

Implementing personal health budgets within substance misuse services

Final Report

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Executive summary

- The personal health budget initiative is a key aspect of personalisation across health care services in England. Its aim is to improve patient outcomes, by placing patients at the centre of decisions about their care.
- 2. In 2009 the Department of Health invited PCTs to become pilot sites to join a programme which would explore the opportunities offered by personal health budgets. The Department of Health commissioned an independent evaluation to run alongside the pilot programme to provide information on how personal health budgets are best implemented, where and when they are most appropriate, and what support is required for individuals.
- 3. Two pilot sites within the pilot programme explored whether personal health budgets had an impact on outcomes and experiences compared to conventional service delivery among individuals with substance misuse problems.

Study design and methodology

- 4. The evaluation adopted a longitudinal approach, and included people with drug and/or alcohol addiction.
- 5. The study used a controlled trial with a pragmatic design to compare the experiences of people receiving a personal health budget with the experiences of people continuing under the current substance misuse treatment support arrangements. After applying initial selection criteria, in one pilot site people were randomised into the personal health budget group or a control group. In the second pilot site, the personal health budget group was recruited from patients of those health care professionals in the pilot offering budgets, and a control group was recruited from patients of non-participating health care professionals.
- 6. A mixed design was followed where both quantitative and qualitative methodologies were used to explore patient outcomes and experiences, service use and costs, as well as the experiences of those implementing the initiative. In total, an active sample of 166 participants was recruited: 119 in the personal health budget group and 47 in the control group. Within the active study sample, 55 participants had drug and alcohol addictions and 111 participants had an alcohol addiction only.
- 7. The qualitative analysis involved interviews with personal health budget holders and organisational representatives. Data were analysed using the framework approach, with the data organised by themes according to the topic guides used in the interviews.
- 8. The difference-in-difference approach was used to explore whether personal health budgets had an impact on an individual's quality of life and relapse rates. The analysis subtracted an individual's follow-up outcome scores from their baseline score. Due to the small sample size, the analysis did not include exploring difference-in-difference multivariate models and therefore we were unable to control for confounding baseline differences.

The content of support plans

 Among the personal health budget group, 103 support plans were returned from the two pilot sites. In terms of the size of the budget, 41 budgets were worth between £1,000 and £5,000 per year, while 4 budgets were worth more than £10,000.

- 10. The majority of care/support plans were managed notionally. While one of the pilot sites did have approval to offer direct payments, we did not find evidence this deployment was offered during the pilot programme.
- 11. Residential detox was the largest single cost category. The more innovative uses of the personal health budget included driving lessons, alternative therapies, leisure activities and educational courses. Enabling people to access community detox rather than residential detox could also be regarded as an innovative use of their budget.

The impact of personal health budgets on relapse rates, quality of life and service quality

- 12. The shortened version of the Alcohol Use Disorders Identification Test (AUDIT-C) was used to detect signs of hazardous and harmful drinking. Difference-in-difference analysis indicated that individuals in the personal health budget group had reduced their excessive drinking at follow-up compared to those in the control group. Similar results were found with the change in drug consumption at follow-up.
- 13. Difference-in-difference analysis indicated that there were greater improvements in care-related quality of life (ASCOT) and psychological well-being (GHQ12) for individuals in the personal health budget group compared to those in the control group, although the difference was not statistically significant.
- 14. Individuals in the personal health budget group were more satisfied with the help paid for by the budget and the care/support planning process than those receiving conventional services.
- 15. While the quantitative results highlighted the positive impact of receiving a personal health budget, firm conclusions around the impact of personal health budgets compared to conventional service delivery could not be made, due to the small sample size.

Views from patients

- 16. Qualitative in-depth interviews indicated that personal health budgets had a positive impact on service quality, relationships with health professionals and views on what could be achieved compared with conventional service detox delivery.
- 17. The importance of effective implementation was highlighted, both in terms of providing the necessary information to enable budget holders to make an informed choice and also to minimise any delays in the process of obtaining and using a budget. Individuals reported that delays could potentially lead to anxiety and distress.
- 18. A list of suggestions of possible uses of personal health budgets would have been useful during the support/care planning stage.
- 19. Personal budget holders reported a lack of after-care services available with this treatment route which could potentially have a longer-term impact on relapse rates. This desire for post-detox care to prevent relapse was especially prevalent at follow-up, when patients had completed their detoxification and required relapse prevention services.
- 20. Individuals receiving conventional detox services expressed more negative views of the relationship they had with health professionals and their experiences of services.

Views from the system

21. Organisational representatives believed that personal health budgets had a positive impact on outcomes for budget holders: the way they accessed services, and to a certain extent the content or

quality of those services. Organisational representatives attributed these impacts to the personal health budgets enabling: increased choice and control for budget holders; increased flexibility; encouraging innovation and creativity; greater 'person-centred' care/support planning; and the opportunity to reduce costs by accessing alternative services or providers of services.

22. A number of challenges within the implementation process were mentioned by organisational representatives. These included: the length of time required to conduct the care/support planning process; the time point at which a personal health budget should be introduced; deciding what can and cannot be included, in particular considering whether the budget should be used for relapse prevention; managing attitudes to risk and the cultural change required for patients in the system; the logistics of managing multi-agencies involved in a person's care; and establishing integration between services and creating a jointly-funded budget.

Recommendations for policy and practice

- 23. A number of recommendations can be made regarding a possible roll-out of personal health budgets within the area of substance misuse from the results of this study:
 - Personal health budgets increased service satisfaction, facilitated a positive relationship with health professionals and improved quality of life supporting a wider roll-out.
 - The budget-holders we interviewed emphasised the value of information and guidance from operational representatives about the size and operation of their budgets, including what services were covered.
 - Direct payments were viewed as playing a critical role in the success of personal health budgets for people with substance misuse problems. However, managing the anxiety and practical challenges around offering this deployment option may need consideration.

1 Introduction

1.1 General overview

Personal health budgets are a key feature of the personalisation agenda for health care in England, based on the ethos of creating a more patient-centred, responsive NHS (Department of Health, 2009). The initiative was first proposed in the 2008 NHS Next Stage Review as a process of giving patients greater control over services they receive and how the support is managed. The importance of personal health budgets has continued to be re-affirmed in a number of policy documents, including the 2010 White Paper *Equity and Excellence, Liberating the NHS,* which presented the initiative as having the potential to "improve outcomes, transform NHS culture by improving choice and control for personal health budget holders, and encourage integration between health and social care" (HM Government, 2010). In 2011, the Government's response to the NHS Future Forum report further emphasised the importance of public involvement in services: "A health system where patients and the public have a stronger voice and more control – no decision about me without me" (HM Government, 2011).

The underlying principles of the personal health budget initiative are to encourage greater choice and control among patients and their families. After an initial assessment, an individual is given a transparent resource within the personal health budget to purchase services and care that meet their identified health needs. There should be flexibility in the range of services and support that can be paid for by the budget, so that potentially different services can be commissioned alongside conventional NHS treatments. Personal health budgets can be managed in three different ways (or potentially a combination of them): notionally, where the budget is held by the commissioner but the budget holder is aware of the treatment/service options and the corresponding cost; managed by a third party; or as a direct payment (in certain approved sites only), where the patient receives a cash payment to purchase services/support. The budget holder should be given the choice as to how they would like the resource managed (Department of Health, 2009).

In 2009 the Department of Health invited PCTs to become pilot sites to join a programme which would explore the opportunities offered by personal health budgets. The Department of Health commissioned an independent evaluation to run alongside the pilot programme to provide information on how personal health budgets are best implemented, where and when they are most appropriate, and what support is required for individuals.

1.2 Personal health budgets and substance misuse

Part of the national pilot programme focused on offering personal health budgets within two pilot sites to people with substance misuse problems. The aim of this report is to sit alongside the main report for the evaluation of personal health budgets pilot programme (Forder et al., 2012). The aim of personal health budgets for people with substance misuse problems is to promote control and potentially to widen the choice of treatments beyond the current conventional NHS detoxification treatment programmes. Based on the policy underlying personal health budgets, it was assumed that the initiative would have an impact on people's experiences of services aimed at reducing substance misuse issues as well as on service efficiency. Both aims are of great importance as the number of people seeking drug and/or alcohol treatment programmes has doubled since 2001. Between 2010 and 2011, 204,473 adults were receiving

drug and alcohol treatment, with central and local government spending over £800 million a year providing treatment and recovery services (National Treatment Agency for Substance Misuse, 2010). The Home Office estimates that drug-related crime costs society £13.9 billion a year; NICE estimates the lifetime crime and health bill for every injecting drug user is £480,000 (National Treatment Agency for Substance Misuse, 2012). The National Treatment Agency for Substance Misuse (2010) predicted that 46 per cent of those that go through treatment will relapse during the following four years. In addition to the danger of addiction, substance misuse has serious health risks and is associated with a range of complications. In 2008 in the UK, there were 9,031 reported alcohol-related deaths and 897 deaths involving heroin or morphine (Office for National Statistics, 2009).

A literature review was initially carried out to establish whether non-pharmacological interventions (psychosocial or alternative medicine), or a combination of pharmacological and non-pharmacological interventions, are more effective at preventing relapse after detoxification than pharmacological interventions alone. It is intended to add to the understanding as to how personal health budgets could be implemented among patients seeking substance misuse treatments in the future. Appendix A provides an account of conventional treatments.

In the literature review, the term substance misuse refers to "the misuse of all psycho-active substances including illicit drugs, non-prescribed pharmaceutical preparations and alcohol" (Department of Health, 2002). Nicotine dependence is not included. In more general terms, the World Health Organisation (2006) defined dependence as "a strong desire or compulsion to take a substance, a difficulty in controlling its use, the presence of a physiological withdrawal state, tolerance of the use of the drug, neglect of alternative pleasures and interests and persistent use of the drug, despite harm to oneself and others" (World Health Organisation, 2006). According to NICE (2005), "dependence is diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) when three or more of the following criteria are present in a 12-month period: tolerance; withdrawal; increasing use over time; persistent or unsuccessful attempts to reduce use; preoccupation or excessive time spent on use or recovery from use; negative impact on social, occupational or recreational activity; and continued use despite evidence of its causing psychological or physical problems" (American Psychiatric Association , 1994).

It is important to note that the term 'relapse prevention' was first used to denote a specific model of cognitive behavioural therapy (see appendix A and B). The term is now commonly used in a much more general sense to describe a whole range of cognitive behavioural therapy interventions. As the aim of this review is to evaluate individual interventions and to differentiate between them, 'relapse prevention' is used throughout to refer to the specific model.

1.3 Literature review

The literature review included searches of the electronic databases and retrieved 312 studies. Five articles were added from general internet searches and recommendations from colleagues, and 24 duplicates were removed, to leave 293 papers. The abstracts of these were screened by one reviewer and 263 were rejected because the type of participant, intervention, study or setting did not meet the inclusion criteria. The full text of each of the remaining 30 reviews was assessed by one reviewer; subsequently six were removed because they did not contain relapse information or they dealt with a dual diagnosis. A further eight were excluded because they were not systematic reviews, leaving 16 studies which were included in the review. Appendix B details the methodology.

Despite the effects of relapse, numerous studies have highlighted that treatment providers do not typically offer on-going support after patients have completed their detoxification treatment. The Department of Health (England) and the devolved administrations (2007) publication *Drug Misuse and Dependence: UK Guidelines on Clinical Management* stated that: "If a patient has successfully completed drug treatment, they still may have on-going needs to prevent relapse into drug and alcohol misuse. Many drug misusers relapse and it is important that they can gain speedy access back to drug treatment if they do. Patients may also require a package of after-care, which may include psychosocial support." Ongoing support from a GP to help maintain health and well-being may also be vital to the success, together with support from social care providers (such as housing, education or employment access schemes). Advocacy and support are also provided through organisations such as Narcotics Anonymous. There are therefore many different components which may need to be in place for successful relapse prevention.

Furthermore, as was demonstrated in the literature review, there are many different types of psychosocial intervention for helping reduce relapse. Finding the best combination of treatments and support to deliver the right sort of relapse programme is essential, not only for patients' well-being but also for long-term cost-effectiveness. The literature review found that psychosocial treatments used in addition to pharmacological interventions are effective in reducing substance misuse (Amato et al., 2011). There was also further evidence that this may reduce both substance misuse and relapse rates. Numerous studies presented evidence that the psychosocial intervention contingency management (CM) added to standard treatment improves the ability of cocaine and opiate using clients to remain abstinent. Various studies have discussed this issue (Amato et al., 2011; Castells et al., 2009; Knapp et al., 2007; Prendergast et al., 2006; Roozen et al., 2004; Mayet et al., 2004). The review also presented evidence that various forms of cognitive behavioural therapy (CBT), including relapse prevention (RP), are particularly effective for combating cannabis and alcohol misuse. Various studies have discussed these issues (Beecham et al., 2009; Magill and Ray, 2009; Dutra et al., 2008; Denis et al., 2006; Irvin et al., 1999). In addition, the review reported on the findings from 'Project MATCH' that demonstrated how an introductory programme based on the 12-step approach,¹ combined with AA meetings, helps to prevent relapse (Slattery et al., 2003). However, crucially, there appeared to be no evidence for the effectiveness of psychosocial interventions alone for preventing relapse into substance misuse.

The review suggested that there is no evidence of any one psychosocial intervention being more effective than another for the prevention of relapse to all substances. However, evidence suggested that some interventions are more effective for certain substance misuse problems than others. Therefore it seems that relapse prevention programmes should be tailored to the needs of an individual and should take into account the substance or substances being misused, along with the setting, client history, background and level of family support, if the programme is likely to work in the long term. It is therefore suggested from the review that patient-based strategies which combine a mixture of treatments and support, and use the best and the most appropriate of each, have the potential to increase the chances of long-term success.

The literature review also revealed that, while there are previous reviews of substance misuse that discuss the many treatments (both psychosocial and pharmacological) that exist to help individuals cease

¹ The 12-step programme is the basis of the self-help philosophy of Alcoholics Anonymous, who view addiction as an illness which can be slowed one day at a time but can never be cured. The first step in the process is a commitment to a substance-free life, where users accept that they are powerless over their addiction (Shearer, 2007; Wanigaratne et al., 2005).

their substance use, there is little emphasis placed on maintaining behaviour change over time. The review highlighted that information about the long-term efficiency of interventions is limited, with few studies focusing on preventing relapse after one year. From the review it would seem that the development and refinement of strategies to reduce relapse by the system are required.

In conclusion, the literature review provides specific direction as to how personal health budgets have the potential to improve outcomes among people with substance misuse problems.

1.4 Aims of the study

Within the national evaluation of personal health budgets, two pilot sites were implementing the initiative among individuals with substance misuse problems. One pilot site addressed both drug and alcohol addiction, while the other pilot site concentrated on alcohol addiction only. As this cohort sits slightly outside the focus of the main evaluation, the Department of Health commissioned a separate study.

The overarching aim of the study was to examine the outcomes for people accessing substance misuse services using a personal health budget compared with people accessing services in the conventional way. The study explored:

- 1. The process of implementing personal health budgets from the perspective of patients and staff;
- 2. The longer-term impact of personal health budgets on substance misuse relapse rates;
- 3. The short- and longer-term impact of personal health budgets on patients' quality of life;
- 4. The short- and longer-term impact of implementing personal health budgets on staff and the 'system'.

2 Methods

2.1 Implementing personal health budgets

During the pilot programme, personal health budgets could be accessed in two ways of in both sites.

Within the pilot site offering personal health budgets to people with alcohol misuse problems, individuals could access the initiative through either a tier-two service (for individuals with low needs or non-complex needs) or a tier-three service (for individuals with complex needs scoring above 16 on the Severity of Alcohol Dependence Questionnaire (SADQ)). Individuals who were assessed as being eligible for a personal health budget and were accessing the initiative through a tier-two service, had the choice of purchasing a fast-track community detox through the budget. Individuals accessing personal health budgets via a tier-three service could purchase more intensive support, and a keyworker was assigned to provide support through the PHB process. All personal health budgets offered within this pilot site were managed notionally, where budget holders were made aware of the level of resource available to them and the money was paid direct to the detox or support provider from the pilot site. The support/care plans were either signed off by the Alcohol team or by a virtual panel when clients decided to purchase a detox, additional support or other interventions which were outside the norm.

Within the pilot site offering personal health budgets to individuals with alcohol and/or drug misuse problems, individuals could access the initiative at the time they presented at the service or individuals were identified through arrest or referral. A care navigator was appointed to each individual assessed as being eligible for a personal health budget. Personal health budgets could be managed on a notional basis or as a direct payment (after the pilot site had been granted new legal powers). The support/care plans were signed off by the care navigator, their manager and a consultant psychiatrist.

In both pilot sites, individuals had a full assessment that identified health needs before the offer of the personal health budget. The level of the budget was assessed through using a Resource Allocation System in both sites, and flexibility concerning the type of services/help that could be purchased was encouraged.

2.2 Overall research design

The study used a controlled trial with a pragmatic design (depending on pilot site arrangements) to compare the experiences of people receiving a personal health budget with the experiences of people continuing under the current substance misuse treatment support arrangements.

Selection of individuals into either the personal health budget or control group occurred in one of two ways, depending on the pilot site. In one pilot site, people who were judged as potentially eligible for a personal health budget were randomised into either the intervention or control group. Individuals selected to the personal health budget group were offered a budget and were asked to participate in the evaluation. The offer of the personal health budget was not dependent on participating in the research. People selected into the control group were also asked to participate in the evaluation, and they continued to receive conventional services. For this pilot site, the starting point for recruitment to the pilot depended on whether an individual was going to have some form of structured treatment for their substance misuse problems.

The second pilot site was set up so that health professionals working within separate substance misuse service sites either offered personal health budgets or recruited to the control group. The control group comprised of patients from substance misuse services who were alcohol-dependent and using conventional arrangements for their inpatient detox. These people were recruited at the various sites by their key workers.

