

Equity and Excellence: Liberating the NHS.

From A [REDACTED] (constituent, also mental health service user).

While the government has committed to reforming the NHS, it is important that during the reorganisations the present patient and public involvement is not lost. There is a danger that primary care trusts, strategic health authorities and GP practice based commissioning groups may turn inward, learning from management expertise and each-other but not from patients. Organisations may transfer their own responsibilities but then patients may not be part of the system until it is fully up and running in 2013. I think it will be hard too at a time when staff morale may be low among managers. Patients and public should be consulted during the next two years more than usual since we don't want the plans to be put in place without our being involved, there will also be tough calls on spending and we need to be part of these decisions, not just get a sense of them once there are fewer services.

I looked at the Equity and Excellence paper though so much is mentioned only to say that it will be consulted on at a later time. The plan refers to physical health eg cancer and stroke survival rates, but a different system of outcomes is needed for mental health. These outcomes may not be about life or death, except for suicides which are a concern, but the quality of life matters and someone getting enough support for their emotional health to become stronger. This can't always be achieved short term or with one treatment, many people have complex needs and need a range of help, possibly over some years.

The government should acknowledge that NHS services are already under pressure. The savings figure is huge and there's a risk that services will be cut, especially in mental health which is a less publicly visible target. As a patient I need to know that there will be enough resources and that I wouldn't be pushed out of my treatment early because of lack of funding. Mental health service users need face to face meetings, rather than going onto a computer or having brief phone calls. This may work in other services eg self testing for a long term condition, but the nature of mental health is different.

If you do cut out numbers of managers/'back room' staff you could be adding to the amount of work that the clinical staff need to do so they will not be able to see as many patients. They will depend on their administrators and receptionists (who are on low pay) but these roles seem lumped together with management costs.

The ideas around giving patients choice and control – no decision about us without us – do sound encouraging. But not all patients want to use that choice and still will rely on what the GP think is the best option. Patients shouldn't feel left to make decisions on their own. There is also a need for 'third parties' – to include trusted local organisations like citizens advice bureaux to help people get online to look up health information. Many people have problems with reading and writing or their first language isn't English, not everyone can grasp information either especially at times when they feel very distressed.

In mental health the concept of choice of provider (to be made available from April 2011) isn't necessarily what matters most. I would be unable to travel to see staff in a different mental health trust for treatment. I wouldn't want to go elsewhere, since I have built up a relationship with staff in the mental health team at [REDACTED], I am visited at home or have a short walk to this office. I want to choose the NHS rather than see private providers step in. Support needs to be close to home with good knowledge of the local community where I live. Choice can't be used when appointments are regular and continuity of care feels important. Where admitted to a mental health hospital, it also matters that it is in a location where friends or relatives can visit. Investing in mental health services – rather than this being a first area where spending is cut – means standards are good enough without needing to look outside the NHS or out of area NHS Trusts. Choice of a hospital for surgery is a different type of contact. I would though be for choice of care coordinator, psychiatrist, treatment and all other supports. Service users should be able to define what they want, and to this end also be involved in drawing up the government's planned 'clinical outcomes.' (and especially those in their own care) It shouldn't be down to professionals to define what patients should achieve as recovery, eg equating recovery only with getting into work.

Some patients are more assertive and informed, but there will be many who have difficulty in getting any kind of service (and don't have relatives or friends or even a good GP to advocate for them). The NHS plans shouldn't open up a division between those who ask for referrals based on information and others who have problems due to illness or personal disadvantage. There is also often a low response rate to patient surveys, so there needs to be more user involvement in the whole feedback process, as well as devising the questions that get asked.

The government should recognise that there is more to mental health services than talking therapies, which tend to be brief and limited to CBT only eg six sessions or a computerised version. This is unsuitable for many people with more complex problems who need a range of support and therapies. Secondary mental health services are essential in supporting people to live in the community –stepping in when crises happen - while living with a 'severe and enduring' mental illness.

