Personal Health Budgets

Equalities Impact Assessment

1. At the outset of the pilot programme, a full Equality Impact Assessment was undertaken as part of the Impact Assessment that was published. This was updated when the legislation for healthcare direct payments moved from the Commons to the Lords. It was also then reissued in July 2010,[1] when more information was available about the potential impact of personal health budgets on different groups of people.

2. There is some additional information that is now available about how different groups of people access NHS services, or disease prevalence among different groups. For example:
    - Population ageing means numbers of people with dementia will increase. This is particularly relevant for people from Black and Minority Ethnic (BME) backgrounds, who are in turn currently under-represented in dementia services. This may be the result of stigma or lower levels of awareness.[2]
    - BME groups are less likely to report a positive experience of NHS service provision, particularly about access and about information and choice.[3]
    - Over 50% of gay men have not disclosed their sexual orientation even though doing so may help their GP to deliver more appropriate healthcare.[4]
    - Black Caribbean men have a much higher prevalence of stroke – a two-thirds greater risk. US research suggests that ethnic minority patients may have more severe strokes and do less well in rehabilitation.[5]
    - Diabetes prevalence is 4 times high for Bangladeshi men, and 3 times higher for Pakistani and Indian men compared to the general population.[6]

3. This information gives a snapshot of some of the differences in needs of individuals, which may be influenced by their background. This gives some context to the environment into which personal health budgets will be introduced. It also gives an indication about some of the issues that may need to be overcome as personal health budgets are implemented. This

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1 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117289.pdf

2 http://www.scie.org.uk/publications/briefings/files/briefing35.pdf and http://www.runnymedetrust.org/uploads/publications/pdfs/TheFutureAgeingOfTheEthnicMinorityPopulation-ForWebJuly2010.pdf

3 http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_100471.pdf

4 Keogh, P, Weatherburn, P, Henderson, L, Reid, D, Dodds, C and Hickson, F (2004) 'Doctoring gay men: Exploring the contribution of General Practice', Sigma Research, Portsmouth

5 Ethnicity and Health, Parliamentary Office of Science and Technology, Jan 2007 and Stansbury JP, Jia H, Williams LS, et al; Ethnic disparities in stroke: epidemiology, acute care, and postacute outcomes. Stroke. 2005 Feb;36(2):374-86. Epub 2005 Jan 6

6 http://www.ic.nhs.uk/pubs/hse04ethnic

includes where personal health budgets may best be targeted. It is also likely to include the provision of information, advice and support, which is discussed in more detail below.

4. The earlier Equality Impact Assessments discussed how personal health budgets could help to address some of the challenges set out above, by helping to make the NHS more responsive to the needs and preferences of the individual. If implemented well, so there are closer working relationships between healthcare professionals and patients, then this should serve to improve things for all patients, regardless of their background. Some of the issues outlined above, and in the original Equality Impact Assessment, will be addressed by closer working relationships.

5. The initial Equality Impact Assessments also discussed the information that was available from social care. This in particular included experience and results suggesting that personal budgets in social care may have benefited younger people more than older people, and that personal budgets may be more beneficial for white people than BME people.[7]

6. The personal health budgets evaluation and pilot programme were informed by previous experience from social care. The original equality impact assessment focused on the areas and protected characteristics where there appeared to be the most risk. This particularly included age, ethnicity and disability. Socioeconomic status was also included, because, as with all choice initiatives, there is a risk that personal health budgets become a tool for affluent, articulate people only. The evaluation team therefore collected information across the following areas:
    - Age
    - Gender (including trans)
    - Disability (from medical records template)
    - Ethnicity
    - Socioeconomic status (measured by type of accommodation; employment; education; and income)
    - Sexual orientation
    - Marital status
    - Religion

7. There are also now findings available from the personal health budgets evaluation. Unfortunately, this does not cover all of the strands outlined above as in some cases numbers were insufficient to undertake any meaningful analysis. For example, there was one person only who was trans, and so any analysis and inferences would not be worthwhile.

[7] "BME people" may not be a helpful group, as there will clearly be major differences between sub-groups within this. However, sample sizes in evaluations of personalisation initiatives have meant that it is not possible to break the BME group down further.

8. Where meaningful analysis was undertaken, there were the following results. None of this suggests that there is a systematic difference in how people from different backgrounds experience personal health budgets, but there are some suggestions of differences that are inconclusive at this stage, and where more work may be required.
    - There was some weak evidence that personal health budgets may have been more beneficial for people aged under 75.
    - People who had a university or college education, or who were not in receipt of benefits, tended to report improved outcomes in some models.
    - There were no significant differences in costs for any of the sub-group analysis.
    - Personal health budgets were more cost-effective for over 75s. This may seem contradictory with the above finding regarding outcomes; the likely interpretation is that less was spent on the care of over-75s without worsening their outcomes.
    - No other differences in cost-effectiveness were found on analysis looking at gender or socioeconomic status.
    - No differences were found in outcomes, costs or cost-effectiveness based on ethnicity. This is included as a finding, but the evaluation team caveat this as numbers of people from BME backgrounds are too low to give robust results.
    - It was not possible to conduct analysis based on disability – for example, to look at people with a learning disability – as the medical record information was incomplete and there the sample size was too low.

