EXPLANATORY MEMORANDUM TO

THE NATIONAL HEALTH SERVICE (DIRECT PAYMENTS) REGULATIONS 2010

2010 No. 1000

1. This explanatory memorandum has been prepared by the Department of Health and is laid before Parliament by Command of Her Majesty.

2. Purpose of the instrument

2.1 These Regulations allow the Secretary of State to set up pilot schemes within which:

- the Secretary of State could make direct payments of cash to or for patients in lieu of providing health care. The Regulations enable the Secretary of State to direct a Primary Care Trust (PCT) to exercise his functions under a pilot scheme; and
- PCTs could make direct payments in lieu of providing mental health after-care.

3. Matters of special interest to the Joint Committee on Statutory Instruments

3.1 None

4. Legislative Context

4.1. These are the first Regulations made under the powers in sections 12A to 12C of the *National Health Service Act 2006*, inserted by the *Health Act 2009.* The Regulations allow the piloting of direct payments for health care or mental health after-care.

4.2. The Regulations require a review of each pilot scheme to take place.

Following a review, the Act provides for either:

- national roll-out, by means of an order for repeal of the provisions that restrict the making of direct payments to within pilot schemes, or
- repeal by order of the provisions for direct payments.

4.3. Either order would be subject to the affirmative resolution procedure.

4.4. National roll-out would require further Regulations, which would be informed by the experiences of the pilot programme.

5. Territorial Extent and Application

5.1. This instrument applies to England.

6. European Convention on Human Rights

As this instrument is subject to the negative resolution procedure and does not amend primary legislation, no further statement is required.

7. Policy background

• ***What is being done and why***

7.1. The Government is piloting direct payments for health care as part of a wider pilot programme exploring the use of personal health budgets. Personal health budgets are intended to give patients a greater understanding of, and more control over, the money spent on their care.

7.2. Personal budgets could be offered in different ways. The budget itself could be held on the patient's behalf by a PCT or a third party; the NHS already has power to offer personal budgets of this kind. Sections 12A to 12D inserted into the *National Health Service Act 2006* by the *Health Act 2009* provide powers to test cash direct payments as an additional option, where the personal budget is given directly to the patient.

7.3. For all types of personal budget, the Government's policy is that:

- receiving a personal health budget should be entirely voluntary;
- a care plan should be agreed between the patient and the PCT describing how the personal budget will be used; and
- no one should be denied essential treatment as a result of having a personal budget.

7.4. There are currently 70 PCTs involved in the pilot programme, testing personal budgets for a range of health conditions and services, including NHS Continuing Healthcare, mental health, long term conditions, end of life care and learning disabilities.

7.5. The Regulations allow for authorised pilot sites to test direct payments. The Regulations provide the framework for administering direct payments and specify how a pilot scheme is made and reviewed.

7.6. The Government recognises that this is a complex and challenging policy, and so is piloting personal health budgets (including direct payments) in order to build evidence on how effective they are and how they should best be introduced. The Department of Health has put in place an independently-led evaluation programme, which will inform any future developments (see 12.1).

7.7. The Department anticipates that, following the pilot programme and in light of the evaluation and lessons learned, there will be a further review of the policy. If a decision is taken to extend direct payments more widely, further

secondary legislation will be required, and there is likely to be a further period of public consultation.

- ***Consolidation***

7.8. None

8. Consultation outcome

8.1. A consultation on proposals for Regulations and guidance was run between October 2009 and January 2010. The Department received 132 responses, including comments from members of the public, third sector organisations, local authorities, NHS bodies and professional representative bodies.

8.2. Respondents were generally supportive of the Department's proposals. In light of the comments received, a number of changes to the proposals were made, mostly on matters of detail. Key changes included:

- giving power to PCTs to select a representative to hold a direct payment on behalf of an individual who lacks capacity to give consent, where there is no legal representative in place (e.g. a deputy, donee, attorney, or a person with parental responsibility);
- requiring PCTs to advise the patient or nominee of significant risks, the potential consequences of these and the means of mitigating the risks;
- making recipients of a direct payment initially responsible for checking that their health care provider has complied with any necessary registration requirements, and has appropriate indemnity cover where necessary. The patient may ask the PCT to carry out these checks instead – in which case, the responsibility would fall on the PCT. PCTs must also consider these issues during any review of the patient's care plan; and
- making the evaluation requirements more explicit.

8.3. The Government's response to the consultation is available from the Department of Health's website (www.dh.gov.uk), and includes more detail about the changes made.

9. Guidance

9.1. The Department will be issuing guidance to pilot sites to explain the Regulations and core parameters of the personal health budgets policy in more detail. The guidance is likely to evolve as the pilots develop, in order to address emerging issues and to disseminate good practice.

