

Testing consumer views on paying for long-term care

Karen Croucher and Paul Rhodes



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Executive summary

1. Background to the study

Since 1997 the Joseph Rowntree Foundation (JRF) has been engaged in a Policy and Practice Development Programme designed to build consensus around possible mechanisms for meeting the costs of long-term care in the UK. Earlier this year the JRF published a report, *Facing the Cost of Long-term Care: Towards a Sustainable Funding System* (Hirsch, 2005) that drew together some of the key evidence that the programme had generated and presented a number of policy options. To test the viability and acceptability of these options, public attitudes towards these options were tested in a series of eight focus groups. Apart from general issues, four key ideas were tested:

1. Standardised assessment and means testing of domiciliary services
2. Re-packaging Attendance Allowance into a standardised care payment
3. Increasing support for informal carers – either through resources and/or formal help
4. The potential of equity release schemes to pay for domiciliary care costs.

The eight groups were held in different urban and rural locations across the UK (including two groups in Scotland). There were 59 participants, age range 26-90. This was a purposeful sample and included people with experience of being informal carers, people with disabilities, and people from black and minority ethnic (BME) groups. The key points arising from these discussions are summarised below.

2. Overarching findings from the discussion groups

- The current systems of funding are perceived to be inequitable, confusing for the consumer, and unsustainable in the long term. Hard work and thrift are perceived to be penalised. For many people the best strategy for funding their own long-term care appeared to be spending their assets to ensure they qualify for state support.
- Many people, particularly older people, still feel that the state should fund long-term care. There was also, however, a grudging acknowledgement that the current system will become unsustainable due to the growing numbers of older people, and

that individuals in the future will have to contribute more towards the costs of their care.

- For many of the proposals forwarded by JRF ‘the devil was in the detail’. People observed that a number of changes would need to be made to assist people across a broad range of financial and personal circumstances, and thus none of the options discussed were universally favoured above the others.
- Mechanisms were welcomed that allowed people to start planning sooner, thus allowing them to be in control in the future should they have needs for long-term care.
- There was considerable interest in a ring-fenced tax to pay for long-term care.
- There was enormous mistrust of any private sector financial ‘packages’ or ‘products’, whether equity release or private insurance.
- There were concerns about the quality of care now and in the future, and also concerns that older people should have choices; for example, the option of being cared for at home rather than in institutional settings and choices about the type of services they receive and the way services are delivered.
- The researchers observed a receptiveness to change that should encourage policy makers to think boldly – for example considering raising tax.

3. Exploring the solutions proposed by the Joseph Rowntree Foundation

This section summarises participants’ responses to each of the JRF-proposed solutions. It also addresses other key questions: whether the state or individuals should take on the responsibility of funding long-term care costs; whether people should be allowed to keep more of their assets and still be eligible for state assistance; and whether individuals or the state should pay for different elements of residential care.

3.1. *Standardised assessment and means testing of domiciliary services*

The JRF report *Facing the Cost of Long-term Care* suggests that there should be a national scale of fees for home care by bands of income (Hirsch, 2005, p 28), for example, a maximum of 25% of income above £136 to be payable for domiciliary services.

- There was support for a national scale of fees for home care. A more finely tuned ‘tapered’ system of charges, where assistance from the state was not totally withdrawn but reduced for those on higher incomes, was seen to be fairer than the current ‘all or nothing’ system. This was still, however, perceived as means testing by another name, and many people opposed means testing on principle because they felt it penalised thrift.

3.2. *Re-packaging Attendance Allowance into a standardised care payment*

People with care needs can claim Attendance Allowance, a non-means-tested, non-taxable benefit for people over 65, to help them pay for their care. One of the suggestions in *Facing the Cost of Long-term Care* was that that Attendance Allowance might be restructured from the current two levels of payment (£40 per week to cover day time personal care, £60 per week for day *and* night time personal care) to allow different levels of payments for different levels of needs.

- Across the groups there was general support for more fine-tuning of Attendance Allowance as people were generally highly supportive of mechanisms that promoted independence and allowed older people choices.
- Reflecting on the implications of such changes, there were concerns that the relative simplicity and universality of Attendance Allowance might be lost.

3.3. *Increasing support for carers either through resources or formal help*

In the groups we explored attitudes towards informal caring and family responsibilities, how support for carers might be improved, and people’s preferences for cash payments to carers or services.

- There was no broad consensus on this issue, although the notion of more support for carers was supported.

- Views expressed by older carers suggested that the notion of the duty to care for a loved one would hinder take-up of payment by some older carers, especially if it was perceived as a welfare benefit.
- There was broad support from all age groups for the idea that carers of working age, unable to work as a result of their caring responsibilities, should receive a reasonable payment or 'wage' from the state to compensate them for loss of income. A carer's wage would encourage children to care for elderly parents, and reduce older people's sense of 'being a burden'.
- There was generally much support for services (such as day care, respite, home care) that assist carers with their caring tasks. However, it was acknowledged that they were not always appropriate to the needs of all individuals.
- Carers' Support Services, such as carer groups that provided advocacy, support and information, were highly valued.
- Cash payment in lieu of care services would offer some people more choice, but were not seen as useful to all, particularly older carers who may be frail and vulnerable themselves, and in need of practical support rather than cash payments.

3.4. The potential of equity release schemes to pay for care costs

In all the groups we explored people's attitudes towards the release of housing equity to provide funds for domiciliary care, and in particular their views towards the possible provision of 'government guaranteed' equity release schemes.

- A viewpoint that came through very clearly was that older people should not have to forfeit or borrow against their homes to pay for care. The perception that older people 'have their homes taken away' when they need care underlined much of the sense of injustice and inequity that people expressed in the groups. For many this was an overriding principle, although a smaller number of people, of different ages and backgrounds, contested this 'natural right to pass on assets' and felt individuals should use their resources including property for their own benefit. Two groups (one composed of younger people, and the other a BME group) felt that

if children were not prepared to look after their parents, then parents had no obligation to leave them any money.

- For the group of BME respondents, domiciliary care was a desirable option, as they felt services tended to be culturally inappropriate for their needs. Using the equity in their homes to enable them to purchase domiciliary care services was of great interest.
- A trustworthy (that is, government guaranteed, rather than private sector) form of equity release was seen as an improvement on the current system. It could allow greater choice over whether people stayed at home or went into residential care. In all groups it was felt that a 'government guaranteed' equity release system was *inherently* better than any private sector schemes where organisations would profit from the system.
- Care in the home/supported housing was considered to be more desirable than care in residential settings, and domiciliary care was instinctively felt to be cheaper to fund.

3.5. Contribution from the state, families or individuals

People were asked in each of the groups where they thought the responsibility for the funding of long-term care should lay, with the state, with an individual or with families.

- Older people still affirmed and considered binding the postwar contract to be looked after '*from the cradle to the grave*'. Acknowledging that in future there will be greater numbers of older people, it was largely accepted by most of the participants – irrespective of age, location, whether people were disabled or carers – that the current system is not sustainable in the long term, and that in future individuals will have to contribute in some way to the costs of their long-term care. Despite this acknowledgement, most participants still felt that the state had some role to play. Only three people (one retired couple, and a disabled person) across all the groups felt it was the individual's responsibility to make provision for their own future care needs, and to use their own resources for this purpose.
- Whatever mechanism was adopted to enable individuals to contribute more towards the costs of their long-term care, it was largely accepted that individuals should contribute more when working rather than once they retired and their income was more

constrained. Older people felt that young people should be encouraged to start making provision for their long-term care needs, and that incentives and/or compulsion would be required to ensure they did.

- Increasing general taxation was seen to be fairer than the current system, with the burden spread across the population, with those who could afford to paying more. This would guarantee a certain level of support that individuals could supplement with their own resources.
- There was much interest in the idea of a national fund or a specific tax for long-term care, although guarantees would be required that the ring-fenced fund would not be drained for other purposes.
- Some participants felt that taxes should not be increased and that additional funds could be found if the government had different priorities, and was less wasteful.

