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Personal Health Budgets: Process and context following the national pilot programme

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Acknowledgements

Contents

1 Introduction

Over the past decade, there has been a developing focus on personalising support and services within the care sector in England. Personal budgets form part of the current personalisation agenda from Government, with the aim of placing individuals and their families at the heart of all decisions about their care and support. The overall intention is to provide people with greater choice and control by offering a new way of arranging and managing services or support to meet desired outcomes. Three distinct principles underlie the personal budget initiative, in terms of individuals or their representatives: 1) knowing how much they have available for healthcare and support within the budget; 2) being involved in the design of the care plan; and 3) being able to choose how they would like to manage and spend their budget, as agreed in the care plan (NHS England, 2014).

In 2005, the Department of Health announced it would conduct a national pilot programme and commission a two-year independent evaluation of individual (personal) budgets involving thirteen pilot sites (Glendinning et al., 2008). A randomised controlled trial sat at the heart of the evaluation to compare the experiences of people who were offered an individual budget with the experiences of those receiving conventional services. Glendinning et al. (2008) found evidence to suggest that individual budgets were cost-effective in achieving social care-related quality of life (measured through the use of the Adult Social Care Outcomes Toolkit - ASCOT) (Netten et al., 2012) and psychological wellbeing (using the 12-item General Health Questionnaire - GHQ-12) (Goldberg, 1992) for some recipient groups. The impact of individual budgets varied, nonetheless, between client groups, indicating that there was no one format that was suitable for all people.

The national evaluation included an in-depth strand that involved interviewing organisational representatives implementing individual budgets during the pilot programme and budget holders. The evaluation team found that the organisational representatives were overall supportive of the underlying principles of individual budgets. However, a number of implementation delays were reported during the pilot programme which appeared to be related to the way the cultural change had been managed (Glendinning et al., 2008). Among the 130 budget holders who were interviewed, it was thought that the advantages of receiving a budget included increased choice and control, continuity of care workers and the ability to pay some family carers. However, some older people reported anxieties about the responsibility of organising their own support and managing their budgets (Glendinning et al., 2008).

The aim of individual budgets was to integrate a number of different funding streams (including social care funding, integrated community equipment services, access to work, Disabled Facilities Grants and the Independent Living Fund). Glendinning et al. (2008) found limited evidence to indicate that integration of the different funding streams into one individual budget had occurred. During this national evaluation, the government announced that personal budgets (limited to social care expenditure) would be made available to people

with needs eligible for publicly-funded adult social care (HM Government, 2007). The right of individuals and informal carers to have a personal budget to meet their eligible needs has since been enshrined in law (The Care Act, 2014).

In 2009, personal budgets moved into health-related support with the introduction of the personal health budgets pilot programme. The Department of Health announced the programme would explore the impact of personal health budgets among people with long-term health conditions, such as chronic obstructive pulmonary disease (COPD), diabetes, mental health problems, as well as people with co-morbidities who were using NHS Continuing Healthcare services.

1.1   Impact of personal health budgets on outcomes and costs

To explore the impact that personal health budgets have on health and social care outcomes, the Department of Health commissioned a three-year evaluation that ran alongside the pilot programme of the initiative (Department of Health, 2009). The overall aim of the evaluation was to identify whether personal health budgets delivered better health and care outcomes when compared to conventional service delivery and, if so, to identify the most effective implementation process (Jones et al., 2013; Forder et al., 2012). There were 64 pilot sites: 20 formed the in-depth evaluation with the remainder forming the wider cohort. Overall, personal health budgets were assessed to be cost-effective regarding care-related quality of life (as measured by the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al., 2012)) relative to conventional service delivery, particularly for people with mental health problems and those receiving NHS Continuing Healthcare. Furthermore, informing the budget holder of the indicative personal health budget amount and offering greater choice and control over the support that could be purchased were also cost-effective regarding ASCOT outcomes. Personal health budgets valued at £1000 or more per year were also cost-effective (Jones et al., 2013; Forder et al., 2012).

An in-depth strand of the national evaluation of the personal health budget pilot programme explored the implementation process from the perspective of organisational representatives (Jones et al., 2010a, 2010b) and budget holders (Irvine et al., 2010; Davidson et al., 2012).

1.2   Implementing personal health budgets: Views among organisational representatives during the national evaluation

Personal health budget project leads working in the 20 in-depth pilot sites were asked to participate in an interview between April and June 2010 (Jones et al., 2010a). A further round of interviews with 43 operational staff, health professionals, third-party budget holders and commissioning managers was conducted between September and October 2010 (Jones et al., 2010b). Jones et al. (2010a, 2010b) found evidence of support for the overall aim of personal health budgets offering choice and control over the services that were available to individuals and their families to meet their desired outcomes, in terms of the services/support that could be purchased through budgets. A number of organisational representatives thought that the personal health budget process could also improve the relationship between the NHS and

budget holders (Jones et al., 2010b). However, similar to the experience in social care with the implementation of individual budgets, it was reported among organisational representatives that the implementation of personal health budgets was slower than expected owing to the many challenges that pilot sites had to overcome during the initial setting-up phase. At the time of the interviews, the delays in implementation had been attributed largely to the degree of culture change required within pilot sites, which seemed to be exacerbated by the climate of reduced resources and increasing uncertainty (Jones et al., 2010a, 2010b).

1.3 Personal health budgets from the viewpoint of the budget holder and carer during the national evaluation

Fifty-eight budget holders were interviewed three months after the offer of the budget, and 52 were interviewed after nine months. Thirteen carers were also interviewed three and nine months after the offer of a personal health budget (Irvine et al., 2011; Davidson et al., 2012). At nine months, the majority of personal health budget holders and carers reported a positive impact on their health and wellbeing, health care and other support arrangements and for other family members. Most budget holders and carers appreciated the increased choice, control and flexibility of the personal health budget, although some thought that the benefits were reduced due to the restrictions placed on the support that could be purchased through a budget, lack of services, and budgets being too small to meet health-related needs. At the time of the interviews, a minority of interviewees reported that they did not know the size of their budget; most people also did not know how the size of the budget had been calculated. People with direct payments were generally satisfied, while people with a managed budget reported experiencing long delays in receiving services. As to be expected during a pilot, there was at times some confusion about procedures for procuring support. Finally, ongoing contact with personal health teams was valued among both the budget holders and carers (Davidson et al., 2012).

Following the national evaluation of the personal health budget pilot programme, on 25 September 2012 the Government announced that £1.5 million was going to be made available to support the roll-out of the initiative beyond the pilot programme. On 4 October 2011, the Secretary of State for Health announced that, subject to the evaluation, by April 2014 everyone in receipt of NHS Continuing Healthcare (NHS CHC) would have the right to ask for a personal health budget, including a direct payment. The Secretary of State for Health in England made a further announcement that by October 2014 everyone in receipt of NHS CHC would have the right to have a personal health budget, including a direct payment (Department of Health, 2012). In 2014, the NHS Mandate outlined that, by 2015, patients who could benefit from a personal health budget would have the option to hold one as a way to have more control over their care (Department of Health, 2014).

1.4 Next Steps and outstanding issues

The national evaluation conducted research on the personal health budgets under 'pilot' conditions, at a time where procedures and implementation were developing, and challenges were being overcome within the pilot sites. As such, the national evaluation could only form tentative conclusions as to the continued impact of personal health budgets and the affordability of the initiative after the pilot programme. Following the national pilot programme, it was assumed that personal health budgets would represent a significant reform of NHS commissioning, the provider landscape and continued empowerment among budget holders and their families (Forder et al., 2012).

The quantitative analysis of the different implementation models suggested that knowledge of the budget size was important in achieving cost-effectiveness, along with the improved opportunity for the person to plan their care. There was also some evidence that personal health budget holders were changing their support relative to the control group and, more tentatively, that they were making more use of wellbeing services, potentially secured outside the NHS. The related conjecture was that having choice over providers would be important to achieving the best outcomes from personal health budgets (Forder et al., 2012).

The Department of Health commissioned the current study to explore the continued implementation of personal health budgets following the national pilot programme, both in routine-use settings and in terms of gaining a better understanding of why and when PHBs might work the best.

The research team have produced two reports to explore the processes and operation of personal health budgets that potentially explain how improved outcomes were achieved during the national evaluation, and what factors affected the achievement of better outcomes. We also aim to reflect on whether the context has changed since the pilot, and the potential implication of any such change. The two reports have been produced due to delays encountered during the recruitment process.

