

Personal health budgets and NHS Continuing Healthcare

Discussion paper January 2012





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1. Introduction

This document is a discussion paper which explores personal health budgets for people receiving NHS Continuing Healthcare. It will be of interest to healthcare professionals who have a role in NHS Continuing Healthcare or are considering the future implementation of personal health budgets. This is the first of a number of informative documents looking at personal health budgets and NHS Continuing Healthcare.

Personal health budgets are currently being piloted in the NHS in England, with over 2,700 participants across 20 sites. A number of sites are piloting personal health budgets with people eligible for NHS Continuing Healthcare. In October 2011, the Secretary of State for Health announced that subject to the evaluation, by April 2014 everyone in receipt of NHS Continuing Healthcare will have a right to ask for a personal health budget, including a direct payment. This will form part of a broader rollout of personal health budgets to people with long-term health conditions.



2. What are personal health budgets?

A personal health budget is an amount of money that is allocated to an individual to allow them to meet their health and wellbeing needs in a way that best suits them. At the heart of a personal health budget is a care plan. This sets out the individual's health (and social care) needs and includes the desired outcomes, the amount of money in the budget and how this will be spent. The care plan is agreed between the individual and the professional, before being checked and signed off by the NHS. The money in a personal health budget can be managed in three different ways:

- A notional budget
- A third party arrangement: an organisation legally independent of both the individual and the NHS (for example, an Independent User Trust or a voluntary organisation) holds the money on the individual's behalf, and buys or provides the goods and services the person has chosen.
- A direct payment for healthcare: the money is transferred to the individual, and the individual buys the goods and services the person has chosen. Some direct payments support organisations will act as an agent and help the individual manage the direct payment. Only DH approved pilots sites can offer direct payments at the moment.

The NHS is already able to offer personal health budgets via a notional budget or third party arrangement.

Personal health budgets will not be right for every health situation, nor will everyone want one. It is not likely that they will be used to meet all of an individual's NHS funded care – for example, things like elective surgery or emergency care would not be included. They are generally more suitable for people with long-term conditions who are higher users of NHS services or those people with complex health needs. There may also be a role for personal health budgets in preventative public health and other areas of health care.

Personal health budgets potentially offer greater integration of health and social care for both individuals who need care and their carers, and better partnership working between the NHS and local authorities.

An independent evaluation of the pilots will be published in 2012. The evaluation team are producing a number of interim reports during the course of the pilots, in advance of the final report. The four interim reports published so far have focused on the early experiences of pilot project managers, practitioners and budget holders, and on set-up costs¹.

More information on the pilot programme can be found at:
www.dh.gov.uk/personalhealthbudgets

¹ The reports, and more details about the evaluation, are available at www.phbe.org.uk



3. What is NHS Continuing Healthcare?

NHS Continuing Healthcare is a package of care (health, personal care and accommodation costs) arranged and funded solely by the NHS. Anyone assessed as having a certain level of care needs may receive NHS Continuing Healthcare. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If a person's overall care needs show that their primary care need is a health need, then they should be eligible for NHS Continuing Healthcare.

NHS Continuing Healthcare can be provided in a range of settings, including care homes, or a patient's home. Eligibility for NHS Continuing Healthcare is a complex and highly sensitive area that can affect people at a very vulnerable stage of their lives.

In October 2007, the Department of Health produced the NHS Continuing Healthcare Framework. The framework, which was revised in 2009, sets out a single national system for determining eligibility for NHS Continuing Healthcare irrespective of location, diagnosis or personal circumstances. This framework does not connect levels of need of those deemed eligible, to amounts of funding or provision; and in fact, people get a wide range of different responses in what is subsequently offered.

Currently, around 53,000 people in England are in receipt of NHS Continuing Healthcare.

More information on NHS Continuing Healthcare can be found at:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_106230



4. Government announcement on personal health budgets and NHS Continuing Healthcare

The Government announced in October 2011 that, subject to the evidence from the pilots, people eligible for NHS Continuing Healthcare will have the right to ask for a personal health budget, including a direct payment, from 2014.

This means that from April 2014 people will legally have the right to ask for a personal health budget if they are eligible for NHS Continuing Healthcare funding. This does not automatically mean they will be given one, but it is likely that the majority of people who ask for a personal health budget will receive one.

The NHS Future Forum recommended that the Government set out a clear ambition for the role that personal health budgets will play in the future. This announcement is the first step towards introducing a wider right to ask for a personal health budget. Subject to the evaluation, personal health budgets will be rolled out nationally on a voluntary basis to any patients who would benefit from them.