3.6. Increasing value of assets people are allowed to keep, with people paying top up for 'more' services

People were asked whether the amount of assets older people are allowed to keep and still receive state assistance should be increased.

- Participants were supportive of increasing the amount of assets people could keep and still receive state assistance. It was acknowledged that those who could afford to do so would continue to use their own resources to pay for any additional services they required.

3.7. Residential care

Participants were also asked about residential care, and whether the 'state should pay' or whether individuals should pay for certain elements, for example the accommodation/hotel aspects of living in a care home.

- People did not understand how service charges were calculated, and did not make distinctions between 'personal' or 'nursing' care. It was very difficult to draw any conclusions regarding attitudes towards paying for different elements of residential care.

4. Discussion and conclusions

Overall, the people involved in the focus groups were in agreement that the current system needed to change. They were unsure of the type of changes that should be made or how they might work in detail, but were willing to support a system that was fairer. Participants welcomed concepts that seemed more straightforward than the current system – for example a national scale of fees for home care and other services, or a wage for carers. They were generally less responsive to more complex or less developed ideas – for example around changing Attendance Allowance.

A more informed debate will be required to support any proposals for change – this debate should be informed by the three main issues raised in the focus groups set out below.

4.1. Negative perceptions of older people's services

Despite a number of significant government initiatives to improve older people's services, the findings of this study indicate that public perceptions of older people's services were generally negative. Older people are still seen to be unfairly treated, particularly with regard to the current system for funding long-term care. The system was considered inequitable and confusing.

4.2. Penalising thrift

Currently the view that 'thrift is penalised' is deeply entrenched. All participants supported movement towards a more equitable system. The biggest challenge for policy makers will be to ensure that any new solutions or changes to the system are perceived to be equitable, or at least more equitable than the current system, and not seen to be penalising those who have worked and saved.

4.3. Individual versus state responsibility for care

Most participants felt that the state should pay for long-term care, and most were reluctant to countenance the notion that older people should contribute towards the costs. Another significant challenge for policy makers will be to promote wider acceptance of the concept that individuals should contribute to the costs of their long-term care. Very few individuals reported making provision for future care needs; most were determined to reduce their assets as they got older in order to ensure they received financial support from the state.

4.4. Levels of support for the Joseph Rowntree Foundation proposals

There was strong support for standardised assessment and a national scale of fees for home care and other services; however, the proposals that these charges should vary by income band was not well received. People felt this was another example of ‘thrift being penalised’.

People in England often referred to the Scottish model of ‘free care’, although it was clear that they had a limited understanding of how the system operates in practice, and many assumed that all services for older people were free, which is not the case. Careful consideration is required to determine how this model might be translated across the UK. Current evidence suggests that the introduction of free personal care in Scotland has been problematic in some areas, for example the definitions of ‘personal care’ vary from local authority to local authority, and there is some evidence that other types of support services for older people (for example day care) are being curtailed to assist with the funding of free personal care (see Age Concern Scotland, 2003).

People were highly supportive of increasing the value of the assets that people can keep and still receive state assistance.

There was considerable support for increasing general taxation to pay for long-term care, and much interest in the idea of a ‘ring-fenced national fund’ or a specific tax for long-term care to create a national fund. Such a system was felt to be inherently fairer, with everyone contributing according to their means.

Reference was consistently made in the groups to older people “losing their homes” or having their “homes taken away” if they need care. This was perceived to be a great injustice. It seems that any policy that makes assumptions about people willingly drawing on their housing equity will be poorly received unless it is carefully presented as a route to maintaining independence and choice and not inevitably ending in the sale of the property.

4.5. Requirement for more informed debate

The discussion about the future funding of long-term care is outside most people’s normal terms of reference, although people acknowledged that there would be difficulties in the future. Participants in the groups were unable to comment except in the broadest possible terms on some of the

more complex ideas presented to them, and could discern potential problems in each of the solutions. If a set of acceptable policy options is to be generated, there is first a need for a much more informed public debate. What is clear from these discussions is that people would welcome changes, and may be prepared to think about quite radical solutions – for example paying into a fund set aside for personal care, or opting to pay more when working in order to safeguard property and assets later on.

4.6. Concerns about quality

As well as concerns about costs, there were concerns about quality of services. If policy moves towards making people contribute more towards their own long-term care costs, people will expect some guarantees that quality services will be in place when they need them. There may be an argument for something akin to the *National Service Framework for Older People* (DH, 2001) that makes explicit what people can expect in terms of quality for long-term care services, how people's needs are assessed, and what they might expect as a minimum level of provision, in terms of quality, quantity and type of service.

4.7. Conclusion

It seems the public will be receptive to changes to the current system partly because the system is held in such low regard, and partly because the system is seen to be unsustainable in the long term. It may be problematic, however, to achieve consensus on what form any such changes might take.

There is a general reluctance to acknowledge that individuals will have to contribute significantly more towards the costs of their long-term care. Proposals to improve mechanisms to facilitate individuals saving or paying more were poorly received. Participants felt that the state has a major part to play in funding services for all older people, not just the poorest or most vulnerable. Consequently increasing taxation was seen by many to be the best way of ensuring there were greater contributions from individuals, and sufficient resources for the state to meet its responsibilities. The public's receptiveness to the notion of tax increases may require further testing; however, this study indicates that tax increases may be acceptable if they are linked to clearly defined policy objectives and specific service provision.

1. Background to the study

As our population ages, there are growing concerns about how the services that will be required to meet the future long-term care needs of older people will be funded. Current systems of funding are perceived to be inequitable, confusing for the consumer, and unsustainable in the long term, particularly as demands for services will increase. The Joseph Rowntree Foundation (JRF) has a long-standing interest in how long-term care can be funded, and published the results of its own inquiry into *Meeting the Costs of Long-term Care* in 1997 (JRF, 1997). Building on this earlier work, JRF has been engaged in a three-year Policy and Practice Development Programme, designed to 'identify, encourage and build consensus around the implementation of a sustainable model for meeting the costs of long-term care throughout the UK'.

The programme, which began in 2003 and will be completed in 2006, has been considering how long-term care is currently funded, and what the building blocks for the future should be. The intention is to change and influence government policy, and contribute towards the development of a system of funding for long-term care based on the key principles of consistency, sustainability, equity, and clarity around the respective roles and responsibilities of the state and the individual.¹

Earlier this year JRF published a discussion paper *Facing the Cost of Long-term Care: Towards a Sustainable Funding System* (Hirsch, 2005) that brought together some of the key evidence and discussions that the programme had generated. In setting out the challenges for policy makers, the paper provided a number of possible policy options for discussion and further development.

Following publication of *Facing the Cost of Long-term Care*, researchers from the Centre for Housing Policy at the University of York, and QA Research (a private sector research company, also from York) were asked to test public attitudes towards the policy solutions it presented. Apart from exploring some of the more general issues, researchers were asked to test attitudes towards the following four key ideas:

1. Standardised assessment and means testing of domiciliary services

¹ Work undertaken by the programme has included: a study of future demands and predicted levels of spending on long-term care (Wittenberg et al, 2004), an investigation into the funding mechanism for long-term care adopted in other countries (Glendinning et al, 2004), and a consideration of possible private funding mechanisms for long-term care (Johnstone, 2005). In addition, the programme has hosted a number of consensus events.

2. Re-packaging Attendance Allowance into a standardised care payment
3. Increasing support for carers – either through resources or formal help
4. The potential of equity release schemes to pay for care costs.

The study was intended to inform the ongoing work of the JRF programme, and to facilitate a better understanding of the viability and acceptability of the possible solutions the programme had identified.

