

Personal Health Budgets for Carers in Northamptonshire: An Evaluation

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The Centre for Health and Wellbeing Research

The Centre for Health and Wellbeing Research (CHWR) is the product of a partnership between the University of Northampton's School of Health and NHS Northamptonshire. Launched in 2008, CHWR prides itself on working closely with commissioners and we strive to respond effectively to the needs and aspirations of our clients. We believe that the level of experience each member of our project teams brings to our studies significantly enhances the resultant outcomes.

CHWR is fully resourced to undertake evidence review and primary data collection using both quantitative and qualitative evaluation methods (e.g. large questionnaire surveys, social surveys, one-to-one interviews, SPSS analysis, focus groups, in-depth discussion groups, semi-structured and open interviews, and tape transcriptions). All members of project teams have extensive experience of research and evaluation projects.

During 2009-12 members of this project team have successfully contributed to the following research and evaluation projects:

- Early Lung Cancer Detection in Corby (an NIHR portfolio study commissioned by the British Heart Foundation).
- Examining Drinking Cultures: Motivations and behaviours of young people who binge drink in Northamptonshire (project commissioned by Northamptonshire Partnership).
- Resilience and Families with a disabled child: A review of the evidence (literature review commissioned by Scope).
- Supporting Successful Transitions: How do patients in medium secure units react to environmental change? (project commissioned by St. Andrews Healthcare).
- An evaluation of the Pilot Healthchecks scheme in Northamptonshire (project commissioned by NHS Northamptonshire).
- An evaluation of the General Practitioner Referral Tool, Pathfinder (project commissioned by Nene Commissioning).

Executive summary

Aim

A pilot of carer Personal Health Budgets (PHBs) was instigated as part of the Northamptonshire Carers Strategy Demonstrator Site in 2011, in partnership with one of Northamptonshire's Clinical Commissioning Groups: Nene Commissioning. The Centre for Health and Wellbeing Research (CHWR) was tasked to evaluate this pilot. The aim of the evaluation was therefore to *evaluate the effectiveness of the pilot programme Personal Health Budgets for Carers in Northamptonshire*. This report presents the findings the evaluation which was undertaken between September 2011 and May 2012.

Methods

It is our practice to work closely with our clients regarding both evaluation design and operational aspects to ensure effective data collection and agreement on project objectives.

The evaluation employed a mixed-methods approach. Ten carers were selected by the commissioner from those who completed a baseline assessment questionnaire. Six carers participated in the resultant study. The elements of the evaluation, and the methods proposed to investigate those elements, were as follows:

- **Carer questionnaire** (baseline and follow up). The questions contained within this survey were defined by the commissioner of the evaluation.
- **Interviews:** A face to face interview was completed by a Researcher from the Centre for Health and Wellbeing Research with each carer to review perceived impact based on the experiences of the carers.
- **Carer self-assessment questionnaire** (baseline and follow up). The questions contained within this survey were defined by the commissioner of the evaluation.
- **Health outcomes supplementary data:** Information designed to supplement the data provided by carers relating to the aims and outcomes of the PHB for each participating carer was sought by the commissioners (with the full consent of each carer) from relevant organisations/health professionals. The tool for this element of data collection was developed by the commissioner of the evaluation.

The evaluation did not necessitate review through NHS Research Ethics Committee procedures, however in line with CHWR ethical practice the protocol for the study was reviewed by a University Research Ethics Committee and was approved through the evaluation and information sharing governance processes of NHS Northamptonshire.

Summary

The following provides an overview of the main findings of the evaluation. This should be read in conjunction with the detailed findings presented in the main body of the report.

The two repeated questionnaires (the carer questionnaire and the self-assessment questionnaire) revealed improvements over the period they had received the personal health budgets from at least half of the carers in areas relating to general health and wellbeing issues. This included questions relating to life satisfaction, happiness, feelings of worry, general health and social life. However, although questions relating to depression and anxiety (e.g. 'how happy did you feel yesterday', 'how worried did you feel yesterday') revealed improvement, those directly asking about depression and anxiety ('I am not/moderately/extremely anxious or depressed') did not. Similarly, when asked directly about their quality of life ('Thinking about the good and bad things that make up your life, how would you rate the quality of your life as a whole') no change was reported from most carers, although more indirect questions relating to aspects of quality of life did show improvements. Although the reasons for this apparent anomaly are not directly addressed, it could be that the carers are reluctant to use the emotive diagnoses of anxiety or depression when considering their own health and may find the overarching concept of quality of life difficult to evaluate.

Where the same areas were addressed by different questions, the findings were very similar which suggests that the responses were reliable. There were a number of question areas that would not be expected to be affected by the use of a carer's personal health budget. These included issues relating to the physical health of the carer (e.g. pain, continence) or their ability to care for themselves. The responses of the carers to these questions showed little or no change, which again supports the reliability of the findings.

In the interviews, carers reflected positively on the way that the PHB process had been managed, emphasising the support that had been offered to them during discussions relating to the form that their own PHB would take, and they found this opportunity to reflect on their own needs to be helpful in its own right. Each of the carers interviewed felt

that they had been offered choice and control during the process. During the interviews for the study, carers noted a range of benefits relating to physical health, primarily as a result of increased mobility and improved sleep patterns, however they were realistic about those aspects of their lives which were capable of being improved with the help of a personal health budget and recognised that some of their physical health problems were unlikely to be affected.

The interviews provided further evidence that the carers had felt the most benefit in relation to their mental health. Time out from caring responsibilities afforded them opportunities to socialise with family or friends, or to reflect on their individual needs. Where their PHB offered them the opportunity to remove themselves from stressful situations this was also welcomed.

It proved to be very difficult to evidence the intended outcomes of the personal health budgets by obtaining objective 'hard' evidence from their health professionals. This was, in part, due to difficulties encountered by the carers in contacting their health professionals to obtain their assessment but may also have been because of the more intangible nature of the benefits sought and reported by the carers.

Recommendations

The following general suggestions have been identified for future quality enhancement. They are not in priority order and should be read in conjunction with the detail provided in the body of this report.

- Consideration should be given to the timeframe over which the funding offered via a PHB can be spent. This would reflect the wishes of carers who may wish to use the money allocated to them over a longer period.
- A review of the mechanisms via which a PHB is reviewed / approved is recommended in order to ensure that carers do not experience a lengthy delay between application and feedback. Alternatively, information letters informing carers of the timeframe for review would set realistic expectations.
- A review of the questionnaires for the PHB assessment process and for review and evaluation of the impact on carers is recommended. Assessment and evaluation tools which are better targeted at the needs of carers and the realistic potential benefits of PHBs would enable more effective gathering of evidence.

- Future evaluation of the effectiveness of providing personal health budgets for carers should be built into the PHB process to allow evidence from a greater number of carers to be gathered. This would enable statistical analysis to be performed on the results providing more generalisable evidence. Consideration should also be given to longer term follow-up of those in receipt of PHBs to allow for the evaluation of long term benefits.
- Based on the challenges encountered in gathering information from General Practitioners, it is recommended that consideration is given to the collection of evidence of the effectiveness of the PHB against the original agreed outcomes being carried out by a Carer Assessment and Support Worker (CASW). The evidence that health professionals may be able to provide is dependent on the outcomes identified for individual carers. Where outcomes relate to more general aspects of well-being they are often more challenging to obtain from health professionals as part of their routine contact with the carer. CASWs may have better opportunities for eliciting appropriate evidence from the carers and, where appropriate, from those who have regular contact with carers.

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1 Introduction

In February 2011 the University of Northampton's Centre for Health and Wellbeing Research was approached by NHS Northamptonshire to develop and implement a local evaluation of Personal Health Budgets for Carers in Northamptonshire.

In March 2010, the Centre for Health and Wellbeing Research began a local evaluation of the Northamptonshire Carer Strategy Demonstrator Site. The Northamptonshire demonstrator site is one of 25 across England, and one of 7 Better NHS Support for Carers sites. This two-phase evaluation was completed in November 2011.

A pilot of carer Personal Health Budgets (PHBs) was instigated as part of the Northamptonshire Carers Strategy Demonstrator Site in 2011, in partnership with one of Northamptonshire's Clinical Commissioning Groups: Nene Commissioning. Northamptonshire is currently the only area in the country which is incorporating PHBs for carers.

Sixteen local carers have received a Carers Assessment via a member of the Carer Strategy Demonstrator Site (CSDS) team and have identified their own particular physical or mental health needs. The current evaluation was commissioned by NHS Northamptonshire. The study sought to evaluate the effectiveness and impact of the personalised health budget on Carers for the pilot group in Northamptonshire.

2 Aims

This report details the findings of a local-level evaluation which the Centre for Health and Wellbeing Research was tasked by NHS Northamptonshire to develop and implement. The aims of the evaluation was as follows:

To evaluate the effectiveness of the pilot programme Personal Health Budgets for Carers in Northamptonshire.

This report presents the findings the evaluation which was undertaken between September 2011 and May 2012.

3 Methods

It is our practice to work closely with our clients regarding both evaluation design and operational aspects to ensure effective data collection and agreement on project objectives. Some of the evaluation tools used in this project were selected by the commissioner as they were being used in a national evaluation and/or were being used in the PHB assessment process. Others were jointly developed by the CHWR team and the commissioner of the evaluation. The methods used to conduct the study were developed to combine the need for objective and relevant data collection and analysis, with the resources available.

The evaluation employed a mixed-methods approach. Ten carers were selected by the commissioner from those who completed a baseline assessment questionnaire. Six carers participated in the resultant study. The remaining four carers opted out of the study or were unable to participate due to personal health reasons. The elements of the evaluation, and the methods proposed to investigate those elements, were as follows:

- **Carer questionnaire:** Carers completed a health questionnaire at the beginning of the assessment process for award of a PHB. This was repeated six months later, distributed via post. The questions contained within this survey were defined by the commissioner of the evaluation (see Appendix, page 56. Data entry and analysis of the baseline and follow up surveys was completed by CHWR.
- **Interviews:** A face to face interview was completed by a Researcher from the Centre for Health and Wellbeing Research with each participating carer. These

were conducted in the carers' homes, unless another venue was preferred by the carer. The purpose of these interviews was to review perceived impact of the pilot from the perspective of the carers who were participating. The discussions provided qualitative feedback on carer PHB experiences. The interview schedule was developed by the project team in collaboration with NHS Northamptonshire (see Appendix, page 73). The interviews were recorded, with the carer's consent, transcribed and thematically analysed by the CHWR project team.

- **Carer self-assessment questionnaire:** Carers completed a self-assessment questionnaire (see Appendix, page 56) as part of the initial PHB assessment process. They responded to these questions a second time (six months later) when they were interviewed for this evaluation. Data entry and analysis of these baseline and follow up questionnaires was completed by CHWR.
- **Health outcomes supplementary data:** Information designed to supplement the data provided by carers was sought by the commissioners (with the full consent of each carer) from relevant organisations/allied health professionals (AHPs). The nature of the information gathered was specific to each carer and related to the particular health outcomes identified at the outset of the PHB process (see Appendix, page 81, for the information template used).

4 Ethical issues

Following consultation with the Research and Development Lead, NHS Northamptonshire, it was agreed that this study fell within the scope of a service evaluation. The protocol for the project was therefore vetted by a University of Northampton Research Ethics Committee in compliance with the shared protocol for evaluation governance agreed between NHS Northamptonshire and the Centre for Health and Wellbeing Research. As an evaluation the project did not necessitate review through NHS Research Ethics Committee procedures.

CHWR's project work was underpinned by the following ethical terms of reference:

- Carers/ Health professionals responded to each of the tools of their own free will after being fully informed of where and how the information would be used;
- At all times during the collection of data confidentiality was assured;

- All analysis done by CHWR used anonymised data. Reported results do not include direct quotations where inadvertent identification of the participant may be possible;
- Participating carers were fully informed of the ways in which the data collected would be used by the commissioners of the evaluation and their partners;
- All research active staff of the Centre for Health and Wellbeing Research are trained to follow strict ethical codes of practice and are CRB cleared;
- All data collected as part of the project was stored and transferred securely. Storage of data followed the guidelines set by the Data Protection Act and the Freedom of Information Act.
- The project was approved through the evaluation and information sharing governance processes of NHS Northamptonshire.

Each section of the report which follows begins with an explanation of the specific methods employed to collect the data which is analysed and subsequently presented in that section.

5 Carers' personal health budgets in Northamptonshire

Carers in Northamptonshire who participated in the pilot Personal Health Budgets project were identified via a streamlined approach which was facilitated by Carer Assessment and Support Workers (CASWs) and the PHB Lead for the County. Figure 1 shows the process by which carers were identified and the process through which PHBs were agreed and delivered.

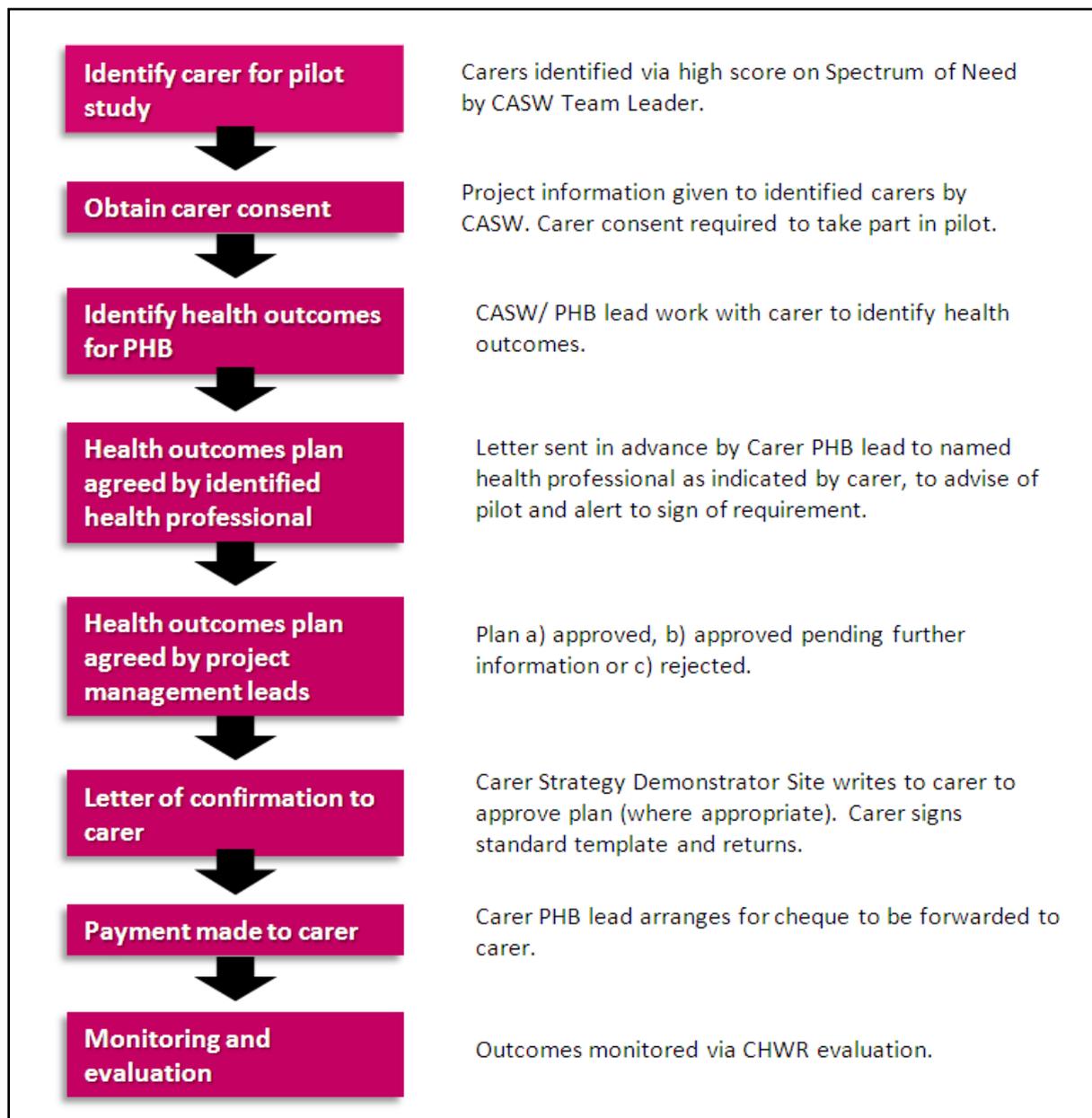


Figure 1: Carers Personal Health Budget flowchart

Sixteen carers received a Personal Health Budget as part of the pilot project in Northamptonshire. At the outset of the project their needs were discussed on an individual basis, and a Personal Health Budget plan was agreed by all parties. Carers used the funding offered to them as part of their PHB in a variety of ways, some of which included membership of gyms, home improvements and short breaks away from caring.

Given the small sample of carers involved in this evaluation study, the results which follow do not make specific links between participant demographic information and the personal health budget that they received. Care has been taken to ensure that confidentiality is maintained during the presentation of the results. Following discussion with the commissioner of the study it is recognised that the particular needs of the carers may render them identifiable to members of the Carer Strategy Demonstrator Site team because of the close working relationships that have been formed with the carers as users of the service. These individuals are, however bound by strict professional confidentiality protocols. Table 1 shows the range of ways that carers were able to use their PHB, projected overall cost and the anticipated health outcomes.

Expenditure	Cost	Anticipated health outcomes
Orthopaedic mattress Gardener hours to maintain garden	£1,000	Improved sleep: use of better mattress/ less pain Improved ability to care: due to less pain Reduced stress and pain: support for gardening Improved general health and wellbeing
Garden restoration Massage/relaxation	£700	Reduced stress and anxiety/able to continue caring: by spending time in garden Improved mental health and sleep: via use of garden and massage therapy
Purchase Wii Fit and Exercise Games Purchase Laptop and accessories Spending money for short break	£880	Improved physical/mental health: use of daily Wii Fit exercise programme to lose weight and increase physical activity and use relaxation techniques Improved diabetes management: access internet diabetes support Improved confidence: use of Wii Fit to support weight loss and improve physical health Improved household management: online shopping Reduced social isolation: use of internet to keep in touch with family/ friends Spending money: to support break
Purchase of family gym membership	£828	Improved physical health: by use of gym 2-3 times per week and weekend family use, to help reduce blood pressure and generally improve health Reduced depression and stress/able to continue caring: time out from caring and as a result of activities
Annual gym membership/ Aqua aerobics Associated equipment	£828	Improved physical health: 2-3 gym sessions per week to lose weight, increase fitness/mobility; reduce blood pressure; improve general wellbeing Reduced pain: through increased exercise Reduced social isolation: increased social contact from activity Improved mental health: by increasing ability to cope with caring role; ability to relax more
Purchase a second-hand mobility scooter Purchase a portable oxygen cylinder holder	£1,100	Improved mental health: use of mobility scooter will allow joining family on walks and outings Reduced social isolation: increased ability to get out and meet others Improved coping mechanisms: more able to cope with health and life

Table 1: Identified Personal Health Budgets for carers included in the evaluation

6 Results (health data)

6.1 Carers' questionnaire

A questionnaire for use by carers in receipt of personal health budgets had been developed by the national evaluation team and used in this project. It was lengthy (17 pages) and comprised eight separate sections, each with a number of related questions. The full questionnaire can be found in Appendix 11.1. Although no details of how the questionnaire was devised were available, it seems that some sections were based on, or replicate, existing scales. Where possible, the questions in these sections have been scored according to the original scales scoring instructions (e.g. section 2, GHQ12). However section 3, for example, contains many of the questions of the Adult Social Care Survey but some have been omitted and adapted for this questionnaire, making any consolidation into scale indices invalid. These questions have therefore been treated as individual questions for the purpose of this analysis.

The questionnaire was completed by the carers at their initial assessment and again six months after receipt of their personal health budget.

The questionnaire would have been designed for the examination of population trends, using large samples. This local evaluation is based on a sample of only 6 carers and it would be inappropriate to attempt any statistical analysis of the results. The data obtained is therefore presented descriptively.

