

PERSONAL HEALTH BUDGETS GUIDE

Options for managing the money



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Personal health budgets

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

What are the essential parts of a personal health budget?

The person with the personal health budget (or their representative) will:

- Be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a health care professional
- Know how much money they have for their health care and support
- Be enabled to create their own care plan, with support if they want it
- Be able to choose how their budget is held and managed, including the right to ask for a direct payment
- Be able to spend the money in ways and at times that make sense to them, as agreed in their plan

How can a personal health budget be managed?

Personal health budgets can be managed in three ways, or a combination of them:

- Notional budget: the money is held by the NHS
- Third party budget: the money is paid to an organisation that holds the money on the person's behalf
- Direct payment for health care: the money is paid to the person or their representative

The NHS already has the necessary powers to offer personal health budgets, although only approved pilot sites can currently make direct payments for health care.

What are the stages of the personal health budgets process?

- Making contact and getting clear information
- Understanding the person's health and wellbeing needs
- Working out the amount of money available
- Making a care plan
- Organising care and support
- Monitoring and review



1 Introduction

The government's aim is that in future, everyone in England who could benefit will have the option of a personal health budget. This commitment includes parents of children with special educational needs and disabilities. By April 2014, people eligible for NHS Continuing Healthcare will have the right to ask for a personal health budget, including a direct payment for health care. The NHS will also be able to offer personal health budgets beyond NHS Continuing Healthcare – for example to people with long term health conditions or those with mental health problems.

Personal health budgets have been piloted in over 70 locations in England. An in-depth evaluation of 20 sites, published in November 2012,¹ supports the planned national roll out.

This guide describes the different ways a person can receive a personal health budget and manage their money.

A personal health budget means:

- giving people the level of choice and control they want over how their health needs are met
- having a clear understanding of what is to be achieved, as determined during the care planning process.

Having a range of options available to receive and manage a personal health budget ensures that people can select the most suitable option, or combination of options, to meet their requirements.

A whole-system approach to personal health budgets

A personal health budget has five essential parts (see page 7). If any of these are missing, people are less likely to be able to make decisions about their health that matter most to them, and the personal health budget is less likely to be effective.

If a range of options for managing the money is to be made available to people, organisations need to take a whole-system approach to implementation. Learning from social care and from interviews with pilot sites¹ shows that a number of issues need to be considered and resolved at policy and procedural level in order to make personal health budgets a real option for people. By creating a positive and supportive organisational environment in which personal health budgets are understood by staff at all levels, people with long term conditions and impairments will have the chance to shape their lives and make decisions about their health and wellbeing.

... we have gone through a journey, from responding to requests in a traditional “the NHS doesn’t fund that” manner, to looking at the reasons why something might be a valid use of resources to achieve an agreed outcome. We might contest the amount, but not the solution, as long as we can draw a clear connecting line between the need and the outcome.

- Personal health budgets pilot site

Pilot sites interviewed for this guide identified the importance of the following factors:

- leadership – including a clear strategy signed up to by a senior manager
- straightforward systems – with light-touch monitoring that is proportionate and focuses on outcomes

- good communication – with accessible information that is easy to understand
- informed, well trained staff – introducing more choice, flexibility and control over the health services and care people receive requires a multitude of shifts in practices, attitudes and processes
- effective local support organisations – many people found joining up with the local direct payment support service to be helpful
- peer support – supporting the development of local peer networks for people taking up personal health budgets²
- flexible commissioning – supporting personalised support and the development of new types of service provider.



2 Deciding how to manage the money

The type of arrangement put in place should support the purpose of each personal health budget and be adapted to suit each person's circumstances.

Some people may be clear from the start how they wish to receive and manage their personal health budget. It is still important, however, that professionals are able to present alternatives for consideration by the individual so they are able to make an informed choice. Different aspects of a person's care plan may require different approaches to managing the money.

Some people may be clear from the start how they wish to receive and manage their personal health budget. It's still important that professionals are able to present alternatives so that people can make an informed choice. Different aspects of a person's care plan may require different approaches to managing the money.

