

# Gathering the Evidence:

Making Personal  
Budgets Work for All

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# Foreword

Personalisation is based on the idea that people who need support want to have a good life not just a good service. The Care Act 2014 did not only enshrine a right to personal budgets in law, it set out a vision for a social care system which intervenes early and offers choice in the pursuit of wellbeing and a good life.

During implementation of the Care Act, however, local authorities have seen their budgets for social care reduce year on year, with much debate about social care focused entirely on its funding and its impact on hospital budgets. Personalisation could be part of the solution to resource pressures, through helping people to achieve as much independence as they are able and to stay well, but whilst the mechanisms of choice and control are now embedded in law, not every area has embraced the deeper changes embedded within the Care Act.

The National Audit Office report on *Personalised Commissioning in Adult Social Care* helpfully highlighted that where personal budgets are properly implemented, supported by well equipped practitioners and effective commissioning, evidence suggests that they are popular and effective. It was also correct to point out that the evidence base could and should be stronger. Whilst it is a challenge to understand the impact of big changes that have not been consistently implemented, not enough use is made of what we already know and there are significant gaps, for example how personal budgets can be made to work consistently well for older people.

This report sets out a response to the NAO study and charts a direction for how the evidence base for personal budgets can be improved. It is based on three principles. Firstly, what matters most to people who use services and carers should be the starting point for research, and identifying what matters most, can only be done through co-production with those people. Secondly, understanding impact upon services and their budgets is important, but research should always recognise people do not live their lives in separate compartments. Thirdly, that the evidence for personal budgets must be situated in the broader context of personalisation. The report and its recommendations are based on these principles.

Think Local Act Personal makes a number of recommendations to Government and system leaders in this report and will produce an action plan detailing the contribution we wish to make, in partnership with government, sector bodies and people themselves, to ensuring that personalisation can in future work for all.

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# Summary

The National Audit Office's (NAO) report on ***Personalised Commissioning in Adult Social Care***, published in March 2016, drew attention to the lack of a coherent evidence base for the impact of personal budgets.

The Think Local Act Personal partnership (TLAP) responded to the challenge by setting in motion the production of a sector response in order *“to consider the existing evidence base for personalisation to identify gaps and to inform the commissioning of new research and data collection initiatives.”* In undertaking this work, TLAP has convened three round table meetings with representatives from across the care and support sector and others with knowledge and involvement of data collection and evaluation, in the field of adult social care.

Our key conclusions are that the impact of personal budgets must be viewed within the broad context of personalisation and wider system transformation. This requires a plurality of approaches to gathering evidence, whilst preserving a focus on the experience and insights of people receiving care and support and carers as central to evaluation. The overarching purpose of gathering and using evidence is to make sure that personal budgets work for all. With that purpose at the forefront the main themes arising from our work are that:

- More use could and should be made of the existing comparative data and evidence in order to shed light on the reasons for variation in outcomes and experience.
- As much as possible, evidence should be generated from mainstream systems, using routine and commonly collected data.
- The development of any new measures and approaches to research and evaluation should be informed by people with lived experience and carers.
- There is considerable scope for improving sharing of evidence of what works best and applying this in practice more consistently.
- The development of evidence should embrace the ambition to achieve integrated care and support for people reflecting the reality of people's lives rather than service boundaries.

- There is a need to develop a coherent, proportionate and sustainable longer term strategy for gauging the impact of personal budgets (including well conducted evaluations in areas of concern), which will require leadership from the Department of Health, in partnership with the care and support sector.

Based on this analysis we make a number of recommendations for improving the gathering and use of evidence and how learning can be shared and acted upon more widely. They are organised around the themes of:

- Increasing the use made of the existing evidence base
- Taking forward development through co-production
- Improving the sharing of what works best
- Developing a long-term strategy for building the evidence base.

# Introduction

This report is a sector response to the National Audit Office (NAO) report into ***Personalised Commissioning in Adult Social Care***<sup>1</sup> and the recommendations that the Department of Health (DH), with its partners, should take action to:

- Improve the evidence on, and understanding of, the relationship between the different ways to commission personalised services and improvements in outcomes (20a).
- Use this improved understanding, supplemented by shared intelligence from established networks, to identify successful local approaches to personalised commissioning and share this learning across all local authorities (20b).
- Apply learning on successful approaches to personalised commissioning in social care to the roll-out of personal budgets in the health sector (20c).

## Background and purpose

In March 2016 the NAO published its report on ***Personalised Commissioning in Adult Social Care***. The NAO scrutinises public spending for Parliament and its studies evaluate the value for money of public spending, nationally and locally.

The findings of the study were based on field work with nine local authorities, together with analysis of existing national data and a literature review. The focus was on social care that is fully (or partly) paid for by councils and excluded carers who receive personal budgets in their own right. The study took place prior to the introduction of the Care Act in April 2014 which made personal budgets a legal requirement for the first time (see Appendix 2 for Department of Health Guidance on personal budgets).

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<sup>1</sup> *Personalised Commissioning in Adult Social Care, National Audit Office, March 2016*

The NAO study aimed to answer these four main questions:

- 1) Is personalised commissioning resulting in better outcomes for people?<sup>2</sup>
- 2) How and why does the use of personalised commissioning vary between councils?
- 3) What are the financial implications of personalising commissioning?
- 4) Is there capacity in the care market for local authorities to develop personalised commissioning?

The NAO found widespread support for personalisation, but also found that councils were taking different approaches to implementation and some were struggling to make it work. The latter chiefly a consequence of councils limiting personalisation in order to save money, for example, by introducing block contracts which afford economies of scale but can limit choice. Some were found to have established a good process for delivering personal budgets and for allocating resources to this.

The study found significant variation between local authorities in the proportion of people receiving personal budgets and the type of personal budget taken (i.e. direct payment, managed by the local authority, managed by a third party/individual service fund). This was related to their finding that front line practitioners in some places were adopting differing and limited definitions of personalisation, for example regarding a personal budget as only being a direct payment.

In answering the question 'does personalised commissioning result in better outcomes for people?', they concluded that whilst the existing evidence does suggest that personal budgets benefit most people, they could not find any link between the proportion of people with personal budgets and overall levels of satisfaction at a local authority level. They also concluded that the available data does not make it possible to analyse the best way to implement personal budgets to maximise improvements in individual outcomes so that *"there is a strong case for [making] better use of existing surveys and evidence gathering, so the Department and its national partners understand the relationship between the different ways to commission personalised services for people and improvements in outcomes."*

(NAO report p.11)

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2 The term 'user' originally referred to in the NAO report has been substituted to reflect that this is no longer the preferred term for describing people who receive care and support.



