Evaluation of the personal health budget pilot programme

Executive summary

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Executive summary

1. 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. Giving people greater choice and control, with patients working alongside health service professionals to develop and execute a care plan, given a known budget, is intended to encourage more responsiveness of the health and care system.
2. The personal health budget programme was launched by the Department of Health in 2009 after the publication of the 2008 Next Stage Review. An independent evaluation was commissioned alongside the pilot programme with the aim of identifying whether personal health budgets ensured better health and care outcomes when compared to conventional service delivery and, if so, the best way for personal health budgets to be implemented.

Study design and methodology

3. The evaluation took a longitudinal approach and included people with any of six conditions: chronic obstructive pulmonary disease, diabetes and long-term neurological conditions; mental health; stroke; and patients eligible for NHS Continuing Healthcare.
4. Of the 64 sites in the personal health budgets pilot at onset, 20 sites were selected to be *in-depth* evaluation sites, with the remainder being *wider cohort* sites. Sites implemented personal health budgets in different ways, varying the choice people had about what services could be purchased with the budget, flexibility as to how the budget could be managed, how explicit the budget size was and how the size of the budget was calculated.
5. The evaluation used a controlled trial to compare the experiences of people selected to receive personal health budgets with those of people continuing with conventional support arrangements. A pragmatic design was used. After applying initial selection criteria, in some sites people were randomised into the personal health budget group or a control group. In other sites, the personal health budget group was recruited from patients of those health care professionals in the pilot offering budgets and a control group from patients of non-participating health care professionals.
6. The evaluation followed a mixed design, using both quantitative and qualitative methodologies to explore patient outcomes, experiences, service use and costs. Just over 1000 individuals were recruited into each arm of the study in order to give the analysis sufficient statistical power. The study used methods to deal with a range of issues, including: attribution of effect (addressed using a difference-in-difference approach and testing with confounding factors); missing data (multiple imputation); allocation of costs (a costing model); and statistical inference regarding the significance of sample results (parametric and bootstrap estimators, powered sample sizes). Limitations with respect to these methods should be noted.
7. Cost effectiveness was assessed by estimating whether the personal health budgets group experienced greater benefits than the control group who received conventional service delivery, after netting off the difference in service and support costs between the groups. Net benefits were expressed in monetary terms for this purpose, using willingness-to-pay thresholds. The groups were compared at a target 12-month after initial recruitment, with any baseline differences (in net benefit levels) between the groups subtracted from the follow-up difference to reduce attribution bias.
8. The qualitative analysis involved interviews with organisational representatives, personal health budget holders and carers of budget holders. The framework approach was used for the analysis, with the data organised by themes according to the topic guides used in the interviews.

The impact of PHBs on quality of life and care-related outcomes

9. A personal health budget might have an impact on outcomes in three different ways:

    - Through the direct benefits of having more choice and control on quality of life;
    - From the change in the services and support people fund using their personal health budgets, allowing them to tailor care and support to their own needs and preferences. This process could improve the recipients' health and functioning and, in turn, their quality of life. There might, conversely, be a negative effect if people make ill-informed choices about their care; and
    - From any change in the overall level of funding of people's personal health budgets as compared to what they would have received under conventional service arrangements.

10. A range of 'impact' indicators were assessed, including clinical effectiveness measures; mortality rates; care and health-related quality of life measures; psychological health scales and overall wellbeing indicators. Changes in these impact indicators between the personal health budget and control groups indicated the *benefits* consequences of the initiative.

11. People's use of a wide range of services and support was assessed between the groups, including: community health; therapy and nursing services; social care services aimed at meeting health and care needs; well-being services; and also, primary and secondary services (which might be affected indirectly from the use of a personal health budget). Changes in service expenditure between the personal health budget and control groups indicated the *cost* consequences of the initiative.

Findings

12. The main benefit-related implications of personal health budgets were as follows (unless otherwise noted, significance is assessed at the 95% confidence level):

    - The use of personal health budgets was associated with a significant improvement in the care-related quality of life (ASCOT) and psychological well-being (GHQ-12) of patients (at 90% confidence).
    - Personal health budgets did not appear to have an impact on health status *per se* over the 12 month follow-up period. No significant effects were found with regard to two clinical measures (HbA1C and lung-function tests, used where relevant) and there was no significant difference in mortality rates between the groups. Consistent with these results, the study did not find that personal health budgets had a significant effect on EQ-5D compared to the control group.

13. The configuration of personal health budgets also appeared to be important. Generally, a more positive effect on outcome indicators was seen where sites: choose to be explicit in informing the patients about the budget amount; provided a degree of flexibility as to what services could be purchased; and provided greater choice as to how the budget could be managed. Some negative impacts were found for sites using configurations with less flexibility and choice than other sites.

14. Separating personal health budgets into high-value (i.e. a budget of more than £1,000 per year) and low-value, it was the former that showed a significant positive impact on care-related quality of life (ASCOT) and psychological well-being (GHQ-12). High-value budgets were more likely for people with greater levels of need or where sites opted to be more inclusive about what budgets could cover.