9. Therefore, it would tend to appear that personal health budgets can benefit everyone regardless of background, as there is nothing above that gives conclusive evidence about people from specific backgrounds specifically doing worse. None of the findings outlined above would be defined as robust, as they have only been observed in one particular model. That said, they do give indications of where they may be potential challenges.

10. Information, advice and support will be vital to overcome any problems that may arise. As set out above from the 4th and 5th interim reports, the information, advice and support that people received had a major impact on their experience of the pilot programme. This is likely to be the case regardless of the individual's background. There were some good examples of sites providing information, advice and support during the pilot programme, as set out below:
    - In one of the pilot sites, dedicated work to reach BME people and those from deprived backgrounds resulted in referral figures from these communities into personal health budgets programmes being the same as for referral figures more generally.
    - One of the SHAs has a "roadshow", in which a tour bus travels around travellers' sites, areas with high BME populations and areas with high levels of deprivation. This both introduces the concept of personal health budgets, and has GPs and health visitors on the bus to offer services.

- One of the pilot sites has flexible information provided and tailored as required. This includes translation of material as provided, health and 3rd sector staff on hand to help explain information as required, and individual brokers. They are also getting feedback from people as they go through the process about what is successful and what is less so to help them revise the provision of information, advice and support over time. This has led to the inclusion of pictures and easy-read versions of documents to help simplify them.

11. This is in addition to the work that has been done nationally around promoting personal health budgets. For example, there are a number of stories on the personal health budgets website, that are also available on DVD, that help explain to people what personal health budgets are and what people's experience of them has been. These have proven to be very helpful locally, and a second DVD is currently in production. Some local areas are also producing their own material.

12. There is still a long way to go. While there are some good examples of what sites have been doing, it is not yet certain how best information, advice and support should be provided, in what formats, or at what time and place. This is likely to vary between individuals, and the information, advice and support that people receive should be personalised to them in the same way that services are.

13. Recognising the importance of this area, and that while progress has been made, there is not yet a complete answer, the Department has commissioned some additional work around information, advice and support. This aims to summarise what has already been done and learn from it, to then recommend how best information, advice and support should be provided in practice. This will build on what is already known from the pilot sites about what they did, what worked and what they changed, and the team undertaking the work is aiming to provide a final document outlining principles about what commissioners should consider when implementing personal health budgets. Where unanswered questions remain, these will also be included and discussed, with suggestions for what could be done where there is no practical work to draw on.

14. This will then inform the longer term implementation of personal health budgets. As the implementation of the policy is transferring to NHS England, as set out in the Mandate, it will be for them to decide what national guidance and support to local commissioners may be required. NHS England is subject to the same equality duty as the Department of Health, and therefore they will ensure that future work will incorporate equality principles. If they devolve responsibility for personal health budgets to clinical commissioning groups, the same will apply to them.

15. Where there remains a lack information about how personalisation and personal health budgets should best be implemented to not be discriminatory, it will be up to NHS England to address. So, for example, as there is no information about trans people, NHS England could work with the Gender Identity Research and Education Society to ensure that trans people are not unintentionally discriminated against as personal health budgets are offered to more people.

16. On 1 March 2013, the Government launched '*Direct payments for healthcare: a consultation on updated policy for regulation'*, to help decide our approach to any necessary amendments. The consultation ran for 8 weeks, in line with the Government Code of Practice, and closed on 26 April 2013. The following question was included in the consultation:

Could the proposals have any perceived or potential impact on equality including people sharing protected characteristics under the Equality Act 2010?

17. A large number of responses did not answer this question at all. The majority of the remaining responses received on this question in the consultation felt that there would be no impact on equality or they provided suggestions on how any impact would be minimised.

18. Based on the evaluation of pilot sites, there is no evidence that personal health budgets for healthcare lead to a deterioration in equalities. In areas where personal health budgets for healthcare were implemented well, the beneficial effects were greater. Personal budgets for healthcare could lead to better outcomes for some groups, whose needs were poorly served by conventional health services, including people from different ethnic backgrounds, people with learning disabilities and people with mental health problems. People will clearly need the right information, advice and support to enable them to take up personal health budgets but as long as this is available the potential to create a fairer system is good.