Your Health in Your Hands

The impact of Personal Health Budgets (PHBs)

Catherine:

This is Your Health In Your Hands, a podcast from the Open University. My name is Catherine Carr.

Personal Health Budgets or PHBs are the next major step towards personalising healthcare. They've been designed to allow people more choice and control over the money spent on meeting their healthcare and wellbeing needs.

These budgets have been trialled in various places across England, mainly for people living with long term conditions. The NHS hopes to, ultimately, offer a PHB to anyone who could benefit.

In this discussion three people involved in implementing PHBs explain what they're going to mean for healthcare in England.

I'm joined to discuss PHBs by **Anne-Marie Mason**, who's the director of a company called Health Your Way, which provides consulting services to clinical commissioning groups and advice to individuals who have or would like to have a personal health budget. **Professor Julian Le Grand** is a professor of social policy at the LSE. He was a senior policy adviser to Tony Blair. And **Alison Austin** is the lead on personalisation and control at NHS England. She's been involved in PHBs right from the beginning.

So Alison, as I said, PHBs are part of a broader process of personalisation in health and social care. When did personalisation emerge as an idea?

Alison:

I think they go back to the 1970s when people with disabilities, people with complex needs were placed in residential care. So you had young people who were in residential care and they didn't want that, quite understandably, and so there was a disability lobby to enable people to live independently.

In social care in the mid-1990s direct payments came in where people were given money so that they could organise their own care and support and live independently, and self-directed support in social care. I think in health we've moved on since about the early 2000s to think about actually to enable people to live better lives with the NHS. The NHS has to do things differently.

Catherine:

Julian, you were first introduced to the idea of personalisation through a visit abroad, I understand.

Julian:

Yes, I was attending a seminar at Davos, at the World Economic Forum where we were discussing whether people really, who were terminally ill or very close to death, whether they really wanted all these vast amounts of hi-tech and very expensive medicine injected, both literally and metaphorically, to keep them alive. We discussed the possibility of actually maybe offering people the choice. They can have the choice of having all this hi-tech medicine or maybe the money instead. There was quite a lot of interest in that idea.

So when I got back to the UK I wrote a memo to the Prime Minister, who was Tony Blair at the time, and he was quite interested in the idea, and the rest is history so to speak.

Catherine:

Improving wellbeing and health, were those the benefits that immediately struck you towards moving towards personalisation in this way?

Julian:

I think it was more, it was the benefits of making people feel more in control of their lives. Health is a very debilitating and very demoralising and destructive psychologically as well as physically, ill health is. So actually this was a way of giving people greater control in a period of great misery and distress for them.

Catherine:

Is that something that you have witnessed as well Anne-Marie?

Anne-Marie:

Yes, absolutely I think people feel more in control and actually have a lot more autonomy about things really. It’s a much more positive experience, it’s not just about the healthcare needs or their wellbeing needs. It has a greater impact on their quality of life as a whole. It’s not just about the person, that person is usually a part of a family, and a condition has an effect on a family as a whole.

Catherine:

I guess with this new way of working together with the individual and the practitioners there's a whole new relationship, isn't there, to be understood and developed, and perhaps that takes some time to bed in.

Alison:
It does and actually it's not the change in the relationship, so moving from a very paternalistic model where clinicians tell people what they got to do to a more enabling empowering model where patients and carers are seen as partners in the healthcare. Actually it's recognised that their experience of how their long term condition affects them is as important as a clinician's knowledge. So where it is very important for personal health budgets it's not in isolation and it's part of a wider drive to make the NHS more responsive.

Catherine:
When it comes to the individual then, I guess, whether it's the individual who's looking for a budget or actually the commissioning body there's a lot of negotiating and sorting through paperwork. I guess that's where you come in Anne-Marie.

Anne-Marie:
Yes, I guess where it kind of starts is that people obviously need information and advice about what their options are, what it all is and if it's going to be right for them, because it's not right for everybody. That's one of the fundamental principles is that it must be voluntary for people.

I guess once people have had their options, people complete a support plan. Sometimes people want to do that on their own, but actually sometimes people need some support with that and that's something that Health Your Way would do is that we would work with the person to work out what it is they want, what's working for them and maybe what isn't working.

