

# Personal Health Budgets:

a revolution in personalisation

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## About this publication

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The personal health budget (PHB) is the most revolutionary expression of personalisation ever introduced to the NHS. It embodies and epitomises the Government's vision of a patient-centred NHS, summed up by the often quoted edict 'no decision about me, without me'. Yet it is impossible to ignore professional concern and disquiet around the implementation of PHBs. This report responds to some key fears and objections with learning and best practice emerging from the pilot programme.

Between 2009 and 2012 the NHS undertook a pilot programme to find out whether Personal Health Budgets would benefit patients with certain conditions. Notably, those receiving NHS continuing healthcare, those with mental health issues, stroke survivors, those suffering from long-term neurological conditions, diabetics, and those with chronic obstructive pulmonary disease. The positive outcomes from this pilot were significant improvements in the quality of life and wellbeing of many of the patients. This led the Care and Support Minister Norman Lamb to announce the roll out of PHBs and confirm the Government's (2011) commitment to see everyone entitled to NHS continuing healthcare given the right to request a PHB by April 2014.

During the course of this work we benefited from interviews and discussions with many of those working in this field. We would like to thank all those who contributed to this research, and in particular we would like to thank our Steering Group for their advice and support throughout the project.

This report was funded by an unrestricted educational grant from Denplan. We are indebted to Denplan who enabled this research to be undertaken, and to all our sponsors. As well as driving our on-going work of involving frontline professionals and the public in policy ideas and development, sponsorship enables us to communicate with and involve officials and policymakers in the work that we do. Involvement in the work of 2020health is never conditional on being a sponsor.

**Julia Manning**  
Chief Executive, 2020health  
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## About the authors

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Gail worked in the NHS for over 30 years, latterly as an Executive Director at Barts and the London NHS Trust. She trained as a general nurse at St Bartholomew's Hospital before undertaking a course in Renal Nursing at the Royal Free Hospital. After a number of senior nursing posts within London she moved into management taking a Masters in Health Management at City University, before becoming Director of Operations at BLT. Since leaving Barts and the London NHS Trust she has worked as an independent consultant in healthcare. Gail was a member of the team that produced the Independent Review of NHS and Social Care IT Commissioned by Stephen O'Brien MP. Gail's main interests are in creating a society that values the contribution older people make, compassion in caring and preventing disease caused by poor lifestyle choices.

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Jon joined 2020health in 2011, transferring his writing, editing and research skills from the worlds of film, television and classical music. In a research and writing capacity Jon has contributed to a number of health IT reports, including 'Personal Health Records: Putting patients in Control?' and 2020health's independent evaluation of the 'Yorkshire and the Humber Regional Telehealth Hub'. More recently Jon co-authored 'Making Connections', a report preparing for a transatlantic exchange between the US VHA and England's NHS to support the adoption of digital health. Jon is 2020health's project lead on Personal Health Budgets.

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Charlotte has recently graduated from University College London (UCL) where she studied French and Philosophy. As part of her Bachelors, she spent a year studying at La Sorbonne, Paris IV in France. Her studies have mainly focused on ethical and political philosophy, in particular surrounding current debates in the UK and abroad in areas such as euthanasia, abortion, the legalisation of drugs and the Human Right to Health. She has previously volunteered in the Policy Department at Marie Curie Cancer Care and has a particular interest in end of life care. She is also currently volunteering as a Researcher for 28 Too Many, a charity who work to eradicate Female Genital Mutilation (FGM).

## Sponsor's Foreword

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In many ways, Personal Health Budgets (PHBs) up-end the traditional concepts of systematised, centralised public healthcare. They put decision-making, behaviour change and considered choice truly into the hands of patients.

Dental diseases are largely chronic, lifestyle-mediated and multifactorial problems. Whilst for the most part they are less detrimental to the individual than many of the conditions for which PHBs have been introduced, on a population scale – due to their near universality – they are highly impactful and a significant socio-economic burden, as Locker and many others have pointed out.<sup>i</sup>

In dentistry, public healthcare systems are less about affordability than about ‘payability’: the need to ensure that the technical and personnel costs of healthcare provision are met whilst containing costs within centrally-set budgets.

PHBs put decisions about healthcare management – coping and healing strategies – firmly into the hands of patients, with appropriate oversight and controls. The capitation model of dental health care targets similar aims. In this case individuals choose to pay into a ‘capitation plan’ designed to assist most effectively in the prevention or mitigation of the consequences of ill-health and to co-contribute to the cost of reparative care. It is estimated that in the UK 2.6 million patients<sup>ii</sup> currently have elected to follow this route.

The parallels between PHB and oral care programmes variously include:

- Concept of early detection of disease and its management
- Use of a familiar and trusted resource base
- Increased likelihood of positive behaviours
- Flexibility of commitment planned around the patient

If capitation is introduced – as currently conjectured – to NHS dentistry primarily as a means of remunerating dental professionals it is likely to fall into previously experienced issues of ‘unintended consequences’.<sup>iii</sup>

If, on the other hand, it is introduced as a means of influencing behaviour change in health care professionals and patients, and to usher in a truly preventive approach, it may succeed, but only if the autonomy of patients is respected and incorporated.

At present the future of publicly-funded management of chronic oral disease is under review and further major change is likely. The traditional approach of technology-driven, resource-intensive activity may prove uneconomic. We have supported this in-depth analysis into personal health budgets because it brings into question this basis for addressing chronic health issues generally. It raises questions and opens debate about alternative approaches.

**Roger Matthews,**  
Chief Dental Officer,  
Denplan

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i. Locker D, Quinonez C (2010) – to what extent do oral disorders compromise the quality of life?

ii. Lang and Buisson – Dental Market report 2011

iii. House of Commons Health Committee: Dental Services (HC 289-1) 2008. The Stationery Office London

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# 1 Executive summary

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The personal health budget (PHB) is the most revolutionary expression of personalisation ever introduced to the NHS. The PHB revolves around care planning and seeks to marry the expertise of the clinician with the experiential expertise of the individual. It is a system that promotes patient choice and control by means of self-directed support, allowing individuals to manage budgets and purchase services and equipment according to their own needs and timetable. Seeking a 'whole-person' approach, the PHB holds considerable potential for health and social care integration, facilitating joint planning, joint budgets and efficient, personalised commissioning. The PHB appears to epitomise the Government's vision of a patient-centred NHS, one summed up by the oft-quoted edict 'no decision about me, without me'.

## **The PHB journey so far**

Between 2009 and 2012 the NHS undertook a pilot programme involving 64 PCTs to find out whether PHBs would benefit users of specific NHS services. The core targeted areas were continuing healthcare, mental health, stroke, long-term neurological conditions, diabetes, and chronic obstructive pulmonary disease. An independent evaluation of the pilot was led by the Personal Social Services Research Unit (PSSRU) at the University of Kent and the London School of Economics and Political Science. The evaluation used a controlled trial to compare the experiences of PHB users and traditional service users, with just over 1,000 individuals recruited into each group.

The evaluators issued a full pilot report in November 2012 and with it some strong validation of the PHB system, noting that 'the use of personal health budgets was associated with a significant improvement in the care-related quality of life and psychological wellbeing of patients'. While PHBs did not appear to have a notable impact on health status as such, a marked decrease in the use of primary and acute care services was found among the continuing healthcare and mental health PHB cohorts. Potential cost efficiencies among these two groups were considered 'significant'. The evaluators identified particular cost-efficiency with high-value PHBs, and thus recommended that 'personal health budgets should be initially targeted at people with greater need'.

Following the evaluation, Care and Support Minister Norman Lamb announced the roll out of PHBs and confirmed the Government's (2011) commitment to see everyone entitled to NHS continuing healthcare given the right to request a PHB by April 2014. The offer of PHBs to others who might benefit would remain discretionary,

for the time being at least. It was also announced that nine pilot sites would be 'Going Further, Faster', to embed PHBs more widely across service areas and generate further learning and best practice.

## **Report background and themes**

2020health's assessment of the PHB programme was informed by an extensive review of published literature and opinion (UK and abroad), including the PSSRU interim publications and final PHB pilot evaluation. Our work also involved 35 semi-structured interviews with 39 experts and stakeholders in the field. The project was undertaken between June 2012 and February 2013, coinciding with the final pilot evaluation period.

It is impossible to ignore professional concern and disquiet around the implementation of PHBs. This report responds to some key fears and objections with learning and best practice emerging from the pilot programme. It also discusses in some detail the two areas that appear to have responded most favourably to the PHB: continuing healthcare and mental health, and in the latter category we include alcohol misuse. A scoping section then explores how PHBs might be used in the future (particularly short-term interventions) as direct payments become business as usual for Clinical Commissioning Groups (CCGs).

## **PHBs in continuing healthcare**

Home care provision accounts for the majority of PHB spend in continuing healthcare (CHC). For clients the PHB offers access to alternative care arrangements where care-agency provision lacks suitable flexibility or consistency, or is indeed hopelessly inadequate. With a PHB, a client (or their representative) can employ their own personal assistants (PAs) and exercise control over workloads and timetables. They can make immediate changes to care arrangements if necessary. The PHB also allows for continuity of care, enabling social care PAs to transfer seamlessly across with clients into NHS continuing care.

The pilot evaluation confirmed the viability of PHBs for continuing healthcare, finding an overall positive response from patients involved, higher social-care related quality of life (ASCOT-measure), and cost-efficiency at the 90% confidence level. These findings have galvanised the Government's intention to make PHBs widely available to CHC clients by April 2014.

2020health considers this target ambitious, because CHC individuals and their families should not simply wish to see the PHB mechanism made available. Rather, they should expect a fully prepared PHB system that has multi-

# 1 Executive summary

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agency cooperation, with user-led charities on board and local Peer Networks established. This is the groundwork necessary to allay the fears of professional bodies like the Royal College of General Practitioners and the Chartered Society of Physiotherapy, who have rightly warned of the potential rise in health inequalities under the PHB system.

CCGs meanwhile may be seeking assurance that PHBs in CHC are sustainable in the long term. This report notes some important financial unknowns in CHC – particularly where individuals are taking on employer’s responsibilities, with the variable staffing overheads of maternity benefit and sickness pay; and added to this are the potentially considerable staff redundancy costs on the death of PHB holders themselves. The possibility of Third Party insolvency creates yet more financial uncertainty.

CCGs might therefore want to consider tracking, with contingency funds, the potential redundancy costs of each CHC client’s staff, year by year, or entering into risk-sharing partnerships within CCG Federations.

## **PHBs in mental health**

Mental Health was probably the clearest area of achievement within the PHB pilot. The PHB group experienced higher social-care related quality of life (ASCOT-measure), and their indirect costs (mainly inpatient costs) were reduced by ‘a significantly greater amount’ than those of the control group.

The PHB journey in mental health has been a remarkable one, since the system demands radical change management. Clinicians involved in the PHB pilot have had to come to terms with a shift away from the old medical, prescriptive ‘expert to patient model’ to one much more focused around shared decision making, holistic interventions and outcomes. As one GP lead told us,

*‘The outcomes are not based on the medical outcomes that we’ve always looked at; they’re much more based on real life outcomes, being able to do something rather than hitting a target.’*

This approach entails interventions that straddle both health and social care. There is, after all, little point in treating the person without seeking to address root causes of their mental health condition. With NHS money service users are choosing unconventional interventions – laptop, college course, art materials, car repairs, summerhouse, kitchen equipment, and so on – with the appropriateness of an intervention assessed by the outcome, not by the thing bought. It is vital to remember that the NHS is (in theory) not spending any more money

than it would do providing traditional services.

There are challenges facing the roll-out of PHBs in mental health, beyond the seismic shift away from old clinical models. These include block contracts, which are largely incompatible with personalised commissioning. And it is unclear as to how the PHB system and its ambitions around greater health and social care integration will work in tandem with the new Payment by Results tariff system. But it is worth noting that the Royal College of Psychiatrists and Association of Directors of Adult Social Services (ADASS) have recently given their joint support to the introduction of PHBs in mental health, particularly to encourage the agenda of greater social and health care integration (March 2013).

## **Southampton’s Alcohol Misuse PHB: change management**

NHS Southampton was one of two sites to test out PHBs in alcohol detoxification. The programme has proved remarkably successful in terms of its change management processes, which have included the decommissioning of block-contracts. Now there is choice and flexibility, with nine providers registered under spot-purchasing arrangements. These providers include two that were previously block-contracted.

Southampton have seen waiting lists for tier-three community-based treatments virtually disappear; previously people could be waiting up to six months for a detox, during which time their health condition could deteriorate significantly. People now have better value for (NHS) money: residential stays for up to 12 days are costing less than five-day detoxes under former NHS inpatient arrangements.

## **Future possibilities for the PHB?**

PHB leads and commissioners contributed ideas for future applications of personal health budgets. Perhaps the most oft-cited and widely supported example was GP-issued PHBs. This system would enable GPs to issue low-value PHBs from funds held by, or immediately accessible to, the practice itself or, where they exist, larger GP Provider Organisations. Some PHBs may need to be applied as additional, not replacement, interventions.

Elsewhere in the NHS, and contingent on the learning from Going Further, Faster sites, PHBs should be made available to arthritis sufferers, who were surprisingly overlooked by the pilot programme. PHBs may also prove useful to both falls-prevention and reablement programmes, and facilitate cheaper and more flexible transport options for haemodialysis patients.

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## Conclusion

The 2009–12 pilot programme demonstrated that limited-choice PHBs are generally ineffective. Unless patients are empowered with real choice and control, the NHS cannot expect to see improved outcomes and the corollary of reduced service use. Accordingly, the Department of Health states that ‘the person with the personal health budget (or their representative) will:

- Be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a healthcare professional
- Know how much money they have for their health care and support
- Be enabled to create their own care/support plan, with support if they want it

- Be able to choose how their budget is held and managed, including the right to ask for a direct payment
- Be able to spend the money in ways and at times that make sense to them, as agreed in their plan’

There are many reasons to carefully push forward the PHB programme with close monitoring and measured roll-out. The PHB can help people better understand and manage their health conditions: no other system of personalisation has offered such significant choice, control and flexibility. Indeed for many, PHBs have brought life-transforming benefits – we recommend viewing the inspiring videos on NHS England’s personal health budget website for just a few of these stories. At the same time there are some very real risks around implementation and the system demands enormous culture change, as this report explores. 2020health’s key findings and recommendations are summarised as follows:

### Learning from the Dutch experience

Key learning	For
The NHS must ensure efficient monitoring of PHB holders’ expenditure and be careful not to rely too much on trust.	CCGs / Local councils (Joint Commissioning Units)
Monitoring and review must continue year on year to assess long-term benefits and cost-efficiencies.	CCGs / NHS England / Department of Health / Care Quality Commission (CQC)
Third Party brokerage arrangements need to be transparent and regularly monitored. Third Party organisations offering PHB services should be already established partners within the local community.	CCGs / Local councils / NHS England / CQC

### Reducing financial risk

Recommendation	For
CCGs should consider safer methods of budget allocation where possible by employing the prepaid card (such as the ‘Kent Card’) or by initiating a voucher system as an extension of the NHS-held notional budget. We also encourage subcontracted arrangements with Community Interest Companies to bring increased flexibility to notional budgets.	CCGs / NHS England



# 1 Executive summary

## Equity will not be ensured without multiagency cooperation

Recommendations	For
Comprehensive third sector integration should be a priority from the outset; this includes the close involvement of user-led organisations and the creation of (investment in) local Peer Networks. These partners can help shape the PHB framework, raise awareness and assist equitable access across a range of service areas.	CCGs / NHS England / Local councils / Health and Wellbeing boards / CQC
NHS England should consider publishing regional performance metrics (perhaps via NHS Choices) to bring increased accountability and transparency to the PHB system. By making the system transparent to the public, individuals are more likely to experience equitable treatment and equal access to non-traditional services.	NHS England / Department of Health / CQC
To support access to the wider PHB programme, greater GP advocacy will be needed. GPs are ideally placed to communicate to CCGs (and patients) the merits of PHBs and encourage roll out.	GPs / NHS England

## To reduce variability of financial risk in continuing healthcare (CHC)

Recommendations	For
Individual PHB contingency reserves should be increased and rolled over year on year to track the potential redundancy costs of a CHC client's staff. The CCG would hold the fund and may reduce it if personal assistants leave the client's service.	CCGs
(And/or) With excess contingency and reclaimed (unused) PHB monies CCGs should create a sinking fund for their full CHC cohort. They might also consider creating CCG Federation risk-sharing strategies to cover CHC redundancy packages and other emergencies (such as third party insolvency) in the PHB system.	CCGs / CCG Federations

## Mental health

Recommendations	For
Going Further, Faster sites and other former pilot sites need to demonstrate PHB best practice within the context of Payment by Results before other CCGs push ahead with the programme.	Going Further, Faster sites / Former pilot sites / NHS England / Monitor
Once PHB best practice (and therefore viability) has been established within the context of PbR, the Government will need to decide whether to mandate the offer of PHBs in mental health throughout England. Access will otherwise be variable across regions, and patient choice and control thus highly inconsistent.	NHS England / Department of Health

## 2 Introduction

A personal health budget (PHB) is an amount of NHS money given to an individual to support them in managing their healthcare and wellbeing needs, as planned and agreed between themselves (or a representative) and their local NHS team.<sup>1</sup> Intended to maximise patient choice and control, the PHB is itself not an altogether new idea, since the concept builds on the experience of personal budgets (PBs) in social care, which have been established for some 16 years in England and widely used since 2008. Built around support (or care) planning, the PHB emphasises the whole-person approach; it is intended to improve quality of life, maximise resources, and at the very least be as economically viable as conventional NHS service delivery. NHS PHBs are not subject to means testing, unlike PBs in social care.

### 2.1 Background

Between 2009 and 2012 the NHS undertook a PHB pilot programme involving (initially) 64 Primary Care Trusts (PCTs) to find out whether PHBs would benefit users of specific NHS services. The core targeted areas were continuing healthcare, mental health, stroke, long-term neurological conditions, diabetes, and chronic obstructive pulmonary disease.

An independent evaluation of the programme was led by the Personal Social Services Research Unit (PSSRU) at the University of Kent and the London School of Economics and Political Science. Five interim reports were published between 2010 and 2012, with a final appraisal appearing in November 2012.<sup>2</sup> Findings from 20 in-depth evaluation sites gave the authors confidence to state that the PHB ‘has a direct impact on quality of life via improved choice, control and tailoring of services to personal needs and circumstances.’ The evaluation found the most compelling response to the PHB programme among the continuing healthcare and mental health cohorts, identifying improved social-care related quality of life and reduced service usage (such as acute care), thus indicating health and wellbeing benefits. Cost efficiencies were considered ‘significant’.

The Government had already stated (October 2011) ‘that subject to the evaluation, by April 2014 everyone in receipt of NHS Continuing Healthcare will have a right to ask for a personal health budget, including a direct payment.’<sup>3</sup> This mandate now stands. The Government hopes that PHBs will in time be made available more widely, particularly among mental health service users and those living with long term conditions. Such applications by Clinical Commissioning Groups (CCGs) are currently discretionary.

Whilst there is significant support for the basic healthcare ideology of PHBs, professional reaction to the PHB programme has been mixed due to uncertainty surrounding the implementation strategy and the less than encouraging experience of the Netherlands.

