



**‘YOUR Care, YOUR Say’  
– Manchester LINK Submission to  
DH Green Paper Consultation**



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## Executive Summary

This report describes the Manchester Local Involvement Network's (LINK) process for engaging local people in the Big Care Debate and summarises the feedback we have gathered at our 'YOUR Care, YOUR Say' event organised in partnership with the Manchester Alliance for Community Care (MACC).

On the basis of this we conclude the following:

We feel that the consultation process fell short by not recognising Local Involvement Networks as key consultation partners and providing more targeted support, failing to provide accessible documents in appropriate formats and styles and using effective promotional tools and media, limiting the possible range of responses by imposing prescriptive and leading consultation questions, not clearly defining the role and responsibilities of Local Authorities in the process, and not addressing the needs of BME and other marginalised communities. Consequently we do not feel that the wider public has been reached and engaged in a meaningful way.

In principle, the Manchester LINK welcomes the creation of a National Care Service and the proposal to introduce a basic universal entitlement. We note, however, that the Green Paper misses out a number of important points or remains too vague. It doesn't define 'basic' or clarify what a National Care Service will deliver on services and quality. Neither does it clarify what the role of carers will be in the new system or how the National Care Service will link up with the NHS and effect on the National Service Framework. It maintains the current arbitrary division between "health" and "social" care services that is already a massive issue within the current system. Also, the proposals are largely focussed on the needs of older people and not working-age adults with long-term care needs. Finally, like MACC we are now concerned that this issue is becoming a political football in the increasing debate between the major parties as we approach the next election. We need to move the debate on to an all-party agreement about an equitable and practical mechanism for funding social care for the long term.

Attendees of the 'YOUR Care, YOUR Say' event were not particularly in favour of any of the suggested funding options due to the lack of detail and guarantees about the proposed systems. Forced to choose they opted for the comprehensive state-insurance model whilst making it clear, however, that this was the best out of a bad bunch rather than a good solution. Attendees did not even consider the basic partnership model and were definitely opposed to a private insurance system. They also strongly opposed proposals to use attendance allowance to fund the basic level of care, highlighted the need to look at raising the level of personal allowance for people living in residential care, and requested the option to pay for social care contributions at the end of life out of the estate. Most importantly, however, attendees joined us in asking why social care could not be funded through general taxation or why this option was excluded from the consultation process from the outset.

The Green Paper argues that general taxation is simply not an option because of demographic changes and the assumed unfair pressure this would put on taxpayers.

However, as one of the attendees of the 'YOUR Care, YOUR Say' event has pointed out some of the assumptions made will simply not be true in the future. Also, there is no costed analysis of this option at all. More importantly perhaps there is also a failure to acknowledge the fact that any form of compulsory insurance effectively is taxation. As MACC has commented the suspicion here must be that this is window dressing as no Government wants to propose new forms of taxation ahead of a General Election due next year. What perhaps is not realised, is that many people are aware that the cost of social care is changing and would not object to paying a little extra tax. This was clearly demonstrated by the final vote at the 'YOUR Care, YOUR Say' event where slightly more than half of the attendees voted for a National Care System paid out of general taxation. Therefore we believe that this option needs to be explored in full and the public given a choice in whether or not this would be viable and supported.

We also strongly believe that a fundamental debate is needed around the extent to which responsibility for social care is defined on a personal or collective approach. Related to this we concur with MACC that the Green Paper fails to evaluate the potential impact of the proposed funding options in terms of equality. For instance, the proposals completely ignore the already existing discrimination within the National Insurance system against parents who put their career on hold to raise children, as well as furthering expectations that carers allowance provides adequate support not to mention compensation for loss of earnings. Any Government making proposals of this kind is overlooking the £75 billion contribution made by unpaid carers to the social care economy and failing to secure that contribution for a future.

To summarise, while we welcome the Green Paper proposals to establish a National Care Service in principle, we believe that the Green Paper in its current form is still far from presenting a viable way of doing so. It falls short in a number of important ways and a lot more work is needed to tie up the loose ends and iron out inconsistencies and inequalities.

