

Beyond social care:

Keeping later life positive



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Executive summary

Most people do not want to think about getting old and will not plan for the possibility of needing care. Behavioural research suggests that this will remain the case even if people are better informed about how the social care system works, the choices they may face and the costs they may incur.

So it is important that the design of the social care system reflects this and can respond quickly and effectively at times of crisis. People need to be able to find relevant information and advice and be supported to make good decisions quickly.

The Which? Elderly Care website helps people make care choices and, informed by research to tell us what people want and need from our site, a new and improved site will be live from September 2018: Which? Later Life Care.

Prevention needs to be framed positively. Rather than encouraging people to plan for care, it would be more effective to encourage people to take steps to continue to live independently and enjoyably at home for as long as possible.

This means marketing products and services positively and not using messages which stigmatise getting older. The Government's Ageing Society Grand Challenge, funded through the Industrial Strategy Challenge Fund,¹ provides an opportunity for the development of well designed, innovative and attractive options that promote the positive concept of choice and active living.

Consumers will respond better to those they trust. And we know that people trust GPs and healthcare professionals, relevant charities and friends and family. So a redesigned social care system should recognise this. The Government should consider how the work of GPs and social workers can be more closely integrated to identify vulnerable patients and provide signposting and information on social care. Health and social care provision needs to be much more integrated to meet the needs of older people. It is important that the Government presses ahead with proposals for joint health and social care assessments, plans and budgets.

¹ The Industrial Strategy Challenge Fund aims to bring together the UK's world-leading research with business to meet the major industrial and societal challenges of our time. This challenge will invest up to £98 million in research and innovation to support the aspirations of people as they age and provide better, more effective care when it is needed. It aims to help people to live independently in their homes, tackle loneliness, increase independence and wellbeing.

Introduction

Which? is the largest consumer organisation in the UK with more than 1.3 million members and supporters. We operate as an independent, apolitical, social enterprise working for all consumers and funded solely by our commercial ventures. We receive no government money, public donations, or other fundraising income. Which?'s mission is to tackle consumer detriment by making individuals as powerful as the organisations they have to deal with in their daily lives. We empower consumers to make informed decisions and campaign to make people's lives fairer, simpler and safer.

Older people who need social care support are increasingly being expected to act as consumers - often with enormous price tags attached. Around one in ten elderly people with care needs now face care costs of over £100,000.² But the social care market does not function effectively. Consumers are often not presented with meaningful choices about the care they receive and they often make decisions under stress and without proper information. We welcome the Competition and Markets Authority's consultation on draft consumer law advice for care homes. This provides clear advice to care homes on their existing legal obligations to provide key information to consumers. But there is still inadequate support to guide people through the full range of choices and options open to them. Once care is in place people are often nervous about complaining for fear of making matters worse. This social care market is not working for the people it is intended to serve.

The Government is planning to publish a long-awaited Green Paper on social care in England in the autumn. Using our unique understanding of how consumers think and behave, this report looks at how consumers engage with social care in practice. We want Government to design proposals which go with the grain of consumer behaviour to meet the needs of those who are using the system and make a positive impact. In particular, we look at whether consumers should or could be better prepared for care and whether they can be better encouraged to make choices which enable them to lead an independent and fulfilling later life for longer. And given that many consumers will need to access the formal care system at a time of crisis, we look at how they can be supported when they are at their most vulnerable.

This report is based on: behavioural science; a demographically representative survey of 2,104 UK adults in June 2018; a roundtable discussion with experts in the field of social care; and existing evidence and consumer insight.

² Lord Darzi (June 2018) *Better Health and Care for All: A 10-point plan for the 2020s - The Lord Darzi review of health and care final report* IPPR.

Over the summer we will be looking in more detail at the experiences of people navigating the care system in England and the extent to which people in later life are managing to remain independent at home.

As social care is a devolved matter, this report references how social care is organised in England, but discussion of consumer views and behaviour is likely to be relevant across the UK.

Chapter 1 – Consumers will resist thinking about care until they need it

Most people don't want to think about - let alone plan for - their potential future care needs. This may be in part due to widespread misunderstanding about how the social care system works and the choices people may face. But it is also driven by innate human traits. Behavioural research suggests that simply providing more information is unlikely to make much of a difference. Most people will only think about care when they are approaching, or are already at, the point of need.

Life is unpredictable

It's hard for any of us to know what our needs will be in the future. And most of us do not want to think about getting old and the possibility that we might not be able to look after ourselves or our loved ones in the future.

Preparation and early engagement with the care system could help individuals to receive the care they want and avoid unnecessary stress.^{3 4 5} Last year's care homes market study by the Competition and Markets Authority highlighted how, by planning ahead, consumers could have a better understanding of how the social care system works and what their options are, enabling them to make more informed choices under less stressful circumstances than if they delay and end up in crisis.⁶

Whilst there is evidence to show that consumers who plan ahead have better outcomes,⁷ our research suggests that it is unrealistic to expect most people to do this planning.

More than eight in ten (84%) people 65 years and over say that it is difficult to predict whether or not they will need care in later life and half (52%) say that it is more of a priority for them to plan for other things they want or need to do now or in the immediate future. Only four in ten people aged 65 years and over have discussed their preferences for the care needs they may have in

3 Mullick, A., Martin, J. & Sallnow, L. (2013) *An introduction to advance care planning in practice*. BMJ, 347, p.f6064.

4 Detering, K.M., Hancock, A.D., Reade, M.C. & Silvester, W. (2010) *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*. BMJ, 340, p.c1345.

5 Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

6 Competition and Markets Authority (November 2017) *Care Homes Market Study: Final report*.

7 Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

later life with a relative or friend.⁸ This is not surprising - asking consumers to state clear preferences for later life care is impractical when their future state of health and well-being is unknown.⁹ And not only is it difficult for anyone to predict their future care needs, but also what the future itself might look like in 20 to 30 years' time.¹⁰ While older people acknowledge the benefits of 'being prepared', they also say it is important 'not to worry too much about the future'.¹¹ People worry that trying to plan for all the possible eventualities outside their control could cause anxiety and end up being counterproductive.¹²

"I think you've just got to take it as it comes, sort of thing, you know. I think if you planned in advance for (getting worse), you'd, sort of, be a bit of a defeatist. You know, you'd think, 'Oh, it's going to happen so I might as well accept it,' whereas I'm not like that, I'm the other, sort of, way round, you know. I just think, 'Yes, if it happens, it happens', but I'm not going to live my life thinking negatively."

*"I always feel it's being a bit pessimistic if you, sort of, especially where you are fit and healthy and you start thinking, 'Oh, well, in a few years' time I might have this, and I might have that. I'll have to plan.' You've just got to live your life in my opinion and wait and see if it happens, and then work round it. That's how I feel about it, because otherwise you can get so pessimistic that you can almost think you've got things wrong with you when you haven't. Then, when you have got things wrong with you, you've just got to still get on with it."*¹³

People have a negative view of social care and focus on 'worst case' scenarios

When asked about social care, older people jumped immediately to discussing severe care needs which would require moving into a care home,¹⁴ despite the fact that only a quarter are likely to need residential care during their lifetime.¹⁵

8 Which? (June 2018) *Elderly care - Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

9 Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

10 Roundtable discussion held with stakeholders on 18 June 2018. A note of this discussion is at Annex 2.

11 Age UK (April 2018) *Financial resilience during retirement: Who is well placed to cope with life events?*

12 Age UK (April 2018) *Financial resilience during retirement: Who is well placed to cope with life events?*

13 Collaborate Research, on behalf of Which?, conducted interviews with 29 older adults aged 60 years or over, along with 12 carers. The sample comprised the following groups: people living in their own home with no support but show signs of vulnerability; people receiving local-authority funded care in their own home; people living in age-specific accommodation without any formal care; and people living in age-specific housing with some formal care. Interviews were all conducted face-to-face during July 2018 and the locations covered included Greater London, Eastbourne, Yate (a small semi-rural town in the South West), Birmingham and Newcastle. This research is on-going and unpublished.

