



Gearing Up for Personal Health Budgets

Report 2015

Round One

Summary Report

Personal health budgets are an allocated sum of money to help people meet their identified health and wellbeing needs, as planned and agreed between the person and their local NHS team. The aim is to give people greater choice and control over the healthcare and the support they receive.

People in receipt of a personal health budget work with their local NHS team to develop a care plan that describes:

Their individual health needs

The health outcomes they want to achieve

The amount of money in the budget

How the budget is going to be spent



The Gearing Up programme is commissioned and supported by the Personal Health Budgets delivery team at NHS England and Peoplehub were one of the original partners and played a key role in inputting the voice of people with lived experience of a personal health budget into the programme.

Introduction

The personal health budget programme was launched by the Department of Health in 2009 and an independent evaluation was commissioned alongside the pilot programme.

In 2009 an independent evaluation was commissioned alongside the pilot programme. The evaluation of the pilot programme showed that the benefits of personal health budgets depend on how they were introduced. For best results people should know the budget up front with advice and support available, choice and flexibility over how to spend budget and choice on how it is managed.

Major findings of the latest health POET (Personal Outcomes Evaluation Tool is a practice based evidence research tool which evaluates how a range of intervention effects people's outcomes in life, in this instance it was personal health budgets)

- The majority of personal health budget holders reported their views had been included in different aspects of the personal health budget process.
- A small but significant number, around 15% of personal health budget holders said that some aspects of the process were difficult for them.
- The overwhelming majority of personal health budget holders reported their budget having a positive impact on their quality of life, independence, and arranging support.
- More than two thirds of personal health budget holders reported their budget having a positive impact on their self-esteem, feeling safe, control over life, family relationships and dignity.
- People who felt their views were fully included at key parts of the personal budget process (needs assessment, support planning, budget setting) were significantly more likely to report a positive impact of their budget.
- People who found different aspects of the personal health budget process was easy were more likely to report a good outcome.
- Over three quarters of carers said that the person they care for having a personal health budget had made things better or a lot better in 5 of the 8 aspects we asked about.

Personal Health Budgets, If you are going to do it...
do it right.



What did the programme aim to do?

In April 2014 NHS England working with In Control invited community and voluntary sector organisations to apply to take part in a community development programme to support local organisation to give advice and guidance to people (adults eligible for NHS Continuing Healthcare and children in receipt of continuing care) who wanted to find out more about personal health budgets.

“I do not think the engagement with the sector would have happened at such an early stage without Gearing Up.”

This was in recognition that the investment to roll out the NHS personal health budgets agenda needed to be with communities and people alongside the input being given to CCG's and other statutory organisations.

30 local organisations took part in the programme and were given a small grant administered by In Control. 3 of these organisations who already had extensive experience acted in a mentorship role to organisations that were new to this agenda.

Clinical Commissioning Groups have a responsibility for the delivery of personal health budgets and also to provide information, advice and other support to eligible persons and their representatives to assist them in deciding whether to request a personal health budget in respect of a relevant health service.

Evidence from the PHB pilot Evaluation showed that to work well, personal health budgets need

- **good support from all parts of the system**
- **co-production with people with direct experience**

The Gearing Up programme was set up to equip local voluntary sector organisations with more knowledge and connections around personal health budgets so they can be ready to support the demand and ensure that information is available locally for people.

The organisations who joined the programme were supported to develop their knowledge and understanding about personal health budgets by attending a series of development days. The development days looked at different aspects of delivering personal health budgets and gave the organisations opportunity to network and explore the personal health budget process in-depth.

The programme helped ensure:

- **Local information was available** That voluntary sector organisations are able to help people and families get a good sense of what should be expected from the NHS, and equip them with the information and policy to help them get a personal health budget in line with established national best practice.

- **Support was available for initial demand**

That, for a small number of people and where necessary, voluntary sector organisations can support eligible people to get a personal health budget, including offer some advocacy and mediation support where needed.

- **Opportunities for voluntary organisations to work together with CCGs**

That voluntary sector organisations work to develop productive relationships with CCGs and support them to introduce personal health budgets well.

