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Personal health budgets: Targeting of support and the service provider landscape

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Table of content

1   Introduction

The personalisation agenda continues to be a key focus in the political arena in England as a mechanism to provide individuals and their families with more choice and control over the support and services available to them to meet their needs. Personal budgets form part of this agenda, with the universal implementation among all adults from 2010 with eligible social care needs (HM Government, 2007). Subsequently, the Care Act 2014 created the first legal entitlement to a social care personal budget among eligible individuals and informal carers. In 2014-15, 350,000 clients were supported in the community through a CASSR (Councils with Adult Social Services Responsibilities) managed personal budget. Overall, 144,000 clients received a community direct payment at some point during the reporting year. Potentially, some of the direct payments would be the delivery option for personal budgets. In 2014-15, 92,000 carers received a direct payment, with 14,000 receiving a CASSR-managed personal budget (NHS Digital, 2015).

The implementation of personal budgets in England follows the individual budget pilot programme and the Department of Health-funded independent national evaluation (Glendinning et al. 2008). Unlike individual budgets that aimed to integrate a number of funding streams (e.g. social care funding; Access to Work; the Independent Living Fund; Supporting People and the Disabled Facilities Grant), personal budgets contain only social care funding. As part of the personal budget process, individuals are informed of the budget amount following an assessment, and have choice over how the resource is managed and used.

Glendinning et al. (2008) found some evidence to suggest that individual budgets were cost-effective in achieving social care-related quality of life but not psychological well-being, although this impact varied between client groups. During the pilot programme, the average gross cost of an individual budget was around £11,450 per year. The qualitative strand of the evaluation included in-depth interviews with organisational representatives that involved service providers and commissioning managers. The initial reactions among providers (N=16) were positive, with some reporting that they had been successful in increasing their client base at the expense of less flexible agencies. The seven commissioning managers interviewed spoke of the importance of supplying providers with the information on which to plan their services (Glendinning et al. 2008). Similarly, Baxter and Rabiee (2015) explored activities to enable choice and flexibility in homecare services for older people using council-managed personal budgets within three local authorities. Baxter and Rabiee highlighted that communication issues and information flows need to be improved if brokerage systems are to work effectively.

In 2009, personalisation moved into health care with the national pilot programme of personal health budgets in England. Following the principles underlying social care personal budgets, there are a number of stages within the personal health budget process, including (NHS England, 2014):

1. Making contact and getting clear information

2. Understanding the person's health and wellbeing needs
3. Working out the amount of money available within the budget
4. Organising care and support
5. Monitoring and review

According to NHS England, personal health budgets do not include new money but rather NHS money that would normally have been spent on a person's care being used in a more flexible way to meet their health-related needs.[1] A personal health budget allows individuals to manage their healthcare and support such as personal care and equipment in a way that meets their healthcare needs as outlined in their approved support plan. It works in a similar way to personal budgets, which allows individuals to manage their social care needs. [2]

The Department of Health commissioned an independent evaluation to run alongside the personal health budget pilot programme. The overall aim of the evaluation was to identify whether personal health budgets delivered better health and care outcomes among people with long-term health conditions compared to conventional service delivery and, if so, to identify the most effective implementation process (Jones et al. 2013; Forder et al. 2012). The evaluation followed a mixed design, with a quantitative and qualitative strand to explore outcomes, experiences, service use and costs. Overall, 2,700 patients were recruited to the evaluation, of whom 2,235 were included in the active sample. Within the active sample,[3] 1,171 were offered a personal health budget and recruited into the personal health budget group, and 1,064 patients were recruited into the control group and received conventional services during the evaluation (Forder et al. 2012).

1.1.1 Personal health budgets impact on outcomes and costs

The evaluation explored the effect of personal health budgets by measuring whether the average change in the relevant outcome and cost indicators in the personal health budget group between baseline and follow-up was higher than the average change in that indicator for the control group (Forder et al. 2012). The use of personal health budgets was associated with a significant improvement in care-related quality of life as measured by the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al. 2012) and psychological well-being of patients (GHQ-12, Goldberg 1992). Generally, a more positive effect on outcome indicators was seen where sites: decided to be explicit in informing the patients about the indicative personal health budget amount; provided a degree of flexibility as to what services could be purchased; and provided greater choice as to how the budget could be managed. Personal health budgets of more than £1,000 per year showed a significant positive impact on care-related quality of life and psychological well-being. Using care-related quality of life measured net benefits,

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[1] https://www.england.nhs.uk/learning-disabilities/improving-health/personal-health-budgets/
[2] https://www.nhs.uk/NHSEngland/patient-choice/personal-health-budget/Pages/about-phb.aspx
[3] The active sample excluded participants for whom baseline or follow-up outcome information was missing, participants in residential care at baseline, participants under the age of 18 years or who had died before follow-up

personal health budgets were cost-effective relative to conventional service delivery, particularly for the NHS Continuing Health Care and mental health cohorts (Forder et al. 2012).

1.1.2 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 among 43 operational staff, health professionals, third-party budget holders and commissioning managers was conducted between September and October 2010 (Jones et al. 2010b). Organisational representatives who were interviewed during the early stage of the implementation phase suggested that personal health budgets had the potential to alter perceptions of voluntary and third sector organisations. However, while it was thought that personal health budgets could encourage market development, concerns were raised as to whether there was choice and control during the pilot phase. The lack of market development appeared to add to the uncertainty around having choice and may have had an impact on the full potential of personal health budgets during the pilot phase.

"Is there really choice or are we just going to get the same things but in a different way? Is it really developing that area? How do you review and monitor this? But from my point of view it can only be positive as service users are more in control of their own care" (Health Professional).