The aim was to recruit 220 individuals to the study (110 to the personal health budget group and 110 to the control group). While the sample would not be sufficient to produce robust results, it was thought the data collection would add to overall understanding on how and when personal health budgets should be implemented among patients with substance misuse issues.

Allocation into either the personal health budget group or the control group was followed by a number of quantitative and qualitative data collection points over a 9- to 12-month period.

2.3 Data collection

The data collection process and instruments followed the main evaluation of the personal health pilot programme. Figure 2-1 outlines both quantitative and qualitative data collection that was followed to explore:

- Patient outcomes and experiences;
- Implementation experiences.

2.3.1 Individual outcome data

Within the quantitative data collection, outcome data were collected on two occasions: at the time of consent and between 9 and 12 months after consent.

Organisational representatives working within the pilot sites carried out the baseline outcome interviews between February 2011 and October 2011. The follow-up interviews took place between 9 and 12 months later; they began in July 2012 and continued until September 2012. These interviews were conducted by a research fieldwork agency.

The outcome questionnaires included the following outcome measures:

- Social care-related outcomes (ASCOT Adult Social Care Outcomes Toolkit);
- Health-related quality of life (EQ-5D Euro-QoL);²
- Psychological well-being (GHQ-12);
- Alcohol Use Disorders Identification Test (AUDIT-C).

² © 1990 EuroQol Group. EQ-5D^m is a trade mark of the EuroQol Group.

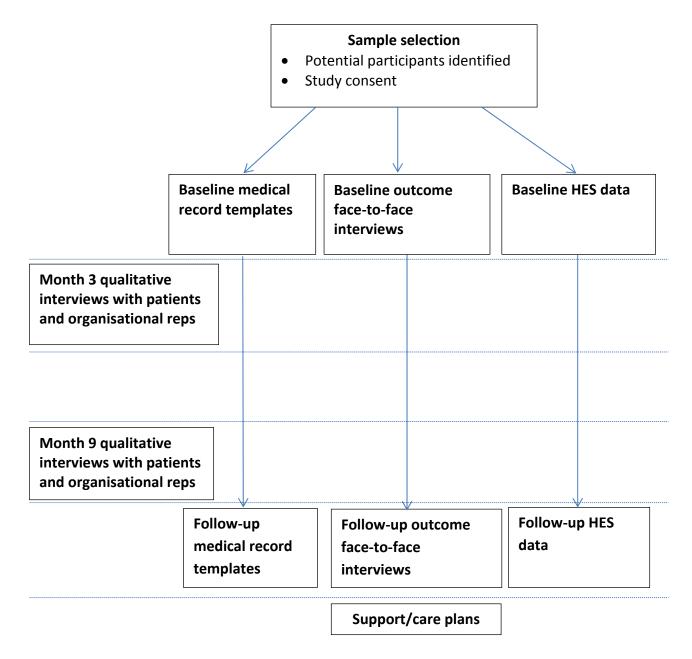
Further details of the outcome measures can be found in Appendix C. The outcome questionnaire also collected information around primary care service use. In addition, demographic (for example, ethnicity, age, gender) and socio-economic (for example, highest education level) information was collected, as well as information about current circumstances (household composition, employment status).

2.3.2 Primary and secondary care service use

A medical record template was designed by the evaluation team to gather information from GP records about participants' health status and their use of primary health care services.

This information was collected at two points during the study period: first, around the time of consent to explore the previous 12 months activity; second around 9 to 12 months after participants had agreed to take part to gather information for the year following consent. Information about secondary health care service use during 2008 and 2012 was gathered from Hospital Episodes Statistics (HES).

Figure 2-1. Data collection sequence



2.3.2.1 Information about the support/care plan and personal health budget

For the personal health budget holders, the evaluation team asked the project leads within the two pilot sites for a copy of the support/care plan that outlined the following information:

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

2.3.2.2 Qualitative data on patient outcomes and experiences

A subsample of participants in both the personal health budget group and control group was interviewed on two occasions to explore their experiences of receiving a treatment programme. The first was three months after participants had been offered a budget (or after the date of consent for the control group) and a follow-up was conducted six months later (nine months after being offered a budget or date of consent for the control group). The topic guides were based on data collection instruments used within the main evaluation of the personal health budget pilot programme and research commissioned by the Drug and Alcohol Information and Research Unit, Department of Health, Social Services and Public Safety, Northern Ireland (Deloitte MCS, 2004).

Interviews lasted between 60 and 90 minutes. The topic guide was used flexibly. While all key themes were covered with participants, certain questions were omitted where not applicable to that person's circumstances. Before each interview, the nature and context of the research study, and what the findings would be used for, were explained to the participants. It was emphasised that participation would be anonymous, and consent was sought to record the interviews, which was granted in each case. Interviews were conducted over the telephone, were digitally recorded and subsequently transcribed and coded.

2.3.2.3 **Qualitative data on implementation issues among organisational representatives**

Semi-structured interviews were also conducted with organisational representatives from the substance misuse pilot sites on two occasions at month 3 and month 9. Interviews explored their views of the implementation process and the perceived success of the local pilot. During the first round of interviews, the focus was on exploring early experiences of implementation. The second wave of interviews focused on the impact of implementing personal health budgets on working practices, as well as the perceived impact that the initiative had on patients. The organisational representatives interviewed as part of this process included project leads, commissioning managers, health professionals, care navigators³ and front-line operational staff.

³ In this report, the term care navigator refers to any staff member who is involved in organising the patient's care/support package.

3 The sample

3.1 Quantitative sample

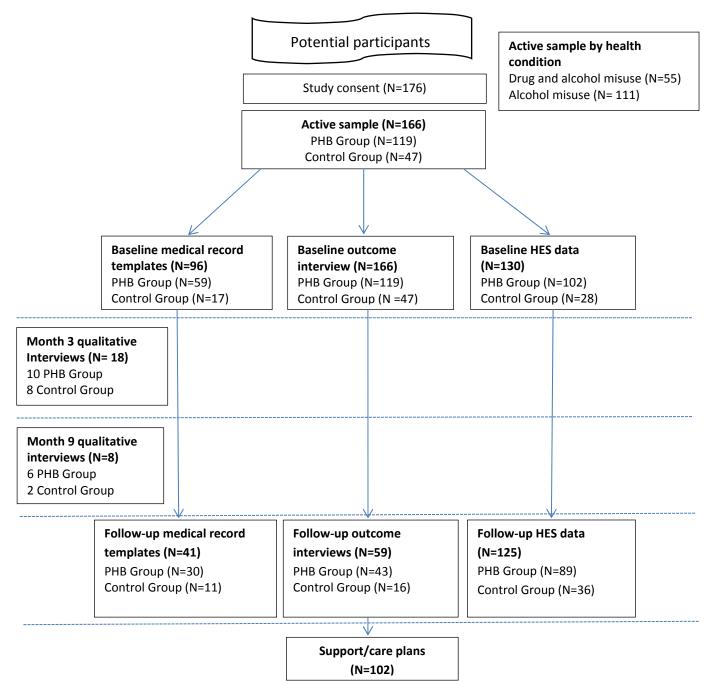
Figure 3-1 outlines the sample. Study consent was originally gained from 176 people, with 166 participants included in the active study sample (119 in the personal health budget group and 47 in the control group). This active sample excluded participants who had not completed a baseline questionnaire or who had withdrawn before follow-up. Within this active study sample, 26 participants withdrew from the study (25 participants in the personal health budget group and 1 in the control group). The majority of these participants had dropped out of treatment and so withdrew from the pilot, but four people had been sent to prison and one had died.

Within the active study sample, 55 participants had drug and alcohol addictions and 111 had an alcohol addiction only. Due to the sample size, it was not possible to carry out sub-group analysis and therefore the samples were combined into one overarching substance misuse group. In terms of the follow-up sample, the fieldwork agency received contact details for 144 participants and interviewed 59 (43 in the personal health budget group and 16 in the control group).

Within the active sample, the baseline medical record template was completed for 76 participants (46 per cent of the active sample) and 41 participants at follow-up. In terms of secondary care service use, information from the Hospital Episodes Statistics database was collected for 130 participants at baseline and 125 at follow-up⁴⁵. Figure 3-1 shows that the breakdown between groups was uneven, with a smaller sample for the control group. The small sample resulted in analysis not being carried out to explore whether personal health budgets had an impact on primary and secondary care service use compared to conventional services. Support/care plan data were also received for 102 budget holders.

⁴ Baseline medical record and HES data was collected for the year before consent date and one year after consent.

Figure 3-1. The sample



3.1.1 Completed baseline outcome questionnaire by age, gender and ethnicity

Table 3-1 combines information on age, gender and ethnicity. The table shows that 26 per cent of the sample (N=43) were female and 12 per cent were from a black and minority ethnic community (N=20).

	Mean age	Per cent female % (N)	Per cent BME % (N)
Overall	42 years	26 (43)	12 (20)
Personal health budget group	43 years	20 (33)	10 (16)
Control group	40 years	6 (10)	2 (4)

Table 3-1. Sample characteristics of the baseline outcome questionnaire

3.1.2 Household composition and education level

Table 3-2 shows that individuals in the control group were marginally more likely to be living alone (52 per cent) compared to people in the personal health budget group (47 per cent).

	PHB Group	Control Group
	% (N)	% (N)
Married/cohabiting	21 (25)	27 (12)
Single	79 (92)	73 (33)
Lives alone	47 (55)	52 (24)
University/college graduate	21 (24)	27 (12)
Secondary school education	49 (57)	56 (25)
Primary school education	9 (10)	0 (0)

3.2 Qualitative sample

Overall, 18 participants (10 personal health budget holders and 8 patients in the control group) were interviewed at the first time point; by the second time point the sample had reduced to eight (6 personal health budget holders and 2 people accessing services in the conventional way). There were a number of reasons for the reduced sample at follow-up, including refusing to be interviewed again, moving address and clients going into prison.

Table 3-3 shows the gender and age of individuals participating in the in-depth qualitative interviews. Table 3-1 shows that 20 clients from a BME community were recruited into the overall study. However, the timing of the qualitative interviews and delays in receiving the permission from project leads to make contact⁶ reduced the potential sample to be invited to participate in the in-depth interviews to eight. This potential sample either refused to be interviewed or we were unable to make contact with them.

Characteristics	3 month	ı interview	9 month	9 month interview	
Gender	PHB	Control	PHB	Control	
Male	5	6	2	1	
Female	5	2	4	1	
Mean age	48	34	43	39	
BME	0	0	0	0	

Table 3-3. Sample characteristics of the qualitative sample at both time points

⁶ Project leads were initially contacted to make sure that it was appropriate that the research team got in touch with participants.

4 The content of the personal health budget support/care plans

4.1 Introduction

A number of principles underlying personal health budgets were outlined in Chapter 1. To summarise, personal budget budgets holders should be:

- 1. Informed of the level of resources available in the budget before support/care planning;
- 2. Encouraged to develop a support/care plan outlining how the resource will be used to meet identified health needs and outcomes.
- 3. Given the choice of how the resource is managed.

In this chapter we describe the level of the personal health budget funding, the content and management of support/care plans, and the degree to which individuals were taking advantage of the flexibility in deciding how to manage the budget and the innovative services/support that were purchased. Throughout this chapter we will also draw on qualitative evidence that was gathered during the study from patients and organisational representatives.

4.2 Method

All the information about the level and use of personal health budgets was drawn from the support/care plans. Among the personal health budget group, the research team received 102 support/care plans from the two pilot sites.

4.3 Size of the budget

Table 4-1 shows that 41 budgets were worth between £1,000 and £5,000 per year, while 4 budgets each were worth more than £10,000. There are three different ways that personal health budgets can be managed (or potentially a combination of them): notional, where the budget is held by the commissioner but the budget holder is aware of the treatment/service options and the corresponding costs; managed by a third party; or as a direct payment (in certain approved sites only), where the patient receives a cash payment to buy services. The majority were managed notionally (79 per cent), while 20 per cent (N=20) of budgets contained a combination of deployment options.⁷

Thirteen budgets had a nil value due to a number of reasons, including:

⁷One pilot site had powers to offer direct payment; however during the evaluation we did not receive information suggesting that this deployment was being offered. For the study, a combination of deployment options refers to notional and third-party funding arrangements.

- No services had been decided or had been agreed;
- Detox had not been completed;
- No services were currently being purchased.

	Ν	Mean	SD	Min	Max
Overall budget	102	£1,503	£2,619	£0	£16,805
Between £200 - £500	25	£380	£100	£250	£500
Between £501 - £1000	17	£708	£175	£550	£1,000
Between £1001 - £5000	41	£1,612	£534	£1,005	£2,914
Between £5001- £10,000	2	£6,901	£779	£6,350	£7,452
Between £10,001- £17,000	4	£12,964	£2,846	£10,292	£16,805

Table 4-1. Average costs for the overall substance misuse personal health budget group

Table 4-2 shows the cost breakdown of services within the support/care plan. Residential detox was the largest single cost expense category, and transport was the lowest mean. Transport costs included Oyster cards, taxi fares and bus journeys, among other things, and enabled budget holders who did not drive or could not afford transport to attend the detoxification centre and obtain their treatment. It is possible that funding transport gives greater control and independence over treatment, and enables budget holders to feel less reliant on family or friends for lifts. One budget holder said: "the personal health budget really helped me because I couldn't afford to get a taxi there [to the treatment centre] every day to have my medication, and it's very difficult where I live to get a bus; there's only one every hour. So it was ideal for that. I don't know what I would have done without it because I don't drive, so I really appreciated it."

Table 4-2. Service and support costs, by type

		Mean	SD	Min	Max
Conventional detox	Community Detox	£1,909	£3,681	£325	£13,228
	Residential Detox	£3,834	£4709	£120	£15,700
Transport		£77	£136	£8	£710
Leisure [*]		£241	£142	£55	£385
Contingency		£370	£251	£7	£949
One-off purchases ^{**}		£419	£299	£40	£926
Support services (i.e. counselling)		£405	£334	£104	£1,068

*Leisure included gym classes, swimming, a football ticket and a theatre ticket

**One-off purchases included clothing, passports and IT equipment (such as a laptop)

Underlining the initiative is the principle that budget holders should know the value of their budget so they can begin the support/care planning process. When the budget level was known, most budget holders reported being satisfied with the amount; some thought it was "very generous, plenty for what [they] needed". However, similar to the main evaluation of personal health budget pilot programme, the in-depth interviews revealed that, three months after the offer, a number of individuals still did not know the level of the budget. At nine months, two budget holders were unaware of the level of the budget. There seemed to be a degree of uncertainty around how services were funded: out of the personal health budget or from conventional PCT/LA funding. One budget holder argued that if she had known the actual amount of the budget before the support/care planning process began, she would have made different choices.

Enabling people to access community detox rather than residential detox could be regarded as a significant switch for clients and an innovative use of their budget. Aside from this shift, however, relatively few support/care plans showed personal health budgets being used to purchase other innovative support/services. We can only speculate why this might be the case. One possible reason may be because the support/care planning process coincided with individuals being at a crisis point. The interviews with organisational representatives suggested that, for some individuals, it may be at the later relapse prevention phase that a personal health budget would work best: after detox when people are free of substances and in an appropriate condition to consider a personalised package for their after-care. This suggestion is developed further in Chapter 6.

Table 4-3 provides further information on the specific services/support that were purchased through the personal health budget. The table shows that a small number of budget holders did request services/support that might be regarded as more innovative than conventional services. For one budget holder, these included driving lessons to enable greater independence, taking some GCSEs to give greater life chances, and an internet connection to aid in revision and to be able to research further courses to

attend once the course had been completed. This budget holder believed that life improvements would have a positive impact on well-being, and the alcohol cravings would eventually disappear.

Type of use	Examples
Technology	Laptop, internet access
Transport	Taxi fare
Alternative therapy	Acupuncture, massage
Detoxification	AA, private detox clinics, self-help groups
Care	Employing a carer/PA to take patient to appointments
Leisure activities	Gym, swimming
Education	GCSE courses

Table 4-3. Services budget holders reported purchasing during the semi-structured interviews

4.4 Discussion

Similar to the main evaluation of personal health budgets pilot programme, this chapter highlights that varying degrees of choice and control were given to budget holders seeking support from services aimed at helping with substance misuse problems. While one of the pilot sites did have approval to offer direct payments,⁸ we did not find evidence that this deployment option was being offered during the study period. The in-depth interviews with organisational representatives explored the various implementation issues and challenges around offering the direct payment deployment option to this client group, which will be discussed in chapter 6.

⁸ There were restrictions to the general power to offer direct payments; for example, people on certain criminal justice system orders/community sentences were excluded. The Department of Health placed further restrictions on sites offering direct payments for substance misuse (Department of Health, 2010).

5 Do personal health budgets have an impact on patients' quality of life and perceptions of what can be achieved?

5.1 Introduction

A key objective of the study was to identify whether personal health budgets had an impact on quality of life and relapse rates among patients seeking treatment for substance misuse problems compared to conventional service delivery. The purpose of this chapter is to describe the change in quality of life and relapse rates for individuals in the personal health budget and control groups between baseline (before the intervention began) and up to 12 months after consent date (follow-up). Quantitative and qualitative findings will be used to explore three questions:

- What were the experiences of individuals receiving treatment via the personal health budget and those receiving support from conventional service delivery?
- Is there evidence that personal health budgets lead to improved relapse rates compared with conventional service delivery?
- Is there evidence that personal health budgets lead to better quality of life outcomes compared with conventional service delivery?

This chapter is structured as follows. In the next section we briefly review the methods relevant to this chapter and the sample of participants that we used to assess the effects of using personal health budgets. Section 5.3 reports the results, and we end with a discussion of those results in Section 5.4.

