

Commission on the
Future of **Health** and
Social Care in England

**Final summary
of the work and
recommendations
of the experts by
experience group**

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Background to the experts by experience group

The Commission on the Future of Health and Social Care in England convened a group of nine experts by experience to provide advice from October 2013 to September 2014.

Who are the experts by experience?

This is an extract from a blog by Claire Jones, one of the experts by experience:

This group consists of nine people who have personal experience of using and caring for people who use health and care services. All of our group have developed a high degree of expertise within the system as it stands and have experienced different patient, carer, or service user roles in different services, sometimes holding multiple roles. Some of our group also hold additional roles in the health and care system, as health and care professionals, as patient leaders, as activists, through working with the voluntary sector, or social enterprise, or as members of local Healthwatch organisations.

The commission's experts by experience are Eleni Chambers, Clenton Farquharson, Brian Gumbley, Heather Hughes, Becky Huxtable, Claire Jones, John Lish, Sally-Ann Marciano and Dominic Stenning.

The role of the experts by experience group and what it achieved

The commission and The King's Fund intended the role of the experts by experience to be more than simply providing stories or evidence of experience. Members of the group were recruited for their direct experience of the boundary of health and social care, and their ability to use that experience to offer strategic thinking on that boundary. The intention was that the group would be able to provide different perspectives and thoughtful challenge to the commissioners' thinking.

There were three specific elements to the role.

- **Adviser** – to use their experience to offer advice and ideas about:
 - how health and social care services could be different in the future (and particularly the boundary between the two)
 - the commission's overall approach and remit
 - the commission's thinking or 'direction of travel'
 - how the commission takes account of the voice and views of patients, service users, carers and the public in their final recommendations.
- **Critical friend** – to constructively challenge the commission's thinking and be a critical friend speaking from a patient and public perspective.

■ **Partner in the process:**

- whose support needs are met to ensure participation
- who work as a group to co-design any experts by experience meetings and reports
- with transparent and open access to what the commission is considering
- who is clear about the possibilities and boundaries of the role.

It is important to say – because this was an early challenge that came from the group – that the experts by experience group was not set up to work in full co-production with the commission. The Commission on the Future of Health and Social Care in England is an independent commission and has determined its own recommendations, albeit with the support and advice of The King's Fund, their experts by experience and stakeholders. As far as possible within these parameters, the group has aspired to follow co-production principles.

The experts by experience have, however, had significant influence on the thinking of the commission and have been an invaluable part of the process of developing recommendations that are grounded in the experience of those who use and will use services. And beyond that, they have influenced thinking within The King's Fund in relation to how it involves patients in its work.

In his blog for The King's Fund, Dominic Stenning commented:

The experts by experience group has been a small step, but a giant leap for patient and public involvement. I've been humbled to be a part of this group of experts and know we have all had an impact on the thinking of the commission, influencing the [interim] report by putting real lives and experiences on the table. With a report like this, which focuses heavily on economics and structures, it's very easy to forget about the real lives that will be affected by the ideas suggested.

However, that's just a small part of what the group has achieved so far. Not only have we reminded the commission of what it's like to be on the receiving end of a system that is far from joined up, we have gone on to give our thoughts on the interim report and challenge the commissioners on how any proposed changes will affect patients and carers. We've even tried to come up with our own solutions as we know that's the hardest part!

As important as this report is, I'm aware that, as the first experts by experience group working with the commission and The King's Fund, we are treading new ground and laying the foundation for others to build upon. This whole process has been extremely challenging and although it's not perfect, we have made significant progress towards co-producing the report and this must not be overlooked.

The King's Fund has set the bar high with a new standard for others to follow. I really hope that we've shown just how much a group like ours can achieve working on such complex and ambitious ideas to make an NHS that is truly joined up and fit for the 21st century.

Clenton Farquarson MBE and member of the experts by experience group said:

All the experts by experience should be commended for their open and honest contribution to this piece of work. I would like to add that co-production takes time and I'd like to thank The King's Fund and its staff for the courage to let go of the power within this piece of work. I think The King's Fund should be recognised for this because it can be challenging.