14 Age UK (April 2018) *Financial resilience during retirement: Who is well placed to cope with life events?*

15 Dilnot Commission (July 2011) *Fairer Care Funding: The Report of the Commission on Funding of Care and Support*.

“I wouldn’t want to go into a care home. I’ve worked in them. They’re not all bad but I’ve seen some really bad ones. My mother was in a really bad one, and in the end they got closed down and taken to court.”¹⁶

Unlike most consumer engagement which generates feelings of satisfaction and happiness, engagement with the social care sector is frequently a matter of necessity and produces strong negative feelings. This also discourages people from engaging with the care market until the last possible moment.¹⁷

Improving people’s understanding of the social care system is unlikely to compel them to plan for it

Even if consumers are better informed about the possibility of needing to arrange social care in the future, most will not voluntarily make significant plans for it unless and until they are approaching the point of need. This is backed up by behavioural science. The Behavioural Insights Team identified behavioural factors which make people unlikely to engage early in decisions about care:¹⁸

- Guilt and anxiety – these lead us to underestimate the benefits and overestimate the risks of a scenario. People have a fear of care homes, of home care, and of losing their or their loved ones’ assets. Relatives can often feel guilty at admitting they are no longer able to care for a loved one themselves.
- Optimism bias – the idea that ‘it won’t happen to me/my relative’.
- Availability bias - we make judgements based on what we know. A recent Which? survey found that three in ten people thought it unlikely that they would get good quality care through the social care system.¹⁹ If expectations are low, people are put off engaging early with the care system.
- Present bias - we tend to overly discount the costs and benefits of something that might occur in the future. So people are putting their resources into a present need rather than planning for potential future social care needs.
- Status-quo bias – we tend not to take action on something unless our attention is actively drawn to it or we have no other choice.
- Omission bias – people have a strong preference to avoid *actively* doing something that might potentially lead to a negative outcome because they then feel less responsible for the potential harm.

¹⁶ Collaborate Research, on behalf of Which?, conducted interviews with 29 older adults aged 60 years or over, along with 12 carers. The sample comprised the following groups: people living in their own home with no support but show signs of vulnerability; people receiving local-authority funded care in their own home; people living in age-specific accommodation without any formal care; and people living in age-specific housing with some formal care. Interviews were all conducted face-to-face during July 2018 and the locations covered included Greater London, Eastbourne, Yate (a small semi-rural town in the South West), Birmingham and Newcastle. This research is on-going and unpublished.

¹⁷ Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

¹⁸ Behavioural Insights Team (November 2017) *Helping people make better decisions in the care home market: Final report for the Competition and Markets Authority*.

¹⁹ Which? (June 2018) *Elderly care - planning for later life* Populus, on behalf of Which?, surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

Behavioural research carried out on behalf of Which?²⁰ supports these findings and also highlights additional factors that would be a challenge for any policy interventions to overcome:

- Unfamiliarity – since planning for potential care needs is both unfamiliar and based on predictions about unknown future needs, consumers are unable to express clear preferences about what care they will want in later life.
- Lack of urgency – a perceived lack of urgency can impede people from planning early.
- Fear of regret – faced with an array of choices, people can feel confused, stressed and anxious for fear of making the wrong choice,²¹ viewing other options as missed opportunities.^{22 23 24}
- Stereotypes of ageing – stereotypes of ageing in most Western cultures are primarily negative, depicting later life as a period of ill health, loneliness, and mental and physical decline. Ageing triggers fears of frailty and illness and discourages people from seeking medical attention.²⁵ Research has shown that activating negative ageing stereotypes in older adults reduces their likelihood of choosing care options that would prolong their independence or improve their quality of life.²⁶
- Affective forecasting – this term refers to the fact that people generally overestimate their ability to adapt emotionally to living with declines in health and to overcome adversity.²⁷ They are also generally poor at predicting their ability to control emotions such as anxiety, uncertainty, sadness, and guilt that may influence behaviour and preferences.²⁸ Consumers may delay care decisions, thinking they can cope with crises as they come.²⁹ Yet in the care sector, physical discomfort (e.g. pain), crises and emotionally-charged states (e.g. anxiety) normally contribute to more impulsive behaviours, including choices which may not have been made if given more time and support.³⁰

20 Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

21 Umali, G., Case, R. & Miller, B. (2016) *Older people are paying the price for cuts to social care*. The King's Fund. Available at: <https://www.kingsfund.org.uk/press/press-releases/older-people-social-care-cuts> [Accessed May 18, 2018].

22 Iyengar, S.S. & Lepper, M.R. (2000) *When Choice is Demotivating: Can One Desire Too Much of a Good Thing?* *Journal of Personality and Social Psychology*, 79(6), pp.995–1006.

23 Botti, S. & Iyengar, S.S. (2006) *The Dark Side of Choice: When Choice Impairs Social Welfare*. *Journal of Public Policy & Marketing*, 25(1), pp.24–38.

24 Schwartz, B. (2004) *The Tyranny of Choice*. *Scientific American*, 290, pp.70–75.

25 Auman, C., Bosworth, H.B. & Hess, T.M. (2005) *Effect of health-related stereotypes on physiological responses of hypertensive middle-aged and older men*. *Journals of Gerontology – Series B Psychological Sciences and Social Sciences*, 60(1), pp.3–10.

26 Levy, B., Ashman, O. & Dror, I. (2000) *To be or not to be: The effects of aging stereotypes on the will to live*. *OMEGA*, Vol. 40(3), 409–420.

27 Winter, L., Moss, M.S. & Hoffman, C. (2009) *Affective forecasting and advance care planning: Anticipating quality of life in future health statuses*. *Journal of Health Psychology*, 14(3), pp.447–456.

28 Loewenstein, G. (2005) *Hot-Cold Empathy Gaps and Medical Decision Making*. *Health Psychology*, 24(4, Suppl), pp.S49–S56.

29 Croucher, K. (2008) *Housing Choices and Aspirations of Older People*. Research from the New Horizons Programme, DCLG.

30 Behavioural Insights Team (2017) *Helping people make better decisions in the care home market*. Available at: <https://assets.publishing.service.gov.uk/media/5a1fd914ed915d458b922ec0/bit-cma-care-home-market-report.pdf>

Taken together, these innate human behaviours and the unpredictabilities of planning for old age mean that most people are unlikely to proactively plan for their care before they need it. We believe efforts should focus instead on building a better public understanding of how the social care system works in order to make it easier for people to navigate the system if and when they need it, and on encouraging people to make positive changes to enable them to live independently for as long as possible. We discuss in the next chapter how this can be best achieved, starting from where consumers are currently prepared to engage.

Chapter 2 – What can be done to engage people in preparing for later life?

Products and services which are specifically marketed towards ‘the elderly’ are viewed negatively and with the stigma of ‘old, frail, vulnerable’ attached. People can also be put off installing home adaptations because they do not wish to ‘medicalise’ their home.³¹ Yet people overwhelmingly want to remain living in their own home. This chapter explores how people might be motivated to make lifestyle choices to enable this if the messages, products and services are marketed positively.