The House of Commons Committee of Public Accounts (PAC) subsequently endorsed the findings and recommendations of the NAO in its own report ***Personal Budgets in Social Care*** published in June 2016.<sup>3</sup> In November 2016, the DH published its response to the PAC report.<sup>4</sup>

Think Local Act Personal partnership (TLAP) responded to the challenge by setting in motion the production of a sector response in order “to consider the existing evidence base for personalisation, to identify gaps and to inform the commissioning of new research and data collection initiatives.” To this end, TLAP convened three round table discussions of representatives from across the care and support sector and others with knowledge and involvement of data collection and evaluation and in the field of adult social care. A list of contributors can be found at Appendix 5. This report is based on the outcome of these discussions and covers:

- The big picture: understanding the complexity of personalisation.
- The need for, and availability of, evidence using a framework for analysis.
- Our key conclusions and recommendations.

## The big picture: understanding the complexity of personalisation

### Context for evidence

The NAO report is viewed by the sector to be useful since it highlights some of the gaps in evidence for personal budgets and personalisation. In responding to the issues raised by the report it is necessary to draw distinctions between mechanisms (personal budgets), specific system changes (the commissioning of personalised care and support services) and broader whole system transformation.

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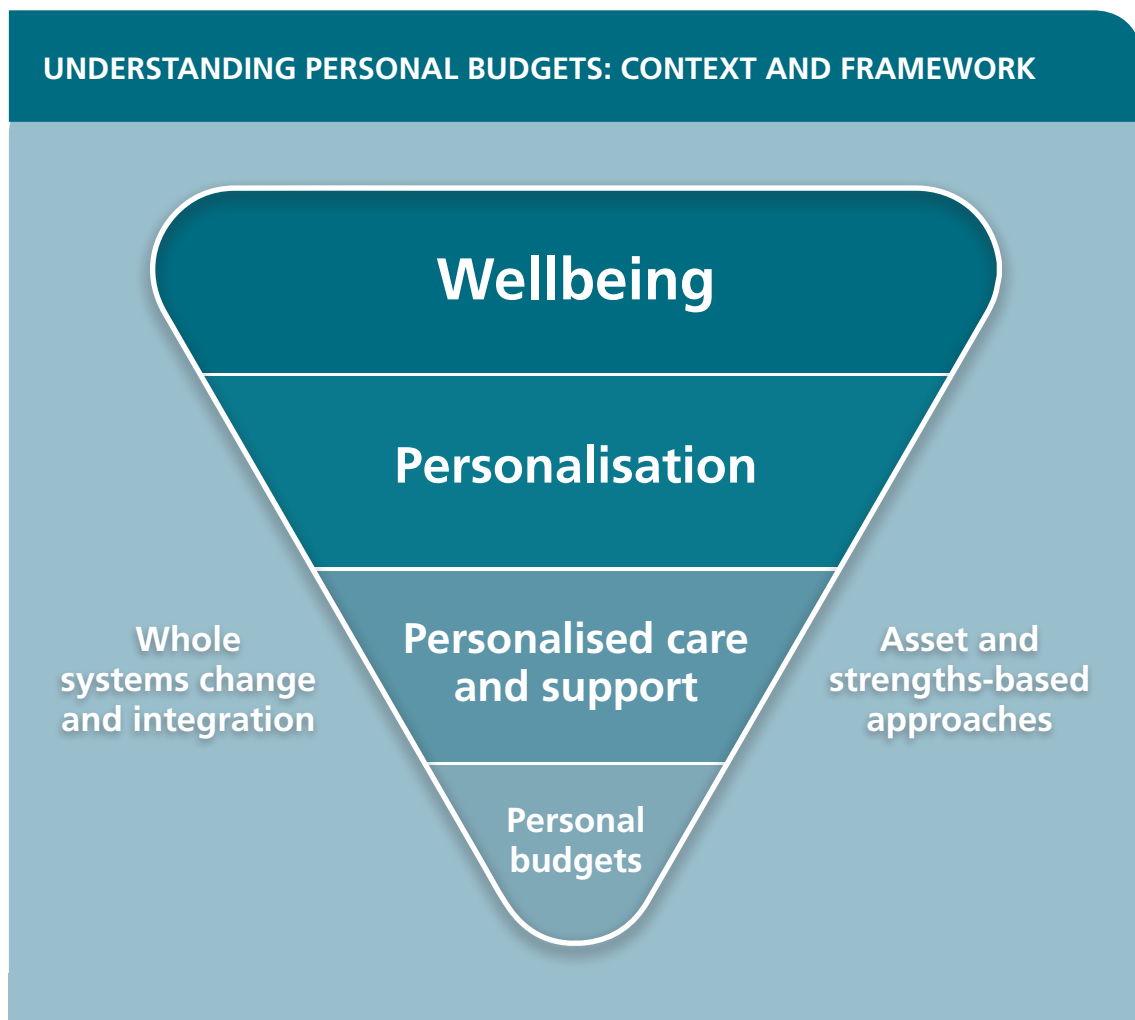
<sup>3</sup> *Personal Budgets in Social Care*, House of Commons Committee of Public Accounts, June 2016

<sup>4</sup> *Department of Health response to House of Commons Committee of Public Accounts report on Personal Budgets in Social Care*, November 2016

The purpose of personal budgets is to help people choose and shape their own care and support as one part of the personalisation movement which aims to **enable people to lead better lives in more inclusive communities**. Improving the evidence base on the impact of personal budgets therefore needs to be situated within the wider ambition of transforming:

- The care and support system;
- Other linked sectors such as health, housing, the voluntary, community and social enterprise sector (VSCE).
- And ultimately transforming communities themselves.

This is to be achieved through a wide range of public service interventions becoming more asset-based, preventative, joined up and personalised – all geared to improving health and wellbeing. Personal budgets cannot therefore be viewed in isolation as the diagram below demonstrates.



## Existing evidence

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Between 2005 and 2007, 13 council areas piloted personal budgets (then known as individual budgets). The pilots were subject to a detailed academic evaluation<sup>5</sup> and the largely positive findings were influential in the government's decision to roll out personal budgets. There has been no comparable systematic evaluation since then.