## The Manchester LINK – Who are we?

Local Involvement Networks (LINKs) aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported - the role of LINKs is to find out what people want, monitor local services and to use their powers to hold them to account. LINKs have been established in most areas by the end of 2008. Each local authority (that provides social services) has been given funding and is under a legal duty to make contractual arrangements that enable LINK activities to take place.

A LINKs role once it is up and running is to:

- ask local people what they think about local healthcare services and provide a chance to suggest ideas to help improve services;
- investigate specific issues of concern to the community;
- use its powers to hold services to account and get results;
- ask for information and get an answer in a specified amount of time
- be able to carry out spot-checks to see if services are working well (carried out under safeguards)
- make reports and recommendations and receive a response
- refer issues to the local 'Overview and Scrutiny Committee'

The Manchester LINK has been established in April 2008. It is the umbrella organisation which brings together other networks, organisations, communities and individuals in Manchester to give them a voice in improving health and social care services. We do this by working in a collaborative and inclusive way across Manchester taking account of the rich diversity of the people of Manchester and their needs.

## Promoting the Big Care Debate

In order to enable the people of Manchester to find out about and become involved in the Big Care Debate the LINK has promoted the Green Paper and accompanying consultation extensively to its membership and the wider community.

For this purpose we have put together a small leaflet briefly outlining the proposals (→ see Appendix 1) that was given out at community events and during LINK outreach activities. This was necessary as materials provided by the Department of Health (DH) were insufficient for effective community engagement. The complete Green Paper is 132 pages long and a rather heavy document. It was impossible for LINK community engagement officers to consistently take sufficient copies of these along to events and other outreach activities. You have to consider that while it is already a challenge to get people interested in the future of social care to begin with, it is nigh on impossible to convince them to pick up and read a document of that size without having captured their attention first. For future DH consultations the LINK therefore recommends the production of smaller leaflets to be used alongside more in-depth documents.



In addition to speaking to community groups and individuals about the Green Paper and handing out leaflets, we promoted the consultation through our monthly newsletter. From August to October 2009 every newsletter featured an article focusing on the consultation and reminding LINK members to become involved (→ see Appendices 2 – 4).

Finally, the LINK in partnership with the Manchester Alliance for Community Care (MACC) organised an event entitled 'YOUR Care, YOUR Say' to gather local people's views on the government proposals (→ see Appendix 5).

## 'YOUR Care, YOUR Say'

The event took place on 14<sup>th</sup> October 2009 and was aimed at anyone and everyone. We were hoping to engage people who wouldn't usually be involved with health or social care services in this important debate by providing relevant background information and structuring the event to be interesting and fun.

Therefore, we split the event in a morning and an afternoon session.

During the morning session, which was opened by Councillor Glynn Evans, Ruth Enright and Andrea Koudellas from Manchester Adult Social Care (MASC) gave presentations on the current social care system, available services in Manchester and Individual Budgets. They also answered lots of questions from the audience and gave attendees a good insight into what social care is like at the moment. In addition, MASC brought a stall to the event to provide further information and help attendees with personal queries if required.

During the afternoon session, which was chaired by BBC Radio's Allan Beswick, David Jones from DH set the scene by introducing the green paper and outlining the debate. Then Mary Duncan from MACC, Nik Barstow from Black Health Agency and Valeska Matziol from the LINK talked attendees through the three funding options highlighting advantages and disadvantages of each option. Mike Wild from MACC gave his organisation's view on the proposals and explored alternative options. Finally, attendees were asked to take part in group work to discuss their views further and agree their preferred funding option.

The comments from the event reproduced below are mostly based on notes taken by LINK and MACC staff during the group work session. However, they also include comments made and questions asked following David Jones' presentation. We have tried to capture attendees' comments as accurately and succinctly as possible. In order to protect the authenticity of what attendees told us we have decided to simply reproduce those notes here exactly as we have received them without further embellishments or explanations. In addition, we have decided not to categorise attendees' responses according to the consultation questions. While a lot of what people told us fits in with the questions asked by the DH, some things do not and we didn't want to exclude these from the consultation process. For us effective engagement is about enabling people to voice their opinions freely and without restrictions. As a result we often find that people want to talk to us about topics or issues that we or other agencies might not have considered relevant or important. We're committed to giving the people of Manchester a space to do that and to hand over control over consultation processes to them as far as possible.

