**Funding and planning for social care in later life: a deliberative focus group study.**

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**Abstract:**

This study examined people’s perceptions and behaviours in relation to planning for their social care needs, and their values and priorities concerning how social care should be funded. Eight deliberative focus groups were conducted in May 2018 with 53 participants, aged 25-82 years, in London, Manchester and rural locations near York and Sheffield.

Multiple uncertainties created significant barriers to planning for social care needs. These included not knowing how much to save; not thinking it possible for an average person to save enough to meet significant needs, reluctance to plan for something potentially unnecessary, lack of suitable and secure ways of saving, and a perception of social care policy as unsettled. Participants also had significant concerns that they would not be able to obtain good-quality care. Most thought it realistic to only expect families to provide low-intensity, supplementary care.

Participants thought any new arrangements should be inclusive, personally affordable, sustainable, transparent, good-quality and honest. They preferred to contribute regularly rather than find considerable sums of money at times of crisis, and preferred to risk-pool, with everyone obliged or heavily encouraged to contribute. Use of housing assets to pay for care was considered unfair, for home-owners and non-home-owners, but more acceptable where people were childless or had substantial assets. People wanted transparency so those better at *‘working the system’* were not able to benefit unfairly. They wanted to know that, if they contributed, they would be assured of good-quality care. Trust in Government and other institutions, however, was low.

New funding arrangements should incorporate measures to increase transparency and trust, be clear about the responsibilities of individuals and the state, provide meaningful options to save, and place significant focus on improving actual and perceived care quality. For acceptability, proposals should also be framed to emphasise their affective dimensions and positive values.

**What we know**

* The social care system in England is complex and people’s understanding of it poor
* Previous research shows that people make few preparations to meet their future care needs. However, underlying reasons remain little explored
* Previous studies on attitudes to social care funding have generally focused on preferences for different funding models rather than underlying values and priorities

**What this paper adds**

* Multiple uncertainties created significant barriers to planning for social care needs
* These included not knowing how much to save, lack of advice, lack of suitable and secure ways to save and concerns about obtaining good-quality care
* People wanted the funding and provision of social care to be inclusive, personally affordable, sustainable, transparent, good-quality and honest

**Keywords:** social care; paying for care; chronic illness and disability; long-term care

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**BACKGROUND**

In virtually every country, people are living longer. Some additional life-years will be spent in good health, but not all, with resulting increases in chronic disease burden (Lancet GHM, 2017). This trend is set to continue. In England, 20-year projections suggest significant expansion of morbidity amongst those aged 65+ (Kingston et al, 2018). There is also a demographic ‘bulge’ of ‘baby-boomers’ reaching old age, with those aged 65+ expected to increase by 4.5 million, from 18%-23% of the population, by 2033. These changes are predicted to increase demand for social care but, in England, publicly-funded social care is available only to those with high needs and few resources, with anyone with assets or income over £14,250 making a contribution and those with £23,250 or more funding all their care. For residential care, housing assets are taken into account providing a spouse or dependent no longer resides in the home. No voluntary long-term care insurance is currently available. However, public understanding of this system is poor, with many believing social care to be free (IPPR and PricewaterhouseCoopers, 2009; Hewitson et al., 2011; Ipsos MORI, 2011; Gregory, 2014; Bottery et al., 2018; Ipsos MORI, 2018) and few making preparation for their future care needs (IPPR and PricewaterhouseCoopers, 2009; Fernández and Forder, 2010; Gray and Devine, 2015; Ipsos MORI, 2017). Around 75% will require some social care in their lifetimes, with 10% incurring costs of over £100,000 (Commission on Funding and Care Support, 2011; Fernández and Forder, 2010).

In light of these pressures, many countries are considering, or have implemented, reforms to their health and social care systems (Robertson et al, 2014). While there is wide consensus in England about the need for a more financially sustainable and fair social care system, this remains politically challenging to achieve. Critically, the public underestimate the funding challenge, with many believing they have sufficiently contributed to care costs through taxes (Croucher and Rhodes, 2006; Hewitson et al., 2011; Hanratty et al., 2012; Overton and O'Mahony, 2017; Bottery et al., 2018; Ipsos MORI, 2018). Policymakers, therefore, need evidence about the likely acceptability of different reforms. Existing research includes surveys, in the UK and elsewhere, measuring preferences for different funding models (IPPR and PricewaterhouseCoopers, 2009; Local Government Association, 2009; Fernández and Forder, 2010; Gray and Devine, 2015). These can be difficult to interpret, with different funding models included and variable results. One consistent finding, however, is low support for using housing assets to fund care, with qualitative research suggesting that people consider themselves to have the right to control their housing assets and leave an inheritance (Overton and O'Mahony, 2017; Hanratty et al., 2012; Hewitson, 2011). Surveys also consistently show low support for reliance on family care, with older adults reluctant to burden their children and their children, in turn, focusing limited resources on supporting their own children (Bottery et al., 2018; Ipsos MORI, 2018).