5.2 Quantitative data collection

As described in Chapter 2, quantitative outcome information was collected at the time of consent (baseline) and between 9 and 12 months after consent (follow-up). Participants were invited to be interviewed face-to-face using a questionnaire containing a number of well-being measures. Appendix C describes the measures in more detail, and here we briefly summarise them.

- **Psychological well-being:** The GHQ-12 aims to measure the psychological well-being of service users by exploring whether respondents have experienced a particular symptom or behaviour over the past few weeks.
- *Health-related quality of life*: The EQ-5D utility scale aims to measure a person's quality of life in domains likely to be related to their underlying health status.
- **Care-related quality of life**: ASCOT (Adult Social Care Outcomes Toolkit) aims to measure people's ability to achieve everyday activities, including basic capabilities such as dressing and feeding themselves.
- Alcohol use disorders identification test (AUDIT-C) includes three questions which are used as a screening to identify individuals with hazardous and harmful patterns of alcohol consumption.

As outlined in Chapter 2, to explore whether personal health budgets had an impact on an individual's quality of life and relapse rates, we used the difference-in-difference approach. The analysis subtracted an individual's follow-up outcome scores from their baseline score. A full description of the approach can be found in the main evaluation of personal health budget report. However, due to the small sample size, the analysis did not include exploring difference-in-difference multivariate models, and therefore we were unable to control for confounding baseline differences.

Further to this, as outlined in Chapter 2, a sub-sample of patients from the personal health budget and control groups were invited to take part in in-depth qualitative interviews. The interviews explored the experiences of receiving services/support to help with their substance misuse problems. The qualitative findings have been used in this chapter to help answer the research questions outlined above.

5.3 Views from patients receiving a personal health budget or conventional treatment services

5.3.1 Satisfaction with services

Personal health budgets were seen to have the potential to be better than conventional treatment pathways, if properly implemented and managed. One personal health budget holder stated that they had high hopes for it.

It's been a really positive experience for me and it's what I've needed for a long time. The [personal] health budget [paid for] the carer to take me to detox every day and that was really helpful and she was very good, she was very supportive and I got on very well with her. I didn't have to ask anybody in the family to take me 'cause that's quite a commitment isn't it'.

Initially, those receiving a personal health budget seemed excited about the concept, and overall they seemed happier than patients receiving conventional services. Patients receiving conventional services often mentioned feeling unhappy and disappointed with the service. One patient in the control group discussed the potential benefits of receiving a more personalised, one-to-one care. The patient said:

I go to groups, but not everybody feels comfortable in a group situation. It's peer-led, so it's kind of like the blind leading the blind, if you like. I was hoping for a bit more one-to-one stuff, with somebody that I can actually kind of like be full and frank with.

This individual said that "no choice whatsoever" was offered. "They [the GP] didn't want to know my other problems, just basically he gave me a prescription for Prozac and that was that. And so I was quite disappointed with that." This participant talked about broken promises and being "fobbed off" by the promise of medical intervention to help beat the addiction.

Furthermore, individuals using conventional services also expressed frustrations and anxieties, often regarding delays in receiving treatment. One individual in the control group argued:

It has been fairly difficult; it took a long time to get any kind of real support. I was initially told by my GP that services were available and then... it took a long time to actually get things moving. There's a long waiting list as well, so, I just sort of had to tough it out really. However, there were also a number of delays in the personal health budget process, as outlined in Section 5.3.3.1.

5.3.2 Relationships with health professionals

There seemed to be a consistent view among individuals in the personal health budget group that the process had a positive impact on their relationship with health professionals. Patients talked about improved relationships with their health professionals due to a closer and a more power-equal relationship. They thought they were given more time and were listened to and understood more. One individual in the personal health budget group stated: *"because you've got more control you're getting on better with care workers and you've just got a better relationship."*

This view is consistent with those held by organisational representatives (reported in the next chapter) who also discussed the potential personal health budgets offer for neutralising the power staff hold over patient treatment journeys. For example, one operational staff member argued:

It's created an equalisation of power, as they are doing their own self-assessment. They're telling you things that they wouldn't have told you before. You're spending more time with them. There is a lot more care that goes into this care plan. It has opened our minds, so rather than just banging them into rehab we're looking at the full picture/

In comparison, patients receiving conventional treatment (control group) services tended to express general dissatisfaction with health professionals: *"The GP was a bit dismissive of my other problems. They were quick to pass me on, and my other medical problems have been a concern for me for a long time and I was basically just shunted towards dealing with, I suppose the big problem, which was my drinking. I felt that the GP didn't manage my other problems at all."*

It was also felt that GPs were ill-informed about possible treatment centres that patients could attend. Another patient from the control group reported: *"I think GPs should have more information. Initially I went with depression and an alcohol problem and I was not advised. I'm angry with them because there was not one mention of any form of place... for any form of alcohol treatment. Not one thing was mentioned, and I found that frustrating. They don't seem to be trained enough in any form of addiction."*

Many of the individuals in the personal health budget group did report dissatisfaction with their GP before the onset of the personal health budget. This dissatisfaction centred mainly on the GPs' perceived lack of sympathy and failure to address their problems in a holistic way.

5.3.3 Personal health budget process

The majority of individuals in the personal health budget group were generally happy with the process and the plans for spending their budget. Furthermore, it was consistently thought that personal health budgets could enable access to more individualised treatments to suit their lifestyles: *"So I was fully involved in that process, yes. I could say what things I would like to do and she made some suggestions about what things she thought would be good for me to do and then she referred me to those groups. So I guess that was the closest I ever came to having a care plan."*

However, there seemed to be a number of barriers within the personal health budget process, such as delays and a lack of information.

5.3.3.1 Delays in the process

The reasons for the delays were often not known, but some assumed it to be 'bureaucracy' and others believed it to be staff inexperience.

At the moment it's a waiting game. I asked for acupuncture months ago to help with cravings. A lot of people would have relapsed by now. It needs to be sorted much quicker.

These delays caused individuals great distress and anxiety. Those who felt this way attributed it to poor communication on the part of the personal health budget team. Such emotions are not conducive to overcoming substance misuse problems, as one budget holder stated:

People who have substance abuse problems often suffer from severe anxiety and depression as part of their illness, and it's been really worrying. There must be people who've become more ill because they've been so worried about it. I think I did drink more because I was so anxious.

While these cases had potentially serious implications for individuals, one pilot site reported that waiting times had been reduced for clients accessing detox services.

5.3.3.2 Provision of information

Initially, there seemed to be a degree of uncertainty around the personal health budget process and how the resource could be used. During the initial interviews, a consistent theme was for the need for more information concerning the ways that the personal health budget could be used. Budget holders stated that they wanted lists of suggestions of possible uses, and information on how other people in similar situations had used their budget to help them think of suitable ways to use the resource themselves. It would seem that staff members within this cohort have an important role, within helping the budget-holder generate ideas: *"If I had had more knowledge at the time, more information, it might have changed what direction I went in. More information would have led to more questions and enquiries. I think the service provider was struggling themselves."*

This finding is similar to that in the main evaluation of personal health budgets. The fourth interim report published during the main evaluation described how most people felt that they had sufficient information in deciding to try a personal health budget, but that the level and format of information required can vary significantly between individuals (Irvine et al., 2011). A minority of people interviewed as part of the main evaluation thought that they would have benefited from additional information regarding how they could spend their budget. This can be made increasingly complicated for individuals with substance misuse problems, for example, when they present with varying degrees of impairment due to alcohol or drug use, which may then change over time. A small number of substance misuse participants forgot that they had a budget. The variety and duration of participants' information needs suggests the importance of a flexible and individualised approach to information, advice and support for budget holders, with on-going opportunities for further queries to be answered.

In summary, the findings from the in-depth interviews outline some of the positive impacts that personal health budgets can have on individuals. Individuals in the control group consistently reported more negative experiences, while individuals in the personal health budget group were more positive in terms of the relationship they had with health professionals and their experiences of services. However, the qualitative findings also highlight the importance of effective implementation, both in terms of providing

the necessary information to enable budget holders to make an informed choice, as well as to minimise any delays in the process of obtaining and using a budget.

The next section will explore the variation in satisfaction with received services and support/care planning.

5.4 Satisfaction with services and support/care planning

Table 5-1 shows that patients in the personal health budget group were more satisfied with the help they received paid for by the budget and the support/care planning process, compared to those in the control group. Furthermore, they were more likely to agree that they had enough choice and control over the help they received paid for by the personal health budget. While the results were not statistically significant, they do indicate a potential positive impact of receiving a personal health budget.

Table 5-1. Satisfaction	with services	s and support,	care planning

	PHB group	Control group
	Mean (SD: N)	Mean (SD; N)
Satisfaction with help received	2.76 (1.64: N=17)	3.69 (2.02: N=16)
Satisfaction with the support/care- planning process	3.37 (1.23: N=43)	4.19 (2.10: N=16)
I had enough choice over the help I wanted	2.72 (1.70: N=25)	3.25 (1.48: N=16)
I had enough control over the help I wanted	2.56 (1.39: N=25)	3.38 (1.36: N=16)

Note: lower mean ratings indicate higher levels of satisfaction

The above results are supported by some of the qualitative in-depth interviews with budget holders. Positive experiences of support were characterised by a good rapport with well-informed, accessible and responsive organisational representatives or health professionals. Conversely, if contact between the health professional and patient was poor, patients reported feeling unsupported and vulnerable. *"They were very supportive at the beginning, but then it just sort of fizzled over the last few months and now I don't know what has happened to my budget. Yes I do feel so anxious about it, you know."*

However, there was a sample of budget holders that did not recall the support/care planning process, which possibly indicates the issue of when the personal health budget process should begin, as outlined above.

I haven't been given any other paperwork saying I've got a health budget. But if I had a health budget, knowing what it is then maybe there's other services which I don't know of and definitely use them.

5.5 Variations in outcome change

The next section explores whether personal health budgets had a significant impact on quality of life and relapse rates compared to conventional service delivery. The difference-in-difference analysis was run on the quantitative outcome interviews at baseline and follow-up. Due to the small sample size, difference-

in-difference multivariate models were not explored. We will begin with exploring the impact that personal health budget had on relapse rates.

5.6 Variation in relapse rates

The shortened version of the Alcohol Use Disorders Identification Test (AUDIT-C) was used to detect signs of hazardous and harmful drinking. Table 5-2 suggests that individuals in the personal health budget group were less likely to meet the cut-off point for excessive drinking (score of 4 or more for men and 3 or more for females) at follow-up compared to those in the control group. Similar results were found with the change in drug consumption at follow-up. However, the sample size was too small to show a meaningful difference, and the results need to be treated with caution.

		PHB group		Control group	
		Mean	SD	Mean	SD
AUDIT_C	Baseline	.950	.220	.872	.337
	Follow-up	.983	.129	.979	.145
	Change	.034	.024	.106	.055
Drug use	Baseline	.655	.478	.489	.506
	Follow-up	.163	.374	.375	.500
	Change	628	.094	200	.223

Table 5-2. Alcohol and drug consumption at baseline and follow up

Note: Not meeting the cut-off point for excessive drinking indicates a reduction in alcohol intake

While the initial signs in Table 5-2 are positive among individuals in the personal health budget group, a consistent view held among budget holders focused on the lack of after-care services available with this treatment route that could potentially have a longer-term impact on relapse rates. The desire for post-detox care to prevent relapse was common, especially at follow-up, when patients had completed their detoxification and required relapse prevention services. Many budget holders stated that they felt that after-care was often lacking as part of the personal health budget, and interviewees could not understand why after-care counselling was not also financed through their personal health budget.

It's just the relapse prevention that is the problem. I just keep relapsing. That's where the services should be. What will happen once the PHB runs out? Will I get more funds? Because I kept sort of relapsing.

However, this desire for after-care was not exclusively expressed by the personal health budget patients. It was also reported to be a concern by one individual in the control group, who said:

Something of a misleader was the after-care package, which doesn't really exist. It's just a word. I know they have a helpline that you can ring and that sort of thing, but I mean at the end of the day so do the Samaritans. So this after-care package I think it's buffered as a sort of like it's all going to be good and all that. And really it's not, you're released out into the wild and that's why so many people fail.

In terms of the personal health budget process, the views held by patients corresponded with how some staff felt. Operational staff suggested that a crisis point was not always an appropriate point in the treatment journey to implement the personal health budget. One operational staff member who felt that the budget would be more suited to the recovery period, argued: *"I think the place where this will end up fitting in perhaps will be with after-care. Not crisis; people who are in crisis they just want rescuing, they don't want to be thinking too much."*

Interviews from both patients and staff raised the question of when and what is the best and most appropriate use of personal health budgets: should it be used at crisis point or as a recovery (after-care) budget? The findings from this research seem to suggest the latter; when an individual had successfully undergone detoxification treatment, they would be better able to benefit from the choices offered through the personal health budget.

5.7 Variations in subjective outcome change

The next section explores whether personal health budgets had a significant impact on subjective outcome measures compared to conventional service delivery.

Table 5-3 shows the outcome change for individuals in both the personal health budget and control groups. The results suggested that, on average, there were greater improvements in care-related quality of life (ASCOT) and psychological well-being (GHQ12) for individuals in the personal health budget group compared to those in the control group, although the difference is not statistically significant.

		PHB gro	up	Contro	l group	Difference
		Mean	SD	Mean	SD	Mean
ASCOT	Baseline	3.88 (n=113)	1.14	4.00 (n=45)	1.09	-0.13 ^{NS}
	Follow-up	4.35 (n=43)	1.22	4.22 (n=16)	1.22	0.13 ^{NS}
	Change	0.41	1.29	0.17	1.06	0.24 ^{NS}
EQ-5D	Baseline	0.59 (n= 117)	0.24	0.60 (n=45)	0.24	-0.01 ^{NS}
	Follow-up	0.52 (n=43)	0.22	0.54 (n=16)	0.22	-0.01 ^{NS}
	Change	-0.59	0.31	-0.55	0.24	-0.04 ^{NS}
GHQ12	Baseline	21.39 (n=117)	8.13	22.19 (n=42)	7.88	-0.8 ^{NS}
	Follow-up	18.26 (n=43)	8.42	20.44 (n=16)	7.74	-2.18 ^{NS}
	Change	-2.95ª	9.88	-1.80	8.53	-1.15 ^{NS}

Table 5-3. Outcome measures – means and differences, baseline and follow-up

Note: ^a A negative change denotes an improvement on GHQ12.

The positive impact of receiving a personal health budget was echoed in the in-depth interviews. Consistently, it was felt that the personal health budget process gave greater choice and control over the provision of care. One person whose budget paid for a carer to take them to the substance misuse drop-in centre expressed great satisfaction with the budget:

It gave me control, I felt as though I was more in control of the actual detox because I wasn't relying on friends and family to take me. I have stuck at it this time.

Another interviewee anticipated that the increased independence created through the personal health budget would help them move towards obtaining paid work. Others anticipated improvements in their motivation and morale by being more in control of their treatment.

However, a minority of individuals said the personal health budget did not have an impact on their health outcomes, nor did they predict any: they believed the personal health budget had merely replaced their previous provision. One individual reported: *"Nothing has changed, still doing the same detox."* Equally, no-one reported that their outcomes were made worse as a result of their personal health budget. Nonetheless, the majority of budget holders suggested that further information and more efficient implementation would have improved their experience of having a personal health budget. In relation to this, one budget holder commented: *"If this is to work it can't continue to run on and on like this. Especially for people with addictions as they are more likely to relapse and then what's the point of it all?"*

5.8 Conclusion

A number of key quantitative and qualitative findings discussed in this chapter could be used to guide the national roll-out of personal health budgets among individuals in need of services to help them with their substance misuse problems. The quantitative findings suggest that personal health budgets have a positive impact on reducing relapse rates and improving individuals' quality of life and psychological well-being at follow-up. However, due to the small sample, firm conclusions around the impact of personal health budgets compared to conventional service delivery cannot be made; and difference-in-difference multivariate analysis could not be carried out and so confounding baseline characteristics were not explored. However, the findings from the qualitative in-depth interviews with clients suggest that offering more choice and control through personal health budgets could be beneficial to clients in need of support with their substance misuse problems. However, a number of negative views of the personal health budget implementation process were expressed in the qualitative interviews that will need to be addressed in any future roll-out of the initiative.

6 Views from the system

This chapter focuses on the views of organisational representatives implementing personal health budgets within substance misuse services.

6.1 Method

The aim was to conduct a total of 20 interviews with 10 organisational representatives at two time points. Interviews were conducted between March and April 2011 for the first wave, and between June and July 2012 for the second wave. In total, 20 interviews were conducted with 12 organisational representatives. Two organisational representatives were no longer in post when it came to the second wave of interviews so could not be re-interviewed. In both cases the replacement member of staff was interviewed. Table 6-1 shows the roles of the 10 organisational representatives who were interviewed across the two pilot sites and time periods.

Table 6-1. Interviews with organisational representatives

Type of organisational representative	Number of interviews
Project leads / managers	3
Commissioning managers	2
Health professionals	2
Support workers	1
Front-line operational staff	2

During the first round of interviews with organisational representatives, the focus was on exploring early experiences of implementation. The second wave of interviews focused on the impact that implementing personal health budgets had on the system and patients. The organisational representatives interviewed as part of this process included project leads, commissioning managers, health professionals, care navigators and front-line operational staff.

The interviews were semi-structured, allowing participants to share their views on implementation, the impact of personal health budgets and other relevant issues. Each interview lasted approximately 1.5 hours. Interviews were transcribed and coded in accordance with the areas covered in the topic guide.

A number of themes emerged during the interviews, and these can broadly be separated into two areas: the impact of personal health budgets on providers and patients; and implementing the personal health budgets pilot. These are explored here with reference to a number of sub-themes.