The current report focuses on the views of personal health budget leads, commissioners and budget holders. The second report focuses on the views among managers of service provider organisations and budget holders. The report also explores the content of current personal health budget support plans and the organisation of budgets following the pilot programme.

2 Aims and methods

The general approach of the current report – in line with process evaluation methods (Moore et al., 2015) – was to learn from (a) the experience of organisational representatives with responsibility for personal health budget policy and practice; and (b) budget holders since the national pilot programme and also (by way of some contrast) from the experiences of new budget holders. In particular, we sought to infer key mechanisms of effect, and reflect on the contexts in which they operated (Pawson and Tilly, 2007). Together, mechanisms and context help us understand why we saw the outcomes of personal health budgets that were found in

the national evaluation, and conjecture on how changing context – specifically, post-pilot operation of the policy – might have an impact.

Based on the studies to date, the following process factors were expected to be important in determining the success of personal health budgets:

- Different budget-setting process

- Support planning and review process

- The development of the range of services available and availability of providers

- The extent of integration between health and social care

We explored these issues using a process evaluation approach that involved interviews with both organisational representatives – i.e. people charged with implementing personal health budgets – and with budget holders. Semi-structured interviews were conducted, with topics framed around the hypothesised process factors. Audio-files of the interviews were transcribed verbatim and were analysed using software NVivo 10 for Windows (QSR International Pty Ltd).

2.1   In-depth interviews with organisational representatives

During the national evaluation, twenty primary care trusts out of 64 sites participated in the in-depth strand of the study, with the remainder forming the wider cohort (Forder et al., 2012). Initially, personal health budget leads from one of the original in-depth sites were invited to participate in the current study. Due to recruitment issues, the invitation to participate in the current study was extended to all sites.

Between March and November 2015, semi-structured telephone interviews were conducted with eight organisational representatives whose work involved the delivery of personal health budgets within CCGs. Six interviewees were working in CCGs that had participated as in-depth pilot sites in the original national personal health budget pilot programme and had over 100 personal health budget holders living in their area. Two interviewees worked in CCGs that had been 'wider-cohort' sites during the national pilot programme, which were still relatively early in their implementation of personal health budgets and had fewer individuals using personal health budgets in their area.

The organisational representatives included personal health budgets leads, commissioners and one service manager. Five transcripts were analysed using a general inductive approach (Thomas, 2006) by one researcher, and three transcripts were analysed using a top-down approach based on the interview schedule by a second researcher. Coding was compared and discussed between the researchers until a final coding framework was agreed. In order to ensure consistency, transcripts were coded for a second time applying the final coding framework, by a different researcher where possible. Each code was then reviewed and

summarised, paying attention to the convergence and divergence of views among organisational representatives.

2.2   In-depth interviews with personal health budget holders

Initially, personal health budget holders who had participated in the national evaluation within one of the in-depth sites were invited to participate in the current study. Due to recruitment issues, the invitation to participate in the current study was extended to personal health budget holders who received their budget following the national pilot and evaluation.

Twenty-three personal health budget holders were interviewed by a member of the research team between March 2015 and January 2016. Nine of the personal health budget holders received the budget during the national evaluation, seven were new budget holders (e.g. received their budget following the national evaluation) and seven were former budget holders, having been part of the pilot programme.[1] The interviewees included both men and women, aged from their 20s to 70. Two interviews were conducted with a proxy (the spouse) as the personal budget holder was unable to participate in the interview themselves. On both occasions the spouse managed the budget for the patient.

The interviews explored the personal health budget process, management of the personal health budget, and the support or services purchased via the budget. The topic guide was used flexibly, enabling participants to express their views, and ensuring that issues could be discussed in more detail. Interviews lasted from 60 to 90 minutes and were carried out by one researcher.

The transcripts were analysed thematically using a general inductive approach (Thomas, 2006) to allow the development of a framework using the reported experiences and processes underlying the raw qualitative data. One researcher completed the analysis, with key themes and conclusions being verified through discussions with the wider research team.

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[1] Following the national pilot programme and focus of the initial roll-out of personal health budgets, participating CCGs reported that they were offering budgets only to individuals who were eligible for NHS Continuing Healthcare (CHC). A number of organisational representatives reported that any remaining personal health budgets falling outside this condition (CHC) were stopped following the national pilot programme.

3 Results

3.1 Views among organisational representatives

3.1.1 Personal health budget process

A number of principles underlie personal health budgets, including the following: after initial assessment, recipients should know the indicative level of resource available to them; recipients should be encouraged to develop a support/care plan that details how resources will be used; and recipients should be able to decide how they would like their budget to be managed (notionally, managed by a third party or as a direct payment) (NHS England, 2014). In addition, commissioners need to engage with communities to help inform people about the existence of personal health budgets.

The national evaluation suggested that differences in the implementation of these principles would have impact on the cost-effectiveness of personal health budgets. All organisational representatives stated that they were currently offering personal health budgets in line with the original principles of the initiative.

3.1.1.1 Budget-setting

Following the main principles underlying personal health budgets, for some organisational representatives the process of generating a budget began with creating an 'indicative budget' to approximate the initial cost, or giving a maximum amount for that budget as a guide or starting point for that individual. Organisational representatives reported various tools that could be used to do this (mostly Resource Allocation Systems (RAS) but also bespoke tools devised by original pilot sites). They were essentially predicated on the same principles:

> "For continuing healthcare we use the kind of [place name] model which is a ready spreadsheet whereby we've got local rates for personal assistance across the city that are provided by existing providers and we look at those per number of hours of support that are needed. The way the model works is you look at the cost of the conventional continuing healthcare package and say, you know, ...set the budget so it tends to follow looking at cost of a conventional package for CHC." (Personal Health Budget Lead)

For those organisational representatives that did not use this indicative budget approach (and some contended that this was unnecessary), a maximum amount or cap was discussed, which was generally the cost of current provision. Arguably, this could still constitute a provisional indicative sum for the budget.

> "I've spent a lot of time looking on the websites and all the help out there and it all talks about the indicative budgets and having resource allocation systems. I personally don't think any of those are really needed. We've never used those and it just seems to me to add an extra stage to the process. We always found that by

definition you can't spend more on a personal health budget for the budget and
the process to deliver it than you would have done for continuing healthcare and
the cost of delivering that. That's your maximum." (Personal Health Budget Lead)

Almost all organisational representatives described having a mechanism in place that allowed some flexibility regarding the initial indicative or maximum budget amount. Where this was exceeded, it was based on identified clinical need, and when this occurred it was counter-balanced overall by other budgets which cost less than statutory arrangements.

"If someone needs extra funding then it will need a clinician to do a clinical check
on it and that's the process--. As long as it's clinically justified, by and large we'd
say yes to it. If it's not or if they feel the service is already procured elsewhere via
existing contracts, then it will be rejected. If someone wants to use their budget
within the amount, that's relatively easy to sign off because it's within the total
amount." (Personal Health Budget Lead)

Despite the variation in how to set the budget, all organisational representatives held the view that personal health budgets were not about saving money per se but about providing high-quality care tailored to individual needs. This was within pragmatic boundaries, though (see budget-setting above), and all organisational representatives contended that it was not feasible for care packages to greatly exceed the cost of statutory provision. Overall, organisational representatives reported that personal health budgets had led to an increased awareness of service costs for both staff and patients:

"I think more aware of services in the community, so more aware of things like the
hourly rate of personal assistance, the costs of--, so whether that's a day service, a
night service, special requirements, you know, to support people, clinical tasks, so
much more aware of that." (Personal Health Budget Lead)

"But yeah, some people do go, 'My God, that costs a lot,' and then try not to spend
it--. Equally some people don't really seem to care about the cost." (Personal
Health Budget Lead)

"So we're buying more hours of care within the same budget overall but, yes,
individual packages would be cheaper if people chose PAs rather than agency
care." (Personal Health Budget Lead)

The use of (indicative or other) caps and the greater awareness of costs is consistent with the national evaluation finding that costs in the PHB group were not statistically significantly different from conventional support used by the control group. The flexibility that was available on a case-by-case basis is also consistent with the key hypothesised impact mechanism associated with personal health budgets: that is, the ability to tailor care to individuals' needs.