Existing research can also be difficult to interpret given that respondents commonly lack background knowledge about existing arrangements and the funding models they are being asked to consider, including likely distributional and other impacts. Deliberative approaches may help to address knowledge gaps. For example, support for shared public-private funding increases when people have accurate information about demographic and financial pressures (King's Fund and Caring Choices, 2008; Hewitson et al., 2011). Exploratory research may also be needed to adequately reflect the complexity of people’s views. Moreover, research focusing less on funding systems and more on people’s relevant personal experiences and values may provide policy-makers with more useful, readily interpretable evidence (Stone and Wood, 2010; Ghandi and Bowers, 2008). The focus group study reported here takes this approach, while grounding discussions in the current social care system and context. Focusing specifically on social care for older people, it aimed to explore:

* whether and how people prepare for future social care needs, and factors influencing this
* values concerning how social care should be funded and provided.

**METHODS**

We employed focus group discussions as these allowed participants to explore and develop their views through interaction and are useful where a deliberative approach is indicated (Ritchie et al., 2013; Rothwell et al., 2016). Eight groups of 5-7 people were recruited in England using an ISO20252 certified UK-based qualitative recruitment agency. Participants were drawn from the general population and recruited on the street, online and from maintained databases. We conducted groups in four geographical areas, urban and rural. We ran separate groups for different age-bands. No information about previous social care experience was available for recruitment, although participants were found to have a range of personal experience (Table 1).

[insert Table 1]

Information about participation in the study was provided by recruiters and consent obtained. At the beginning of each group, participants were reminded that participation was voluntary, and that they could choose not to answer any question and withdraw at any time. They were provided confidentiality assurances and opportunity to ask questions. Participants were paid a £40 incentive payment. Each group lasted 90 minutes and was facilitated by a senior qualitative researcher (JD) with assistance from a second qualitatively-trained researcher (AT).

The groups were designed to be deliberative, with relevant stimulus materials and information provided incrementally throughout the discussion (Ritchie et al., 2013; Rothwell et al., 2016). Both topic guide and stimulus materials were developed with input from all authors. Information presented drew on national research studies and statistics, and was presented in accessible language, avoiding technical or policy jargon.

We began each group with a brief explanation of social care and relevant demographic pressures. After participants had introduced themselves, we gave a brief explanation of the system for funding social care in England and informed participants about the average costs of homecare and residential care. The remainder of each session was divided into three parts.

The first part was used to explore whether participants had thought about how they would pay for, or obtain, social care if they needed it. Responses were probed thoroughly and people’s reasons were fully explored. At a suitable point in this discussion, we told participants about the proportions of people requiring social care in their lifetime and associated lifetime costs (covering median, average, average for someone with dementia, top 10%). We explored the topics further in light of this new information.

In the second part, we discussed three fictional individuals (Table 2), exploring options for meeting their existing or future social care needs and the preparations that each should make. These depersonalised discussions, while keeping them practical and focused, and enabled people to consider issues from multiple viewpoints.

[Insert Table 2]

In the third part, we briefly presented alternative approaches for increasing the total amount of funding going into social care, including increasing income tax, introducing a new ring-fenced tax or social insurance payment or a voluntary insurance product (Table 3). These were presented simply and briefly with opportunity for questions. People were not asked to rate or choose between approaches. Rather, the information was used to stimulate discussion about priorities and values for how new funding for social care should be obtained, with evidenced-based estimates of costs and benefits provided to help participants understand the financial implications.

[Insert Table 3]

All information was provided orally, with complex information also provided in summary written form. Throughout, we encouraged reflective discussion, avoiding, as far as possible, more polarising issues.

Group discussions were audio-recorded with permission and transcribed in full. Data were analysed by two researchers using Framework, a matrix-based approach for the comprehensive and systematic thematic analysis of qualitative data (Gale et al., 2013; Ritchie et al., 2013). Following Ritchie et al (2013), an initial Framework matrix, comprising five matrices, each with 5-6 thematic headings was developed based on the topic guide and reading of the transcripts. Each focus group was allocated a row in the Framework matrix into which transcripts were then charted in their entirety, with sections of text cut and pasted (coded) under the relevant thematic heading. References to page numbers in the full transcript were retained. The Framework matrix was refined during initial charting of transcripts. Once all transcripts were charted, data within and across thematic columns were interrogated and new analytic themes (codes) were iteratively developed. All relevant data, including negative cases, were accounted for in each round of coding. The primary aim was to map range and diversity (of factors influencing if and how people made preparations for future care and their values related to how social care should be provided), using meaningful categories and themes, capable of taking account of all available data and of providing new insights. Analytic notes were taken throughout and the researchers regularly discussed emerging themes and categories. These were discussed with the other authors who provided critical input and commented on drafts of this paper. The study was approved by the London School of Economics and Political Science’s research ethics committee and undertaken in line with its policy and procedures.

