



Personal Health Budgets – Should Patients Be Able to Manage their Care in a Way that Suits Them? A Concise Narrative Review

ABSTRACT

RESEARCH OBJECTIVE: The aim of this concise review is to both demonstrate the pros and cons in regards to personal health budgets (PHBs), as well as critically evaluate their performance and possibilities. Another purpose of this paper is to familiarize the wider public with the concept of PHBs.

THE RESEARCH PROBLEM AND METHODS: The reason behind introducing PHBs and direct payments was to bring social care and long-term healthcare “closer” to the patients in order to personalize treatment and support. By “personalization” we understand the possibility of choosing services that best meet the unique and individual needs of a specific person. However, the tempting concept of PHBs carries with itself both pros and cons. This qualitative, comprehensive narrative review brings to light the current state of knowledge and different parties’ opinions on PHBs.

THE PROCESS OF ARGUMENTATION: A PHB is an allocation of public/private financial resources used to identify and meet the health-related needs of a specific person. Such a resolution should potentially lead to new and innovative ways of spending the available funds, outside what traditional services offer, in order to personalize healthcare, increase its effectivity, and decrease the cost/benefit ratio. However, PHB’s are not all-inclusive but cater to needs easily overlooked in the traditional healthcare system.

RESEARCH RESULTS: The described PHB organization combines the best available clinical experience with the cumulated health- and care-related experience of the patients. This way both long-term and new short-term needs can be addressed and the intervention that has begun can last as long as the patient needs it.

CONCLUSIONS, INNOVATIONS AND RECOMMENDATIONS: The healthcare system faces difficult times, and PHBs may be a potential solution to at least a part of the problems. The only question is will they be implemented correctly

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becoming a positive driver of change or will they become the anchor that pulls down a sinking ship?

→ **KEYWORDS:** **PERSONALIZED MEDICINE, PERSONAL HEALTH BUDGETS, COST EFFECTIVENESS, SOCIAL CARE**

Introduction

The reason behind introducing personal health budgets (PHBs) (more information available under www.personalhealthbudgets.england.nhs.uk) and direct payments was to bring social care and long-term healthcare “closer” to the patients in order to personalize the treatment and support the patients were receiving. By “personalization” we understand the possibility of choosing services that best meet the unique and individual needs of a specific person.

While in social care this concept has been about for several years, in healthcare in 2012 a pilot-study was introduced in England to test the effectiveness of PHBs (Department of Health, 2012). Since October 2014 all patients who are eligible for continuing healthcare have the right to own a PHB – currently this totals approximately 56 thousand people. The UK government has extended PHBs for long-term conditions, including mental health, from April 2015.

What is true is that many clinicians do not know about the existence or possibilities that PHBs carry with themselves. However, we have to remember that, where there are possibilities there are also limitations.

The aim of this qualitative, comprehensive review is to both demonstrate the pros and cons in regards to PHBs as well as critically evaluate their performance and possibilities. Another purpose of this paper is to familiarize the wider public with the concept of PHBs.

What is a personal health budget (PHB)?

A PHB is an allocation of public/private (in the case currently described – public) financial resources that is meant to be used to identify and meet the health-related needs of a specific person. Such a resolution should potentially lead to new and innovative ways of spending the available funds, outside what traditional services offer, in order to personalize healthcare, increase its effectivity, and decrease the cost/benefit ratio (Understanding PHB's, 2012). Personal health budgets are not

only used to finance health-related services such as traditional therapies (medications), nursing and physiotherapy care but also social services such as social assistance in shopping, preparing meals, home assistance (ex. cleaning), and services that increase one's well-being such as extracurricular activities – sports, art, cinema, theater etc.

The above does not mean that a patient can spend his or hers PHB funds on whatever he or she pleases. Certain goods and services are excluded from this list, as well as there are some core services that are still only covered by the country's health system – such as emergency care, family medicine, in-patient (hospital) care, and refundable pharmaceuticals (Understanding PHB's, 2012). Thus PHB's are not all-inclusive in terms of the services offered but cater to needs that can be easily overlooked in the traditional healthcare system.

The described PHB organization aims to combine the best available clinical experience of health-care professionals with the cumulated health- and care-related experience of the patients. This way both long-term and new short-term needs can be addressed the moment they arise, and the intervention that has begun can last as long as the patient needs it. In this light PHBs have a lot in common with other, already existing, models of care such as shared decision-making or the house of care model (Coulter, Roberts, & Dixon, 2013).