- **Opportunities for partnership, support and co production**

That voluntary sector organisations support the development of local partnerships and connect to people who are eligible for personal health budgets to help them understand their right to ask for a personal health budget and what this might mean for them. Help people make the first steps in getting a personal health budget through their local NHS service.

What happened?

The Gearing Up organisations worked with a range of people, some of which were generic to their organisation and some condition specific. Organisations took different approaches to raising awareness and giving information.

For example

- Hosting carers information days in public locations or GP practices.
- Direct contact with people and organisations through presentations and provider forums.
- Working in partnership with condition specific agencies to run awareness raising sessions.
- Visits with the local personal health budget lead. Information packs with suggested uses for a personal health budgets.

Advocacy played a lesser role in the overall Gearing Up programme but for a small number of organisations advocacy was part of their local offer and in some cases played a significant role in terms of having a high impact on individuals' lives.

Relationships with clinical commissioning groups (CCGs). Organisations reported a range of experiences when working with CCGs. Some of the approaches used when working with CCGs included working with and through the local Health Watch and using this as a networking opportunity, meeting with and working with continuing health care assessors and other members of the CCG to deliver information sessions and in some cases support assessments. Others set up initial meetings with their local CCGs and passed on potential personal health budget recipients to them. One was invited to be part of the Peer Support network for the CCG and shared contact information offering independent advice and support. Some organisations were members of personal health budget project boards and secured service user representative for the Board. Some worked with the NHS England Regional lead who invited them to the regional personal health budget leaders network. Another attended the NHSE Practitioners network and discussed insurance, pensions and delegation of health tasks to PAs.

Some organisations reported that CCGs were not prioritising the roll out of personal health budgets beyond CHC. This has put a brake on the need to engage with the voluntary and community sector (VCS). Others said that there was reluctance to get involved with the voluntary sector for fear of a deluge of requests for personal health budgets. In some areas the CCG had a lot of the support on PHBs already in place and therefore the activity they undertook focused more on awareness

raising. Another organisation facing a similar situation networked with those providing administrative support for personal health budgets and identified gaps in the provision for example advocacy, support planning and peer networks. Others used their Commissioning Support Unit to work through and reach other CCGs. In one case the CSU asked the organisation to co-design a service specification for brokerage locally.

Where organisations were building on good existing relationships, some were able to work at a more strategic level for example working to develop models to support the delegation of health care tasks to personal assistants (PAs). Another co-produced an engagement strategy with the CCG and the local authority and another met with head of partnerships at the CCG, CSU and the personal health budget lead to discuss rolling out PHBs. This led to two events with the CCG on long-term conditions. An interesting development for one organisation is working with the CCG to roll out personal health budgets to the homeless community with local charities.

Working in partnership – partnerships between Gearing Up organisations and other local stakeholders have already been demonstrated above. However broadly speaking organisations developed partnerships with: GPs, social workers, NHS professionals, carers, Health Watch, local authority direct payment team and other VCS organisations.

