POLICY AND INTERNATIONAL DEPARTMENT

Policy Briefing #6/11

Personal health budgets: An overview of policy in England so far

19 September 2011

Royal College of Nursing

Introduction:

This paper seeks to provide a broad overview of personal health budgets (PHBs) including what they are and what they aim to do, the findings of the current pilots, key issues for the RCN and the RCN's position. The summary below identifies the RCN's key concerns, which are more fully explained in the briefing.

Summary of key concerns for the RCN:

- Given the present financial and policy context, the RCN has serious doubts about the impact of PHBs and feels they pose the following risks:
  - Erosion of the principles of the NHS, namely being free at the point of delivery. The RCN opposes any move towards a top-up system in health care, as in social care.
  - Exacerbation of inequalities. To ensure that all eligible patients can access a budget holder, a range of different support and resources will need to be in place, which will have significant cost implications.
  - Endanger the delivery of 'traditional' or existing services, which provide choice to those who are unable to manage or who choose not to manage their own budget.
  - Place vulnerable patients at risk. Currently the RCN does not believe there are adequate safeguarding mechanisms in place to guarantee the safety of budget holders.
  - Prevent PHB budget holders from becoming best practice employers, and deliver pay, terms and conditions in align with Agenda for Change.

Background:

Personal health budgets can be seen as part of a wider d rive to personalise health services or one way of enabling people to self-direct their care, and give people more control and choice over the care they access.

Personal budgets in social care

Personal budgets or individual budgets were first introduced in social care. Since 1996 it has been possible for social care service users to receive their personal budgets as a direct payment. A national pilot in 2005-7 to evaluate personal budgets amongst a range of users showed personal budgets did improve service users' sense of choice and control over their care and outcomes for *some* groups. Subsequently, successive governments have been keen to encourage their uptake.[1] A national indicator was set for local authorities to achieve 30% take-up of personal budgets amongst social care service users by March 2011, and

[1] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_089506.pdf

another more recently set to have all eligible users on personal budgets by April 2013. It was reported in June 2011 that although two-thirds of councils had met the 30% target, one in seven had less than 20% of users and carers on personal budgets.[2]

Personal health budget (PHB) pilots

The piloting of personal health budgets was announced in the Darzi Review of 2008, *High quality of care for all.*[3] The pilot programme runs for three years until 2012. There are 61 pilot sites across the country, 20 of which are being evaluated in-depth.[4] Each site receives £100,000 annually for taking part. The sites are piloting a range of patient groups: long-term conditions (including chronic obstructive pulmonary disease, diabetes and long-term neurological conditions), mental health, NHS continuing healthcare and stroke. Two specialist services have also been included: maternity and end-of-life care. The evaluation in the in-depth sites also uses control groups so that the experiences of people selected to receive PHBs are compared to those using conventional services and support.

The evaluation is being conducted by a partnership of three institutions, led by the University of Kent. The team have published three interim reports so far.[5] The whole project is being monitored and reviewed by the Personal Health Budget Programme Board, set up by Department of Health (DH), consisting of a range of stakeholders – **including the RCN.**

What is a personal health budget?

A personal health budget is:

- *"an allocation of resources made to a person with an established health need (or their immediate representative)."*[6]
- or, according to DH "*makes it clear to you and the people who support you how much money is available for your NHS care so you can discuss and agree the best way to spend it. This gives you more say over the care you get.*"[7]

Within the current pilots, there are three ways an individual's resources or money can be allocated:

1. a notional budget held by the commissioner;
2. a budget managed on the individual's behalf by a third party; and
3. a cash payment to the individual (a 'healthcare direct payment').

Through this resource allocation, DH believes people will have more choice, flexibility and control over the health services and care they receive – i.e. they will be able to have a greater say over which services they access, which may differ from those traditionally accessed. Under the current government, this policy sits neatly with their proposal to diversify providers in the healthcare market.[8]

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[2] http://www.communitycare.co.uk/Articles/2011/06/14/117009/most-councils-have-30-of-service-users-on-personal-budgets.htm
[3] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085828.pdf
[4] http://www.personalhealthbudgets.dh.gov.uk/_library/Resources/Personalhealthbudgets/2011/PHB_site_list_June_2011.pdf
[5] http://www.personalhealthbudgets.dh.gov.uk/Topics/latest/Resource/?cid=8306
[6] http://www.in-control.org.uk/support-for-individuals,-family-members-carers/what-is-self-directed-support.aspx
[7] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117260.pdf
[8] Reference health bill

A central component of a PHB is the care plan, which is drawn up between the health care professional and budget holder, or their representative, and details how the resources will be used to meet identified health needs and outcomes. This is regularly reviewed and therefore is intended to act as a check and balance to ensure care is appropriate and meeting agreed aims.

