Personal health budgets: A mechanism to encourage service integration?

Abstract

Purpose: Integrated care continues to be a central aim within health and social care policy in England. Personal budgets and personal health budgets aim to place service users at the centre of decision-making and are part of a wider long-term initiative working towards personalised and integrated care. Personal budgets began in social care with the national pilot programme of individual budgets, which aimed to incorporate several funding streams into one budget, but in practice local authorities limited these to social care expenditure. Personal budgets then moved into the health care sector with the introduction of a three-year personal health budgets pilot programme that started in 2009. The purpose of the paper is to explore the post-pilot implementation of personal health budgets and explore their role in facilitating service integration. We examine this through the RE-AIM framework.

Design: During 2015 and 2016, eight organisational representatives, 23 personal health budget holders and three service providers were interviewed, 42 personal health budget support plans were collected, and 14 service providers completed an online survey.

Findings: Overall, personal health budgets continued to be viewed positively but progress in implementation was slower than expected. Effective leadership, clear communication and longer-term implementation were seen as vital ingredients in ensuring personal health budgets are fully embedded and contribute to wider service integration.

Originality: The paper highlights the importance of policy implementation over the longer-term, while illustrating how the venture of personal health budgets in England could be a mechanism for implementing service integration. The findings can serve to guide future policy initiatives on person-centred care and service integration.

Key words

Personal health budgets, personalisation, integration, health and social policy implementation, change management.

Introduction

Integrated care continues to be a central theme within health and social care policy in England, at a time when the care sector is facing unprecedented challenges in terms of caring for an ageing population, alongside continued austerity measures (HM Government, 2021). Healthcare requirements increase with age, with health-related costs rising from 65 years of age. In 2015-16, the five-year age group with the greatest number of hospital episodes was patients aged 65 to 69 (1.6 million) (NHS Digital, 2016a). Social care requirements also increase with age. The COVID-19 pandemic has further highlighted the inter-dependence of the health and social care systems (HM Government, 2021).

The rising demands occur at a time when the NHS is required to deliver £22 billion in efficiency savings by 2020-2021 (HM Treasury, 2015), alongside coping with the COVID-19 pandemic. The integration of care is often perceived as part of the solution to these financial challenges, with personal budgets offering a potential mechanism to encourage joint working via a single integrated health and social care personal budget. Personal budgets were developed from the earlier individual budget initiative within social care. There are three distinct principles underlying the personal budget initiative: a transparent budget following an assessment, individuals playing a central role in the support planning process, and offering options on how to manage the resource (NHS England, 2017).

Box 1 outlines the differences between individual budgets, personal budgets and integrated budgets.

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Background to personal budgets in social and health care

Individual budgets in social care were piloted between 2005 and 2008 and the Department of Health[1] commissioned an independent evaluation to run alongside (Glendinning *et al.,* 2008). Glendinning *et al*. (2008) found some 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) but not for psychological well-being (using GHQ-12) (Goldberg, 1992) although the impact varied between client groups. Little evidence of integrated funding was found during the pilot phase.

[1] Now the Department of Health and Social Care

Following the national evaluation, personal budgets have continued to have a positive impact on service users (Webber *et al.,* 2014; Larkin 2015) and carers (e.g. Turnpenny *et al.,* 2020; Larkin, 2015; Woolham *et al.,* 2018). However, some carers have reported feeling stressed with the management of personal budgets (Larkin, 2015; Woolham *et al*., 2018). A systematic review, on the effectiveness of personal budgets for people with mental health problems conducted by Webber *et al.* (2014), found that personal budgets have a positive impact in terms of choice and control, quality of life, service use and cost-effectiveness.

From 2010 there was universal implementation of personal budgets among all adults with eligible social care needs (House of Commons Committee of Public Accounts, 2016). The Care Act in 2014 legally endorsed this. In 2019-20, of the 838,530 clients accessing long-term support, 376, 675 received a Local Authority Managed Personal Budget (NHS Digital, 2020a). Of the 218,130 carers supported in 2019-20, 10,700 received a Local Authority Managed Personal Budget (NHS Digital, 2020a).

