PERSONAL HEALTH BUDGETS IN ENGLAND: MOOD MUSIC OR DEATH KNELL FOR THE NATIONAL HEALTH SERVICE?

Alex Scott-Samuel

Personal health budgets in England are National Health Service (NHS) funds that can be allocated to certain groups of patients to allow them, together with their NHS support staff, to purchase services or equipment that they believe will enhance their health and well-being. Some see this as a welcome personalization of health care that increases people's control over their health. However, personal health budgets are being introduced at a time when rapid privatization of the English NHS is taking place and when restrictions are being placed on people's access to health care. As a result, many view their introduction as a diversionary gimmick designed to help pave the way for the conversion of the NHS into the insurance-based system, which many believe is the intention of the U.K. government. This article describes the research and policy context in which this controversial intervention is being introduced and presents recent expert debate between proponents and opponents of personal health budgets, from e-mail discussion lists.

According to the U.K. government, a personal health budget (PHB) is "an amount of money to support your identified healthcare and wellbeing needs, planned and agreed between you, or your representative, and your local National Health Service (NHS) team" (1). PHBs are NHS funds that can be allocated to patients in England to give them more choice, flexibility, and control over the care they receive (2). In 2009, the Department of Health in England launched a national pilot program to evaluate PHBs, covering 70 primary care trusts (administrative divisions), a range of long-term conditions (chronic obstructive pulmonary disease, diabetes, long-term neurological conditions, mental ill health, and stroke),

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maternity care, and end-of-life care. The evaluation concluded that PHBs are cost-effective and recommended a wider rollout (3, 4)—following which, as of April 2014, the government gave individuals receiving continuing health care funding (non-hospital NHS patients with complex ongoing health care needs) the right to request a PHB (4). After April 2015, PHBs will become available to anyone with a long-term condition who could benefit and the chief executive of NHS England has stated that 5 million people could be receiving PHBs by 2018 (5).

Some NHS services are not covered by the PHB scheme; these include "emergency care, and care you normally get from a family doctor" (1). Revealingly, the Department of Health also found it necessary to state that among other exclusions are "gambling, debt repayment, alcohol or tobacco, or anything unlawful" (1). This hints at the very wide range of uses to which PHBs had been put in the pilot projects: these included neurolinguistic sessions, acupuncture, a personal trainer, gym membership, reiki, manicure, driving lessons, mobile phones, and theater and football tickets (6).

EFFECTIVENESS OF PERSONAL HEALTH BUDGETS

The pilot projects found that PHBs were most commonly used for physical exercise, for alternative therapies, and to pay carers (6). In terms of impact, PHBs did not significantly improve either clinical outcomes or health-related quality of life, though they did significantly improve care-related quality of life and psychological well-being. These latter findings allowed the researchers to conclude that PHBs are cost-effective relative to conventional service delivery (4).

However, an independent reassessment of the evidence from the pilot projects found the evaluations to be methodologically unsound and their conclusions to be based on misleading use of data and of individual case histories. It concluded that PHBs as currently conceived are incapable of achieving the personalization of services that is their central objective (7).

A review of Dutch PHBs found substantial use of ineffective therapies and inappropriate consumer spending, as well as widespread fraud (8, 9). Studies of Singapore's medical savings accounts demonstrate "hospitals simply competing on superficial and visible indicators of quality" (10). Despite inconclusive international evidence on their effectiveness, there is, however, consensus that recipients of PHBs generally feel more empowered and confident about their care (11).

PERSONAL HEALTH BUDGETS AND NATIONAL HEALTH SERVICE PRIVATIZATION

For many people in England, it is, however, an entirely different aspect of PHBs that causes concern. All U.K. governments since that of Thatcher have

implemented policies that have contributed to privatization of the English NHS (12), with the current Cameron government doing the most to explicitly legislate for denationalization and corporate takeover (13, 14). Following the Health and Social Care Act 2012 (15), a wide range of enabling structures and functions are being introduced to facilitate the dismantling of the NHS in England as a public service.