3.1.1.2 Deployment options

All organisational representatives stated that the three deployment options (notional, third-party and direct payments) were available in their area. However, there was some variation in the uptake of these options, which appeared to be based not solely on the preference of recipients but also on local requirements. One Personal Health Budget Lead thought that the managed budget was the best option as the patient does not feel scrutinised when asked for receipts. Another Lead reported a specific system issue with using notional budgets in the context of the NHS Shared Business Services system (SBS), although this was not reported by any others:[2] *"I think it's because of the payment options since we changed to NHS Shared Business Services, SBS. It's made it very, very difficult to get payment through for anything that's slightly different from normal… It becomes really difficult to process anything through it."*

Aside from some practical issues, there was no clear message that the choice of deployment option in itself was a main driver of differences in the impact of personal health budgets.

3.1.1.3 Care and support planning

Organisational representatives viewed care and support planning as a vehicle through which to deliver person-centred care. It was seen universally as a valuable process, allowing the discussion of care options in partnership with individuals and their families.

> *"Early on I went out to a family, it was somebody who was dying; he'd been discharged home to die and it was a Friday afternoon so it was a rush job, 'could I go out to this person who was just being discharged from the hospice?' And I went out to see him, I walked in to see him and I spent about an hour and a half with him about what his needs were. He said, 'Do you know, you're the first person ever to ask me what my needs are?'"* (Personal Health Budget Lead)

Support planning is still being carried out by clinicians, personal health budget facilitators or external provider organisations, as was previously described in the first interim report of the pilot evaluation (Jones et al., 2010a). Careful support planning was described as a way to enable forward-planning and avoid the need for crisis management.

> *"They can plan for things that they want to do in advance without having to go through somebody else to make a different arrangement in terms of care provision. We find that people who have personal health budgets tend not to go into that kind of crisis situation in the way that people who perhaps don't manage their budget directly have often had that situation arising."* (Personal Health Budget Lead)

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[2] On 1 April 2016, the administrative and support services for primary care on behalf of NHS England transferred from NHS Shared Business Services to Primary Care Support England (www.sbs.nhs.uk).

Organisational representatives from CCGs which were in-depth sites in the original pilot programme reported that decision-making processes had become more efficient as implementation progressed and as the number of personal health budget holders rose. The organisational representatives from the wider cohort sites seem to have too few personal health budgets to have experienced these efficiencies.

> *"..whereas this time two years ago we might get eight or ten, now we're getting 18 or 20 in a session, so we're having to tighten up on how quick we make decisions and go through it and make the panel work a bit more smarter, not harder."* (Commissioning Manager)

Although it was acknowledged that support planning can be a time-consuming process, it was also noted that it is important to get it right, not only to ensure that an individual and their family's needs and preferences have been taken into account, but also to save work in the longer term.

> *"I think it's probably about the same [time to complete care planning before/after pilot], because it is quite a time-consuming process. But I think it does save time in the long run. But this has particularly been reported in continuing care, because they have a lot of people that would be phoning them on a weekly basis saying that their support was wrong and wasn't working for them and things like that, whereas actually support planning, sitting down with a family to discuss what would work for them and, you know, what the best thing for them would be, it's just reduced those frequent calls."* (Commissioning Manager)

3.1.1.4 Engagement

The organisational representatives recognised the benefits that personal health budgets can bring to individuals, but making all the steps necessary for implementation can prove to be more challenging. Commissioners reported engaging closely with people, which suggests that commissioning has become more 'person-centred'.

> *"You know, we've got a Twitter, a Facebook, we're in the local paper, you can get to people easier and people can email you, so the world has changed generally and the NHS has changed with it. Personally, I enjoy engaging with patients. It's a challenge because they ask you questions that you don't get asked by your fellow peers and your fellow professionals. It puts you on your toes and you think 'Oh, I hadn't thought of that'; so yeah definitely, we definitely engage more than we've ever done before."* (Commissioning Manager)

3.1.2 Accommodating choice of services and provider development processes

3.1.2.1 Range of services available

The findings of the national evaluation suggested that having a range of available services from which to choose was a potential mechanism for producing good outcomes. In the current

interviews, a number of organisational representatives talked about being creative and innovative where appropriate, and valued the freedom to 'push boundaries' where it was deemed that this would lead to a specific benefit for the budget holder. Organisational representatives also explained that outcomes remained the primary focus, and that in cases where non-statutory services or equipment were being requested, these could only be approved once the outcome benefit to the patient could be clearly identified:

> *"We try not to have limits, really. If somebody can show that something is meeting their health outcome and it's within their budget, then we would be very likely to tell them to go ahead."* (Commissioning Manager)

Organisational representatives reported that patients living within their area continued to access a wide range of equipment and/or services using their personal health budget that would not be available via statutory NHS provision:

> *"If you didn't have a budget there are certain care organisations you could not go to 'cause they haven't signed an NHS contract… but perhaps they're too small so they would never be interested in signing an NHS contract. So, with the budget, suddenly they become available."* (Personal Health Budget Lead)

However, in discussing the options available for patients, one interviewee explained that, while this was very open, providers of personal care services needed to be registered with the Care Quality Commission (CQC) to be eligible for purchases using a budget. This was in place to safeguard people accessing services using a budget.

Organisational representatives reported that allowing flexibility in support that can be purchased through the personal health budget can have a positive impact on reducing expensive hospital service use:

> *"We've had ones where we've given alternative therapy, so Reiki, for example. A PHB paid for some Reiki and because of this Reiki, which was £800, the person who received the Reiki hasn't used Mental Health Services. You know, the crisis team hasn't come out once since this Reiki happened and if you could unpick the contract and if you could break it down to the level, you would see that that £800 as part of the personal health budget has paid as a positive that ten times over."* (Commissioning Manager)

Furthermore, organisational representatives regarded the opportunity offered by personal health budgets to deliver more appropriate, adequately-tailored care to people who are 'seldom heard' as a reason for their better outcomes.

> *"…. But it's had a better impact on LD [patients with learning disabilities], partly 'cause the budgets are quite high to begin with so there's always that much more funding to play with. But also because of their more unique needs than perhaps physical disabilities, for example, where obviously everyone's still an individual but you might be limited in what you can do."* (Personal Health Budget Lead)

"We have just only a handful probably of people funded who are not White British. But actually for those few families, what they have been able to do is employ family members to be paid carers and that's been hugely beneficial for them because of the cultural differences and the language differences. Especially when people have a condition that involves cognitive impairment or challenging behaviour, being able to have familiar people providing care is really key, people that speak the same language." (Personal Health Budget Lead)

3.1.2.2 Provider development

It was thought that voluntary sector providers were particularly well placed to deliver flexible services and, after some initial resistance, some greater flexibility has emerged from established providers.

"Yes, they've had to adapt to what it is. So instead of pitching up at somebody's house at ten o'clock in the morning, different people every day, you know. I mean some of the horror stories I've been told about some of the poor agencies that go in, they now are prepared to bend to get the business, if you like. I mean, you know, you don't want to say business, but unfortunately, that's what it is so, yes, definitely I've seen a change in providers." (Commissioning Manager)

Through flexible services, it was thought that personal health budget holders can now access a wider range of service providers and secure continuity of care.

"Well, they've had more choice and control over who comes in and out of the house, haven't they? The people eligible for continuing care, I think they've found it particularly beneficial because they've been able to employ personal assistants that they've chosen and are able to, you know, tell them the times that they want them and what they want to do with them, and train them to do certain clinical tasks, like change dressings and things like that. And I think that's been the best." (Personal Health Budget Lead)

However, despite some improvements in flexibility, it was reported that providers were struggling to recruit care workers, particularly in rural areas and especially for personal health budget holders who had complex needs, which is likely to be a growing market in the future. Reported problems of recruitment and retention of care workers in rural communities are not new (e.g. Patmore, 2003) and not specific to personal health budgets.

"It seems to be, from talking to them, that the issue is that some of these individuals are discharged from hospital with very, very complex needs, and a few years ago they wouldn't have been discharged at all, they would have remained in the hospital. And actually, you know, you're looking at a very niche market. But on the whole, you know, for people whose needs are less complex, we are able to find provision." (Personal Health Budget Lead)

Consistently it was suggested that the economy of scale was a major issue that can hinder market development, which in turn impacts on patient choice.

