



ISSUE 2 – November 2010

PHBE NEWSLETTER

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1. PHBE UPDATE

PHBE is now a year older and making good progress

331 participants have been recruited in 17 of the 20 in-depth sites: 230 PHB Group and 101 Comparison Group.

4 participants have been recruited in the wider cohort.

We appreciate all the work that is being carried out to ensure that the evaluation is a success.

We have carried out interviews with operational staff, health professionals, commissioning managers and 3rd party budget holders about *implementation* experiences within the 20 in-depth sites.

The draft 2nd interim report on the implementation experiences is now with the Department of Health. The final report will be uploaded on the relevant websites by 23rd November 2010.

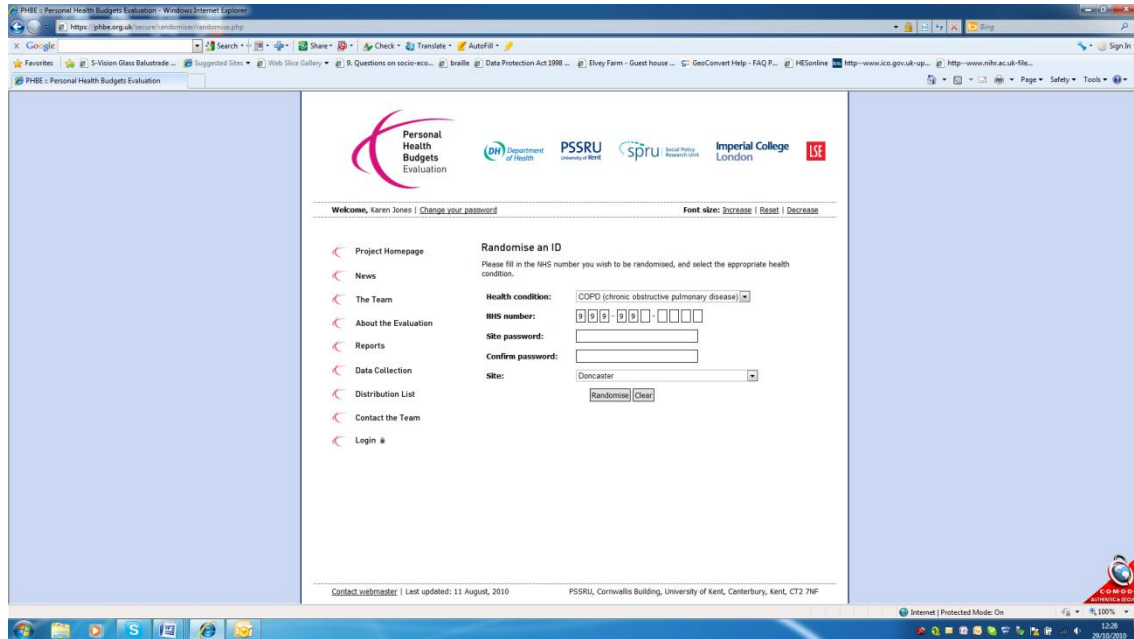
We are keen to involve carers of people either receiving the personal health budget or receiving conventional services. Please ask the potential participants whether they give permission for their carer to be contacted. The appropriate consent form is enclosed in each PHBE documentation pack.



2. A GUIDE TO RANDOMISATION

R&D offices are currently approving the use of the NHS number to randomise. I will let you know as soon as your local R&D office has approved the process if you are using the randomisation tool.

As usual you need to login to the secure section on the PHBE website and click on the randomiser option: You should see the following information:



The screenshot shows a web browser window displaying the PHBE website. The page title is 'PHBE - Personal Health Budgets Evaluation'. The main content area is titled 'Randomise an ID' and contains the following form fields:

- Health condition:** A dropdown menu with 'COPD (chronic obstructive pulmonary disease)' selected.
- NHS number:** A text input field with five digits entered: '2 2 2 2 2'.
- Site password:** A text input field.
- Confirm password:** A text input field.
- Site:** A dropdown menu with 'Doncaster' selected.

Below the form fields are two buttons: 'Randomise' and 'Clear'. The page also includes a navigation menu on the left with links like 'Project Homepage', 'News', 'The Team', etc., and a footer with contact information for PSSRU at the University of Kent.