To read about a positive experience of budget holder in the pilot and how they can work well in practice, click here: http://www.personalhealthbudgets.dh.gov.uk/_library/Resources/Personalhealthbudgets/DebbieBrian_PHB_pilot_story.pdf

Personal health budget evaluation:

The evaluation is looking at the short and longer term impact on personal health budgets on different groups of people and their carers, at the process and cost (effectiveness) of their implementation and management for individuals, carers and the organisation, including their impact on the workforce. To date the evaluation team have published three evaluation reports, key points so far include:

- Difficulty in extracting or disaggregating the funds for personal health budgets from existing contracts.
- Identifying the scope of services that could be accessed by a budget holder – i.e. where are the boundaries for what could be legitimately included.
- Additional professional costs involved in supporting the budget holder to manage their plan, and particularly those required to mitigate inequity of access (some patients will require more support than others).
- Challenges around the culture and the understanding of risk – the RCN is working closely with DH on this issue (see delegated responsibility below).
- Considerable costs of set-up, implementation and oversight (for instance an overall average cost of £93,280 within the first year would be required to implement the initiative, and the average cost of the project board was £52,760 with an additional cost of £19,150).
- There is not a diverse healthcare market so choice is limited for budget holders, meaning budget holders are often limited to accessing traditional services.

Key issues for the RCN:

PHBs and choice and control:

In a RCN social care survey this year, 58% of respondents agreed that PHBs improve choice and control, 24% neither agreed nor disagreed, whilst 18% disagreed. Almost the same percentages were reflected in members' responses to whether everyone should be entitled to a personal health budget (57%, 24% and 19% respectively).

Members' mixed views may have stemmed from the mixed findings of the evaluation of personal budgets in social care: personal budgets have proved successful in improving the sense of control that ***some groups of people*** who require social care support have over

their lives, particularly younger physically disabled people.[9] On the other hand, older groups found them to be an "additional burden", whilst differences between control groups and budget holders around outcomes were not significant.[10] In a recent National Audit Office report on personal budgets, around two-thirds of budget holders reported a positive impact on aspects of their well-being, but 3-8% reported being worse-off. 31% of budget holders found it difficult to cope with being an employer, with some instances of employment tribunals being made against budget holders.

In light of these varying results in social care but also in view of the complex nature of some health conditions, the RCN believes that for some people – especially the vulnerable – personal health budgets simply do not represent a viable solution to their care needs. There are issues around safeguarding (discussed in section below) a patient's cognitive ability and the skills and degree of support needed to make appropriate decisions, become an employer and manage the processes involved. Research carried out by the NHS Confederation has confirmed that these fears are shared by GPs, psychiatrists and psychologists too.[11] **The RCN believes that patients should have the choice not to have a PHB therefore; PHBs must be optional.**

In light of the fact that PHBs will not be suitable for all patients who are eligible, there will be an **increasing need to deliver and manage existing 'traditional' services alongside additional services that personal budget-holders commission.**

PHBs and cost implications

Mixed support for PHBs also stems from concern over views that they will save money.[12] The RCN is concerned that this could be a motive for policy implementation and has identified the following reasons why significant, not fewer, resources will be needed:

- Demand on the NHS is increasing – in particular numbers of those patients suitable for PHBs, such as those with long term conditions, are increasing as they live longer.

- **Since PHBs must be optional and to realise its goal of maximising patient choice,** Government will have to deliver 'traditional' services alongside this initiative, and to therefore consider the cost of and critical mass required to maintain them.

- Budget-holders will continue to require **considerable clinical support** in the assessment and review of their care needs. **Such competencies cannot be delegated to less expensive members of staff.**

- Budget-holders will require **a range of different support** to help them manage their PHB and make appropriate choices, including both staff and suitable information resources and diverse formats. In some cases this will be extensive support, and whilst it may be in the best interest of the patient, it will have significant cost implications (as was found in the personal budget pilot evaluation, with older people requiring significant support from their care coordinator). **Without this support,**

[9] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_089506.pdf
[10] Ibid
[11] http://www.nhsconfed.org/Publications/reports/Pages/Facing-up-to-the-challenge-of-personal-health-budgets.aspx
[12] http://www.in-control.org.uk/media/6115/qipp%20and%20personal%20health%20budgets.pdf

there will be legitimate concerns wagered about PHBs increasing health inequalities, if the lack of support available prevents some from having a PHB.

