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Personal Budgets and Health: a review of the evidence

February 2013

Dr Erica Wirrmann Gadsby

Centre for Health Services Studies, University of Kent

Disclaimer:

This research is funded by the Department of Health. The views expressed are those of the researchers and not necessarily those of the Department of Health.

Acknowledgements:

I am particularly grateful to the Personal Health Budget team at the Department of Health for allowing me to work with them for three months, and to the PRUComm team for valuable feedback on an earlier draft of this report.

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1. Introduction

The Government has committed to expanding the use of personal health budgets for health service users following the evaluation of the pilot programme which ran from 2009-2012¹. This is part of a wider 'personalisation' agenda, which has become a central theme in the reform of health and social care in England, and also features increasingly prominently in the policies of other UK governments, in addition to governments of many other developed countries around the world.

Personalisation is defined by central government as "the process by which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and the services they receive" (Cabinet Office 2007 p33). There are a number of drivers behind the desire to 'personalise' health care in England: 1) it is expected that personalisation is a route towards better integration of health and social care services, through its focus on the whole person; 2) personalisation might help to improve people's management of long term conditions through a strategic shift towards early intervention and prevention; 3) personalisation will encourage the provision of services that will allow people to be maintained at home; and 4) personalisation will improve patient experience and outcomes through promoting choice, control and flexibility.

As a concept, however, personalisation remains vague and can be defined and interpreted in a number of ways, and with different implications for service users and providers – particularly in terms of the mechanisms used to achieve a greater degree of personalisation (Dickinson et al. 2010). Some mechanisms, such as personalised care planning, are about addressing an individual's full range of needs, taking into account their health, personal, social, economic, educational, mental health, ethnic and cultural background and circumstances. They recognise that there are other issues in addition to medical needs that can impact on a person's total health and wellbeing. Other mechanisms, such as individual or personal budgets and direct payments, are concerned with extending the service-user's choice and control over how money is spent on meeting their care needs.

Personal or individual budgets are all about making the financial aspect of healthcare more explicit at the individual level. By specifying the individual's budget, and allowing the individual to decide how it should be spent, the personal budget (theoretically) offers more choice, control and flexibility to the budget holder. It also places a duty on the individual to identify and potentially source the most appropriate services, and to varying degrees, manage the budget and be accountable for how it is spent.

Direct payments are cash payments given to service users in lieu of directly provided services they have been assessed as needing. Direct payments mean that service users employ people and commission services for themselves. Personal or individual budgets may be given in the form of a direct payment, or in the form of a notional budget (where the money is retained, but spent on the individual's behalf), or a real budget held by a third party, to which the individual delegates responsibility for commissioning and purchasing the services. Individuals may alternatively decide on a combination of these options, where they might receive part of their budget as a direct payment, leaving the rest to others (e.g. the NHS team or a third party) to manage.

¹ Announced by Care and Support Minister Norman Lamb on 30th November 2012.

Other terms to describe schemes that are similar to personal budgets and direct payments include: consumer-directed care, self-directed care, cash for care, cash and counselling, individualised funding, and personalised allocations. They vary considerably, but all are based on a premise that giving individuals the control of a budget with which to purchase services allows them to tailor their care to meet their specific needs. In doing so, they can empower service users and their families by expanding their degree of choice and control over services (Alakeson 2010).

Direct payments have a long history. Their use in the UK dates back to 1997, when they were introduced for disabled people eligible for adult social care, following nearly two decades of sustained lobbying by disabled people's organisations (Glasby et al. 2009b). Following the success of pilot programmes, the Department of Health pledged to implement personal budgets across the whole of adult social care (Department of Health 2008). Personal budgets are also an international phenomenon, with many countries in Europe and North America experimenting with some form of individualised funding and greater self-directed support, particularly for long-term care (Dickinson et al. 2010).

In the UK, the concept of personal budgets for health care divides opinion. For some it is a desirable solution for giving greater control and choice to patients. Glasby et al (2009a) argue that the commitments around choice, control and patient-centred services within any recent health policy document fit exactly with the ethos and values of direct payments and personal budgets. For others, though, it is a step too far that challenges the very foundations of the NHS, and carries with it great risks (see for example British Medical Association 2010; Royal College of Nursing 2009).

In 2009, however, in the face of some opposition and scepticism (e.g., from the public service union Unison, the British Medical Association, the Royal College of General Practitioners, and the Royal College of Nursing, as well as many doctors and nurses), a 3-year pilot programme for personal health budgets began. According to then health minister Lord Darzi, "The main aim of introducing personal health budgets is to support the cultural change that is needed to create a more personalised NHS" (quoted in Royal College of Nursing 2009). In the pilot programme, a personal health budget was defined as an allocation of funding given to users to support their individual healthcare and wellbeing needs, planned and agreed between the individual or his/her representative and the local NHS team. The intention was that users could either take their personal budget as a direct payment, or – while still choosing how their needs are met and by whom – leave the NHS team (or a third party) with the responsibility to commission the services on their behalf.

At the heart of the personal health budget is the patient's care plan. Under this plan, the patient should be given help to decide their health and wellbeing goals, and to set out how the budget should best be spent. Budget holders are theoretically able to use their budget for a wide range of things to help them meet their goals including, for example, complementary therapies, personal care, and one-off items such as a computer or a wii fit. The budgets cannot be used to pay for emergency care or care normally received from a GP. Neither can they be spent on gambling, debt repayment, alcohol or tobacco, or anything unlawful. Those exclusions aside, the pilot programme tested the idea of personal health budgets broadly and openly, allowing local areas to be innovative and creative (or alternatively risk averse and restrictive).

Running alongside the 3-year pilot programme was an in-depth independent evaluation². These evaluation findings, published in November 2012, add significantly to an international body of literature that has been very weak (see section 3 below). They will also inform the subsequent roll-out of the personal health budget programme.

2. Purpose of this review

A number of other countries around the world have experimented with various forms of personal budgets, although predominantly for the purchasing of care that, in the UK, would be described as *social* rather than health care³. Programmes - and their contexts – vary enormously. There is no programme elsewhere that is directly comparable to personal health budgets in England. There is therefore no *directly relevant* evidence from which we might extrapolate. However, this paper collates evidence on those various programmes in order to examine the case for investing further in personal health budgets. It incorporates the findings of the recently published final report of the evaluation of the personal health budget pilot in England (Forder et al. 2012). This evidence is explored in order to address the following key questions:

1. Which countries have developed personal budget-type programmes, and what are their key features?
2. What evidence is there nationally and internationally about the impact of personal budgets on health and wellbeing?
3. What evidence is there to indicate potential affordability and value for money of personal budget programmes?
4. What evidence is there on the implementation of personal budgets, and what lessons can be learnt regarding implementation?

2.1 Methods

A search was made of bibliographic databases, reference lists of identified articles and reviews, and the websites of relevant organisations for information available as of August 2012. Further information was identified through informal contact with key personnel at the Department of Health, the Policy Research Unit in Commissioning and the Healthcare System, and within the Personal Health Budget (PHB) evaluation team.

The databases included Web of Knowledge, MEDLINE, the Cochrane Library, Google Scholar, the WHO library, and Health Management Information Consortium. All databases were searched from 2008⁴ until present using search terms such as personal health budgets, personal budgets, individual budgets, individualised budgets, individualised funding, cash for care, direct payment, consumer-directed care and cash and counselling.

² The evaluation was undertaken by a collaboration led by the Personal Social Services Research Unit (PSSRU) at the University of Kent. Other partners were the Social Policy Research Unit (SPRU), Imperial, and the London School of Economics. More information is available at www.phbe.ac.uk.

³ In the UK, a distinction has historically been drawn between what is health care (commissioned and largely delivered by the NHS), and what is social care (mainly commissioned by local authorities and individuals, and provided by many different sources). This distinction is much discussed, but little understood, and there are in practice many overlaps and confusions between the two.

⁴ 2008 was used as a start date for the searches to reflect the fact that this work would be building on the Health Foundation review (2010), and that the researcher's time was limited. However, where particularly useful and important evidence and other background literature from pre-2008 was identified, this was not excluded.

Whilst there is a fairly extensive theoretical literature on personal budgets and consumer-directed care, my aim in this review was to identify descriptive detail on the different schemes to examine their key features and implementation processes, as well as empirical evidence on the experiences of, and outcomes for, people using these schemes. A further aim was to identify empirical evidence regarding the impact (or potential impact) of the schemes on the healthcare system (particularly with regards to resources).

Only studies or abstracts available in English were eligible for inclusion, and the most relevant articles were selected for review. Similar to Arksey and Kemp's (2008) narrative review of cash-for-care schemes, I specifically sought evidence on:

- the eligibility criteria and permitted uses of the budget
- factors restricting the exercise of choice
- factors facilitating choice
- the outcomes of the programmes.

Some 280 articles were considered relevant to the topic area. These included nine programme evaluation reports (two of which had a randomised controlled trial-based design), and 28 reports of empirical research published in peer-reviewed journals. They also included 14 articles which offered a cross-national perspective. Articles and reports of empirical research were assessed against five quality criteria: the clarity of the research question(s); the appropriateness of the study design; the adequacy of the sampling strategy; the robustness of the data collection; and the rigour of the analysis. Data from the articles in the final review was extracted using the following fields: quality appraisal; client group / eligibility criteria; allowed uses of budget; key programme features; health outcomes; cost-effectiveness outcomes; additional information; comments; associated articles.

3. Discussion of evidence

In 2010 the Health Foundation published the report of a research scan on Personal Health Budgets (Health Foundation 2010). This scan collated more than 60 articles about personal health and social care budgets in the UK and internationally. The report provides a brief synopsis of evidence to help gauge the level of research in this field so far. The scan found that there was little high quality research available to guide policy and practice. Most of the research is descriptive rather than evaluative, and there are particular gaps around impacts on health outcomes and cost effectiveness.

In a narrative review of cash-for-care schemes, Arksey and Kemp (2008) highlight the significant methodological limitations in much of the research on this topic:

1. Many of the studies are based on research of cash payment recipients only, so that meaningful comparisons with users of traditional agency-provided services cannot be made.
2. Many of these studies suffer from potential 'selection effects', given that they involve people who have opted for such payments. Very few studies have involved random assignment of users into 'treatment' and 'control' programmes.

3. Outside of the United States, the research is dominated by qualitative studies. This needs to be complemented by more quantitative survey data to identify the impact of particular characteristics that help to make such schemes a success.
4. Whilst almost all studies have focused on the perceptions and experiences of recipients, relatively few have examined more objective measures using validated instruments.
5. Most studies are cross-sectional rather than longitudinal, limiting their ability to identify impacts of cash-for-care schemes over the longer term.

International interest in personal budgets is growing fast, and they now operate or are being tested in a number of countries. The body of literature examining social care budgets and direct payments in the UK is important and growing. There are also some useful studies coming from the US, the Netherlands and Australia.

The availability and detail of information on these programmes varies considerably. However, by drawing on a range of resources, this paper outlines programmes in eleven countries. It summarises key features of the programmes, comments on any notable implementation issues, and analyses evidence, where available, on the programmes' costs and outcomes. The list of programmes is not exhaustive; other programmes exist, but insufficient information was available to describe them here. Evaluation reports are available (in English) for programmes in four of the eleven countries described (see table 1). The report also takes into account studies in peer-reviewed journals relating to personal budget programmes in any of the eleven countries, and evidence and comments from relevant organisations (such as the Expertise Centre Independent Living, in Belgium).

None of the evaluations give us a long-term perspective on the impacts and implications of introducing personal budgets. Indeed, in most studies, the evaluations have taken place alongside the implementation of the pilot, with much data collection occurring at early stages. In most cases, implementation was slower than anticipated, with methods and processes evolving over a period of time. As a result, several of the evaluation reports included 'impact' or 'follow-up' data from participants who had either not yet received their budget, or who had only had it for a very short period of time. The impacts (and wider implications) of the initiatives were unlikely to have been fully evident.