From a commissioner perspective, Julian Le Grand commented:

The commission spent a great deal of its time on government statistics and reports, and there was always a risk that, in its struggle with these and with the general mechanics

of policy reform, it would lose touch with the reality of the health and social care world. The members of the experts by experience group were enormously important in keeping the commission grounded in that reality. The group, ably facilitated by Becky Seale, were able to bring the numbers and reports to life, showing us in graphic detail the perversities, injustices and frustrations of the system. Moreover, they brought the wisdom of experience, as well as a more general thoughtfulness and understanding, to the various ideas for reform that the commission produced at stages of its work and, as a result, have materially affected its recommendations. It is fair to say that a large part of any merit that the commission's reports might have is due to the activities of the group; and I think I can speak for all the commissioners in saying how impressed we were by their work and how grateful we are to them for it.

What the experts by experience did

The group met formally for three whole-day sessions:

- 29 November 2013 – establishing the group and initial discussions
- 25 March 2014 – developing views on the options outlined in the interim report
- 15 May 2014 – finalising recommendations in discussion with commissioners.

Several commissioners took part in the discussions at these meetings, with all commissioners present at the final meeting. The group provided written reports to the commission summarising their discussion and advice after each meeting, and one additional report to provide early responses to the interim report.

In between face-to-face sessions, the experts by experience had many discussions – in person, by email and phone – to inform their thinking. They reviewed the interim report, prioritised options for discussion at face-to-face meetings and produced and reviewed summary reports of their discussions to provide to the commission. Several experts by experience provided the stories that were included at the beginning of the interim report as a key part of the case for change.

Members also attended the interim launch event, a conversation with stakeholders, and submitted their own evidence and views outside of meetings and reports.

- Dominic Stenning was on the panel at the interim launch, alongside journalists Jackie Ashley and Camilla Cavendish, and Kate Barker. He gave a speech that formed the basis of a blog published on The King's Fund website.
- Both Claire Jones and Dominic gave their views in videoed interviews that were posted on The King's Fund website.
- John Lish produced an easy-read version of the interim report in order to support the submission to the call for evidence of a group he works with, the Adult Consultation Work Group, which is hosted by the charity Autism West Midlands.
- Several experts by experience tweeted using the commission hashtag #barkercomm and provided comment to many of the press articles published in response to the interim report.

In the final formal meeting, members came together in discussion with the commissioners to provide their perspectives on the direction of the final report and the options that were being considered.

Final advice to the commission

Below is a summary of the experts by experience group's advice to commissioners across all meetings with some commissioner response where available.

Guiding philosophy

As well as providing specific views and perspectives on the options that the commission was considering, the experts by experience, throughout their tenure, offered advice on the overall approach or principles that the commissioners could consider when developing and presenting their thinking.

Bringing other perspectives into the report and making it accessible

The group has always emphasised that it will be important for the commission to consider multiple perspectives when making decisions, particularly considering those whose lives would be affected should its recommendations come to pass. These groups include those living in poverty, from different genders, age and ethnic background.

...on poverty, this kind of sprung to mind when I was reading the section about prescription charges: saying that there's a yearly charge that would save people £100 or whatever it was. But you would have to fork out a certain amount of money up front, but not everybody can do that. Just even to find £100 in one block sum can be hard for some people.

Similarly, there are some issues around race. I mean, you might employ a carer, but you might also need to employ someone with particular language skills so that you can understand each other if you speak a different language. There are a lot of equity issues like that which cost people more. If you've got mental health needs or dementia that requires certain training, certain specialist knowledge. Again, you're not just looking at a sort of bog standard carer, you're looking at somebody with particular expertise, which costs more.

Expert by experience

For me it's about your values and which model you ascribe to that influences your values and therefore influences your thinking about all of this. And I think in general people with lived experience [of health and social care], us lot, have a different set of values from people who haven't got that lived experience.