6.1.1 Sample characteristics

Most of the carers were aged between 45 and 59 years. None were less than 35 years old (see Figure 2).

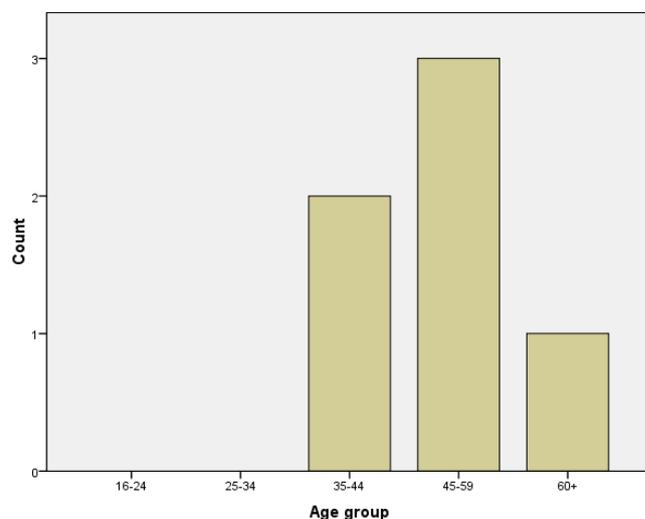


Figure 2: Age distribution of carers

Three of the carers lived with their spouse or partner, one with their parents, one with their son or daughter and one with their sister. Most (n=4) lived in a semi-detached house with one living in a detached house and the other in a bungalow. Three were owner occupiers and three were tenants.

All described their ethnicity as white-British.

Two of the carers reported being self-employed; one of these also said that they had part-time work on the second survey but not the first. One of the carers was retired; they reported on the first survey that they were also doing voluntary work but they did not include this on the second survey. None of the carers were looking for work.

The questionnaire did not ask for information relating to gender.

6.1.2 Questions about the carer

Question 1 on the carer questionnaire (see Appendix 11.1) asked 5 questions relating to how the carer felt about themselves. Each question was associated with an 11-point numerical rating scale (0-10) whose end points were defined.

6.1.2.1 'Overall, how satisfied are you with your life?'

The end points for this question were 0='not at all satisfied' to 10='completely satisfied', therefore higher scores are associated with greater satisfaction.

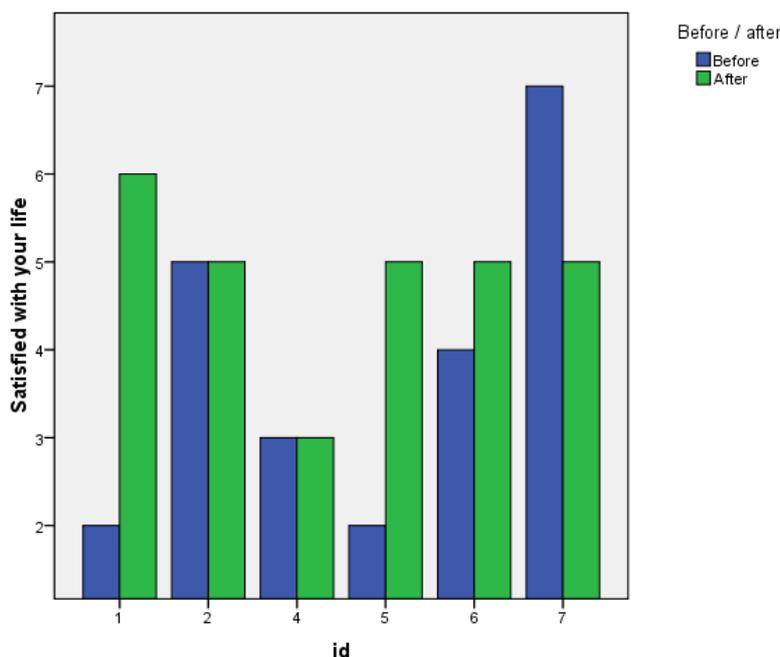


Figure 3: Life satisfaction

Figure 3 shows the scores before and after receipt of their personal health budget for each of the carers. It can be seen that there was a wide range of initial satisfaction levels, from 2 to 7, but only the carer with the highest initial satisfaction showed a subsequent decrease. Three of the carers (50%) indicated increased satisfaction whilst the remaining two showed no change.

6.1.2.2 'Overall, how happy you feel yesterday?'

This question was scored 0='not at all happy' to 10='very happy', therefore higher scores are associated with greater happiness.

Figure 4 illustrates these scores for each carer before and after receipt of their personal health budget. Again, there was a wide range of initial happiness scores (from 2 to 6) and only the carer with the highest initial score showed a subsequent decrease (this was the same carer that showed the reduction in satisfaction in question 1a). Four of the carers (67%) reported increased happiness scores with the remaining one showing no change.

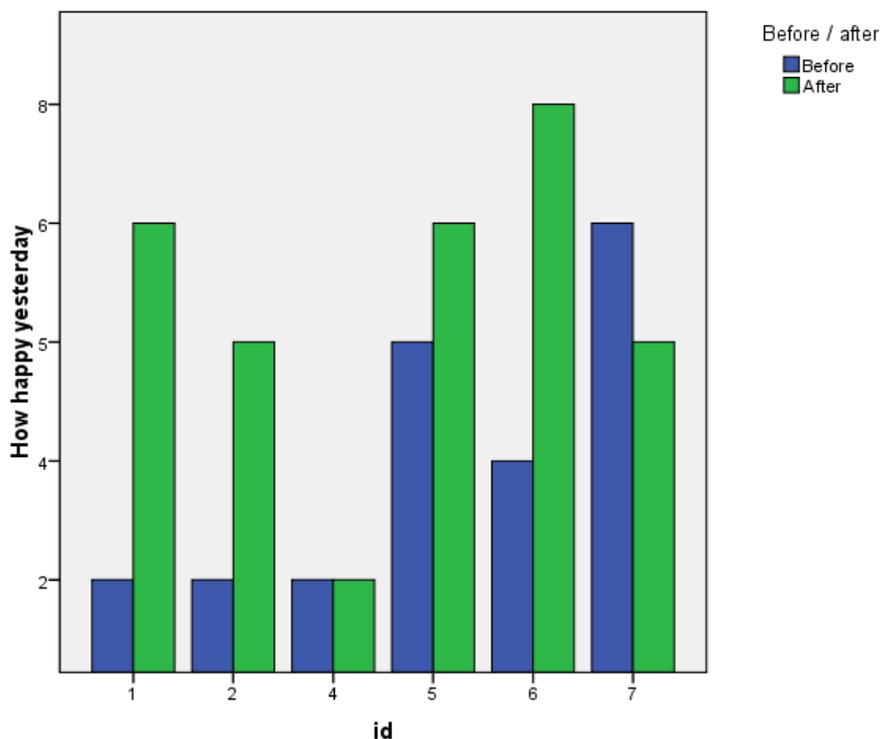


Figure 4: Happiness

6.1.2.3 'Overall, how worried did you feel yesterday?'

This question was scored 0='not at all worried' to 10='very worried' and so an increased score is a negative finding, denoting increased worry.

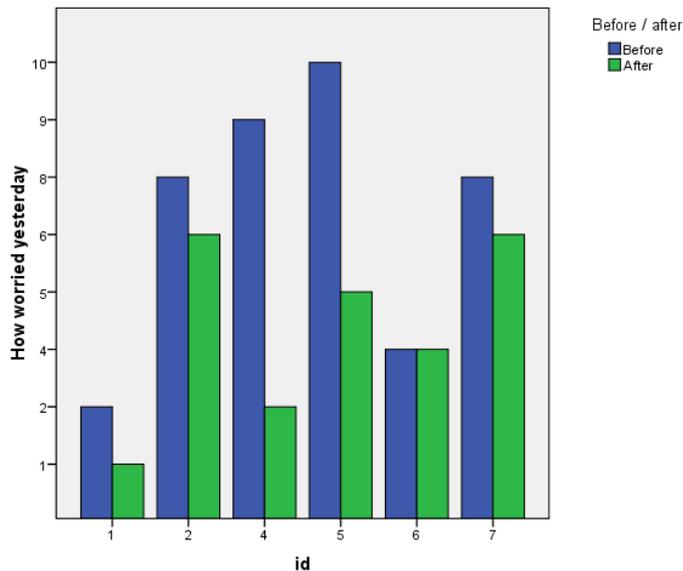


Figure 5: Worry

Figure 5 shows the carers' scores before and after receipt of their personal health budgets. All but one showed a decrease in how worried they felt. The remaining carer showed no change.

6.1.2.4 'Overall, how satisfied are you with your health?'

Higher scores for this question are associated with greater satisfaction (0='not at all satisfied', 10='completely satisfied').

Four of the carers (67%) reported being more satisfied with their health after receipt of the personal budget. The remaining two showed no change (see Figure 6).

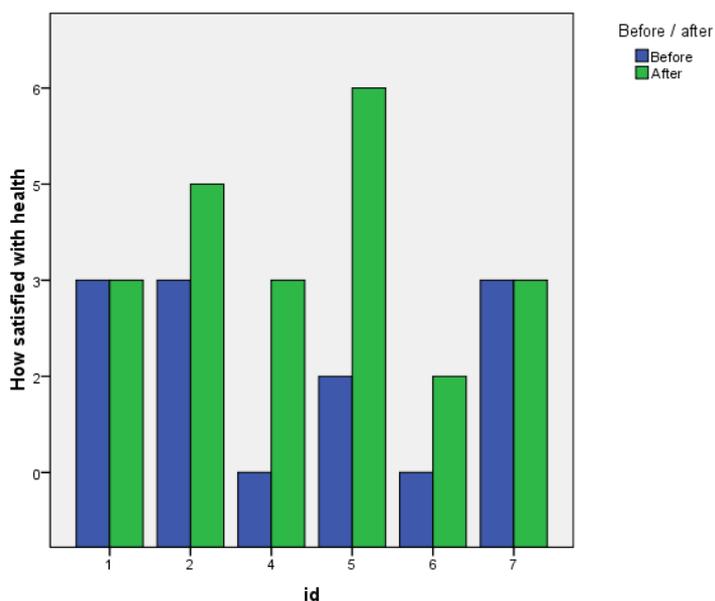


Figure 6: Satisfaction with health

6.1.2.5 'Overall, how worried are you about your health?'

This question was scored 0='not at all worried' to 10='very worried' and so an increased score can be interpreted as a negative outcome as it denotes a greater level worry.

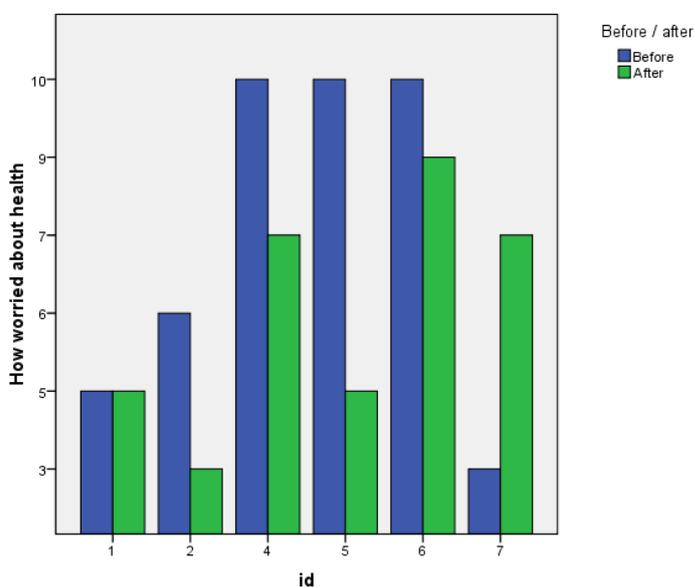


Figure 7: Worry about health

Figure 7 shows four of the carers reported less worry about the health after receipt of their personal health budgets. One (carer 7) reported a large increase, with the remaining one showing no change.

6.1.3 General Health Questionnaire

Question 2 (a-l) of the carer questionnaire comprised the 12 questions from the validated GHQ-12¹. The four category scoring on questionnaire was transformed using the recommended GHQ scoring method in which the first two categories (denoting improvement or no change) are scored as zero, whilst the third and fourth categories (denoting worsening) are both scored as one. GHQ-12 only allows for a total score over the 12 questions with no subcategories.

Figure 8 shows the total GHQ-12 score for each carer before and after receipt of their personal health budget. The threshold score for the GHQ-12, denoting poor general health for those without physical illness, is between one and two. It can be seen that all of the carers were initially above that threshold with one (carer 4) having a maximum score. However, their reported scores after receipt of the personal health budget indicate that 50% of the carers had GHQ-12 scores of zero, indicating good general health. Carer 4's maximum score remained the same whilst carer 7 slightly increased their score.

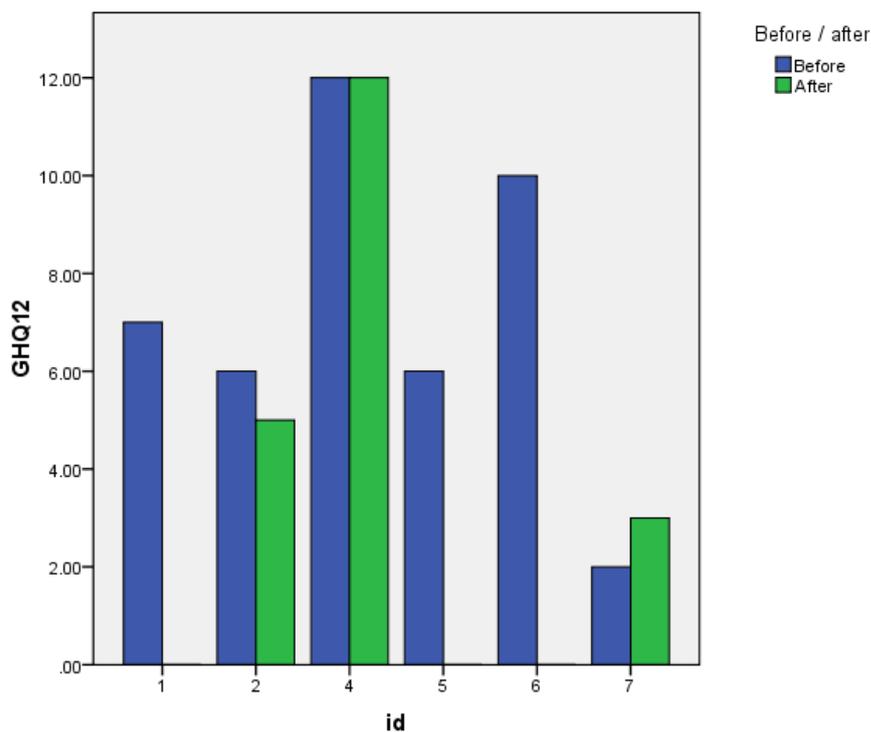


Figure 8: GHQ-12

¹ For details see http://www.gla-assessment.co.uk/health_and_psychology/resources/general_health_questionnaire/faqs.asp?css=1

6.1.4 Health and quality of life

6.1.4.1 'How is your health in general?'

The responses to this question were denoted by a five point scale and was coded from 1= very good to 5= very bad.

Figure 9 shows that three of the carers reported an increase in their general health, with the other three showing no change.

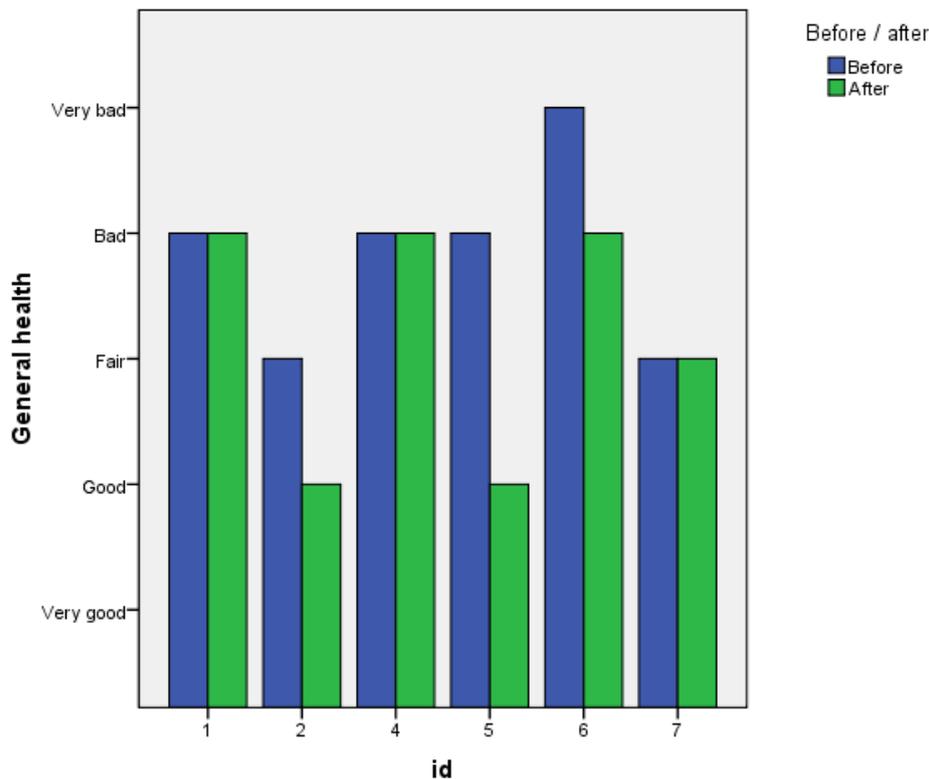


Figure 9: General health

6.1.4.2 'Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?'

This question, together with the next 10 questions, appear to have been extracted and adapted from the Adult Social Care Survey. However, because the questions have been changed, the scoring method and indices for this validated questionnaire cannot be used and the responses to the individual questions are presented here.

Figure 10 shows that most (4/6) carers felt that their quality of life was 'alright', and this did not change. One felt that it was 'bad' and this also did not change stop. One carer felt their quality of life had improved from 'bad' to 'alright'.

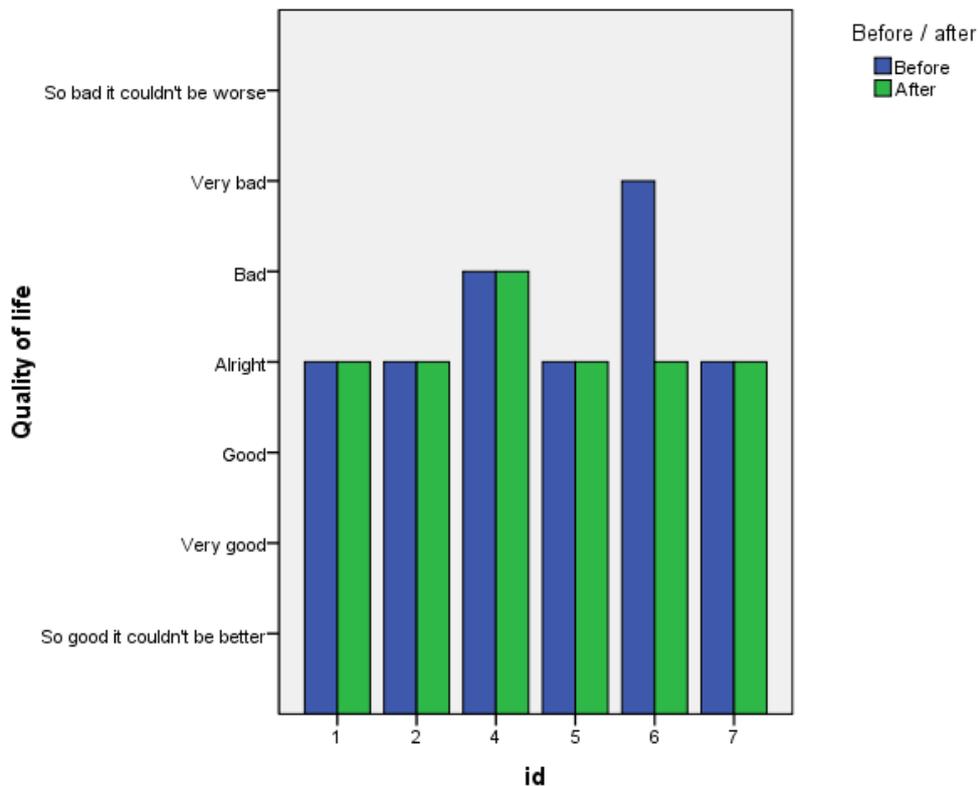


Figure 10: Quality of Life

6.1.5 *Life and home*

6.1.5.1 Control over daily life

This question asked the carer to choose which of three statements best described their present situation: I have as much control over my daily life as I want; sometimes I don't feel I have as much control over my daily life as I want; I have no control over my daily life.