6.2 Impact of a personal health budget on providers and patients

The interviewees unanimously agreed that there were a number of advantages for both patients and service providers in implementing personal health budgets within the area of substance misuse. A number of consistent themes emerged, including: increased choice and control; more flexibility; and encouraging creativity and innovation. These will be discussed here, along with a number of other themes.

6.2.1 Increased choice and control

Perhaps in contrast to what some clients felt themselves, organisational representatives consistently stated that using personal health budgets enabled the budget holder to have more choice over the services they could access, and gave them more control over those services. The introduction of choice meant that a wider range of options could be presented to patients which, according to interviewees, enabled a more 'person-centred' approach to be taken when considering potential courses of action. It also meant that, where some providers were regarded as 'better' or more appropriate, these could now be utilised.

Where we've always used, or historically we've always tended to use the same detox provider, and we were never happy with the service that they offered but there was never any other choice, it's just nice to be able to give them the choice rather than having to stick with the same old detox regime. [Operational staff]

Interviewees consistently spoke about the impact of having 'control' for clients. The impact of this was two-fold: first, that clients appeared to appreciate having control over when and where they could access services which, according to interviewees, made it more likely that clients would attend or engage with those services; and secondly, that giving clients more control over the services or treatment options that they engaged with led to clients taking greater responsibility for their own care. This element of 'taking control' for clients was particularly important; health professionals, support workers and front-line operational staff all reported that in some cases this contributed to successful outcomes for clients where previously they had relapsed into drug or alcohol misuse. Interviewees believed that this was due to an attitudinal shift in the way that clients approached having control over other aspects of their lives. Interviewees suggested that having greater control over their support/care plan helped some clients to recognise the role that they could play in 'helping themselves'. This gave clients greater encouragement to achieve what they wanted, not only in dealing with the substance misuse issues that they had presented with, but also carrying this forward in to other aspects of their lives, such as returning to education.

6.2.2 Increased flexibility

All interviewees expressed the view that, as a result of being able to incorporate flexibility within care packages, people were getting a better service than could conventionally be provided. This was because

people now had the opportunity and flexibility to be able to build services around their lives rather than be passive recipients of services that were 'prescribed' to them.

For the people that are lower grades⁹ I think that the advantage for them most definitely is that they're probably getting a much better service. They have a choice of a detox that gives them the extra support, but they don't necessarily have to go in somewhere to do that. So, for instance, it might be somebody who's drinking lower levels, whose withdrawal symptoms aren't quite as bad and, you know, might have children. So they can actually fit their detox around their life style. [Operational staff]

So people who previously would have just gone straight to the [provider], now they would be going there with the support package around the times which suit them; someone popping in, someone making sure they're all right, someone maybe staying overnight and all sorts of things like that. [Project lead]

One of the most important aspects of increased flexibility was that it led to a provision of extra support that would not otherwise be provided. This was possible as support/care planning afforded care navigators increased opportunities to address clients' needs in ways that had previously been unavailable to them.

I found that actually it is much better and people are liking the fact that they can have someone that will come pick them up, take them to wherever they need to go to pick up their medication in the morning, and then be there perhaps two or three times if they want in that day, and still be within their band. So it's brilliant in that respect, so we can actually buy in sort of extra support for them. [Operational staff]

As well as these benefits, staff also believed that the fact that clients were encouraged actively to make their own, fairly free choices was in itself therapeutic and beneficial, and this active participation in their own recovery represented as much a key part of the recovery process as the actual treatments chosen.

Neither of the sites that took part in this study offered direct payments for patients to purchase their own services (despite one site having these powers), and all personal health budgets were held on a notional basis. Nonetheless, when asked about the potential use of direct payments, one project lead was in favour of making these available to clients, and expressed the view that this would increase flexibility even further. In particular, smaller or more ad-hoc purchases, such as paying a public transport fare, would become far easier. This would have the two-fold benefit of decreasing administrative burden on organisations and increasing the 'responsiveness' of being able to provide services or items for clients.

We haven't at the moment [got powers to use direct payments] but I think it would make life a lot easier, even for the smaller things that people need, so that they can be even more personalised ... I think one of the problems we have is not having fluid cash, to be able to say yes, you know, yes you can do that and there's that money to do that. [Project lead]

⁹ as measured using Alcohol Use Disorders Identification Test (AUDIT-C).

While also supporting the potential benefits of direct payments, one interviewee expressed caution when considering offering this deployment option to a vulnerable client group such as drug or alcohol misusers. In their view, there was potential for direct payments to make them more vulnerable.

Well, I think the problem with our client group is that our client group have relapse periods quite often. Or sometimes they're so vulnerable; they can be subject to the criminal activity of others, and criminal manipulation. So I think in terms of our client group, once it's been allocated from the local authority, if it's not held by the care navigators, as we're calling them, or managed by the care navigators, then it has to be a responsible adult either within the family or an independent broker, or someone of that calibre, simply because of our client group. [Project lead]

When asked to consider what would facilitate the use of a direct payment for this client group, the interviewee stipulated that a condition of abstinence would need to be met in order for clients to be offered a personal health budget via direct payment. However, this may negate the potential benefits of using a personal health budget, particularly during the initial period when the client may benefit from building services around them to meet their needs.

I think we would have to say that our client group has to be fully abstinent from drugs or alcohol. I would say total abstinence and probably a given period, so that a person would have been totally abstinent from drugs and alcohol for a period of a year, 12 months to 24 months... And that would probably facilitate them being able to hold perhaps their own personal health budget. [Project lead]

Notwithstanding this, there was a sense from some interviewees that substance misusers as a client group were being discriminated against because it is assumed that *"these people can't be trusted with money."* However, one operational staff member claimed that only through using direct payments could it be argued that substance misusers had absolute control over their budget.

It's about breaking those perceptions people have got. And, you know, those perceptions aren't just in the council estates or in the pubs, they're in governments and they're in councils. I think this whole thing makes us think about what we're doing and why we're doing it, I really do. I think people should be getting their direct payments whenever possible. [Operational staff]

People need to own it themselves, they need to say, "This is in my bank account, this is mine." Obviously with strings attached and we need our safety nets, of course we do. [Operational staff]

6.2.3 Encouraging creativity and innovation

As a result of the flexibility that personal health budgets afforded care navigators, almost all interviewees took the view that this encouraged creativity and innovation in the support/care planning process with clients. In some cases, this also led to a decrease in costs, which was facilitated by choice or the ability to 'shop around' and find the best and most efficient providers of the service that was required. The support/care planning process allowed people to have a greater, more in-depth understanding of a person's need, and people reported being able to use that knowledge or understanding more effectively because of the available options.

I think when you've only got a choice of A or B there's not a lot of discussion to be had. Whereas when people can start choosing other things then there's lots more discussion and work in terms of us checking out services or the things that people want to do. So yeah, I think it's actually enhancing practice...and through this we're actually having much more creative care plans and getting to know people much better I think than we were when we were simply offering A or B. [Health professional]

In some cases, having the choice to offer a community detox rather than a residential one opened up opportunities to address clients' needs in a different way. In this sense the use of community detox as an alternative could be viewed in its own right as an innovative use of a personal health budget.

6.2.4 Early outcomes perceived by organisational representatives

One of the overarching aims of this study is to explore whether personal health budgets improve quality of life for the budget holder in need of support for substance misuse problems compared with the conventional service delivery. The overwhelming view among staff was that the process has the potential to benefit the budget holder by increasing self-confidence, self-esteem and a 'sense of purpose'.

Rather than just banging them into rehab, now we're looking what package we could put around them in the community...We are looking at the full picture. Support plans are more holistic as they look at things outside of the medical. [Operational staff]

6.2.5 Support/care planning

One of the major ways of enabling the 'advantages' of personal health budgets that organisational representatives discussed was through the support/care planning process. As illustrated above, one common theme was that care navigators got to know their clients better as a result of the support/care planning process, and because of that were better equipped to meet their needs. This also meant that the support/care planning process became more 'personalised' in relation to what services or interventions could be utilised that would be appropriate for the client and more likely to lead to a positive outcome.

We've actually changed our care plans totally now so they're a lot less prescriptive and it's about the person and what they think and what they feel is a need, so yeah our care plans they've totally changed. [Project lead].

The support/care planning process was widely seen as the vehicle by which choice and control were enabled through allowing the budget holder to engage in activities that promote independence.

Service users know what is good for them. They know what works and so I think it is a real positive in terms of control and choice and enabling them to stay in the community and enabling them to come to their own solutions. [Health professional]

Organisational representatives welcomed the greater patient involvement in planning their own care. A number of interviewees explained that, especially with this client group whose problems of addiction can make contact and relations difficult, the very nature of clients and professionals working actively together breaks down barriers and increases respect and understanding on both sides. Talking about the impact of personal health budgets compared to the conventional service delivery, a health professional argued:

I think it's because they have the actual input. Because when the treatment plan is made up, it's what they want to do. The assessment is all about their journey, what they want to do, what outcomes they're after. And I think there is more work done on the integration because it's not just getting clean off the drugs, it's actually getting back into the community, getting a life back, becoming a normal person. [Health professional]

Organisational representatives discussed how the support/care planning process was beneficial to the care navigator and the client; however, one drawback appeared to be that it was more time-consuming and therefore more resource-intensive. This could potentially contribute to the cost of a larger roll-out of personal health budgets if, for example, it necessitated more care navigators or operational staff to carry out support/care planning with individuals.

The planning at the front end once you've done the need assessment, putting together the person centred plan, putting together that initial plan which pulls out all their needs and starts putting the package around all their needs, is far more time-consuming; it takes a lot more of the practitioners' time. [Project lead]

6.2.5.1 Improved relationships between the NHS and budget holders

In addition to the likely positive impact on budget holders, a consistent view expressed by staff (and patients) was that the personal health budget process could improve the relationship between front-line staff and budget holders. They thought that it provided a way of finding out the real needs and preferences of budget holders because the personalised support/care planning process is all-encompassing, and thus requires staff to spend more time with the patient and look at their situation holistically.¹⁰ There was also the view that the new personalised support/care planning process is enhancing practice, as practitioners are getting to know their patients better.

It's created an equalisation of power, as they are doing their own self-assessment. They're telling you things that they wouldn't have told you before. You're spending more time with them. There is a lot more care that goes into this care plan. It has opened our minds, so rather than just banging them into rehab we're looking at the full picture. [Health professional]

One project lead at follow-up argued it has been an 'eye-opener' for staff:

Staff now see individual journeys in a way that they didn't see them before. And I think that's been revelatory to our staff, on several levels. One, I think it's made them really aware of the complexity of individual journeys and the fact that journeys aren't necessarily linear and that they don't always move forward.... But the other real eye opener for care navigators has been the real appreciation of the true demands that are placed on the individual worker if you're going to support people effectively right through their treatment journey. [Project lead]

¹⁰ We would assume, that as personal health budgets are embedded further into the system, the time required for support/care planning could be reduced.

Comparing the personal health budget model to the conventional service delivery model, staff talked about the benefits of the former, in that all care navigators, regardless of the agency they work for, have access to the same level of funding for clients, from the same central source. The level of funding for each individual is determined through bespoke assessment. Under conventional service delivery, funding is determined by individual agencies, and treatment is specific to the episodic involvement of the service. One care navigator argued:

We were working with little bits of the client rather than the whole client. And I think that what we're developing here is a much closer relationship with the core elements of the client. I'm actually liaising with the criminal justice system, the health system, this person's children's nursery, all on one client who's got a health budget. It didn't happen before because the role of the care manager would be to meet the person, to assess what treatment they would need in the community and more or less say to them, "We think you should go to some counselling. So I'm going to send you there for four weeks." There also wasn't a lot of client ownership in that.

6.2.5.2 Understanding the personal health budget

While many of the attributes that underpin the personal health budget initiative were lauded by organisational representatives (such as choice, control, personalised support/care planning), two of the operational staff members we interviewed explained how clients often did not understand the principle tenet of what their personal health budget was, or how it worked (i.e. that it was money based on a personal assessment available for their care). Of more importance to clients was simply the act of being able to choose and 'have a say' in how they were treated, and getting to the treatment itself. This may partially explain why, as illustrated in the previous section, budget holders were not always clear on whether they had received a budget, but were more concerned with the services accessed as a result of it. Indeed, this was highlighted by one interviewee.

I'm not 100 per cent sure that all of our clients understand exactly what it is that we are doing and I think if some of our clients are asked, "how was the personal health budget, how did you find that process?" They'd probably say, "Yeah, the detox was great," but probably wouldn't remember the beginning bit. It's a lot of information to give over and I don't know how much they do understand of it. [Operational staff]

6.2.5.3 Knowing the level of budget

The reason for the lack of complete understanding on the part of clients may partly be due to the timing of when the information regarding the personal health budget is communicated. According to one interviewee, clients did not appear to be interested in the level that their budget had been assessed at:

They're not really interested in what the pilot study's going to help them with and how much budget they're getting or anything like that, they really just say, please help me I just, you know, want to feel better. [Operational staff]

An apparent lack of interest on the part of the client could potentially be because of the urgent need for treatment or services, or incapacity (at the time) to take in all of the information that is being conveyed to them. This raises the question of when exactly clients receive or are told information about the budget and in what detail. The timing of the personal health budget offer is discussed further in Section 6.3.1.

A number of operational staff and project leads discussed whether it was even necessary for clients to have an acute understanding of the workings of the personal health budget. One point of view put forward was that, providing the client was benefiting from the elements of choice and control, flexibility and person-centred support/care planning and achieving the outcomes that they wanted, did it matter how much understanding they had about the mechanisms that allowed these things to happen? From this perspective, the emphasis was more on 'enabling' these processes for the benefit of clients.

6.2.6 Budget-setting

Where budget holders did appear to understand the process of holding a personal health budget, staff members believed budget holders were happy with the level at which they were set. According to interviewees, a clear and transparent budget is essential for the true personalisation of health care so that all parties concerned know the limits and range of possibilities within which they are working.

People have seemed happy with the level of their budgets...one of the fears was that people wouldn't have enough money and that they would be sort of suffering, but in fact I haven't heard of that happening. It seems to be that people have ... been able to get the treatment that they need. [Project lead]

The total amount of available resource for allocating personal health budgets was based on current expenditure. One pilot site used a banding system to assess the level at which budgets should be set. These were based on need using screening tools, clinical assessment and previous case studies. The other pilot site used a points-based resource allocation system. Here, all care navigators, regardless of the agency they worked for, had access to the same level of centrally-sourced individual funding for clients.

So you've got medium, medium plus, high and high plus, and we ask them to put indicators, clinical indicators against those bands. So, obviously, high plus is your very complex physical needs - withdrawal symptoms, fits, stuff like that, there's no way that person can ever do it in the community, must be an in-patient, must have 24-hour medical support available etc. So then when the RAS is done, when the assessments are done and the scores are kind of calculated, so it's SAD-Q plus the AUDIT score. [Project lead]

In addition to client assessments, flexibility was actively encouraged during discussions on budget levels and how they should be spent. It was unanimously felt that this fitted with the ethos of the personal health budget initiative. This gave care navigators the autonomy they needed, for example, to consider the history of the client, which could lead to greater and improved outcomes.

There are some clients that although they haven't reached the top band as in, the most amount of money, we felt that it was appropriate to put them in [detox] anyway...I think just, it's more like looking at the risks and sometimes people on the paperwork, you can't have every box for everyone, can you, and so sometimes it doesn't show up as being particularly risky but actually when you know them and you know the history, and you know what would work for them. [Operational staff]

6.2.7 Safety and accountability

One aspect of the personal health budgets initiative that raised (provisional) concerns was the principle of accountability. Whilst the increase in autonomy and flexibility was welcomed by everyone who took part

in the study, there was some anxiety as to where accountability would lie if something were to go 'wrong' with how a personal health budget was used.

There's been some sort of teething problems with kind of getting people the money. I think there was a concern about, you know, how this might be viewed if anything went wrong. And it's quite kind of a sort of concern about 'The Daily Mail' effect really. [Health professional]

There was also a fear that there could be a potential conflict between the 'need' of budget holders and what they (the budget holder) 'wanted'. This led to questions around how operational staff ensured the maintenance of professional and clinical accountability. The overwhelming view was that the monitoring of risk was crucial to ensure the safety of the budget holder. This was a key issue that was discussed in the interviews in terms of how to deal with a situation when the choice and wants of the service user conflict with professional opinion and the problems this causes for everyone concerned. This problem was discussed by a project lead who said:

We did have one client who, when he looked at the cost of what he was recommended for, inpatient detoxification, was surprised at how much it cost. His instinct was immediately to minimise the amount of money that was spent on his medical intervention because he wanted to spend more money on other aspects of his recovery. That lead us into a difficult situation and he did relapse and ended up needing another detox, but again only wanted another short detox. So we had that issue about it's my budget, it's my money. [Health professional]

Another concern raised was about what happens if a patient relapses during or after treatment, but the personal health budget has already been spent.

One of the worries that people have about the PHB was, well what happens if people use all their money and then they relapse and go back using drugs again? Will we have to spend all the same money all over again? [Health professional]

Much of the anxiety was mitigated when protocols were put in place to deal with decision-making and how a budget should or should not be used. Pilot sites either used panels of experts or held regular meetings made up of a combination of people involved in the budget recipient's care, such as clinicians, social workers, care navigators, team managers, finance staff, commissioning managers and support workers.

Mmm, and part of me was thinking, they're asking me to take risks that I'm not happy with taking...Whereas actually it's not like that really, everything that we do, it's still as safe as it used to be. [Operational staff]

To avoid unnecessary bureaucracy, standard packages of care did not require approval by the panel. The panel meetings were used specifically where care navigators were unsure as to where the line should be drawn between balancing risk, what constituted appropriate spending and enabling choice. One project lead commented: "ultimately as well, it's how much do you allow the individual to make choices." One example of this was a case where someone wanted to use their personal health budget to purchase a video game. The purpose of this was to help keep the budget holder occupied and engaged with something during a difficult detox period. The panel was convened to discuss two main issues: firstly, was

this an appropriate use of a personal health budget; and secondly, whether it would be beneficial to the client and help achieve the outcome that they wanted.

