Department of Health

Consultation on Direct Payments for Healthcare

Government response

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Government response

Prepared by the Department of Health

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Introduction

1. Personal health budgets are a concept which form part of the Government's wider drive to give people more choice and control over how their NHS needs are met. They build on already operational programmes of personal budgets in social care and personalised care planning for people with long term conditions. In order to succeed in giving people more choice and control personal health budgets have a central core which is a carefully prepared care plan. This is developed in partnership using the clinical knowledge and expertise of professionals and the individual's knowledge of how their condition affects them and what works for them.

2. Personal health budgets do not create new money; they simply use funds, which would have been spent on an individual's care, in different ways. The plan and the budget enable people to meet their needs in ways that work for them. They could choose to access traditional services and equipment and non-traditional services such as complementary and alternative therapies. Once it has been developed, the plan is then subject to clinical governance and sign off.

3. Between 2009 and 2012 personal health budgets were piloted in over 60 sites across England. As with personal budgets in social care, people with a personal health budget could choose how their budget was spent to meet their individual needs, in line with a care plan which they agreed with the NHS. The pilot programme looked at the use of personal health budgets for people with conditions and services such as NHS Continuing Healthcare, diabetes, Chronic Obstructive Pulmonary Disease, mental health and other long term conditions.

4. There was an independent evaluation of the pilots, led by the University of Kent,[1] and the final evaluation report was published on 30 November 2012. The evidence from the evaluation was positive, but did suggest some amendments. As a result the Government want personal health budgets to become an option for people across the country, starting with those receiving NHS Continuing Healthcare. CCGs will also be able to offer them to other people who they feel would benefit but this would be a decision for CCGs to make locally and, in some cases, after consultation with NHS England. The benefits of having a personal health budget however should always outweigh any additional costs.

5. Legally, it is already possible to offer people a personal health budget where the money is held by the NHS or a third party. However the option of a cash direct payment is not allowed outside the pilot areas. Both Houses of Parliament have agreed to amend the primary legislation, using a Parliamentary Order, to remove the pilot restriction, thus paving the way to making direct payments an option across England.

[1] http://www.personalhealthbudgets.dh.gov.uk/_library/Resources/Personalhealthbudgets/2012/PHBE_personal_health_budgets_final_report_Nov_2012.pdf

6. On 1 March 2013, the Government launched '*Direct payments for healthcare: a consultation on updated policy for regulation'*, to help decide our approach to any necessary amendments. The consultation ran for 8 weeks, in line with the Government Code of Practice, and closed on 26 April 2013.

7. The consultation sought views on the proposed changes which related to:-

- Regulation 7 – who should be eligible for a direct payment for healthcare.
- Regulation 8 – separating out 'direct payments for healthcare for children' and 'direct payments for healthcare for people who lack capacity'.
- Regulation 11 – care planning and what NHS services should be excluded from direct payments for healthcare.
- Regulation 12 – information, advice or other support provided to individuals by a CCG or the board.
- Regulations 13 and 14 – conditions to be applied to making one-off payments.
- New regulation – remuneration for family members for administration of complex direct payments for healthcare.
- New regulation – that direct payments for healthcare could include some public health services.

8. This document summarises the main findings and conclusions from the consultation and explains the approach the Government has taken in revising the direct payment for healthcare regulations which came into force on 1 June 2010.

1. The Consultation

Who contributed and how?

1.1 During the consultation, we were able to reach out to a broad audience in a range of ways:

- We gave people the opportunity to respond to an online questionnaire.
- We provided people with an email address and a postal address so that people could respond in different ways.
- We published an easy read document which explained the changes in a more accessible way.
- We carried out a cascade consultation to seek the views of groups who are traditionally harder to reach.

1.2 We received 140 consultation responses in the form of letters, email responses and responses to the online survey which we set up to poll what people thought about direct payments for healthcare.

1.3 A breakdown of the organisations that responded can be found at Annex A. Responses were also received from people who use health and care services, carers, NHS staff and the wider health and care workforce. We analysed all of the feedback we received.