"We need training about packages of choice, how to facilitate choice; we don't know this at the minute" (Health Professional).

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

Following the pilot phase, the NHS Mandate (2016-17) set out an expectation that, by 2020, people will have a personal health budget or an integrated personal budget. This commitment to service integration through personal budgets follows the continued impetus that service integration can help improve the efficiency of services, improve outcomes for individuals and is often perceived as a solution to the current financial challenges. The care sector is facing unprecedented challenges in terms of caring for an ageing population alongside meeting the recent austerity measures. On average, £3,000 is spent on health and social care services in one year per individual with one long-term health condition, increasing to just under £8,000 for those with three or more conditions (Department of Health, 2012). The demand arrives at a time when the NHS is required to deliver £22 billion in efficiency savings by 2020-2021 (HM Treasury, 2015). In addition, the proportion of councils' spending on adult social care is set to increase from 35.6% in 2016/17 to 36.9%, despite councils having to make additional 8% cuts in overall budgets (Association of Directors of Adult Social Services, 2017). Within the personal budget process, integration has the potential to avoid duplication of assessments and provide a mechanism for pooled budgets to cover both identified health and social care needs. During the national evaluation, Forder et al. (2012) suggested that greater integration could lead to a

change in the balance of services used. The research team suggested that personal health budgets should be considered as a vehicle to promote greater service integration especially where social care personal budgets and personal health budgets could be integrated around established bank accounts, accounting and payroll arrangements (Forder et al. 2012).

1.2   Next Steps

At the time of the national pilot phase, the evaluation team could only make tentative assumptions as to the continued impact of personal health budgets among service provider organisations and budget holders. The Department of Health commissioned the current study to explore the implementation and impact of personal health budgets following the pilot phase to gain an understanding of when budgets might work best outside of pilot conditions. The degree to which the context has changed following the national evaluation in terms of market development and service integration potentially could have an impact among current budget holders, in terms of the budget size, the purchasing of innovative support and their continued experiences of the budget process.

The current study includes two strands 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. The aim was also to reflect on whether the context has changed since the pilot, and the potential implication of any such change on the personal health budget initiative. Due to low recruitment issues encountered during the study, two reports have been produced covering each strand.

The first strand focused on conducting in-depth interviews among organisational representatives and budget holders about the potential reasons why personal health budgets had either positive or negative effects. The second strand focuses on the views among managers of service provider organisations who were offering their services via a personal health budget. This strand continues to explore the views of personal health budget holders around the budget process and the content of current support plans, including the organisation of budgets following the pilot phase.

1.2.1   Stand one - the views among personal health budget leads, commissioners and budget holders

Jones et al. (2017) focused on the first strand that gathered views among a number of organisational representatives and budget holders about the reasons why personal health budgets had either positive or negative effects. 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 Clinical Commissioning Groups (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 budgets in their area.

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 (Jones et al. 2017).

Overall, the respondents in the study identified a number of positive outcomes in their experience of personal health budgets. A message identified by the organisational representatives and budget holders was that personal health budgets can improve outcomes by: giving people a greater sense of control and empowerment; facilitating a supported 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 (Jones et al. 2017).

A number of challenges were also identified that could potentially impact on the effectiveness of personal health budgets, including:

1. Personal health budgets reported that levels of professional guidance and support had reduced since the pilot phase, 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.

2. Organisational representatives 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.

3. Some budget holders experienced difficulties with finding the right care solution, especially in rural areas. In part, the significance of this problem will be reduced 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.

4. 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 tightening of restrictions on what could be purchased as the personal health budget policy developed after the pilot. Finding a balance between flexibility and guidance is difficult (Jones et al. 2017).

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 (Jones et al. 2017).

1.2.2 Strand two – the views among managers of service provider organisations and budget holders. Also the content of support plans and the organisation of budgets

The second strand focuses on the provider landscape from the perspective among managers of service provider organisations and the perceptions among budget holders around the personal health budget process. The strand also explores the content of current personal health budget support plans and the organisation of budgets following the pilot phase. The current report focuses on this strand.

2   Aims and methods

Following a process evaluation design (Moore et al. 2015), the study explored whether the context of personal health budgets had changed following the pilot programme, from the perspective of service providers and budget holders, including the content of support plans. Following Pawson and Tilly (2007), the aim was to infer key mechanisms of effect, and reflect on the contexts to further our understanding of how post-pilot operations might have a current impact on the personal health budget process, market development and reported experiences among current budget holders.

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 Clinical Commissioning Groups (CCGs) covering one or more of the original in-depth sites were invited to participate in the current study. There were a number of challenges regarding recruiting CCGs to the current study. To help with the process, the study was advertised following a number routes, including:

1.   Personal health budget evaluation website (phbe.org.uk/phbe2)
2.   NHS England's personal health budget learning network
3.   Social media

In some areas, securing consent from participants who participated in the national evaluation of the pilot programme was problematic due to some extent to the time lag between the two studies. The research team took additional steps to help improve the recruitment of CCGs and participants, including:

1.   Extending the invitation to all CCGs covering one or more of the sites that participated in the national evaluation;

2. Extending the invitation to personal health budget holders who had received their budgets following the national evaluation.

The National Research Ethics Service conferred a favourable ethical opinion for the evaluation. Subsequently, the research team obtained the relevant Research & Development approvals to commence the study in each participating CCG.

2.1 Service provider landscape

Managers of service provider organisations were invited to complete an online survey and to be interviewed by a member of the research team.