**RESULTS**

**Factors influencing whether and how people prepare for their future social care needs**

Participants discussed a range of factors that influenced whether and how they prepared for possible future social care needs. In some cases, views were informed by a relative’s care experiences or by participants’ experiences of helping someone to obtain, social care. The factors they described primarily related to uncertainties of different kinds, including around social care need, personal finances, family and community, social care market, funding vehicles and government policy. Multiple uncertainties across all of these areas created significant barriers to planning for social care needs.

***Social care need:*** Participants generally had a poor idea of their likelihood of needing social care in later life. Even those who had previously provided care to relatives were optimistic about their chances of not needing care, referring, for example, to the longevity of family members and to keeping active.

“To me, it's trying to keep myself healthy and I still do, I push myself, a lot of people don't do that. A lot of people just think, ‘Oh dear!’ and sit down.’ (London, F, older)

Sometimes, however, this was tinged with a suggestion of wishful thinking.

“I’ve got an uncle who is 84, lives on his own, people go and check on him, but he does everything himself, so I tend to focus more on the people like that and say, ‘Well, hopefully I’m going to be one of those people.’” (London, M, younger)

Others had not thought about it, sometimes because it seemed far away.

“Just feel like it’s a million miles away, so it’s not really something you think about really.” (Manchester, F, younger)

Older participants, sometimes did not think about it because it worried them.

“I’m just burying my head in the sand, I don’t even think about it.” (Sheffield, F, older)

“This lady’s just mentioned one word, and I forgot to mention it, and it’s ‘scary’. I try not to think about tomorrow, but then again, in quieter moments, I think what’s going to happen?” (Manchester, M, older)

Two participants with experience of serious illness thought they would not live long enough to need social care. Exceptionally, participants with a family history of poor health expected to need social care at some point.

“Everyone on my grandma’s side has had problems with strokes, problems with blood clotting as well, so that’s kind of the thing that you think about.” (Manchester, M, younger)

Participants sometimes suggested that improved healthcare services, community-based support and extra-care housing could reduce social care need.

***Personal finances:*** No participant had saved explicitly for social care. Some were building pension or other savings but varied in whether they thought these would be sufficient to meet social care costs. Barriers to saving included uncertainty about how much to save, with the amount potentially required ranging from zero to hundreds of thousands of pounds. For larger sums, it was also thought that an *‘average person’* could not afford to save this much. Participants were also sometimes reluctant to save for something they might not need.

“You could walk in front of a bus tomorrow, you know, you just don’t know. I don’t think you can plan so far ahead, but once you get to perhaps, you know, sixties, late sixties then you start thinking ‘Well, maybe...’ but then it’s too late isn’t it?” (Manchester, F, middle-aged)

“I think you’d have a real job to get 40-year olds interested in an insurance for care, if they ever needed it.” (Sheffield, M, older)

Other barriers included existing financial commitments associated with raising a family or providing financial support to adult children, or unplanned life events such as divorce. Home-owners commonly assumed they would need to sell their home to pay for care, while some took steps to protect housing assets. For example, one participant had given money from her divorce settlement to her son. Others used solicitors to establish legal arrangements such as trusts to protect housing assets, with many saying that solicitors actively promoted these services. Commonly, however, people expressed discomfort about doing this.

“That’s the way we’re sort of thinking at the moment about it. It might not be the right way but it’s... probably not the most ethical thing to do, but then it’s like who else is going to look after your family once sort of my mum goes?” (Manchester, M, younger)

***Family and community:*** Some participants planned to rely on family care. Several participants from various minority ethnic groups stated that this was more expected in their communities. Others invoked ideas of reciprocity and mutual support within families.

“I’m bringing up my kids so, later, when I’m like, you know, I can’t do anything, they can look after me. And they see me looking after my dad as well, so it’s like sort of generation after generation.” (London, F, middle-aged)

More commonly, however, participants were concerned about burdening their children. Adult children might also live far away or be working long hours, with fewer stay-at-home mothers than in previous generations. Despite higher living standards, younger generations were thought to have more financial pressures, including higher levels of student debt and housing costs.