Table 1: Evaluation designs in different programmes

Country	Programme	Evaluation
United States	Cash and counselling pilot	Randomised controlled trial (RCT)
	Florida self-directed care	Matched-comparison design
	Empowerment initiatives brokerage evaluation	Base-line and follow-up surveys with participants and programme staff (very small sample)
England	Individual budgets	RCT-based design
	In Control evaluation of personal budgets	Aggregated findings from locally implemented evaluation questionnaires with budget holders
	Personal health budgets pilot	Non-randomised comparative design using mixed methods

Canada	Individualised quality of life project	Non-comparative evaluation
Australia	New South Wales direct funding pilot	Comparative evaluation (very small sample)
	Government consumer-directed care initiative	Process evaluation, non-experimental design, some comparative data.

The following four parts of this section consider the available evidence in relation to each of the questions set out in section two. First, we look at the key features of programmes in the eleven countries included in the report, namely: England, Belgium, France, Germany, the Netherlands, Austria, the United States, Canada, Australia, Finland and Sweden.

3.1 International Programmes

The Health Foundation research scan (Health Foundation 2010) highlighted that personal budgets are implemented differently in different countries, with the degree of patient choice and control varying significantly. In addition, the contexts in which the different programmes are run differ in many ways – structurally, organisationally and culturally. A further complication lies in the fact that different countries tend to draw arbitrary lines between different categories of services – for instance, between health care and social care (e.g. in the UK and Austria). In the UK, people with ongoing healthcare needs might be eligible to receive NHS funded continuing healthcare (CHC). In other countries (e.g. US, Canada, Germany), some aspects of care covered by NHS CHC would fall within long-term care packages, often provided by long-term care insurance. In the Netherlands, the entitlement criteria for long-term care are much broader than, for instance, in the UK or Germany. These differences in the way in which different services are ‘packaged’ and financed, and differences in the way personal budget programmes are conceived, designed and implemented, make international comparisons difficult. Despite this, it is useful to compare key aspects of different programmes, such as their motivations, eligibility criteria, and scope, as well as key features associated with the ways in which individuals with budgets are supported, the extent to which they are monitored, and the ways in which the budgets are deployed.

As the Health Foundation (2010) note, most programmes aim to reduce overall costs to health and social care, although different countries have varying motivations for introducing personal budgets (see Table 2). In England, personal health budgets fit within a wider government agenda to promote choice, autonomy and personalisation of health and social care services. Most countries aim to increase the independence and freedom of choice of individuals by expanding the options available for home and community-based long-term care. In some countries (e.g. Belgium, France, Germany) there is an expectation that this will lead to reduced pressure for care homes, and therefore reduced costs. Several countries (the Netherlands, Austria, Finland) are explicitly trying to promote private sector provision, or stimulate the care service markets more generally, to drive down costs and to address limitations in the current system.

Most programmes are focused on home-care for older people and/or disabled people, and increasingly on people with long-term conditions, although eligibility and target audiences differ widely between countries (see Table 2). The eligibility criteria in the Netherlands were the broadest, and have allowed a wide range of service users access to personal budgets. However, due to budgetary restraints, this is being substantially scaled back from 2012. A number of programmes have more recently been expanded to include individuals with mental illnesses, and in the US, several programmes exist specifically for people with severe mental health conditions.

The many differences in aims and scopes of international programmes are important and limit the extent to which research findings can be generalised to other contexts. Whilst there are several comparative studies examining the similarities and differences of personal budgets in social care between selected countries (e.g. Kodner 2003; Wiener et al. 2003; Timonen et al. 2006; Glendinning et al. 2009; Glendinning 2010), there are very few similar reviews about healthcare. One exception is Alakeson's (2010) review of personal budget programmes in England, Germany, the Netherlands, and the United States. She notes that countries have tended to adopt one of two models. The first model is an 'open' model, where cash payments are allocated with few strings attached and with no accounting mechanisms. Usually, the only restriction is that individuals receiving the allowance and their relatives must ensure that adequate care is obtained. The wellbeing of the care recipient is reviewed periodically, and, if care is deemed insufficient, the cash allowance is withdrawn in favour of services provided by a home care agency. In practice, the majority of the cash allowance goes to pay informal caregivers.

The other model - the budgeted or planned model – maintains a more direct connection between a participant's needs and the goods and services purchased to meet those needs (Alakeson 2010). There are more restrictions placed on how the money can be spent (although these vary widely), and they are audited more carefully. This second model is more dominant, and incorporates a number of common processes:

1. An individual budget is calculated (through a variety of means) for an eligible person, indicating how much is available to spend.
2. Individuals, usually with a professional (a broker or care planner), identify their needs and desired outcomes through a person-centred planning process. This forms the basis for a spending plan, which must fit within the overall budget allocation.
3. The spending plan must be approved by the funding agency or a designated agent.
4. There is often choice as to how the budget is allocated – whether it is given as a direct payment to the individual; passed to a third party, to which the individual delegates responsibility for commissioning and purchasing the services; or retained by the commissioning organisation (as a 'notional' budget) to spend on the individual's behalf. In some cases, an individual may be able to opt for a combination of these payment methods.
5. Individuals must then account for any purchases made against their approved spending plan.

The programmes in the eleven countries reviewed here suggest that the differences within models (particularly in the key processes in the planned model) are as important as those between them.

Table 2 summarises the development of each of the country programmes, the primary motivations, eligibility, and the ways in which the budgets can be used. Cash for care programmes have been operating since the late 1980s, and their use in much of Europe and North America, at least for people with long-term care needs resulting from physical disability or mental illness, is well established. A further flurry of developments in the late 1990s likely reflects the difficulties faced by governments in controlling the costs of care for a growing aging population, and for ever increasing numbers of people living with long term conditions. It also likely reflects the growing push for independent living and person-centred approaches to care.

Most programmes allow budget holders to employ their own carers, or to purchase care services from a choice of providers. Different countries place different limitations on what the budget can and cannot be used for. Some countries restrict choice to a list of approved providers (as in Finland), or to specific care packages (as in France). Other countries (like Sweden, Austria, or Germany's cash payment), place very few restrictions on how the money can be spent. In some countries (like England, Australia, the Netherlands, and the US), the scope is theoretically very broad, but is restricted in practice by conditions and processes that, for example, link the spending of money to specifically identified outcomes, or lists of approved services or goods. The key features of a programme impact significantly on the level of autonomy, and degree of choice realised by individual budget holders.

Table 3 summarises some of the key programme features in each country, highlighting ways in which some of the common processes vary. As well as variations between programmes, there are frequently variations *within* programmes too, where local areas design different processes and adopt different criteria to each other. Since many features of a programme interact with each other to either enhance or limit an individual's eventual autonomy, it is difficult to categorise each programme on this basis. However, it is useful to examine the relationship between autonomy – that is, the theoretical autonomy afforded to the individual in deciding on how to meet his/her care needs; and programmatic involvement – that is, the degree to which providing or commissioning organisations are involved in 'managing' the process.

Some programmes require less in the way of programmatic involvement – for instance, where cash is given with no (or few) conditions, and where there is little in the way of financial reporting. Examples would be in Austria or Finland. The degree of autonomy afforded to the individual in these programmes can be relatively high, although the actual degree of choice would be limited in practice in particular by: the adequacy of the budget (for example where the budget setting process is not sufficiently individualised), and; the availability of services / service providers (for example in sparsely populated areas of Finland, where there are often no non-state providers). In addition, where programmes are very simple, and incorporate little or no support to budget holders, eligibility may be restricted to those who are able (and willing) to manage their own budget and purchase their own care, without support from professionals.

In other programmes where there is a little more programmatic involvement, features of the programme can act to restrict the autonomy of the budget holders. For example, in France and Belgium, individual assessments are carried out, but these are defined by professionals, and serve to check eligibility, and to determine their budget allocation based on nationally set tariffs for different categories of need. In France, budgets are allocated by direct

payment. In Belgium, individuals can have a notional budget or a direct payment, but the choice is not always theirs. In both countries, little or no support is provided, but individuals are expected to account for all expenditures. In Sweden too, there is more programmatic involvement, although the budget setting process is related to an evaluation of needs, and it is not clear whether personalised care planning plays a role. Individuals can find support from peer support groups, and can commission other organisations to take on employment responsibilities, but direct payments are the default deployment option.

Sometimes, a programme can involve considerable input from commissioners or providers, but with little resulting autonomy for the budget holder. For example, in the Australian consumer-directed care programme, individuals went through a process of personalised care planning, but the budgets calculated tended not to be closely linked to that care plan. Operational guidelines directed the use of budgets, and providers retained responsibility for holding the budget, performing the bookkeeping of the services, and for ensuring quality care was provided. Individuals had relatively more choice only when the care planning process was more personalised and goal-driven, and where individuals were either determined enough to push boundaries, or encouraged by providers to be innovative.

Other programmes also involve considerable input from commissioners or providers, but with the aim of increasing the level of autonomy afforded to the individual. For instance, England, the Netherlands, the US, Canada, and Germany (with the relatively new personal budget programme), have programmes: that link the budget setting process to a personalised care plan; that require spending plans to be authorised; and that require expenditures to be accounted for. They all incorporate various support services for budget holders (although in the Netherlands this is not automatically provided, but rather available from third party organisations), and often include a number of options for budget deployment to help ensure the suitability of the programme for a wider range of users (although in Canada, direct payments are not possible).

Whilst the theoretical level of autonomy is high in these countries, the actual degree of choice afforded to the individual is limited in practice in a variety of ways. This might be through the adequacy of the budget (particularly in the Netherlands), or through the complex processes involved in implementation. Implementation processes that might affect actual choice include: the extent to which the development of a personalised care plan is holistic, and focused on the own individual's goals; the authorisation processes for the spending plans, which might vary in their complexity, their 'remoteness' from the individual, and their willingness to accept risk, and; the detail and complexity of financial reporting procedures. This is highly dependent on the culture of local organisations (and experience and attitudes of professionals) with regards to being person-centred or risk-averse.

This analysis illustrates the broad range of programme features, and the ways in which these can impact on the resulting degree of autonomy afforded to budget holders. It is within this context that we now go on to examine the impact of these programmes on health and wellbeing.

Table 2: International programmes: programme development

Country	Programme Development	Primary motivations	Eligibility	Use
England	Individual (social care) budgets (IB) piloted 2005-07 and subsequently rolled out. Personal health budgets (PHB) piloted 2009-12, with plans for further rollout.	Part of the wider government agenda to promote choice, autonomy and personalisation of health and social care.	People with long-term care needs. Plan to have all council-funded service users and carers on personal budgets by approx 2015. PHBs piloted mainly for individuals with a range of long term conditions.	IBs usually used to purchase mainstream services, employ personal assistants (PAs) and pay for leisure activities; sometimes used for wide range of one-off purchases. PHBs used to employ PAs or purchase goods or services that contribute to health goals in personal plan. Not to pay for GP services or emergency health services.
Belgium	Personal Assistance Budget (PAB) introduced 1997 in Flanders region. Personal budget (PGB) piloted in 2008.	To extend autonomy, freedom of choice, and help prevent unnecessary care home places.	People with any major long-term restriction (disability), as long as they apply before they are 65 years old.	PAB can be used to employ a PA. PGB can be used to employ PAs and purchase services from choice of providers. At least 95% of the budget must be used for the payment of salaries.
France	Cash for care piloted in 1994-5; made national in 1997. Expanded in 2002.	Reduce burden on care homes. Increase individual's independence and autonomy.	<i>L'allocation personnalisée à l'autonomie (APA)</i> : over 60's with care needs from physical disability or mental illness.	Used to fund specific care packages, and/or to employ a PA.
Germany	Cash payments for care introduced 1995 and extended in 2008 (to include mental illness). Personal budgets piloted 2004-8, with intention to rollout stated in 2008.	Cash payments – cost saving. PBs – increase choice; increase competition; reduce nursing home admission rates; cost saving.	All people 'frequently or to a considerable extent' in need of care because of physical, psychological or mental illness or disability during their daily activities, or for a period of at least 6 months.	To purchase transport, nursing, assistance at workplace, leisure activities, therapy costs, support equipment, etc, and services provided by health insurance/care insurance, when needed regularly and on a supplementary basis. GP costs cannot be paid for.
The Netherlands	Personal budgets introduced 1996. Scope and eligibility significantly scaled back from 2012.	Address limitations in current system; stimulate market to better meet needs; promote choice and control.	People with disability, chronic illness, psychiatric problems or age-related impairments. By 2014, only those who would otherwise have to move into care or nursing home will be able to keep/apply for a budget.	To buy personal care for help with daily living; nursing care; support services (e.g. day-time activities), and short stay and respite care for short holidays/weekends. Not allowed for alternative treatments, medical treatments, or treatment by allied health professionals.
Austria	Cash payments introduced in 1993. Covers home care and institutional care, and covers whole population. All state support for home care is through cash allowances.	Promote autonomy, choice and market-driven developments	Those over 3 in need of long-term care (requiring 50+ hours of care per month), due to physical disabilities and/or mental illness. Medical assessment of need conducted.	Largely used to compensate family members for informal care.
US	Cash and counselling piloted 1998- 2002. Some states developed self-directed care for adults with serious mental health conditions. In 2012, majority of states offer consumer direction in Medicaid programs. Some allow for consumer direction in non-Medicaid elderly assistance programs and for some veterans services.	Expand options for home and community based long-term care.	Older people and people with disabilities in need of home and community-based long-term care. Some programmes support individuals with serious mental health problems.	Varies between programmes. Can employ PAs and purchase care-related services and goods. States control the range of services and equipment that can be purchased. Some programmes include purchasing of some elements of health care such as skilled nursing and long-term rehabilitative therapies. Some include clinical recovery services for people with serious mental health conditions.
Canada	1997, individualised funding pilot (IQOL) launched in Toronto. Rolled out from 2000. Similar initiatives in other provinces.	Promote home and community based living.	People with developmental disabilities in need of support.	To purchase disability-related supports. Not for costs related to medical supplies or equipment, home renovations, electronic equipment or leisure, recreation & personal/family costs.

