



**IPC AND PERSONAL  
HEALTH BUDGET SUPPORT  
AND DEVELOPMENT  
PROGRAMME:**

**LEARNING AND  
NEXT STEPS**

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# THE VOLUNTARY VOICES PARTNERSHIP



**The Voluntary Voices partnership comprises three voluntary and community sector organisations, Volunteering Matters, National Voices and NAVCA which share the objective of promoting person-centred care and integration across health and social care.**

Established in 2012, the partnership has an extensive national reach to individuals, user-led organisations, and local and national Voluntary, Community and Social Enterprise (VCSE) sector organisations. It has also has much experience in delivering and advising on personalised practices.

Over the last two years, the Voluntary Voices partnership has been raising awareness of the importance of local VCSE organisations in the personalisation of health and care services, particularly their role in enabling people to access and make effective use of Personal Health Budgets (PHBs).

We would like to thank all those colleagues from NHS England, from clinical commissioning groups (CCGs) and from the VCSE sector who attended the events we hosted and whose contributions inform this report.



# FOREWORD

**In his blog, posted in June 2017, James Sanderson, Director of Personalised Care at NHS England wrote about “a new personal relationship between the NHS and the people it supports.” This entails, “moving towards a more equal relationship between services and people in all of our local communities.”**

James' blog reflected and amplified the commitment made by Simon Stevens, Chief Executive of the NHS in October 2014, when in setting out the ambitions for the *Five Year Forward View* for the NHS, he addressed the need for the empowerment of people through increasing “the direct control patients have over the care that is provided to them... We will introduce Integrated Personal Commissioning (IPC), a new voluntary approach to blending health and social care funding for individuals with complex needs. As well as care plans and voluntary sector advocacy and support, IPC will provide an integrated, “year of care” budget that will be managed by people themselves or on their behalf by councils.”

**NHS England summarises the aims of the IPC programme as follows:**

Integrated Personal Commissioning (IPC) is a nationally led, locally delivered programme that is supporting healthcare empowerment and the better integration of services across health, social care and the voluntary and community sector.

The critical role of our sector – the voluntary and community sector – is therefore signalled from the very outset. To achieve the transformed relationship between citizen and state outlined by Simon Stevens and James Sanderson, our sector must be fully engaged, fully committed and fully equipped to play its part.

Through our work for the IPC and Personal Health Budget Support and Development Programme we often heard compelling evidence about PHBs enabling people to make new choices, take more control and share responsibility for their own health and wellbeing. We heard from people with lived experience how PHBs had helped them to be

active citizens, in control of their own lives and included in the lives of their communities. From CCGs we often heard that it was engagement with VCSE organisations that made these individual transformations possible. This, of course, is why the VCSE sector must be at the heart of the personalisation of health and care services and in the promotion, arrangement and delivery of PHBs.

However, this is no small task. Since the NHS and Community Care Act in 1990, voluntary and community sector organisations across England have found themselves (by no means always willing) players in a contract culture, which privileges competition over co-operation and sees organisations bidding for ever diminishing pots of money, packaged in the form of block-contracts with highly specified output indicators; all of which might have little to do with people's actual, expressed needs and wishes.

**The grip of “procurement processes” has begun to loosen in the last decade with the introduction of personal budgets and more person-centred approaches (initially in social care) but there is still a very long way to go and the more so in relation to healthcare.**

PHBs are a marker of success for IPC. In his blog of June last year, James goes on to describe a “mandated commitment” to “ensure 300,000 people benefit from personalised health and care by 2018/19, including 40,000 people with a PHB and for 50-100,000 people to have one by 2021.” PHBs are not for everyone; this is a really important point and one not to lose. Nonetheless, the requirement on CCGs to deliver on these numbers and to develop the capacity to offer PHBs which make a real difference to the health and wellbeing of people with complex and long-term health conditions – should bring with it associated changes in culture and process which will impact across the whole NHS system.

Our sector is uniquely placed to bring to the table features which are essential for the success of this programme. The most important of these features is a grounded-ness in community, which is the essence of most voluntary and community organisations. We bring local people and their concerns with us, because our sector consists of those local people and concerns.

The IPC programme posited “five key shifts” necessary for success: a proactive approach; a different conversation; a shift in control over resources; a community and peer focus; and a wider range of care and support options. VCSE organisations have expertise in each. When the programme set out the need to “intervene early” in order to “prevent, reduce or delay the need for crisis intervention or acute care” it was speaking to our core mission as a sector.

**So, there is little doubt of either the rationale for our involvement or of the fact that NHS England is persuaded of this. But what of the reality?**

This report sets out what the Voluntary Voices partnership has learnt in the last two years, as we have worked across the nine regions of England to encourage learning and develop mechanisms for mutual support. There have been many encouraging signs, and examples of good practice, encompassing a wide range of topics and areas of need.