1.4 We would like to thank those who took the time to contribute. It enabled us to hear many different perspectives and views and the feedback helped to shape the approach we took to updating the regulations, *The National Health Service (Direct Payments) Regulations 2010*.[2] The updated regulations were laid in July.

[2] http://www.legislation.gov.uk/uksi/2010/1000/contents/made

2. Summary of responses and key changes

What we heard

2.1 We asked about proposed changes to some parts of the regulations and asked whether others should remain the same as they were during the pilot programme. The response we received was generally positive and supported the suggested changes we made to the regulations and ultimately the implementation of direct payments for healthcare.

2.2 However a very small number of responses did not agree with the policy as a whole or felt that direct payments should be restricted to NHS Continuing Healthcare. Others suggested additional things that should be included in the regulations.

Changes we have made

2.3 Some of the responses suggested that we should update the regulations to strengthen the intention. For example, we asked you whether you thought one off payments should be able to be received into a personal bank account and you agreed that this was a good idea. Following this feedback we have decided to amend the regulations to allow for this. The pilot programme supported this approach, indicating that although a separate bank account is a good idea overall, it does not work in all circumstances.

2.4 Other responses we received made suggestions that people thought were necessary in order to make the regulations clearer. We considered these and believe that they may be better placed in guidance for Clinical Commissioning Groups on how direct payments should work. Others are, or will be, included in the wider information contained within the personal health budget toolkit.[3]

2.5 Finally, one area upon which we sought views, where there was less consensus, was payment of family members for managing direct payments. After careful consideration we have decided to keep this part of the regulations the same. A better understanding of the implications of paying family members to manage direct payments for large or complex care packages is needed before a decision can be taken on whether to allow payment in these circumstances. Essentially, more time is needed to explore the full implications of the policy, including implementation, any financial implications and the best ways to align health and social care policy in this area. Regulations could be updated in the future to allow payments in these circumstances.

[3] http://www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/

3. Eligibility for direct payments for healthcare; persons to whom a direct payment may be made.

Question 1: Do you agree that these are the right criteria to be used to determine eligibility for a personal health budget? Should they be prescribed in regulations?

3.1 There was overwhelming agreement that the eligibility criteria for direct payments were correct. A national UK charitable organisation said, "*We agree that it is appropriate for PHB eligibility to be based on level of need rather than particular diagnosis as this approach should be better able to accommodate people with multi-morbidities*". Over half agreed with it in its entirety and 84% of people who responded to this question agreed but wanted further clarification. There was a lot of support for the criteria to be based on need rather than on particular conditions or diagnoses in order to ensure that those with genuine need had greater control over their healthcare. We learnt lessons from the pilot which assisted us with getting the eligibility criteria right to ensure that the right people would be able to access direct payments for healthcare. The consultation showed that you agreed with our suggested criteria.

3.2 There were a large number of responses which stated that a national definition of eligibility was required to avoid local decisions and a postcode lottery. The concern was that without this there might be local variation. One member of the public said, "*I think there should be national guidance otherwise this becomes a postcode lottery*". Other responses felt that decisions should be made at a local level on a case by case basis in order to take account of individual need and local priorities. A County Council said, "*The criteria should allow for flexibility and balance at the local level and support decisions about the effective use of resources across the health economy*". We feel that the best way to deal with these competing views and other queries raised in the consultation is to issue guidance which will assist the local NHS to make the best decisions on eligibility. This will be published by NHS England in summer 2013.

4. Direct payments for healthcare in respect of children and persons who lack capacity.

Question 2: Do you agree with our proposal to separate out clauses in respect of children and adults who lack capacity? Are there any other capacity related issues you would like to see addressed?

4.1 93% of responses we received agreed that clauses in respect of children and adults who lack capacity should be separated. A charitable organisation said, "*In the interests of consistency it will… be more convenient to keep the arrangements separate for people who lack capacity*". These positive responses included all of the Clinical Commissioning Groups, charities, professional bodies and local authorities who responded to the consultation.