In this context, there are well-founded concerns that the introduction of PHBs will be rapidly expanded to create a consumerized, commodified health system like that in the United States. As Leys put it, "If a personal (social care) budget proves inadequate, the patient has to top it up—if they can afford to. For NHS care, such 'top-ups' will be payments for what was previously free. . . . This raises the possibility that personal health budgets, with personally-paid top-ups, will become the basis of most, or conceivably all, NHS care. This approach is strongly backed by advocates of health insurance. They propose that everyone should have a personal health budget, sometimes called a 'health protection premium,' paid for by the state, equivalent to the NHS's average annual spending on health care per person. This would entitle everyone to a defined package of entitlements. Anything beyond that would have to be paid for by the individual. For most people that would mean taking out medical insurance for a wide range of other conditions and treatments—if they could afford to, and if insurance was available (pre-existing conditions may not be insurable)" (16).

Significantly, PHBs were first proposed by Alan Milburn, who as Secretary of State for Health had initiated the Blair government's NHS privatization policies. In a 2006 speech to the Care Continuum Congress in Washington, DC, Milburn said, "The idea would be to give . . . patients a choice between receiving a package of care from the NHS, as they do now, or instead having their own budget—an NHS credit—which they could control directly. . . . The patient could then buy his or her care from the NHS or a private provider" (17).

RECENT DEBATE ON PERSONAL **HEALTH BUDGETS**

For many U.K. citizens who have grown up with a needs-based system that, since 1948, has provided a more or less full range of health services free at the point of use in every part of the United Kingdom, the prospects of charging for care, rationing of treatments, and inequalities in access and outcomes that Leys and others suggest are being systematically introduced in England through the process of NHS privatization are horrifying. This is the context in which the discussions that follow took place. They consist chiefly of edited contributions to specialist e-mail discussion lists and they add a rich and nuanced understanding to the descriptions of PHBs provided above.

Scott-Samuel, A., to Baroness Young, Chief Executive, Diabetes UK (18)

Dear Barbara,

As I think you know, I am both an academic public health doctor and a Type 1 diabetic. I am also someone who has written about and campaigned against the Health and Social Care Act 2012 which, it is now generally accepted by most people not in government, is intended to implement and has already substantially taken forward the full privatization of what was formerly our National Health Service.

A central purpose of this—still not admitted by Government but acknowledged by key actors such as Mark Britnell (former Department of Health Director of Commissioning) (19) and Oliver Letwin (Conservative government cabinet minister) (20)—is to create a health insurance based market similar to that in the US, with a poorly funded, poor quality public service for those without access to health insurance. Many elements of the Health and Social Care Act such as the creation of clinical commissioning groups (CCGs) which are patient based rather than population based and the dropping of the Secretary of State's duty to provide a comprehensive National Health Service are designed to facilitate the creation of an insurance based health care market.

Another key facilitator is personal health budgets: these will of course in future be used to purchase individual health insurance. Equally or more worryingly for people with diabetes and other chronic conditions who are expensive users of health services, there is the likelihood that in future, individual budgets will be capped in a way which will restrict access to essential care. And of course diabetes care is not like shopping for baked beans: I want my care prescribed by my diabetologist and my primary care team, not by my own subjective whims and prejudices—which in Cameron's envisaged future will of course increasingly be manipulated by the marketing activities of big pharma and "big equipment."

I hope and expect that Diabetes UK will strongly oppose the introduction of personal health budgets for diabetics—see article in *Pulse* on new research demonstrating their serious problems (21)—and will form alliances with other key voluntary and professional organizations to raise public awareness of this during the next 12 months.

With best wishes, Alex

Baroness Young to Scott-Samuel, A. (22)

Dear Alex,

Thank you for your email. Diabetes UK's position is that the complex and unpredictable nature of overall clinical care means that personal health budgets are unsuited to this area of diabetes care delivery.

Health care provision for people with long term conditions must be of high quality, regardless of whether people choose to use a facility such as personal health budgets. In addition to this, not all people with diabetes will wish to use a mechanism such as personal health budgets to personalize their care. People with diabetes and their carers have responded to a consultation on this subject and several important issues about personal health budgets were raised, including:

- Whether individuals would wish to manage a budget.
- Whether such a mechanism will improve care, particularly for people with multiple and complex health conditions.
- High quality care should be available for all regardless of whether they have a personal health budget.
- What care will be covered by a personal health budget and what will not, and the implications of this for current care provision.
- How budgets will be calculated for conditions that are complex and unpredictable and whether they will be sufficient to meet people's needs.
- The impact such a system will have on achieving quality standards of care and whether it will lead to the fragmentation of services.
- The availability of information to support informed decision making.
- The importance of piloting and evaluation to identify uptake, understanding of the scheme and the costs involved in managing the system.