The personal health budget pilot programme, launched by the Department of Health in 2009, with a three-year independent evaluation commissioned to run alongside (Forder *et al.,* 2012), was intended to encourage the NHS to be more responsive to patients' needs. The evaluation followed a mixed design, with a quantitative and qualitative strand to explore outcomes, experiences, service use and costs. Forder *et al.* (2012) found personal health budgets to be cost-effective in social care-related quality of life as measured by ASCOT compared to conventional service delivery, particularly for the NHS Continuing Healthcare and mental health cohorts. Current evidence exploring personal health budgets in mental health suggests they have continued to have a positive impact on individuals' health and well-being (Cooney *et al.,* 2020) alongside providing choice and control (Ayoola and Butt, 2021). However, a new way of working in the NHS is required to be able to offer true choice and control (Cooney *et al.,* 2020).

The NHS Mandate set out that by 2020/21 between 50-100,000 people would have a personal health budget (NHS England, 2018a). Since July 2018, Clinical Commissioning Groups are required to complete the mandatory personal health budgets data collection (NHS England 2018a). The NHS Oversight Framework for 2019/2020 is in place and personal health budgets remain within the mandatory data collection. In 2019/20, 88,953 people had received a personal health budget (NHS Digital, 2020b).

Initially, only adults receiving NHS Continuing Healthcare and children in receipt of continuing care could have a personal health budget (NHS England, 2018b), but according to the NHS Long Term Plan

published in 2019 up to 200,000 people will benefit from a personal health budget by 2023/24. This will include provision of bespoke wheelchairs and community-based packages of personal and domestic support (NHS England, 2019a), alongside expanding the offer to mental health services, for people requiring after-care services under section 117 of the Mental Health Act 1983, for people with a learning disability, people receiving ongoing social care support and those receiving specialist end of life care (NHS England, 2019b).

Personal budgets are seen as a mechanism to encourage service integration which remains a key theme within Government policy. The NHS Long Term Plan (2019) outlined that the whole of England was to be covered by an integrated care system (ICS) from April 2021, meaning that individual service user budgets would cover both personal health and social care (NHS England 2019a). The Comprehensive Model for Personalised Care brings together six evidence-based and inter-linked components of personal care, with personal health budgets and integrated personal budgets being one component (NHS England, 2019a). Within the personal budget process, integration has the potential to avoid duplication of assessments, whilst joining up accounting arrangements. However, the realisation of the opportunity provided by personal health budgets and integrated budgets involves longer-term commitment from all parties including the Government, organisational representatives and personal health budget holders. In February 2021, the Department of Health and Social Care White Paper 'Integration and innovation: working together to improve health and social care for all', proposed to establish statutory ICSs in all parts of England from 2022. (Department of Health and Social Care, 2021). However, the Government outlined that legislation can only be part of the picture, and the support of local organisations would be needed to ensure that integration becomes a reality. (Department of Health and Social Care, 2021).

In 2014, the Department of Health commissioned a study to explore the implementation of personal health budgets over the longer-term, and the success of integrated budgets following the pilot phase. This paper will explore the experiences of organisational representatives, service providers and budget holders beyond the pilot phase of personal health budgets As a framework for analysis, we will use the RE-AIM (Reach, Effectiveness, Adoption, Implementation and Maintenance) model, which captures the complexity of 'real world' settings and includes five inter-related dimensions which operate at the individual and organisational levels (Glasgow *et al.*, 1999). This allows us to explore the promises of personal health budgets as a mechanism to foster service integration and offering greater control with the reality; thus capturing the gap between policy, research and practice.

1. **Reach** the intended population to receive a personal health budget.

2. **Effectiveness** of personal health budgets.
3. **Adoption** of personal health budgets by staff, settings and systems.
4. **Implementation** of personal health budgets.
5. **Maintenance** of the impact of personal health budgets on individuals and setting over time.

The paper will explore four dimensions within the model: Effectiveness, Adoption, Implementation and Maintenance. The Reach dimension covers the intended population to receive a personal health budget.