Can I just give you a little example? I can't travel for free on public transport where I live. I have a mobility bus pass that covers me, but I'm not able to access a bus or a tram by myself... so I have to have a carer with me constantly. I have applied for a 'with carer' pass, which should mean that they should be able to travel with me all the time for free, because I've got a disability. Why should I have to pay for my carer? But I'm not allowed it. And the reason I'm not allowed it is because they used a ridiculous illogical eligibility criteria for getting 'with carer' bus passes. You have to be entitled to high rate care DLA [Disability Living Allowance] in order to access a 'with carer' pass. I don't receive that. You can only receive that if you need support at night time. Now I have to question: what has having support needs at night time got to do with me being able to travel on a bus in the day time? It wasn't users that set that eligibility criteria; it was 'professionals'. And they did that because it's easiest for them, nothing to do with whether those people deserved to travel on the buses or not. And I think if I was a user setting that criteria, I would have been starting off from the logical viewpoint: can the person access the bus by themselves or not?

Expert by experience

It would be quite useful, I think, to have the group sort of quality-assuring major recommendations that we might be making, and whether they look sensible from a number of different perspectives that are represented around this table.

Commissioner

On the same basis, the group suggested that the report itself should be made accessible to those it would affect – service users and taxpayers – as well as those delivering and commissioning services.

Actions agreed were:

- the views of the experts by experience would be woven through the final report
- commissioners would share their shortlist of options with the expert by experience group.

Equity: unpacking ‘equal support for equal need’

Equity and fairness were themes that ran through many of the experts by experience conversations and were driving principles in discussions around the options. The group told the commission: ‘The fairness of your recommendations is crucial. Options will impact differently in the population requiring an impact assessment of all options for particular groups.’ The group provided the following rationale for unpacking the principle of ‘equal support for equal need’.

- Equity of service/access will require different levels of support for different needs in the population. For example, people with autism may require specialist support in order to achieve the same level of service.

Autistic adults, as a group, feel excluded from a lot of support that comes, and the one service they do get is often adapted because it’s at such a low level that they actually find it more stressful. It needs that knowledge of the client and what their needs are. So, to be able to access support, social care support that will help their lives, requires more than just the budget, the low-level care. So, I think equity can be quite difficult if you want equal support for equal needs; it’s something that you need to put out there.

Expert by experience

This fits with a human rights perspective and the potentially higher and different resources needed to achieve equity of access to a flourishing life and being a full part of society.

Equity and the idea of equal support for equal needs could be unpacked in two directions I think. One is, of course, where that phrase is often used it’s called horizontal equity: equal treatment for equal need, equal support for equal need. There is another, which is vertical equity: unequal treatment for unequal need, or something like treatment in proportion to need, or relative to need. And that might be one direction to think about it. But I was also thinking about your point, or Claire’s point, about rights. There might be something about equality, equality of access to the conditions of life or to... flourishing.

Commissioner

So when you’re talking about a situation where we’ve been restricting access to the independent living fund for years, but now we’re going to close it and throw everybody else that’s on it off it and leave it down to the local authorities to fund that participation. It’s not going to be ring-fenced. That participation is not going to be funded. Those people are going to be isolated. They’re going to be left on their own. They’re going to be oppressed, not by their impairments, but by the disabling

impact that society has on them. So in terms of the funding, it's about ... getting your head round the idea that some things are around individual risk and some things are around collective risk and a recognition of the financial cost and benefit of social exclusion in disabled people.

Expert by experience

The experts would like to make the reader aware that long-fought-over disability rights have been and are being lost due to short-term thinking cost cuts, that don't take this rights-based history into account.

Expert by experience

Funding should be person-centred, ie, based on individual needs rather than clinical diagnosis or condition (this would argue against special funding conditions for dementia, for example). The group cautioned that carrying out financial evaluations when making decisions are insufficient; the commission should also take into account and give equal weight to broader outcomes and recognise that it can be hard both to quantify what makes a difference to people and to effectively and wholly define needs.

Actions agreed were:

- commissioners requested volunteers from the expert by experience group who would be willing to explore the impact of each of the shortlisted options on their own situation (in terms of finance and wellbeing).

Ensuring a balance of focus between health and social care

The group also raised equity issues around the focus and funding given to health and social care, and to areas within them. The group voiced concerns that even in a ring-fenced budget, there is a risk that social care may remain the little sister of health. Will funding influence culture, or could health still dominate in practice? The group was concerned that health care (in contrast to social care) focuses on 'fixing' and makes everyone a patient (historically a passive role) with little focus on experience. The group advised that the commissioners' decisions bear this in mind, and that the language they use reflects a balance between health and social care cultures.