10. Impact

10.1. The impact on business, charities or voluntary bodies is not anticipated to be significant.

10.2. There will be some impact on the NHS. At this stage, the level of impact is uncertain, but will be evaluated as part of the pilot programme.

10.3. The same Impact Assessment is being used as was used for the primary legislation; relevant sections are attached to this memorandum. The Impact Assessment addresses the personal health budget programme as a whole, as there is no firm evidence for any additional costs associated with direct payments compared with other mechanisms. The figures quoted continue to be accurate.

11. Regulating small business

11.1. These Regulations do not apply to small businesses.

12. Monitoring & review

12.1. An independent evaluation team led by the Personal Social Services Research Unit at the University of Kent has been appointed to review the personal health budget pilot programme. The report of the evaluation is scheduled for the end of 2012, and this will inform any decision on the future of personal health budgets and direct payments for health care.

13. Contact

Dr Alison Austin at the Department of Health (Tel: 0207 210 4947 or email: Alison.austin@dh.gsi.gov.uk) can answer any queries regarding the Regulations.

ATTACHMENT 1: IMPACT ASSESSMENT
NATIONAL HEALTH SERVICE (DIRECT PAYMENTS) REGULATIONS 2010

This information has been extracted from the Personal Health Budget Impact Assessment used for the Health Act 2009. The figures remain relevant. The full impact assessment can be found at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_093305

Section III COSTS OF DIFFERENT OPTIONS

Option (c) – piloting personal health budgets

We have now received 74 expressions of interest in becoming pilot sites, and we anticipate the majority will become part of the pilot programme. The depth to which they are evaluated will vary, as it is not feasible for an evaluation team to cover such a large number of sites in equal depth. The exact structure of the evaluation will be determined once a research team is in place (see section XI). However, it is likely that to get a representative sample of areas we would aim to evaluate around 20 sites in detail, while the other sites would feed in information and data. This sample is likely to include urban and rural areas, affluent and deprived areas, a range of patient characteristics, and a variety of methods of delivering and supporting personal health budgets. A large enough sample, together with a range of control groups, would give enough information for more informed conclusions about the likely impact of personal health budgets, including system effects, than we would have in the case of permitting and encouraging the use of personal health budgets only.

Estimated additional costs of offering personal health budgets

As above, we have limited evidence upon which to base assumptions as to the additional costs per patient, which are again estimated to be £0 for the reasons given above.

Estimated one-off and transitional costs of piloting personal health budgets

As with option b), there is likely to be a one-off cost to PCTs piloting the policy, which would cover the cost of additional support, administration and care management (as outlined above derived from the social care Individual Budgets pilots and detailed in Annex B). This is projected to cost around £½ million per pilot site over two years, or £¼ million per year. The Department of Health is envisaging providing some financial support to pilot sites, primarily linked to the costs they will incur in supporting the evaluation.

Given the prevailing uncertainty around the costs and benefits, the pilots would be accompanied by a robust evaluation over the course of the pilots. This would also include the introductory phase. Over a three-year pilot programme, this evaluation would require a significant amount of money, a cost incurred centrally. There will be

further costs around project support, pilot design, start-up costs around redesigning data systems and on going programme costs, covering shared learning events, managing communications and so on.

Following discussions with those involved with the social care Individual Budgets pilots, these costs are assumed to total £5 million per year over 5 years from 2008/9, including the transition costs incurred locally.

The assumptions underpinning this figure have altered since the initial Impact Assessment was published, though the figure itself has remained the same. The £5 million per year was originally based on approximately 20 pilot sites with large numbers of patients (1,000 individuals included per site). In practice, the Department received more pilot proposals than expected, and of a higher quality, so there will be more than 20 pilot sites. The majority of the proposals were intending to include relatively lower numbers of individuals. Therefore, with a lower number of individuals per site and a larger number of sites, we are assuming at this stage that the cost of the pilot programme will remain approximately as per the previous version.

The available central funding from the Department has not altered, and it is not anticipated that the overall cost to the NHS will be significantly different (though the distribution of it will be, as it will be a lower average cost across a greater number of sites). Based on some of the bids received that include cost information, the costs outlined in Annex B may be more applicable to the larger bids.

Many of the costs outlined in Annex B, such as the re-designing of data systems, are vital in order to provide the required information for the evaluation team to draw robust conclusions. Therefore, it is likely that the Department will give the majority of the programme funding to those pilot sites that are included within the in-depth evaluation, recognising the extra costs associated with this. Other pilot sites would receive a small amount of programme funding.