“I really don’t want my children, though I’m sure they would, to get that much involved. I don’t think it’s really fair to them to that extent, because they’ve got so much on their plate now, more responsibilities and things like mortgages and costs of living.” (Sheffield, M, older)

Families might also not be emotionally close and it was recognised that family care could be fraught, emotional and break down. Participants generally thought families should provide low-intensity, supplementary care. Personal care, in particular, should be provided by a paid professional, with this considered a dignity issue.

“If her mum could have seen what she has to do for her, if she could have seen that ten years ago, she’d be mortified.” (York, F, older)

Participants also spoke about a decline in care from wider family networks and neighbours. This was often regretted, although others were not sorry, arguing that the previous need for such care reflected *‘harsh necessity’* in the absence of formal social care services.

***Social care provision:*** There was a widespread view that whether or not one received good care was *‘pot luck’*. Participants described relatives and friends receiving poor care and media reports of poor care and abuse.

“The care that they get for what they’re charged, and even if they have it four times a day, rip through the door, ‘You alright?’ ‘Yeah’ ‘Cup of tea?’ ‘Yeah’ and they’re gone, that’s care. This is first-hand of people telling us.” (Sheffield, M, older)

“Well, you hear of some places, where they say they’re not treated well, you know.” (Manchester, M. middle-aged)

“You see them on the telly where they’re getting abused and hit and stuff, you’d like to think, it shouldn’t happen in any of them.” (York, M, middle-aged)

Participants also described relatives receiving good-quality care, although this sometimes surprised them.

“My father was in a nursing home in Sheffield, and it was beautiful, absolutely fantastic. I used to make a contribution, but a minimal amount, it was no more than around about £60 a month but he was well-cared for.“ (Sheffield, M, older)

“My dad’s in a Council one; think it’s lovely. I was expecting the absolute worst, I was thinking we didn’t have a choice, that was all that was available because we couldn’t get the care sorted. But it’s lovely.” (York, F, middle-aged)

Some were also concerned about paying privately for a care home, running out of money and having to move to another with potentially worse standards.

“I think sometimes under the media you tend to hear where people have moved from nursing to nursing home and you know, deteriorate, it’s cheaper, someone’s… and I think that’s one of the biggest fears that a lot of people have.” (Sheffield, M, older)

Accessing care was also thought difficult, with long waiting lists and care home closures. Participants additionally expressed concerns about poor pay in the sector, associating this with poor care. Overall, participants generally found it hard to imagine good-quality of life with significant social care needs, with some reluctant to save for something negative and, occasionally, discussing suicide or assisted dying.

“If you don’t want to go into a care home, and probably like your girlfriend who works in them, she’ll probably never want to go into a care home, why would you be saving for something that you don’t want to do?” (Manchester, F, younger)

“You think, I would be festering away in a place for a long time and my children won’t get any of this, what’s the point?” (London, F, middle-aged)

***Funding vehicles:*** Participants identified a lack of advice and structures for saving for social care, particularly compared to pension savings.

“It’s tricky, because all you ever talk about when you get older is pension, that’s all I’ve had forced kind of in my face and it’s like, in a way, you need another option.” (Manchester, M, middle-aged)

Occasionally, participants wondered if private insurance was available (researchers informed them it was not). Housing was identified as the main source of funding for social care. This was commonly thought unfair. Those without property were reliant on means-tested state support and expected to contribute from pension income, with some likening this to the Poor House*.*

“I’m in private rented, so all I’ve got is my savings so once that’s gone, I would be at the mercy of the system.” (Sheffield, F, older)

Some thought, however, that home-owners stood to lose everything while others received *‘free’* care.

“It seems really unfair for people who have worked hard, saved hard, paid off their house, own it outright, whereas other people didn’t and they get their care paid for nothing, albeit perhaps not in the same types of care homes.” (York, F, middle-aged)

Using housing assets to fund care was more acceptable where people did not have children, where children were financially secure or where there were substantial assets.

“I think the fairest thing would be, okay, if you’re living in a very expensive house, you’ve got lots of assets, then I think, okay, you should pay.” (Manchester, M, older)

However, reliance on housing assets to pay for care was considered unsustainable, with younger people finding it harder to buy a home and less likelihood in future of housing rising in value.