## Some Figures – Who took part?

The event was well attended by a total of 50 people made up of 31 women and 19 men. However, not everyone attended both the morning and afternoon sessions and some people floated in and out depending on their availability. We did not collect personal monitoring information from attendees but asked them to indicate whether they were attending the event as an individual member of the public or as a representative of an organisation or group. Indeed, the vast majority of attendees (45 people, 90%) were either professionals within health or social care or belonged to various community and voluntary sector groups or initiatives such as Valuing Older People, the Manchester Carers Forum, the Manchester Older People's Network, etc. In this sense most attendees represented not just their own personal views but also brought in concerns and comments from their organisations, groups, service users and local or ethnic communities.

## The Responses – What attendees told us

### 1. Comments following the afternoon presentations<sup>1</sup>

- There are some big assumptions made in the report: It is assumed that the retirement age is 65. This is almost definitely going to change.
- What will happen if people don't pay insurance; will they not be able to receive care?
- Both Insurance and Partnership models have serious issues. There will be a two tier system where the people who can afford to pay more into their insurance policy will receive better care and the people who cannot, will receive basic care. The definition of basic care, as a safety net for people who cannot afford their own care, is not clear and people will always slip through this net.
- The Green Paper doesn't appear to have looked into the implications of a compulsory insurance policy on peoples beliefs. Muslims aren't allowed to borrow or lend money so options based on such a system would be problematic.
- The insurance policy doesn't have any confirmation that services will continue as they are or improve. It's not fair for someone to pay for an insurance policy for care that might change in the future.
- A National Care Service is a great idea but I don't understand why Social Care should not be treated like healthcare etc.
- There isn't any information to say how expensive it will be to deliver the service. Costs could be saved by making some clear decisions and adding an additional amount onto tax.

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<sup>1</sup> NB: These notes were taken at the beginning of the afternoon session. They cover what attendees told us during and after the presentation by David Jones, the panel introducing the three funding options, and Mike Wild's alternative view point.

- People with the lowest incomes have the worst health. Are we expecting the people with the lowest incomes to pay the most into their insurance schemes?
- There needs to be more information released about the economics. Will young people in the future need to buy a house to pay for it?

## 2. Comments from group work<sup>2</sup> – Group 1

### Organisations/Groups:

- Taxation will put a bigger burden on people than compulsory insurance.
- People can barely afford to live now. Some people won't be able to afford insurance.
- Where do informal carers fit in?
- This doesn't address people on low income.
- Assumption that older people own property – not true
- People who have long-term conditions will find it harder to pay into an insurance system. NB: Basic need mentioned in green paper – what is basic need? Will it fit everyone?
- National Care Service? Need to look at minimum standards
- It is vital with an insurance policy that you get what you paid for.
- Over 65s often care for their spouses. You wouldn't be happy to care for someone if you had paid for an insurance policy.
- How will this fit into joined-up working suggested already? National Service Framework
- 136 pages – found the word ethnic twice. Concerned consultation process is not fully inclusive
- Problem with move to institutionalised services – you want to have a say if you have paid – only people with money will have a choice.
- Green paper has very selectively quoted from research – Singapore, very different society, New Zealand → don't mention these differences

### Individuals:

- Without the political will this could be shelved. Subsequently I think it is unfair to ask people to pay for insurance at 65. Need to start looking at a system that works across the board.
- Problem with charging young people – they don't have much money to start with.
- There is a massive shortage of care workers – not seen as a good career. Low money, low status → Will we see a shortage in the future?
- Doesn't give a clear definition of health. Needs to be clear because health care is free – e.g. dementia

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<sup>2</sup> NB: These are the full and original notes taken by LINK and MACC support staff who facilitated the group work.