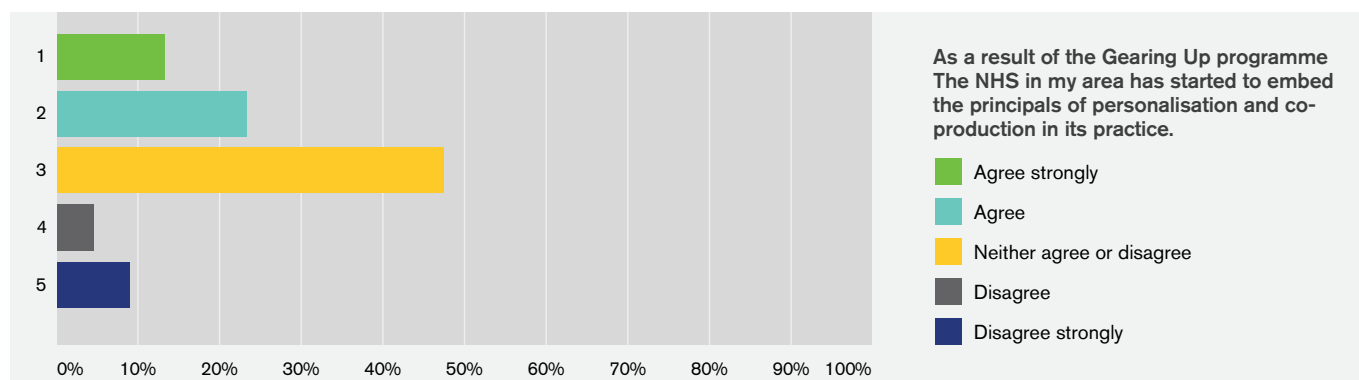


Fig 1. Your experience of the Gearing Up programme IC survey results

What was the impact?

Local people -

Gearing Up organisations reported that the impact of the programme has been slow as well as the take up and work with CCGs. Where organisations were carrying out awareness raising activity then some were reaching up to 500 people.

At a more specific level some organisations were able to meet with individuals and families prior to seeing the CHC assessor to help them understand personal health budgets and to decide if they wanted a budget or not.

One organisation, through the centre for independent living, had contact with Asian communities and supported people who are new to the country.

One group helped local people to make the transition from social care to personal health budgets. In one case the Gearing Up organisation reported no impact on local people as they were not able to carry out any information and advice work or advocacy because the local CCG asked them not too because they were not ready. Others reported that the impact of Gearing Up has highlighted where there are myths and mis-communications about personal health budgets and helped to dis-spell this.

They feel they have a role in hearing peoples' feedback to the CCG and to support the CCG to make changes. Around half felt it had helped to empower patients in their area.

Work with CCGs – One organisation reported that Gearing Up has facilitated the promotion of personal health budgets for the CCG who now refer people to them for independent advice. Many organisations reported that changes in perceptions within the CCG and personal health budget team after working with the VCS organisations. The CCG now recognises that the VCS can be quicker to respond to individuals and be impartial and independent.

They can also be a conduit for engagement and feedback from people. Positive working with the CCG has helped to break down barriers between institutions and the voluntary sector. CCGs have appreciated VCS organisations giving advice to people about personal health budgets and helping think outside the box. Many reported that the work of CCGs on continuing health care was at early stages and many were not in a position to offer a full and complete service. Some organisations have used training in understanding personal health budgets as a way of overcoming hurdles to engagement especially with the CCG and local authority.

“We really valued being part of the Gearing Up programme and it enabled us to strengthen our links with our 2 local CCGs.”

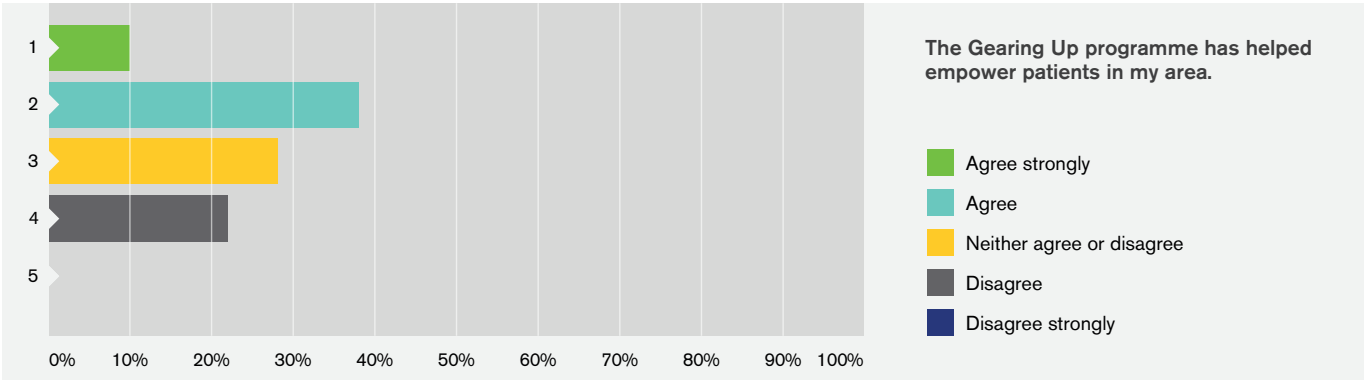


Fig 2. Your experience of the Gearing Up programme IC survey results

Conclusion

The Gearing Up programme revealed a great difference in readiness to move forward with personal health budgets and cautiousness to working with VCS organisations.