A further concern related to accountability was the risk associated with going out to the market place to purchase support and services that would conventionally be used or accessed under a block contract agreement. Project leads expressed concern around ensuring that support services that were purchased using a personal health budget conformed to standards of good practice and were clinically safe for people to use as part of their care package. To safeguard their clients, pilot sites screened new service providers to ensure they were suited to their clients' needs, and these were added to a list of registered providers.

If it's a clinical aspect, so it's a new provider offering the detox, if it's medical detox, the provider has to be screened by the clinical lead...a consultant medical lead, has to sign that package of care off. So we've started to put together sort of what we call a provider framework; it's a series of checks that sort of says we expect a provider to have all this stuff, CRB check, to have this in place, have that sort of quality assurances. [Project lead]

Some of the concerns around accountability raise the question of whether this could create a culture of being 'risk-averse' and potentially stifling any innovative or creative thinking during the support/care planning process. There was no direct evidence of this among the interviews. However, one operational staff member did describe how they initially approached the initiative with some reservations, but that these were allayed when they started to see positive outcomes for clients and understood the protocols in place to mitigate clients being subjected to any danger or potential for misuse of the budget. This suggests that any future roll-out of personal health budgets among this client group may need to be accompanied by details of how any similar uncertainties among operational staff can be addressed.

I think at first it felt very risky, you know, they would maybe be detoxing people that we wouldn't have considered before in the community and at first it was a bit like, oh, I don't know if this is sitting comfortably, but I think the more successes we get and the more successful completions we get in, the happier I am with it all. [Operational staff]

6.2.7.1 Disaggregating block contracts

While utilising services beyond what was already commissioned under block contract arrangements was a source of some apprehension for some, project leads also described a sense of freedom in breaking free from these conditions and embraced the opportunity to stretch beyond the existing comfort zone that had developed with current providers.

It was also a very restrictive block contract which nobody was really happy about apart from the provider receiving the contract... So it became part of an early trend and it really helped the flexibility as well, because it's actually the commissioners that have freed up the block contract. [Project lead]

6.2.8 Market development

Departing from conventional services meant pilot sites needed to access the private or third sector to provide services for their client group. Developing the market place (and, in particular, choice within the market place) was identified as a key element of sustaining the personal health budget initiative, and

project leads and operational staff all expressed this. Regarding moving forward and sustaining the initiative, one project lead said:

From my perspective I think we've still got a long way to go but that's about developing the market confidence, you know what I mean, the providers' confidence, or stimulating the market I think is probably the best way to describe it, because we're going from set providers who've been delivering in-patient detox to encouraging a much more community-based detox provision. [Project lead]

During the first wave of interviews, operational staff explained that they were looking towards 'the market' to provide alternative choice to current provision. At this point, however, interviewees described something of a dearth of options and that choice was lacking in the market as it existed.

But I would still like to be able to see more providers; I still think it would be nice if we had another couple of detox units that we could use. But there just isn't any of them out there. [Operational staff]

6.2.8.1 Encouraging market development

In the second wave of interviews, project leads and a number of operational staff discussed the work that had been on-going since the first round of interviews in order to develop or stimulate the market. There was evidence here that this work had been successful and that providers were coming on board with the pilot and developing their potential to extend their involvement.

I think [project lead] did some events around getting lots of care agencies involved and trying to basically say, "This is what we're doing, would you be interested?" So we're now working alongside care agencies, we're working alongside different detoxes that we wouldn't have worked with before, really. [Operational staff]

6.2.8.2 Market forces

Project leads viewed stimulating and developing the market as introducing an element of competition which could then be used to drive cost down and quality up. One project lead described obtaining and using provider costs to encourage competition between providers:

Initially we weren't allowed to say the cost of [provider A] because they wouldn't let out, they wouldn't say. I think it has [led to competition between providers], especially with the care agencies who are looking to provide support. But there's definitely between the care agencies, there is some rivalry 'cause they kind of want to know how much so and so is costing and this and that. So there's kind of some sort of market forces at work there in that sense. [Project lead]

6.2.8.3 Driving quality

Project leads, commissioning managers and operational staff also described how they had seen the quality of services improve, and they attributed this directly to the impact of using personal health budgets. Interviewees described how services had become more responsive to the needs of clients and also how they now felt empowered by the potential that they could 'take their business elsewhere'. This meant that project leads and operational staff were also more likely to raise issues of poor quality service

with the provider whereas previously they would not have. Under former block contract agreements, both parties knew that there were no other options and that essentially they (the provider) were the only source of the required service. However, the introduction of personal health budgets appeared to change the dynamic of the relationship between providers and commissioners, and shifted power towards commissioners and (indirectly) to the people using those services.

Yeah, I think the detox provider that we're using as a residential unit more, I mean the one that's getting more business, is making its provision better and better really because, we kind of have the power now, don't we, to say, "Well no actually, I'm not going to send anyone to you," we're having conversations with them and saying that, you know, "Some of our clients are saying that they're a bit bored, is there some more groups that they can do?" and they're putting more groups on. Whereas before when we were having troubles with [provider] we would be saying, "Look, they're not even doing any group work," they'd say, "Go and find another detox then. Oh, there isn't one. [Operational staff]

6.2.9 Cost savings

One of the key questions around using personal health budgets among substance misusers was whether or not it was an efficient way of delivering services to people. Project leads and operational staff unanimously expressed the view that they could see how cost savings could, and were already, being made by implementing personal health budgets. One of the reasons given for this was simply down to the option that care navigators had to use another provider to deliver services:

I think so [that personal health budgets can reduce costs] because, you know, we were in a position, for instance, where we only had one detox unit to use - and that would be for the most expensive place around. So I can already see that although we may be only detoxing maybe nine people a month, the same as what we always were, that's nine less people going into [provider]. So obviously yes, to me that adds up that it's going to be less money. [Operational staff]

Another way in which one project lead and members of their operational staff explained that they were spending less was through changing the method by which someone would be treated from a residential centre to community care via new providers that were now accessible to commissioners. Prior to using personal health budgets, people that were assessed as having lower medical need were attending the same centres as those that were assessed as higher need because the services were not available to treat people in the community. Now that this option was available, operational staff felt that clients could be treated in a way that was 'more appropriate' for their level of need.

Conventionally we would've been looking to detox somebody residentially at well over £2,000 for five days, and now we can detox three people for that, if not more. [Operational staff]

Overall among interviewees, there was a sense that they were able to do more for their clients within the same budgetary limits. This was achieved via a combination of not being locked into one provider, alternative methods of providing the same (but cheaper) treatment, and avoiding unnecessary referrals to residential detox centres.

We've shifted the [providers].... the in-patient providers have changed and we're getting more for our bucks. [Project lead]

Although all interviewees in one of the participating sites expressed the view that personal health budgets were cost saving, this was not necessarily because services were available at a cheaper rate. In fact, in some cases the unit cost price for some services was actually seen to increase due to the loss of spending power that the block contract had previously afforded them. Nonetheless, interviewees reported cost savings because these services were commissioned less now that greater choice and flexibility of care arrangements could be utilised.

That [detox service] is costing more money on a kind of case-by-case basis but of course, that's as a result of the change in contracts. But they are, overall, definitely saving money. Because obviously you're not sending everyone to [provider]. [Project lead]

Despite many of the interviewees discussing how cost savings could and indeed were being made as a result of using personal health budgets, one commissioning manager explained that, in its current form, the initiative could not be rolled out across the local population as the cost would be too high. This was because, while savings could be made in many cases, there were too many people that required high-value services and as such were spending a disproportionate amount of the total allocated budget. However, this was potentially because the boundaries between what should be included and excluded in the budget may have been unclear, and the interviewee here did recognise this, as well as the potential for savings to be made:

Currently the way that the pilot was designed, we couldn't run the service for the whole population in that way because what we found from the cost of the pilot was that a few individuals that required quite expensive treatment...So in regards to that point of view, we need to look at what elements should be part of the personal [health] budgets, and what elements should be part of the standard healthcare provision that's open to everybody. I think once we've ironed that part out, we can see that it will be cost effective because people use alternatives to the mainstream high cost treatment provision. [Commissioning manager]

6.3 Implementing the personal health budget pilot

As well as the positive impacts that interviewees reported for both providers and clients as a result of using personal health budgets, there were also a number of challenges that interviewees experienced during the process of implementing the pilot and these will be addressed here.

6.3.1 Are choice and control always beneficial?

One concern stressed by some staff during interviews was that there is a general misconception that not all people with substance misuse problems will be able to 'handle' a personal health budget. One care navigator felt strongly that this was not the case, and people with substance misuse problems were in fact just as capable and deserving of a budget as anyone else.

There is a kind of mythology that the people with substance abuse problems are different than anybody else. But our experience now is that once they've got a handle on what it is that they're coming to the service for and what can be done, they're quite as capable as anybody else at thinking through what they might want and how they might get there, how they might achieve it. Choice and control were indeed lauded by interviewees as one of the benefits of using personal health budgets for clients and care navigators in the support/care planning process; it was also cited as potentially difficult to convey to clients. One operational staff member described how some clients, while they appreciated the degree of choice and engaged with the support/care planning process, were still quite dependent on the substance misuse team for guidance and advice. This may be due to the fact that previously people were used to being treated in a more prescriptive way, and being 'told' what to do.

You could spend a week, you know, or you could spend an hour talking to them about, "These are your different choices," and at the end of it what they'll probably tend to come back and do is say, "Well, what do you think is best?" [Operational staff]

Another key area where the merits of choice and control were less clear was for people who presented at 'crisis point'; clients in these situations often did not welcome the choice and control being offered to them. All of the front-line operational staff who took part in an interview explained that they had seen at least one client that had felt overwhelmed by the choice that was being offered to them and that, rather than empowering them, it added to their stress and anxiety. In these cases, operational staff found that what people wanted was more prescriptive help rather that to take control themselves. This suggests that in these situations personal health budgets may not be the most appropriate way of accessing substance misuse services at the point of first presentation, but that the support/care planning process and the personal health budget should be introduced at a later follow-up. Findings from the fifth interim report published during the main evaluation of personal health budgets, echo these here for users of stroke services (Davidson et al., 2012). Interviewees who were offered a personal health budget shortly after a stroke (within days of quite severe strokes and whilst still in hospital) felt that they were offered it too soon and were not in a position to plan their support needs. Those offered budgets a number of years after a stroke felt more able to take information on board, and use it effectively, as they were not so overwhelmed by recent events.

What they want to be able to do is to know that they're going to be going somewhere that's actually going to make them feel better, that's really all they need and want. So when you talk to them about the pilot study, they kind of like look to you and say, look do whatever it takes to get me in there. [Operational staff]

6.3.1.1 Using the budget for prevention and recovery

Further to the question of *when* personal health budgets should be used, another key question that emerged from interviews was *what* should be included in the budget. One interviewee stated: *"are we talking about budgets that will include funding for medical interventions, or are we talking about a more recovery-orientated model of personal health budget funding."* One health professional felt strongly that personal health budgets would be best suited to being implemented at recovery rather than crisis point:

I think that [relapse prevention] is perhaps the most important part of the whole treatment journey. I mean its one thing to get the client clean, so to speak, but the main thing is to keep them clean and to keep them focused and moving forward in life. So reintegration is really important, I think that might be even more important than the actual detox. [Health professional]

An example of where a personal health budget had been successfully used for relapse prevention was the case of one individual who had previously gone through a detox but was still at risk of relapsing. This

person used the budget to purchase a desktop computer and college courses, and was subsequently able to help set up their own business and take the focus away from addiction towards something positive, investing in the addiction-free future. This kind of purchase would not have been possible without the personal health budget. This individual has been "signed off benefits, is running [their] own business, going to college, has done a computer course and done a NIC refresher course, and that's all done in the integration stage."

One project lead believed that if personal health budgets are to be implemented more widely in the future, it must be made clear what they can and cannot be used for. To clarify its purpose, it was suggested that calling the budget a "recovery and resettlement budget" would drive home its best possible application.

6.3.2 Bureaucracy, support/care planning and time consumption

Related to explaining the choices and options open to people using a personal health budget was a fear, particularly among operational staff, that going through the support/care planning process with people, and explaining the degree of choice that was now open to them, would be too time-consuming and create unwanted bureaucracy. However, while some of these fears were borne out initially, interviewees stated that they had become used to the change in processes. Operational staff also went on to say that they could justify spending more time on the support/care planning process, especially where it was possible to see benefits in terms of clients' care and eventual outcomes.

I think initially when we first started it; I think you'll probably find the majority of staff thought, well, this is going to take so much time. I think now we're up and running, it's like anything new that comes through; you get on with it, it's part and part of what we've got to do. We probably just allocate the extra time for it now, you know? [Operational staff]

Some concerns around experiencing an increase in workload may reflect the nature of setting up a pilot programme. Nonetheless, there was evidence that implementing the personal health budgets pilot had impacted on workload for front-line professionals. This potential resource implication may need to be considered in the light of any future roll-out of the initiative among substance misusers.

It is additional work pressure on me. I'm working within a team of other clients. I'm carrying two different types of work at the same time. Working with some clients in the normal way, and then working with another set of clients as a care navigator [for PHBs]. And there's too much paperwork involved. So many demands and so I've got this increased pressure of work on me as an individual. [Operational staff]

6.3.3 Cultural change

Cultural change also applied to organisational representatives that had become accustomed to dealing with clients in a more prescriptive way. One senior member of staff described how, as a result of using personal health budgets, they had seen a more general change in attitudes from staff towards tackling client needs in a different, more innovative way. This did not just apply to those who were in receipt of a personal health budget but other clients as well.

It's gone beyond just the people who are on budgets, that it's made people think differently about care plans generally. It's also made people think about patients more as customers. It

has made people think actually we're here to serve the patient; it changes the dynamic. [Health professional]

It was also conveyed that strong local leadership is a crucial variable to bringing about successful culture change. It was widely believed that an 'inspirational leader' who has vision and passion is fundamental to changing perceptions and enthusing people into backing the initiative and undertaking the work involved. One health professional argued:

I think enthusiasm in the people that are bringing change in [is important for culture change]. I think it's very important to have people who say 'why don't we do this'. So I think having inspirational people around who are prepared to ask those difficult questions is vital. You need people who will actually challenge the sort of conventional orthodoxy really. We had a fantastic project lead, who was really supportive and amazing. I think you really need somebody like him to inspire people and sort of carry it along. I think that helps.

One operational staff member did also discuss, however, that for some members of the team it was a challenge to their own way of thinking and going about designing support/care plans and treatments for their client group.

Probably because they'd been within the service for such a long time and this is the way that we do it. So for somebody to come along and say, "Actually, you know, let's change our thinking around this," it takes [time]; change is difficult for some people, isn't it? [Operational staff]

6.3.3.1 Culture and attitudes to managing risk

In the context of making personal health budgets available to individuals with a substance misuse problem, it may be important to consider the issue of risk, and particularly 'perceived risk' more generally. Some of the issues faced by people operationalising the policy suggest that, if direct payments are to be implemented more widely and successfully among this client group, the concerns and attitudes not only of staff but potentially the wider public may need to be taken into account.

As discussed in section 6.2.7, initial responses from a number of members of staff included apprehension around the 'risk' that would be involved in implementing personal health budgets among substance misusers, but this was later dispelled by having appropriate measures of control in place. One related factor that could potentially influence the decision-making process was coined 'the Daily Mail effect' by one health professional. There was concern among a number of participants about sanctioning leisure activities and general 'non-conventional' services or equipment to substance misusers not traditionally available through the NHS. One participant discussed being worried that a tabloid newspaper might obtain information about an unconventional purchase made using a personal health budget and report it in a disparaging way. This appeared to heighten the need to justify decisions made about the use of budgets, and was exacerbated by the downturn in the economy and the climate of austerity measures.

One project lead acknowledged that the use of personal health budgets for this client group could and would be regarded as controversial and therefore create problems or introduce 'extra' considerations to account for during the decision-making process. Nonetheless, direct payments were considered a critical part of successfully using personal health budgets among people with substance misuse problems. There

was also a sense that individuals with a substance misuse problem should not be excluded from being able to potentially benefit from using direct payments on the basis of unfounded anxiety around risk.

Inevitably it has been quite a controversial issue, but we definitely wanted direct payment power because it was important to us that we should make that decision about risk, rather than people with substance misuse problems being simply discriminated against and told, "Well no, you can't have the power". [Project Lead]

6.3.4 Logistical challenges

Project leads and the health professional that took part in the interview pointed to the logistics of organising so many different services and organisations. This was a potential drawback of more choice being available to both care navigators and clients of substance misuse services. One disadvantage highlighted for staff was the increase in workload and taking responsibility for co-ordinating the different services and or agencies that could potentially become involved in someone's care, as outlined in Section 6.3.2.

When discussing the impact of increased choice and working with increased numbers of service providers, one project lead expressed concern over the lack of continuity this may lead to for clients. This may be detrimental to, for example, people feeling that they know where to go to if they have any problems or concerns related to services provided through their care package. It could also be a potential source of anxiety if a person is seeing many unfamiliar people as part of their care package.

There's no one agency which just says, yeah we'll be there all the way round...they're going to go and meet some new people...for the assessment, they're also then going to have some new people that they don't know coming in during the day to support them. If they need someone at night, that'll be another person coming that they don't know, so sometimes continuity, that's the only thing that could suffer. [Project lead]

6.3.5 Integration

The potential for the pilot to help establish greater links between health and social care services was anticipated by project leads, and commissioners in particular. Between the two pilot sites there were some differences regarding the level and impact of the pilot on integration.