### 2.2 Report purpose and structure

This report aims to inform, caution and encourage those involved in the implementation of personal health budgets – CCGs and supporting services in particular. Though we spotlight some important financial unknowns, particularly around continuing healthcare, we also cite valuable learning from the Dutch experience and highlight best practice emerging from the pilot programme.

We begin by understanding what a PHB is and its place within the wider personalisation agenda. We then consider some key concerns voiced by professionals in response to the PHB programme; we bear in mind the evolving nature of the PHB system while exploring possible risks both to individuals and commissioners.

In the report’s central sections we summarise the findings from the 2009–12 pilot programme evaluation. We focus specific attention on the two service areas that demonstrated the most favourable response to the PHB system: continuing healthcare and mental health. In the latter context we include a case study of Southampton’s Alcohol Misuse PHB pilot. Lastly, we consider some applications of PHBs that have to date been barely explored, or are new ideas entirely. These were suggested to us during our interviews, mostly by PHB leads and commissioners, and demonstrate something of the versatility and potential of the PHB system.

1. Department of Health, 2012. ‘Understanding personal health budgets’

2. Forder, J., Jones, K., Glendinning, C., et al (2012) ‘Evaluation of the Personal Health Budget Pilot Programme.’ (PSSRU University of Kent; Imperial College London; London School of Economics and Political Science; SPRU University of York)

3. <http://www.dh.gov.uk/health/2012/02/personal-health-budgets-and-nhs-continuing-healthcare/>

## 2 Introduction

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### **2.3 Process adopted**

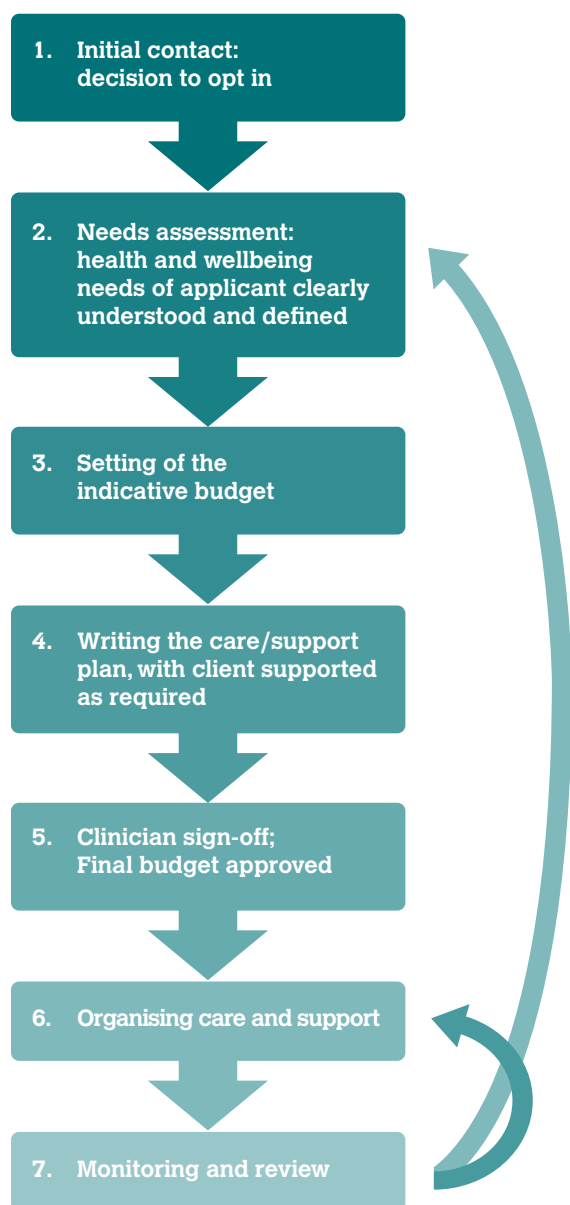
In preparation for this report 2020health undertook an extensive review of evidence, commentary and opinion on social care personal budgets and personal health budgets in England and abroad. We also conducted 35 semi-structured interviews involving 39 experts and stakeholders across England. Participants were interviewed either in person (22) or by telephone (17), and three corresponded with us principally via email. Those interviewed included PHB leads and commissioners (PCTs and shadow CCGs), GPs and LTC leads, third sector and patient group representatives, the Department of Health, and other specialists in the field of personalisation. We are indebted to all our interviewees for sharing their learning and experiences, and to the various PCTs who supplied information directly to us. This includes both qualitative and quantitative data from pilot sites, some of which appears in case studies, while other information is cited but not specifically attributed. A list of those interviewed and corresponded with for this report may be found in the Appendix.

### 3 Personal health budgets: what are they?

Entirely optional, the personal health budget presents an opportunity for an individual to become proactively involved in their own healthcare planning as never before. The system draws together both clinician expertise and the patient's 'lived expertise'; it puts patients in the driving seat and allows them to procure care and equipment according to their own needs and timetable. The person's allocated budget should not exceed the amount estimated for conventional NHS service delivery.

The workings of the personal health budget vary according to individuals' needs and circumstances, but seven fundamental stages may be identified, as outlined in diagram 3.i:

**Diagram 3.i.**



- (1) It is vital that the PHB applicant fully understands the obligations and implications of the PHB system before making a decision to opt in. For an individual with very complex needs, this decision (which may be made by a representative) will need considerable thought and time.
- (2) A clinician undertakes an assessment of the applicant's healthcare needs; this process involves a two-way discussion and enables the applicant to identify outcomes and goals.
- (3) The assessment creates an indicative budget, an approximation of the costs involved in meeting the client's healthcare needs and outcomes. The indicative budget may be fairly accurate where it is based on the costs of delivering specific services, such as psychotherapy or physiotherapy. For the more complex cases, close observance of the indicative budget may not be helpful. For example, in Budget Setting for NHS Continuing Healthcare the Department of Health states, 'as a guide, a tool for calculating indicative budgets is good enough for the purpose if it achieves predictions that are within 20% of the final cost for 80% of people.'<sup>4</sup>
- (4) With full knowledge of the indicative budget, the PHB applicant begins a support-planning (or care-planning) process. A care-coordinator – perhaps an occupational therapist, community psychiatric nurse or charity worker – may assist in the actual writing of the support plan, although the individual (or their representative) is entitled to undertake this alone or with help from family or friends. DH guidance<sup>5</sup> states that in the support plan the individual should identify:
  - Their health needs
  - The outcomes they want to achieve
  - How they intend to use their budget to do this
  - How any risks will be managed
  - The name of the care coordinator responsible for managing the support plan

4. Department of Health, 2012. 'Budget Setting for NHS Continuing Healthcare' (P.9)

5. Department of Health, 2012. 'Personal health budget guide: Implementing effective care planning'

## 3 Personal health budgets: what are they?

- (5) The support plan is reviewed by the lead clinician (or clinical team), who appraises patient risk and health and wellbeing outcomes. The clinician signs off the support plan, and a Commissioning Manager / Head of Service signs off the final budget. Very high value PHBs and particularly complex cases are also reviewed by a risk panel.
- (6) The PHB client is then able to begin implementing care and support arrangements, according to the type of fund management option they have chosen (see sub-section 3.1). The care coordinator can assist the client as required.
- (7) Ongoing monitoring and evaluation are key, but the frequency thereof varies depending on the circumstances of individuals. A CCG may want to consider the more frequent evaluation of alternative care pathways which are more experimental and less evidence based.

### 3.1 Managing the PHB

The PHB client should have a choice over how the budget is to be managed – that is, what sort of involvement they would like in the commissioning process. Budgets are traditionally managed in one of three ways:

- **Notional budget:** where the budget is held by the CCG, who commissions or provides services chosen by the individual. The individual is fully aware of the budget value and has a degree of choice, but restrictions tend to apply. It is not possible for a person to employ private personal assistants with a notional budget, and access to non-traditional services or items may be limited.
- **Third Party arrangement:** where the budget is held by an organisation (such as a user-led or voluntary organisation, a Community Interest Company or Independent User Trust) which manages the money and makes purchases on the individual's behalf. The Third Party organisation is legally independent of both the NHS and individual, although the individual (or their representative) retains significant control.

- **Direct payment:** where the individual (or their representative) receives the money into a specific, personal bank account, set up exclusively for PHB payments and transactions. The budget holder signs a legally-binding contract, agreeing to use the money as stated in the approved care/support plan. They are free to purchase the identified services and/or equipment at their convenience. Receipts are typically sent back to the CCG each month.

There may be instances where a combination of the above will prove favourable and might reduce unnecessary financial risk to CCGs. It should also be noted that with a direct payment an individual may purchase third-party support, for example from a charity or user-led organisation. This can be particularly beneficial for those individuals who employ personal assistants (PAs) but do not want the administrative workload around bank account management, payslips, PAYE, Disclosure and Barring Service (formerly CRB) checks, and so on. We examine this in more detail in Section 7 (Continuing Healthcare). At the time of writing, direct payment powers had not been extended to PCTs/CCGs outside of the pilot sites.

### 3.2 What can the PHB fund?

The guiding principle behind legitimate PHB spend is that the chosen service or equipment should clearly address the person's health and wellbeing needs. In Sections 7 and 8 we explore in some detail what continuing healthcare and mental health service users are purchasing with PHBs. The following list shows some of the items that have been purchased during the PHB pilot by people living with other long term conditions:

- 1) Exercise equipment, such as treadmill, exercise bike, Wii-fit
- 2) Gym membership with personal health trainer
- 3) Massage/acupuncture (to improve circulation and pain relief)
- 4) Aromatherapy (to reduce anxiety)
- 5) Slimming club membership
- 6) Leisure activities/hobbies to reduce social isolation
- 7) Mobility scooter
- 8) Archery, for muscle training (MS sufferer)
- 9) Air-conditioning or de-humidifying equipment (help with breathing difficulties)
- 10) Orthopaedic mattress, to reduce pain
- 11) Pet (company for MS sufferer)

### 3 Personal health budgets: what are they?

- 12) Singing lessons, as alternative to respiratory therapy (COPD patient)
- 13) Sat nav (to give confidence to stroke victim)
- 14) Equipment to improve access around the home and garden
- 15) Equipment to improve communication (tablet, computer software)
- 16) Personal assistant(s)

PHB leads and advocates implore cynics to examine expenditure by the outcome, not by the thing bought. While choice is given to the individual, the clinician (and exceptionally a risk-panel) has to decide whether a particular activity or intervention is safe and rational. Ongoing support and evaluation are central to the PHB system: if the support plan is not working, the client will be encouraged to consider alternatives.

In some cases budget-pooling has allowed PHB holders to ‘bulk-buy’ access to services. One group of COPD service users, following a six-week pulmonary rehabilitation course, requested ongoing NHS support. With pooled PHBs they were able to gain weekly gym access as a group at a very reasonable cost, thereby reducing their isolation and giving them increased motivation to continue exercising.<sup>6</sup>

Though patients are encouraged to think outside the box, many simply want to use the PHB system for its flexibility and provider access. With a PHB a client can arrange what are essentially conventional services at their own convenience – such as home visits, or out of hours physiotherapy or pain relief massage. The flexible care arrangements afforded by the PHB have been of arguably greatest benefit to NHS continuing healthcare clients, as we describe in Section 7.

NHS money is not allowed to be spent on gambling, debt repayment, alcohol or tobacco, or anything unlawful. The PHB does not fund acute care, nor the majority of primary care services, such as GP surgery visits.

*People may want to use their budgets for treatments where there is no clinical evidence to support their use. This should not automatically prevent approval as, despite not being supported by clinical trials, a selected treatment may work for an individual.*

**‘Personal health budgets – Guide for GPs.’  
Royal College of General Practitioners, 2012**

6. PHB lead interview with 2020health, October 2012

## 4 Why might we want PHBs?

*The extra choice and control, and its consequences, are the main reasons why personal health budgets produce greater net benefits than conventional service delivery.*

**PHB evaluation team, November 2012**

Supporting arguments for the personal health budget system stem from both service user and NHS perspectives. The PHB is, first and foremost, intended to offer the service user increased choice, control and convenience; it represents a responsive and adaptable mechanism that brings wider access to both traditional and non-traditional services. The PHB therefore holds particular value for those living with long term conditions who are not achieving outcomes via conventional NHS provision.

*PHBs are more than a budget; they are the basis of a different conversation between individuals, those who support them and clinical professionals, in which each shares information and expertise to produce better outcomes.*

**Centre for mental health, 2012**

‘Personalisation’ within the context of the PHB system entails partnership working. That is, the PHB does not diminish in any way the value of clinical expertise, but it does recognise another vital stream of learning: the lived experience of the individual. The old ‘expert to patient’ medical model has been stultifying to public health literacy and responsibility; the PHB on the other hand encourages a dialogue in which expertise is shared.

In terms of NHS incentives, clinicians of course want to help individuals achieve best possible outcomes. Care planning and partnership working is comparatively new ground, but the NHS community is increasingly recognising the importance of this agenda. Improving integration is another important strategy, breaking down the silos that obstruct efficient commissioning across health and social care.

The PHB will for many become a counterpart to their social care personal budget. But true integration means taking a whole-person approach, the objective being one health/social care plan, one (pooled) budget operated from a dedicated bank account, and personalised commissioning that maximises resources. Procurement is therefore no longer split between services; rather it is undertaken from the central point of the individual, tailored to that individual and carried out according to their timetable. This activity will depend heavily on efficient partnership working with the third sector, drawing especially on the support, skills and knowledge of user-led organisations and Peer Networks.

*What service users and carers would really like to see is continuity in care, with health, social care and the voluntary and community sector working together from a single care plan and process.*

**NHS Confederation, 2011 PHB survey**

### 4.1 QIPP and the PHB

A cursory review of PHB literature and opinion of the last three years reveals a great deal of Quality Innovation Productivity and Prevention (QIPP)-aligned arguments for the PHB, which have the potential of turning the PHB programme into a cost-savings exercise. While this must not become the primary objective, there is of course an expected corollary of personalisation and prevention, which is long term reduced service use. Proving the economic viability of PHBs has always been an essential task, as we investigate in sections 7 & 8.

The charity In Control, advocates for the PHB system from the outset (having pioneered Personal Budgets in social care), has stated that the potential ‘QIPP’ benefits and efficiencies of the PHB system include:

1. improving shared decision-making and responsiveness to individual needs;
2. improving health outcomes through genuine co-production;
3. developing alternative, less costly packages of care;
4. reducing overall service utilisation through greater prevention;
5. improving coordination between services; and
6. increasing competition between providers.

## 4 Why might we want PHBs?

In terms of points 1 to 5, the PHB evaluators have verified a range of success in continuing healthcare and mental health. And they agree, more generally, that the PHB appears to enhance quality of life 'via improved choice, control and tailoring of services to personal needs and circumstances.' This report examines these themes further in its later sections.

In terms of competition (point 6), the PHB is currently too small scale to have a major impact on the provider market (Southampton's Alcohol detoxification service notwithstanding – see section 8.5). But the clear consensus among PHB advocates we interviewed was that the NHS should not be propping up substandard providers. In the present system, poor quality services are effectively sustained by the lack of patient choice and control. Clearly this is neither helpful to service users nor the NHS.

*'There must be a willingness to allow poor providers to fail; to decommission services that aren't delivering what people want out of their healthcare. That's a tough place to go.'*

**PHB lead**

### PHBs in partnership with Year of Care?

The Year of Care (YOC) model is an important strategy to the personalisation agenda. In terms of its patient-centred approach it shares many values with personal health budgets, such as:

- Collaborative care planning
- Shared decision making and self-management support
- Holistic approach to patient care
- Integrated support and commissioning

YOC targets those patients with long term conditions who require an integrated approach to care. Individuals are placed within a tariff band that represents their approximate service usage costs for a 12-month period. The YOC programme has used risk profiling (low, medium and high) in tariff-setting deriving from a holistic approach to assessment – identifying goals and outcomes – rather than breaking down costs associated with each specific long term condition.

Since tariff banding in YOC is very broad, the associated value would not be suitable for conversion into a personal health budget. But the two systems could certainly cooperate, with a PHB extracted from part of the YOC tariff. Barriers emanating from block contracting exist for YOC as they do for PHBs, so fluid commissioning models need to be developed to facilitate these and other personalisation strategies. It is expected that the wider YOC model, as tested in the recent diabetes YOC pilot,<sup>8</sup> will in time extend patient choice beyond conventional NHS boundaries to non-traditional providers, increasing common ground between YOC and the PHB.

8. Year of Care: 'Thanks for the Petunias' – a guide to developing and commissioning non-traditional providers to support the self-management of people with long term conditions (2011). Available from website: [www.diabetes.org.uk](http://www.diabetes.org.uk)



## 4 Why might we want PHBs?

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### 4.2 Not a perfect fit for everyone

To the NHS there are few words that carry a greater imperative than ‘personalisation’, ‘prevention’ and ‘integration’. The PHB takes its place as a tool for all three agendas; at the same time it represents an option within a menu of choices – it has never been espoused as a panacea or a perfect fit for everyone. After all, if a service user is content with their current provision of care, there will be fewer incentives to take up a PHB. Some patients during the pilot opted only for the care planning feature of the PHB, turning down budget-holding responsibilities.<sup>9</sup>

The PHB is admittedly the most radical, and therefore controversial, strategy of the ‘choice and control’ agenda, and the change management requirements are enormous. Outside of continuing healthcare the PHB is heavily reliant on GP advocacy to gain widespread traction, and more work is needed by the Department of Health to bring GP champions on board. For now, many frontline professionals working outside the PHB pilot sites consider the current levels and mechanisms of personalisation sufficient to be moving the agenda forward.<sup>10</sup> Why introduce more risk into the system?

The next section therefore considers some of the more general fears and objections that remain topical even following the various successes of the PHB pilot programme.

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9. PHB leads interview comments, August – October 2012.

10. NHS Confederation, 2011. ‘Facing up to the challenge of personal health budgets: The view of frontline professionals.’

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## 5 Why is there some nervousness about PHBs?

In this section we consider some of the key concerns and fears expressed over the PHB programme. The BMA is just one of the professional organisations to have recently questioned the PHB strategy,<sup>11</sup> having found in their own survey that ‘seventy-two per cent or 155 of the 214 doctors who responded...felt not very well informed or not at all informed about the introduction of PHBs.’ They concluded that ‘any proposed implementation should be delayed until doctors have a thorough understanding of the initiative’.

We understand that a great number of CCGs and individual GPs remain ill-informed about the personal health budget programme.<sup>12</sup> And many of those who are informed harbour concerns that the PHB system will:

- Exacerbate health inequalities
- Prove unsustainable due to an increased burden on the NHS (particularly in light of the Dutch experience)
- Be liable to widespread fraud
- Destabilise traditional services
- Put vulnerable individuals at risk
- Present substantial financial risk to CCGs

We consider these pressing concerns under three central themes:

1. The Dutch experience: will it happen to us?
2. Will the PHB system fuel health inequalities?
3. Handing over control: what are the financial risks to commissioners?

### 5.1 The Dutch experience: will it happen to the NHS?

The Dutch equivalent of the PHB programme, the *persoonsgebonden budget* (PGB), has recently been severely curtailed due to spiralling costs, principally due to the rise of new state ‘applicants’. The PGB is currently only available to those who would otherwise need to move into a care home or nursing home.

Launched through social care in the mid 1990s, the Dutch PGB scheme was devised to give control and choice to service users, allowing informal care to be arranged to suit

to individual need, thereby tackling inflexible care agency arrangements as well as long waiting lists.