"…you get care home providers saying, 'We want to open in [place name], can you guarantee that you'll be able to send us 20 people with learning disabilities?' Well we can't 'cause I haven't got a crystal ball and you're looking two years in advance, you know. It's the same with this, I don't think there's sufficient numbers 'cause if you were setting a brokerage firm up yourself, you're going to go where the business is and you can't just sort of open and hope it turns up. So I think that's the issue." (Commissioning Manager)

Part of the problem was a seeming lack of demand for personal health budgets in some CCGs, despite localities publicising the availability of personal health budgets among eligible patients.

"I think the numbers are just steady. There hasn't been any increase or decrease probably. We've certainly, since the right to have, haven't had anybody phoning up and saying, 'I'd like a personal health budget,' just on the back of knowing that now there's a 'right to have'." (Personal Health Budget Lead)

In addition to the volume of patients who are using a personal health budget to meet their needs, the existence of block contracts with providers has continued to affect the personal health budget process and the commissioning of services. Disaggregating block contracts was highlighted as one of the biggest challenges to the wider roll-out of personal health budgets.

"No, we've not been able to decommission them. Because it's difficult, isn't it? If we've got a physio, for example, and somebody is prescribed a six-week course of physio and they decide that they're going to employ a personal assistant or join a gym instead, then we can't sack that physio." (Commissioning Manager)

Many organisational representatives stated that they had seen some growth in new providers being available, but acknowledged that this was slow. Increased availability in the provider market was needed to give patients greater choice. A Commissioning Manager provided the following example about an alternative respite service for younger MS sufferers:

"That's what they want and it isn't out there. It is very difficult, isn't it? Unless you've got entrepreneurial providers who are seeing that there is a market, and there probably isn't, you're probably talking half a dozen people."

Encouraging market changes, such as the introduction of new service providers or the expansion of existing services, was described by many to be a slow process but potentially important in being able to move away from block contracts. Despite the challenges, there was a clear appetite to disaggregate large block contracts to free up funding in order to operate personal health budgets among other patient groups in addition to CHC patients. Many organisational representatives viewed this as the 'end goal' for policies such as personal health

budgets (as well as others, for example the Integrated Personal Commissioning (IPC)[3] programme and the Better Care Fund) and expressed enthusiasm to do this in the future.

Tackling the apparent constraints posed by block contracts need not just mean stopping their use. One Personal Health Budget Lead suggested retaining block contracts and working with contracted providers/partners to free up funds to deliver equipment/services devised in the care plans. This, according to the Lead, would negate the need to disaggregate large contracts, but was not without its own challenge:

> "I was talking to the director of finance at the [hospital] about a particular project that we're looking at and he says, 'Well, look, as a provider I think I should be funding that and actually providing the money for the personal health budgets out of my block contract.' And I know our mental health demonstrator, our mental health provider has the same attitude, that actually we are paid to deliver the service. If this delivers it better we should be funding it from our block contract; how we fund it, the logistics, is another matter, but we should be doing it. In principle, and it is a case now of working that through into practice, how do we actually get the money within the block contract to actually give to individuals under NHS procurement rules?" (Personal Health Budget Lead)

Furthermore, a Commissioning Manager explained that they had developed a mechanism to prevent double-running in their mental health cohort of patients:

> "We have worked with our mental health provider to ensure that we are not double funding for our mental health personal health budgets and we've got a system by which we reclaim money back (from the provider) that we have paid out for personal health budgets."

3.1.3   Integrating health and social care

The degree to which organisational representatives stated that they had achieved or worked on integration with local authority colleagues can be divided into three areas: pooling budgets; joined up working; and single care assessments.

3.1.3.1 Pooling budgets

A number of organisational representatives stated that they had been able to arrange pooled budgets where appropriate for their budget holders, and this appeared to be encouraged by

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[3] IPC is a new approach to joining-up health, social care and other services at the level of the individual (www.england.nhs.uk/commissioning/ipc/)

the introduction of personal health budgets. While some pooled budgets were more fragmented, for example by requiring two separate payments (one from 'health' and one from 'social care') into the same bank account, others were combined so that only one payment was required. A Commissioning Manager explained how they had arranged their pooled budgets with the local authority:

> *"We've got a Section 75 agreement in place with [City Council] and [County Council], so that they are able to make direct payments on our behalf and then they re-charge us on a quarterly basis, so that helps, particularly for the joint funded patients because then they receive one payment into their account and then there's one lot of monitoring involved. You know, it is quite good in that respect. We've also got a joint brokerage team so that [City Council] host the team and they write plans across health and social care, and we contribute towards that team. So that again helps with the joint-funded people."* (Commissioning Manager)

3.1.3.2 Joined up working

A minority of organisational representatives stated that they had not yet arranged any pooled budgets with local authority colleagues; however, all but one of the organisational representatives stated that the personal health budgets initiative had enabled them to establish better working relationships with social care colleagues than previously. According to organisational representatives, this led to a more seamless transition experience for patients moving from a personal budget (social care) to a personal health budget (health). In general, organisational representatives reported greater joined-up working, for example by sharing information regarding current need and social care services being provided to meet that need.

> *"On the other hand, we do talk with our colleagues in Social Services more than we did. So at handover, for example, we get a much clearer idea of what services people are currently getting and when they've got a direct payment how much that is and what they're using it for, which is very useful when setting the budget going forward."* (Personal Health Budget Lead)

3.1.3.3 Single care assessments

One of the most difficult aspects of personal health budgets appeared to be collaboration of assessment of need and care planning across health and social care. All of those interviewed stated that, while this was part of the overall ambition going forward, this was yet to be accomplished.

> *"No, we don't have a joint assessment or a joint review. We don't have that level of integration at all, I'm afraid."* (Commissioning Manager)

Overall, there was some evidence of progress with the integration of health and social care support and creating more holistic packages of care following the national pilot programme, but further progress is yet to be made.

3.1.4   Reflecting on personal health budgets

Organisational representatives were asked to reflect on their experience of implementing and operationalising personal health budgets, and made comments based on lessons learned, what they would change in hindsight, and ongoing challenges.

The importance of having and retaining key members of staff to include strong leaders or 'champions', as well consistent team members involved in care planning and administration, was identified in the national evaluation. This was also cited as a key aspect of driving the policy forward and retaining the momentum created during the pilot phase:

> *"Having key people who are still aware of what the principles are but how this works and understand the learnings that have happened and why it is the way it is. Which I guess we've been fortunate in* [place name] *that we've had the same group of key people involved from the outset. The broker that we originally had is still involved, the service manager is still involved and one of the Commissioners that was involved in the pilot is still involved. We've had that key group of personnel who have managed to keep it going and where the learning has continuously developed, as opposed to dropping off."* (Personal Health Budget Lead)

One concern expressed by a number of operational staff (project leads, care navigators, frontline clinicians) in the national evaluation was the risk of patients misusing funds or even defrauding the NHS. The experience of the organisational representatives showed that this anxiety was unfounded and that incidents of this nature were extremely rare:

> *"Yeah, well out of all the cases we've done, which is over 300 since we started, it's about 350, something like that now, we've only had one that we felt was quite dodgy and that was more incompetence than dodgy. And they actually voluntarily said, 'Actually we don't think we should be managing this because we are getting confused and mixed up.'"* (Personal Health Budget Lead)

In hindsight, some organisational representatives suggested that a more 'top-down' approach would have been useful as a guide to how best implement the policy. However, this may have impacted on the usefulness of the pilot in terms of establishing local practice by allowing, at least provisionally, a high degree of autonomy. One element on which all organisational representatives agreed was the challenges encountered regarding tax and employment law that had to be tackled because some budget holders effectively became employers. This continued to be demanding for project leads, and was cited as an area where more guidance would be useful.

> *"I think more [guidance] in terms of the legal stuff. I think people are quite confident and comfortable discussing the assessed needs and how to meet those needs and some of the decisions around budget spend. I think it's the employment stuff and the tax stuff."* (Personal Health Budget Lead)

All organisational representatives recognised the challenges attached to disaggregating block contracts, but related to this was the need for market development. While many organisational representatives stated that they had seen some growth in new providers emerging, they said that this was slow, and increased growth in the provider market was needed to give patients greater choice.