Country	Programme Development	Primary motivations	Eligibility	Use
Australia	Individual funding first introduced 1988. Small scale projects set up in a number of states. 2010 Government pilot of consumer directed care (CDC) programme for older people.	Promote choice and control; promote more flexible and responsive services.	People with disabilities in need of support. CDC programme specifically for older people in need of support.	CDC programme: includes purchasing of personal assistance, nutrition, home help, transport and emotional support.
Finland	Home care service vouchers, introduced late 1990s. Proposal announced in 2009 to extend vouchers to all municipal health & social services.	Promote choice; stimulate private sector provision	Older people with assessed care needs. Plans to extend eligibility further.	Purchasing of care (and, post 2009, health) services from specified providers.
Sweden	Assistance allowances introduced by law 1993.	Promote choice, control, and personalisation	Those with major difficulties in daily life (needing more than 20 hours assistance per week).	No restrictions, except it cannot cover medical treatment. Generally used to employ PAs.

Table 3: International programmes: programme features

Country	Can employ family members?	Dependent on a personalised care plan?	Types of support available	Budget setting	Budget deployment	Financial reporting
England	No	Yes	Mixed: health professional (or other in-house), community, peer support.	Locally determined processes. Often use 'indicative budgets' based on best guesses, and/or previous care packages.	Notional budgets, budgets delegated to third parties, or direct payments.	Detailed financial accounting.
Belgium	Yes	Yes (set of assessment tools)	Associations of budget holders are supported and subsidised by the Flemish Fund.	Assessment by multi-disciplinary teams using needs assessment tools with parameters that correspond with nationally fixed budget levels.	Notional budgets (budgets with a drawing right) or direct payments. The choice is not always that of the individual.	Budget holders have to account for all expenditures
France	Yes (not spouse)	Yes (defined by professionals)	No formal support	Level of dependence and disposable income used to determine budget according to nationally set tariffs.	Direct payment, or paid directly to the service provider.	Use of budgets strictly controlled and users must justify expenditure.
Germany	No	Yes	Local authorities provide help with management of the budget.	Determined by a (needs-based) assessment. Equal to cost of alternative agency-directed care.	Direct payment or notional budget.	Accounting always necessary but varies according to locality. Some areas have very strict procedures; others less so.
The Netherlands	Yes (with contract)	Yes (introduced 2012)	Peer support; user-led organisations; independent brokers. A 'social insurance bank' provides free services for salary administration.	Following needs assessment, care levels are categorised; care liaison office officially determines the actual budget according to nationally fixed tariffs (based on averages). Always about 25% lower than equivalent agency-directed service costs.	Direct payment with options to outsource some aspects (e.g. salary administration), delegate in full to 3 rd party organisation, or to establish a foundation (e.g. pooling budgets to collectively engage assistants).	Budget holders must submit periodic costings of how they spent (all but a tiny percentage of) the money. Costly budget holders are assigned to use a fiscal agent.
Austria	Yes	No	No formal support.	Monthly budgets calculated based on seven levels of need for care (expressed in terms of hours).	Direct payment. Where individual is cognitively impaired, someone is appointed to manage the budget.	None
US	Sometimes	Yes	Independent professional brokers	Assessment made of number of care hours needed. Budget calculated using number of care hours and cost of care for	Cash and counselling pilot used flexible vouchers. Some states provide cash directly, others use	Budget holders must account for almost all their expenditure.

Country	Can employ family members?	Dependent on a personalised care plan?	Types of support available	Budget setting	Budget deployment	Financial reporting
				geographic area. Budget is capped to not exceed cost of agency-directed care.	fiscal intermediary to handle payments.	
Canada (IQOL)	No	Yes	Independent professional brokers; community resource facilitators; network facilitators.	Budget based on goal planning. Plans/budgets highly individualised, within a set maximum.	No direct payments. Funds managed by an agency.	Individuals submit 'purchase of service' reports, along with invoices, bi-weekly or monthly.
Australia (CDC)	No	Yes	Care professionals (providers)	Local sites developed budgeting templates. In most cases, providers set budgets to match the subsidy income paid to the provider for that client (even though subsidy funds are often pooled for standard packaged care).	No direct payments. Provider always holds the budget.	Limited responsibilities for individuals.
Finland	No	Yes	Support from municipal care planning team.	Based on needs assessment, reviewed every 6 months.	Service vouchers, given directly to the individual.	No information available.
Sweden	No	-	Individuals can outsource employment responsibilities to the municipality, a cooperative society or a private organisation. Peer support groups and cooperatives assist with various other roles.	Evaluation of needs, with individual's family situation taken into account. Budget is not means-tested.	Direct payment, unless beneficiary specifically requests that it be paid to the chosen service provider.	Budget holder sends simple monthly report of the hours of work carried out by the assistants.

3.2 Impacts on health and wellbeing

The evidence demonstrating impacts of personal budgets on health and wellbeing is weak. Most of the international evidence about this comes from the US and suggests that some improvements are possible, but the literature is far from conclusive and studies are small and open to challenge (Health Foundation 2010). A further complication is that, owing to the complexity and variety of the programmes, it is not possible to identify what were the key success factors in any reported health outcomes – for instance, whether it is managing one’s own budget that is important, or being involved in a personalised care-planning process, or having personalised support from an assistant. With these caveats in mind, key findings on health impacts are summarised below.

3.2.1 Health outcomes

There are a number of arguments in the literature that personal budget programmes will have a positive effect on health, because they incorporate various approaches that are linked to health improvement or better management of conditions. For instance, Alakeson (2007b) argues that self-direction creates the flexibility to personalise self-care; in turn, care that is more tailored to individual needs and preferences is more likely to be effective because individuals will tend to stick with it. There is various evidence that patients with chronic diseases who are more involved in their own care make better progress (Department of Health 2004). And there is good evidence to support the importance of patient engagement and care co-ordination in the management of care to older people, particularly to those living with long-term medical problems (Curry et al. 2010). Personal budgets also build upon some evidence that becoming a more effective personal manager of your condition carries benefits. Various studies have found patient activation – or having the knowledge, skills, and confidence to manage one’s health - to be related to health outcomes (e.g. Greene et al. 2012, Donald et al. 2011).

It has been suggested on the basis of such evidence, that where personal budgets support some of the common elements for improved outcomes (such as patient-centred care planning, self-care and patient activation), it is possible that personal budgets will lead to better health. However, there is no evidence, nationally or internationally, to confirm that they have done so.

Alongside these arguments, the potential for *negative* consequences regarding health outcomes is an important consideration for those introducing personal budgets. These might be anticipated for two key reasons: a) the use of a personal budget often leads to an increase in the use of non-authorized care providers; b) individuals, when given control of the budget, may choose treatment or service options that are not supported by evidence, and may choose to avoid traditionally recommended options.

The available evidence largely allays concerns about possible harms to health (although it is predominantly concerned with using personal budgets to purchase long-term personal care, such as assisting with normal daily tasks like dressing, bathing and toileting). Evaluations of consumer-directed, compared with agency-directed, home care in the US suggest largely unchanged health outcomes, despite the increased use of non-authorized care services

(Benjamin et al. 2000; Wiener et al. 2007; Alakeson 2010; Robert Johnson Wood Foundation 2006; Benjamin et al. 2007; Brown et al. 2007).

Importantly, evaluations show the same largely unchanged health outcomes for elderly and non-elderly individuals with a diagnosis of mental illness (Shen et al. 2008a; Shen et al. 2008b). By analysing data on a number of adverse events (such as falling, seeing a doctor due to cut, burn or scald, and being injured while receiving paid help), Shen et al's (2008a) study of the New Jersey cash and counselling programme concluded that the self-directed care programme had no significant effect on the safety of the individual (where the individuals are non-elderly beneficiaries with a diagnosis of mental illness). It also reported on five variables to measure health problems including 'shortness of breath developed or worsened' and 'had a respiratory infection'. Consumers in the self-directed care group experienced significantly less likelihood of reporting respiratory infection problems than those in the control group ($p < .05$). However, no significant differences were found between the treatment and control groups for any of the other four indicators. The results did, at least, indicate that self-directed care was at least as safe as agency-directed care for this patient group (Shen et al. 2008a).

Findings from the US are complemented by evaluations elsewhere – for instance, in Germany, where the effects of a consumer-directed home care programme were evaluated to find that, compared with agency care, personal budgets extend the support by independent providers, but leave health outcomes unchanged. Compared with cash payments⁵, however, the same evaluation found that personal budgets tend to improve health outcomes⁶, although at a higher financial cost (Arntz et al. 2011).

The evaluation of the personal health budget pilot in England found that the programme had no significant impact on health status⁷ or on mortality rates. This finding was further supported by the result that people in the personal health budget group did not report significant improvements in health-related quality of life (using EQ-5D) compared to those in the control group. The EQ-5D instrument aims to measure a person's quality of life in domains that are likely to be related to their underlying health status (Forder et al. 2012).

3.2.2 Wellbeing, quality of life and patient satisfaction

One of the most consistently found conclusions of personal budget evaluations and studies is that they bring positive outcomes in terms of patient satisfaction, feelings of wellbeing, and quality of life for the majority of users.

A narrative review of cash-for-care schemes found that almost all studies report that they bring positive outcomes to those who use them (Arksey et al. 2008). Evaluations of personal budget programmes in the US, the UK, and Australia have shown that service users who self-direct their home care arrangements gain control and express a higher level of satisfaction than those who receive agency-directed care (Benjamin et al. 2000; Foster et al.

⁵ In Germany, patients eligible for Long Term Care Insurance benefits can choose between two types of home care programs and nursing home care. Home care recipients can either receive cash payments or in-kind benefits, so-called agency care. However, the cash payment amounts to half the monetary value of the agency care. See section on international programs for further detail.

⁶ Health outcomes were measured using a number of proxy indicators: hours of care provided; the self-assessed ability to accomplish activities of daily life; and the self-assessed satisfaction with the current health situation.

⁷ Two clinical measures were used – a blood glucose test for the diabetes cohort, and a lung function test for the Chronic Obstructive Pulmonary Disease cohort.

2003; Wiener et al. 2003; Alakeson 2010; Carlson et al. 2007; Fisher et al. 2008; Gordon et al. 2012; Tyson et al. 2011).

