



Personalization of health care in England: have the wrong lessons been drawn from the personal health budget pilots?

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Abstract

The Government has introduced personal health budgets in England's National Health Service (NHS). A three-year programme of pilots has shown that personal health budgets have improved outcomes and are generally cost-effective. They are seen as a key step toward creating a personalized service. However, the Government is attributing the success of the pilots to entirely the wrong factors. It believes that a process similar to the one introduced in social care – where it is called self-directed support – based on the person being given a sum of money 'up-front' with which to plan their own care – is responsible for the better outcomes. However, this is not supported by the evidence from the pilots which points to quite different factors being at play. The consequences are potentially very serious. The success of the pilots will not be repeated in roll out. Further, there is the potential to greatly weaken the service by creating confused process and practice, and additional dysfunctional bureaucracy. The practice and process implications from a correct reading of the reasons for success within the pilots centre on replacing the consumerist concepts underpinning self-directed support with what we have called 'flexibility through partnership'. This will require freeing up the resource base as cash and creating a policy framework to enable decisions about how much resource each person should get within a cash-limited budget that will almost certainly be less than would be required to meet all assessed need.

Keywords

personal health budgets, use of research in policy, personalization

Context

Personal health budgets (PHBs) have been introduced in England as part of a drive towards promoting the 'personalization' of health care services and are now central to future plans for the National Health Service (NHS).¹ Their aim is to place patients at the heart of decisions about the health services they receive, to improve efficiency and make the service more responsive to the needs of patients. The ideas that underpin PHBs have emerged from earlier work on social care and the development of *self-directed support*.² Self-directed support has as its central feature a personal budget arrived at through an 'up-front' allocation of money. It was introduced as formal policy in 2008, with an original target that all service users should have a personal budget for social care by 2011.

In this paper, we critically look at some of the evidence used by the UK Government as it seeks to justify the roll out of PHBs across England. This paper

addresses what is happening in England; however, it has relevance to other countries that are exploring PHBs and personalization more broadly.

There are a number of key principles that underpin the use of PHBs and frame their development.¹ These include a commitment to ensuring their use remains consistent with NHS policy, services remain free at

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the point of delivery, full transparency of the services and level of support available, and flexibility in their use. Users must also be free to decide how they wish to manage their PHB.

The Government's confidence in the value and efficacy of PHBs is based on an evaluation of a three-year programme of pilots carried out by Forder et al.² and published in 2012. On the basis of this report, the Government committed to the introduction of PHBs for a range of NHS patients by April 2014. All people with continuing health care needs have a right to a PHB, while local commissioning groups will be enabled to offer them to others with a long-term condition.

The evaluation of the pilots

This evaluation was commissioned by the Department of Health and was carried out by a team drawn from four universities led by Julien Forder. It was a longitudinal controlled trial and included people with various long-term conditions. Twenty pilot sites were evaluated and some 1000 patients were given a PHB. It compared their progress with a control group made up of a similar number of patients who did not have a PHB. Patients were allocated to a PHB or not on a randomized basis or on the basis of a natural experiment where the outcomes of patients with a PHB were compared to those of a similar group without a PHB.

The evaluation employed a range of quality of life measures and concluded that patients with a PHB had significantly better outcomes over a range of measures including improved care-related quality of life (ASCOT) and psychological wellbeing (GHQ 12), albeit at the lesser used 90% confidence interval. There was also some evidence to suggest that PHBs may be cost effective on a range of different measures. No improvements were found in health status, mortality rates or health-related quality of life.³ The UK Government used this evaluation to justify its support for PHBs.⁴

In this paper, we seek to examine why Forder et al.'s study produced the improved outcomes recorded and suggest that they may not be due solely to the use of PHBs. We argue that there is a danger that the wrong conclusions from the evaluation are being drawn and

that, far from endorsing that the policy improves outcomes, the evidence from the evaluation contradicts this view and, indeed, the conclusions of the evaluation team.

The evaluation team classified 19 of the 20 sites into four models based on three factors (one site was too small in the number of patients and idiosyncratic to allow classification):

- whether the person was told their budget 'up-front';
- how much flexibility was offered in service options; and
- how much flexibility was offered in managing the budget and whether a direct payment was an option.