People want to stay living in their own home

Six in ten (61%) people aged 65 years or over said that they would happily move to a different property if their current one no longer met their care needs in later life and just under half (47%) said that they would be willing to move into sheltered housing or a retirement village if their health and mobility deteriorated.³²

However, once the need to move actually arises, people tend to be reluctant to make the change. Older people have often invested in their homes over a long period of time and feel a strong sense of attachment to their home and community.³³ A recent study of older people with reduced mobility found that despite facing many challenges within their home environment, the majority wanted to stay in their own homes and rejected opportunities to move to a more suitable property.³⁴ Separate research found that, after the onset of significant disability, more than four-fifths of older people wished to remain in their present homes, supported by community-based services. Only 5% wanted to move either to a residential home or in with family members.³⁵ Seventy-nine per cent of people said they would prefer their end of life care to be at home.³⁶

31 Powell, J, Mackintosh, S, Bird, E, Ige, J, Garrett, H, Roys, M. (November 2017) *The role of home adaptations in improving later life* Centre for Ageing Better, UWE, BRE.

32 Which? (June 2018) *Elderly care - planning for later life* Populus, on behalf of Which?, surveyed 2104 UK adults online between 11th and 12th June 2018. The data were weighted to be demographically representative of the population.

33 Hughes, N. (April 2012) *A better fit? Creating housing choices for an ageing population*. Shelter.

34 Centre for Ageing Better (July 2018) *Homes that help: A personal and professional perspective on home adaptations*.

35 Wanless, D (2006) *Securing Good Care for Older People: Taking a Long Term View*, London: Kings Fund.

36 Public Health England (2014) *What We Know Now*.

People we interviewed³⁷ with increasing care needs displayed a strong desire to stay in their own home even when those homes appeared to be increasingly unsuitable for their needs:

A 72 year old woman suffers from Parkinson's Disease which affects her mobility and speech and she has herniated spinal discs. She lives in a basement flat with her partner which has six stairs that she is finding increasingly difficult to manage, yet she is reluctant to move if it is avoidable. She is very attached to her long-term home - she has lived there 25 years – and has a wide circle of friends in the local area.

An 83 year old male with complex health needs including a severe vision impairment and insulin dependent diabetes has had a number of falls at home and is recovering from shingles. He rents a two-bedroom Housing Association flat where he lives with his wife. He has lived there for 13 years. The flat has 16 stairs leading up to it, no lift, and very few adaptations (just grab rails and a toilet frame). Despite its lack of suitability for his current care needs, he does not wish to move out of his current home as his children live nearby. He worries that he would be forced to move too far away if he asked the council for more suitable accommodation.

People could be motivated to make lifestyle changes to support independent living

Which? thinks that people can be better motivated – and should be encouraged – to think more widely about lifestyle changes they might make to support an active and independent later life in the home of their choice. This might include moving home (e.g. downsizing or moving to one level) and/or adapting their existing home or lifestyle (e.g. home adaptations, home help services and new technology and equipment). Experts at our recent roundtable discussion noted that actions can also include more widely accessible, less financially burdensome activities such as developing and maintaining social networks and adopting a healthier lifestyle.³⁸ All these options could improve people's quality of life in later years and increase the chances of people being able to stay in their own home for longer.

Nine in ten (92%) people aged 55 years and over say they would be willing to install home adaptations if their health and mobility deteriorated and nearly nine in ten (89%) say that they would be willing to use mobility aids outside the home.³⁹ More than eight in ten (86%) people aged 65 years or

37 Collaborate Research, on behalf of Which?, conducted interviews with 29 older adults aged 60 years or over, along with 12 carers. The sample comprised the following groups: people living in their own home with no support but show signs of vulnerability; people receiving local-authority funded care in their own home; people living in age-specific accommodation without any formal care; and people living in age-specific housing with some formal care. Interviews were all conducted face-to-face during July 2018 and the locations covered included Greater London, Eastbourne, Yate (a small semi-rural town in the South West), Birmingham and Newcastle. This research is on-going and unpublished.

38 Roundtable discussion held at Which? on 18 June 2018. A note of this discussion is at Annex 2.

39 Which? (June 2018) *Elderly care – Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

above said that, if their health and mobility deteriorated, they would be willing to use a gardener, cleaner or handy person to help with activities that might be more difficult and six in ten (62%) say that they would be willing to use smart technology. Experts at our roundtable discussion noted that increasing numbers of over people over 65 years old are using internet connected technology.⁴⁰ Nonetheless, there are limited levels of awareness of the technologies available, how to access them, and their potential benefits, and equipment can be both expensive and appear complicated. Of carers not already using telecare or telehealth⁴¹ services, almost two-thirds were unaware of the support available from this technology and a quarter would like to use it but simply do not know where to find it.⁴²

Minor home adaptations can have positive results

There is strong evidence that minor home adaptations are a cost-effective intervention for preventing falls and injuries, improving performance of everyday activities and improving mental health. Low-cost home modifications could lead to a 26% reduction in falls that need medical treatment and savings of £500 million each year to the NHS and social care services in the UK.⁴³ Adapting homes could also offset the need for residential care for many; the average Disabled Facilities Grant (used to adapt homes) is £7,000 (one-off payment) compared to the average residential care cost per person of £29,000 per year.⁴⁴ Interviews we carried out with people with a range of care needs demonstrated how the right mix of aids and support could enable them to stay living at home and improve their quality of life.⁴⁵ The best outcomes are achieved when individuals, families and carers are closely involved in the decision-making process around home adaptations, focusing on individual goals and what a person wants to achieve in their own home.⁴⁶

People are put off by ‘ugly’ adaptations and products marketed to ‘the elderly’

Whilst people say they would be willing to consider home adaptations if they need them in the future, the reality is that people are often put off from installing them until they reach a point of crisis because they do not

40 Roundtable discussion held at Which? on 18 June 2018. A note of this discussion is at Annex 2.

41 Telecare is support and assistance provided at a distance using information and communication technology. It is the continuous, automatic and remote monitoring of users by means of sensors to enable them to continue living in their own home, while minimising risks such as a fall. It can include gas and flood detection and prompts e.g. to take medicine. Telehealth systems can be used to remotely monitor health signs, such as blood pressure.

42 Carers UK (September 2012) *Carers and telecare* supported by Tunstall Healthcare.

43 Centre for Ageing Better (November 2017) *Room to improve: The role of home adaptations in improving later life*.

44 Foundations (2015) *Linking Disabled Facilities Grants to Social Care Data* available at <http://www-foundations.uk.com/media/4210/foundations-dfg-foi-report-nov-2015.pdf>

45 Collaborate Research, on behalf of Which?, conducted interviews with 29 older adults aged 60 years or over, along with 12 carers. The sample comprised the following groups: people living in their own home with no support but show signs of vulnerability; people receiving local-authority funded care in their own home; people living in age-specific accommodation without any formal care; and people living in age-specific housing with some formal care. Interviews were all conducted face-to-face during July 2018 and the locations covered included Greater London, Eastbourne, Yate (a small semi-rural town in the South West), Birmingham and Newcastle. This research is on-going and unpublished.

46 Powell, J, Mackintosh, S, Bird, E, Ige, J, Garrett, H, Roys, M. (November 2017) *The role of home adaptations in improving later life* Centre for Ageing Better, UWE, BRE.

wish to change or ‘medicalise’ their home.⁴⁷ Products specifically marketed towards ‘the elderly’ are viewed negatively and with the stigma of ‘old, frail, vulnerable’ attached.⁴⁸ If people are to be encouraged to make changes in preparation for later life - which might include, for example, installing a downstairs toilet, grab rails, investing in labour-saving devices – it is important that there are options available that are attractive and which promote the positive concept of choice and active living.