1.1. Methods

Between October and December 2005, we undertook eight focus groups in which 59 people took part (male $n=32$, female $n=37$; age range 26-90). The groups were recruited purposively in various locations in the UK² to ensure participation from a range of age groups, disabled people, carers and people from different ethnic groups. In the groups we explored participants' perceptions of the various options for funding long-term care that have been developed by the JRF programme. Appendix A provides a profile of the participants in the groups. The topic guide is presented in Appendix B.

For the purpose of this study, long-term care was defined as:

Care provided for people over 65 years of age who are unable to look after themselves without some kind of support. It includes care provided in the home, in sheltered housing, residential or nursing homes but NOT care provided in hospital unless it is intended to be permanent. It includes people who need help for a couple of hours a day through to people who need care day and night³.

1.2. Outline of the report

We begin by presenting the over-arching findings that emerged from the discussions (Chapter 2). We then move on to report the outcome of the discussions around the four key themes that were the main focus of the study (Chapter 3). In the final section we explore the policy implications of these findings.

² Locations included: Islington (an inner-city London borough), Edinburgh, Galashiels, Leicester, Newcastle, North Yorkshire and the Lake District.

³ This definition was taken from Diba (1996), a study undertaken as part of JRF's earlier inquiry into the financing of long-term care for older people.

2. Overarching findings from the discussion groups

Participants in all the groups acknowledged the challenge that the future funding of long-term care presents both for government and individuals, and recognised that the system needs to change. However, they were less clear about possible solutions.

There appears to be a broad consensus that the current system is confusing, complex, intrusive, and – importantly – perceived to be inequitable *as hard work and thrift are seen to be penalised*. Many of our older participants with experience of the current system were highly resentful of the current level of intrusion into their private financial affairs.

“All the help you do get seems to be means-tested, all the time, even if you need it, it is means-tested. So if you have worked all your life, or a lot of your life, all the money you’ve got in the bank, because it’s there and you’ve worked for it, you’re not entitled to any help in your old age. Whereas if you’ve just been extravagant in your life, you get everything.” (pensioner)

“I don’t mind paying because I am able to pay but nevertheless what annoyed me at that particular time was all the harassment, and it was harassment, with the letters and having to produce all sorts of bank statements, pension receipts, you name it. Your life was quite torn to shreds and I still resent that.” (pensioner)

Consequently the main plank of many people’s strategies for funding their own long-term care appeared to be spending their assets to ensure they qualify for state support. As one participant said, “the trick is to keep one step ahead of the government”.

Despite the recognition that there would be difficulties in the future, and that the current system needed changing, *there was a general reluctance to acknowledge that individuals in the future will have to contribute significantly more towards the costs of their care*. In the groups, the majority of people felt that the state should fund long-term care, and were also willing to acknowledge that this would require an increase in taxation. The message here is that although most people would welcome changes to the current system, *it will be a tough battle for policy makers to convince people that they should contribute more themselves toward the costs of their care in the future whatever mechanisms are adopted to enable individuals to contribute*. Many of the people taking part in focus groups, including pensioners, had not previously thought about paying

for long-term care, so the issue is arguably not yet visible enough in the eyes of the general public. Although the mechanisms suggested by JRF (Hirsch, 2005) were of great interest to participants, it appears there are some fundamental barriers to moving towards change, not least of which will be convincing people that they need to make some provision themselves for their own future care needs.

We addressed a number of possible ways of funding long-term care in the future in the groups. None of the options discussed appeared to be universally favoured above the others. In the discussions people often questioned the detail of how different proposed solutions might work. They noted that different mechanisms will work for some people and not others, so a number of changes need to be made to assist people across a range of different financial and personal circumstances. Mechanisms were welcomed that allowed people to start planning sooner, thus allowing them to be in control in the future should they have needs for long-term care. There were concerns about the quality of care now and in the future, and also concerns that older people should have choices, for example, the option of being cared for at home rather than in institutional settings, and choices about type of services they receive and the way they are delivered.

3. Exploring the solutions proposed by the Joseph Rowntree Foundation

Here we report the outcome of the discussions that focused on the specific ideas that were generated by the JRF programme and introduced to the participants in the discussion groups. As outlined in Chapter 1, four main ideas were tested: standardised assessment and means testing of domiciliary services; re-packaging of Attendance Allowance; increasing support for carers; and the potential of equity release schemes to pay for care costs. We also tested some of the other ideas generated by the programme including: whether the state or individuals should take on the responsibility of funding long-term care costs; whether people should be allowed to keep more of their assets and still be eligible for state assistance; and whether individuals or the state should pay for different elements of residential care.

3.1. Standardised assessment and means testing of domiciliary services

The JRF report *Facing the Cost of Long-term Care* suggests that there should be a national scale of fees for care by bands of income (Hirsch, 2005, p 28). Some progress has already been made with the introduction of the minimum income below which charges for care cannot be levied. However, because social services are a local authority function, people in different parts of the country get different levels of access to services, and pay different amounts for service.

There was much support for a national scale of fees for home care services. People did feel it was unjust that access to services and charges varied in different areas. It was noted that people do not get different amounts of pension according to where they live. There was mistrust of how some local authorities managed their finances, and the way individuals in those areas were effectively penalised because of local financial mismanagement. Some participants also highlighted that if people in Scotland get “free care”, why should people pay in other parts of the UK? It was acknowledged that if a national scale of fees were to be introduced some local authorities – particularly those with a large elderly population – might struggle to raise the required funds to meet care needs, and thus central government funding would be required.

“The finances I’d require in England are different from the finances I’d require in Scotland – they’ve got free nursing care and here you’ve got to pay for it. The whole United Kingdom is split differently into sections and there are different conditions for

different regions or areas, which to me is wrong.... The thing is the local authority doesn't pay the pensioners different pensions. Everybody gets the same income situation and the same facilities.” (pensioner)

“No, I think that [national scale of fees] is the right way to be going, it stops local authorities fiddling things to suit themselves, which undoubtedly they do. Sometimes they have to of course.” (pensioner)

“Everybody knows where they are if there's a national rate, everybody knows where they are.” (urban participant)

Participants were, however, much less comfortable with the proposals by JRF that there should be a national scale of maximum fees by bands of income above the minimum income.⁴ The JRF report suggested two mechanisms. The first suggestion was that there could be a maximum charge for care services related to income. The second suggestion was that there should be a maximum percentage of income above a certain level that people would be expected to contribute to their care costs. Introducing a more finely tuned or tapered system of charges where assistance from the state was not totally withdrawn but reduced for those with higher incomes was generally seen to fairer and an improvement on the current 'all or nothing' system, but it was still perceived as means testing by another name. Any type of means testing was often opposed on principle. It was also thought that such tapering would be difficult to implement because of its potential complexity.

“We're at an age where we all paid into the system, therefore, if we don't get the full amount paid by the government, it should be a sliding scale, rather than a cut off scale.” (carer)

That's [tapered system of charges] an incentive not to have a lot of money and there would be feelings of unfairness in the middle bands which had some [assistance] but not lots. It's a marginal effect but I think that's how people would feel.” (pensioner)

In some groups the discussion also turned not only to standardisation of national charges, but also the requirement for 'standardisation' of services, and importantly quality standards for services. People were

⁴ The JRF report (Hirsh, 2005, pp 28-9) provides two examples of how such a system of charges might work. The first example suggests a limit of £30 a week for people under twice the guarantee level of Pension Credit. The second suggests a maximum of 25% of income above £136 to be payable for domiciliary services. Please note that we used slightly different examples in our discussion groups to ensure clarity for the participants.

concerned not just with the inequity of being charged different fees in different places, but also with the differences in the type, extent and quality of service provision. Reflecting on the content and outcome of the discussion, it appears that there may be an argument for a National Service Framework for Long-term Care Services, which makes explicit how people's needs are assessed, and what they might expect as a minimum level of provision, both in terms of quality, quantity and type of service.

