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Social Care

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Extending legal rights to personal health budgets and integrated personal budgets: consultation response

Response from the government and NHS England

Prepared by the Department of Health and Social Care,
and NHS England

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Chapter 1: Summary of consultation

Purpose and background to the consultation

Within the NHS and across social care, there is an ever-growing shift towards personalising care – including an increasing number of people choosing to take up personal health budgets. It is clear that people value being involved in the planning of their care, being able to make choices and personalise their support so it best meets their needs. The evidence suggests that, by doing so, individuals are more satisfied with their care, have better outcomes, and are able to explore more innovative approaches to meet their needs (<https://www.phbe.org.uk/>, 2015).

Personalised care matters to the NHS. It can enable the commissioning of more appropriate, better coordinated and more cost-effective services, which genuinely meet individuals' needs. The evidence suggests that, as a result, people get more of the right care, in the right place and in a place that works best for them (<https://www.phbe.org.uk/>, 2015). NHS England and the Government are therefore committed to increasing the extent to which people can exercise greater choice and control over their care. Personal health budgets and all other features of a personalised care approach including shared decision making and personalised care and support planning building on the work conducted to date through Integrated Personal Commissioning (IPC), and are the key mechanisms for delivering this change.

Currently, only adults in receipt of NHS Continuing Healthcare, and children and young people in receipt of continuing care, have the 'right to have' a personal health budget (as defined in in the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012) – although clinical commissioning groups can offer personal health budgets to other groups where appropriate. Despite the legal right only extending to these groups, in 2017/18 over 28,000 people had a personal health budget and the evidence of their success is positive. As a result, the Department of Health and Social Care and NHS England recently consulted on proposals to extend the 'right to have' a personal health budget to other groups that might benefit.

The consultation asked for views on a series of proposals aimed at extending the 'right to have' a personal health budget (and/or an integrated personal budget) to other specific groups. We proposed the following five cohorts, but also asked for views on any other groups that might benefit. The specific cohorts we consulted on were:

- People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services.
- People eligible for Section 117 aftercare services and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services.

- People leaving the Armed Forces, who are eligible for ongoing NHS services.
- People with a learning disability, autism or both, who are eligible for ongoing NHS care.
- People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.

The consultation also sought views on whether, when extending the right to a personal health budget for these five groups, an additional right should be created to include an explicit right to have this budget managed through a direct payment, if the CCG is satisfied that a direct payment is appropriate. We also asked whether the right to have a personal health budget for NHS Continuing Healthcare funded home-care should also be expanded to create a standalone right to a direct payment, as currently the 'right to have' for this group does not extend to the right to receive the personal health budget in a specific way. This is on the basis that the evidence suggests certain groups can benefit more when they receive a budget via a direct payment, as it allows individuals to take on more control and responsibility (<https://www.phbe.org.uk/>, 2015). However, this would only occur if the CCG were satisfied this method of receiving the personal health budget was appropriate for an individual. It is important to note that this does not mean the direct payment method is the only method available; rather, we want to ensure that it is an available option.

Finally, we consulted on 'integrated personal budgets', which bring together personal health budgets and personal budgets in social care into a single integrated personal budget. These would wrap around the individual's health, social care, and in the case of children, educational needs. A person with an integrated personal budget will have all their health and social care needs considered during an aligned or joint assessment, will have a bespoke care and support plan and, potentially, one integrated budget that meets their needs. The overall aim of integrated personal budgets is to enable the person and their carers to exercise greater choice and control over how all their health and social care needs are met, whilst avoiding the need for multiple assessments and managing separate budgets.

NHS England has developed a comprehensive model for personalised care (figure 1, page 19); a whole population, all ages approach to giving people more control over their health and the NHS care they receive. Personal health budgets including integrated budgets are one of 6 key components in the model. Work is currently at an early stage in developing integrated personal budgets, with ongoing development through NHS England's Personalised Care Demonstrator Programme and the Integration Accelerator Pilots announced by the Secretary of State in March 2018.

However, we believe it may be possible to go even further with integrated personal budgets, and are exploring whether we could also integrate other funding streams into the integrated personal budget. We therefore asked for views on which other funding streams could theoretically be incorporated into integrated personal budgets, which we can build into our work moving forward.

This document summarises the main findings and conclusions from the consultation, and provides an analysis of each individual question. The document also explains the approach the Government and NHS England are going to now take following the conclusion of the consultation.

Consultation outcome

The consultation ran from 6th April 2018 until the 8th June 2018. During the consultation, we sought views by:

- giving people the opportunity to respond to an online questionnaire;
- providing people with an email address and a postal address so that people could respond in different ways;
- publishing an easy read document which explained the proposed changes in a more accessible way;
- utilising social media to promote the consultation; and
- Commissioning the Equality and Human Rights Commission to run focus groups to enable access to hard to reach groups.

Overall we received 402 responses to the consultation. The majority of the responses were submitted by individuals, whilst a range of organisations also formally responded. Responses were also received from multiple individuals who use health and care services, both formal and informal carers, NHS staff and the wider health and care workforce. All responses received were analysed jointly by the Department of Health and Social Care, and NHS England.

Analysis of the consultation demonstrated broad support for our proposals with an average of 83.5% agreeing with each proposal. On average 12.2% of people did not agree with the proposals we made, while on average 4.3% of people chose not to respond to individual questions. When removing those who did not answer each question, the average rate of 'agreement' to extending legal rights to have personal health budgets and integrated budgets for each group identified, was 87%. The questions on extending rights to direct payments were on average supported by 86%, demonstrating strong levels of support. For a more in-depth analysis of each individual question, please see Annex A.

For those who did not agree with our proposals, there were a number of common and consistent themes expressed. To prevent repetition throughout this document when providing analysis on each individual question, we explore the common themes in more depth in Chapter 2.

We would like to thank those who took the time to contribute. It enabled us to hear many different perspectives and views, and the feedback we have received will help us in shaping the direction of the future policy.

Chapter 2: Common themes and narrative

Consultation themes expressed by respondents

Overall, the consultation demonstrated a strong positive endorsement towards the questions posed, with on average 87% of respondents agreeing with each proposal. Questions about including a right to a direct payment were agreed with by 86%. This demonstrates highly positive support for extending the right to have a personal health budget to the groups proposed.

There were a range of similar comments throughout the consultation response, which we have clustered into themes. These were the most common responses to all questions in the consultation, relating to integrated and personal health budgets in general.

Positive themes

Independence and freedom

Many responses referenced the independence and freedom that people are able to achieve through adopting a more personalised approach. In particular, direct payments were identified as a mechanism that can really enable individuals to take the responsibility they want when managing their own care:

“Direct payments enable the most freedom for individuals to govern their own care”

(Spinal Injuries Association)

“Improvements in health and wellbeing accelerate when people are treated as individuals”

(Anonymous respondent)

More broadly, there is good evidence suggesting that enabling people to have more independence, freedom and control over decisions about their care can lead to people accessing more appropriate services, improve the coordination of their care, improve their outcomes and experience, and reduce costs for the NHS (<https://www.phbe.org.uk/>, 2015). Personal health budgets are part of a growing shift towards greater personalisation and integration of services, and as people are now living longer and with more complex health needs it is increasingly recognised that new approaches to managing care are required, to ensure the health service respond effectively to people’s individual needs.

Personal health budgets build on experience of personal budgets in social care and personalised care and support planning for people with long term conditions, and start from the principle that

people who need long-term support should be seen as experts in their condition and partners in their care, rather than passive recipients of services.

Some respondents to the consultation also suggested that personal health budgets allow a person to have autonomy, meaning they feel empowered in their own healthcare. This individual approach contributes toward recovery, as they feel invested in their treatment and care. Dylan's story, below, demonstrates this.

Dylan's story

Dylan is determined to live as independently as possible, despite having cerebral palsy that results in spasms and restricts the use of his legs. He was able to specify additional features on his wheelchair to enable him to live independently and not rely on any carers. These enable him to shower by himself and recharge his chair without help, as well as enabling him to raise his height to walk alongside his friends.

Joint decision-making

The importance of having joint decision-making between clinician and the person receiving care was also referred to by respondents as a vital component of individuals taking on a more personalised approach to their health and care:

“The principle of shared decisions is paramount”

(Kidney Care UK)

Shared decision making combines the clinical knowledge of a professional, with the personal experience and awareness that an individual has of both their condition, and life. These two need to combine to make decisions to ensure the most effective treatment for an individual. This joint decision-making can be achieved through personalised care and support planning discussions which are at the heart of all personal health budgets. Such discussions support the individual who knows about their personal situation and needs to be empowered to make appropriate decisions.

National surveys tell us that over 40% of people want to be more involved in decisions about their care (CQC patient surveys, 2015); personalisation, and personal health budgets/integrated personal budgets provide an opportunity for that to occur. In addition, research studies have consistently shown that when people are more involved in decisions they:

- have fewer regrets about decisions;
- report better relationships with clinicians;
- adhere better to treatment; and
- report a better experience including more satisfaction with the outcome.

In other words, shared decision making and the decisions made following such conversations as part of a personal health budget can have a fundamental impact on the safety and effectiveness of personalised care.

We already know that by involving people in decisions about their health and care, we can improve health and wellbeing, improve the quality of care, and ensure individuals make informed use of available healthcare resources. We also know that involving people in their own health and care does not only add value to the individual's life; it also creates value for the taxpayer. The challenge

now is to shift the focus of care and support services from ‘what is the matter with you?’ towards ‘what matters to you?’ Darren’s story, below, provides an example of how joint-decision making can provide individuals with care packages that better meet their bespoke needs, and can best support them in achieving their desired outcomes.

Darren’s story

Darren is in his 40s with tetraplegia. His 24-hour care package enabling him to live at home was provided by a single agency, but he wanted more independence. He discussed with commissioners how he could go out with his carers to a wide range of social activities, and without them being dressed in uniform. Together they agree he will employ a team of personal assistants, using a personal health budget. He was supported to achieve this, and is now enjoying being able to socialise with friends.

Access to alternative forms of support

This shift in choice and control can also enable individuals to identify and access alternative forms of support and care, which will better support them in meeting their health and wellbeing goals. In particular, respondents suggested that a more personalised approach can enable individuals to tailor their pathway in a way that works best for them, that enables appropriate levels of control, whilst continuing to be supported by healthcare professionals:

“[Personal health budgets] can allow wonderfully creative uses of mental health support which actually help people to recover in ways that conventional services cannot always achieve”

(Anonymous respondent)

As the number of personal health budgets rises we are seeing a range of ways that alternative support can be provided to improve outcomes for people. An example from Warrington CCG provides an example of how this has been done in practice:

End of Life Care in Warrington

Having conversations around people’s preferences for the end of their own life is difficult, but Warrington CCG has pioneered the use of personal health budgets for this. In 2017, their programme raised the number of people able to die in a place of their choice from 26 per cent to 83 per cent. Each care plan was unique, but themes such as flexible support, respite for carers and being able to die at home were common threads, alongside pain management and symptom control. Crucially, not one person requested a care package resembling the standard care offer. As well as making a profound difference for those who benefitted, the CCGs saved up to half the cost of conventional services.

This supports the findings from the evaluation of the personal health budget pilots. A large majority of personal health budget holders (82.6%) felt confident or very confident that their specific needs would be met with their personal health budget, with the remainder (17.4%) undecided; no one reported feeling unconfident or very unconfident that their needs would be met.

Positive impact on outcomes and quality of life

Finally, many respondents linked the confidence that people had that their specific needs would be met, to the benefits of recovery and the positive impact on outcomes and quality of life:

“The impact of not getting personalised support can be very serious, for example, it can lead to escalation of needs”

(Mencap, a UK charity for people with a learning disability)

“Research found that two in five people [with mental health needs] did not have a plan on leaving hospital, and personal health budgets could be an important link to ensuring people get the support they need”

(Mind, the mental health charity for England and Wales)

Personalisation ties in closely with the concept of ‘recovery’, which is about the individual having choice and taking control of their health and wellbeing. By enabling an individual to have increased control over their health and care, it can enable a more person-centred focus that can incorporate the individual’s bespoke needs and personal circumstances. Malcolm’s story provides an example of how this can be done in practice:

Malcolm’s story

Malcolm was diagnosed with frontotemporal dementia shortly after retiring, and within two years had been placed in care under section, with little expectation of him being discharged. His personal health budget allowed his family to purchase the care that enabled him to live safely at home by employing five members of staff. All the family were involved in decisions about his care, giving flexibility in the hours and support provided. Malcolm did not return to care, becoming calmer, requiring less medication and becoming calmer. He was supported in the community for the last six years of his life. The saving to the health and care system was at least £100,000 in the last two years of his life alone, but the benefits in terms of quality of life and wellbeing were priceless for all the family, including Malcolm.

Staying healthy and well is an important part of managing any long term condition and by giving people the confidence to better manage their healthcare, the burden on health and care services can be reduced.

The findings from the evaluation of the personal health budget pilot (<https://www.phbe.org.uk/>, 2015) found that there was a reduction in health care service use for people who were able and confident to take day to day control of their healthcare showing that more choice and control can positively impact on individual’s recovery and ongoing health and wellbeing.

Points Raised

Despite this overall positive endorsement, there were also some concerns raised from both individuals and organisations, which we will also respond to in this chapter. There were a number of cross-cutting themes arising, and rather than repeatedly address them while responding to each question, we have chosen to address them collectively in this chapter. We have taken on board these concerns and will consider the responses in our approach to strengthen the delivery of personal health budgets moving forwards.

Support to people with personal health budgets

The main concern raised within the consultation was that whilst personalisation, and specifically personal health budgets and integrated personal budgets, were largely positively endorsed, they would only be successful if there was adequate support and provisions in place to support the individual; particularly when taking a direct payment:

Proper safeguards and support must be in place to ensure individuals are realistically capable of managing their own affairs and making informed choices”

(Anonymous respondent)

We fully agree with this point. It is imperative that individuals are able to access timely and effective support when taking on a more personalised approach; particularly when managing their budget. Clinical Commissioning Groups (CCGs) should ensure that the person receives adequate information and support at every stage of the process, including during the discussion about whether to take up a personal health budget, during personalised care and support planning discussions, to support the management of a direct payment and when reviewing the personal health budget.

This support should be available from the very first stages of planning the budget. When an individual or representative is deciding whether to have a personal health budget and during the process of developing their personalised care and support plan with their local health team, the level of support the individual requires, and would like, should be taken into account; and arrangements should be put in place to ensure the individual feels fully supported.

We also recognise that for direct payments, CCGs need to put in place additional, and specific support for the person to whom direct payments are made (including representatives or nominees). This may take the form of information, advice and other support for example direct payment support services; and can be provided either directly or by another organisation working on behalf of or in partnership with the CCG. Access to good support will ensure people receiving their personal health budget by a direct payment experience the best possible outcomes and experiences, enabling them to have greater choice and control over their care therefore fulfilling the full potential of delivery of care in this way.