Much of today's evidence comes from the national Adult Social Care Outcomes Framework (ASCOF) set by the Department of Health with data collected from all councils by NHS Digital. Recent work has been undertaken by NHS Digital to make the data collected more accessible and useable. A high-level overview of the data collected on adult social care has been made available in the form of a **Social Care Dashboard**.<sup>6</sup> Further developments include a suite of online summary reports aimed at helping councils compare and benchmark their performance. In addition, two different tools have been developed that local authorities can choose to use:

- The Personal Outcomes Evaluation Tool (POET)<sup>7</sup> and,
- The Adult Social Care Outcomes Toolkit (ASCOT).<sup>8</sup>

The former, developed by In Control and Lancaster University with national reports published; bring together results of surveys undertaken by participating councils.<sup>9</sup> The latter developed by the Personal Social Services Research Unit (PSSRU) at the University of Kent. Additionally, TLAP's **Making it Real framework**<sup>10</sup> describes what good personalisation looks like from the perspective of people receiving care and support and carers, and provides a framework which can help councils and organisations check how well they measure up in achieving personalisation, including personal budgets. Making it Real is being updated to reflect the introduction of the Care Act and other changes since it was first produced. Councils may also adopt local methods for obtaining feedback. Further detail on sources of existing evidence can be found in [Appendix 3](#).

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5 Glendenning, C., Moran, N., Knapp, M., Fernandez, J.-L., Netten, A., Jones, K., Challis, D., Wilberforce, M., Jacobs, S., Manthorpe, J. and Stevens, M., (2008), *'The Evaluation of the Individual Budgets Programme: Final Report'*, London: Department of Health.

6 NHS Digital Social Care Dashboard <http://bit.ly/SocialCareDashboard>

7 [www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx](http://www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx)

8 [www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot)

9 [www.thinklocalactpersonal.org.uk/Latest/Personal-Outcomes-Evaluation-Tool-POET-for-adults-in-receipt-of-social-care-support-2017/](http://www.thinklocalactpersonal.org.uk/Latest/Personal-Outcomes-Evaluation-Tool-POET-for-adults-in-receipt-of-social-care-support-2017/)

10 *Making it Real: Marking progress towards personalised, community based support*, TLAP, 2012

## A framework for analysis

Our analysis suggests that a proper understanding of the impact of personal budgets can only come from seeing them in a wider context that encompasses the different elements of change demanded by personalisation, considers the different perspectives of those involved, and which seeks to understand variation in provision, experience and outcomes. This framework for analysis is described below. The tables start to map out the evidence sources that exist and the gaps where little or no evidence exists for this framework.

### Elements of change

Table one sets out a hierarchy of the elements of change that need to be considered with the main existing evidence sources mapped against them.\* The diagram below further illustrates the nature of the hierarchy. Terms and abbreviations, together with links to the sources cited, can be found at [Appendix 1](#).

**TABLE 1: ELEMENTS OF CHANGE**

ELEMENT OF CHANGE	EXISTING EVIDENCE SOURCE
<b>1 Wellbeing:</b> to what extent are the overarching wellbeing goals of the Care Act being achieved for people with care and support needs and their carers? Wellbeing is defined holistically in the Care Act so progress cannot be measured by looking at the impact of services alone.	<ul style="list-style-type: none"><li>• Emerging evidence from the Wellbeing Centre and What Works Wellbeing network, although no specific work on personalisation.</li></ul>
<b>2 Personalised services:</b> to what extent is care and support being personalised? What impact is that personalisation having on achieving wellbeing?	<ul style="list-style-type: none"><li>• ASCOF in part, although NHS Digital surveys of people receiving care and support and carers may not be fully representative.</li><li>• POET in part.</li><li>• ASCOT in part.</li></ul>

*\*The list of evidence sources is based on our preliminary analysis and may not be fully comprehensive.*

ELEMENT OF CHANGE	EXISTING EVIDENCE SOURCE
<b>2.1</b> Choice, control and personal budgets are part of personalising services.	<ul style="list-style-type: none"> <li>• Original personal budget evaluation (IBSEN) published in 2008, with subsequent one for carers. Subsequent evaluation of personal health budgets pilot.</li> <li>• ASCOF in part.</li> <li>• POET.</li> <li>• ASCOT.</li> </ul>
<b>2.2</b> Market development and innovation is also crucial to services being personalised.	<ul style="list-style-type: none"> <li>• Market Position Statements.</li> <li>• Health and Wellbeing Board Strategies.</li> <li>• Local Accounts.</li> <li>• Sustainability and Transformation Plans.</li> </ul> <p>All available at local level, but lack of systematic review.</p>
<b>3</b> Personal budgets: the implementation of personal budgets as a specific mechanism. What is the contribution to personalisation and the achievement of wellbeing of?	
<b>3.1</b> Direct Payments?	POET
<b>3.2</b> Managed budgets?	POET
<b>3.3</b> Individual Service Funds?	<ul style="list-style-type: none"> <li>• POET.</li> <li>• Some evaluations of Individual Service Funds (ISFs) and learning from TLAP action learning sites on ISFs (forthcoming).</li> </ul>
<i>The implementation of personal budgets includes consideration of the implementation of a number of defined systems and processes including information and advice, assessment, planning, review, advocacy and support to make choices, resource allocation.</i>	<ul style="list-style-type: none"> <li>• POET.</li> <li>• TLAP Care Act Survey.</li> <li>• Alzheimer's Society research for Making Personal Budgets Dementia Friendly Charter.</li> </ul>

ELEMENT OF CHANGE	EXISTING EVIDENCE SOURCE
<b>4</b> The contribution of other parts of council, NHS and system activity to achieving wellbeing?	Limited.
<b>4.1</b> Building community capacity.	TLAP Building Community Capacity: Evidence, efficiency, and cost-effectiveness. Some evidence from the NESTA Realising the Value programme. Public Health England: A guide to Community-Centred Approaches to Wellbeing.
<b>4.2</b> Interaction with the NHS and NHS personalisation programmes such as personal health budgets, Integrated Personalised Commissioning (IPC), self care, peer support.	NHS England data collection on personal health budgets and joint personal budgets and programme of evaluation for IPC. PSSRU ongoing research into Personal Health Budgets Sustainability and Transformation Plans. NESTA for peer support.
<b>4.3</b> The relationship with and investment in the VCSE sector.	The Joint Voluntary and Community, Social Enterprise Review.
<b>4.4</b> The relationship to public health.	Local Joint Strategic Needs Assessments contributing to Health and Wellbeing Strategies. Limited connection to the Public Health Outcomes Framework with two indicators on self-reported wellbeing 2.23iii & 2.23iv.
<b>4.5</b> Housing policy.	Quality Assessment Framework for Supported Housing. No longer mandatory, but some councils adapting for use in social care.

## ELEMENTS OF CHANGE

### WIDER SYSTEM INFLUENCES

#### Building Community Capacity

Building Community Capacity (BCC) including contribution of Voluntary Community Social Enterprises (VCSE)

Universal services and prevention e.g. public health, housing, information and advice.