Finally, all organisational representatives highlighted the cultural shift required both institutionally and on the part of clinicians in acknowledging the 'patient perspective' and the role that this lived experience can play in identifying the equipment or services required to generate good patient outcomes. Again, while many organisational representatives were able to identify improvements, there was also a recognition that continued work was needed to establish personal health budgets more firmly within internal processes:

> *"Yeah, I think there's been a massive culture change, and people do accept that personal health budgets are here and the benefits of them, and they can see how they would work. I just don't think… You know, they're seen as quite a positive thing, but I still don't think people see it as part of their role. If they're just a normal commissioner, they still don't see how it would impact on them. And I suppose, until it does get bigger, they're not going to see it as part of that role."* (Commissioning Manager)

Overall, the organisational representatives reported a positive impact of personal health budgets on individuals and their families. It was thought that personal health budgets had provided an opportunity for individuals and their families to access a wider range of services and support. Examples were reported of individuals being empowered to meet their desired health and quality of life outcomes, and there was anecdotal evidence of this resulting in reductions in secondary care use.

> *"She used to have to carry around a portable oxygen tank. She's quite elderly, she's quite frail and it was starting to give her really bad problems in her shoulder. So we purchased for her through PHB some new batteries, lightweight batteries, that powered the oxygen tank. The week after we did it I saw her just outside of work with a group of friends in a pub, bless her, you know, with a group of friends and she just looked better. She just looked happier because she wasn't being, you know, held back by this thing."* (Commissioning Manager)

3.1.5   Changing context: personal health budgets policy in localities - continuity and eligibility

Moving beyond the pilot phase has somewhat changed the context in which personal health budget policies are deployed. The transition to routine operation in itself is a change, but there are also changes in the more general policy environment regarding personalisation and integration, and changes in funding and eligibility.

Overall, organisational representatives saw their personal health budget policy as one part of the range of personalisation policies that generally aim to place individuals at the heart of all decisions about the support required to address their health and wellbeing:

> *"We're seeing personal health budgets as really part of a whole personalisation or person-centred care agenda that we're developing as part of our better care programme, so the whole aim is trying to keep people at reduced hospitalisation, reduced care home admissions, by using a number of different initiatives, self-management, telehealth, telecare, support for carers, and personal health budgets are one of those."* (Personal Health Budget Lead)

Organisational representatives from CCGs that were involved in the national pilot programme stated that the policy itself, in addition to their understanding of it, had remained unchanged. There was an indication by one Personal Health Budget Lead that the process had become more complicated following the pilot phase. However, such a view appeared to be local in nature, as the guidance from NHS England concerning the personal health budget process has remained the same following the pilot programme (NHS England, 2014).

> *"People have the right to have a budget, hasn't changed at all but the actual process around them having a budget has become slightly more complicated and the legal implications thereof, particularly about being an employer."* (Personal Health Budget Lead)

A number of organisational representatives discussed the information they had developed during the pilot phase as having the potential to be used as examples of local practice for areas beginning the roll-out of personal health budgets.

> *"I think the information available to patients is probably quite good, but that's because we've had quite a long time to develop it, we've had the last six years to develop it."* (Personal Health Budget Lead)

However, it was acknowledged that, while the national pilot programme had been completed, there was a need for a longer-term implementation process to fully embed personal health budgets. For example, it was suggested that each case was unique and could present complexities which previously had not been encountered.

Consistent with embedding a new initiative into a pre-existing working practice, the need for longer-term implementation of personal health budgets was highlighted as important to help ensure the continued awareness among colleagues and to resolve concerns.

> *"I've been in many situations where I've been in a room with one set of people going, 'Right, this is how it is. This is how you'll do it,' you know, talking about this and then I've been a week later sat with a load of finance people and they're going, 'What? You're kidding,' and what I've wanted to do is take them, put them in a room with NHS England and let them fight it between them. I've felt like middleman in the middle delivering unpopular messages to either side and I've*

always felt like the referee in delivering the message to be told, 'No, that's rubbish. No, that can't be true. The government can't be expecting us to buy laptops for people and stuff.'" (Commissioning Manager)

Such frustrations potentially could have been caused by continued uncertainties that have remained about what is and is not available for patients following the national pilot programme: *"I think there's a lot of confusion around what they are, what you can have"* (Commissioning Manager).

Such uncertainties can lead to frustrations among patients about whether or not they are eligible to receive a personal health budget:

> *"Obviously people do pick it up because we do get phone calls from somebody going, 'I want a personal health budget. And we're like, 'Okay. Well, you know...' 'Somebody told me I could have one.' 'Well, you can't,' and then we have to go through the whole thing. 'If you are eligible for Social Care services then you can have a personal budget. You need to be assessed by them to get one. For a personal health budget there are these people,' you know. And they're usually not within that bracket because it's 0.1% of the population who are CHC eligible. And they'll go, 'But I have MS,' or something like that. I'm not saying you don't have a health need but unfortunately personal health budgets are only available in these areas.' So I think it's patchy."* (Commissioning Manager)

The position being described in this example is a locally-determined policy on eligibility, rather than following national policy. The NHS Mandate (2014) clearly set out that, by 2015, patients who could benefit from a personal health budget would have the option to hold one (Department of Health, 2014). These examples highlight that the availability and eligibility for personal health budgets vary between localities. The impact of personal health budgets on local populations will therefore depend on the local context.

In addition to local eligibility decisions, the shape of local personal health budget policies will depend on how processes are developed in the locality and the nature of training for individuals who are new to personal health budgets:

> *"So the processes have evolved over time and there's a lot of training happening at the moment to really develop the competencies of the clinicians so that they do become experts in at least understanding the process on a very straightforward level but then knowing when they need to find posts for more specialist organisations for the extra help."* (Personal Health Budget Lead)

During the national evaluation of the pilot, organisational representatives reported that one of the challenges related to implementing budgets concerned gaining 'buy-in' from other individuals that were not directly involved with the pilot: that is, changing the cultural context for personal health budgets. For example, NHS middle management, health professionals and, in one case, a chief executive were reported during the national evaluation to be either unaware of the initiative or reluctant to engage with it and therefore unable to commit to it

fully. While discussing the range of services available for budget holders, a Personal Health Budget Lead in the current study reported that this context was changing, although relatively slowly:

> *"I don't know, resistance is too strong, but this kind of lack of knowledge, this counter-cultural don't really understand these, you know…I think there's immediately people fall into, 'Well that's more social care and they should be funding that,' so it's that, it's that definition of wellbeing, you know if you look at PHBs it talks a lot about health and wellbeing, it's the wellbeing bit I think people still find difficult to describe, to accept that we would fund it. And it is changing, it is changing."*

Organisational representatives reported slowness in getting the 'PHB message' across to clinicians. They did acknowledge the difficulties for clinicians and the competing priorities for those working in the clinical field:

> *"I was at an event yesterday and talking about communication, GPs don't know. Well, GPs won't, will they? When they see three people a year who are eligible, it's not really crossing their radar is it?"* (Commissioning Manager)

Furthermore, there were still mixed views as to the policy intention of personal health budgets. One Personal Health Budget Lead thought the view that some saw personal health budgets about cost-saving: *"I would say there has been a retrograde step in personalisation. It is seen as a cheaper alternative than commissioning care through an agency, and it is deemed as still being personalised because it is the person's choice who their carer is."* This perception contrasts with the view that personal health budgets are intended to help people also achieve better outcomes than when using conventional approaches.

Changes in the financial context could also have a bearing on how far the mechanisms of change offered by personal health budgets (e.g. the capacity to exercise choice) were able to produce benefits. For example, one interviewee explained how their CCG had been challenged around the spending of budgets and that this had resulted in options for patients becoming more limited following the pilot. The implication of this, they argued, amounted to a less holistic approach than had been taken previously (during the pilot), and a departure from the intended ethos of the policy. One example of this was restricting a policy that allowed budget holders to spend money saved (e.g. by accessing required services for less cost) on additional wellbeing services:

> *"There has been a significant tightening up of what people are allowed to spend their money on… It is becoming more prescriptive, it is more and more just around care, there is less around--, less flexibility around other things outside of care. So if people have saved on their budget by managing their care in a better way, where we allowed them to then utilise things to meet other health goals or you know, psychological needs, emotional needs, cultural needs, that is now being taken away."* (Personal Health Budget Lead)

According to this Personal Health Budget Lead, the local changes outlined above had effectively reduced the impact or potential advantage of accessing services via a personal health budget and made it less personalised. This view arguably underlines the point that a key mechanism of change that comes from personal health budgets is the flexibility in how to use the budget. If there is a perception that this flexibility has been reduced, for whatever reason, then this implies that the potential of personal health budgets is more limited.

