

Personal Health Budgets

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Summary of overall position

The RCGP believes strongly in the importance of personalised care and shared decision making to deliver better patient outcomes. Personal health budgets are one of a variety of tools that may have the potential, under the right circumstances, to help realise these benefits for some patients. In particular, personal health budgets may provide patients with the opportunity to access different services that are better suited to their needs, and act as a stimulus for shared decision making and an increased focus on care planning.

At the same time, the implementation of personal health budgets poses a number of challenges that the government in England, to date, has yet adequately to address. Key issues include:

- achieving the appropriate balance of responsibilities for ensuring the clinical effectiveness and quality of services purchased
- managing the impact of the introduction of personal health budgets on Clinical Commissioning Group (CCG) costs and on the financial sustainability of existing NHS services
- setting appropriate budgets in line with the principle of the provision of comprehensive health services on the basis of clinical need, free at the point of use
- ensuring that personal health budgets do not give rise to new health inequalities.

Before proceeding with the roll-out of personal health budgets in England, the government should allow the opportunity for the outcomes from the pilot sites to be fully evaluated and discussed, and for conclusions concerning the implications for future policy to be drawn. More detail is also needed of the policy framework that the government intends to put in place for personal health budgets – how will it be designed to maximise the benefits to patients, while mitigating the main areas of risk? There are many variables for patients and their personal and professional carers to consider, and the College would wish to see these fully explored in further proposals. We would also like to be involved in the further development of the policy and its formal and systematic evaluation.

Recommendations

The RCGP considers that in developing the policy of personal health budgets the following recommendations should be taken into account:

- roll-out in England should not be commenced until a thorough analysis of the risks and benefits of personal health budgets can be carried out, based on a full evaluation of the pilot sites
- patients should be asked to agree the outcomes of their care plan and the way in which their budget will be utilised to support these, with key carers also being kept informed, subject to normal procedures for patient consent
- GPs should review all personal health budget plans and ensure that their patients are fully informed of the potential risks and benefits
- commissioners must put in place sufficient resources to support the additional up-front time investment required to support the care planning process, and to ensure that patients receive the assistance they need with managing their budgets and making arrangements to purchase care
- the National Commissioning Board should consult on the development of a national personal health budget methodology, drawing on the experience gained from the pilots. This must be unambiguously based on the principle of the provision of services according to health need, free at the point of use
- there must be nationally set rules that make clear that the budget amount allocated must be sufficient to meet in full the cost of the services identified in an individual's care plan as being necessary. The current policy against permitting individuals to top up personal health budgets out of their own private resources should remain
- each CCG should have a clearly defined set of criteria for taking decisions on what treatments and services can be included within a personal health budget
- service areas that will not be included in any future roll-out of personal health budgets should be clarified. These areas should include the current exclusion of general practice and emergency care, as well as medication and elective care
- CCGs should have the flexibility to refuse direct payments where objective grounds exist for doing so. For those patients that do receive direct payments, adequate processes must be put in place to ensure this works successfully
- the government should consider requiring that, for service areas where national tariffs exist, all providers of services bought using personal health budgets adhere to these
- commissioners should require that, where regulated activities are funded through a personal health budget, the provider should be obliged to share relevant information with the patient's GP, so that their healthcare record can be kept up to date.

2 Introduction

A personal health budget is an amount of money that is allocated to a patient to allow him or her more choice, flexibility and control over the care that he or she receives.^{1,2} The budget is intended to cover the individual's health needs within the context of a care plan to achieve agreed health outcomes.

In England, personal health budgets are being rolled out from October 2012, initially for patients eligible to receive NHS Continuing Healthcare.¹ The government has committed to giving all such patients the right to ask for a personal health budget by April 2014. To help prepare GPs for this, the RCGP will shortly be producing a guide, which will be available on the RCGP website.

Since April 2009, the government has funded personal health budget pilots across 64 sites in England, covering NHS continuing care, stroke, mental ill health and care for long-term conditions such as chronic obstructive pulmonary disease (COPD) and diabetes.³ An evaluation of 20 pilots is being undertaken, with the final report expected in October 2012. This position statement draws on the evidence available so far from the pilots and other sources to set out the RCGP's policy position on personal health budgets and their implementation.

¹ See www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103161.pdf for a full definition.

3 The potential benefits of personal health budgets

Personalisation is a key dimension of the quality of care. It is strongly associated with better patient outcomes and experience,^{4,5} and is rooted in the same values of holism and patient centredness as general practice.