Of course the PHB is not a “free-for-all” service – at its center is a detailed care plan which is developed in consensus between the individual patient, an experienced clinical team (consisting of physicians, nurses, physiotherapists and social workers), and the national/regional health care provider who finances the PHB and controls the balance of a PHB. It is up to the individual to decide to what extent would he/she like to manage his/hers PHB and how much financial responsibility would he or she would like to tackle.

Evidence supporting the use of personal health budgets

The “PHB idea” already has some evidence to back up its introduction. In chosen medical disciplines (this review takes psychiatry as an example due to its wider links with social care), while the preliminary data is positive, it is also limited in its scope and not adequate to fully inform policy and practice (Webber et al., 2014). However in different fields of health care there is enough “hard” data available to support the wider roll-out of PHBs into everyday practice. In the UK (Forder, 2012) the national health budget evaluation study was based on a 3-year longitudinal observation “conducted by the Personal Social Services Research Unit (PSSRU), involving

a total of just over 2000 people across treatment and control groups and a mixed-methods design with randomization in some, but not all, local areas” (Alakeson, 2016). The results of this trial showed that overall patients deciding to divert a part of their health care finances to a PHB had higher health-related quality-of-life and level of psychological well-being than those individuals deciding to rely on the standard model of care. As to costs, it came to light that for patients requiring long-term care there was an evident cost benefit, making the PHBs in such cases very cost-effective. However, in the case of other illnesses the study was not able to produce conclusive results due to the small sample sizes of the different patient subgroups. The cost-effectiveness of PHBs mostly stemmed from the fact that patients basing their health care in part on PHBs had lower indirect costs due to using less often emergency and primary care services. This leads to the conclusion that PHBs provide greater net benefit in comparison to conventional services. The data to back this up showed that for patients using PHBs the overall costs at follow-up demonstrated a 12% decrease, while for the conventional treatment (control) group this was an 8% increase in costs. What is also interesting is that the less restrictive the PHB was the more cost benefit was attained. Comparing two groups – one where the patients were able to choose freely how their PHB was spent and the other with more national health payer introduced restrictions, the study found that the first group had significantly better overall outcomes. At the same time the most restrictive PHB models tested produced results worse than those obtained by the “standard treatment” group.

Data supporting the use of PHBs flows not only from the UK. In the US several studies have also found that introducing PHBs brings positive changes into the health care system, and for the patients themselves (Dieleman et al., 2016).

As in regards to every subject there is strong division whether PHBs carry with themselves more opportunities or threats. As with every solution – it is a mix of both. The following paragraphs will present some of the situations that will have to be addressed before a wider roll-out of PHBs is possible.

The balance between the individual choice of the patient and the potential risk

Allowing patients to use their PHBs in the way they see fit, no doubt empowers them and makes them feel more in control of their illness and lives. It also motivates individuals to engage more in their own care, often

changing their stance from passive to active in the course of their treatment. We have to remember that the patient has to play a crucial role in the development of a PHB in order for the latter to be successful – both in terms of individual patient health care as well as for the system. The act of planning a PHB brings together the patient and a multidisciplinary team of experts. This meeting should result (and often results) in developing or increasing the partnership between an individual and the health care professionals, as well as motivate the patient to identify the risks connected with the disease and its treatment, and how to manage the disease safely to achieve the best outcome possible. Luckily (and this has to remain a must) each PHB has to be approved by an experienced clinician who took part in the process of PHB planning, and will only signed off on a final PHB if it fully addresses the risks and identifies contingencies.

An important problem develops when the patients start making different choices than those the clinicians would make in regards to their care. For example a PHB will allow a patient to use alternative medicine products, even though their effects may be totally unproven, without any scientific data to back up their effectiveness. However, the alternative/complimentary medicine industry has a powerful lobby, and strong (even aggressive) marketing strategies, which often lead the patients into believing that alternative medicine products actually work and can be used for effective treatment. Introducing such elements into a correctly prepared treatment plan will almost certainly increase the patient health problems and put him/her at an increased risk of harmful side-effects. On one side the patient can argue that he sees alternative medicine treatment as a way to not only impact his physical but also psychological well-being (referring to the placebo effect), on the other hand approving the existence of such elements in a PHB stands in opposition to what physicians should believe in. When there is no hard data to back up a treatment option (we live in an era of evidence-based medicine but also post-truth) (Brown, 2016) or no quality assurance to make certain that a substance will not be harmful in the long-term or will not lead to the patients stopping effective treatment due to the placebo effect, such PHB elements should be strongly avoided, and patients should be actively discouraged from their use.