Some questions to consider in deciding which approach will work best include:

- the outcomes identified in the care plan
- the level of support the person requires
- the nature of services the person wishes to buy to achieve their outcomes, and the options for purchasing them
- the degree of flexibility in the services and support they want
- how much direct control of the money and budgetary management the person wants
- which aspects of the care plan the person wants to take full responsibility for and which they want help with (eg employment, payroll, accounting, training)
- the impact on any carer or family member.

These points should also be considered at each review to take account of how well things are working, and changes in circumstances and aspirations.

Having considered what is important to the person (and, where appropriate, to their carer) for successful delivery of the care plan, the options for managing the money can be explored.

3 Options for managing the money

People can have a personal health budget in one, or any combination, of three ways:

- a direct payment for health care (currently available only in approved sites)
- a third party budget
- a notional budget.

Each option is summarised in the diagram opposite and explained in more detail below.

Direct payments for health care

- With a direct payment, money identified for the personal health budget is transferred to the person, who then purchases the services and support they want in line with the agreed care plan.
- The care plan should set out the health needs the direct payment is to address and what outcomes are to be achieved.
- Direct payments for health care must be paid into a separate bank account used solely for that purpose. A personal health budget can be paid into the same account as another personal budget a person may have, for example their direct payment for social care.

- Direct payments for health care can be given only to a person who consents, or who consents to a nominated person receiving direct payments on their behalf. If they do not have the capacity to consent, direct payments can be given to their representative (eg a person with a lasting power of attorney – health and welfare) if they consent on the person's behalf.

As well as giving people more control and independence, direct payments carry greater responsibilities for people than traditionally commissioned health care. The person receiving the direct payment for health care (or, if they have one, a nominee or representative) will be responsible for the way the money is spent. If they use the money to employ people, they will also be taking on additional responsibilities as an employer.³ There are also increased responsibilities if they enter into contracts with a provider organisation.

THE ESSENTIAL PARTS OF A PERSONAL HEALTH BUDGET:

Being able to choose the health and wellbeing outcomes they want to achieve, in agreement with a health care professional.

Knowing how much money they have for their health care and support.

Being enabled to create their own care plan, with support if they want it.

Being able to choose how their budget is held and managed, including the right to ask for a direct payment.

Being able to spend the money in ways and at times that make sense to them, as agreed in their plan.

A PERSONAL HEALTH BUDGET CAN BE:

Paid into an account held by the person (or held in an account on the person's behalf by someone else) as a **direct payment** for health care.

Paid to an organisation outside the NHS as a **third party budget**.

Held by the NHS as a **notional budget** with services directly commissioned.

(OR ANY COMBINATION OF THESE)

THESE CAN BE MANAGED:

With help from **direct payment support services**.

With help from **family members, friends, or peers**.

By using a **prepaid card**.

Through a **support provider**, or other **organisation independent of the NHS**.

Through a **trust** or similar arrangement.

By **NHS staff**.

Haris's story – a direct payment

Haris is 53, lives in Kent, and is determined to maintain his independence. He has Parkinson's disease and heart disease, and has had several strokes. He requires support for his everyday needs. With a direct payment for health care, Haris can take more control of his health, care and finances.

I live on my own and have no family members who can help look after me. So I depend on paid carers to meet my everyday medical and care needs. I used to have a social care package provided by Kent County Council. The funds to cover this care came to me as a direct payment into a separate bank account under my control. This gave me a choice to decide how to pay for my required care. But when my health deteriorated last year, responsibility for my care came under NHS Continuing Healthcare.

So health broker Rebecca and I sat down to consider how my health care needs could be met, and she suggested a personal health budget. We drew up a care plan, detailing how care would be provided and associated costs. Above all else, there was no way I wanted to end up in a nursing home. I am only in my fifties. But I'm completely reliant on outside assistance – I need help getting up in the morning, showering, preparing breakfast, lunch and dinner, assisting me with my medication, taking my blood pressure every day, and help getting to bed at night.

I decided to receive my personal health budget as a direct payment. This enables me to cover care visits to my home every day – two hours in the morning, 45 minutes at lunch and one hour 45 minutes in late afternoon. Plus, it covers someone to do three hours' shopping for me per week, and a six-hour social call per week.