Personal health budgets are one of the tools through which, for some patients, the benefits of personalisation can be realised. In particular, they have the potential to:

- act as a stimulus for increased care planning, with its focus on outcomes and its emphasis on shared decision making⁶
- provide new opportunities for patients to access different types of help better tailored to their needs – for example activities such as exercise classes aimed at preventing ill health, non-traditional treatments, and services provided by the voluntary sector
- empower patients, giving them the ability to exercise greater control and flexibility over who provides their care and when – for example by employing their own personal assistants/carers⁶
- allow greater integration of care around patient needs and across the boundary between health and social care, especially for patients with complex and multiple conditions.

However, it must be stressed that, at present, evidence for the benefits of the introduction of personal health budgets remains limited, with much of it deriving from other healthcare systems such as the US or from the social care field. In particular, while there is reasonably good evidence that personal health budgets are associated with increased patient satisfaction and empowerment, the evidence for a direct positive impact on health outcomes is currently sparse.²

4 Risks and challenges

The main areas of risk and challenge posed by the proposed introduction of personal health budgets are as follows:

Clinical effectiveness

Personal health budgets provide patients with the flexibility to exercise greater choice over not only how and by whom their treatment is provided, but also the type of treatment they receive. As such, they have the potential to allow patients to access treatments not traditionally provided by the NHS, the clinical effectiveness of which may not have been established, or which may even have been disproven.

The RCGP accepts that certain treatments traditionally prescribed by the NHS do not work for some individuals and that, conversely, some treatments not traditionally prescribed by the NHS may be effective in improving health outcomes in certain cases. In addition, personal health budgets may be used to fund care that, although it can be clearly linked to improved health and wellbeing, has not in the past been available through the NHS due to being classified as social care.

Set against this, there is a risk that funds allocated to patients through personal health budgets will be spent in ways that do not turn out to be effective in improving their health outcomes. At worst, and without proper safeguards, this could lead to patients switching from current treatments, experiencing deterioration in their health or suffering actual harm. In an environment where the NHS is under considerable financial pressure, it is also important to ensure that scarce resources are used in a way that maximises effectiveness in achieving improved health outcomes.

Cost escalation and workload implications

While the personal health budget pilots in England received some additional funding, the government has made clear that there will be no extra funding to support the roll-out of personal health budgets nationally. Despite this, there are real risks that the introduction of personal health budgets could generate additional costs, of both a one-off and recurrent nature.

One very important unknown is the impact that personal health budgets will have on overall levels of demand, if patients who previously were not in receipt of NHS-funded services take up the offer of a personal health budget. The Netherlands experienced a tenfold increase in the demand for personal health budgets, from 13,000 to 130,000 between 2002 and 2010,⁷ which led to temporary closure of the scheme to new applicants and restrictions on eligibility. Although the scheme in England is not about new money, but rather spending money on health care in a different way, increased demand could still occur. For example, individuals who previously relied on informal carers for support,⁸ or who paid privately for certain treatments, could opt to meet these needs through a personal health budget instead.

Evidence from social care suggests that the use of personal health budgets can be expected to lead to additional administrative and support costs, associated with the need for more detailed care planning, brokerage and monitoring.⁹ In its impact assessment for the personal health budget pilots in England, the government expressed a hope that these costs would be offset by savings from the optimisation of care facilitated by the introduction of personal health budgets, for example due to a shift in resources towards prevention, and lower levels of hospitalisation.¹⁰ However, at this stage these predicted savings remain highly uncertain, and may be realised elsewhere in the healthcare system. In addition, the care planning aspect of personal health budgets will give rise to an upfront increase in GP workload, for example in signing off care plans. Nevertheless, this may be offset over time if the process results in better self-management and a less frequent need for GP visits.¹¹

Finally, the move away from traditional NHS services towards a greater multiplicity of providers may have the effect of creating additional costs, both for individual budget holders and for the NHS as a whole. Potential drivers of this include:

- double running costs, due to commissioners being unable to release money from existing long-term contracts
- reduced scope for providers to drive down costs by realising economies of scale
- less power in the market, as the procurement of services is fragmented between multiple purchasers.⁸

Quality and availability of services

GPs and commissioners cannot guarantee the quality of services provided through personal health budgets, and patients may not have the knowledge to judge good-quality services from poor-quality services. Although some service providers may be registered with the Care Quality Commission (CQC), where a patient uses an individual budget to arrange his or her own personal or nursing care without agency involvement, this service is exempt from the requirements for CQC registration. In addition, most complementary and alternative therapies are outside the scope of CQC regulation.

There is also a risk that the move away from planned provision towards a free market-led approach may jeopardise the continued survival of certain services if too many users switch. Most vulnerable to this are specialist services that rely on minimum numbers of patients – for example in the case of motor neurone disease.