The Dutch PGB, like the English PHB, is not means tested. Cash payments through PGBs were issued at a 75% value of the equivalent professional agency spend, on account of avoided agency overheads. (Some sites in England make downward adjustments in setting their indicative budget; during our interviews we learnt of 5%, 10% and 20% reductions.)

Between 2002 and 2010 the number of personal budget holders in the Netherlands increased ten-fold (13,000–130,000) and spending increased from €0.4bn to €2.2bn during the same period.<sup>13</sup> And whilst of minor financial significance, there were some highlighted cases of fraud, particularly around third party arrangements, which gave the PGB programme negative press and reduced political support.

As early as 2003, a Dutch academic paper<sup>14</sup> had warned of the substantial risk of an increased burden on the social care system with unpaid informal care being replaced by paid informal care through the PGB. Many family caregivers, having previously not solicited agency assistance, were now applying for direct payments. Parents of disabled children (including young people with psychiatric disorders) represented a significant group of new applicants within the system.<sup>15</sup>

Another contributing factor to the rise in PGB applications, and expense generally, was the broadening definition of ‘disability’. Only comparatively recently have conditions such as child hyperactivity and OCD been officially recognised and accepted as eligible for state support.

Crucial questions for the NHS are:

- Will the PHB programme create new NHS applicants and thereby increase levels of demand?
- How will the NHS minimise fraudulent activity by unscrupulous third parties, or even patients themselves?

11. <http://bma.org.uk/news-views-analysis/news/2012/november/government-set-to-push-ahead-with-personal-health-budgets> Accessed November 2012

12. Westminster Health Forum, 24 January 2013; feedback from PHB leads

13. Van Ginneken E, et al. ‘Personal Health Budgets: what England can learn from the Netherlands?’ *BMJ*2012; 344:e1383

14. Van den Berg, B and Schut F.T., 2003. ‘The end of free informal care?’ *Economische Statistische Berichten*, 88,4413; 420–2

15. Schut F.T. and Van den Berg, B., 2010. ‘Sustainability of Comprehensive Universal Long-term Care Insurance in the Netherlands.’ August

## 5 Why is there some nervousness about PHBs?

There will almost certainly be some sort of rise in NHS demand, which for the Royal College of General Practitioners is ‘a very important unknown’.<sup>16</sup> However there are good reasons to believe that this is unlikely to replicate the Dutch experience.

The assessment of eligibility within the Dutch system has been described as flexible and ‘largely based on trust’, while ‘accountability and control mechanisms are lenient’.<sup>17</sup> One of the key elements working in favour of the NHS system is the care/support planning process with both clinician and CCG sign-off. This goes beyond the needs-assessment stage and gives the PHB a level of scrutiny and accountability that the Dutch system never properly acquired. Moreover, PHB methodology generally seeks to engage family members and account for the hours of care they are able to provide without payment. The family/social network was hardly factored into the Dutch PGB system.

Another consideration is the fact that England’s social care personal budgets (PBs), unlike NHS PHBs, are subject to means-testing; whereas in the Netherlands both social and health care are universal. The Dutch system, with its PGB crossing social and health care, had a proportionally heavier burden to carry.

In terms of fraudulent behaviour, there will always be those who attempt to play the system – whatever its composition – so close and efficient monitoring is clearly an essential. (We consider user fraud in Section 5.3.) Brokerage in the Netherlands was not closely monitored, and now specialised PGB agencies are no longer able to receive direct payments on behalf of individuals. The English system should therefore ensure that budgets held by third parties are fully disclosed to the patient; the arrangement requires Local Authority/CCG oversight, and accounts and payments need to be transparent and regularly audited.

### Learning from the Dutch experience:

1. Be clear on eligibility criteria. Where demand has the potential to escalate, the NHS may want to stratify patients to prioritise those who will benefit most from a PHB.
2. Although the NHS may not want to increase administration costs unnecessarily, it must ensure efficient monitoring and audit of PHB holders’ expenditure and be careful not to rely too much on trust.
3. The process of care/support planning – besides its essential focus around needs, goal-setting and outcomes – increases patient responsibility and accountability, and builds trust between stakeholders. The use of risk-enablement panels should continue in order to support vulnerable individuals with complex needs, although their wider involvement in the PHB programme may drive up costs.
4. Close, continued monitoring and review, including the tracking of hospital admission rates, are essential to understanding long-term benefits and cost-efficiencies. The Dutch system, as of 2010, lacked robust data to demonstrate the benefits of PGBs.<sup>18</sup>
5. Third party arrangements should be fully transparent to both the CCG and PHB holder. The third party themselves should ideally be an already established and trusted partner within the local community.

16. Mathers N, et al, 2012. RCGP Position Statement: Personal Health Budgets.

17. Van Ginneken E, et al. ‘Personal Health Budgets: what England can learn from the Netherlands?’ *BMJ*2012; 344:c1383

18. Interview comment by Dr Bernard Van den Berg, 2020health, Nov 2012.

## 5 Why is there some nervousness about PHBs?

### 5.2 Will the PHB fuel health inequalities?

A number of professional organisations have expressed concerns that the personal health budget system might exacerbate health inequalities.<sup>19,20,21,22</sup> And specifically in terms of ensuring equal access to the PHB system, some PHB leads we interviewed highlighted a variety of difficulties. But these should not be viewed as insurmountable problems.

#### 5.2.1 Equality of access to the PHB system

Due to its devolved nature, NHS care can be prone to a ‘postcode lottery’, and many healthcare professionals we interviewed feared that, with commissioning yet further decentralised under the CCG system,<sup>23</sup> the potential for this problem might only increase. This could impact the PHB programme in that:

- some areas may make PHBs widely available to continuing healthcare (CHC) individuals and beyond, while others may restrict availability, perhaps by applying different eligibility criteria or making the application process unreasonably difficult;
- some CCGs may sign off on requests for services and materials (reiki, aromatherapy, car repairs, laptop, pet, business course, etc.) that others do not; and
- the essential involvement and integration of user-led organisations and Peer Networks may vary greatly depending on CCG groundwork.

The extent of patient ‘choice and control’ might therefore fluctuate considerably across the country. It is thus crucial that best practice is well disseminated and that the system has public oversight. NHS England (formerly known as the NHS Commissioning Board) will hold CCGs to account for undertaking statutory duties, but national guidelines and protocols need to be in place to ensure that the PHB system offers requisite flexibility and choice to users.

Third sector integration and the creation of local Peer Networks need prioritising – CCGs should not go the journey alone, as these stakeholders can help shape the PHB framework, increase awareness among relevant groups, and assist equitable access across a range of service areas. In time, published performance metrics on access (proportion of successful applicants in given service areas, for example) would seem a logical means of promoting fairness across the system. This information could be made accessible via the NHS Choices website.

#### Recommendation:

**NHS England should consider releasing regional PHB ‘choice and control’ data, perhaps via NHS Choices website, to bring increased accountability and transparency to the system.**

**By making the system transparent to the public, individuals are more likely to experience equitable treatment and equal access to non-traditional services.**

#### 5.2.2 PHB uptake and patient risk

Some fear that the PHB could be seen as an exclusive option. Take-up may be high among those with significant health-literacy, while others may be confounded or put off by the complexities of the system. The benefits of the PHB may appear dependent on the necessary aptitude of an individual or their representative, or perhaps on the patient’s ‘social capital’.

Many already involved in PHB programmes confirm that the answers lie in care coordination, engaging user-led organisations and Peer Networks, and the process of ongoing review. Some individuals will need greater support in the care-planning process and day to day handling of the PHB, and will therefore receive proportionally more help (perhaps at greater cost) under the guiding principles of NHS equity. This is vital to the safeguarding of care arrangements and minimising of risk for the most vulnerable.

19. RGCP Position statement, June 2012: Personal Health Budgets

20. RCN Policy briefing, Sept. 2011: ‘Personal Health Budgets: An overview of policy in England so far’

21. ‘Liberating the NHS: Local democratic legitimacy in health’ BMA Response, 2010

22. Chartered Society of Physiotherapy correspondence with 2020health, February 2013

23. There are approximately 40% more CCGs than there were PCTs.

## 5 Why is there some nervousness about PHBs?

Another area of patient risk derives from the repercussions on traditional services of large-scale PHB uptake. The British Medical Association has stated that ‘using PHBs to pay for non-traditional services could take money out of the NHS...This could lead to the destabilisation of existing services as the loss of funding from budget holders leaves providers unable to maintain the level of service they wish to provide to non-PHB holders.’<sup>24</sup>

CCGs will of course need to examine carefully how PHBs might affect traditional services and make appropriate interventions to maintain a suitable quality of existing NHS care. It is conceivable that to protect the efficiency, quality and availability of a specialised service, the PHB option may have to be restricted for the greater good of the cohort – this is fundamental to NHS equity. Outside of the obligations around continuing healthcare, it is for now up to CCGs to determine how best to implement PHBs and how far (and fast) to extend the programme. Measured and efficiently-monitored roll-out will mitigate risk in this respect.

### Recommendation:

**CCGs need to prioritise third sector integration and the creation of local Peer Networks to shape the PHB framework and assist equitable access across a range of service areas. This is vital to maximising potential of the PHB system and ensuring equality of access for all individuals.**

### Recommendation:

**CCGs need to examine carefully how PHBs might affect traditional services and make appropriate interventions to maintain a suitable level and quality of NHS care. In rare circumstances they may need to restrict the availability of PHBs.**

### 5.2.3 Greater benefits to the better off?

A third issue of health inequality arises from the potential benefits to individuals who purchase additional private care that is in some way contingent upon their NHS care. For example, under conventional NHS provision, no patient desiring extra physiotherapy or massage can request extra time to a session, or further sessions, billed separately. They would have to seek a private provider for the extra service, typically at another time in another place. Under the PHB system, a patient could, theoretically, immediately follow up a PHB-funded session with extra care purchased privately with the same provider at the same location. Such an arrangement would not be against the letter of NHS rules if the additional care fell outside of the patient’s NHS care-plan, was conducted on private premises, was voluntarily requested and separately accounted for.

From our interviews it became clear that this kind of ‘legal’ topping-up was inevitable. The main issue, PHB leads argued, was that patients should not *have* to top up their care to meet their assessed needs. Disagreements over budgets and care provision arise because ‘needs’ are subjective: patients and the NHS will not always see eye to eye. This is as true outside the PHB system as it is within it.

Our interviews also brought to light one of two cases of voluntary co-pay – arrangements that gave particular patients a level of opportunity that would have been unavailable to some less well-off patients. These co-payments were signed off by the respective PCTs as a pragmatic solution to a specific problem. It is our impression that such cases are few and far between and not embedded as systematic practice.

24. <http://bma.org.uk/news-views-analysis/news/2012/november/government-set-to-push-ahead-with-personal-health-budgets>

## 5 Why is there some nervousness about PHBs?

### 5.3 Handing over control: what are the financial risks to commissioners?<sup>25</sup>

If CCGs hand over substantial control to individuals via personal health budgets, should the CCG alone carry the associated financial risk? Consider the questions:

- What if the PHB holder overspends?
  - They cannot be denied NHS services.
- What if the PHB holder fires their PA(s) unfairly?
  - The CCG may face costs of employment tribunals.
- What happens when the CHC PHB holder dies?
  - The CCG has to find potentially tens of thousands of pounds per CHC client to fund staff redundancy packages.

We consider redundancy (and other contingency) issues in Section 7: Continuing Healthcare, since nowhere does this issue become more pronounced and complex than where individuals or third parties (trusts or organisations) are employing staff and controlling annual budgets to the value of £200,000 or more.

So we consider here, specifically, the risks around the abuse and overspend of personal health budgets. How do CCGs, without excessive monitoring and administration, ensure that individuals play by the rules?

In social care, problems of abuse and mismanagement have not derailed the personal budget (PB) programme, which has been in full swing for five years and dates back some sixteen. But this is not to claim that the problem is insignificant. While the Audit Commission in October 2010 stated that ‘experience from direct payments thus far suggests that levels of abuse are low,’<sup>26</sup> they have more recently recommended that social workers receive fraud awareness training. Moreover,

*Councils should also seek to strengthen and promote whistleblowing arrangements among staff, care providers and the public to encourage early identification and reporting of fraud or financial abuse.*<sup>27</sup>

The safeguards around social care’s PB system include care planning and ongoing monitoring. If monitoring is lax, then clearly fraudsters can play the system. But misuse does not always equate to fraud. One site reported to us that while there had been cases of PB misuse in their region, money had been reclaimed and (to date) never through the courts. In many cases budgetary misuse is simply a matter of carelessness.

The PHB system does not have quite the same scope for abuse as the PB system in social care. There will be fewer opportunities for applicants to make false claims, since an experienced clinician (as well as a care coordinator) should always be involved in the needs assessment process and care/support plan sign-off.

One of the prime opportunities for PHB abuse is within the context of carers as fund managers – a problem known to the social care system.<sup>28</sup>

#### 5.3.1 What CCGs can do

The care coordinator should forewarn the PHB holder that they may have to pay back any budget overspend out of their own pocket, unless this can be compensated through their own PHB funds at no risk to their own health.

A CCG has the power to revoke a direct payment privilege and move any abuser of the system back into conventional service provision. If clients know this is likely following budgetary mismanagement, they are more likely to follow procedure.

A CCG should also threaten the withdrawal of a direct payment where a PHB client fails to reveal expenditure through bank statements and receipts as stipulated in their agreement. System efficiency of course demands robust, ongoing monitoring and review by the PHB team itself.

CCGs may also want to consider other methods of budget holding that will give flexibility to users while reducing financial risk. We discuss some of these options below.

25. For an in-depth consideration of PHB system risks (including double-running costs), see Audit Commission’s ‘Making Personal Health Budgets Sustainable’ (2012)

26. Audit Commission, October 2010: Financial management of personal budgets

27. <http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1583/1583we08.htm>

28. Audit Commission, November 2012. Protecting the public purse. p.26

## 5 Why is there some nervousness about PHBs?

### 5.3.2 Alternative PHB management

We have made reference to the three principal options of budget management: direct payment, third party arrangement, and notional budget. CCGs should exercise flexibility to allow a combination of these where appropriate, which itself may help reduce risk.

CCGs are in time expected to issue a great many PHBs as single payments or short-term allocations. During the pilot there was some flexibility among sites as to how these could be allocated, but best practice is as yet unclear. Many applicants will be put off by the requirement to open a new bank account for a short-term PHB,<sup>29</sup> while notional budgets will be subject to NHS constraints.

One suggestion is to allow single or short-term PHB payments into existing bank accounts, providing that clients are willing to supply all invoices and bank statements. An argument against this, historically, has been that such an arrangement would reveal to the CCG the client's private expenditure and would therefore deter uptake. However, there already exists a similar procedure in housing benefit applications with local authorities, where the supply of bank statements is standard practice. CCGs may want to consider this as an option.

If commissioners seek to further reduce risk, there are other payment options to consider.

#### Prepaid (debit) card

Prepaid cards are already used by some 40% of local councils, primarily for personal budgets in social care. The card is a chip-and-pin debit card that can allow the user wide access to non-traditional providers. The LA/CCG uploads the direct payment onto the card, has full oversight of client expenditure, and can even restrict the use of the card to certain services.

Client benefits include:

- No bank account necessary
- Services can be purchased face to face, via the internet or over the phone
- Monthly statements are sent to the client, who can also view expenditure online
- Card can be used to pay personal assistants and other home services

CCG/Local Authority benefits include:

- Full monitoring capability of client spend, month by month
- Streamlined, largely paperless administration
- Facility to integrate social and healthcare budgets
- Swift blocking of Direct Payments if card is abused

Prepaid card systems, such as the Kent Card,<sup>30</sup> are now well established and offer considerable flexibility for both small and large PHB allocations.

#### Voucher system

Another option is to initiate a PHB voucher system. This has not been implemented within the PHB programme to date, but the NHS already has great familiarity with similar concepts, witness vouchers in dental care and eye care, as well as prescriptions. The PHB voucher would obviously not be subject to the same means-testing.

The PHB voucher system would necessitate non-traditional providers (NTPs) across a range of services to register themselves with the local CCG or Local Authority, much in the same way as opticians and dental practices do currently. The system would require providers to agree to deliver specific services according to set tariffs.

The voucher (which could be tailored to services or generic) would be issued and signed by the clinician who allocates the PHB. The voucher would then require a signature from the registered non-traditional provider, as well as a signature from the client themselves, and include information about service and delivery. It is then up to the NTP to redeem the voucher with the CCG or Local Authority, as appropriate.

This system is admittedly more restrictive than the prepaid card, but it minimises the risks to CCGs with:

- Client access to registered non-traditional providers only
- Tariff system controlled by CCG
- Three-signature verification (referring clinician, client, provider)
- Voucher of notional value only

29. Some sites allow clients to present an existing bank account with no money registered, on the understanding that the account will subsequently be used only for the PHB.

30. [http://www.kent.gov.uk/adult\\_social\\_services/leaflets\\_and\\_brochures/kent\\_card.aspx](http://www.kent.gov.uk/adult_social_services/leaflets_and_brochures/kent_card.aspx)

## 5 Why is there some nervousness about PHBs?

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### Sub-contracting PHB administration to a Community Interest Company

Some sites (e.g. Hull and Northampton) have managed to bypass some of the constraints surrounding notional budgets by commissioning a Community Interest Company (CIC) to run a PHB service. This arrangement, in some respects similar to that of an Individual Service Fund,<sup>31</sup> gives a trusted third-sector organisation the power to purchase non-traditional services and/or equipment on clients' behalf. (This is quite different from the third-party budget holding arrangement, since the PHB does not itself fund the service.) The arrangement necessitates the close partnership working of CCG and contracted organisation, but does allow for greater access and flexibility beyond the potential confines of NHS-held notional budgets.

#### Recommendation:

CCGs should consider safer methods of budget allocation where possible by employing the prepaid card, or by initiating a voucher system as an extension of the NHS-held notional budget.

#### Suggestion:

A CCG may want to consider sub-contracting some of its PHB administration to a non-profit Community Interest Company (CIC), so to create a middle ground between notional budgets and full third-party arrangements. At the request of PHB clients, the CIC would procure non-traditional services or items that are not readily accessible via NHS-held notional budgets.

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31. Sanderson, H et al, 2011. 'Choice and control for all: the role of Individual Service Funds in delivering fully personalised care and support'

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## 6 Where are PHBs appearing to work most successfully?

The independent evaluators of the 2009–12 personal health budget programme built their evidence base from the experience of 20 pilot sites. While most of these sites had direct payment powers, only half offered all three budget deployment options – direct payment, third party and notional budget.<sup>32</sup> Participants for the pilot programme were recruited from six principal service areas:<sup>33</sup>

- NHS continuing healthcare
- Mental health
- Diabetes
- Chronic obstructive pulmonary disease
- Stroke
- Long-term neurological conditions

Evidence was gathered via a controlled trial, largely non-randomised, with just over 1000 individuals recruited into each arm of the study. Both quantitative and qualitative approaches were used to analyse data and feedback from a 12-month period. The evaluators employed three principal measurements: social care-related quality of life (ASCOT), health-related quality of life (EQ-5D) and psychological well-being (GHQ-12). Measurements of clinical benefit were restricted to mortality rates, diabetes HbA1C tests and COPD FEV1 (forced expiratory volume in 1 second). However the evaluators also collected data around levels of service use and admission rates, which helped to corroborate cost effectiveness and health/wellbeing benefits.

