

Experiences of implementing personal health budgets: 2nd interim report

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1 Executive Summary

This is the second PHBE interim report that focuses on the personal health budget implementation process. During the first wave of interviews for the first interim report, the focus was on exploring early experiences of implementation across the 20 in-depth pilot sites among project leads. This second interim report focuses on the views of a number of organisational representatives around the implementation of personal health budgets within the 20 in-depth sites.

Over the period September to October 2010, 43 interviews were conducted among operational staff, health professionals (for example, community nurses and occupational therapists), commissioning leads and third-party budget holders across the 20 in-depth sites.

The interviews were semi-structured, allowing participants to discuss their implementation processes and other relevant issues. Each interview lasted approximately 1.5 hours. Interviews were transcribed and coded in accordance with the areas covered in the topic guide. A number of themes were covered in the interviews which can broadly be separated into two areas: 1) How the personal health budget process impacts on the budget holder and carer; and 2) Local challenges of implementing the personal health budget pilot programme.

In summary, there was an overwhelming view that personal health budgets would have a positive impact on both budget holders and carers. This positive impact was attributed to:

1. Increase in choice and control over services;
2. Encouraging flexible and creative services;
3. Improvements in outcomes as self confidence, self-esteem and sense of purpose is increased;
4. Improved relations between the NHS and personal health budget holders as views are being listened to.

However, a number of issues were also highlighted that contributed to delays in implementation. These included:

1. The need for more time to be allocated to the care planning process;
2. A lack of choice of services;
3. Challenges around the culture change required.

The delay in implementation of personal health budgets resulted in a number of organisational representatives not being in post at the time of the interview. The evaluation team will continue to collect information on implementation issues and will compare processes, commissioning strategies and other issues over the coming 24 months. In addition to the impact of personal health budgets at an organisational level, we will be exploring the experiences of personal health budget holders and carers. Findings from all interviews will be reported at various points during the next couple of years.

2 Introduction

This is the second PHBE interim report that focuses on the personal health budget implementation process. During the first wave of interviews for the first interim report, the focus was on exploring early experiences of implementation across the 20 in-depth pilot sites among project leads. This second interim report focuses on the views of 43 organisational representatives (including operational staff, health professionals, commissioning managers and third-party budget holders) around the implementation of personal health budgets across the 20 in-depth sites.

All budget holders are providing information about their outcomes and experiences throughout the pilot programme. In addition to this, 55 budget holders will be interviewed in much more detail over the next few months to discuss their experiences of receiving a personal health budget.

2.1 Policy context

The piloting of personal health budgets is seen as a key feature of the personalisation agenda for health care in England, with the ethos centring around greater choice and control over services (Department of Health, 2009). The potential of personal health budgets has been reinforced in the 2010 White Paper *Equity and Excellence – Liberating the NHS*. The White Paper outlined that the new initiative has the potential to improve outcomes, to transform NHS culture by increasing choice and control among personal health budget holders and to encourage the integration of health and social care services.

This new way of delivering health care requires an immediate cultural shift at all levels of the NHS. While the priority of the Government has to be focussed on reducing the deficit, the re-organisation of the NHS has come when Primary Care Trusts (PCTs) require resources to be able to effectively implement personal health budgets within the local pilots. With such significant changes, such as the abolishment of Strategic Health Authorities by 2012 and PCTs by 2013, there has been an impact on the implementation of personal health budgets within the pilot programme.

The wider situation must be borne in mind when reading this report. Whilst there are major positives, and it is clear that sites have moved on since the last report (Jones et al., 2010), sites are experiencing difficulties maintaining the momentum of personal health budgets given the context of the abolition of PCTs. Some of the problems experienced in implementation will be attributable to this. Readers also need to acknowledge that any change in how services are delivered, especially in an organisation such as the NHS, may make people more anxious and worried about the change which could have had an impact on responses.