Increased inequality

Alongside increased choice and empowerment, personal health budgets also have the effect of shifting responsibility and risk from the NHS and on to the individual.⁶ Without appropriate support, there is a danger that some groups of patients may prove less able than others to cope with this, potentially leading to increased inequalities. This is particularly likely to be an issue for older people,⁹ those who are more vulnerable, and for patients with direct payments.

The introduction of personal health budgets may also lead to increased scope for the emergence of postcode lotteries between different areas. This could arise, for example, as a result of differences in the budget-setting methodologies adopted, or in decisions taken regarding what treatments and services personal health budgets can be used to purchase. Patients could also be disadvantaged if their budget runs out prior to the end of its allocated span, for instance because their needs have changed, or simply because of the inherent difficulties of establishing a budget formula that accurately reflects need. This risk is likely to be greatest for patients who are least inclined or able to argue the case for their budget to be increased.

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Recommendations

As stated above, the RCGP believes that full and systematic evaluation of the potential risks and benefits of personal health budgets is required before the government goes ahead with their implementation. If personal health budgets are rolled out, the RCGP considers that this must be done in a way that reflects the following recommendations.

The care planning process

It is essential that the policy framework for personal health budgets is firmly rooted in the adoption of a care planning approach. There is strong evidence to suggest that care planning leads to better quality of life and improved health outcomes for patients, and more cost-effective use of healthcare resources.¹¹

Crucial to successful care planning is collaborative working between patients and healthcare professionals to set person-centred goals, review outcomes and plan care on an ongoing basis. This process must form the context for decisions about how personal health budgets are spent, with patients being asked to agree the outcomes of their care plan and the way in which their budget should be utilised to support these. Key carers should also be made aware of the contents and outcomes of patients' care plans subject to normal procedures for patient consent.

The role of GPs is crucial in the development of care plans, providing a clinical perspective to inform the assessment of patients' health needs and the evaluation of their health outcomes. This is particularly important for patients with multi-morbidities, where GPs' generalist expertise is required to manage the potential interaction between different diseases and treatments.

In the pilot schemes, individual care plans have been put together by the patient in conjunction with specially trained care brokers, specialist nurses, or with help from the voluntary sector. In addition, GPs should review all personal health budget plans and ensure that their patients are fully informed of the potential risks and benefits. Commissioners must put in place sufficient resources to support the care planning process, and to ensure that patients receive the assistance they need with managing their budgets and making arrangements to purchase care. Improving links with the voluntary sector is an important part of this, as voluntary agencies, in particular those with a specialist health focus, are well informed to signpost patients to locally available services.

Budget setting

One of the most critical issues concerning personal health budgets is how the amount of the budget is set. Different approaches are being evaluated as part of the personal health budget pilots in England, but at the time of writing the government is yet to announce how it intends to proceed.

The RCGP considers that the methodology for setting personal health budgets should be unambiguously based on the principle of the provision of services according to health need, free at the point of use. There must be nationally set rules that make clear that the budget amount allocated must be sufficient to meet in full the cost of the services identified in an individual's care plan as being necessary. In all cases, patients must be told how much their personal health budget is, how the figure has been arrived at, and how to request that it is reviewed. In cases where money runs out, patients should be referred to a local panel, administered by the CCG, in order to ensure that their health needs continue to be met. The current policy that rules out the use of private means to top up personal health budgets should also remain.

To assist commissioners, the RCGP recommends that the National Commissioning Board consults on the development of a national personal health budget methodology, drawing on the experience gained from the pilots. This should aim to eliminate unwarranted variation in approach, while enabling commissioners to reflect legitimate differences, such as in the cost of labour. It should also be capable of predicting the costs not just of patients with single diseases, but crucially also those suffering from multi-morbidity.

On what should it be possible to spend personal health budgets?

In most of the personal health budget pilots, local assessment panels have been established to take decisions on what kind of treatments personal health budgets can be used for. In practice, different approaches to this task seem to have been adopted in different areas, with some panels adopting a more 'permissive' philosophy than others.

It is important that each CCG has a clearly defined set of criteria for taking decisions on what treatments and services can be included within a personal health budget. These must be clearly understood by patients, clinicians and brokers alike, and there should be an established process for resolving disputes concerning their application. Possible criteria include:

- proposed treatments and activities must be clearly linked to the health outcomes set out in the patient's care plan
- while approval should not be withheld on the grounds that there is no evidence of clinical effectiveness, there should be reason to believe that the proposed treatment or service could be beneficial to the health of the individual concerned
- approval should not be given to services or treatments where there is evidence to suggest that they will be harmful to the patient
- personal health budgets should not be used to pay for treatments that the NHS would not normally fund because a decision has been taken by NICE or an

equivalent body that they are not a cost-effective use of NHS resources.