The online survey was developed through consultation with the project's advisory group that involved stakeholders, academics and patients/members of the public. The web-based questionnaire was carried out using the computer package Qualtrics. The aim of the quantitative web-based questionnaire was to capture information on the current landscape among service providers. The quantitative data collection aimed to explore:

- The characteristics and sector of the provider.
- Provider sustainability.
- The impact on the scale of provision resulting from commissions from personal health budget (PHBs) holders.
- The market effects on the providers and types of services provided.
- The degree to which service providers find it easy to meet personalised service packages.
- The degree to which opportunities for secondary services have been realised among providers.
- Whether there are types of services where provision could be improved.
- The degree to which providers have moved away from traditional services, the extent to which they have moved away from NHS services, and the impact of this move on the system and patients.

In order to gain richer data about changes in service provision, service providers were also invited to take part in an in-depth telephone interview with the research team. The qualitative in-depth interviews were designed to explore in more detail the provider landscape within areas where the focus is on offering personalised services. Specifically, the aim of the qualitative interviews was to explore:

- The degree to which integration now exists between personal health budgets and social care personal budgets (PBs) in terms of their assessment, commissioning and delivery.
- The degree to which service providers have adapted to meet the demands of the personalisation agenda. For this purpose we asked whether there have been changes in commissioning patterns within personal health budgets; for example, is more

expenditure now going to non-conventional NHS providers than was the case under the pilot conditions?

- Whether service providers believed, since the pilot programme, that personal health budgets were continuing to have an impact on service users' quality of life and service experience compared to conventional service delivery.

The topic guide was used flexibly, enabling participants to express their views, and ensuring that issues could be discussed in more detail. Each interview lasted from 40 to 60 minutes and was carried out by one researcher. Interviews were transcribed verbatim and were analysed using the computer software package Nvivo for Windows 10 (QSR International Pty Ltd). The data were analysed thematically using a general inductive approach (Thomas, 2006) to be able to develop a framework using the reported experiences and processes underlying the qualitative data. One researcher completed the analysis, with key themes and conclusions being verified through discussions with the wider research team.

The recruitment of service provider organisations was slower than initially envisaged. To help the recruitment, the research team carried out a search of provider organisations who were advertising personal health budgets on their websites. The service provider organisations were contacted to explore if they would like to participate in the study. In addition,

1. One participating CCG sent an email advertising the online survey to a sample of their service providers.
2. One participating CCG provided a list of contact details for their service providers following consent for this information to be past to the research team.
3. One participating service provider circulated an email to other provider organisations and sent tweets about the study.

2.2   Personal health budget support plans

Copies of the personal health budget support plans were requested to explore the potential implication of any context change, in terms of the budget size, the management of the budget and the purchasing of innovative service/support following the pilot phase. The support plans provided information on:

- The budget per year, and the total level of funding in terms of health service expenditure, recurrent annual and one-off payments (where applicable);
- The formal organisation of the budget in terms of deployment options;
- The activities in the care plan that the budget was to be spent on; and
- The cost of the individual services identified within the care plan.

2.3   Patient outcome and experiences

The aim of the study was to explore the potential implication of any context change on service satisfaction and quality of life compared to conventional service delivery following the pilot

phase. A postal questionnaire was circulated to participants between June 2015 and January 2016. The questionnaire included the following outcome measures

- Health-related quality of life (EQ-5D – Euro-QoL)[4];
- Care-related quality of life (ASCOT);
- Psychological well-being (GHQ-12);
- Perceived quality of life (a seven-point scale);
- Perceived health (a five-point scale).

The outcome questionnaire also collected information around social care and primary care service use. In addition, demographic and socio-economic information was collected, as well as information about service experience.

2.4 Objective outcomes

An aim of the study was to explore the impact of personal health budgets on secondary care service use compared to conventional service delivery following the pilot phase. The data collection involved extracting secondary care service use from the Hospital Episodes Statistics (HES) database that is held by NHS Digital (www.digital.nhs.uk). Participants were initially asked if they consented for their secondary care service use to be extracted.

2.5 Limitations

We encountered significant recruitment delays, which limited the breadth of the current study. The sample of patients (or consultees) who participated in the national evaluation of the personal health budget pilot programme and the current study limited the analysis. The small sample resulted in the research team being unable to explore the continued impact of personal health budgets on quality of life among participants and on secondary care service use following the pilot phase. The intention had also been to compare the experiences of patients in CCG's where personal health budgets (PHB's) were well-established, with those in CCG's that had adopted PHBs more recently, however the sample was too small to make meaningful comparisons. However, the research team were able to explore service experience among personal health budget holders who participated in the national evaluation and those who received their budget following the pilot phase. While the sample of personal health budgets support plans was small, the data indicated how the context had changed following the pilot phase, in terms of the budget size, the management of the budget and the purchasing of innovative service/support following the pilot phase.

The study aimed to gather the views of service provider managers about personal health budgets and the challenges they face during the current roll-out of the initiative. It was not

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[4] © 1990 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

designed to be representative of the service provider sector. One limitation of the study was that views were gathered from a self-selected sample, and from a small number of service provider organisations. While the sample of service providers is small, the findings add to the existing literature exploring the continued implementation of personal health budgets following the pilot phase (Jones et al. 2017) and the potential impact of the continued implementation process.

Overall, strand two of the current study provides an insight into how the context of personal health budgets had changed following the pilot programme, from the perspective of service providers and budget holders, including the content of support plans. However, due to the small sample, firm conclusions cannot be made and the interpretation of the findings requires caution. Despite this limitation, the current study (including strand one) highlights the need for longer-term implementation of personal health budgets and the continued attention from policymakers.

3   Data

Overall, 14 CCGs agreed to participate in the study: 11 CCGs covering one or more of the original in-depth sites from the national evaluation of the personal health budget pilot programme; and two CCGs covering one or more of the original wider cohort sites.