2.2 Setting up personal health budgets

In 2009 the Department of Health invited PCTs to become pilot sites to join a programme which will explore the opportunities offered by personal health budgets. The pilot will give individuals more choice about the care and services they receive through giving them more control over the money that is spent on their care. After an initial assessment, an individual is

given a transparent resource to purchase services and care that meets their desired outcomes. There are three different ways that this resource can be delivered (or potentially a combination of them): a notional budget; a third-party budget; a direct payment (in approved pilot sites, once local processes are in place). Overall, some 70 sites were chosen around the country and are part of the evaluation. The Department of Health commissioned an independent evaluation to run alongside the pilot programme to provide information on how personal health budgets are best implemented, where and when they are most appropriate and what support is required for individuals. In addition, the wider organisational impact on the health system of personal health budgets will be explored. Twenty sites from all the pilots were selected to be in-depth evaluation sites with the remainder being wider cohort sites.

2.3 The national evaluation

The in-depth evaluation across the 20 selected sites focuses on individuals with the following health conditions: long-term conditions (including chronic obstructive pulmonary disease, diabetes and long-term neurological conditions); mental health; NHS Continuing Healthcare; and stroke. In addition, the evaluation will explore whether personal health budgets have an impact on two specialist services: maternity, and end of life care.

The over-arching aim of the evaluation is to identify whether personal health budgets ensure better health and social care outcomes when compared to conventional service delivery and, if so, the best way they should be implemented (for full details go to www.phbe.org.uk). Part of this evaluation is to inform the national rollout of personal health budgets by providing information about how the initiative *should* be implemented.

3 Aims and methods

Over the period September to October 2010, 43 interviews were conducted with operational staff (OP), health professionals (HP), commissioning leads (CM) and third-party budget holders (TP) across the 20 in-depth sites.

Type of organisational representative	Number of interviews
Operational staff	18
Health professionals (for example, community nurses and occupational therapists)	10
Commissioning managers	11
Third-party budget holders	4

The interviews were semi-structured, allowing participants to discuss their implementation processes and other relevant issues. Each interview lasted approximately 1.5 hours. Interviews were transcribed and coded in accordance with the areas covered in the topic guide.

4 Caveat

With the overwhelming changes occurring at a local level, the consistent view was that the organisational representatives who were interviewed were of the opinion that the implementation process was in its infancy and so their views were based on potential rather than actual experience. The delays in the implementation process also lead to a number of organisational representatives not being in post at the time of the interview. As with all research, the people who volunteered to be interviewed could hold very different views compared with those who did not participate. Therefore the views included in this report can only be viewed as those held by the participants and may not reflect the views of the organisational representatives that were not interviewed.

5 Interviews

A number of themes were covered in the interviews which can broadly be separated into two areas: 1) How the personal health budget process impacts on the budget holder and carer; and 2) Local challenges of implementing the personal health budget pilot programme.

5.1 Impact on the budget holder and carer

5.1.1 Positive impact

According to the Department of Health: *“A personal health budget helps people to get the services they need to achieve their health outcomes, by letting them take as much control over how money is spent on their care as is appropriate for them”* (Department of Health, 2009). We found unanimous support for this view among organisational representatives. A number of consistent key themes emerged including: encouraging choice and control; creating more responsive services; improving perceptions of services, improved outcomes for the budget holder and carer and; better relationship between NHS care planners and the budget holder.

5.1.1.1 Increased choice and control

The care planning process was very much seen as a vehicle to increase choice and control for the budget holder:

“Service users know what is good for them so they know what works and so I think it is a real positive in terms of control and choice and enabling them to stay in the community and enabling them to come to their own solutions” (HP14).

“It’s good for patients [budget holders] in that they have more choice and can get what they want, what is important to them” (OP12).

“The reason people want to go on to a personal health budget is that while agencies are very good at providing care, they do not provide consistency. For example, someone might be having four visits a day, and within those four visits they have four different people, and those four different people may be different on the next day, so

there's no consistency...People want their own carer to come at times that suit them so they have more choice over who walks in their front door" (CM19).

It was thought however, that while there were three deployment options, the direct payment option would only lead to true choice and control: *"It's all about direct payments for them, that's the whole idea of doing it, there's no point otherwise" (OP12).* It is difficult to ascertain whether this view is consistent across the pilot sites. However, there is a risk that the other two deployment options may not be explored at great length if the majority of frontline staff and budget holders hold the same opinion.

5.1.1.2 Flexible and creative services

It was consistently thought that increased choice and control could potentially encourage more flexible services that fit better around an individual's lifestyle:

"It has enabled people who would have otherwise had to come out of the community to stay in the community" (HP14).