As can be seen in Figure 11, half of the carers felt that they had increased control over their daily lives following receipt of their personal health budgets. Two reported no change and one perceived a reduction in control.

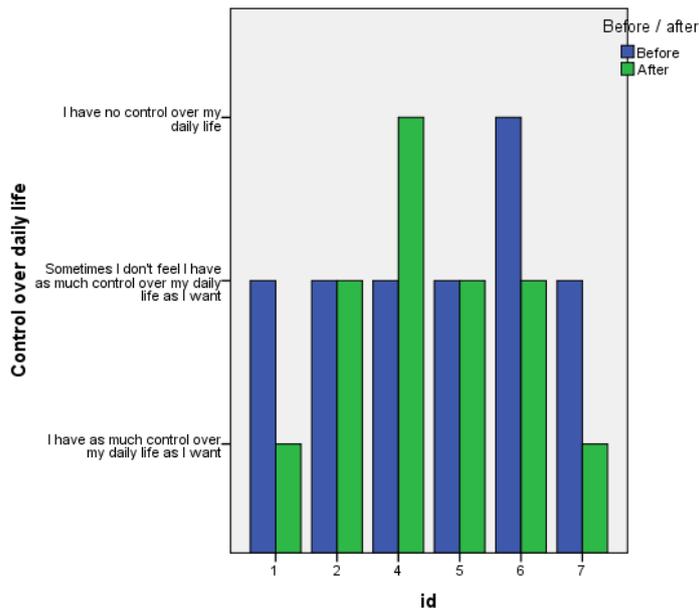


Figure 11: Control over daily life

6.1.5.2 Personal hygiene

This question asked respondents to select one of three statements which best described the way they looked and felt. These statements were: I feel clean and wear what I want; I sometimes feel less clean than I want or sometimes can't wear what I want; I feel much less clean than I want, with poor personal hygiene.

Figure 12 shows that most (4/6) felt clean and could wear what they want both before and after personal budgets. Only one carer reported a worsening in this area.

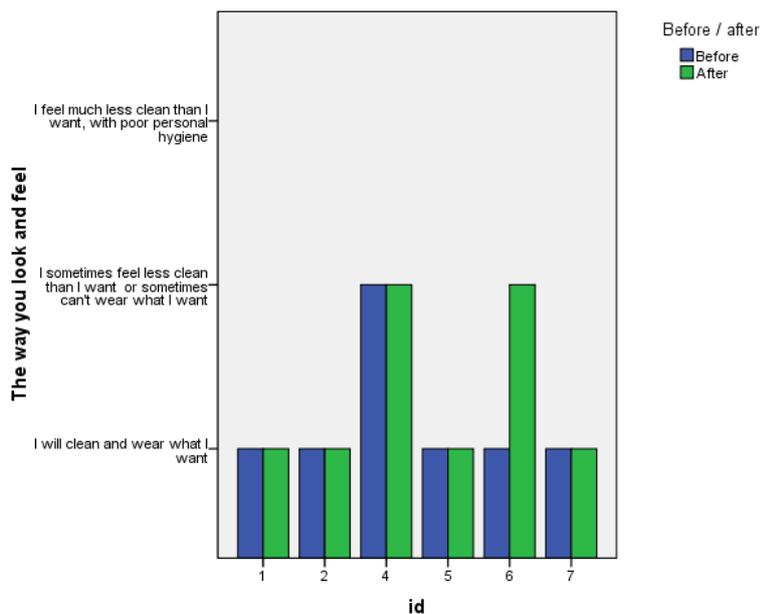


Figure 12: Personal hygiene and clothing

6.1.5.3 Meals

This question asked the carers to select one of the three following statements which best described their present situation: I eat the meals I like when I want; I don't always eat the right meals I want, but I don't think there is a risk to my health; I don't always eat the right meals I want, and I think there is a risk to my health.

Figure 13 shows that there was a range of responses but for all but one case the response did not change. Carer 7 reported an improvement.

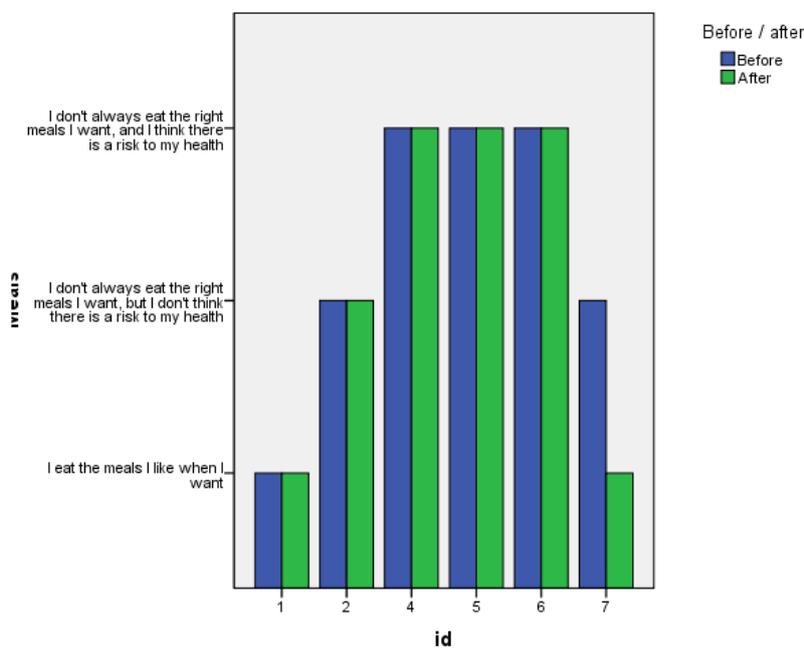


Figure 13: Meals

6.1.5.4 Safety

Carers were asked to select one of three statements to reflect how safe they felt. There were advised that not feeling safe could be due to fear of abuse, falling or other accidental physical harm and fear of being attacked or robbed.

Figure 14 shows that three carers reported feeling safer after receipt of their personal health budgets, one felt less safe and for two there was no change.

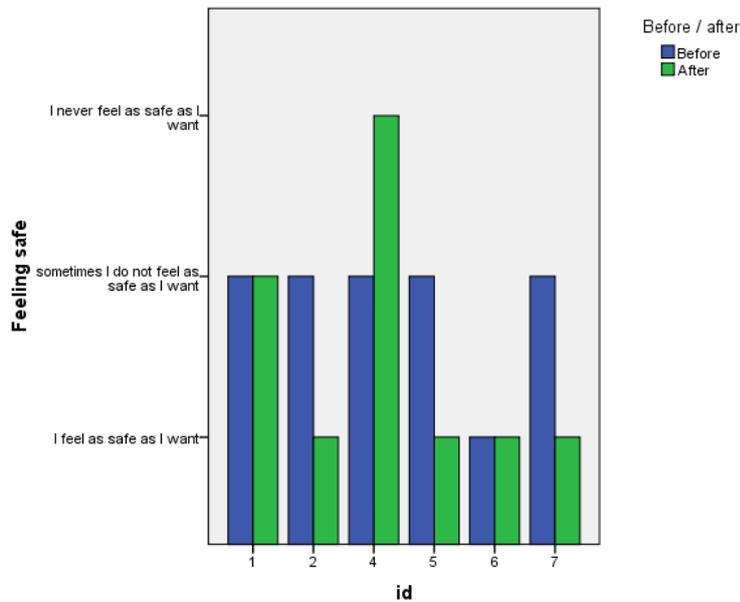


Figure 14: Feeling safe

6.1.5.5 Social situation

Carers were asked to choose one of three statements which best described their social situation. Social situation was defined as keeping in touch with people and spending time with people that you want to be with.

Figure 15 illustrates the responses to this question. It can be seen that none of the carers were content with their social situation. Half felt that this had improved after receipt of personal health budgets with the other half remaining unchanged.

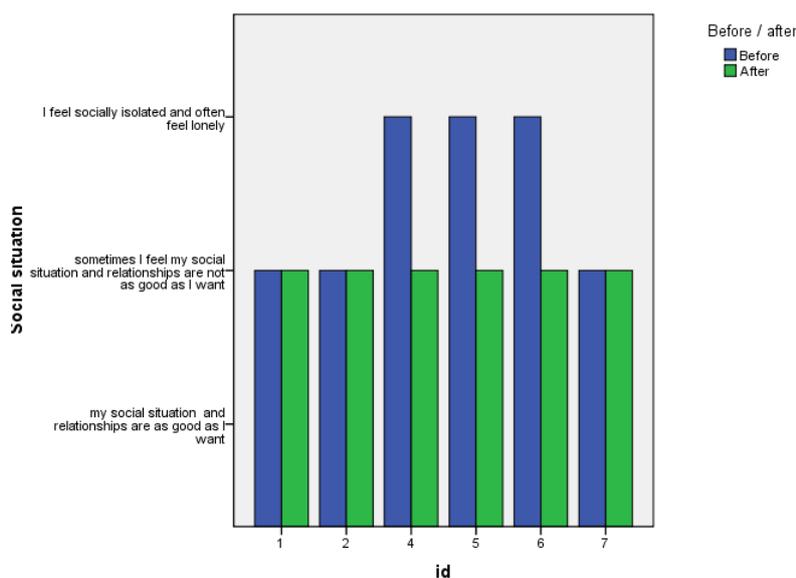


Figure 15: Social situation

6.1.5.6 Activities

This question related to carers usual activities including leisure, doing things for others and paid or unpaid employment.

Figure 16 shows that none of the carers were able to do all of the activities they wanted to do. The responses from four of the carers remained unchanged, one improved and one worsened after receipt of their personal health budgets.

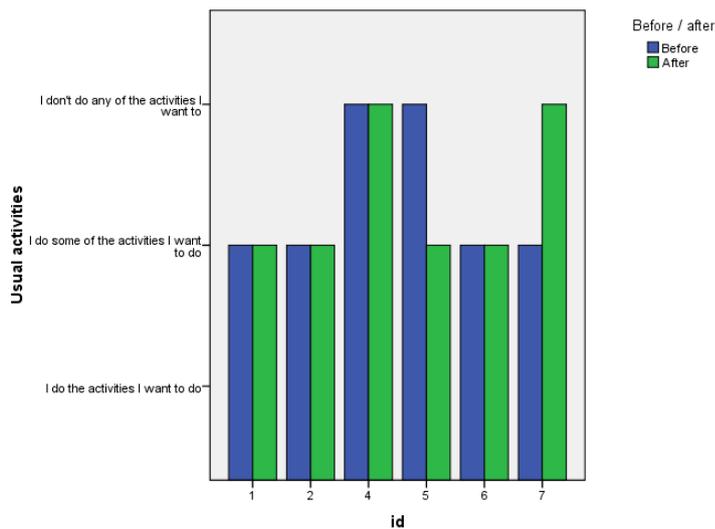


Figure 16: Usual activities

6.1.5.7 Home

Carers were asked how clean and comfortable their home was. Figure 17 summarises their responses. It can be seen that most were happy with their homes. The responses of five of the six carers did not change, with the remaining one showing an improvement in perception after receipt of a personal health budget.

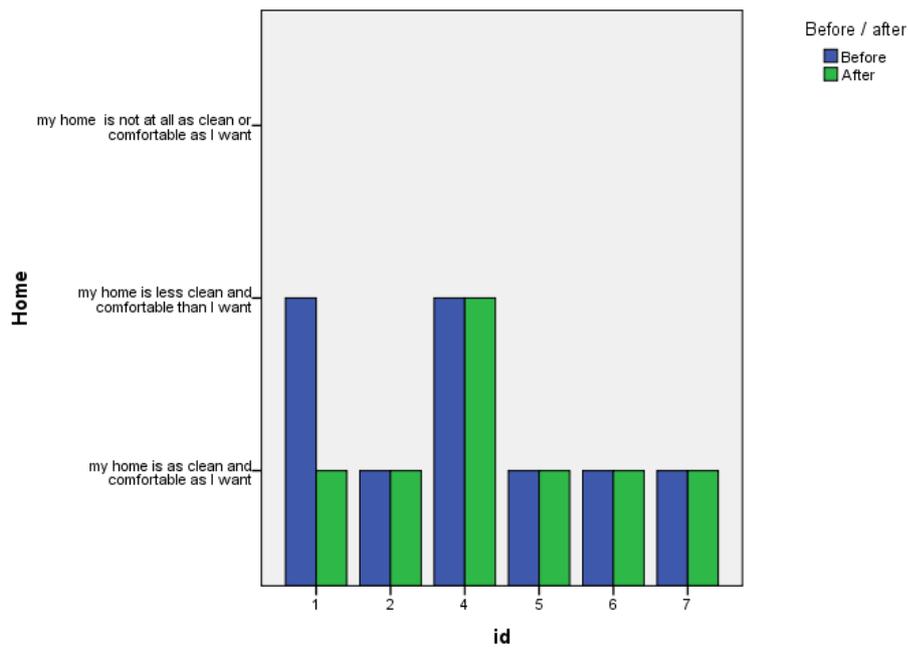


Figure 17: Home

6.1.5.8 Worries and concerns

Figure 18 shows the carers' selection of statements relating to how worried or concerned they felt before and after receipt of their personal health budgets. All reported having at least some worries and concerns. Three reported an improvement after receipt of their health budgets, one worsened and the remaining two stayed the same.

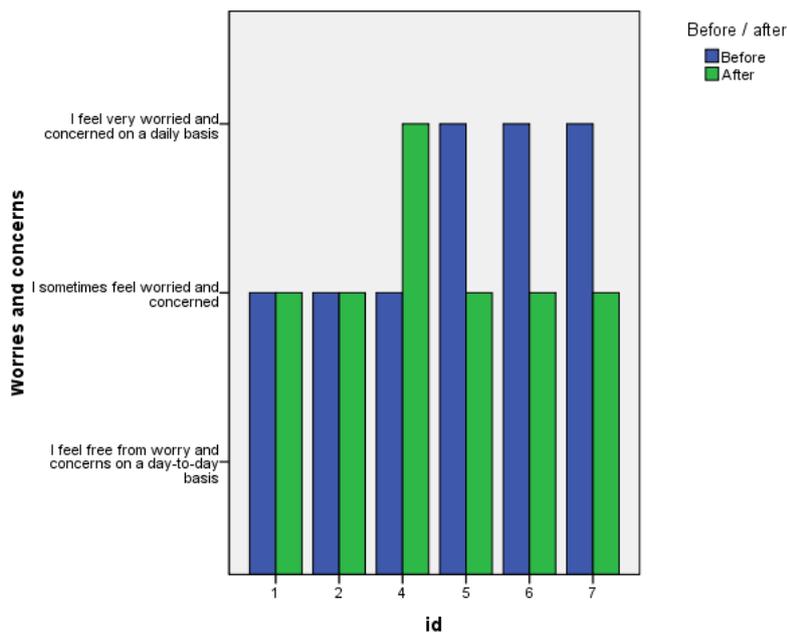


Figure 18: Worries and concerns

6.1.5.9 Treatment by others

This question explored how the carers perceived they were treated by other people. Figure 19 shows that initially all six carers felt that they were sometimes not treated by others with the dignity and respect that they wanted. Half of the carers reported that this had improved after they had their personal health budgets.

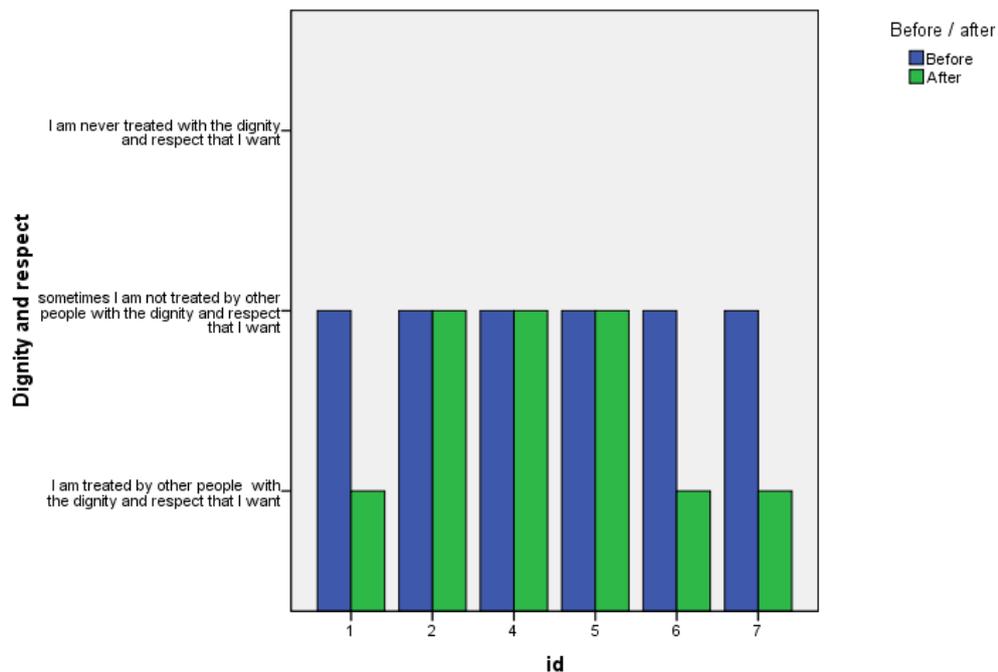


Figure 19: Treatment by others

6.1.5.10 Providing care and support to others

Respondents were asked about the care and support they provide to others such as children, husband, wife or partner. Figure 20 shows that initially all six carers found it difficult at times to provide others with the kind of support that they wanted to provide. After receipt of the personal health budget, three reported that they were able to provide the level of support that they wanted to, two reported no change and one reported that that the situation had worsened.

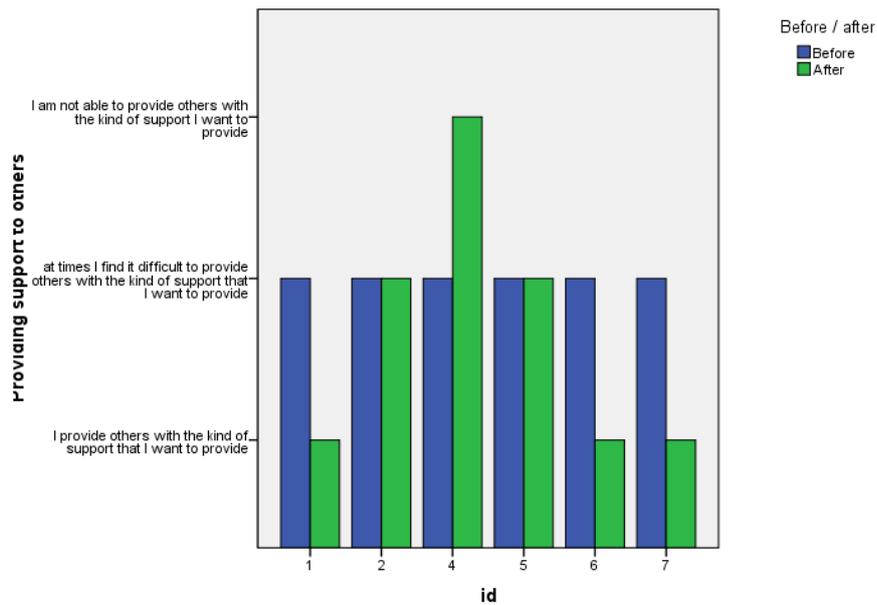


Figure 20: Providing care and support to others

6.1.6 Carers' health

Section five of the questionnaire comprised six questions relating to different aspects of carers' health.