The first of these criteria, knowing the budget before support planning, was seen as the essential cornerstone of the process. The 19 sites were divided as shown in Table 1.

The evaluation found that whilst there were significantly better outcomes for the people with a PHB compared to the control group amongst models 1, 2 and 4 (albeit only at the 90% confidence interval), this was not the case in relation to model 3, where it was found that the PHB 'had a negative' impact.^{2(p76)}

Overall, these findings led the evaluation team to conclude that '... possibly that it is the greater choice and flexibility that is more important than knowing the budget level'.^{2(p76)}

In their recommendations they declined to advocate any particular model, confining themselves to the following, 'That personal health budgets should be configured to give recipients choice and flexibility over how the budget can be used'.^{2(p158)}

This was a very complex intervention and the evaluation did take sufficient account of the differences in implementation within and across sites.

Model 4 did not offer an 'up-front' allocation, yet still achieved the better outcomes found in models 1 and 2. Conversely, model 3 did offer an up-front allocation. This suggests that an up-front allocation was not key to the improved outcomes.

There is even a question about whether those sites who claimed that they made the budget known before support planning actually did so. The PHB evaluation

Table 1. Models of PHB delivery compared in the national evaluation of PHBs.

Model 1	Budget known before support planning	8 sites – 390 people
Model 2	Budget known before support planning	4 sites – 283 people
Model 3	Budget known before support planning	3 sites – 206 people
Model 4	Budget not known before support planning	4 sites – 225 people

team did not test the extent to which the up-front allocations played a meaningful part in the process and anecdotal evidence they did gather suggests it may not have happened to the extent supposed. Fifty-eight service users with a PHB gave in-depth interviews at three months. This group were asked what they knew about their budget and ‘... only a minority knew how much their budget would be’.^{2(p162)}

On the basis of this evaluation, the Government’s endorsement of the policy appears to owe more to a commitment to a particular ideology than to the evidence, which not only fails to support their view but actually contradicts it.

The consequences of basing policy on such an erroneous view are two-fold:

- Damage to the service – especially as the process moves from well-resourced pilots to full roll out. In this respect, there are lessons for the NHS from the experience in social care;
- Failure to address the real challenges in delivering a model that will really bring about the agreed benefits of greater flexibility.

Lessons from social care and the roll out of self-directed support

There is a rapidly increasing body of evidence that shows that self-directed support in social care has created a very expensive bureaucracy to create an ‘up-front’ allocation, but which is so inaccurate as an estimate of how much people require as to be meaningless, whilst making no improvement to outcomes.⁵ Nearly all councils are using some form of resource allocation system (RAS) to create an up-front allocation and this has become the sole performance target of delivery of ‘personalization’. Guidance makes clear that the ‘up-front’ allocation should be as close as possible to what people require. However, recent research has shown that the creation of a RAS that produces reliable allocations before the costs of meeting the person’s needs is known is not achievable.^{6–8} Each of these studies, based on Freedom of Information requests (covering over 40 councils), compared the up-front allocation with what people actually received. In none of the councils surveyed could the relationship be said to be close.⁵

Whilst in theory allocations are made on the basis of a RAS, in practice resource allocation occurs *after* support planning and appears to be quite independent of the up-front allocation systems. This led Series and Clements to conclude that the RAS was ‘Like a cog spinning in a machine with which it does not engage’.^{6(p21)}

The accompanying rapid growth in bureaucracy in social care in the delivery of the RAS has made the situation even worse. Slasberg et al. showed that in the first four years of implementation staff levels increased by over 8% while the amount of work produced fell with a loss of productivity in the region of 20%.^{5(p10)} They conclude that far from being a model of good practice, self-directed support is actually damaging social care.

The real challenges in delivering PHBs successfully

The second deleterious consequence of pursuing a model that is not fit for purpose is that it will lead to a failure to address the real challenges that currently face the health services. There are a number of dimensions that have to be addressed if PHBs are to be effective for all. These include the relationship between the service and its users, the range of services on offer and the allocation of resources. These are discussed below.

A new relationship

The achievement of flexibility calls for the process to deliver PHBs to be re-envisioned and replaced with one that might be better described as flexibility through partnership. Table 2 shows a comparison of the two in relation to the key processes of resource allocation, balance of power between the person and practitioner, and how services are selected.