In total, 104 patients (or consultees) agreed to take part in the study: 72 patients (or their consultees) from the national evaluation of the personal health budget pilot programme: 42 from the personal health budget group and 30 from the control group. The remaining 32 participants were recruited from CCG's covering one or more of the original wider cohort sites.

3.1   Service provider landscape

Fourteen service providers, from seven CCGs, completed the online survey between March 2015 and March 2016. Of these, seven were from a private company, three were from a charity/voluntary organisation, one was from a local organisation with just one branch, one was from a community organisation and one was from an organisation dealing with more than one CCG. Seven service providers stated that they did not have a contract with the NHS. The types of services being offered included: training services, administrative services, domiciliary services, home help, professional health therapies (such as physiotherapy, occupational therapy), complementary therapies (such as Reiki), brokerage services, advocacy services, services which employ PAs on behalf of the budget holder, counselling services and nursing services. In terms of numbers: five included training services, five included administrative services (such as payroll services, DBS checks), three were offering domiciliary (personal) care services, three offered home help, three were professional health therapies (such as physiotherapy, occupational therapy), three offered complementary therapies (such as Reiki), three offered a brokerage service, two offered advocacy services, a further two were organisations that employ PAs on behalf of the budget holder, one offered a counselling

service and one was offering nursing care. Most organisations were providing more than one of these services.

An invitation to be interviewed by a member of the research team was included within the online survey. Three service providers agreed to be interviewed between March 2015 and February 2016.

3.2   Personal health budget support plans

Sixty-nine personal health budget holders provided consent that the research team could have a copy of their support plan. The research team received 42 personal health budget support plans from four participating CCGs.

3.3   Subjective outcomes

A postal questionnaire was sent to the 104 patients (or consultees) who gave their consent to take part in the study between June 2015 and January 2016 to explore the potential implications of any context change on service satisfaction and quality of life.

Fifty completed questionnaires were returned, providing a response rate of 48%: 34 from the personal health budget group and 16 from the control group. The sample of participants was too small to explore the continued impact of personal health budgets on quality of life following the pilot programme. The postal questionnaire also gathered perceptions of the personal health budget process among budget holders (n=34). The research team explored the perceptions of the personal health budget process among budget holders, which will be the focus of this report. The report will explore the following themes:

1. Satisfaction with the financial arrangement, the care planning process and support/services purchased by the personal health budget.
2. The degree to which personal health budget holders perceived that they had enough help, choice and control when deciding what support they would like to purchase using their budget.
3. The extent to which the process had changed their view on what could be achieved in their life.

3.4   Objective outcomes

Overall, 92 participants consented for their secondary care service use to be extracted from the HES database. Sixty-four participants participated in the national evaluation (37 in the personal health budget group and 27 in the control group) and 28 were budget holders who had received their budget following the pilot phase and evaluation. The sample of participants was too small to explore the continued impact of personal health budgets on secondary care service use.

4 Results

4.1 Personal health budget process: The views among service providers

A number of principles underlie personal health budgets, including providing greater choice and control over the services and support that can be purchased through the budget. Following the national guidance from NHS England (2014), the process begins with an initial assessment and informing the recipient of the indicative amount of the personal health budget. Individuals are encouraged to develop a support plan to identify their needs and outcomes, together with their NHS team.

Overall, service providers were generally positive about the concept of personal health budgets in terms of its key aims and concepts. They perceived that holding a budget provided more choice and control and a sense of purpose for patients, as well as greater efficiency of service delivery.

> *"I think it's a great idea because I do feel that people should be given some responsibilities and rights to decide what treatments they would prefer for any of their health problems, treatment and help".* (Qualitative interview)

Furthermore, service providers reported that they perceived that giving people greater choice and control not only positively affects the patient but also has an impact on the health service.

> *"I do quite like the idea not only because it gives people a choice but I would hope that it would mean that the hospitals and GP services would be relieved, the pressure would be slightly taken off these places because people would seek help in other places and hopefully have a service which would mean that they would not need to go and see your GP as much, not need to go to A&E and hospital appointments as much."* (Qualitative interview)

Such views are consistent with those held among personal health budget leads, commissioners and budget holders (Jones et al. 2017).

4.1.1 The impact of personal health budgets on the service user and their family

Consistent with the views held among personal health budget holders, personal health budget leads and commissioners (Jones et al. 2017), service providers perceived that personal health budgets have the potential to impact on both service users and their families. The benefits were attributed to increased choice and control and greater flexibility over services, leading to an improved sense of independence and dignity.

> *"It gives the individual…full reign over their support. Giving them independence and dignity."* (Online survey)

> *"Advantages are control over their care, flexibility, not having to deal with so many agencies, so less transaction time, ability to have continuing kind of*

relationship with particular carers, or particular care providers rather than a changeable number of people. Ability to bring in other forms of care that traditional healthcare hasn't thought about, such as acupuncture. Overall it's an advantage I think in terms of the flexibility around the person and they're able to get the care that allows them to do things that they wouldn't normally be able to do for giving carers time off or personal health budget holders to do things that sort of, you know, maybe move around the country more, sort of be more in control of their own lives." (Qualitative interview)

"PHBs has led to clients getting more control over their lives and increased wellbeing." (Online survey)

Service providers reported patients with a personal health budget relied less on their family for care and support, which in turn reduced the pressure on informal carers. As a consequence, this meant that time spent with loved ones was "*quality time*", unburdened by care duties.