3.2. Re-packaging Attendance Allowance into a standardised care payment

People with care needs can claim Attendance Allowance, a non-means-tested, non-taxable benefit for people over 65, to help them pay for their care. One of the suggestions in *Facing the Cost of Long-term Care* was that that Attendance Allowance might be restructured (Hirsch, 2005, p 20).

In the groups we explored attitudes towards Attendance Allowance, and possibilities for 'fine-tuning' this benefit to cover a wider spectrum of needs.⁵ People were generally highly supportive of mechanisms that promoted independence, and allowed older people choices, and across the groups there was general support for more fine-tuning of Attendance Allowance. It was felt that the upper limit (currently around £60 per week) was inadequate for those with high levels of care needs. Similarly having a lower level of allowance which people could use to pay for help with low level support needs was also received very positively, especially by older participants, many of whom spoke about the services they wanted and could not get (for example, help with shopping and domestic tasks).

However, when they reflected on the implications of such changes, some people felt that the relative simplicity and universality of Attendance Allowance might be lost. Many noted that the Attendance Allowance assessment is already quite complex even though income and assets are not currently taken into account. A lot of our older participants had needed help to make an application. When asked whether the additional costs of extending Attendance Allowance should be contained in part by means testing or by making the benefit taxable, people were more circumspect. Means testing was universally disliked, and again discussions turned towards the notion that prudence and hard work would be penalised.

⁵ Currently Attendance Allowance is payable at two levels, approximately £40 per week for people needing *personal* care in the day or in the night, or approximately £60 per week for people needing care in the day *and* in the night. See www.dwp.gov.uk/lifeevent/benefits/attendance_allowance.asp

3.3. Increasing support for carers either through resources or formal help

In the wider discussion about how the responsibility for the future funding of long-term care should be apportioned, we explored people's attitudes towards family responsibilities, and whether families should receive payments for caring for their older relatives.

Older participants who were caring for a spouse or other family member often spoke about duty and their responsibility towards a life partner or older parents. Although caring was hard, many wanted to 'care'. They did not expect to be paid, and many people saw any form of payment or allowance as a 'wage'. There were suggestions that even if there were additional statutory benefits for carers, older carers in particular might be reluctant to claim them because they felt caring was their duty, and something "you just do".

"You just do it don't you? As a spouse, it's automatic, you just do it." (pensioner)

Participants in one group (composed of mainly younger, disabled people from a relatively deprived inner-city borough in London) did think that older spouse carers should be paid a wage in recognition of the money they were saving the state. Here participants felt very strongly that carers were generally poorly supported, and that financial assistance offered to carers was inadequate. They felt that financial support for carers should be increased, including older carers, as to do otherwise would be discriminating against older people.

"It costs the state a lot more when the family breaks down and that person has got to go into care and they've got to pay to keep them." (younger, disabled participant)

When people of working age were caring for someone, and consequently could not take on paid employment, then there was broad support across all the groups that they should receive a reasonable payment, equivalent to a 'wage', to compensate them for loss of income. Some people felt that this would encourage younger people to become family carers, especially those who might want to care for their relatives, but simply could not afford to give up paid employment because they had young families of their own to support. One group composed of Punjabi elders were particularly supportive of this idea. They felt that care services generally were not attuned to their cultural needs, and thus care provided

by family members was particularly important to them. They felt payments to carers would encourage and enable their children to care for them. Participants in other groups also felt payments to carers would reduce the sense of 'being a burden' that older people felt when their children were caring for them and suffering financial hardship as a consequence. Building on the discussion in the groups about how younger people can be encouraged to think about saving and making provision for their care needs in the future, participants also noted that younger carers who cannot work would not only suffer the immediate financial consequences of being without a wage, but would also find it extremely difficult to make provision for their own future care needs.

"If your dependants have to pay for your care, they're losing their quality of life and who's going to pay for them when they require care? It's a vicious circle." (rural participant)

"If you pack up work to go and look after them, all that money you're losing and you go to get the Carer's Allowance whatever it is – big, big job. They should come up with a bit more than that [Carers' Allowance] for leaving work." (urban participant)

"If you do think about money and for example you have children, and they are working, if they were given a wage they would give up work to look after their family but it is actually not affordable because they have got their own families. Some people just can't give up work to look after their family – they've got children, they've got a mortgage to pay. But actually if they could afford to say, 'I can give up my job, even though I've got a mortgage and I really want to do that for you'." (carer)

One group compared the differences in funding between support for carers of older people and people who foster children:

"How can you justify not paying a carer for looking after somebody elderly when you can pay a foster parent up to £400 per week to look after a young kid. They pay it to keep the child out of a home so therefore you should be prepared to pay for the elderly to be kept out of a home also[...]. What's the difference, it's only the age of the person, they still have requirements and needs?" (rural participant)

There was much support for improving carers' services generally (for example, sitting services, respite and day care), although it was acknowledged that even when such services were in place, they were not always appropriate to the needs of all individuals. Services that were

for carers themselves, such as carer groups that provided support and information, were highly valued. For the carers we spoke to such services not only offered them support as individuals but advice and information about how to access services and benefits.

Discussions also touched on whether people would rather have services, or cash payments that people could use to purchase services of their choice. Participants could see value in both options. It was not clear from our discussions whether people would prefer to have 'cash payments' instead of services. It was acknowledged that cash payments offered people the choice of how they spent the money, whether on services or on the 'little extra things' that are needed when you are caring for someone.

"It's down to you what you do with the money – you've got no one saying spend it on this, whereas with services they just give it to you and you've got to take it. With cash-in-hand you can just do what you want with it."
(urban participant)

"There are extras you've got to buy for them in any case. I mean, I'm caring for my husband, who comes home from day care at anything from 3.30-4.30 every night. I've got him all day Wednesday, and I've got him Saturday and Sunday and you've got to have these little extra things in that you wouldn't be buying normally." (carer)

Some participants were concerned that payments would do little to help some carers, particularly older carers who desperately needed practical help.

"I could do with physical help for my husband. In the last week he has been put on pills and been wandering about all night. I had to try and help him into bed – and he's just skin and bone, but it's no good for my back. I have had a hernia and things like that – and that's the help he needs – physical help." (carer)

I would like to see a wee bit more energy thrown into elderly carers.... I actually heard the doctor saying he was going around about houses and he didn't know who was the carer, two eighty-odd people, one was looking after the other, what about people like that? I can't see how getting a wage would have helped in that situation." (carer)

To conclude, there was then no consensus across the groups. Some older carers found it difficult to accept that that carers should be 'paid a

wage' for doing their duty. Any payment would be seen as a 'wage' and would be reluctantly accepted, if indeed it was accepted at all. Others felt that payments to carers or 'wages' would enable people to care who had financial responsibilities, and might otherwise be unable to provide informal care. Cash payments to purchase services were seen to offer some people more choice, but were not felt to be all that useful to those who were struggling the most (that is, older spouse carers). Clearly some participants in our groups felt 'practical' help was more needed in some circumstances rather than financial assistance. It may be that the responsibility for sourcing and arranging care services would be particularly onerous for some carers, particularly frail elderly people. For such people, assistance presented in the form of services rather than 'payment' might be more appropriate. Participants in the groups could think of examples where both cash payments and services would be more or less appropriate.

3.4. The potential of equity release schemes to pay for care costs

As noted in *Facing the Cost of Long-term Care* (Hirsch, 2005), many people requiring domiciliary care have considerable assets in the form of their home. Evidence suggests that although older people are becoming more willing to use these assets for their own benefit rather than leaving large legacies to their relatives, they are suspicious of current equity release mechanisms (Rowlingson, 2005). In all the groups we explored people's attitudes towards the release of housing equity to provide funds for domiciliary care, and in particular their views towards the possible provision of 'government guaranteed' loans that would be repaid with the eventual proceeds of the sale of the home (Hirsch, 2005, p 26).