Personal health budgets and evidence-based medicine

As PHBs, in some part, can be spent in any way the patient desires, as long as he or she can argue that the specific purchase is connected with his/hers well-being or healthcare, there is a looming threat (or is it an

opportunity?) that financial resources will be spent in a way that does not stand in line with our current understanding of evidence-based medicine (EBM). The patients are not restricted in their choices by any EBM guidelines. On one side this is a large opportunity to move away from the traditional system and provide the patients with the flexibility necessary to respond to each individual's needs rather than expecting them to fit into the form (treatment) that the current system provides. Such an approach brings us ever closer to the concept of personalized medicine – not only at a genomic level but also on the social/psychological level (Juengst et al., 2016). It is often those differences, that deviate from EBM that allow and/or are crucial to a patient's recovery. Such an approach is especially valuable for patients who have exhausted all EBM approved or experience-based means of treatment and did not achieve a favorable treatment outcome. Without being able to use their PHBs to look for further treatment, these patients would otherwise stop treatment at all. There is literature evidence that patients who are heavily engaged in managing their long-term health problems achieve better outcomes. This self-engagement is exactly what PHBs can and should foster and facilitate (Epstein et al., 2010).

Unfortunately there is also the “flip side of the coin” to this story. There is always a risk that deviating from EBM guidelines, which have a massive amount of data behind them, will lead to poor allocation or misallocation of the system's financial resources which, in the best case, will end up not helpful, and in the worst case scenario – harmful (O'Shea & Bindman, 2016). The burden of correct allocation of PHB funds still rests on the shoulders of clinicians which help to negotiate and approve PHBs (O'Dowd, 2016). It is up to their best clinical experience whether they think that alternative medicines or a weekend at the spa can actually benefit the specific patient. A question remains to be posed – are the clinicians that we train today able to correctly assess such needs or do we need to reshape the medical education system as well, to make it go in pair with the restructuring of the healthcare system? Whatever the answer, these new challenges will no doubt have a large impact on future patient-physician relations, and it is this moment (and the way in which we introduce the changes) when we are slowly introducing PHBs that will determine those relations for the years to come.

Patient's individual choice versus efficiency and cost

The main goal of PHBs is to maximize the efficiency of care (not so much to minimize the costs) – meaning that each individual receives the

best potential care he needs, rather than trying to deliver the same care for everyone. This might stem question whether gender, ethnicity or age will have a negative impact on the use and availability of PHBs. However the pilot-test study run in the UK did not confirm such worries (Department of Health, 2012). The concept behind PHBs allows to leave the decision-making to either the patient, his family (in cases when the patient is not able to plan for himself) or on the contrary – protect the patient from potentially harmful plans of the family. In cases when the patient suffers from a disease that has a fluctuating course, the PHB can also be prepared to work on a pre-planned basis depending on the patient's state. In cases where there are valid concerns that the family will try to exploit a patient's PHB, third parties are also allowed to supervise such a PHB. We have to remember that a PHB is heavily supervised both by clinicians and government authorities, making it impossible to construct a PHB that would not be in the best interest of the patient. However, doubts always remain as some policy makers question whether patients with PHB's actually receive the best available care (Wise, 2016). Some authors even question the validity of evidence on which the concept of PHB's is based, arguing that a large portion of the available body of knowledge is outdated and no longer functional in the modern society (Limb, 2016). An interesting prospective pilot study has been carried out in the NHS in 2009 (Jones et al., 2013) to ass whether PHBs have an impact on outcomes and costs. One thousand "PHB" patients were compared with a control group of 1000 "non-PHB" NHS patients over a period of 12 months. The study showed that the use of PHBs was associated with significant improvement in patients' care-related quality of life and psychological well-being. The use of PHBs had no impact on health status, mortality rates, health-related quality of life or costs. The main finding from the study was that PHBs were only cost-effective in terms of care-related quality of life. However, this was enough to support a wider roll-out of PHBs in the NHS, providing the samples from the study were representative of the overall UK patient community.