I wanted to retain the sense of control of my care and finances that a direct payment enables. It's my life. That's why a direct payment for health care works for me.

There are a number of ways in which people can be supported to manage a direct payment for health care. These could include:

- direct payment support services
- carers, family members and friends
- peer support
- advocates and brokers
- using a prepaid card.

Direct payment support services

A good local support service can make all the difference in making direct payments successful for people. Direct payment support services may be provided by the local council, user-led organisations or voluntary or independent organisations.

Dorset – third party support for direct payments

Dorset has contracted with a voluntary sector agency, Enham, to provide support to people using direct payments. Enham already provides this support for the local council.

The personal health budgets process in Dorset works as follows: the personal health budget care co-ordinator provides the initial information and application support. Once the care co-ordinator has worked with a person to develop a care plan, the person has the option to work with Enham to develop a more detailed plan of their support needs (Enham refers to this as a support plan). The personal health budget co-ordinator remains in contact with Enham as necessary, and conducts the personal health budget reviews.

Through two dedicated workers, Enham provides and co-ordinates the level of support the person asks for (eg recruitment, ongoing employment support, queries, day-to-day monitoring). The dedicated workers liaise with the care co-ordinator as questions arise. Enham can also engage the services of Pro-Disability, which provides payroll services, keeping the user support and payroll functions separate.

About 80 percent of people with a direct payment in Dorset use the services of Enham and Pro-Disability.

You need a support organisation that understands the issues being faced by the people using personal health budgets. From the start we looked at how to operate personal health budgets so that they could be managed alongside personal budgets from the council.

- Personal health budgets programme manager

If a person doesn't want to manage a direct payment by themselves, they are put in touch with our support service which offers either a payroll service or a managed account service. Our support service registers the budget holder as the employer but pays invoices on their behalf. People using the payroll service send time sheets at the end of the month and pay is calculated.

- Personal health budgets pilot site

A support service can provide people with help and support in managing many different tasks, including:

- recruitment
- staff management
- budgeting and account management
- training
- payroll
- employment law and advice.

Carers, family members and friends

Where carers and family members are involved in supporting a person with their direct payment, it is important that they are both willing and able to provide this support, and that it is made clear that alternative sources of support are available if wanted. Carers and family members can provide a range of support if they are willing and able. For example, some people who are concerned about managing the direct payment

themselves may choose to have it paid into a separate account managed by a family member, and this person may also provide support in accounting for expenditure. Another form of support with managing a budget, which often involves family members or carers, is a circle of support.⁴

Peer support

In some places, people are enabled to share their experiences and support each other. This is known as peer support. Local peer networks have proved very useful in supporting people taking up personal health budgets.²

Our peer support group help each other with decision making. People discuss employment issues, how to recruit personal assistants, what's working and what's not working. It's developing into a vibrant community.

- Personal health budgets pilot site

Advocates and brokers

Some people manage their direct payments and source any additional support independently of local direct payment support services. Brokers or advocates may be paid to be involved in some aspects of managing arrangements.

Where people pay others to help manage their budget, funding for this will need to be included in the care plan.

Using a prepaid card

Prepaid cards function in a similar way to debit cards. A prepaid card may be less flexible than money in the bank. It is important that the arrangement is made in a way that gives people the necessary freedom to use the card to meet

the agreed needs and outcomes specified in their care plan.

A prepaid card can include accessing cash amounts as well as direct purchasing of goods and services. It can also be useful in situations where a person has difficulty in opening a bank account.

Kent – a prepaid card for direct payments

The Kent Card is a prepaid card operated by Kent County Council. In Kent, direct payments for health care are made through the council's existing direct payments team, making it possible to receive both health and social care direct payments on the Kent Card. The advantages to both the local authority (working in partnership with NHS Kent and Medway) and people using the card are that the bank provides both with itemised statements of card use, making it easier to account for the use of the budget.

A number of people already had direct payments from the local council before starting to receive health direct payments, so already had their personal assistants in place and the Kent Card set up, and were able to carry these arrangements on. Others have chosen to start using the Kent Card as a way to manage their health direct payments.