### 3. Comments from group work – Group 2

#### Organisations/Groups:

- If the insurance model was the preferred model would this involve paying a premium? If so would this mean that those who have a high risk background will have to pay a higher premium?
- Which ever mechanism is put in place it needs to be a service which gives quality of life.
- Got to be state insurance
- Needs to be a minimum of what you get
- What safeguards will be put in place to ensure people don't find a way around paying into the scheme?
- If you are living in a different country will you still get treatment while abroad or would you have to come back to the UK and would you still receive treatment if you have been out of the country for a number of years

#### Individuals:

- Should get a bill at the end – opportunity to pay out of estate

#### All:

- Want to see government offer a partnership scheme where they will top up the payment if the individual is unable to pay the full £20,000; this should be carried out by means testing.
- Shouldn't be private partnership option as this would depend on the current market situation and would fluctuate

### 4. Comments from group work – Group 3

#### Organisations/Groups:

- Current levels are unfair across the board.
- Agree with government principles around choice – a need for fairness and clarity
- Issues over how much insurance people would actually need to pay out £8k or £25k
- Need to be a debate about 'basic entitlement'
- Can't use attendance allowance to fund this social care system because people will not be able to cope without having attendance allowance, without this couldn't live. Also people have control on how they spend attendance allowance, choice.
- We've started a campaign not to remove attendance allowance.
- Should not be down to local authorities to decide. If we pay into insurance, etc. equally, we should receive equally.
- What happens if we save into this and then system falls down and stops – all money lost

#### Individuals:

- Pay into government scheme – fairest scheme. If working can afford to pay it, if not working are supported by those who are able to work
- Life insurance should not be ring-fenced e.g. not ‘entitled to this but not to that
- Go back to government and say – don’t like any options, go back and start again
- Suggestion for care to be funded – everyone pays as additional tax from day you start work
- If go to private scheme not guaranteed they won’t go bust, etc.

#### All:

- Agree state scheme as ‘trust’ them more, more accountable, should be government rather than private
- Agree would prefer a national system
- Re owning your own house, equity release – Don’t like it, would like to leave something to children

### 5. Summaries from group work sessions<sup>3</sup>

#### Group 1

Preferred option: None of the above

- Doesn’t say what a National Care service will deliver on services and quality
- Doesn’t say what the role of carers is – how they can be supported (e.g. Carers Allowance after 65?)
- Doesn’t say how will link up with NHS and effect on national service framework – If NHS isn’t going to be free it should say so!
- Don’t trust the comparisons with other countries – very selective. England is a rich country – but other countries do both
- If you’re rich you’re sorted, if you’re poor... Choice only for those who pay extra.

#### Group 2

Preferred option: Comprehensive

- Insurance model but in partnership with Government where they will top up funding for those on low incomes
- There needs to be a set minimum of what you can expect to receive.
- There should be the option to pay the bill at end of life out of the estate.

#### Group 3

Preferred option: Comprehensive

- Agree and should be an insurance scheme managed by government – prefer idea of national framework system for allocating funds
- In favour of our welfare state

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<sup>3</sup> NB: These are summaries of the most important points the different groups covered in their discussion. They were used by the groups to feed back to each other and projected in the background for all attendees to read.

- Question: What do the authors of green paper mean by “basic level of care”?
- Concerned by proposal to take away attendance allowance to fund basic level of care. There must be other options to fund this.
- Need to look at raising level of personal allowance for people living in residential care.
- Proposals not easy to understand, not clear, want more details and guarantees about proposed systems

#### 6. Comments following the group work session<sup>4</sup>

- The National Care System should be on a par with the NHS and free at the point of delivery.
- I don't trust private insurance companies because they are just trying to make money. I'm not sure whether we can trust the government either though.
- The green paper does not explain the link between the NHS and social care. Are we still going to be talking about health and social care baths in the future? It's important for the government to clearly indicate where responsibilities lie.
- Don't take away attendance allowance!
- In order to decide which option would be the best we first have to know more about how much each of them is going to cost. The green paper does not provide any detail on that at all, which simply isn't good enough.
- Disappointment that there is no new funding for social care - Wanless identified the gap of £6bn.
- In terms of 'valuing older people' maybe we should start with the Treasury Department!
- Older People are the biggest users of social care and age discrimination is, and always has been, rife in social care and is institutionalised into its very structures and funding.
- People with Dementia and needing long-term care - concerns that if they are diagnosed early (before retirement age) – they probably won't be eligible for insurance, especially if it is a private insurance company.
- The Government needs to give us the detail - what do they mean by 'basic levels of **social** care'?
- If they fund basic levels of social care by taking away Attendance Allowance, this could seriously affect people on very low incomes needing care and support. This could also have an impact on family (informal) carers, who, like me, have looked after an aged parent for years. She gets AA and can pay for some of her care.