"Younger people don't want to go to day care, they would prefer to use the direct payment system and choose to be with people they've got more in common with" (OP08-2).

At the time of the interviews, respondents stated that the initiative has the potential to have a positive impact on black and minority ethnic (BME) budget holders, and that it could improve equity: *"I'm sure it would be a lot easier to find people more appropriate services. For example rather than put somebody who cannot speak English or does not speak English as a first language in a day centre with people who are all English speaking, it would be easier to find a more appropriate group. Or further to that it could even be a family member setting something up using a direct payment that could run a group for others as well" (OP08-2).*

However the emergence of flexible services can only be a reality if the market begins to develop around what the budget holder actually wants. One commissioning manager suggested that there was early evidence that some new services were being developed, in part, as a result of the emergence of the personal health budgets pilot: *"There are some organisations that are setting up in [site] to deliver services to mental health service users. It's not the only reason but they are aware of personal health budgets and we've met with them a few times" (CM08).*

5.1.1.3 Improving perceptions of services

A number of commissioning managers thought that personal health budgets had the potential to alter the perception of voluntary and third sector organisations as 'second rate' compared with statutory services. It was thought that all providers will need to be more flexible in their provision of services, particularly the home care providers: *"Services may well change in that they have to be more flexible because people will want carers to pop in for 20 minutes when the patients [budget holders] want them to" (CM19).* Furthermore, it was suggested that home care providers could potentially be used as a support mechanism for people employing their

own carers outside of commissioning: *“Current homecare providers may be used as a contingency so that if care, that patients [budget holders] have organised themselves, goes wrong because someone is sick, then they can then go back to the more established providers and say what can you offer me because I need a carer tonight”* (CM19). A consistent view was that providers need to begin to be flexible and competitive which would only have a positive impact on market development in the future.

5.1.1.4 Improved outcomes

One of the aims of the overall evaluation is to explore whether personal health budgets improve quality of life for the budget holder compared with the conventional way of delivering services. We received an overwhelming view that the process has the potential to benefit both the budget holder and carer by increasing self-confidence, self esteem and ‘sense of purpose’.

“I think they [budget holders] are having more input into it because support plans that are drawn up will be more in-depth and more holistic in terms of quality of life compared to the care plans that are existing already. They will be more holistic as they look at things outside of I guess the medical. It is not just about the care but it is enabling them to have a life outside of their disability. It will give them more flexibility in terms of spending time with family or getting out of the home and so having the budget will allow them to do more with their lives instead of just always focusing on the medical condition” (HP22).

“It can have a huge impact on mental or psychological health and I think that it will have an impact on keeping people healthy rather than this kind of dependency that people can get when they sit back and aren’t involved [in their care]. Giving them [the budget holder] the control and making them the person managing their health rather than being managed is quite a big win here” (HP26).

Personal health budgets have the potential to have a positive impact on the budget holder’s quality of life and outcomes by giving them control over the services that will meet their desired outcomes. This potential could also be realised for the carer as a vehicle of having a positive impact on their caring role. It seems that a number of frontline staff have begun to realise this potential even at the early stage of implementation:

“I think it’s positive for carers. In one case we were able to provide more respite for the carer. The carer was only getting one day a week from day care because that’s all they could provide, but with a personal health budget we were able to get more from elsewhere and increase the respite they were getting which has helped the whole family” (OP08).

“I think informal carers will be recognised for their contributions and they will be financially better. I think it will be less stressful for them as they will have more choice” (OP14).

“Personal health budget care plans are far more likely to take into account the needs of carers than our current system. If for example, the patient has to rely on the carer to

run them to appointments or to social activities then if they have a budget and they choose to spend their money on hiring a driver, it doesn't just give the patient more independence but the carer is automatically freed up too. So it could have a huge positive impact on carers" (OP01).

5.1.1.5 Improved relationships between the NHS and budget holders

In addition to the likely positive impact on budget holders, a consistent view was that the personal health budget process could improve the relationship between the NHS and budget holders. It was thought that the process provides a way of finding out the real needs of budget holders and their preferences:

"The major advantage is you get a kind of personable energy with people [budget holders], and people start to engage with you very much more on a level where they feel that they can trust you. It's a process of working through what we need to do in terms of the planning and as a bi-product you get to know the person [budget holder] much better which benefits both [care planner and budget holder]" (OP05).

