

Kent Academic Repository

Jones, Karen R., Welch, Elizabeth, Fox, Diane, Caiels, James and Forder, Julien E. (2018) *Personal Health Budgets: Implementation following the national pilot programme; overall project summary.* Personal Health Budgets England.

Downloaded from

https://kar.kent.ac.uk/98754/ The University of Kent's Academic Repository KAR

The version of record is available from

This document version

Author's Accepted Manuscript

DOI for this version

Licence for this version

CC BY-ND (Attribution-NoDerivatives)

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).



Personal Health Budgets: Implementation following the national pilot programme; overall project summary

Karen Jones, Elizabeth Welch, Diane Fox, James Caiels and Julien Forder

Working Paper 2949

August 2018

www.pssru.ac.uk

Research commissioned by the Department of Health

Acknowledgements

We would like to thank the participating Clinical Commissioning Groups and NHS England for advertising the study on their Personal Health Budget Network. We are also grateful to the organisational representatives, patients and their families who agreed to participate in the study.

We would like to thank a number of our colleagues from PSSRU at the University of Kent for administrative, technical and research support. During the study period, support was offered by Jane Dennett, Edward Ludlow, Alan Dargan and Sarah Godfrey at PSSRU. Finally, the Project Advisory Group provided useful feedback on the topic guides and the recruitment process. The Advisory Group involved stakeholders, academics and patients/members of the public.

This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health and Social Care. The views expressed in the publication are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care or its arm's length bodies or other government departments.

Introduction

- 1. The underlying principle of personalisation is to offer people greater choice and control by providing the opportunity to make care decisions in partnership with professionals.
- 2. Personal health budgets (PHBs) are funds for individuals to purchase services, support and equipment to achieve their health goals, which are set out in a care plan agreed by the individual and health professionals stating the budget amount, what will be purchased and how the budget will be managed.
- 3. The personal health budget pilot programme was launched by the Department of Health¹ in 2009 and an independent evaluation was commissioned to run alongside (Forder et al. 2012). The aim of the evaluation was to identify 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.
- 4. The evaluation found that, over a 12-month follow-up period, the use of personal health budgets was associated with a significant improvement in patients' care-related quality of life and psychological well-being.
- 5. Using care-related quality of life measured net benefits, personal health budgets were cost-effective: that is, budget holders experienced greater benefits than people receiving conventional services, and the budgets were worth the cost.
- 6. The Department of Health commissioned the current study to explore the continued implementation and impact of personal health budgets following the national pilot programme.

Study design and methodology

- 7. During the national evaluation, 20 primary care trusts (as they existed then) out of 64 sites participated in the in-depth strand of the study, with the remainder forming the wider cohort. Initially, personal health budget leads from Clinical Commissioning Groups (CCGs) covering one or more of the original in-depth sites were invited to participate in the current study. In addition, personal health budget holders who participated in the national evaluation were invited to take part in the current study. Due to recruitment issues, the invitation was extended to all CCGs covering one or more of the sites (in-depth and wider cohort) that participated in the national evaluation. In addition, the invitation to participate in the study was extended to personal health budget holders who had received their budgets following the national evaluation.
- 8. Fourteen CCGs agreed to participate in the study: 11 CCGs covering one or more of the original in-depth sites from the national evaluation of the personal health budget pilot programme; and two CCGs covering one or more of the original wider cohort sites.
- 9. Between March and November 2015, semi-structured telephone interviews were conducted with eight organisational representatives whose work involved the delivery of personal health budgets within the participating CCGs. Twenty-three personal health budget holders were interviewed by a member of the research team between March 2015 and January 2016.