#### NHS

Personal Health Budgets

Integrated Personalised Commissioning (IPC)

Self Care

Peer Support

**Wellbeing in The Care Act**

**Personalised Services, which contribute to wellbeing**

**Personal Budgets for Choice and Control**

#### Personal Budgets

Direct Payments  
LA Managed  
Individual Service Funds

#### Market Development

Diverse  
High quality  
Sustainable

### Frames of reference

For each of these elements of change shown in the table above, there are some different frames of reference to consider, which are set out in the following table.

**TABLE 2: FRAMES OF REFERENCE**

FRAMES OF REFERENCE	EXISTING EVIDENCE SOURCE
The experience of people and families.	<ul style="list-style-type: none"> <li>• POET.</li> <li>• ASCOF (in part).</li> <li>• Individual statutory reviews.</li> </ul>
The rights of people and families e.g. the right to private and family life, the right to independent living, the rights set out in the Care Act, and the role personalisation and personal budgets specifically play in achieving those rights.	<ul style="list-style-type: none"> <li>• In Control research for the Independent Living Strategy Group.<sup>11</sup></li> <li>• TLAP Care Act Survey.</li> <li>• Individual statutory reviews.</li> </ul>
The outcomes achieved including care and independent living and health outcomes.	<ul style="list-style-type: none"> <li>• ASCOF in part, although current collections do not track individual experience and outcomes over time (longitudinal).</li> <li>• Individual statutory reviews.</li> </ul>
The cost-effectiveness and efficiency of services and systems such as assessment, planning, review and resource allocation.	NHS Digital social care returns on activity and expenditure in part.
The safety and quality of services including support purchased through personal budgets and variation.	<ul style="list-style-type: none"> <li>• Care Quality Commission for regulated services.</li> <li>• Local Government Ombudsman reports.</li> </ul>
The economics of social care and of local areas.	<ul style="list-style-type: none"> <li>• NHS Digital returns on activity and expenditure in part.</li> <li>• Association of Directors of Adult Social Services budget survey work.<sup>12</sup></li> </ul>

<sup>11</sup> [www.in-control.org.uk/media/243039/independent%20living%20survey%202016%20v2.pdf](http://www.in-control.org.uk/media/243039/independent%20living%20survey%202016%20v2.pdf)

<sup>12</sup> [www.adass.org.uk/media/5994/adass-budget-survey-report-2017.pdf](http://www.adass.org.uk/media/5994/adass-budget-survey-report-2017.pdf)



**The different frames of reference are likely to be more or less important to different groups of stakeholders:**

- 1)** People with care and support needs are likely to regard their rights, experience and outcomes as the most important.
- 2)** Families and carers will share a similar focus on rights, experience and outcomes for the individuals they care for, as well as for themselves.
- 3)** Front line practitioners and managers are likely to regard outcomes, and safety/quality as important, although in the current climate they are also very likely to be concerned with costs.
- 4)** Provider organisations may see outcomes, safety/quality and cost-effectiveness as most important.
- 5)** Commissioners may have a similar focus to providers.
- 6)** Strategic leaders who aim to take a rounded view whilst meeting significant and continuing financial challenges.

An expanded set of key questions for these groups are explored in more depth in [Appendix 3](#).

There is also apparent variation for different groups and different areas. So, to consider the frame of reference of the experience of people and families, we need to consider:

- The overall trends for the population as a whole.
- Local and regional variation and its causes and the underlying conditions.
- The particular experience of different age groups, and in particular the challenges facing personalisation for older people and their families.
- The experiences of different groups such as people with learning disabilities, people with mental health problems, people with dementia, people with physical and sensory impairments, people who misuse substances, people who lack capacity to directly manage a personal budget themselves.
- The experiences of people across the full spectrum of equalities e.g. people from black and minority ethnic groups.

**A number of conclusions can be drawn from this analysis:**

- Much of the existing evidence is concentrated in and around personal budget delivery, with relatively little systematic gathering of evidence taking place within the broader context of personalisation.
- It is not possible to understand the impact upon people's wellbeing or the cost effectiveness of services by considering the implementation of personal budgets alone.
- Gathering and using evidence is likely to need segmenting by group, area, and community to capture what are believed to be significant variations.

# Our conclusions

The conclusions of discussions to date, and desk research, are set out below and form the basis for the recommendations that follow in the next section.

- 1 There already exists a good deal of evidence of personal budget delivery, although as the NAO found, it is rather disparate. Across the sector more use could be made of this evidence base (covering experience, outcomes, process, efficiency and cost effectiveness) and all councils should be making sure that they regularly capture and make use of feedback from people receiving personal budgets and carers. There is a need to consider this evidence and carry out any further evidence gathering within the bigger picture of personalisation through the prism of wellbeing, as defined by the Care Act.
- 2 Evidence should also be 'case sensitive' i.e. broken down by group, area and community to capture and shed light on what are believed to be significant variations. Context is important. The fundamental objective is to seek and use evidence which identifies the conditions needed for personal budgets: what works for whom, in what circumstances and why.
- 3 When seeking to improve the evidence base, it is important to evaluate what matters most to people receiving personal budgets and carers – and not just to consider the system perspective or a narrow range of outcomes. As the health and care system is subject to continuous change, this makes it all the more important to preserve a focus on the person receiving care and support and their supporters.
- 4 Co-production with people using services and carers is central to personalisation. The ***Making it Real framework*** is already a good example of how people using services and carers have defined what they think good personalisation looks like, including personal budgets. We should look at ways of extending co-production into the design of how we measure the implementation and effect of personal budgets and personalisation more generally.

5 More effort should be directed to embedding 'data capture' in mainstream systems and processes such as assessment, support planning and review. This may require both system and cultural change. Progress could be made if agreement was reached on a handful of 'universal' core questions that could be asked by councils, providers and others, to help build comprehensive and comparable evidence over time.

6 The main gaps in the evidence base have been identified in the following areas.

- Current statutory collections still tend to focus on activity, rather than the outcomes and experience of people in receipt of personal budgets. This is not to say that outputs and process are not important. For example, as we know from POET and other sources, the process for getting a personal budget can affect individual outcomes.
- There is relatively little evidence on the effect of personal budgets on wellbeing.
- Understanding how personal budgets (and the mechanisms around them) can be made to work better for all, particularly older people where the evidence is less strong at present. This should include appreciating the vital part played by well delivered (and received) information, advice and support and developing a better understanding of how personal budgets meet equality objectives.
- Ways of gauging the long-term impact of having a personal budget at the level of the individual (including where there are integrated budgets) and on the health and care system.
- In the context of the market shaping duty in the Care Act, there is a need to better understand the relationship and interaction between individuals receiving care and support and supply and innovation in the market, including the role of local commissioning. This should extend to the role of councils in creating the conditions for people to directly commission their own care and support, including when they choose to pool their budgets and collectively commission.
- Not enough is known about how personalised approaches can be consistently implemented in services directly commissioned by councils and the NHS.
- Understanding the relationship between personal budgets and the rest of personalisation, particularly the spread of strength-based approaches and building community capacity (social capital) in the context of wider whole system change. Concerning the latter, the field of understanding change in complex systems is still emergent.
- The role and impact of co-production with people with lived experience, including carers.