Early indications from the pilots are that the vast majority of services and treatments being funded from personal health budgets are things that would normally be funded by the NHS, but that are being delivered by different providers or in different ways. So long as providers of such services or treatments comply with the appropriate legal and regulatory requirements, the expectation is that the choice of provider should not normally constitute a reason for the contents of a care plan to be rejected.

The RCGP strongly supports the government's exclusion of general practice and emergency care from the scope of personal health budgets. However, the pilot evaluation has highlighted a degree of confusion as to whether certain other services, such as medication and elective care, can be included within the ambit of personal health budgets. It is our view that this could be complex and risky, while offering little in the way of practical benefit. The RCGP accordingly calls on the government to clarify that these areas will not be included in any future roll-out of personal health budgets.

The use of direct payments

While direct payments can offer benefits to some patients, it is important to recognise that they will not suit everyone. Patients should be offered the opportunity to opt for a nominal budget or third-party arrangement if they prefer.

Direct payments transfer control of expenditure from the NHS into the hands of the patient. Because of this, there may be some patients for whom direct payments are not appropriate, for example if there is good reason to believe that they will not adhere to what has been agreed through their care plan. Consequently, the RCGP recommends that, as has been the case with the personal health budget pilots, CCGs should have the flexibility to refuse direct payments where objective grounds exist for doing so.

For those patients that do receive their personal health budget via direct payments, it is vital that adequate support systems are put in place to ensure that the process works successfully.

Creating the right consumer and regulatory frameworks

Patients and healthcare professionals need to be able to access information about services that can be purchased using personal health budgets. Commissioners should take steps to provide reliable and up-to-date information concerning the different types of treatment and activity that patients might want to consider, and the range of different providers available. In addition, where the evidence base concerning the effectiveness of particular treatments and activities is currently inconclusive, opportunities should be sought to conduct research into their health outcomes, in order to provide a better basis for future decision making.

Commissioners should carefully monitor the impact of the introduction of personal health budgets on existing NHS providers who may lose patients as a result, and should be prepared to take action to protect the continued availability of key services if necessary. They should also seek to encourage the development by providers of new, clinically appropriate healthcare services, in order to cater more effectively to the diverse needs of personal health budget users.

Personal health budgets potentially offer providers a means of circumventing national tariffs, whether by increasing their prices above the tariff level or by engaging in price competition at the expense of quality. This will become increasingly relevant as the tariff system is extended to cover community health services in England. In order to avoid such behaviour, the RCGP recommends that the government gives serious consideration to requiring that, for service areas where national tariffs exist, all providers of services bought using personal health budgets adhere to these. Furthermore, in order to promote integrated care, commissioners should require that, where regulated healthcare activities are funded through a personal health budget, the provider should be obliged (subject to the patient's consent) to share relevant information with the patient's GP, so that the patient's healthcare record can be kept up to date.

References

- 1** Personal health budgets, www.dh.gov.uk/health/category/policy-areas/nhs/personal-budgets/.
- 2** Health Foundation. *Personal Health Budgets: research scan*. London: Health Foundation, 2010.
- 3** Department of Health. Personal health budgets pilot programme site list, www.personalhealthbudgets.dh.gov.uk/_library/Resources/Personalhealthbudgets/2012/PHB_pilot_site_summary_sheet_Jan_12.pdf.
- 4** Hibbard J, Stockard J, Mahoney E, *et al*. Development of the Patient Activation Measure (PAM): conceptualising and measuring activation in patients and consumers. *Health Service Research* 2004; **39(4)**: 1005–26.
- 5** Alakeson V. *Active Patient: the case for self-direction in healthcare*. The Centre for Welfare Reform/University of Birmingham, Health Services Management Centre, 2011, www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/active-patient-paper.pdf.
- 6** Irvine A, Davidson J, Glendinning C, *et al*. *Personal Health Budgets: early experiences of budget holders: fourth interim report*. London: DH, 2011.
- 7** Health Foundation. *Improvement in Practice: the personal touch. The Dutch experience of personal health budgets*. London: Health Foundation, 2011.
- 8** Poole T. *Direct Payments and Older People*. Background paper to the Wanless Social Care Review. London: King's Fund, 2008.
- 9** Glendinning C, Challis D, Fernandez J, *et al*. The Ibsen Project. *National Evaluation of the Individual Budgets Pilot Projects*. York: University of York, 2008.
- 10** Department of Health. *Impact Assessment of Piloting Personal Health Budgets*. London: DH, 2008, www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094799.pdf.
- 11** RCGP Clinical Innovation and Research Centre. *Care Planning: improving the lives of people with long term conditions*. London: RCGP, 2011.

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