So far:
Lord Darzi announced in his NHS Next Stage Review that in 2009, we will start piloting personal health budgets, as a way of giving patients greater control over the services they receive and the providers from which they receive services. The pilots will draw on the experience of other health systems and in social care.

Since then we have been talking to a whole range of people about their reactions to the news, and the work they are already doing to increase personalisation in healthcare. This note starts from where the “Initial Information” sheet from July left off, so get in touch if you’re looking at this in isolation as you may find the first sheet helpful as background.

Where are we up to?

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The diagram sketches out the overall process we are following. It’s worth remembering that of the different budget models we sketched out, direct payments will not be available until the legislation is in place, i.e. from 2010 (subject to Parliamentary process). This will give people time to increase their experience of other models possible within existing flexibilities (eg a notional budget held by the PCT, or a real budget held by a third party) and put systems in place before tackling the challenge of administering direct payments.

The period from now until November/December is the crucial time for getting in touch to help form the policy and share any concerns or advice. We are talking to people both outside and inside the Department, both informally and at major events. We will set out key learning from all our engagement, together with the scope and principles of the pilot programme, in a document in December this year. At the same time we will ask for formal expressions of interest to take part in the pilots, but the document itself should be useful for anyone starting out in this area, not just organisations wanting to be formal pilots. Overleaf you’ll find a bit more about what we’ve heard over the past few months.
Focus on Staying in Control
On 18th September, In Control (http://www.in-control.org.uk/home.php) officially launched a programme called Staying in Control. Staying in Control represents a community of 36 PCTs and their partner LAs who are exploring how personalisation models tested in social care can best be amended and tested within the NHS. It is led by early innovators who are working collaboratively to produce a first practical model - considered and debated across a range of different conditions and care needs - of how personal health budgets can be applied in parts of the NHS. For more about the Staying in Control programme, please contact Rita Brewis, rita.brewis@in-control.

What’s the connection between the DH pilot programme and Staying in Control? The Department and Staying in Control have agreed to work very closely together. Staying in Control is a valuable developmental programme which is well-timed to inform the DH pilots next year. The programme will highlight some of the key changes and developments needed to make personalisation a success in practice. We will feed this very valuable early learning and experience into designing the DH pilot programme, which will provide robust information about the operational changes needed and the long term implications of personal health budgets. We hope some of the Staying in Control sites will want to become part of the DH pilot programme, and that we can build a learning community together of all those interested in this issue.

Focus on staff
We’ve engaged widely with PCT and LA staff so far and increasingly over the next few weeks we’ll be looking to build stronger links to key networks and communities of frontline staff who be crucial in developing personal health budgets with people and supporting them to use them. We therefore want to involve these groups at this early stage not just to help design the pilot programme, but so they can tell us what support they need to help them deliver.

Focus on patients, users, carers
We’ve already sought input from many representative bodies about their views on personal health budgets, and what they think are the key challenges. However, we’re looking over the next few weeks to hear more from patients, users and carers themselves, either independently or through user-led organisations. At events we held recently where we were lucky enough to hear from speakers from the US about their experiences with self-directed support, they really emphasised the importance of peer support. Please do forward this leaflet around to anyone you think might be interested and get in touch.

Signposting other key areas
Many different areas of policy connect to personal health budgets. Getting this right in an organisation will depend on different teams working together – so one of the most obvious links is to work on Integrated care. You may well have heard of the Integrated Care Network (ICN), one of the CSIP networks, who have already developed materials to help people work together and with whom we are also working closely. You can find out more about ICN and CSIP via this link: http://www.networks.csip.org.uk/icn/. Another link in the same area is to the Integrated Care Pilots, also announced in the Next Stage Review – expressions of interest will be invited next month. (http://www.dh.gov.uk/en/Healthcare/IntegratedCare/index.htm)
Personal Health Budgets

What we’ve heard so far
It’s obviously still early days, but there have been some consistent themes and we were particularly pleased at how people got stuck in at the major event we held on 24th September for PCTs and LAs who had particularly expressed an interest. What you’ve told us covers issues of principle, scope, context and systems:

Don’t be too restrictive about who could be offered a personal health budget – think about the types of services, rather than conditions, and what would most benefit the individual….

This is about personalisation, not about money. In some cases, the budget may be the lever for the other changes necessary to bring about the personalised approach. In other cases the same outcomes may be possible without a personal health budget being in place - the person-centred approach is the prize.

A clear explanation of how Personal health budgets fits with other areas of DH policy like World Class Commissioning is needed.

…not everything should be included within a budget – e.g. acute/emergency care, elements where there is very little choice (e.g. certain drugs or interventions where there are no alternatives)….

…in terms of getting going though, some areas seem to offer particular opportunities, e.g. mental health services, maternity, substance misuse, NHS Continuing Healthcare and long term conditions…so far.

There will need to be careful risk assessment, and a healthy attitude towards taking appropriate risks, with the appropriate safeguards in place – both financial and clinical. Regular monitoring will be essential.

Don’t let personal health budgets slip from being voluntary to mandatory.

Making this work needs wholesale cultural change.

More help is needed understanding what existing mechanisms there are for setting up personal health budgets.

Information and support for the individual and their carers/relatives is crucial.

Some thoughts on some of these aspects overleaf…..

Comments? Questions? please write to personalhealthbudgets@dh.gsi.gov.uk
Making Progress – acting on what we’ve heard so far.

We’ve really appreciated your input so far on what needs to happen to make this work (see snapshot on previous page). We want to design the pilot programme with you - so do let us know if there are things we’ve missed. Think innovatively, think broadly, think about the key communities in your area that might be missing out at the moment.

We can’t answer all of your questions. In particular, some people asked us to set out precise details for the pilots – indeed, what exactly a personal budget will look like. The reason we can’t do that is that organisations need to put in place the people, resources, and systems appropriate to the particular aims of that project and the local situation. Then, each budget needs to be arranged in a way that works for the individual.

That said, there will be certain pre-requisites both in terms of systems and principles – e.g. the capacity and capability to draw up person-centred care plans; the existence of safeguards to make sure no one is denied care if the budget runs out; robust local partnership arrangements. These will be set out in the December document. We currently anticipate most pilots will be PCT-based, with close ties to Local Authorities. However, it’s clear that other organisations (e.g. mental health trusts) may be well placed to host a pilot and we would welcome thoughts from you on this.

The best place to start understanding what’s already possible is with existing experience in social care. You might find the principles in this guide helpful: http://www.networks.csip.org.uk/Personalisation/PersonalisationToolkit/Blueprint/ManagingtheMoney/. We understand that many of you have particular concerns around legal boundaries and we’ll do our best to make things as clear as possible in the December document. However we won’t be able to advise you on specific situations so you would have to seek your own legal advice.

Finally, the point about “cultural change” poses perhaps the biggest challenge - it will never happen if we try and lead it from Whitehall. Those hoping to become pilot sites will have to engage internally and locally, involving clinicians, patients, service users, partner organisations and local third sector organisations who might help provide that all-important advocacy and support role.

Next steps

We will continue to talk to key people and organisations to inform the policy development, but don’t wait for us to call you! Do get in touch if you have something to offer. In the next few weeks we hope to set up a DH website as well as working with colleagues to develop a learning community that we hope will help people share their experiences and vision for personal health budget more directly. For now, please keep in touch with us via the mailbox.