4.2 Some of the responses expressed concerns about safeguarding against fraud, mismanagement of funds and also issues related to fluctuating capacity. One member of the public said, "*What safeguards would be put in place to ensure there was no mismanagement/fraud?*" and a community group said, "*when working within the framework of the Mental Capacity Act, it needs to be clear are all times that decisions about capacity are flexible decisions that are time specific…*". These are important issues which are addressed in clauses of the regulations which deal with fraudulent misuse of funds and the requirement for a review process, whether or not the person's capacity changes. The guidance will discuss safeguarding and more information will be available in the personal health toolkit, which is being designed to assist CCGs.

4.3 We listened to what you said on separating out the clauses for children and adults who lack capacity and have separated the clauses in the regulations to reflect this.

5. Care planning and co-ordination

Question 3: Do you agree that personal health budgets should not be allowed to be spent on the services listed? Are there any other services which should be excluded?

5.1 It is the belief of the Government that personal health budgets and direct payments are not right for everyone nor should they be used for every NHS service a person may need. The majority of responses we received agreed that there should be a list of excluded services as laid out in the consultation. A County Council said, "*We agree with the list of restrictions detailed in the consultation document and what a direct payment for healthcare can be spent on should remain broad meaning that people are able to meet their health and wellbeing outcomes in ways which make most sense to them*".

5.2 The responses we received suggested a number of other helpful suggestions on what should be excluded and indeed what should be included. A CCG said, "*Specialised commissioning services/ areas should also be excluded as should private room charges (if the facility is alongside an acute facility for example)*". A charitable organisation said, "*PHBS should not be allowed to be used for the services listed such as GP services, prescriptions, sight tests, immunisations and emergency and unplanned care. These are all areas that should continue to be met through existing arrangements and budgets*".

5.3 The suggestions made on further inclusions and exclusions provided us with some useful ideas. The regulations are not designed to contain an exhaustive list of what services could be included but rather a list of ones which we think should be excluded at this stage. We believe that CCGs should be able to make decisions on what services could be included on a case by case basis without central Government removing all means of flexibility. We will keep the list of excluded services under review as we learn more about personal health budgets.

5.4 Taking into account all the comments received on this question, the exclusions listed in the consultation document will be included in the regulations.

6. Information, advice and other support.

Question 4: Do you agree that the list of information, support and advice that patients are entitled to ask their PCT or CCG for should be supplemented with the items listed in the consultation document?

6.1 The majority of CCGS, local authorities and professional bodies who responded showed general agreement with the supplementary information suggested. A City Council said, "*We believe these additional elements are essential*" and another City Council said, "*We agree that the list of information, support and advice that patients are entitled to ask for should be supplemented [as suggested]*". Only 6% of responses disagreed with the list of information, support and advice being supplemented with other items detailed in the consultation paper. The remainder of the responses we received were either positive or held no particular views on this question.

6.2 The responses we received generally felt that information should be freely available and people interested in direct payments should not have to ask. An independent consumer organisation said, "*We do not believe that it should be left for individuals to ask for information. It is reasonable to expect that CCGs will provide this information as standard. The information listed is fundamental in order for an individual to make an informed decision on whether to opt for a PHB or not*". The evaluation of the pilot programme and wider learning is clear that having the right information and support is key to the success of direct payments for healthcare and personal health budgets more widely. Section 9(1) clearly states that a health body must make arrangements for a patient, representative or nominee to whom direct payments are made to obtain information, advice or other support in connection with the making of direct payments.

6.3 Some responses we received felt that information should be available in a variety of formats to ensure that people with learning disabilities, dementia and mental health issues were able to access it. A local Council said "*All necessary information should be provided in an easy to understand and jargon free language to enable an individual, with support from their CCG, heath professional or third party organisation if they want it, to make informed decisions*". Accessibility is something that CCGS will be familiar with already and they will have to work towards ensuring that information is available in various formats based on local need.

6.4 Some responses suggested a variety of other ideas on what should be included in the information supplied, such as how the budget should be calculated and how the budget can be spent. The list we provided in the consultation document is not intended to be comprehensive

and CCGs will be able to add to it if they wish. The personal health budget toolkit includes more information for CCGs and others on information, support and advice.

