

Personal Health Budgets for Continuing Healthcare: The 10 features of an effective process

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Introduction

Personal health budgets (PHBs) were first proposed in the 2008 NHS Review conducted by Lord Darzi, with a national pilot programme launched a year later alongside an in-depth evaluation. Around 70 Primary Care Trusts (PCTs) have been involved in piloting PHBs over the past three years, of which 20 are taking part in an in-depth, controlled evaluation. Pilot sites have implemented PHBs across a wide range of long term conditions, including mental health problems, diabetes and chronic obstructive pulmonary disease and within certain service areas and funding streams such as maternity services, end of life care and continuing healthcare.

Based on early evidence of positive impacts, the Secretary of State for Health committed to roll out the right to ask for a PHB in continuing healthcare from April 2014 in advance of the official publication of the national evaluation in October 2012. The 2012/13 NHS Operating Framework, therefore, instructs PCT clusters to prepare for roll-out. Local implementation of PHBs should be included as part of planning for the transition from PCT clusters to clinical commissioning groups.

NHS continuing healthcare (CHC) was chosen as the first area for roll out for three main reasons. First, there was clear evidence that individuals and their families were benefiting from the choice and control provided by a PHB. Second, pilot sites reported average savings of 20 per cent from using a PHB compared to existing care packages. Third and most importantly, there is significant bottom-up demand for PHBs from individuals who become eligible for CHC having already had experience of choice and control through self-directed support in social care and are at risk of having to return to traditional services.

This report is part of a broader programme of support for PCT clusters in the North West region to prepare for the roll out of PHBs in 2014. It draws on the learning of pilot sites in the region and nationally to outline 10 features of an effective PHB process within NHS continuing healthcare. In doing so, it recognises that the current pilot programme has not been driven by a blueprint for how PHBs should be implemented and, therefore, there is a significant amount of variation in how the process has been designed and the outcomes that have been achieved for people. In identifying the features of an effective process, the report intends to inform future implementation to ensure that PHBs deliver the best possible outcomes for individuals and families. This report should be read alongside the Department of Health's forthcoming publication, *Personal health budgets: A guide to effective care planning*, which provides further detail of how to implement PHBs in line with the 10 features outlined in this report.

What is a personal health budget?

A personal health budget is NHS money allocated to someone with an identified health need that enables them to have greater control when planning and meeting their chosen outcomes. Its purpose is to ensure that people with long-term health conditions and disabilities have the chance to shape their lives by making the decisions about their health and wellbeing that matter most to them.

Personal health budgets have much in common with other initiatives in the NHS that intend to bring about a shift in the relationship between individuals and clinical professionals such as shared decision-making and self management. But they enable greater choice and control in the following distinctive ways:

- The person knows how much money they have, so they can use that information to plan and to budget in an ongoing way.
- The person chooses the outcomes to be achieved, in agreement with their health professionals.
- The person is enabled to create their own care plan, with whatever support they may want, to meet care planning criteria.
- The person freely chooses the way in which their budget is held and managed.
- Whichever option is chosen to hold and manage the money, the person is able to spend it flexibly, to achieve their planned outcomes, (provided NHS exclusions are avoided).¹

¹ Department of Health, *Personal Health Budgets: A guide to effective care planning*, forthcoming

The basics of the personal health budget process within NHS continuing healthcare

It is important to remember that PHBs do not change eligibility for NHS continuing healthcare. As such, the PHB process begins once an individual has been assessed as eligible for CHC and opts for a PHB rather than for a traditional care package.

There are seven basic steps to the PHB process which are similar to the process for self-directed support. This section outlines the steps, recognizing that these basic steps can be implemented differently. For example, the approval process described below can be simple and follow transparent rules or can be time consuming and subjective. The steps set out below should, therefore, be understood in the context of the 10 features of an effective process discussed in the next section.

The seven step process

1. The first step is to engage the individual with the concept of a personal health budget, ensuring that they get good information and are able to make an informed decision about whether to take up the offer of a PHB. It is absolutely critical that a person makes an active choice to have a PHB as this is the start of the culture shift for the individual – from passive recipient to active participant. If the person is not engaged at this stage, they will be a ‘passenger’ throughout the process and the PHB is less likely to succeed.
2. Once an individual has opted for a PHB, it is necessary to identify the cash value of the PHB to which that person is entitled based on his or her needs. There are different ways in which this can be done but it is important that this process recognises an individual’s health and social care needs and the strengths and assets they have to contribute and does not simply allocate resources based solely on the clinical needs identified in the Decision Support Tool.
3. The PHB allocation provides the starting point for an individual to develop a support plan which identifies the goals that individual has for his or her health and well being and how those goals could be met. The support plan can be developed with informal support from friends and family or with the support of an independent broker, and the process should involve the individual’s clinician