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<sup>4</sup> NB: These notes were taken at the end of the event during the general discussion after the groups had fed back to each other.

## 7. Comments submitted in writing<sup>5</sup>

- The Green Paper says 'money will be spent wisely' but this is a loose word to choose. Who decides what is a wise amount of money? If the senior care manager is having a 'bad' day, does this mean the service user misses out on 'services out there'?
- What is care and how can you standardise care for all when care is different for everyone?!
- The new care system will work as long as there are enough 'quality' services to be offered to the individual that will take into account their all round needs.
- Joined-up services – yes, please if only. Social workers and care managers need to have less case loads, more resources to choose from. There is a massive lack of day care provision for younger people with needs, especially stroke survivors. It isn't appropriate for a 30 year old to go to a day care facility with people of 60 year plus's.
- When I have asked in the past for feedback from an assessment I have not had anything back. It would be nice to be invited for our thoughts as well to assist the service user in their future care.
- Barriers: more services for service users to choose from, not just 10 agencies in Manchester and not because they are cheap;  
care services – current services are inadequate in providing quality care with fully trained care givers  
4 hours out of 24 hour day is not sufficient, the carer may be the only person the service user sees that day, too many horror stories including service users not getting their morning call and breakfast till 1pm. This is a major problem and has to be addressed.  
Service users deserve quality after all they gave us our lives and freedom!  
More re-enablement services and equipment to be offered as soon as the need is 'needed'
- Preferred funding option: None! Why should our parents who worked so hard all of their lives, who saved their savings to ensure their children have a better start to life and who have paid their National Insurance stamp be expected to pay for care when they need it?! By paying NI they have paid and deserve free treatment. Isn't that why it was set up in the first place?  
This is very age discriminative.  
People can barely live now and pay into pensions. Debts are rising at a great rate, to pay into an insurance will mean more debts! Also, are we going to be like America as they have medical insurance, if not = no medical treatment!  
If people who are working 'have' to pay into a 'care system', do you think they will not work so that the care if they need it is free? This then means more debt and unemployment.
- Local vs. national government as decision-maker: No local government should decide because some areas are more affluent than others. If it was a national decision people wouldn't miss out.

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<sup>5</sup> NB: These comments have been submitted in writing by one attendee representing an organisation completing the consultation questionnaire.

## 8. The final vote

At the end of the event Allan Beswick asked attendees to vote for their preferred option by show of hands. Of the 34 people still present at this stage all initially voted for none of the three options proposed in the Green Paper in favour of an alternative. Having been pushed to make a decision for the preferred of the available options, everyone agreed that a comprehensive insurance model would be the best. However, attendees clearly saw this option very much as the best of a bad bunch rather than a good solution. Interestingly, when Allan Beswick asked attendees to indicate whether they would like the future National Care System to be financed through general taxation, still slightly more than half of the audience (18 people) were in favour.

## Conclusions, LINK Comments and Recommendations

### 1. Engaging effectively

Even though the Manchester LINK welcomes the DH's efforts to consult widely on the Green Paper, we feel that the consultation process fell short in some vital areas. Firstly, as a Local Involvement Network funded by the DH to engage people in health and social care services we are ideally placed to carry out consultation locally. We would have welcomed if the consultation team had recognised the important contribution LINKs across the country had to make to this process and provided more targeted support. At the same time we would like to note the support we have received from the regional Department of Health team, notably David Jones and Zennie Major.