The assumed audience [for the interim report] is a medical audience, because social care is the invisible partner. And what we're saying is the framework for understanding these issues that comes from a more social model understanding of disability, which means that you have to reframe the way you discuss these issues.

Expert by experience

So the basic difference for me between a kind of health model or a medical model and a social care model is that the medical model locates the illness, the condition, the disability within the individual and says that this person has got heart disease or this person has asthma. The social model says that the problem is that you are disabled in the same way that Wi-Fi is disabled when it's turned off. So society turns off your participation. It prevents your participation. The problem lies in society; it doesn't lie in your individual blood type or whatever. So that then has implications for who has responsibility for that issue? If it is an individual problem, if it's your blood, then it's your mum and dad and it's you that has that responsibility and your doctor. If society is actually preventing you from doing something that you have a right to do, ie, participate, it is a collective responsibility of society to sort out.

Expert by experience

I'm certainly conscious of the need to be really careful of the language because the big battalions of health will quickly suck in social care otherwise and indeed institutionally

we know that there are some people that think, 'Why the heck don't you give it all to health?' And I was struck very early on in coming in to the world of social care and someone who received social care said, 'Look, I don't want to be a patient. You know, I don't want to be a patient again.' And I think we need to be very much aware on that of all the language we use and all the recommendations we make. That this is not about making people patients again. So I accept that entirely.

Commissioner

In the legislation that's just passed, there is this focus on wellbeing and outcomes. You know, I'm always terrified that people will lose their health input if we focus always on social care. Because health input doesn't need to make you a patient, it's health and wellbeing that makes life possible.

Commissioner

It's actually correcting the common names between the two sections because they use the same words but [mean] different things to each other. And if you're going to have a singly commissioned budget then you're going to need to start to create knowledge that's shared, and I think again that's another ongoing consequence to this change is that you actually need to create the sort of knowledge that's accessible by both social care and health care.

Expert by experience

More focus on mental health

Although mental health is just one part of the jigsaw that a singly commissioned, singly funded service will help to bring together, it is one that, in the experience of the group, gets insufficient attention in terms of funding, entitlement and commissioning and therefore deserves specific focus in the final report for the following reasons.

- Mental health is often lost within discussions of social care and health because it does not fit fully in either sector. The experts by experience group suggested there should be three areas included in the discussion: physical health, social care, and mental health. The group also highlighted the potential for a more preventive focus around mental health and wellbeing to save money. They suggested it would be useful to insert some figures around the costs of absence from work due to stress in the final report.

I know some people in social care are very clear that mental health is separate from social care, so that's where it gets complicated. So I think in the report when you say social care and you mean mental health as well, you need to actually say mental health, because it will get missed by a lot of people. It really will.

Expert by experience

...most people associate health with physical health, and wellbeing is looking after yourself generally. Where is the mental health in that? Unless we highlight that, the cost to this country is going to be tremendous.

Expert by experience

For me it's about looking at me as a person, you know, I'm a holistic being I can't separate my mental health from my physical health. So, just a little example, shortly after I was out of hospital after having both legs amputated, I was told by a physical health social worker, 'Oh we can't assess your needs for mental health, I can only look at physical health.' I mean to say that to anybody in those circumstances is not great really. Now, I find myself without a personal budget, so I haven't had one since the end of last year. I've been out of hospital over a year now and this is because mental health are arguing with physical disabilities about who wants to fund me, and it's me that

loses out on that: as a result I get funded by nobody. Which is the bit about putting the two pots of money together and changing practices at the same time, otherwise nothing is going to get better.

Expert by experience

We joined up one side; we put mental health, adult social care and mental health care together. But we've left the other side over, which is the physical health from the mental health, in a separate pot of money. I think we should be acknowledging those things and obviously talking about one single pot of money is a way of trying to bring those things a step further together. But that won't solve the problem you're talking about without some additional work on the ground.