Catherine:
I guess from a policy point of view, Julian, as well, it requires the commissioning bodies to fundamentally change some of their structures.

Julian:
Well in some ways yes, but I think it is more a change in attitude. It was actually quite interesting when we first began discussing all this was this question about whether should patients be allowed to buy anything that they chose and what should be the role of the clinician in trying to check it out? We were always worried about what we call the Daily Mail test, the danger that if you allowed patients to choose e.g. a holiday in Bermuda, that might be splashed all over the Daily Mail and there'll be all sorts of stories about waste of NHS money and so on.

In the end though we did decide that it would be better to allow people to spend money pretty much as they chose, but with this clinician approval and sign off.

Catherine:
That’s difficult though surely for the commissioning body, if they’re dealing with a much wider variety of new providers, they’re going to have to respond to the market in a very new way, aren’t they?

Julian:
They are, and of course the other problem associated with that is that if people choose to spend money on providers that are different from the ones that the commissioner has been dealing with, the commissioner may have to spend extra money in order to fund these new purchases and these new providers. One being unable to take the money away from the old providers.

Catherine:
Alison, in the trial period I guess that wasn’t significant because the numbers we were talking about are so small, but once this opens up more widely that could be a real problem.

Alison:
I think it could be, and I think thinking about it in perspective we think the numbers of people initially who will want personal health budgets are small. This is going to be a gradual roll out. I think when you think about commissioners, commissioners at the moment are supposed to be moving away from those very large, very rigid block contracts to a more person centred and more flexible approach. So it has to be part of that process.

Actually one of the cases that made me feel really impressed during the pilot was one of the sites eight out of ten of their stroke people wanted to have a particular rehab service that was provided by a third sector provider. The commissioner going, “We don’t need to have personal health budgets. I should just be commissioning it if people want it”. So actually personal health budgets could help commissioners look at what services individuals actually want and provide those more widely.

Julian:
But I do think that’s quite an important point that actually one of the interesting things about personal health budgets is that it shows that patients and their carers are perhaps the best people to monitor the quality of the care being provided. We tend to look to regulators or we look to commissioners to check on the quality, but actually one of the interesting aspects of

this is that the best judge at the end of the day of the quality of care may well be the patient and their carer.

Catherine:
Have you seen an outcome, Anne-Marie, in the work that you do where a care package is being sort of redesigned by the individual and it’s so much better because their expertise, as Julian is describing, has been implemented?

Anne-Marie:
People have made very different choices to what maybe I’ve not really thought of. To give one example is where somebody had thought about the respite or the break for the person and the family wasn’t working. They actually chose to have a therapy room built in the garden and it was a room that the person could use outside of their bedroom to use for the different therapies that they were accessing. Some of those were purchased through the personal health budget. That was used with about half a year’s worth of their respite money but they’ve still got it three or four years on and will continue to do so for years to come.

Catherine:
Actually if you’re looking after your own budget of course you look for bargains I suppose. You look to make your pound go further for you. Is that something that you’ve both witnessed?

Alison:
Yes, and actually it’s something that a lot of the peer network talk about. They all know that the NHS isn’t cash rich, as it were, and actually they want to make the money go as far as they can for their loved ones. And actually are also very happy if they don’t spend it all, which a lot of them don’t need as much money, they’re more than happy to give it back to the NHS because they know that other people could use the money. They actually get a sense of satisfaction from that.

Julian:
I think actually people have always been fairly aware that the NHS is heavily restricted, the amount of money that they can spend. People are actually, believe it or not, really quite economical quite often in the healthcare they use. This is actually an opportunity they have to, in a sense, cash that out. They can actually, by their own actions, they can actually affect the amount of money being spent. The result is often very favourable with people wanting actually to give the money back.

Catherine:

Let’s go back slightly to the timeline, how is somebody deemed eligible for continuing healthcare and therefore for a PHB at the moment? What are the measures that you use?

Alison:
It’s people whose primary needs are healthcare needs. So they’re usually people who are needing support with things like feeding, breathing, maintaining a safe environment, things like that. So there are, I can’t remember if it’s seven or eleven criteria, but there are quite a lot of criteria to go through to become eligible for NHS continuing healthcare.