More information on CCGs responsibilities in relation to providing guidance and support, can be found within the Guidance on Direct Payments for Healthcare (Direct Payments for Healthcare, (2017), <https://www.england.nhs.uk/publication/guidance-on-direct-payments-for-healthcare-understanding-the-regulations/>).

Potential for abuse

Some respondents also felt that receiving a budget through a direct payment could potentially result in fraudulent use of funding, with recipients spending their budgets on holidays or luxuries that were not intended within the plan. There was concern that personal health budgets could lack proper governance mechanisms around planning and accountability; and that we need to ensure that there is effective governance and monitoring in place to eradicate fraudulent activity:

“Proper and routine monitoring of expenditure should be undertaken and any inappropriate expenditure should be reclaimed”

(Anonymous respondent)

While there are clear benefits to giving people more control over their care, we do recognise that there are some challenges in ensuring that all decisions are fair, appropriate and beneficial, and ensuring that the public have confidence in the system. However, to date there is little evidence of abuse. To ensure proper use of funding, a person or their representative must first agree a personalised care and support plan with the local NHS team. No money can be spent on things not agreed in the personalised care and support plan. There are also clear exclusions in place within the regulations that set out what cannot be purchased through a personal health budget. These include alcohol, tobacco, gambling or debt repayment, or anything that is illegal (<https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf>, Annex A, 2014).

Furthermore, the NHS retains responsibility for oversight of spending via a personal health budget as it remains public money. As a minimum, all personalised care and support plans must be reviewed formally within three months of care being in place. Following this, reviews should be at appropriate intervals, but at least yearly. Throughout, individuals are also required to provide evidence of spend to the local health team and the CCG, so that there is assurance that the funds are being appropriately used as agreed to within the plan.

If a CCG determines that an individual has misused their budget, they can stop making a direct payment and care will be provided through a traditional package of care or notional or third party personal health budgets. In some circumstances, the CCG may ask for all, or part of, the direct payment to be repaid. The decision to seek repayment, and the amount of money to be reclaimed, is at the discretion of the CCG.

Experience to date shows that instances of unauthorised spending are extremely rare. As we progress with this agenda, we are confident that the systems CCGs have in place will help to ensure that cases of fraudulent activity will remain few and far between. For more information on the systems in place, the ‘Monitoring and Review’ section of Guidance on Direct Payments for Healthcare (<https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf>), explains this in further detail.

Impact on workforce and carers

Another concern raised was in relation to when individuals do not feel comfortable, or able, to manage a budget; with the additional burden then presumably being picked up by workforce or carers:

“Some people are unable to manage a budget, employ a support worker or carer and feel this adds to their stress and anxiety”

(Anonymous respondent)

We are aware that personal health budgets are a new way in which care is delivered to an individual. They require a changed relationship between individuals and the workforce who will require training and support to move to this new way of working. NHS teams who have made this transition report this change in relationship can reduce the number of crisis situations and input on a day to day basis, as people are more in control of their care. The overriding focus on prevention

and keeping people healthy and out of health services, can also help to reduce the direct burden on workforce in primary and acute care.

To help facilitate this new way of working, NHS England are working with CCGs across the country to help support and train the workforce to ensure they have the skills and confidence to work in this way.

In relation to carers, it is our belief that personalisation more broadly can benefit carers, through identifying and supporting their health and wellbeing needs alongside that of the individual they care for. By including carer's needs within the planning phase, the burden on them can be better understood and managed – and the responsibilities and roles of the carer in relation to the personal health budget, can be set out clearly and coherently.

More personalised and integrated commissioning also offers an opportunity to develop a more person-centred and integrated approach when identifying, assessing, and supporting the health and wellbeing needs of both the individual, and any carers involved. The joint or aligned assessment and single personalised care and support plan can help to ensure that the needs of both the individual and carer are met. Personalised approaches can also deliver transformational change by working with carers as expert care partners; fundamental in the planning, design and shaping of services (Carers Action Plan – 2018-2020, <https://www.gov.uk/government/publications/carers-action-plan-2018-to-2020>, (2018)). We are aware that receiving care via a personal health budget or integrated personal budget could in some cases increase the administrative burden on carers – for example, if they are managing recruitment for personal assistants on behalf of the individual. In such cases, support should be available, for example through direct payment support services. We are clear that no carer should ever be required to take on more responsibility than they are happy too; and as stated above, the roles and responsibilities of carers should be taken into account during the development of the care plan.

Personal health budgets and NHS core values

Finally, a small number of respondents felt that the use of personal health budgets undermine the NHS' core values. The main aim of a personal health budget is to give people more choice about how their needs are met. They are underpinned by core NHS principles, in particular, that the NHS should be free at the point of need and fully cover the health need of the individual. Currently, CCGs commission a range of services from the NHS, the voluntary and community sector and private providers, based on the needs of people in their area. NHS Continuing Healthcare is already primarily spent in the independent sector on services such as care agencies and nursing home provision. Personal health budgets do not change this – rather, they give people the chance to negotiate tailored packages with agencies, get services from different providers, or employ their own staff directly, in a way that suits them, meets their needs, and helps them to achieve the desired outcomes. Due to this flexibility to tailor packages of care personal health budgets can also reduce health inequalities as there is more scope to ensure people receive the care that best suits their needs.

Chapter 3: Equalities and impact assessment

The purpose of this consultation was to collect views on the possibility of extending individuals' rights to have a personal health budget and integrated personal budgets, including an assessment of whether an extension of the right to the groups identified within this document is something that respondents want. As outlined throughout this document, the results of the consultation are conclusively in favour of extending legal rights to personal health budgets and integrated personal budgets to other groups – and we will therefore continue to test and refine our approach.

This consultation also explored public opinion on whether personal health budgets and integrated personal budgets could be extended to incorporate other funding streams related to health and social care. Again, there was a broad consensus that individuals would welcome the opportunity to incorporate or align other funding streams to an integrated personal budget and work will therefore continue across government to determine how best this can happen.

Throughout the development of the policy, and as necessary, we will undertake an analysis of equality issues in line with Secretary of State's statutory duties and other legal tests and duties, including the public sector equality duty.

Within this consultation we asked the public for their views on whether they believed anything set out in this document might have a beneficial or adverse impact on any equality issue, in particular, on the protected characteristics as defined in Section 149 of the Equality Act 2010. In total, we received 259 responses to this question, with the majority of responses suggesting they could foresee no specific significant beneficial or adverse impacts on equalities, providing appropriate support is in place for individuals in receipt of a budget.

For those individuals who believed there would be adverse impacts as a result of this policy, the following three key themes were highlighted:

- Adverse impact on carers
- Personal health budgets will enhance inequalities as more wealthy individuals will be able to access 'better' services
- Possible disadvantages to older people, and people who cannot access technology

Firstly, some individuals stated that carers, both formal and informal, would be adversely impacted as a result of this policy. Specifically, there were concerns that carers may be directed to manage the personal health budget or integrated personal budget on behalf of the individual, adding to their workload through creating an additional burden.

We do not consider that carers will be adversely impacted as a result of this policy. The overall aim of this policy is to enable the person and their carers to exercise greater choice and control over how their needs are met and achieve better outcomes, avoiding the need for multiple assessments and managing separate budgets. There is also evidence to suggest that families and carers can benefit when the individual has additional choice and control over their care and wellbeing, and can help to prevent some individuals from going into residential care (SCIE, <https://www.scie.org.uk/personalisation/specific-groups/learning-disability>). No individual or carer should ever be forced to take on more responsibility than they feel comfortable with, and CCGs should ensure appropriate support services are available for individuals and carers so they are supported appropriately to make decisions about how a personal health budget will be managed on a day to day basis and provide ongoing management support where needed.

More widely, the universal personalised care model (Figure 1) aims to deliver transformational change by working with all carers as expert care partners. This could include, where appropriate, involving carers both in planning care for the person they care for and in the planning, redesigning and shaping of services. Carers will also be identified as champions and leaders in developing the universal personalised care model which will directly benefit carers by identifying and supporting their health and wellbeing needs, as well as those they care for.

Furthermore, there is no necessity for carers to manage the individual's budget on their behalf. There are three money management options available for personal health budgets or integrated personal budgets and carers will only manage the budget on behalf of the individual if both they and the individual they care for, agree it is appropriate and fair:

- Notional budget – the council or the NHS manages the budget and arranges care and support on behalf of the individual.
- Third party budget – an organisation independent of the person, the council and the NHS commissioner – for example, a charity -manages the budget and is responsible for ensuring the right care is put in place. The third party will work in partnership with the individual and their family to ensure the agreed outcomes can be achieved.
- Direct payment – the budget holder has the money in a bank account, or an equivalent account, and takes responsibility for purchasing care and support.

Given this, we do not consider there should be any additional burden on carers as a result of this policy; unless they are happy to play a greater role in managing a budget. The impact on carers will also be further examined and outlined within future impact assessments, prior to any rollout.

The second key theme suggested that personal health budgets and integrated personal budgets favour the wealthier. The suggestion is that individuals, who are in a position to do so, could 'contribute' to their personal health budget or integrated personal budget, enabling them to buy 'better' services, thus creating a two-tier system. A few responses then linked this to the development of an insurance system.

Whilst we recognise these concerns, we do not consider these to have merit. Contributions are not allowed in NHS care, and within social care, means-testing applies that calculates how much individuals are required to contribute towards the cost of their care and support. In this respect, this helps to create a more equal service; in social care, individuals who are able to contribute towards the overall cost, can, whilst those who are not in a position to contribute, are not required to.

As such, the amount allocated to individuals within their personal health budgets is based on the full cost of meeting someone's agreed needs, the regulations are clear you cannot "top-up" or contribute to your personal health budget. For integrated personal budgets, the total amount

provided to the individual therefore takes into account the full cost of meeting their agreed needs and any means tested personal contributions for the social care element only. Regulations and guidance are also clear that any costs associated with setting up a personal health budget or integrated personal budget should also be covered in the whole budget for example on costs for recruiting and employment of personal assistants.

Personal health budgets, integrated personal budgets, and person-centred care more broadly, is simply about providing individuals with a mechanism to control and tailor their own health and care. This should be based on their own individual needs, in a manner that abides by the constitutional values of healthcare being free at the point of delivery, based on clinical need, not on ability to pay. This approach uses existing money in a different way, and does not interlink with health insurance in any way. Personal health budgets can also help reduce health inequalities due to the way packages of care can be tailored.

The final key theme was about possible disadvantages to older people as a result of this policy. Specifically, responses focused on access to technology and personal health budgets as an additional burden to older people – therefore meaning fewer older people will potentially choose to take up a personal health budget. This is an issue we are aware of and CCGs should ensure that anyone who would benefit from a personal health budget, regardless of age, condition or ability, should be able to access support in this way. Relevant information, advice and support services should be available to those who require help locally.

The three options for managing the money, as described in this section, means that everyone should be able to access personalised care without necessarily taking on any additional burden of managing the money if they do not wish to.

We are conscious of the need to make personalised approaches as accessible as possible, which is why many of the personalised care demonstrator sites are exploring the benefits of personalised approaches to different cohorts of the population, including older people. Whilst we already have some evidence, demonstrator sites will be providing further evidence in relation to this in due course.

We are keen to ensure that all groups within the population feel adequately supported in taking on a more personalised approach to their care, if they so wish and if appropriate to them. It is important to note firstly that no one will ever be forced to have more choice and control over their care than they want. If individuals do choose to take on a personal health budget it is vital that the help, support and guidance is in place to enable them to do this. Skills for care, in partnership with NHS England, have published a range of guidance available to individuals to help them when taking on a budget. We will continue to work with them to review publications to ensure they are adequate.

Many respondents also believed that the extension of personal health budgets and integrated personal budgets could have beneficial impacts on equalities – providing a greater equity of service and opportunity, reducing isolation, and improving social connectedness for people who have trouble connecting with the health and social care system. There was particular emphasis on the population who live with complex disabilities, with a common view that personalisation can enable this cohort to more easily access the health and care they need, rather than simply that which is available.

NHS England's health inequalities action plan outlines specific actions to further reduce inequalities within health care including within personalised care (NHS England Board Meeting Paper, <https://www.england.nhs.uk/publication/nhs-england-board-meeting-papers-24-may-2018/>). Further evidence on any beneficial or adverse impacts as a result of this policy will continue to be tested within the personalised care demonstrator sites. Evidence will be used within any future impact assessment or equality analysis in relation to this policy.

Chapter 4: Conclusion and next steps

Since the 1970s, there has been an ongoing drive towards personalisation of health and social care services. Personalised care allows people who use NHS and social care services to access services in a way that fits them as an individual, and enables the services to be tailored to their particular needs.

There is a growing consensus that this is the right approach: one which enables people to have the same choice and control over their health and wellbeing that everyone has come to expect in every other part of their life. Our ambition therefore is to move towards joined up and integrated provision across health and social care, via a comprehensive model of integrated, personalised care, with personal health budgets and integrated personal budgets a key component of this ambition. This can mean having meaningful, joined-up and aligned assessments, developing into integrated bespoke personalised care and support plans addressing an individual's whole needs. It may also mean, where needed, one multidisciplinary team working and supporting the individual in both developing and implementing their plan, and, if the individual chooses to take one, an integrated personal budget. We believe that when we get this right, personalised care can improve outcomes, enhance satisfaction with the services received, and improve quality of life.

In short, personalised care represents a new relationship between people, professionals and the health and care system, providing a positive shift in power that benefits both people and professionals. This is something that we are committed to and want to progress. As such, we are very grateful to all those who responded to this consultation, and it is hugely positive that the vast majority of respondents agree with both our direction of travel in relation to personal health budgets and our specific proposals contained within the consultation.

We received a broad mix of contributions and received many constructive responses, which will help with future policy development. For each proposal regarding extending legal rights to the various cohorts identified within the document, there were high levels of support, and an overwhelming sense that personalisation is the right way to go.

The comments we received have also been helpful in illustrating some of the challenges we face when implementing this policy and the benefits which could be reaped from making personalised care fundamental to the future of the health and care system. What has become increasingly clear is the importance of ensuring our messaging is right, to make certain appropriate support is in place for both recipients and staff, and ensuring that everyone is aware of the benefits a personalised approach can bring.

Given the feedback, we now intend on taking a plethora of next steps to really drive and embed personalised approaches to health and care. The recently published NHS Long-Term Plan, (The

NHS Long Term Plan, <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>, (2019), sets out our plans for the continued expansion of personalised care over the next decade; including the introduction of the comprehensive model for personalised care (Figure 1). This model is a whole-population, all ages approach to giving people more choice and control over their health, and the NHS care they receive. It includes personal health budgets, integrated personal budgets and a range of other evidence based approaches that are aimed at giving more choice and control; shared decision making, personalised care and support planning, patient activation and patient choice.