IV IMPACTS OF PERSONAL HEALTH BUDGETS

Most domestic and international evidence on the use of self-directed care comes from personal budgets in social care in the UK and from projects covering mental health in the US. There is evidence that self-direction improves individual's well-being by promoting a more preventive approach to care. Consequently, self-direction has also lowered the costs of care by shifting care away from costly acute interventions. The US experience has generally focused upon more deprived groups of people, and the benefits achieved have served to reduce health inequalities. An overview of the US projects and English experience in social care is provided in Annex C, which also includes a discussion of the potential benefits. As social care and the US healthcare system are not directly comparable within the NHS, the figures quoted are indicative only.

There is a lack of quantified evidence on the benefits. These potential benefits are based upon improvements in satisfaction, wellbeing and the feeling of being in control reported in both the social care pilots and the evidence from the US.

Some patients will experience lower levels of benefit and there is a risk of a patient opting for a personal health budget when they would do better under traditionally commissioned NHS services (though the continued involvement of the NHS should in general ensure this is spotted early and corrected). A well-designed pilot will give information on the groups that are likely to benefit from personal health budgets, and will identify how tailored support can increase the benefits for these groups. For example, as illustrated in Annex E, older people initially experienced fewer benefits from the social care Individual Budget pilots, but this appears to have been in the short term only, as the implementation of the individual budgets has been adapted to offer more tailored support for this group of people.

Annex D includes some indicative quantification of the potential benefits of both immediate promotion of personal health budgets and initial piloting. This is based upon plausible assumptions, but the quantification itself should not be considered anything other than an indication. It is included to show the potential benefit from piloting above immediate promotion of the policy.

V VALUATION OF IMPACT OF DIFFERENT OPTIONS

Option (c) – Pilots

Improvements in well-being during the pilots

As above, there will be some benefits associated with improved wellbeing and satisfaction, but at this stage it is not possible to state with any certainty what the monetised benefits will be. Therefore, Annex D again contains indicative values only.

The value of information from piloting in future years

The pilot programme and evaluation will be designed to give as much information as possible about the conditions that are most appropriate for personal health budgets. It will also give information about which patients are most appropriate, and what support services are required for different types of patients.

Annex D provides some plausible, but indicative, results as to what the potential benefits could be at a patient level. It illustrates the likely increase in expected benefit per patient. It is reasonable to conclude that a substantial increase in net benefits may arise as a result of piloting, informing how the policy should best be implemented, including what support services are required. In the event that the benefits are not as high as predicted and that the policy is not cost-effective, then we will reconsider the policy from a more informed viewpoint. On this basis, we believe that the costs incurred in piloting personal health budgets are justified.

VI UNCERTAINTIES

There are many uncertainties within this policy. Piloting will reduce these uncertainties and give us significantly more information as to if and how the policy should proceed in the longer term.

Overall demand for personal health budgets, and a potential increase in demand

There is significant uncertainty over potential take-up and likely trajectory of take-up, as discussed above. We also expect that a successful pilot will increase the general demand for personal health budgets.

Switch from private to NHS funding of healthcare

Success of personalisation could reduce the attraction of private insurance as NHS service becomes more responsive. This would lead to increases in demand on NHS resources.

Impact upon health inequalities

While previous personalisation programmes have been encouraging, the impact of personal health budgets upon health inequalities is uncertain, and is likely to require tailored and culturally sensitive support. This will be monitored as part of the evaluation. Pilot proposals will be assessed as to their likely impact on inequalities.

Impact on different groups according to background

As outlined in the equalities impact assessment (Annex E), there is the potential for personal health budgets to impact differently upon groups according to their background, and also to help groups that currently do not access NHS services. This will require knowledge, sensitivity and potentially innovative ideas from the pilot sites to overcome disengagement. This again will be one aspect on which pilot proposals will be assessed.

Public perception

There is a risk that as budgets start being used in non-traditional, though cost-effective, ways the public will perceive that the money is being used frivolously. This is not an issue of effectiveness, but it means that the policy will require sensitive handling.

Transition costs and system impacts

In the interim, and while uncertainty persists about what individual choices will be, there are likely to be double-running costs, as PCTs and providers adjust from traditional provision of services towards a more responsive service. In the short-term at least, both would be provided. There may also be a risk of destabilisation of existing services, where recipients are given more choice and opt away from the care they would traditionally have received. We do not know the likely scale of this – the pilot will provide more information as to whether this is a likely effect.

Economies of scale forgone

It may be more cost-effective to meet care needs through a uniform service than a personalised service; some such areas may not be suitable for personal health budgets.

There have, however, been some examples in social care of groups of individuals pooling their budgets to commission services at a lower cost per person; this too is something that the pilot programme may be able to explore.