6.3.5.1 PHB pilot helping integration between services

Interviewees from one site (site A) all agreed that the pilot had had a positive impact on encouraging improved joint working between health and social care services. Interviewees described how they felt that relationships had developed between them and other statutory service providers, and communication between teams had improved so that work (for example, assessments) was not being duplicated unnecessarily.

I mean, the team's been brilliant and it's just really linking up, linking up with other services as well and seeing what's out there, sort of getting a portfolio together of what free things, you know, what we can utilise. And hopefully I'm going to sort it out with our website, the [Trust] website, and have the information on there as well, and yeah definitely, I mean, I go to the [meeting], and they ask me for an update all the time as well. So that links up into all the voluntary sectors. [Project lead]

Interviewees from the second site (site B) had more mixed views as to whether the pilot had had an impact on the integration of services across health and social care. A commissioning manager and a health professional who took part both described how the pilot had encouraged joint working across different teams that were linked with people receiving a personal health budget. One comment from the commissioning manager emphasised the importance of support at a senior management level in encouraging integration.

It has had an impact, it has, but at times it's also very complex as well. But I think what's happened is that we have some senior managers here that are quite supportive of the personal health budget pilot, and have been able to drive things forward. [Commissioning manager]

One of the health professionals from site B held a different view, however, and described how they did not feel that the pilot had impacted on health and social care services being more integrated:

If I'm being totally honest, no [the pilot has not had an impact on integration]. I don't expect a lot of difference to be honest. Because the health side of it are still doing what they've always done, you know, they're still putting people into detox, but they're just doing it for shorter periods of time if we ask them. But no, I've not had a feeling that there's a new kid on the block that, we're all working towards this thing. No. But I mean there may be at senior management level, there may be. But I don't get that feeling here. I've never had one of my colleagues come across to me and say, "Have you got anybody on the health budget at the moment, can we have a look together at how they're spending their money, is there any way that we can do this a little bit better from our end?" [Health professional]

6.3.5.2 Joint funding

Another major difference between the two sites was joint funding. Site A was not using integrated or pooled budgets, although people did report high levels of joint working. The project lead in this pilot site made it clear that they would welcome the joint funded aspect of integration and how in many ways this would be the final 'piece to the puzzle', given the progress that had been made with joint working:

I mean, dual funding would be great but there's not dual funding, it's totally separate. So that's why I come across a lot of things, which comes under a social budget, rather than a personal health budget. [Project lead]

The project lead from site A also discussed some of the difficulties that not having joint funding raised, and as a result some of the strategies employed to overcome these:

Initially with the detox providers, I was told no, that couldn't go ahead because that comes under social care, that money. So basically what I did is I went back and I discussed with the providers about basically reforming, rewording and putting a brand new package together, and coming back to me with that and then I could pass that because it didn't include groups. So the minute I said, you know, there's groups at a place that people could attend, then that comes under social. [Project lead] Site B was using joint pooled budgets and these appeared to have been successfully and fully integrated. The project lead described how this level of integration worked, and what systems needed to be in place to enable a fully functioning pooling of budgets:

Under the system that we've set up in [site] for the pilot, the funding has been fully integrated, and the funding has come from a number of sources. One is funding that comes from the National Treatment Agency for Substance Misuse, often what's known as pooled treatment budget. Funding has come from NHS [site] and from [site] Council, but it's been pooled and so you don't have one agency saying, oh well that's our money, even though we're trying to spend it in an integrated way. So we haven't got any of that, I mean, money has just come in to a pool and it is there for the different agencies both statutory and nonstatutory to use. [Project lead]

6.4 Summary

The purpose of conducting interviews with organisational representatives was to examine the experiences of people implementing personal health budgets pilot within the area of substance misuse.

Organisational representatives overwhelmingly held the view that personal health budgets had a positive impact on both outcomes for budget holders, the way they accessed services, and in some case the content or quality of those services. These impacts were attributable to personal health budgets enabling: increased choice and control for budget holders; increased flexibility; encouraging innovation and creativity; greater 'person-centred' support/care planning; and the opportunity to reduce costs by accessing alternative services or providers of services.

A number of challenges were identified as part of the implementation process. Among these were: the length of time required to conduct the support/care planning process; the time point at which a personal health budget should be introduced; deciding what can and cannot be included; the logistics of managing multi-agencies involved in a person's care; and establishing a fully integrated and jointly funded budget. Some of these implementation difficulties are likely to reflect the challenges of setting up a new pilot programme. It could therefore be expected that they may diminish over time, as new systems become established. However, some of these may need to be directly addressed if the pilot programme is to be rolled out on a national scale.

7 Conclusions

The overarching aim of the study was to examine the impact of receiving a personal health budget on quality of life and relapse rates compared with accessing services via the conventional treatment pathway. The findings from the study will be used to add to our understanding of how personal health budgets could be used by people with substance misuse problems, and the potential impact this could have on this client group in the future.

Similar to the main evaluation of the personal health budget pilot programme, in terms of the overall resource level included in the budget there seemed to be varying degrees of choice and control transferred to budget holders. While one pilot site had been approved to offer the choice of direct payments, due to various challenges this option was not realised within the pilot programme. However, within the future roll-out of personal health budgets, potentially budget holders will be given the choice of managing the resource via a direct payment which may increase the degree of choice and control they feel they have.

Both the quantitative and qualitative findings among clients indicated that personal health budgets had a positive impact on reduced relapse rates, service satisfaction, having a positive relationship with health professionals, quality of life, and views on what could be achieved compared with conventional service delivery. However, a number of concerns were voiced around whether there was choice and control in reality, and the implementation process in terms of delays, not being fully engaged within the process, and the lack of information initially offered. Furthermore, there seemed to be some confusion as to the availability of after-care support, something that was felt by organisational representatives to be vital to maintain reduced relapse rates. An interesting point raised in the interviews with organisational representatives was whether the personal health budget process should be delayed until after the individual had gone through a detox programme, rather than offered immediately and potentially at a time of crisis. The timing of the personal health budget offer within the pilot programme could potentially have had an impact on some of the views held by budget holders.

The implementation of personal health budgets among this client group presented a mixed picture as to the benefits and challenges. In terms of the positive impact, it was consistently thought that personal health budgets had the potential to:

- Improve relationships between client and health professionals;
- Increase choice and control for budget holders;
- Improve quality of life for budget holders;
- Encourage market development;
- Drive service quality;
- Improve service efficiency;
- Encourage integration between health and social care services.

However, organisational representatives mentioned a range of challenges within the system including:

- Logistical challenges in terms of organising support from different organisations;
- Managing the required cultural change for clients and within the system;
- Support/care planning being more time-consuming.

While this study was multi-faceted and provided valuable information for the pilot programme, the small sample of individuals participating in the study was a major limitation. The small sample had an impact on the degree to which the results could be generalisable to the whole population of people with substance misuse problems. Furthermore, the small sample also had an impact on the degree to which we could fully explore the impact of personal health budgets compared to conventional treatment and services. The following multivariate analysis could not be explored within the study:

- Explaining outcome change at follow-up: the difference-in-difference multivariate models could not be carried out, and therefore we could not minimise the potential biases within the sample by controlling for baseline characteristics.
- The study was unable to explore whether the initiative was cost-effective compared to conventional service delivery. However, it was frequently mentioned by organisational representatives that personal health budgets had the potential for cost savings within the system.
- The study could not explore whether personal health budgets were more beneficial for specific groups of clients.
- The study could not explore whether personal health budgets had an impact on primary and secondary health care service use compared to conventional service delivery.

A further limitation is that the study was carried out within only two pilot sites focusing on implementing personal health budgets among individuals seeking support for their substance misuse problem, which would also have an impact on the degree to which the results can be generalisable.

Despite the limitations, the study provided important information for the national roll-out of personal health budgets in the future. In summary, the key messages are:

- The personal health budget process should not be viewed as one size fits all. The findings suggest that some individuals would benefit more from receiving their budget post-detox rather than at a crisis point.
- Personal health budgets have the potential to improve the link to after-care services, which are seen as an important strategy to reduce relapse rates.
- While direct payments are viewed as providing more choice and control for people who wish to opt for this deployment option, there are various challenges to overcome within the system for this option to be realised among this client group.

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Table A-1. Overview of studies included in the review	Table A-1. Overview of studies included in the review	
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Appendix A Overview of treatment for substance misuse

A.1 Types of intervention

A.1.1 Psychosocial interventions

Psychosocial treatments for substance misuse are therapies based on theories of human behaviour. While the many different models have different goals, generally the aim is to increase the client's understanding of their cognition, emotion and behaviour in order to help them make changes in their substance-using behaviour. Most are based on theoretical models of addiction which are broken down into parts, each part being addressed by certain aspects of the treatment. The Mesa Grande project, an on-going systematic review of the randomised controlled trials of treatments for alcohol misuse, lists 87 alternative treatments (Slattery et al., 2003). This demonstrates the quantity and variety of non-pharmacological interventions for alcohol misuse alone. The following is a summary of the main types of non-pharmacological interventions, as found in the reviews. They can be categorised broadly into behavioural treatments and cognitive treatments.

A.1.2 Behavioural treatments

Behavioural interventions are based on the view that substance abuse is a learned behaviour controlled by the stimuli which immediately follow an action. This behaviour 'operates' on the environment to receive reinforcement. Providing alternative reinforcers which are not substance-related may help reduce substance use.

A.1.2.1 Contingency management (CM) or voucher-based therapy

This treatment provides positive reinforcement for behaviour change in the form of a voucher that can be exchanged for goods or services which are compatible with a drug-free lifestyle. Vouchers are received when treatment goals are achieved, usually drug-free urine samples. The value of these 'incentives' or vouchers increases with each drug-free sample (Shearer, 2007; Prendergast et al., 2006).

A.1.2.2 Community reinforcement approach (CRA)

CRA is a form of CM which seeks to identify behavioural reinforcers in the user's life which are incompatible with the drug-use reinforcers. It involves changes in family relationships, recreational activities and social networks. The aim is to increase satisfaction with a substance-free lifestyle (Shearer, 2007).

Reinforcement-based intensive outpatient treatment is a form of CRA with voucher incentives designed specifically for inner-city heroin users (Mayet et al., 2004).

A.1.2.3 Cue exposure therapy

Cue exposure therapy is based on the theory that exposure to stimuli associated with substance use, such as drug-using friends and places, may 'cue' drug craving and relapse. Treatment consists of repeated

exposure to these stimuli without drug use, leading to the loss of the connection between the two and the extinction of the autonomic response (Shearer, 2007).

A.1.2.4 Behavioural self-control thinking (BSCT)

BSCT aims at controlled use rather than abstinence, particularly for alcohol problems. Users are taught to drink more slowly, to increase the intervals between drinks and to choose less alcoholic drinks. They are also taught to recognise high-risk situations for relapse and to set personal goals (Slattery et al., 2003).

A.2 Cognitive treatments

Cognitive behavioural therapy (CBT) was originally developed for the treatment of depression but was later used for mental health disorders, including substance misuse. CBT looks at maladaptive patterns of thinking, such as overgeneralisation, catastrophising, personalising and self-defeatist thinking. It aims to help patients recognise and understand drug-related problems, and to alter the dysfunctional thoughts which may be causing or perpetuating the substance use. For the purposes of this review, CBT was not considered to be a single intervention but an approach or model underlying many more specific treatments.

A.2.1 Relapse prevention (RP)

Relapse prevention is a form of CBT which specifically addresses the nature of the relapse process and suggests coping strategies for maintaining changes in behaviour. It is based on the idea that addictive behaviour is 'learned' and linked in the user's mind with immediate rewards which increase pleasure or decrease pain. The immediate rewards of following addictive behaviours serve to maintain their frequency and continuation, despite the obvious negative consequences which can be severe and long-lasting. The aim of using CBT for the treatment of substance abuse is to eradicate the connection between pleasure and substance use, and to build a new set of behaviour and coping skills (Marlatt et al., 2002).

The RP model has been developed over 30 years by Marlatt and colleagues (Marlatt and Gordon, 1985; Larimer et al., 1999), and focuses on the events surrounding the first substance use after a period of abstinence, and strategies to prevent a single lapse becoming a full-blown relapse (Shearer, 2007). An RP programme will include: identifying high-risk situations for relapse and triggers for craving; developing strategies to reduce exposure to these high-risk situations; developing skills to cope with negative emotions without substance use; learning to manage lapses and develop an 'emergency plan'; and creating activities, relationships and a lifestyle which bring rewards and pleasure without a link to substance use (Wanigaratne et al., 2005).

The phrase 'relapse prevention' initially described a specific intervention model, but it is now increasingly used as something of an 'umbrella' term encompassing many CBT and coping skills programmes. This tends to complicate efforts to define and evaluate relapse prevention strategies, so, in this present review, we have tried to focus on RP as a particular 'Marlatt-based' model.

A.2.2 Coping skills/social skills training

These are interventions which focus on reducing the possibility of relapse by increasing the client's ability to cope with high-risk situations.

A.2.3 Motivational interviewing (MI)

This is a brief, 'client-centred' CBT approach which relies upon counselling skills such as asking openended questions, listening and summarising. The counsellor summarises the ideas the client has expressed and reflects them back for affirmation. This helps users to identify their own problems and feel competent to change. The principle is that substance users can persuade themselves and their counsellor that change is desirable and achievable. MI can be delivered in two stages; the first works on the client's motivation to enter treatment, and the second strengthens adherence to that treatment (Shearer, 2007; Wanigaratne et al., 2005).

A.3 Other treatments

A.3.1 Counselling

Counselling is a 'client-centred' non-directive approach. It is a systematic process designed to give individuals the chance to increase their sense of well-being. It may address improving relationships, dealing with conflict, making decisions or coping with crisis (Wanigaratne et al., 2005).

A.3.2 Interpersonal psychotherapy (IPT)

This is based on the concept that psychiatric disorders, including substance dependency, are associated with dysfunction in interpersonal relationships (Knapp et al., 2008). Supportive expressive psychodynamic therapy is one example of IPT. It examines ways to help users discuss personal experiences and identify relationship themes which have a connection with drug use and problem feelings and behaviour (Shearer, 2007).

A.3.3 Family therapy (FT)

This term is used to describe a number of types of intervention involving family members and close friends. Structural FT works towards altering family structure using therapy sessions. Strategic FT looks more at family interactions outside the therapy sessions. Key features are a non-judgemental approach and an emphasis on behavioural change (Wanigaratne et al., 2005).

The term FT has also been used to describe interventions where family is involved in engaging and retaining the substance-user in treatment.

A.3.4 Residential rehabilitation/Therapeutic communities (TCs)

In this treatment, drug-free residential settings focus on psychosocial rehabilitation (Malivert et al., 2012). TCs simulate a family model, and the 12-steps principles are often used. Elements include enforced behavioural normalities, and clearly-defined roles and responsibilities with associated rewards and penalties (Shearer 2007).

A.3.5 Twelve-step programme

This is the basis of the self-help philosophy of Alcoholics Anonymous, who view addiction as an illness which can be slowed one day at a time but can never be cured. The first step in the process is a

commitment to a substance-free life, where users accept that they are powerless over their addiction. Individuals are encouraged to acknowledge the harm their addiction has done to themselves and to others, and to make amends (Shearer, 2007; Wanigaratne et al., 2005).

A.3.6 Mindfulness meditation

Mindfulness has been defined as 'the intentional, accepting and nonjudgmental focus of one's attention on the emotions, thoughts and sensations occurring in the present moment' (Zgierska et al., 2009, p.267). Clients can be taught to achieve this focused attention with techniques such as meditation. Mindfulness meditation can be viewed as the opposite to everyday 'autopilot' mental functioning. It may therefore be useful to substance users because it provides an alternative to the habit-driven, 'autopilot' state of mind. It may be used to complement CBT.

A.3.7 Brief interventions

Brief interventions are time-limited, structured counselling sessions which follow a specific plan and have timetables for the adoption of specific behaviours. They are characterised by five or fewer sessions lasting one hour or less. They tend to be used for moderating harmful behaviour where a substance user is at risk.

A.3.8 Traditional medicine

The use of acupuncture and herbal medicine to treat drug abuse is relatively new to Western medicine, and few clinical trials exist. It is possible that these complementary approaches may reach beyond conventional interventions and improve their efficiency.

Appendix B Literature review

B.1 Objective

The aim was to establish whether non-pharmacological interventions (psychosocial or alternative medicine), or a combination of pharmacological and non-pharmacological interventions, are more effective at preventing relapse after detoxification than pharmacological interventions alone.

B.2 Search strategy

Initial investigative scoping searches indicated that a large amount of literature on this topic already existed, including a number of systematic reviews. Consequently, our search was limited to reviews so that our findings would provide an overview of current research rather than repeat searches which had already been made.

Search methods for identification of studies

We searched the following electronic databases:

The Cochrane Library (Wiley)

CRD Databases (DARE, NHS EED and HTA, Centre for Reviews and Dissemination, University of York)

PubMed (National Center for Biotechnology Information, U.S. National Library of Medicine)

Web of Science (Thomson Reuters)

Three groups of search terms were used.

#1 MESH terms Substance Related Disorders OR Alcholics OR Drug users AND MESH term Psychotherapy.

Where MESH terms not available (substance* OR drug* OR alcohol* OR heroin OR opioid OR opiate* OR cocaine OR marijuana OR barbiturate*) AND (abuse* OR dependen* OR use OR misuse OR disorder* OR addict*)

#2 treatment* OR therapy OR therapies OR intervention* OR program* OR pathway* OR detox* OR engagement

#3 relapse* OR recur* OR abstinence OR abstain OR "relapse prevention" OR "maintenance treatment" OR "drop out" OR retention OR retain

See section B.8 for details of each search.