*“The [raised] toilet seat, at the moment it’s in the boiler room. I’m saying I’ll try and manage without it, I can do it. We used to have it in the bathroom and it didn’t look very nice did it really. If we could buy something that looks nicer, you know?”*⁴⁹

The ability to ‘future proof’ a home will be driven, to large extent, by affordability. People who need assistance to get adaptations will not qualify for support until the need arises, and even then they may have to wait a long time for installation. There is evidence of council tenants, for example, waiting twelve months for a stairlift to be installed and six months for a walk-in shower.⁵⁰ Tenants in privately rented accommodation may also struggle to obtain agreement from the landlord to make changes to the property, especially if there is no perceived immediate need.⁵¹

There is a shortage of accessible housing stock that is ‘fit for a lifetime’

Older people who have sought to move have not found it easy to find suitable properties either to buy or to rent,⁵² and evidence suggests there is a shortage of desirable accessible housing and bungalows in both the private and social sectors.⁵³ In 2005–06, over 750,000 people aged 65 and over were estimated to need specially adapted accommodation because of a medical condition or disability. Of these, 145,000 reported living in homes that did not meet their needs.⁵⁴ Age UK argue that these figures are now likely to be even higher.⁵⁵ The proportion of housing having all four of the following accessibility

47 Powell, J. Mackintosh, S. Bird, E. Ige, J. Garrett, H. Roys, M. (November 2017) *The role of home adaptations in improving later life* Centre for Ageing Better, UWE, BRE.

48 Centre for Ageing Better (July 2018) *Homes that help: A personal and professional perspective on home adaptations*.

49 Collaborate Research, on behalf of Which?, conducted interviews with 29 older adults aged 60 years or over, along with 12 carers. The sample comprised the following groups: people living in their own home with no support but show signs of vulnerability; people receiving local-authority funded care in their own home; people living in age-specific accommodation without any formal care; and people living in age-specific housing with some formal care. Interviews were all conducted face-to-face during July 2018 and the locations covered included Greater London, Eastbourne, Yate (a small semi-rural town in the South West), Birmingham and Newcastle. This research is on-going and unpublished.

50 Croucher, K. (February 2008) *Housing Choices and Aspirations of Older People*. Research from the New Horizons Programme, DCLG.

51 Arthur, S. Christie, A. and Mitchell, R. (March 2018) *Unsuitable, insecure and substandard homes: The barriers faced by older private renters* Independent Age.

52 Croucher, K. (February 2008) *Housing Choices and Aspirations of Older People*. Research from the New Horizons Programme, DCLG.

53 Communities and Local Government Commons Select Committee (9 February 2018) *Housing for Older People*.

54 House of Commons Women and Equalities Committee (25 April 2017) *Building for Equality: Disability and the Built Environment*.

55 Age UK in evidence to House of Commons Women and Equalities Committee (25 April 2017) *Building for Equality: Disability and the Built Environment*.

features – level access to the entrance, a flush/level threshold, sufficiently wide doorsets and a toilet at entrance level – was just 7% in 2014.⁵⁶

The Women and Equalities Select Committee⁵⁷ and RIBA⁵⁸ have both called for the National Planning Framework to make better provision for accessibility and inclusion. In addition, earlier this year the Communities and Local Government Select Committee⁵⁹ called for the Framework to be amended to emphasise the importance of the provision of housing for older people and to ensure that the assessment of need explicitly addresses the housing needs of older people.

Despite nearly half (47%) of people over 65 years old surveyed saying they would be willing to consider sheltered housing or a retirement village in later life,⁶⁰ concerns about the cost of, and costs associated with, specialist housing, as well as its resale value, may deter older people from purchasing this type of property.⁶¹ Specialist housing tends to cost more to buy than its non-specialist equivalent and most is leasehold. Leaseholders are required to pay regular service charges for the upkeep of the facilities and for the shared services. They may also be required to pay ground rent. In addition, substantial fees payable by the leaseholder, typically on the sale of the property, are common.

“I think it’s all far too much money, because my son’s mother in law, she was going to see about one, actually. They’ve got a bigger house than us, and she said, ‘No, we just can’t afford it. We just can’t afford that.’ It was all, like, the extras that you had to pay, you know, like the upkeep of it, and all things like that. I mean, it looked lovely, and I did see some brochures that she showed me. I don’t think it would have been for us.”⁶²

We need to change the narrative around later life

With the population aged 85 and over set to double over the next two decades or so,⁶³ a fundamental shift in the way we think about preparing for later life is required. This needs to move away from thinking about ‘care’ and towards consideration of the lifestyle changes people can make to ensure they can continue living independently, enjoyably, and safely in their own home. Better

56 House of Commons Women and Equalities Committee (25 April 2017) *Building for Equality: Disability and the Built Environment*.

57 House of Commons Women and Equalities Committee (25 April 2017) *Building for Equality: Disability and the Built Environment*.

58 RIBA (2016) *Housing Matters: Twenty ways to tackle the housing crisis*.

59 Communities and Local Government Commons Select Committee (9 February 2018) *Housing for Older People*.

60 Which? (June 2018) *Elderly care - planning for later life* Populus, on behalf of Which?, surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

61 Communities and Local Government Select Committee (9 February 2018) *Housing for Older People*.

62 Collaborate Research, on behalf of Which?, conducted interviews with 29 older adults aged 60 years or over, along with 12 carers. The sample comprised the following groups: people living in their own home with no support but show signs of vulnerability; people receiving local-authority funded care in their own home; people living in age-specific accommodation without any formal care; and people living in age-specific housing with some formal care. Interviews were all conducted face-to-face during July 2018 and the locations covered included Greater London, Eastbourne, Yate (a small semi-rural town in the South West), Birmingham and Newcastle. This research is on-going and unpublished.

63 Office for National Statistics (October 2017) *National Population Projections: 2016-based statistical bulletin*.

designed, innovative products and services which support people to live independently and are attractive and enjoyable to use can enable consumers to feel they are making a positive choice about the way they wish to live as they get older. And planning for the future can go beyond home adaptations and the purchase of gadgets to include healthy living – diet, exercise and the maintenance of social networks. The NHS has long recognised the benefits of disease prevention. It is now time for this to be translated into the realm of social care. But for this to work it is imperative that there are options available that promote the positive concept of choice and active living.

Older adults have been shown to rate positive pamphlets as more informative than negative ones and to remember a higher proportion of positive to negative messages.⁶⁴ This suggests that older people are open and potentially more responsive to positive messaging around health and social care.

The Ageing Society Challenge⁶⁵ provides an opportunity for the development of well designed, innovative and attractive options that promote the positive concept of choice and active living. The Government should also consider how it can better support people with lower disposable incomes and those living in private rented or social housing to receive the adaptations and support they need at an early stage.

64 Shamaskin Garroway, A. M., Mikels, J. A., & Reed, A.E. (2010) *Getting the Message Across: Age Differences in the Positive and Negative Framing of Health Care Messages* cited in Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

65 The Ageing Society Challenge is funded by the Industrial Strategy Challenge Fund which aims to bring together the UK's world-leading research with business to meet the major industrial and societal challenges of our time. This challenge will invest up to £98 million in research and innovation to support the aspirations of people as they age and provide better, more effective care when it is needed. It aims to help people to live independently in their homes, tackle loneliness, increase independence and wellbeing.

Chapter 3 – The social care system needs to support people to take decisions in a crisis

The design of any new social care system needs to recognise that most people will not plan for care and must ensure that the system can respond quickly and effectively to people's needs as they arise. Given that social care is complicated and unfamiliar, many people will need direct support at the right time to help them make the best choice for their circumstances.

