Consultation response
26 September 2012

The NHS draft mandate to the NHS Commissioning Board / Department of Health

Contact:
Bernd Sass, Disability Rights UK Strategic Partnership Manager bernd.sass@disabilityrightsuk.org; 07906 521536
12 City Forum, 250 City Road, London EC1V 8AF www.disabilityrightsuk.org

About Disability Rights UK
Disability Rights UK was formed through a merger of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012. We aim to be the largest national pan-disability organisation led by disabled people. Our vision is of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK’s objectives are to:
• mobilise disabled people’s leadership and control
• achieve independent living in practice
• break the link between disability and poverty
• put disability equality and human rights into practice across society.

Consultation response

1. Will the mandate drive a culture which puts patients at the heart of everything the NHS does?

The focus on outcomes (taken from the NHS Outcomes Framework) does potentially put the patient at the centre, but on its own this is not sufficient. The tension which does not yet
The individual clinical encounter is a core but by far no exclusive contributor to positive health outcomes. Alongside this the individual has a whole life to live which in all its domains determines their health and well-being. Individual involvement has a direct impact on health outcomes. Advice and most importantly peer support (from someone who has walked a similar path in the past) would empower the individual to contextualise a condition and make sense of it within their whole life domains. That is, the greater the extent to which someone is being involved in their care and support the greater will be their positive health outcomes. There are multiple positive knock-on effects, including productivity gains. However, involvement, peer support and empowerment are not hardwired into the draft mandate. Better alignment with the NHS Constitution would be indicated to ensure ‘The NHS belongs to all of us’.

In its current form the NHS draft mandate therefore leaves too much discretion to clinical judgement as to how any of the set objectives will have to be achieved. In consequence, no true benchmarks or precedents will evolve of how well any of the objectives could be achieved on the back of strong involvement. There is concern that with the ‘clinical-led’ focus on clinical senates and networks direct patient empowerment, experience and voice will not be given the required status to truly drive whole systems improvement. For example, the right to request personal health budgets has been announced for 53,000 patients in NHS Continuing Care from 2014 but actually receiving them will again depend on clinical judgements. Furthermore, there can be tensions between clinicians opting for certain treatments when patients would rather opt against them.

We recognise that shared decision-making is about cultural change but these examples may show that first a more level playing field needs to be established for patients and clinicians to work and achieve that cultural change together.

2. Do you agree with the overall approach to the draft mandate and the way the mandate is structured?

Again, there may be a danger that the overall approach and structure are too loose to ensure good outcomes (across people’s whole life domains and not just a clinical encounter).
For instance, in terms of partnership-working current incentives for cooperation between NHS and community agencies do not seem to be supported in the NHS draft mandate. Such incentives have been put in place elsewhere, eg for services to review budgets and framework agreements and to consider consortia in order to deliver services jointly. For example, the NHS Operating Framework 2012-13 requires commissioners to co-commission VCS agencies with the joint delivery of outcomes (rather than services) and also incentivises more targeted, preventative support by expanding best practice tariffs. We want to see partnership-working strengthened and informed by people who – sometimes concurrently – use social care and NHS services.

To this end, integrated cross-sector pathways with bundled, proportionate tariffs could be developed and particular pathway stages (associated with specific outcomes) costed and allocated between a range of (‘any qualified’) providers – large and small. Individual and public involvement (as well as the commissioning decisions taken by personal health budget holders) could inform which types of support – including peer support – should be defined and integrated into those pathways. We believe such community-driven and innovative approaches to joint commissioning, (information) pathways, shared decision-making and integration should be featured and driven much more explicitly by the draft mandate.

At the very least, the NHSCB and CCGs should be appraised of the benefits of co-commissioning and sub-contracting to smaller community-driven agencies such as user-led organisations.

Finally, the draft mandate does not address short-termism, eg with regards to 1) managing the tensions between immediate financial gains and investment in person-centred quality, 2) aligning individual service business interests with integration, and 3) prioritising short-term achievements on certain easy objectives over long-term and more sustainable achievements on more difficult objectives and hiding this through aggregation.

3. Are the objectives right? Could they be simplified and/or reduced in number; are there objectives missing? Do they reflect the over-arching goals of NHS commissioning?
We believe the objectives need to be much more specific and measurable. As regards individual experience and the involvement duties in the Health and Social Care Act 2012\(^1\), straightforward items may be indicated such as 'Have you been involved to the extent you wanted to be involved in...?'

Beforehand, the individual must have been provided with information and support, in order to provide meaningful and valid responses. Therefore, this particular item on involvement flags up the need for much wider patient and public education to empower people in understanding and reaping the benefits of involvement, choice and control in both social care and the NHS – especially for long-term conditions for which there is no cure but only co-produced ongoing care and support.