As with every entitlement there is a risk that patients and their families start perceiving PHBs as a long-term source of income for their home budget. This way a false sense of dependency may develop, while in fact PHBs should be viewed as a support tool to facilitate coming back to health, and with the return to health minimize the support from the PHB. There is also a justified risk that when patients start managing their PHBs in a different way than the system has planned or has allocated funds before, some healthcare services may end up not being funded, as patients will chose to go elsewhere/use different services. The problem will

not be major if all patients decide to move away from a specific service. The problem will start when those patients that overall feel better will move away from a service, thus reducing funding to it, while the more dependable patients will stay but will not contribute enough funds in order to sustain the existence of such a service. This will create a problem that the less privileged or sicker will end up not being able to receive the service they need (O'Shea & Bindman, 2016).

Chance for prevention or risk of spending resources and returning to the system?

First we have to recognize that in the current system, when a patient spends all his financial resources available on his PHB, he will still not be denied care in the public system. This is of course the humane approach. Some economists would argue that this opens the "flood gates" for the financial resources to escape the system through poorly supervised PHBs (Iacobucci, 2015). That is why it is paramount for the PHBs to be closely supervised by clinicians within the system, as well as external experts which monitor the system and its finances from the outside, and importantly, not from the view of a physician but rather an administration officer.

Of course, through the ideas behind PHBs, patients are able to better steer their care and thus potentially avoid unnecessary hospitalizations or emergency department visits. This is again supported by the results of the pilot study performed in the UK, which showed that patients utilizing their PHBs in a correct manner, less often require in-patient and emergency care (Department of Health, 2012). However with the PHB approach there is always the risk that those patients that make poor choices in regards to their care may end up spending all the resources that are available to them, and at the same time not meeting any (or meeting only partially) of their health needs. This once again underlines the importance of close monitoring of PHBs, both by the clinicians and the system. However, with the vast amount of monitoring planned we have to ask ourselves what will be the costs incurred by the system in regards to all the capacity needed to correctly and constantly monitor the use of PHBs?

Personal health budgets – more bureaucracy and documentation or more time for the clinicians to focus on the patients?

Taking into consideration what has been written above, regarding the amount of oversight needed for the correct functioning of PHBs, as well as the fact that there exist studies showing that PHBs may come with the addition of very complex bureaucratic processes, and additional costs (Slasberg et al., 2014), we have to consider if PHBs will not overburden clinicians and force them to devote their time to documentation rather than the patients. There are of course ways to solve or avoid this problem. Firstly, the infrastructure (both clinical and administrative) should be prepared before introducing PHBs on a wider scale. Secondly, additional administrative personnel should be hired and introduced to the system to correctly steer patients and their PHBs. At this point it could be argued that it should not be the clinicians who will supervise PHBs but rather trained administrative personnel with adequate qualifications, receiving periodical input, as well as current situation assessment, from the clinician. This way we could free at least part of the clinicians time which could be devoted strictly to patient care. The question is, whether in the case where we hire additional personnel, thus leading to additional system cost – do we actually need PHBs? Maybe it would just be easier to hire additional personnel to staff the current system and allow the physicians to spend more time with their patients, thus having the time to better explain them the nature of the disease, planning and executing their short-term care or planning long-term care? Such an approach could still provide the patients with a considerable amount of freedom in choosing the type of care they are interested in (due to the physician having enough time to walk the patient through all the available treatment options) while at the same time providing the much needed oversight and close control of patient health-care related spendings.

Conclusions

As with every novel solution, PHBs carry with themselves potential benefits and risks – both in regards to the patients and the system. If properly implemented and closely monitored they allow for higher quality, better tailored care for patients with long-term illnesses, as well as flexibility and choice, thus empowering the patient in the very positive sense of this word. If executed properly, PHBs may increase the quality

of care and potentially lower the costs incurred by the healthcare system. However PHBs also carry with themselves a number of risks, some of them very significant like the outflow of funding from some health services which may still be needed by a minority of patients not able to self-sustain a service. They may also end up costing the system a lot more than the current budget allows, through poor patient choices.

In order to successfully implement PHBs there has to first be a clear set of implementation guidelines, appropriate infrastructure has to be prepared beforehand, and the personnel that is to run and supervise PHBs has to be adequately trained.

This comprehensive review pinpoints the main questions that will need to be addressed before a wider roll out of PHBs will be possible. They can hopefully serve as a basis for constructing future quantitative, prospective studies, necessary to build a solid knowledgebase for the practical implementation of PHBs.

The healthcare system, as always, faces difficult times, and PHBs may be a potential solution to at least a part of the existing problems. The only question is will they be implemented correctly, becoming a positive driver of change or will they become the anchor that pulls down a sinking ship?

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