Overall the evaluation recognised that ‘the use of personal health budgets was associated with a significant improvement in the care-related quality of life and psychological wellbeing of patients.’ Though it did not find overall a statistically significant effect on health status or clinical measures, it is worth bearing in mind the limited scope of the three clinical measurements used. Moreover, the authors stated, ‘as the follow-up period was for one year we may not expect that personal health budgets would have an impact on health status.’<sup>34</sup>

The most positive effects on outcome indicators were seen where sites:

- 1. chose to be explicit in informing the patients about the budget amount;**
- 2. provided a degree of flexibility as to what services could be purchased; and**
- 3. provided greater choice as to how the budget could be managed.**

Some negative impacts and frustrations were found where sites implemented the programme with less flexibility and choice, as compared with other sites. The report noted that ‘some thought the benefits were curtailed by restrictions on what the budget could be used for, lack of services and budgets being too small for their needs.’ Even so, there was a majority view (70%) among users that the PHB had to some extent increased their sense of what could be achieved in terms of outcomes and lifestyle.

By studying the full PHB cohort the evaluators were able to analyse data that was likely to be more statistically significant. However, generalised claims made thereof need to be treated with caution, since there was considerable variation in PHB value, use and perceived effectiveness among subgroups.

Breaking down the full PHB cohort gave the evaluators better insight into the potential of the PHB in specific service areas, even if the findings were likely to be less statistically significant. The evaluators were nevertheless able to state with significant confidence that PHBs demonstrated health benefits and notable cost-efficiencies for the mental health and continuing healthcare subgroups. They found particular cost-efficiency within high-value personal health budgets, and thus recommended that ‘personal health budgets should be initially targeted at people with greater need’.

Evidence around health benefits and cost-efficiencies for other conditions was largely inconclusive, owing primarily to the small sub-sample sizes. Further, among the full PHB cohort, nearly one third of all allocated budgets were £500 or less.<sup>35</sup> Some of the smaller allocations might, for example, allow an individual to attend an art class to reduce isolation; a COPD patient to choose singing lessons

32. PHB Evaluation report, November 2012; p.56

33. Various service areas were included in pilot but not subject to in-depth evaluation, such as end of life care, maternity services for vulnerable women, and young people in transition.

34. PHB Evaluation report, November 2012; p.60

35. Just over half were under £1000. PHB Evaluation report, November 2012; p.55

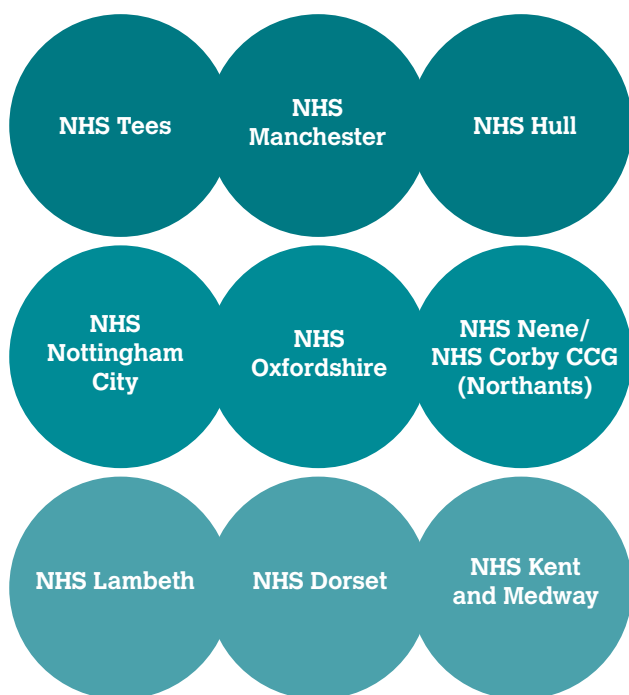
## 6 Where are PHBs appearing to work most successfully?

in place of respiratory therapy; or an MS sufferer archery instead aquatic therapy. Such PHBs are designed to increase choice and well-being, first and foremost, encouraging people to actually turn up to programmes/treatments and even enjoy themselves in the process. (As mentioned earlier, it is a guiding principle that the NHS allocates no more money to an alternative intervention than it would have spent on conventional services for that person.)

The evaluation stated that ‘the majority of budget-holders and carers reported positive impacts of the personal health budget – on their health and well-being, healthcare and other support arrangements and for other family members...Most interviewees appreciated the increased choice, control and flexibility of the personal health budget.’

The evaluators singled out COPD in particular, acknowledging that for this cohort, ‘personal health budgets were associated with improvements regarding ASCOT-measured outcome change, psychological well-being and subjective wellbeing.’<sup>36</sup>

It is freely acknowledged that the PHB programme has more to learn from trialling. There are now over 70 sites operating personal health budgets, and nine of these have been enlisted as Going Further, Faster sites to undertake further work to mainstream PHBs across a range of conditions. These sites are:



There is a great variety of work underway across these areas. NHS Tees and NHS Manchester, for example, are developing personal budgets for children with special educational needs as part of the Department for Education’s pathfinder project. Four of these sites (at the time of reporting) had already invested in local Peer Networks. And the majority of these sites are undertaking specific work to develop integrated systems for joint budgets, for those accessing both health and social care services.

The Going Further, Faster sites (and other former pilot sites) will generate more learning around the use of PHBs among those living with chronic conditions. The general opinion of PHB leads is that individuals should not be classified into disease-specific groups for the purposes of PHBs. Many individuals in any case have multiple morbidities; ‘We’re not looking at conditions,’ one Going Further, Faster PHB lead told us, ‘just people with needs who need support.’ Work includes identifying accurate budgets that are necessarily extracted from different service funds, most of which are currently associated with block-contracts.

The Department of Health hopes that as CCGs take full control of their commissioning responsibilities, they will not only provide the option of PHBs to those eligible for NHS continuing care, some 56,000 people, but also to ‘others who clinicians feel may benefit from the additional flexibility and control that personal health budgets offer.’<sup>37</sup>

Some CCGs will be hesitant to take what one member described as ‘a leap of faith’ over personal health budgets. This is in part due to some widely-acknowledged professional unease about PHBs, as we explored in Section 5. So we have decided to focus our response to the pilot programme around the two areas that have thus far demonstrated the most compelling results with the PHB system: continuing healthcare and mental health – and in the latter category we include alcohol misuse.

36. PHB Evaluation report, November 2012; p.10

37. <http://mediacentre.dh.gov.uk/2012/11/30/thousands-set-to-take-control-with-personal-health-budgets-cash-for-care/>

## 7 The case for PHBs in continuing healthcare

*‘...the use of a personal health budget has a direct impact on quality of life via improved choice, control and tailoring of services to personal needs and circumstances’*

**PHB evaluation team, November 2012**

Around 35 pilot sites – more than half of all sites in the pilot programme – tested out personal health budgets in continuing healthcare (CHC). Individuals eligible for NHS CHC have substantial ongoing health needs and complex medical conditions. The NHS covers their entire care package, which typically includes care agency services or accommodation costs in a nursing home.

From the outset, CHC was considered the ‘safe bet’, the one area of healthcare that would surely benefit most from the flexibility and responsiveness of PHBs. Many CHC individuals and their families have been frustrated by the often inflexible and impersonal arrangements of traditional care services. With a PHB, an individual (or their family/representative) can control the timetable and exercise considerable choice as to who comes into the home to do the caring. For the NHS the initiative was expedient in part because there are (normally) no block contracts involved in agency care, so the economic dangers of ‘double-running’ services were largely irrelevant. Freeing up the money to fund the programme was comparatively easy.

*I believe I represent not only myself but a large group of people with disabilities who have battled hard to maintain independence in their lives, to avoid institutional care, and have the maximum opportunity and choice to control our lives. I feel it is a human right.*

**Continuing healthcare PHB holder**

The pilot evaluation confirmed the viability of personal health budgets for CHC, finding an overall positive response from patients involved and cost-efficiency

(using the ASCOT scale) at the 90% confidence level. The evaluators included a caveat, however, ‘that the size of the NHS Continuing Healthcare sample was relatively small due to a number of ineligible study participants and higher mortality rates after baseline. As a result, statistical significance was low, even though effect sizes were often very high compared to other groups.’<sup>38</sup>

Whilst the guiding principles behind PHBs are to improve personal choice and control without increasing costs to the NHS, it is of course encouraging that the pilot appears to have demonstrated outcomes for CHC clients while potentially reducing NHS costs. Care packages generally cost less under the PHB system, although any indirect cost savings from reduced service use remain largely theoretical at this stage. The pilot enrolled 155 CHC patients onto the PHB programme; the average (mean) PHB allocation was £37,418, the largest £378,524.

### 7.1 The process: referral to uptake

Individuals eligible for NHS continuing care<sup>39</sup> are typically alerted to the personal health budget scheme by their principal clinician. It is important that the individual, or their representative, understands from the outset:

- what the PHB might offer as compared to conventional service provision;
- what their support plan needs to take account of;
- what help is available to them to write and manage their support plan;
- their personal responsibilities as a PHB holder; and
- the options and implications of notional budgets, third party arrangements or direct payments (as described in Section 3).

The individual or their representative needs to grasp all these points to make an informed decision as to whether to take up a PHB, and a clinician or care coordinator needs to be certain that the client has full understanding.<sup>40</sup> If a PHB option is chosen, the next step is a needs assessment, which takes into account both health and social care needs. This process should ideally engage family members (and acknowledge other social capital<sup>41</sup>) in order to identify an appropriate level of NHS-funded care, initially set out as an indicative budget.

38. PHB Evaluation report, November 2012; p.126

39. For eligibility criteria see: NHS confederation – ‘NHS continuing Care: Detailing what NHS organisations need to know and do.’ Briefing; November 2012

40. PAs cannot be employed privately under ‘notional’ budget arrangements.

41. Also described as ‘Real Wealth’, to include personal resilience and capacity, friends and other community support (faith groups, social clubs, etc). See <http://www.cenreforwelfarereform.org/library/authors/simon-duffy/real-wealth1.html>

## 7 The case for PHBs in continuing healthcare

**Recommendation:**

**No PHB should be allocated unless the potential PHB holder demonstrates (to a clinician or care coordinator) full appreciation of the implications of PHB uptake.**

With full knowledge of the indicative budget, the individual creates their support plan (or ‘care plan’). Support planning may be undertaken by the individual alone, or with family or peer support, or with additional assistance from an independent care coordinator/broker or clinician. Once complete, the plan needs to be signed off by a clinician or clinical team, and the final budget approved by a CHC manager at the CCG. A risk-enablement panel at the CCG may be involved if complex risks need to be considered further.<sup>42</sup>

*‘With some CHC packages, we couldn’t give them an indicative budget prior to the care-planning because their needs were so complex. We instead worked out needs and personal assistants...and costed that backwards, as it were.’*

**PHB lead**

The support planning process helps the client decide how they would like the PHB fund to be managed. Some people will simply not want employer’s responsibilities, others might have very complex needs, and in these cases a third party arrangement may be preferred, where all money, purchases and employment contracts are handled on the client’s behalf. Though legal responsibilities lie with the third party organisation, the client retains choice and control.

If a direct payment is chosen, the client is required to sign a contract with the CCG, committing them to spend the budget as agreed in the support plan. They take on full employer’s responsibilities, including advertising for staff, decisions on rates of pay and employee requirements. The care coordinator may help with some of these tasks, although extensive administrative assistance may be purchased (with the PHB) from a third-sector broker (see case study 7a). The PHB may also fund extra staff training on certain health tasks.

CHC support plans and budgets should be reviewed regularly, but the frequency of review and monitoring should be guided by the needs of each individual and their circumstances. Some people may have relatively straightforward needs and care arrangements; others may have fluctuating conditions, some may be particularly vulnerable. At the minimum, new PHB holders will have a review at three months and twelve months, and yearly thereafter. Individuals are able to contact the CHC team at any point if healthcare needs change.

**Recommendation:**

**It is vital that CHC budget-setting methods should be fully transparent to the applicant (or their representative) from the outset.**

**Recommendation:**

**CHC plans and budgets should be reviewed regularly, but the frequency thereof should be guided by the needs of each individual and their circumstances.**

42. <http://www.in-control.org.uk/media/7890/risk%20enablement%20panel.pdf>

## 7 The case for PHBs in continuing healthcare

**The indicative budget is a well-informed estimate of the costs involved in giving an individual the appropriate level of support to meet their assessed needs and achieve their wellbeing outcomes. The indicative budget informs the care/support planning process, which itself creates the final budget.**

During the pilot, indicative budget-setting methods varied across sites. Some methods were needs focused, while others were outcomes focused. Some sites implemented percentage downward adjustments (or 'top-slicing') on the costs of conventional agency care, and not all informed the PHB applicants of this process.

One clear finding from the evaluation was that individuals who knew their indicative budget from the outset achieved better results than those who did not. Patient knowledge, in this regard, has become best practice.

However even now, following the three-year pilot programme, a definitive indicative-budget setting process has not yet been identified. For the time being, CCGs have to make their own choices about how to proceed. The DH states, 'as a guide, a tool for calculating indicative budgets is good enough for the purpose if it achieves predictions that are within 20% of the final cost for 80% of people.' Budget-setting tools for CHC are available as part of the DH's personal health budget Toolkit.<sup>43</sup>

### 7.2 How are CHC patients using their budgets?

Continuing healthcare PHB holders spend the majority of their budget on private personal assistants and/or agency care. Individuals with complex needs who choose private arrangements may require a small workforce, perhaps two full-time staff members and other part-time staff; in such cases a third party option is sometimes preferred, with all administration funded by the PHB. Otherwise, clients may choose to use a portion of their PHB to fund brokerage services, typically for payroll (HMRC, producing wage slips) and bank account management, while maintaining other employer's responsibilities (see case study 7a).

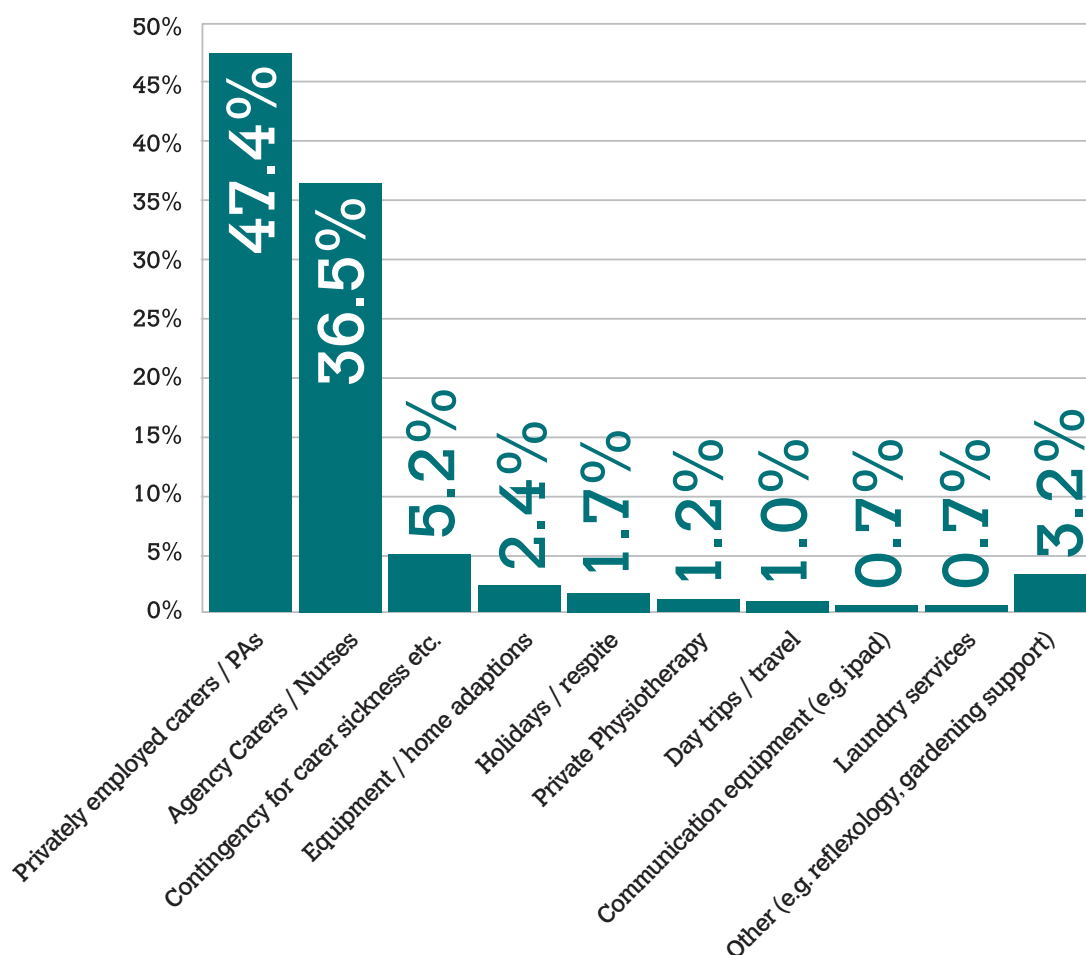
The chart below reveals the distribution of planned PHB spend among Somerset's CHC pilot cohort. The relatively high level of demand on care agency services from PHB holders may be a characteristic of the pilot programme only. Unless agency care becomes more flexible, CHC PHB holders are likely to opt for more responsive private arrangements. Brokerage services during the pilot were purchased by the PCT and so do not feature here.

43. Budget setting guide available: [www.personalhealthbudgets.dh.gov.uk/\\_library/Resources/Personalhealthbudgets/Toolkit/HowPHBwork/SettingBudget/PHB\\_guide\\_Budget\\_setting\\_for\\_NHS\\_CHC\\_v2.pdf](http://www.personalhealthbudgets.dh.gov.uk/_library/Resources/Personalhealthbudgets/Toolkit/HowPHBwork/SettingBudget/PHB_guide_Budget_setting_for_NHS_CHC_v2.pdf)

## 7 The case for PHBs in continuing healthcare

**Graph 7.1**

Somerset CHC pilot:  
personal health budgets – planned expenditure



The contingency reserve may seem small at 5.2%, representing 19 days-worth of budget allocation for the year. We found contingency allocations budgeted at four weeks in other areas (7.6% of total PHB). The chart also registers a comparatively small expenditure, at 1.7% in Somerset at least, on holidays and respite. These are, however, the expenses that all too often grab the headlines. As PHB leads insist, we should evaluate expenditure by the outcome, not by the thing bought. We heard of one couple (not in Somerset) who saved a years' worth of their own respite money to buy their disabled son a

summerhouse.<sup>44</sup> The building provided a space for the boy's art and music therapy; it was also a place to be quiet, a convenient shelter when outside, and a storage space for various pieces of equipment. The PCT signed off the purchase because the wellbeing benefits to the boy were clearly understood and at no extra cost to the NHS.<sup>45</sup> Indeed, efficient continuing healthcare planning has to recognise that an individual's wellbeing is directly linked to their environment: attending to the person without taking into account their living arrangements results in poorer outcomes.