Negative effects of introducing choice

Experimentation and choice encouraged through personal health budgets may result in patients picking 'wrong' treatments. This is partially mitigated through the care planning process, but the experimentation will still lead to some people picking non-optimal treatments.

Budget does not match patient's needs

Should health needs exceed those expected, a personal health budget holder will not be barred from further treatment. However, if need is less than expected, budget holders may have spare resources to buy services of higher quality, or to meet more marginal needs.

VII COMPETITION IMPACTS

A more personalised approach to service commissioning should encourage a more flexible response from providers – by rewarding responsiveness and efficiency on the part of providers in meeting the varied needs of patients. Personal health budgets could also strengthen choice and contestability within community settings. This builds on the care planning and community service currency development policies.

Some benefits of increased contestability may arise during piloting; however, the full benefits are unlikely to arise unless the policy is introduced nationally. We will need to re-evaluate the effects upon competition in this event. The likelihood of increased competition may vary by area, with urban areas experiencing more market entry than rural areas. This is not a definite effect – again, piloting would provide some information and an indication as to the extent to which this will happen, although the full effects will not be felt during piloting.

VIII HEALTH IMPACTS

Annexes C and D provide some information as to plausible effects of introducing personal health budgets. Piloting first will help to mitigate some of the identified risks. Possible impact on people from different socioeconomic groups is outlined within the Equality Impact Assessment (Annex E). It is not possible at this stage to identify differential impacts for urban and rural backgrounds, though piloting would give more information as to whether this is an issue. There is a clear opportunity to reduce health inequalities, as discussed in the Equality Impact Assessment, but this will depend on appropriate and sensitive support services being introduced along with the personal health budgets themselves.

IX EQUALITY IMPACT ASSESSMENT

It is likely that the effects of personal health budgets will vary depending upon an individual's background and personal characteristics. This includes the projected benefits and the support services required, as well as the likely method of implementation. The extent of this variation, and what can be done to overcome it, is uncertain at this stage, and previous work, most notably the Individual Budgets pilots, has shown initial variation in experience of people depending upon their age. This fell during the pilot period, with learning around how the policy should be implemented growing over time.

The full Equality Impact Assessment is included in Annex E. It covers evidence around current prevalence of long-term conditions across different groups and some evidence of current experience of different groups with the health system. It also includes a discussion of the impact on different socioeconomic groups.

Annex B – costs of personal health budgets

The Care Planning Impact Assessment assumes that between 50% and 90% of patients with long-term conditions take up the offer of care plans, with 70% as the midpoint estimate. It is likely that the majority of people taking up offers of personal health budgets would, in the absence of the policy, take up a care plan, though it is possible that some people will be more inclined to participate in personal health budgets than care planning alone, due to the added control offered.

Option b) – permit and promote a range of personal health budget models

Local one-off and transition costs

Estimates of these costs come from the evaluation report of the individual budgets pilots in social care[1], set out in table B1. The social care individual budgets pilot involved 13 Local authorities (LAs) including two London boroughs, five metropolitan boroughs, four county (shire) authorities and two unitary authorities. Information was collected from 12 of the 13 pilot sites. The estimates represent the costs incurred by LAs for relatively small groups of personal budget recipients, so may not be wholly applicable to PCTs dealing with large groups of patients. Nevertheless, they provide an indication of the costs associated with implementing personal health budgets.

The following are average costs for items identified in the IBSEN report:

- to **design systems** (for example, assessment, resource allocation, support planning, review, financial administration and information system set up) – **£42,594**
- to **train the workforce** (for example, initial training/involvement in design) – **£13,100**

[1] Glendinning, C., Wilberforce, M., Moran, N., Netten, A., Jones, K., Manthorpe, J., Stevens, M., Knapp, M., Fernàndez, J., Challis, D., Jacobs, S., Evaluation of the Individual Budget Pilot Projects (April 2008), University of York, University of Kent, King's College London, London School of Economics, University of Manchester.

- to **develop support planning/brokerage** *(*for example, peer support, developing a private/voluntary sector role and developing marketing materials for in-house services) – **average for social care pilots was £51,710, though this is based on predictions**
- re-negotiating contracts and managing transitional arrangements (for example, development of a procurement and commissioning strategy, contract renegotiation, transitional arrangements) – **only two social care pilot sites identified this as a cost, and the figures they gave varied significantly (from £1,030 to £10,440)**

Data is from LAs at a time when the full costs associated with the categories mentioned above – except for 'designing systems' - were unlikely to have been fully realised by every LA taking part in the pilot. The table below outlines the range, and the total cost if the average is taken for 'designing systems' and the maximum for everything else.