- Health care staff will require **training and support** to be able to deliver PHBs. Nursing is the biggest professional group delivering frontline care in the NHS and as such is the backbone upon which new services and ways of working are delivered. Adequate investment into their training and education will be essential in the successful implementation of this policy.

- **Economies of scale that are currently realised in NHS provision will be lost** if delivering PHBs does mean budget-holders choose from a much more diverse and plural market. In the personal budget evaluation this was described as "potentially a major tension between volume discounts and delivering individualised services."

- In light of the different funding mechanisms, in social care personal budgets can be 'topped up', an option that is likely to become more prevalent as personal budgets are reduced and restricted to meet budget cuts.[13] **The RCN does not support the introduction of top up payments in the NHS**, and would be extremely concerned if this policy took a similar direction, particularly given the £20 billion 'efficiency' savings the NHS has to make, in addition to paying for a costly, wholesale reform.

In the Netherlands the belief that costs would be reduced by PHBs was not realised and the Dutch Secretary of state for health said recently the programme's expenditure had "risen immensely over the last few years and this growth cannot be sustained". Indeed increased demand for PHBs amongst younger patient groups in the Netherlands has seen an escalation in costs, resulting in the tightening of eligibility criteria.[14]

Given the current financial context the RCN does not believe appropriate resources will be forthcoming to ensure PHBs are able to preserve NHS principles, respect the choice of individuals, and tackle rather than exacerbate inequalities.

PHBs and safeguarding

Budget-holders will be responsible for commissioning their care and will become employers, raising the following legitimate concerns to consider around safeguarding:

<u>For the budget holder:</u>

- Appropriate mechanisms and support will be needed to safeguard budget-holders whose mental capacity may fluctuate against:
  - Potential financial exploitation of the budget-holder by their family, carers or employees.
  - Potential abuse of the budget-holder by their family, carers or employees.

[13] http://www.guardian.co.uk/society/2011/sep/13/coping-with-cuts-councils-disabled-services

[14] http://www.health.org.uk/publications/personal-health-budgets/?utm_medium=email&utm_source=The+Health+Foundation&utm_campaign=PHB+Case+Study+Email+1+-+England+&dm_i=4Y2,GXN4,1TZP0B,1DR85,1

The care plan will be a key element of the safeguarding process. The influence of clinicians involved in agreeing and reviewing the care plan will be an important way to monitor the budget holder's health outcomes, and their general wellbeing. It will also be important that all clinicians involved in delivering care to the budget holder are able to feed back to the clinician in charge of coordinating the care plan. Such relationships will help manage the risk of abuse, exploitation and fraud for instance.

CRB checks offer another means to help safeguard. However the new system will be voluntary for personal care assistants and whether **this will be adequate protection for risk remains to be seen.**

The RCN has been calling for mandatory regulation of health care assistants for some time, and recently endorsed the Nursing and Midwifery Council's recommendation for a system of mandatory, not voluntary, regulation of health care assistants. The RCN believes there is a public protection issue, particularly around care of the elderly and as witnessed in recent cases such as Winterbourne View. The RCN is now committed to working with the NMC about how to make this a reality.

- There will be issues around the sustainability of new providers entering the market. The National Audit Office's report on personal budgets in social care discussed how disruptive and costly provider failures can be, where alternative providers may need to be found which are lower in quality, higher in cost, or both – at short notice. It discussed the case of Southern Cross and highlighted how it fell on local authorities, in light of their duty to ensure continuity of care, to react to the crisis. How the NHS would be affected by and whether it could have the capacity to deal with such provider failures in the future is a significant risk, and would have huge implications for patients.

- There will also be issues around the credentials of new providers and how budget-holders are given information about their services to ensure that they make informed decisions. It will be important that they are not 'sold' services through the result of, for instance, a provider's superior advertising and marketing techniques.

- Fraudulent use – there may be some cases where budgets are misused and again appropriate mechanisms will need to be in place to mitigate against this.

For the workforce:

- There will be safeguarding issues to consider for the employee too, and ways to ensure they are not abused or exploited by the budget holder. Budget holders and new providers will have to uphold, and where necessary be supported to do so, the best practice in employment and HR management.
- These safeguarding issues include pay, terms and conditions and the RCN would like to see new providers and employers align contracts with Agenda for Change terms and conditions.

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- There may be conflict of interest for those either responsible for the care plan assessment or for co-ordinating care if the budget-holder wants to discuss choice of provider.