Secondly as noted above (→ see 'Promoting the Big Care Debate') we did not feel that the consultation documents were accessible enough and available in the right formats and styles. We urge the DH to improve on this for future consultations. Related to that we feel that the consultation questions were very prescriptive and somewhat leading, which narrows the range of possible responses and the extent to which people can engage with the Green Paper openly and freely. Some of the responses we have received at the 'YOUR Care, YOUR Say' event highlight that providing people with a space to look at the proposals without any superimposed restrictions can generate important new insights and debate about areas neglected by the consultation questions. It also reinforces our belief that consultation should be led by the public and people been giving an opportunity to discuss what is of relevance to them – not what is of relevance to the policy makers or politicians. Thirdly, we are unclear as to the level at which Local Authorities were asked to contribute to and support the consultation process. Locally we feel that more could have been done to engage the wider public in this important process. As far as we are aware efforts to gather feedback were limited to: two Care and Support Stakeholder events, an event organised for the Voluntary and Community Sector by GMCVO, the 'YOUR Care, YOUR Say' event, and an invitation by Manchester City Council's Adult Social Care department to send in comments for their submission. Of course, other organisations have also encouraged their members, service users and stakeholders to participate in the consultation or contribute to their organisation's

submissions and thus ensured some wider participation. However, we feel that a large proportion of local residents have not been reached at all. Apart from the rare exceptions, most people the LINK Support Team have spoken to about the Green Paper while doing outreach activities had never heard of it or seemed to think the consultation was not relevant to them since they were not currently in receipt of social care services. Considering how far removed most people are from understanding the social care system or taking future care needs into consideration, it was vital to demonstrate the relevance of this debate to the public and promote it appropriately for example through large-scale television advertising, etc. We do not feel this has been achieved. Furthermore, we have concerns about the insufficient extent to which the needs of BME and other marginalised communities have been addressed in the consultation process.

## 2. Quality of Service

In principle, the Manchester LINK joins other organisations such as the Manchester Alliance for Community Care (MACC) in welcoming the creation of a National Care Service and the proposal to introduce a basic universal entitlement. However, we strongly urge the DH to define 'basic' and provide more concrete details as to what a 'basic universal entitlement' would cover.

We also agree with MACC that the proposals would end the unfairness in the present system of the post-code lottery of eligibility criteria for state funded support as different Local Authorities could not use budgets to determine different criteria. Furthermore, the proposals would end the exclusion of "self-funders" from state support. This would be a great improvement of the current system, in which in many Local Authorities, those who pay the full cost of their own care receive no support or even basic assistance with making their care arrangements.

However, while we welcome the proposals in principle and believe they are a step in the right direction, the Green Paper misses out a number of important points or remains vague. As pointed out by attendees of the 'YOUR Care, YOUR Say' event the Green paper doesn't clarify what a National Care Service will deliver on services and quality. Indeed, it seems that the quality of care provision, equity of access, and the real needs of people are all largely ignored.

The Green Paper also doesn't clarify what the role of carers is in the new system or how they can be supported better in the future. We feel this is a huge oversight as carers are at the centre of the current care system and make by far the largest direct contribution to social care. If it wasn't for carers the system would be completely untenable. This needs to be recognised and effective support systems put in place to ensure that carers will not continue to be disadvantaged.

Importantly, too, the Green Paper does not make it clear how the National Care Service will link up with the NHS and effect on the National Service Framework. It maintains the current arbitrary division between "health" and "social" care services that is already a massive issue within the current system. This division is potentially becoming further complicated by an additional mechanism of public funding.

Also, the proposals are largely focussed on the needs of older people and not working-age adults with long-term care needs such as, for instance, people with learning disabilities or stroke survivors.



Finally, like MACC we are now concerned that the timing of this Green Paper moves the issue of the funding of social care directly into the wider debate about the levels of public spending and taxation during the recession and post-recession periods. The publication of the Green Paper means it is now too late to introduce legislation before the next General Election and it is arguable that a “state insurance scheme” is a new form of taxation. This issue is too central to the quality of people’s lives for it to become a political football in the increasing debate between the major parties as we approach the Election. We need to move the debate on to an all-party agreement about an equitable and practical mechanism for funding social care for the long term.