Commissioner

- In the experts' experience mental health gets lower priority than physical health in funding, entitlement and commissioning and is extremely under-resourced, despite its prevalence in the population. As an example (provided by one of the experts by experience) the Resource Allocation System (RAS) for mental health gives less funding for the same number of points than the RAS for adult social care, ie, physical disability. As a result, one of the experts by experience had seen her indicative budget decrease because it is split between physical and mental health needs. The group advised that there is a stigma around mental health, which makes ensuring parity at a commissioning and funding level even more important.

This, along with the continuous underestimation of the impact of mental health, both lead to underfunding. I believe unless this is pointed out then it will simply continue to be underfunded.

Expert by experience

The interim report covers the reasons why we should put the two funding streams together. But if they go on doing what we're currently doing in terms of the services, it's not going to make any difference.

Expert by experience

We believe mental health should have a focus, due to lack of investment in the past and the risk that a single commissioned NHS and social care budget could see mental health and the savings made through mental wellbeing, early intervention and prevention, lost if not given enough attention.

Expert by experience

I think there's going to be a limit to the number of problems that we can solve in the report. On the other hand, I couldn't agree with you more. A commission like this has got to add its voice to those that are pointing out that mental health has got to be given equal status... There will be opportunities in the report for us to make that point strongly and we should take them.

Commissioner

- Parity of esteem was also raised as a huge problem for those living with dementia. One member of the experts by experience group in particular felt strongly that dementia was often seen as a 'social problem' as opposed to a health issue and for this reason, seriously ill people are often denied the NHS funding they would receive if their symptoms were caused by a different illness.

Actions agreed were:

- commissioners will include a statement supporting greater parity of esteem for mental health in the jointly commissioned and funded service they are recommending.

Focus on the aspiration: paint a picture of the prize

Given the hard choices and the risks for politicians in taking them up, the group strongly advised the commissioners on the importance of really selling the vision, ie, what are the benefits of the pooled funding? Why bother?

It feels like the technical solution but people have got to see the benefit.

Expert by experience

We're very keen that the report is foolproof against people who say, 'Well okay, wonderful recommendations, very interesting, what the heck has changed as a result?' What's going to change as a result of this? How are people's lives going to be better? And if people's lives aren't better and all we've done is move the numbers around then we've largely wasted our time. So, I think your help in us being clear about what's changed, hopefully what's improved, is really, really important.

Commissioner

Actions agreed were:

- commissioners will ensure they make clear their vision for the changes suggested upfront in the final report, with help from the experts by experience who volunteer to illustrate the potential impacts via their own situations (as above).

The options for change

The experts by experience group support the analysis around the need for greater alignment and the inadequacy of current social care funding. The group favour more closely aligning social care with health entitlements, ie, making social care more freely available. Group members provided their own experiences as evidence of this need.

While broadly supportive of the commission's views, the group question the implications of a single commissioning mechanism and whether this could limit the range of providers and types of service commissioned, thus restricting the options and choices available to individuals.

The group recognise the need to raise more revenue. Below is an outline of its preferred means of doing so, as well as options it does not support.

Taxation

This is the group's preferred form of raising revenue, because it enacts collective rather than individual responsibility, which they feel is the most appropriate protection for those in the population who require high levels of care and support through no fault of their own. The experts by experience agree with the commission that wealthy pensioners should be the focus of tax increases for the reasons outlined in the interim report. However, the group is conscious that many within this population group are asset, rather than cash, rich and suggest this is borne in mind. The group favour hypothecated taxation (ie, ring-fenced spending increase on health and social care), which could include:

- removing the upper cap on National Insurance
- removing winter fuel payments for pensioners overseas
- means-testing some universal benefits, eg, winter fuel, TV licences. There was disagreement about means-testing bus passes as some view this as a key part of promoting wellbeing, regardless of wealth
- restricting tax relief on pensions for those over the basic tax rate.

We did like the idea of some sort of tax increase to health and social care in particular. Now whether you do that through an increase in National Insurance itself or whether you do it by, say, removing the ceiling on NI or increasing the ceiling on NI to generate funds. What we like about changing the ceiling levels is that it helps this idea of equity making it fairer across the board. So that it means that it's less aggressive than the current NI system.