The full press release can be read here:

www.personalhealthbudgets.dh.gov.uk/News/item/?cid=8349



5. Why personal health budgets for people receiving NHS Continuing Healthcare?

There are clear benefits coming from the pilot sites for giving personal health budgets to people eligible for NHS Continuing Healthcare. Emerging findings from the pilot are positive and there are many encouraging anecdotal stories. More than half of the responses to the 'Greater Choice and Control' consultation supported the use of personal health budgets, with a range of views as to who should be eligible, which included people in receipt of NHS Continuing Healthcare. More information about the consultation can be found at this link: www.dh.gov.uk/en/Consultations/Liveconsultations/DH_119651

Quantitative information about the impacts on effectiveness, patient experience and costs will not be available until the end of the pilots; early indications are that outcomes are being met, experience is improving and costs of NHS Continuing Healthcare packages are being reduced.

Many people who had been assessed as eligible for NHS Continuing Healthcare were transferred from social care, where they had a personal budget or a direct payment. When they moved over to NHS Continuing Healthcare, they lost all the control they had, as legislation did not allow direct payments in the NHS, causing distress to those involved. At present, direct payments for healthcare are only permitted in pilot sites specifically authorised by the Department of Health.

Introducing personal health budgets is complex, but early evidence from the pilots suggests that this is easier in NHS Continuing Healthcare than other areas. More is known about the costs of individual NHS Continuing Healthcare packages people receive, and both healthcare professionals and individuals who are eligible for NHS Continuing Healthcare are more used to personalising and developing individualised packages of care.



6. How do personal health budgets change the NHS Continuing Healthcare pathway?

Traditional NHS Continuing Healthcare pathway	NHS Continuing Healthcare delivered through a personal health budget
A person is assessed as being eligible for NHS Continuing Healthcare	A person is assessed as being eligible for NHS Continuing Healthcare
Level of need is assessed and agreed	Level of need is assessed and agreed. NHS Continuing Healthcare team discusses the option of a personal health budget, individual/carer agrees
NHS Continuing Healthcare team commission the care and support the individual needs	Indicative personal health budget is given. Care planning process led by the individual, their carer in partnership with broker and or NHS Continuing Healthcare team. Care plan is signed off by NHS and budget holder
	Personal health budget is set.
	Person selects which way the budget will be delivered: direct payment, notional budget or third party. Care and support is arranged
Care is delivered	Care is delivered
Review of care	Review to ensure needs are being met, and financial review to ensure the personal health budget direct payment (if selected method) is being used as agreed within the care plan



7. Some practical considerations

- There are many lessons that pilot sites are learning about how to implement personal health budgets for NHS Continuing Healthcare patients. There is a detailed work programme underway programme to explore a number of core generic areas including: financial issues, care planning, integration, workforce issues and provider development. The NHS should use these experiences to help them prepare for rollout from 2014.
- From April 2013, clinical commissioning groups will have responsibility for delivering personal health budgets. In practical terms, the announcement means that by 2014 all clinical commissioning groups will need to have the capability and capacity to deliver personal health budgets. How they do this will be a local decision. Options include:
 - developing the capacity in-house
 - developing cluster capacity
 - commissioning a third party
- NHS Continuing Healthcare teams will need to understand how personal health budgets sit within the NHS Continuing Healthcare pathway, including how and when they should be offered and the potential scope of them, as well as being able to deliver them. They will also need to understand the significant cultural shift that is necessary to make personal health budgets a success for people eligible for NHS Continuing Healthcare. Personal health budgets lead to partnership working between the healthcare professional and the individual concerned.
- Personal health budgets do not alter the legal obligations to assess for NHS Continuing Healthcare, nor do they alter the eligibility criteria or the assessment of the level of need. Personal health budgets should be considered as a way of planning and delivering NHS Continuing Healthcare once the level of care has been agreed, and clearly fit into the pathway.
- Some people are already choosing to use a personal health budget in order to be able to live independently outside of a care home. A high proportion of people receiving NHS Continuing Healthcare are living in residential or nursing homes. Current social care policy does not allow direct payments for residential care, but people may still be able to have a personal health budget, and possibly direct payments for other aspects of their care. The personal health budgets team will be working closely with social care colleagues as the issue of direct payments for residential care is considered as part of the Social Care White Paper.
- One of the learning points from work in pilot sites concerns the contribution being made by relatives and other carers in providing support. Some people taking up personal health budgets are receiving a high level of care and support every day from an unpaid carer. When deciding the amount of a personal health budget, or indeed the level of care for someone eligible for NHS Continuing Healthcare more generally, it is important not to assume that carers will remain able and willing to continue providing support at the same level. It is possible that specific advice on how carer support should be taken into account when setting budgets will be needed. Paragraph 45 of the National Framework for NHS Continuing Healthcare reminds PCTs and councils that carers have a right to have their needs assessed and these needs could also be met through a personal health budget.



