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NHS Clinical Commissioners response: consultation on extending the legal rights to have personal health budgets and integrated personal budgets

8 June 2018

I. NHS Clinical Commissioners

NHS Clinical Commissioners (NHSCC) is the membership body of Clinical Commissioning Groups (CCGs). Established in 2012, we have over 91% of CCGs in membership. We offer a strong national voice for our members on specific policy issues and support them to be the best they can to commission services effectively for their local populations.

Our response to this consultation has been developed based on a survey of our membership, supplemented by in-depth conversations with directors of commissioning and personal health budget (PHB)/NHS Continuing Healthcare leads who have experience of implementing PHBs locally. CCGs we spoke to covered both those who have already extended their local offer and those who currently only offer PHBs to individuals with a legal 'right to have' one. Through this consultation response, we welcome the opportunity to highlight the learning of our membership thus far and to ensure that the voice of CCGs feeds into policy development in this area.

II. Overarching comments

Our members are supportive of the broader personalisation agenda, highlighting the benefits of shared decision making and person-centred care planning. Several members emphasised the view that PHBs are only one part of this agenda; the process of producing a person-centred care plan is key and it is through this process and discussion that a lot of value is gained – PHBs are just one outcome.

While the scale and maturity of local PHB processes varies significantly, the benefits that PHBs can bring to certain groups are well acknowledged, and our members highlight examples where the effect on individual budget holders has been transformative. However, from a commissioner perspective, a number of concerns will need to be addressed for PHBs to be successfully extended:

1. *Affordability*

PHBs have been piloted and evaluated, yet significant evidence gaps remain regarding their medium- to longer-term financial impacts. There is a need for CCGs to ensure that the implementation of PHBs is balanced with current capacity and the efficient use of financial resources at a time when they are facing substantial financial challenges, and a clearer understanding of financial impact is required.

2. *Ensuring clear patient communications, with a continued role for professional judgement*

If a 'right to have' as opposed to a 'right to request' a PHB/integrated personal budget/direct payment is pursued for the expansion of PHBs, it is vital that this right is subject to exceptions. Healthcare professionals must be free to exercise clinical judgement in declining or withdrawing a PHB and/or direct payment when they deem it necessary. This must be clear in national public-facing communications.

3. *Key implementation issues*

Our members have identified key learning points from implementation thus far and highlight a range of issues that need to be addressed before an extension is rolled out. One issue surrounds professional

culture, with members feeling a significant culture change will be needed to resolve an existing tension between granting patients control – including the option to fund activities that have not been found to be clinically effective – and ensuring clinical outcomes. This, alongside other key issues, is outlined in section VI: implementation challenges.

4. Provision of additional support

Additional support will be required for CCGs to extend their PHB offer. CCGs are facing considerable financial challenges and without funding to cover at least additional implementation costs, they will struggle to implement the changes proposed without reducing spending on other key areas. Members would also benefit from more of a national steer regarding key aspects of a PHB offer through publication of a framework and the sharing of good practice. We discuss details of the support that is required in section VII: further support.

III. Extending PHBs to additional population groups

There are concerns that the extension of PHBs to groups beyond those in receipt of NHS Continuing Healthcare and children's continuing care will pose a greater financial risk to CCGs and will serve as an additional cost. Once a person is determined as being eligible for NHS Continuing Healthcare it is in effect a distinct budget, managed at an individual level. It is therefore one of the areas most readily adapted to PHB implementation, without producing significant double running costs. Many other areas of local commissioning such as mental health are operated through block contracts which will make their adaption to PHBs more complex. The removal of block contracts in some of these areas risks destabilising crucial services.

Our members are also concerned about the additional workload and process requirements of scaling up PHBs. CCGs are currently operating PHBs at a scale where processes such as budget management and quality assurance can be reasonably managed but this will become more difficult if PHBs operate at a greater scale. There will be additional workload demands for professionals involved in the co-production and ongoing management of personal care plans as significant support is required to help patients manage their budget.

Whilst noting the above concerns, our members recognise that certain areas may benefit from a more personalised commissioning approach. Past work by NHSCC has highlighted issues in wheelchair commissioning,¹ and where existing processes are not meeting individual needs, there is scope for a more personalised and flexible approach to be beneficial. Some of our members note that PHBs may be particularly suited to high volume service users. In order to realise the potential benefits of PHBs, CCGs need sufficient support and guidance to successfully implement them, and key challenges need to be addressed. We strongly urge that PHB implementation is worked through with CCGs.

IV. Including the right to a direct payment

Our members note many instances where direct payments are working well and offer PHB recipients flexibility to best meets their needs. For direct payments to work well, members have found it important to put key processes in place. One example of a system working well is the use of a pre-paid card, commissioned by the CCG through the same provider that the local authority uses. As an established approach, the payment card system benefits from robust oversight and controls such as being able to block online purchases, making it adaptable to an individual's requirements.