There is also evidence highlighting the psychological benefits for recipients that come from having greater choice and control. These can include feeling more confident, optimistic and positive, as well as increased levels of independence and being motivated to explore new openings or opportunities in ways that might not have seemed possible before (Arksey et al. 2008). However, the introduction of greater choice in practice raises many difficult questions: Does choice lead to confusion rather than clarity? What information and support enables people to make an informed choice? How do you commission a range of services to ensure that choice is meaningful? How do health professionals feel about taking on board patients' preferences, which may not be their own? What happens if people choose badly? Who should make decisions when a person lacks the capacity to make them for themselves? (Warner et al. 2006). Answers to these questions are not always clear, but may prove to be instrumental in achieving any benefits.

In Control – a UK national social enterprise set up in 2003 by the Department of Health, several local authorities and *Mencap*⁸ – pioneered the concept of self-directed support and individual/personal budgets, and started building a series of small, local pilots in 2003. They have presented a number of evaluations that each reported important improvements in quality of life amongst those using personal budgets (Poll et al. 2006; Hatton et al. 2008; Tyson et al. 2011).

The national evaluation of the Department of Health individual (social care) budget pilots – known as the IBSEN report – was a complex study, but it presented findings from 13 local authority sites over a two year period, that were largely consistent with those found in the *In Control* evaluations (Glendinning et al. 2008). Benefits to service users with individual budgets included:

- mental health service users reported significantly higher quality of life than the comparison group;
- physically disabled adults reported receiving higher quality care and were more satisfied with the help they received;
- people with learning disabilities were more likely to feel they had control over their daily lives.

However, older people in the study reported⁹ lower psychological well-being, perhaps because they felt the processes of planning and managing their own support were burdens.

An evaluation of the US Cash and Counselling model of consumer-directed care in Arkansas, Florida and New Jersey used a treatment and control study to compare cash and counselling consumers with those who relied on *Medicaid*¹⁰ services as usual. The study found that the cash and counselling consumers were more likely to receive paid care, had

⁸ Mencap is a UK charity providing advocacy and a range of other services for people with a learning disability, their families and carers.

⁹ In the case of more vulnerable older people, proxy respondents (usually a relative) spoke on the budget-holder's behalf. In these instances, the researchers note that higher levels of anxiety appear to have been systematically attributed to the older people. It is unclear whether this is due to the concerns of the older person, or their relatives.

¹⁰ Medicaid is the largest source of funding for medical and health-related services for people with limited income in the United States. It is a means-tested program, jointly funded by the state and federal governments.

greater satisfaction with their care, and had fewer unmet needs than control group members in nearly every state and age group (Carlson et al. 2007).

While the majority of personal budget recipients in the US cash and counselling pilot project were satisfied, a substantial minority left the programme. The main reasons for people giving up were because the payment was not regarded as large enough, they had difficulty coping with being an employer, or they decided that they preferred agency services (Wiener 2007).

The recent evaluation of the community-directed care pilot for older people in Australia (Gordon et al. 2012) used (non-matched) participant and comparison groups to examine a number of process and outcome variables, and included a validated measure of wellbeing and quality of life¹¹. After a short period of operation, the programme appeared to be associated with a higher level of satisfaction with participants' various aspects of their life (such as their ability to participate in social and community activities, their ability to visit family and friends, and their perceived health and wellbeing). However, on the validated measure of wellbeing, there was no statistically significant difference between the participant group and the standard packaged care comparison group (Gordon et al. 2012).

There is a range of evidence to suggest that mental health service users can benefit from self-directed care programmes that involve using a personal budget (Alakeson 2007a). The Florida self-directed care programme provides an opportunity for individuals who have been diagnosed with severe and persistent mental illness to assess their own needs, determine how and by whom those needs should be met, and manage the funds to purchase those services. The programme includes the availability of independently brokered services from life/recovery coaches and quality advocates. The report on the effectiveness of this programme (based on an evaluation using a matched comparison design) found that participants in self-directed care made significantly less use of crisis stabilisation units and crisis support compared to non-participants and greater use of routine care and supported employment (Florida Department of Children and Families Mental Health Program Office 2007). A further study examined the data of 106 participants in the year before and the year after enrolment. It reported that, on average, participants at the end of the programme spent significantly more days in the community than before entering the programme; scored significantly higher on the Global Assessment of Functioning scale¹²; and were more likely to be in education and training (Cook et al. 2008). A similar pre and post study of the Empowerment Initiatives Brokerage in Oregon for adults with mental health, substance misuse and homelessness problems, showed an 80% increase in the number of participants in employment after the first year, and an 83% increase in the number of participants in education and training (Sullivan 2006). This research reflects a general finding that self-direction promotes prevention and early intervention by providing greater access to support services rather than intervening following an acute episode (Alakeson 2007b).

¹¹ The study used a five-item tool (the ICECAP-O tool) to derive a single measure of wellbeing. This tool provides a broader measure of wellbeing and quality of life than other validated tools available, which generally focus on health-related quality of life or health outcomes and which may not have been designed specifically for older people. Further information is available at www.icecap.bham.ac.uk

¹² The Global Assessment of Functioning Scale is a widely used rating scale for evaluating the overall social, occupational and psychological functioning of adults.

The overall success of personal budget initiatives in terms of improving individuals' satisfaction with their care, and aspects of their quality of life, is established in international research. The evaluation of the personal health budget pilot in England (Forder et al. 2012) indicates that these outcomes can also be achieved when extending self-direction into healthcare. The evaluation found that, after accounting for confounding factors, there were significant positive effects of using personal health budgets on social care-related quality of life (measured using ASCOT) and psychological wellbeing (measured using GHQ12). An interim evaluation report (Davidson et al. 2012) discussed qualitative data from respondents at the early stages of managing a personal health budget. This data indicates that some budget holders appreciated having greater choice and flexibility in their health care arrangements. A few people said that, after receiving a personal health budget, they had more motivation to do more for themselves to increase their wellbeing. For other people, the main impact had variously been: improved confidence; improved social life; access to goods and services not available on the NHS that they would otherwise have been unable to afford or had previously been paying for privately; and the opportunity to use alternative therapies (Davidson et al. 2012).

The same interim report, however, does present a complicated picture – partly because the interviewees were in the early stages of managing their own budget (and in some cases were yet to receive their budget allocation). Some of the interviewees had mixed feelings about whether the budget had allowed them increased control, choice and flexibility. Others had their choices curtailed by panel decisions, the lack of services in their area, the lack of control over their budget (where budgets were managed by a third party), and the low level of their budget. According to the report, “Just under a fifth of interviewees said that they did not think that the personal health budget had had any impact at all on their quality of life” (Davidson et al. 2012, p11). It was clear that benefits were not universally felt.

The evaluation (Forder et al. 2012) found important evidence that the impact of personal health budgets depends greatly on the way in which the programme is implemented. It analysed outcome changes within five different ‘implementation models’¹³ described in the report. In sites where personal health budgets were being implemented following the basic principles underlying the initiative (that is, there is some degree of flexibility in what services can be purchased, and there is choice in deployment options as to how the budget holder would like the resource to be managed), there was a statistically significant positive impact on social care-related quality of life, although no impact on health-related quality of life. However, in sites where there was relatively little flexibility built into the personal health budget process, the evaluation found that personal health budgets had a negative impact – that is, the change in health-related quality of life (EQ5-D), psychological well being (GHQ12) and subjective well-being was significantly *lower* among budget holders in such sites than for people in the control group.

When examining outcomes, it is interesting to consider the types of services / goods that individuals choose to purchase with their personal budget, and how they differ from traditional packages. This is important because we might be able to make various hypothetical predictions about outcomes, based on the care that is purchased. For instance,

¹³ The distinction between these models was not clear in the report. Models 1 and 2 contained the most flexible approaches; model 4 contained a similar degree of flexibility, but did not make the budget known to individuals before support planning; model 3 represented the least flexible (although the budget was known to individuals at the support planning stage); and model 5 was a combination of models 1 and 2.

if individuals use their budget to purchase leisure activities, complimentary therapies, or other 'wellbeing' related services, we might expect their feelings of satisfaction and sense of wellbeing (but not necessarily their health) to improve. If individuals have similar services to before, but have more control over where and when those services take place, we might expect some improvement in quality of life (but again, not necessarily their health). Unfortunately, information on how individuals spent their budgets is only rarely available, and where it is available, it is not in sufficient detail to allow comparisons with standard packages of care. Consequently, we are not able to draw any conclusions regarding these hypothetical predictions.

In the Australian consumer-directed care pilot evaluation, participants with the personal budget chose similar types of supports as those available under standard packaged care, and generally used their package for 'core services'. They exercised choice and control over how the services were delivered, including choice of support worker, and being flexible in delivery days/times and tasks undertaken by support workers. Some participants also used part of their package funds for innovative and non-traditional supports, though provider attitudes to requests for supports that were different from the 'usual menu' of services varied. The examples of 'creative and innovative' uses of package funds given in the evaluation report (p.62) include ideas of modifications that decrease the individual's reliance on a personal assistant (for instance, one person bought a shower stool and arranged for bathroom modifications to enable her to shower independently; one participant purchased a light-weight vacuum cleaner so he could clean his flat himself) (Gordon et al. 2012). These are quite modest in comparison with some of the more 'creative' purchases made by English personal health budgets.

In the English Individual (social care) Budget pilot, the evaluation showed that many with individual budgets had purchased mainstream services (59% of people (169) for whom information was available) (Glendinning et al. 2008). This was sometimes because they felt the amount of the budget was inadequate to cover any support over and above their personal care. Others felt they had fought hard for the services they were already receiving, and did not want to let these go. Some people were hesitant or anxious about spending their budget on new services or different patterns of support. However, as in the Australian pilot, the budgets allowed people to exercise greater choice and control, even in the use of mainstream services. Individual budgets were also used to pay for leisure activities by 37% (105) of people for whom information was available, and short holidays (by 22%, 62 people), as well as for a range of other, one-off purchases (Glendinning et al. 2008).

In the US Cash and Counselling pilot, for any state or age group except Florida's children and younger adults with developmental disabilities, about 80 to 90 per cent of those receiving a budget used part or all of it to hire workers. Most consumers (58 to 78%) hired family members. Only a few consumers in any state (2 to 10%) said they used their allowance to modify their homes, and only about one per cent used it to modify a car. The proportion using the allowance to purchase equipment or supplies varied widely across states and age groups, being especially high in Arkansas, and very low for elderly consumers in Florida and New Jersey. Sizeable proportions (30-60%) of each age group in each state opted to take some of their allowance in cash for incidental purposes (these amounts were limited by the states to 10 or 20% of the allowance). Unfortunately, there is no further information on what individuals purchased with their budget, or how their packages compared to traditionally-provided packages (Brown et al. 2007).

In the evaluation of the English personal health budget pilot programme (Forder et al. 2012), it was found that, whilst budget amounts varied hugely (mean £10,402; max £378,524), over half (53%) of the 1171 budgets allocated were worth less than £1000 per year, and more than three quarters (77%) were worth less than £5000 per year. It is unlikely that this amount would have covered many elements of a complex care package. Indeed, in many cases, it might have simply represented a small additional resource on top of what was being conventionally provided. The types of goods and services purchased with the budgets were categorised as:

- a) social care service-related – for example, home care, day care, meal services;
- b) well-being-related services – for example, complementary therapies, leisure and equipment;
- c) therapy and nursing services – for example, nurse and physiotherapy visits; and
- d) other health services – for example, dentistry or specialist continuing health care services.

The overall patterns of expenditure showed that the majority of the money was spent on social care-related services, although spending patterns varied depending on the health condition of the budget holder. Budget holders were found to have changed the mix of services they secured with their budget (although these changes were relatively modest). In particular, significant increases were found in the use of well-being services and other health services such as specialised continuing healthcare. It seems that in many cases, additional resources were provided that enabled individuals to pay for extra services or one-off goods. It is perhaps unsurprising, therefore, that overall improvements were found in wellbeing amongst budget holders.