Consumers need support to make good decisions when needs arise

Decisions around formal social care are often made as a result of a crisis event such as a fall, bereavement and/or loss of informal care (usually a partner), under stress and time pressure. Our research suggests that this is unlikely to change. The social care system must therefore recognise this.

Time pressure can have a detrimental effect on decision making ability.⁶⁶ Anxious individuals are more likely to rely on advice and tend to be less discerning between good and bad advice.⁶⁷ Consumer research around care homes⁶⁸ finds that people feel they have little support to help them navigate the system or understand the complexities of the sector, with many left feeling overwhelmed by the process and powerless, feeling their final choice is forced.⁶⁹ Forty per cent of care arrangers found the experience of arranging care and support for themselves or on behalf of someone else to be stressful or distressing.⁷⁰

For those looking to move elderly relatives into a care home, the pressure from hospitals to free bed space, competition for limited care home spaces and need to settle the resident quickly means the search for a care home is often urgent and people feel rushed into making decisions. Time pressure and stress, combined with perceived lack of choice, means that many opt for a home that is 'good enough', with 17% of care arrangers saying they settled for a home they had reservations about and 18% saying they had regrets about their choice.⁷¹

66 Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

67 Tay, E. and Massaro, S. (2018, working paper) *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review*.

68 Ipsos Mori (August 2017) *Care homes: consumer research*. Report for the CMA.

69 Ipsos Mori (August 2017) *Care homes: consumer research*. Report for the CMA.

70 Which? (April 2014) *The Care Maze: The challenges of navigating care for older people*.

71 Which? (September 2017) Populus, on behalf of Which?, surveyed 764 UK adults online who had arranged residential or nursing care for either themselves, a family member or friend in the previous 12 months, between 14 and 20 September 2017. The data is not weighted as there is not a definitive profile of people who have helped to arrange care.

Our research has found significant failings in the advice and information provided to consumers by care homes and frequent problems with unfair contracts.

In a survey of people involved in arranging a care home place, only 53% agreed that they had all the information they needed to make the right decisions and 21% disagreed.⁷²

We contacted 50 care homes on behalf of an elderly relative requesting documents including a sample contract – fewer than one in ten provided the information. We received four contracts – three of which included terms that could be considered unfair to residents – including charging fees for a month after death and the right to terminate a contract with 24 hours’ notice for undefined “detrimental behaviour”. The other 46 homes did not send a sample contract, in most cases urging our investigators to visit or directing them to websites that did not provide the information.⁷³

In addition, Which? spoke to more than 500 people about their experiences with care homes and only 54% said the provider checked if the resident or their relative understood the contract. More than a quarter (27%) said no-one from the care home checked if they understood the terms and conditions, while 19% said they did not know if checks were made. Of those who said no checks were carried out, almost a third (31%) said they did not understand the contract at all, or did not understand it very well. Although most people in the care arrangers survey (81%) claimed to understand their care home contract well, there was confusion around important terms.⁷⁴

The Competition and Markets Authority is working to address these issues by preparing consumer law advice for care homes.⁷⁵

Which? welcomes this and has responded to the consultation.

Consumers need to know where to go for information and advice

Many consumers are unsure where to go for information and advice about social care. Whilst the local authority is responsible for social care, nearly half (45%) of the population say they would approach their GP to explore care and support options for either themselves or a loved one, and this increases to nearly six in ten (57%) of those aged 65 years or over.⁷⁶ People trust their GP to give good advice

72 In November 2017, Which? carried out a survey among 1,012 members of the general public who had been involved in arranging long-term care in a care home for themselves or someone else. 573 people responded to questions about care home contracts.

73 Which? contacted 50 care homes by telephone posing as the relative of a prospective resident to request additional information, including contracts in June/July 2017.

74 In November 2017, Which? carried out a survey among 1,012 members of the general public who had been involved in arranging long-term care in a care home for themselves or someone else. 573 people responded to questions about care home contracts.

75 <https://www.gov.uk/government/consultations/care-homes-for-the-elderly-draft-consumer-law-advice>

76 Which? (June 2018) *Elderly care – Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

and support (81% compared to 60% for social workers)⁷⁷ whilst older people overwhelmingly have a negative view of social workers, unless and until they have a good experience of one.⁷⁸ This is largely driven by a lack of understanding about what constitutes ‘social work’ and what social workers do.⁷⁹ However, GPs are often not well versed in the variety of care options open to older people and they can tend to focus their advice around care homes. GPs themselves underestimate the influence they have over people’s social care decisions, with only 9% thinking they have a significant influence over people’s care choices.⁸⁰

Only a third of those whose care is fully self-funded had consulted their local authority for information and advice on care compared to three quarters of those whose care is fully or partly council-funded.⁸¹ Local authority provision of information and advice about adult social care is variable. They do not always co-ordinate the information they provide in a way that is helpful to consumers;⁸² there are wide variations in the quality of information on social care on local authority websites;⁸³ and reliable information on quality providers of care services is often lacking.⁸⁴

A recent Which? survey found that people were most likely to say that they would first do a Google search to explore options on later life care.⁸⁵ Since 2014 the Which? Elderly Care website has provided information and advice to help people make informed decisions around care and support in later life. The site’s advice ranges from financing care and housing options to how to deal with common concerns, including falls and dementia. It also contains a care services directory with details of more than 20,000 care providers across the UK covering care homes, home care agencies and support groups for people living with dementia. Following recent research to tell us more about what people want and need from our website, a new and improved site will be live from September 2018: Which? Later Life Care. A new content structure will make the site easier to navigate, and consumers accessing the site’s services from mobile devices will have an improved experience. Local information will be easier to access through the care services directory and we will have even more information relating to finance, including a new tool to help navigate the complexities around paying for care.

77 Which? (June 2018) *Elderly care – Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

78 Penhale, B. and Young, J. of UEA Consulting Ltd (March 2015) *A Review of the literature concerning what the public and users of social work services in England think about the conduct and competence of social workers* prepared for The Professional Standards Authority.

79 Penhale, B. and Young, J. of UEA Consulting Ltd (March 2015) *A Review of the literature concerning what the public and users of social work services in England think about the conduct and competence of social workers* prepared for The Professional Standards Authority.

80 Which? (April 2014) *The Care Maze: The challenges of navigating care for older people.*

81 Which? (April 2014) *The Care Maze: The challenges of navigating care for older people.*

82 Improvement and Development Agency (IDeA) (March 2009) *Transforming adult social care: access to information, advice and advocacy.*

83 LGA (July 2014) *Adult social care efficiency programme: Final report.*

84 The Nuffield Trust (26 June 2013) *Evaluating integrated and community-based care: How do we know what works?*

85 Which? (June 2018) *Elderly care – Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

Figure 1: On average, those aged 65 years and over are more likely to use a GP, local council website, social worker or friends/family to explore their options for care and support.

Imagine you are looking into care and support options either for yourself, a relative or a friend.
Which of the following, if any, would you use to explore your options?