Expert by experience

- Taxing the benefits – there was interest in the idea of making social care free like the NHS, and then taxing the benefits of using these services. This was contingent on this raising sufficient revenue, and on a full mitigation of adverse effects on vulnerable groups, or those who cannot avoid regularly use services.

We were interested in Julian's taxing benefits idea, and particularly because there are issues round things like means-testing – that you actually create more complications and different costs, and you can create traps – whereas this seems to be a much simpler way of drawing income... There are all those complications, obviously the issue with child benefit recently, in terms of the threshold. We do have questions about how much would it actually raise and in terms of what it would generate, how it would function.

Expert by experience

For instance, say you need support to go down to the local shops because you are disabled, that is not an individual failing. That is down to the disabling effects of society. So that's not something that the individual should be taxed for the benefit of or you know made to pay extra charges for. That's something that collectively as a society we have a responsibility to enable that to happen.

Expert by experience

The experts by experience group is more cautious about the following means of taxation changes:

- removing tax relief on tax contributions – because this could discourage saving
- applying NI after state pension age – due to concern about those pensioners who continue to work because they are struggling for income
- sin taxes (eg, on alcohol and tobacco) – both because this approach is not a stable revenue-raiser – where public health benefits are realised, revenue will fall – and because it stigmatises certain groups.

As additional considerations relating to taxation, the group suggests: a national debate on raising taxes as currently spending is felt to be very opaque; that any tax or NI increase must be carefully implemented in order not to be regressive for vulnerable groups; no change should risk discouraging people saving.

In relation to whether increasing the availability of free social care might encourage dependency and costs that the system can't cope with – as those who are currently coping on their own come forward, and unpaid carers stop caring for free – the group are philosophical. It will require greater attention to how the new system is rationed, based on a better assessment of need. But overall the group felt free access was a small price to pay for ensuring those that really need services get them.

There's also the cost down the line, with carers, because of the nature of the work they're doing very often. I've seen it with my own family, 24 hours a day. I've seen it affect my wife in particular, because I was out of work, but down the line they become the patient, because they don't get sufficient respite.

Expert by experience

Charging

The group is supportive of charging that helps to create greater equity between working age adults and pensioners, eg, increasing the prescription charges exemption in line with pension age but do not support charging that might discourage access to services. In the group's view prescription charges should be extended to those over 65, with the exception of those on pension credit, DLA or Attendance Allowance who are less able to pay.

We were interested in terms of charging on things like prescriptions where, currently, you have 60 as the level where you have free prescriptions. If you move that up to pension age, equalised it, then again that sort of again plays into this idea of sort of fairness, rather than having this age 60, which obviously was used when women's retirement age was set.

Expert by experience

I think generally the group feels that we would prefer tax rather than additional charges to things like the NHS. Again, the principles of different point of views are very important. So the idea of having certain equipment used and paid through taxation, that issue seemed to be a fair way to do it and also it doesn't create barriers to accessing services.

Expert by experience

The group rejects charges for:

- visits to GP – on the same access grounds as the commission
- accommodation in hospital – because of fairness when length of stay is often out of individuals' hands, eg, compulsory mental health detention or discharge delays
- do not attend (DNAs) – due to the administrative burden of chasing debts and groups who might be unfairly penalised, eg, those with mental health or substance abuse issues
- flat rate charge per episode – on the basis that some health conditions require multiple visits
- prescription charge extensions to all – on the basis that some population groups genuinely can't afford even 45p and that this would disincentivise uptake, create a potential for TB outbreaks, etc.

Private insurance

The group rejected the idea of a private insurance model on practical and ideological grounds.

In practical terms, some people will be uninsurable; potential inconsistency of application for those with health or social care needs; those in most need will be least able to pay the premiums and navigate the claims process (a 'double whammy' for those with high health and social care needs and low incomes); implementation would require substantial education and even then the behavioural response is uncertain; as savings will be made over the long term, this does not meet the immediate funding need.