Comprehensive Model for Personalised Care

All age, whole population approach to personalised care

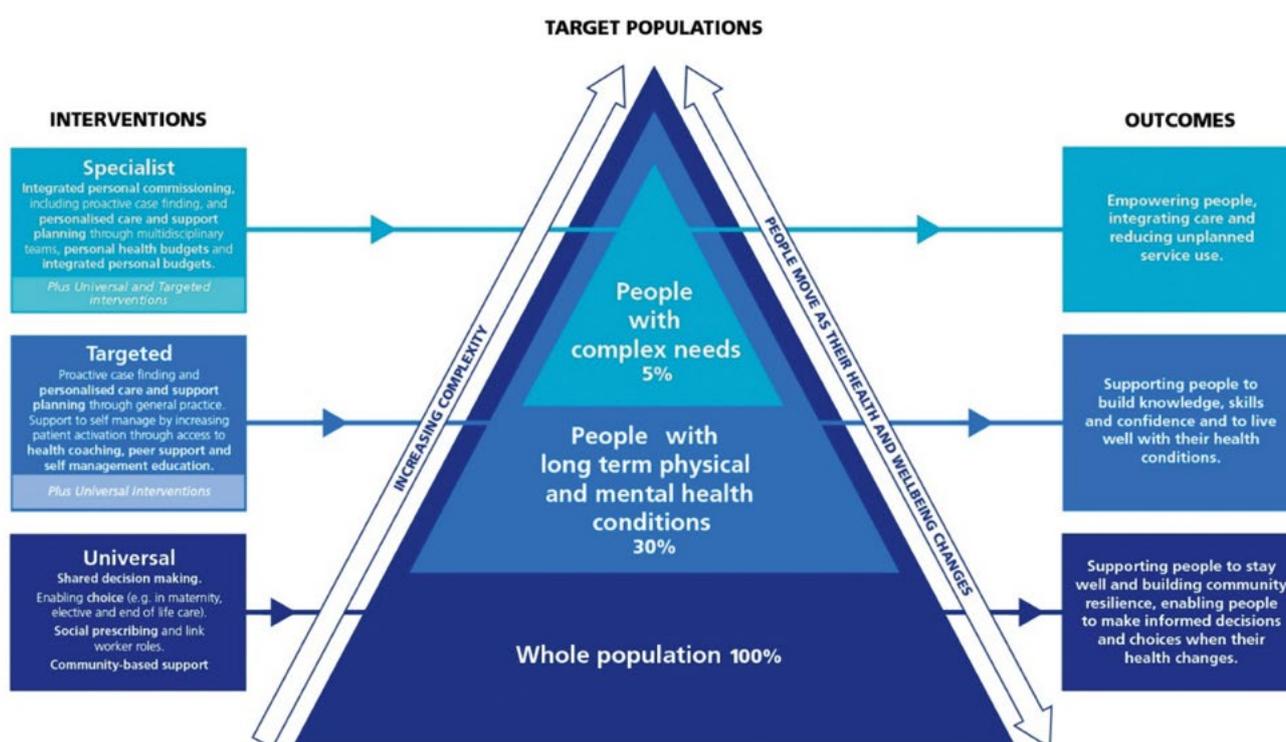


Figure 1: Comprehensive Model of Personalised Care (NHS England)

Rollout of this model will reach 2.5 million people by 2023/24; with our intention being to double that again within a decade. As part of this 2.5m, we envisage over 200,000 people having a personal health budget by 2023-24, giving people greater choice and control over how their care is planned and delivered. Of these 200,000, many will be from the five groups we consulted on here.

Following the results of the consultation, we will now be taking forward legislation for some of the groups we consulted on. We intend to take forward work to extend the legal rights to people eligible for Section 117 aftercare services, and people who access wheelchair services, whose posture and mobility needs impact their wider health and social care needs. We will also continue to further explore both the other groups we consulted on, and additional groups who we believe could also benefit from having a right to have a personal health budget.

We will continue to expand access in a range of areas including the provision of bespoke wheelchairs and community-based packages of personal and domestic support. We will also expand our offer in mental health services, for people with a learning disability, people receiving social care support and those receiving specialist end of life care.

As the NHS Long-Term Plan detailed, we have increased the number of areas implementing this model of personalised care, with a third of England now covered. By September 2018, over 200,000 people had already experienced a personalised approach to care with over 32,000 of these having a personal health budget; a quarter of which being jointly funded with social care.

We also commit to further consulting on other groups who we believe will benefit from being given a right to have a personal health budget.

But this is just the start; there is plenty more happening in the wider personalisation space. For example, through social prescribing, the range of support available to people will widen, diversify and become accessible across the country. We will ensure that link workers, within primary care networks, will work with people to develop tailored plans, and connect them to local groups and support services. Over 1,000 trained social prescribing link workers will be in place by the end of 2020/21 rising further by 2023/24, with the aim that over 900,000 people are able to be referred to social prescribing schemes by then.

We will also personalise and improve end of life care. Through working with patients, families, health and care organisations and the voluntary sector at both a national and local level, and through training staff to help identify and support relevant patients, we will introduce proactive personalised care planning for everybody identified as being in their last year of life.

More broadly, we will trial, and if successful, roll out, new technology that can help to facilitate personalised approaches. We will support the workforce in embedding a person-centred approach to health and care; providing resources and guidance where required. And we will explore how incentives can align and drive a person-centred approach throughout the system.

Throughout the development of this policy, and alongside the changes we have proposed, we will continue to work closely with all our partners and stakeholders, and welcome your feedback on how the policy is progressing in practice. The consultation has served to prove that people are positive about the direction we are travelling in, and the benefits personal health budgets can bring. With a phased implementation process enabling us to learn and build on our experiences, the continued roll out of personal health budgets and expansion of personalised care more broadly will pave the way to a more person centred future for the NHS.

Annex A: Breakdown of responses by question

Supporting people with ongoing social care needs, who also make regular and ongoing use of relevant NHS services

Rationale

There is a broad push across Government to integrate the way health and care services work together and are commissioned. Currently, individuals can hold both a personal health budget, to meet their health needs, and a personal budget, to meet their social care needs. This means that individuals could theoretically have two separate budgets, two separate plans, and two separate needs assessments. Integrated personal budgets, which bring the two budgets together into one, is one way that we believe individuals can experience a more streamlined service that addresses both their health and social care needs.

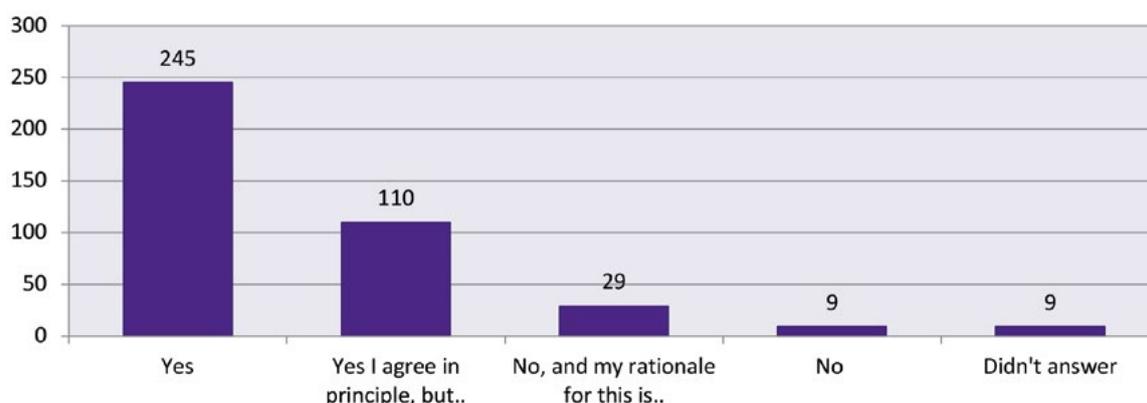
In 2017/18, around 4000 people had joint personal budgets: a number that NHS England expects to rise substantially with the increased roll out of personal health budgets. Enabling this cohort to have an integrated personal budget will provide them with the opportunity to plan their entire care in a more holistic, and integrated manner.

Q1a. We are proposing that people who are eligible for both a personal budget and a personal health budget should have the right to an integrated personal budget. Do you agree?

Consultation outcome

A total of 393 people responded to this question, with 355 of these people agreeing that people in this cohort should have the right to an integrated personal budget. This amounts to 90.3% of people who agree and 9.7% of people who disagree with the proposal.

Q1a. We are proposing that people who are eligible for both a personal budget and a personal health budget should have the right to an integrated personal budget. Do you agree?



Of the 90.3% who agreed, the main reasons for supporting the proposal were that:

- this would enable a more complete and holistic package of care that is more streamlined and enables the individual to more seamlessly move between health and social care, in a way that works best for them. Respondents said they believed this would help support them in keeping healthier and staying out of hospitals;
- this will make the process easier for people; processes can be aligned, reduced and simplified, reducing the burden people face in having their needs met; and
- this would help to facilitate conversations between health and social care professionals, aiding the transition between the two. This would reduce duplication and a person having to explain their condition numerous times to a range of professionals.

Of the 9.7% who did not agree with this proposal (largely made up of individuals rather than organisations), the main reasons given were that:

- There was potential for abuse of the budget;
- it would lead to a reduction in the overall budget available; and
- there were concerns over whether integrated budgets could be executed in practice.

The first concern related to instances of misuse and the possibility of personal health budgets being used for fraudulent activity. To reduce possibilities of fraud, as a minimum, there will be a formal review within three months of the person first receiving a direct payment. This will focus on ensuring the agreed outcomes are being met and the direct payment is being spent in line with meeting these outcomes. There may be instances when genuine mistakes are made but if fraud is detected at these reviews, it will be possible to stop the direct payment immediately. A more detailed response to this concern is available in chapter 2 (points 39-43).

There were concerns raised that the integration of health and social care budgets will result in a reduced overall budget, with some respondents suggesting that health care needs would be prioritised. We are keen to emphasise that the roll out of integrated personal budgets is not a cost-cutting exercise, but instead one where the aim is to reduce the burden on the individual. The budget will still be based on meeting all assessed needs, but will be accessed in a different way. This will result in a more streamlined service for example rather than having to employ two personal assistants for different needs, it would be possible to employ one personal assistant to complete

two sets of tasks. In this example there may be instances when this does save money in the budget as less money is required for recruitment and employment costs but this reduction will be an outcome based on how individuals have chosen to receive their care.

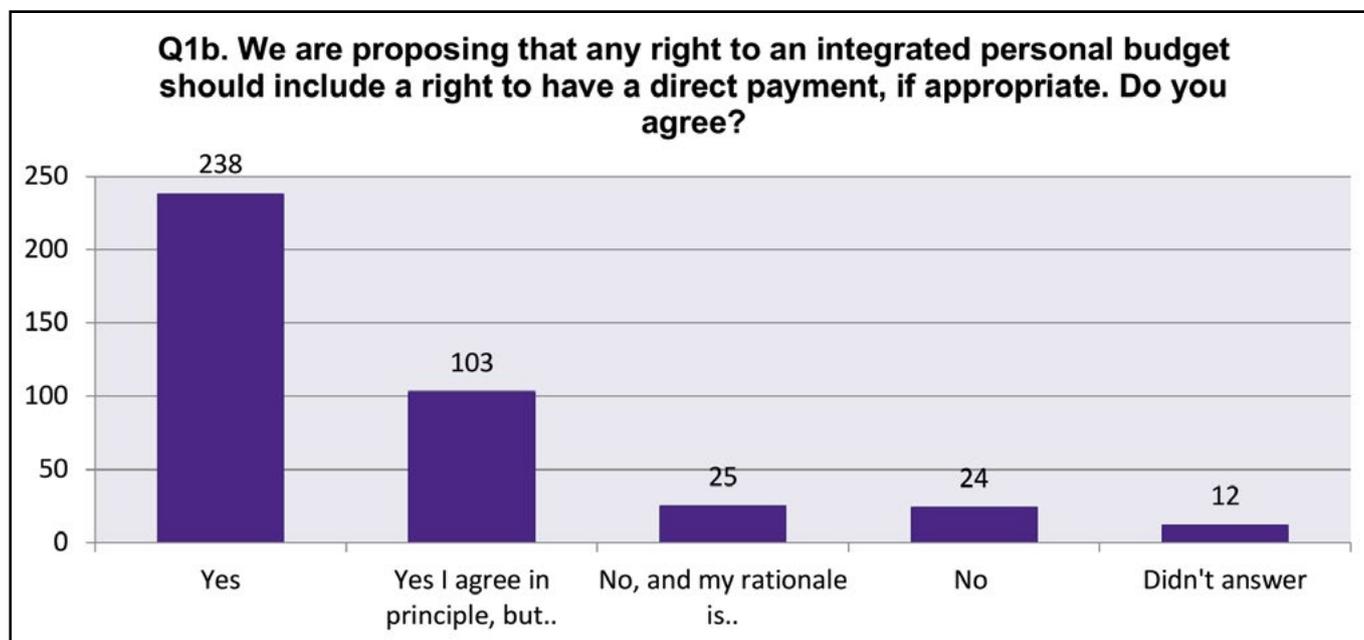
Introducing a wide-scale roll out of integrated personal budgets is not an easy task and adequate infrastructure needs to be in place for this to be successful. This is why we are committed to this in the long-term, as integrated personal budgets will be phased in, with appropriate systems in place to manage this.

We are currently running pilots looking into integrated care and how greater collaboration in relation to assessments and care planning can best be managed. Learning from this and the wider personalised care demonstrator programme will inform rollout. There are currently different systems, processes and regulations in place across health and social care which we will review and work to remove any barriers where needed.

Q1b. We are proposing that any right to an integrated personal budget should include a right to have a direct payment, if appropriate. Do you agree?

Consultation outcome

A total of 390 people responded to this question, with 341 of these people agreeing that people in this cohort, who have the right to an integrated personal budget, should also have an explicit right to a direct payment. This amounts to 87.4% of people who agree and 12.6% of people who disagree with the proposal.



Of the 87.4% who agreed, the main reasons for supporting the proposal were that:

- direct payments can offer individuals additional control; leading to a positive impact on wellbeing for many;
- would act as a lever to ensure individuals receive the services they need, rather than the services they are offered and would enhance choice; and
- allows people to feel empowered and have greater autonomy in their holistic care.

Of the 12.6% who did not agree with this proposal, the main reasons given were that:

- lack of support in place for recipients; 49/341
- potential for abuse of the budget; please see points 39-43 in Chapter 2) and
- provision of direct payments will result in an additional burden on the workforce undertaking the planning and review process.