44. Respite allocations can vary considerably, depending on patient's care arrangements.

45. PHB lead interview with 2020health, August 2012

## 7 The case for PHBs in continuing healthcare

### Case study 7a: PHB expenditure – brokerage services

Cheshire Centre for Independent Living (CCIL) is a not-for-profit charitable user-led organisation. It has become an invaluable third-sector resource for the personal health budget programme in Cheshire, offering:

- Information about employing staff or arranging support through a care agency
- Care planning support
- Disclosure and Barring Service (formerly CRB) checks on PAs
- Recruitment support and advice on employment law issues
- Signposting to relevant services, including staff training opportunities
- Peer support and ongoing advice
- Payroll service
- Managed bank account service
- Continuing Healthcare and general advocacy
- Learning Service (training for individual employers and their PAs)

Most of CCIL's services are provided to the PHB client free of charge, with the exception of the Payroll Service and The Managed Bank Account Service, which are funded out of the client's PHB. The PHB Support Service is currently funded jointly by Central and Eastern Cheshire PCT and Western Cheshire PCT.

**Managed bank account service: £13.97 per month.**<sup>46</sup> CCIL opens and manages the bank account on the client's behalf. The service includes the arrangement of payments for wages and invoices (as instructed by the PHB holder), reconciliation of expenditure on a monthly basis and provision of documentation for local authority / PCT audit.

**Payroll service, for up to 5 PAs: £15 per month. Each additional PA: £3 per month.**<sup>47</sup>

As a payroll provider, CCIL produces wage slips on a weekly through to monthly basis, as required. They ensure that tax and NI are correctly calculated and that statutory deductions to wages are made. As PAYE agent, they liaise with HMRC on the client's behalf; they offer guidance on statutory sick pay and maternity pay, and holiday entitlement. They submit Employer's Annual Returns online and provide P60s to employees, and P45s to those who leave the client's service.

Case Study 7a demonstrates how third sector/user-led organisations can offer comprehensive PHB administrative support at a very reasonable cost. We cannot stress enough the importance of such services to the success of the PHB in continuing healthcare. User-led organisations hold vital skills and knowledge; they are often uniquely positioned to signpost, and their not-for-profit status can bring exceptional value for money. Further, the third sector has already extensive experience around personal budgets (PBs) in social care. We highlight these issues because Local Authority funding cuts (as well as falling donations from the public) are impacting charities and many are under threat of having to downsize or close.<sup>48</sup>

It is incumbent on Local Authorities and CCGs to minimise cuts that may destabilise the PB/PHB programme. System efficiency, equitable support and access, and improved health outcomes will only be possible with reliable and durable third sector involvement.

44. Respite allocations can vary considerably, depending on patient's care arrangements.

45. PHB lead interview with 2020health, August 2012

46. Correct as of Aug 2012

47. Correct as of Aug 2012

48. <https://www.cafonline.org/media-office/press-releases/2012/0912-charities-fear-closure.aspx> Accessed Feb 2013

## 7 The case for PHBs in continuing healthcare

### 7.3 Outcomes and efficiencies in continuing healthcare PHBs

The PHB has proved itself a highly responsive mechanism within continuing healthcare, rewarding individuals with greater choice and control, and contributing to health and wellbeing outcomes that in turn reduce indirect costs.<sup>49</sup> A restricted survey also found that carers of people with PHBs (within the pilot) were generally reporting 'better quality of life and perceived health than carers of people in the control group.'<sup>50</sup> Moreover, packages of care are more cost efficient under the PHB system as clients turn from care agency provision to cheaper (yet more flexible) private staffing arrangements.

The evaluation noted that some were frustrated by 'restrictions on what the budget could be used for, lack of services and budgets being too small for their needs'. Though it is recognised that the PHB will not be a perfect fit for all, these problems may possibly be attributed to an emergent system that has necessarily been testing out a variety of structures and procedures. Noted earlier, learning from the pilot tells us that inflexible arrangements around PHBs generally lead to inferior outcomes. The dissemination of best practice should therefore serve to reduce client frustrations.

Part of the PHB's strength, emphasised to us in our interviews, is the bridge it provides across social care and health care. From its very introduction, direct-payment PHBs allowed the option of social care PAs transferring seamlessly across into NHS continuing care. The PHB can also finance basic healthcare training to be given to such PAs, where necessary. Traditional NHS arrangements, however, usually force the effective redundancy of a social care PA on client transferral into CHC. Such disruption can place great emotional strain on the cared-for individual and be detrimental to their health outcomes.

To illustrate some of the potential outcomes and efficiencies of the PHB we present two case studies. Case Study 7b demonstrates how the PHB has enabled efficiency and continuity across social care and health care, while highlighting both patient and family outcomes. Case Study 7c summarises Norfolk's continuing healthcare pilot programme and includes comparative service-use data.

#### Case Study 7b: Stafford – from social care into NHS continuing healthcare<sup>51</sup>

##### Under social care

Patient C is a 16 year old boy with multiple health issues including cerebral palsy, epilepsy and curvature of the spine; he is gastrostomy fed and experiences nocturnal choking episodes. He is cared for at home and attends school during the week.

The previous package of care consisted of two PAs employed through Social Care (on direct payments) during the day; Patient C's parents covered at night, while other family members contributed time where possible. However, the boy's mother has MS and her own health condition was gradually deteriorating.

When Patient C was assessed as eligible for NHS continuing healthcare, there was a threat of Direct Payment support being withdrawn as it was felt that PAs were performing health tasks that should not have been funded by Social Care.

##### The case for the PHB

It was important for the patient and his family to have continuity of carers. Patient C has no verbal communication and it takes a substantial amount of time for carers to learn what gestures and noises mean. The existing PAs had worked with the patient extensively and knew how to best care for him and what activities he enjoyed. The PAs had developed a good relationship with the family also and knew other people closely involved, for example at Patient C's school.

The personal health budget allowed Patient C to receive this continuity of care. Ensuring NHS standards, the PAs received accredited training for some of the health tasks that they had previously been performing under social care. The PHB also allowed the parents to have increased control over the package with flexibility to adapt to 'normal' family life as required.

Family life appears more settled, although Patient C's mother, due to her progressive health condition, requires additional support in her own right. Having a flexible PHB package is allowing her to pursue this. It is also giving the family time to look to Patient C's future needs as he is of an age for consideration of transition to adult services.

49. For pilot data see PHBE report, November 2012; p.93–94

50. PHBE report, November 2012; p.12

51. Abridged version of case study supplied to 2020health by Staffordshire Joint Commissioning Unit, November 2012.



## 7 The case for PHBs in continuing healthcare

### Case study 7c: Norfolk continuing healthcare PHB

Norfolk, one of the in-depth evaluation sites, ran their PHB pilot programme with CHC and three long-term condition groups (MS, mental health and COPD). The CHC cohort comprised 28 people, and data around their usage of NHS services during the year prior to the pilot was collected.

Norfolk tested out one of the most straightforward budget-setting systems, based partly on a 5% reduction of traditional care agency costs for the region, since direct payment PHBs would not be covering agency overheads. A few individuals, some of whom had previously self-funded their care, felt the final budget did not provide the level of care they wanted.<sup>52</sup>

All CHC users obtained up-front cost-efficiencies through their PHB, although some saw their condition deteriorate during the year and had to renegotiate more expensive care packages. Some of the savings derived from unused contingency reserves; patients were allowed to carry over up to £2,000 contingency to the following year, while anything above that figure was reclaimed.<sup>53</sup>

At the end of the pilot year, Norfolk found that for CHC users the PHB system had resulted in 116 fewer primary care contacts and eight fewer hospital contacts (see table 7c.1 below).

**Table 7c.1.** Data representing activity of 28 patients on Norfolk's continuing health care PHB pilot. Number of contacts with services for year before PHB, and year after.

GP Contact	Pre-Budget	Post-Budget	Reductions
GP at Practice	36	30	6
GP at home	28	18	10
GP on phone	28	11	17
Practice / DN	132	45	87
Allied Health <sup>54</sup>	1	5	-4
<b>Hospital</b>			
Outpatients	40	34	6
Inpatients	7	5	2

In traditional arrangements, doctors are often called upon to help CHC patients at weekends (or weekdays out of hours), in circumstances where conventional care has broken down and agencies are shut. The PHB gives the patient (or their representative) the

control and power to tackle such problems without calling for GP or district nurse assistance. This is where many of the saved hours of clinicians' time have been realised.

52. These findings are consistent with the evaluation across PHB sites generally. See Fifth Interim Report: 'Personal Health Budgets: Experiences and outcomes for budget holders at nine months,' June 2012.

53. Accurate according to pilot programme. The contingency allocations have since been reduced, due to review of patient experience. Source: email contact with NHS Norfolk CHC.

54. Such as speech and language therapy

## 7 The case for PHBs in continuing healthcare

### 7.4 Sustainability of PHBs in continuing healthcare

The Department of Health claim that ‘if half of the people eligible for NHS Continuing Healthcare chose to take the offer of a budget, this could imply a potential saving of around £90 million.<sup>55</sup> The estimate thus relates to a CHC cohort of some 28,000 individuals with PHBs (equating, crudely, to an average saving of £3,200 per PHB client). Given such high uptake and the efficiencies of the PHB system, this potential saving does not at first appear unrealistic. The PHB efficiencies in continuing healthcare relate to cheaper (yet more effective) care packages and reduced indirect costs. With 90% confidence the evaluators stated that indirect costs of continuing healthcare PHB clients fell by an average of £4,040 on the pilot programme.<sup>56</sup>

In terms of programme viability, the evaluation did not factor in start-up costs, nor did it measure the ‘transaction’ costs of PHBs in comparison to the control group (that is, costs involved in commissioning and arranging services, such as staff time in supporting the care planning process).<sup>57</sup> And owing to the infancy of the PHB programme there are additional financial unknowns to consider (beyond those cited by the evaluators), the most conspicuous of which are the PHB holder’s staffing costs relating to:

- Maternity benefit
- Long-term sick leave
- Redundancy packages

Whilst sick pay is being factored into PHB contingency funds, this is effectively short term costing; the CHC PHB programme has not yet identified the true costs deriving from long-term sickness, nor true costs around maternity benefits. And at present, PHB contingency money does not cover redundancy. A statutory redundancy payment (e.g. resulting from a patient’s relocation or death) would generally only apply if the personal assistant(s) had worked for that employer for at least two years. Added to this are the ramifications of any unfair dismissal and the employment tribunals that may follow. The application of personal budgets in social care has begun to throw up some of these issues, but the cost-implications of redundancy on the PHB system have barely been felt.

Related to this issue is the potential insolvency of third party organisations, which themselves may be employing staff on behalf of multiple individuals. The likelihood of such an event and its cost implications can be only vaguely speculated.

Another unknown is the extent of new costs to the NHS as previous self-funders apply for direct payments. This was one of the principal miscalculations of the Dutch system, although the impact of such activity on the NHS within CHC itself will be nothing like as great due to the much smaller number of eligible individuals (see also Section 5.1).

Additional problems deriving from budgetary mismanagement (or even fraud) were examined in Section 5.3, and naturally have a bearing on cost efficiency in CHC.

The Department of Health are mindful of the above concerns and yet appear confident that, long-term, CHC PHBs will maintain economic efficiency as compared with traditional service provision. To summarise, these efficiencies derive from cheaper, though more effective, packages of care (especially with the absence of agency overheads),<sup>58</sup> decreased activity around high-cost institutionalised care and, further down the track, released savings from reduced primary care contacts and hospital admissions (that is, CHC PHBs playing a part within the wider QIPP or PHB programme – CHC numbers are otherwise too small on their own to reduce service infrastructure in any given region). Other cost-saving aspects of the PHB system were presented to us by two CHC specialist sites,<sup>59</sup> who noted that a large proportion of their users underspent their allocated budget due to unused contingency reserves or not taking up services previously budgeted into their care plan.

55. <http://www.dh.gov.uk/health/2012/11/phb/> (Accessed 21.01.13)

56. That is, there is a 10% probability that this result was produced by chance (see PHBE report, November 2012, p.94 for data).

57. PHBE report, November 2012; p.80-81; p.150

58. The Centre of Welfare Reform reported in 2011 that five pilot sites implementing PHBs in CHC were seeing average savings of 20% on existing care packages. See: Centre of Welfare Reform, 2011. Health Efficiencies: The possible impact of personalisation in healthcare

59. Norfolk and Somerset

## 7 The case for PHBs in continuing healthcare

### Risk in perspective

PHB leads and other advocates were keen to point out to us that serious budgetary mismanagement is rare. The system is embryonic, of course, but CHC clients are generally demonstrating responsibility and even caution in using their PHBs; regular monitoring and review is an essential lever in this respect (see also Section 5.3). The issue of unfair dismissal has raised its head in the social care personal budgets programme,<sup>60</sup> emphasising the importance of promoting employer/employee responsibility and fairness by ensuring that both the budget holder and PA(s) fully grasp their respective responsibilities under employment law.

The implications of maternity benefits and long-term sickness of PAs, along with redundancy pay-outs on the death of PHB holders, are very real and difficult to predict. Redundancy costs especially, since amounts awarded on redundancy relate to the PAs' length of service to a specific client. We know that those costs are inevitable and may in some cases be substantial.

Employer's liability insurance is already a statutory element of PHB planning. But such is the variability of risk in the system, some smaller CCGs may want to consider entering into risk-sharing partnership through CCG Federations (probably depending on the size of their PHB cohort). Alternatively CCGs might want to consider factoring in redundancy within the client's PHB contingency fund. This means increasing the contingency budget and allowing roll-over, year on year, to keep track of potential staff redundancy costs. This mechanism would allow CCGs to monitor PHB efficiency more closely. CCGs could otherwise consider the creation of a CHC sinking fund with reclaimed PHB monies and contingency reserves, so to help protect against the financial burden of long-term sickness and redundancy within the entire CHC cohort.

### Recommendations (exclusive or combined) – reducing the variability of risk in CHC:

- CCGs should consider factoring staff redundancy costs into individuals' PHB contingency reserves. This needs to be a roll-over linked fund, thus corresponding to the redundancy costs of a PHB holder's staff in any given year. The CCG may reduce the fund (as appropriate) if personal assistants leave the client's service.
- With excess contingency and reclaimed (unused) PHB monies CCGs could create a sinking fund for their full CHC cohort. The funds would help finance redundancy packages on the death of PHB clients.
- CCGs should consider creating CCG-Federation risk-sharing strategies to cover CHC redundancy packages and possible third-party insolvency in the PHB system.
- CCGs' arrangements with third party organisations need to recognise and prepare for the financial impact of possible insolvency.

60. See for example CommunityCare article: [www.communitycare.co.uk/articles/06/06/2011/116947/the-employment-rights-of-personal-assistants.htm](http://www.communitycare.co.uk/articles/06/06/2011/116947/the-employment-rights-of-personal-assistants.htm) (Accessed February 2013)

## 7 The case for PHBs in continuing healthcare

### 7.5 Moving forward

CCGs do not have the luxury of a 'wait and see' approach to CHC personal health budgets. Despite remaining questions and uncertainties, CCGs are expected to be fully up and running with available PHBs in NHS continuing healthcare by April 2014. The Government insists that by that time anyone eligible for NHS CHC should have the right to ask for a PHB. NHS England will hold CCGs to account for undertaking their statutory duties.

*'The pilot evaluation demonstrated that applying tight restrictions on PHBs is generally counterproductive.'*

In terms of best practice, the pilot evaluation demonstrated that applying tight restrictions on PHBs is generally counterproductive. Unless patients are empowered with real choice and control, we cannot expect improved outcomes and the corollary of reduced service use. Accordingly, the Department of Health states, 'The person with the personal health budget (or their representative) will:

- **Be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a healthcare professional**
- **Know how much money they have for their health care and support**
- **Be enabled to create their own care plan, with support if they want it**
- **Be able to choose how their budget is held and managed, including the right to ask for a direct payment**
- **Be able to spend the money in ways and at times that make sense to them, as agreed in their plan'**

These, then, are the core foundations of the personal health budget. Beyond our cited learning from the Dutch experience, described in Section 5.1, we should highlight some other immediate essentials relating to the PHB roll-out strategy in continuing healthcare.

**Support Networks.** Peer support networks are an essential resource for the personal health budget programme, as is coordinated third sector involvement, particularly at a local level. These stakeholders can help shape and develop the framework, besides supporting it on an ongoing basis. It is critical that such support is in place before roll out.

National peer support is being championed by People Hub,<sup>61</sup> a Personal Health Budget Network that seeks to provide reassurance and encouragement by sharing learning, best practice and inspiring stories. (The Department of Health has also set up a Learning Network for healthcare professionals.<sup>62</sup>) Regional peer networks need establishing also, as these can additionally spread knowledge and experience of local resources. And as CCGs implement the necessary administrative mechanisms for PHBs, they should at the same time begin coordinating Third Sector involvement beyond the brokerage level, bringing local expertise on board to support NHS care navigators and combat potential health inequalities. Faith-based organisations may be able to supply further layers of support, without charge.

The setting up of such networks, as People Hub confirmed to us, can take considerable time, not least as some conditions in CHC are very rare and require different types of support. Support networks should therefore become an immediate priority for all CCGs in preparation for CHC roll out.<sup>63</sup>

*'A local peer network creates a space where issues can be raised and debated alongside key decision makers. It creates an opportunity to hear what's working well and what could be done differently, as personal health budgets are rolled out more widely.'*

**DH, March 2013**

61. <http://www.peoplehub.org.uk>

62. <http://www.personalhealthbudgets.dh.gov.uk/Login/?pageID=1719&referer=%2FLearningNetwork>

63. Brewis, R et al. 'Personal health budgets Guide: Implementing effective care planning.' DH 2012.

## 7 The case for PHBs in continuing healthcare

**Needs assessment and drawing on social capital.** The needs assessment is the starting point of determining what level of support an individual requires. It is important that this process acknowledges social capital; the NHS may simply not need to fund every aspect of an individual's care arrangements. This is not to deny any individual's requisite care free at the point of need. But family members often want to provide care and support without payment, so this is a discussion that needs to happen. In one case we heard of a youngster in Norfolk who was assessed eligible for 24–7 care, but received just four hours per day, because the family wanted to provide the other hours of care themselves, unpaid.

**Indicative budget.** As noted above, even after a three-year pilot, a definitive indicative budget-setting model for continuing healthcare does not exist. A standardised model/tool, flexible enough to take account of local costs, would greatly assist CCGs new to the personal health budget system and also encourage consistency and fairness across regions and localities.

**Monitoring and evaluation.** Close monitoring and ongoing evaluation – activities that were lacking in the Dutch system (see Section 5.1) – are of vital importance to each CCG. This emphasises the strategy of gradual roll-out, prioritising those who will benefit most from a PHB. Monitoring and evaluation encompasses health and wellbeing outcomes and expenditure, but also patient risk. The use of risk-enablement panels, however, should be reserved for cases where there are complex risks facing vulnerable people. The panel should not be used where clinical team members agree that risks to the PHB holder are minimal.