3.2.3 Better integration of care

A substantial proportion of people with long-term conditions experience co- or multi-morbidity. A particularly common form of multi-morbidity is the existence of mental health problems such as anxiety or depression, or neurological problems such as dementia, alongside physical health problems such as diabetes, arthritis or cardiovascular disease. Co-morbidities are also common between physical long-term conditions (Goodwin et al. 2010).

The impact of multi-morbidity is profound and multi-faceted. Individuals with more than one chronic condition have poorer quality of life, poorer clinical outcomes, are more likely to suffer from depression, have longer hospital stays and more post-operative complications, and are more costly to health services (Fortin et al. 2007; Smith et al. 2012).

Evidence suggests that a patient-centred approach that addresses a person's various needs in an integrated way leads to better quality care. For example, collaborative care models that integrate mental health and primary care lead to better depression outcomes for people with medical co-morbidities (Narasimhan et al. 2008). Research shows that self-management approaches are important to people with multiple morbidities, with evidence indicating that willingness to learn such approaches is higher among people with multiple conditions than among those with a single condition (Noel et al. 2007). In particular, people with multiple conditions express the need for approaches that enable them to manage their medications, cope with stress, manage pain, and change their diet and lifestyle (Noel et al. 2005).

In interviews with individuals receiving a personal health budget during the English pilot programme, it was common for people to report a number of improvements to their health and wellbeing, not just improvements to the specific health condition for which the budget had been allocated to them. It was also not unusual for people who had been given the personal health budget for a mental health condition to report improvements in their physical health, and vice versa (Davidson et al. 2012). This suggests that where personal budgets enable healthcare users with long-term conditions or multi-morbidities to address their needs in an integrated way, there is some potential for improved health outcomes and quality of life. At the moment, the suggestion that personal budgets might lead to a better integration of services is theoretical rather than evidence-based. What is clear, however, is that when piloted, personal health budgets were generally not well co-ordinated with social care personal budgets. Only a minority of those budget holders with both types of budget were able to manage them through a single bank account. Moreover, there were instances of considerable confusion about what could be funded from each budget (Forder et al. 2012).

Overall, evidence indicates that personal budgets do nothing to affect short-term health outcomes of individual budget holders, but can often improve social-care related quality of life, feelings of wellbeing, and service-user satisfaction. This can also have considerable knock-on benefits for informal carers of those individuals (Tyson et al. 2011; Glendinning et al. 2008; Forder et al. 2012). The next section explores evidence on cost-effectiveness, to examine the value-for-money of personal budget programmes, and issues affecting their overall affordability.

3.3 Affordability and value for money

Personal health budgets are emerging at a time when the costs of healthcare are increasing, and the pressures on health services are growing, fuelled by ageing populations and the rise in long-term conditions. Personal budget schemes across the world have often been supported by the belief that they could be an effective means of curbing or even driving down the costs of health and social care by delegating the control of budgets to the end user, and by enabling a reduction in the use of expensive residential or acute care.

The Health Foundation research scan (Health Foundation 2010) concluded that it is difficult to evaluate the cost or value for money of personal budgets given the paucity of outcomes, information and accurate costings available. Though some studies have found reductions in health service use and resource costs, analysts suggest that many studies do not accurately cost comparison groups or fully account for implementation costs (Health Foundation 2010).

There is some evidence to suggest that individuals with a personal budget may spend less on their care than those receiving agency-directed services. For instance, in the Netherlands, the value of the personal budget is 25% lower than the equivalent costs of care in kind, on the grounds that there will be fewer overheads. On top of this, each year around 10-15% of budget holders repay some of their annual allocation (White 2011). However, whilst the personal budget programme is popular, there is no evaluation to examine whether budget holders are getting a comparable level of care from the reduced levels of funding; or indeed whether some of the costs are being displaced to elsewhere in the system.

In England, a study (Leadbeater et al. 2008) comparing costs of care packages before and after a personal budget (for social care) in ten local authorities estimated that personal

budgets cost about ten per cent less than comparable traditional services. However, this investigation did not account for the wider costs of starting up and delivering the personal budgets (Carr et al. 2009).

The evaluation of the individual (social care) budgets pilot in England presented complex cost-effectiveness analyses, although the complications of drawing definitive conclusions from the findings are pointed out by the authors. Across all user groups combined, the authors conclude that there is some evidence that individual budgets are more cost-effective in achieving overall social care outcomes (Glendinning et al. 2008). However, there is virtually no reliable evidence on long-term cost implications for individual budget schemes in the UK or elsewhere (Carr et al. 2009).

The final report of the English personal health budget pilot evaluation also presented complex analyses of costs and cost-effectiveness (Forder et al. 2012). Overall, both the personal health budget and control groups showed increased total cost averages between baseline and follow-up, although the rate of increase was lower for the personal health budget group (£800 per person per year, as compared to £1920 increase for the control group). However, there was a high degree of variation of each participant's costs around these mean values, so the differences were not statistically significant.

The task of calculating cost effectiveness was extremely complex, and made even more difficult by the different processes that sites were using to determine a) the value of the budget, and b) what services were covered by the budget. In addition, most budgets were too small in value to be substituting for conventional care packages, and many were likely to be additional money given to budget holders. Changes in direct and indirect costs were extremely difficult to calculate, since people in the personal health budget group used a mix of both conventional services and those funded from their budgets.

The evaluation team estimated the net monetary benefit of personal health budgets by converting observed changes in the quality of life scales into monetary values. Using changes in the ASCOT scale (measuring social care-related quality of life) and the EQ-5D scale (measuring health-related quality of life), the personal health budget group showed higher net monetary benefits than the control group, but these were not statistically significant at the 5% level. Subgroup analyses showed stronger and more significant effects in some instances: for continuing health care patients and patients in the mental health cohort; where personal health budgets were implemented in accordance with the principles set out (that is, with a high degree of user flexibility and choice); or where budgets were larger (over £1000 per year). However, these cost-effectiveness calculations do not take into account any cost implications of using personal health budgets that fall outside the health and social care system, such as family-incurred costs, and they do not include the set-up costs for personal health budgets, or the 'transaction' costs incurred in commissioning and arranging services (Forder et al. 2012). There is no evidence, therefore, to prove that personal health budgets are cost-effective when compared to conventional service delivery.

In the US, cost analyses of the Cash and Counselling programmes found that overall, *Medicaid* personal care costs were higher under Cash and Counselling than under the traditional agency model, mostly because enrollees received more of the care they were authorised to receive. However, these increased *Medicaid* personal care costs were partially

offset by savings in institutional and other long-term care costs brought about by the Cash and Counselling scheme. In addition, analysts concluded that Cash and Counselling need not cost more than traditional services if states carefully design and monitor their programmes (Robert Johnson Wood Foundation 2006).

The Florida self-directed care programme for people with serious mental illness was not allocated additional funds to operate the programme. However, it was found not to be cost-neutral, as the department spends more, on average, to serve personal budget holders than the average cost to serve adults with serious mental illnesses in the traditional community mental health system (Office of Program Policy Analysis and Government Accountability 2010). It is not known whether this extra cost is recouped later through sufficiently reduced use of other services.

In all programmes, decisions will have been made regarding how to handle additional costs arising from planning, administering and coordinating a personal budget programme. The English personal health budget pilot evaluation team indicated that set-up costs of introducing personal health budgets will vary considerably. Pilot sites reported an average implementation cost of £93,280 for the first year (range between £35,000 and £175,750). It was consistently reported that the project board would be required for two years in order to effectively introduce personal health budgets – this would be at an estimated average cost of £146,040 per site (Jones et al. 2011). Other ongoing transaction and administration costs were not investigated.

In Australia, there is evidence that at least some of those costs associated with programme set up and administration were passed on to budget holders, leaving a reduced portion of the budget to be spent on care services and goods. Whilst the amount of money spent on administration and care planning and management varied, it amounted to a considerable proportion of an individual's package¹⁴. However, the Australian programme evaluation generated no robust and consistent data with which to compare levels of support accessed by personal budget holders with levels of support accessed by standard packaged care participants (Gordon et al. 2012).

In all countries, cost-effectiveness analyses over the short-term are weak in their ability to draw conclusions and comparisons; over the long-term, they are non-existent. This has led to much speculation about whether personal budgets might cause costs to spiral out of control, or conversely whether they might save money across the system as a whole.

One economic argument in favour of introducing personal health budgets suggests that the competitive pressure brought in by giving patients a greater degree of choice will act as a driver for efficiency; health care providers will raise their game to attract business. A review of the theoretical and empirical evidence on choice in health care concludes that whilst there is neither strong theoretical nor empirical support for competition, there are cases where competition has improved outcomes (Propper et al. 2006). In the Netherlands, the anticipated stimulation of the market, and improvements in quality expected from the introduction of the personal budget programme, have failed to materialise (White 2011). In Sweden, meanwhile, some studies suggest that the personal budget scheme has reduced

¹⁴ Costs for administration accounted for between 12 and 17% of a consumer-directed care package, on average. Care planning and management accounted for a further 8-14% of the total.

costs overall since the production of personal assistance costs less in the competitive market that has developed, than it did in the public sector (Expertise Centre Independent Living 2010).

Alakeson (2007b) argues that self-direction in the US has been found to promote a more preventative approach to care by providing greater access to support services. This is associated with a shift away from costly, acute interventions. The evaluation of the personal health budget pilot in England found (in the short term) a reduction in the use of hospital care by the personal health budget groups compared to the control group (Forder et al. 2012). Evaluation of the Florida programme of personal budgets for people with serious mental illness indicated that individuals with personal budgets are more likely to make use of routine and early intervention services that support their ongoing recovery and less use of crisis services, compared to a matched sample of individuals without personal budgets (Florida Department of Children and Families Mental Health Program Office 2007). In the cash and counselling pilot in Arkansas, the cost of other Medicaid services, primarily nursing home and other types of long-term care, were around 20 per cent lower for those directing their own services than for the control group over a three year period (Dale et al. 2006)

Important differences in the way health and social care in England are funded make experiences of personal budgets difficult to compare. One important difference is that health care is not means-tested, and is considered to be based on need, rather than ability to pay (with the exception of charges for prescriptions, optical and dental services). Personal health budgets therefore must be sufficient to meet in full the cost of services identified in an individual's care plan as being necessary. The current policy does not permit individuals to top-up their personal health budget out of their own private resources. Social care funding, however, is dependent on individuals' contributions, and individual budgets can be topped up.

Health care funding is also partly complex because of the way many services are traditionally purchased, through block contracts, which might be costly or take time to deconstruct.¹⁵ But it is also complex due to the unpredictability of patients' health care needs. In health care, funds can rarely be easily re-allocated, because patients cannot be denied subsequent health care (e.g. GP visits or hospital admissions) on the basis that they have had a personal budget. It is important to bear in mind that where patients spend their personal health budget *and* continue to draw on NHS services, costs will increase.

An additional complication lies in the fact that whilst it might be possible to carve money out of commissioning budgets for secondary care, this will only represent a cost saving if secondary care capacity can subsequently be reduced. This is notoriously difficult in the NHS, where 'freed-up' capacity is rapidly used by other patients in the system. It becomes, therefore, a politically delicate issue to take that capacity away entirely. Currently, there is no evidence to suggest that personal budgets will significantly reduce demands on primary or secondary health care.

Concerns regarding the future affordability of personal budget schemes have been heightened in part by experiences in the Netherlands, where the popularity of the PGB

¹⁵ Ninety per cent of funding for community services and two-thirds of funding for mental health services is provided under block contracts (Monitor 2010 <http://www.monitor-nhsft.gov.uk/monitors-new-role/regulating-prices-nhs-funded-care/pricing-now-and-the-future>).

scheme, and the consequences of the 'woodwork effect' (where people whose needs were not being met by traditional services find solutions in personal budgets), led to uncontrolled cost increases. A radical overhaul of the programme was required to make it affordable, substantially restricting both access to the scheme, and the scope of what the budget covers (White 2011). In the Netherlands, as elsewhere, it is difficult to predict whether the money they have invested will pay itself back in fewer problems later on. In Belgium too, individuals 'came out of the woodwork' following the introduction of the personal assistance budget, when they saw an unexpected rise in demand for support as new requests were made by non-institutionalised physically disabled people who previously made few calls on public services. Here, though, the government prevented this turning into a budgetary crisis by limiting the number of new budgets approved each year. This in turn has limited the impact of the programme, and created a long waiting list of people hoping to become budget holders in the future (Waterplas et al. 2005).