Base: All respondents (2,104) 65+ (479)

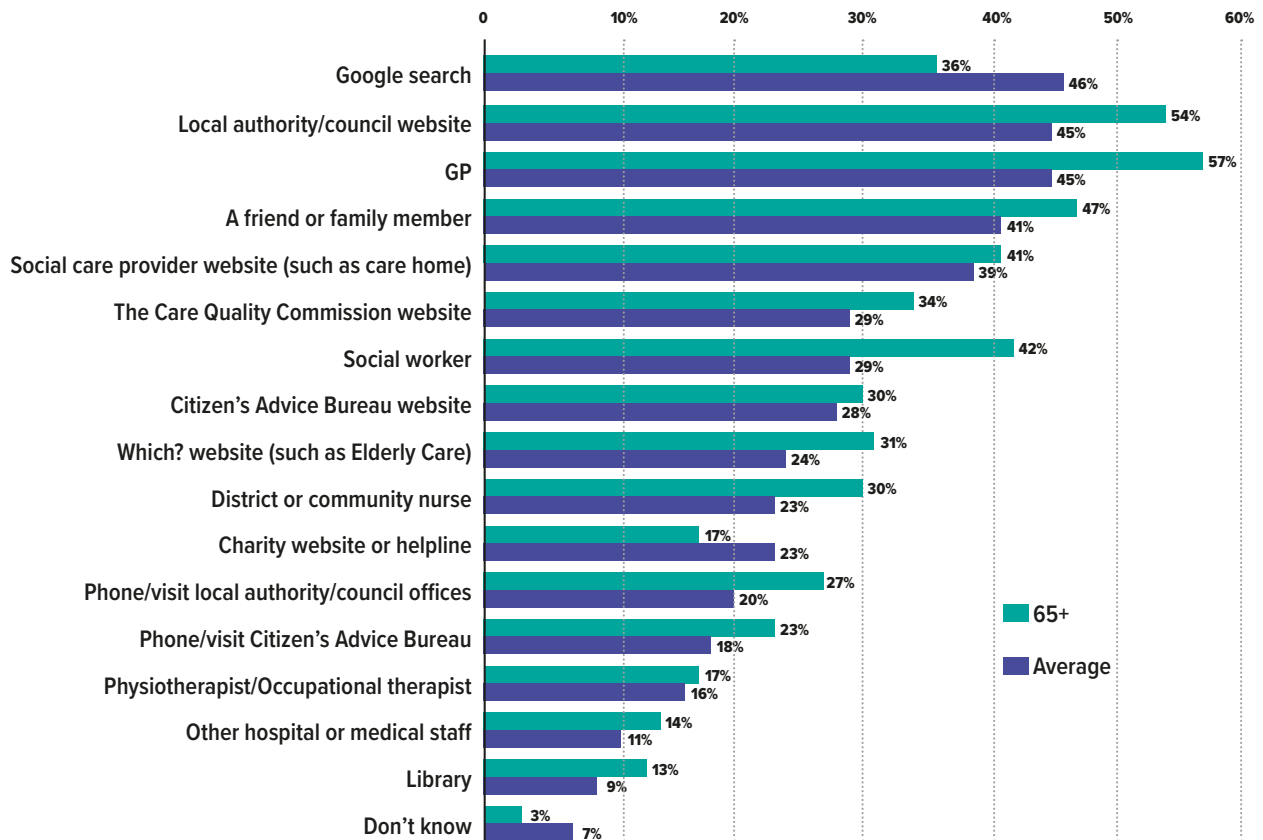
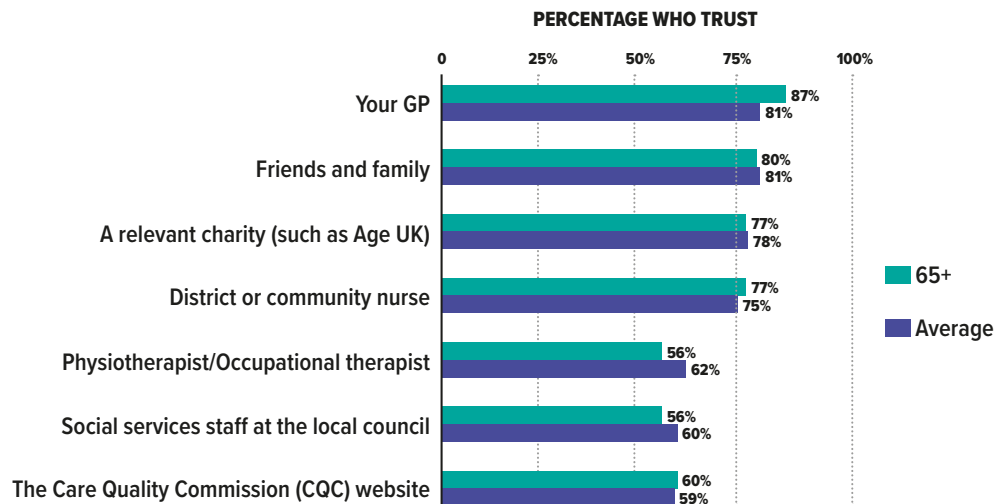


Figure 2: Significantly more over 65 year olds trust their GP to provide good advice about care and support than any other source.

How much do you trust the following to provide good advice about care and support?

Base: All respondents (2,104) 65+ (479)



Our survey found that eight out of ten (78%) people trust relevant charities to give good advice about care options.⁸⁶ Charities such as Age UK provide valuable advice and support to help older people remain independent in their own home, including through ‘Care Navigators’. These navigators provide a wide range of advice and support such as: managing money and benefits; home adaptations; finding appropriate care and support; help to complete forms; and support to navigate the care assessment process. But this cannot be left to charities; the Government must act to ensure that all consumers have access to high quality information, advice and support.

Consumers need high quality, tailored and joined-up advice about care options

People need support not only to work out what type of care would be appropriate but also to be made aware of all the different factors that could be relevant to their situation – from benefits and funding advice to support for carers. For example, 70% of care arrangers either incorrectly thought their entitlement to a local authority needs assessment depended on their level of assets or income or didn’t know whether it was or not.⁸⁷

In 2014 Which? called for consumers to have access to holistic information and advice in the form of a ‘care consultation’ designed to identify all potentially relevant issues, before being referred to more specialist sources of advice. Yet in July 2018 the Care Quality Commission highlighted that integrated service provision continues to be patchy. Where it has seen evidence of inter-agency cooperation, this results in safer and more caring customer journeys, but there continues to be a need for health and social care provision to be much more integrated to meet the needs of older people.⁸⁸

Sixty-three per cent of people think the NHS provides social care services for older people⁸⁹ so many look to their GP – or other NHS healthcare professionals – for advice on care needs. The Government’s Green Paper on social care should acknowledge this and put forward plans to better signpost people to the right advice when they need it. Since increased care needs are generally associated with deteriorating health, GPs are likely to play a role in identifying an impending need for care. The recent Care Quality Commission local authority area reviews concluded that the role of general practice in providing signposting and information is critical.⁹⁰ The Government should consider how the work of GPs and social workers can be more closely integrated to identify vulnerable patients and provide signposting and information on social care. This move could also increase levels of trust in social workers and bridge the gap between where people look for advice (their GP) and who holds that information (social services).