**Recommendation:**

**CCGs need to prioritise the creation of local Peer Support Networks and ensure coordinated third sector involvement before PHB roll out.**

**This activity takes time and CCGs now have less than a year to make PHBs available to all those eligible for NHS continuing care. Work must begin immediately.**

### 7.6 Conclusion

We have identified both efficiencies and important unknowns in continuing healthcare PHBs, and there is clearly an evolving strategy for roll out – various important aspects of the system have not as yet become protocols. CCGs need to first undertake work on the ground to ensure that a robust and supportive infrastructure is in place before roll out; this includes work around support networks, perhaps requiring a CCG Federation initiative if CHC numbers are low. They may then want to consider prioritising those with the greatest needs; we would alternatively encourage CCGs to simply prioritise those who will benefit most from a PHB. The workload is manageable: the comparative rarity of CHC individuals means that initial applicants in any given CCG region will appear in their 10s at most, never in their 100s. Many CCGs will preside over areas that have no more than 200 CHC patients in total, and not all are going to want to take up the option of a PHB.

There are many excellent care agencies that provide an invaluable service to our communities. These will always be in demand. But what the PHB can offer is alternative care arrangements where agency provision lacks suitable flexibility or consistency, or is indeed hopelessly inadequate. Some (arguably many) families are frustrated by agency bureaucracy and the fact they have no choice as to who comes into their home – week in, week out, year after year. The personal health budget allows clients and their families full choice and control over their care arrangements, and at what appears to be lower cost to the NHS. Since those eligible for CHC are some of the most vulnerable and disadvantaged people in our society, it is surely right that CCGs prioritise the mandate to make available the option of personal health budgets to all eligible for continuing healthcare.

## 8 The case for PHBs in mental health

*PHBs are important tools for recovery. They give greater control to individuals and allow them to go beyond statutory services... the very approach embeds the three core components of recovery: hope, control and opportunity.*

**Royal College of Psychiatrists, December 2012**

Over one third of all pilot sites tested out personal health budgets in mental health, which itself proved one of the clearest achievements of the PHB pilot. Success can be attributed to the buy-in of mental health teams to the PHB programme, previous experience around personal budgets in social care, and most importantly the empowering impact of PHBs on the mental health of service users, who were thereby able to take control of their care, identify outcomes and choose tailored pathways.

The PHB and its associated care/support plan deliver holistic advantages that have enormous benefit to mental health. Both the Royal College of Psychiatrists, quoted above, and the Centre for Mental Health have stated that the PHB mechanism ‘embeds the three core components of recovery – hope, control and opportunity’.<sup>64</sup> The pilot evaluators stated that within the mental health sub-group, PHBs demonstrated higher care-related quality of life (ASCOT) benefits than conventional services (at the 90% confidence level). The evaluation also registered, most tellingly, a marked reduction of service utilisation by PHB holders:

*In the mental health cohort, individuals’ indirect costs (mainly inpatient costs) were reduced by a significantly greater amount in the personal health budget group than in the control group.*<sup>65</sup>

The PHB, at the first instance, represents a flexible pathway for those patients whose conventional care packages are proving ineffective. At the same time, clinicians involved in the PHB pilot have had to come to terms with a shift away from the old medical, prescriptive ‘expert to patient model’ to one more holistic and outcomes-focused. Care planning and partnership working with patients are vital, and these in themselves have enormous benefits to mental health. Indeed, such practice should be business as usual, PHB or not.

### 8.1 The process: referral to uptake

Currently, clinicians (such as a Community Psychiatric Nurse or GP) decide whether a mental health services user may benefit from a personal health budget. As noted previously, the service user needs to understand at the outset the full implications of the PHB – its intended function, the care/support-planning process, the methods of delivery and their own responsibilities – to make an informed decision as to whether to opt in.

The process of needs assessment, indicative budget setting and support planning follows that described in Section 3. In support planning and deciding how to spend the budget, individuals are encouraged to think about what they want to achieve – the emphasis is on outcomes, not the management of symptoms. For many, the most important outcome is the avoidance of acute care, since repeated hospitalisation often has a profoundly negative effect on mental health. The PHB applicant is under no pressure to complete their support plan in a given period: this is done at their convenience and meanwhile conventional NHS care is ongoing.

The support plan, with its identified services and equipment, is assessed and signed off by a clinician or clinical team and, perhaps for more complex cases, a risk enablement panel at the CCG. The PHB applicant normally has the choice to receive the budget in one of three ways (again, see Section 3 for more details):

- **Notional budget:** where the money is held by the CCG
- **Third party arrangement:** where the budget is held and controlled by an organisation or trust
- **Direct payment:** where the patient (or their representative) holds the budgets and arranges all expenditure

We discuss alternative payment options in Section 5.3.2, but at this current time, these three described (or a combination thereof) are the most common approaches.

Notional budgets can be somewhat restrictive in terms of non-traditional interventions, although they become more flexible if handled through a Community Interest Company (see Section 5.3.2).

64. Centre for Mental Health: Recovery, Personalisation and Personal Budgets, September 2012.

65. At 1% significance level (99% confidence level). PHBE report, November 2012; p. 125

## 8 The case for PHBs in mental health

Direct payment PHBs, which are accompanied by legally-binding contracts, require users to supply bank statements and receipts to the CCG regularly. PHB holders should be monitored two to three times throughout the year to ensure that money is being spent as agreed and that they are making progress towards their health outcomes. This process allows clinicians to recalibrate the support plan and budget, if necessary, according to decreased or increased health needs. Advice may be given and changes made if the purchased services and/or equipment do not appear to be benefitting the patient.

**Budget setting-methods across sites were not uniform. Some took into account historical usage of services and/or current level of need to estimate a cost for the year ahead; one site we spoke to was setting budgets according to the individual's identified outcomes (e.g. in mental health, reduce drug dependency; stop self-harming; prevent build-up of muscular pain, become more independent), thus estimating the costs involved in achieving those outcomes.**

**Moving forward, personal health budgets in mental health will be linked to Payments by Results cluster tariffs, of which there are 21 categories. Exactly how this will work, particularly bearing in mind the increasingly outcomes-focused nature of MH personal health budgets, remains to be seen.**

### Recommendation:

**Those Mental health patients who do not want a PHB (or who are not deemed suitable for one) should still benefit from increased personalisation and flexible arrangements, including self-directed support.<sup>66</sup> At the minimum, care planning should be embedded for all mental health service users.**

### Recommendation:

**Risk panels should not be used where clinical team members agree that risks to the PHB holder are minimal. Administration costs will otherwise be significantly increased unnecessarily.**

### 8.2 How are MH patients using their budgets?

Mental health patients throughout the pilot made many straightforward purchases of counselling, psychotherapy and other traditional services. But individuals were also encouraged to think about alternative services and equipment that might better help them achieve wellbeing goals and health outcomes. Some tried new interventions such as reflexology or hypnotherapy, in place of conventional talking therapy, to help alleviate stress. Others chose even more holistic approaches. During our interviews we heard from PHB leads how non-traditional purchasing and 'out-of-the-box thinking' at times created tensions and obstacles with finance departments, since never in its history had the NHS bought patients business courses, summer houses, vacuum cleaners and vehicle repairs. 'How, at a time of austerity, can we justify this?' was a common question.

The table on the next page itemises some of the unconventional services and equipment bought by mental health patients with personal health budgets; it also lists various associated outcomes, as identified by patients themselves. These are by no means isolated examples.

66. For more on self-directed support, see 'TLAP Choosing Recovery: Towards personalisation in mental health. Available: [http://www.thinklocalactpersonal.org.uk/\\_library/HSCP/MH\\_SDS\\_Choosing\\_Recovery\\_-\\_Final.pdf](http://www.thinklocalactpersonal.org.uk/_library/HSCP/MH_SDS_Choosing_Recovery_-_Final.pdf)

## 8 The case for PHBs in mental health

**Table 8.i.** Mental health: non-traditional interventions and intended outcomes

Non-traditional services bought		Outcomes
<b>IT equipment</b>	Laptop / printer Dragon DSA (voice recognition software)  PDA 'tablet' organiser  Electronic reader  Sat Nav	<ul style="list-style-type: none"> <li>Take some online courses and increase my education for future job prospects</li> <li>Equipment to support me to pass my college course</li> <li>A laptop that I can talk to instead of type so I can engage with training/learning activities</li> <li>To help me keep in touch with others, organise my diary and access information</li> <li>Because I am dyslexic, reading anything is very stressful; with a reader I won't need to ask anyone else to help me</li> <li>To feel in control, competent, useful and maintain my independence</li> </ul>
<b>Education</b>	Self-confidence courses  College Course	<ul style="list-style-type: none"> <li>To feel safe and confident when on my own so my wife will not have to be 24/7 carer, and improve my ability to engage in social activities</li> <li>Long term goal to be in employment and financially independent</li> <li>To work and become a part of society again, long term aim – to live on my own independent from my family</li> </ul>
<b>Equipment for physical needs</b>	Kitchen equipment: food processor, kettle tipper, iRobot Vacuum cleaner. Mattress and pillow	<ul style="list-style-type: none"> <li>I will keep my home in a clean, orderly state – this has a positive impact on my mood, which will lead to a reduction in self harming</li> <li>To help me sleep</li> </ul>
<b>Exercise</b>	Shiatsu sessions Gym membership Personal trainer Equipment/clothing for exercise Swimming	<ul style="list-style-type: none"> <li>Weight reduction, control or reverse Diabetes type 2 diagnosis</li> <li>Increase healthy lifestyle, improve self-esteem, gain confidence, reduce stress and anxiety</li> <li>Increase strength and reduce pain</li> <li>Learn to swim</li> </ul>
<b>Hobby</b>	Art materials	<ul style="list-style-type: none"> <li>A distraction when disturbed by voices in head</li> </ul>
<b>Body Image</b>	Laser hair removal Botox for reducing sweating	<ul style="list-style-type: none"> <li>I will have a sense of self-worth, improved self-esteem and will be washing, cleaning teeth, wearing clean clothes on a regular basis</li> </ul>
<b>Other support</b>	Vehicle repair costs Costs towards clothing  Therapy SAD light  Bath installation Massage chair Summerhouse Conversion of outhouse into play room + storage units	<ul style="list-style-type: none"> <li>Reduce isolation</li> <li>I will feel comfortable and confident about my appearance, which increases my self-esteem and motivation</li> <li>To help alleviate the effects of depression caused by low light levels in the winter</li> <li>To alleviate chronic back pain, reduce/manage stress, improve relaxation</li> <li>Provide my own space, maintain and improve relationships with my family, reduce admissions</li> </ul>



## 8 The case for PHBs in mental health

Table 8.1 reveals some common ground with social care and this indeed may seem curious. To highlight the first entry in IT equipment, the purchase of a laptop and printer would not be unusual under social care, in order to facilitate employment prospects for someone with a learning disability, for example. But it was approved and signed off under the PHB system since needs and outcomes were clearly identified within the context of the benefits to mental health, as can be seen in Case Study 8a.

Some may baulk at a several of these cited examples. And this wide-ranging list indeed begs the question: how will the NHS achieve consistency across areas? What is signed off in one location may well be rejected in another.

But we return to the challenge to consider not the thing bought, but the outcome achieved. The Centre for Welfare Reform, in a 2011 report, cited the case of a lady who was regularly distressed by voices in her head. She was making frequent visits to A&E, sometimes several a week, calling on the ambulance service and being discharged (usually after some quiet time and a cup of tea) with a taxi home. In one year her costs to the NHS approached £200,000. The lady was given a £2,000 personal budget to purchase art materials – she was a talented artist and felt that this would help preoccupy her when distressed. Subsequently her visits to A&E were dramatically reduced.<sup>67</sup>

With such examples we can begin to understand how the PHB evaluators were able to identify significant reductions of inpatient costs within the mental health cohort (see sub section 8.4). It is also worth repeating that where PHBs were most flexible, it generally followed that they were most effective, both in terms of patient well-being and cost-efficiency.

This flexibility includes increased access to conventional mental health services. Counselling and psychotherapy under the traditional NHS system is typically restricted to a few sessions during ‘office’ hours; under the PHB system these can be open-ended and delivered out of hours, if necessary. In this arrangement the patient might have to forgo other NHS services, so as not to increase upfront costs. But hence patient choice and control: the PHB is responsive and non-prescriptive and is intended to help people get on with their lives.

*‘If anyone asked what [the PHB] did for me I’d say it gave me my life back; honest, it has changed me completely’*

**Mental health patient**

### Recommendation:

**More work is needed around peer learning networks, on both a regional and national level, to increase PHB support and information in mental health. This will help decrease problems of inequality and variability across the system.**

### Recommendation:

**CCGs and clinician validators need to recognise that rigid control over what is permissible under a PHB can be counterproductive.**

### 8.3 Measurable outcomes

*‘The outcomes are not based on the medical outcomes that we’ve always looked at, they’re much more based on real life outcomes, being able to do something rather than hitting a target.’*

#### GP PHB lead

The improved wellbeing of mental health patients, evidenced in part by their decreased use of primary care and acute services, derives from a range of factors. Partnership working between clinicians and patients has given patients themselves greater ownership of their condition and an increased sense of responsibility. Care-planning has been a reality check for some individuals, a process that has brought under the spotlight the true nature of their condition while providing the opportunity for realistic goal-setting. The process has likewise shifted the clinicians’ perspective towards a more holistic view of the patient. And the PHB itself, affording control, choice and flexibility, has empowered patients and given them confidence to identify and achieve health outcomes.

67. Alakeson, V. Duffy, S (2011). ‘Health Efficiencies: The possible impact of personalisation in healthcare.’ Centre of Welfare Reform

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Northampton, one of the in-depth sites specialising in mental health, collated the following list of measurable health outcomes in April 2012. These are outcomes that their MH patients with PHBs were at the time either making progress towards or achieving:

- An increase in their independence and their confidence, they feel much more in control
- An increase in social interaction and social activities of many different types
- Improvement in mood, reduction of stress/anxiety and a change in behaviour, which has enabled increased contact with family, children and friends
- Being able to give much more support to others
- An increased understanding of their condition/disease and how and why it is impacting on their life
- Improvements in general physical health including losing weight, learning to swim, attending a gym regularly
- A reduction or ceasing of self-harming
- Studying for new qualifications, gaining or returning to employment both paid and unpaid/voluntary work; development of a back to work plan
- Reduction of, or stopping, medication
- Managing crisis/exacerbations of condition/disease, recognising triggers and managing symptoms, keeping safe
- Reduction in the need for and use of acute and primary care services

### Case study 8a

Claire lives in Northamptonshire and has been using mental health services for four years. She applied for her PHB while living with her parents and has since moved into sheltered accommodation. Last year Claire had nine contacts with the crisis resolution team and 67 inpatient stays.

Measurable outcomes from Claire's PHB plan:

- To reduce support required from the Community Mental Health Team
- To reduce hospital admissions
- To reduce self-harming behaviour
- To reduce reliance on medication
- Decrease in impulsive behaviour and improvement in coping skills
- Improve socialisation, less reliance on family and increase in independence

Claire used her personal health budget to buy a laptop and fund a college course in animal welfare. The course itself has given Claire increased confidence:

*At first I was really nervous [going to college] and staff came with me to settle me in; but now I get a taxi in the morning and a bus back. That was something I could never do before, the thought of a bus just freaked me out, but now every Wednesday I get a bus back.*

Claire's admissions at the local mental health inpatient centre fell dramatically under the PHB programme, although at the time of interview she confessed she was struggling with her medication.

*I have not been in the Welland Centre... for eight months now, which is the longest I've ever done. I have self-harmed a couple of times but nowhere as many as I used to... Every month I have tried to celebrate, it sounds really stupid but it's such an achievement for me not to be back in.*

Claire's increased wellbeing has resulted in reduced hours of clinical support. It has also enriched her relationship with her family:

*We are going on holiday in a couple of weeks and this is something we couldn't really do before... They [my family] have said 2009 was probably the worst year, 2010 wasn't as bad, 2011 was better but now in 2012 they just can't believe it.*

## 8 The case for PHBs in mental health

### 8.4 Sustainability of PHBs in mental health

A financial analysis of the pilot mental health cohort according to the ASCOT scale found that the ‘average net benefit was £4880 greater for people in the personal health budget group compared to people in the control group’ (90% confidence level).<sup>68</sup> Currently, however, block contracting is obstructing cost efficiency in mental health PHBs. Double running costs are inevitable until commissioning practice itself becomes more supportive of personalisation.

Southampton’s alcohol misuse PHB programme, described in sub-section 8.5, offers an example of service reconfiguration in the light of personal health budgets. Moving beyond block-contracting, even amid the PCT to CCG upheaval, has been possible with supportive buy-in and efficient partnership working.

It is hoped that the ‘clustering’ strategy of mental health Payment by Results (PbR) will in time force the reconfiguration of block contracts, if not terminate them entirely.<sup>69</sup> The detail remains unclear. There is also uncertainty as to how PbR will better facilitate integrated pathways with social care.<sup>70</sup>

The pilot evaluators found an average reduction in indirect costs (mainly inpatient costs) among the mental health PHB group of £3,050. This was one of the most remarkable and confidently stated findings of the pilot programme. However such cost-savings can only be properly realised upon the decommissioning of services. Until that time, reduced service use equates largely to theoretical savings.

It is also important to understand that cost-efficiencies apparent in ‘year one’ of an individual’s PHB programme will not necessarily be replicated in ‘year two’: a patient’s response to a new intervention may be short-lived. However, if the all-important rule of ‘cost-neutrality’ is applied year on year (following the decommissioning of block contracts, that is), cost-efficiencies should be maintained, since the NHS will never be spending more on an individual than it would have spent otherwise. Moreover, the power of the PHB lies in its own responsiveness to patient need and identified outcomes: care/support plans can be routinely monitored and altered, and new interventions employed as necessary.

The engagement of Mental Health Trusts is vital in the implementation and sustainability of PHBs. We were surprised to learn during our evidence review that not all PHB sites had developed this critical relationship.<sup>71</sup> And as with continuing healthcare, third sector support needs to be secured before roll-out. Closer working with social care can only increase efficiency long term, while Peer Networks (national and regional) will have an important part to play in the dissemination of information and supporting an equitable system across England.

### 8.5 Moving forward

New money is needed to get PHB programmes up and running. First-year regional start-up costs have been estimated at £93k, or around £146k over two years (assuming that ‘as personal health budgets become more mainstream...the level of resource required will be reduced’).<sup>72</sup> But the main challenge is for clinicians and CCGs to come to terms with the revolutionary partnership strategy of PHBs, which necessarily means giving away substantial control to the PHB holder.

Our interviews with commissioners confirmed that some CCGs will be reluctant to take on this risk, certainly in the immediate future. Whereas continuing healthcare has a mandate pushing the PHB agenda, there are no similar obligations around mental health. It may be that some CCGs will want to watch further developments with the ‘Going Further, Faster’ pilot sites – it is important that ongoing evaluation builds a more extensive picture of best practice within the context of Payment by Results, and tackling block-contracting is a necessary first hurdle.