The first point here is that many of our respondents, particularly older people, felt very strongly that older people should not have to lose or borrow against their homes to pay for care. For a large number of people this was an overriding principle. This links very closely with the belief that those who had worked hard, "gone without", and owned their own homes were being penalised for their thrift. Some of our participants wanted to leave something to their children, noting that with increasing costs of home ownership, financial support from their parents or other relatives would be the only way younger people could enter the housing market.

"You just want to pass something on, particularly in this day and age because, my niece, she was talking about the price of houses last night and she said, 'The prices! There's just no way'. I mean, she's got her degree from university, she's got debts of £12,000

and she's got an overdraft and there's just absolutely no way she can afford a house! So older people like to pass something on. Okay, £400,000 might be too much, but £100,000 is not unreasonable in this day and age to be left with." (carer)

"Why should we have to borrow on properties we've worked for all our lives? Getting ourselves into debt again. I don't think that's right." (urban respondent)

Others, however, were more reflective, and questioned whether or not inheritance was a 'natural right'. They felt that older people *should* use their resources for their own benefit, and property was a resource to be used. Some felt that their children wanted them to do this.

"Is it a natural right to leave something for your children to inherit?[...] We are going to get older, we're going to become less able and we've been putting money away for that kind of thing. We personally accept the fact that one or other of us is going to have to go into care [...] and the money for it is going to have to be found from the money we've put aside. Now you could say we've been fortunate to be able to do that but we've got to accept the fact that that is our responsibility and however much I feel for the people whose house has to be sold, I feel that that is fairer to society than the alternative." (pensioner)

"I think the attitude is to bring up your children to look after themselves, because the parents will do their best to look after themselves. Perhaps it doesn't apply equally to everyone, because it depends on your situation doesn't it?" (pensioner)

A group of younger participants felt that if children were not prepared to look after their parents then they should not expect to inherit a property and "get something for nothing". Of particular interest are the views of the group of Punjabi elders. Like the group of younger participants, they felt that if children were not prepared to look after their parents, then parents had no obligation to leave them any money. They were concerned about the lack of care homes that provided culturally appropriate services, thus for them domiciliary care was a very desirable option, and using the equity in their home to enable them to purchase domiciliary care services was of particular interest.

Despite the reluctance of many people to countenance the idea that the 'home' could be used as a mechanism to fund care, many people acknowledged, albeit a little grudgingly, that a trustworthy form of equity release would help people with housing equity considerably. Trustworthy

equity release would be an improvement on the current system. It could be a mechanism for allowing greater choice over whether people stayed at home or went into residential care. It was also felt that some older people “hang on” in their homes without asking for help because they are fearful of losing their homes completely, thus gradual equity release might encourage people to ask for help when they needed it rather than wait until crisis point. People felt that care in the home was on the whole more desirable than care in residential settings, and instinctively felt that domiciliary care must be cheaper.

In all the groups participants felt that a ‘government guaranteed’ equity release system was *inherently* better than any private sector schemes. This is a key point. Generally there was great mistrust of any private sector financial ‘packages’, whether equity release or private insurance.

“Yes, because loan sharks get into this equity release and we do not trust that scheme for that reason. If it was government controlled or officially approved [...] then I’m sure it would be a big success.” (pensioner)

“I mean, it [equity release] might not help everybody in every single circumstance but the thing is, because the situation now is so bad, anything is an improvement.” (carer)

As with many of the options presented to the groups, people were concerned with the detail of how equity release would work. For example, some participants asked at what point the house would have to be sold to repay the loans, and what would happen if the equity released from a house ran out, or what would happen if there was still family members living there who needed a home.

3.5. Contribution from the state, families or individuals

We began each of the groups with an opening question, “Who do you think should pay for long-term care – the state, individuals, or families?”. This question was intended to start a general discussion about where people thought the responsibility for funding long-term care should lie. *Across the groups there were strongly held views that the state should carry the main responsibility for the future funding of long-term care.* This view was sometimes tempered with the caveat that if individuals had the means they should however contribute ‘something’.

Older participants referred consistently to the postwar social contract, and considered this contract was still binding for the current generation of older people who had paid taxes and National Insurance all their lives,

and had believed they would be looked after “from the cradle to the grave”.

Across all groups participants also felt that the current system was unjust because people who had been careful and thrifty all their lives were being penalised. This was a consistent theme, and people had very strong views. There were concerns that pensioners were being “set against each other”, as some were entitled to assistance and others with similar needs were not. There were also concerns about the amount of benefits paid to some younger people who appeared to have contributed little if nothing in the way of taxes while older people with a lifetime of contributions were forced to pay for services they needed.

“Your kids are paying for your healthcare when your 60 and 70, they will have to keep re-assessing it as there are more old people. What grinds with most people is the out and out spongers, that just gets everybody’s back up and you think why should I, they do sod all and don’t pay any taxes and all they do is get everything under the sun.” (rural participant)

Thus there also appears to be some potential for intergenerational conflict and dispute. Any changes to the current system will have to go some way to address these concerns if they are to be accepted.

“Everyone should be entitled to be taken care of, but people who have worked all their lives – why should they have to still pay for things when others don’t?” (carer)

“Something has to be done to level things out and to make all pensioners, every single one of us, not saying that this one should have a free license and this one shouldn’t, or this one should have housing benefit and this one shouldn’t, it should be levelled out in some form right across the board. What the government has done now, they’ve turned pensioner against pensioner.” (pensioner)

There were, however, a very small number of participants who considered that it was the individual’s responsibility to make provision for their own future care needs, and to use their own resources for this purpose. When asked whether anyone had made any plans regarding paying for any care, only one elderly couple (see quotation above, page 26) reported they had put money aside specifically to cover the costs of any future care needs (although they recognised not everyone would be in a position to do this). Another individual intended to use the equity in his property. We were not offered any further examples of people making such specific provision for care in later life, although as noted in Chapter

2, a number of people reported reducing their assets to ensure they were eligible for state assistance, and others accepted that this was a sensible strategy.

There was also a more general acceptance that the system will have to change in the future, and that it is unrealistic to expect ‘the state to pay’ because of the growing numbers of older people, greater longevity and fewer numbers of younger people to pay tax.

“I think we all have a responsibility to look to our future”. (pensioner from Cumbria)

“Obviously things can’t tick over as they are or we’re going to be very top heavy and not enough young people will be able to pay to keep us older people in the life of luxury in a nursing home!” (pensioner from Newcastle)

“When the National Health Service came into being in 1948 you were looked after from the cradle to the grave, and that was obviously wrong. It’s just not possible.” (pensioner)

Participants were asked how the funds for long-term care should be raised. Generally older people felt that whatever mechanism was adopted, individuals should contribute more when they were working rather than once they had retired, when their income was more constrained. They felt that young people should be encouraged to start making provision for their long-term care needs and that incentives or an element of compulsion would be required.

“I think it should be really drawn to the attention of people when they are younger.” (pensioner)

“If you had government-funded or government-backed insurance and with the proviso that if you are in this scheme, they’ll actually leave your property alone as well, then that would also help. If there was tax relief and that sort of thing – so if you incentivise people to do this.” (carer)

“You’ve got to give an incentive to people to join company pension schemes and for people to save.” (pensioner)

From younger people there were mixed views as to whether they could be reasonably expected to make provision for their future care needs while they were still young. They felt that the financial pressure on younger working people was already considerable.

“It is unfair though to put the burden solely on working people – if you have children you have to pay university fees and save for your pension. It is impossible to bring up a family and pay more.” (carer, aged 40)

“I have just got a re-mortgage, I’ve got Life Assurance, critical illness, pension, buildings, contents, house insurance. How many pots do we have to throw our money into? Private pension as well, I have that on the go. To be honest personally I would rather, if the rate is 22 pence in the pound on tax, I would be quite happy for it to be 24 pence and that these extra things are covered.” (rural participant, aged 28)

When pushed to think about how best the state should raise the additional funding that would be required, there was acknowledgement that saying the ‘state should pay’ meant increased taxes. Some pointed to the higher levels of taxation in Scandinavian countries where people enjoyed high levels of service provision. Increasing general taxation, however, was seen to be fairer in some ways than the current system. The burden was spread across the population, with those paying more who could afford to. This was also seen as a means of ensuring everyone had a certain level of support that could be then ‘topped up’ by individuals with their own resources. There were suggestions that VAT could be increased to raise funds specifically to pay for care.