86 Which? (June 2018) *Elderly care – Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

87 Which? (April 2014) *The Care Maze: The challenges of navigating care for older people*.

88 Care Quality Commission (3 July 2018) *Beyond Barriers: How people move between health and social care in England*.

89 National Audit Office (4 July 2018) *The health and social care interface*.

90 Care Quality Commission (3 July 2018) *Beyond Barriers: How people move between health and social care in England*.

Conclusions

Social care is in urgent need of reform. We need a care system that provides consistently high quality care regardless of an individual's health condition, their ability to pay or their postcode. In order to fix this broken market, the social care system must be designed to meet the needs of the consumers who will be using it. It is positive that the Government has recognised this by committing to publishing a Green Paper. The new social care system needs to be realistic about how consumers are likely to engage with it. The Green Paper must recognise that:

- 1. Consumers will not plan for care** – Most consumers will not voluntarily plan or make provision for their future care unless and until they are approaching the time of need - which is often a crisis point. Evidence shows that there are a range of innate human behaviours which, taken together with the unpredictabilities of old age, mean most people are unlikely to proactively plan for their care before they need it. More than eight in ten (84%) people over 65 say that it is difficult to predict whether or not they will need care in later life and more than half (52%) say that it is more of a priority for them to plan for other things they want or need to do now or in the immediate future.
- 2. The social care system must work effectively for people at their time of crisis** – People need personal support along with high quality, tailored advice to help them make the best choices for their situation. The new Which? Later Life Care website, which will be live from September 2018, provides this, but there is more to be done by Government to better integrate health and social care and provide signposting and information. Forty per cent of care arrangers found the experience of arranging care and support for themselves or on behalf of someone else to be stressful or distressing.⁹¹
- 3. Prevention should be framed positively** – People are motivated - and should be encouraged - to think about lifestyle changes in the context of continuing to live an active, fulfilled and independent later life in the home of their choice. The Ageing Society Grand Challenge⁹² provides an opportunity for the development of well designed, innovative and attractive options that promote the positive concept of choice and active living. The Government

91 'Which? (April 2014) *The Care Maze: The challenges of navigating care for older people*.

92 The Ageing Society Grand Challenge is funded through the Industrial Strategy Challenge Fund which aims to bring together the UK's world-leading research with business to meet the major industrial and societal challenges of our time. This challenge will invest up to £98 million in research and innovation to support the aspirations of people as they age and provide better, more effective care when it is needed. It aims to help people to live independently in their homes, tackle loneliness, increase independence and wellbeing.

should also consider how it can better support people with lower disposable incomes and those living in private rented or social housing to receive the adaptations and support they need at an early stage.

4. People will respond better to those they trust – both in crisis and prevention.

The Government should consider this as it redesigns the social care system, exploring how best to reach those who would benefit from thinking about lifestyle changes or approaching care needs. Which? research found that nearly six in ten people over 65 would approach their GP for information and advice about social care, with eight in ten people trusting their GP to give good advice.⁹³

⁹³ Which? (June 2018) *Elderly care – Planning for later life* Populus on behalf of Which? surveyed 2104 UK adults online between 11 and 12 June 2018. The data were weighted to be demographically representative of the population.

Annex 1 – An overview of the social care system today

Social care needs have increased considerably in recent decades and will continue to rise

The number of people aged 65 years and over in England grew by 23% between 2006-16 and the number of people aged 85 years and over rose by 28% compared with 8% for all age groups. The number of people aged 65 years and over is projected to increase by a further 45%, and those over 85 years by 90% between 2016–36.⁹⁴ But healthy life expectancy has not kept pace with general life expectancy, such that more people are living longer with complex health problems.⁹⁵ It is thought that there are over 50% more people with three or more long-term conditions in England in 2018 compared to 2008, and by 2030 there will be over 80% more people aged 65 or over living with dementia in England and Wales compared to 2010.⁹⁶

We do not have enough reliable, good quality care.

A third of nursing homes, a fifth of residential care homes and a fifth of home care services in England are rated inadequate or require improvement.⁹⁷ In some places the statistics are even starker – in six local authority areas we looked at, half or more care home beds are in homes rated by the Care Quality Commission as requiring improvement or inadequate.⁹⁸ And supply is not keeping up with demand. A further 42,000 beds could be required across England by 2022, but just 20 local authorities are set to keep pace with the growth in the very elderly population (aged 80+), with 14 areas needing to increase care home bed provision from their projection by at least 25%.⁹⁹

Over a quarter of home care users found the service they received was worse than they expected, with 42% saying they did not feel in control throughout their use of the service. Over half (53%) had experienced a problem and 41% of those who had made a complaint were dissatisfied with the outcome.¹⁰⁰

94 Office for National Statistics, (June 2017) *Annual Mid-year Population Estimates: 2016 Statistical Bulletin*.

95 Care Quality Commission (3 July 2018) *Beyond Barriers: How people move between health and social care in England*.

96 House of Lords Select Committee on Public Service and Demographic Change (2013) *Ready for ageing?* London; . Available from: publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/14003.htm (accessed 2 July 2018).

97 Care Quality Commission (July 2017) *The state of adult social care services 2014–2017: Findings from CQC's initial programme of comprehensive inspections in adult social care*.

98 <https://campaigns.which.co.uk/care-system/> <https://press.which.co.uk/whichpressreleases/half-of-care-home-beds-in-parts-of-england-not-up-to-scratch/>

99 Which (October 2017) <https://consumerinsight.which.co.uk/articles/local-elderly-care-beds>

100 Which? (May 2017) *Detriment Research: Populus Survey*.

The 2017 annual British Social Attitudes Survey found net satisfaction with social care services at 23% – the lowest level since the question was first asked in 2005.¹⁰¹

Increasing numbers of people with genuine social care needs are no longer receiving the care they need

Funding for adult social care is being squeezed: between 2009/10 and 2015/16 spending by local authorities on social care per adult resident fell by 11% in real terms and the number of people receiving publicly funded social care services fell by 400,000.¹⁰² Social care is first needs-tested and then means-tested. Stricter eligibility criteria mean that increasing numbers of people with genuine social care needs are no longer receiving the care they need.¹⁰³ In 2006 53% of councils supported people with ‘moderate’ levels of need. By 2010 only 25% planned to do so in the future.¹⁰⁴

Research suggests only 21% of care for older people is currently local authority funded.¹⁰⁵ With just over 12% of older people with care needs in England paying for it themselves, this leaves two-thirds of caring needs either going unmet or being provided informally.¹⁰⁶ Six and a half million people in the UK are providing care to a family member or friend – that’s one in eight adults. Three million have reduced their working hours to manage, and 2.3 million adults have given up work to care at some point in their lives.¹⁰⁷ Caring can place a huge strain on the carer, with 82% reporting that caring has had a negative impact on their own health, and four in ten (41%) experiencing an injury or reporting that their physical health has suffered.¹⁰⁸

A significant number of older people struggle on without support despite no longer being able to confidently and comfortably carry out everyday tasks or do all the things that make life enjoyable. The number of people not receiving the help they need with essential daily living activities was estimated at 1.2 million in 2016.¹⁰⁹ Having an unmet need for care is associated with poor mental health and anxiety.¹¹⁰ People suffer from boredom, isolation and frustration when they are unable to do the things they used to do and face a daily struggle to meet their basic needs. Social isolation is closely linked

101 Bottery, S., Varrow, M., Thorlby, R., Wellings, D. (May 2018) *A fork in the road: Next steps for social care funding reform The costs of social care funding options, public attitudes to them – and the implications for policy reform* Health Foundation and The King’s Fund.

102 Bottery, S., Varrow, M., Thorlby, R., Wellings, D. (May 2018) *A fork in the road: Next steps for social care funding reform The costs of social care funding options, public attitudes to them – and the implications for policy reform* Health Foundation and The King’s Fund.

103 Health Select Committee (July 2016) *Impact of the Spending Review on health and social care*.

104 Bottery, S., Varrow, M., Thorlby, R., Wellings, D. (May 2018) *A fork in the road: Next steps for social care funding reform The costs of social care funding options, public attitudes to them – and the implications for policy reform* Health Foundation and The King’s Fund.

105 Age UK, Laing Buisson, NHS, Carers UK Source: ‘Why council tax hike for carers raises peanuts’ BBC News 13/12/16 Where older people in England with care needs get help.