4. The support plan is approved on the basis that the goods and services chosen will help meet the objective's set out in the support plan, do not exceed the value of the PHB and do not put the individual at an unacceptable level of clinical risk.
5. Individuals can exercise as much or as little direct control over the money in their PHB as they choose. If their local PCT cluster has direct payment powers, they can receive it as a direct payment which they manage, often with support from a direct payments support service or through a managed bank account. They can use a third party to hold the money and employ people on their behalf or the money can be held as a notional budget by the PCT. Whichever way they choose to receive the money, individuals should be able to exercise control over the decisions that matter most to them.
6. With decisions about the money made, the services and supports in the support plan can be put in place and the individual can get on with living their life with their condition. Irrespective of how the money is held, individuals and families should have as much choice and control as they wish as to how these services and supports are put in place, including making decisions about rates of pay, staff competencies and back up plans.
7. The support plan can be reviewed along the same time line as CHC care packages would generally be reviewed. An initial three month review is common, with an annual review thereafter, although changes can be made to the support plan between reviews as necessary. The effectiveness of the support plan should be judged on the basis of whether the goals identified in the plan are being met. If an individual's needs change significantly, they will need to take part in a reassessment which may lead to a change in the value of their PHB.

Developing a local framework for implementation

To implement personal health budgets effectively, it is important for each local area to develop and agree its own local framework with everyone who will be involved in the PHB process at the table – commissioners, clinicians, finance, brokers, local authority colleagues, individuals and families. The framework defines the way in which the basic process outlined above will be implemented in your area and there needs to be a shared understanding of the framework before individuals start to plan. In its forthcoming paper on care planning for PHBs, the Department of Health identifies the following essential ingredients of a local framework, drawing on the experience of pilot sites:

- Develop a peer network and involve everyone from the start.
- Clarify the purpose and principles of PHBs.
- Be clear about all aspects of the money – when and how a budget is offered; how much money will be offered; the flexibility of spending the money; and what the monitoring and review process will be for the money.
- Develop and provide information, support and training.
- Agree a local approach to choice, safeguarding and risk enablement.
- Agree the criteria which a support plan must meet for authorisation/signoff.
- Agree the process of authorisation and appeals.
- Agree how support plans will be monitored and reviewed.
- Create a strategic commissioning feedback process that will allow what individuals choose to purchase with their PHBs to inform market development.
- Create a local communication strategy for PHBs and a plan for workforce development.²

² Department of Health, *Personal Health Budgets: A guide to effective care planning*, forthcoming

The 10 features of an effective personal health budget process for NHS continuing healthcare

The 10 features discussed below have been identified by examining how different pilot sites have implemented PHBs. No one site has the perfect process and there are lessons to be learnt from each pilot. This list draws out the best features from each site to create an ideal process. Ideal in the context of this report can be seen as a process that works well for all those involved, that supports the idea of PHBs as tools for shared decision-making between individuals and professionals and allows individuals and families to fully exercise choice and control.

1. A PHB covers the full range of an individual's health and social care needs

Although continuing healthcare is intended to cover health and social care needs, as an NHS funding stream, care packages are often narrowly focused on meeting clinical needs. This has been a challenge for PHBs too. Although Department of Health guidance related to PHBs clearly states that PHBs can be used to purchase goods and services that would otherwise be considered 'social care', there is still a tendency in some areas to try and classify things as either health or social care and not approve the latter. As a consequence, in some pilots, it has been difficult to secure approval for anything that is not hands on care. This means that in some pilots, PHBs have only been used to replace agency provided care with care provided by personal assistants. However, other pilots have taken a more flexible approach and have benefited from the creativity that individuals have brought to meeting the full range of their needs.

2. The full continuing healthcare package is included within a personal health budget

In some pilot sites, the scope of a PHB has been restricted to only include personal care, leaving the clinical aspects of the CHC package to be delivered by traditional NHS services. This was largely done as a compromise to ensure that the pilot could move forward, given the scale of cultural change that PHBs require. CHC staff were more comfortable with individual choice and control for personal care than for more clinical types of care. However, by limiting the scope of a PHB in this way, individuals experience choice and control in some aspects of their life but not in others which can make it difficult for them to realise their goals. For example, an individual may hire his own personal assistants to get him up in the morning so he can get to work on time but will have no control over when the district nurse comes to change his dressings, making it challenging to hold down a job.

There are many good examples of individuals managing the full range of their CHC care needs through a PHB that should give PCT clusters confidence to include the full scope of a CHC package within a PHB.