We fully agree with the importance of offering people receiving personal health budget sufficient support. We expect CCGs to offer sufficient support, and they are responsible for ensuring that the person receives adequate information and support at every stage of the process. A more detailed response to this concern and information about the types of support offered is available in Chapter 2.

Some responses also expressed a concern about the burden on the workforce, particularly with the need for reviews and how these would be managed. NHS England is working with CCGs to help support and train professionals, who will be aiding the set up and running of personal health budgets. A more detailed response to this concern is available in Chapter 2.

Direct payments provide individuals with more choice and control over how their care and support is delivered, enabling the individual to commission their own care and support and tailor this to their needs. Once a direct payment has been provided, it is the CCGs responsibility to ensure appropriate systems and processes are in place to oversee the use of direct payment and ensure that the funds are being used in the manner agreed within the plan.

Extending the right to have a personal health budget to people eligible for S117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services

Rationale

Personal health budgets fit well with the recovery-focused approach to mental health services. The recovery model aims to move beyond symptom and risk management to supporting people to re-establish meaningful lives with their mental health condition. It means looking beyond medical treatment to consider wider issues such as housing, employment and relationships.

Many clinical commissioning groups across the country have already successfully implemented personal health budgets in mental health. In 2017-18, there were 1380 personal health budgets for adults with a primary mental health care need, and evidence demonstrates a range of benefits, including providing the individual with a sense of empowerment, a better care related quality of life, and better psychological wellbeing (<https://www.phbe.org.uk/>, (2015)). Local areas are now recognising the potential benefits in offering integrated personal budgets for people with mental health needs whose requirements sit across both health and social care.

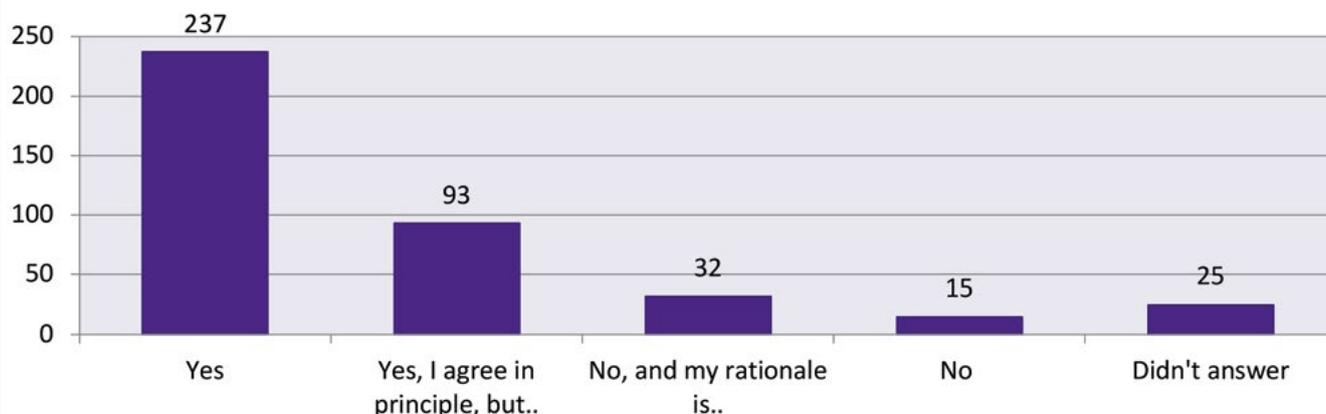
As part of this, we also believe that personal health budgets and integrated personal budgets could be beneficial to people receiving 'after-care' through section 117 of the Mental Health Act 1983. Section 117 after-care services include healthcare, social care, employment services, supported accommodation, and services to meet people's social, cultural and spiritual needs – as long as the needs arise from, or are related to, the person's mental health condition, and help reduce the risk of this getting worse. A personal health budget or integrated personal budget would provide individuals receiving after-care with a tailored approach that is right for them, will empower them, and provide them with a supportive mechanism that can help them to re-establish meaningful lives with their mental health condition.

Q2. We are proposing that a person eligible for Section 117 after-care services under the Mental Health Act 1983 should have a legal right to a personal health budget / integrated personal budget. Do you agree?

Consultation outcome

A total of 377 people responded to this question, with 330 of these people agreeing that people in this cohort should have a legal right to a personal health budget or an integrated personal budget. This amounts to 87.5% of people who agree and 12.5% of people who disagree with the proposal.

Q2. We are proposing that a person eligible for Section 117 after-care services under the Mental Health Act 1983 should have a legal right to a personal health budget / integrated personal budget. Do you agree?



Of the 87.5% who agreed, the main reasons for supporting the proposal were that:

- can lead to more effective, targeted treatments that meet the direct needs of the individual and their specific mental health need;
- can result in more creative and innovative solutions that better address the individual's needs; and
- are able to empower individuals who may have disengaged from traditional forms of support.

Of the 12.5% who did not agree with this proposal, the main reasons given were that:

- lack of support and subsequent possible difficulties in individuals managing the budget;
- lack of services in mental health to make personalisation functional; and
- how people will be assessed for a personal health budget and the guidelines in place for this

We recognise the importance of personal health budget holders being fully supported by their CCG. The CCG is responsible for ensuring that the person receives adequate information and support at every stage of the process. We are aware that often mental health conditions (and indeed other needs) do not have a linear recovery and as a result people may find that they are no longer able to manage a direct payment, when they had once been in a position to do so. In this instance, direct payments could be removed and alternative payment systems established. However, we do not support the assumption that people with mental health conditions do not want a personal health budget or would be unable to manage this given their condition. There is little evidence for this from the current roll out of personal health budgets, as people have been keen to manage their complex health needs in a way that best suits them. A more detailed response about the types of support offered is available in Chapter 2.

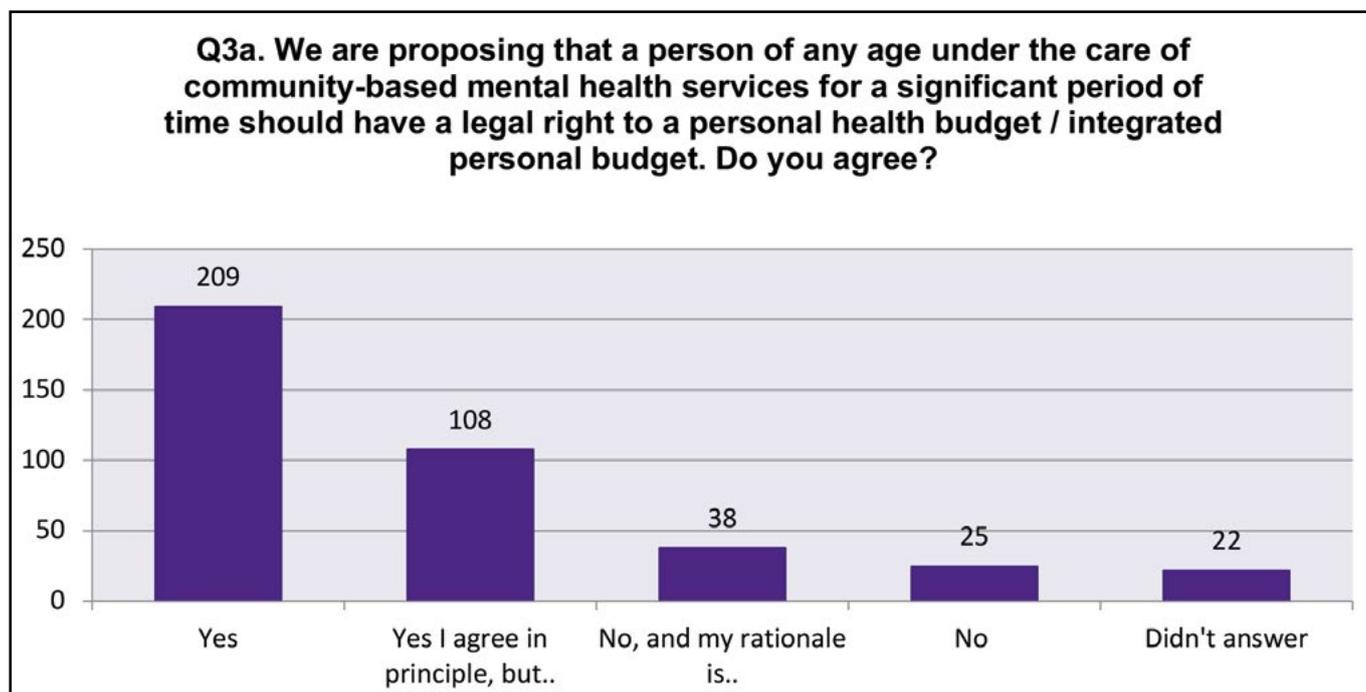
In terms of the concern around lack of services, commissioners should work together with people, families and providers to understand what is needed in their area and encourage providers to offer personalised support and solutions. We have also found that personal health budgets allow patients to access services they may not previously have considered or been able to access. CCGs will be responsible for deciding who is eligible in their area. Before a person has access to a personal health budget, they will first have their health care needs assessed and where these are appropriate to be met by a personal health budget there will be a discussion between the individual

and their health team on how best these needs could be met. These discussions will facilitate an understanding of appropriateness.

Q3a. We are proposing that a person of any age under the care of community-based mental health services for a significant period of time should have a legal right to a personal health budget / integrated personal budget. Do you agree?

Consultation outcome

A total of 380 people responded to this question with 317 of these people agreeing that people in this cohort should have a legal right to a personal health budget or an integrated personal budget. This amounts to 83.4% of respondents who agree, with 16.6% disagreeing.



Of the 83.4% who agreed, the main reasons for supporting the proposal were that:

- able to access support and treatments which are specific to their needs, also can take into account where the individual is in terms of their recovery and tailor treatment to this;
- young people and the elderly were identified as groups that could benefit, with age not being a limiting factor; and
- encourages independence and allows individual to be empowered in their treatment

Of the 16.6% who did not agree with this proposal, the main reasons given were that:

- lack of support and subsequent possible difficulties in individual managing the budget;
- young people would need particular support to manage a budget;
- Lack of clarity on the role of a responsible advocate and how this might work for those under 18:
- concerns around safeguarding – how can we ensure individuals in receipt of budgets remain safe.

The first concern about support refers to the need for information, advice and support to be provided to personal health budget holders. A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A more detailed response to this concern and information about the types of support offered is available in Chapter 2.

Responsibility for safeguarding and patient safety remains regardless of how care is received. We accept that for young people, there may be concerns about safeguarding and age-appropriate support should be made available. This involves the recognition that a legal guardian (representative in the DP regulations) can manage a budget on a child's behalf. The individual who receives the budget should be supported by their local health team and regular reviews take place to ensure that the personalised care and support plan set, and budget allocated, remains correct, fair and safe. If the individual or someone caring for an individual has any concerns in relation to their personal health budget, they should discuss this with their health care professional, who is responsible for overseeing the individual's package of care.

Skills for Care, in partnership with NHS England have published a series of resources to support individuals when taking on a personal health budget, particularly for those receiving their personal health budget via a direct payment (Personal health budgets (PHBs), <https://www.england.nhs.uk/personal-health-budgets/>, 2018.).

We will also be establishing a consistent digital platform for payment, management and monitoring of personalised budgets, and for personalised care and support planning, aligning this with digital and data standards and the work of the Empower the Person digital transformation work. This digital platform could include key resources for individuals taking on the budget, staff that make up the multi-disciplinary team, and all organisations involved within the bespoke plan.

Q3b. What do you feel would constitute a reasonable definition of 'a significant period of time'?

Consultation outcome

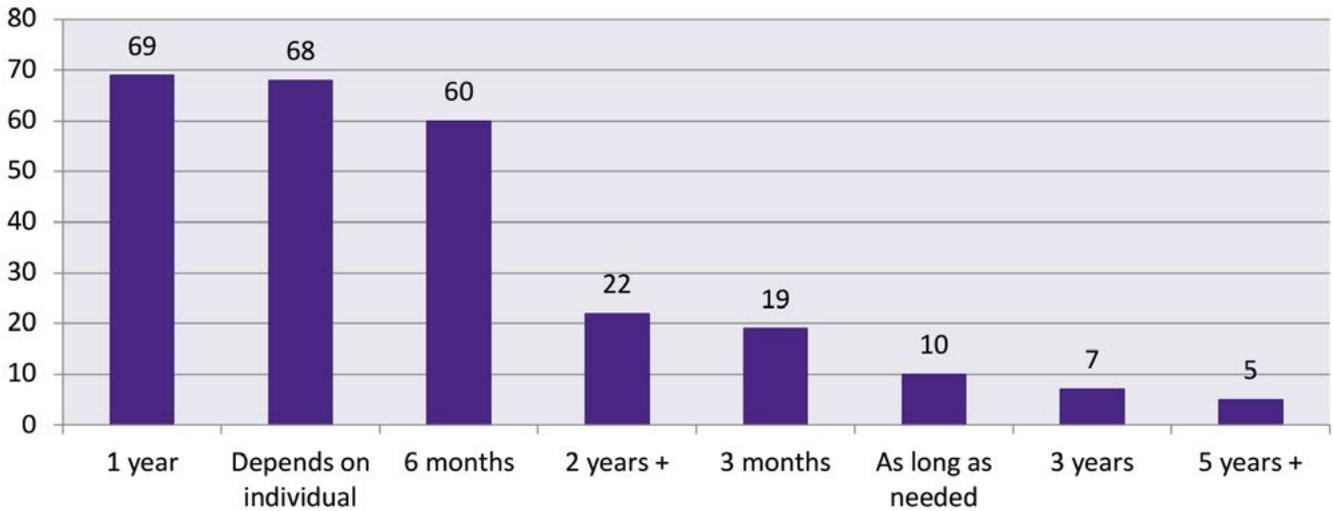
In total, 346 people responded to this question with suggestions on what would constitute a reasonable definition of 'a significant period of time'.

As shown below, many responses suggested that this time period should be based on the individual's condition and unique circumstances. We fully agree that a 'significant period of time' must be based on the individual's circumstances; any length of time specified will simply be used as a guide only. We will also take into account the amount of interaction an individual has with services, and other considerations raised by people in response to this question.

Based on our analysis of the consultation responses, the average time period proposed was approximately one year. We will now work with key stakeholders to discuss this view and agree next steps.

The chart below provides a summary of responses. This is not a full representation of all responses, as some answered 'do not know' or suggested a range of time periods from 1 month to 50 years. As such, only timescales suggested by 5 or more respondents are shown.

Q3b. What do you feel would constitute a reasonable definition of 'a significant period of time'?