15. Sub-group analyses for individual patient groups were limited by the relatively small sample sizes for individual groups (hence low statistical power). Nonetheless, a number of effects were strong enough to emerge in these analyses: personal health budgets were associated with improvements regarding ASCOT-measured outcome change (at 90%), psychological well-being (GHQ-12) and subjective well-being, for the COPD cohort.

16. The main findings of the cost analysis were:
    - The cost of inpatient care (an 'indirect' cost) was significantly lower for the personal health budget group compared to the control group after accounting for baseline differences.
    - The ('direct') costs of well-being and other health services were both significantly higher for the personal health budget group compared to controls.
    - Other categories of direct and indirect cost showed no difference between the groups.
    - The difference in direct and indirect total costs between personal health budget and control groups after accounting for baseline differences were not statistically significant.
17. The cost analyses for the individual health condition groups were mostly inconclusive as a result of the modest sub-sample sizes. However, indirect costs were found to be lower for personal health budget-holders in the mental health and NHS Continuing Healthcare sub-groups (at the 90% confidence level). Total costs were also lower in the group of people with high-value personal health budgets compared to the controls (significant at the 90% confidence level).
18. The change in the balance of services that budget-holders used also suggested that more of their services were secured from outside conventional NHS providers than the control group.
19. Personal health budgets were assessed to be cost-effective relative to conventional service delivery if they produced greater *net benefits* than this usual care comparator. Key findings were:
    - Using care-related quality of life (ASCOT) measured net benefits, personal health budgets were cost-effective relative to conventional service delivery (at the 90% confidence level).
    - There was no significant difference in the net benefit between the groups using health-related quality of life (EQ-5D) measured benefits.
    - Notwithstanding the small sample sizes in the sub-group analyses, personal health budgets showed higher ASCOT-measured net benefits than conventional services for the CHC and mental health sub-groups (at the 90% confidence level).
    - Personal health budgets implemented following the main ethos of the policy (greater choice and control) were cost-effective at the 95% confidence level, as were those with high-value budgets.
20. Sensitivity analysis was used to explore whether the main results changed if some of the assumptions in the analysis were altered (regarding missing data imputation and the costing of personal health budgets). These analyses substantiated our main results in almost all cases. With the main alternative assumptions, personal health budgets were cost-effective (with ASCOT-measured benefits) at the 95% confidence level, rather than the 90% level.
21. Personal health budgets were cost-effective using the ASCOT quality of life measure. Although this measure was developed originally to assess the consequences of social care services, its focus on care-related quality of life implications makes it highly relevant for general use with people managing long-term conditions. Other studies have shown that people value care-related quality of life as measured by ASCOT in that they are willing to exchange shorter life expectancy for better ASCOT-measured quality of life. Improvement in ASCOT quality of life was found for people who were not using social care at baseline as well as for those people who were in receipt of these services.

The impact of personal health budgets on the caring role and quality of life

22. Difference-in-difference multivariate analysis revealed no significant differences in the reported use of informal care between personal health budget and control groups overall.

23. Analysis of a more limited sample of carers of people with personal health budgets suggested that they were more likely to report better quality of life and perceived health than carers of people in the control group. Carers seemed to be satisfied with the personal health budget process in terms of support planning, the amount of the budget and the amount of help that was offered when deciding what services or support to purchase from the personal health budget. The small sample (147) in this case restricted the extent to which confounding factors could be accounted for in this analysis.

User and carer perspectives on PHBs

24. At around three months after the offer of the personal health budget 58 personal health budget holders were interviewed to discuss their experiences of the process. Fifty-two took part in a follow-up interview nine months after the offer of the personal health budgets. Nineteen carers providing assistance to a personal health budget holder were interviewed at three months after the offer; of which 13 carers were interviewed at nine months after the offer of the budget.

25. At nine months after study recruitment, the majority of budget-holders and carers reported positive impacts of the personal health budget – on their health and well-being, health care and other support arrangements and for other family members. Effect on their use of health services or changes in relationships with health professionals were less likely to be reported. Most interviewees appreciated the increased choice, control and flexibility of the personal health budget, although some thought the benefits were curtailed by restrictions on what the budget could be used for, lack of services and budgets being too small for their needs.

Recommendations for policy and practice

26. The findings from the study suggest a number of recommendations regarding the possible roll-out of personal health budgets:

    - The study concludes that personal health budgets were cost-effective, given the assumptions made (esp. regarding the value of ASCOT quality of life) and thus support a wider roll out.
    - High-value personal health budgets were most cost-effective, suggesting that personal health budgets should be initially targeted at people with greater need, to act as substitute for conventional service delivery.
    - Personal health budgets were cost-effective for people with mental health problems and those receiving NHS continuing healthcare but the analyses for other health conditions were inconclusive due to small sub-samples sizes.
    - The budget-holders that were interviewed emphasised the value of information and guidance from sites about the size and operation of their budgets, including what services were covered.
    - The use of personal health budgets is likely to result in greater use of ‘non-conventional’ providers. Further research is required to better understand the scale of these changes.