Diabetes is a complex condition. The development of its complications can be unpredictable and lead to multiple co-morbidities. Research in this area has identified that personal budgets are likely to work best when conditions are stable and predictable.

Therefore Diabetes UK takes the position that personal health budgets are not suited to clinical diabetes care delivery and may impact negatively on quality of care and lead to the fragmentation of services. Our feedback from people with diabetes is that there has not been—and is unlikely to be—much take-up of personal health budgets.

Best wishes. Barbara Young Chief Executive, Diabetes UK

Thompson, K., to Politics of Health Group (PoHG) (23)

This is interesting. In the US I would expect that people with ongoing medical challenges would want personal budgets so they have more control of what they receive—and seen as a move toward empowerment. Curious that it seems to be an anathema in UK in PoHG. I see the worries about privatization but wonder if some concern is also about loss of professional power?

Ken Thompson, MD

Scott-Samuel, A., to Politics of Health Group (24)

Ken, if I have the services of a team of highly skilled professionals who are there to improve my health rather than to make a profit out of me, why would I want to pretend that I am expert in every aspect of diabetes care and presume that I know which services to "purchase" with a personal health budget?

Best wishes, Alex

Thompson, K., to Politics of Health Group (25)

Really good question. What we are finding is that the lived experience of having a condition is an important form of expertise in its own right. And that experts don't usually know the desires and meaningful goals of the lives of the people they serve. We are moving to use the expertise of experts to support the desires and goals of the people they serve.

Hope that's clear. It's person centered and directed by the person. Ken Thompson, MD

Grimes, R., to Politics of Health Group (26)

Alex, thanks for pursuing this, I am pleased to see Barbara Young's reply.

I too have Type 1 diabetes (38 years, mostly complications-free, though I do have eyesight loss due to retinopathy). I am very involved with my local Clinical Commissioning Group as a patient, and to be honest, I get the impression that PHBs will be very limited and will not have much of an uptake. I don't get the impression the CCG know what to do. And I don't think that many patients will want them. It just isn't what we expect as being the NHS way to do things.

At the end of last year I was a member of a group of patients which had a meeting with the CCG about PHBs and, to be frank, I felt a little sorry for the young commissioner chap after I had spent half an hour challenging him. He just didn't have the answers. His presentation was full of the sort of feel good stories about people spending PHBs on season tickets for the local football club, and he even held up the Dutch personal budgets as a success. Indeed, we are seeing cuts in funding where people are being denied cataract operations (or told they can only have one eye done) yet the CCG will pay for a season ticket?

I asked the commissioner if someone with chronic pain could use a PHB to pay for acupuncture (I organize talks by clinicians from my local hospital, and a recent talk about pain management was on my mind). The commissioner said that this would be possible. Then I pointed out that the CCG stopped paying for acupuncture for pain management in 2010, so what he was suggesting was a two-tiered service, where treatment will be only available to those on a PHB. The commissioner—thinking on his feet (I wish he had spent more time thinking in his office)—said that the CCG would draw up a list of treatments that patients could purchase. Oh dear, hardly a personal choice, is it?

I raised the point that most patients will not be able, nor want to manage a budget. The young commissioner had a solution to that. A charity (ie totally, non-publicly accountable, with no statutory patient involvement) would manage the budgets for the patient (after, of course, taking a management fee—nothing is free in this life). Whoa! Who was this organisation? Well, they have offices 40 miles away (and inaccessible by public transport), as opposed to the current people who manage the budget for my care—the CCG—who are 5 miles away, a 15 minute bus ride. This is not localism, it is opaque and unaccountable and, to be honest, the CCG abrogating its duty.

We were told that people with PHBs could put their money together and pay for service together. Err, isn't that what the CCG does already? I have a neighbor with learning difficulties and the county council (who commission social care) closed the day center she used and gave her a direct payment instead. This was a terrible blow to her, isolating her from the staff and friends that she knew from the center. But, the council told her that she could pool her direct payment with the other former users of the center and together they could hire their own location and staff. Honestly, people really do say these things.