However, there are also cases when a direct payment is not a suitable option for an individual. In a minority of cases, PHBs have been misused and the budget holder has been moved from a direct payment to a managed budget. Maintaining such flexibility for occasions where it is required is important, and patient-facing communications need to reflect this. Messaging to patients must set out what a direct payment can be used to purchase, and be clear that it can be revoked if it is not being used appropriately.

¹ NHS Clinical Commissioners and Whizz-Kidz (2014) [NHS Clinical Commissioners and Whizz-Kidz call for changes to improve wheelchair commissioning](#).

V. Integrated personal budgets

Our members are supportive of the principle of integrated personal budgets across health and social care. One CCG we spoke to is already implementing integrated personal budgets through a Section 75 agreement. Others are working towards integration of budgets and have made varying degrees of progress. Some members note a lack of detail regarding the implementation of integrated personal budgets in the DHSC and NHS England consultation document, so further information would be appreciated.

To expand integrated personal budgets, several issues will need to be addressed. At a local level, there are often inconsistencies in the way that personal budgets in social care and personal health budgets are operated, including decisions about what funds can be used for and safeguarding/risk management processes. There are examples of patients who had previously received a social care personal budget, who upon moving onto NHS Continuing Healthcare became subject to different processes, for example with a CCG now requiring a Disclosure and Barring Service (DBS) check for personal assistants/carers. Similarly, one CCG placed a cap on the hourly rate of a carer, which hadn't been in place under the local authority. For fully integrated personal budgets, streamlining would need to take place to ensure that the requirements of personal health budgets are in line with those of personal budgets used in social care.

VI. Implementation challenges

Financial and broader market impacts

We are concerned that extending PHBs will result in the double running of services i.e. commissioners will need to continue funding existing contracted services in addition to PHBs. Our members note that the PHB model is more easily adapted to those with a current legal 'right to have' one as commissioning in this area is already undertaken on an individual, bespoke level. Currently, our members report variation in the financial impact of implementing the standard PHB offer, and the reasons behind this require further understanding. Several members are experiencing continued double running costs, with no associated indirect savings coming from a reduction in the use of services elsewhere, while others have reported end of year financial savings. Importantly, our members do not see that any financial savings could be realised for PHBs that are extended to population groups who do not currently have their needs met through personalised commissioning.

Initial implementation costs – as well as the potential for ongoing delivery costs – need to be recognised. Evidence from the third interim report of the PHB evaluation programme found that an average additional cost of £93,280 was required in the first year to implement PHBs, or £146,040 over two years.² This relates to small-scale pilot conditions. As far as we are aware, evidence of associated costs of scaling up PHBs and ongoing implementation costs are both unknown. Cost is a major concern for our members that hasn't been sufficiently addressed in the consultation document – it was cited as a reason for not extending the PHB offer beyond those groups with a 'right to have' one among CCGs that we spoke to. Those members who have extended their PHB offer have received dedicated funding and support, for example through the Integrated Personal Commissioning Programme, which has enabled them to develop effective processes and systems. All CCGs would benefit from similar dedicated funding in order to offer PHBs to additional population groups.

The extension of PHBs will require additional workforce hours across commissioning, clinical and administrative functions. For example, significant time will be required to produce support plans, manage the budget process and undertake market-shaping work. For CCGs who provide a managed budget, there are also significant workload demands to undertake procurement activities, which require specialist expertise. For the management of direct payments, our members highlight particular administrative and oversight costs. There is a need for significant ongoing support to enable budget holders to make decisions about the use of their PHBs. Findings from the PHB pilot sites suggest that levels of professional support reduced after the pilot ended, which budget holders found difficult,³ so dedicated funding needs to be made available to ensure that support can be sustainably put in place.

² Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Davidson, J., Dolan, P., Glendinning, C., Irvine, A. and King, D. (2011) [The cost of implementing personal health budgets.](#)

³ Jones, K., Forder, J., Welch, E., Caiels, J. and Fox, D. (2017) [Personal health budgets: process and context following the national pilot programme.](#)

Employment liability

Our members express concerns over employment liability when a PHB is used to employ staff such as a personal assistant. One CCG is facing costs from an unfair dismissal case where a PHB-funded personal assistant was dismissed by the individual in receipt of a PHB. Another example was provided of a CCG being pursued for redundancy for a personal assistant when a budget holder died. The claim covered a personal assistant's full employment period for previous years when they were employed by the council, with the PHB holder only recently transferred to NHS Continuing Healthcare funding. This is a complex area that needs to be clearly communicated through guidance to both CCGs and budget holders, and any overlap with local authority funded staff needs to be addressed in a fair way to provide clarity to all.

Developing processes, including risk management and quality assurance

Some of our members have well-established processes in place to manage PHBs, while others are less developed. Several have reported cases of fraud where PHBs were being used inappropriately but felt they had robust procedures in place to identify and address this. A number of our members feel they would benefit from further support, including clear guidance on issues such as managing risk and how services should be quality assured – particularly in the case of those purchased via direct payment.

