



Registered Charity No. 292157

Personal Health Budgets

Workshop to explore patient/public perspectives

Birmingham: 26 February 2009

Introduction

This workshop was organised to gather the patient/public perspective on the introduction of personal health budgets. Twenty-eight PPG members attended from nineteen different Groups. Stoke on Trent Community Health Voice was also present. The event was commissioned by Terry Hawkins, Joint Programme Director for Personalisation at Stoke on Trent.

The day began with a presentation from Terry followed by extensive questions. Delegates then worked in smaller groups to consider some of the most important elements of personalised health budgets, including when they are like to be most/least effective, the associated risks and the needs of patients. The session closed with a general discussion and some reflections on possible next steps.

It is important to note that views differed considerably as to the desirability of personalised budgets, how they should be introduced and the risks associated with them. This note simply reports on the differing views so that they can all be taken into account by those responsible for piloting personal budgets in health.

Understanding personalisation

Personalisation is part of a far-reaching set of changes to the way that public services are provided, known collectively as transformation. This will require all services to see health as part of their business. Transport, leisure, housing etc all have a part to play.

Terry's presentation identified four components of personalisation, namely:

- Universal services
- Early intervention and prevention
- Social capital
- Choice and control

The focus of the workshop was primarily on choice and control through the piloting of personal budgets. These would be similar to the direct payments currently offered by social care but would cover health services as well. Individuals would have control of a budget, if they wished, that might purchase personal help, transportation, laundry, insurance, kitchen and other appliances, medications and medical equipment.



Direct payments have brought a number of benefits to service users and carers, especially in the areas of quality of life, choice and control and personal dignity. Innovations in the area of personal health budgets might include art/music therapy, mediation, acupuncture, massage, fitness, social activities, peer support and so on. One of the main challenges of personal budgets will be to maximise choice and control while effectively managing risk.

In Stoke, 700 people are on direct payments. The authority is keen to spread the benefits to at least some of those who use health services. It is therefore bidding to become a pilot area. Funding will be provided by the Department of Health and the closing day for submissions is 27th March. Pilots will run for three years before a decision is made on their extension. This workshop was designed to help to inform the Stoke bid.

Questions arising from the presentation

What will be the review process for users of personal health budgets?

This has still to be determined. Terry is aware of the risks that the money will be spent too quickly, that it might be spent unwisely on unregulated services, that there may be financial abuse and that arrangements might break down. So, the review process will have to manage these risks - any monies will be transferred on a monthly basis for example.

Can personal health budgets support healthy living?

Yes, they can and there is already some evidence internationally that they can lead to shorter hospital stays and to a reduction in the use of services.

Will the budget take the form of a cash payment?

That is one of the options that are open to people. Monies can also be transferred to third sector organisations or managed by the local authority itself.

Are Primary Care Trusts currently providing personal health budgets?

Personal health budgets are already legal using either third party payments or notional budgets held by the statutory body. Legislation will be required to allow cash payments to be made for health care in the pilot areas only.

Why haven't the two existing legal routes been more widely deployed?

It is a significant cultural shift and, in fact, the two options only became apparent as a result of legal challenge and the subsequent court ruling. There are also concerns about the difficulty of calculating a personal health budget in health since the NHS, in general, finds this more complicated than social care.

What will happen if people overspend?

The budget will be reviewed to see if it was set correctly initially. In direct payments, the spend has typically been reduced by 10-20% and one issue



has been whether any underspend can be carried over into the next year. This tends to be agreed after negotiation.

Is the scheme going to be compulsory?

Personal health budgets are going to be voluntary and service users can choose which services they want to include.

Is this a further step towards privatisation?

This is a legitimate concern but it needs to be set against the benefits to those who will be managing their own budgets. Those who oppose any fragmentation/privatisation of the NHS may also be reassured by the fact that steps are being taken very cautiously and are being evaluated at each stage.

How will the transition to the new system be managed?

There is a worry that the new system will have to be managed on top of existing workloads. However, the pilots will be given additional money to manage the transition and, if it is successful, it should reduce the pressure on existing services.

Will it encourage greater personal responsibility for health?

The NHS is undergoing a major shift away from being an illness service, recognising that prevention is a really high priority for most patients and the public more generally.

Who will carry out the assessment on which the budget is based?

A range of staff will be trained and supported to carry out this role, including some combination of social workers, community nurses, practice nurses etc who are willing to do so.

How will medication issues be managed?