"It has given individuals the chance to do things independently, for example a PHB can help an individual to have driving lessons and this will enable them to gain the necessary skills to get out of the house. This in turns takes the pressure off of both the individual and their families." (Qualitative interview)

"I think it's a great idea because I do feel that people should be given some responsibilities and rights to decide what treatments they would prefer for any of their health problems, treatment and help." (Qualitative interview)

One service provider described the benefits of the personal health budget to the budget holder and their family as "*life changing*". They suggested it is "*life changing for individuals and families, better quality of support, better oversight of agencies and only being charged for hours worked, impacts on families as a whole not just the person.*" (Online survey)

Service providers described the benefits of holding a budget in terms of the choice this offered the patient. For example, it afforded patients the opportunity to purchase non-conventional NHS treatments that were previously unavailable.

"We funded a lady… she's married to a gentleman who's her full-time carer and she's been experiencing mental health…and she was struggling with post-traumatic stress episodes during the night. She was waking up quite fearful and not knowing where she was and the crisis team were having to be called out probably two or three times a week. He'd been reading a lot about reiki and other similar therapies and obviously trying to get her to go to these therapies, but she wouldn't go so he asked if she could have some funding for him to train as a reiki therapist. So we paid for him to go on the first course which was £400, and then he went on the second course which was another £400 the year after so he was able to provide reiki then to his family as a whole and within that, well within the first year really all crisis intervention had stopped…she's now been able to go to counselling where she wasn't ready for counselling before."(Qualitative interview)

Online survey respondents cited the ability for patients to hire their own personal assistants (PAs) using a personal health budget as a particular benefit over traditional health service delivery. Providers explained that PAs can play a pivotal role in creating new opportunities for people to try new activities or access services they hitherto were not aware of, or had been unable to engage with in their current environment.

> "We've got a few people who are from deprived backgrounds and with mental health backgrounds and they've grown up as socially deprived and I would say they've had family members that have perhaps got mental health conditions too. They've had the personal assistant and I think that allows them to see a whole new world, so you know, a personal assistant will take them out just to health appointments. Obviously on the way they'll go somewhere for a coffee, somewhere they've never been before, and on the way back they'll drop them into perhaps a support group that perhaps they've never tried before. The PA will introduce them and leave them there for an hour, all very small things, are impacting and offering them choice and opportunities to make friendships and taking advice from other people in similar situations. It's amazing how a few hours' personal assistance opens up their world." (Qualitative interview)

4.1.2   The impact of personal health budgets on service satisfaction

Service providers reported that personal health budgets had led to improved relationships between health professionals and patients. Interviewees explained that the care-planning process helped foster greater understanding of patients' needs and preferences. Service providers explained that this enabled them to personalise care plans in a more bespoke way to better address patient needs. Asking for patients' own views helped break down traditional hierarchical patient /professional barriers and harboured a feeling of mutual trust.

> "A trusting relationship is built and this in turn allows the person to get the best possible support that they can." (Online survey)

> "Working in close partnership with other organisations, professionals, clients and their families has been at the centre of our services since [name of service] was established in 2003, but we have found that personal health budgets have assisted us in doing this." (Online survey)

Service providers thought that the personalised care packages led to greater satisfaction with the service.

> "We have found that putting people in charge of their own care at home whilst supporting them with the legal responsibilities that come with that gives people full choice and control whilst ensuring safe and reliable services. We have in some cases been able to employ family members to be PAs as we are the third party involved and this gives the clients and commissioners peace of mind that the service is managed and monitored by an experienced and regulated third-party

provider. We feel those who use [name of service] services and personal health budgets have improved satisfaction with their services." (Online survey)

"Life changing for individuals and families, better quality of support, better oversight of agencies and only being charged for hours worked, impact on families as a whole not just the person." (Online survey)

Despite the positive views of personal health budgets among service providers, a number of issues were discussed that potentially highlight changes in implementation during the transition to routine operation. The NHS Mandate (2014) states that, by 2015, patients with a long-term condition who could benefit from a personal health budget should hold one (Department of Health. 2014). However, the availability of personal health budgets seemed to vary locally, which will potentially have an impact on local populations.

4.2   Local context change following the pilot phase

4.2.1   Market development

The national evaluation reported that market development had been slow during the pilot programme. This led to limited choice on offer to budget holders and their families (Forder et al. 2012). Following the pilot phase, personal health budget leads and commissioners asserted that voluntary sector providers were particularly well placed to deliver flexible services. It was thought that personal health budget holders could access a wider range of service providers and secure continuity of support (Jones et al. 2017). However, service providers participating in the current study perceived that there had been a lack of demand from patients in some CCGs following the pilot phase.

"Well it's much less than we expected, I expected there to be much more activity relating to [name of profession] being able to offer personal health budgets, but that hasn't happened." (Qualitative interview)

"I have not had one enquiry.... I sort of expected that over time that there would be more enquiries, yes. And I--, to be honest I simply forgot about it again because nothing happened. So I presume it will take much longer for that to happen." (Qualitative interview)

"I'm not aware that there has been great take-up, I have not heard of any particular take ups. It's difficult because I'm not sure actually how much people are given the choice to include private acupuncturists." (Qualitative interview)

"This is the first time I have been asked about them, and I stay in touch with news....so far as we have not received any information about them, and would be interested to do so." (Online survey)

A long-term implementation period for personal health budgets was viewed as critical for the full potential to be realised. It was felt that the continued implementation would help ensure

the awareness of personal health budgets within the service provider sector and subsequently encourage market development. Despite the NHS Mandate (2014) stating that, by 2015, patients with a long-term condition who could benefit from a personal health budget will have the option to hold one (Department of Health. 2014), a number of service providers expressed surprise that the initiative was being rolled-out.