B.2.1 Selection criteria

We used the following criteria to select studies for inclusion in the review:

Types of participants: Adults over 18 (not pregnant women)

Types of substance misuse: Alcohol, opioids, cocaine, psychostimulant amphetamines, cannabis (not tobacco)

Types of studies: Systematic reviews as this provided assurance of quality. Non-systematic reviews which nevertheless contained relevant findings were not included in the main analysis but were noted and described separately.

Types of intervention: Psychosocial; psychosocial in combination with pharmacological; alternative medicine. Focus to be on treatment for substance misuse not co-occurring mental health disorders.

Comparison: Standard pharmacological treatment, no treatment.

Outcomes: Prevention of relapse; extending period of abstinence (not treatment of withdrawal symptoms).

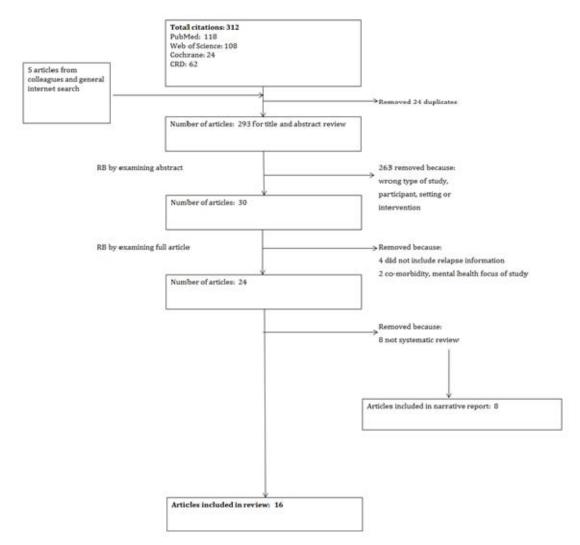
Setting: Community, residential treatment centres (not prison).

Other limitations: English language, 2000-2012.

B.3 Summary of results

See Figure B-1 for a flow chart of study selection. The searches of the electronic databases retrieved 312 studies. Five articles were added from general internet searches and recommendations from colleagues, and 24 duplicates were removed, leaving 293 papers. The abstracts of these were screened by one reviewer, and a large number, 263, were rejected because the type of participant, intervention, study or setting did not meet the inclusion criteria. The full text of each of the remaining 30 reviews was assessed by one reviewer, following which 6 were removed because they did not contain relapse information or they dealt with a dual diagnosis. A further 8 were excluded because they were not systematic reviews, leaving 16 studies which were included in the review.

Figure B-1. Data collection sources



B.3.1 Quality control and selection of type of studies

Non-systematic reviews were not included in the review. This was done in order to control the quality of the information summarised in this review of reviews. Summarising only the data collected during systematic reviews, where the included studies are all high-quality controlled trials, mostly randomised, guaranteed its reliability and ensured that the same standard of information was being compared. This consistency was doubly important in a review which contained so many other variables. Several studies were identified which nevertheless contained valuable information. In these instances, the nature or the novelty of the intervention made controlled trials and systematic reviewing difficult. A discussion of these studies is therefore included as a separate section in this review.

An assessment was made of the quality of each included systematic review, and the strengths and weaknesses were noted. Although some shortfalls were detected, all reviews were judged to be sufficiently reliable for inclusion.

B.3.2 Overview of the studies included in the review

See Table B-1 for an overview of the studies included in the review. The majority of the reviews dealt with a mixture of psychosocial treatments, but mindfulness meditation, relapse prevention, family therapy, therapeutic communities and the community reinforcement approach were addressed individually by specific reviews. The reviews looked at misuse relating to alcohol, cocaine, opiates, cannabis, amphetamines and polysubstances. Many of them dealt with a mixture of substances, but two dealt specifically with opiates, two with alcohol, two with cocaine and one with cannabis. It was not possible to identify the countries in which the studies were located, but it is suspected that most were based in the USA.

B.3.3 Problems and limitations

Heterogeneity was a problem both within the studies themselves and when providing an overview in this review. It was difficult to ensure that like was being compared with like. Not only was a range of different substance misuses being assessed, but outcome measures differed. Although this review aimed to focus on relapse after treatment, such information was hard to pinpoint and extract from other outcomes. For example, the treatment goal in studies might be sustained abstinence, a reduction in use, or improved quality of life and relationships.

The wide range of psychosocial interventions and the way in which they are categorised is also a problem. Slattery's literature search identified over 40 nominally different psychosocial methods for treating alcoholism, but many of these contain the same elements and could be grouped under one method (Slattery et al., 2003). Different treatment approaches may overlap or cut across the boundaries between named models. The way in which the treatments are classified or named in the studies differs. In summarising the evidence for the effectiveness of these treatments, the challenge was to decide when two treatments should be grouped together because they were essentially the same, and when they differed sufficiently to be discussed separately.

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
Mayet et al.	<i>Psychosocial treatment for opiate abuse and dependence</i>	Contingency management, brief reinforcement based intensive outpatient therapy coupled with contingency management, cue exposure therapy, Alternative Program for Methadone Maintenance Treatment Program Drop- outs and Enhanced Outreach- Counselling Program.	Opiates	Enhanced Outreach Counselling and Brief Reinforcement Based Intensive Outpatient Therapy had better outcomes for relapse than standard treatment. Not sustained. Not sufficient evidence to evaluate whether psychosocial interventions alone are effective for opioid dependence.	5	Good. This is a Cochrane review and as such it adheres to the methodology laid out in the Cochrane Handbook for Systematic Reviews of Interventions for minimising bias and producing reliable findings.
Knapp et al.	Psychosocial interventions for cocaine and psychostimulant amphetamines related disorders	Cognitive behavioural therapy (Relapse prevention, coping skills training, reinforcement based therapy, contingency management, community reinforcement approach, service outreach and recovery); Non-behavioural (multimodal treatment, enhanced community care, supportive expressive	Cocaine, amphetamines	No evidence to support a single psychosocial treatment approach preventing relapse, although results in favour of treatment involving some form of contingency management.	27	Good. This is a Cochrane review and as such it adheres to the methodology laid out in the Cochrane Handbook for Systematic Reviews of Interventions for minimising bias and producing reliable findings.

Table B-1. Overview of studies included in the review

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
		therapy).				
Zgierska et al.	Mindfulness meditation for substance use disorders: A systematic review	Mindfulness or mindfulness meditation (MM)	Mixed: cocaine, opiates, alcohol	MM produces comparable results to other behavioural treatments. Subjects receiving MM alongside pharmacotherapy or SOC (standard of care) therapy did as well as or better than those receiving SOC or pharmacotherapy alone.	22, 7 RCTs	Good. Conclusions relating to RCTs and non RCTs separated, methodological quality of studies assessed, limitations of review given.
Irvin et al.	Efficacy of relapse prevention: A meta- analytic review	Relapse prevention (RP). General cognitive behavioural interventions excluded.	Mixed: alcohol, opiates, polysubstance	RP effective in reducing substance use, but RP has more impact on improving psychological functioning than on substance use. RP most effective with alcohol and polysubstance abuse with adjunctive medication.	26	Poor reporting of methodology. Not clear how many reviewers assessed data, so bias possible. Not clear how quality of studies was assessed.
Dutra et al.	A meta-analytic review of psychosocial interventions for substance use disorders	Cognitive behavioural – relapse prevention and contingency management	Mixed: cannabis, cocaine, opiates,	Psychosocial treatments are effective. Outcomes for average patient better than those for patients receiving standard treatment. Most effective for	34	Only RCTs included, quality assessed. Methodology reported but not clear how many reviewers

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
			polysubstance	cannabis, least effective for polysubstance use. RP produced the largest post-treatment abstinence rates.		screened results so bias possible. Publication bias addressed.
Magill and Ray	Cognitive-behavioural treatment with adult alcohol and illicit drug users: a meta-analysis of randomised controlled trials	Cognitive behavioural therapy (CBT), relapse prevention and coping skills	Mixed: alcohol, cocaine, cannabis, opiates, polysubstance	CBT demonstrated a small but statistically significant improvement in treatment outcomes. Most effective for cannabis use and for women when combined with other psychosocial treatments and delivered in a brief format.	53	Lack of information about quality of trials, not clear how many reviewers analysed data so there may be bias.
Andreasson and Ojehagen	Psychosocial treatment for alcohol dependence	Cognitive behavioural therapy, marital therapy, community reinforcement approach, bibliotherapy, motivational interviewing	Alcohol	Psychosocial treatment is effective compared to no treatment or standard treatment. Extended treatment is more effective than a single session. Involving family members in treatment has a positive effect.	164	Poor reporting of review methodology, clinical differences between the studies
Prendergast et al.	Contingency management for treatment of substance use disorders: a meta	Contingency management (CM)	Mixed: cocaine, opiates, polysubstances,	CM an effective treatment for promoting abstinence. CM improves the ability of clients to	81	Methodology reported and more than one reviewer

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
	analysis		tobacco, alcohol	remain abstinent, so they can benefit from other psychosocial treatments. More effective when delivered over shorter rather than longer periods and most effective for opiates and cocaine. Not clear whether effective as a stand-alone treatment.		involved. Studies included were of high quality and efforts were made to reduce heterogeneity problems. Does not include unpublished studies so there may be publication bias.
Malivert et al.	Effectiveness of therapeutic communities: A systematic review	Therapeutic communities (TC)	Mixed: alcohol, cannabis, cocaine, heroin.	Substance use decreased during TC, but relapse was frequent after TC.	12	Non-randomised trials included. Methodological shortcomings in the original studies. Only one database used for searches.
Shearer	Psychosocial approaches to psychostimulant dependence: A systematic review	Contingency management (Community reinforcement approach, voucher reinforcement), cue exposure, motivational interviewing, relapse prevention, cognitive behavioural therapy,	Cocaine, amphetamines	Psychosocial interventions moderately effective in reducing psychostimulant use. Evidence base not strong, but promise of long-term benefits.	43	Only RCTs included, but no reporting of review methodology.

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
		interpersonal therapy, residential rehabilitation, 12- steps programme.				
Castells et al.	Efficacy of opiate maintenance therapy and adjunctive interventions for opioid dependence with comorbid cocaine use disorders: A systematic review and meta-analysis of controlled clinical trials	Opiate maintenance therapy (OMT) with adjunctive contingency management, cognitive behavioural therapy or acupuncture	Heroin and cocaine	A combination of CBT and CM as adjunct to OMT was more effective in helping patients achieve sustained cocaine abstinence than OMT alone. No studies reported data on acupuncture and sustained drug abstinence.	37	Only RCTs included, study quality assessed, not clear how many reviewers evaluated data
Roozen et al.	A systematic review of the effectiveness of the community reinforcement approach in alcohol, cocaine and opioid addiction	Community reinforcement approach (CRA)	Alcohol, cocaine and opioids	Limited to moderate evidence for the efficacy of CRA with or without contingency management or medication in treating various substance related disorders. No conclusive evidence of effect of CRA on continuous alcohol abstinence. Strong evidence that CRA combined with incentives is effective treatment for cocaine abstinence.	11	Methodology reported well. Three reviewers involved so bias reduced. Only RCTs included and quality assessed. No discussion of limitations of review.

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
Denis et al.	Psychotherapeutic interventions for cannabis abuse and/or dependence in outpatient settings (Review)	Cognitive behavioural therapy, motivational interviewing	Cannabis	Continuous abstinence rates small, but frequency of use reduced in all studies. Cannabis dependence not easily treated by psychotherapies in outpatient settings. Extended CBT more effective than brief CBT. CBT most effective when combined with contingency management.	6	Good. This is a Cochrane review and as such it adheres to the methodology laid out in the <i>Cochrane</i> <i>Handbook for</i> <i>Systematic Reviews of</i> <i>Interventions</i> for minimising bias and producing reliable findings.
Amato et al.	Psychosocial and pharmacological treatments versus pharmacological treatments for opioid detoxification (Review)	Contingency management, community reinforcement approach, structured counselling (5 types), family therapy	Opiates	Providing a psychosocial treatment in addition to a pharmacological detoxification treatment is effective for detoxification and for sustained abstinence. No data supports a single psychosocial approach.	11	Good. This is a Cochrane review and as such it adheres to the methodology laid out in the Cochrane Handbook for Systematic Reviews of Interventions for minimising bias and producing reliable findings.
Slattery et al.	Prevention of relapse in	Cognitive behavioural therapy, behavioural self-	Alcohol	BSCT, MET, marital/family therapy, coping/social skills	28	Only RCTs included. Methodology

Author	Title	Interventions	Substances	Findings	No. of studies	Quality of review
	alcohol dependence	control training (BSCT), brief intervention (BI), motivational enhancement therapy (MET), skills training, marital/family therapy, intensive case management		training all effective at preventing relapse from alcohol dependence. Beneficial effects statistically significant. No one treatment found to be more beneficial than another. Project MATCH showed that an introductory 12-step programme combined with AA meetings helps to prevent relapse.		recorded.
Meads et al.	A systematic review of the clinical and cost- effectiveness of psychological therapy involving family and friends in alcohol misuse or dependence	Family therapy	Alcohol	Compared to other treatments, family therapy demonstrated better relationship functioning and an increase in treatment entry rates. Family therapy no more effective than other forms of psychotherapy or counselling in increasing abstinence rates. No evidence on long-term effectiveness of treatments because no research.	34	Only RCTs included and their quality was assessed. Methodology reported. More than one reviewer involved so bias reduced.

B.4 Effectiveness of psychosocial interventions

B.4.1 Findings relating to specific substances

B.4.1.1 Opioid misuse

Mayet's review concluded that there is not sufficient evidence to evaluate whether psychosocial interventions alone are effective for opioid dependence, or whether they are better than any other type of treatment (Mayet et al., 2010). It found that Reinforcement-Based Intensive Outpatient Treatment, a form of CRA, was significantly better at preventing relapse to heroin use than standard treatment, but that this was not sustained by the three months follow-up.

Amato concluded that providing a psychosocial treatment in addition to a pharmacological detoxification treatment is effective both for detoxification and for sustained abstinence. Adding some form of psychosocial intervention to standard treatment improved relapse rates. However, no one psychosocial treatment was found to be any more effective than another at preventing relapse (Amato et al., 2011). It was suggested that this may be due to variations among the population of substance users.

A review of the effectiveness of CM found strong evidence that CM improves the ability of clients to remain abstinent, particularly opiate and cocaine users (Prendergast et al., 2006). As above, CM was most effective as an adjunct to standard pharmacological treatments. The author questioned whether CM would be as effective at preventing relapse over longer periods of time, but referred to one study where a voucher-based intervention had helped clients to remain abstinent for up to a year (p.1555).

B.4.1.2 Cocaine and psychostimulant misuse

Knapp et al. (2008) found no evidence to support a single psychosocial treatment approach preventing relapse, although there was some evidence in favour of treatment involving some form of contingency management (Knapp et al., 2008).

A review into the effectiveness of the CRA found strong evidence that CRA with CM incentives are more effective at achieving abstinence from cocaine than standard care (Roozen et al., 2004). There was no evidence about the long-term effectiveness of CRA in preventing relapse and, as with CM, CRA is a relatively intensive treatment. However, it was pointed out that CRA can be adapted to individual goals, varying from long-term abstinence to reduced substance use.

Shearer's review stressed that there are, as yet, no pharmacological approaches recognised as safe and effective for achieving abstinence from psychostimulant use. His review concluded that, although the evidence base is not strong, psychosocial interventions are moderately effective at reducing psychostimulant use (Shearer, 2007).

Two reviews provided evidence that CM, when used as an adjunct to standard treatment, is among the more effective approaches for promoting abstinence after treatment for cocaine users (Castells et al., 2009; Prendergast et al., 2006).

B.4.1.3 Cannabis misuse

Denis et al. looked at a range of CBT for cannabis use. None of the treatments prevented relapse particularly effectively, and the percentage of participants still remaining abstinent at follow up of a year and over was very small in most studies. However, a reduction of cannabis use was reported across all studies. The author concluded that cannabis dependence is not easily treated by psychotherapies in outpatient settings, that extended CBT is more effective than brief CBT, and CBT most effective when combined with CM (Denis et al., 2008).

Conversely, Dutra et al. found that outcomes for the average patient receiving some form of CBT were better than those for patients receiving standard treatment. This was particularly true for cannabis users. RP produced the largest post-treatment abstinence rates (Dutra et al., 2008). Magill also concluded that CBT was particularly effective for cannabis users (Magill and Ray, 2009).

B.4.1.4 Polysubstance misuse

All reviews stated that dependency on a combination of illicit drugs and/or alcohol was the most difficult to treat and involved the highest proportion of clients with additional mental health issues.

One review demonstrated that, although psychosocial treatments provided benefits, these were weakest for polysubstance users (Dutra et al., 2008). This review also noted that none of the RP studies analysed polysubstance users, so it is of interest that Irvin's meta-analysis showed that RP was particularly effective with polysubstance abuse when used with adjunctive medication (Irvin et al., 1999).

B.4.1.5 Alcohol misuse

Two reviews concluded that psychosocial treatments are effective at preventing relapse from alcohol dependence compared to no treatment or standard treatment (Slattery et al., 2003; Andreasson and Ojehagen, 2003). Specifically, BSCT, MET, marital/family therapy and coping/social skills training all showed beneficial effects which were statistically significant, but no one treatment was found to be more beneficial than another, apart from BI which was not effective at all (Slattery et al., 2003). Project MATCH study showed that an introductory programme based on the 12-step approach, combined with AA meetings, helps to prevent relapse (Slattery et al., 2003).

One review found no conclusive evidence of effect of CRA on continuous alcohol abstinence (Roozen et al., 2004).

Two reviews showed that involving family members in treatment has a positive effect (Andreasson and Ojehagen, 2003; Meads et al., 2007).