Third party budget

- Where a third party budget is used, an organisation legally independent of both the person and the NHS (eg an independent user trust or a voluntary organisation) holds some or all of the money on the person's behalf, and supports them to achieve the outcomes agreed in their plan using the available budget.
- When agreeing to use and selecting a third party, it is important that values and assumptions are agreed – for example, who makes decisions, and the degree of flexibility that will be allowed for people to control what happens themselves. This could include matters such as who is recruited and how, their role, tasks, times, training etc.

- It is also important that there is complete transparency over the money and how it is being used, on an ongoing basis. If this is not established, there is a risk that while the money is held outside the NHS, the power and decision making do not shift to the person. Only with this shift in decision making and control can a third party budget deliver a personal health budget successfully.
 - Using a third party budget will incur costs, which will either be met separately by the NHS or added to the person's personal health budget so they can pay the third party.
 - The structure and processes within a third party budget can act as a financial safeguard. They should be transparent and provide a clear record of decision making processes and outcomes. This can help NHS bodies meet their legal responsibility to ensure public money is used properly and for the purpose of meeting a person's health outcomes.
- There are a two main ways in which a third party budget can be established:
- through an independent organisation
 - through a trust or personal care company.

Gerry's story – a third party budget

Gerry is a 61-year-old man who lives at home with his wife and sons. He was a very outgoing man who lived life to the full until he was diagnosed with dementia two years ago. At first, his family were told he would need residential care, but when they heard about personal health budgets they jumped at the opportunity.

Gerry was eligible for fully funded NHS Continuing Healthcare. His local NHS wasn't able to offer him a direct payment, so his family approached a local organisation to act as a third party. It was a new venture for the organisation, which was more used to providing a traditional domiciliary care service, so they drafted a letter of agreement that set out roles and responsibilities. The organisation employs Gerry's personal assistants and handles the money, while his family manages Gerry's support on a day-to-day basis.

The arrangement is working well. The family appreciate the fact that their third party takes a whole-family approach. They've been supported to provide high quality care for Gerry, but they've also had emotional and practical support from the organisation, which understands the needs of family carers. Gerry is thriving, settled and happy to be living in the family home.

Through an independent organisation

A personal health budget can be paid directly by the NHS to an organisation through a third party arrangement.

Third party budget arrangements can be made with voluntary and private organisations such as domiciliary care agencies, charities and other forms of non-profit-making enterprise such as community interest companies. The local NHS will have its own

rules as to which organisations it is able to pay money to.

The budget is held solely for the purposes agreed in the care plan, and controlled by the person or by someone they have chosen to manage it on their behalf. The organisation pays out the money as requested. The appointed organisation holds and accounts for the money. In addition to a management charge, the organisation may provide other services that are charged to the budget.

Merseyside – using a third party to manage one-off payments

In Merseyside, Imagine (a voluntary sector organisation)⁵ holds the NHS budget for one-off personal health budgets.

An NHS care co-ordinator carries out an assessment with the person. The person then meets a broker employed by Imagine, who works within the local mental health team. The broker works with the person to plan how they will use their personal health budget.

A plan is drawn up, the person says, for example, “£150 to buy sports equipment throughout the year”. If the person is happy to sort it out for themselves, the money can be paid into their bank account. We have based our practice on the personal health budgets direct payment guidance and our experience of running individual recovery budgets.

People keep receipts and bank statements for audit, so the expenditure needs to meet the outcomes of their support plan; the plan is signed by the care co-ordinator, Imagine and the person. Some expenditure is very clearly specified in the plan, while in other cases a general area of expenditure will be given, but tied to a specific purpose (eg “sports equipment to maintain fitness”, without specifying exactly what equipment this might be).

If a person asks us to do it on their behalf, we can carry out research and purchase items using cheques, cash payments, store accounts, BACS transfers, invoicing or a company credit card; or they can use a store card or other form of voucher for items in their support plan. Being a smaller organisation allows for flexibility and speed.

In some instances the independent organisation may also be a support provider. Along with holding the money, the organisation employs the staff and provides services and support in partnership with the person, in line with their wishes as identified and agreed in the care plan.