Assessing progress

4. **What is the best way of assessing progress against the mandate, and how can other people or organisations best contribute to this?**

Building on our response to question 2, we have suggested and asked for some implementation case studies to be set out which would be aimed at CCGs and other local stakeholders such as HWBs, HealthWatch and user-led organisations. These case studies would reflect the different ways the high level outcomes will be achieved on the ground locally and then reported to the NHSCB – including information on involvement channels, co-production, change management approaches and associated business cases. This should include how precisely CCGs will be held to account by the NHSCB for their contributions to the objectives.

5. **Do you have views now about how the mandate should develop in future years?**

As the mandate will be regularly reviewed and evolve over time, it seems appropriate to point this out more clearly and invite the NHSCB to conduct a proper validation exercise of the suggested *interim* objectives across all CCGs.

---

\(^1\) Involvement duties in the Health and Social Care Act 2012: Duty to promote involvement of each patient (13H) and Public involvement and consultation by clinical commissioning groups (14Z2)
Improving our health and our healthcare

6. Do you agree that the mandate should be based around the NHS Outcomes Framework, and therefore avoid setting separate objectives for individual clinical conditions?

Yes, as a Pan-disability user-led organisation we support an approach that encompasses individual conditions and impairments and also considers whole life domains.

7. Is this the right way to set objectives for improving outcomes and tackling inequalities?

As highlighted throughout this response, the most essential stakeholder – patients and wider public – needs to be far better empowered to make informed and supported choices on (health) care and support.

Early adopters in initiatives such as our own national programme on ‘user-driven commissioning’ could pave the way for a greater number of people from all sections of the community to follow. This programme supports commissioners and disabled people for the latter to 1) pool their personal budgets, 2) use the shared insights gained in the process to influence de- and re-commissioning and 3) deliver peer support as defined and integrated element of care pathways. Up-scaling such coherent local pilots will not only drive positive health outcomes but also integration and whole systems improvement.

A solely clinician-led approach means that the experience of patients as peers and of the wider public continues to be the most under-utilised asset in the NHS.

Putting patients first

9. Is this the right way for the mandate to support shared decision-making, integrated care and support for carers?

It seems obvious that further specific objectives around integration for example should equally take on a patient perspective rather than perpetuate a clinical systems view. If one accepts that patients’ own choices— if informed and supported accordingly – are the greatest drivers of integration, then personal health budgets must be strengthened, extended...
and better aligned (if not pooled) with social care, housing and other public service areas.

Access to care records and genuine opportunities to co-produce them, eg in mental health, are excellent levers to involvement and integration: The individual will increasingly own decisions affecting their health. At the same time these very same decisions taken by the individual will foster integration of services to fit around the needs and wishes of users of care and support.

The NHSCB should be asked to demonstrate how CCGs link in with this agenda and community-driven approaches more widely.

Please also see our response to question 2 on integrated cross-sector pathways for a further developed model.

10. Do you support the idea of publishing a “choice framework” for patients alongside the mandate?

We do welcome the choice framework but are concerned that the ‘greater choices’ agenda falls short of considering all the other gaps within integrated cross-sector care and support pathways – in particular information and peer support required to first push for a greater range of care and support options between which the empowered individual can choose.

The broader contribution of the NHS

11. Does the draft mandate properly reflect the role of the NHS in supporting broader social and economic objectives?

No, we think that there should be a much clearer commitment and an ambition to clarify how social value can be achieved locally – for example with regards to supporting disabled people into employment as peer supporters or navigators, within both social care and NHS.

Effective commissioning
12. **Should the mandate include objectives about how the Board implements reforms and establishes the new commissioning system?**

Commissioning is the one area which needs to reflect every genuine agenda such as ‘patient-centred’ NHS care. We would reiterate our point on integrated cross-sector pathways in response to question 2 which should be supported by clear and strong incentives for co-commissioning and sub-contracting to smaller providers (including local user-led organisations).

As highlighted in our response to question 4, we would call for implementation case studies to demonstrate to both NHSCB and CCGs how the high level objectives could be achieved meaningfully on the ground by way of co-production.

We believe that services should generally be commissioned with three layers which should be independent of each other, that is one for core provision (delivering the medical-technical care element), one for support (providing information and signposting including through peer navigators for example) and one for advocacy. A clear commitment to those additional layers must come from within the NHS and the new commissioning system.

It would be completely overwhelming for HealthWatch to be asked to act as the sole lever for community-based information, support and advocacy for patients and the wider public. However, as it stands this is what the NHS draft mandate seems to suggest.