Step 1: Select the health condition.

Step 2: Key in the **last five** digits of the NHS number.

Step 3: Key in a password of **eight or more** characters. Please keep this password safe and use the same one each time you randomise. The password encrypts the last five digits of the NHS number.

Step 4: Confirm the password.

Step 5: Select your site.

Step 6: Click on 'Randomise'.

The process happens before the individual has given consent to take part in the evaluation. Once the person has given consent, the last five digits of the NHS can be decrypted. The decryption process can occur at a convenient time, for example when you are back on the PHBE website.

You will soon be able to decrypt the NHS number. The process for this will be very similar to the encryption process, and will require the password you used to randomise. Therefore it is really important to keep the password safe and use the same one, otherwise decryption will not be possible.

4. KEEPING IN TOUCH

The first point of contact between sites and PHBE is through Karen Jones (email: K.C.Jones@kent.ac.uk; telephone 01227 827953). This will help the PHBE team to coordinate communication with you and ensure we give out consistent messages, whilst keeping one person as the main contact. Please keep us informed of your progress with the evaluation process, and let us know of any concerns if they arise.

5. ETHICS AND RESEARCH GOVERNANCE

We now have all ethics and research governance for recruitment to begin. We are chasing some R&D offices for approval to use the last five digits of the NHS number to randomise people into either the personal health budget group or the comparison group. This process is to minimise selection bias when the same group of health professionals are recruiting people to both groups.

6. PHBE WEBSITE

There are also a number of new FAQs on the PHBE website.

Q. Can a consultee give consent for information from medical records and HES data to be collected?

The evaluation team and the Department of Health would recommend that only a representative who has the appropriate power of attorney or has been appointed as a deputy can give consent for information from medical records and HES data to be collected.

Q. I really want to offer a personal health budget to one of my clients but the randomiser has put them into the comparison group. Can I include them?

It is absolutely critical to the success of the evaluation that the randomiser alone decides who is to be offered personal health budget immediately. This would jeopardise the rigour of the evaluation.

Q. When will participants receive the voucher as a thank you?

Participants will receive a £10 voucher 6 months from the consent date. They will receive an additional £10 voucher after they have completed the 12 month follow-up interview.

Q. Can you remind me what information the evaluation needs on the care plan?

The evaluation needs the following information on the care plan:

1. The budget per year and the total level of funding in terms of health service expenditure, recurrent annual and one-off payments (where applicable);
2. The cost of planning health support;
3. The formal organisation of the budget in terms of deployment options;
4. The activities (interventions, services etc.) included in the care plan that the budget is to be spent on;
5. The cost of the individual services identified within the care plan.

Q. Are the PHBE documents translated?

The standard participant invitation letter and information sheet have been translated into various languages. If you require the other versions of the documentation or the consent form and baseline questionnaire to be translated, please contact Karen Jones. Translation takes only three days and so there will only be a short delay. You can find the translated documents once you have logged in.

Q. The options for some of the questions are not appropriate for a wheelchair user. What should I do?

As we are using standardised outcome measures, we cannot change the scale. If the options are not appropriate, could you provide an explanation in the margin.

Q. Why do we have to ask the participant if they are continent or not?

The incontinence questions form part of a scale and so we cannot change them. If the participant is embarrassed about asking the question, the interviewer could ask them to respond by ticking the appropriate option on the scale and placing the response in an envelope. We have show-cards for all scales in the 'Data Collection' folder which could be used for this purpose.

Q. It is embarrassing to ask about the participant's sexuality.

The interviewer could print out the show-card and ask the participant to tick the appropriate box and then put the response in an envelope.

Q. Will the evaluation team be contacting us to make sure that it is OK to send another questionnaire or arrange an interview time?

Before the evaluation team contacts the participant, we will be contacting project leads to make sure that it is appropriate and whether there is anything else we should know about (for example, how to enter the building).

Q. What happens if an individual refuses the offer of the personal health budget but would still like to participate in the evaluation?

The individual will be included in the 'intention to treat' group which is a sub-sample of the personal health budget group. We will monitor the situation to ensure that we end up with a sufficient number of people in the personal health budget group who accept the offer of the budget. Please mark on the documentation if an individual has refused the offer of a budget and should be included as 'intention to treat'.