

# Report framework

## Project write-up

### Background

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

### Project summary

The project started with the appointment of our Project Lead for Personal Health Budgets, Laura Laidler. Laura embarked on a project plan to implement PHB's within NHS Continuing Healthcare within Suffolk. This required involvement from users who would like to help formulate the policies and process's that future users would follow so their involvement from the start was key. Laura also liaised with provider services who may wish to be involved with PHB patients. This culminated in an event where the people requiring services met the organisations providing services so they users could choose their providers. This event took place on the 1<sup>st</sup> October 2014 which coincided with the official national launch of the right to have PHB's.

### Outcomes

The aim of the project was to include patients within the PHB process and help them to develop our policies and procedures going forward through their experience. Due to the complexity of the patients involved in the process, accessing meetings would be difficult but not impossible with the right technology. Therefore we were looking to purchase some form of tablet so that patients could be part of meetings, can be shown presentations and can view information that is relevant to the project in the setting that is most suitable for their health needs. A significant part of the PHB process also involves developing the use of support plans and we wanted to be able to provide patients with a wide range of support planners that could offer this experience and help, however these would come at a cost which required resourcing. From the patient's experience they could then help develop the process going forward for us advising of the services that worked and those that did not and those that offered the CCG value for money going forward.

## Measures of success

The measure of success would come from feedback from patients on their experience, were they able to be involved? Did they feel they had autonomy? Could they openly suggest ways of improving the service in the future? Did they feel in they had a choice in what happened? These are difficult successes to measure as they would be people's thoughts and feelings as opposed to numerical data that could be measured but still just as important as the patient's perspective would develop the service for future users.

## Impact

The project is having a real impact on the commissioning process. It places the control firmly back within the patient's hands and whilst this is new and at times uncomfortable it is an important shift to make. It involves the changing of mind-sets and views that have been held for many years but ultimately is for the benefit of the patient which in turn benefits the commissioning process.

Within Continuing Healthcare and the range of people looking at having a PHB it is clear there are different levels of complexity and needs, this project helps to address some of the imbalance provided within the NHS where the patient is told what is best for them and instead is asked the very simple question of what would help you? A simple question but can have varying answers and so the importance of the PHB project was to respond to these needs in the most cost effective and appropriate way in collaboration with the patient.

## Evaluation

The general feedback from the project was that our processes were slow but understandable given the loss of our project lead at a crucial time in the process. This has hindered progress which has been frustrating however has highlighted to patients the intricate working of the NHS. The feedback from service providers was that we tackled the project in the correct way. The project was started small but thorough rather than start with a large number of people but not complete the project appropriately.

The project has been a steep learning curve for all involved but a very productive learning curve. As previously stated this project has required a shift in mind-set but has had a positive impact as it is patient centred. The project has involved communicating and developing relationship with other CCG's which has been very positive the majority of time and has helped with working relationships. The people involved with the project have been stretched and asked to complete tasks and work they would previously been uncomfortable

The difference made to patients involved is the exploration of a PHB and ability to explore their care package providing the patient and their family the possibility of further options with their care package, increasing the quality of care with the focus of the patient central to this approach. Our patients and their families general feedback appears to show the more options they have the less they feel suffocated into having choice taken away from them.

## Key learning – ‘how to’

### Assumptions

At the start there were assumptions that we could get the project up and running much quicker than experienced and due to the nature of complexity with the patients involved there were inevitably delays that were incurred relating to the patients conditions. Another assumption would be that the project lead would be able to see the project through to the end which was not the case which has again delayed the project, however there have been positives that have arisen from this, like the inclusion of other people into the project that were previously not so involved and again developing those relationships with other PHB project leads to help support.

### Process / methodology

We have had positive discussions with the care providers the CHC team commissions. These care providers are aware of the new role and possibilities PHB's provides and these providers are looking to support the patient at various levels, where they may explore what type of PHB they want as the care package changes may come at any point within the development of a care package. This can be at the request from a patient and or their representative wanting to build a PHB into an already established care package where they start to take a level of control but do not wish to take total control i.e. they are not wishing to be involved in the finance aspect but they do wish to recruit. This approach enables flexibility for the patients when wanting to adapt their personal package of care.

### Impact/effecting change

We are still at a stage where we are developing the application of PHB's and are keen to continually learn from the opportunities this presents. The Suffolk CHC team has been influential in promoting the roles of PHB's to our patients in Suffolk where we have met with user groups and professional alike (such as local GP's) to advocate the value in this and need for all to embrace this as we can only then provide the service with a unity the

patients deserve. Alongside this the staff of the CHC team on a daily basis discuss the potential impact PHB's may have where we explore where this can be implicated. Our team has a new PHB lead now in post who will explore new ways in advancing this further so that patients may access this with greater ease.

## Shared learning

- 1) Start small but thorough and then build
- 2) Expect delays – these are inevitable and not a failure – learn from them
- 3) Communicate to all people regularly – even when receiving news they did not want  
- people appreciate good communication

We are focused on seeing the patients eligible for a PHB's to have space to feed back any learning as we fully expect challenges will occur yet we are looking to respond to this as the patients deserve and expect. Their maybe areas where a care package has a reduction in cost yet the quality is increased as the patient and or their representative is at the heart of the decision making and is allowed to take responsibility to do so with the support of the CHC team. We will be looking to report internally on how these cases develop as they grow in number we will know more of how to evolve the structure and advertise the critical need for a PHB when applied to the right person.

A positive attitude was important as significant challenges were faced along the way and good communication was important with patients and providers. Everybody wanted the project to move as quickly as possible but all involved appreciated communication when things did not progress as anticipated.

## Lessons learned

Opposition to giving patients the control and freedom to determine how their money is to be spent and the nature of complexity of patients involved means their thoughts, feelings and ideas are difficult to account for and predict what will happen when. The loss of our project lead was disappointing and a setback in the projects progress as there was no one to take the project forward and the same pace in their absence but did give people that were not previously involved the opportunity to be a part of the project.

More time to implement the project appropriately would make a huge improvement in the quality of the project. Involve more people within the roles so that when one person leaves there is someone to succeed that role and take projects forward.

We have learnt a lot and as professionals we have applied our skills in adapting to the challenges our clients face when forming a PHB.

## Evaluation

Evaluation has been delayed so we will hope to evaluate the project once a new project lead is implemented and can take this project forwards. The initial feedback is positive from patients so this is encouraging.

## Quality assurance/accountability

Within the Commissioning role our providers that exist already are one approach to being able to have sight of a developing PHB. We aim to work closely with the patient/representatives so to fulfil accountability to the developing PHB's while accessing the other healthcare professional such as the district nurses when monitoring of the package of care especially where the patient was unable to represent themselves.

The very essence of the project is to involve the patient and for them to be in control of their finances and the way the money from the NHS is spent.

The project is part of the wider approach the CCG has to its CHC patients and would have been addressed in some format. However the funding has provided greater opportunity and potential to affect our patients at a greater rate where we can advertise the potential in PHB's with user groups which the funding then becomes a corner stone in supporting. This funding has also demonstrated to the public the CHC team through the CCG takes the implication of PHB's very seriously and we are looking to grow the support, education, promotion and awareness of the person centered approach which we are extremely grateful to the Patients in control Programme.