"We forget individuals [budget holders] have a lot of skill in thinking through what might be suitable for them. They are sometimes better than the professionals, and emotionally it can be really important to people to know that they are in charge of their own outcomes rather than leaving it to other people, the individual feels in control of the situation. This can have an impact physically as well. Just having the ability to make these choices does change the relationships with the patient [budget holder] and the people around them - their family, the health staff they link into. Even the local community where they live can see the benefits that that person [budget holder] is having from" (OP11).

5.1.2 Challenges to implementing personal health budgets

Although implementing personal health budgets has been viewed as a positive move towards people having more choice and control within the NHS, there were consistent views around the challenges that budget holders face.

5.1.2.1 Care planning process

Consistent with the first round of interviews with project leads, there were questions around whether the care planning process was too difficult for some budget holders to engage with the process. The additional support required was seen as having a cost implication and an impact on the workload of health professionals. Although there was inconsistency around which group of patients [budget holders] this would refer to, it was thought that the process could potentially be more time consuming when people have complex needs:

“The personal health budgets care plan is far more in depth so there will be an element of it being a bit more time consuming, especially with someone with dementia. It may have to be done in two parts because of people’s attention span, it’s very tiring and difficult to focus for any length of time for dementia patients [budget holders]” (OP19).

“From my point of view, I think it will be more time consuming with younger physically disabled people, particularly those in transition from child to adult [services] could be problematic, especially in agreeing what the care plan should be. I think they’re much more aware of their rights. Older people are from a different generation where they would prefer to be told, and believe the doctor is always right, that sort of attitude” (OP12).

The need to provide more support for some groups of people raises the equity question again and whether some people will be intentionally ignored because of the cost implication of having to provide more support to certain people. However, it was thought the offer of all three deployment options has the potential to provide the appropriate support for all budget holders: *“I will be offering all of those [deployment options], it depends on the person, whether they have mental capacity to understand how or what to do with the money, a third party payment may be easier depending on the individual” (OP19).*

While frontline staff thought that personal health budgets have potential to have positive impact on the caring role, there were concerns: *“Personal health budgets might affect the amount of time they [the carer] spend in supporting that person. There was some uncertainty and anxiety about how it would affect everyone’s lives. Is this going to affect my income, my benefits, and the way that I do things for this person? Am I expected to make a contribution and so on” (OP05).* The negative impact on the carer was explored by a health professional: *“I think it will make life more difficult. It’s going to be a nightmare for them” (HP21).*

5.1.2.2 Is there really choice of services?

While it was thought that personal health budgets could encourage market development, concerns were raised as to whether there was actually choice and control currently: *“Is there really choice or are we just going to get the same things but in a different way? Is it really developing that area? How do you review and monitor this? But from my point of view it can only be positive as service users are more in control of their own care” (HP14).*

“They do get a choice around care providers, but in some cases there just isn’t an alternative so we can’t offer them anything. I do think it will come with time though” (HP26).

The lack of a market for services appeared to add to the uncertainty around having choice: *“Patients [budget holders] are unsure about their choice and how to exercise their choice and it doesn’t help that markets are not as responsive as it could be” (HP14).*

5.2 Frustrations with the local personal health budget pilot programme

Although the organisational representatives outlined a number of challenges, the greatest obstacle seems to be the overwhelming frustration they feel over how the pilot programme is progressing locally. Various themes were discussed including: delays in the implementation process; impact on the workforce; accountability and risk management changes; impact on the workplace, integration of health and social care and sustainability.

5.2.1 Implementation delays

Consistently, it was thought that the implementation of personal health budgets was far too slow because of the challenges they face in their PCT:

“Too slowly, too slowly, because of the challenges our PCT is having in terms of administering and assessing for the PHBs” (OP20.2).

“I think it is progressing slower than expected. I think the recruitment of clients hasn't happened as quickly as people hoped but hopefully that is going to improve in the next couple of weeks. There has been a huge amount of background work that has been done, to sort out processes and things and I think we are at that stage now where we just need to start getting clients in and putting them through the process. We can then sort out any teething problems that are coming along the way. I think it has been down to a few things, just getting people on board to get people working toward this new way of putting plans in place for clients. I think it is a staffing issue as well as there have been lots of staffing changes and the project lead works three days a week so that has had an impact. Also getting different levels of commitment from all the groups involved I think has been an issue” (HP22).