Table B1: Estimated Set up Costs: Social Care and Healthcare

	Minimum	**Average**	**Maximum**
Overall Set-Up Costs per PCT, from Social Care Pilots, **including:**	128,470	**286,630**	486,460
Designing systems	5,000	42,594	**148,880**
Workforce Training	918	13,100	**35,800**
Develop support planning/brokerage support	20,000	51,710	**80,000**
Contract renegotiation	1,030	5,720	10,440
Total		**369,734**	

Table taken from the IBSEN report evaluating the effects of individual budgets in social care

It is likely that set-up costs of introducing personal health budgets for health services will vary. Some PCTs will have information and administrative systems more easily adapted to the requirements of personal health budgets than others will, and the costs associated with healthcare are likely to exceed those identified within social care due to the more complex nature of the health system. Therefore, the above figure is likely to be a low estimate, and will also be subject to local variability.

The IBSEN evaluation identified costs in the second year of implementation as well, associated with employing project leads and additional support. The total cost identified - £85,000 per site – may not be a true cost of that which would be incurred within the health system due to the added complexities of the health system. This gives a total of £455,000 per site over two years, which has been rounded to £500,000 as it may be an underestimate, giving £250,000 per year. This is still likely to be an underestimate, but we do not have any evidence at this stage upon which alternative assumptions could be based.

This figure is based on the relatively large pilots within the social care Individual Budgets work. As discussed in the main text, we have received more bids than expected, and they are a higher quality than expected. As they are also of a lower size, we have assumed that the overall cost of the programme, to both the NHS and to the

Department of Health, will remain approximately the same as was identified in the previous version of the Impact Assessment.

Central one-off and transition costs

In addition to the costs incurred locally in offering personal health budgets, some costs would be incurred for central design and in providing some central support for PCTs, incurred in learning events and related. Total costs under this heading are estimated at approximately **£3m**, based on discussion with internal experts.

Annex E – Equality Impact Assessment

The evidence of benefits of personalisation in social care and in overseas healthcare systems is encouraging. However, as discussed above, significant uncertainties remain, which is why we are first piloting the model. This is particularly apparent when assessing the likely impacts of personal health budgets on different demographic or socioeconomic groups. While the IBSEN report provided a lot of information, the following discussion is heavily drawn from grey literature and summary statistics from other areas, which, while relevant, must be interpreted with some caution.

The pilot programme of individual budgets in social care was evaluated within the IBSEN report. The introduction of personal budgets had a generally positive impact, though the evidence is not conclusive. The evidence on impact on different groups of people is more uncertain. For instance, the pilots covered a higher proportion of people from Black and Minority Ethnic (BME) backgrounds than would be a representative sample across the pilot sites, but even so this comprises only 80 or so people (approximately 8% of a 956-person sample). Further, the pilots were then split into four areas – physical disability, older people, learning disability and mental health – meaning that differences between people from different ethnic groups cannot be measured robustly. IBSEN does report that white people are more likely to be satisfied, but this is only weakly statistically significant, and the model itself has limited explanatory power.

IBSEN also considered the impact of age, but the results were largely inconclusive. Age tends to be correlated with improved outcomes (with the exception of the General Health Questionnaire – GHQ – score, which is only statistically significant at the 10% level). However, as we discuss below, this cannot does not necessarily mean that older people will tend to benefit more from personal budgets. This is discussed more in the ‘age’ section below.

Because of the uncertain impact, the proposed evaluation of personal health budgets pilots will have the impact on different groups of people and wider health inequalities as one of its core components.

There is significant overlap between the groups here. The content of the sections below is split in a somewhat arbitrary nature – for example, there is a clear and major overlap between the age and disability sections – and this should be borne in mind when reading.

There is no differentiation in this section between personal health budgets with or without healthcare direct payments; we have little evidence as to differential impacts. There is some evidence that direct payments within the social care Individual Budgets pilots had lower take-up rates within older groups. The reasons for this – discomfort in handling a budget, disempowerment, lack of sensitivity around a perception that older people do not want 'change', and lack of appropriate support services – are likely to be faced in implementing healthcare direct payments, and will be considered in the pilots and the ensuing evaluation.

Ethnicity

There is some evidence available from the Direct Payments and Individual Budgets programme in social care to suggest that personal health budgets are likely to have a differential impact on individuals from different ethnic backgrounds. For example, the social care Individual Budgets evaluation found that white people reported higher satisfaction levels than non-white people, though this was only weakly statistically significant and the model had very low explanatory power, meaning the results must be interpreted with caution. The sample size of BME people from which this evidence is drawn is also very low (around 80 people of the overall sample, so an expected 40 or so will have received an individual budget). When testing personal health budgets, we will seek to ensure that the pilot design allows the impact of an individual's ethnicity to be understood.