However, there have also been difficulties, highlighted in our work and discussions across the country. Not the least of these have been difficulties in communication between statutory and voluntary sector organisations which too often can seem to speak different languages.

Our hope is that this report makes a positive contribution towards helping people come together to develop a greater mutual understanding, to begin to speak a shared language and to work in harmony, to ensure that the person – or citizen – with health and care needs always finds him or herself firmly at the centre of decision making.

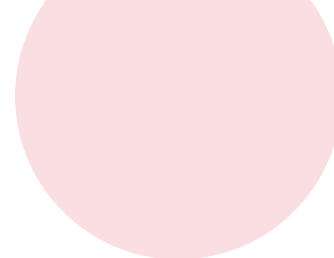
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# INTRODUCTION



**What does it mean to talk about “a new relationship between the NHS and the people it supports”? The foundations for this new relationship have been explored during the three and a half years since the publication of the *NHS Five Year Forward View*. The following NHS England programmes are particularly notable:**

## **PROGRAMMES**

### **1. The *Realising the Value* programme**

This NHS England funded initiative saw the Voluntary Voices alliance join a consortium led by Nesta and the Health Foundation, to identify evidence-based approaches that engage people in their own health and care; and develop practical tools to support implementation. The approaches involved included self-management education courses for people with specific conditions; peer-to-peer support; and community-based activities. The final report of the programme can be found [here](#).

### **2. The *New Models of Care* programme**

The collective name for prototypes of transformed care, this programme has now completed its work in supporting and stimulating the creation of innovative care models that can be deployed in different combinations locally across England.

In outline, the three most significant new models are/were: integrated primary and acute care systems (PACs) which will join up GP, community, mental health and hospital services; multispecialty community providers, which aim to move services out of hospitals and into communities; and models of enhanced care in care homes, which will improve services for older people, joining up health, care and rehabilitation. A summary of the work is available [here](#).

### **3. The *IPC* programme**

Launched in April 2015, this sought to bring about system-wide change in health and social care. The programme attempted to introduce *five key shifts*:

- a proactive approach
- a different conversation
- a shift in control over resources
- a community and peer focus, and
- a wider range of care and support options.

These took shape in associated *service components* – including community and peer support, multidisciplinary teams delivering Care and Support planning, and Integrated Personal Budgets – and result in better *patient outcomes* in relation to quality of life, fewer crises and an enhanced experience of care. This approach is set out in more depth in the *Emerging Framework* document, available [here](#).

Within the context of the IPC programme, Voluntary Voices has been enabling the VCSE sector across England to become better equipped to respond to these new ways of working, and to play a role in relation to the introduction of PHBs.

CCGs are the statutory bodies charged with introducing PHBs. There are a little over 200 CCGs in England, each responsible for commissioning care for around a quarter of a million people. Each CCG operates with a degree of local autonomy and accountability, whilst also being responsible for its performance to NHS England.

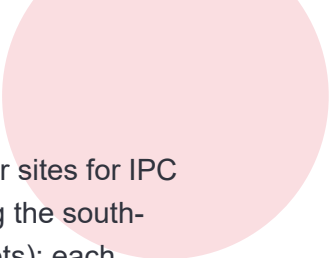
Each CCG is expected to make public (on its website) a *Personal Health Budget local offer*, signed off by the appropriate Health and Wellbeing Board.

Since October 2014, adults eligible for [NHS Continuing Health Care \(CHC\)](#) and children and families eligible for Continuing Care have had a right to have a PHB. This offer should set out which other groups of people can benefit from and start receiving PHBs from April 2016. The local offer should also make clear how the arrangements will work in practice and set out the governance process to support this activity.

In addition, from 2016-17, CCGs have targets and mandatory data collection requirements placed upon them for PHBs; these requirements followed an NHS Mandate commitment to have in place “50,000 to 100,000 Personal Health Budgets by 2020.”

Advice, assistance and guidance is available to CCGs from NHS England’s Personalised Care Group to help them with these challenges. This is provided through an online Learning Network, which produces monthly newsletters with links to case studies, toolkits and guidance documents. NHS professionals can also join webinars, attend national events and consult with advisors.





There were eighteen designated demonstrator or early adopter sites for IPC across England. They were of different sizes (the largest being the south-west region, the smallest the London Borough of Tower Hamlets); each with different target groups, as determined by local need and priorities. Each site committed to the implementation of the IPC programme, as the preferred approach which enabled people with multiple health conditions and complex needs to get the help and support they needed. Each site also committed to working with colleagues from NHS England to develop and review this new way of working; and to taking a lead role for IPC within their Sustainability and Transformation Partnership (STP) footprint area.<sup>1</sup>

Voluntary Voices' initial remit on the IPC programme was to work with VCSE organisations in the nine regions of England with a view to developing a series of regional networks. In the course of the work, and in response to some of the factors which became apparent, our aim shifted slightly. The following sections describe the process which we facilitated; give some examples of the conversations we had during this process; and show how (with the guidance of NHS England colleagues) we adjusted the programme remit as the work progressed. We also include in this report two case studies that illuminate some of the positive aspects of the work to date.