Methodology

During the personal health budget 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). 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. In addition, personal health budget leads were invited via the personal health budget evaluation website (phbe.org.uk/phbe2), NHS England's personal health budget learning network and via social media. Due to a low response rate among the CCGs from the 'in-depth' strand of the pilot study, the recruitment criteria was broadened to include those from the wider cohort.

Organisational representatives and service providers

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 Group (CCGs). The organisational representatives included personal health budgets leads and commissioners.

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 which advertised personal health budgets on their websites. NHS England also advertised it through their personal health budget-learning network. Forty-three service provider organisations were asked if they would like to participate in the study. In addition, one participating:

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

Fourteen service providers completed the survey from seven CCGs between March 2015 and March 2016. 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.

Personal health budget holders

In total, 104 patients (or consultees) agreed to take part in the current study: 72 patients (or their consultees) from the national evaluation of the personal health budget pilot programme: 42 from the original 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.

Twenty-three personal health budget holders were interviewed between March 2015 and January 2016. Nine of the personal health budget holders received the budget during the national evaluation (Forder *et al.,* 2012) and seven were new budget holders (i.e. received their budget following the national evaluation). A further seven were former budget holders, having been part of the pilot programme only.

A postal outcome questionnaire was also sent to 104 patients or consultees who participated in the initial national evaluation of the personal health budget pilot programme (Forder *et al.,* 2012) between June 2015 and January 2016. Fifty completed questionnaires were returned, providing a response rate of 48%: 34 from the personal health budget group and 16 from the control group.

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 support following the pilot phase. Sixty-nine personal health budget holders consented to this. The research team received 42 personal health budget support plans from four participating CCGs.

Data Analysis

The data from the outcome questionnaire and the personal health budget support plans was analysed using STATA (version 13).

During the in-depth telephone interviews, the topic guides were used flexibly, enabling participants to express their views, and to discuss issues in more detail. Three researchers (EW, DF, and JC)

carried out interviews of up to 90 minutes. Interviews were transcribed verbatim and were analysed using the computer software package Nvivo for Windows 10 (QSR International Pty Ltd).

The transcripts involving personal health budget holders and service providers 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 (EW) completed the interviews and analysis, with key themes and conclusions being verified through discussions with the wider research team.

For the transcripts involving organisational representatives, the inductive and top-down approaches were followed. Five transcripts were analysed using a general inductive approach (Thomas, 2006) by one researcher (DF), and three transcripts were analysed using a top-down approach based on the interview schedule by a second researcher (JC). 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 theme was then reviewed and summarised, paying attention to the convergence and divergence of views among organisational representatives.

Ethical approval

The study gained a favourable ethical opinion by the NHS Health Research Authority, and NHS Research and Design approval was also obtained from all relevant CCGs. The IRAS reference number was 14/LO/0788.

Findings

Effectiveness

Personal health budgets continued to be offered in line with the original principles of the initiative with recipients: 1) being informed of the budget level following an assessment; 2) being encouraged to develop a support plan detailing how resources could be used; and 3) deciding how they would like their budget to be managed. Positive outcomes were mainly attributed to increased choice and control and greater flexibility over services:

> *"To be able to be a part of your own recovery….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." (Personal health budget holder, interview)

"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." (Service provider, interview)

The support planning process was perceived as a valuable process, to deliver person-centred care, 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?' … 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 even to ask me what my needs are?" (Personal health budget lead, 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". (Service provider, interview)

Table 1 shows that among the 34 personal health budget holders who returned their outcome questionnaire, 21 reported that they were currently receiving support purchased through their budgets; of these 18 reported that they were either extremely or very satisfied with the support they received from their budgets and 10 were satisfied with the support planning process. However, five budget holders felt that they needed more support to decide how to spend their budget. The analysis of 42 personal health budget support plans highlighted that budget holders *were* continuing to purchase support to meet a health or well-being need following the pilot programme.

>Insert table 1<

Adoption

Strong leadership was seen by participants as a key factor in adopting personal health budgets and integrated budgets.