Table E1 suggests a lower prevalence of long-term conditions among BME groups. However, the sample size is relatively small (around 23,000 across Great Britain, of whom 2,000 are from BME groups), meaning it may be unrepresentative. Also, BME groups tend to have a younger age profile than white groups, which may drive lower prevalence.

Table E1 Proportions of people with Long-Term Conditions by ethnic group

Ethnicity	**Has a Long-Term Condition**
White British	33%
Other White	26%
Mixed race	21%
Asian - Indian	24%
Asian - Pakistani & Bangladeshi	17%
Asian - Other	22%
Black Caribbean	34%
Black African	15%
Other Black	20%
Not recorded/Other	15%
All Ethnic Groups	**31%**

Source: General Household Survey 2006, Office for National Statistics

In contrast, Table E2 shows a much greater proportion of people reporting daily difficulties in BME groups than for the White British group. In particular, those from Asian backgrounds report higher proportions of daily difficulties than the average.

This is consistent with the hypothesis that individuals in BME groups being less engaged with the NHS.

Table E2 Proportions of patients reporting 'daily difficulties' by ethnic group

Ethnic group	No	Yes	Proportion saying yes
African	4,296	2,486	36.7%
Any Other Asian Background	3,559	3,149	46.9%
Any Other Black Background	828	645	43.8%
Any Other White Background	18,320	14,230	43.7%
Any Other Mixed Background	895	686	43.4%
Bangladeshi	1,380	1,591	53.6%
Caribbean	5,327	4,020	43.0%
Indian	7,803	8,184	51.2%
Pakistani	4,097	5,593	57.7%
Undefined	1,146	658	36.5%
White British	364,616	282,697	43.7%
White Irish	6,360	6,060	48.8%
White And Asian	689	445	39.2%
White And Black African	527	353	40.1%
White And Black Caribbean	759	508	40.1%
Total	**420,602**	**331,305**	**44.1%**

Source: GP Patient Survey 2007/8

We are especially interested in how personal health budgets might improve services for groups that may currently be underserved. Personal health budgets will help to deliver more flexible care, which is sensitive to the patient's needs and preferences, although there are likely to be some significant language and cultural barriers to overcome.

Cultural barriers may be especially difficult, notably for communities where deference to doctors is a particularly strong feature. Translation services are a core component of NHS services – not an add-on. They should either be explicitly costed within the personal health budget or provided free. This is likely to be particularly important when considering the impact of personal health budgets by different racial groups, and the setting of budgets.

'No Patient Left Behind', a report for the Department of Health by Professor Mayur Lakhani, looked into patient experience of GP services by background. It reported a substantial sense of disempowerment and disengagement among most BME groups in planning and using their care. This specifically stemmed from a communication problem between patients and practices, higher disease burdens of BME groups, variable quality of GP services and different expectations of patients.

No Patient Left Behind also showed that BME groups are 5-10% less satisfied with GP services than white communities are; in particular, Bangladeshis are 20% less satisfied. Although personal health budgets are not expected to be applied to

traditional GP services, if they are successful in increasing flexibility of other services they may help to improve satisfaction among such groups. It is likely that the family or carer education required to make a success of personal health budgets will vary between different groups (not just race, but across all aspects of equality), and pilot proposals will be required to demonstrate that they have considered this as part of the application process.

We will be looking for pilot schemes that plan to actively involve communities that are not currently well served. Culturally competent staff, raising awareness of some of these issues and engagement with third sector organisations should serve to reduce inequalities of access and of outcome.

Religion or belief

We do not have any reason to suspect that personal health budgets will differentially affect patients because of their religion or belief, although the ability to select more culturally appropriate services may be useful in maximising engagement from some groups. Where possible, this will be monitored within the pilots and the evaluation to see if there is any variation in the impact of the policy.

Disability

We expect many recipients of personal health budgets to have long term and complex health needs, often in conjunction with needs traditionally covered by social care services. These will include significant numbers of people who are disabled. Many will also be older people.

Disabled people are expected to benefit, though the size of the impact is unknown. Personal health budgets will give people greater control over their care, allowing them to choose the services that best suit their needs. The evidence from the social care Individual Budgets pilots suggest that both people with physical disabilities and people with learning disabilities benefited from the additional control given by personal budgets.

There is some evidence that people with learning disabilities have worse levels of healthcare interventions than other groups. For example, a report from the Disability Rights Commission entitled *'Equal Treatment: Closing the Gap'* identifies that people with learning disabilities and diabetes having fewer measurements of their body mass index than other groups, and those with stroke have fewer blood pressure checks than others, as well as low cervical and breast cancer screening rates.