6.5 One important factor which was highlighted in the consultation was the need for guidance on employing staff. It is important to note that anyone who is using a direct payment to employ people will need to meet their legal obligations which would apply to any employer/employee relationship and includes paying tax and national insurance. It is important that any information on this is up-to-date and so links to other agencies such as HMRC are a more reliable way to enable people to have a good understanding of their obligations.

7. Conditions applying to the making of direct payments for healthcare.

Question 5: Do you agree that there should be the option of paying one off direct payments for healthcare into an individual's personal bank account?

7.1 Although the majority of people in receipt of direct payments will have regular payments made to them there are some where a one off payment to cover the cost of specific things is appropriate. The pilot programme, and evidence from how direct payments for social care have worked, taught us that asking those people to set up a separate bank account for a one off payment was overly bureaucratic and time consuming. We asked whether you thought that people should be able to have a one off payment paid into their personal account and 75% of the responses we received agreed that this was a good idea. It was felt that it would make it easier for people to explore the benefit of using direct payments. A charitable organisation stated, "*This will help unnecessary duplication of administrative tasks and will also enable the individual to tailor an integrated care programme*".

7.2 However, it was strongly felt that there should be a clear audit trail to ensure that money was being used as agreed in the plan. Those responses which did not agree felt that it opened the system up to abuse and could lead to payments being used fraudulently. A national charitable organisation said, "*There needs to be accountability and easy monitoring of how such monies are spent, including monitoring of incidences of patients supplementing PHBs with other monies*".

7.3 Other responses showed concerns about the continuing costs which may flow from a one off payment, for example to cover maintenance of equipment, where the one of payment was for something such as a wheelchair or stair lift.

7.4 All direct payments for healthcare will be reviewed by CCGs to ensure that the money has been used effectively. This may include inspection of receipts. CCGS will consider whether maintenance is needed during the care planning stage and include this in the plan. If during the review there is a suggestion that the money has been used inappropriately then this will impact on whether the recipient will be able to access direct payments for healthcare in the same way in the future and appropriate action may be taken. In the most extreme cases CCGs will be able to recover funds which have been used incorrectly and the regulations set this out clearly.

8. Direct payments for healthcare and public health.

Question 6: Do you agree that local authorities should be included in the scope of the regulations for direct payments for healthcare?

8.1 The majority of responses we received were positive and we heard that the involvement of local authorities was extremely important to the integration of health and social care. A national charitable organisation said "*It is important to ensure that people receive joined up health and social care support and to avoid duplication*".

8.2 Many responses mentioned that they wanted clarity around responsibilities and boundaries of each organisation on who funds a person's direct payment. One national charity said, "*Need to clarify what part of the budget lies with the local authority and what lies with the CCG, and this needs to be explained to the service user*". A local charitable organisation said, "It will be important to have clear lines of demarcation as to when the Authority becomes involved in relation to healthcare matters".

8.3 Integrating health social care and other services around the needs of service users and local communities is key to improving their experience of services and delivering personalised care. The '*Caring for our future: reforming care and support*' White Paper sets out the Government's vision for a comprehensive reform of the care and support system, with the aim of achieving greater consistency in access to care and support and improving the integration of different services.

8.4 Delivering the vision will rely on good partnerships, across the NHS, public health, local government, the voluntary sector and local communities themselves. In the reformed health and care system, Health and Wellbeing Boards will play a crucial role in bringing together local partners to improve health and care outcomes, delivering meaningful Joint Health and Wellbeing Strategies and maximising opportunities to integrate health, social care and other services.

8.5 In many parts of the country, health and social care teams are already working closely together in a more integrated, person centred way. They have found that a more stream-lined, joined up approach results in a better outcomes and a better experience.

8.6 We also heard that there is a need for local authority staff to receive training to help direct payment holders make the best decisions about their health care and to understand health care options. Training and development of all staff is important and learning on this is included in the toolkit which will evolve over time as we learn more about implementing personal health budgets well.