*“The way things appear to be going now, let’s project forward the next thirty years, I don’t know whether people are going to be sat on these big value housing assets.” (London, M, older)*

***Government policy:*** Policy on social care was seen as unsettled. Multiple funding pressures on government, including the NHS, were acknowledged and the commitment of successive governments to address problems was doubted, with some describing social care as *‘a political pawn’.*

“By then, there will have been] thirty governments, sixty new rules. Nobody even knows if there’ll be a state pension when they retire.” (Sheffield, M, older)

**Values and priorities for funding social care**

Participants widely agreed that the current system needed an *‘overhaul’.* Six underlying values for an alternative system were identified; inclusive, personally affordable, sustainable, transparent, good-quality and honest.

***Inclusive:*** Those who had *‘paid in’* to the system by paying taxes or *‘working hard’* were widely thought the most deserving. However, it was recognised that not everyone could make the same contribution, and also that one could not leave people without care for ethical reasons, and because of impacts on families and wider society. To limit non-coverage, there was thus a widely-held preference for a shared system into which everyone contributed, in advance of needing care and according to their means. Although some valued personal choice, individual solutions such as voluntary insurance were thought of limited usefulness since not everyone could or would plan effectively, necessitating a large public safety net.

“You know, not everybody’s organised and planned and thinks about the future and doesn’t make them bad people, it’s just different circumstances”. (York, F, middle-aged)

If contributions were to be voluntary, arrangements similar to employment-based auto-enrolment pensions were suggested as way of encouraging take-up.

***Personally affordable***: If saving were needed, it was widely considered more manageable to pay a small sum, regularly, over a long period, rather than a one-off lump sum.

“Well it just becomes the norm doesn’t it? You don’t really see it. It’s on the right-hand side of your payslip.” (York, M, middle-aged)

Some participants, however, thought that regular saving would need to be incentivized, potentially through tax-relief, and that some would struggle to make any additional payment regularly.

***Sustainable:*** Competing priorities for government funding, including but not limited to the NHS, were identified, with some arguing that government could not keep raising taxes for each new priority.

“Yeah, but does it stop though? When you say right, social services need extra money, fire service, council needs extra money... if you put it out to everyone it just goes up and up.” (Manchester, M, younger)

However, there was wide agreement that addressing the challenges of social care funding and provision should be a priority, with one participant describing it as *‘the most worrying one’.*

***Transparent:*** The existing system was commonly seen as unnecessarily complicated, with some believing that those better at ‘working the system’ could arrange their financial and legal affairs to benefit unfairly.

“They all get different, just by knowing the system, filling the forms in or whatever, he gets it for nothing, and people know this and, you know, I think this is what people are unhappy about aren’t they?” (Manchester, F, younger)

Participants were sometimes prepared to pay more in taxes (or other payment) for everyone to have free social care. This was seen to protect housing assets and reduce administration costs. Compared to systems involving asset thresholds and lifetime caps on personal payments, it was also thought to be less confusing and open to manipulation.

“I don’t like it. I feel that people will fiddle that. The government, or people will... ‘Oh, you’ve got this much, oh, you’ve got £101,000 you’re still.’ I don't like it.” (Manchester, M, older)

***Good quality:*** Participants placed considerable emphasis on quality of care. This was seen as a value-for-money and ethical issue, and was the source of considerable anxiety for many.

“It’s absolutely terrifying, the thought of it, at my age, I’ll be 75 in a couple of weeks or so and the thought of it is just terrifying.” (Sheffield, M, older)

Good quality care was associated with the effective functioning of the social care market, including the relationship between cost and quality, care worker pay and care home failures.

“Really, the cost doesn’t always necessarily reflect the quality does it?”

These were widely seen as issues that needed to be addressed holistically.

***Honesty***: Ring-fencing had support from some because it sounded more secure, but others mistrusted this option, believing that, in practice, the money might be spent on something else.

They don’t use it for that though, do they? They promise you, and they say “This is for the fire, the police, the potholes… you can up this, and up that, up the other, but do you see the benefits from it, because every time you switch the TV on or read the paper, it’s well, there wasn’t enough in this fund, even though everybody’s paid into it.” (Manchester, F, middle-aged)

Mistrust was not confined to government, but extended to other institutions, including arm’s-lengths bodies and insurance companies. There was particular mistrust of entitlement-based schemes involving stewardship of large funds, with people citing, for example, the collapse of large-scale occupational pension schemes and ongoing changes to the state pension age. There were also concerns that insurance-based solutions could usher in a US-style system of care, with profit motives driving the type and quality of services.