“This is what we are paying our taxes for, so I think most people wouldn’t mind paying an extra 1p or 2p in the pound if you knew all these things were going to be taken care of.” (rural participant)

There was also much interest in the idea of a national fund or a specific tax for long-term care to create a national fund (and in some groups the idea of a national ‘ring-fenced’ care fund was suggested by people in the group without it being introduced by the researchers). People felt that some guarantee would be required that the ring-fenced fund would not be drained for other purposes. One group suggested that an element of the current National Insurance contribution could be diverted towards a care fund. People generally lacked confidence that any fund would truly be ring-fenced for care, and that people’s future care needs would be met. There were some participants as well that felt that such a system would be unfair on those who paid in over their working lives but did not “get anything out” either because they did not need any care or because they died prematurely.

“If it was ring-fenced people would be more inclined to say ‘yes, we must pay something in’.” (pensioner)

“It would be better if there was some kind of plan you could pay into along the way and that took care of it when you needed it.” (pensioner)

“If it was going in your own personal little pot then yes [I would pay more tax], but if you were paying for everyone else, then you’re in the same position as you are now. Like on the television today, you have 15 kids and stay at home all day. If it goes into your pot it’s like having your own private health insurance, isn’t it?” (rural participant)

Some participants felt that taxes should not be increased and that additional funds could be found if government had different priorities, and was less wasteful.

In terms of private insurance schemes and partnerships between private insurance and government, participants were on the whole highly suspicious of the private sector, noting recent scandals around private pensions, and insurance schemes that failed to pay out, or required top-up payments as people got older. They were also reluctant to see private ‘profits’ being made out of people’s needs for care. Older people also felt it would be difficult to persuade younger people to take out private insurance. There were also concerns about some groups (for example, disabled people, people on low incomes) who could not easily get insurance. On the positive side, some participants in one group (younger people in North Yorkshire) noted that private insurance would be a way of providing for your own future care needs, without paying for the ‘current’ generation of older people. This view was, however, challenged by other participants. They used the example of how private health insurance operates in the US, leaving those with no insurance without access to healthcare, while others with insurance were effectively over-treated for minor ailments. Moreover they felt that younger people *should* help support older people.

“But you have to have confidence that the money you have provided is going to do what they say. I mean you just have to look at the private pension schemes that have folded and left people with nothing, and they have paid into that. Now, how can that happen?” (carer)

“It’s going to be very hard, being disabled, to get the funds to pay for any form of insurance because we’re not working. So how do you get over that situation?” (urban respondent)

3.6. Increasing value of assets people are allowed to keep, with people paying top up for ‘more’ services

Across all groups people were highly supportive of increasing the amount of assets people are allowed to keep and still receiving assistance from the state (see Hirsch, 2005, p 28). Again at the heart of this discussion in the groups was the perceived injustice of a system that appeared to penalise thrift. It was felt that allowing people to keep more of their assets would be one way to make things fairer. People felt that the upper limit on the amount of assets they could keep should be generally much higher than current allowances. In many groups it was felt that even half the value of the average-priced house (as suggested by JRF) was not enough.

“You’d feel less robbed [being allowed to keep more assets] – that’s the thing. People pay all their life and they get robbed – they get mugged by the government!” (carer)

However, the idea of people using their own assets to ‘top up’ a basic entitlement from the state was supported in some groups. One group suggested this without prompting from the researchers.

“Couldn’t you establish an average, so that the general requirement for people needing assistance is X hundred pounds a week. If you have a case where somebody is very dependent maybe needs 24 hours care that’s over and above and that’s like treated like a special case, once you get beyond that if you have the resources available you start to contribute towards your care.” (rural participant)

“If you want something plush and five star with all the fancy gold tap fittings you pay extra.” (rural participant)

People felt that this was happening already, and those with the financial resources would inevitably have more choice and control as they do in other spheres of life. Others, however, felt that a ‘two-tier’ system was undesirable.

“But would that [two-tier system] be evident? It’s like children go to school and their parents are on benefit. They should get their

school lunch given to them, they should get the same as any other kid and it shouldn't be obvious whose parents are on benefit and whose parents are paying. So therefore [with] older people, why should it be evident that you haven't had the money?" (pensioner)

3.7. Residential care

Participants were also asked about residential care, and whether the 'state should pay' or whether individuals should pay for certain elements, for example the accommodation/hotel aspects of living in a care home. Most people felt it that the state should pay; however, they also acknowledged that paying 'something' gave people a greater sense of self-esteem.

"I think that people should pay something – it will give them a little bit of self-esteem. A lot of times people don't want to go into a home because they call it charity. There are some people where I live and they don't take their pension because it's charity. I just can't believe that. I think at that age, you've still got your self-esteem, and it's charity, so they would rather pay something than not, even if it's a small amount, like the widow's mite for instance. It still gives you self-respect, if you have it for nothing, you're down and out". (pensioner)

It was clear that even those people who had relatives in residential care did not understand how services were charged for, and did not really make the distinction between 'nursing' care and 'personal' care, although in some instances, for example for people with dementia, they recognised the requirement for specialist staff. It is clear from the experiences that people related in the groups that the complexities of the current system of charging for residential care cause considerable grief and financial uncertainty, indeed hardship, for relatives. Moreover, alongside concerns about payment, there were great concerns about the quality of services, and the quality of life enjoyed (or not) by residents. There were also discussion of how care staff were to be recruited in the future given the low wages and difficult working conditions that characterise the care industry. In summary it was difficult to draw any conclusions regarding attitudes towards paying for elements of residential care.

3.8. Conclusions

The task for the researchers was to present some of the ideas generated by the JRF programme and to develop some understanding of how

acceptable the different ideas were to people of different ages, in different parts of the UK, from different cultural backgrounds, and with different life experiences. These discussions indicate that many people still feel the state has an important role in funding long-term care. Given the growing numbers of older people, generally it was also recognised that individuals might have to contribute more in the future. Participants were, however, less clear about how this might best be achieved. People were interested in the various mechanisms proposed by JRF for making it easier for individuals to contribute. However, it seems that the detail of the proposals would need to be clearer if people are to be convinced of their value. For many of the participants the best way to ensure that individuals contribute more would be to increase taxation, ideally with guarantees that the funds for long-term care will be 'ring-fenced'.

4. Discussion and conclusion

In earlier sections we have presented in some detail the content and outcome of the discussions in relation to the specific ideas we were asked to test. Here we reflect on some of the themes that appeared to underpin people's views and perceptions, and draw out what seem to be some of the main messages for policy makers.

4.1. Negative perceptions of older people's services

In the last decade there have been a number of significant government initiatives to improve older people's services, with a determined focus on promoting choice and independence across health, social care, and housing.⁶ A recent report, *Opportunity Age* (DWP, 2005), details government progress in tackling inequalities in income and health among older people, and outlines future government strategies for an ageing society. In this context of apparent improvement, it is perhaps disappointing that views expressed in the discussion groups indicate that public perceptions of older people's services generally appear quite negative. In discussions concerns were raised regarding the quality of care services for older people (particularly private sector residential care provision) both now and in the future. The major driver of these negative perceptions, however, does appear to be the view that the current system for funding long-term care is inequitable and confusing. Older people were generally perceived to be getting "a raw deal", particularly those who were neither wealthy nor sufficiently poor to be eligible for state assistance.