### 3. Funding

The feedback we received at the ‘YOUR Care, YOUR Say’ event regarding the proposed funding options was unequivocal: Attendees were clearly in favour of our welfare state and wanted to see it protected in future. Furthermore, they were not particularly in favour of any of the proposed options. It was generally felt that the proposals were not easy to understand and attendees wanted more details and guarantees about the proposed systems. Indeed, we strongly feel that it is misleading and irresponsible to ask the public to decide between the proposed options without giving them detailed information and projections about the personal spending required for each. The data provided is far too vague and general to allow informed decisions to be made.

On the basis of the available information none of the options seemed viable to the attendees. Forced to choose they opted for the comprehensive state-insurance model whilst making it clear, however, that this was the best out of a bad bunch rather than a good solution. Attendees did not even consider the basic partnership model and were definitely opposed to a private insurance system as they did not feel they could trust private insurance companies. The Manchester Alliance for Community Care (MACC) supplements this argument by highlighting that insurance is not an equitable option as presented in the Green Paper. We know that those on the lowest incomes generally have the poorest health outcomes and that this is a generational cycle within families. Insurers will therefore see those with a family history of poor health as high risk and consequently charge a higher premium to those on lower incomes, if indeed they are willing to offer insurance at all. So there is an inbuilt discrimination against both old age and chronic illness. Also, we feel that a voluntary insurance system would not be cost-efficient and sustainable as a large percentage of the population would opt out of taking out insurance and continue to rely on state-funded services.

Attendees at the ‘YOUR Care, YOUR Say’ event raised other important points. For instance they highlighted the need to look at raising the level of personal allowance for people living in residential care, and requested the option to pay for social care contributions at the end of life out of the estate.

And unsurprisingly the proposal to take away attendance allowance to fund the basic level of care has raised concerns and criticism. Attendees argued that there must be other fairer options to fund this and that taking away attendance allowance from people who are heavily reliant on this form of support would be disastrous. We endorse this criticism and strongly urge the DH to reconsider this proposal.

Most importantly, however, we join MACC in asking why social care could not be funded through general taxation or why this option was excluded from the consultation process from the outset.

The Green Paper argues that general taxation is simply not an option because of demographic changes and the assumed unfair pressure this would put on taxpayers. However, as one of the attendees of the 'YOUR Care, YOUR Say' event has pointed out some of the assumptions made will simply not be true in the future. For example it is assumed that the statutory retirement age will remain at 65 even though this is almost definitely going to change. Also, there is no costed analysis of this option at all. Yet in many ways it would be the cheapest to implement as the systems for collecting and distributing taxes already exist. More importantly perhaps there is also a failure to acknowledge the fact that any form of compulsory insurance effectively is taxation, just more costly since a whole new infrastructure will need to be created. It is also more risky, given that a scheme based on insurance within the private sector will have a built-in incentive, as in all insurance, for insurers to avoid paying out wherever possible. Of course, this risk would be reduced if this were a state run (or underwritten) scheme – which again brings back the point that this is therefore effectively taxation, but with hugely increased administrative costs.

As MACC has commented the suspicion here must surely be that this is window dressing as no Government wants to propose new forms of taxation, particularly with a General Election due next year. What perhaps is not realised, is that many people are aware that the cost of social care is changing and would not object to paying a little extra tax – in the same way that people do not object to paying tax to fund the NHS so long as the money is used efficiently and distributed fairly. This was clearly demonstrated by the final vote at the 'YOUR Care, YOUR Say' event where slightly more than half of the attendees voted for a National Care System paid out of general taxation. While we would not want to argue that everybody would be happy to pay higher taxes to fund a social care system that is free at the point of delivery, we do believe that this option needs to be explored in full and the public given a choice in whether or not this would be viable and supported.

We also strongly believe that a fundamental debate is needed around the extent to which responsibility for social care is defined on a personal or collective approach. This has again been completely ignored in the Green Paper and is long overdue. Related to this we concur with MACC that the Green Paper fails to evaluate the potential impact of the proposed funding options in terms of equality.

It is proposed that older adults could potentially start paying for social care insurance from the point at which they retire from work. However, the majority of older adults are on fixed incomes which therefore decrease in value year on year and many will simply be unable to afford a sudden extra cost of "insurance". The proposal to impose effectively a tax on people who are by definition least able to earn is staggering enough but the fundamental point is that this would be a tax on old age – in complete contradiction to the Government's stated aims around equality and tackling ageism.