6.1.6.1 Mobility

Figure 21 shows that four of the carers had some problems in walking about whilst the other two had no mobility problems. None of the carers reported any change following receipt of personal health budgets.

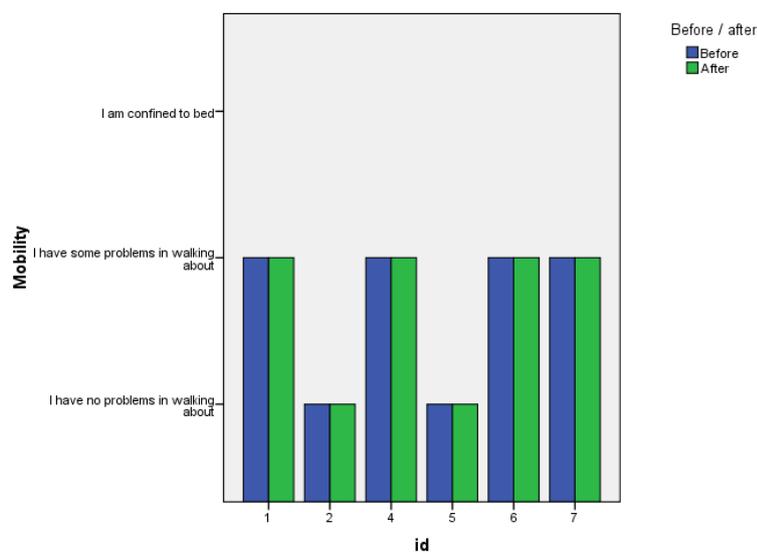


Figure 21: Mobility

6.1.6.2 Self-care

Figure 22 shows that four of the carers had no problems with self-care and this was unchanged following receipt of their personal health budgets. The other two initially had some problems washing or dressing themselves which had improved in the follow-up questionnaire.

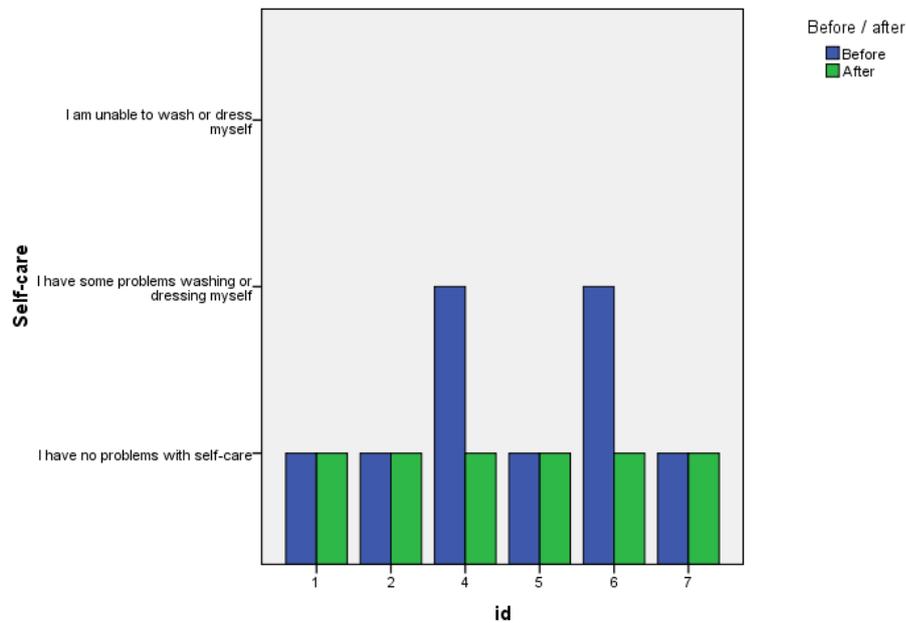


Figure 22: Self-care

6.1.6.3 Usual activities

This question defined usual activities as work, study, housework, family or leisure activities. Figure 23 illustrates that all of the carers initially reported having some problems with performing their usual activities. Following receipt of the personal health budget, four remained unchanged and the remaining two reported having no problems.

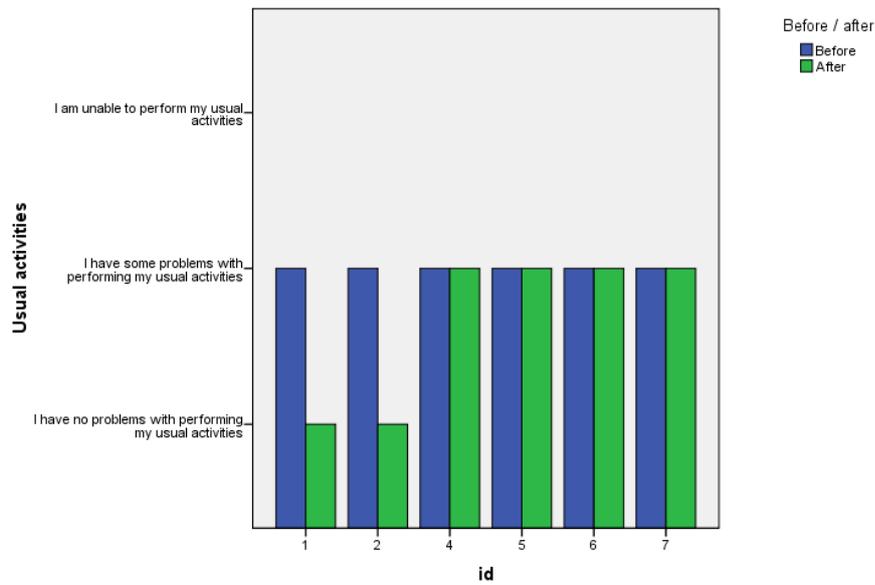


Figure 23: Usual activities

6.1.6.4 Pain/discomfort

Figure 24 illustrates the level of pain or discomfort reported by the carers. Only one of the carers initially said they had no pain or discomfort, which was also the case at follow up. Four of the carers initially reported having moderate pain or discomfort. One of these reported an improvement after receipt of their personal health budgets whilst the other three remained unchanged. One carer reported extreme pain or discomfort which, again, was unchanged at follow up.

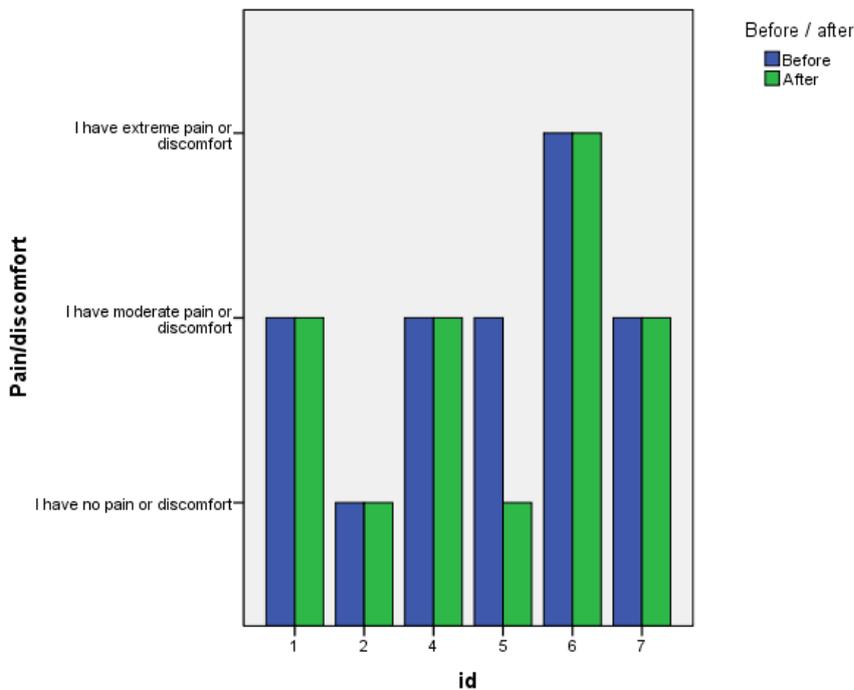


Figure 24: Pain and discomfort

6.1.6.5 Anxiety/depression

Figure 25 shows the levels of anxiety or depression reported by the carers. Only one carer reported that they were not anxious or depressed (both before and after receipt of the personal health budget). Only one carer reported that their level of anxiety or depression had improved (from extremely to moderately). There was missing initial data for carer 5.

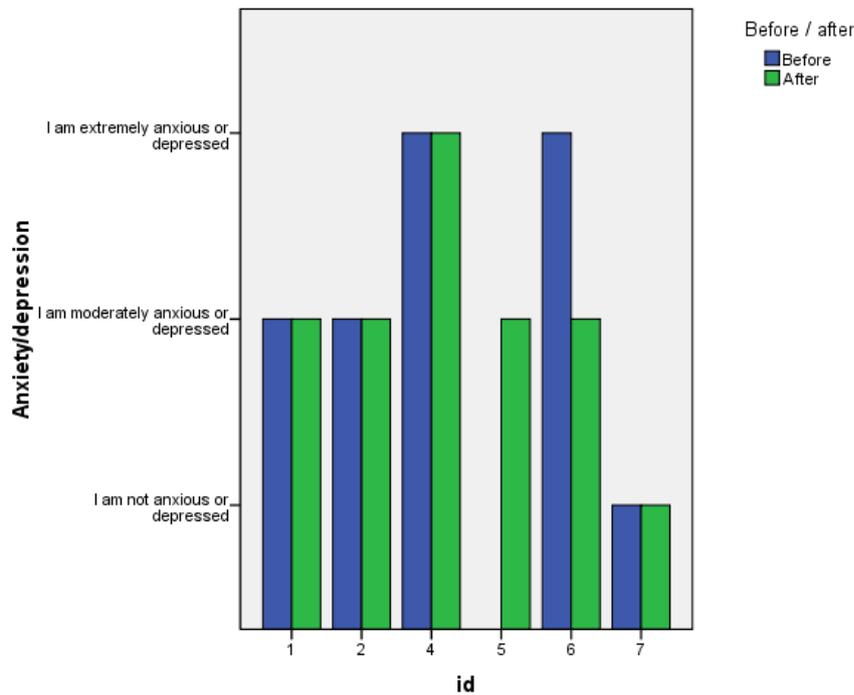


Figure 25: Anxiety or depression

6.1.6.6 Health state compared to 12 months ago

Figure 26 shows that all carers initially assess their health as worse than 12 months ago but all showed an improvement after receipt of their personal health budget.

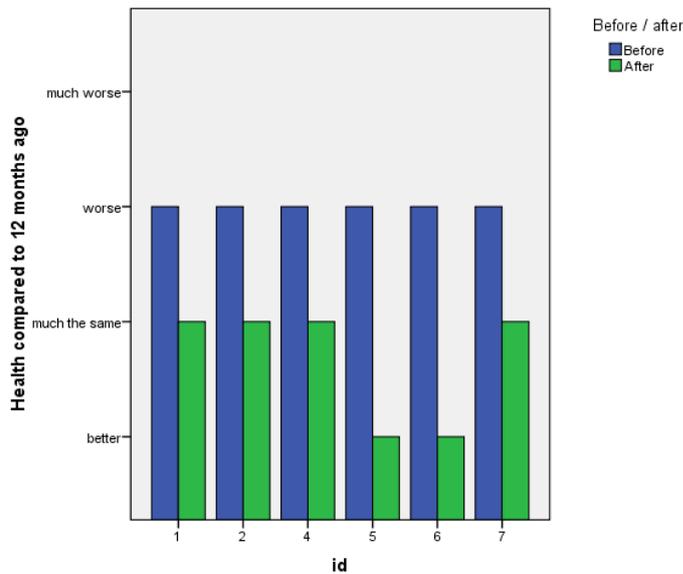


Figure 26: Health state compared to 12 months ago

6.1.6.7 Current health state

Carers were asked to assess their current health state by drawing a line on a visual analogue scale ranging from 0= worst imaginable health date to 100= best imaginable health state. Figure 27 shows how each carer scored their health state before and after receipt of their personal health budget. It can be seen that initial scores ranged between 30 and 70. The carer with the lowest initial health score (carer 4) reported no change at follow-up but all of the other five showed an increase in their perceived health state. Carer 2 showed the greatest increase, improving from a score of 50 to a score of 90.

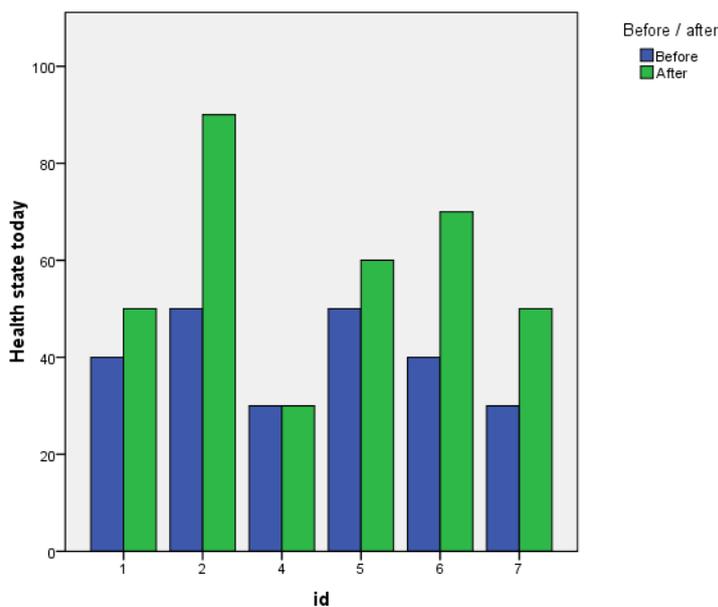


Figure 27: Current health state

6.1.7 Self-management

This section of the questionnaire focussed on the ability of the carer to do things for themselves and comprised ten questions on different aspects of self-care.

6.1.7.1 Get up and down stairs or steps

Figure 28 illustrates the responses of the carers relating to negotiating steps and stairs. It can be seen that all report they manage independently although with varying levels of difficulty. All but one reported the same level of mobility before and after receipt of their personal health budget. One carer reported increased difficulty at follow-up.

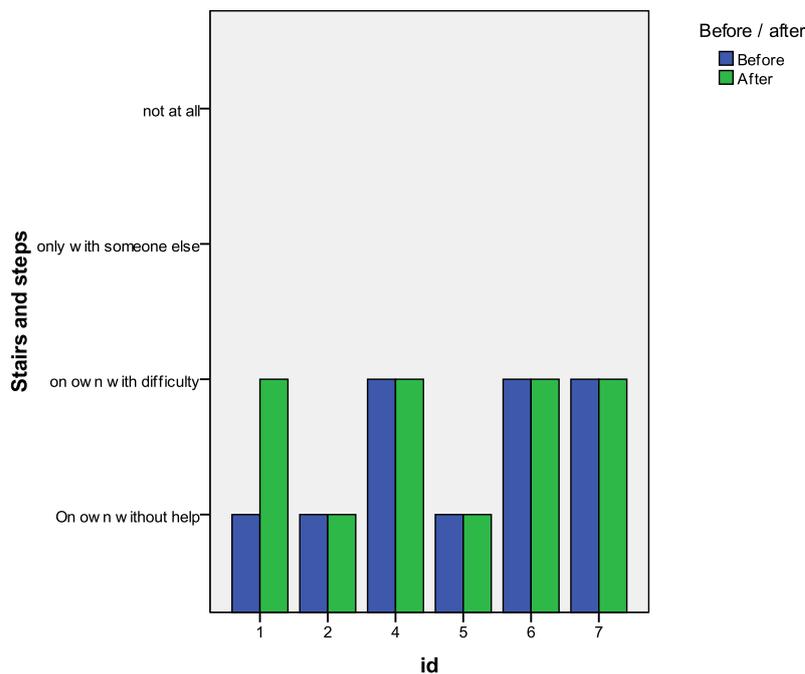


Figure 28: Stairs and steps

6.1.7.2 Go out of doors and walk down the road

Figure 29 shows that all the carers were initially able to walk down the road, although three reported that they did this with difficulty. Only one carer reported a change over the period between the two questionnaires, during which time they went from walking with difficulty to not being able to do this at all.

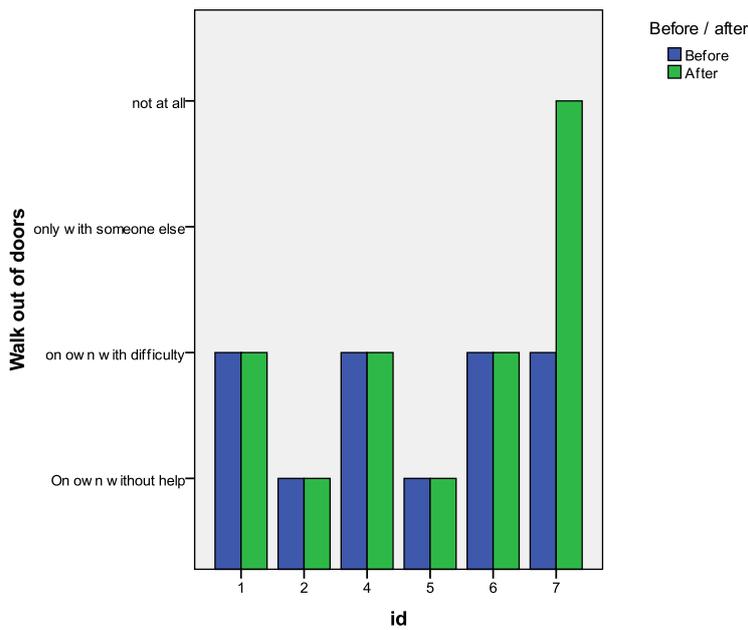


Figure 29: Walk out of doors

6.1.7.3 Get around indoors (except steps)

Figure 30 show the responses to this question. All could get around indoors on their own, although one reported difficulty on both questionnaires. Only one carer reported any difference over the study period, going from getting around on their own without help to getting around on their own with difficulty.

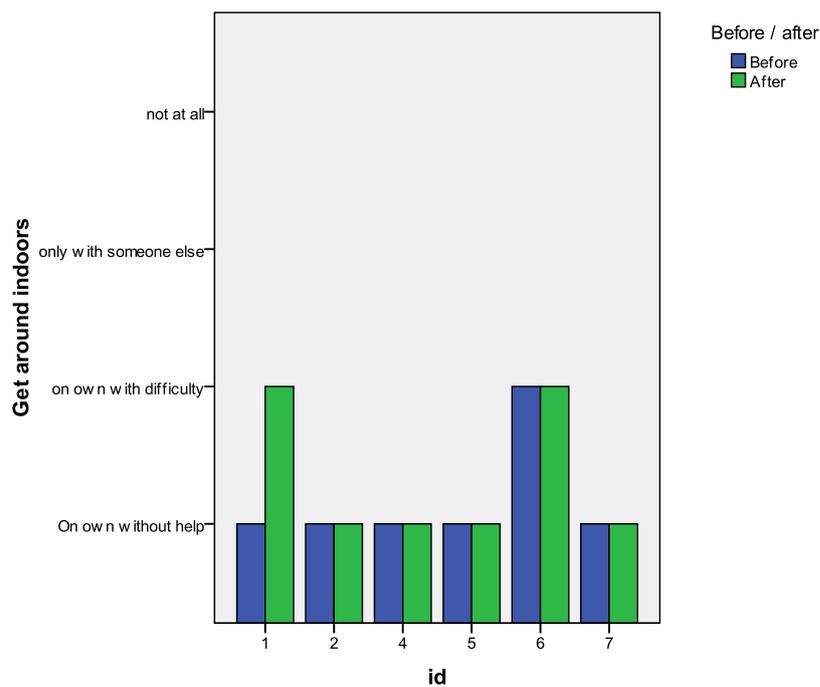


Figure 30: Get around indoors

6.1.7.4 Get in and out of bed (or chair)

Figure 31 shows that all the respondents could get in and out of bed/chair on their own, although three had difficulty in doing this. Only one carer reported a change, improving from having difficulty to doing it on their own without help.