It is clearly difficult to generalise about how any changes in the budgetary and related environment would affect the impact of personal health budgets. In particular, we would need to know how these changes would affect the experiences of people were their services secured by conventional means, rather than using a personal health budget. On this point, it is worth noting the evidence from the national evaluation which highlighted that there were no statistically significant differences in the costs of services that could be directly secured using a personal health budget (such as nursing, therapy and care services). Furthermore, total costs (direct and indirect) were not statistically significantly different between the personal health budget group and control group after accounting for baseline differences (Forder et al., 2012).

3.1.5.1 New budgets and budget cessation

After the close of the national pilot programme with its focus on the initial roll-out of personal health budgets, participating CCGs reported that they were offering budgets only to individuals who were eligible for NHS Continuing Healthcare (CHC). A number of organisational representatives reported that any remaining personal health budgets falling outside this condition (CHC) were stopped following the national pilot programme.

The NHS Mandate in 2014 outlined that patients who could benefit would have the option to hold their own personal health budget. The focus on CHC was taken predominantly for pragmatic and local reasons in relation to no longer operating under 'pilot conditions', and in particular no longer having funding available for those conditions:

> *"The people who had the budgets from the pilot, so that was MS, COPD and mental health, they weren't able to continue with those. We only offered them for the pilot."* (Personal Health Budget Lead)

In some sites, some (non-CHC) budget holders were able to continue with their budget. These budget holders had successfully challenged (at least temporarily) the cessation of their budget due to the perceived benefit they gained: *"those people we haven't got a statutory duty to provide, they're not CHC so they were going to be closed down. The backlash from the individuals, the GPs, their MPs has been quite considerable."*

This potentially raises an important question concerning the experiences among patients with long-term health conditions following a national pilot programme. However, one CCG had gone beyond their original remit of offering budgets to patients diagnosed with diabetes and COPD, and extended their offer to patients with other respiratory conditions.

3.2   Views from personal health budget holders

The budget holders we interviewed in this phase of the study expressed unanimous support for the overall concept underpinning personal health budgets, believing that they offered more opportunities for the budget holder than conventional service delivery. They perceived that holding a budget provided greater choice and control, greater sense of purpose, and efficiency of service delivery. The majority of budget holders who were interviewed also appeared generally happy with the use and the amount of their budget, and reported that, following the national pilot programme, their budget had a positive impact on their life and their families that exceeded their expectations.

> *"Well I was shocked really. I was amazed. You know, I thought 'Wow!' You know, it was something that I thought I would like but never thought that I would have."*

> *"I think having that flexibility means that other people have to worry less about me. My wellbeing reflects on my behaviour and if I'm depressed and upset then obviously that affects people around me. So having that increased responsiveness of the care agency and a higher level of care provision means that generally my wellbeing is better and that reflects on other people around me, meaning that they're less worried about me and makes their lives in turn better."*

The positive impact on budget holders' mental wellbeing and the perceived improvement on their physical health seemed to be more prevalent now compared with the findings within the national evaluation. Interviewees reported that having something positive to focus on meant they no longer felt all-consumed by their illness.

> *"After I left the hospital, the generic stuff didn't suit my needs and I became extremely depressed, my marriage broke down and then I tried to commit suicide. Having a personal health budget has sort of given me a kick up the bum to try and sort of dig myself out of this hole, it's a real lifeline to me……It's made me feel more valuable as a person again. It's had a huge impact really and it's helped to improve my outlook on life."*

During the national pilot programme, budget holders reported varying degrees of understanding of the key concepts underpinning personal health budgets and personalisation more generally. Two years following the pilot programme, budget holders interviewed in this study seemed to have a better understanding of the overall aims of personal health budgets. This finding might be expected, given that some of those that took part in this study were long-term budget holders. Perhaps more significant is the reasons people gave for their positive outcomes. We found that people mainly attributed their improvement to the core principle underlying personal health budgets – increased choice and control and greater flexibility over services:

> *"To be able to be a part of your own recovery. Yeah, rather than people telling you how it should be, you being able to have your own voice and saying how you'd*

like it to be, how you think your life might improve by doing such-and-such a thing and actually having people listen to you and say, 'Okay, let's give it a try.' You know, it's like a massive leap forward, it really is."

These findings, which are consistent with the views among organisational representatives, clearly indicate that personal health budgets are highly valued by some people. It may be that some people do not have a good experience with personal health budgets and – as a follow-up study of mainly budget holders – we would not be reflecting these views. Nonetheless, the implication that can be drawn from these results is that if personal health budgets can be targeted, and people have a choice over how they are deployed, benefits can be achieved. The focus here is on understanding why (the people interviewed, at least) had a positive experience.

3.2.1 The support/care planning process

The personal health budget holders interviewed in this study spoke positively about the notion of a personalised support planning process and the greater control the process provided to budget holders. Many of those receiving the budget for an ongoing long-term physical health condition (such as multiple sclerosis) and those in receipt of NHS continuing healthcare (CHC) reported the benefits of being able to choose who provided their care and not, for example, having to rely on an unknown agency that could be unreliable. They reported that their personal health budget had improved their mental health as a consequence of feeling more in control of their health condition and knowing that they had continuity of care. The importance of continuity of care echoes the views among organisational representatives. The positive impact of not having to rely on family members as informal carers was also discussed, alongside a reduction of unplanned hospital admissions.

All of those interviewed found the care planning process to be very helpful. It was thought a more holistic approach was being followed that takes account of both health and social care needs. However, budget holders described the discussions they had with their health practitioner as more focused on singular clinical outcomes rather than overall wellbeing.

During the national pilot programme, a number of budget holders discussed feeling anxious or apprehensive about the process. Budget holders in this study discussed 'enjoying' the process and the control it gave them over their support and care. Budget holders also seemed to have a better understanding of how the budget was calculated, what they wanted to use the budget for, and accessing the support than was the case in the national evaluation. Again, we find that having control was a positive experience for the people interviewed here. Clearly, others who are less inclined to value greater control would be less likely to choose a personal health budget. But even if this is the case, it does not detract from our finding here that some people do value this outcome.

3.2.2   Uses of the personal health budget

Personal health budgets were being used to fund a wide range of services, which included traditional NHS support and non-traditional, alternative and complementary treatments/support. All budget holders were aware of the possibility of purchasing 'alternative' treatments, and many stated that they were doing so with their budget. Some of the more innovative uses discussed included:

- Gym equipment
- Hiring a gardener
- Fitness centre membership
- Leisure activities, such as angling club membership
- Cinema tickets for budget holder and their personal assistant (PA)
- Drum kit and drumming lessons
- Reflexology

Following the national pilot programme, the personal health budget had, for some, evolved in line with individual needs, underlining the potential for diversity and its flexibility. One budget holder who was also involved in the national pilot stated:

> "Well, my health has changed since I first started. As I say, I've gone less mentally ill and more physically ill and the budget has changed with me. And that's enabled me to carry on, like not needing the hospital and things like that."

During the national evaluation, a number of budget holders reported that more information was required around what could be purchased. Currently, some budget holders felt they had been given sufficient information to be able to make informed decisions about how they could use their budget. However, this view was not held by all budget holders, which will be explored below.

3.2.2.1 Changes in flexibility of the budget since the pilot programme

Some insight can also be gained about the importance of the flexibility available to people in how they could use their budget by comparing people's experience regarding flexibility during the national pilot with their experience thereafter. Perhaps not surprising given the exploratory nature of the pilot phase, some people reflected that they had greater flexibility during that pilot period as compared to now. While people were very happy with the flexibility in terms of being able to recruit their own carers and therefore having greater continuity of care, it appeared that more specific criteria in terms of *what* could be purchased through the budget had subsequently been imposed.

> "The flexibility in the pilot was different from when it was rolled out. After the pilot phase things tightened up and there was less flexibility in the budget. So in the pilot phase there was more flexibility to do different things with the money, and now basically it's just paying agencies, but it's still very useful."