It is worth emphasising the need to move forward with fresh ideas. The impact of mental illness on society is enormous: the Centre for Mental Health estimates that mental illness reduces GDP by 4.1%, or £52 billion a year. In a report published in June 2012, the London School of Economics noted that while the share of mental health in NHS expenditure is around 13%, the share of mental health in the burden of disease is 23%. Accordingly, the LSE have prevailed on the Government to increase investment:

68. PHBE report, November 2012; p.104

69. National Development Team for Inclusion, December 2011. ‘Getting it together for mental health care: Payment by Results, personalisation and whole system working’

70. Clark, M, 2011. ‘Mental health care clusters and payment by results: considerations for social inclusion and recovery’

71. Together for mental wellbeing/In Control Personal Health Budgets for Mental Health Learning Set; [www.personalhealthbudgets.dh.gov.uk/\\_library/Resources/Personalhealthbudgets/2011/Personal\\_health\\_budgets\\_for\\_mental\\_health\\_learning\\_set\\_year\\_1\\_report.pdf](http://www.personalhealthbudgets.dh.gov.uk/_library/Resources/Personalhealthbudgets/2011/Personal_health_budgets_for_mental_health_learning_set_year_1_report.pdf)

72. Jones et al., PSSRU 3rd Interim Report, 2011

## 8 The case for PHBs in mental health

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*‘The need for a rethink is urgent. At present mental health care is, if anything, being cut. It should be expanded. This is a matter of fairness, to remedy a gross inequality, and it is a matter of simple economics – the net cost to the NHS would be very small.’<sup>73</sup>*

It is important that the PHB features among the menu of options in mental health, as ADASS and the Royal College of Psychiatrists have recently confirmed in their joint position statement (March 2013).<sup>74</sup> And in the light of the figures quoted above, the start-up costs of the PHB system are surely not a real barrier. The real barriers are commissioning structures and culture change. Mental health is searching for new directions, and these have to include much greater integration between health and social care, and more responsive mechanisms to personalisation. The PHB can help bring about both.

### Recommendations:

- Former pilot sites need to demonstrate PHB best practice within the context of Payment by Results before other CCGs push ahead with the programme.
- Once PHB best practice (and thus viability) has been established within the context of PbR, the Government will need to decide whether to mandate the offer of PHBs in mental health throughout England. Access will otherwise be variable across regions, and patient choice and control thus highly inconsistent.
- The strategy of integrated budgets and joint planning needs prioritising in mental health. There were few examples of joint health and social care budgeting (operated from one bank account) under the pilot programme. Joined-up planning barely exists currently. The PHB has provided a lever to stem duplication and maximise resources.

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73. The London School of Economics and Political Science, June 2012. ‘How mental health loses out in the NHS’

74. Royal College of Psychiatrists and Association of Directors of Adult Social Services. March 2013: ‘The integration of personal budgets in social care and personal health budgets in the NHS.’ Joint position statement.

## 8 The case for PHBs in mental health

### 8.6 In focus: Southampton alcohol detox PHB programme

#### The alcohol misuse PHB scheme.<sup>75</sup>

NHS Southampton was one of two sites to test out personal health budgets in alcohol detoxification. They built on their experience with the National Treatment Agency's system change pilot (2009–11), through which they had devised a Resource Allocation System (RAS) to enable substance misusers to use personal budgets to access support and community-based activities.

Specific to alcohol misuse, the Southampton PHB programme has employed the RAS to translate levels of need and clinical complexity into a 'score' that places individuals in one of five bands, A to E. Each band, except band A, has an associated indicative budget which can be used by the individual to select a personalised care package. Those in band A, who are not dependant drinkers, do not receive a budget as such, but are offered services such as group work, education around reducing their alcohol intake, relapse prevention and referral on to other community agencies whilst being supported by a member of the Community Alcohol Team.

Using notional budgets, higher banded individuals (B to E) have a choice of different providers, with options of both residential and community-based day services. They may also purchase supporting services, such as transport or a facility to kennel their dog while undergoing detox. Users of the PHB detox programme are able to suggest alternative services to those provided if these are deemed affordable and clinically appropriate.

#### What has changed?

Following the introduction of the PHB system, block-contracting has been decommissioned. Now there is choice and flexibility: at this current time there are nine providers (as far afield as London and Somerset) competing under spot-purchasing arrangements. These providers include two that were previously block-contracted.

Most providers used by Southampton have become more flexible in response to the PHB and the personalisation agenda, changing their rules about length of stay, facilitating mixed packages of residential stay and community day detox; some previously did not provide standalone detoxes.

*'I found the detox as an inpatient and then at home a strange concept, but I have to say there was a lot of input from all staff which was very helpful. I have been dry now since the detox, still attending AA meetings.'*

**PHB client**

Flexibility has also increased around community detoxification services: individuals are now able to detox at home with domiciliary night support, something that was previously not possible under the NHS.

Other wrap-around services are helping more individuals to take the step into detox: the kennelling option, noted above, has been an important incentive for some who were previously disinclined to enter detox programmes because there was no-one to look after their dog.

#### And the results?

In Southampton's PHB programme more than 400 people have now had an alcohol detox. Tier-three waiting lists (for community-based treatments) are virtually non-existent; previously people could be waiting up to six months for a detox, during which time their health condition could deteriorate significantly.

People now have better value for (NHS) money. Residential stays for up to 12 days are costing less than five-day detoxes under conventional NHS inpatient arrangements. Upfront cost-efficiencies have been noted within a cohort of 106 clients, whose detox costs within the PHB programme averaged nearly £300 cheaper per person than those for traditional services. Post-detox, individuals are expected to attend relapse prevention workshops and groups, as before.

75. Information supplied by Southampton Central PCT to 2020health, October 2012 / January 2013

## 8 The case for PHBs in mental health

Influenced in part by Southampton's PHB success, **Portsmouth's Integrated Commissioning Unit** is decommissioning their block contracting in detox services. They plan to bring some 300 patients onto the **Portsmouth substance misuse personal health budget scheme**, starting from April 2013. Portsmouth hopes to continue using their old provider with services spot-purchased, as with other new providers.

The high uptake of community detox has met the needs of dependent drinkers who would have previously been overlooked by services. The PHB's strengths in terms of prevention and productivity, as well as quality, choice and responsiveness, are in clear alignment with the values of QIPP.

Comparative data around relapse, at the time of reporting, was unfortunately unavailable. Moving forward, Southampton is undertaking further work around relapse prevention through PHB funding, at the same time as looking at carer needs and support. They are also reviewing the RAS in light of alcohol PbR pilots and seeking greater integration of health and social care budgets.

### At a glance: achievements of the Southampton PHB programme

- A large rise in community detoxes
- Person-centred choice and control around their detox and support
- A growth in the market place for detox providers who can be spot purchased at competitive prices
- A decrease in costly private hospital admissions
- A growth of support agencies providing wrap around support for community detox, including a new service dedicated to providing this
- A new direct pathway for people who do not have complex needs to access a fast track community detox
- A vast reduction in the tier 3 waiting list
- An increased number of detoxes at a reduced cost to the NHS, therefore linking in with the Quality Innovation Prevention Productivity (QIPP) Agenda
- A sustainable and cost effective way to continue detoxing
- Operational policy completed.

### Case study 8b:

Lynn (band D) was living in shared housing with other alcohol and drug users; she had mental health problems and occasional other drug use. She chose to go to a residential detox for 11 nights. Whilst there she worked on some of her anxieties about her living accommodation and relationship breakdowns, which she found very helpful. After detox she attended the day programme provided by the New Road Centre, changed her accommodation and was successfully discharged from treatment.

### Case study 8c:

Jen (band D) and Jack (band B) were service users of the care co-ordination drug service, both stable on opiate substitute prescriptions. Both needed an alcohol detox. They were married and had previously detoxed separately. They were able to pool their budgets so that they could have joint pickups together and support within their own home. Both chose a community detox with support and detoxed together, which they said worked really well for them. They were still abstinent three months later.

## 9 PHBs: New Horizons?

In this section we consider some applications of the PHB system that barely featured within the pilot programme, or did not feature at all. Most of these were suggested to us by PHB leads and commissioners during our interviews. We endeavour to describe the function, benefits and feasibility of these applications. As will be seen, some may be trialled without great infrastructural upheaval and with measured financial risk to CCGs.

### 9.1 Arthritis PHB

Arthritis was not included among the core long term condition disease groups of the PHB pilot programme. This is surprising considering that arthritis is a common comorbidity among the elderly and the principal cause of pain and disability in England. Osteoarthritis represents an annual cost to the NHS of around £5 billion, and in combination with rheumatoid arthritis up to three times that amount to the wider economy.<sup>76</sup>

Arthritis Research UK has explored the potential benefits of the PHB system to people living with arthritis.<sup>77</sup> In their own survey, a large majority (77%) of respondents agreed that that having a personal health budget would make them feel more in control of their condition. Most felt it would give them more choice of specific services and therapies. But while they recognised the empowering and collaborative potential of the PHB, over half of respondents were concerned that the PHB might reduce their access to traditional services.

Maintaining the stability of traditional NHS service provision in tandem with the PHB will be a common challenge across a range of conditions. Moreover, we do not want to see the PHB system dilute the efficacy of integrated care teams. Another, more specific, challenge to the implementation of PHBs for arthritis is the very nature of the condition, which can produce sudden and irregular flare ups. PHB planning for people with musculoskeletal conditions should make provision for review, and enable 'planning in the good times for the bad times' (ARUK 2012).

Recommendations made by Arthritis Research UK around PHBs for arthritis and other musculoskeletal conditions include:

- Those involved in care planning for people with arthritis should take account of the nature and impact of arthritis, in particular allowing for contingencies during exacerbations and for regular reviews.
- A range of options and/or case studies should be developed for potential PHB holders, with an explanation that these represent illustrative, but not exclusive, choices.
- The supportive role of third sector organisations needs to be properly described so that it can be harnessed appropriately and effectively.

It is also important for care coordination around arthritis to engage professional input, that of a rheumatologist or GP, who can review the care-plan and wellbeing outcomes. Both national and local Peer Networks would provide a further resource of advice and support.

Moving forward it would seem sensible to prioritise the offer of PHBs to those who have greatest potential to benefit from personalised services (see Case Study 9a), as part of the wider adoption of proactive approaches to care-planning. However there are also low-cost applications of personal health budgets that could bring enormous benefit to a range of individuals. Some of these might be focused around increasing physical activity to improve joint movement and strengthen muscles. Other applications might involve alternative approaches to pain management – hydrotherapy, massage or acupuncture, for instance – especially in cases where strong pain relief drugs are producing unwanted side effects and debilitating the patient even further. 2020health considers such forms of small-scale PHB best issued from GP surgeries (with a practice nurse as coordinator), implemented as notional budgets or through a prepaid card scheme or voucher scheme.

76. Arthritis Research UK 'Understanding Arthritis: a parliamentary guide to musculoskeletal health.' 2012

77. Arthritis Research UK 'Personal Health Budgets: perspectives from people with arthritis and other musculoskeletal conditions.' 2012

## 9 PHBs: New Horizons?

### Arthritis: Nikki's Story

Nikki has Still's disease, an aggressive form of arthritis. Whilst rare, the condition shares common ground with other forms of chronic, autoimmune disease. A flare-up can immobilise an individual, leaving them bed-ridden for days, even weeks.

During a flare-up Nikki becomes disabled within hours; she cannot move, she cannot even suck on a straw – water has to be syringed into her mouth. Her body pulses with pain. Prior to receiving a personal health budget she was regularly admitted to hospital, for up to seven weeks at a time, and treated with pain killers, including morphine. The pain killers only prolonged her symptoms.

Social services drew Nikki's doctor's attention to the personal health budget scheme. Nikki now has three carers who provide flexible cover at home. She has also secured a leisure pass and a wheelchair. Nikki is visited at the start of each day, but if she feels a flare-up developing, she can phone her carers any time.

One of the carers was a close friend, who had known Nikki since childhood. *'It's been really positive for Nikki... she knows if anything happens, she's safe and she's at home and being looked after by people that love her...which is the most important thing, I think.'*

The benefits to Nikki's general wellbeing are considerable: *'Now, I haven't been in hospital for 15 months. My flare-ups that were lasting for weeks on end... have been cut down to two or three weeks now at home.'*

Nikki's improvement has substantially reduced her contact with her GP, who confirms, *'Since the personal health budgets have come into force, I don't see Nikki very much. She used to be a very frequent visitor, or I'd see her at home, or we'd be on the telephone an awful lot.'*

*I have to say, looking at the results, it's been the perfect solution. We've broken a pattern of frequent admissions, to Nikki enjoying a very long spell of very good health.'*

Nikki concludes:

*Having a personal health budget has given me a life...one that I can take control of and actually enjoy... It's allowed a freedom that I never thought I'd ever have; I'm excited about waking up, excited about what the day's going to bring, whether that's an illness or not. I feel very fortunate to have been given this breakthrough, and I'm running with it, physically, mentally and emotionally! And I'm dealing with each day as it comes.'*

*'Having a personal health budget has given me a life... one that I can take control of and actually enjoy'*



## 9 PHBs: New Horizons?

### 9.2 Haemodialysis transport PHB

There were some isolated examples of personal health budgets being used for hospital transport within the 2009–12 pilot. In one case we noted a patient using a PHB for a wheelchair-accessible taxi in place of conventional ambulance transport; the weekly service cost was reduced from £280 to £152, a saving of £128.

For many regions the costs involved in non-emergency patient transport run to several million pounds. Transport may seem an obvious avenue to explore with the PHB system, yet only NHS Barnsley concentrated on this area, specifically around haemodialysis transport. Potential interest in the PHB was thought to be significant, as Barnsley PCT had registered a level of dissatisfaction among patients with the (then) block-contracted provider.

The process: Approximately half of Barnsley's 64 renal patients were deemed eligible for a haemodialysis transport personal health budget. Of these, ten expressed interest in the scheme and four opted in. It is thought that the paperwork involved, together with the requirement to set up a new bank account for PHB payments, was off-putting to many. However, a 13% uptake among eligible patients nevertheless represents a fairly respectable figure. While NHS Barnsley implemented the scheme, Barnsley Council administered the payments and their administration fees were costed into each client's PHB. Following the introduction of the PHB, one patient had a successful transplant and was taken off the scheme.

**The results.** In terms of cost-efficiency and convenience, the PHBs demonstrated very positive outcomes. Cost efficiencies were in fact substantial, approaching a combined £2,500 reduction on the yearly costs of £8,990 for three patients using conventional services. Participants expressed satisfaction with the service:

*'Having a Personal Health Budget has greatly improved my quality of life. Previously, after attending dialysis I could be waiting for my transport home, at times for around an hour, feeling increasingly unwell and becoming more and more stressed. However, now that I have my PHB, as soon as I have finished my treatment, my taxi is there and takes me straight home, without dropping off other patients first. As I attend dialysis three times per week, this gives me significantly more time to myself.'*

NHS Barnsley was unsure whether haemodialysis transport PHBs would prove cost-efficient for patients in remote rural regions. More work is needed.

**Unpicking block contracts / moving forward.** A number of regions, including East Midlands and North West, have abandoned block-contracts and are now commissioning services from non-emergency transport providers who offer more flexible and responsive arrangements. During the pilot programme, South Yorkshire went out to tender and three private providers secured contracts. The former provider, Yorkshire Ambulance Service, was unsuccessful in its bid, though it continues to provide emergency transport services.

NHS Barnsley considers the quality of non-emergency transport services to have improved considerably and patients are reporting much higher levels of satisfaction. This development is expected to lessen the demand for PHBs. But with the PHB system now in place for renal dialysis, the option may yet be carried forward under new CCG arrangements.

#### Streamlining the transport PHB?

If transport PHBs can demonstrate cost-efficiency against new provider contracts then CCGs may desire to streamline the system to encourage uptake. This could involve engaging a third-party fund holder (such as a Community Interest Company) to manage payments on behalf of local patients.

There is also a strong argument for using the prepaid card system (see Section 5.3.2), since many taxi firms accept card payments.

Another option is to abolish the requirement of patients setting up a separate bank account for their transport PHB. So long as the PHB holder supplies bank statements – as standard in social security applications, e.g. housing benefit – along with receipts, then sufficient accountability should be ensured.

As PHBs become business as usual in continuing healthcare, CCGs may be more inclined to offer PHBs among the menu of choices for renal dialysis transport. The flexibility of the PHB cannot be matched by conventional Patient Transport Services, although cost-efficiencies will have to be examined under the light of new contracts with NHS and private sector providers. We would not expect quite the same level of savings as realised in the Barnsley pilot against a block-contracted service, since competition is now forcing value for money.

## 9 PHBs: New Horizons?

### 9.3 Falls prevention PHB

Falls are estimated to cost the NHS and social care £2.3bn per year in relation to hip fractures alone, of which there are some 70,000 annually.<sup>81</sup> The true costs of falls are much greater. Around one in ten ambulance call-outs respond to older people who have fallen, of whom around one quarter do not need to be taken to hospital.<sup>82</sup> Others will need medical attention at A&E, though not an inpatient stay. But falls and fractures in those aged 65 and over account for more than four million bed days each year in England and injurious falls are the leading cause of accident-related mortality in older people.<sup>83</sup>

Age UK's report 'Stop Falling; start saving lives and money'<sup>84</sup> has highlighted a lack of initiatives around falls-prevention programmes. They cite some regional exemplars, such as the Greater Glasgow and Clyde Community Falls Prevention Programme and the Cambridge City Falls Exercise Pathway, but find in general that 'such services are not available to all older people at the time when they need them.' Community programmes designed by health and social care partnerships (under the auspices of a local authority) are generally focused around encouraging mobility and exercise; many more of these need to be established regionally with a range of access times. Other aspects of prevention, such as home modifications, lie in the domain of social care or the third sector (or personal, private spend). Age UK provides a free falls-prevention service, where a coordinator visits elderly people in their homes and recommends and/or implements modifications free of charge.

CCGs may want to consider the application of falls-prevention PHBs as part of their prevention and early intervention programme. It is a logical step to extend the PHB rationale to home modifications and equipment for the frail and elderly, since these interventions directly relate to health outcomes. While many such interventions have previously resided with other parties, social care especially, it is right that the NHS invests more in prevention, given the otherwise substantial costs to the healthcare system which will only increase with an aging population.

**Eligibility.** Elderly individuals eligible for a PHB to manage long term conditions should have falls-prevention factored into their care planning, if at risk. Those frail and elderly who are not debilitated by LTCs may be considered eligible for a PHB following a falls-risk assessment. The PHB should accompany a referral to a community mobility/exercise programme.

**Third-party involvement.** Trusted charities and non-profit organisations could become third-party PHB facilitators, handling expenses on behalf of individuals and providing follow-up assistance and coordination. Some might even hold PHB funds on behalf of commissioners, awarding these at discretion under the guiding principles of NHS care.

### 9.4 GP-issued PHBs

GP involvement in the PHB pilot was largely confined to referral and advocacy. A new option would be to enable GPs to issue small discretionary personal health budgets from funds held by, or immediately accessible to, the practice itself or (where they exist) larger GP Provider Organisations. The application of such PHBs could be considered where both the GP and patient agree that conventional therapies or drug treatments are proving ineffective.

The idea of GP-issued PHBs was suggested to us on three separate occasions, in interviews with two PHB leads and one commissioner. We learnt that a variation on the idea had already been tested in Gnosall, Stafford, in relation to warfarin monitoring via telehealth.<sup>85</sup>

We presented the idea of GP-issued PHBs to other regional leads and healthcare professionals and found a significant response in favour. Some PHB leads were immediately able to illustrate the potential of GP-issued PHBs with references to real-case scenarios which had come to light during the 2009–12 pilot. We present two of these below together with a hypothetical example (#3), also suggested by a PHB lead.

81. Age UK. 'Stop Falling; start saving lives and money.' 2010.

82. J.L. Newton et al., 'The Costs of Falls in the Community to the North East Ambulance Service,' *Emergency Medicine Journal*, 23: 479–81 (2006) doi:10.1136/emj.2005.028803

83. Royal College of Physicians, 2010. 'Falling standards, broken promises. Report of the national audit of falls and bone health in older people' 2010.