I really do want personalization, but it does not need me to have the money to make it happen. I think that PHBs will damage the covenant patients have with the NHS, and I think that for most patients with long term conditions it will make personalization less likely rather than more. I worry that real personalization will not happen because commissioners will be distracted by thinking that PHBs deliver personalization, whereas they deliver individualism and often, isolation.

Reading some of the responses from people from the US I think it is worth pointing out what the NHS means to those of us who use it. We know that we will get care appropriate to our condition and that care is provided according to our clinical need. That may mean that when waiting in a clinic someone sicker gets seen before you, but we accept this because we know that if we were that sicker person, we would be seen sooner too. We know that the NHS does not discriminate due to wealth, location, gender, age, ethnicity, sexuality or disability. Sickness is a powerful leveler and the NHS recognizes this. We know that the NHS is not judgmental, we are offered help to improve our condition, but we are not blamed for how we are. But above all, the NHS is the most fundamental of the welfare state's safety nets; when we need medical care no one ever doubts that the NHS will be there for us.

Kelly, J., to Politics of Health Group (27)

Hello

Interesting debate and inferences about experts' capacity to support their patients. Whilst acknowledging that in some cases for some individuals personal budgets may be of benefit, as someone with type 2 diabetes I agree with Barbara Young / Diabetes UK and Alex's summary. I am horrified at the thought of trying Josie Kelly

to manage a budget and negotiate with different care providers, especially if vulnerable at those moments when trying to deal with an episode of illness or the emergence of a new complication of the condition. I am not convinced that better care would follow. As a patient with some knowledge of how my condition affects me, my understanding is incomplete and requires support and the expertise of scientifically informed and skilled practitioners.

More critically, what is really reprehensible is that personal budgets can and will be reduced or not increased with inflation. Patients will be denied certain treatments or will be invited to make a financial contribution to the cost. Personal budgets will be a major incentive to those clinicians so minded to monetarize their expertise. None of this is surprising as current policy on personal budgets is driven by neoliberals' dislike of the UK health service based in collective action (on preventive public health interventions) and risk pooling in terms of curative health care that is free at the point of use, funded by general taxation.

Thompson, K., to Politics of Health Group (28)

In the US the notion seems to be that having control of a personal budget will allow people to buy and control services with the explicit idea that this will actually decrease health need. Presumably if these budgets decreased health need and therefore reduced cost, personal budgets are likely to be increased.

But in US they aren't about buying health services, they are about buying services and materials that people believe would enhance their capacity to live. Interestingly, in US I don't think people feel that making their own choices—with expert guidance if they choose it (which they generally do)—is a burden. It would be seen as freedom.

Ken Ken Thompson, MD

Abrahams, D., MP (Labour Member of Parliament) to Politics of Health Group (29)

All too often personal health budgets are conflated with personalized care and empowering patients.

We definitely want personalization and empowerment. But for me the international evidence suggests PHBs can detract from this and this needs to be recognized.

Mukhopadhyay, B., to Politics of Health Group (30)

It seems to me personalized health budgets might be useful for a patient who was highly aware of the range of services available, and understood what long-term consequences of intervening or not intervening in certain ways would be. For people who do not have access to information, or where the information is

too overwhelming, or where information is skewed by marketing / advertising principles—surely, it could be disastrous for health outcomes? Baj.

Rathfelder, M., to Politics of Health Group (31)

Personal budgets seem to work well for a small group of people with stable but severe disabilities and the intellectual capacity to make informed decisions. But they are being sold as the answer to every problem.

Barstow, N., to Politics of Health Group (32)

I think that this is really about two issues: firstly, class—of course working class people are perfectly capable of managing but...there are a whole lot of issues around being informed enough to cope with this sort of thing; secondly, collective action—collective provision brings both economies of scale (NHS versus US private provision) but, more importantly the ability to organize together to improve services. Individualization can mean atomization.

Nik

Thompson, K., to Politics of Health Group (33)

Hi Nik

Agree. It's critical that there are supports / solidarities that make it possible for previously disempowered people to pursue their desires.

That of course raises the issue of atomization. Ideally we each support the achievement of the desires of the other. From each according to their ability, to each according to their need. Collective individualism. Or I prefer—people living with each other.

Ken

Ken Thompson, MD

Molloy, C., to Politics of Health Group (34)

Labour could commit to reversing the law that made this possible, quite simply, by committing (if they regain control) to repeal the law which was quietly sneaked through parliament last August (it lifted the initial restriction of PHBs to pilot areas).