The delays in implementation have been attributed largely to the degree of culture change within pilot sites, which seems to have been exacerbated by the current climate of reducing resources and increasing uncertainty. It was made clear by organisational representatives that meeting need has to be balanced with resources and spending which needs to be taken seriously: *“How do you square that with the resources that we have? Bear in mind that PCTs have a responsibility not to overspend work within their budget” (OP12).* It was thought, particularly among commissioning managers that it will be commitment of managers, strong leadership that will drive the culture changes.

5.2.2 Understanding the process

To be able to work effectively, personalisation needs the support of staff: those who support and agree the care plans and budgets, those who monitor the use of the budget and conditions of individuals, and those who deliver services. Staff engagement and training to understand the process is critical if the full potential of personal health budgets is to be realised. However, delays in the implementation of personal health budgets were in part attributed to the lack of workforce training. The purpose of this training is to ensure that the frontline staff are in the best position to begin offering personal health budgets and to provide

the necessary advice and support to the potential budget holder. It was thought that in order to be able to set out conditions, or guide budget holders in terms of what would be considered a legitimate use of a budget, operational staff need the appropriate information that at times is missing.

“I’m speaking as someone who is confused, but I think when it is implemented and more understandable and the direction is more specific, then there will be choice” (OP12).

“I think it’s important that the people on the ground that are going to be actually operationalising this need guidance so they’re not left thinking, “I’ve got this option but I don’t know what I am supposed to do.... if they [operational staff] don’t make it happen then it’s not going to happen” (OP12).

“From just working with people [service users] generally, they don’t understand the system very well. So if they don’t understand it and the person working with them [care navigator / health professional] doesn’t understand it then they won’t get the best out of the system... it’s the process, what’s involved and how to actually manage the situation once you’ve got the services you need” (OP19).

“We need training about packages of choice, how to facilitate choice, we don’t know this at the minute” (HP4).

“We have been given no extra resource and no extra training. We have kept involved purely because we want to be involved in the decision making and be included in the implementation. But we have not actually had any resource to help us with this and it has impacted on our service as we have no extra resources for this. We do feel very much in the dark, it is just so complicated a process we perhaps need rigorous guidelines and extra training, and resources” (OP14).

Illustrating the need for increased guidance one interviewee had a question regarding the process when a budget holder is denied a request on their care plan, and whether there is an appeal process: *“If they are refused something, is there an appeals process and how does that work?” (OP12).* Where the appropriate training and guidance was in place it was thought the care planning process was a joint effort. The care planning process: *“should reduce the risks to patients and staff as it is a multi-disciplinary team and each member has an input in the care planning, and we are hoping they will get a better service through the personal health budget” (HP21).*

5.2.3 Accountability and risk management

Operational issues around guidance on the legitimate use of personal health budgets could potentially be borne out of concerns around accountability. There was a view that there could be a potential conflict between reflecting the need of budget holders with what they [the budget holder] ‘want’, because almost anything could potentially come under the umbrella of ‘good for my well-being’. This also led to questions around how operational staff actually

ensure the quality of services and the maintenance of professional and clinical accountability: *“It is very unsettling and worrying – where does the line of accountability lie, with staff or is it with patients [budget holders]? If the patient [budget holder] is really solely responsible for choosing their care package then that is very scary, very scary. There has not been enough guidance regarding the line of responsibility given out by Department of Health, you know leaving staff feeling very unsettled”* (OP21). This quote emphasises the lack of guidance being given to frontline staff in this pilot site as budget holders are not solely responsible for choosing their care package, and plans always need to be reviewed and signed off by the appropriate representatives within the PCT.

The overwhelming view was that the monitoring of risk was crucial to ensure the safety of the budget holder:

“I don’t think they actually understand the risks in planning the care. The majority of who we have are joint funded or NHS continuing healthcare and so joint funded already have DPs [direct payments] through social services and they either have a PA or agency staff. But the occasional person has a member of their family now that is fine when it comes to social care but if it comes to actually healthcare and it requires someone who is qualified to administer that healthcare they do not feel the risks involved are that important. So that is one of the big issues we have. Take for example if someone has a tracheotomy tube and that tube needs suctioning and changing then the person needs to be qualified in how to do that, and they do not really understand the risks. It’s scary isn’t it” (TP21).