> *"Well the tightening up of the rules means that there's restrictions on things outside NHS services."*

Although alternative or exploratory services were still evidently being purchased, some of the budget holders involved in the pilot believed that the use of alternative services had been reduced. One interviewee reported that they were now no longer allowed to purchase any alternative treatments: *"I was on a personal health budget which would just pay for alternative therapies with the idea of reducing my medication and saving money, basically. That was part of the pre-pilot [sic], but when the pilot ended they stopped that bit of funding. So they changed the criteria."*

New budget holders who were not involved within the national pilot programme thought that there was a general "over-promotion of alternative therapies" instead of a holistic approach for the benefit of the individual patient. Possibly, this differing perspective is due to the budget holders not involved in the national pilot programme not experiencing the flexibility offered during the pilot. Nonetheless, budget holders did discuss a certain rigidity as to how they were allowed to spend their budget, but this was not in terms of alternative therapies (for example, reflexology and massage services) being restricted. The budget holders not part of the national pilot programme generally wanted to use their budget to continue with their NHS treatment pathway, rather than purchasing alternative therapies.

> *"Well, the only things that were actually agreed was the sport. So I get my aerobics paid for, which is fine, but it didn't replace my specialist mental health care, to me that was just a bonus. It wasn't my bread and butter care that I needed. I said all right, thank you very much, and I got this money…it turned out to be totally inappropriate. You know, it wasn't mental health care. It was somebody to help with their shopping or that sort of thing, which I didn't need. I needed specialist mental health care."*

Budget holders involved in the national pilot and those who had received the budget following the pilot both discussed a lack of flexibility in terms of purchasing things not deemed directly relevant to their 'health' status.

> *"You know, the whole point that we've been led to believe is outcomes, whereas we're being told that's not health. The person I spoke to said, 'Well, that's not health, that doesn't come under health.'"*

Other budget holders reported a lack of flexibility in altering the budget to reflect their health status change since the end of the pilot scheme. One budget holder stated:

> *"My budget isn't actually big enough to buy what I want around here, but they won't increase the amount I'm allowed to pay per hour…But I'm doing without them [extra carers] because, well I can't find them for the money that's in the budget. So it's all confused and it's further confused but my state of health hasn't been very good over the last year. Even now, I'm in the middle of chemo and it's dropped to the bottom of the priority list. I just couldn't be bothered fighting it."*

There was some speculation as to why flexibility had changed since the pilot.

> *"I think the attitude towards it has changed. I think when I got the budget, when it was awarded, there was a lot more flexibility implied to be in it than I have found. I've found it far less flexible than I think it should be."*

Budget holders perceived that their budget was not yet acting in a fully personalised way; one individual who took part in the national pilot referred to it as an "unfinished jigsaw". He argued:

> *"I'm a raving fan of personal health budgets. Don't get me wrong, I think they're a great idea. I don't into hospital as much, I don't go into nursing home care, but it's only if you can get all the bits of the jigsaw in place that you can achieve the outcomes. If you can't, then it is like an unfinished jigsaw. There's holes everywhere and that's where it becomes a little bit stressful…I'm a fan of the philosophy and the concept and everything. I think it gives the individual freedom, it gives them peace of mind, it gives them the potential to achieve a lot more than if you didn't have one and so you get a better quality of life. It ticks lots of happy face boxes. But the main problems are achieving the desired outcomes because of all the bureaucratic or marketplace issues, and that's the frustration; you get offered this [laughs] wonderful nice Pandora's box, where everything comes out, looks wonderful but in a way you can't actually turn the things into reality."*

3.2.3   The management of the budget

Over half of the 23 budget holders interviewed were managing the budget as a direct payment. Two had a notional budget, where the budget was held by the commissioner but the budget holder was aware of the service options and costs, and one had recently changed from having a direct payment to managing the budget via a third-party organisation. Those who were managing the budget themselves believed the process ensured greater control but also recognised the challenges with managing it. They expressed reservations about the practicalities of managing the budget if a person was not an "*organised and assertive individual*." All those managing the budget reported it to be a difficult task, and that it did entail greater stress. However, budget holders also reported that they believed the direct payment option offered much better healthcare outcomes, and was therefore, as one budget holder put it, a "*necessary evil*". The budget holder explained:

> *"In order for me to have the flexibility I need in my life, I need to employ my own PAs which is great, you know, it's helped with that aspect of my life, but in order to employ my own PAs it's very, very complicated. There's a lot of paperwork, there's a lot of legal responsibilities and when you're not well and you still have to manage all of that it can be extremely difficult…So that aspect of having a health budget is very stressful."*

Those who reported coping well with managing the budget themselves stated that they had previous managerial experience in their working life. They acknowledged what a challenge it

was, and recognised that it would probably not be appropriate for those without prior managerial experience.

> "Well I think if you haven't got no idea you don't necessarily realise how much responsibility you've got… I think sometimes if I think of what could go wrong I'd probably freak out, but I try not to think about all those things."

> "I cope well with it. I've found it the best thing out, to be honest, and I manage it well. Luckily I'm good with figures so there is a lot of paperwork with it, but I can manage all that."

Many respondents noted the importance of professional support in managing their budgets. Alongside the difficulties with managing the personal health budget, budget holders expressed frustrations with the general lack of professional support available to them. Those who were involved in the pilot programme mentioned the reduced level of support available post-pilot, while new budget holders remarked on an absence of support.

During the national pilot evaluation, budget holders discussed the desire for better information and greater guidance regarding the use of their budget. Some budget holders involved in the national pilot required support in planning how to use their budget and with identifying potential legitimate uses for their budget. Consistent with this view, the budget holders involved in the current study reported that they would benefit from more information being available to aid choice or to help identify the best use of their budget or to know what was a legitimate purchase. Some budget holders reported being given documentation to aid their support planning; these people also remarked on the unwieldly form of this information: *"the health documents can be a bit heavy and, you know, it would be nice to have it a bit simpler so you can make better choices and not get overwhelmed too much"*.

3.2.3.1 Changes in support since the national pilot

Interviewees also commented on the importance of support, reflecting on the implications of reduced levels of support that some experienced after the national pilot.

Budget holders discussed how during the national pilot they had someone to support them through the care planning processes and generally guide them in decisions of how to spend their budget. However, they stated that now that they had less support:

> "I used to have a social worker but the system's changed and you don't get any support now."

> "I don't have anybody helping me with guidance on what I could do or even how to go about it. And to be honest, it's just all become too much of a hassle now."

A lack of continued guidance left some budget holders feeling that the level of control had declined following the national pilot programme, and they were not able to make 'informed choices' about what to spend their budget on.

Although some budget holders had their support plans reviewed after the pilot, over half of the sample had not. Their level of help and budget remained the same. Clearly, reviewing support plans is important where health needs are changing.

> *"Basically my budget it's taken from the pre-existing contract with the agency that I had before and the level of funding has not changed from that."*

> *"Well, from then [the pilot] until now I haven't seen or heard or met or spoken to anyone about anything, really."*

Whilst budget holders not involved in the national pilot felt that budgets gave them flexibility, as noted above, some felt that support planning could be more *personalised*. Support plans described as 'impersonal' and 'unstructured' detracted from the value of holding a personal budget. Personalised support planning does require time and effort, and is constrained if, as some felt, staff did not have the capacity to fully engage with it or where staff were not well informed themselves.

There was also some suggestion that having a main contact member of staff was effective. Those who reported that a number of different staff members were involved with the support planning process, felt that this did not help to contribute to continuity of care, key to a personalised care package. The evaluation of the personal health budgets found that a good rapport with staff who were accessible and well informed was key for a positive support planning experience.

> *"No, they've declined that. That was on the support plan that the agent lady drew up with me, but she obviously didn't represent me well enough because that was declined and the [other item requested] was also declined…So I put that down to the agent not knowing me well enough and not doing a good enough job representing me. You know, I think it's silly that someone of my intelligence, average intelligence, can't put together her own plan."*

Consistent with the findings from the national evaluation, organisational representatives reported that guidance handbooks would be useful to help them make better-informed purchasing choices. Training and workshops were discussed as a possible way to help people deal effectively with managing the budget themselves.

3.2.4   Anxieties around the future of personal health budgets

One theme that emerged during the interviews was anxiety about the future of their personal health budget, underlining the benefits these people felt from having the option to hold their own budget. We identified a general perception among interviewees that personal health budgets were no longer high on the political agenda and therefore on health practitioners' radar. One budget holder reported that personal health budgets were "*not being flavour of the month anymore*". Naturally some people were anxious about the possibility of losing their budget, and these perceptions seemed to contribute to these anxieties about the future of their personal health budget.