Absolutely no-one I know can tell me why PHBs are different from Thatcherite vouchers, though whenever I ask, highly paid advocates like to aggressively bombard me with emotive cherry-picked stories of individuals who've benefitted, without ever responding to my comment that this isn't really a rigorous evidence based approach and that the rigorous evidence points to such benefits as the exception not the rule...

Wrigley, D., to Politics of Health Group (35)

Caroline,

You are right and they are wrong.

PHBs are superficially attractive but we know that when an individual's funds run low they can't afford further care. Those with adequate funds in the bank can purchase as much extra care as they need. Completely against the founding ethos of the NHS but perfect for the marketeers.

It is however great news for insurance companies who will swarm over this like bees round a honeypot...

David

Reynolds, L., to Public Health for the NHS (36)

PHBs are an important component in the transition of our health system to be predominantly run by insurance companies using private hospitals, with only a minimal NHS cover for the very poor (though some of the technical advisers on the changes have advised that the NHS should be reduced to Accident and Emergency only!).

The funding to CCGs to pay for referral care (= treatment) for patients will be transferable to a private insurance company as payment for an insurance premium for private care, on the patient's say-so and signature. That is what the 2010 White Paper meant by "money following the patient." The detail of this was set out in the Adam Smith Institute's 1988 "The Health of Nations" (37) as a way to transition the UK into US-style health care, which has been the goal behind pretty much all change to the NHS since the 1980s.

The transfer out of CCGs will be offered by insurers only to healthy, low-risk individuals, thus at a stroke depriving CCGs of the cross-funding they need to pay for those of their patients who need treatment, and allowing the insurance company usually to pocket the full payment as no claim will be made on an insured healthy person in most years. It is likely the insurers will offer a free gym subscription or similar as an incentive to sign for the transfer.

This transfer will destabilize the funding to CCGs and force them into dramatic reduction in the services they are able to provide to patients—the death of comprehensive care under the NHS.

But it won't work unless the chronically ill are removed from the system during the changeover time. This is because if people with chronic conditions decide they'd like a gym sub for free too and apply, the insurer will reject them or will say they won't cover all their care, as treatment related to pre-existing conditions will be excluded. This would probably soon make people realize en masse that they are being tricked into an inferior system (many people in this country think that health insurance can replace a universal comprehensive care system like the NHS, but it cannot—insurers are perfectly at liberty to run things whatever

way they find most profitable, and that is the way things are done in the USA, where exclusion boosts insurer profits) (38).

So the PHBs represent a bung of spendable cash to people with chronic conditions, which is intended to keep them from approaching insurance companies until the NHS is on its very last legs and the insurers have got most of the healthy affluent people signed out of the CCGs.

(As in the Netherlands) PHBs won't be in existence long here either, just long enough to cover the breaking of CCG budgets through money following healthy patients out of the NHS. Then their flaws will be acknowledged and they'll be abolished, having played their part in the privatization.

Cheers, or not,

Lucy

DISCUSSION

The discussions above reflect the complexities of current debates about the future of the NHS in England (note: although Scotland, Wales, and Northern Ireland are also within the powers of the U.K. government, their devolved administrations are responsible for health care policy—and have all chosen to retain national health services with virtually no privatization). While in different circumstances, many of the issues discussed could be seen either as technical aspects of personal health budgets, or as relating to specialist social policy themes such as consumer culture or self-care, the current threat to the fundamental nature of the NHS in England dictates that debate about PHBs cannot avoid taking place within the broader context of the debate about NHS privatization.

It would be interesting to imagine some of these discussions taking place in a stable political situation—in such circumstances, issues such as personalization, control, and consumerization of health care would clearly be discussed differently. But while such a discussion would undoubtedly add new perspectives and information to the English debate about PHBs, the absence of this discussion should not be seen as problematic. All societies, all public policy discussions, and hence all potential interventions to promote the personalization of health and social care, are inherently political—and thus the optimum strategy for effectively personalizing health care, whether in England's choppy political waters or in calmer seas, will be political too.

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Direct reprint requests to:

Dr. Alex Scott-Samuel
Department of Public Health and Policy
University of Liverpool
Whelan Building
Liverpool
L69 3GB
UK

alexss@liverpool.ac.uk