The evidence in relation to self-directed support in social care would suggest that the NHS is likely to save a great deal of time and resource if it makes an early decision to abandon up-front allocation.

Service range

The Audit Commission noted that roll out of PHBs will require ‘moving away from block contracts, unbundle tariffs, set local unit costs for services’.^{9(p16)} The currency for support planning would thus become *cash not services*. This would be true whether the person chooses supports unique to them or a costed share of services from the provider market.

This has enormous implications for the NHS market for, as Gadsby¹⁰ reports, 90% of funding for community services and two-thirds of funding for mental health services is provided under block contracts. The NHS would need to find a strategy to carry out large scale reconstruction whilst remaining true to the founding principles of the NHS and much of the available resources would have to be focussed on this task.

Table 2. Comparison of self-directed principles and flexibility through partnership.

	PHBs through upfront allocation	Flexibility through partnership
Resource allocation	Allocation happens up-front using a resource allocation system, modified after support planning	No up-front allocation is required
Power relationship	Power rests with the person, with the professional in a supporting role	Power is shared between the person and professional
Service selection	The person makes their own choices within parameters set by professionals	The person and professional bring respective expertise to create the best fit of services to needs

Allocation of resources

The Audit Commission report does not examine how the NHS will be able to control spending within an assessment regime which has the potential to expose it to an unknown level of need and to a level likely to exceed the available cash. It has, the potential to 'make financial aspects (and therefore rationing) of health and social care provision explicit'.^{10(p37)}

In making her case, Gadsby points to the experience of The Netherlands, where an early rush to PHBs had to be reined back when the cost consequences were realized: 'The Dutch experience demonstrates the difficulty of reconciling the open-ended character of personal budgets with inevitable budget ceilings'.^{10(p37)}

While there is a popular perception that the NHS provides a comprehensive health care service driven by clinical need, the reality is quite different. Currently, rationing takes place at two levels. Decisions are taken at a national level about which health care services will be made available and therefore what will not be available, what Rumbold et al.¹¹ term the 'benefit package'. At the individual level, clinicians also make decisions about what is and is not available, sometimes referred to as bedside rationing.¹² Clinical need is therefore a judgement made by a clinician about whether one of a range of available health services should be provided to the individual. Health services adopt a service centred approach to assessment of need in that it only recognizes needs for which there is an established service. PHBs derive from an approach to assessment that starts from the person's situation rather than eligibility for a service. Such approaches have been termed person-centred, in social care, as opposed to service-centred.

The represents a new challenge to the NHS and it will need to examine how such decisions will be made. It will need to do this in a way that ensures spending is within budget, resources allocated fairly and also in ways that will deliver best value for money. There is, as Russell et al.¹³ point out some appetite to make

clinical decision making more transparent. Social care also needs to find a better solution than it has hitherto employed to the same challenge and if a joint framework to support decision making in relation to resource allocation could be created, it would pave the way for meaningful pooling of health and social care budgets.

Level of resourcing

The evaluation did not address the significance of resource allocation in its recommendations, merely saying, under a section addressing 'Size of the budget', that a PHB should be offered to 'people with greater needs'.^{2(p160)}

Despite this, there is some evidence to suggest that the size of the budget may have been a factor in achieving better outcomes overall. The respective mean values of support packages were^{2(p87)}: PHBs £15,100; versus the control group £11,200.

To explain this differential, the report states: 'We can clearly infer that the people in the control group are healthier and have lower care needs than the PHB group',^{2(p88)} ascribing this large differential to bias in the selection process, which 'underlines the difficulty in selecting study participants for interventions, like PHBs, that are not "blind" and which are process oriented'.^{2(p88)}

There is, indeed, some evidence to support this view. Activities of daily living were assessed for each group at baseline and statistically significant differences were reported. They showed that, for example, 29% of the PHB group were unable to get up or down stairs compared to 22% of the control group; 14% of the PHB group were unable to get around indoors compared to 10% of the control group.^{2(p49)} Mortality was also greater in the PHB group.