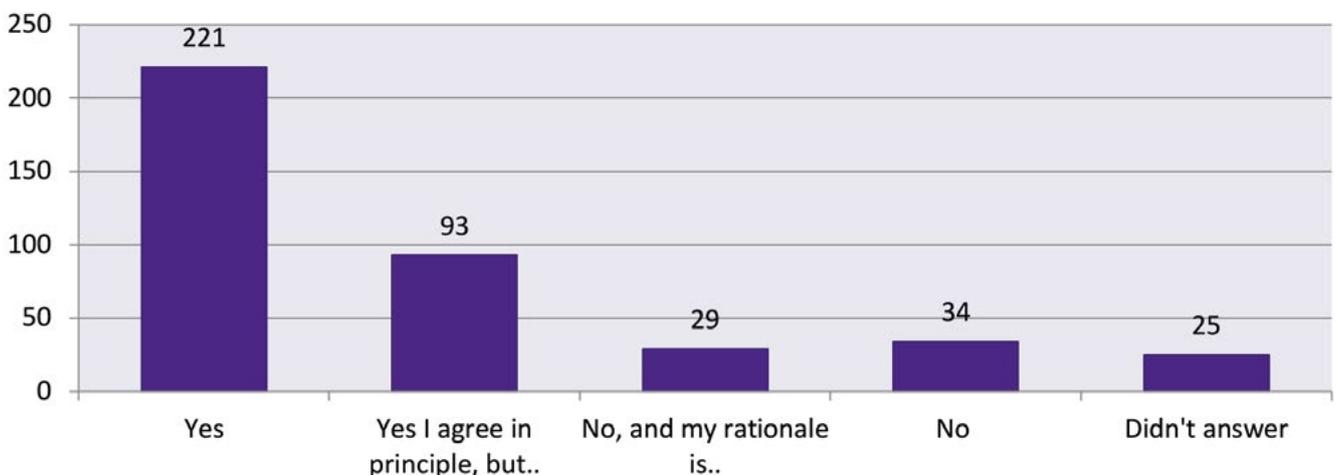


Q3c. We are proposing that any right to a personal health budget for mental health should include a right to have a direct payment, if appropriate. Do you agree?

Consultation outcome

A total of 377 people responded to this question with 314 of these people agreeing that people in this cohort who have the right to an integrated personal budget should also have an explicit right to a direct payment. In percentage terms, this amounts to 83.3% of people who agree with 16.7% of people disagreeing with the proposal.

Q3c. We are proposing that any right to a personal health budget for mental health, should include a right to have a direct payment, if appropriate. Do you agree?



Of the 83.3% who agreed, the main reasons for supporting the proposal were that:

- people are able to have more control with a direct payment, allowing increased flexibility of treatment options
- personal health budgets result in more choice, with the need of the individual being paramount
- the above combination of increased choice and control allows for autonomy, meaning the individual feels empowered and able to contribute to their treatment more fully, as they are aware they are being fully understood
- with the appropriate checks and safeguards in place, personal health budgets will be hugely beneficial

Of the 16.7% who did not agree with this proposal, the main reasons given were that:

- people may be unable to manage a personal health budget without additional support
- extra burden on workforce and carers; and
- direct payments in this area could result in a reduced quality of care, given the lack of services.

The first concern about support refers to the need for information, advice and support to be provided to personal health budget holders. A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A more detailed response to this concern and information about the types of support offered is available in Chapter 2.

There were also concerns raised in the consultation about the administrative burden this would place on clinicians and recipients of a personal health budget, or someone who would manage a personal health budget on someone's behalf. NHS England is working with CCGs to help support and train professionals, who will be aiding the set up and running of personal health budgets. For carers or individuals managing a personal health budget, support is available for this. A more detailed response to this concern is available in Chapter 2.

We are keen to ensure that direct payments do not lead to a reduced quality of care and firmly believe that they will result in increased quality and improved outcomes instead. However, should someone feel that this is not the case; it will always be possible to revert to a more traditional approach where the professional commissions services on the person's behalf. Personal health budgets are not mandated, but an additional choice that we want people to have the right to have, as we are aware of the benefits they can provide.

Moreover, there will always be support for people especially if they opt to have a direct payment. There will be a healthcare professional who can monitor spend and provide guidance. However, as the person begins to take greater control of their healthcare outcomes, the evidence suggest they rely less on GPs and other health care professionals and need fewer appointments. This will mean a reduction in workload around these individuals, with fewer check-ups. This is a direct result of people becoming increasingly confident in managing their care.

Extending the right to have a personal health budget to people leaving the armed forces, who are eligible for ongoing NHS services

Rationale

Around 2500 people are medically discharged from the armed services each year (Ministry of Defence, Annual Medical Discharges in the UK Regular Armed Forces, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627223/20170713-MedicalDisBulletinFinal-O.pdf, (2017)), some of whom have ongoing NHS support needs. For these individuals, personal health budgets are one way of providing them with more choice and control over how their needs are met.

The amount and type of NHS care needed by people leaving the armed forces will vary considerably and there will be cases where personal health budgets may not be appropriate. If so, it would be the responsibility of the clinician to explain this to the individual, including the rationale as to why it is not appropriate.

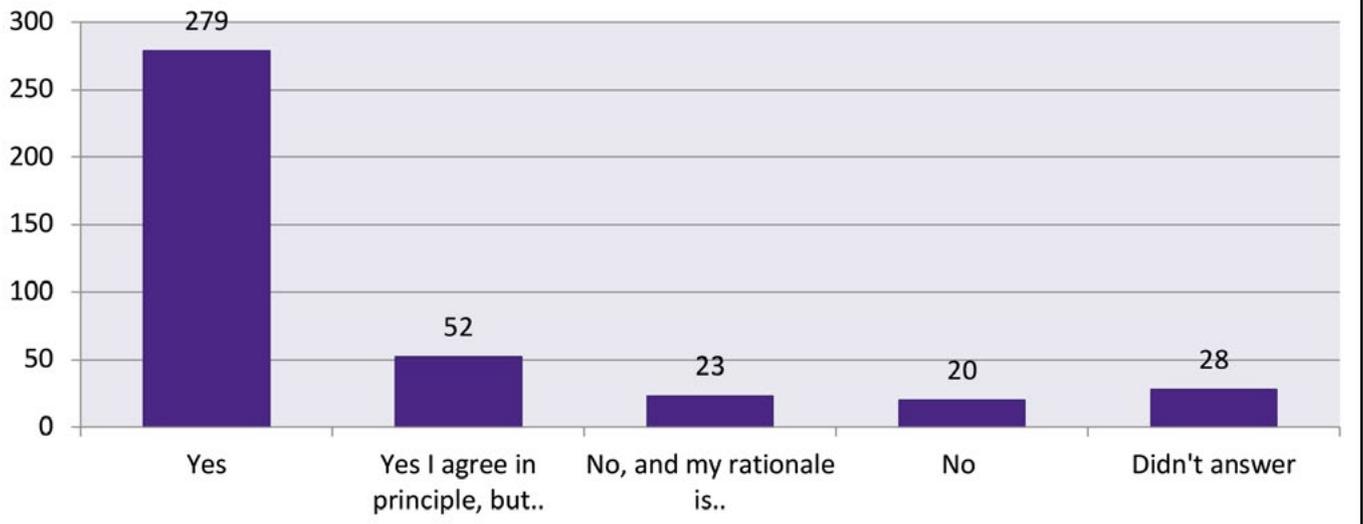
However, in some cases, we believe a personal health budget would be appropriate and would provide the individual with the opportunity to receive a more tailored, personalised package of care that meets their needs. In cases where the individual also has a social care need, an integrated personal budget could provide the individual with a more integrated, personalised package of care that meets their health and social care need.

Q4a. We are proposing that people leaving the armed forces who have a requirement for ongoing care through NHS services (with some exclusions including primary care and pharmaceuticals), should have the right to personal health budgets where appropriate. Do you agree?

Consultation outcome

A total of 374 people responded to this question with 331 of these people agreeing that this cohort should have the right to a personal health budget where appropriate. This amounts to 88.5% of respondents who agreed with 11.5% disagreeing.

Q4a. We are proposing that people leaving the armed forces who have a requirement for ongoing care through NHS services (with some exclusions including primary care and pharmaceuticals), should have the right to personal health budgets where appropriate.



For all questions relating to this group of people, there were few comments submitted. Those who did comment were largely supportive of this proposal. They suggested that the independence that personal health budgets and integrated personal budgets can provide have the potential to be extremely beneficial to those leaving the armed forces, particularly focusing on the sense of control that a personal health budget can provide.

Other respondents queried why people in the armed forces have been singled out specifically. This group faces a unique set of challenges. The amount and type of NHS care needed by people leaving the armed forces varies considerably: many of the conditions are long-term and can be relatively 'unique'. In this respect, a personalised approach can really help to support individuals in this group manage their condition in a way that works for them and enables them to maintain the level of control and independence that they want.

The ongoing work in NHS England's personalised care demonstrator programme and the support provided to CCGs by the personal health budgets delivery team will continue to collate evidence on different cohorts and the impact personal health budgets and person centred care more broadly can have on them. It is our expectation that for individuals in different cohorts who could benefit from a personalised approach, and if appropriate, personal health budgets they will remain an option open to them. It is encouraging that people want personal health budgets to be expanded to even more groups of people.

Of the 88.5% who agreed, the main reasons for supporting the proposal were that:

- Personal budgets would allow an individual to have a bespoke care package to meet their individual needs, which can be beneficial for people transitioning to civilian life, who may have alternative needs to the general public
- The ex-service community have a comparatively high proportion of people with long-time illness or disability, with multi-morbidity often being the case. Personal health budgets allow people to tailor treatment according to their multiple needs; and
- Will lead to greater inclusivity.

Of the 11.5% who did not agree with this proposal, the main reasons given were that:

- Access to personal health budgets should depend on need, rather than occupation; and
- People in this category already receive support from the armed forces.

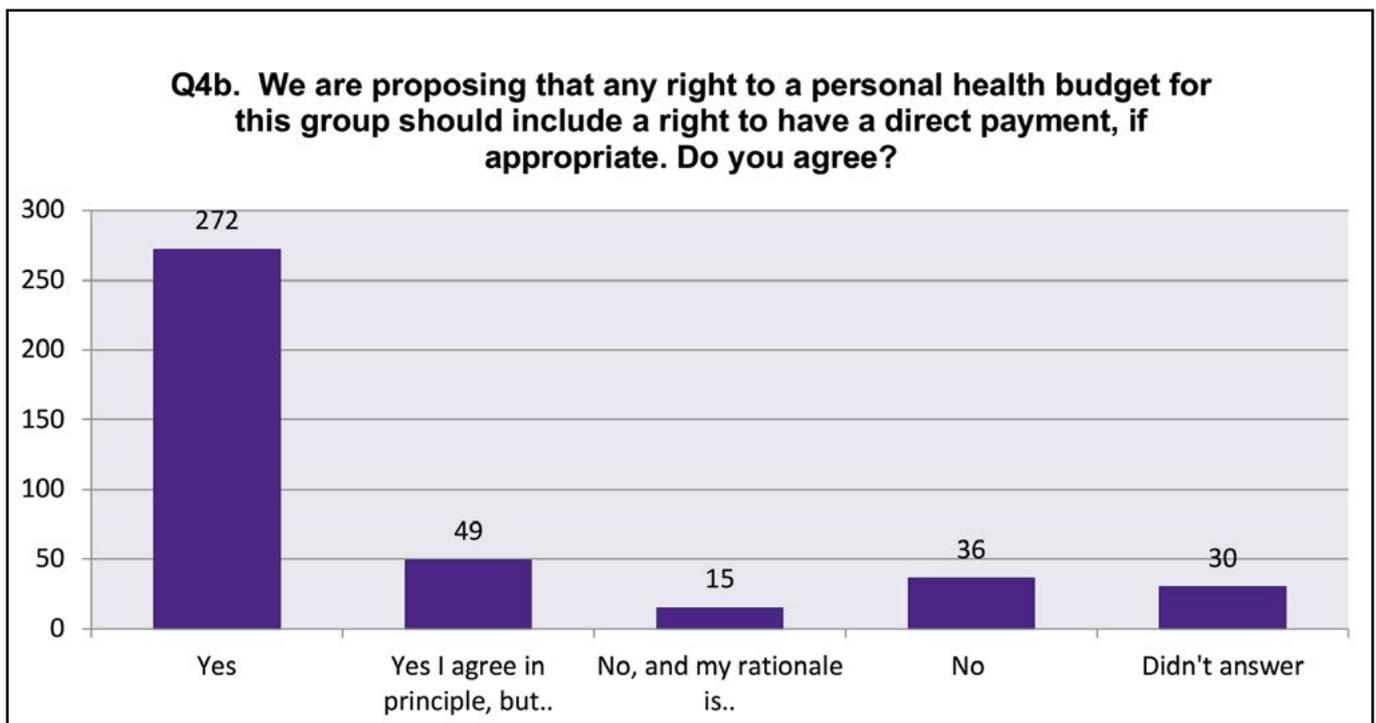
Where personal health budgets are being offered to people leaving the armed forces, who are eligible for ongoing NHS services this is not related to their profession, but takes into account that there are people who have additional needs as a result of being in the armed forces where they may have sustained physical injuries or now suffer from mental health issues related to their service. They will usually access NHS services as a result of this, but personal health budgets enable their care to be offered in a different, more person centred way. This right to have will enable all individuals to access care in this way, rather than this being at the discretion of the CCG (as is the case currently).

There will be further consideration about the point at which personal health budgets will be applied in the case of people leaving the armed forces. We are aware that people leaving the armed forces have different levels of support, including from representatives from the Defence Medical Services. We will provide guidance to such representatives on the management of personal health budgets, but they will primarily be offered to those accessing NHS services.

Q4b. We are proposing that any right to a personal health budget for this group should include a right to have a direct payment, if appropriate. Do you agree?

Consultation outcome

A total of 372 people responded to this question with 321 of these people agreeing that any right to a personal health budget for this cohort should also contain an explicit right to receive that budget as a direct payment, if appropriate. This amounts to 86.3% of respondents who agree with 13.7% disagreeing.



Similarly to responses to 4a, there were few comments made for 4b, and comments that were provided, largely mirrored those provided at 4a. Those who did comment reiterated the need to ensure that budgets are appropriate for individuals and that they remain optional.

Of the 86.3% who agreed, the main reasons for supporting the proposal were:

- Greater levels of control; and
- Flexibility of treatment/care options.

Of the 13.7% who did not agree with this proposal, the main reasons given were:

- Inadequate levels of support to manage a personal health budget, particularly that having a direct payment should be an informed decision and ensuring people are aware of the responsibilities that come from for example the implications of employing a personal assistant);
- Not offering people a choice in having a direct payment; and
- People not being able to end having a direct payment, when they want to switch to a more traditional form of support where the professional has control of commissioning

Support will be provided to all personal budget holders, including providing guidance on how to employ a personal assistant (if applicable). A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A more detailed response to this concern and information about the types of support offered is available in Chapter 2.