84. Available at [www.ageuk.org.uk/documents/en-gb/campaigns/stop\\_falling\\_report\\_web.pdf?dtrk=true](http://www.ageuk.org.uk/documents/en-gb/campaigns/stop_falling_report_web.pdf?dtrk=true)

85. For information on wider PHB work in Staffordshire, led by Dr Ian Greaves, see: <http://www.viewm.net/wp-content/uploads/2012/10/Personal-Health-Budgets-in-Staffordshire.pdf>

## 9 PHBs: New Horizons?

- Example #1: when treatments are not working.** Two patients were on pain medication at a cost of £100–£150 a month. Their pain was not greatly alleviated and they were severely debilitated by the treatment and virtually house bound. Each patient was given a £60/month PHB – additional to the drug treatment – allowing them to purchase two sessions of massage or acupuncture per month, ongoing. As a result, both individuals became much more functional: the GP was able to reduce the drug treatment for one considerably, while the other came off morphine altogether. (NB Unlike drug treatments, continuous therapy such as acupuncture or massage is not possible under conventional NHS arrangements.)
- Example #2: high impact users.** A GPs’ practice was struggling with a high-impact patient. In discussion with the lady one of the GPs discovered that she was socially isolated and very lonely. The lady was allocated a small taxi budget to get to and from a local community centre. On her first visit she found a free pick-up/drop-off service run by a member. The lady now barely visits her local surgery, and the PHB proved a one-off cost of around £15.
- Example #3: early intervention.** Currently the NHS system is not well disposed towards early intervention. GPs may be well placed for the task, but often their hands are tied. It was recommended to us that GPs should be able to allocate PHBs for early alcohol misuse intervention, in order to reach patients who have mild to moderate dependence without complex needs. A budget of up to £500 could be issued to refer individuals into community Day Detox programmes, thus bypassing the often lengthy referral and waiting times (during which the patient’s health may further deteriorate). The budget could cover a 7-day detox programme (c. £350), leaving the GP surgery money for extra support on site.

For PHBs to be directed from a GP practice or GPPO’s medical centre there needs to be on-site staff trained in basic care-planning and signposting. The practice nurse would be well placed for this role. If only a handful of PHBs are issued each week, the staffing implications could be fairly minimal.

We would recommend that where possible, GP Practices should issue budgets notionally and undertake the payment of invoices on behalf of patients. The CCG would need full oversight of all GP-issued PHBs, ensuring accountability and transparency – the CCG would after all be effectively subcontracting the work as it might to a Community Interest Company.

### 9.5 Continence pads PHBs

During our interviews several experts, including two commissioners, brought to our attention the possibility of a personal health budget for continence pads. Their collective concern around current NHS provision highlights a great disparity of product range and availability across England. The NHS Choices website acknowledges these issues:<sup>86</sup>

*‘For people with severe leakage, continence clinics and district nurses can supply pads...but they tend to be big and bulky...What’s available on the NHS varies throughout the country. Each primary care trust has its own contract to supply incontinence products and its own eligibility criteria.’*

The charity PromoCon (Promoting Continence and Product Awareness<sup>87</sup>) confirms that in many parts of England continence pads are rationed to the point where patients are effectively forced into a system of co-payment. Further, many with light incontinence are denied NHS pads altogether, even after prostate surgery, where leakage is common. Added to this, continence expertise is under threat due to NHS cutbacks. In short, the public is subject to a postcode lottery.

A PHB specific to continence pads would, for many, not solve the rationing problem, since high street or online brands are much more expensive than the products supplied by the NHS.

But where this may not prove to be the case is for high-needs individuals. Pads are often supplied to such people by the NHS in considerable bulk, and if that person’s condition changes, their pads may become useless. They are not allowed to return them to the NHS, for health and safety reasons. Some will pass these onto friends with similar needs; others may sell them on eBay. If individuals were given a budget to buy in pads according to their immediate needs, such wastage could be avoided;

86. NHS Choices: <http://www.nhs.uk/Livewell/incontinence/Pages/Incontinenceproducts.aspx> Accessed January 2013

87. PromoCon provides a national service, working as part of Disabled Living Manchester.

## 9 PHBs: New Horizons?

increased efficiency could raise allowances and perhaps even widen the range of available products. Charities may be well placed to facilitate the scheme, buying products in bulk and acting as central wholesalers. A prepaid card or voucher-code payment system would prove best suited to this arrangement, rather than a direct payment PHB.

A variation on this idea is being considered by PromoCon. For high-needs individuals especially, a voucher/prescription scheme could increase patient choice beyond the limited range of NHS products. The pads voucher would be similar to the wheelchair voucher – that is, non-means-tested – with the notional value of the NHS product used as a payment towards something more discrete, comfortable or effective, purchased on the high street or online. The scheme would need to be undertaken in cooperation with specific retailers.

The voluntary co-pay aspect of this scheme may appear controversial, though it takes note of the fact that the NHS has itself placed continence pads on the very fringe, or even outside, of services free at the point of need. But this strategy is indeed a compromise. PromoCon argues that the best solution to the wide challenges facing continence service provision – above all, staff training – is increased NHS investment. Cutbacks in this area will only increase the burden on secondary care, long term (see right).

**PromoCon is campaigning** for improved continence services and an end to the current postcode lottery. To achieve consistency across the NHS there needs to be a standardisation of continence pad allocation, sufficient and relative to specific continence problems.

More widely, PromoCon insist that cutbacks to continence services are a false economy. By reducing services and the number of trained healthcare workers in this area, the NHS loses the necessary expertise to adequately assess and deal with the root causes of incontinence – which in some cases may be as simple as addressing lifestyle issues. If the cause of incontinence is undiagnosed or misdiagnosed, the health of the individual can deteriorate (and their dependency on pads increase). This, in turn, results in many such people ending up in secondary care, and at a much greater cost to the NHS.

## 9 PHBs: New Horizons?

### 9.6 Reablement PHBs

The flexible arrangements offered through the personal health budget may well bring benefits to reablement. The reablement service, sometimes called Living Independently or rehabilitation, supports individuals following hospital discharge, or can be provided to those struggling to live independently at home. Councils identify typical eligibility where individuals:

- Are returning home after a period in hospital or residential care
- Have new physical disabilities
- Are recovering from a period of illness
- Are older and need some support to remain living at home
- Want to regain daily living skills and the confidence to live independently

The service draws together an integrated care team comprising social workers, nurses, occupational therapists, physiotherapists and other rehabilitation support staff. Normally a six-week programme, reablement begins with support planning and goal setting. Within the context of post-crisis support, this means offering the PHB option to the patient during their hospital stay. The arrangement may necessitate a patient representative and would ideally involve family members.

The NHS Confederation has recognised the potential of reablement PHBs, confirming that, ‘service users can be better supported during transition from hospital inpatient to community settings if they have personal health budgets put in place before discharge.’<sup>88</sup> Though reablement did not feature as a concern of the PHB pilot, the following case was highlighted to us by Staffordshire’s Joint Commissioning Unit.

A man registered with the Gnosall surgery outside Stafford suffered a stroke and was admitted to hospital. He had suffered strokes previously and was expected to remain in hospital for at least eight weeks. Dr Greaves, a GP at Gnosall and personal health budget advocate, arranged an early discharge after four weeks with the help of the PHB Project Manager and social care colleagues. Funds were combined to provide reablement care at the patient’s home.

The intervention freed up many excess bed days and hospital resources, whilst also enabling the man to be at home with his family, manage his own condition and reduce the risk of further illness.

The example illustrates how reablement PHBs would typically be a joint-funded undertaking; however this is simplified where reablement is run by Local Authorities with budgets that already include transferred NHS funds.

Apart from the potential savings of PHB-enabled early discharge, the PHB philosophy – that patient choice and control leads to greater sense of wellbeing – appears especially apposite to reablement, where it is important that individuals feel both supported and empowered to achieve identified outcomes. The PHB offers particular advantages (for the NHS/Local Authority included) where patients live in more rural regions, since it enables access to non-traditional support where NHS services may not be readily available.

Social care has already introduced personal budgets for older individuals following reablement to help them cope with new living conditions. The Social Care Institute for Excellence has argued that the transition between reablement and new living conditions needs ‘a much more flexible interface’.<sup>89</sup> As a responsive and versatile mechanism, a reablement PHB may help address this specific concern.

88. NHS Confederation, 2011. ‘Facing up to the challenge of Personal Health Budgets.’

89. SCIE, 2011. ‘Keeping personal budgets personal’ Available: <http://www.scie.org.uk/publications/reports/report40/files/report40.pdf>

## 10 Conclusion

PHBs undoubtedly challenge the traditional status of GPs and other clinicians, besides uprooting conventional models of healthcare delivery. The culture shift is enormous, but necessary for individuals to become sufficiently informed and empowered, as the pilot evaluators have noted:

*The extra choice and control, and its consequences, are the main reasons why personal health budgets produce greater net benefits than conventional service delivery... Choice and control can be valued for its own sake and as a means for people to secure services and support that better fits with their own needs and circumstances.<sup>90</sup>*

The various successes of the personal health budget pilot programme, together with the increasing prevalence of personal budgets (PBs) in social care, perhaps herald a new dawn for the NHS. But while PBs are high on the social services agenda, with the Government's objective to increase the proportion of service users on PBs to 70% by April 2013,<sup>91</sup> 2020health does not recommend comparable ambitions for NHS PHBs. It is right that the option of a PHB is offered widely to give healthcare service users greater choice, control and flexibility; but if CCGs are set targets for uptake then there is a danger that individuals' freedom to refuse a budget (or return to conventional services) may be compromised.

NHS England is now driving forward the Government's pledge to give people receiving NHS continuing healthcare the right to request a PHB by April 2014. CHC has been prioritised because:

1. Individuals eligible for NHS CHC are among those with the highest needs
2. The PHB enables continuity of care arrangements from social care into NHS CHC
3. Block contracts are rarely applied in CHC, therefore the dangers of double running services do not apply
4. The independent pilot evaluation has confirmed that CHC individuals generally respond very favourably to the flexibility and efficiencies of the PHB system
5. Carers (of PHB holders) are generally reporting better quality of life

6. PHBs in CHC appear to be cost efficient. Further, high-value PHBs have on balance demonstrated the greatest cost-efficiencies, and CHC budgets are typically of this kind.

Whilst much best practice has been identified for CHC, it needs greater dissemination. This includes the essentials of having in place third-sector involvement and Peer Networks before roll out. The PHB system will not attain sufficient levels of equity without this. 2020health also urges a more open discussion about the financial unknowns and variable risks to CCGs. The lack of official Department of Health comment in this regard is surprising considering the momentum for PHBs that now exists.

As the pilot evaluation demonstrated, mental health service users have responded particularly well to the PHB system in terms of health and wellbeing outcomes, and with a marked reduction of service use. The application of PHBs within the context of Payment by Results is work for the next phase, a task that needs undertaking alongside greater health and social care integration. Where block contracting is eliminated, as seen in Southampton's alcohol detox service, there is considerable scope for the PHB system.

The Department of Health hopes that CCGs will also offer PHBs to other people with long term conditions who may benefit.<sup>92</sup> The pilot evaluators were unable to make bold claims for various LTC groups, even if the results around COPD were promising. More work is now underway among the Going Further, Faster sites to bring the PHB into mainstream service provision and increase health and social care integration. Learning from these sites needs to be circulated efficiently for equal access to be realised across regions. To this end the system will demand a greater presence of GP PHB advocates, who are ideally placed to mobilise the wider deployment of PHBs.

As PHB leads and commissioners pointed out to us, the PHB has further scope in such areas as reablement, haemodialysis transport and falls prevention, and could soon be issued from GP surgeries where conventional treatments or pathways are proving ineffective.

90. PHBE report, November 2012; p.151

91. <http://www.communitycare.co.uk/articles/26/10/2012/118640/lamb-scraps-100-personal-budgets-target.htm>

92. DH: <http://www.dh.gov.uk/health/2012/11/phb/>

## 10 Conclusion

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In summary, the independent Personal Health Budget Evaluation has green-lighted the PHB for CHC and supports its introduction to mental health, but has largely invited a new stage of trialling elsewhere. Learning and best practice are now in place for the next phase. Robust monitoring and evaluation must continue to create further learning – particularly around patients with LTCs/ comorbidities – and the obstacles of block contracting need urgent attention. With personalised, responsive commissioning comes enormous potential for the PHB programme.

## Appendix: List of interviewees

The following lists those we interviewed or corresponded with for the report. The columns on the right indicate the mode of interview: P = in person, T = telephone; E = communication principally via e-mail. Some professionals voiced their thoughts on an entirely anonymous basis and are not included below.

### Department of Health/NHS/County Councils

Organisation	Name	Role	P	T	E
Department of Health	Dr Alison Austin Martin Cattermole Trudy Reynolds	Head of PHB team National PHB programme manager DH PHB policy lead	✓		
Department of Health QIPP – LTC Workstream	Jacquie White	Nat. Project Lead for LTC Year of Care Funding Model		✓	
Barnsley PCT	Rebecca Campbell	Renal Network Manager (Yorkshire and the Humber)		✓	
Birmingham South Central CCG	Dr Andrew Coward	CCG Chair		✓	
NHS Dorset/ NHS Bournemouth & Poole	Cindy Shaw-Fletcher	Deputy Director of Joint Commissioning and Partnerships		✓	
Hull City Health Care Partnership	Stuart Lane	PHB Project Manager	✓		
Eastern and Coastal Kent	Georgina Walton	Project Manager	✓		
NHS Kent and Medway	Dr Habiba Rawoof Victoria Nystrom-Marshall Dr Greg Rogers	PHB Project manager LTC Lead GP lead	✓ ✓ ✓		
NHS Midlands and East Cluster SHA	Jay Dobson	PHB Lead	✓		
NHSCC/NHSCB	Dr Johnny Marshall	Interim Partnership Development Director/Advisor		✓	
North Lincolnshire CCG	Alison Cook	Chief officer		✓	
Northamptonshire Teaching PCT	Gill Ruecroft Matthew Davies Julie Passmore	PHB Lead GP PHB Lead Programme Director of Integrated Care Partnership	✓ ✓ ✓		
NHS Norfolk	Peter Witney	PHB project manager	✓		
NHS Nottingham City	Gemma Newbery	PHB Project Manager	✓		



## Appendix: List of interviewees

### Department of Health/NHS/County Councils (continued)

Organisation	Name	Role	P	T	E
Oxfordshire CCG	Ian Bottomley	Deputy Head of Partnerships		✓	
Portsmouth CC Integrated Commissioning Unit	Barry Dickinson	Joint commissioning manager		✓	
Sandwell PCT	Dr Niti Pall	Vice chair at Health works GP commissioning consortium		✓	
NHS Somerset	Liz Little	PHB Lead/Quality Improvement Manager			✓
Southampton CCG	John Richards	Chief officer		✓	
NHS Southampton City / Solent NHS	Sandra Jerrim Mo Poultney Natalie Garwin	Project manager QIPP, Alcohol initiative PHB Alcohol Broker Alcohol Day Detoxification Service Business Administrator	✓		✓ ✓
Staffordshire Joint Commissioning Unit	Claudia Brown Matthew Oakley	Commissioning Manager (LTC) PHB Project manager		✓	
Staffordshire (Gnosall)	Dr Ian Greaves	GP PHB lead	✓		
Thanet CCG	John Neden	LTC & planned care lead		✓	

## Appendix: List of interviewees

### Professional organisations, third sector/charities and independent experts

Organisation	Name	Role	P	T	E
Arthritis UK	Laura Boothman Benjamin Ellis	Policy manager Policy advisor	✓		
Cheshire Centre for Independent Living	Anne-Marie Mason Lindsey Walton Hardy	PHB coordinator Deputy Chief Executive	✓ ✓		
Chartered Society of Physiotherapists	Clare Claridge	Professional advice service			✓
Hempsons Solicitors	Nadya Wolferstan	Partner		✓	
Peoplehub/DH	Jo Fitzgerald	Co-founder of People Hub/DH PHB board member/Mother of PHB user		✓	
Peoplehub	Rita Brewis	Co-founder of People Hub/Independent consultant		✓	
PromoCon	June Rogers	Director		✓	
Terrence Higgins Trust	Sir Nick Partridge	CEO	✓		
University of York: Centre for Health Economics	Bernard van den Berg*	Reader; commentator on Dutch PGB programme	✓		

\* speaking in an individual capacity rather than as an institution's representative.

### Steering group members

Organisation	Name	Role
2020health	Gail Beer	Consultant Director
SCIE	Dr Sarah Carr	Research Analyst
Denplan (Sponsor)	Roger Matthews	Chief Dental Officer
2020health	Jon Paxman	PHB report lead
BCS Health, The Chartered Institute for IT, Cerner Limited	Matthew Swindells	Chair (BCS Health, The Chartered Institute for IT) Senior Vice President (Cerner Limited)
	David Walden	Independent advisor

# Personal Health Budgets:

a revolution in personalisation

Gail Beer  
Jon Paxman  
Charlotte Morris  
July 2013

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## 2020health's mission: working to improve health

2020health is an independent, social enterprise think tank working to improve health through research, evaluation, campaigning and relationships.

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### 2020health research and activity includes the following workstreams:

#### Fit-for-School

To create a holistic picture of wellbeing and what children need from the early years onwards in order to thrive at school, and identify ways of enabling more children to flourish and and make the most of their education.

#### Fit-for-Work

To build on our previous work looking at the importance of work for health and health for work. Understanding how those who experience illness receive timely and appropriate support and raising the profile of how worklessness impacts on economies and society as a whole.

#### Fit-for-Later-Life

To ensure that people are ready for retirement, prepared for increasing dependency and to participate in decisions about their end-of-life. We will consider new models of provision, raise the status of caring, embed respect for ageing and ensure inclusion.

#### Forgotten Conditions

To promote awareness and insight into the management and care of people with rare or unusual health conditions. We want to ensure that they have equality in access to provision of care in the NHS.

#### Integration

To champion the implementation of integrated care, using modern technologies to empower people at scale. Finding new ways of delivering care including new commissioning models and a suitably trained workforce.

#### Innovation

To campaign for people to have access to innovation in all its forms and keep the UK at the forefront of R&D.

#### International

To share best practice across international boundaries, increase our knowledge of different models of healthcare systems and their relevance to the UK. To learn from those countries that care for people better than we do.

#### Social Care

To empower the vulnerable and elderly as well as their families and carers to make decisions based on reliable information and access to high quality care.

#### Healthcare Economy

To develop sustainable funding models, explore new settings to deliver care, utilising new technologies to deliver more efficient and effective services. Preventing ill health through personal responsibility and exploring political accountability.

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“Passionate about patient power and won't flinch from promoting their interests.”

Dr Mark Britnell, Chairman and Partner,  
Global Health Practise, KPMG

“Always striving to keep people's needs at the centre of what the NHS delivers.”

Dr Johnny Marshall, GP, Head of Policy,  
NHS Confederation

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The logo features a stylized heart shape formed by the number '2020' in a light blue color. Below this, the words 'HEALTH', 'WELLBEING', and 'RESPONSIBILITY' are stacked vertically in a bold, dark blue, sans-serif font.

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