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1 For this programme of work CCGs were the main targeted statutory partner. However, the context was changing around this as we worked. At a higher regional level, Sustainability and Transformation Partnerships, joining health and care commissioners and providers in 44 regional 'footprints', were formed and tasked with planning for a more sustainable future. By the end of our programme these were assuming increasing importance; with the most mature being encouraged to become Integrated Care Systems (ICSs).

# 1. OUR AIMS: WHAT WE DID AND HOW WE DID IT

## **Our overarching aim was to work with local VCSE organisations across the country, to make the most of PHBs.**

Some organisations were very poorly informed about PHBs. In response, we provided them with information to help them understand the underpinning principles and the mechanics, and made suggestions as to where to go for more ideas and information.

Other organisations knew about PHBs but hadn't systematically thought about the options in terms of their role or begun any business planning to make that role a reality. Hence, we tried to provide space to begin that process.

Our aspiration was to bring organisations together to learn and plan, and in doing this nurture support networks. These networks would, we hoped, continue beyond the duration of our involvement. And as a result, local organisations in each locality would find themselves ready and able to work effectively in support of PHB holders. The box below shows how we described the networks in our initial publicity.

### **WHO is the network for?**

- Voluntary sector organisations practising the values underpinning personalisation, peer support and working with people with lived experience;
- Organisations seeking to offer support to people who are interested in or eligible to receive a PHB.

### **What will YOU get from the Network?**

- Understanding of PHBs;
- Up to date briefings on national policy and developments;
- Knowledge of what your CCG's local offer is;
- Guidance on how to engage with PHBs and work in partnership with CCGs;
- Appreciation of how you can work together to develop local solutions;
- Opportunity to share experiences, learn from good practice, and build local connections.

## To this end, we undertook the following activity:

- *In summer/autumn 2016, we delivered nine **day one** events, one in each of the English regions, “**Introduction to PHBs, VCSE engagement.**” The main agenda items were:*
  - 1) Purpose of the networks; Defining terms; Lived experience
  - 2) Your experience, the role of the VCSE
  - 3) The local offer: engaging with CCGs
  - 4) Good practice
  - 5) Visioning.
- *In winter/spring 2017, we delivered nine **day two** events, one in each of the English regions, “**Proactive engagement.**” The main agenda items were:*
  - 1) Review of learning and progress since day one; Commissioning PHB support with CCGs
  - 2) Good practice examples of VCSE organisations
  - 3) Your vision; Tools
  - 4) Network development.
- *In autumn/winter 2017, we delivered nine **day three** events, one in each of the English regions, “**Action Planning.**” Key agenda items were:*
  - 1) Updates and learning since day two
  - 2) Co-production with people with lived experience, how we can learn from NHS England’s work
  - 3) Working in partnership – example of CCG and VCSE organisation working together
  - 4) The key elements of a local framework
  - 5) Your network going forward.

Our original plan was that in each region we would identify and work with a *self-defined closed group of champions*, drawn from organisations with differing degrees of expertise/readiness – but all of which were keen to improve, and which would progress together over the course of the three days. This group of organisations would then form the backbone of a continuing regional network.

## This model proved not to be feasible in its pure form, for two main reasons:

1. Whilst there was some degree of continuity in attendance in most regions, the reality was that for a variety of reasons (changes in personnel or in role, changes in prioritisation of the PHB work, other demands, personal issues) attendance was by no means uniformly consistent across the three days of the programme. Conversely, we also came across new organisations keen to join the programme part way through. So, the idea of a closed group was shown to be unhelpful.
2. The regional level proved to be problematic and, in our meetings, we often found that the common ground between organisations was limited. In fact, we were met with a huge variety in the scope and reach of the organisations we attracted. Some were condition-

specific, some had an interest in a particular demographic, ethnic or cultural community, some were “infrastructure organisations” – and some had the remit to serve a geographic community. Rarely did organisations serve the entire region; and very often the relevant boundaries within the region did not coincide with those of NHS organisations.

**In consultation with NHS England colleagues, we therefore came to the view that we needed to build more flexibility into the process. We agreed to do this in several ways:**

- We decided to allow in new joiners at certain stages in the programme. To aid these new joiners, we agreed to provide two additional webinars in summer 2017, which covered the ground in summary form, of the day one and two events.
- We responded to the fact that delegates had different degrees of exposure to the IPC programme – hence we tried hard to introduce a degree of variability and flexibility into our delivery, particularly in the latter stages.
- At the point at which we were planning the day three events, we agreed with NHS England that (for the reasons given above) nine networks arranged to reflect NHS regions would not in fact be a workable outcome.