Individual service funds

An emerging type of arrangement is an individual service fund, where the NHS directly places all or part of a person's personal health budget with a provider organisation chosen by that person.

This is used in accordance with an individual service fund agreement made between the person and the provider. The principles of an individual service fund are described on page 16.

One-off payments

Third party organisations may also be used to manage one-off payments (money paid for a non-recurring service or a single item). In the Merseyside example, some payments are given as cash sums, vouchers or card payments. In other cases the third party organisation purchases items directly.

Through a trust or personal care company

Trusts

A trust arrangement may be known as an:

- independent user trust

- user-controlled trust
- independent living trust.

A trust may be particularly helpful when:

- the NHS body does not have the power to offer direct payments
- a person does not want to manage a direct payment
- a person is not in a position to manage their own budget
- a family wish to make arrangements that do not depend on them being involved.

A trust is independent of both the NHS and the person receiving care, making it an independent agency equivalent to any other agency set up to provide care.

A trust commits to managing the person's budget by establishing a board of trustees who are responsible for providing the services agreed in the care plan. The NHS can transfer funds to the trust to meet a person's health needs in line with their agreed care plan.

An independent user trust can employ staff and make purchases. If the trust employs staff, the trustees become the legal employers. This role brings responsibilities, so it is important that trustees have access to up-to-date information and adequate support.³

Trustees are also responsible for ensuring a person's health outcomes are being met and that contingency arrangements are adequate.

The paper 'Personal health budgets and independent user trusts' gives more detail on how trusts can work in health care.⁶

Personal care companies

Personal care companies are a variation on the trust arrangements described above. They are usually set up to provide support to a person with a large health care package and high support needs.

The company is a separate legal entity, which manages an agreed sum of NHS money on behalf of the person. There is a contract between the company and the local NHS commissioning body to provide services for the person in a way that puts them at the heart of decision making and gives them choice and control in their life. The company is managed by a board of directors. The number of directors can vary, but if a family member wishes to be a director, there need to be at least two other directors. The family member does not control the board as they are in a minority, which means they cannot exercise a veto.

Learning from the peer network

Here are some things the Department of Health personal health budgets national peer network⁷ says are important for a third party budget to work well. These points could form a useful basis for drawing up a contract between a person receiving a personal health budget and a third party organisation.

- The budget needs to be held in a separate/dedicated bank account in the person's name. The arrangement needs to be transparent – the third party must share

bank statements and financial information in an ongoing way.

- People want the freedom to choose personal assistants for their personal qualities rather than their qualifications. The right person can be trained to fulfil the role. The budget holder (or their representative) should write a person specification (with help, if required). People want to be able to take a competency-based rather than a qualifications-based approach.
- People and families need to have a say in the employment arrangements, including the employment contract, pay rates and conditions. Disciplinary procedures need to be clear and must involve the person or their family, and be consistent with the law. People with a personal health budget recognise the need to value their employees. The third party needs to value and respect this.
- There need to be clear lines of reporting through the person/family, and people want the family's role to be respected in the package. Everyone needs to be clear about where responsibilities lie.
- The third party organisation must have the right values and remember who the customer is. The third party has to be sufficiently knowledgeable and supportive. They also need to understand personal health budgets and the national context.
- There needs to be good communication and rapport between the third party and the person/family.

- Safety – monitoring has to be the person/family’s responsibility and must not be remote.

For more information about the work of the personal health budgets national peer network (the co-production group working with the Department of Health) and peoplehub (a wider group of people with direct experience of personal health budgets), visit www.peoplehub.org.uk

Notional budgets

- The money continues to be held by the NHS, but the person has a clear understanding of the amount of money allocated for their care and support.
- The person has been fully consulted and involved in developing a care plan that is responsive to their personal needs and preferences, and money is spent in line with that care plan and reviewed accordingly.
- The NHS arranges and pays for the agreed services and supports, including the employment of care and support staff, through its usual contracting processes with providers.