B.4.2 Findings relating to specific treatments

B.4.2.1 Relapse prevention

Only one study reviewed RP specifically (Irvin et al., 1999). It concluded that RP was effective for reducing substance use and improving psychosocial adjustment. It was at its most effective when used with adjunctive medication for alcohol and polysubstance use. However, none of the studies in Irvin's

review collected data for any longer than one year, so it remains unclear whether RP is effective for long-term change.

B.4.2.2 Therapeutic communities

One review evaluated TCs. All studies in this review showed that substance use decreased during TC, but relapse was frequent after TC. The long-lasting benefits of TC are therefore uncertain.

B.4.2.3 Mindfulness meditation

Data from the controlled trials pooled in one review suggest that clients receiving MM adjunctive to pharmacotherapy do as well as those receiving pharmacotherapy alone (Zgierska et al., 2009).

B.5 Findings from non-systematic reviews of alternative therapies

A number of complementary and alternative therapies are being tried in the treatment of substance use disorders, and as personal health budgets offer patients the potential to access complementary and alternative therapies, it is necessary to evaluate these. They include: herbal medicine, acupuncture, homeopathy, mind body interventions (yoga, meditation, electroencephalogram biofeedback (EEG)) and relaxation therapies (such as aromatherapy, meditation, massage). All of these are non-pharmacological treatments that are not routinely offered to substance misuse patients on the NHS. By definition, these interventions are not accepted by conventional medicine because they have not yet been shown to be clinically effective. While research has been undertaken in this field, there is a lack of rigorous trials, and therefore there are no systematic reviews. The search did, however, locate several other notable papers, which are discussed below.

A non-systematic review by Lu et al. (2009) showed that there was some evidence for acupuncture helping to manage withdrawal and maybe prevent relapse for opiate users, but not for alcohol. There were not enough trials to reach any conclusion about the efficacy of acupuncture for cocaine users. There was also insufficient evidence for the use of herbal treatments. Lu et al. (2009) concluded that acupuncture combined with herbal medicine deserved further study as a treatment for some types of addiction. One study reported that 20 out of 26 heroin addicts stayed drug free for one to one and a half years following the combined administration of Chinese medicine and acupuncture (Lu et al., 2009, p.7). Behere et al. (2009) similarly concluded that none of the alternative therapies provides sufficient evidence yet for the treatment of substance misuse, and that these treatments face methodological difficulties relating to standardisation of procedures and the use of a control. Acupuncture, EEG biofeedback and two herbal remedies (kudzu and ibogaine) showed promise.

Moreover, other notable studies, not necessarily looking at the relapse prevention phase but at earlier stages, such as by Shwartz et al. (1999), also illustrated the value of acupuncture programmes in substance abuse treatment. Working in the USA, they compared residential (conventional) detoxification re-admission rates to those of outpatient acupuncture programmes. Using multivariate analysis, they demonstrated that the acupuncture patients were less likely to be re-admitted within six months. Carlson and Larkin (2009), also working in the USA, found that mindfulness meditation, by reducing stress levels, enabled patients to find coping strategies to deal with their addiction, thus making them more likely to stop the substance misuse and less likely to relapse. They argued that 'stress can contribute to addiction, and stress also results from the consequences of addiction'

(Carlson and Larkin, 2009, p.379). However, Alterman et al. (2004) conducted a similar study and found no significant positive effects of using mindfulness meditation to treat substance misuse. Eighteen randomised substance-abuse recovery house patients were given eight weeks of mindfulness meditation alongside standard detoxification treatment. These were compared to 13 patients simply receiving standard detoxification treatment. Over a five-month follow-up period, the only significant difference found between both groups, in the multi-dimensional measure of various life problems, was greater improvement in medical problems among those offered mindfulness meditation, according to Addiction Severity Index composite scores. No differential group change was found in urine toxicology results or in measures of psychological health. Thus, this evaluation yielded relatively little indication that meditation enhanced treatment outcomes for the substance abuse patients studied. In these hard economic times, this lack of conclusive evidence of beneficial outcomes must be taken into account when deciding whether to implement personal health budgets more widely.

Wright (2006) also discussed the need for non-pharmacological options in the treatment of substance misuse problems. She designed an anecdotal review to explore whether spa treatments could be a tool in the rehabilitation of people with alcohol and drug problems. She concluded that, while her review lacked any scientifically robust evidence, the generated interest and sufficient anecdotal support suggested that further investigation was definitely needed. Weissberg (2002, p.1) also discussed the need to take a holistic approach to treating drug and alcohol addictions, citing a number of possible treatments, such as light therapy, aromatherapy and meditation, arguing "most Western medicines take care of the symptoms of a disease, preferably with a 'quick fix' rather than looking at the symptoms as an indication of the body being out of balance. The body might be saying that it is overworked, undernourished or out of balance because of emotional stress."

These studies and the non-systematic reviews illustrate the need to find new effective and feasibly priced treatments for substance misuse in this age of ever-increasing demands on the NHS and shrinking resources. Thus, this evaluation aims to build on this knowledge-gathering and contribute to the development of this area of study by providing evidence of the efficacy, or lack of it, of psychosocial treatment as part of the personal health budget, as in the current economic climate it is essential that money is spent only on treatments of proven efficacy.

B.6 Conclusions

This review found that psychosocial treatments used in addition to pharmacological interventions are effective in reducing substance use. In fact, this can be taken further, as it is clear that adding some form of psychosocial intervention to standard pharmacological treatment actually reduces relapse rates. There is strong evidence that CM added to standard treatment improves the ability of cocaine and opiate using clients to remain abstinent. Various forms of CBT, including RP, are particularly effective for combating cannabis and alcohol misuse. Project MATCH demonstrated that the 12-steps approach, combined with AA meetings, helps to prevent relapse to alcohol. The weakest effect of psychosocial interventions is among polysubstance users. However, there is no evidence for the effectiveness of psychosocial interventions alone for preventing relapse into substance misuse.

Any review of substance misuse will reveal that many treatments (both psychosocial and pharmacological) exist to help individuals cease or reduce substance use, but there is not as much

emphasis on helping substance users to maintain behaviour changes over time. This was illustrated in this review by the fact that information about the long-term efficiency of interventions is limited, with few studies focusing on preventing relapse after one year. The tremendously negative consequences of relapse, both for the individual and for society, mean that the development and refinement of strategies to reduce relapse are critical. Treatments which incorporate a continuing-care approach should be adopted so that substance treatment is considered as long-term.

This literature review aimed to establish whether non-pharmacological interventions (psychosocial or alternative medicine), or a combination of pharmacological and non-pharmacological interventions, are more effective at preventing relapse after detoxification than pharmacological interventions alone. It is hoped that this review will provide important information about how personal health budgets should be best implemented among patients seeking substance misuse treatments based on the existing evidence-base. Indeed, it was found that there is no evidence for any one psychosocial intervention being more effective than another for the prevention of relapse to all substances. However, it was discussed that some interventions are more effective for certain substance problems than others. Therefore it appears that relapse prevention programmes which are tailored to the needs of an individual and which take into account the substance or substances being misused, along with the setting, client history, background and level of family support, are more likely to work in the long term, meaning that the best possible use is made of each specific intervention. It can therefore be concluded that patient-based strategies, which combine a mixture of treatments and support and use the best and the most appropriate of each, increase the chances of long-term success. This literature review therefore provides important findings that must be noted if personal health budgets which adhere to the principles of greater choice and control – properties intrinsic to personalisation – are to be successfully implemented with this client group.

B.7 References

B.7.1 Studies included in review

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B.8 Details of searches

B.8.1 The Cochrane Library

(Wiley)

- #1 MeSH descriptor Substance-Related Disorders explode all trees
- #2 MeSH descriptor Drug Users, this term only
- #3 MeSH descriptor Alcoholics, this term only
- #4 (#1 OR #2 OR #2)

(substance? OR drug? OR alcohol* OR heroin OR opioid OR opiate? OR cocaine OR

- #5 marijuana OR barbiturate?):ti,ab,kw and (abuse* OR dependen* OR use OR misuse OR disorder? OR addict*):ti,ab,kw
- #6 (#4 OR #5)
- #7 (treatment? OR therapy OR therapies OR intervention? OR programme? OR pathway? OR detox* OR engagement):ti,ab,kw

(relapse? OR recur* OR abstinence or abstain OR "relapse prevention" OR

- #8 "maintenance treatment" OR "drop out*" OR retention OR retain OR maintain):ti,ab,kw
- #9 (#6 AND #7 AND #8)
- #10 MeSH descriptor Psychotherapy explode all trees
- #11 (#6 AND #7 AND #8 AND #10)
- Searched 22 June 2012
- 623 results; 18 Cochrane Reviews, 6 Other reviews

B.8.2 CRD Databases

1 MeSH DESCRIPTOR Substance-Related Disorders EXPLODE ALL TREES 567

2 MeSH DESCRIPTOR Drug Users EXPLODE ALL TREES 2

3 ((substance* OR drug* OR alcohol* OR heroin OR opioid OR opiate* OR cocaine OR marijuana OR barbiturate*)) AND ((abuse* OR misuse* OR use OR dependen* OR disorder* OR addict*)) FROM 2002 TO 2012 2545

4 #1 OR #2 OR #3 2729

5 (treatment* OR therap* OR intervention* OR program* OR pathway* OR detox* OR engagement) FROM 2002 TO 2012 29997

6 MeSH DESCRIPTOR Psychotherapy EXPLODE ALL TREES 1349

7 ((relapse* OR recur* OR maintain* oR abstain OR abstinence OR "relapse prevention*" OR "maintenance treatment*" OR "drop put*" OR retention OR retain OR maintain)) FROM 2002 TO 2012 4309

8 #4 AND #5 AND #6 AND #7 62

Searched 22 June 2012

62 results

B.8.3 Web of Science

1 252,350 Topic=((substance? OR drug? OR alcohol* OR heroin OR opioid OR opiate? OR cocaine OR marijuana OR barbiturate?)) AND Topic=((abuse? OR misuse? OR use* OR dependen* OR disorder? OR addict*))

2 1,937,534 Topic=(treatment? OR therap* OR intervention? OR pathway? OR detox* OR program* OR engagement)

3 733,069 Topic=(relapse? or recur* OR maintain* OR "maintenance treatment" OR abstain OR abstinence OR "relapse prevention" OR "drop out*" OR retain OR retention)

4 10,243 #3 AND #2 AND #1

5 2,142 #3 AND #2 AND #1

Refined by: Document Type=(REVIEW)

#6 108 #3 AND #2 AND #1

Refined by: Document Type=(REVIEW) AND Web of Science Categories=(SUBSTANCE ABUSE)

Databases=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH Timespan=2002-2012

Timespan=2002-2012

Searched 22 June 2012

108 results

B.8.4 PubMed

#25 Add Search (((#14) AND #15) AND #16) AND #19 Filters: published in the last 10 years; Review; Systematic Reviews; Meta-Analysis; English; Adult: 19+ years 118

#24 Add Search (((#14) AND #15) AND #16) AND #19 Filters: published in the last 10 years; Review; Systematic Reviews; Meta-Analysis; English 583

#23 Add Search (((#14) AND #15) AND #16) AND #19 Filters: published in the last 10 years; Review; Systematic Reviews; English 583

#22 Add Search (((#14) AND #15) AND #16) AND #19 Filters: published in the last 10 years; English 2191

#21 Add Search (((#14) AND #15) AND #16) AND #19 Filters: published in the last 10 years 2460

#20 Add Search (((#14) AND #15) AND #16) AND #19 4593

#19 Add Search "Psychotherapy" [Mesh] 138099

#16 Add Search relapse* OR recur* OR abstinence OR abstain OR "relapse prevention" OR "maintenance treatment" OR "drop out" oR retention OR retain 672447

#15 Add Search treatment* OR therapy OR therapies OR intervention* OR program* OR pathway* OR detox* OR engagement 8524659

#14 Add Search (#12) OR #13 2783410

#13 Add Search (substance* OR drug* OR alcohol* OR heroin OR opioid OR opiate* OR cocaine OR marijuana OR barbiturate*) AND abuse* OR dependen* OR use OR misuse OR disorder* OR addict* 2652165

#12 Add Search ((#11) OR #8) OR #7 250333

#11 Add Search "Alcoholics"[MeSH Major Topic] 44

#8 Add Search "Drug Users" [MeSH Major Topic] 464

#7 Add Search "Substance-Related Disorders" [MeSH Major Topic] 250187

118 results

Searched 26 June 2012

Appendix C Quantitative data analysis

C.1 Outcome questionnaires

The questionnaires contained a number of outcome indicators and measures.

C.1.1 Psychological well-being

The psychological well-being of service users was measured by the 12-item version of the General Health Questionnaire (Goldberg, 1992) that explores whether respondents have experienced a particular symptom or behaviour over the past few weeks. Each item is rated on a four-point scale (less than usual, no more than usual, rather more than usual, or much more than usual). There are two scoring methods: the bi-modal (0 to 1) scoring style that indicates the likely presence of psychological distress according to a designated cut-off score of 4 or more; and the Likert scoring scale (0 to 3) which generates a total score ranging from 0 to 36, with higher scores indicating worse conditions. The GHQ-12 has been extensively used in national studies, including the British Household Panel Survey and the Health Survey for England, providing the scope for comparative analysis in the future.

C.1.2 The Alcohol Use Disorders Identification Test (AUDIT_C)

The Alcohol Use Disorders Identification Test (AUDIT) was developed by the World Health Organisation (Babor et al., 2001) as a tool to identify individuals with hazardous and harmful patterns of alcohol consumption. AUDIT_C is a shortened version of the test using the first three questions (Bush et al., 1998; Bradley et al., 2007). Optimal screening thresholds for alcohol misuse among men (four or more) and women (three or more).

C.1.3 Health-related quality of life (EQ-5D)

The three-level Euro-QoL (EQ-5D) measure includes three parts to this measure.

Part 1: Participants are asked to indicate what level of difficulty they have in carrying out five tasks: mobility, self-care, usual activities, managing pain/discomfort and managing anxiety/depression. The levels of difficulty are, 'no problems', 'some problems' and 'extreme problems/unable'.

Part 2: Participants are asked to say how they feel their 'general level' of health has changed compared to the previous 12 months, whether it has got better, is much the same, or worse.

Part 3: Participants are asked to indicate how good or bad their heath state is on a 'thermometer' that runs from 0 (worst imaginable health state) to 100 (best imaginable health state).

C.1.4 Service satisfaction and quality of services

Measures of service satisfaction were based on quality indicators derived from the extensions to national user experience surveys for older home care service users and younger adults (Jones et al., 2007; Malley et al., 2006).

C.1.5 Social care outcomes

The Adult Social Care Outcomes Toolkit (ASCOT) is a preference-weighted indicator that reflects need for help and outcome gain from services across seven domains, ranging from basic areas of need such as personal care and food and nutrition to social participation and involvement and control over daily life. The questions ask respondents to choose from a series of three deteriorating situations. Table C-1 shows the responses actually used in the interview. Rather than assuming that each domain and level is of equivalent importance, the measure is weighted using population-based preferences (see Burge et al., 2006).

Domain	Need level	Description
Control	No	I have as much control over my daily life as I want
	Low	Sometimes I don't feel I have as much control over my daily as I want
	High	I have no control over my daily life
Personal care	No	I feel clean and wear what I want
	Low	I sometimes feel less clean than I want or sometimes can't wear what I want
	High	I feel much less clean than I want, with poor personal hygiene
Food and	No	I eat the meals I like when I want
nutrition	Low	I don't always eat the right meals I want, but I don't think there is a risk to my health
	High	I don't always eat the right meals I want, and I think there is a risk to my health
Safety	No	I feel as safe as I want
	Low	Sometimes I do not feel as safe as I want
	High	I never feel as safe as I want
Social	No	My social situation and relationships are as good as I want
participation	Low	Sometimes I feel my social situation and relationships are not as good as I want
	High	I feel socially isolated and often feel lonely
Activities/	No	I do the activities I want to do
occupation	Low	I do some of the activities I want to do
	High	I don't do any of the activities I want to do
Accommodation	No	My home is as clean and comfortable as I want
	Low	My home is less clean and comfortable than I want
	High	My home is not at all as clean or comfortable as I want
Level of worry	No	I feel free from worry and concerns on a day-to-day basis
and concern	Low	I sometimes feel worried and concerned
	High	I feel very worried and concerned on a daily basis
Dignity and	No	I am treated by other people with the dignity and respect that I want
respect	Low	Sometimes I am not treated by other people with the dignity and respect that I want
	High	I am never treated with the dignity and respect that I want

Table C-1. Options provided for each domain to reflect each need level

Table C-2 gives the weights that we applied to each of the attributes. For example, if a person reported that their personal cleanliness was at a desired level then this would be scored at 4.54. In this way, all nine attributes are weighted and summed for a total score. The maximum possible score is 41.08 and the minimum possible is 10.82.

Table C-2. Preference weights for attributes and levels

	Desired	Adequate	Poor
Control over daily life	5.18	1.5	0
Personal cleanliness	4.54	1.87	1.09
Meals and nutrition	4.16	2.59	1.96
Safety	4.71	1.71	1.14
Social participation	4.67	2.36	0.76
Activities/occupation	4.50	3.95	1.69
Home cleanliness and comfort	4.38	2.47	1.76
Anxiety	4.69	1.88	1.24
Dignity and respect	4.25	1.63	1.18

C.2 References

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Appendix D Glossary of abbreviations

BI	Brief intervention
BSCT	Behavioural self-control thinking
CBT	Cognitive behavioural therapy
СМ	Contingency management
CRA	Community reinforcement approach
FT	Family therapy
IPT	Interpersonal psychotherapy
MET	Motivational enhancement therapy
MI	Motivational interviewing
MM	Mindfulness meditation
OMT	Opiate maintenance therapy
RCT	Randomised controlled trial
RP	Relapse prevention
SOC	Standard of care
TCS	Therapeutic communities