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Whilst personal budgets are defined in the Care Act and accompanying DH Guidance,<sup>13</sup> as the NAO found, there is inconsistency in how they are being implemented in practice, often linked to the way some councils' have approached the need to save money by restricting choice and control. Since publication of the NAO study, other reports have highlighted continued difficulties faced by people receiving or needing care and support as a result of reduced funding for social care (e.g. In Control's study for the Independent Living Strategy Group: *Promoting People's Right to Choice and Control under the Care Act*<sup>14</sup>). There is a risk that the lack of money in the system has a negative effect on the wellbeing of those requiring care and support and that underfunding of social care is mistakenly read as a failure of personalisation.

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It is also the case that personalisation is evolving in different ways as councils (some now coming together as part of devolved arrangements) and their partners develop strength-based approaches that make more use of people's own assets and community resources to support them, coupled with the drive to join up services. In this changing environment, there is a strong case for restating the principles and practice of personal budgets in the wider context of personalisation and system change. It also means that the evidence needs to 'stretch' to cover how personalisation is evolving.

There are a few notes of caution that should be considered when moving forward to address these gaps. We recognise that there is a need to avoid an unintended consequence of creating a costly and over ambitious system for gathering evidence. We should not add to the 'burden of collection' and risk causing 'consultation fatigue' amongst those whose views are sought. This means being disciplined in the questions we seek to ask and reinforces the benefits of some consolidation of existing approaches. A related challenge is to determine what should be left to local discretion and what should be mandatory. In seeking to improve the evidence base, care should also be taken to avoid the 'evidence trap' which can stall investment in new models of care and support.

<sup>13</sup> *Care and Support Statutory Guidance, Department of Health, December 2016 (updated)*

<sup>14</sup> *Promoting People's Right to Choice and Control under the Care Act: How are local authorities performing?, In Control, 2015*

# Our recommendations to government and system leaders

Our recommendations are organised around the themes of:

- Increasing the use made of the existing evidence base.
- Taking forward development through co-production.
- Improving the sharing of what works best.
- Developing a long-term strategy for building the evidence base.

It should be noted that whilst the NAO report excluded carers who receive personal budgets **in their own right**, our recommendations are intended to apply to carers as well.

## Recommendations for improving the use of the existing evidence base

To make best use of what evidence already exists, the following areas will be taken forward:

- 1** Increase the number of councils who routinely seek and act upon the views of people receiving personal budgets and their carers by promoting the existing tools and the data they generate. This should also entail:
  - 1.1** Encourage the sharing of different data sets to help build a more comprehensive picture of what is happening.
  - 1.2** Develop existing tools, particularly through embedding questions into routine and mainstream data collection and reporting.
  - 1.3** Produce practical guidance to improve standards on the collection and use of evidence.
  - 1.4** Work with NHS Digital to explore how more use can be made of existing data sets to help councils improve personal budget delivery, including understanding the reasons for variation in experience, outcomes, process, efficiency and cost effectiveness.

## Recommendations for developing the evidence base through co-production

To get co-production at the heart of developing and implementing approaches to data collection and evidence production, the following areas will be taken forward:

- 2** **Link the gathering and using of evidence to the refreshed Making it Real framework that TLAP is producing.**
  - 2.1** Agree some 'universal' questions designed to gather the views of people receiving care and support that can be asked by councils, providers and others in order to build a strong picture of the lived experience and outcomes for individuals over time. The search for suitable questions should start with those already in use. The logic of this development is that, once agreed, these questions could then be incorporated into ASCOF.
  - 2.2** Work with providers and the VCSE sector to co-design research and evaluation, to include developing easy to use tools that providers can use to collect and report information on outcomes (including the 'universal' questions above) and cost effectiveness.

## Recommendations for improving sharing the evidence of what works, and informing the roll out of personal health budgets

In order to help spread learning across the system, the following areas will be taken forward:

- 3** **Organise an annual multi-disciplinary symposium bringing together academic organisations involved in research and evaluation, 'data gatherers and users', and people with lived experience to share evidence of what is working well and identify solutions to barriers. The symposium should help identify priorities for the funding of future research and evaluation.**
  - 3.1** Continuing to collect and promote good practice in personalised approaches to care and support (including any worthwhile local measures and approaches) and work with experts in research and evaluation to make sure that evidence is gathered in a robust a way as possible to enhance reliability and transferability.

- 3.2** Consider the need to develop new measures that capture the experience of more joined-up and integrated care and support (e.g. whole family assessments, joint personal budgets) and the shift towards a more strength-based approach to care and support.
- 3.3** TLAP's Self-Directed Support work-stream will continue to share best practice and the evidence for this, through:
- Collaborating with the Integrated Personalised Commissioning Team at NHS England and Coalition for Collaborative Care to exchange and promote dissemination of learning and good practice on the provision of personal budgets, personal health budgets, development of integrated personalised commissioning, and spread of person-centred approaches more generally.
  - Promoting the Personal Budgets Minimum Process Framework which defines good practice for making the process for getting a personal budget as straightforward as possible.
  - Sharing learning from TLAP's Individual Service Fund action learning sites on how best to gauge the effectiveness of this option for taking a personal budget, and from work designed to help unlock the barriers to increasing personal budgets and their effectiveness for people with mental health needs.
- 3.4** TLAP's Care Markets and Quality Forum will:
- Identify and share innovative and emerging models of care and support and how the evidence can be generated to support their development.
  - Subject to available resources, undertake a piece of work to identify and share best practice and emerging evidence on the process and outcomes from people commissioning their own support, including when people come together and share their personal budgets to collectively commission.
- 3.5** Support the development of shared approaches to data and evidence across localities to reflect the 'new geographies' being created through devolution and integration.