> *"Well I actually didn't--, I wasn't even aware that it was being rolled out generally. I heard that this was coming but I don't actually know at this moment in time whether this is generally rolled out all over England or whether it's just a few regions where this is an option. So I have--, I just don't know, which means the information is not getting to me and so it doesn't get to anybody else, I presume."* (Qualitative interview)

Consistent with the views among organisational representatives and budget holders (Jones et al. 2017), service providers thought that more information around personal health budgets was still required following the pilot phase. It was thought that uncertainties remained among patients about personal health budgets and the type of support that could be purchased. Service providers suggested that a significant stumbling block for market development was the lack of awareness of personal health budgets among patients. They argued that more guidance and information could help them target patients and advertise their services as being available to purchase through a personal health budget.

> *"I think the information that you can find on the internet, I think it needs to be broken down more clearly for new organisations to get to know the process a bit better and the ins and outs, I think it's not broken down enough."* (Online survey)

> *"Everyone that I have worked with have stated that they didn't know that this existed or what it could do and how it could help. There needs to be a lot more information for people available on how to get a PHB and what it can be used for."* (Online survey)

Conferences run by NHS England were thought to be particularly effective in advertising personal health budgets. One service provider suggested that more events were needed to help promote the initiative and share ideas and experiences across different groups.

> *"[the conference] was really interesting and I think that needs to happen more often so service providers and professionals can be involved, and service users in how that process is done and what it would look like in their area."* (Qualitative interview)

4.2.2 Strong leadership

During the national evaluation of the pilot, organisational representatives reported cultural challenges in relation to implementing personal health budgets. This included encouraging 'buy-in' from middle managers and health professionals to highlight the potential benefits and use of personal health budgets among their staff (Jones et al. 2010a, 2010b). This view is

consistent with those held among personal health budget leads and commissioning managers following the pilot programme (Jones et al. 2017). Similarly, service providers suggested that professional support and strong leadership were vital for the longer-term implementation of personal health budgets and market development.

> *"I think there needs to be greater national leadership on this. I think the personal health budget team have done a great job, but maybe there needs to be more, more that can be done by NHS England on it... More sort of championing that can be done of how it does improve care and by … national leadership, and it seems to be compartmentalised rather than sort of generic change. Perhaps that's because there's bigger kind of issues within the NHS that are taking precedence, but there needs to be a positive step which can sort of counterbalance the negative sides of the budget constraints. [There needs to be] greater focus on it, 'cause it's been quite a slow burn."* (Qualitative interview)

Jones et al. (2017) found that organisational representatives had seen some growth in new providers offering personalised services. However, a number of service providers felt unsupported by their CCG following the pilot phase: "*CCGs aren't even giving the most up-to-date information*". Some service providers held the view that their CCG did not want personal health budgets to be in operation within their area. As outlined by Jones et al. (2017), changes in the financial context following the pilot phase could have a bearing on how far personal health budgets are currently being advertised.

> *"CCG don't want to do PHBs and don't have the capacity or systems to set them up properly, and so staff within CCG have obstructed them. We were told (off the record) not to promote PHBs as they couldn't deal with them. CCG's are very paternalistic, and don't understand the personalisation philosophy underpinning PHBs - GPs are also very resistant to this way of working."* (Online survey)

> *"For the small number of cases where it worked, it has enabled people a lot more choice and control. However, CCG has lost a lot of trust with patients after miscalculating budgets and subsequently dramatically reducing them - this has meant that there has been no additional benefit to having a PHB, as costs cut so that just basic care needs have been met."* (Online survey)

> *"We had to lay two staff off due to a CCG not working with us due to changing their procedure for PHB."* (Online survey)

Similar to the views held among organisational representatives (Jones et al. 2017), there was a sense from a few service providers that GPs still had a paternalistic way of working and are reluctant to change. As highlighted by Jones et al. (2017), while organisational representatives reported slowness in getting the 'PHB message' across to clinicians, they did acknowledge the competing priorities for those working in the clinical field.

> *"We've had quite a negative response from GPs in general…Because it's taken too much time up, so if somebody went to ask them to do a referral, even though*

they've filled in the support plan and they're just asking their doctor to agree that that would help, knowing their history, they feel like it's taking up too much time to discuss it with the patient and sign the paperwork." (Qualitative interview)

"The only real thing I could say really is that we need to get GPs onboard a lot more in [CCG area]...I think they think it's going to be giving them a lot more workload, whereas they're looking short term rather than long term, I think if people looked long term then obviously it would reduce their workload, it's just initially they have to put that bit of extra work in." (Qualitative interview)

There were also some uncertainties around how personal health budgets were offered. It was assumed that GPs would set up the process with the patient, which potentially contributed to the view that GPs were a barrier to market development.

"I actually don't know even, you know, how people can access this. I mean is it through their GP? That's why I mentioned GPs because that's my assumption that they first had to see their GP, but I don't even know whether that's true." (Qualitative interview)

4.2.3   The impact of personal health budgets on service integration

Service providers believed that without pooled budgets and joined-up working, personal health budgets may not function as intended.

"The fact is that there are still two budgets with different accounting processes. Different terminology between health and social care. Social care still having a contribution-based approach." (Online survey)

Furthermore, service providers perceived that market development had been hindered by the lack of integration due in part by the degree of commitment and communication between health and social care colleagues to help bring the two infrastructures together.

"Health and social care don't seem to be able to work together properly - each one doesn't know what the other is doing and it seems impossible to work together for the best for the individual." (Online survey)

 "Readiness to work in true partnership in the best interests of the clients, improved communication and sharing of information between health and social care professionals, consistent approaches." (Online survey)

While there were perceived barriers hindering service integration, one service provider highlighted that at the very least the "*PHB has started a debate on who pays for what, when and why*".