We proposed to delegates that they adopt a variety of strategies when considering their needs for further support. Many delegates responded positively to our championing the need for on-going discussion of PHB issues with peers in other organisations; but, very importantly they were clear that any such discussion needed to be conducted on a local (and not a regional) basis. In these cases, we proposed to delegates that they work towards developing local or sub-regional networks. In practice, this usually meant a network at the level of a CCG or local authority area.

## 2. WHAT WE LEARNT FROM THE PROGRAMME DELIVERY

Participants raised a wealth of discussion points at our events. Many colleagues were positive about the potential (and sometimes the actuality) of PHBs. Others, the majority in fact, were animated by frustration about the difficulties in engaging, developing a working relationship with the appropriate CCG and then capitalising upon that relationship.

**Following the sequence of three events, we used SurveyMonkey to ask delegates for feedback about their learning and confidence levels. In summary:**

- The percentage of delegates stating that they had at least “sufficient” knowledge of PHBs increased from 42% at the start of the programme to 97% at the close
- The percentage of delegates stating that they were at least “quite confident” of working with their CCG on PHBs at the close of the programme was 72%
- The percentage of delegates stating that they were confident in their ability to include people with lived experience in designing and introducing PHBs at the close of the programme was 74%
- We also received a long list of (free text) suggestions from delegates in response to a question asking what in their view was needed in their locality to sustain the work on PHBs. We pick up these issues in the sections that follow.

Many of the points made by delegates at the events were strongly felt; and the day three events were characterised by high levels of expressed emotion about these issues.

### **1. VCSE organisations often find it very difficult to know what is happening about PHBs in their area.**

*“The CCG is a bit of black box.”*

*“Who the hell do we talk to in the CCG?”*

Many factors contributed to this issue.

Some VCSE organisations had a very limited understanding of the PHB process and what they should expect. Some did not know that there

should be a local offer or where to look for it.

Some VCSE organisations had little or no knowledge about the importance of Continuing Health Care (CHC) in the PHB process to date – or about the plans to expand the scope beyond CHC.

Quite a number of organisations had very limited contact with the CCG and/or had limited understanding about roles and responsibilities within the CCG, or who to contact to find out more about this.

These issues were particularly difficult for the smaller, more specialist or more local organisations. Some organisations struggle with practical issues such as insurance liabilities. There were often particular difficult where there was no effective VCSE infrastructure organisation to take on the job of interpreting, filtering and passing on information about the CCG and its role.

Often the reality seemed to be that information about the local strategy for PHBs was genuinely difficult to uncover. Roles and responsibilities within CCGs seemed to change frequently, with senior people often in post on an interim basis, making it difficult to know who to ask for up to date information.

Some CCGs appeared not to have a local strategy and there was no PHB local offer on their website at all. Practice appears to be very variable within and across regions, and this proved a cause of great frustration for VCSE organisations working across CCG areas.

## **2. There often seemed to be a deep cultural divide between the CCG and VCSE organisations.**

This was the case even when the specific knowledge and information issues mentioned above didn't apply.

***“There is a real need for the NHS to understand the third sector.”***

***“Please don't tell us ‘we know how to do these things better than you’.”***

***“There are high expectations of us from the NHS.”***

As well as VCSE organisations struggling to understand or communicate with the CCG, the same is sometimes true in reverse. Many CCGs appear to have had only very limited experience of working with their local voluntary sector.

This gap is difficult to encapsulate easily in a few words; but in outline, CCGs seemed more focused on systems, process, targets and performance; and VCSE organisations on community, reciprocity, responsiveness and flexibility.

The delegate who spoke about “high expectations” of voluntary organisations from the NHS went on to describe a due diligence process which “shines a spotlight” on VCSE systems and processes, in ways which don’t always feel very helpful or realistic.

Another delegate made the point that it is inherently difficult for NHS colleagues to “get their head around a vibrant third sector... the sector is always changing and what in fact may be needed for good PHB delivery is different organisations to become involved at different stages of the process.... the NHS struggles to understand this.”

The gap is by no means unbridgeable: a delegate spoke about the need to evidence good practice through “cold, hard measurable indicators.... combined with real life examples of change for individuals.” Where the gap is bridged, this seems to be down to individuals on both sides who appreciate the importance of the relationship – and who have a real understanding of the perspective and the pressures of those on the other side.