“We need to make sure that patients receive the appropriately skilled staff to perform their care. There is the problem of risk and what would happen if someone wants to spend their money on a holiday to the Bahamas and then come back and say I need a contingency support fund now because I’ve got nothing left in my budget to pay for my care. Our nurses are very worried about that clinical side of it” (CM19).

While this is a fear expressed by staff, the PCT has to sign-off the care plan, upon which the personal health budget is based. Nevertheless, sites need to develop appropriate processes to minimize the potential for fraudulent behaviour: *“I suppose it [the personal health budget] gives them the control that they desperately want in regards to the health. We are hoping it isn’t going to be one of the pitfalls as well as we do have people who could potentially use and abuse the funding that they get. There are a lot of people who are on direct payments in social care who don’t seem to be able to manage it very well. So unless it is monitored, well it’s a huge issue. I mean what do they do if they spend all the money in one whack? What do you do, do you just give them more or up it? It needs to be very closely monitored”* (OP21).

It is possible that the issues related to accountability and risk management for patients has led to a delay in implementation. Further to this, if these issues are not resolved there is potential for further delay within pilot sites that are not in a position to begin offering personal health budgets.

5.2.4 Impact on the workplace

In addition to the lack of training and guidance in some pilot sites it was thought that the change in process would initially increase the workload of frontline staff which could have potential resource implications: *“Initially it will increase our workload because of explaining to patients [budget holders] and working out the care plan and monitoring and making sure people are trained”* (OP12).

“The more people that you are talking to, the further in advance that you’re booking your time. The more people that you’re looking to see the less time you get to do all the paperwork associated with that, so resource then becomes an issue” (OP05).

“It will be hard and if we had 50 patients [budget holders] walk through the door tomorrow then it would be a full time job on its own. But the more patients [budget holders] you have the amount of time you need is reduced...and it becomes quicker and easier as you go” (HP26).

It was thought that following the national rollout of personal health budgets, the additional workload would be absorbed into the natural working processes. At the time of interview, many members of frontline staff were being proactive in finding ways to manage the increase in workload: *“It will increase the workload but if you have a key worker to sign-off on things it doesn’t necessarily require the key worker to go out and do all the form filling and so on. We have volunteers that are trained within aspects of dementia who would be perfectly capable of filling in a form for us, and then the key worker just has to make sure everything is in place before it’s signed off. So yes it is time consuming, it could be a drain on resources but I think there are probably ways of managing it as well”* (OP19).

5.2.5 Sustainability

The aim of the evaluation is to provide evidence on both how personal health budgets *should* be rolled out rather than *if* they should be. Based on the criteria, a central question seems to be how personal health budgets and services can be sustained. A number of commissioning managers saw it as being driven centrally by policy and legislation: *“It depends on legislation; you need the underpinning legislation there to support it. If the personalisation agenda continues then I think the scheme will continue”* (CM19). However despite legislation there was concern that some services could be under more threat than others, which may not be linked to the standard of service provided:

“There are certain services that will be under more threat than others. Things like speech and occupational therapy are not likely to disappear because they hit such a wide-range of needs, although they may reduce slightly. At a little more risk are things that have long waiting lists, but then are only for a one-off session, say if someone is waiting for a podiatrist” (HP26).

“If people are saying they want a service that is much more reactive and statutory services can’t provide that then there could be a risk that that service would disappear.”

If you look at the way you get glasses, you used to go to the NHS but now you just go to your high street, and people have made that shift” (HP26).

While sustainability of services will be associated with the degree of need for services, it was also thought that it would come down to cost-effectiveness. It was thought that within the current climate, the initiative needs to save money:

“If services can be provided at home, and more people do want to stay at home, then it’ll definitely be cheaper and that makes it much more sustainable. But it depends on the services that are out there, the services need to be in place to allow that” (OP08).

“Many severely disabled people or highly dependent people have a lot of hospital admissions because of inadequate care. So if you look at the cost of getting people in an ambulance and a hospital bed then you could save money there if people no longer needed to use them because their care was better” (OP08-2).