People will always be able to choose the level of control they have over the budget for their care, and the way this care is arranged should be reviewed regularly and amended if necessary, so that, for example, if a person no longer wishes to receive a direct payment, they do not have to do so. Appropriate support will always be provided to all individuals with a direct payment and they will always be able to revert to a notional or third party payment if they no longer want to have full control of the money. This is made clear in guidance provided to healthcare professionals. People will always have a choice, and if this means they choose not to have a direct payment, we fully support this decision, recognising that the level of control that a direct payment provides, is not for everyone.

Extending the right to have a personal health budget to people with a learning disability, autism or both, who are eligible for ongoing NHS care

Rationale

People with a learning disability, autism, or both, currently have legal rights to personal health budgets if they are eligible for NHS Continuing Healthcare, or continuing care in the case of children and young people. They also have rights to personal budgets through social care. In 2017/18 around 2700 people with a learning disability, autism, or both, had a personal health budget or integrated personal budget; a number NHS England anticipates will rise to around 10,000 people by March 2021. In addition to this, there are a further 400,000 people who receive social care via a personal budget.

Early learning from the personal health budget pilot sites and the implementation of personal budgets in social care showed that person centred care and support could lead to better outcomes for many marginalised groups and people with complex needs, including people with a learning disability, autism, or both.

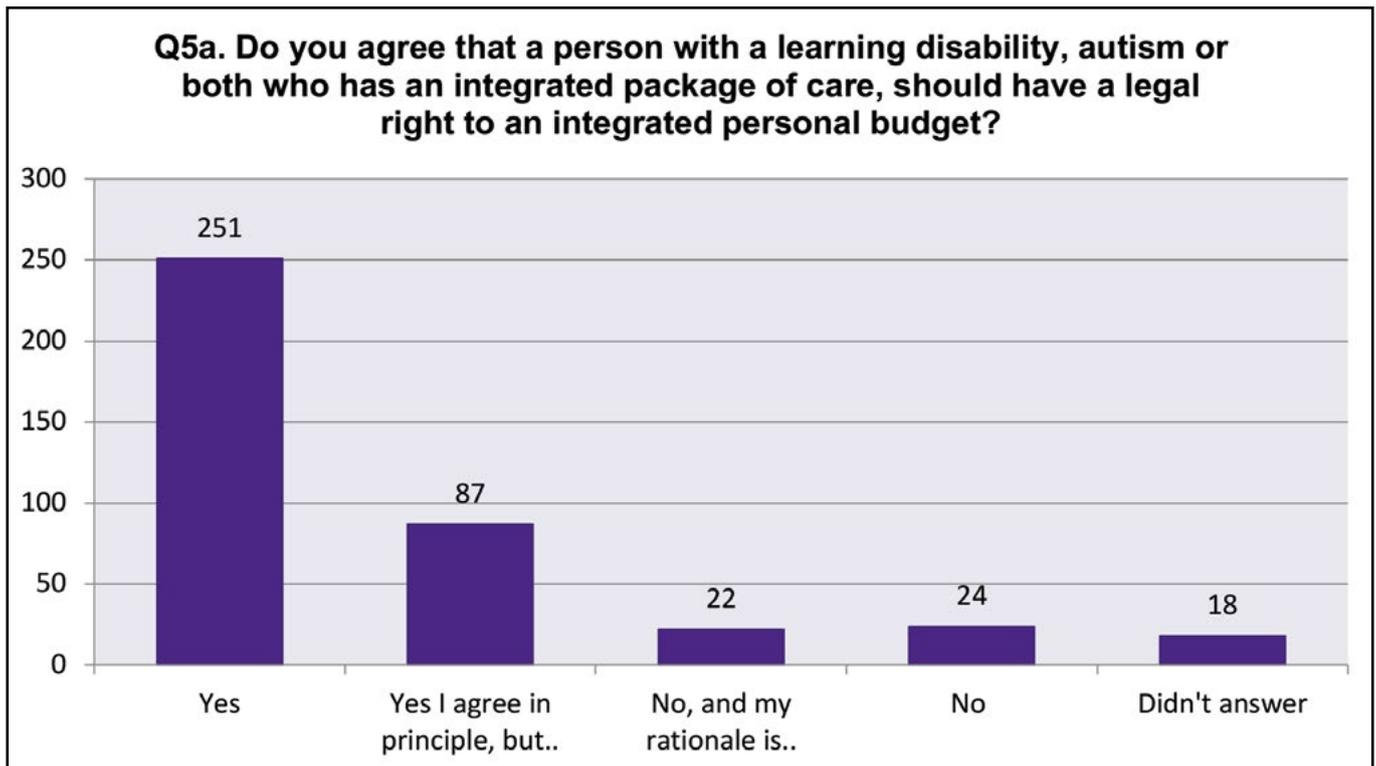
The Social Care Institute for Excellence also found that for people with a learning disability, autism or both, personal budgets and personalised care and support can make a significant difference. They found that families and carers can benefit when the individual has choice and control over their care and wellbeing, and that budgets can improve life for this group and can help prevent some individuals from going into residential care (Social Care Institute for Excellence, Personalisation, <https://www.scie.org.uk/personalisation/specific-groups/learning-disability>).

However, if an individual receives a jointly funded package, there is currently no right to have an integrated personal budget. Existing programmes, such as the Care Programme Approach are already used to support people with a learning disability, autism or both (and others such as people with complex mental health conditions). However the use of personal health budgets or integrated personal budgets alongside the Care Programme Approach will further increase the choice and control people have, enabling them to meet their needs in ways that work for them. It is thought there are around 20,000 people with a learning disability, autism or both, who are on the Care Programme Approach. It is our belief that these people could directly benefit from having access to a personal health budget or integrated personal budget.

Q5a. We are proposing that a person with a learning disability, autism, or both, with integrated packages of care should have a legal right to an integrated personal budget. Do you agree?

Consultation outcome

A total of 384 people responded to this question with 338 of these people agreeing that this cohort should have the right to an integrated personal budget where appropriate. This amounts to 88% of respondents who agree with 12% disagreeing.



Of the 88% who agreed, the main reasons for supporting the proposal were:

- clear, solid evidence base that personalisation can benefit this cohort;
- integration makes logical sense, as it works for the individual in a much more effective way

Of the 12% who did not agree with this proposal, the main reasons given were:

- unclear who is eligible for this and the guidelines that will be in place around this
- people may be unable to manage the burden of having a personal health budget – either themselves or their carers. This increased administrative workload for them could lead to more stress.

Guidelines around eligibility for personal health budgets will be provided locally by CCGs. We expect all CCGs to be developing plans to introduce personal health budgets to additional groups of people, based on local circumstance and national priorities. Every CCG should have information made publically available about who is able to access a personal health budget locally. This should be accessible via their website.

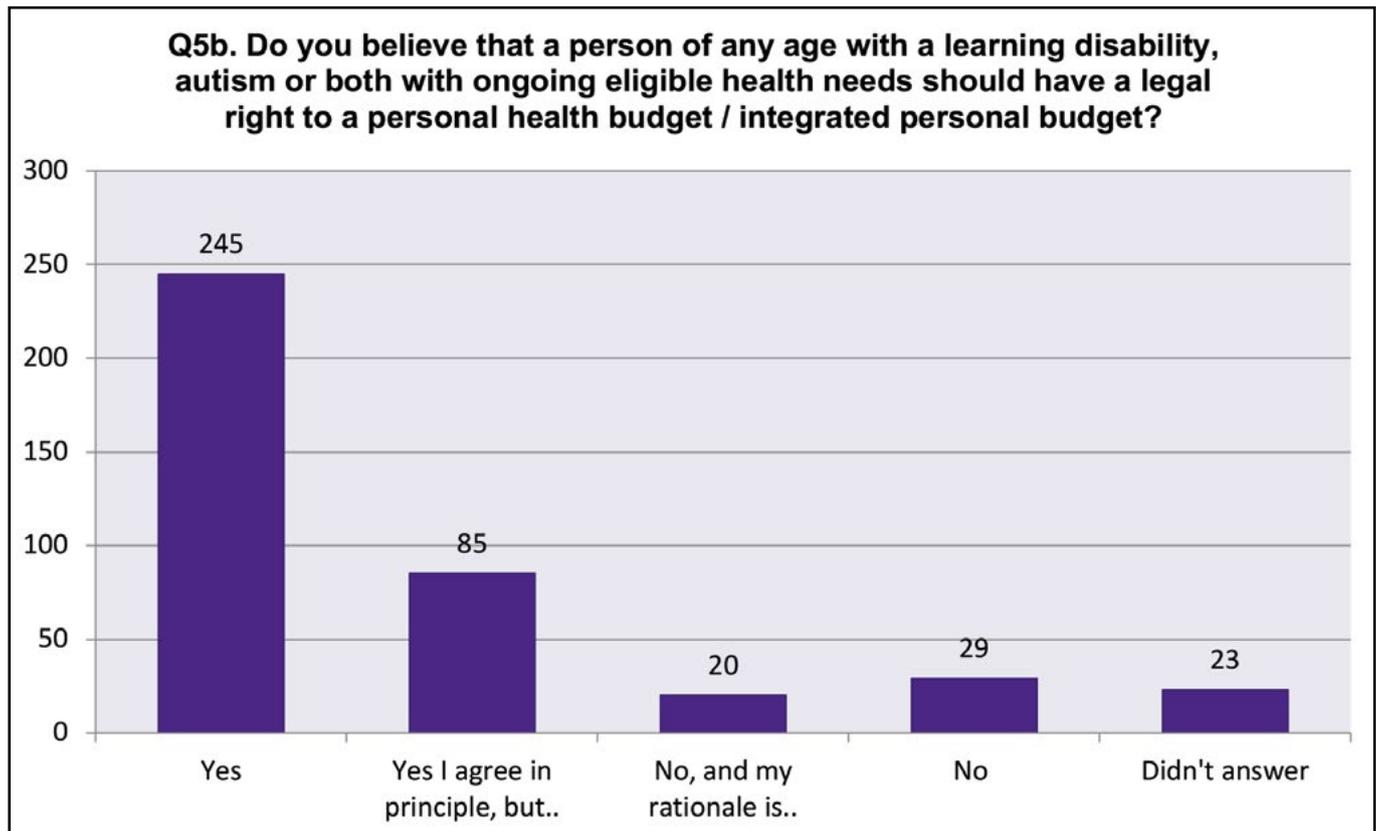
Before a person has access to a personal health budget, they will first have their health care needs assessed and where these are appropriate to be met by a personal health budget there will be a discussion between the individual and their health team on how best these needs could be met. . These discussions will facilitate an understanding of appropriateness. Personal health budgets will not be suitable for everyone, and they will not be appropriate for all aspects of NHS care, such as primary care services, unplanned care or operations.

We also recognise the concerns about a personal health budget being an extra burden. A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A more detailed response to this concern and information about the types of support offered is available in Chapter 2.

Q5b. We are proposing that a person of any age with a learning disability, autism, or both, with ongoing eligible health needs, should have a legal right to a personal health budget / integrated personal budget. Do you agree?

Consultation outcome

A total of 379 people responded to this question with 330 of these people agreeing that this group of people should have the right to a personal health budget or an integrated personal budget. This amounts to 87.1% of respondents who agree with 12.9% disagreeing.



Of the 87.1% who agreed, the main reasons for supporting the proposal were:

- clear, solid evidence base that personalisation can benefit this group of people;
- integration makes logical sense, as it works for the individual in a much more effective way

Of the 12.9% who did not agree with this proposal, the main reasons given were:

- appropriate support, and ability to manage. Vital that there are support structures in place to support this group of people; and
- the guideline process for eligibility – what does ‘if appropriate mean?’

Concerns about how people could manage a personal health budget were raised in the consultation. This mainly related to being able to manage the employment of personal assistants and the processes involved in this, as well as other administrative elements of budget management when having a direct payment. A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A more detailed response to this concern and information about the types of support offered is available in Chapter 2.

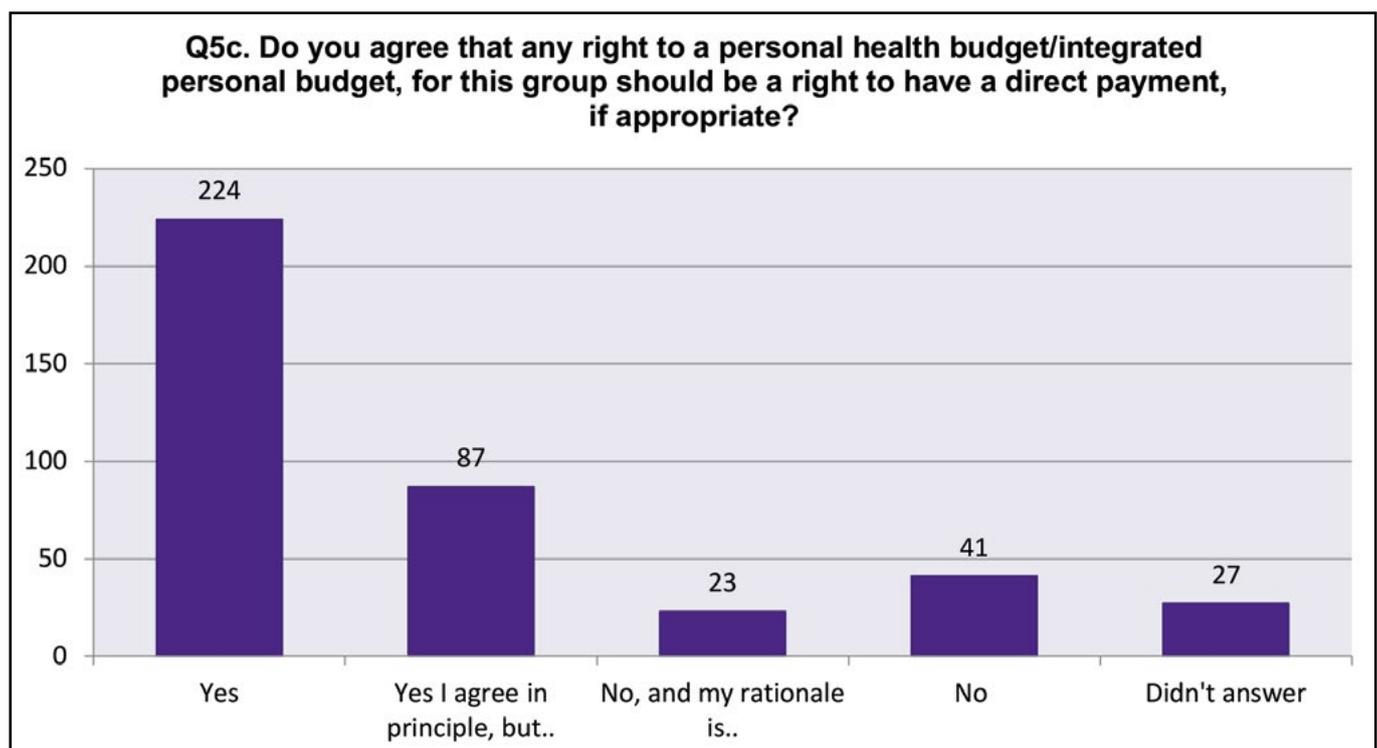
In terms of eligibility, CCGs will be responsible for deciding who is eligible in their area and ensuring this information is available. Before a person has access to a personal health budget, they will first have their health care needs assessed and where these are appropriate to be met by a personal health budget there will be a discussion between the individual and their health team on how best these needs could be met. These discussions will facilitate an understanding of appropriateness.