**Discussion and conclusion**

To the best of our knowledge, this is the first study to consider, in-depth, people’s reasons for whether and how they prepare for future social care need. Our findings highlight the complexity of the current system, with multiple uncertainties making it difficult for people to know what is best or how to take effective action. Even when people know that social care is not free, they cannot know how much to save, with the amount needed ranging from zero to hundreds of thousands of pounds. They may also be unable to save enough, particularly for high needs. Many also want to leave an inheritance to their children. There are no special savings vehicles or insurance options, limited available advice, and no tax deductions or other incentives. People also expect to have little control over the availability, quality or continuity of care, a view supported by the Care Quality Commission (2017), which finds wide, unexplained variation in the quality of care homes across the country. At the same time, families are commonly only able to offer low-level, supplementary care. Moreover, people had limited expectation of government action or of a clear, stable policy framework emerging.

Possible measures for addressing these challenges emerged in discussions. Participants preferred to avoid social care need and supported investments in prevention, a policy direction increasingly emphasised in national policy (NHS, 2019). Participants also worried that it was a false economy if people with moderate needs could not afford to get support since they risked eventually needing higher levels of social and NHS care. They preferred to contribute regularly over time rather than have to find considerable sums of money at times of crisis, and to risk-pool, with everyone obliged or heavily encouraged to contribute. If means-tested provision was needed, they wanted it to be a safety net rather than a regular part of the system, with current arrangements fuelling resentments about people receiving ‘free’ care at the tax-payer’s expense or being perceived as similar to Poor House measures (Hanratty et al, 2012; IPPR and PricewaterhouseCoopers, 2009). These echo findings from a recent citizen’s assembly, which identified ‘equity’ and ‘universality’ as two of five key principles for the provision of social care (Involve/ House of Commons, 2018) and findings from a UK-based discrete choice experiment involving nearly 3,000 people, which found a strong preference for a collectively-, rather than individually-based, system of paying for care (Sussex et al., 2019). Participants also wanted transparency, associating complexity with being able to manipulate the system. Participants favoured hypothecated tax or social insurance payments over funding from general taxation, as this offered a greater guarantee that funds would be spent on the purposes intended, but considerable mistrust in government and other institutions remained (Wenzel et al. 2018).

Views on the use of housing assets broadly reflected those in the literature (Hewitson et al, 2011; Fernández and Forder, 2010; IPPR and PricewaterhouseCoopers, 2009; Hanratty et al, 2012; Overton et al, 2017). However, while various proposals have emphasised limiting catastrophic costs (Commission on Funding and Care Support, 2011), participants in our study generally thought that those with substantial assets could well afford their care and needed less protection. At the same time, there was widespread support for allowing people to keep a greater amount of their housing wealth, by substantially raising the threshold at which people are expected to contribute. In Wales, this threshold is currently £40,000 (compared to £23,250 in England) and, under the Conservative Party’s recent (now deferred) proposals, £100,000 (although housing assets would have been taken into account for both home care and residential care). Overwhelmingly, participants also wanted assurances that they would receive good-quality care, reflecting findings from the earlier-mentioned citizen’s assembly, in which ‘high-quality’ and ‘dignity and respect’ were identified as two of five key principles for social care provision (Involve/ House of Commons, 2018).

Previous debates about social care funding have commonly focused on funding models and mechanisms. Behavioural economics provides us with the insight that, when it comes to highly complex planning decisions, knowing the most appropriate actions to take is cognitively challenging, and that consequently people rely more on affective judgements and ‘rules of thumb’ (Hardcastle, 2012). Participants in our focus groups had limited understanding of the complex distributional effects and wider economic implications of different funding options, or of how these may affect the potential for closer integration between social care and the NHS for example, which are factors that policy-makers need to consider. However, in discussing their experiences of preparing, or not, for possible future care needs and their thoughts about how social care might be provided in the future, we were able to identify a range of underlying values. These were that any arrangements for providing social care should be inclusive, personally affordable, sustainable, transparent, good-quality and honest. These values broadly overlap with those identified in other recent research and consultation (Involve/ House of Commons, 2018; Sussex et al, 2019). Ours was a wide-ranging exploratory study. Future qualitative research could explore some of these values in more detail, while quantitative research could examine the prevalence and distribution of these values and explore potential trade-offs. The possibility of proposals for funding social care being implemented successfully depends on acknowledging people’s experiences and framing proposals in ways that emphasise their affective dimensions and positive values.

**References**

Adams, J., Curry, C., Hu, B., King, D., Wittenberg, R., Espuny Pujol, F., Hancock, R., and Morciano, M. (2018). *Care and State Pension Reform: The Conservative Party manifesto proposal to include housing wealth in the means test for home care: how might it affect public spending on long-term care for older people?* . Pensions Policy Institute/ Personal Social Services Research Unit/ University of East Anglia

Bottery, S., Varrow, M., Thorlby, R., and Wellings, D. (2018). *A fork in the road: Next steps for social care funding reform*. London: Health Foundation/Kings Fund

Care Quality Commission (2017). The state of health care and adult social care in England 2016/17.