### **3. VCSE organisations are not always good at identifying and responding to the business opportunities that PHBs offer.**

*“Organisations need to decide...are they brokers or are they providers, or what... where they fit... then they need to work this up and sell it to the CCG.”*

*“VCSE organisations need a business plan, to know what the resource implications of their proposals are and how they will make money to keep going.”*

In part, this issue was a result of some organisations’ poor appreciation of how PHBs work, and how the different components of the PHB system fit together. This meant they therefore struggled to set out how their expertise might be brought to bear.

Sometimes, the problem was the result of constrained capacity, limited systems for information gathering, storage and sharing and for analysing and responding to potential funding opportunities.

Poor, under-resourced or underdeveloped business modelling and business planning systems were also a major issue, again particularly so for the smaller VCSE organisations.

Opportunities tend to arise for a limited time, and organisations need to be ready to respond: one delegate spoke about the advantage of understanding “where we are in the commissioning cycle” in order to be ready to make the most of opportunities. CCGs need to appreciate that VCSE organisations must cover overheads and therefore generate some surplus: a good business plan can demonstrate this and play a big part in helping to bridge the cultural divide.

**4. PHBs are still in the early phases of their development, and it is not always clear that they yet make good business sense for VCSE organisations.**

*“We are biding our time to see if this really takes off...”*

Some VCSE organisations – certain larger organisations, some Centres for Independent Living, and some infrastructure organisations – have embraced this work, developed robust processes and are able to make money from it. But, leaving aside the issues about capacity and business process discussed above, it is by no means obvious that PHBs at this stage always make good business sense. This is particularly true in localities where per capita CHC numbers are low and/or where the PHB local offer is underdeveloped.

It is also clear that some CCGs are yet to make a viable PHB offer and put in place good support arrangements for PHB holders – and when it comes to extending that offer beyond CHC, the situation is even more tentative. In light of this, some organisations tell us that they have made a rational, considered decision not to enter the arena at this stage.

**5. The commissioning model adopted in a locality impacts sometimes adversely upon the response from VCSE organisations.**

*“It doesn’t do anything for us [the VCSE sector] ...and it doesn’t help PHB holders if the CCG just procures one big, cheap service for the whole area.”*

Some CCGs appear to have come to a view that the most efficient and effective way of commissioning support services for PHB holders, is to bundle most or all the necessary service components into one contractual package and award a contract through a traditional competitive process. The composition of bundles of this sort varies; but they often include:

- advice and information services
- brokerage
- care and support planning
- money management and payroll
- direct care services.

This sort of “bundling” does not seem to be appropriate for involving the VCSE in PHBs – one organisation is unlikely to be good at all of this. Such arrangements do not offer the sort of opportunities for VCSE organisations envisaged in our programme. On the contrary, they close off options for innovation and new business.



Frustrations were clearly expressed at events in some localities. A VCSE delegate at one event stated that PHB work had become “exclusive and elitist,” in ways which (in their view) run directly counter to the programme’s stated aims and values.

## **6. VCSE organisations are better at collaborating than competing – collaboration in this way is the bedrock of this programme.**

*“It really doesn’t help if we are fighting each other all the time for an ever-diminishing pot of money.”*

This is closely allied to the previous point. Commissioning organisations in health and care have been encouraged over the years to promote competition as a means of securing the best possible value for public funding. VCSE organisations have (sometimes reluctantly) found themselves competing for these contracts. It is hard to see this as a helpful or appropriate approach when thinking about support arrangements for PHB holders, in part because of the multiple interlinked components in the PHB pathway and the fact that many holders will of necessity need a mix of community services – provided by organisations which are in competition with one another.

## **7. Co-production with people and families was at the heart of IPC and PHBs, but sometimes neither the CCG nor local organisations seemed to have fully understood how co-production can work well, or how it might help.**

*“What kind of organisation would be useful for people on the receiving end? Surely we need to ask people?”*

In day three of our programme, we invited Lived Experience Advisors from NHS England to join us and share their experiences. We heard a diversity of powerful and moving personal stories. We also heard about how, in developing PHBs, NHS England has recognised and embraced the central place of lived experience.

We heard inspiring examples of great local practice where the voice of people with lived experience has been crucial. But we also heard about many other instances where this was not the case. While most of the VCSE organisations who attended the events were very open to co-production in principle, in practice it had very often “fallen off the agenda” because of time or resource pressures.

There is a real imperative and an opportunity for the NHS and for VCSE organisations to work together to build the voice of lived experience into each stage of local PHB implementation, much as NHS England has done in their design and testing.

# 3. TOWARDS SOLUTIONS

Despite the difficulties described above, many of our discussions with VCSE colleagues in the regions were characterised by a sense of optimism. The system we have in place to commission, regulate and oversee healthcare today is necessarily complex and it provides opportunities as well as challenges. Some of the ideas which we heard about in the course of this programme were as follows.