"I think there needs to be greater national leadership on this…..the personal health budget team have done a great job, but maybe there needs to be more 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." (Service provider, interview)

Strong leadership could help to resolve the many challenges in offering integrated personal care, and advancing the agenda; however some organisational representatives reported a reluctance among colleagues to adopt a leadership role during the continued implementation of personal health budgets. Service providers also discussed a lack of commitment from managers and frontline health professionals which stifle the changes in organisational culture necessary to embed personal health budgets. Service providers discussed feeling unsupported by their CCG following the pilot programme:

"*CCGs aren't even giving us the most up-to-date information*". (Service provider, interview)

"CCG don't want to do PHBs and don't have the capacity or systems to set them up properly, so staff within CCG have obstructed them. We were told (off the record) not to promote PHBs." (Service provider, online survey)

According to the organisational representatives interviewed, stronger leadership was necessary to continually encourage the adoption of this new initiative.

Implementation

The majority of organisational representatives stated that they had achieved or were working towards integration with local authority colleagues in three areas: integrated budgets, inter-sector working and single care assessments.

Integrated budgets

Organisational representatives stated that they had been able to arrange integrated budgets for their budget holders, and this appeared to be encouraged by the introduction of personal health budgets. While some integrated budgets were more fragmented, for example 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 integrated budgets with the local authority:

"We've got a Section 75 agreement in place … 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… 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." (Commissioning Manager, interview)

Service providers believed that without integrated budgets and joined-up working, personal health budgets might 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."* (Service provider, online survey)

Inter-sector working

The majority of the organisational representatives perceived that the personal health budget initiative had enabled them to establish better working relationships with social care colleagues, leading to a more seamless transition 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.

> *"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, interview)

Similarly, one service provider highlighted that at the very least the *"PHB has started a debate on who pays for what, when and why*". However commitment and communication issues between health and social care colleagues were seen as barriers towards bringing 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."* (Service provider, online survey)

Single care assessments

Integration should avoid duplication of assessments, providing a mechanism for pooled budgets, but it was viewed as difficult to achieve at the time of the study.

> *"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, interview)

Service providers also discussed a lack of investment from management and health professionals which could enable change in the cultural context for PHBs. Service providers discussed feeling

unsupported by their CCG following the pilot programme: "*CCGs aren't even giving us the most up-to-date information*". (Service provider, interview)

> *"CCG don't want to do PHBs and don't have the capacity or systems to set them up properly, so staff within CCG have obstructed them. We were told (off the record) not to promote PHBs."* (Service provider, online survey)

Personal health budgets generated opportunities for inter-sector working but communication breakdowns, a lack of staff commitment and dual systems for assessment and budget administration were barriers to the implementation of personal health budgets and to integration more widely. The scale of system reconfiguration required to align assessments and budget administration demanded longer term implementation to fully embed personal health budgets into practice.

Maintenance of personal health budgets

The analysis of 42 personal health budget support plans highlighted that while the majority of spending was 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. However, the existence of integrated budgets was not evident in the support plans. According to organisational representatives, challenges were still to be resolved to provide a mechanism for service integration, and to encourage the care sector to work together flexibly.

The majority of the personal health budgets (N=35) were worth £1000 or more per year; of these 28 budgets provided over £1000 per annum to purchase social care-related support to meet a health need (e.g. health-funded home care) and 11 budgets of over £1000 were used for well-being support. Following the assumption around substitution from the national evaluation (Forder *et al*., 2012), some personal health budgets in the current study were used as a substitute for existing services following the pilot phase, rather than as an additional resource, evolving in line with individual needs, underlining the potential for diversity and flexibility (Jones *et al.,* 2017).

> *"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."* (Personal health budget holder, interview)

However, for others it appeared that more specific criteria had been introduced following the pilot phase, regarding *what* could be purchased through the budget.

> *"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."* (Personal health budget holder, interview)

The intended scope of the personal health budget programme therefore appeared to reduce over time as CCG's tightened criteria, indicating a lack of maintenance.