Anne-Marie:
It can be quite a long process because, obviously, it’s not just based on what people say, it’s based on evidence. It is quite a stressful period for people really to go through. If people needed support then that’s something we could support them with. It’s making it clear as well that the process of applying for continuing healthcare is a completely separate part to the personal health budget process. If you’re not eligible for continuing healthcare then you should still be looking at social care to look for a personal budget.

Alison:
One of the really interesting things about that, because you think about the planning at the very beginning, you think about things like contingency, so what happens if my carer is off sick? Whereas in a traditional service they don’t think about the contingency, so the plans actually can be a lot more robust in the longer term and we see that in evidence that people don’t come back.

Catherine:
How then can we ensure parity across the country between CCGs in terms of who, when they ask, will get? What they will get? What services are commissioned in their area and therefore what care package they can design? It’s all too easy, you talked about the Daily Mail test, it’s all too easy to imagine that someone with rheumatoid arthritis living in the North West has access to services; A, B, C, therapies; D, E, F. Somebody living down in the South east with the same condition may have a completely different situation to contend with.

Julian:
Well yes, the dreaded postcode lottery. It’s always a tension in any health service or indeed in the social care services to what extend you allow local discretion or the extent to which you try and enforce a national service where everybody gets the same regardless of where they live. We’ve principally gone down the route of allowing local discretion. So we’re allowing clinical commissioning groups or we’re allowing local authorities to make the relevant decisions about what people are entitled to and what people should get.

I think it’s a tension that just simply can’t be resolved easily. You just have to accept that if you’re going to allow that we’re going to move at a local level, then yes, you will get variation across the country. If you want a national system, then you remove all discretion from local government and from clinical commissioning groups and just have everything standardised at the centre.

Catherine:
So what guidelines do exist for establishing what budget an individual gets at the moment?

Alison:
During the pilot programme, beyond continuing healthcare there were a variety of different methods that were used. We took the approach we shouldn’t come up with a method for working out the money before we piloted, because we could spend so much time working that out that we wouldn’t actually have time to test. So there’s a couple of documents on the learning network that talks about different ways that people try and we’re continuing to develop those in early roll out stage.

So things like people may look at the package of care that an individual gets at the moment and say, “This is what it would cost,” so that’s your initial starting point. For others it might be worth looking at what’s your wider care. So actually you go to A&E 20 times in a year and actually you end up in hospital 15 of those for three days that costs x amount and using a proportion of that money to enable people to do things differently.

So the way the system works is that there’s a sort of an indicative budget that’s set to enable people to plan properly because none of us plan to buy a house without knowing our budget. Care planning is done and then the budget is refined.

Catherine:
Julian, I know you have some concerns about the way that costing might happen once personal health budgets have rolled out more widely. Would you like to explain what those are?

Julian:
One of the issues is what people can buy with their personal budgets? Now we might be moving to a world where at the moment you can’t buy for example GP services or emergency care through these budgets. I think on the whole I would not be in favour of moving in that direction, of extending personal budgets so they’re covered in some senses all forms of healthcare. That would mean that all forms of healthcare had to be priced and costed and so suitable for the budget. I think that might be possibly a step too far.

Catherine:
So finally for PHBs, we've talked about them requiring a change in relationship. What do you think overall are the benefits of rewards of moving towards an approach like this?

Anne-Marie:
I think people really want to have a say in how their healthcare is managed. At the end of the day we need to remember this is people's lives and they're not just another number on a tick sheet really. So I think people having the benefits of this is real choice and control.

Catherine:
Julian?

Julian:
One of the troubles with illness is that it diminishes your sense of control over your own life. It makes you feel a victim and actually that worsens both your sense of wellbeing and also your health itself. Actually giving people much greater degree of control over this area of their lives I think will improve both their wellbeing, and I think their long term health as well.

Catherine:
And Alison?

Alison:
Thinking about people who have mental health problems, people who've got long term conditions actually they want to get better. They don't want to use NHS services, and so as would happen in normal traditional services, if you got better those traditional services would reduce. It's the same for personal health budgets.

Catherine:
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