Sometimes in mental health, the patient can lose the ability to make the most wise decisions and risks go up, eg when seriously depressed, or in psychosis. Advance directives drawn up ahead of such crises can be useful. But advocacy is also important, and professionals who know the patient working with the person in crisis. If Health Watch does take on advocacy work, there would still need to be separate mental health advocacy provision (to include independent mental capacity advocates).

Patients should be involved from the outset of planning future changes. At times consultations can happen with the outcome already decided and instead patients are only able to have a say in the general 'shape' of the service. Patients and carers should be able to have real input into the actual details of what is made available. In mental health there should be a stronger role for ex patients to be part of teams, helping others still in the service. There has already been frequent service redesign in mental health (including in the mental health trust, currently in community teams), with services and staff changed around in the name of

improving services – which does create uncertainty and anxiety for service users. There should be a period of stability for services, and a focus on what individual patients need.

Public involvement means that documents (such as this one) should be easier to read. Many people probably don't understand the different tiers of the NHS and what change will mean in their own lives. There should be people on hand, eg working in the health service, ready to explain changes rather than to say that they don't know what is happening themselves. PCTs have done work on public and patient involvement eg NHS West Kent, any new system could use good experience there, as well as not letting user involvement work stop until the new system is in place. The Kent LINK has also tried to involve different people from the local population and look at health treatment across a wide area. I would want more reassurance that new GP consortia would in future have patient involvement rather than closed meetings with no feedback or user representation there.

I worry about there being adequate mental health knowledge in the government's plans. GPs may vary in the amount training they have done, their interest and commitment to mental health. When GPs are new to commissioning they will need training in this too, so it will be a big learning curve. Mental health charity Rethink carried out a survey of GPs which showed that 'only 31% of GPs feel equipped to take on the commissioning role for mental health. While three quarters of GPs say they can take responsibility for diabetes and asthma services, less than a third felt the same for mental health services.'

http://www.rethink.org/how_we_can_help/news_and_media/press_releases/white_paper_to_hand.html

This does lead to the question of whether GPs will commission enough mental health services, and the best ones, if they don't all have expertise. Will GPs tender this commissioning out, and will other providers then try to reduce mental health spending more than it should be for local people. Could GPs also watch their own budgets so not make necessary referrals since they don't want to fail financially? Even if this was not true, patients may wonder if this is the motive when they are not referred to a service. I am also concerned about whether my GP would have enough time to see me? I look to this ongoing relationship with the same responsive and caring GP who knows my history. GPs should not lose patient time to become managers first (unless they want to change roles).

With NICE's role extending to social care I don't know whether they would be biased towards cost effectiveness. The Cancer drugs fund will need to mitigate the effects of their decisions not to fund some cancer drugs which are seen as too costly for the amount of life. Patients need to be able to trust that the standards for the NHS are not driven mainly by cost.

With Health Watch, it does sound like a greater role for the public/patient voice. LINKs across the country may not give enough focus to mental health since they have so many other health areas, which they may get more member/public reports on eg cleanliness in general hospitals. There is a risk in having a wide reach across all health areas so it would be essential that Health Watch prioritises mental health services. Members of Health Watch should also be recruited to make sure they have an interest in mental health. You should

though try to keep the loyalty of existing LINK members who do know already a lot about the local health services.

Arms length bodies are often not known or understood by public and patients. I think for those bodies that are kept there needs to be more chances to get involved. Perhaps with Monitor the time taken to authorise foundation trusts could be reduced, since potential foundation trusts seem locked into a long process before getting that status. I do think that the government are moving fast on changing the NHS eg the news on 28th August that NHS Direct will be scrapped. Consultation about all changes is due especially when experienced clinical staff will be lost to save money.

As patients we also want to be reassured that services are not due for cuts, and that mental health will be a priority area for the government. I worry the reforms will mean that any good work done (by the current organisations) is thrown out and we face a future of much more limited services, with uncertainty and instability for a long time, without the involvement of patients until it's too late.