1. Explore ways of making PHBs more “demand-led.” A programme of public information, led by PHB holders and families may help.
2. Make use of some of the same, simple person-centred approaches used in care and support planning – what is working, what is not working? what in your life makes for a “good day” (or a “bad day”?) etc. – to talk with patients and families about PHBs and how they can best work for them.
3. Support and encourage a real meeting of minds around PHBs between CCGs and the VCSE sector. This is essential at all levels (national, regional, local). It may require getting issues on the agendas of existing forums, or it may mean convening dedicated events. All this will need resourcing. Conversations need to be held based on equality, and must be mindful of the cultural differences referred to above.
4. Explore whether Healthwatch England and local Healthwatch groups have a role to play in brokering better, joined-up practice.
5. Explore the role of VCSE infrastructure organisations. In some places, they take on important leadership roles in this work, but in others they appear not to be involved at all.
6. Connect with the Joint Strategic Needs Assessment (JSNA) process, which seeks to capture the health and care needs of local populations. This is perhaps especially the case as JSNAs are now coming to focus not just on needs but also on community assets, in a way which closely mirrors the IPC model.
7. Promote and articulate PHBs through STPs and ICSs – today’s major vehicles for NHS improvement. In particular STPs are charged with



taking forward the vision expounded in the *Five Year Forward View*. Some delegates made the point that these new arrangements are built on the same foundations as IPC and PHBs. As such, they should be well placed to promote person-centred approaches within the NHS and beyond.

8. Get PHBs onto different agendas. Delegates said it was important to seek out opportunities to help different players in different parts of the system see that PHBs can help them to achieve their goals, such as integration. As one delegate put it, the sector needs to “become a bit canny” in joining up the dots.





## 4. GOOD EXAMPLES OF COLLABORATIVE WORKING

**It is important to record some of the very positive examples of partnership working presented at the events. The points below are by no means exhaustive but illustrate the breadth of positive developments that were identified.**

We heard from one partnership about the importance of understanding the organisational drivers of “the other side” and appreciating the pressures that these drivers bring. For CCGs, the drivers tend to be pre-defined numerical targets (e.g. numbers of PHBs); VCSE organisations by contrast are more usually driven by the need to meet the health and wellbeing outcomes of groups or of geographical or cultural communities. We were told that the fact that the CCG lead in the area concerned had previously worked in a voluntary organisation helped enormously in fostering mutual understanding and in maintaining the developing relationship. This sort of understanding is particularly relevant when partners come under pressure to deliver against organisational imperatives.

**A second partnership provided some specific “tips” for VCSE organisations who are finding it hard to identify who to talk to in the CCG, and then to build a good working relationship.**

- 
- Put time into following a trail to the right person, (“contact someone you know already, ask questions.... don’t be deterred if it seems no one can help...”)
  - Think about the precise questions you need to ask (“who is it best for me to talk to about the CCG’s offer in relation to PHBs?” “who can I talk to about continuing health care and PHBs?”)
  - Persist – “Don’t give up!”
  - Maintain relationships. Once you have an established contact, ask to meet, put time into developing the relationship, and don’t be thrown if the person leaves. If this happens, try and make sure you find out who is taking over and get to talk to the new person early.
  - Invest time and emotional energy into managing the relationship with the CCG – it will probably pay off.
- 

A third partnership talked about how their developing relationship had been helped by a decision to focus in on a defined group of people – in this instance people with MS. This was a relatively circumscribed group, with some specific shared issues and challenges – and this fact meant that the PHB support offer could be shaped accordingly. This work built upon and further developed an already existing positive relationship between the CCG and the local Age UK. We were also told that here the original approach came from the voluntary organisation, who contacted the CCG to say, “We think we have something we can offer you...and this is how.”

A fourth partnership explained that the joint VCSE-CCG work on PHBs built on a strong pre-existing relationship. This enabled them to agree a menu of support to a wider range of potential PHB holders, and to do this through a model which involved close joint work on the ground, including joint staff visits to address issues with which individuals were struggling. The services which the VCSE organisation provided in this instance included recruitment, induction and supervision of Personal Assistants; support with payroll and HR functions; and a liaison role on the PHB holder’s behalf with other local organisations.



# 5. VOLUNTARY VOICES' PERSPECTIVE

**Voluntary Voices believe that it is critical that there is a continued commitment to help the VCSE sector to make the most of the learning accumulated in the years we have worked on this and related programmes. Our learning is not value-neutral: it is informed by our shared commitment to and belief in the capacity of local people and local communities as the bedrock of a new NHS.**

This learning is also informed by the VCSE's unique position: to a large extent, we are constituted by these same local people and communities and can therefore help in ways which statutory organisations cannot.

