paying for personal care could be a problem, especially in England; (for couples) in HWC we can live together, and my partner can probably carry on caring more easily than where we lived before ... as long as s/he remains in good enough health.

Will the HWC scheme stay the same? That's more difficult to predict ... of course there will always be changes – nothing in life stays the same – but it also depends on wider commissioning and funding decisions (if publicly funded) or change of provider (all sectors) ... , ... and whether as residents we will have any control (or even be consulted) is an area that needs more attention from HWC providers, commissioners and funders.

Will I be able to stay here until the end of my life? Well ... it would help if the staff were able to be clearer with me – but then how much am I willing to talk about it either? At least as a self-funder I may have more choice than residents who are fully state funded, if I am willing to spend money to buy in extra help – but it will also depend on the facilities and staffing models offered in my HWC.

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