106 Local Government Association (October 2017) *Adult Social Care Funding: State of the Nation 2017*.

107 Carers UK (December 2017) House of Commons Work & Pensions Select Committee Inquiry on employment support for carers – Written evidence from Carers UK.

108 Carers UK (May 2015) *State of Caring Report 2015*.

109 Age UK (February 2017) *Briefing: Health and Care of Older People in England 2017*.

110 Ipsos Mori (July 2017) *Unmet need for care Independent research funded by NIHR School for Social Care Research*.

with poor well-being and can be an issue even for people who are, ostensibly, receiving support with their care needs. In-depth interviews with users of at-home domiciliary care revealed that some felt they were being given lots of support to stay alive and live longer, but limited help in living out their years enjoyably.¹¹¹

Those that pay for their own care can face catastrophic costs

For some consumers the costs of care can be catastrophic: around one in ten elderly people who enter the care system face care costs of over £100,000.¹¹² And often the fact that they need to pay for care at all comes as a shock. Nearly half of the population think that social care is free to use¹¹³ and people don't always understand what health conditions fall under the remit of social services as opposed to the NHS – people are often surprised to learn that support for dementia patients, for example, often falls under social care as opposed to the NHS.

This misunderstanding around the distinction between health and social care means that people are upset and angry when they discover the costs involved in social care and that it is not automatically funded by the State. There is a widely-held misunderstanding that people have 'paid in for social care all their life' when in fact they have not.¹¹⁴ This means that funding proposals for the future of social care which discuss how to support consumers to part-fund their own care can easily fail to garner public support because people do not understand how the system currently works and what would change. Reports have highlighted a persistent hostility towards using housing assets to pay for care, even from those who do not own a home.¹¹⁵ There is widespread agreement that, to support any type of reform, people need a better understanding of the problems; only then can an informed public debate around the future of social care take place.¹¹⁶

The care system is inconsistent and unfair

The Care Quality Commission's recent local authority area reviews found people experiencing variation in availability of and access to services.¹¹⁷ Local authorities have an element of discretion in how they provide care assessments and how they arrange to meet the care needs that they identify. They are

111 On behalf of Which?, ten face to face and ten skype interviews were carried out with self-funding consumers of care and support in their homes and their care arranger between March and April 2018. In addition, six care and support professionals were interviewed on the self-funding care at home market during the same time period.

112 Lord Darzi (June 2018) *Better Health and Care for All: A 10-point plan for the 2020s* – The Lord Darzi review of health and care final report IPPR.

113 Shrimpton H, Cameron D, Skinner G. (26 October 2017) *State of the State 2017–18: austerity, government spending, social care and data*. London: Ipsos MORI on behalf of Deloitte LLP. Available from: www.ipsos.com/ipsos-mori/en-uk/public-perceptions-austerity-social-care-and-personal-data (accessed 9 May 2018).

114 Roundtable discussion held with stakeholders on 18 June 2018. A note of this discussion is at Annex 2.

115 Bottery, S., Varrow, M., Thorlby, R., Wellings, D. (May 2018) *A fork in the road: Next steps for social care funding reform The costs of social care funding options, public attitudes to them – and the implications for policy reform* Health Foundation and The King's Fund.

116 Roundtable discussion held with stakeholders on 18 June 2018. A note of this discussion is at Annex 2.

117 Care Quality Commission (3 July 2018) *Beyond Barriers: How people move between health and social care in England*.

exercising this discretion against a backdrop of continuing pressures on social care funding and the consequent need to make savings.¹¹⁸ Ultimately this can lead to two people with very similar needs receiving different packages of care based on where they live. NHS Continuing Healthcare (CHC) funding which may pay for care needs that are predominantly health related is also subject to regional variations – in 2017/8 the proportion of people receiving CHC funding in Salford was nearly 25 times higher than in south Reading¹¹⁹ (figures are adjusted to reflect differences in population).

When it comes to care homes, the insufficient fees paid by local authorities means that self-funded residents are subsidising the costs of residents whose fees are paid by the local authority. The Competition and Market Authority's assessment, based on larger care home providers, is that self-pay fees are now, on average, 41% higher than those paid by local authorities for places in the same care homes (an average differential of £236 a week or over £12,000 a year).¹²⁰ With a lower means test threshold set at £14,250, self-funders are often not wealthy individuals; as John Jackson of ADASS observed: "Even quite poor people pay an awful lot for their care".¹²¹ And it isn't just self-funded residents who suffer because of this: providers are becoming increasingly focused on the self-funder market, resulting in a reduction in services in less well-off areas.

118 Health Select Committee (July 2016) *Impact of the Spending Review on health and social care*.

119 NHS England continuing healthcare (NHS CHC) snapshot data at end of quarter 3, 2017/18 – Oct/Nov/Dec 2017.

120 Competition and Markets Authority (2017) *Care Homes Market Study*.

121 The Housing, Communities and Local Government and Health and Social Care Committees' joint report (27 June 2018) *Long term funding of adult social care*.

Annex 2 – Social care for older people roundtable discussion held at Which? on 18 June

Is it unrealistic to expect people to plan for care?

The round table focused on how people might plan for later life, and what those plans (or lack of) mean for the provision of social care.

People are not likely to readily engage in planning for care

- There are two aspects that could be planned for in advance: what care preferences people might have; and how they might fund their care.
- There is an assumption by many people that social care works the same as the NHS, i.e. free at point of need. Therefore they don't plan but expect to receive support when needed.
- Getting people to plan would take more than a nudge as it is rational to gamble on not needing social care.
- Those with assets or on higher incomes have the option to plan for care. There is less choice for those without assets so they are less likely to engage in pre-planning.
- It is difficult not only to predict one's future care needs, but indeed what the future itself might look like (e.g. 20–30 years' time) and hence care.

People are more likely to plan for good quality of later life

- But choices would be limited for those on low incomes.
- The best thing that can be done is keeping up social networks and healthy living (not smoking, eat well, take exercise etc).
- There can be good outcomes from adapting the home in order to maintain one's existing social networks – especially given that the majority of the housing stock in which people will grow old over the next 20–30 years has already been built. This option is easiest for those who own their home, yet rental is a growing sector and the options for adaptations there may be more restricted.
- Products marketed as for the 'elderly' are unattractive to older people. Instead products, including housing, should be designed well including being life-long adaptable.
- Technology that can support later life remains underdeveloped but over-65s are the fastest growing adopters of internet-connected technology.¹²² Exploring ways of making use of the everyday devices and technologies we already have to support our independence.

The social care system is widely misunderstood

- People are often very angry when they realise that social care is not provided free like the NHS. A common misunderstanding is saying they thought they had ‘paid in all their lives’ for social care; they had not.
- People do not distinguish between a health need and a care need, e.g. don’t expect that dementia patients are unlikely to receive Continuing Healthcare funding.
- It is likely that people would need to be compelled to save for social care; the suggestion was akin to pension auto-enrolment.
- There is an expectation currently that families will do a lot of the caring/ support, in particular women.
- There was a suggestion that older people should get social care funded by the state just as children’s education is funded by the state.

It would benefit society to improve understanding of care

- Increasing public awareness of how social care works (and is funded) may encourage people to plan for a better quality later life.
- It may also encourage people to look more positively on proposals for renewing the social care system.
- All ages should be engaged; suggestion that school curriculum should cover this topic as part of learning about society.
- Public health messages apply: live life so that you end up with a better later life

The consumer voice on social care needs to be heard

- The provision of care is said to be a market yet the consumer voice is very quiet in the debate on social care. Consumers of social care are particularly vulnerable, e.g. unwilling to challenge situations about poor care in their own homes.

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