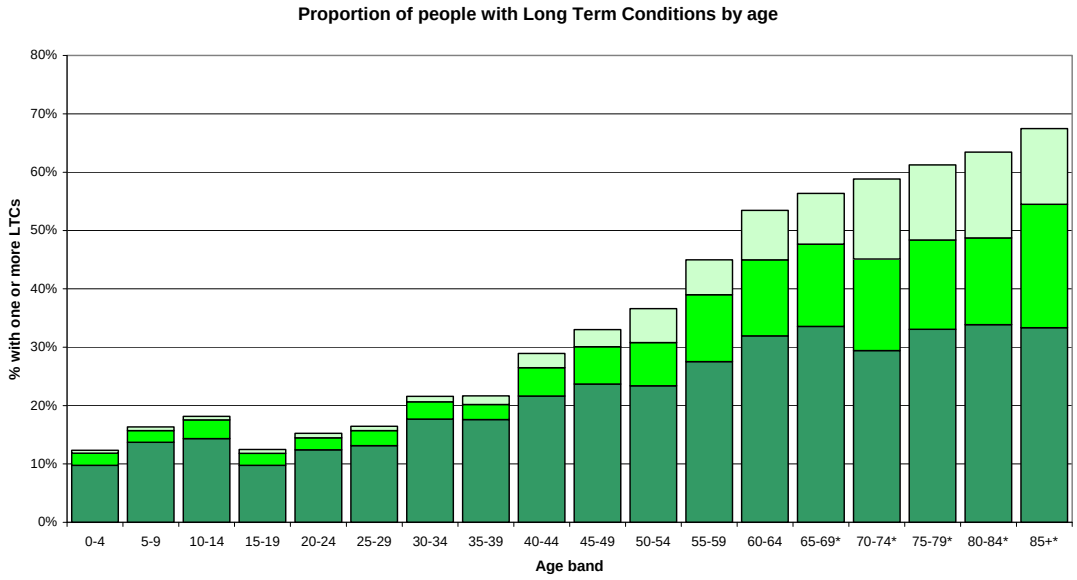
As with the other groups, personal health budgets can indirectly help with this, as they could drive greater flexibility and responsiveness in the NHS, and delivery of care that is more appropriate for individual needs and preferences.

Age

Graph E1 shows that higher proportions of older people have one or more long-term condition than younger people. Therefore, understanding how older people can best

be supported to get maximum benefit from a personal health budget is particularly important.

Graph E1 Prevalence of long-term conditions by age group



Sources: 2005 General Household Survey and 2004 Population census estimates.

* For those aged over 65 an adjustment has been made using 2001 census data to account for those living in communial establishments.

A recently published report, *'Making personal budgets work for older people: developing experience'*, outlines how personalisation can serve to empower older people. The initial findings of the IBSEN evaluation showed negative effects for older people, through lower levels of wellbeing and higher anxiety levels. However, by the end of the pilots older people tended to report higher levels of satisfaction, through factors such as being able to move indoors independently, though the explanatory power of the model was very low. The *'Making personal budgets work for older people: developing experience'* report describes some of the things that are required for personal budgets to work and may be particularly pertinent for older people including:

- starting from the person;
- flexible solutions that are tailored to the needs of the individual; and
- good support.

The following quote summarises some of the key issues:

> *'Generally speaking, it seems that for older people and their carers, little changes can have a great impact on quality of life. Unfortunately, there are still assumptions that older people don't like changes and prefer to be cared for than involved in their care support. We found that the service users and their support network usually grab the opportunity to tell us what is important to them, very easily. Our experience with various partners highlighted the fact that the way self-directed support is presented … is key to the uptake of the option'.*

Therefore, we do not believe that personal health budgets are discriminatory. Older people may benefit just as much from personalisation of services as any other group, provided they are offered appropriate support to overcome any administrative burden Indeed, the evidence from social care suggests that where personalisation has been successful, it has had a dramatic impact on quality of life for older people. Traditionally managed services will always be available to those who do not wish to manage their own budget, so personal health budgets will not prevent anybody receiving the services they need, just as now.

Age will not be a barrier to participation of patients in the pilots. We anticipate that PCTs will approach each person on a case-by-case basis, and would not refuse any person access to an appropriate model of personal health budget on grounds of age, although some models may be generally more suitable for older people than others will.

There is a clear role here for advocacy services to act as independent guides and support for older people making choices about their care. This also applies to other groups, and the best applications have considered how best advocacy can be included in a sensible way to benefit potential recipients. There may also be a role for PCTs to work alongside the third sector in raising awareness and supporting older people to adopt personal health budgets.