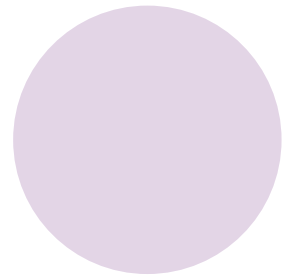
The VCSE has a unique role in ensuring that change is inclusive, genuinely moving power to communities, including those sections of communities that are most disadvantaged and distant from decision-making.

It is with and through the VCSE that individuals and communities should be enabled to engage and inform the design, commissioning and provision of personalised health and care services.

For **Volunteering Matters** the contribution and value of volunteering and social action is central to this programme. This point was also made by several delegates who attended the events. Volunteering and social action can be the way of shifting from what is essentially a deficit-based view of the world ("what's the matter?") towards an asset-based view ("what matters to you?"). The range of roles which volunteers might play in delivering IPC and PHBs is very broad and only now beginning to be explored and understood. For more on this see our [Top Tips guide for Realising Person Centred Care through Volunteering](#) and the report by Alex Fox for Think Local Act Personal (TLAP) on [Asset Based Areas](#).

**National Voices** has pioneered and championed person-centred approaches in health and care for many years now. The intent is that people must retain or gain as much control and influence as possible over decisions that affect their own health and care – as patients, carers and members of communities. We expect that people are partners in the design of services and partners in research, innovation and improvement. Our experience is that co-design and co-production are the keystones of success in programmes like IPC; these programmes will stand or fall to the extent that they embrace these values and approaches.

**NAVCA** is the national voice of local social action, the membership charity for local voluntary sector infrastructure – the people who help others set up and run charities and community groups. Our strongly held view is that, to succeed, the IPC programme and PHBs need the expertise our members offer. We are familiar with the points made by delegates about culture and about business planning: this is why VCSE infrastructure organisations are of such critical importance and it is why we base our work on collaboration and the promotion of understanding and excellent communications.



# CASE STUDY 1: WARRINGTON

## **The NHS and the VCSE working together for better care at the end of life**

The programme led by Warrington CCG to provide more personalised care when someone is approaching the end of their life is a great example of how NHS systems can operate in *flexible* ways to meet the requirements of specific groups of people. An acid test of healthcare systems is how responsive they are to very sick and terminally ill patients.

Whilst PHBs are becoming well established for people in receipt of continuing healthcare funding, there was some local scepticism as to whether the programme could be extended to those in need of fast track funding for end of life care – people whose conditions are deteriorating rapidly and who need to get a support package put in place quickly, sometimes within 48 hours.

Warrington is one example where this has been achieved. The programme was led there by Sarah Leach, the PHB Implementation Manager in the CCG. (There are four other CCG areas where similar work is in train: Crawley, Horsham and Mid Sussex; East Lancashire; Northern Eastern and Western Devon; and South Derbyshire.)

## **This ground-breaking work in Warrington is built upon a critical contribution from local VCSE organisations:**

- St Rocco's hospice in Warrington is the main delivery partner in this programme, providing the specialist care and support that PHB holders in end of life care rely on;
- Input from the much-respected Cheshire Centre for Independent Living (CIL) was also critical, drawing on many years of experience in supporting social care personal budget holders and more recently, PHB holders. Staff from Cheshire CIL worked to help the specialist hospice staff identify how best to get alongside people and identify the health and wellbeing outcomes that make sense to them – and to think creatively about how these outcomes might be met;
- and as more people have taken up the offer of a PHB, other community organisations with specialist skills, for example in helping people manage anxiety, or in addressing specific practical issues, have come to play a part.



This work is premised on excellent working relationships between statutory and VCSE organisations in the Warrington Borough and on an appreciation of the individual needs of every person served. It is also based on a sophisticated understanding of the different components required to make the PHB process effective, efficient and responsive.

More than 100 people in Warrington have already benefited from holding a PHB towards the end of their life; and the programme is now extending its reach to support people leaving acute hospitals to help them experience a good death in their own homes.



# CASE STUDY 2: BEDFORDSHIRE

## The Disability Resource Centre

The Disability Resource Centre (DRC), based in Dunstable, has a long record in supporting people with social care personal budgets. Four years ago, they began work with Bedfordshire CCG to build on this experience with a view to providing support for holders of PHBs.

The DRC has developed a comprehensive menu of support from which people can select. Melanie Hawman, the CEO, makes the point that if support is to be truly “personal,” people need to be able to make their own decision about how “hands-on” they are and how much others do.

Some PHB holders are clear that they want as much control as possible over their support services: For many, this means they become employers of Personal Assistants. They therefore need to have access to the tools and the support that makes this possible. These tools include assistance with budget management, financial returns, recruitment, payroll, employment advice and other on-going support.

Other people require specific support in relation to payroll support, and this includes: employer registration, full payroll process from timesheet to payslip, changes – i.e. new employees and leavers, annual leave calculation and record, HMRC reporting, ongoing payroll advice and pensions support.