9. Administration of direct payments for healthcare.

Question 7: What are your views on friends and family members being paid for managing complex or large healthcare packages? How should this be defined, for example should it be linked to the size of the direct payment?

9.1 We received a range of responses to this question. Over half of the responses to the question supported paying family members. The majority of the responders who were positive said that carers should be recognised for the contribution they make and are often best placed to know what is required. A local charity said, "*Yes I agree and think it's an excellent opportunity to recognise and identify the difference between the unpaid informal care that friends/families provide when living with someone, and the additional care which is over and above what should be deemed as unpaid*".

9.2 However a number of respondents raised issues with the complexity, risks and challenges of implementing such a policy. These included potential risks of abuse and difficulties that some family members may experience in carrying out this role.

9.3 People raised a number of practical challenges to implementing the policy, including how CCGs would decide who should be paid and how much, whether there should be a single national eligibility criteria and payment rates or whether this should this be left to local decisions. Questions were also raised as to how it would fit with other payments carers receive such as carers allowance and other state benefits.

9.4 It was suggested by some respondents that the policy of paying family members to manage budgets in social care, should be changed too, so that the same rules applied in health as in social care. Others suggested that paying family members to manage budgets should be kept in line with paying family members for providing care and that it should only be allowed in exceptional circumstances in both health and social care. A professional association said, "*There are risks that the recipient of the direct payment maybe placed under undue pressure from relatives to spend the budget in a certain way, and the risks are greater the more significant the size of the direct payment*".

9.5 Some responders said that one size does not fit all so there would need to be flexibility to allow CCGs to work with families in the decision making process. A CCG said, "*This depends on individual circumstances and needs to be flexible and subject to approval by CCG*".

9.6 In light of the responses received, we have decided not to change the regulations. This means that family members living in the same household will only be able to be paid to care for the individual in exceptional circumstances. We believe that a better understanding of the implications of paying family members to manage direct payments for healthcare for large or complex care packages is needed before a decision can be taken on whether to allow payments in these circumstances. Further work is needed in this area.

10. Areas of direct payments for healthcare policy we proposed to keep the same.

Question 8: Do you agree that the regulations described in Annex C should remain the same? If not, what would you like to see changed?

Question 9: Are there other areas that you would wish to see in regulations? If so, what are they?

Question 10: Could the proposals have any perceived or potential impact on equality including people sharing protected characteristics under the Equality Act 2010?

10.1 Of the responses received the majority did not want a change to the regulations described in Annex C of the consultation. However 20 per cent of responses did suggest that additional areas should be included.

10.2 Some of the suggestions included:-

- a need to have a better definition of care co-ordinator;
- the suggestion that information should be provided orally;
- the suggestion that money should take account of inflation and that funds not spent should be able to be carried over;
- flexibility of reviews to accommodate people with long term conditions which fluctuate in their severity;
- a repayment approach which is proportionate and sensitive to the situation concerned;
- a need for commissioners to give full reasons for stopping payments;
- a need for guidance on mistakes which do not amount to fraud;
- timescales to ensure that personal health budgets decisions are made before people give up on the idea.

10.3 A national charitable organisation said, "*While we agree that fraudulent use of the money should require a repayment, the regulations need to allow for the accidental, in good faith, use of the money on health care that it should not have been spent on*". A Clinical Commissioning Group said, "*A better definition of care co-ordinator is required. It needs to be clear what this*

role is". Another national charity said, "*provision of information should make allowances for individuals to provide information verbally and for this to be transcribed. This is particularly important for those who have problems with writing or use sign language*".

10.4 The regulations are not designed to include all eventualities and scenarios which may arise. Other mechanisms such as the guidance and toolkit will help CCGs, and others, implement personal health budgets, including direct payments for healthcare. The guidance and toolkit[4] already includes information on many of the areas suggested in the consultation responses and we will use your ideas to help these documents evolve.