Patients may want a more expensive drug than is recommended by their GP. But that is not a new issue under personal health budgets. Already, patients have to negotiate with their clinician to get the best care for them and their family, while the clinician takes a wider view on the overall use of resources.

What about people with their own assets?

Health will remain (largely) free at the point of delivery but the issue does become complicated when the service user is having to pay for any social care under the current means testing arrangements. This will require clarity about the demarcation between health and social care.

How will this encourage health and social care staff to work together?

Historically, the values between these two staff groups have been different. Both can feel sceptical about the prospects for success but integrated teams are increasingly common and the journey to develop a shared culture is well and truly under way (though not always as fast as it should be).

Delegate Feedback

Settings in which personal health budgets are most likely to be effective....

- Managing obesity
- For people who are able to control their care
- For responsible people who take care of their health
- To promote preventive care
- Help smokers to quit long term
- Ongoing conditions like diabetes or thyroid problems
- Those already in receipt of services who want an alternative model of care
- Long-term conditions where the future paths are fairly predictable
- Health prevention and promotion to keep people healthy
- Cases where there are clear options for services and support
- To promote individualised care in hospital

Settings in which personal health budgets are least likely to be effective....

- Dementia
- Pre-diagnosis
- Where people won't take care of their health
- Where there are no other options eg emergency services
- Elective surgery
- To top up treatment
- People with complex care needs
- Where there is no agreed health plan
- People who live alone without support
- Some mental illnesses
- Where professionals are hostile

What are the risks of personal health budgets?

- Use of budgets in ways that are not socially acceptable
- Abuse of budgets by a family member or third party
- Patients not understanding the options or the evaluation
- Lack of flexibility in the Health Plans
- Health Plans may be incomplete
- Vulnerability of patients when negotiating with providers
- Clinical governance issues, liability, accountability
- Integrating health and social care cultures, charging and IT systems
- Affordability, including cost of implementation and monitoring
- Patient safety
- People who run out of the money that is allocated

- Managing language and cultural differences
- Moving further down the road to privatisation
- Patients may have to “top up” to get all of the care that they need
- Conflicts between patients and clinicians about care plans, treatment, medication etc
- System may be communicated poorly
- Patients who lack skills to manage budget themselves and don't have proper help and support from others
- Generation of unequal health services
- May increase health inequalities
- Overstretched workforce
- Appeals regime may not work well for patients

What do patients need in order to make a success of personal health budgets?

- Maximum information
- Directory of local services and support
- Knowledge of banking system
- Financial advice
- Holistic approach by different professionals
- Clear guidance
- Named coordinator
- Robust support plan
- Effective support organisation
- Trust between patients and professionals
- Better colocation of relevant services to ease patient navigation
- Education of patients to know when action is needed eg prevention
- Direct telephone line for ongoing support

General discussion

In several cases, delegates' views on personal health budgets had shifted during the morning. Some general comments were:

- Piloting is crucial and the pilots need to be learnt from
- NHS does need a big shake up to recognise the individual
- Principle seems fine but it may be expensive to administer, open to abuse, confusing and there are sure to be major teething problems
- Model has worked well in social care
- Concern that people will find themselves paying for health care
- Scheme needs to generate improved health outcomes, not just improved experiences
- Advice and support will be of paramount importance
- Not clear how we can navigate from the current realities of the NHS to the personalisation plan.

Evaluation

To be judged successful, the pilot should deliver:

- An effective working model of joint health and social care interaction
- Reduced dependency on medication
- 10%, say, of total expenditure coming through personal health budgets
- Demonstrable patient benefit using quality of life and patient reported outcome measures
- Increased clinician support for the model
- Clarity on what is covered and what is not
- Patient expectations met or surpassed
- Detailed demographic and socioeconomic data on who has benefitted
- Data on anyone who was turned down and on the reasons why patients chose not to take part
- Success relative to other pilot sites
- Improved supplier side of care
- A well-regarded independent arbitration and complaints service

Next Steps

Please let Audrey know which of the following describes your personal position (you can choose more than one):

1. No further involvement
2. Receiving occasional emails (for information) on the progress of the pilot
3. More detailed involvement in thinking through the next steps (the virtual working group approach) handled by email
4. Attendance at a review meeting in September (with expenses paid)

Thank you

Our sincere thanks go to everyone who attended and to Terry Hawkins for commissioning the workshop. This report was finalised after delegates were given a month to suggest any corrections and improvements.

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