Commission on Funding and Care Support. (2011). *Fairer care funding*: *the report of the Commission on Funding of Care and Support.* (the ‘Dilnot report’)

Croucher, K., and Rhodes, P. (2006). *Testing consumer views on paying for long-term care* (1859354785). Joseph Rowntree Foundation

Fernández, J.-L., and Forder, J. (2010). *Ageing societies: challenges and opportunities*. London: Bupa

Gale, N. K., Heath, G., Cameron, E., Rashid, S., and Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *Bmc Medical Research Methodology, 13*(1), 117. doi:10.1186/1471-2288-13-117

Gandhi K, Bowers H. (2008) Duty and obligation: The invisible glue in care and support. York: Joseph Rowntree Foundation.

Gray, A. M., and Devine, P. (2015). *No Change: Northern Ireland attitudes and social care policy (Research Update 114). Northern Ireland Life and Times Survey 2015*. ARK

Gregory, S. (2014). *Attitudes to health and social care: review of existing research (for the Commission on the Future of Health and Social Care in England)*. The King’s Fund

Hanratty, B., Lowson, E., Holmes, L., Grande, G., Addington-Hall, J., Payne, S., and Seymour, J. (2012). Funding health and social services for older people–a qualitative study of care recipients in the last year of life. *Journal of the Royal Society of Medicine, 105*(5), 201-207. doi:10.1258/jrsm.2012.110189

Hardcastle R (2012) How can we incentivise pension saving? A behavioural perspective. Working Paper no 109. Department for Work and Pensions.

Hewitson, B., Seale, B., and Joyce, L. (2011). *Public engagement exploring care and support funding options: TNS-BMRB report of findings in Fairer care funding: supporting documents*. HM Government

HM Revenue and Customs. (2018). Direct Effects of Illustrative Tax Changes. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/714482/SS18\_Direct\_effects\_of\_illustrative\_tax\_changes\_bulletinFinal\_v1.1.pdf

Involve, and House of Commons. (2018). Citizens’ assembly on social care recommendations for funding adult social care.

IPPR, and PricewaterhouseCoopers. (2009). *Expectations and aspirations: public attitudes towards social care. London: IPPR. 2009*. London: IPPR

Ipsos MORI. (2011). *Public opinion research on social care funding. A literature review on behalf of the Commission on the Funding of Care and Support, in Fairer care funding: supporting documents*. London: HM Government

Ipsos MORI. (2017). *Public perceptions of the NHS and social care: an ongoing tracking study conducted for the Department of Health, December 2011*. London: Department of Health

Ipsos MORI. (2018). *Understanding public attitudes to social care funding reform in England: report prepared for the Health Foundation and the King’s Fund*.

King's Fund, and Caring Choices. (2008). *The future of care funding: time for a change*. London: King's Fund

Kingston A, Robinson L, Booth H, Knapp M, Jagger C for the MODEM project (2018) Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model. *Age and Ageing*. 47,3 :374–380,

LaingBuisson. (2017). *Care of Older People UK Market Report, twenty-eighth edition*. London: LaingBuisson

Local Government Association. (2009). *Call to make the care of our ageing population a priority for all political parties*. London: Local Government Association

NHS Digital. (2017). *Adult Social Care Activity and Finance Report: Detailed Analysis England 2016-17*.

NHS (2019) The NHS Long Term Plan.

Overton, L., and O'Mahony, L. F. (2017). Understanding Attitudes to Paying for Care amongst Equity Release Consumers: citizenship, solidarity and the ‘hardworking homeowner’. *Journal of Social Policy, 46*(1), 49-67. doi:10.1017/S0047279416000416

Ritchie, J., Lewis, J., McNaughton Nicholls, C., and Ormston, R. (2013). *Qualitative research practice: a guide for social science students and researchers* (2nd ed.). London: SAGE.

Robertson R, Gregory S, Jabbal J (2014) The social care and health systems of nine countries. A report for the Commission on the Future of Health and Social Care in England. London: Kings Fund.

Rothwell, E., Anderson, R., and Botkin, J. (2016) Deliberative discussion focus groups. *Qualitative Health Research,* 26(6): 734–740.

Stone E, Wood C. (2010) A funding settlement that works for people, not services. *Quality in Ageing and Older Adults.* 11:14–23

Sussex J, Burge P, Lu H, Exley J, King S (2019) *Public acceptability of health and social care funding options: Funding options for the NHS and social care in the UK*. London: Health Foundation.