- Parents of children in receipt of care through the National Framework for Children and Young People's Continuing Care will have the right to ask for a personal health budget. There are obvious links between the National Framework for Children and Young People's Continuing Care, personal health budgets and the Special Education Needs and Disability (SEND) Green Paper Pathfinders announced in September 2011. Pathfinders will be able to offer personal budgets for health, including direct payments (once they have approval to do so from DH). The announcement fits with the SEND Green Paper commitment that, subject to piloting, children with SEND will be able to have a personal budget by 2014.
- Transition from children's to adult services can be a traumatic experience, and while personal health budgets will not alter the legal requirements for assessment; it is expected that personal health budgets will make the process smoother. We will be exploring issues around transition and personal budgets.
- Personal budgets have the potential to improve integration of health and social care at the level of the individual. One of the key workstreams for the final year of the personal health budget pilot programme is exploring this in detail. The personal health budgets team is also exploring links with the Right to Control trailblazers² to understand the implications for the small number of adults who may be eligible for both the Right to Control and PHB³.

² A new legal right for disabled people, giving disabled people more choice and control over the support they need to go about their daily lives.

³ <http://www.education.gov.uk/childrenandyoungpeople/sen/b00191706/send-green-paper-pathfinders>
<http://odi.dwp.gov.uk/odi-projects/right-to-control-trailblazers.php>



8. Next steps for personal health budgets and NHS Continuing Healthcare

The right to ask for a personal health budget will come into force in April 2014, subject to the evaluation. Although the final evaluation report is not due until October 2012, NHS Continuing Healthcare teams need to start considering how to implement personal health budgets.

If you would like further information on personal health budgets or NHS Continuing Healthcare, please follow the links below. Any PCT/CCG that would like to join the personal health budget pilot programme as part of the wider cohort should contact the team via the email address: personalhealthbudgets@dh.gsi.gov.uk

Web links

Personal health budgets

www.dh.gov.uk/personalhealthbudgets

NHS Continuing Healthcare

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_106230



9. Case studies

Debbie was able to care for her father at home during his last months, using a personal health budget to arrange flexible nursing, which allowed her to care for her father while working and caring for her son.

Louise, 90, has Alzheimer's disease. Her personal health budget, managed as a direct payment for healthcare by her daughter, pays for personal assistants to care for her at home. Louise's daughter Mary says that Louise's quality of life has "increased exponentially".

Anita has Huntington's disease and has been cared for at home by her husband who used a personal budget in social care to employ a personal assistant (PA) to help with daytime support. Anita's condition has changed as she now needs 24-hour care and is eligible for NHS Continuing Healthcare. A personal health budget means that Anita's husband can continue to employ the same PA during the day and they arrange the additional care she now needs – for example at night. This ensures continuity of care and saves money as no agency fees are paid.



10. Q+As

For general FAQs on personal health budgets, please visit:

www.personalhealthbudgets.dh.gov.uk/About/faqs/

Q: Why doesn't the right come into force until 2014?

Evidence from our third interim report⁴ suggests that it takes around two years to implement personal health budgets. This is likely to be shorter during rollout given the learning from the pilot sites, but there needs to be assurance that all areas are geared up to deliver personal health budgets; it is likely to take until 2014 to do this.

Q: How are people assessed for NHS Continuing Healthcare?

The National Framework for NHS Continuing Healthcare, published in 2009, sets out the principles on who should qualify for NHS Continuing Healthcare – for more information please visit:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_106230

The assessment is carried out by the Primary Care Trust using a multi-disciplinary team of health and social care professionals to assess the totality of an individual's needs.

Q: How will the level of someone's budget be set?

The pilot sites are exploring this, including work that a number of them are engaged on to use the decision support tool to help set budgets; a model for this is currently being tested.

Q: Can I (as a PCT/CCG) still join the programme?

Yes. You will not be able to join the in-depth evaluation sites, but can join as part of the wider cohort, and can apply for direct payment powers. Please contact the DH team for more information (personalhealthbudgets@dh.gsi.gov.uk)

Q: What can I in a PCT/CCG be doing to prepare?

PCTs/CCGs should understand how personal health budgets fit into the NHS Continuing Healthcare pathway, including how and when they should be offered and the potential scope of them, as well as being able to deliver them.

Personal health budgets are not about new money and so funding for budgets will need to be freed from existing contracts/work. Finance managers and commissioning leads within PCTs/CCGs should start to consider how personal health budgets will impact local commissioning practices, particularly when commissioning block contracts.

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http://www.personalhealthbudgets.dh.gov.uk/library/Resources/Personalhealthbudgets/2011/Cost_of_implementing_personal_health_budgets.pdf



Q: Which personal health budget pilots are currently offering them to people in receipt of NHS Continuing Healthcare?

Of the 20 in-depth pilot sites, the following have included NHS Continuing Healthcare in their scope:

Doncaster	Northamptonshire
Dorset	Nottingham
Eastern and Coastal Kent	Outer North East London
Hull	Oxfordshire
Inner North West London	Tees
Manchester	Torbay
Norfolk	