A tension between patient control and clinical health outcomes

There is some concern that through a PHB, scarce NHS money can be spent on services that do not deliver proven clinical benefits. While the PHB evaluation found beneficial impacts to care-related quality of life (ASCOT) and psychological well-being (GHQ-12) measures, it found no evidence of health improvements *per se*.⁴ Of the two clinical outcome measures used for diabetes and COPD patients, no significant differences were found. No difference was found in the health-related quality of life indicator (EQ-5D) which measures quality of life in areas that are likely to be related to a person's underlying health status, such as mobility. Potential medium- to longer-term impacts of PHBs on health outcomes are not known and will need to be monitored.

Our members report staff concerns that patient outcomes may deteriorate, particularly for those with complex long-term health conditions who conventionally access ongoing self-management support. There is a concern that patients are accessing services such as massage therapy delivered by providers who lack specialised knowledge. The tension between patient control and a culture that focuses upon clinical effectiveness is apparent both within and across CCGs. One CHC lead reported healthcare professionals being able to make funding decisions up to a certain level, above which a panel of GPs must review it. Some members of this review panel saw an inequity in the fact that PHB holders can use NHS funding to access services that have not been proven to be clinically effective and that would not otherwise be funded by the NHS. Such judgements on what should be funded by a PHB varied significantly among members we spoke to. Work needs to be done at both national and local levels to better understand and address this complex issue, and NHSCC is willing to work with DHSC, NHS England, and any other relevant bodies to progress this.

Patient communications

There is a concern that the national narrative may raise patient expectations, and it is vital to ensure that patients are clear about the parameters of PHBs and how they can be used. The language of a 'right to have' does not clearly articulate the fact that a PHB must be signed off by a healthcare professional and that it can be declined or withdrawn if it is no longer deemed appropriate.

VII. Further support

Financial support

Extending the PHB offer to further population groups will require additional resource, at least for the initial implementation stage, and there is significant potential for ongoing costs. At a time when CCGs are facing substantial financial challenges, they need to be provided with sufficient financial support to implement the proposed changes. This should be accompanied by clear messaging around the financial impact of PHBs.

⁴ Forder, J., Jones, K., Glendinning, C., Caiels, J., Welch, E., Baxter, K., Davidson, J., Windle, K., Irvine, A., King, D. and Dolan, P. (2012) [Evaluation of the personal health budget pilot programme](#). Final Report.

A national framework for personal health budgets and integrated personal budgets

There is a need for a clearer national steer with regards to the processes behind implementing PHBs. Given the PHB evaluation finding that the way in which PHBs are implemented is key to the realisation of benefits, with one model resulting in adverse outcomes, this is crucial.⁵ It is our view that a national framework for PHBs and integrated personal budgets should be published, reflective of other national frameworks such as the National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care. A framework for PHBs should build upon existing guidance and clarify important processes such as how to determine whether an individual falls within one of the groups with a 'right to have' a PHB. Members also raised the issue of uncertainty surrounding clinical delegation. Some professionals are not comfortable delegating tasks to a carer or personal assistant who is not employed by the NHS and there is a lack of understanding in how this should be approached, with clear guidance required.

Without more of a national steer, we are concerned that the result will be significant local variation both in the number of PHBs being awarded and their coverage – a 'postcode lottery' in provision. We have seen the impact of such variation in terms of NHS Continuing Healthcare decisions, and are mindful to avoid any parallel situation that could result from guidance that is unclear. NHSCC would welcome the opportunity to work with DHSC and NHS England in the development of further resources, including a national framework.

Sharing good practice

Publication of a framework should be accompanied by the dissemination of good practice. Our members have benefited from a range of resources including NHS England masterclasses, regional network meetings and peer networks. Those that are part of the Integrated Personal Commissioning Programme received significant central support and note that there may be more valuable learning from this programme that is yet to be shared.

Local action sharing across neighbouring CCGs has been found to be helpful, and further expansion of such activities through dedicated funding could produce valuable learning opportunities for areas addressing similar local challenges. In addition, our members would benefit from good practice examples regarding quality assurance and risk management approaches. Examples of innovative uses of PHBs – and their impact – would also be helpful, as would guidance as to how best value can be achieved in their implementation.

For more information

If you would like any further detail on our response please do not hesitate to contact our Head of Policy and Delivery, Julie Das-Thompson j.das-thompson@nhsc.org or Senior Policy Officer, Emily Jones at e.jones@nhsc.org.

⁵ Forder, J., Jones, K., Glendinning, C., Caiels, J., Welch, E., Baxter, K., Davidson, J., Windle, K., Irvine, A., King, D. and Dolan, P. (2012) [Evaluation of the personal health budget pilot programme](#). Final Report.