3. Individuals know how much they have to spend before they start planning

It is difficult to plan for anything without knowing how much you have to spend. This is equally true of continuing healthcare. People need to know how much is in their PHB before they can start developing their support plan because they will have to make choices about how best to meet their needs within the budget they have. Some pilot sites found it a slow process to get a budget figure from the relevant PCT and were, therefore, forced to plan without a budget. But this is not ideal and does not help get the most creative ideas from people and is unlikely to provide good value for money. Not everyone will want to make major changes initially. In some pilots, individuals took a PHB but continued to use agency care initially while they developed the confidence to take on more control. This may also be necessary for the period of transition from a traditional care package to a PHB given the size and the complexity of some CHC packages. But knowing how much is in the budget allows people to incrementally make changes to their care as their confidence grows.

4. The indicative budget process is based on needs not hours of care

The indicative budget setting process is the system that a PCT uses to convert an assessment of need into a budget amount for a PHB. Three different approaches have been tried in the pilot programme. The first assigns points to different levels of need which then translate into a cash amount. The second uses the number of hours of care an individual is entitled to and a standard hourly rate to calculate a budget and the third calculates the value of the traditional care package the individual would have received. The experience of pilot sites suggests that an indicative budget process based on hours of care can create a bias towards approving hands on care over other types of goods and services. An indicative budget process that converts assessed health and social care needs into a budget amount can avoid exacerbating what is already a bias within NHS continuing care.

5. Clinicians are involved from the very beginning but do not dominate

Individuals who are in receipt of NHS continuing care have significant health needs that need to be well managed as an integral part of them enjoying a good life. Access to clinical knowledge and advice will be important to individuals, although individual choices and preferences need to be factored into the way in which clinical care is delivered and who delivers it. This means that clinicians need to be involved in discussions from the beginning

and need to work closely with individuals to ensure that clinical needs are met in ways that fit an individual's wider goals and fit with the entire's family's preferences. In doing so, clinicians need to acknowledge and respect the expertise of individuals and families and work with them to make a reality of their choices rather than dismissing them as too risky or not clinically proven. In an ideal process, a clinician should have been involved enough in the development of a support plan to not be surprised by what is in it when it is submitted for approval. Unusual choices should already have been discussed and their motivation and value understood well before the point of approval.

6. Adequate support is available to PHB holders for support planning

Many people will have clear views about how they want to use their PHB and will be able to plan without support or with the support of family and friends. But others will need support. While clinicians need to be closely involved in support planning, pilots have generally found that individuals are better supported by an independent person, such as a broker, a representative from a health charity or a peer with experience of using a PHB. These independent advisors can help individuals identify their goals, research different ways of meeting those goals and ensure that clinical needs are adequately met. This is particularly important in continuing healthcare where individuals often have significant and complex needs. Independent advisers can also ensure that clinicians are brought into the support planning process from the beginning to discuss with individuals how their clinical needs can be best met in line their wider support plan. One of the challenges that PCT clusters will have to grapple with is how to provide support for PHB holders on a sustainable basis.

7. The support plan is written in an individual's own words and is not a clinical care plan

Although a support plan can be physically written by anyone, it should reflect an individual's own views about the things that are going well in their life and the things that are not and what they would like to change (see following box for further details). It should not be based on clinical domains or be restricted to an individual's clinical needs. This does not mean neglecting an individual's clinical needs as these can be a matter of life and death and are integral to an individual living a good life. But it means personalising the way in which those needs are met to help individuals meet their wider objectives. For example, it can mean changing the way in which clinical records are kept to ensure that the information that is important to the person's care is recorded rather than the standard information that is generally required. Risks need to be discussed and documented in the support plan and back up plans put in place rather than unduly restricting individual choices because of risk. A

well written support plan will depend on close collaboration between the individual and their family, the relevant clinicians and the broker, if one is involved.

What should be included in a support plan for PHBs

At the heart of a personal health budget is a support or care plan developed in partnership. A care plan is a record of the discussions and agreements between the person and their health team. For people using a personal health budget it will specifically include their health needs, the outcomes they want to achieve, how they intend to use their budget to do this, and the name of the care coordinator responsible for managing the care plan. The following topics must be covered and recorded during care planning:

- Individuals need to be given information about PHBs before planning starts and be helped to understand the local framework for PHBs so that the rules and procedures are clear from the beginning
- Individuals need to be supported to identify what is and is not working related to their health and how it impacts on their ability and the ability of their family to live the life they want.
- The support plan should include details of what matters to individuals as well as what matters for their health. This is the route to truly personalising how someone's clinical needs can be met.
- The support plan should identify and address any risks in order to support individual choices
- The support plan should identify the individual's goals and outcomes for their health and well being. Additional outcomes should not be imposed by clinicians or other professionals at the end of the process
- An action plan should be included that specifies clearly who will do what and when. It will show who is taking responsibility for each task and how they will do it.