Discussion

The paper has explored the current impetus around personal health budgets and integrated budgets following the pilot phase. The Re-Aim framework provided a tool to explore how personal health budgets and integrated budget have been implemented into practice in England. Overall, the current study found that personal health budgets continue to be viewed positively among organisational representatives and budget holders, however, a number of challenges remained at the organisational level that hindered full implementation and integration. This is consistent with current literature that points to the positive impact of personal health budgets while highlighting the challenges (e.g. Webber *et al.*, 2014; Cooney *et al.,* 2020; Ayoola and Butt; 2021) and the need for further high quality studies to inform policy and practice (Webber *et al.* 2014).

The findings from this study highlight potential future challenges in implementing the aims of the NHS Long Term Plan (NHS England 2019a) which included:

- 200,000 people to benefit from a personal health budget by 2023/24, which includes provision of bespoke wheelchairs and community-based support packages.
- Expanding the offer in mental health services to, people with a learning disability, people receiving social care support and those receiving specialist end of life care.
- NHS and partners moving to create ICSs by April 2021, including individual service user budgets through personal health and social care budgets. This has been subsequently superseded by the 2021 White Paper 'Integration and innovation: working together to improve health and social care for all', which proposes to establish statutory ICSs in all parts of England from 2022. (Department of Health and Social Care, 2021).

There is a clear remit from Government to encourage service integration and the COVID-19 pandemic has highlighted the importance of health and social care systems working together. The

findings from this study, alongside current literature, can be used to inform the Government's stated aim of promoting service integration and establishing statutory ICSs in all parts of England from 2022. The findings support their view that legislation can only be one part of the picture and the commitment of the workforce and leadership is essential to ensure that integration moves from policy to practice.

Change management literature could also inform the continued implementation of the Government's integration plans. Mason *et al* (2014) highlighted the need for competent commissioning and well informed staff. Leadership has been found to be an important success factor to motivate change (e.g. Mwakisagh 2019; Higgs and Roland 2011), alongside a clear understanding of the intervention (e.g. personal health budgets) (Higgs and Roland 2011). Bamford and Daniel (2007) outline a number of important elements that facilitate implementation and organisational change, including clear communication and positive leadership that can help illustrate the organisation's commitment to implementing a new initiative. Echoing the findings of this study, failure to secure 'buy in' from middle managers could mean that personal health budgets and integrated personal budgets may not reach their full potential (Martinez and Pritchard 2019).

This study alongside the existing literature highlights a number of facilitators that could enhance the Government's commitment to service integration and Integrated Care Systems, including: (a) commitment among professionals and good leadership; (b) the need for information and training; (c) listening to the anxieties among frontline staff; and (d) market development.

The success factors mirror those found with other integration policies such as the Vanguard New Care Models programme (Checkland *et al.,* 2019); Integrated Personal Commissioning programme (Agur *et al.,* 2018) and the Integrated Pioneer programme (Erens *et al.,* 2016). An NHS England report details the lessons learnt from the Integrated Care Pioneer programme, including the need for good engagement across the sector; good leadership, and committed and enthusiastic people to drive change (NHS England, 2016). Checkland *et al*., (2019) also found that a number of enabling and inhibiting factors has an impact on the implementation of the new care models, such as robust and multi-modal communication, strong local and national leadership, over-optimistic expectations from the national programme and issues with data sharing between organisations. The consistent findings highlight some of the processes and practices that can assist within the implementation of the Government's ambition for overall service integration and integrated personal budgets.

The consistent findings should be acknowledged as they highlight some of the processes and practices that would assist in the implementation of the Government's ambition for overall service integration and integrated personal budgets.

In summary, the findings highlight the importance of effective leadership and communication to drive the required change to ensure service integration becomes a reality not just in policy rhetoric, but in practice. While the current study explores the reality of a new policy initiative following a pilot phase and the complexities that can continue, a number of limitations should be acknowledged when interpreting the findings. The study was limited to a small sample of organisational representatives and personal health budget holders who accepted the invitation to participate. The small sample meant we were unable to explore the continued impact of personal health budgets on quality of life among participants and secondary care service use following the pilot phase. Despite the limitations, the current study highlights that the completion of a pilot programme represents the beginning of implementation, rather than the end, and this should be acknowledged in future Government decisions.

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