The Lancet, Global Health Metrics (2017) Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. 390, 10100: P1211-1259 online: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32154-2/fulltext#articleInformation

Wenzel L, Bennett L, Bottery S, Murray R, Sahib B (2018) Approaches to social care funding: Social care funding options. Kings Fund/ Health Foundation

**Table 1: Sample composition**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Age** |  |  | **Employment** |  |  | **Experiences of social care**  Participants had a range of experiences involving social care. Around a third of the sample had provided care to one or more relatives, commonly parents, at different levels of intensity. Around one in ten had contributed to collective family efforts to provide low-level support to a relative, including running errands or transporting to medical appointments. Some of these participants described the involvement of paid home carers or had helped their relative access a care home, while others actively avoided using social care services, for financial reasons, cultural reasons or because they believed their relative wanted this.  A few participants had experience of social care services through work including for a charity, a care home and an adult social services department.  Around half of participants, especially younger ones, had limited or no prior experience of social care or social care services. |
| Younger (25-44) | 13 |  | Full-time | 25 |  |
| Middle-aged (45-65) | 20 |  | Part-time | 11 |  |
| Older (65+) | 20 |  | Unemployed | 2 |  |
|  |  |  | Retired | 15 |  |
| **Sex** |  |  |  |  |  |
| Male | 25 |  | **Marital status** |  |  |
| Female | 28 |  | Single | 8 |  |
|  |  |  | Co-habiting | 10 |  |
| **Geographical area** |  |  | Married | 22 |  |
| London | 20 |  | Divorced | 8 |  |
| Manchester | 20 |  | Widowed | 5 |  |
| Rural (York, Sheffield) | 13 |  |  |  |  |
|  |  |  | **Children** |  |  |
| **Housing** |  |  | Yes, living at home | 18 |  |
| Home-owner | 23 |  | “Empty nest' | 26 |  |
| Rent privately | 17 |  | No | 9 |  |
| Social housing | 13 |  |  |  |  |
|  |  |  | **Total** | 53 |  |
|  |  |  |  |  |  |  |

Table 2 Case examples

|  |  |
| --- | --- |
| Name | Alan |
| Age | 78 |
| Marital status | Widower, wife died 5 years ago |
| Children | Son (51) Daughter (53). Both live within 30-minute drive. |
| Employment | Retired |
| Condition, if any | Mild COPD (so he could need more care later on if his COPD gets worse) |
| Housing | Renting |
| Savings | £10,000 |
| What’s happened? | Had a fall, hurt hip and shoulder, finding it hard to move around and do daily tasks |
| What care is needed? | He has had some intermediate care services (help in the first few weeks after leaving hospital) but recovery may take 6-12 months. He is struggling without help with shopping, preparing meals, washing and dressing |
| What will it cost? | A paid carer for 10 hours a week would cost £160 a week. This is £8,000 a year. His needs are not serious enough to qualify for Government-funded care |

|  |  |
| --- | --- |
| Name | Grace |
| Age | 83 |
| Marital status | Widow, husband died 8 years ago |
| Children | Son (58) Daughter (61). Both live within 30-minute drive |
| Employment | Retired |
| Condition, if any | Has had dementia for 4 years |
| Housing | Owns outright £180,000 |
| Savings | She has £13,000 left in savings after paying for home care for the last few years |
| What’s happened? | Dementia has worsened |
| What care is needed? | Her needs are such that she now needs to go into a care home. |

|  |  |
| --- | --- |
| Name | Helen |
| Age | 41 |
| Marital status | Married to partner, also 41 |
| Children | Son (16) Daughter (18) living with her |
| Employment | She earns £34,000 per year and her partner earns £32,000 per year |
| Condition, if any | No condition |
| Housing | They own their home, worth £300,000 and with £260,000 outstanding mortgage |
| Savings | £15,000 between herself and her partner |
| What’s happened? | Nothing yet but planning for the future |

**Table 3: Estimated costs and benefits of alternate funding approaches presented to participants**

A one-percentage point increase in income tax or an equivalent ring-fenced payment could raise the assets threshold to £100,000 and provide a £36,000 lifetime cap, while a two-percentage point increase could fund ‘free’ social care for eligible needs, eliminating the need for means testing.

A one-off private insurance payment at age 65 of £15,000 could, for that individual, raise the assets threshold to £100,000 and introduce a £72,000 lifetime cap, while a payment of £20,000 could raise the assets threshold to £100,000 and introduce a £36,000 lifetime cap

PSSRU estimates drawing upon Commission on Funding and Care Support, 2011; LaingBuisson, 2017; NHS Digital, 2017; Adams et al., 2018; HM Revenue and Customs, 2018