There are also concerns that overall costs might increase where personal budget programmes are flexible enough to allow individuals to use their budget where they might previously have paid for something themselves (for instance, alternative or complementary therapies), or which might previously have been provided informally. In Germany, cash payments for individuals were seen as an effective cost-saving measure, since they amounted to only around half the value of the formal services. However, when personal budgets were introduced as an alternative to cash payments or agency care, personal budget holders were granted the full monetary value of agency care as a cash benefit. Arntz et al have highlighted that the use of personal budgets at the more generous level is leading to a 'crowding out' of informal care by formal care. They conclude that long-term care spending is likely to increase in the short to medium run following the roll-out of personal budgets in Germany (Arntz et al. 2011; 2010).

In the UK, the evaluation of the personal health budget pilot (Davidson et al. 2012) shows a great deal of confusion about what personal health budgets can and cannot be spent on. Overall, it was more common for people to (plan to) use the personal health budget to buy new, additional services or items, or to fund items they were previously purchasing privately, than to buy alternatives to existing NHS care. One of the most commonly mentioned uses of a budget was for alternative and complementary therapies. Budgets were also used to buy a range of non-health care items, such as computers and other communication devices, or items to facilitate social activities and hobbies. Whilst the use of such goods and services might lead to improved wellbeing and quality of life, there is no evidence to suggest that those individuals benefiting from them will subsequently require fewer health services or resources as a result. In the pilot sites, costs associated with shifting resources into complementary therapies or non-health care items were manageable. However, this issue would require important consideration before any wider roll out.

Overall, whilst personal budget programmes have been piloted without incurring considerable expense, there is little evidence to suggest whether (and to what degree) they are cost-effective in the long term. Moreover, there are some important concerns around longer term implications and their future sustainability.

3.4 Implementation issues

The implementation of personal budget programmes has proved to be complex and challenging in any setting, because they require substantial change across a large number of existing service systems. In the UK, the individual (social care) budget evaluation reported widespread implementation difficulties, and new stresses were faced by budget holders, their families, staff and agencies as they adapted to new procedures (Glendinning et al. 2008). Carr and Robbins (2009), in their overview of international research on the implementation of individual budgets in adult social care, found the introduction and implementation of individual funding to be complex and challenging, and programmes took time to become embedded in their local service system.

Various states within the US have managed individual funding programmes for over three decades; the implementation of new programmes, however, remains challenging. The evaluation of the cash and counselling programme highlighted numerous implementation and programme design issues that needed improvement (Brown et al. 2007).

The implementation of the personal health budget pilot programme in England also faced many challenges, and it did not fit comfortably within existing ways of working (Jones et al. 2010). An important finding from the evaluation of the pilot is that the effectiveness (and cost-effectiveness) of the programme depends fundamentally on the way it is implemented. Those sites implementing personal health budgets according to a model that incorporated flexibility in what help can be purchased and variation in the degree of deployment choice, had a significant positive impact on wellbeing and social care-related quality of life. However, those sites implementing a model with less flexibility, no deployment choice, and a budget setting process that was not necessarily personalised, tended to show *negative* effects (Forder et al. 2012).

Within the eleven countries discussed in this paper, the take up of personal budgets has been slow in England, Belgium, Germany, and Finland. This likely reflects challenges in implementation as well as a lack of interest/demand from service users. In Belgium, the slow take up has been deliberate as the number of new budget holders is strictly controlled to ensure costs are contained. In England, the US, Australia and Sweden, there was considerable local variation in the ways programmes were implemented, which impacted on the experiences of and outcomes for budget holders. In England, major challenges were faced in changing the attitudes and working practices of care managers and other staff. Developing the budget setting processes and 'freeing up' the funding required for budgets were also key issues.

In some countries, notably the US, Canada, Finland and Sweden, programmes did not always solve the problem of shortages of workers, and indeed, were sometimes hindered by personnel shortages. In the US and Sweden, some budget holders were left unable to find care workers to hire. In the Netherlands, it was found that the programme did not stimulate the market as anticipated, and there are longer term concerns that the programme is driving down the wages of service providers, impacting on the nature and quality of provision.

In England (individual social care budget), Belgium, the Netherlands and Finland, the suitability of the programme for some service users (e.g. older people, those less able to take on complex administrative tasks, those with dementia) has been called into question. In

addition, in the Netherlands, there have been problems with some care mediation offices taking too much control from individuals and becoming involved in too many aspects of the process (including both managing the budgets and providing the care). In some cases, this has led to instances of fraud (Expertise Centre Independent Living 2010; van Ginneken et al. 2012).

The problems faced in the implementation of the personal budget programme in the Netherlands are perhaps the most frequently discussed, particularly since they led to costs spiralling out of control, and to the scheme being frozen in 2010. Since then, the scheme has been re-launched, but is being considerably scaled back, with tighter eligibility criteria, more stringent financial accounting, and specific regulations to prevent further cases of fraud (van Ginneken et al. 2012; White 2011). In Sweden, too, a growth in the number of people receiving budgets, and the increase in budgets, has led to the government tightening assessment processes, redefining eligibility criteria, and tightening financial regulation (Da Roit et al. 2010; Expertise Centre Independent Living 2010; Waterplas et al. 2005).

Despite the considerable differences in the various programmes, the following key lessons emerge from their implementation:

- implementation takes time;
- personal budgets often challenge the current way of working and the prevailing attitudes of some service providers. It may take considerable time and effort to bring about the changes required to ensure successful implementation;
- significant structural change is required to various systems, and in some cases, different systems will not operate neatly alongside each other;
- take up by individuals is difficult to predict, and may be much slower than anticipated;
- costs need to be managed carefully, through controlling eligibility or restricting budgets. In most countries, individuals either contribute or pick up the short-fall.

In addition, a number of issues emerge that require further examination. These are: how to achieve inclusivity and ensure equity amongst programme beneficiaries and other service users; how to ensure risk and safety issues are appropriately managed, without diluting the aims or potential impact of the programme; how to best manage the care planning and budget setting processes; and how to manage funding issues. These are discussed in the remainder of this section.

3.4.1 Programme beneficiaries - achieving inclusivity, ensuring equity

Personal budgets have generally been implemented for older people in need of assistance with daily living, and people with long-term care needs, including children and adults with physical and learning disabilities, and people with diagnoses of mental illness. The English pilot of personal health budgets includes individuals eligible for NHS Continuing Healthcare, people with mental health problems and people with long-term conditions. There were also pilot sites looking at substance misuse (both drugs and alcohol), people receiving end of life care, and maternity services. There is, so far, no evidence to suggest which care needs are best met by personal budgets.

It might be logical to suspect that personal health budgets could have the biggest impact amongst those with the most complex needs. Individuals who receive a very small number

of, or very specific, health services have little room to make changes in their service package. There is little evidence to either support or refute this hypothesis. Evidence from the personal health budget pilot in England indicates that the overall positive effect of personal health budgets in terms of care-related quality of life and psychological well-being is not strongly associated with particular health conditions. There was, however, some weak evidence that personal health budgets showed more effect for people under 75 than for those over 75. In addition, results showed that larger monetary value budgets had a significantly different impact on both costs and cost-effectiveness than smaller personal health budgets (Forder et al. 2012). Findings from the evaluation of the community directed care initiative in Australia also suggested that satisfaction with various aspects of life was generally higher for 'high care' participants than for 'low care' participants, indicating that there is potentially more benefit for people with higher levels of need, and receiving more sizeable packages (Gordon et al. 2012).

International experience has shown that personal budgets can be successfully implemented for a wide range of people, including older people, people with severe mental illness, and people with learning disabilities (see for example Glendinning et al. 2008; Gordon et al. 2012; Robert Johnson Wood Foundation 2006; Tyson et al. 2011; Coyle 2011; Shen et al. 2008a). The concern that personal budget programmes might exacerbate existing inequality in the NHS stems from the assumption that those who are able to choose effectively (because of higher levels of education and good social networks) will benefit most from personal budgets, leaving the less well educated to cope with the consequences of poor choices (Alakeson 2007b). A paucity of research in this area means that no conclusions can yet be drawn regarding the interrelationships between personal budgets and equity.

Self-direction has been successful in *Medicaid*, which serves a less well educated and lower income population than other parts of the US healthcare system, but it must be noted that the US healthcare system is both one of the more personalised and inequitable in the developed world. Alakeson (2007) notes that the design of the US Cash and Counselling programme has a strong bearing on how well they serve more vulnerable populations. An evaluation of the Florida Self-Directed Care programme in mental health found that participants were less likely to be of a minority status, and more likely to have a high-school education than non-participants in the mental health system (Florida Department of Children and Families Mental Health Program Office 2007).

Research in the Netherlands has pointed out that the complexity of the personal budget programme might exclude some groups¹⁶. It found that whilst the majority of budget holders were satisfied with their personal budget, 70 per cent found the rules complicated and a third found administering the budget and its paperwork difficult. Only 35 per cent administered the budget fully independently, with some getting help from a family member or a professional, and others leaving the administration entirely to others (Ramakers et al. 2007; cited in van Ginneken et al. 2012). Consequently, there is evidence that parents of young budget holders are better educated, and that budget holders (or their parents) tend to have a higher income and be better able to manage complicated regulations (Ministry of Health 2011; cited in van Ginneken et al. 2012).

¹⁶ The original research paper is published in Dutch. The numbers presented here were cited in van Ginneken et al 2012.

The community directed care initiative in Australia included a range of participants from 'special needs groups'. Whilst numbers are too small to draw any conclusions relating to the benefits and impacts of the initiative for these groups, the evaluation team were able to highlight a number of valuable observations (Gordon et al. 2012). Providers indicated that there was a lower than anticipated take-up of the initiative by Aboriginal and Torres Strait Islander clients, suggesting that the programme may not be culturally appropriate in its current form. However, culturally and linguistically diverse clients indicated similar levels of satisfaction with the planning process, choice of services, level of control and quality of care as any other group. Of particular importance to these clients was having the ability for services to be delivered by workers who spoke the same language as the care recipient (which was not always possible outside of major cities) (Gordon et al. 2012).

People in the homelessness special needs group experienced significant benefits from highly tailored and flexible responses, and the provision of 'wrap-around' supports from a range of other providers. The benefits experienced by people in this group were clearly related to having access to care and services, and access to case management support.

Participants and carers living in rural and remote areas often had less choice of service providers and/or increased costs involved in using services (because of the transport costs involved in engaging out-of-area providers). However, people in these groups indicated similar levels of satisfaction as any other group with the planning process, choice of services, level of control and quality of care. It was suggested that the goals-based approach to planning was particularly helpful for participants and carers in rural and remote areas where there were limited formal services because it encouraged innovative thinking to respond to identified goals and needs (Gordon et al. 2012).

There is no reliable evidence to indicate who might have the most or the least to gain from personal budget programmes. In the absence of this evidence, and clear guidelines, frontline workers make their own judgements about who is and isn't suitable. Evidence from UK individual social care budgets (Carr et al. 2009) shows that frontline workers may not be adequately informed of individual budgets; where they are, there might be attitude barriers preventing them from offering them to people who might stand to benefit. Workers who support them in principle might judge them to be unsuitable for their own case load (Carr et al. 2009).

Evidence from personal budgets in social care suggest that staff attitudes and expectations may hinder the delivery of direct payments to people with mental health problems (Taylor 2008; Spandler et al. 2006), and to older people (Ellis 2007; Leece et al. 2006). Research on consumer-directed care in the US indicated that there could be a risk of a two-tier system emerging for people with different degrees of learning disability, with those with more severe difficulties being much less likely to live in their own homes and to experience choice (Neely-Barnes et al. 2008; cited in Carr et al. 2009).