Notional budgets within existing contracts

In social care, individual service fund agreements have been introduced within notional budgets.^{8,9}

An individual service fund for a notional budget applies to an agreement where all or part of the person’s personal budget is held by a provider of their choice under the terms of a contract between the council and the provider. Individual service funds can be used to individualise arrangements within existing block contracts or alongside spot purchasing from framework contracts.¹⁰ They do not require new or different contractual models to be put in place, and can be used regardless of the prevailing contractual situation so long as there is a willingness to collaborate and be flexible.¹¹

Where a block contract exists, the provider agrees to determine the funding amount for each person as an individual service fund. This is then used in accordance with an individual service fund agreement (which relates to the person’s care plan) solely for that person.

Block contracts are a barrier, so we have to get new standard clauses into new contracts which will ensure that providers have to work in support of people choosing a personal health budget.

- Personal health budgets pilot site

Where providers agree to this, it is understood as a starting point for a transition from block contracting to individualised contracting. The NHS and the provider agree a timescale for this transition. Initially, the arrangement is a notional personal health budget, as the personal health budget amount (or at least



Pat's story – a notional personal health budget

Pat worked with her nurse to decide what were her most important health care objectives. These included being able to walk to the local bus stop within the next 12 months, treating her depression, losing one stone within six months, and increasing her confidence.

Breathlessness is the most severe COPD (chronic obstructive pulmonary disease) symptom I have. I can't walk far. I just seize up and I'm unable to breathe properly. This can make me very anxious. I have also had a heart attack, and have problems with my weight. Before receiving my personal health budget I was also struggling with depression, which was related to the disabling effects COPD has on my life.

The only help I used to receive was when I went to my GP to discuss my medication, including inhalers. I also occasionally went to a professional-led pulmonary rehabilitation class for people with COPD. It was at this group that it was suggested I apply for a personal health budget.

I was granted a personal health budget, which was used to buy an exercise bike and complementary therapies to help with my anxiety. Doing regular exercise is vital to enable me to improve my health and confidence so I can walk to places. Exercise also prevents the symptoms of COPD from worsening. As well as using the bike myself, I lend it to a patient-run pulmonary exercise/support group which I attend.

The personal health budget is managed by Birmingham Community Healthcare NHS Trust. This arrangement works well for Pat. Sandra is Pat's COPD nurse. She says:

Before the personal health budget process began, Pat said she was becoming more and more withdrawn and low in mood. The process allowed us to look beyond the normal services that are available and to decide together what could improve Pat's quality of life and wellbeing. For example, the provision of reflexology to help her manage her depression and anxiety in conjunction with the support and medication she received from her GP was most beneficial.

Indeed, the whole personal health budget process has helped Pat. She's so much more confident about managing her disease and is less fearful about her breathlessness. This has resulted in her being less anxious, exercising more and having a far better quality of life, with increased social interactions. All in all, Pat's a different lady.

that part of it paid to this provider) is part of a larger contracting arrangement, but this arrangement is used to begin the process of converting block contracts into a series of individual contracts, which ultimately should work as a third party arrangement.

As indicated on page 14, an individual service fund can also be used where the NHS pays one person's personal health budget directly to a provider.

In either situation, the agreement should have the following features.

- All or part of a personal health budget is held by a provider on a person's behalf, and the money is restricted for use on that person's support and accounted for accordingly.
- The personal health budget holder is empowered to plan with the provider the who, how, where, when and what of any support provided in line with the agreed care plan.
- There is flexibility to carry money forward into future weeks or months and to "bank" support for particular purposes, as agreed in the care plan.
- The individual service fund is accompanied by written information that explains the arrangement clearly and confirms any management costs to come from the personal health budget.
- There is portability, so the personal health budget holder can choose to use the money in a different way, or with a different provider.⁸

4 Conclusion

Personal health budgets centre around a plan that sets out a person's health outcomes or needs, how much money is available to meet these, and how it will be used. People can manage their personal health budget in one of three ways:

- a direct payment for health care
- a third party budget
- a notional budget.

For each approach a number of delivery and management options can be used, and people can be supported in different ways. People can choose just one, or a combination of them – whatever works best for them and enables them to achieve their agreed health outcomes.

In deciding which approach works best for a person, consideration needs to be given to:

- their specific circumstances
- the degree of flexibility and control they want
- the nature of the services they want to buy.

It is also important to consider the impact of the arrangements on any carer or family member.

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