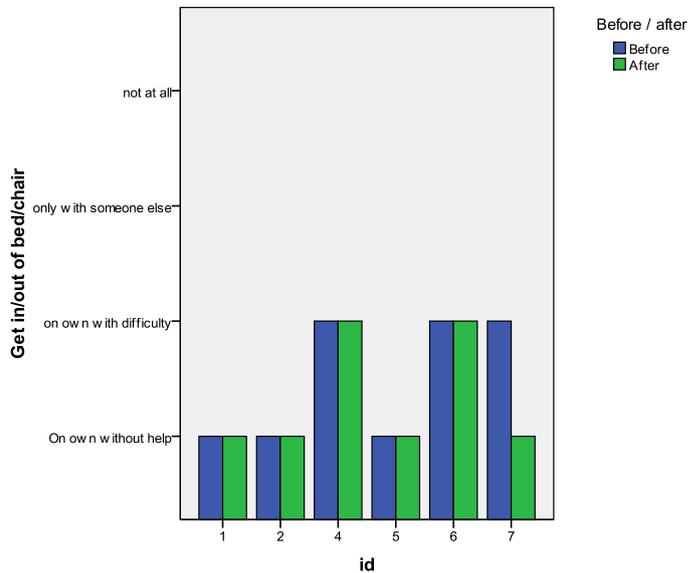


Figure 31: Get in/out of bed or chair

6.1.7.5 Use WC/toilet

Figure 32 shows that five of the carers could use the toilet on their own without help and did not change over the study period. The remaining carer reported having difficulty initially but improved at follow-up.

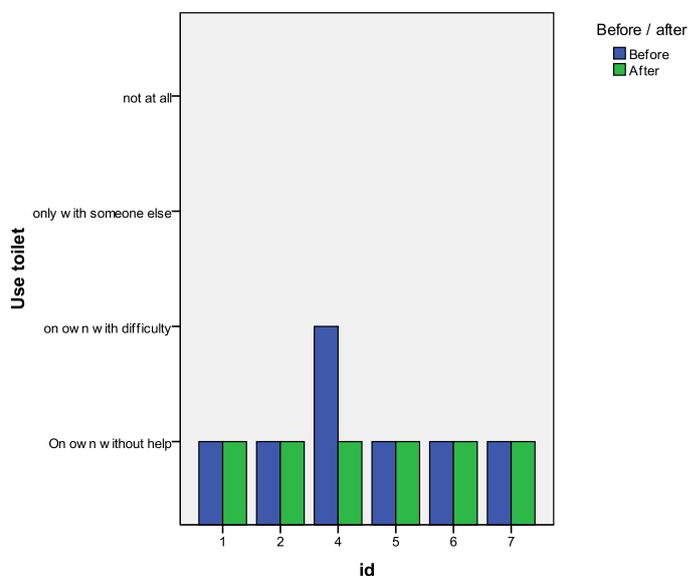


Figure 32: Use toilet

6.1.7.6 Wash face and hands

Figure 33 shows that all six carers could wash their hands and face without help and no change was reported from any over the study period.

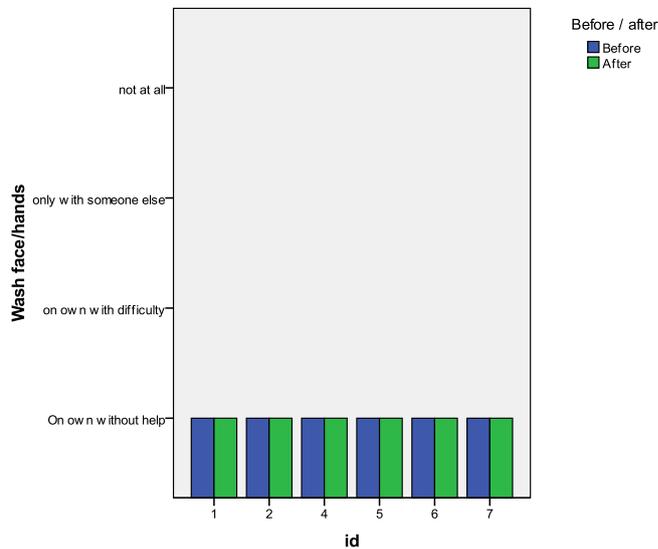


Figure 33: Wash face and hands

6.1.7.7 Bath, shower or wash all over

Figure 34 shows that three of the carers could bath or shower on their own without help and did not change over the study period. One carer who could initially do this without help reported doing it with difficulty at follow-up and two initially reported having difficulty but could manage without help at follow-up.

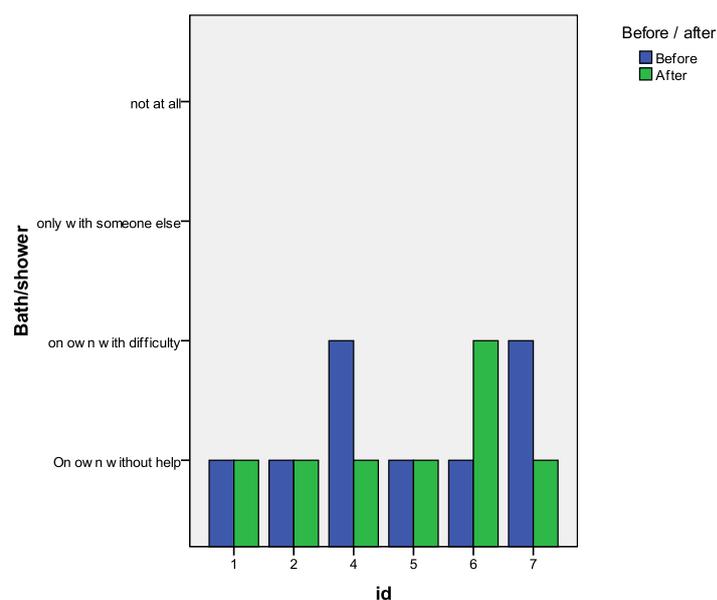


Figure 34: Bath, shower or wash all over

6.1.7.8 Get dressed and undressed

Figure 35 shows that all could get dressed and undressed on their own. One of the carers initially reported difficulty in doing this but could manage without help at follow-up. Two did not fill in this section of the follow-up questionnaire and the other three reported no change.

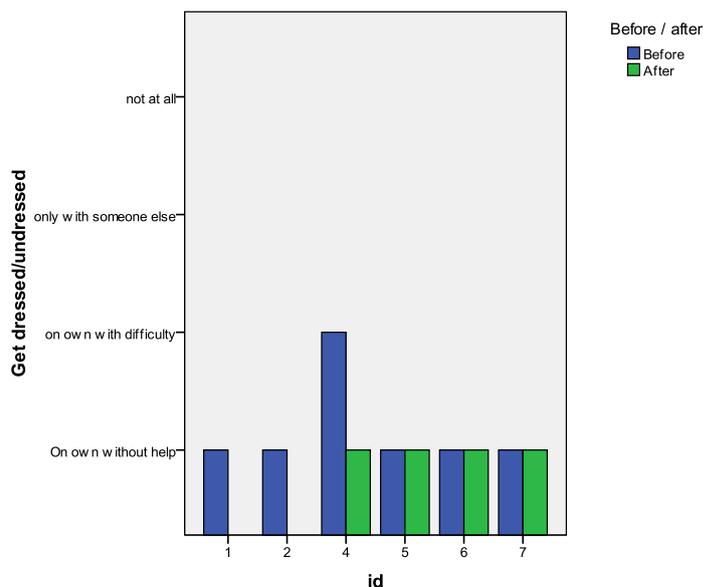


Figure 35: Get dressed and undressed

6.1.7.9 Feed yourself

Figure 36 shows that all the carers could feed themselves unaided throughout the study period.

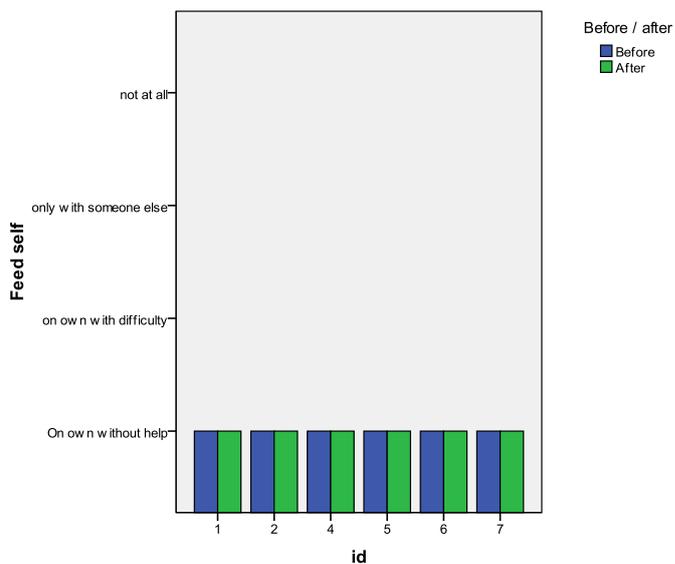


Figure 36: Feed self

6.1.7.10 Which of these statements describes your ability to control your bladder?

Figure 37 shows that all were continent. One initially reported having occasional bladder accidents, but not at follow-up. The remaining carers showed no change.

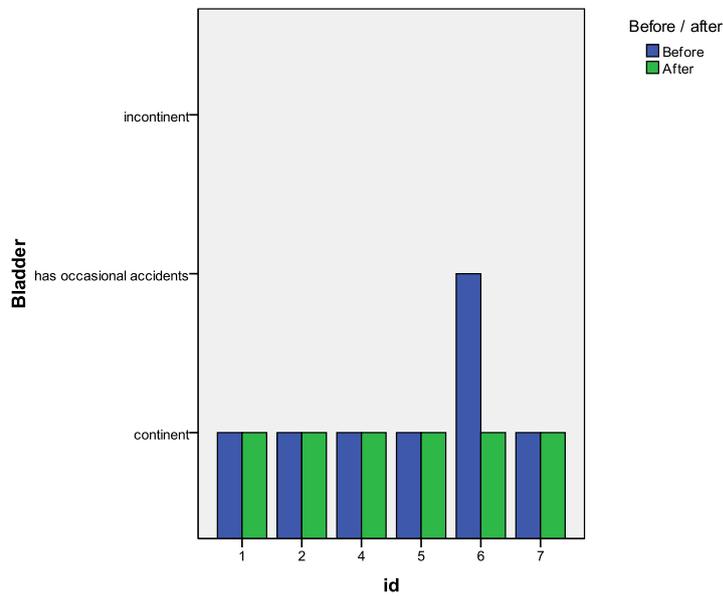


Figure 37: Control of bladder

6.1.7.11 Which of these statements describes your ability to control your bowels?

Figure 38 illustrates that all six carers reported being bowel-continent throughout the study.

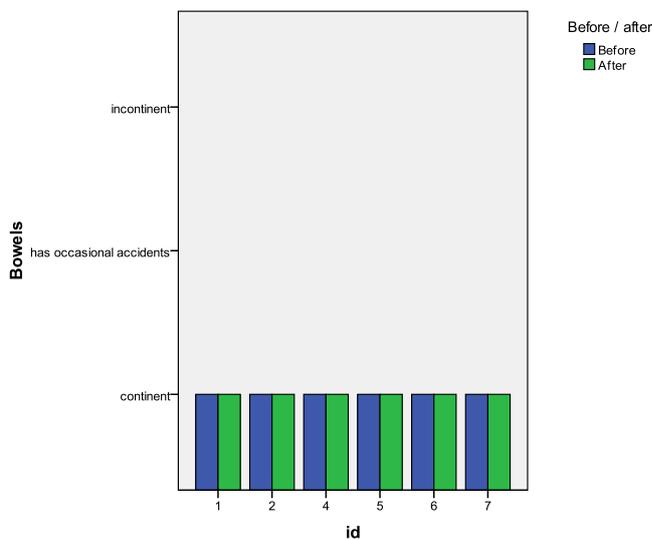


Figure 38: Control of bowels

6.2 Carer self-assessment questionnaire

At the outset of PHB assessment, carers completed a self-assessment questionnaire which was adopted by the commissioner of the study based on an ongoing national evaluation of Personal Health Budgets. At the time of evaluation (February-March 2012) interview carers were asked to complete these questions for a second time. These questions focussed on the physical and mental health and wellbeing of the carers before and after receiving their PHB. This section of the report details the responses of the carers to these questions.

6.2.1.1 As the carer, is your physical health affected by your caring role?

Figure 39 illustrates that during follow up three carers felt that they had experienced an improvement in terms of the affect that caring had on their physical health. Two carers had shown no change and one carer was experiencing increased levels of impact.

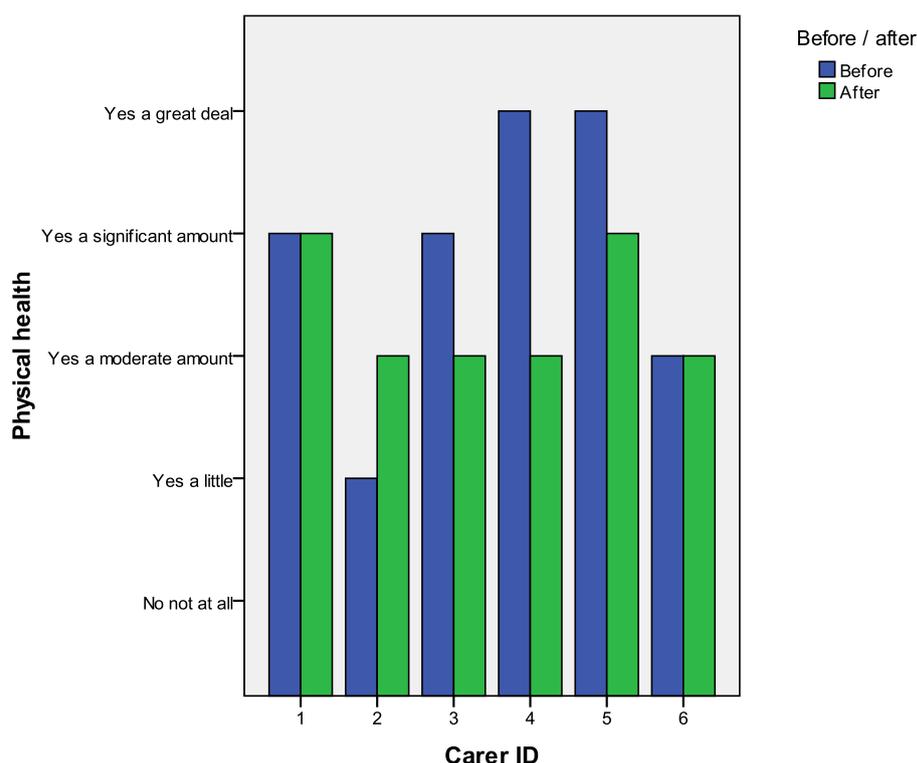


Figure 39: Effect on physical health

Carers were also asked to comment on whether they had had to resort to medical assistance or treatment as a result of any impact(s) on their physical wellbeing. Figure 40 shows that four carers had already received medical treatment or assistance at the start of the project. Two of these carers showed no change at follow up and one did. Two

carers were not receiving any medical assistance or treatment at the beginning of the project but were at follow up. One carer declined to respond to this question at follow up.

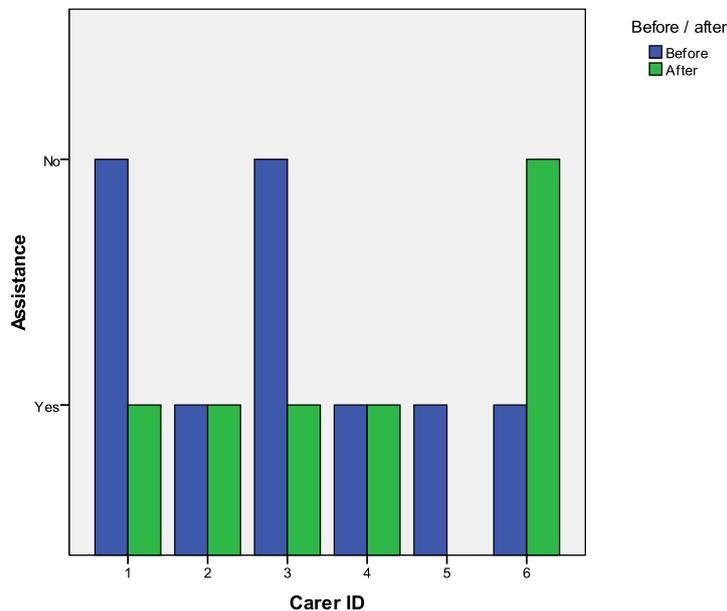


Figure 40: In receipt of medical assistance or treatment (physical health)

6.2.1.2 Are you able to keep up to date with housework that needs to be done around the home?

As Figure 41 shows, three of the carers felt that they were able to complete housework tasks at the beginning of the project, whilst three could not. At follow up, no change was reported by five of the carers, however one stated that whilst they had not been able to complete housework tasks at the outset of the pilot, they were now able to do so.

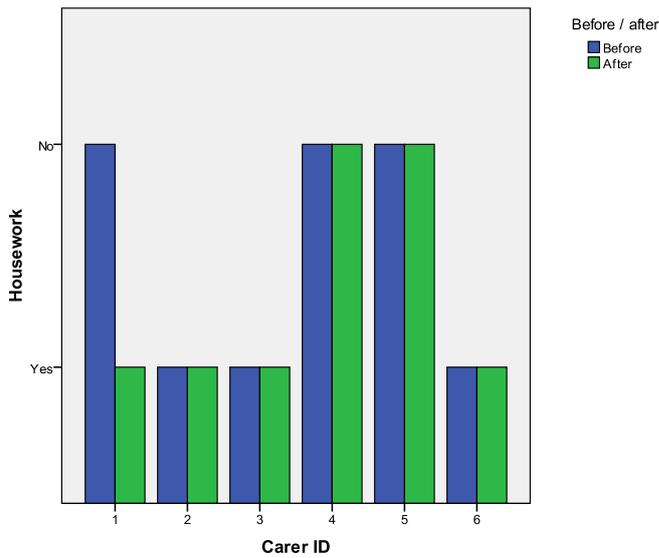


Figure 41: Ability to complete housework

6.2.1.3 Are you able to keep up with gardening jobs that need doing?

As Figure 42 shows, at the beginning of the pilot two carers felt able to complete necessary tasks in their gardens and four could not. Responses at follow up showed no change.

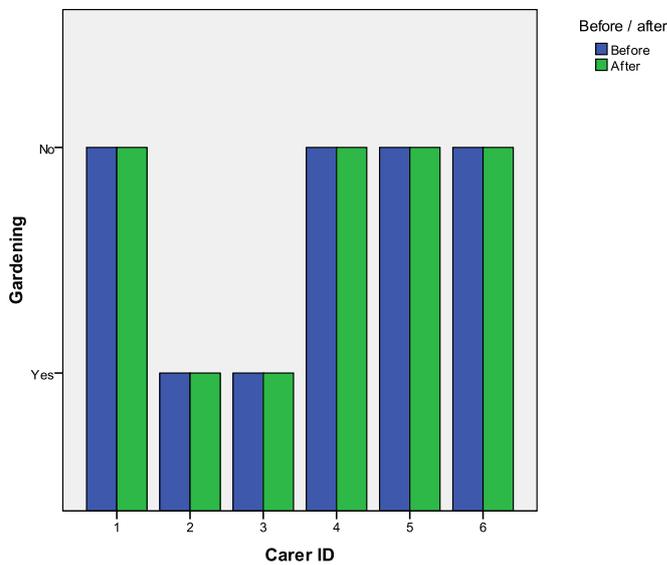


Figure 42: Ability to complete gardening tasks

6.2.1.4 As the carer, is your mental health affected by your caring role?

As Figure 43 illustrates, at the beginning of the pilot, all six carers reported that caring had an impact on their mental health. At follow up two carers showed no change, whilst

each of the other four carers noted an improvement. At follow up, one carer reported that their mental health was no longer being affected.