4.3   Current content of personal health budgets

The analysis of the 42 personal health budget support plans provided an insight into the level of budgets, how budgets are currently being managed and the support/services that are being purchased since the national pilot programme. The current personal health budgets showed an average spend of £42,530 per year. Thirty-one personal health budget plans reported the deployment option, with 26 managing the budget as a direct payment and five as a managed-budget either via a third-party arrangement or NHS-managed. During the national evaluation, we had to identify which services were in addition and which substituted conventional services based on the personal health budget value. In the main analysis, we assumed a threshold of £1000 per annum: that is, personal health budgets of £1000 or less in each service category were provided in addition to conventional services. Budgets over £1000 were regarded as substituting conventional service delivery. It was also assumed that personal health budget-funded expenditure that was made as a direct payment could be viewed as an indication of the amount of expenditure that went to non-public providers in the study (Forder et al. 2012). In the current study, the majority of the personal health budgets (N=35) were worth £1000 or more per year; of these 28 budgets contained over £1000 per annum to purchase social care-related support and 11 budgets contained over £1000 for well-being support. Following the assumption around substitution from the national evaluation, some personal health budgets in the current study were potentially acting as a substitute for existing services following the pilot phase. Due to the small sample, firm conclusions cannot be made. However, this assumption is supported, to some extent, by the views among personal health budget leads and commissioners who 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 (Jones et al. 2017). To explore this view, the expenditure included in the current personal health budget support plans was interrogated. Following the methodology from the national evaluation (Forder et al. 2012), expenditure was divided into four categories.

- **Social care service-related service** required to meet both health and social care needs – for example, home care, respite, day care;
- **Well-being-related services** – for example, complementary therapies, leisure and equipment;
- **Therapy and nursing services** – for example, nurse and physiotherapy visits;
- **Nursing and therapies** – for example, nurse and physiotherapy visits.

Table 1: Overall patterns of expenditure funded in personal health budgets

	Mean	Median	SD	Min	Max
Total budget	£42,530	£19,180	£53,190	£330	£220,790
Social care	£38,780	£16,600	£53,200	£0	£218,670
Well-being	£830	£3	£1,400	£0	£5,770
Therapy	£0	£0	£0	£0	£0

Note: Only one personal health budget contained funding for nursing and therapies and therefore cannot be reported as there is a potential of identifying the budget holder.

While, the majority of budgets was spent on social care-related services such as health-funded home care, budget holders were also purchasing well-being services, such as complementary therapies and gym membership. The findings are also consistent with the views among personal health budget holders (Jones et al. 2017), who were aware of the possibility of purchasing 'alternative' treatments, and many stated that they were doing so with their current budgets. Some budget holders, particularly among those who participated in the national evaluation, thought that there was a reduction in the degree of flexibility of what support could be purchased via the budget following the national evaluation (Jones et al. 2017).

4.4   Perceptions of the personal health budget process

During the national evaluation, 43% (n=285) were either extremely or very satisfied with the support planning process. Overall, 44% (n=289) expressed being either extremely or very satisfied with the financial arrangement, and 38% (n=201) reported that the personal health budget process had changed their view on what could be achieved in their life a lot.

The analysis of the completed postal outcome questionnaires provided some insight into the perceptions of the personal health budget process following the pilot phase. Overall, 34 personal health budget holders completed the postal outcome questionnaire during the current study. Table 2 shows that among the 34 personal health budget holders, 21 reported that they were currently receiving support purchased through their budget. Of the 21 participants still purchasing support via a personal health budget, 18 reported that they were either extremely or very satisfied with the support received from the budget and 10 were satisfied with the care planning process.

Table 2: Personal health budget process

	N
Receiving support from the budget	21
Extremely or very satisfied with the support received from the budgets	18
Extremely or very satisfied with care planning process	10
Strongly agree or agree 'I had enough help when deciding what to spend my PHB on'	12
Strongly agree or agree 'I had enough choice over the help that I would like my PHB to pay for'	15
Strongly agree or agree 'I had enough control over the help that I would like my PHB to pay for'	14
Extremely or very satisfied with the financial arrangements	12
The PHB process has changed my view a lot on what can be achieved in my life	12
Strongly disagree or disagree 'I had enough help when deciding what support to spend the budget on'	5

There was a view among five budget holders that they needed more support to decide how to spend their budget. Overall, the findings indicate less satisfaction with the care planning

processes following the pilot phase, although firm conclusions cannot be made due to the small sample size.

When asked if there was anything participants would like to use their budget for (but there were insufficient funds), the responses centred around travel and health and wellbeing support, for example: a customised wheelchair; attending an exercise class; and physiotherapy.

5   Discussion

A number of new initiatives in England have been piloted and rolled-out with the aim of transforming the health and social care sector. The implementation of new schemes, such as personal health budgets, requires fundamental cultural changes within the care sector. In this discussion, we comment on some of the key challenges of implementing personal health budgets identified by service providers following the pilot phase. The discussion will also consider the possible consequences of the challenges during the current roll out, in terms of the budget size and content of current personal health budgets and the reported experiences of budget holders.

5.1   Mechanisms of effect

A message that emerged among service providers focused on the positive impact of personal health budget holders in securing personalised support, leading to a sense of choice and control. During the national evaluation, 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 current findings seem to highlight the importance of implementation in determining the degree to which this capability was realised, in terms of sites following the main principles underlying personal health budgets. However, caution is required when interpreting the findings due to the small sample size. The importance of the implementation process is supported by the change management literature (e.g. Bazzoli et al. 2004; Fleuren et al. 2004) that suggests change and innovation failure occurs because organisations are unable to successfully implement them rather than the new strategy being inappropriate (cited in Caldwell et al. 2008). Klein and Sorra (1996) suggest two factors that can have an impact during the implementation phase of a new initiative:

(a) Organisational members' perceptions of the fit of the innovation to their values (e.g. employee commitment towards an innovation).