And other people need support to enable them to hold accounts: initial checks and setup, managing funding, payments oversight, managing expenditure, payroll support, financial returns and reconciliation, personal contributions and ongoing support.

### **One parent, who holds a PHB on behalf of her adult daughter, comments:**

***“As hard as it is to watch my [adult] child deteriorate and how difficult being an employer has been at times, I wouldn’t change a single thing. Having a PHB has helped me keep us together as a family for longer and with a better quality of life.”***

This approach – offering a range of support options to suit different individuals and circumstances – mirrors best practice in social care personal budgets. It recognises that there is an administrative burden associated with holding a personal budget and people need differing kinds of help with that. It also builds on guidance from Think Local Act Personal and Skills for Care. A flexible approach of this kind based upon learning from the field of social care, which pioneered this way of working, must be the route towards a truly *integrated* health and social care system with the person at the centre.



## 6. NEXT STEPS: STRATEGIC

**The final section of this report is addressed to NHS England, who commissioned this work; and secondly to organisations from within the VCSE sector who are its primary audience.**

Voluntary Voices' work for the IPC Voluntary Sector Partners Programme was commissioned with the intention of *building local networks of support* for VCSE organisations, so those organisations might play a role in PHB design and delivery. This is a small part of a much deeper ambition in health and social care, one articulated in legislation in the Care Act (2014) as the *wellbeing* principle; and in similar terms in chapter two of the *NHS Five Year Forward View*.

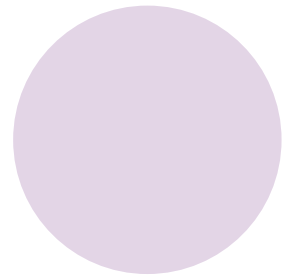
**This ambition comprises no less than a wholesale re-thinking and re-definition of what it means today to be a professional, a clinician, a client or a patient.**

It involves deep shifts in the basis of knowledge, of power and of responsibility. It involves a shift away from the traditional "medical model" whereby the doctor always knows best. Some have described this as a recalibration of the fundamental contract between the citizen and the state and services which mediate this relationship. As such the challenges involved are significant.

Based on our learning from this programme, the Voluntary Voices partnership suggests the following actions:

1. Work to provide more intensive support to a small number of CCG-VCSE partnerships across the country. Select them based on their potential and diversity. Advise, assist and learn from these partnerships and publicise the learning.
2. Seek to find ways to put the issues highlighted in this report in front of CCGs. Meet them on their own ground, try to show how working in this way can assist them to meet their goals and hit targets.
3. Provide further support for local networks of VCSEs to work on person-centred care and PHBs. Several embryonic networks were identified in our work, but most will only survive if properly resourced and supported; in return we should find ways to require that the networks demonstrate their value.

4. Continue to promote the values and principles of person-centred care with citizens and support them to build demand. Gather more inspirational stories of personal change and put these stories in front of the wider public.
5. Seek to restore capacity to the VCSE sector and for its mission. Restore and ring-fence funding for infrastructure organisations; take proactive steps to promote volunteering and social action in relation to person-centred care; and ensure that co-design and co-production (“nothing about us, without us”) are built into all health and care specifications.



# 7. NEXT STEPS: FOR THE VCSE SECTOR

**The primary audience for this report is the VCSE sector. In addition to the broad recommendations outlined above, we have several suggestions for the sector.**

1. Think through and define what it is that your organisation can offer. Be clear as to whether you can support PHBs and/or the wider person-centred care and support agenda.
2. Be prepared to change or challenge your way of working and delivering services, possibly fundamentally revising how you operate.
3. Think about what it means to work in partnership or consortium with fellow VCSE providers. Talk to others about this.
4. Find a way to build strong relationships with your CCG and local authority. Engage them in discussions about personal budgets, PHBs, integrated approaches and person-centred thinking and planning. Try and get them to appreciate how by working together you can help them meet their legal duties and hit their targets.
5. Join with others in doing this, make use of the resources and influence of your infrastructure organisation where possible. Where there is no effective infrastructure organisation, work out how else to get support.

## CONCLUSION

Personal Health Budgets (PHBs) are an important and exciting innovation, whose potential is only now just beginning to be realised. If approached in this light, they will be a launch-pad for a better health and care system for people with multiple and long-term conditions. They will also be a key component in our collective drive to build a different and more liberating style of public services and a new manifestation of what it means to live and participate in caring communities.

If this vision is to become a reality, then VCSE organisations have a pivotal role to play. These organisations often grow organically from our communities and are at their heart. Theirs is not a role that statutory organisations are able to duplicate. For this reason, it is imperative that all those involved in developing, promoting and advocating for PHBs and other person-centred approaches collaborate to create the sort of vibrant local alliances we have attempted to describe in this report.