4.2. Penalising thrift

In respect of current systems for funding long-term care for older people, the view that 'thrift is penalised' appears to be deeply entrenched. Although participants felt that people without sufficient means to pay for their care should be supported by the state, there was much discussion about how those who had 'squandered' money 'got everything free', while others with often meagre assets were effectively penalised by the state for a lifetime's hard work and thrift when they needed care in their old age. Similarly, participants pointed to young people who had never worked or contributed to 'the system' and yet were receiving considerable 'handouts' from the state. These were common themes in

⁶ See, for example, the establishment of the National Care Standards Commission, the introduction of the *National Service Framework for Older People* (DH, 2001), the recent White Papers *Independence, Well-being, and Choice: Our Visions of the Future of Social Care for Adults in England* (DH, 2005), *Our Health, Our Care, Our Say: A New Direction for Community Services* (DH, 2006), and the series of Audit Commission reports *Older People: A Changing Approach* (Audit Commission, 2004).

all the discussion groups. *The apparent strength of this feeling is cause for concern, and appears to be eroding people's confidence and support for the social welfare system, as well as generating resentment among pensioners, and between different age groups.*

This perception of thrift being penalised, and the system generally being inequitable (for example, people being charged different rates in different places, and having access to different services in different places) emerged in all the discussions, and coloured people's judgements about the possible mechanisms for funding care in the future. All participants supported movement towards a more equitable system. Reflecting on the possible changes to the current system proposed by JRF, people were concerned primarily with whether or not the changes would make the system fairer. For any policy to be considered acceptable, it will first have to be perceived as equitable, or at least more equitable than the current system. *Perhaps one of the biggest challenges for policy makers will be to ensure that any new solutions or changes to the system are not perceived to be penalising those who have worked and saved.* On a positive note most people felt that currently the system was so inequitable that they had few expectations of dramatic improvements, and felt any improvement would be welcome.

4.3. Individual versus state responsibility for care

The findings of the JRF Policy and Practice Development Programme make it clear that in future individuals will have to make contributions towards the costs of any long-term care they may need. The majority of our participants found this very hard to accept; some referred to the government's refusal to accept the recommendations that long-term care should be free made by the Royal Commission on Long-term Care (Sutherland, 1999). If the findings of this study are compared to other studies that have investigated people's attitudes towards the future funding of long-term care (for example, Diba, 1996; Parker and Clarke, 1997; Deeming and Keen, 2000; Age Concern England, forthcoming), public attitudes appear to have changed very little in the past decade despite awareness of the challenges that changing demography will present. In line with the findings of these earlier studies, the majority of our participants still felt that the state should pay for long-term care, and were reluctant to countenance the notion that older people should contribute towards the costs of their long-term care needs. *Another significant challenge for policy makers will be to promote wider acceptance of the concept that individuals should contribute in some way to the costs of their long-term care.*

Only a very small number of individuals reported making plans for any future care needs. Again this is linked to the notion that such planning would be effectively penalised through the application of means-tested service charges. It appeared from the discussions that most people thought the best strategy was to reduce their assets as they got older to ensure they received financial support from the state should they need care. In the discussion groups, people above retirement age frequently reported transferring money and property to family members. Younger people too gave examples of older relatives who were adopting similar strategies. Knowledge about the legitimacy of some of these arrangements varied. For example, people were usually aware that they can 'gift' certain amounts of money to family without paying tax. However, knowledge of the seven-year ruling (where property must have been transferred seven years before care is required if it is not to be counted as an asset) appeared to be patchy. The consequences of these 'asset dumping' strategies are difficult to predict; however, it does seem that they are not without risk to individuals. It was easy to imagine how some of the property transactions described (for example, one participant had sold a house to a sibling for much less than its market value to move into rented accommodation) might lead to unforeseen difficulties, particularly if care was required relatively quickly following a 'transfer'. The apparent prevalence of these 'asset dumping' strategies seem to indicate that any mechanism adopted to allow people to start saving or planning for future care needs (for example, insurance schemes) will need to have either an element of compulsion or some incentive to encourage people to contribute.

Perhaps a further reason underlying people's reluctance to plan or save for their long-term care needs is related to the difficulties for individuals in predicting with any accuracy how much money will be required and for how long. Younger people found it difficult to think about planning for so far ahead for something that may or may not be needed, particularly when they had other more immediate concerns such as paying their mortgage, and supporting their children through university. Many people thought it would be unlikely that they could save sufficient amounts to cover an extensive period of residential care. This may in part explain why the idea of a tax, or national insurance scheme was attractive.

4.4. Levels of support for the Joseph Rowntree Foundation proposals

Mechanisms that were perceived to improve equity were broadly supported. There was general support for standardised assessment and a national scale of fees for home care and other services. People in

England often referred to the Scottish model of 'free care', although it was clear that they had a rather rosy impression. They did not fully understand how the system actually operated, and assumed all care for older people was free. This is not the case (see Age Concern Scotland, 2003). Careful consideration is required of how this model might be translated across the UK. People were highly supportive of increasing the amount of assets people could keep and still receive state assistance. *There was considerable support for increasing general taxation to pay for long-term care, and much interest in the idea of a 'ring-fenced' national fund or a specific tax for long-term care to create a national fund.* Such a system was felt to be inherently fairer, with everyone contributing according to their means.

A particular bone of contention in all the groups was the perception that older homeowners have to sell their homes to pay for care. Although small numbers of people felt that individuals should use their own resources to pay for their care, and that property was a resource like any other, for many people – including people who were *not* homeowners – it was unacceptable that people should be forced to sell their homes. They were more circumspect, however, about the possibility of gradually releasing some housing equity (although only via government guaranteed schemes rather than private sector schemes); some participants felt this would be acceptable if it allowed people to purchase home care services and remain in their own homes. *It seems that any policy that makes assumptions about people willingly drawing on their housing equity may be poorly received unless it is presented as a mechanism to promote independence and extend choice, and does not inevitably lead to the sale of the property.*

Assumptions that there will be a future role for the private sector, either through provision of insurance or through equity release schemes, may be flawed. There was great mistrust of any private sector financial 'packages'. This was in part because people were reluctant to see profits being made out of people's care needs, but also because people were aware of the collapse of some pension schemes, and scandals involving the misappropriation of funds or people being sold financial products that failed to produce the promised returns. As noted above, the uncertainties around how much care individuals will need and for how long were seen to make it difficult for people to identify appropriate policies that they could depend on 'come what may'.

4.5. Requirement for more informed debate

The discussion about the future funding of long-term care is outside most people's terms of reference. Although people acknowledged that there

will be difficulties in the future, and were aware of the ageing population, participants in the groups were unable to comment except in the broadest possible terms on some of the more complex ideas presented to them. People could discern potential problems in each of the solutions that were discussed. These ideas may need more development before people can be convinced of their potential to make the system more equitable and more efficient. If a set of acceptable policy options is to be generated, there is need for a much more informed public debate. Our participants welcomed the opportunity to take part in the discussions. Many said they had found the discussions interesting and thought-provoking, and were interested to hear about possible mechanisms for funding care in the future. They also wanted to know how systems worked in other countries. There is a requirement for raising awareness around some of the complex issues and a wider debate. What is clear from these discussions is that people would welcome change, and may be prepared to think about more radical solutions than those proposed by JRF. Perhaps the most obvious would be an increase in taxation, or a specific tax to fund long-term care.

4.6. Concerns about quality of care and quality of life

There were concerns about quality of services. If policy moves towards making people contribute more towards their own long-term care costs, people will expect some guarantees that good quality services will be in place when they need them. There may be an argument for something similar to the *National Service Framework for Older People* that makes explicit what people can expect in terms of quality for long-term care services, covering issues such as how needs are assessed, and what they might expect as a minimum level of provision, both in terms of quality, quantity and type of service.

An unexpected theme in the discussions related to greater length of life, and there were some jokes made about voluntary euthanasia. This was a topic that was only touched on, so it is perhaps unwise to make too much of it; nevertheless, within the discussions about long-term care there was clearly a concern about quality of life at end stage, and some older people were clearly very fearful of being “kept going too long” by medical interventions.