## Recommendations for developing a long-term strategy for building the evidence base with support from the Department of Health

4

To develop a coherent, proportionate and sustainable approach to producing evidence that is capable of being used across the sector and at different levels (local, regional, and national), the following areas will be taken forward:

- 4.1 Commission longitudinal research and evaluation, where it is needed to capture the particular experience of groups or communities, with a focus on those experiencing health and wellbeing inequalities or inequalities of access to support. Considering first those gaps in the evidence base identified earlier in this report.
- 4.2 Explore with the National Wellbeing Centre, the feasibility of developing a consistent approach to evaluating the impact of personalisation on wellbeing which can be aligned to the Government's National Wellbeing Programme.
- 4.3 Support is given to embedding data capture into mainstream processes and systems (e.g. assessments and reviews), avoiding the need for separate collection and reporting.
- 4.4 Develop and support means of data capture that allow the tracking of individual experience and outcomes over time, and effects on the system (e.g. prevention).
- 4.5 Explore how technology can be used to produce data in 'real time', including feedback from those receiving care and support.
- 4.6 Consider guidance on what data should be collected by all and what should be left to local discretion.
- 4.7 Explore, develop, use and articulate models of evidence gathering which are appropriate to the complexity of whole-system transformation and cultural change.

As a next step, TLAP will work with its partners (including the Department of Health) to produce a worked-up strategy for improving the evidence base for personalisation, together with a more detailed action plan, setting out how these recommendations will be taken forward (where they are not already in progress or need accelerating) and by whom.



## Summing up

Personal budgets are a central plank of the ambition to transform the care and support system to make it more personalised and community based. Under the Care Act, councils must ensure that all long-term community support for people with eligible needs is provided through a personal budget.

Whatever form the personal budget is taken in, councils should ensure that the process for getting and experiencing a personal budget provides for as much choice and control as possible. As the NAO point out, for this to work well requires not only good processes and well informed 'can do' practitioners, but also a vibrant and sufficiently funded market that is able to provide care and support in the myriad of ways that people need and want. It also requires councils and system partners to act in ways that positively encourage and support people to commission their own care and support. All of this equally applies to the health world.

In carrying out this work we support the conclusions of the NAO that the evidence base for personal budgets needs improving and point to the direction this could take, with the overriding goal of striving to make sure that personal budgets work for all.

In our view, there is scope to make better use of the existing evidence and for the transfer knowledge of what works best. The focus should be on locating the evidence base for personal budgets within the bigger personalisation picture that has been described in this report. Central to all forms of evidence gathering should be people with lived experience and this should be built into the process for developing a long-term approach for gathering and using evidence which is coherent, proportionate, sustainable, and avoids excessive burden. In this way, we should move towards a position where the potential of personal budgets to improve wellbeing and help people achieve the outcomes that matter most to them, will be brought closer to a consistent day to day reality.

# Appendix 1: Terms, Abbreviations and Sources in Table 1

**What Works Centre for Wellbeing and Network** – An independent collaborative organisation and associated network to develop and disseminate evidence on understanding and measuring wellbeing. <https://whatworkswellbeing.org/>

**ASCOF** – Adult Social Care Outcomes Framework designed to measure outcomes for people using care and support services and carers, based on statutory returns completed by councils and compiled and published by NHS Digital on behalf of the DH. <http://content.digital.nhs.uk/article/3695/Adult-Social-Care-Outcomes-Framework-ASCOF>

**POET** – Personal Outcomes Evaluation Tool designed to provide practice based evidence on the views and experience of personal budget holders (and their carers) on the personal budgets process and impact on their life. [www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx](http://www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx)

**ASCOT** – Adult Social Care Outcomes Toolkit designed to capture information about an individual's social care related quality of life across a number of domains, with a version for carers. <http://www.pssru.ac.uk/ascot/>

**IBSEN** – Evaluation of the Individual Budgets Pilots published in 2008 reporting the introduction of personal budgets (then known as individual budgets) in 13 local authority pilot sites. Findings published covering experience, outcomes and cost effectiveness. A follow up study was undertaken for carers. [www.kcl.ac.uk/sspp/policy-institute/scwru/res/roles/ibsen.aspx](http://www.kcl.ac.uk/sspp/policy-institute/scwru/res/roles/ibsen.aspx)  
[www.pssru.ac.uk/pdf/IBSENCarersRep.pdf](http://www.pssru.ac.uk/pdf/IBSENCarersRep.pdf)

**Personal Health Budgets Evaluation** – Evaluation of the personal health budget programme, published in 2012. [www.phbe.org.uk/index-phbe.php](http://www.phbe.org.uk/index-phbe.php)

**MPS** – Market Position Statements produced by councils setting out their view of the type and range of care and support services to meet the social care needs in their area to inform commissioning and provider development. [www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#chapter-4](http://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#chapter-4)

**JHWBS** – Joint Health and Wellbeing Board Strategies produced by Health and Wellbeing Boards setting out high level priorities for improving the health and wellbeing of the local population based on a Joint Strategic Needs Assessment. [www.local.gov.uk/sites/default/files/documents/The%20power%20of%20place%20health%20and%20wellbeing%20boards%20in%202017.pdf](http://www.local.gov.uk/sites/default/files/documents/The%20power%20of%20place%20health%20and%20wellbeing%20boards%20in%202017.pdf)

**Local Accounts** – Produced by councils reviewing their past performance and setting out future plans for care and support. They are not mandatory.

**STPs** – Sustainability and Transformation Plans produced under the direction of NHS England covering 44 areas across England setting out plans for improving health and care. [www.england.nhs.uk/stps/](http://www.england.nhs.uk/stps/)

**Individual Service Funds** – TLAP report, Individual Service Funds and Contracting for Flexible Support: Practical guidance to support implementation of the Care Act cites research and evaluation undertaken into ISFs. [www.thinklocalactpersonal.org.uk/assets/Resources/SDS/TLAPISFsContractingFINAL.pdf](http://www.thinklocalactpersonal.org.uk/assets/Resources/SDS/TLAPISFsContractingFINAL.pdf)

**TLAP – The Care Act 2014 Survey Results:** Exploring the impact of the Care Act on the lives of people with care and support needs. [www.thinklocalactpersonal.org.uk/assets/Resources/TLAP/CareActSurveyResults-002.pdf](http://www.thinklocalactpersonal.org.uk/assets/Resources/TLAP/CareActSurveyResults-002.pdf)

**Alzheimer's Society** – Research undertaken with councils looking at how well personal budgets for people with dementia were being provided, leading to the publication of a guide and charter to help councils make improvements. [www.alzheimers.org.uk/downloads/file/3222/making\\_personal\\_budgets\\_dementia\\_friendly\\_-\\_our\\_charter](http://www.alzheimers.org.uk/downloads/file/3222/making_personal_budgets_dementia_friendly_-_our_charter)

**TLAP – Building Community Capacity:** Evidence, Efficiency, and Cost-Effectiveness. [www.thinklocalactpersonal.org.uk/Latest/Building-Community-Capacity-Evidence-efficiency-and-cost-effectiveness/](http://www.thinklocalactpersonal.org.uk/Latest/Building-Community-Capacity-Evidence-efficiency-and-cost-effectiveness/)