It is possible that the difference between younger and older people will disappear over time, as people used to running personal health budgets from at a young age move into old age. However, this will not happen during the anticipated three-year duration of the pilots.

Personal health budgets also have the potential to benefit young people suffering from long-term conditions, such as sickle cell anaemia and cystic fibrosis. Again the support services required will need to be thought through and developed throughout the pilot programme. There is a link here with the Department for Children, Schools and Families pilots for Individual Budgets for disabled children within their *'Aiming High for Disabled Children'* policy. We are exploring the potential here for overlaps and synergies, both in the piloting and in the evaluation.

Deprivation and Health Inequalities

One potential criticism of the policy is that personal health budgets will benefit the informed, self-confident and better educated, who tend to be from higher economic groups, more than other groups. Further, the highest prevalence of long-term conditions is within routine and manual groups (Table E3).

We believe that, provided appropriate support is available, personal health budgets have the potential to benefit people across the socio-economic spectrum. Some of the pilots in the US were undertaken through Medicare and Medicaid, and as such were targeted at more deprived groups. Although the US healthcare system and the NHS are clearly different, the US experience suggests that personal health budgets have the potential to reduce health inequalities caused by deprivation. We will be expecting pilot schemes to actively engage with groups who have traditionally had less NHS involvement and less successful outcomes.

Table E3 Long-term condition patients by socio-economic group

Socio-economic group	Has a long-term condition
Managerial and professional occupations	32%
Intermediate occupations	37%
Routine and manual occupations	42%
Never worked and long-term unemployed	30%
Not Classified	16%
DNA/NA	31%
Total	**35%**

Source: General Household Survey 2006, Office for National Statistics. This only covers people over the age of 16 – i.e. those currently of working age, or who have been of working age in the past.

Personal health budgets could improve health outcomes disproportionately for more deprived groups, as better-informed groups already tend to benefit from more personalised services; personal health budgets give historically underserved populations more of a voice. Therefore, personal health budgets may help to reduce health inequalities stemming from deprivation.

Sexual orientation

There is some evidence that gay men and lesbian women find current practice and sometimes practitioners discriminatory, and so are less likely to request help. There is also evidence that Lesbian, Gay and Bisexual people are less likely to report their sexuality due to fear of discrimination. Personal health budgets may have an indirect effect on this, by changing attitudes of NHS staff to put the patient at the heart of the decision-making process.

Transgender

There is evidence to suggest that transgender people experience lower satisfaction with the NHS than other groups. Some were refused treatment as the doctor or nurse did not approve of gender reassignment, some reported being treated adversely by healthcare professional more generally, and some reported that GPs in particular did not appear to want to help or refused to help with treatment. As above, personal health budgets may have an indirect effect on this, by changing attitudes of NHS staff to put the patient at the heart of the decision-making process.

Gender

We do not believe that patients will differ in the benefits they receive from this policy because of their gender. However, male and female experience of the NHS is very different in some specific cases. For example, men tend to visit a GP less often than women do, and women tend to have coronary heart disease and related conditions picked up less often than men do. While these are important differences between the groups, they are not something we could reasonably expect personal health budgets to address.

There is a risk that the burden of managing personal health budgets may fall disproportionately on to women. As women are often the primary carer, as a wife, a mother or a daughter, it is possible that much of the administrative burden of personal health budgets will fall disproportionately on them, if this is not carefully managed through appropriate support services. The pilots will provide more information.

We would expect care co-ordinators to show regard for the interests of carers when supporting a patient in designing their care package. Peer support and advocacy may also have a role to play, and pilot sites should consider setting up things such as support groups for carers, as has happened in some of the social care Individual Budgets areas.

If properly managed, we anticipate that personal health budgets will have a positive impact on familial carers, as services may be redesigned to better meet the needs of individuals, thereby lessening the day-to-day support required from family members. We will seek to test this as part of the pilot programme. We have engaged with some carers groups as part of the consultation we have undertaken around the personal health budgets policy. We fully expect pilot sites to do a similar thing when piloting the policy. This also applies to children as carers – as noted above outset, some of the issues within this section span several of the considered groups.

There is also a wider social issue: the majority of low paid carers in the NHS and social care are female, and often face poor career prospects. If managed correctly, there is the potential for using personal health budgets to empower carers and for them to have greater career prospects than at present. There is, however, a simultaneous risk that carers become involved in the lives of the patients, with potentially less flexibility. The successful applicants for the pilot sites are expected to consider this, and to design their pilots and support networks accordingly – there was a separate section covering workforce in the form for expressions of interest. This also applies to race: recent migrants comprise a disproportionate number of carers. The effects on staff (not just carers) again will be something that is specifically covered within the evaluation.

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