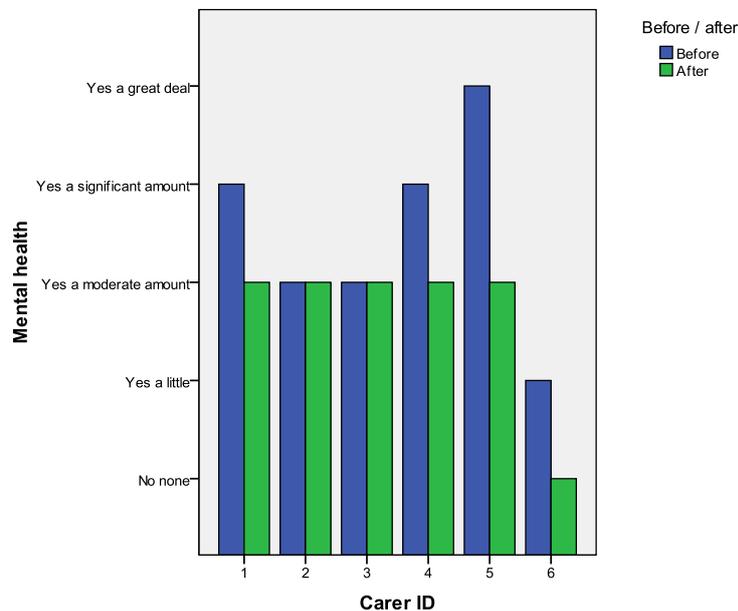


Figure 43: Effect on mental health

In addition, carers were asked whether they had received any medical assistance or treatment relating to their mental health, for example counselling, as a result of any impact that caring had on them. Figure 44 illustrates that at the beginning of the pilot two carers had not received any support of this kind, whilst four had. At follow up two carers showed no change in their response, whilst one carer had received this kind of assistance in the intervening timeframe. Two carers did not report receiving support of this kind at follow up and one declined to answer.

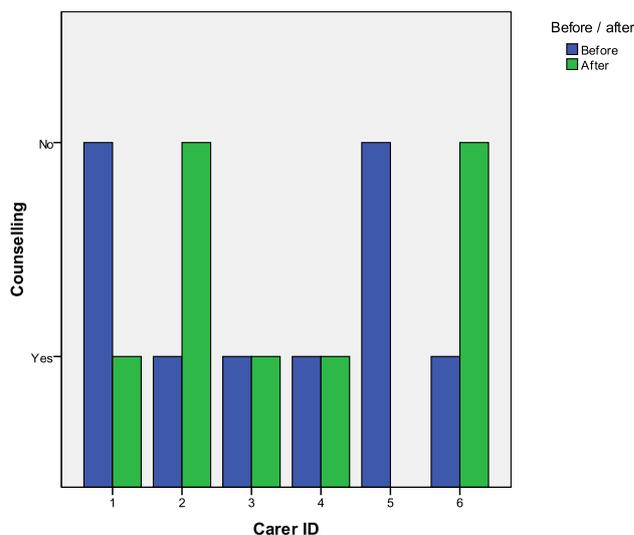


Figure 44: In receipt of medical assistance or treatment (mental health)

6.2.1.5 Do you suffer from interrupted sleep because of your caring role?

At the outset of the project five carers reported that they experienced interrupted sleep which they attributed to their caring role (see Figure 45), indeed three of these carers selected the highest level of interruption possible in the multiple choice responses offered. At follow up four carers reported improvement. One carer in particular showed a marked improvement at follow up (one carer showed no change and one noted that whilst their sleep was previously uninterrupted, they now experienced a little interruption).

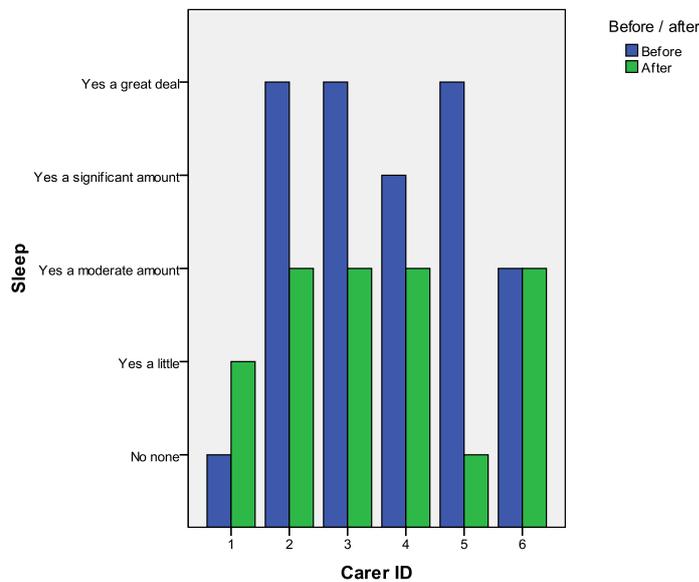


Figure 45: Experience of interrupted sleep

6.2.1.6 Are you able to keep up to date with odd jobs that need to be done around the house?

Figure 46 illustrates that at the outset of the pilot, four of the carers did not feel able to complete essential odd jobs in their homes and one did (one carer declined to respond to this question in both phases of the study). Whilst four carers showed no improvement one noted that whilst they were not able to complete odd jobs at the beginning of the project, they could at follow up.

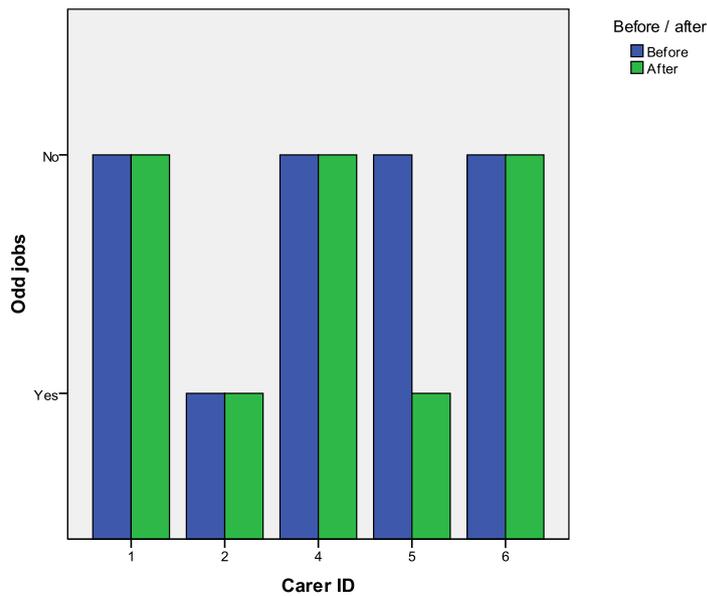


Figure 46: Ability to complete odd jobs

6.2.1.7 Do you have all the equipment you need to carry out your caring role (such as a hoist, stair lift, lifeline etc.)?

Carers were asked before and after receiving their PHB whether they had access to all of the equipment that they needed to carry out their caring role. At the outset of the project, four carers felt that they did have what they needed and one did not (one carer declined to respond at the outset of the pilot). At follow up, three carers showed no change and two reported that they no longer had all of the equipment that they needed (this may have related to increased awareness of what was available in the intervening timeframe). Figure 47 illustrates these responses.

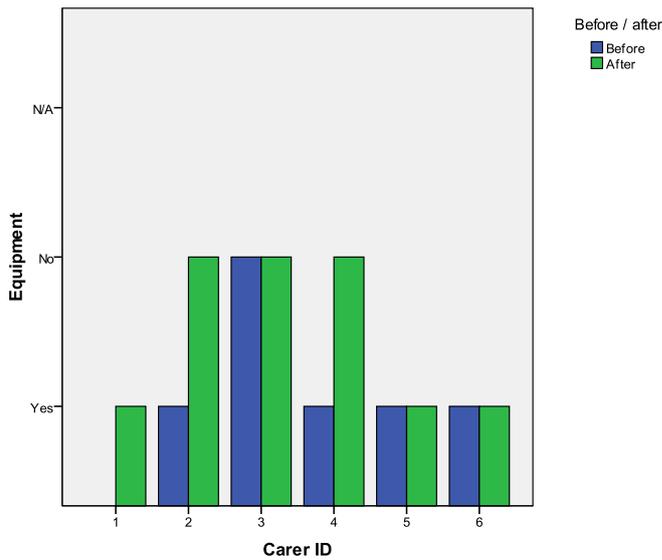


Figure 47: Access to necessary equipment

6.2.1.8 Do you feel you need moving and handling training to help you with your caring role?

At the outset of the pilot only one carer felt that they needed moving and handling training to support them in their caring role (four did not feel that it was needed and one carer declined to answer). At follow up five carers suggested that did not need moving and handling training and one felt that they now did. Two carers had changed their responses. These replies are illustrated in Figure 48.

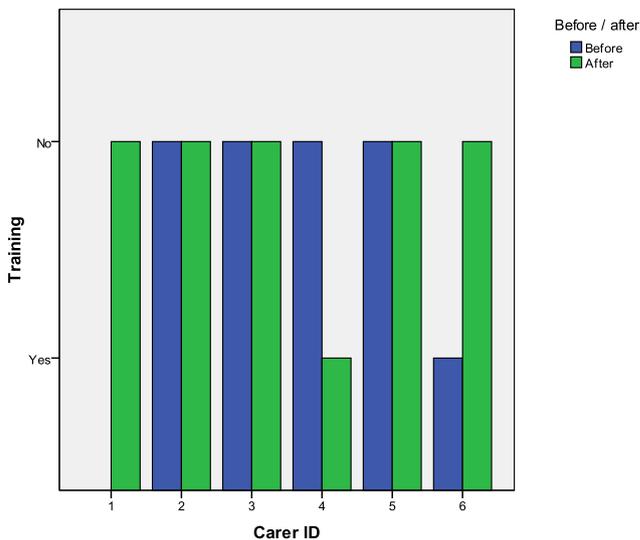


Figure 48: Carer needs: moving and handling training

6.2.1.9 As a carer do you feel you have to manage verbal abuse at times?

Carers were asked whether they experienced verbal abuse as part of their caring role. At baseline, half of the carers (3) did not report experiencing verbal abuse, and half did.

Figure 49 shows that at follow up five carers reported no change. One carer suggested at follow up that they had begun to experience verbal abuse.

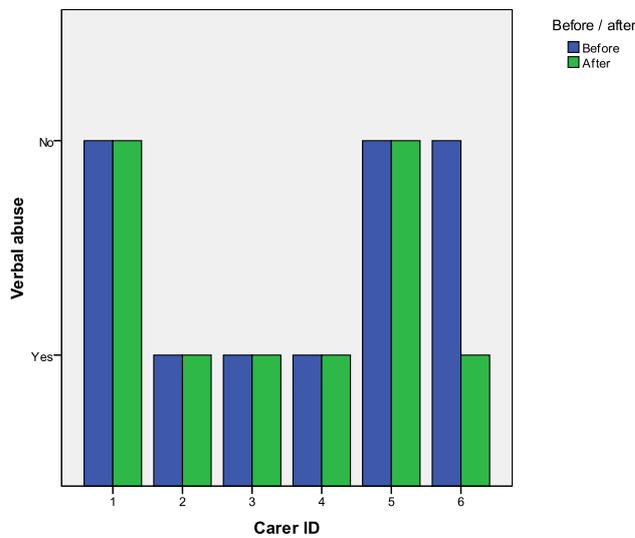


Figure 49: Experience of verbal abuse

6.2.1.10 As a carer do you feel you have to manage aggressive behaviour from the person you care for sometimes?

At the outset of the pilot, half of the carers (3) reported experiencing aggressive behaviour from the person that they cared for and half did not. At follow up one carer changed their response, noting that they no longer had to manage this kind of behaviour (no other changes were observed). These responses are illustrated in Figure 50.

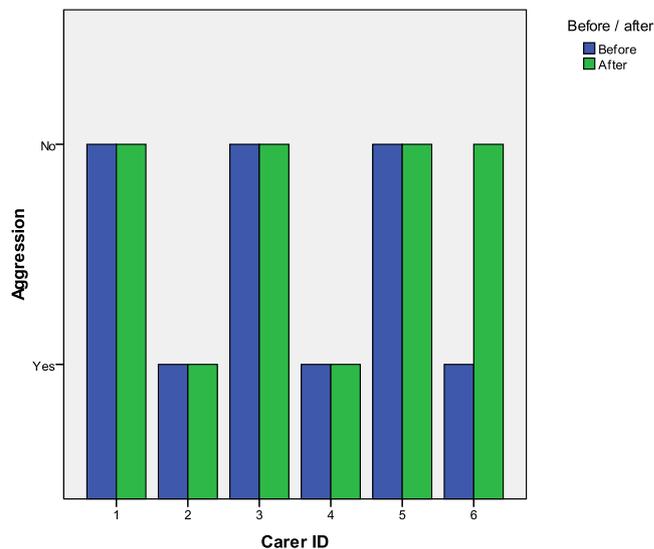


Figure 50: Experience of aggressive behaviour

6.2.1.11 Do you ever feel that your personal safety as a carer is in danger?

At the outset of the pilot four carers felt that their personal safety as a carer was not in danger and two did. No changes were observed at follow up. One carer noted at the outset of the study that they received 'threats of physical violence' from the person that they cared for. At follow up the same carer noted that the person that they cared for displayed 'physical outbursts' and a second carer reported that they had experienced 'punching and threatening behaviour'.

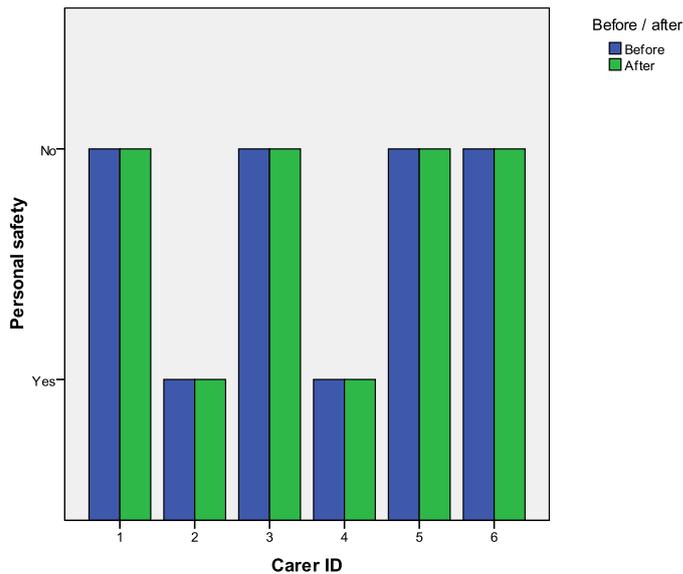


Figure 51: Personal safety concerns

6.2.1.12 Do you feel that your opinion is taken on board with service planning for the person you care for?

Figure 52 shows that at the outset of the pilot half of the carers (3) felt that their views were taken into account in the care planning of those that they cared for, and half did not feel that this was the case. At follow up, three carers felt that their views were taken into account and two did not (one carer declined to answer). One carer reported a change: where their views had not previously been taken into account, by the end of the pilot they had experienced improvements in this area.

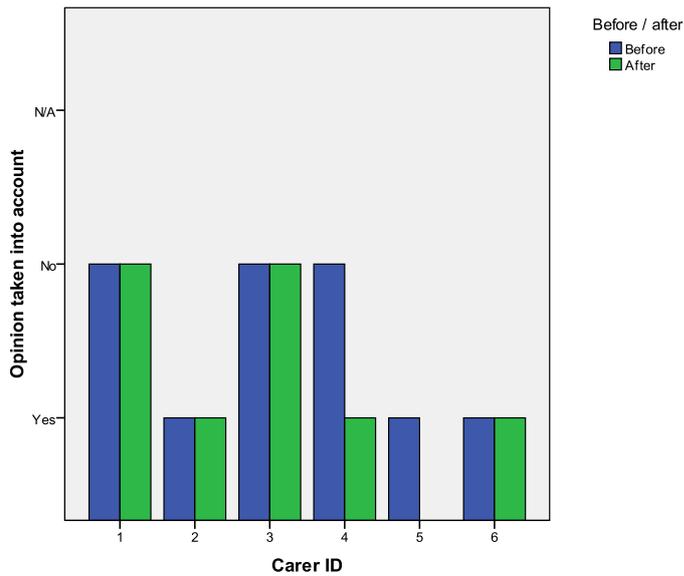


Figure 52: Opportunity to share opinions in the care planning of cared for person

6.2.1.13 Personal health during the preceding twelve months

At the outset of the pilot, all of the carers rated their personal health as 'poor' or 'very poor' during the preceding twelve month period. At follow up two carers reported no change. Four carers noted an improvement to their personal health. Improvements led two carers to rate their personal health as 'fairly good'. No carers rated their personal health as 'good' or 'very good' in either timeframe. Figure 53 illustrates these changes.

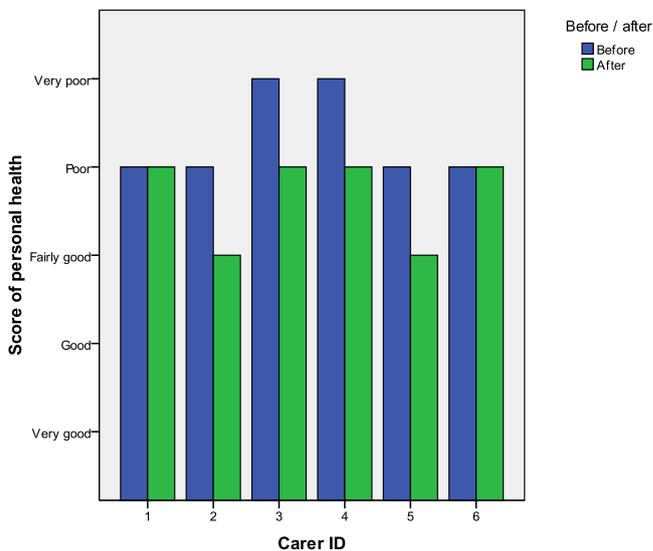


Figure 53: Level of personal health (preceding 12 months)

6.3 Health outcomes supplementary data

In order to facilitate the collection of evidence against the projected health outcomes associated with the carers' Personal Health Budgets, the commissioner of this study developed a feedback mechanism for completion by carers in conjunction with an identified health professional (see Appendix, page 81). Five forms were completed by health professionals for carers who participated in the study. This approach offered a number of different challenges. As Table 2 illustrates three of the health professionals noted that they were not in receipt of information with which to evidence change (or otherwise) in their patient, primarily because they had not seen the carer for the duration of the project, or else no information of relevance to the outcomes was included in the patient's file. Two carers noted challenges in obtaining an appointment to speak to the health professional who had been identified to complete the proforma. Where carers had completed the form their responses provide useful, targeted summaries of any impacts that they felt had been achieved. One carer also highlighted the impact of pressures which had increased during the project (where the person that they cared for had developed additional challenging behaviours which had increased their levels of stress).