Guidelines around eligibility for personal health budgets will be provided locally by CCGs. We expect all CCGs to be developing plans to introduce personal health budgets to additional groups of people, based on local circumstance and national priorities. Every CCG should have information made publically available about who is able to access a personal health budget locally. This should be accessible via their website.

Q5c. We are proposing that any right to a personal health budget/integrated personal budget for this group should include a right to have a direct payment, if appropriate. Do you agree?

Consultation outcome

A total of 375 people responded to this question with 311 of these people agreeing that any right to a personal health budget or integrated personal budget for this cohort should also contain an explicit right to receive that budget as a direct payment, if appropriate. This amounts to 82.9% of respondents who agree with 17.1% disagreeing.



Of the 82.9% of people who agreed, the main reasons for supporting the proposal were:

- clear, solid evidence base that personalisation can benefit this cohort;
- integration makes logical sense, as it works for the individual in a much more effective way

Of the 17.1% who did not agree with this proposal, the main reasons given were:

- appropriateness and a lack of support in place to enable this; and

- ability to manage direct payments
- potential for fraud and abuse

In terms of appropriateness, people were concerned about how the eligibility of people receiving a personal health budget could be assessed. Guidelines around eligibility for personal health budgets will be provided locally by CCGs. We expect all CCGs to be developing plans to introduce personal health budgets to additional groups of people, based on local circumstance and national priorities. Every CCG should have information made publically available about who is able to access a personal health budget locally. This should be accessible via their website.

Before a person has access to a personal health budget, they will first have their health care needs assessed and where these are appropriate to be met by a personal health budget, there will be a discussion between the individual and their health team on how best these needs could be met. These discussions will facilitate an understanding of appropriateness.

Many people express a desire to have a personal health budget; indeed an often-repeated comment on the consultation was the need for more people to be able to access a personal health budget. However, this is not a 'one-size-fits-all approach' and any decision to organise care via a personal health budget will be discussed and agreed in partnership between the individual and health care professionals.

The potential for fraud and abuse of the budget was raised. Direct payments provide individuals with more choice and control over how their care and support is delivered, enabling the individual to commission their own care and support and tailor this to their needs. Once a direct payment has been provided, it is the CCGs responsibility to ensure appropriate systems and processes are in place to oversee the use of direct payment and ensure that the funds are being used in the manner agreed to within the plan. A more detailed response to this concern and information about the types of support offered is available in Chapter 2

Extending the right to have a personal health budget to people who access wheelchair services whose posture and mobility needs impact their wider health and social care needs

Rationale

NHS England, as part of their wheelchair improvement programme, has been introducing a range of measures to support CCGs improve how wheelchair services are delivered. In 2016, as part of this programme, NHS England's Chief Executive, Simon Stevens, announced that personal wheelchair budgets would replace the current voucher system (<https://www.england.nhs.uk/2016/05/nhs-to-offer-thousands-more-people-a-greater-choice-of-care-with-more-control-for-wheelchair-users-over-their-provision/>), (2016).

The existing voucher scheme for wheelchairs was introduced in 1996, with the aim of providing individuals with additional choice of wheelchairs they can access (<http://www.legislation.gov.uk/ukxi/1996/1503/made>). Personal wheelchair budgets build on this by introducing holistic, personalised assessments, taking into account both the individual's health and social care needs, whilst providing them with the opportunity to use integrated personal budgets to access their wheelchair.

Personal wheelchair budgets increase the choice and control people have in obtaining a wheelchair that meets their health, social care and educational needs as appropriate.

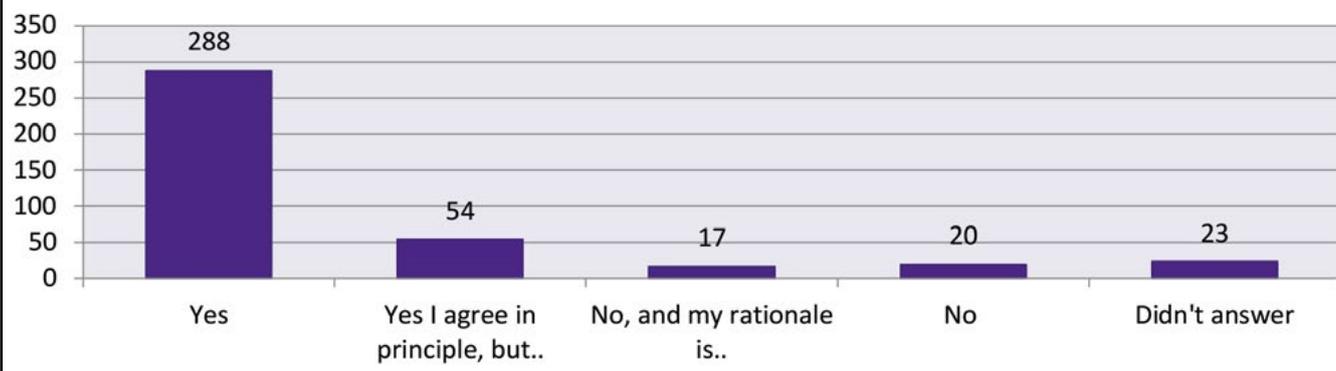
Given this, we now want to go further by exploring options to establish a legal right to a personal health budget or integrated personal budget for people who are eligible for wheelchair services to help support them to access the wheelchair that meets their holistic needs as appropriate, and help to improve their health and wellbeing outcomes.

Q6a. We are proposing that people who access wheelchair services, whose posture and mobility needs impact their wider health and social care needs, should have the right to a personal health budget or an integrated personal budget. Do you agree?

Consultation outcome

A total of 379 people responded to this question with 342 of these people agreeing that this group of people should have the right to a personal health budget or an integrated personal budget. In percentage terms, this amounts to 90.2% of respondents who agree, with 9.8% disagreeing.

Q6a. Do you agree that people who access wheelchair services whose posture and mobility needs impact their wider health and social care needs should have the right to a personal health budget or integrated personal budget?



Of the 90.2% who agreed, the main reasons for supporting the proposal were that:

- can result in the individual receiving equipment that meets their direct needs, not simply what is available to them from traditional services;
- strong evidence that enabling control and independence can really benefit this group of people (providing appropriate support is in place);
- can result in a more well-rounded package of care that meets the wider needs of the individual.

Of the 9.8% who did not agree with this proposal, the main reasons given were that:

- should not result in an overall lower quality of care
- complex issues around wheelchair ownership when purchased through a personal health budget or an integrated personal budget and will the privately purchased wheelchair meet the necessary standards;
- some respondents did not see a need to move away from the existing NHS Voucher Scheme

Personal health budgets or integrated personal budgets for wheelchairs are for the equipment only and still require an assessment of need from NHS commissioned services. Once a need has been identified a personalised care and support plans will be developed which then requires clinical 'sign-off' from the clinician involved in the persons care, meaning the introduction of personal wheelchair budgets should not result in lower quality care for the individual. Instead, it means greater flexibility of the use of the budget. NHS provision can still be accessed but with the potential of accessing additional accessories or higher specification equipment which were not previously available. As with the voucher system, people can also use their budget to access alternative options from independent retailers. This will result in more variety, flexibility and choice.

NHS England has been working with CCGs across the country to introduce personal wheelchair budgets. As part of this work, a series of frequently asked questions have been developed which help CCGs think through some of the issues raised above and address some of these concerns (<https://www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets/frequently-asked-questions>).

Issues around ownership and the type of chair to be purchased will need to be agreed as part of the personalised care and support planning process. This issue is addressed in the FAQs produced

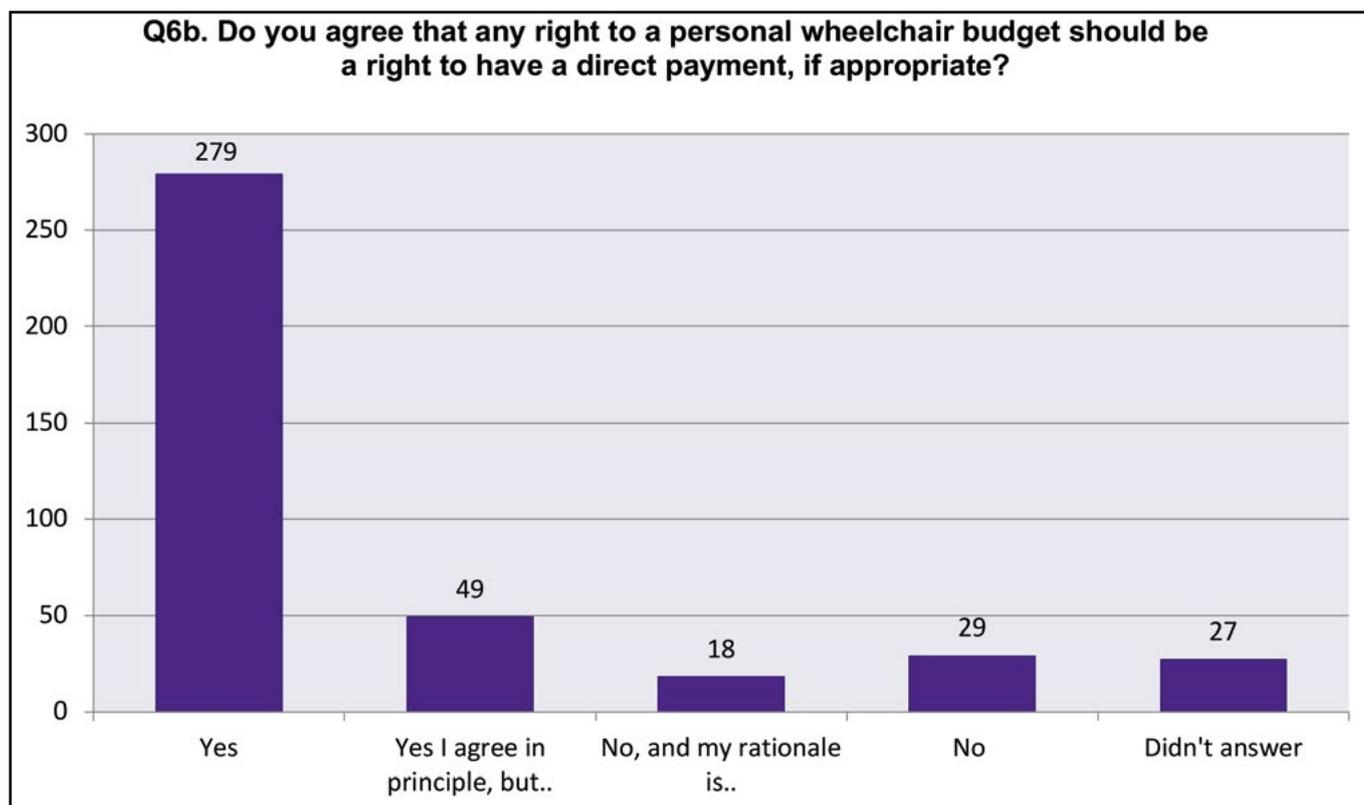
by NHS England. Everyone should have an assessment focussed on the health and wellbeing outcomes and goals they wish to achieve, and have the opportunity to have their wider needs considered. As part of the care and support planning process, the personal wheelchair budget will need to be agreed by the responsible clinician involved in that person’s care. They will need to agree the wheelchair chosen is the correct specification to meet someone’s assessed clinical needs.

Working with key stakeholders in wheelchair services, NHS England carried out a scoping exercise to assess the current voucher system. It was found to be inconsistently applied with some areas not offering this option at all. Personal wheelchair budgets build on the functionality of the voucher system and introduce opportunities for multi-funding streams to support integration around the person and governance structures to combat inconsistency. All CCGs must ensure vouchers remain available throughout the transition period.

Q6b. We are proposing that any right to a personal wheelchair budget should include a right to have a direct payment, if appropriate. Do you agree?

Consultation outcome

A total of 375 people responded to this question with 328 of these people agreeing that any right to a personal health budget or integrated personal budget for this cohort, should also contain an explicit right to receive that budget via a direct payment, if appropriate. This amounts to 87.5% of respondents who agree with 12.5% disagreeing.



Of the 87.5% who agreed, the key rationale for this was very similar to 6a, specifically that having a direct payment can result in the individual receiving equipment that meets all their needs and can help improve quality of life. Throughout, this was caveated that appropriate support, resources and guidance must be in place to help manage the direct payment and ensure the budget is being used appropriately to meet the needs of the person.

Of the 12.5% who did not agree with this proposal, the main reasons given are as follows:

- will require support to manage a personal health budget and ensure that this is spent appropriately in a way that benefits the individual ;
- concerns that the amount provided in a direct payment will be less than that provided through the existing wheelchair voucher scheme
- direct payments in this area could result in a reduced quality of care, given the lack of services.

NHS England has been working to address some of these concerns already, as discussed above in response to question 6a. In practice the operation of the voucher system was found to vary across the country with some CCGs not offering vouchers at all or restricting their use to only manual chairs. Some voucher schemes had no governance from CCGs, with no requirement for care and support plans. Established sites who are currently offering personal wheelchair budgets are reporting that the most effective outcomes are being achieved when other funding streams are also incorporated. The FAQs published by NHS England give more information on personal wheelchair budgets (NHS England, Frequently Asked Questions on personal wheelchair budgets: <https://www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets/frequently-asked-questions/#q13>).

The first concern relates to the support in place for those managing a personal health budget. A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A fuller response to this concern can be found in chapter 2.

The second concern related to the amount of a personal health budget and if this would be less than the current vouchers offered. The amount an individual receives will be based on the cost to the CCG to meet their assessed clinical needs. This will not result in less than the amount currently available through the voucher system. Indeed, in some areas there has been an increase in the amount available to people. This is due to the CCG being able to review the previous voucher amounts against the actual amount for the cost of a wheelchair in contracts with the commissioned service.