For both budget holder and the workforce:

- Delegated responsibility – the RCN has been working with key stakeholders to consider delegated responsibility and the personalisation agenda. There currently appears to be confusion amongst some providers over what can and cannot be delegated to unregistered staff or carers, and an unreasonable fear of prosecution and being reported to regulators for poor delegation. The essential issue is that Registered Nurses should not be delegating assessments or decision-making outside of protocols. In other words, tasks can be delegated to competent people; clinical judgement cannot. Guidance to reduce anxiety around delegation issues may be required.
- The RCN has developed the following tool about accountability and delegating responsibility: http://www.rcn.org.uk/development/health_care_support_workers/accountability_and_delegation_film

PHBs and integration with personal budgets

The Government has proposed the integration of social care personal budgets and personal health budgets. Such integration could be a fix to the problems that RCN members identified last autumn around working with social care including confusion over who pays, 'bed blocking', the 'revolving door', eligibility assessments and duplicative paperwork.[15] Budget integration for people with disabilities or with long term conditions could help improve the quality of patient care and the patient journey across the two systems.

However, the desperate underfunding of social care and the imminent cuts the sector is facing is a cause for concern. When determining the integrated budget for care, transparent mechanisms will need to be in place to calculate costs of a budget-holders' social and health care needs. **NHS care is free on the point of delivery and must remain so.** Moreover, the NHS should also not be asked to pick up the tab for any social care shortfall in a personal budget.

RCN position

When implementing PHB pilots and policy, DH stated that personal health budgets should:

- *Uphold NHS values*
- *Support safeguarding and improve quality*
- *Support tackling inequalities*
- *Be voluntary*
- *Support working in partnership*
- *Support decision-making as close to the patient possible*

[15] http://www.rcn.org.uk/support/consultations/responses/future_funding_of_care_and_support_in_england

These are principles that the RCN wholeheartedly support. However, the RCN is not convinced that these same principles are driving the policy currently. Given the present financial context and other challenges outlined above, the RCN has serious concerns that the Government will be able to deliver optional, appropriately resourced and supported PHBs within an appropriate system of safeguards. The RCN fears that the current context and challenges pose many risks for PHBs, budget holders and the NHS, namely that the policy will:

- Erode the principles of the NHS, namely being free at the point of delivery. The RCN opposes any move towards a top-up system in health care, as in social care.
- Exacerbate inequalities. To ensure that all eligible patients can access a budget holder, a range of different support and resources will need to be in place, which will have significant cost implications.
- Affect the running of 'traditional' or existing services, which provide choice to those who are unable to manage or who choose not to manage their own budget.
- Place vulnerable patients at risk. Currently the RCN does not believe there are adequate safeguarding mechanisms in place to guarantee the safety of budget holders. **The RCN sees the mandatory regulation of health care assistants, alongside regular clinical review of PHBs, as a part of the solution.**
- Prevent budget holders from becoming best practice employers, and deliver pay, terms and conditions in align with Agenda for Change.

Of particular concern for the RCN is safeguarding, and we ask the Government to lay out how it intends to ensure budget holders are appropriately protected and supported as employers and commissioners of their own care.

In addition, whilst the RCN can see merits in PHBs it believes it is important to note the distinction between personalised care, care tailored to the needs and preferences of individuals and PHBs. They are not one and the same. PHBs are one tool to help deliver personalised care and the RCN would like to see the Government acknowledge this distinction. The RCN strongly supports the delivery of personalised care, 88% of RCN respondents in a survey this year felt that individuals should be able to tailor their care to their own preferences and needs.

Even with appropriate resourcing and safeguarding in place, the RCN does not believe that PHBs will be an appropriate way to deliver personalised care for all patient groups and individuals. Different methods to personalise the care of some patient groups and individuals will be required, and this will mean using existing services. **Therefore, the RCN believes that patients should have the choice not to have a PHB and that they must be optional**. To maximise choice and personalisation, the Government will have to look to resource and deliver **existing 'traditional' services alongside additional services that personal budget-holders commission.**

These issues should be understood in the context of the need for a huge cultural shift for both patients and the workforce to make PHBs work and should not be under-estimated – people have been engaging with the NHS on current terms since its inception.[16] This again demonstrates the need for optional PHBs and the maintenance of existing services.

Finally, the RCN continues to call for the Government to follow a best practice process and learn from and fully review the findings of the personal health budget evaluation before implementing the initiative nation-wide. In light of the scale of the challenges and issues that PHB implementation will need to overcome, a timely and carefully planned approach is essential.

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[16] http://www.nhsconfed.org/Publications/reports/Pages/Personal-health-budgets.aspx and http://www.nhsconfed.org/Publications/reports/Pages/ShapingPersonalHealthBudgets-aviewfromthetop.aspx