However, it is not clear on what basis the evaluation team made the assumption that the differential was due solely to levels of need. There was other evidence in the report to challenge this assumption. As Gadsby points out 'It seems that in many cases, additional resources[in

the PHB group] were provided that enabled individuals to pay for extra services or one-off goods. It is perhaps unsurprising, therefore, that overall improvements were found in wellbeing amongst budget holders'.^{10(p13)}

The evaluation does acknowledge that those who were in receipt of a PHB were in the main satisfied with the level of services they received. Amongst those with a PHB that gave an in-depth interview, the report stated that, 'the majority appeared satisfied because the amount had allowed them access to the services or items they had felt they needed'.^{12(p76)}

This indicates the satisfaction owes as much to the level of support received as to the way that it was delivered.

Further evidence to support a view that the amount is important was found by The Audit Commission. It noted: 'Pilot sites have found that unmet needs will be identified in care/support planning'.^{9(p16)}

The pilot sites will almost certainly have met these needs, partly because they were funded projects, and partly because the NHS culture does not allow the service to acknowledge needs it does not go on to meet. These are needs that would not be revealed through the conventional processes that the control group would have experienced. Indeed, it was the uncovering of unmet need, with resultant expansion in spending, that led to the collapse of the policy in the Netherlands.¹⁴

There are therefore reasons to believe that the level of resource was a factor in the better outcomes achieved by the PHB group which the evaluation team may have too readily disregarded. It is certainly the case in social care that evidence is now emerging to show that where better outcomes occur, it coincides with significantly better resourcing of support plans, despite the fact that one of the early claims made for personal budgets was their ability to achieve better outcomes at lower cost.¹⁵

Woolham and Benton¹⁶ compared a cohort of social care personal budget holders with a control group within a large Shire County. They found that personal budget holders of working age had significantly better outcomes than a control group. At the same time, the personal budget holders enjoyed 44% more resource than the control group. Slasberg et al.⁷ have shown that an impression that personal budgets bring about better outcomes has been created by showcasing the success of the small number of people able to take a direct (cash) payment (using 1996 legislation that predates the self-directed support strategy by a decade) and attributing their success to the personal budget process. A national survey of 2000 personal budget holders found that a large majority reported better outcomes. However, the sample consisted of over 90% with a direct payment. At that time, only 7.7% of

older and disabled people had a direct payment nationally, thereby making the sample grossly unrepresentative. Significantly, while only 7.7% of service users had a direct payment, they commanded 13.7% of the relevant budget.

Conclusions

There is no dispute that 'personalization' of health care – whereby the patient is offered the services best placed to meet their unique needs – is an appropriate policy objective and one that is consistent with the founding principles of the NHS. Increasing patient expectations, along with the need to get best value from scarce resources, demand it. There is a legitimate concern that the NHS places too little emphasis on matching service responses to individual need for people with continuing health needs. It too often commits its resources to pre-purchased services which too often operate in paternalistic ways. However, there has been unease expressed as to whether the personal budget idea is the right approach to address this challenge. At the outset of the PHB pilots, Beresford¹⁷ noted that little attention had been 'paid to the broader issues of principles, values and philosophy that are raised by the extension of personal budgets to the NHS'. The NHS is a universalist service, free at the point of delivery and it is hard to see how this can be reconciled with the values that apply to a means tested, non-universalist system such as social care.

The evidence and argument in this paper point to the challenges of personalizing NHS services being complex if it is to also deliver on a key principle of the NHS which is availability to all. This is reflected in a report by the Nuffield Trust which, whilst uncritical of the self-directed support ideology supposed to have underpinned the pilots, nonetheless notes the NHS had not resolved some key issues.¹⁸ These included how to decide how much resource to give people and how to create a new market for personal support.

The notion of an 'up-front' sum of money to allow the person to make their own support plan is very attractive to politicians, fitting current rhetoric about consumer power and carrying no cost implications. However, it is a simplistic strategy and wholly inadequate for the task. It cannot change the prevailing system and will only allow a few to achieve their own personalized system of support. If government is serious in its wish to personalize NHS support to all people with continuing health needs whilst remaining true to the principles of the NHS, it has to address the challenges of fundamental change of the prevailing system. A new model, one that will deliver flexibility through partnership between the person and the service, is called for.

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