We are aware that wheelchair provision is a technical area with clinical guidance being required to support people. However, personal health budgets can allow wheelchair users to be more adaptive and does not involve the simple purchasing of a wheelchair. For example, one father used his personal health budget to help pay for an iPad bracket, meaning that his needs were much more flexibly met and he was less dependent on others. These small considerations which may be less obvious to a healthcare professional can be life-changing for an individual, who then has increased control in a way that best suits them.

Proposals for other groups

Q7. Are there any other groups that you believe would benefit from having a 'right to have' a personal health budget and/or integrated personal budget?

Consultation outcome

In total, 250 people responded to this questions with suggestions on which other groups may benefit from having a 'right to have' a personal health budget and/or an integrated personal budget.

Specifically, people experiencing end of life care and people with long-term health conditions were identified as groups who could benefit from having a right to have. Respondents felt that personal health budgets and/or integrated personal budgets could enable independence and control; both of which it was felt that the two groups outlined above, could benefit from. Additionally, respondents felt that provision of a more personalised experience of care would give people more of a say in the care they receive, whilst taking into account their preferences and other choices, such as where there care is received, and their preferred place of death. This could subsequently be brought together into a single, integrated package of care that takes all these choices into account.

Within the Personalised Care Demonstrator programme, end of life care is one of the areas that is being developed. Looking to the future and the ambitions for end of life care and palliative care NHS England has worked with five CCGs to prove that it is possible to deliver personal health budgets at end of life; with the initial project focusing on adult services (NHS England, PHBs in end of life care, <https://www.england.nhs.uk/personal-health-budgets/personal-health-budgets-in-end-of-life-care/>). The learning and resources from this project have been incorporated into the PHB delivery programme and CCGs can join masterclasses to learn more throughout 2018/19.

We agree that personalisation can really benefit individuals with long-term health conditions. The premise for personal health budgets is based on the principle that people who need long-term support should be seen as experts in their condition and partners in their care, rather than passive recipients of services. This is something we will continue to explore to ensure that, where appropriate, anybody with a long-term health condition, who could benefit from one, will have access a personal health budget or integrated personal budget to manage their care.

The groups that most people mentioned are as below:

- Children with additional needs;
- People experiencing end of life care;
- People with Alzheimer's or dementia;
- Carers;
- Individual in receipt of community equipment;
- Individuals with multi-systemic conditions;
- Individuals with multiple-sclerosis.

Some of these groups may be eligible for a personal health budget or integrated personal budget either because they are in receipt of NHS Continuing Healthcare or are included in other cohorts in this consultation. NHS England will continue to work with CCGs to design and test the use of personal health budgets for other groups of people and service areas. This continuous learning will inform future decisions around the roll out and extension of legal rights for personal health budgets.

Incorporating relevant other funding streams

Q8. Are there other funding streams that you believe would be beneficial to incorporate into integrated personal budgets?

Rationale

People with complex health conditions are often eligible for a range of other funding and support. This can mean that people receive money from a number of different places with often more than one funding stream coming from the same place. This can be confusing for people who have to deal with multiple agencies and professionals with differing processes and requirements. This process can make it difficult for people to plan their lives more holistically.

Responses from previous consultations have made clear that sharing information regarding work and health between interested parties could improve the care and support provided to someone at risk of falling out of work, or on sickness absence. More aligned, joined-up and person-centred care was seen as an effective way of addressing wider social needs that can affect individual's health and wellbeing. This consultation therefore sought to gauge public opinion on whether there are any other additional funding streams that could be incorporated into integrated personal budgets, to enable a more aligned and joined-up approach to health and care.

Consultation outcome

In total, 260 people responded to this question with suggestions on other funding streams that may be beneficial to incorporate into integrated personal budgets. Broadly, the response to this question was positive; respondents could see value in incorporating other funding streams, or the plans concerning that funding stream, into integrated personal budgets, that could enable a more streamlined approach that meets individual's wider need.

Specifically, it was felt that this could aid simplicity, through joining-up both streams and professionals across a range of areas linking to health and wellbeing, and mean that individuals will not have to tell their story to every individual. However, there was discussion around whether incorporating other funding streams would work best through keeping the budgets separate, but aligning within the planning phase, or whether incorporating all budgets into one single budget would work, and be practical, feasible and achievable.

One of the most commonly cited funding streams was the Disabled Facilities Grant, along with a range of other housing related grants. Grants relating to community equipment was also frequently cited as a possible funding stream that could be incorporated into the wider integrated personal budget process.

Throughout the duration of the consultation, we have been conducting work determining the feasibility of aligning or incorporating a range of different funding streams into the integrated personal budget process. Based on your response, work will continue into the areas outlined above; taking into account the wider ongoing reviews that are currently taking place, such as the review of the disabled facilities grant. We will provide an update on this work in due course.

Establishing a right to direct payment in NHS continuing healthcare funded home-care

Q9. We are proposing that people who are managing their NHS continuing healthcare funded home care as a personal health budget should have the right to a direct payment, if appropriate. Do you agree?

Rationale

NHS Continuing Healthcare is a package of ongoing care, arranged and funded by the NHS, to meet the needs of people aged 18 or over who have been assessed as having a primary health need. (Further information about NHS continuing healthcare is available on NHS Choices: <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx> and NHS England's NHS continuing healthcare website <https://www.england.nhs.uk/ourwork/pe/healthcare>).

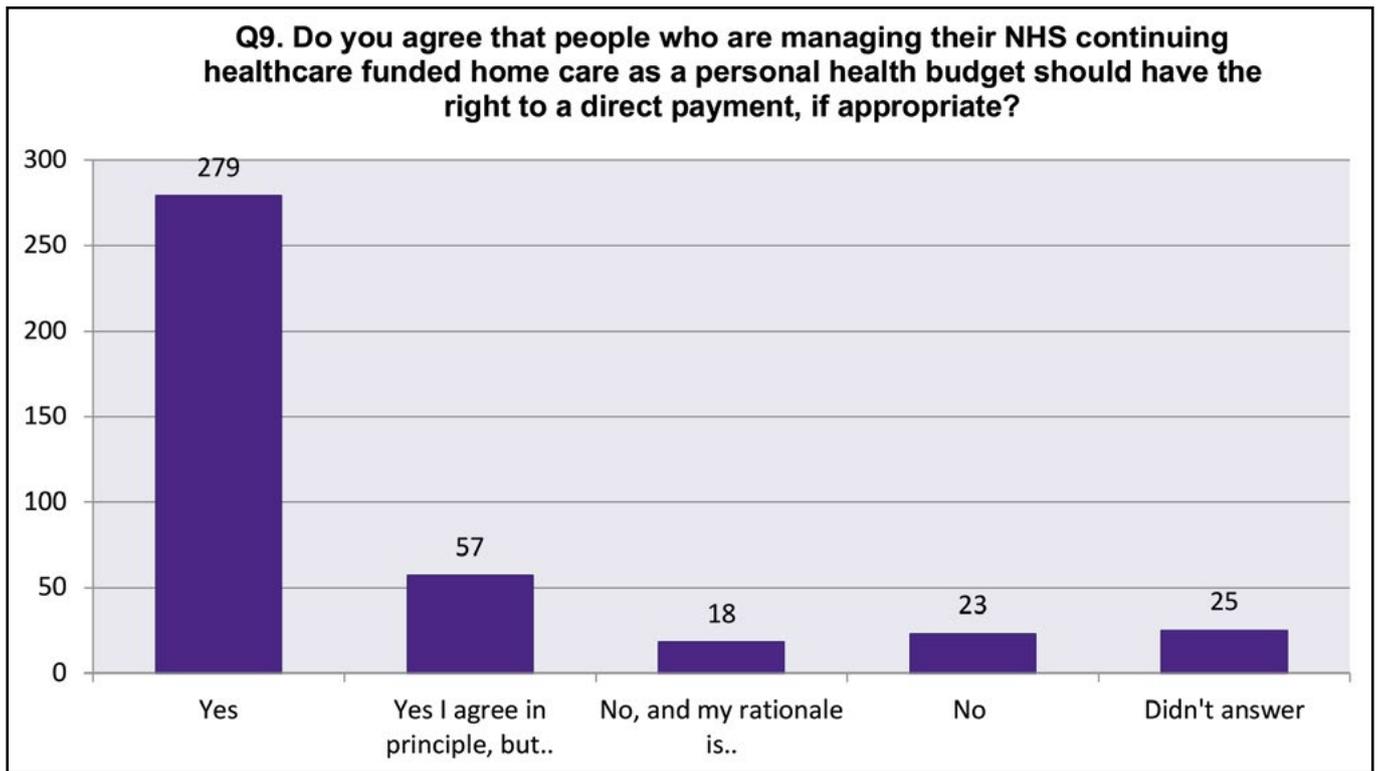
Adults in receipt of NHS Continuing Healthcare have had the right to a personal health budget, subject to exceptions, since October 2014 (<https://www.england.nhs.uk/publication/guidance-on-the-right-to-have-a-personal-health-budget-in-adult-nhs-continuing-healthcare-and-children-and-young-peoples-continuing-care/>). This right enables the budget to be managed in three different ways – notional or third party budget, or via a direct payment. Evidence suggests that the greatest benefit to this group comes when the personal health budget is managed via a direct payment (<https://www.phbe.org.uk/>, (2015)).

The majority of people in receipt of NHS Continuing Healthcare receive their care and support in care homes. However, a significant proportion (between 25-30% at any one time) receive care and support in their own home. Personal health budgets are already routinely offered by some clinical commissioning groups for this group as they provide people with more choice, flexibility and control over who comes into their home, the type of care and support they get, and when.

However, the current 'right to have' does not give individuals a right to a specific type of personal health budget. Given the evidence suggests that personal health budgets work best for this group when managed through a direct payment (<https://www.gov.uk/government/consultations/changes-to-direct-payments-for-healthcare>) we want to ensure that for anybody within this group who wants to manage their budget in this way (with some exceptions), they can do so.

Consultation outcome

A total of 377 people responded to this question, with 336 of these people agreeing that any right to a personal health budget or integrated personal budget for this cohort, should also contain an explicit right to receive that budget via a direct payment, if appropriate. This amounts to 89.1% of respondents who agree, with 10.9% disagreeing.



Of the 89.1% who agreed, the main reasons for supporting the proposal were that:

- direct payments can offer individuals additional control; positive impact on wellbeing for many;
- would act as a lever to ensure individuals receive the services they need, rather than the services they are offered; would enhance choice;
- direct payments will lead to greater competition, driving up quality and standards.

Of the 10.9% who did not agree with this proposal, the main reasons given were that:

- appropriateness, appropriate support, and ability to manage; and
- potential for abuse of funds, and fraud.

A person with a personal health budget should have access to information, advice and support in their area. CCGs are responsible for ensuring that individuals receive adequate information and support at every stage of the process. A fuller response to this concern can be found in chapter 2.

Concerns relating to fraud stated that it would be possible to misuse a direct payment, for something other than care needs. As a minimum, there will be a formal review within three months of the person first receiving a direct payment. This will focus on ensuring the agreed outcomes are being met and the direct payment is being spent in line with meeting these outcomes. There may be instances when genuine mistakes are made but if fraud is detected at these reviews, it will be possible to stop the direct payment immediately and the person will either revert to traditional services or a notional or third party personal health budget will be put in place. A fuller response to this concern can be found in chapter 2.

Annex B: Glossary

Children's Continuing Care – A package of continuing care needed over an extended period of time for children or young people with continuing care needs that arise because of disability, accident or illness, which cannot be met by universal or specialist services alone. Children and young people's continuing care is likely to require services from health and local authority children's and young people's services.

Continuing Healthcare – NHS continuing healthcare is the name given to a package of care that is arranged and funded solely by the NHS where the individual has a 'primary health need'.

Direct Payments – One way of managing a personal health budget is a direct payment where money is given directly to an individual or their representative for the management of their NHS care. This option became legal on 1 August 2013 and is in addition to the pre-existing legal options for managing a personal health budget – by the NHS, or through a third party. Direct Payments for social care needs via local authorities have been available since 1997.

Integrated Care – An organising principle for the care delivery with the aim of achieving improved patient care through better co-ordination of services.

Integrated Package of Care – A combination of resources, planning, co-ordination and support designed to meet an individual's combined health and social care needs.

Integrated Personal Budgets – where the budget includes funding from both the local authority and the NHS at a minimum, commonly with a single assessment, and single, integrated plan based on the individuals holistic needs.

Notional Budgets – The personal health budget holder knows how much money is available for their assessed needs and decides together with the NHS team how to spend that money. No money changes hands, but they are still able to participate in the decision-making process. The NHS is responsible for holding the money and arranging the agreed care and support.

Patient Experience – A term used for individual and collective feedback. (1) Individual patient's feedback about their experiences of care or a service e.g. whether they understood the information they were given, their views on the cleanliness of the hospital where they were treated. (2) A combination of all the intelligence held about what patients experience in services, drawing on a range of sources including complaints, compliments, and reporting of incidents and serious incidents.

Personal Budgets – Sums of money allocated by a local authority to service users to be spent on services to meet their care needs. They can be managed on behalf of users by the authority, or a third party, or given to users as direct payments: money to spend themselves. They enable users

to have more choice and control over the services they receive, tailoring their care to their personal circumstances and the outcomes they want to achieve.

Personalisation – Personalisation means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support. The traditional service-led approach has often meant that people have not been able to shape the kind of support they need, or receive the right kind of help. Personalised approaches involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives.

Person-Centred Care – Person-centred care takes patients and their families as the starting point of all decisions. Patients are equal partners with health professionals in planning, developing and assessing care to ensure it is most appropriate to their needs. It involves putting patients and their families at the heart of all decisions and requires a different kind of interaction between patients and healthcare professionals.

Personal Health Budgets – A personal health budget is an amount of money to support an individual's identified healthcare and wellbeing needs, planned and agreed between them, or their representative, and their local NHS team. At the centre of a personal health budget is a care plan. The plan sets out the individual's health and wellbeing needs, the health outcomes they want to achieve, the amount of money in the budget and how they are going to spend it. Personal health budgets can be used to pay for a wide range of items and services, including therapies, personal care and equipment. This allows individuals to have more choice and control over the health services and care they receive. For more information please visit the NHS England website.

Personalised Care Planning – A personalised care plan is an agreement between a patient and their health and care professional(s) which links support for self-management and clinical care to help the person manage their health day-to-day. The process of care planning is based on a collaborative discussion about the goals the patient wants to work towards; the support services the patient wants and needs; who is in charge of providing these services; what the support services have agreed to do and when they will do it. It may also include plans for medication, diet and exercise. These discussions are recorded in a written document and should be regularly reviewed.

Third party budget – An organisation independent of both the person and the NHS commissioner (for example an independent user trust or a voluntary organisation) is responsible for and holds the money on the person's behalf. They then work in partnership with the person and their family to ensure the care they arrange and pay for with the budget meets the agreed outcomes in the care plan.



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