Ideologically, insurance places the emphasis on the individual taking responsibility for making payments in a context where social care needs (like health needs) are highly unpredictable and few will plan for such events. There was concern, based on experience, that this could lead to further rationing. Insurance models introduce the possibility of compulsion, ie, insurance companies able to stipulate what individuals can and can't do in order to stay within the bounds of policy restrictions.

The group did not discuss the Japanese/German social insurance model at meetings, but one of the experts by experience, Clenton Farquarson, provided this submission:

With regards to Germany and Japan, social insurance programmes are universal, support family carers, and allow individuals considerable flexibility in securing the services they require. There are differences between Germany and Japan in programme goals, eligibility process, scope, size, and sustainability but there are possible applications for the United Kingdom. The United Kingdom also has the highest share of households reporting people taking part-time work to care for an older person or someone with long-term conditions. Current policy discussion about reforming adult care funding in England focuses around changes to the current means-tested arrangements for personal care, which provide a 'safety net' for those on lowest incomes who need care for long-term conditions. The United Kingdom (excluding Scotland) and the United States have 'safety net' or means-tested schemes for personal care costs. The future shape of adult care funding in England is still the elephant in the room.

Cons that come to mind (but not an exhaustive list):

- *putting money from social insurance into private accounts means moving retirement savings from a simple, easy-to-comprehend system into a complex structure of investment portfolios and stock market shares that is more difficult to understand*
- *many people either do not know, or do not want to know, how to make the sound decisions about their own long-term investments that private accounts require*
- *the upfront costs of setting up the individual accounts and of advising individuals about the system would take away any fiscal benefits that moving towards privatisation could bring*
- *invested private social insurance accounts will not benefit the UK economy but will put billions of pounds in brokerage and management fees into the pockets of financial services corporations*
- *instead of upsetting the system through a new plan like privatisation, future budget shortfalls can be fixed within the system. The current system will work reducing benefits, increasing taxes, and/or raising the retirement age.*

The group did not choose to discuss rationing the NHS because it understands it is not an option the commission is considering. Equally, the group did not choose to focus on getting better value from existing health and social care, because it understands that will not be a major focus for the commission; however, group members suggest that it should be a condition of new revenue raising, that existing resource is being used well. The group believes that the 'huge amount of waste in the system' should be tackled first, before any additional finance is raised. For example, radical decommissioning of services that are both costly and unsuitable, such as short-term assessment units.

Biographies

Eleni Chambers is a long-term user of health and social care services, a researcher, and is passionate about user involvement.

Clenton Farquharson MBE is a long-term user of health and social care services, consultant in social justice at Community Navigator Services CIC, and passionate about co-production.

Brian Gumbley is founder director of service user-led company Music in the Mind, long-time mental health service user, recently widowed. Brian has worked on lots of initiatives in health and lives in Lancashire.

Heather Hughes is the daughter of an amazing woman who experienced severe and enduring periods of delirium and in between times was determined to keep her independence. Heather is also a veteran social care and health professional appalled by the way the system responded to her mother's complex health needs.

Becky Huxtable is the daughter of a dementia sufferer who is constantly fighting for her father to receive the care to which he is entitled and for dementia to be treated as an illness and not a social problem.

Claire Jones is a disabled mum of two, and a qualified occupational therapist with expertise in mental health service delivery. She advocates the use of asset-based approaches in health and care, including patient leadership and use of inclusive technology to facilitate service provision. She has extensive experience of using both mental and physical health services, and is supported by carers to live at home with her family. You can find her tweeting about #barkercomm as @ClaireOT

John Lish is a long-term social activist, user of health and social care services and committed to improving the quality of life for those on the autistic spectrum.

Sally-Ann Marciano is a recovery nurse and experienced emergency care nurse. Having cared for and lost her father to Alzheimer's disease, she has used Twitter to engage at national level with senior policy-makers; she sits on the Department of Health Nursing Dementia Task and Finish Group and a panel at the Royal College of General Practitioners' annual conferences on dementia and campaigns for investment in specialist dementia nurses.

Dominic Stenning uses his experience of mental illness and recovery to influence change in the health service in the East of England and nationally, and has a keen interest in leadership practice. He is a member of the first Citizens Senate for the East of England and works closely with NHS England on various projects.