_

¹ Now the Department of Health and Social Care

- 10. Fourteen service providers, from seven CCGs, completed the online survey between March 2015 and March 2016. Three service providers agreed to be interviewed between March 2015 and February 2016.
- 11. A postal questionnaire was sent to 104 patients (or consultees) who gave their consent to take part in the study between June 2015 and January 2016 to explore the potential implications of any context change on service satisfaction and quality of life. Fifty completed questionnaires were returned, providing a response rate of 48%: 34 from the personal health budget group and 16 from the control group.
- 12. Sixty-nine personal health budget holders provided consent that the research team could have a copy of their support plan. The research team received 42 personal health budget support plans from four participating CCGs.
- 13. Overall, 92 participants consented for their secondary care service use to be extracted from the Hospital Episode Statistics (HES) database. Sixty-four participants participated in the national evaluation (37 in the personal health budget group and 27 in the control group) and 28 were budget holders who had received their budget following the pilot phase and evaluation.
- 14. The small sample of participants resulted in the research team being unable to explore the continued impact of personal health budgets on quality of life among participants and on secondary care service use following the pilot phase. The intention had also been to compare the experiences of patients in CCGs where personal health budgets (PHBs) were well-established, with those in CCGs that had adopted PHBs more recently; however the sample was too small to make meaningful comparisons.
- 15. There are two strands to the current study. The first strand aims to gather views among a number of personal health budget leads, commissioners and budget holders about the reasons why personal health budgets had either positive or negative effects (Jones et al. 2017). The second strand focuses on the views among managers of service provider organisations and perceptions among budget holders regarding the personal health budget process. This strand also explores the content of current personal health budget support plans and the organisation of budgets following the pilot phase (Jones et al. 2018).

Findings

- 16. Organisational representatives and budget holders perceived that personal health budgets have the potential to impact on both service users and their famillies. The benefits were attributed to:
 - a) Giving people a greater sense of control and empowerment; facilitating a supported care planning process; and by allowing people to secure services and support in a more innovative and flexible way to meet their specific care needs.
 - b) Relying less on family for care and support, which in turn reduces the pressure on family carers.
 - c) Improved relationships between health professionals and patients.
 - d) Improved working relationships with social care colleagues.
- 17. A number of challenges were identified that could potentially impact on the continued effectiveness of personal health budgets, including:
 - a) Reduced levels of professional guidance and support following the pilot phase.

- b) Perceived lack of awareness of personal health budgets, which potentially influences market development.
- c) Strong leadership was viewed as important for the longer-term implementation of personal health budgets and market development. However, leadership was perceived to be problematic following the pilot phase.
- d) Freeing up resources tied to block contracts with existing providers.
- e) The lack of a fully integrated personal budget process in terms of assessment, support planning and reviews.
- 18. The analysis of 42 personal health budget support plans showed an average spend of £42,530 per person per year (median = £19,180). Thirty-one personal health budget plans reported the deployment option, with 26 managing the budget as a direct payment and five as a managed-budget.
- 19. Among the 34 personal health budget holders responding to a questionnaire, 21 reported that they were currently receiving support purchased through their budget. Of the 21 participants, 18 reported that they were either extremely or very satisfied with the support received from the budget and 10 were satisfied with the care planning process. Five budget holders perceived that they needed more support to decide how to spend their budget.

Recommendations for policy

- 20. Personal health budgets continue to have a positive impact on individuals and families alongside having benefits within the care sector.
- 21. The implementation of new schemes requires fundamental cultural changes within the care sector that takes time to fully embed into work practices. Strong leadership is a vital ingredient for the required cultural change and for the longer-term implementation of personal health budgets.
- 22. Some of the implementation challenges and barriers are not specific to the personal health budget policy and mirror those found with the implementation of the current integration policy initiatives such as the Integrated Pioneer programme.

References

Jones, K., Welch, E., Fox, D., Caiels, J. and Forder, F. (2018). *Personal health budgets: Targeting of support and the service provider landscape*. Personal Social Services Research Unit, University of Kent, Canterbury.

Jones, K., Forder, J., Welch, E., Caiels, J. and Fox, D. (2017). *Personal Health Budgets: Process and context following the national pilot programme*. Personal Social Services Research Unit, University of Kent, Canterbury.

Forder, J., Jones, K., Glendinning, C., Caiels, J., Welch, E., Baxter, K., Davidson, J., Irvine, A., Windle, K., King, D. and Dolan, P. (2012). *The evaluation of personal health budget pilot programme*. Canterbury: Personal Social Services Research Unit, University of Kent.