However, in some cases there were success stories of building relationships and partnerships that eventually lead to an appreciation of the capacity, expertise and agility of VCS organisations to respond and the added value to the CCG of working in partnership.

Going forward how do we support the VCS sector to support the roll out of personal health budgets?

This can be thought of at a range of levels:

- I Feedback from the programme suggests that there is potential added value in bringing CCGs together with the VCS organisations locally to support the expansion of personal health budgets beyond CHC.
- II A more targeted approach may be required as not all areas will be ready to move forward in this way. There is perhaps some value in considering a regional programme of events that includes more focused activity that is aimed at CCGs and VCS

organisations who are already working with PHBs but who want to develop the roll out and move forward to work with a wider range of groups.

- III At a more operational level there is value in supporting VCS groups to network and problem solve perhaps through an action learning programme or learning networks.
- IV Building links across the other strands of work
- V This mixed picture of progress shows more steps need to be taken >

Next steps will include:

NHSE will be evaluating the second round of Gearing Up organisations and building on key messages.

A national event to bring round one and two organisations together to hear about developments in the wider roll out of personal health budgets, share learning and network together.

Using the intelligence gathered from the evaluation reports to identify areas where we can continue to work with organisations

to establish a reference group to work with the personal health budget delivery team.

Strategic planning event with representatives from the voluntary and community sector and stakeholders to map out on-going support around the delivery of personal health budgets.

Embedding a programme of work at a regional level which aims to bring VCS organisations together at a more local level, create opportunities for CCGs and local VCS organisations to work together to support the roll out of personal health budgets and develop a local offer. This would include linking with Going Further Faster and IPC sites.

References in this doc:

- Evaluation Report of Gearing up round one – Alix Crawford
- Survey response from Gearing up – In Control
- Personal Health budget Holders and family carers POET 2015 – In Control published by TLAP
- PHB publications – NHSE

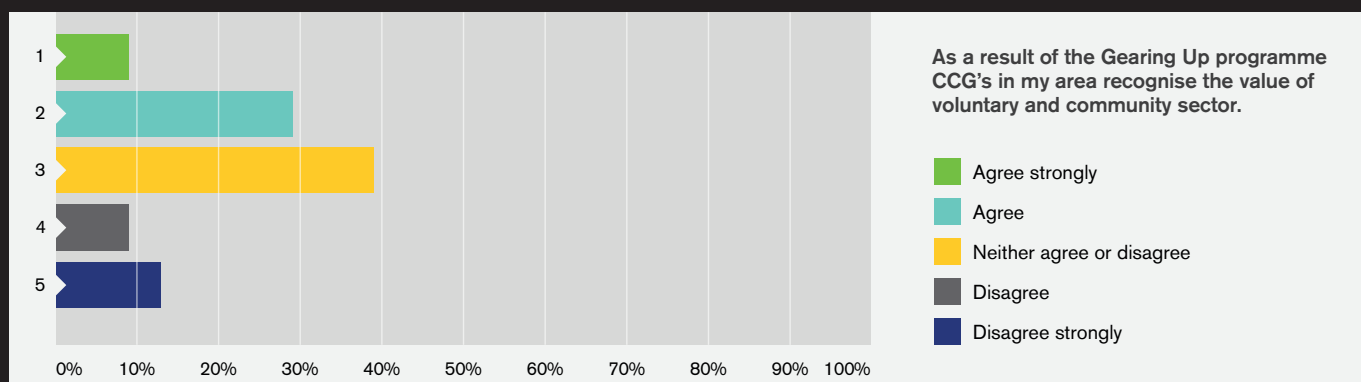


Fig 3. Your experience of the Gearing Up programme IC survey results



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