Agreed PHB	Anticipated health outcomes	Reported outcomes (carer)	Reported outcomes (health professional)	Additional notes
Orthopaedic mattress Gardener hours to maintain garden	Improved sleep	"Excellent mattress improved sleep straight away. Not so stiff and less pain when getting up in the mornings"	"Patient reports much better"	N/A
	Improved ability to care	"It has helped a little. I have to go to a gym weekly to keep me mobile"	"Has not really affected ability to care"	
	Reduced stress and pain	"Having the garden done is a great help. I haven't had to struggle in pain to do it myself"	"Garden looks nice"	
	Improved general health and wellbeing	"My health did improve slightly. But due to behaviour problems from the person I care for I have had more stress"	"Slight improvement generally"	
Garden restoration Massage/relaxation	Reduced stress and anxiety/able to continue caring	"Spending time in my garden has reduced my stress loads, i.e. I can escape, it's quite nice to look at – makes me happier than before"	"Sounds as though adequately achieved"	N/A
	Improved mental health and sleep	"Since having massage and garden done, has relieved some stress, worries and time to relax just for me at that time"	"Sounds as though adequately achieved"	
Purchase Wii Fit and Exercise Games	Improved physical/mental health	Form not completed by carer	Weight not checked for duration of project. Mental health reportedly stable.	Carer reports challenges in obtaining appointment to see health professional.
Purchase Laptop and accessories	Improved diabetes management		No information available to evidence outcome	
	Improved confidence		No information available to evidence outcome	

Spending money for short break	Reduced social isolation		No information available to evidence outcome	
	Spending money		No information available to evidence outcome	
Purchase of family gym membership	Improved physical health	Form not completed by carer	No information available to evidence outcome	N/A
	Reduced depression and stress/able to continue caring		"Reported mood much improved. Unclear if due to antidepressants or increased activity..."	
Annual gym membership Aqua aerobics Associated equipment	Improved physical health	Form not completed by carer	No information received to evidence outcome	N/A
	Reduced social isolation		No information received to evidence outcome	
	Improved mental health		No information received to evidence outcome	
Purchase a second-hand mobility scooter Purchase a portable oxygen cylinder holder	Improved mental health	Form not completed by carer	Health professional reports that carer has not made contact. Unable to comment.	Carer reports challenges in obtaining appointment to see health professional.
	Reduced social isolation			
	Improved coping mechanisms			

Table 2: Health professional feed back

7 Results (carer interviews)

Six carers who were in receipt of a Personal Health Budget participated in a face to face interview with a CHWR researcher as part of this evaluation (one carer was unwell during the data collection period and therefore had to withdraw from the study).

Carers were asked a range of questions during the interviews. The interview schedule for this element of the study is included in the Appendix of this document (see page 76). Questions ranged from the carers' experiences of obtaining a PHB and their expectations of the project, to any ways in which they felt that taking part in the process had impacted on them as an individual. The remainder of this section of the report discusses these issues, drawing on the words of the carers where possible to illustrate their views.

7.1 Carer experience of Personal Health Budgets

At the beginning of their interviews, carers were asked a range of questions regarding their experience of the process of applying for and obtaining a PHB, and their expectations and subsequent experiences of the process.

In general, the carers who participated in the evaluation reported that they had received an approach from a health professional or member of the Carer Strategy Demonstrator Site (CSDS) team, which was the first time that they had heard of PHBs for carers.

...it came out of the blue, didn't even know it existed.

In the very beginning, before I had my assessment, I didn't know anything about it, it was a carer support worker that suggested that I be put forward through a budget 'cause she said that I could benefit from it..

Some carers noted that they had no personal expectations of what participation in the project would offer beforehand, others noted that they had not expected to be selected for the pilot, or that it would not come to fruition.

I did think at the time, you know, 'Oh that would be nice for me to have' but whether I'd get it, I don't know.

I expected not to hear off anybody quite honestly...'cause we've been promised things before and nobody has turned up.

When asked about their actual experiences of participating in the pilot, all of the carers who were interviewed spoke positively about the way that the process had been managed.

I don't see, on the process that I went through, that you could change anything.

I think it was very efficient and self-explanatory.

When asked for their feedback on the process of applying for, and obtaining a PHB, the interviewees noted the ease with which they had been able to develop and submit applications. The paperwork required as part of their applications was considered straightforward by all of the carers.

I think the PHB, the actual paperwork was minimal and it was quite well set out and self-explanatory and wasn't a problem to fill in at all.

The paperwork is set out easy, the questions are fine and giving you options to answer, that's set out in a good way.

It's just like filling in forms and loads of asking questions and you know, and things like that, it wasn't too bad.

Carers also commented on the level of support that was offered to them during the application process, particularly with the completion of relevant forms. One carer, in particular, reflected on her need for support with defining the form that her Personal Health Budget would take.

...I needed some people to suggest what I'd want to be honest...I think you get to a stage where you can't see anything...I didn't know what was going to make it easier...

...[the forms were] ok and the people that came were really good and really nice so...

The discussions that formed part of the application process were also seen as valuable. The application process was considered to have offered carers an opportunity to reflect on their own needs as individuals, rather than as carers, and to share the challenges that they were facing with others.

...in the middle of all of this is I'm dealing with everything, all of it, but I have to keep going because if I stop going then what happens...so it was really difficult to decide what I would like because I just don't come into the equation...

...it gets it off my chest what I've got to say...I can talk to somebody who I don't know and they don't know me.

A recurring theme across a number of the discussions (and which is highlighted through the quotes above) was that some carers were unused to considering their own needs. Deciding on the best use of the PHB was therefore considered a challenge. Five of the carers specifically noted the importance of the time that they had been given between receiving information about the pilot and making their decision. Time to reflect on their needs and therefore how the funding could be put to best use was considered an important element of the application process.

'Cause just talking to somebody, you can't, I think you need say a week, you know, a week to think about what your needs are.

...she explained the process and said I needed to think about what I would like, what could make life easier, what could make things better for the whole family. So they went away and then came back...

This reflection time was also discussed in relation to the amount of choice and control that they were able to exert during the PHB process. Without exception the carers all noted that they had been able to affect their own Personal Health Budget, and how the funding was spent. This, coupled with the points made above regarding the supportive nature of the application process, suggests that the carers felt positive about how the process had been managed. Carers commented that they had been able to share their views in relation to both the outcomes that they felt needed to be prioritised, and in the decision-making on how they would direct the funding.

...because you're on benefits or whatever, you haven't got the money. So I could go out and buy the bits and pieces, or if it was a specialised piece of equipment...maybe someone would help me get the equipment...this was helping myself.

Yeah, they said within reason you can decide what it was that you thought would make life easier for us...I just wanted something to make mentally and socially and physically...I thought it was the best thing to go for...

I think she sort of let me, you know, decide what I wanted to use it for...

Whilst the carers were altogether positive in their reflections about their experience of the PHB process, one carer offered constructive feedback on the time taken from application to award of the Personal Health Budget. Another noted what they felt were restrictions in the timeframe in which they were able to spend the money.

...it seemed to take quite a while to go through 'cause it had to go to different people and then they had to agree it and then they had to get the cheque sent out...and I think it took quite a while...

I would say the one negative thing was with it was I more or less had to spend it all at once.

7.2 Perceived impacts of Personal Health Budgets for carers

The six carers who participated in the evaluation noted a range of impacts arising from the pilot. In order to prevent inadvertent identification of participants their discussions here are not related directly to the specific Personal Health Budget that they received. Instead, recurring themes are identified. Section 8 of this report (see page **Error! Bookmark not defined.**) provides a summary of overall impact across all of the participants.

7.2.1 Physical health

Following receipt of their PHB, five carers noted a positive impact in relation to their level or physical activity and / or to their general physical wellbeing. Increased mobility for these carers was deemed to have led to a range of related benefits. One carer felt that they were in less pain following the interventions offered through their PHB. Another considered that they had lost weight and a third noted increased energy and improved blood pressure. Two of the carers also noted improved sleep.

...I'm not in so much pain as I was...I was at one time taking liquid morphine...overall generally taking that medication, well I take it once in a blue moon now.

I think I've lost a bit of weight, I've got a medical to go to with the doctor soon so he weighs me and I've got to have a check-up to see how I'm getting on.

I think my blood pressure's a lot better and my physical health is better...I think I've got a lot more energy...

Yeah, it did make me sleep a bit better you know...I'd come home, probably get, you know, get the tea and that and then I'd probably have a better night's sleep...

One carer did not feel that they had experienced any benefits to their physical health following the PHB experience. Their discussion is not included here in order to maintain the anonymity of their responses; however they noted that a previously-existing health condition may have influenced the extent to which the process could have impacted on their physical health. This issue is discussed further in section 7.3.

7.2.2 Mental health

Mental health was perhaps the area where carers discussed the most impact arising from their participation in the PHB pilot. They discussed general improvements to their mental health, in particular a perception of decreasing levels of stress.

Yeah, so it does, it makes a big difference to your, you know, mentally thinking...

If I hadn't have had the Personal Budget, I'd probably have more stress.

Additionally, the ability to take some time for themselves was thought to have offered some the opportunity to spend time alone, taking their mind off stressful events and situations.

I think to reduce the stress has given me the time out to go there and relax...I think that's nice, after getting over the initial I feel guilty feeling...

...it takes me mind off being stressed and worrying about things you know, I'm busy trying to do other bits and pieces.

Some discussed how this time offered opportunity for reflection and a reassessment of their individual needs.

...you do need you time in all of this 'cause it just does, there's not a magic wand to make it any better but I think if you don't have that time for yourself then it just spirals literally out of control and things get, I think that's when things get out of hand. But for me, I'm a different person to what I was 12 months ago definitely.

Well from 12 months ago, I couldn't see the light to anything...And I couldn't see a way out of it and everything was just spiralling out of control, where now I can actually smile and laugh...

7.2.3 Socialisation

Half of the carers who were interviewed (n 3) specifically noted the increased opportunities that their PHB had offered them in terms of socialisation. These carers discussed the increased opportunities open to them to meet with friends or socialise with new people.

...you can meet other people that you haven't seen for a long while and sit and chat quite happily...so you know the socialisation is great because I can bump in and meet people or even go out with somebody if I want...

Because I've changed because I didn't really want, I suppose for a long, long time, I didn't really want to interact with people...so I've actually got it, I'm making a lot more friends and it's...my confidence has improved.

Two carers noted increased opportunities to spend time with family members who did not live with them and a change for the positive in terms of the activities that they did together, for example using the internet or via home-based activities that the PHB had funded. Another carer, who chose to be interviewed with a relative present, reflected on the impact of the PHB on their family life within their home. This carer had felt less stressed since the introduction of the scheme and their family had noticed an impact in terms of the level of irritability that the carer displayed. The improvements to the garden of another carer (two PHBs included gardening support) was deemed to have offered benefits to the family of one carer as well as benefits to themselves.

7.2.4 Freedom and independence

A number of the carers discussed the opportunities that their PHB had offered for them to have some time away from caring. This increased independence often afforded a chance to reflect or relax when the pressure of caring mounted. Some of the carers discussed welcoming these opportunities in a general sense, whilst others noted how welcome the chance to remove themselves from a particularly stressful situation was.

I just think that, it sounds stupid but just being, having that freedom, that independence and being out in the fresh air, you know.

They gave me a life to be honest. When they said, "What is it you want?" and I thought, "Well I don't know what I could have to change anything". I can't change anything physically and emotionally but I thought, "I need something to get me outside of this house", and they gave me somewhere to escape, even if it's eight o'clock at night, I can escape there...

...if things get quite uptight in here, I can go down to the garden and yeah, and you know, and just sit down the bottom of the garden out of the way...whereas before...

Additionally, two inter-related themes which were discussed by the carers concerned their self belief and potential opportunities for the future. Where the use of a PHB had enabled them to try new opportunities and develop new friendships some carers also discussed a renewed consideration of their future. In particular they discussed the potential for seeking out new employment or training opportunities, alongside setting new goals for themselves. In the shorter term, two carers also discussed how the activities afforded them by participation in the pilot had highlighted the importance of them taking time out for themselves.

...I can just go and do what I need to do and it's taught me to take, try and take a day off each week to just be me so, which is something I never had before so it's nice that it's given me that, taught me how to do that really, just to take time out.

...it has changed things dramatically for us to be honest because it's given me part of me back and I think you get completely lost when you don't know who you are, all you're known as is...a carer or the person that goes and picks this, that and the other up and to give you you back is a start...you need to be in a situation where you can work out who you are and you can carry on with life and I think that's what I've enjoyed out of it.

7.3 Contextualising impact

All of the carers who participated in the interviews noted that taking part in the pilot had been of benefit. The level of impact that each discussed varied immensely. Each interviewee recognised that there were some impacts of caring that the scheme could not improve, and each reflected on this during the discussion. Two carers, for example, noted the ways in which caring impacted on their own existing medical condition(s), or caring challenges which were exacerbated by the presence of such conditions. Whilst others noted some positive impacts of participation in the pilot, they showed awareness that its remit was not all-encompassing.

I do feel better. I don't think you ever feel 100% because you can't rest properly and to be able to rest properly you need to not do the 24 hour day job that you do so I think to feel better is a start...

It's relieved the stress but because of, my health problems are ongoing, it couldn't help in that respect.

8 Summary of findings

The following provides an overview of the main findings of the evaluation. This should be read in conjunction with the detailed findings presented in the main body of the report.

The two repeated questionnaires (the carer questionnaire and the self-assessment questionnaire) revealed improvements over the period they had received the personal health budgets from at least half of the carers in areas relating to general health and wellbeing issues. This included questions relating to life satisfaction, happiness, feelings of worry, general health and social life. However, although questions relating to depression and anxiety (e.g. 'how happy did you feel yesterday', 'how worried did you feel yesterday') revealed improvement, those directly asking about depression and anxiety ('I am not/moderately/extremely anxious or depressed') did not. Similarly, when asked directly about their quality of life ('Thinking about the good and bad things that make up your life, how would you rate the quality of your life as a whole') no change was reported from most carers, although more indirect questions relating to aspects of quality of life did show improvements. Although the reasons for this apparent anomaly are not directly addressed, it could be that the carers are reluctant to use the emotive diagnoses of anxiety or depression when considering their own health and may find the overarching concept of quality of life difficult to evaluate.

Where the same areas were addressed by different questions, the findings were very similar which suggests that the responses were reliable. There were a number of question areas that would not be expected to be affected by the use of a carer's personal health budget. These included issues relating to the physical health of the carer (e.g. pain, continence) or their ability to care for themselves. The responses of the carers to these questions showed little or no change, which again supports the reliability of the findings.

In the interviews, carers reflected positively on the way that the PHB process had been managed, emphasising the support that had been offered to them during discussions relating to the form that their own PHB would take, and they found this opportunity to reflect on their own needs to be helpful in its own right. Each of the carers interviewed felt that they had been offered choice and control during the process. During the

interviews for the study, carers noted a range of benefits relating to physical health, primarily as a result of increased mobility and improved sleep patterns, however they were realistic about those aspects of their lives which were capable of being improved with the help of a personal health budget and recognised that some of their physical health problems were unlikely to be affected.

The interviews provided further evidence that the carers had felt the most benefit in relation to their mental health. Time out from caring responsibilities afforded them opportunities to socialise with family or friends, or to reflect on their individual needs. Where their PHB offered them the opportunity to remove themselves from stressful situations this was also welcomed.

It proved to be very difficult to evidence the intended outcomes of the personal health budgets by obtaining objective 'hard' evidence from their health professionals. This was, in part, due to difficulties encountered by the carers in contacting their health professionals to obtain their assessment but may also have been because of the more intangible nature of the benefits sought and reported by the carers.

9 Recommendations

The following general suggestions have been identified for future quality enhancement. They are not in priority order and should be read in conjunction with the detail provided in the body of this report.

- Consideration should be given to the timeframe over which the funding offered via a PHB can be spent. This would reflect the wishes of carers who may wish to use the money allocated to them over a longer period.
- A review of the mechanisms via which a PHB is reviewed / approved is recommended in order to ensure that carers do not experience a lengthy delay between application and feedback. Alternatively, information letters informing carers of the timeframe for review would set realistic expectations.
- A review of the questionnaires for the PHB assessment process and for review and evaluation of the impact on carers is recommended. Assessment and evaluation tools which are better targeted at the needs of carers and the realistic potential benefits of PHBs would enable more effective gathering of evidence.

- Future evaluation of the effectiveness of providing personal health budgets for carers should be built into the PHB process to allow evidence from a greater number of carers to be gathered. This would enable statistical analysis to be performed on the results providing more generalisable evidence. Consideration should also be given to longer term follow-up of those in receipt of PHBs to allow for the evaluation of long term benefits.
- Based on the challenges encountered in gathering information from General Practitioners, it is recommended that consideration is given to the collection of evidence of the effectiveness of the PHB against the original agreed outcomes being carried out by a Carer Assessment and Support Worker (CASW). The evidence that health professionals may be able to provide is dependent on the outcomes identified for individual carers. Where outcomes relate to more general aspects of well-being they are often more challenging to obtain from health professionals as part of their routine contact with the carer. CASWs may have better opportunities for eliciting appropriate evidence from the carers and, where appropriate, from those who have regular contact with carers.

10 The evaluation team

The evaluation team for this project included:

Professor Jackie Campbell PhD MInstP CPhys CStat FCOT is Professor of Neurophysiology at The University of Northampton. Her experience of multi-professional working is particularly valuable and she has successfully worked with a wide variety of different professional and multi-professional groups. Professor Campbell has led many major evaluation projects, including the first national evaluation of the Duke of Edinburgh's Award (for Pears Foundation and the Duke of Edinburgh's Award), a review of placements for looked after children in Northamptonshire, surveys of self-esteem and health needs within Northamptonshire (for NCC) and a review of footcare needs of older people (for Help the Aged). She is an expert in quantitative research methods and is a chartered statistician. She was a member of the Northamptonshire Research Ethics Committee.

Professor Campbell's own research interest is in the field of health where she has an international reputation. She has also made a major contribution to the development of research in the professions allied to medicine, and to podiatry research in particular. She has a substantial publications record, publishing in journals relating to children,

older people, nursing, podiatry, computing, occupational therapy and psychiatry amongst others and has presented her work at many prestigious international conferences. She is a referee for grant applications for many national bodies and is a regular reviewer for international journals. Until recently she held the post of Chair of the national Research Forum for Allied Health Professions.

Dr. Michelle Pyer BA (Hons), PhD, FRGS is a full time Researcher for the Centre for Health and Wellbeing Research at the University. She has completed over fifteen research and evaluation projects for local and national organisations since her appointment in 2009. Michelle is particularly proactive in developing projects which engage members of the public in their development. Her PhD research considered the impact of particular spaces on the leisure and wellbeing of teenage wheelchair users. Michelle has worked on a number of research projects in relation to the needs of carers and families of disabled people in both third sector and local authority contexts and has wide ranging experience of working in home environments as a family support worker for children with additional needs. She is a member of a Midlands NHS Research Ethics Committee and as part of her work for CHWR regularly provides support and guidance to researchers applying for ethical review.

Professor Annie Turner MA, DipCOT, FCOT works part time as professor of occupational therapy at the University of Northampton. During her occupational therapy career Annie has been lead editor of seminal texts over 20 years and has been involved in a range of research and international projects. Last year she was chosen to deliver the prestigious Casson Memorial lecture at her profession's annual international conference and has a long-standing professional interest in issues of identity and autonomy. In addition Annie is a registrant member of the Health Professions Council, the regulator of 15 health professions within the UK, as well as a trustee of the Marie Curie Trust and the Elizabeth Casson Trust.

11 APPENDICES

11.1 Carer questionnaire



Carer Questionnaire

Personal Health Budget for Carers

Personal Health Budgets are a new way to arrange health care. They are being tried out in a number of areas including where you live. In order to find out whether this new approach is a good one, the Department of Health has funded a study of Personal Health Budgets.

Locally we are seeing how this works for a small group of 20 Carers. Because we do not know what, if any, difference this new approach might make, it is important to find out the views and experiences of carers like you. The interviewers will not use your name or anything that identifies you or the person you care for in any report of this work and it will not be made known who took part.