“If it saves money then that will be a massive indicator towards sustainability and in the long-term it could save money. If someone is employing staff themselves they haven’t got the overheads of an agency and there could be cost-benefits associated with that” (CM19).

5.2.6 Integrating health and social care

The 2010 White Paper *‘Equity and Excellence: Liberating the NHS’*, puts an emphasis on the need for both the NHS and the social care system to be integrated to ensure better, more cost-effective outcomes for people. There were positive views on the need to integrate and in some pilot sites both the NHS and social care systems are effectively working alongside each other. However, in other sites there were practical concerns where there isn’t an integrated system and that this could act as a barrier.

“We are theoretically integrated but the practical side is still yet to be sorted out yet. The big downfall is that we don’t yet have an I.T. system that talks with each other but we do communicate, and make sure that we don’t double up on things” (HP26).

“I think the financial part of how the split budget works is more complicated. Social services and the PCTs can charge people (in terms of their financial budgeting) in different ways... If [service users] were given the budget and they were buying traditional services through social services it would cost them less than if they were buying services direct from an agency. So the financial aspect of it is quite difficult but that’s something that the finance departments are still working with. Social services would only charge the patient a percentage of that agency cost whereas the PCT would charge the patient the full cost, not literally but for their own budgeting purposes. So you can’t buy as many hours with your money from the PCT as you can with social services and those processes need looking at. That’s the challenge for the organisations” (OP08-2).

“There are many complications in doing it [pooling budgets] and we’re not doing it at the moment. There are issues in setting it up and the financial management of it. The I.T. systems would have to be the starting point for doing it. But in practical terms it would be easier for the client because more often than not they don’t even know where the money is coming from and they don’t care” (HP26).

6 Conclusion

This report highlights experiences of implementing personal health budgets across the 20 in-depth pilot sites at a time of significant change in the NHS. When interpreting the findings, readers need to bear in mind that the views included in this report can only be viewed as those held by the participants and may not reflect the views of the organisational representatives that were not interviewed.

In summary, there was an overwhelming view that personal health budgets would have a positive impact on both budget holders and carers. This positive impact was attributed to:

1. Increase in choice and control over services;
2. Encouraging flexible and creative services;
3. Improvements in outcomes as self confidence, self-esteem and sense of purpose is increased;
4. Improved relations between the NHS and personal health budget holders as views are being listened to.

However, despite holding a positive view on the potential of personal health budgets, there were many frustrations with the progress of the pilot programme in some pilot sites. The main concern is the lack of process implementation which could be the result of many local factors. One possibility is whether the reforms outlined by the new Parliament are overshadowing the priority given to personal health budgets by the management structure within the pilot sites.

The delays in implementation in some pilot sites have largely been attributed to the degree of cultural change required which has been exacerbated by the current climate of deficit reductions. In some pilot sites, it would seem that a group of organisational representatives are being expected to implement personal health budgets without having the appropriate training to be able to guide budget holders through the process. A common theme that emerged was around the little guidance being offered to frontline staff which was leaving them confused as to the process. The lack of guidance was illustrated by one participant being unaware of the appeals process and whether they actually had one in place.

Furthermore, personal health budgets can only be offered once all the processes are in place. Whilst the interviews were carried out during months 10 and 11 of the evaluation, there was still uncertainty within some pilot sites around accountability and risk management to ensure both the safety of the budget holder and also to minimize the possibility of fraudulent behaviour.

The evaluation team will continue to collect information on implementation issues and will compare processes, commissioning strategies and other issues over the coming 24 months. In addition to the impact of personal health budgets at an organisational level, we will be exploring the experiences of personal health budget holders and carers. Findings from all interviews will be reported at various points during the next couple of years.

7 References

Department of Health (2009) *Personal Health Budgets: First Steps*, Department of Health, London.

Department of Health (2010) *Equity and Excellence – Liberating the NHS*, Department of Health, London.

Jones, K., Caiels, J., Forder, J., Windle, K., Welch, E., Dolan, P., Glendinning, C. and King, D. (2010). *Early experiences of implementing personal health budgets*. PSSRU discussion paper no. 2726/2. Personal Social Services Research Unit, University of Kent.