The expected concerns were reported by these people. Would the programme continue? In what format would it continue and for how long would it continue? What would happen to them if it stopped? Furthermore, some budget holders reported that they had been given a budget to cover the costs of a specific therapy, such as massage therapy, or a specific item, such as gym membership, but had not been told if this funding would continue when the current budget ran out. Budget holders who believed their health had been very positively affected due to support purchased by the budget questioned whether they would be able to afford this service if the personal health budget was to stop. Where people perceived a lack of available support, they were anxious about whom to contact to discuss the future of their personal health budget.

As noted above, many budget holders in this study reported notable improvements in their physical and mental health, and therefore had come to rely on the help or support funded through the personal health budget. They discussed their anxieties about deteriorating health through not being able to fund this support with their own money should their budget be discontinued:

> *"…what will happen when they take it away because I'm sure at some stage it will be, and what provision will they put in then because unfortunately I have a history of really serious suicide attempts, so I can't imagine that in my case there'd ever come a time when they'd said, 'No, you don't need any home support', because the impact that that's likely to have on my mental wellbeing would be quite devastating. But it might be that I get to a situation where I'm sort of getting so little support it hardly seems worth it, so that worries me. And I think that worries the people that work closely with me, like my psychiatrist and my psychologist. Unfortunately it doesn't seem to worry the people who agree the budgets, does it?"*

The value that people ascribed to having a personal budget during the pilot also meant that they felt its loss after the pilot programme had finished. Some felt this loss keenly:

> *"I was devastated, absolutely devastated. I can't tell you the difference it made, you know. I couldn't understand how it could be stopped after two years, with not a letter telling me why or anything. Just like that…I tried to get my MS nurse to help me find it, my doctor saying why has this suddenly stopped? I've been using it so much. And yeah, I don't know why it stopped and I wish it hadn't, and it wasn't that I wasn't using it properly 'cause I certainly was."*

The merits or otherwise of conducting pilots (including the consequences of when the pilot ends) is beyond the remit of this study. However, the transition from pilot to routine practice was a source of change in experience that people discussed and in turn provides us with a better understanding of what people felt about the policy and how it was configured.

4 Discussion

The national evaluation found an overall improvement in outcomes for personal health budget holders as compared to a control group. The present study explored, with both existing and new budget holders and organisational representatives, some of the potential reasons why personal health budgets might have worked, and what the constraining factors might have been. This follow-up study was not designed to assess changes in outcomes in any systematic or comparative way. Indeed, the study sample consisted of longer-term budget holders who we might expect to have had good experiences with personal health budgets. Rather, the focus was on the features and operation of personal health budgets – including the changes in these features and PHB operation since the national pilot – that interviewees felt to be important in why personal health budgets might have worked, and in terms of what could be improved.

In this discussion we comment on some of the key mechanisms of effect of personal health budgets identified by interviewees, and consider what factors mediated these effects. We also consider the changes that have occurred in the operation of personal health budget policy between the national pilot programme and the current rolling-out of personal health budgets.

Overall, the respondents in this study identified a number of positive outcomes in their experience of personal health budgets. These views echo those found during the in-depth interviews among organisational representatives (Jones et al., 2010a, 2010b) and budget holders (Irvine et al., 2010; Davidson et al., 2012) in the national evaluation of the personal health budget pilot programme. However, respondents also identified challenges that could potentially impact on the effectiveness of personal health budgets.

This study aimed to gather the views of a number of organisational representatives and budget holders about the reasons why personal health budgets had either positive or negative effects, as relevant to their case. It was not designed to be representative of all potential recipients of personal health budgets and, indeed, some of the reasons that interviewees expounded for positive outcomes might result in negative outcomes for others. As limitations, the study gathered the views of a self-selected sample, and from a relatively small number of interviewees, and these shortcomings need to be recognised. Nonetheless, the study indicated the reasons why some people benefited, and that they were given the opportunity to do so from the policy. Giving people with similar inclinations, these opportunities – provided by the availability of personal health budgets – should mean that they too would realise the benefits.

4.1 Mechanisms of effect

Consistent with the previous national evaluation, a clear message emerging from this study is that personal health budgets can improve outcomes by: giving people a greater sense of control and empowerment, facilitating a supported, in-depth care planning process; and by allowing people to secure services and support in a more innovative and flexible way to meet their specific care needs. In this respect, allowing flexibility in the use of personal health budgets is an important policy direction.

In some sense, personal health budget holders are *potentially* empowered. There was a suggestion from the interviews that the realisation of this opportunity involved commitment, capacity and willingness on the part of budget holders. In particular, the 'transaction costs' of securing services and support, such as employing personal assistants, and care planning were seen as challenging in some cases. As such, personal health budgets would be more likely to work for people with such commitment or capacity.

Building on this issue and consistent with the change management literature (e.g. Bamford and Daniel, 2007), a strong message was that professional support is vital to ensure that people can manage the personal health budget process effectively. Many personal health budget holders highlighted the importance of having support and guidance from professionals around how and on what they could use their budget. It was indicated that levels of professional guidance and support had reduced since the pilot, which budget holders found difficult in the main. This finding points to the benefit of having a longer-term implementation process to fully embed personal health budgets during the current roll-out of the initiative. In a similar vein, the report published by the Cabinet Office (2013), *The Barriers to Choice Review*, highlighted the need for information, signposting and personal face-to-face support to help people choose the support they require.

The capability offered by personal health budgets for people to be innovative in securing care solutions appeared to be an important mechanism for good outcomes. The extent of this capability was seen to be affected by (a) the rules regarding the flexibility people have over how they can use their budget; and (b) the potential availability 'in the market' of a range of innovative care solutions and options. The following themes were important in this regard.

First, organisational representatives, in particular, identified the challenge of freeing up resources that were tied to block contracts with existing providers. As well as moving commissioning away from block contracts in general, some potential solutions could include: personal health budgets being made available by block-contracted providers, not commissioners; and also arrangements to allow 'buy-out' of personal health budgets from block contracts.

Second, the diversity of the provider market will be a key factor to the continued implementation of personal health budgets. Some budget holders experienced difficulties with finding the right care solution, especially in rural areas. In part, the significance of this problem will reduce by exploiting economies of scale and scope: that is, if the number of personal health budget holders increases. It was thought that the relatively modest number of budget holders had, so far, limited the size of the market for care solutions and hindered provider development.

It was thought that, through flexible services, budget holders could access a wider range of service providers and secure continuity and flexibility of care. However, encouraging market changes such as new service providers or provision of new or expanded services is challenging. A similar message has recently been highlighted in a report published by the National Audit

Office (2016) *Personalised commissioned in adult social care* in terms of local authorities reducing the number of providers they contract with, to achieve economies of scale.

A growth in the use of personal health budgets would help to realise economies of scale in this regard. Where prospective providers see increasing demand in a local market, this creates an opportunity to offer more innovative care solutions. To further realise these benefits, an option would be for commissioners to work more closely with providers to develop care solutions. Another option would be for commissioners to assume part of the financial risk, through the offer of pump-priming funding to providers, for example.

Third, there were differences in how, and on what, budget holders were allowed to use their budgets. This variation might reflect different interpretations of the key principle that support options can be chosen if they are expected to meet the needs and improve outcomes for the budget holder. A relevant example is whether people can use their budget to pay for alternative therapies, especially where conventional clinical evidence is not supportive but where people feel that wellbeing benefits would arise. The interviews with budget holders indicated that there had been a degree of tightening restrictions on spending as personal health budgets policy developed after the pilot. Finding a balance between flexibility and guidance is difficult. Potential solutions in the spirit of personal health budgets might be to allow some 'trial and error' in this respect, and also to continue to recognise more holistic aspects of people's quality of life and outcomes.

Flexibility and consistency for many budget holders with complex needs also depend on good integrated working between health and social care commissioners. Most respondents reported that a single personal budget could be created by pooling health and social care funding, and improving working relationships between sectors. However, fully integrated assessment and care planning support did not appear to have been achieved and was perceived as challenging. The new integration initiatives and models, especially integrated personal commissioning (IPC), could be seen as a potential solution to these issues.

There are significant developments in policy around person-centred care and integrated working including, most relevantly, the Integrated Personal Commissioning programme and the personal maternity budgets, but also the wider Vanguards programme. Better understanding of why and how personal health budgets can produce better outcomes, and for whom, stemming from this work, should be valuable evidence to help support this overall policy development. Moreover, the findings here should help to improve the experience of budget holders, particularly with further policy attention on establishing the right level of support for budget holders and on efforts to develop the provider market.

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