Furthermore, it is argued that adults of working age could start "saving up" for their own social care costs in the future. While undoubtedly some could, an insurance system perpetuates a gamut of income inequalities: from people on low incomes through to those with high costs (e.g. student debts, childcare, carers, mortgage costs or the hope of saving up enough for a deposit on a house).

Finally, we know, for example, that there is already discrimination within the National Insurance system against parents who put their career on hold to raise children – just as there is an expectation that carers allowance provides adequate support not to mention compensation for loss of earnings. Both of these issues are fundamentally ignored by the proposals – and yet these are the very people who are currently subsidising social care. Any Government making proposals of this kind is overlooking the £75billion contribution made by unpaid carers to the social care economy and failing to secure that contribution for a future. It again exposes the fact that these solutions are based on getting over a demographic and economic hurdle, not focusing on quality of provision or indeed any concept of a social contract.

To summarise, while we welcome the Green Paper proposals to establish a National Care Service in principle, we believe that the Green Paper in its current form is still far from presenting a viable way of doing so. It falls short in a number of important ways and a lot more work is needed to tie up the loose ends and iron out inconsistencies and inequalities.

#### 4. Recommendations at a glance

- Recognise Local Involvement Networks (LINKs) as key partners in consultations and provide targeted support.
- Provide accessible documents in different formats and styles and take into account promotional requirements.
- Clearly define the role and responsibilities of Local Authorities in national consultation processes.
- Engage the wider public by means of effective promotion through means such as large-scale television advertising.
- Ensure that the needs of BME and other marginalised communities are met in the consultation process.
- Define 'basic' and provide concrete details of what a 'basic universal entitlement' would cover.
- Eliminate the current post-code lottery of eligibility criteria for state funded support.
- End the exclusion of "self-funders" from state support.
- Clarify what a National Care Service will deliver on services and quality.
- Clarify what the role of carers is in the new system and how they can be supported better in the future.
- Clarify how the National Care Service will link up with the NHS and effect on the National Service Framework.
- End the current arbitrary division between "health" and "social" care services and put a truly integrated system in place.
- Address the needs not only of older people but also working-age adults with long-term care needs such as, for instance, people with learning disabilities or stroke survivors.
- Move the debate on to an all-party agreement about an equitable and practical mechanism for funding social care for the long term rather than allowing it to become a political football in the increasing debate between the major parties as we approach the Election.
- Provide detailed information and projections about the personal spending required for each of the proposed funding options before asking the public to make a choice.
- Ensure that if an insurance system was introduced it would be state-governed and comprehensive.
- Raise the level of personal allowance for people living in residential care.
- Offer the option to pay for social care contributions at the end of life out of the estate.
- Reconsider proposal to take away attendance allowance.
- Provide a convincing argument for why social care can not be paid for out of general taxation.
- Explore the option of having a tax-based system fully and allow the public to make a choice as to whether or not this would be viable and supported.
- Encourage a fundamental debate around the extent to which responsibility for social care is defined on a personal or collective approach.
- Evaluate the potential impact of the proposed funding options in terms of equality.

## Contact – Get in touch to find out more

If you would like to find out more about the ‘Shaping the Future of Care Together’ green paper, consultation process, this report or any other LINK project, please contact Valeska on 0161 214 3981 or by email to [valeska@blackhealthagency.org.uk](mailto:valeska@blackhealthagency.org.uk). Alternatively, please visit our website available at [www.manchesterlink.org.uk](http://www.manchesterlink.org.uk) for further information.

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Manchester, 13<sup>th</sup> November 2009*

## Appendices

- 1) LINK 'Shaping the Future of Care Together' leaflet
- 2) LINK Newsletter – Issue 11, page 6, August 2009
- 3) LINK Newsletter – Issue 12, page 3, September 2009
- 4) LINK Newsletter – Issue 13, page 5, October 2009
- 5) Flyer and Event Programme for 'YOUR Care, YOUR Say'