**NESTA Realising the Value Programme** – Programme funded by NHS England which collected evidence on what good person and community-centred care looks like and associated cost savings and wider social value. [www.nesta.org.uk/project/realising-value](http://www.nesta.org.uk/project/realising-value)

**Public Health England** – A guide to Community-Centred Approaches to Wellbeing which cites various research and evaluation that have been conducted into the family of community-centred approaches aimed at improving health and wellbeing. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/417515/A\\_guide\\_to\\_community-centred\\_approaches\\_for\\_health\\_and\\_wellbeing\\_full\\_report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417515/A_guide_to_community-centred_approaches_for_health_and_wellbeing_full_report.pdf)

**PSSRU Research into Personal Health Budgets** – Continuing evaluation to explore the continued impact of personal health budgets on people receiving them and on commissioners and providers. [www.phbe.org.uk/phbe-2/](http://www.phbe.org.uk/phbe-2/)

**Integrated Personalised Commissioning** – Partnership programme between NHS England and Local Government Association to pilot an approach to supporting people with complex needs through blending health and care funding into a single budget controlled by the person. IPC is being subject to a number of evaluations. [www.england.nhs.uk/commissioning/ipc/](http://www.england.nhs.uk/commissioning/ipc/)

**Joint Voluntary and Community, Social Enterprise Review** – Joint review by the DH, Public Health England and NHS England which recommended ways in which the VCSE sector can play a bigger part in improving health, wellbeing and care outcomes. [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/524243/VCSE Investment Review A.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/524243/VCSE_Investment_Review_A.pdf)

**Public Health Outcomes Framework** – [www.phoutcomes.info/](http://www.phoutcomes.info/)

**QAF** – Quality Assessment Framework for Supported Housing originating in 2003 to collect information on outcomes for people in services funded through the Government's Supporting People programme. With the ending of the Supporting People Programme reporting is no longer mandatory. Some councils have adapted the framework as a quality monitoring approach within adult social care. [www.sitra.org/policy-good-practice/quality/#qaf](http://www.sitra.org/policy-good-practice/quality/#qaf)

## Appendix 2: The Care Act

The Care Act 2014 provides the legal framework for making care and support more strengths-based, personalised, preventative, and integrated. Central to the Act is the promotion of wellbeing, which has at its heart the principle of control by the individual of their day to day life to help them achieve the outcomes they want. This is a rights based approach. Section 6 of the Care Act has made personal budgets mandatory (see below for chapter and verse).

Extract from Care Act Guidance December 2016:

*“Personal budgets are a key part of the Government’s aspirations for a person-centred care and support system...The Act places personal budgets into law for the first time, making them the norm for people with care and support needs.”*

*“The personal budget is the mechanism that, in conjunction with the care and support plan, or support plan, enables the person and their advocate if they have one, to exercise greater choice and take control over how their care and support needs are met. It means:*

- *Knowing, before care and support planning begins, an estimate of how much money will be available to meet a person’s assessed needs and, with the final personal budget, having clear information about the total amount of the budget, including the proportion the local authority will pay, and what amount (if any) the person will pay.*
- *Being able to choose from a range of options for how the money is managed, including direct payments, the local authority managing the budget and a provider or third party managing the budget on the individual’s behalf (an individual service fund), or a combination of these approaches.*
- *Having a choice over who is involved in developing the care and support plan for how the personal budget will be spent, including from family or friends.*
- *Having greater choice and control over the way the personal budget is used to purchase care and support, and from whom.*

*The key principles for delivering personal budgets in the way intended by the Care Act are that the process for setting a personal budget is based on principles of “transparency, timeliness and sufficiency.”*

## Appendix 3: The existing evidence base and what good looks like

Much of the existing evidence comes from the national Adult Social Care Outcomes Framework (ASCOF) set by the Department of Health and collected from all local authorities by NHS Digital. Of particular relevance to personal budgets are the indicators:

- 1A Social care-related quality of life.\*
- 1B: The proportion of people who use services who have control over their daily lives.\*
- 1C(1a): The proportion of people using social care receiving self-directed support.
- 1C(1b) The proportion of carers receiving carers receiving self-directed support.
- 1C(2a) The proportion of people using social care receiving direct payments.
- 1C(2b) The proportion of carers receiving direct payments for support direct to carer.
- 1A Overall satisfaction of people who use services with their care and support.\*
- 3B Overall satisfaction of carers with social services.\*
- 3D The proportion of people who use services and carers who find it easy to find information about support.\*

The 'experience' indicators denoted with an asterix (\*) come from surveys that local authorities are required to carry out and submit to NHS Digital: annually for people receiving care and support and every other year for carers. The other 'activity' indicators come from SALT (Short and Long Term Statutory Return).

In addition, two different tools have been developed that local authorities can choose to use: the Personal Outcomes Evaluation Tool (POET) and Adult Social Care Outcomes Toolkit (ASCOT). The former developed by In Control and Lancaster University with national reports published, bringing together results of surveys undertaken by participating councils. The latter developed by the Personal Social Services Research Unit at the University of Kent.

There has been growing interest in measuring wellbeing, and the Office for National Statistics (ONS) lead for the Government a ***Measuring National Wellbeing Programme*** and a What Works Wellbeing Centre has been established. At present, it appears that there are no direct connections being made with recipients of adult social care.

In Control is working with a small number of councils to embed POET into mainstream processes and systems. The West Midlands Individual Service Fund action learning site, supported by TLAP, is considering how best to capture outcomes from ISFs. The Northern Ireland Health and Social Care Board have a programme to roll out ASCOT to all five of the Health and Social Care Trusts that provide health and social care in Northern Ireland. The National Institute for Health and Care Excellence is developing guidance on the experience of care for people using adult social care services. Disability Rights UK has been funded by the Big Lottery to help people with personal budgets get more active through enjoying physical activity. The programme is being independently evaluated and the evaluation methodology includes a 'before and after' survey of each person taking part to gauge the impact on health and wellbeing and whether there has been any change in use of formal health and care support services. There may be other initiatives afoot, and councils may also use their own 'DIY' methods for gauging the impact of personal budgets and report the results in their Local Accounts.

The Local Government Association (LGA) as part of its sector led improvement work has previously undertaken a regular Care Act stock-take (now ceased) and TLAP has also undertaken a Care Act Survey. The DH has commissioned an evaluation of the Care Act implementation.

In recent years, a number of academic research studies have also been published, together with ad hoc studies and reports produced by various organisations.

There are a number of existing frameworks that describe what a good personalised care and support system looks like including personal budgets, notably ***Making it Real*** from TLAP and ***Narrative for Person-Centred Co-ordinated Care*** from National Voices, TLAP and partners. The Alzheimer's Society has published a ***Dementia-Friendly Personal Budgets Charter*** for councils and the Care Quality Commission has recently led on the development of a Quality Commitment.