10.5 The majority of the responses to the consultation felt that there would be no impact on equality or they provided suggestions on how any impact could be minimised. A large number of responses did not answer this question at all. The suggestions given included the need to monitor the system to ensure that inequalities did not surface. One independent national organisation said, "*there is a requirement for continual piloting, modelling and monitoring to ensure that it does not inadvertently widen healthcare inequalities*". Other suggestions highlighted the need to provide information in a variety of formats to ensure accessibility for all and one local charity said, "*consideration will have to be given to the provision of information in formats that are appropriate for the individual*".

10.6 Based on the evaluation of pilot sites, there is no evidence that personal health budgets for healthcare lead to a deterioration in equalities. In areas where personal health budgets for healthcare were implemented well, the beneficial effects were greater. Personal health budgets for healthcare could lead to better outcomes for some groups, whose needs were poorly served by conventional health services, including people from different ethnic backgrounds, people with learning disabilities and people with mental health problems. People will clearly need the right information, advice and support to enable them to take up personal health budgets but as long as this is available the potential to create a fairer system is good.

[4] http://www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/

11. Conclusion

11.1 We are very grateful to all those who responded to the consultation on direct payments for healthcare. We had a broad mix of contributions and received many constructive responses which will help to inform the guidance which will be published before autumn 2013.

11.2 Personal health budgets are designed to give people more choice and control over the care and support they receive and direct payments for healthcare will further enable this. There is much to learn about implementation of the policy and we accept that this will take time. The responses we received in this consultation have been helpful in illustrating some of the challenges we face and the benefits which will flow from the introduction of direct payments for healthcare.

11.3 We will continue to work closely with all our partners and stakeholders and always welcome your feedback on how rollout is progressing in practice. The consultation has served to prove that people are positive about how direct payments for healthcare will make a real difference to people who live with long term conditions and disabilities. With a phased implementation process enabling us to learn and build on our experiences, personal health budgets and direct payments for healthcare will pave the way to a more person centred future for the NHS.

Annexe A: Organisations that responded

Age UK
Age UK Oxfordshire
Arthritis Care
Arthritis Research UK
Aspire
Bedfordshire CCG
Birmingham and Solihull Joint Commissioning Team
Black and Minority Ethnic Outreach Group
BMA
Bracknell Forest Council
British Acupuncture Council
BUPA
Cambridge and Peterborough Foundation Trust
Cambridge Weight Plan
Carers Outreach Group
Carolyn Johnson Associates
Chartered Society of Physiotherapists
Cheshire Centre for Independent Living
CQC
Darlington Association on Disability
Derby City Council
Disability North
East Sussex County Council
Hampshire County Council

Healthcare Financial Management Association
Healthwatch England
Homecare Direct
Independent Living Association
Islington CCG
Jan Net Ltd
Leicester Carers Centre Forum and Carers Action Group
Leicestershire Centre for Integrated Living
Linkage Community Trust
Marie Curie
MENCAP
Mental Health Outreach Group
MIND
MIND in Kingston
Motor Neurone Disease Association
MS Society
Multiple Sclerosis Trust
National Family Carer Network
National LGB&T Partnership
National Obesity Forum
Newcastle City Council
NHS Coastal West Sussex CCG
NHS Confederation
NHS Doncaster CCG
NHS Dorset
NHS Hastings and Rother CCG

NHS Nene CCG
NHS Nottingham City CCG
NHS Protect
NICE
One to One Midwives (NW) Ltd.
Oxford Brookes University
Oxford Health NHS Foundation Trust
People with Learning Disabilities Outreach Group
Peoplehub
Royal College of General Practitioners
Royal Pharmaceutical Society
RUILS
Salford City Council
Sandwell Carers
Sheffield City Council
Southwest London and St Georges Mental Health NHS Trust
Spinal Injuries Association
Staffordshire County Council
Stockton Borough Council
Symbi Consulting
The British Society of Rheumatology
The Lesbian and Gay Foundation
The Mental Health Foundation
The Royal College of Nursing
The Royal College of Radiologists
The Whitehouse Consultancy Ltd.
Together for Short Lives

Unison
University of Edinburgh
University of Kent
University of Leicester
Young Carers in Norfolk Outreach Group
Young Disabled People Outreach Group
Young Onset Dementia Outreach Group