Clearly, the implementation of personal budgets in health care will involve a different workforce to those in social care. However, research undertaken in England suggests that health care professionals might behave in a similar way to social care professionals, with preconceived ideas about which patients are best suited to having choice and control (Dixon et al. 2010). This research found that health care professionals assumed it was the younger and more educated patients who want choice, rather than the elderly, and that there was a

degree of bias against entering into a protracted discussion of health needs and options. This appears to be born out in the personal health budget evaluation, where an analysis of the characteristics of patients in the treatment and control groups suggest that pilot sites may have been selecting or excluding specific groups of patients to be put forward for the study, such as focusing on a younger population in the personal health budget group, or not involving people from a black or minority ethnic community (Forder et al. 2012). This needs to be borne in mind when considering the results of the pilot programme.

Other research has found that the extent to which patients are involved in decisions about their care and treatment varies greatly (Parsons et al. 2010; Picker Institute Europe 2009). An independent inquiry into the quality of care in general practice concluded that patients with long-term care needs were not adequately engaged in understanding their options and making decisions about their own care (Goodwin et al. 2011). This suggests that a great deal of change is required, in both professionals' and patients' attitudes, understandings and expectations, before the key principles behind personal health budgets can be fully attained.

Carr's (2009) research briefing on the implementation of individual budget schemes finds that there is a strong evidence base to show that frontline staff and first-line manager training is vital for the implementation of individual budget schemes in social care in England, to manage change, improve knowledge and assessment practice, to promote equality and diversity awareness and to challenge perceptions about risk and certain groups (particularly older people and people with mental health problems or severe learning disabilities) who could benefit from the direct payment option. It is particularly important that this training is targeted at those staff who are involved in the assessment and decision making processes. The personal health budget evaluation found that the potential success of the programme may stem fundamentally from the views held by the staff members implementing the initiative.

3.4.2 Risk and safety

Whilst some judgments made by staff regarding suitability of patients for personal budgets will be influenced by their attitudes and professional culture, research relating to the implementation of direct payments for people with mental health problems finds that some people may not be offered choice because of professional risk perception and risk-avoidant practice (Arksey et al. 2008; Spandler et al. 2006). There is evidence to suggest that some of these risk-avoidant practices at the front line are geared towards protecting organisations from potential financial and reputational risks. Such practices may compromise how personal budgets are offered and administered (Alaszewski et al. 2005; Taylor 2006; Cambridge 2008; Hall et al. 2008; Glasby et al. 2009b).

A report into risk and safety in self-directed support and personal budgets found that there has been little investigation into risk enablement practice for personal budgets (Carr 2010). There have been no published empirical studies from the UK which evaluate particular strategies. A literature review of self-directed community care for older people with complex needs concluded that "there are no detectable increases in risk to quality, trustworthiness, reliability and safety when compared with agency-directed services" (Ottmann et al. 2009 p.70). Similarly, an OECD working paper (Lundsgaard 2005) on consumer-direction of choice in the long-term care of older persons found that there is no indication of older persons being neglected when relying on consumer-directed rather than agency-based care.

Clearly, issues of risk and safety in a social care personal budget programme will not be the same as for one in health care. There is no international evidence to suggest that there are any particular risks posed where personal budgets are used to purchase health care. However, this is indicative of the lack of research in this area, rather than a lack of risk. Many programmes – like that in the Netherlands - have no official system of supervising the quality of care, since it is assumed that budget holders will make up their own minds on quality (White 2011).

Some consequences may not emerge until sometime after the programme has been implemented. There are concerns about the wider consequences of expanding the market of personal assistants through the use of direct payment programmes. Many of these concerns are debated in all countries offering personal budget schemes. They focus on the need to balance safeguarding and registration with individual choice and control, the emergence of an unregulated 'grey' market, the effects of migrant and gendered labour, quality assurance, employment conditions, training and low wages (Pavolini et al. 2008; Da Roit et al. 2007; Doty et al. 2007). The current evidence base on the possible consequences of expanding the use of personal assistants is not robust enough to offer conclusive findings about any of these concerns. However, investigation into the impact of cash-for-care reforms in France, Germany, Italy, the Netherlands, Sweden and the UK suggested that the introduction of personal budgets has created room for low-quality employment to grow, which has made it very difficult to control the level of quality of both employment and care (Pavolini et al. 2008). Research also indicates that the Western European personal assistant labour market is characterised by migrant, mostly female workers with a high turnover. In Austria and Italy, where budget holders are allowed to spend their allowance as they choose, unregulated, 'grey' markets which fall outside of employment law have emerged and attempts at regulation to protect both the employee and employer have varied in success (Carr et al. 2009).

Commentators on the US Cash and Counselling pilot state that risk minimisation for all parties was considered part of the overall programme design (Knickman et al. 2007; Hall et al. 2008; Robert Johnson Wood Foundation 2006; Doty et al. 2007). They argue that the cash and counselling programme has greater operational clarity and more defined limits and restrictions on how people can spend their personal budgets than the similar UK programmes. The personal budgets were offered in lieu of traditional *Medicaid*-covered services, and were only allowed to meet health and disability related needs – not to cover general expenses or luxury items. A vital part of the programme was the mandatory support and guidance from a 'counsellor'. Doty (2007) says that there was no cash without counselling, and budget holders could only receive the cash option if they 'agreed to be trained and tested on fiscal responsibilities and submit to a periodic audit' (p.384, cited in Carr 2010). Consumer exploitation (as reported by program counsellors) occurred only a 'handful' of times under Cash and Counselling in each of the three pilot states, and abuse of the personal budget was nearly non-existent (Robert Johnson Wood Foundation 2006).

The role of the counsellor or broker appears to be critical in the management of risk – both for the patient (providing a check on safety and quality of services) and for the provider (ensuring costs and expectations are reasonable and managed).

3.4.3 Care planning and budget setting processes

There are several key processes involved in the implementation of personal budgets. An assessment is required to identify whether the individual is eligible, and what that individual's needs are. A more detailed process (such as a care planning process) might clarify the needs to be met by the personal budget, and the goods and services required to meet those needs. A budget setting process will clarify the funds available to that individual. And a review process will monitor the spending of the funds, and the outcomes of the patient.

Few details are available on how these processes are conducted in different programmes. Yet they are potentially crucial to the success of the programme in terms of outcomes, impact and affordability.

In some countries, eligibility is assessed using medical assessments of care dependency. Those found eligible for receiving care support might then be either allocated their budget as a benefit (as in France or Austria), or given the choice as to whether they would prefer a personal budget or agency-directed care (as in Germany or the Netherlands).

In some instances, a care planning process is undertaken to clarify the needs to be met, and the goods and services required. This process varies hugely, and there is no consensus as to the best approach. In the UK, the care planning process is promoted as one that “empowers individuals, promotes independence and helps people to be more involved in decisions about their care. It centres on listening to individuals, finding out what matters to them and finding out what support they need” (Department of Health 2011: p2). However, experience in the English Year of Care programme (which introduces and embeds personal care planning into routine care) has shown that care planning is a complex intervention involving both widespread cultural change, as well as changes to everyday processes and practices for the workforce, across large parts of the NHS (Year of Care 2011).

In the English personal health budget pilot, interviewees' accounts suggest that there are wide variations across the pilot sites in the nature and formality of care/support planning processes. Those who had detailed discussions with healthcare professionals about needs, goals and preferences reported that these were useful in generating ideas for using personal health budgets. However, care/support planning discussions could also be challenging and 'draining', particularly for those with recent onset health conditions who had yet to find out what care or treatment might be helpful. Some of the budget holders interviewed did not recollect anything that approximated to a care/support planning process, and for some the process was additionally difficult without knowing how much their budget would be (Irvine et al. 2011).

In the Australian consumer-directed care programme, a wide variety of tools were used to assist in needs assessment. The evaluation found that the assessment and planning processes tended to merge, and discussions about the individual's goals and objectives would merge into discussions about potential support options and likely budget implications. In many cases, this involved a number of meetings or discussions, depending on the individuals' and carers' insights to their care needs, their ability to identify and articulate goals, and their capacity to engage with self-direction. Those discussions were usually turned into a draft care plan, perhaps with some budget options, for the individual and carer to consider (Gordon et al. 2012).

Whilst there was general consistency to this broad approach, there were variations in the process amongst different providers. The evaluation team identified two approaches to planning: goal-based planning, focusing on identifying the goals, desires and objectives of the participant and carer, before then looking to identify possible support options; and menu-based planning, focusing on the needs assessment and provision of a list of available supports, providers and prices list to the individual or carer. They found that the goal-based approach was more individualised and allowed more scope for innovative use of the package funds, and was clearly a different approach to the standard packaged care approach. The menu-based approach was easy for some individuals and carers to understand, and was easier and less time-consuming to complete. However, the approach tended to focus on pre-defined service types and allowed less scope for innovation (Gordon et al. 2012). Information on how assessments and care plans are developed in other countries is limited, and there is currently no evidence to suggest which approach provides the best outcomes.

Budget setting is another important process that has proved highly complex. Many countries have fixed budgets, often on a scale determined by an individual's assessed level of care dependency (usually calculated in terms of hours of care required). In other countries, the budget is more flexible. Within the Cash and Counselling pilot, different states adopted different methods for calculating the budget. In Arkansas, the method was based on using a set price per hour in the care plan. In Florida, they based their calculation on previous service usage, or on the care plan (where previous usage was not stable). In New Jersey, they used the value of the care plan, minus ten per cent set-aside for support services. Arkansas and Florida applied adjustment factors to the budgets to keep expected program costs comparable to what costs would have been under agency-based care (Brown et al. 2007). Since the implementation of the programmes in the three states differed in many other respects too, it is impossible to say which method was most useful.

In England, calculations are complicated by the fact that costs of existing packages are often unknown. Determining the size of the budget in the personal health budget pilot was viewed as one of the biggest challenges at the early stages of programme implementation (Jones et al. 2010). The pilot sites used a number of techniques to estimate costs. These included: developing an outcome-focused cost-setting matrix, based on the cost of hourly, half hourly or unsocial hourly services that the individual requires; using the cost of existing care packages as a basis for estimation of a budget; and, when it was not possible to calculate accurate costs, sites were 'guesstimating' costs to either derive an indicative amount for each service, to derive an overall indicative amount for each budget holder, or to derive a cost range depending on the severity of the health condition. Within each site, approaches to setting budgets were at least partly dependent on the ease with which funds could be moved around the system (Jones et al. 2010). Whilst the programme evaluation did not examine which methods produced the best results, the programme team have learned much from the pilot process, and this learning has been distilled into guidance and best practice documents¹⁷.

The review process in international programmes is rarely discussed. Within the US Cash and Counselling programme, it is noted that the 'counselling' element incorporates regular checks on the budget holder for evidence of abuse or neglect (which were rarely observed)

¹⁷ See <http://www.personalhealthbudgets.dh.gov.uk/>

(Robert Johnson Wood Foundation 2006). In England, reviews of personal health budget holders varied in formality and timing. Reviews were variously undertaken face-to-face, by telephone or by post. Budget holders commonly felt that the main purpose of reviews was to check that budgets were being used appropriately. The fifth interim report (Davidson et al. 2012) of the pilot evaluation noted that one advantage of having reviews was that they motivated budget holders to continue using the services or equipment purchased with their budget. Reviews also provided opportunities to overcome minor problems or generate new ideas on how to spend the budget. However, over a third of those interviewed who had a personal health budget in place, had not had any form of review. This typically left people feeling 'disappointed', 'abandoned' and 'a bit adrift', as they worried about overspending, were curious about how much money was left in the budget, and were concerned to know that someone was taking responsibility and knew what was going on (Davidson et al. 2012). This highlights the importance of getting the support and communication right. Experience in England shows that it is difficult to guess how much support an individual needs, and those who appear 'able to cope' may often want more contact than they get (Davidson et al. 2012).

Recipients (and potential recipients) of personal budgets are likely to be involved in many processes that are new to them. There is much evidence from a range of countries highlighting the crucial role of support and information systems and advocacy organisations for recipients of personal budgets (Arksey et al. 2008). Individuals need appropriate and varying levels of support to decide whether and how to use a personal budget, and to manage aspects such as purchasing, employment and accounting arrangements. The amount and type of support, and who provides it, varies between countries and programmes, but it is frequently referred to as 'brokerage'. It usually involves the provision of information and advice, but may also offer practical help in relation to tasks such as recruiting personal assistants, drawing up contracts of employment, operating a payroll, and so on.