4.7. Conclusions

The outcomes of the discussions to test public attitudes towards the funding of long-term care for older people, and in particular the proposals made by JRF lead us to the following broad conclusions.

Firstly: The public are receptive to change to the current system of funding for long-term care. Partly because the current system is held in such low regard, and partly because the system is seen to be unsustainable in the long term, with increasing numbers of older people and trends towards greater longevity. It may be problematic, however, to achieve a consensus on what form any such changes might take. Of the specific JRF proposals tested in this project, those that were seen to make the system *fairer* (for example, a national system of charging and assessment for services, a 'wage' for carers) were the ones that held the most popular appeal.

Secondly: There was a general reluctance to acknowledge that individuals will have to *contribute* more towards the costs of their long-term care in the future. Proposals to improve mechanisms intended to facilitate *individuals* saving or paying for their own care (such as private insurance or drawing on housing equity and/or personal assets) were not particularly well received by the participants in our groups. In line with findings of other research, participants still felt the state has a significant part to play in funding services for *all* older people, not just the poorest or most vulnerable.

Thirdly: Increasing *taxation* was seen by many to be the best way of ensuring that individuals contributed more towards the costs of their long-term care. This would ensure that the state had sufficient funds to meet its responsibilities. The public's receptiveness to the notion of tax increases may require further testing; however, this study indicates that people may be receptive to the idea of *tax increases* if these are linked to clearly defined policy objectives and the provision of specific services.

Finally, this is one of a number of studies that has attempted to gauge public attitudes towards the future funding of long-term care. It has clearly demonstrated that people of different ages and from a range of backgrounds and locations, feel very *strongly that the state has a continuing obligation to support and care for older people.*

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Appendix A: The focus group participants

A total of 59 people participated in eight focus groups (male $n=22$, female $n=37$). This was a purposeful sample. We sought representation across a number of variables: age, gender, people living in rural and urban areas, people in Scotland (because of the different ways personal care is funded in Scotland), carers, black and minority ethnic groups (BME) and people with disabilities. Ages ranged from 26 to 90. Slightly more than 60% of the sample was aged 60 or above.

Table A1: Age of participants

Age range	Number of participants
20-30	2
31-40	1
41-50	12
51-60	7
61-70	12
71-80	18
81-90	7
Total	59

Table A2: Proportion of participants from BME groups

	Number	Age range
BME	11 (6 male, 5 female)	40-70s
Non BME	48 (16 males, 32 females)	20-90s
Total	59	

Table A3: Proportion of participants who were carers

	Number	Age range
Carers	12 (1 male, 11 female)	44-79
Non-carers	47 (21 males, 26 females)	20-90s
Total	59	

Table A4: Proportion of participants from rural and urban areas

	Number	Age range
Rural	22 (11 male, 11 female)	20s-80s
Urban	37 (11 males, 26 females)	40s-90s
Total	59	

Appendix B: The focus group discussion guide

Public consultation on the future funding of long-term care

Introduction and background

Introduce researchers

Thank people for coming

Introduce context: concerns about ageing population, people living longer, needing more care. Important to get some ideas of what ordinary people think.

Ask group what they think longterm care is.

Define long-term care.

Care provided for people over 65 years of age who are unable to look after themselves without some kind of support. It includes care provided in the home, in sheltered housing, residential or nursing homes but NOT care provided in hospital unless it is intended to be permanent. It includes people who need help for a couple of hours a day through to people who need care day and night.

Experiences of long-term care

FOR YOUNGER AGE GROUPS.....

- Has anyone had any experience of close older relatives of friends needing care of this kind?
- Were there any problems associated with paying for this care?

FOR OVER 65s

- Are any of you getting the kind of help we've talked about?
- Were there any problems associated with funding?

FOR ALL GROUPS

- Have any of you started to think about your own needs for care in the future?

- What prompted you to think about it?
- How do you expect any care you might need in the future to be paid for?
- Who do you think should pay for long-term care? The state, individuals or families?

Prompt: Has anyone made any financial provision for long-term care themselves?

Introduce JRF project. JRF also has concerns that the current system of funding care for older people isn't working very well. Have made a number of suggestions about how the system could be changed, and we would like to discuss some of these ideas with you today.

Topic 1: State funding

- Who do you think should pay for long-term care? The state, individuals or families?

Prompt: Should it be the sole responsibility of any of these?; if not how should the responsibility vary?

Prompt: What type of care would they expect the state to pay for?

- What do you think about the state paying for long-term care through:

general taxation? Even if it meant higher taxes....

A tax specifically for long-term care to create a national fund that is set aside to pay for care now and in the future?

Prompt: What would be the advantages/disadvantages of either form of tax?

Prompt: Would you be prepared to pay more tax to fund long-term care?

Topic 2: Helping individuals contribute to care costs

- As a general principle, should people be expected to use their own income and savings/investments to fund care?
- What about people who can't pay for long-term care themselves?
- What do think about funding long-term care for yourselves through:

Savings

- How much money should people be allowed to keep, and still receive help from the state?

Prompt: JRF have suggested 50% of the average value of a house (currently about £50,000). Do you think that is too much or too little?

Sale of assets (that is, house)

- Do you think that people should have to sell their homes to pay for care?

Prompt: What do you think about a system of cheap rate loans from the government to allow them to release any extra value in their homes (equity), with the loans paid back when the house is eventually sold?

Private insurance

Prompt: What about formal arrangements between private insurance and the state, with a number of many years paid for through private insurance, and rest covered by state?

Quite often people pay different amounts for care depending on where they live because social services in different areas set their own local charges for care services ... so:

- Do you think it would be better if there were a national scale of charges for care services that would apply wherever you lived?
- Should charges be related in some way to your ability to pay?

If needed: JRF has suggested two possible ways national charges might work....
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EXAMPLE: Could be a maximum charge related to your income. If income between £200-£300 per week, could not be charged more than say £50 per week for care, however much you needed; if income is £300-£400 per week, could not be charged more than £100 per week for care ... and so on.

EXAMPLE: Could only pay a fixed proportion and no more of your income on care. So, If below/on means-tested level, pay nothing. If above means-tested level, would pay no more than 10% of proportion of income above means-tested level towards care. So, if means-tested income is £120 per week, and your income is £140 per week, you would pay no more than £4 a week towards care ($£140 - £120 = £20$; 10% of £20 = £4). If your income is £200 per week, you would pay no more than £8 ($£200 - £120 = £80$, 10% of £80 = £8).

Topic 3: Family support

- Should families be expected to give their time *free* to look after their older relatives or should they be paid for their time in some way?

Prompt: How much care should they be expected to give?

Prompt: a benefit paid to carers like a 'wage', or services such as respite, sitting services, etc.

Topic 4: Ways of making the system more flexible

- Has anyone heard of Attendance Allowance?

Explain "is a non-means tested, non taxable benefit, for people over 65 to help them pay for care, currently, two levels, £40 per week for people needing personal care in the day, or in the night, or £60 per week for people needing care in the day and in the night".

- How does that seem to you?

Prompt: Enough money, too limited in that it only pays for personal care....

Prompt: Should Attendance Allowance be more fine-tuned, and be more directly linked to the amount of care you need?

For example: if you need just a little bit of help, you could receive a lower level of allowance, but also increase the allowance for people who need a lot of help.

- Should everyone get Attendance Allowance regardless of how much money they have?
- If people are being looked after in a residential or nursing home, do you think they should have to pay for their care?

Prompt: What about people who have some savings or assets?

- An alternative might be that nursing care and personal care were free in nursing homes, but you had to pay for accommodation. What do you think about this?
- What do you think about the state paying for a minimum standard of care with people topping up if they wish or they can?

Prompt: Would it lead to a two-tier system?

Finally

- What are your main concerns about how care should be funded in the future?

Prompt: Fairness, affordability, quality of services, ageing population....

Thank and close