(b) An organisation's climate for the implementation of a given innovation that includes the absence of obstacles.

According to Klein and Sorra (1996), a strong implementation climate within organisations fosters innovation use by (a) ensuring employee skill in innovation use; (b) providing incentives for innovation use and disincentives for innovation avoidance; and (c) removing obstacles to innovation use. Following Klein and Sorra's model, the current study highlights a number of

obstacles potentially having an impact on the longer-term implementation of personal health budgets, including: (a) commitment among professionals; (b) market development; and (c) service integration. The obstacles require practical solutions to help foster a climate within CCGs to implement personal health budgets and the ability to achieve the intended long-term benefits of the initiative following the pilot phase.

5.1.1 Commitment among professionals

The continued implementation of personal health budgets requires leadership and management in order to succeed. Jones et al. (2010a, 2010b) initially highlighted the perceived importance of identifying and acknowledging the concerns of middle-level managers. The management and acknowledgement of the cultural change required to implement personal health budgets were seen among organisational representatives as a vital ingredient for the implementation of the initiative.

In the current study, there was a suggestion among service providers that some CCG representatives had been slow to adopt a leadership role during the continued implementation of personal health budgets. There appeared to be challenges around engaging with CCGs, with some service providers perceiving that their CCG did not want personal health budgets to be in operation within their area, and whether the initiative was seen as a priority. Consistent with previous literature (e.g. Caldwell et al. 2008), without the commitment of such employees, particularly middle managers within CCGs, personal health budgets may not reach the full potential during the current national roll out. The challenges outlined by service providers potentially highlight the need for the longer-term implementation of personal health budgets to help ensure the continued commitment among professionals, particularly middle management, following the pilot phase. The commitment among CCG representatives possibly had an impact on the content of current personal health budget support plans, in terms of the services being purchased through budgets and potentially the stricter criteria on the type of support that can be purchased following the pilot phase (Jones et al. 2017).

5.1.2 Market development

During the national evaluation, an important mechanism for good outcomes was linked to the capability of budget holders to be innovative in securing care solutions. As outlined by Jones et al. (2017), the extent of this capability was seen to be affected by the availability 'in the market' of a range of innovative care solutions and options. Service providers play a key role in facilitating the availability of innovative care solutions. However, service providers participating in the current study highlighted a number of constraints, such as communication issues that seemed to have hampered market development. It was thought that continued uncertainties among patients about personal health budgets and what support could be purchased potentially was a stumbling block for providers. Service providers suggested that more guidance and information could help them target patients better and advertise their services that could be purchased through a personal health budget. There was a sense among service providers that while personal health budgets were currently being rolled-out, the demand among patients was slower than expected, which subsequently limited market

development. The commitment among professionals towards personal health budgets has the potential to have a positive impact of market development, leading to future innovative care solutions for budget holders.

As outlined by Jones et al. (2017), growth in the use of personal health budgets would help to realise economies of scale. Potentially, commissioners have an important role to play in stimulating and encouraging market changes and to begin to work closely with providers to develop care solutions (NHS England, 2014). To encourage commitment among commissioners, Community Catalysts and Shared Lives Plus (2012) have produced a guide that aims to help commission for personalisation in social care that could aid the continued implementation of personal health budgets, including:

1. Collect robust information about demand and supply, and deploy that information
2. Review and revise commissioning strategies
3. Co-design your area's response to health and social care needs
4. Take specific measures to encourage community control, provider diversity and service quality
5. Ensure that internal processes support personalisation

5.1.3   Health and social care integration

During the pilot phase, there were positive views on the need to integrate, and in some areas both the NHS and social care system were effectively working alongside each other. However, a number of practical obstacles were present during the pilot programme, particularly concerning the communication systems (Jones et al. 2010a, 2010b). The national evaluation team (Forder et al. 2012) made tentative assumptions that greater integration would lead to a change in the balance of services used, and also that personal health budgets might be a vehicle to promote better integration. The current study highlighted that pooled budgets have been arranged where appropriate, which had appeared to have been encouraged by the implementation of personal health budgets and improved working relationships with their social care colleagues (Jones et al. 2017). However, there seems to be a number of barriers to implementing integrated personal budgets across health and social care. Some of the barriers are not specific to the personal health budget policy and mirror those found with the implementation of the current integration policy initiative such as the Integrated Personal Commissioning programme (SQW, 2017) and the Integrated Pioneer programme (Erens et al. 2016). In order to achieve integration, practical changes seem to be required to the current care system. NHS England (2016) published a report that sets out to describe the lessons learnt from the Integrated Care Pioneer programme. The advice includes:

1. Engage at all levels and across the system
    a. Listen to frontline staff and involve people at all levels
    b. Relationships are key
    c. Get the operational basics right and bring people with you by engaging early to help buy in for when you implement the 'model of care'

2. Focus on leadership and engagement
    a. Systems leadership and shared vision are key to success
    b. The strength of leadership, relationships and ambition is as important as anything else
3. Face forward
    a. Do not underestimate the need for committed and enthusiastic people to drive the change.

Integrated personal budgets form part of all three above initiatives and the findings from the current study alongside the emerging findings from the current integration initiatives provide valuable guidance to the integration agenda and the continued roll out of personal health budgets.

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