While these methods and sources yield important information and insight, as the NAO study concluded, they do not constitute a coherent system for producing evidence on the impact of personal budgets.

A number of key enablers need to be in place to achieve 'what good look like'. These include:

- **Efficient systems and processes** with good information and advice that allow people to exercise genuine choice in deciding the personal budget option that will work best for them (and to be able to easily change this).
- **Competent practice and supportive management** that translates into a confident approach to personal budget delivery across the full spectrum of need, disability and equalities with positive risk enablement.
- **Well developed commissioning and market development** to create the conditions for high quality services which allow people the opportunity to commission their own care and support (individually and by coming together) and to exercise choice over the type of care and support they receive.
- **Capable providers** who can deliver what is asked flexibly to a consistently high standard.



## Appendix 4: Key questions for different groups

### People and Communities

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#### Who?

Personal budget holders and also of interest to carers, advocate and organisations representing people using services.

#### What?

- Is my personal budget helping me to achieve what I want?
- Was the process for getting a personal budget straightforward, were the options for taking the personal budget clearly explained and support offered?
- Do I have enough security about my personal budget to plan ahead for meeting my long-term goals?
- Is the amount of the personal budget enough so that my support is safe and can meet my needs?
- Does it provide me with as much choice and control as I want over the type of support I get, who provides it and when?

#### Who?

Local residents/citizens who help fund care and support through taxation with the Local Account as one accountability mechanism (or other published strategies).

#### What?

- Are personal budgets helping people to stay independent at home?
- Are they providing value for money for council tax payers?
- Is information on how they work easy to find understand in case I or someone else I know needs support in the future?

## The Local System

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### Who?

Local councils increasingly within a whole system approach and where the combined effects of integration and devolution may alter the context.

### What?

- Are personal budgets providing 'authentic' choice and control and helping people stay independent for longer whilst allowing us to live within our financial means?
- Are our systems and processes transparent, timely and proportionate?
- Does the evidence provide information that helps us improve the way we do things, including the key enablers of systems and process; practice; commissioning and market development?
- How are they contributing to our overall ambitions for a transformed and integrated care and support system?

### Who?

Providers of care and support

### What?

- Is my service helping people achieve the outcomes they want and is it in line with what we are commissioned to achieve?
- Are my staff working in ways that uphold personalised support?

## National System

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### Who?

- Department of Health, as steward of the overall health and social care system.
- Local Government Association, as leader of sector led improvement.
- NHS England, as lead for personal health budgets and integrated personalised commissioning.
- Care Quality Commission, as assessor of the quality of provision in the regulated care and support sector.

## What?

- How well is policy being implemented?
- Are there areas of concern and unwanted variation?
- How can we spread good practice and innovation?

Below are some *tentative* conclusions about the extent to which existing evidence sources cover some of the key questions with a rough distinction made between areas of primary interest to People and Communities and System concerns:

Key: P&C = People and Communities    S = System

- The experience of holding a personal budget – POET and ASCOF [P&C]
- Understanding the relationship between the different types of personal budget and outcomes (direct payment, third party, local authority managed) – POET and some from ASCOF. [S]
- The extent and reasons for variation between councils on how the personal budget is taken. Background of concern is whether LA managed personal budgets are consistently providing 'authentic' choice and control and limited spread of Individual Service Funds. – From ASCOF on the numbers and proportions of personal budget types and some on relationship to outcomes. POET analysis covers outcomes by personal budget type. [S]
- The relationship between process and outcomes (we know from POET that there is a strong connection, so that the easier the process and the more control people have over it, is strongly associated with reporting better outcomes). – From POET [S]
- The influence of the characteristics and circumstances of recipients including the role of family, friends and other supports such as the strength of local community – Limited evidence. [P&C + S]
- The differences between user groups, as the existing evidence from IBSEN<sup>15</sup> onwards points towards personal budgets working less well for older people, including those with dementia. Also, possibly:
  - People who have complex disabilities with intense and high support needs
  - People who lack capacity, particularly around the choice and control dimension

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<sup>15</sup> Original evaluation of personal budgets (then termed individual budgets) published in 2008.

- People with mental health needs
- Carers with personal budgets (not covered in NAO report).

From POET and some from ASCOF. Some individual studies/reports published that focus on different care groups. [P&C + S]

- The relationship between the amount of personal budgets and outcomes (link to the effect of LA financial pressures). Some in POET and in the national evaluation of related area of Personal Health Budgets. Some individual studies and reports highlighting negative effect of financial reductions on personal budget delivery. [P&C + S]
- What people spend their personal budgets on: exploring the interaction and relationship with supply, and markets and local commissioning as a mediating factor, including:
  - What and how much control do people take, does this change over time and what does it mean to the individual?
  - Understanding the conditions that result in innovation – both for the individual and for support providers.
  - Development of individual and/or collective commissioning through pooling personal budgets.

Some from POET on how people use their PB and relationship to outcomes.  
Few longitudinal studies [S]

- The impact of having a personal budget on the individual, including integrated budgets with health.
  - Effect on wellbeing, quality of life including end of life
  - Effect on clinical outcomes and mortality
  - Extending to look at the impact on carers, households and families.

Limited evidence. Few longitudinal studies. [P&C + S]

- Tracking the impact on the health and care system including:
  - Use of NHS services particularly acute care and community health
  - Effect on demand for care homes
  - Longer term prevention – ‘changing the path of support needs that people have over time’
  - Cost effectiveness/cost benefits/quality of life adjusted years
  - Impact on other public services such as housing.

Limited evidence. Few longitudinal studies. [S]

- Better understanding of the relationship between personal budgets and the rest of personalisation, particularly the spread of strengths-based approaches to social care and building community capacity (social capital).

Limited evidence. [S]

## Appendix 5: Contributors

This report was produced following two round table discussions (8th April and 6th June 2016) and a workshop (24th November 2016), together with a number of meetings. The organisations listed below all contributed in some way to the process.

- Association of Directors of Adult Social Services
- Care Quality Commission
- Department of Health
- Disability Rights UK
- In Control
- Institute for Government
- King's College London
- The King's Fund
- Lancaster University
- Local Government Association
- National Audit Office
- National Care Homes Association
- National Children's Bureau
- National Institute for Health and Care Excellence
- NHS Digital
- NHS England
- Personal Social Services Unit, University of Kent
- Shared Lives
- Skills for Care
- Social Care Institute for Excellence
- South East ADASS Performance Leads Network

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## Think Local Act Personal

Think Local Act Personal (TLAP) is a national strategic partnership of more than 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support.

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