Source: Department of Health, *Personal Health Budgets: A guide to effective care planning*, forthcoming

8. Individuals are in charge of decisions about training

Many people will choose to use their PHB to hire personal assistants (PAs). In some cases, these PAs will need training in basic tasks as well as specific clinical tasks that relate to caring for the PHB holder and PHBs need to include adequate resources for training. Clinicians have an important role to play helping to determine and agree the clinical competencies that PAs need but decisions about how training to reach these competences is completed should remain with the individual and his or her family. Individuals with serious health conditions want to be cared for by people who are well trained and can ensure their health and safety. Therefore, individuals have the strongest vested interests in making sure that their staff are

adequately trained to meet their particular needs. Individuals need access to training opportunities for their PAs, particularly around clinical tasks, and need to be reminded to keep up to date with training but PCT clusters should not create rigid training requirements such as they would for care agencies. Individuals are best placed to judge whether their staff are adequately trained and may want to broaden the range of training beyond clinical areas to meet their outcomes, for example by including alternative therapies. They may also want to respond to their own staff's interests and personal and professional development needs.

9. The approval process is light touch and transparent

In some pilot sites, there have not been clear rules as to what will be approved and decisions have been subjective. This makes it difficult for individuals who are told to exercise choice but whose choices are subsequently denied without any clear explanation. In some cases, brokers are asked for multiple cost quotations for certain items in a support plan but not for others and there is no consistency. Having a light touch process depends on having transparent rules that everyone understands and can apply. Local areas need to develop clear rules for what will and will not be approved within CHC (see following box for suggested sign off criteria). Everyone involved in PHBs needs to be aware of these rules. If support plans do not go against these rules, are within budget and clearly demonstrate the link between an individual's goals and what is to be bought, then the plan should be approved and should not be subjected to additional scrutiny.

While many pilots have used panels to approve support plans, these tend to slow down the process and are costly. Approval can be devolved to the lead clinician who can take responsibility for securing sign off from the lead commissioner from a financial perspective. Changes to support plans can also be made simply by securing approval from the lead clinician and making an addendum to the support plan. The more steps in the approval process, the less transparent the rules and the more people involved, the longer it takes for individuals to get from start to finish and the less positive an experience the PHB process tends to be for people.

Criteria for authorising a support plan

The plan must:

- Show who the person is, with their strengths and skills, and their personal social context, as well as their health needs. If the person lacks capacity to make their own decisions the plan must show how this decision was reached and identify who will speak on their behalf.
- Describe what is working and not working from their perspective.
- Detail what is important to the person and what is important for their health
- Identify and address any risks and how they will be mitigated to an acceptable level, including a contingency plan if things go wrong, and a point of contact in health services.
- State the health outcomes to be achieved and how it is proposed that those outcomes will be achieved.
- Describe in broad terms how the money will be held and managed and show how it will be used to achieve the outcomes.
- Have an action plan that details who will do what and when to ensure that the plan is carried out.
- Include the name of the person's care coordinator
- State how and when the outcomes, and the money, will be monitored and reviewed. (This will include describing how people will know the plan is going well, and how people would know if things were going wrong.)

Source: Department of Health, *Personal Health Budgets: A guide to effective care planning*, forthcoming.

10. There are adequate options available for how the PHB is held

While a significant number of people in the pilots have opted for a direct payment, some will want control without taking on the responsibility of becoming an employer and will want the back up and expertise that a good third party can provide. This is especially the case in continuing healthcare where people are working with large packages of care and often with complex health needs. Few pilots have used third parties, offering mainly direct payments or notional budgets. This is largely because the market for third parties that can work effectively with families to offer support but allow families the choice and control they want is severely under-developed. As part of roll out, it will be important to ensure that PHB holders have a range of options for how their budget can be held, support to manage direct payments where they choose this options and adequate funding in their PHB to cover these support costs.

Conclusion

Personal health budgets require significant culture change in the NHS to succeed but many of the pilot sites have demonstrated that this is possible and few staff say that they would go back to the old ways of doing things now that they have worked with PHBs and have been able to really put people at the centre of decisions about their care. In those areas that have gone the furthest, PHBs have become the norm in CHC – they are how CHC is done locally, although the option not to have a PHB remains. Given that PHBs for NHS continuing healthcare have now moved beyond the pilot stage to be rolled out nationally, it will be important to learn from the most successful pilots and embed PHBs into the existing CHC process rather than seeing it as an add on. Embedding it into the core of CHC will be the best way to ensure the necessary culture change takes hold.

Further information

For further information on the work being carried out in the North West in relation to personal health budgets, please see our webpages at <http://www.in-control.org.uk/support/regional-support/north-west-transition-alliance/personal-health-budgets.aspx>

This area of the website will be kept updated with the latest information and will soon feature case studies.

Information regarding our wider work in relation to personal health budgets can be found at <http://www.in-control.org.uk/what-we-do/staying-in-control-health.aspx>

Publishing information

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The publication is free to download from www.in-control.org.uk

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