Peer support is recognised as an effective way to share experiences and information about personal budgets, but older people tend to be less keen than other user groups in being involved in peer support groups (Clark 2006; Arksey et al. 2008). In US Cash and Counselling programmes, and the Florida self-directed care programme, brokerage (or 'counselling' or 'life/recovery coaching') is a vital and integral part of the programme. In other countries, such as Germany, Austria and France, support is very limited, and service users might be particularly dependent on a family carer who can take responsibility for managing and spending the budget on their behalf.

In the US Cash and Counselling programmes, evaluations showed that consumers used a range of program services, including counselling on how to set up their spending plans (a required service) and how to recruit and train workers. Over 93 per cent of allowance recipients used the fiscal intermediary services to perform bookkeeping functions. In all states and all age groups, 85 to 95 per cent of users of the various services found the services to be helpful. Consumers in Arkansas were especially likely to receive help from counsellors since the Arkansas programme required counsellors to develop a spending plan within 45 days of enrolment. Younger and older consumers reported similar rates of use of counselling services (Brown et al. 2007).

In the English personal health budget pilot, most of the budget holders interviewed for the fourth interim report were supported by the main lead professionals, with additional support sometimes coming from family members or other health/social care professionals (Irvine et al. 2011). These professionals had significant roles to play in making suggestions about possible uses for the budget, or helping the budget holder generate ideas. Positive experiences of support were characterised by a good rapport with professionals who were well-informed, accessible and responsive. Interviewees valued information about the range of things personal health budgets could be spent on. Some pilot sites and/or individuals avoided doing this, perhaps wanting to encourage budget holders themselves to think broadly about their needs. However, a lack of clarity around what would and wouldn't be acceptable often led to frustration and disappointment when all or part of a care/support plan was turned down by an assessment panel (Irvine et al. 2011).

The question of *who* is best placed to provide support is not yet answered. Some countries have placed an emphasis on the independence of the support brokerage service. Access to an independent support broker is compulsory in the Netherlands, the US and Canada (Williams 2008). An evaluation of the Canadian individualised quality of life project, which provided 150 individuals with learning difficulties and their families in Ontario with personalised planning, support and funding from 1997, found that it was the independence of the planning support which made it especially valued and effective (Roehrer Institute 2000).

The cash and counselling evaluation team also argue that the assessments used to determine individuals' budgets should be prepared by trained independent state staff, who may act more as advocates for the consumer than as objective assessors of need. They also note that provision of counselling by agencies who also provide traditional services is problematic, as such agencies may not be supportive of the scheme (Brown et al. 2007). It is also important that those agencies that play some part in advising individuals on how to spend their budget do not stand to gain financially from decisions made by the individuals. In the Netherlands, the unchecked proliferation of independent support agencies, and lack of financial oversight, proved problematic when unscrupulous broker agencies employed aggressive marketing tactics, and in some cases stole parts of the budget. Whilst it is recognised that support brokerage is an almost inevitable aspect of personal budget / direct payment schemes, it does not amount to a requirement for everyone to have a named broker.

A research review published in 2008 concluded that there is virtually no evidence-base in the UK relating to the practice of support brokerage as it has developed so far (Williams 2008). It is also little discussed in programmes in other countries. Williams (2008) points out, though, that the limited evidence that exists in the UK suggests that individual (social care) budget holders act cautiously and carefully with what they perceive to be their own money, and budget holders are likely to look to 'free' brokerage delivered by professionals, often already known to them, rather than have to make a separate arrangement that may cost them money from their budget. Thus, in the UK, the position is that anyone can take part in delivery support brokerage. Whilst there is a strong argument that people providing this service should be skilled, trained and should meet a set of quality standards, the individual budget-holder would be the one to decide who should act as their broker (Williams 2008).

3.4.4 Funding

Experience has shown that many issues of funding will emerge in the introduction of a personal budget programme. These need addressing in policy and practice. Issues include: how the budget will be allocated to and managed by the budget holder; the extent to which and how this will be audited; where the funding will come from; how to establish the parameters of what is an eligible purchase; and what happens when a budget is not managed well. These issues are handled very differently in different programmes, states and countries, since responses will inevitably be context specific. Whilst no evidence currently exists on 'best practice' for these funding issues, some of the experiences and lessons from the personal health budget pilot are being captured in the Department of Health's Personal Health Budgets Learning Network¹⁸.

Personal budgets make financial aspects (and therefore rationing) of health and social care provision explicit. The Dutch experience demonstrates the difficulty of reconciling the open-ended character of personal budgets with inevitable budget ceilings. In England, this is further complicated by the fact that personal health budget holders will not be allowed to 'top-up' their budget. The situation with social care eligibility criteria and how social care and health funding operate in England, particularly for people with complex needs, means that people are at risk of being labelled as a 'health' or 'social' responsibility. The introduction of personal health budgets shifts the focus from types of service (e.g. health or social), to outcomes. For instance, if a purchase helps a patient meet his health goals, it could come from a personal health budget. This may increase the confusion, and lead to a greater degree of 'cost shifting' – agencies passing the costs of support into other agencies. Alternatively, it may simplify processes and improve access to appropriate services for patients by removing an arbitrary line (between 'health' needs and 'social' needs), and focusing instead on outcomes. Either way, there is no evidence to suggest how these issues might be handled, or what repercussions they may have in the long term.

It is interesting to note that in the Netherlands, a differentiation between 'care' (including personal and nursing care) and 'social care' (including domestic help, adaptations to the home, mobility devices and transport) was introduced only recently, in 2007. In the ongoing reforms to tackle the unmanageable costs of the PGB, this split becomes quite significant, as costs and services (such as support services and day activities) are being shifted from the health budget to the municipality social care budget. This kind of split in the UK has been shown to be persistently unhelpful, particularly in the management of long term and multiple conditions. One marker of success in the personal health budget pilot could, therefore, be the extent to which the programme encourages and enables the integration of services (and the pooling of funds) between health and social care.

4. Conclusion

This review of the evidence on personal budgets highlights the diversity of programmes aimed at promoting choice and autonomy for patients, and controlling costs through expanding options for home and community based long-term care. Whilst many countries have implemented consumer-directed care programmes, or initiatives that use direct

¹⁸ <http://www.personalhealthbudgets.dh.gov.uk/Topics/healthcareProfessionals/>

payments, these tend to have focused on the provision of goods and services that compensate for the impact of physical or mental impairment, and that help to maintain or improve people's independence. In England, this would generally be defined as social care.

The pilot of personal health budgets in England that are intended for the purchase of goods and services that address *health* needs, breaks new ground. It is the first with the focus primarily on treating or managing illnesses. And in theory, it is the most expansive when it comes to the degree of choice and control granted to the patient; in practice, this depends greatly on how the programme is implemented locally.

Consequently, there is little evidence, internationally, to answer some of the key questions regarding how, and for whom, personal health budgets should best be implemented, and what consequences they might have.

This review has described programmes similar to personal budgets trialled or adopted in eleven countries. All of these target people with long-term care needs, and generally focus on people who are highly or moderately dependent on personal care and assistance with daily living.

The programmes vary according to their key programme features. Some – like in Austria and Finland – are relatively basic in their design, require little input from providers / commissioners, and expect little from budget holders in the way of financial reporting. Such programmes have high theoretical levels of autonomy for budget holders, although their simplicity, and lack of support for budget holders, may make them inequitable, and only suitable for individuals who want to and are able to purchase and direct their own care. Others – like France, Belgium, Sweden and Australia – are more involved, but aspects of the design serve to limit an individual's ultimate autonomy. And some countries – like England, the US, the Netherlands, Canada, and Germany - have programmes which are complex in design, and which require considerable input from providers / commissioners, but which are geared towards maximising an individual's autonomy (at least in theory). In most programmes, the ways in which they are implemented in practice can influence the ultimate autonomy and degree of choice afforded to the budget holder.

Few countries have published evaluations of their programmes. For those that have (US, England, Canada and Australia), the evaluations have considerable limitations, and leave many questions unanswered. Table 4 summarises the main conclusions emanating from this review. It also highlights some questions that, on reading the evidence, appear to be critical to the success and affordability of a personal health budget programme, but which remain unanswered by the evidence we have so far. Many of these questions can only be answered through longer-term and more detailed analysis. The careful monitoring and follow-up evaluations of the roll-out of the personal health budget programme will be vital to the programme's sustainability and long term success.

Table 4: Main conclusions and key questions arising from the review of evidence

Main Conclusions	Key Questions
<i>Outcomes</i>	
<p>International evidence suggests that personal budgets have little impact on health outcomes, at least in the short term.</p> <p>Personal budgets can have positive outcomes in terms of consumer satisfaction, feelings of wellbeing, and quality of life for the majority of users (although this will depend on the complexity and administration of the programme, the degree of real choice the programme affords individuals, and the provision of appropriate support to budget holders).</p> <p>The evidence base remains weak and more ongoing evaluation is required, particularly on longer term and wider implications of using personal budgets to purchase health care.</p>	<p>What sorts of services and goods will patients choose, when given choice? To what extent do packages differ from traditionally purchased packages of support?</p> <p>Can personal health budgets improve health outcomes (at a comparable cost to traditionally commissioned services)? For which people/groups of people?</p> <p>Do personal health budgets have any longer term impact on health outcomes?</p> <p>Which factors are most important in the implementation of personal health budgets, to optimise outcomes?</p> <p>Can personal health budgets lead to a better integration of services?</p>
<i>Affordability and value for money</i>	
<p>There are ways in which costs can be contained, and affordability can be ensured, including changing the eligibility criteria, and size and scope of budgets. However, these measures will affect the degree of choice patients have, and will therefore affect the outcomes.</p> <p>There are indications that the use of personal health budgets can lead to cost savings at an individual level. However, there could be a balance between cost and quality. Cost savings at an individual level might reflect an individual: having less care to meet their needs; meeting fewer of their needs; or meeting their needs less adequately with cheaper care.</p> <p>There is no evidence to suggest that there will be cost savings to the NHS in the longer run as a consequence of introducing personal health budgets.</p> <p>There is no evidence to suggest that users of personal health budgets have lower use of health services in the longer term. This would be crucial for their future sustainability.</p> <p>Personal health budgets could cause healthcare spending to increase if individuals use their budget to purchase services or goods that are additional to the NHS services they continue to use, or that they would otherwise have bought themselves.</p>	<p>Can the implementation costs of personal health budget programmes be absorbed into the current system, without impacting on existing services?</p> <p>To what extent can the cost of personal health budgets be contained, whilst maintaining or improving health outcomes, and without dampening the 'spirit' of patient autonomy and choice?</p> <p>Will the number of patients wanting a personal health budget increase rapidly?</p> <p>Will personal health budgets be used to fund (or part fund) goods or services that might otherwise have been purchased out of pocket? If so, to what extent is that a problem?</p> <p>Can the use of personal health budgets lead to cost savings across the healthcare system as a whole? Or might they lead to increased costs?</p>

Implementation and funding

A wide range of personal budget programmes have been implemented in a variety of settings. However, they always face significant challenges along the way, and they often require substantial changes to be made to across existing systems.

Judgments about levels of risk (to patient safety, professional reputation or organisational finance) will significantly influence the way in which personal budget programmes are implemented in practice.

The outcomes of personal health budgets will be dependent to a large extent on the way in which they are implemented, and the people involved in implementing them.

The overall impact of personal health budgets will be difficult to predict where there is significant local variation in implementation.

What is the most effective, reliable and fair way of calculating budget amounts?

What benefits do the allocations of direct payments have over personal budgets that are not directly allocated?

What are the most effective methods of helping budget holders identify how the budget should be spent?

What are the best ways of reviewing personal budgets to avoid personal risks to the patient and financial risks to the organisation?

What types of support should be available to budget holders in order to maximise the benefits? Who is best placed to provide this support?

What degree of local variation in programme implementation is acceptable? What will be the implications of local variation for equity in the NHS?

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