1) I would like to ask you some initial questions about yourself

a) **Overall, how satisfied are you with your life?** Please circle the appropriate number

0 1 2 3 4 5 6 7 8 9 10
Not at all Completely
satisfied satisfied

b) **Overall, how happy did you feel yesterday?** Please circle the appropriate number

0 1 2 3 4 5 6 7 8 9 10
Not at all Very happy
happy

c) **Overall, how worried did you feel yesterday?** Please circle the appropriate number

0 1 2 3 4 5 6 7 8 9 10
Not at all Very
worried worried

d) **Overall, how satisfied are you with your health?** Please circle the appropriate number

0 1 2 3 4 5 6 7 8 9 10
Not at all Completely
satisfied satisfied

e) **Overall, how worried are you about your health?** Please circle the appropriate number

0 1 2 3 4 5 6 7 8 9 10
Not at all Very
worried worried

2) I would now like to turn to discuss how you have been feeling over the past few weeks. These questions may seem a bit odd but they are part of a scale so we have to ask them this way. **Please tick a box for each question.**

a) **Have you recently been able to concentrate on whatever you're doing?**

- Better than usual
- Same as usual
- Less than usual
- Much less than usual

b) **Have you recently lost much sleep over worry?**

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

c) **Have you recently felt that you are playing a useful part in things?**

- More so than usual
- Same as usual
- Less so than usual
- Much less useful

d) **Have you recently felt capable of making decisions about things?**

- More so than usual
- Same as usual
- Less so than usual
- Much less capable

e) **Have you recently felt constantly under strain?**

- Not at all
- No more than usual
- Rather more than usual

Much more than usual

f) **Have you recently felt you couldn't overcome your difficulties?**

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

g) **Have you recently been able to enjoy your normal day-to-day activities?**

- More so than usual
- Same as usual
- Less so than usual
- Much less than usual

h) **Have you recently been able to face up to your problems?**

- More so than usual
- Same as usual
- Less so than usual
- Much less able

i) **Have you recently been feeling unhappy and depressed?**

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

j) **Have you recently been losing confidence in yourself?**

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

k) **Have you recently been thinking of yourself as a worthless person?**

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

l) Have you recently been feeling reasonably happy, all things considered?

- More so than usual
- Same as usual
- Less so than usual
- Much less than usual

3) Thinking about your health and quality of life.

a) How is your health in general?

- Very Good
- Good
- Fair
- Bad
- Very Bad

b) Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

- So good, it could not be better
- Very good
- Good
- Alright
- Bad
- Very bad
- So bad, it could not be worse

4) The following questions are about how you feel at the moment about aspects of your life and home.

Please tick only one box for each of the following questions. Many people value being in control of their daily lives and having independence

By 'control over daily life' we mean you are the one making decisions about your life, and having the choice to do what you want, when you want.

a) Which of the following statements best describes your present situation?

- I have as much control over my daily life as I want
- Sometimes I don't feel I have as much control over my daily life as I want
- I have no control over my daily life

b) Thinking about the way you look and feel, which of the following statements best describes your present situation?

- I feel clean and wear what I want
- I sometimes feel less clean than I want or sometimes can't wear what I want
- I feel much less clean than I want, with poor personal hygiene

c) Thinking about the meals you eat, which of the following statements best describes your present situation?

- I eat the meals I like when I want
- I don't always eat the right meals I want, but I don't think there is a risk to my health
- I don't always eat the right meals I want, and I think there is a risk to my health

d) Which of the following statements best describes how safe you feel?

Not feeling safe could be due to fear of abuse, falling or other accidental physical harm, and fear of being attacked or robbed.

- I feel as safe as I want
- Sometimes I do not feel as safe as I want
- I never feel as safe as I want

e) Which of the following statements best describes your social situation?

By social situation we mean keeping in touch with people and spending time with people that you want to be with.

- My social situation and relationships are as good as I want
- Sometimes I feel my social situation and relationships are not as good as I want
- I feel socially isolated and often feel lonely

f) Thinking about your usual activities including leisure, doing things for others and paid or unpaid employment, which of the following statements best describes your present situation?

- I do the activities I want to do
- I do some of the activities I want to do
- I don't do any of the activities I want to do

g) Thinking about your home, which of the following statements best describes your present situation?

- My home is as clean and comfortable as I want
- My home is less clean and comfortable than I want
- My home is not at all as clean or comfortable as I want

h) Which of these statements best describes how worried or concerned you feel?

- I feel free from worry and concerns on a day-to-day basis
- I sometimes feel worried and concerned
- I feel very worried and concerned on a daily basis

i) **Which of the following statements best describes your present situation?**

- I am treated by other people with the dignity and respect that I want
- Sometimes I am not treated by other people with the dignity and respect that I want
- I am never treated with the dignity and respect that I want

j) **Thinking about the care and support you provide to others such as children, husband, wife or partner, which of the following statements best describes your present situation?**

- Not applicable
- I provide others with the kind of support that I want to provide
- At times I find it difficult to provide others with the kind of support that I want to provide
- I am not able to provide others with the kind of support I want to provide

5) We are now going to move on to discuss your health. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

a) **Mobility**

- I have no problems in walking about

- I have some problems in walking about
- I am confined to bed

b) Self-care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

c) Usual activities (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

d) Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

e) Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

f) Compared with my general level of health over the past 12 months, my health state today is:

- Better
- Much the same

g) To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line to whichever point on the scale that indicates how good or bad your health state is today.

Best
imaginable
health state

100

95

90

85

80

75

70

65

60

55

50

45

40

35

30

25

20

15

10

5

0

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Worst
imaginable
health state

6) The following questions are about managing to do things yourself. Do you usually manage to:

a) **Get up and down stairs or steps**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

b) **Go out of doors and walk down the road**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

c) **Get around indoors (except steps)**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

d) **Get in and out of bed (or chair)**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

e) **Use WC/toilet**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

f) **Wash face and hands**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

g) **Bath, shower or wash all over**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

h) **Get dressed and undressed**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

i) **Feed yourself**

- | | |
|---|---|
| <input type="checkbox"/> On own without help | <input type="checkbox"/> Only with someone else |
| <input type="checkbox"/> On own with difficulty | <input type="checkbox"/> Not at all |

j) **Which of these statements describes your ability to control your bladder? (A person able to manage a catheter without assistance may be described as continent)**

- Continent
- Has occasional accidents
- Incontinent

k) **Which of these statements describes your ability to control your bowels? (A person able to manage a colostomy without assistance may be described as continent)**

- Continent
- Has occasional accidents
- Incontinent

7) The following section asks questions about your caring role and the personal health budget

a) Today we are discussing the care you provide. Is the person cared for your ...

- Parent
- Spouse/partner
- Child
- Other relative
- Other non-relative

b) Would you describe yourself as the sole/main carer for the person cared for? (**Interviewer note: Here, we are only interested in unpaid 'family' or 'informal' carers**)

- Main informal carer
- Caring is a shared/joint responsibility

c) Do you live with the person cared for?

- No
- Yes

d) How many hours a week, in total, do you spend caring?

_____ hours

e) **Overall, how satisfied were you with the process of care planning process?**

- Extremely satisfied
- Very satisfied
- Quite satisfied
- Neither satisfied nor dissatisfied
- Quite dissatisfied
- Very dissatisfied
- Extremely dissatisfied

f) **How satisfied are you with the services the person who care for receives?**

- Extremely satisfied
- Very satisfied
- Quite satisfied
- Neither satisfied nor dissatisfied
- Quite dissatisfied
- Very dissatisfied
- Extremely dissatisfied

8) The following section asks some questions about you

a) Can you tell me which of these age bands you would put yourself into?

- 16-24
- 25-34
- 35-44
- 45-59
- 60+
- Refused

b) **Who do you live with?**

- Alone
- Spouse/partner
- Parents
- Son/daughter
- Other (*please specify*)

c) **What is your permanent accommodation?**

- Bungalow
- Flat
- Semi-detached house
- Detached house
- Terraced house
- Residential home
- Supported setting

d) Is the place where you live owned or rented

- Owner occupier
- Shared ownership
- Rented

e) **Which of the following best describes you?**

- White - British
- White - Irish
- White – any other background
- Mixed – White and Black Caribbean
- Mixed – White and Black African
- Mixed – White and Asian
- Mixed – any other Mixed background
- Asian or Asian British - Indian
- Asian or Asian British - Pakistani
- Asian or Asian British - Bangladeshi
- Asian or Asian British – any other background
- Black or Black British - Caribbean
- Black or Black British - African
- Black or Black British – any other Black background
- Chinese
- Other
- Refused

d) **In addition to your caring role, are you....? (please tick all that apply)**

- Retired
- Doing voluntary work
- In part time education/training
- In full time education/training
- Working full time
- Working part time
- Self employed
- Looking for work
- Not looking for work

Any other comments (*could include comments from the interviewee or problems completing the questionnaire from the interviewer*)

Thank you for completing this questionnaire

11.2 Cover letter and information sheet: carer face to face interviews

[ON CHWR HEADED PAPER]

Dear Carer,

Personal Health Budgets pilot for carers in Northamptonshire: An evaluation

We are an independent evaluation team based at the University of Northampton. We have been asked to complete an evaluation of the above service for NHS Northamptonshire. The study will provide data which the commissioners of the service can use to develop it in the future.

You are receiving this information because you have consented to participate in the pilot service which delivers Personal Health Budgets for carers in Northamptonshire. We would really like to find out about your experiences of participating in the pilot and would like to invite you to meet with one of our Researchers to undertake a short interview about your views. This should take a maximum of an hour, at a time that is convenient to you. The attached information sheet is designed to tell you more about the study. If you have any questions or queries about the interviews and would like to speak to one of our researchers please contact Dr Michelle Pyer (01604 892831 or michelle.pyer@northampton.ac.uk).

We are also enclosing a health questionnaire which we would be grateful if you could complete (I understand that you have seen this twice before but we do need to see whether your health status has changed over time!) and a pre-paid envelope for you to return it to us for analysis. Should you have any questions about this process please contact Nicola Best, Personal Health Budget Lead on 01933 677837.

Thank you for taking the time to read this letter.

Kind regards,

Professor Jackie Campbell
Project evaluation lead
Centre for Health and Wellbeing Research

Personal Health Budgets pilot for carers in Northamptonshire: An evaluation

Information sheet: Interviews

Invitation

You are being invited to take part in an evaluation. Before you decide whether or not to take part, it is important that you understand why this evaluation is being done and what it will involve. If, having read the following, you are unclear about any aspect related to this study please feel free to speak direct to one of the university project team (contact details below).

Purpose of the evaluation

This study seeks to evaluate the use of Personal Health Budgets (PHBs) for carers in Northamptonshire. We aim to collect some important information to help inform the future delivery of the service.

What will I be asked to do if I agree to take part?

We would like to invite you to participate in the evaluation in two ways. **First**, by completing the health questionnaire that is enclosed with this information (we would be grateful if you could return this in the pre-paid envelope provided). **Second**, we would like to invite you to complete a short interview with one of our University Researchers. The questions that we will ask as part of the interview have been designed to provide the commissioners of the service with information to show the kind of impact that participating in the PHB pilot has had on/for you. We are interested in all of your views about the pilot – good and bad. If you agree to participate in the evaluation a Researcher will contact you at the beginning of February to arrange a mutually agreeable time and place to meet. With your permission we will record the interview to make sure that we are able to represent your views faithfully in our report.

Are there any risks?

There are no physical risks to you as a person; you do not have to take part. If you decide to take part now, and later decide that you would rather withdraw we ask that you inform us within two weeks from completion of the interview. After this time your responses will have been entered anonymously onto our electronic database and we will be unable to take out your answers.

Will the information collected be kept confidential?

All of your responses will be completely confidential. Any personal information about you will be stored separately to your responses and your answers will not be traced back to you. All evaluation data will be stored in a secure place, including on a secure University of Northampton server where they are stored electronically. We may use direct quotes from participants in our final report but these will not be included alongside any personal information.

Am I obliged to take part?

No, you are *invited* to take part in the evaluation. Only if you feel happy to proceed should you indicate this when the Researcher contacts you. Please also feel free to ask any questions that you may have at that time.

What will happen with the results?

A final report will be presented to NHS Northamptonshire who have commissioned this service in April 2012. You will also be able to obtain a summary of the report from Nicola Best, Personal Health Budget Lead (01933 677837).

Thank you for taking time to read this information.

University project team:

- Professor Jackie Campbell - School of Health, The University of Northampton
01604 892010
- Dr Michelle Pyer – Centre for Health and Wellbeing Research, The University of Northampton **01604 892831**

11.3 Interview schedule: carer face to face interviews

Information accessed/reviewed by interviewer

- Basic demographics (name, age, living situation, working status)
- Information regarding cared for person (relationship to, level of caring responsibility)
- Any particular communication needs
- PHB contract outcomes (and date of initial assessment)

General questions

1) What were your expectations of PHBs for carers before you had your assessment?

- When did you first learn about PHBs/did you have any knowledge of them before this pilot started?
- How do your experiences compare to those expectations?

2) If you had to describe your experience of PHBs to someone who is not familiar with them what would you say?

Process

We would like to get some feedback on the process that's in place for people getting PHBs...

3) What do you think about the process/paperwork that is involved?

- Are there any improvements that you would recommend to the way that PHBs are awarded/managed?

Outcomes

Every carer that has taken part in the scheme signed an outcomes agreement (prompt)...

4) I understand that you used your PHB to...[quote from participant's identified health outcomes agreement] could you tell me a bit more about that and how it was decided?

- Why did you choose to spend it in that way?
- Did you feel that you had a say in identifying your health outcomes?

5) To what extent to you feel that these outcomes were targeted towards your needs as an individual

6) To what extent has the PHB helped you achieve x (asked for each outcome listed)

Impact

7) What difference has being part of this scheme made to you... and your family (prompt in context)?

- +tive and -tive
- Overall quality of life, social, health-related, general well-being, economic, independence, choice and control, impact on caring role.

8) Is there anything that I haven't asked you about that you think it's important that we record today?

11.4 Carer self assessment trigger questions for entry onto PHB Pilot

Section 2 of the carer self assessment questionnaire encompasses several 'trigger questions'. Following completion of the self assessment questionnaire by the carer and Carer Assessment Support Worker, Section 2 of the completed forms are reviewed by the Carer PHB Leads to assess inclusion of the carer in the pilot.

The questions are summarised as follows:

- A. As the Carer, is your physical health being affected by your caring role?
 - a. Not at all
 - b. Yes a little
 - c. Yes a moderate amount
 - d. Yes a significant amount
 - e. Yes a great deal
- B. If 'yes' have you had to resort to medical assistance or treatment such as physiotherapy etc? Yes/No
- C. Are you able to keep up to date with housework that needs to be done? Yes/No
- D. Are you able to keep up to date with gardening jobs that need doing? Yes/No
- E. As the carer, is your mental health affected by your caring role?
 - a. No not at all
 - b. Yes a little
 - c. Yes a moderate amount
 - d. Yes a significant amount
 - e. Yes a great deal

F. If yes, have you had to resort to medical assistance, or treatment such as counselling? Yes/No

G. Do you suffer from interrupted sleep because of your caring role?

- a. No not at all
- b. Yes a little
- c. Yes a moderate amount
- d. Yes a significant amount
- e. Yes a great deal

H. Are you able to keep up to date with odd jobs that need to be done around the house? Yes/No

I. Do you have all the equipment you need to carry out your caring role (such as a hoist, stair lift, lifeline etc?) Yes/No

J. Do you feel you need moving and handling training to help you with your caring role? Yes/No

K. As a carer do you feel you have to manage verbal abuse at times? Yes/No

L. As a carer do you feel you have to manage aggressive behaviour from the person you care for sometimes? Yes/No

M. Do you ever feel that your personal safety as a Carer is in danger? Yes/No

If you answered Yes to question M please give more details (please note key points):

N. Do you feel that your opinion is taken on board with service planning for the person you care for? Yes/No

O. Over the last 12 months would you say your own health has on the whole been:

- a. Very good

- b. Good
- c. Fairly good
- d. Poor
- e. Very poor

11.5 Health outcomes supplementary data: commissioner letter and information return form



Northamptonshire

Northamptonshire Teaching Primary Care Trust

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Summerhouse Road
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Northampton
NN3 6BF

Tel: 01604 651633

Fax: 01604 651101

Email: sharon.benford@northants.nhs.uk

Web: www.northamptonshire.nhs.uk

23rd January 2012

Pilot ID –4

Dear ...

Personal Health Budgets for Carers Pilot Scheme: Carer name

To support evaluation of the Carers Personal Health Budget (PHB) pilot, I am writing to kindly ask you for feedback on any health outcomes experienced by [carer name] as a result of [carer] taking part in the PHB pilot scheme last August.

You will recall that you were approached by [carer] to approve and sign their request for a Personal Health Budget (PHB) last year. I have attached a copy of the information sheet given to Carers to give to their health professional in case you no longer have it.

Details of their identified health outcomes and the way in which they decided to spend the money are detailed below:

Proposed PHB	Cost	Identified health outcomes
Total	£xxx	

We hope by now that the Carers are starting to experience health benefits as a result of the PHB. We are evaluating the Pilot during the month of January. This will involve carer interviews conducted by the Centre for Health and Wellbeing Research. Carers who are interviewed will be asked about any health gains or improvements, but importantly we also need feedback from the health professional who originally signed their referral for a PHB for their comments about how the Carer has been helped by the PHB.

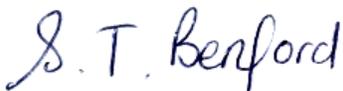
To support this part of the process, I will send [carer] a sheet for him to complete to tell us about the health improvements he thinks he has made since having his PHB. When he has completed his part of this form he will be coming to see you as his signing health professional asking you to complete your section and return it to me in the envelope provided by **February 17th**.

[Carer] has been asked to sign a consent form to say that he is happy that you fill in the sheet giving us information about how you feel the PHB has helped him to achieve his health outcomes.

Thank you for your help in completing and returning this form. We hope that the information collected will be useful in rolling out the PHB pilot for carers and also for the wider pilot being led by Nene Commissioning CCG.

If you have any issues with your support or have any questions please don't hesitate to contact **Nicola Best, Carers Personal Health Budget Lead on 01933 677837**.

Yours sincerely

A handwritten signature in blue ink that reads "S. T. Benford". The signature is written in a cursive style with a large, looped 'S' and 'B'.

Sharon Benford
Development Manager (Carers)

My Personal budget?

<u>My health need(s) is/are?</u>	<u>What I want to buy with my Personal Budget to help me meet these needs</u>	<u>I hope the Outcome of this Personal Budget will be.....</u>	<u>How this will benefit me as a Carer?</u>	<u>Costs of the Personalised Health Budget</u>	<u>*Outcome(s) met</u>

* Section to be filled in at time of review September 2011

Identified Health Outcomes	TO BE COMPLETED BY CARER How far have these been achieved? (Please give evidence as far as possible)	TO BE COMPLETED BY HEALTH PROFESSIONAL How far have these been achieved? (Please give evidence as far as possible)
Improved physical health: details to be added		
Reduced pain: details to be added		
Reduced social isolation: details to be added		
Improved mental health: details to be added		

Any other evidence/ comments? (Do continue on to a separate sheet if you need to)

Carer signature:
Health Professional signature:

Date:
Date:



Personalised Health Budgets for Carers - Additional Information for Health Professionals

1. Background

Personalised health care budgets (PHB) are a new area of development for health. PHB's are an opportunity for pilot sites to think about how to join up services between health and social care in a way that gives choice and control to patients and carers.

A pilot of Carers PHB's has been incorporated as part of the Northamptonshire Carers Strategy Demonstrator Site, in partnership with Nene Commissioning who are the local lead organisation for a national pilot site for personal health budgets. Northamptonshire is the only site incorporating PHB's for carers. The project aims to evaluate the effectiveness of PHB's for a small sample of carers, in line with the health approach to the government's 'personalisation agenda'.

2. Description of the service being evaluated

A sample size of twenty Carers will be offered a PHB. The sample will be identified as follows: Carers will have previously received a Carers Assessment via a Carer Assessment Support Worker (CASW), and answered the identified health needs questions to show they have particular physical or mental health needs of their own (separate from the cared for person).

Carers receiving a PHB will be asked to fill in a questionnaire developed by the University of Kent and will be assisted to identify a personal health plan with an outcome that will improve their health. The baseline questionnaire and personal health plan will be undertaken by trained PHB Co-ordinator and PHB CASW Lead. A relevant health professional e.g. GP or community nurse will be identified by the Carer to approve appropriateness/achievability of the health outcome. In the event that the Carer is unable to identify a health professional, the PHB coordinator will contact the registered GP. The Carer will be supported to make the purchase/and will be evaluated after 4-6 months, repeating the original questionnaire and additional qualitative questions. The repeat questionnaire will be conducted by the Centre for Health Wellbeing and Research at the University of Northampton. The study design and methodology and documentation have been adopted from the national PHB pilot.



Report compiled by:

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