



# Asking you about your health

## long-term conditions

## PROMs pilot for long-term conditions in primary care

### Information for participating practices

This page provides more detailed information for practices who would like to participate in the PROMs pilot.

**Which GP practices are asked to take part?**

**Do practices have to cover all six long-term conditions?**

**Is ethics approval necessary for this study?**

**How will the participants be recruited?**

**What will GP practices have to do?**

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**What will happen with the completed questionnaires and the data?**

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### Which GP practices are asked to take part?

- PCTs in two regions (London and North-West) have been approached to indicate their interest in participating in the pilot.
- A selection of GP practices within participating PCTs will be invited to take part in the pilot.
- Practices are invited into the study through their PCT or through their PCRN (Primary Care Research Network).

### Do practices have to cover all six long-term conditions?

No, participating GP practices have the opportunity to indicate which LTCs they would want to cover and which LTCs they are particularly interested in covering. Preferences expressed by practices will be respected as much as possible, but it may not always be feasible due to differences in prevalence of the LTCs which means that the total number of practices

required to cover each LTC varies. It is anticipated that practices will cover between one and three LTCs.

### **Is ethics approval necessary for this study?**

Yes, ethics approval has been obtained from the National Research Ethics Committee. Local NHS permissions have also been gained from the participating PCTs.

### **How will the participants be recruited?**

- Participants for the pilot will be recruited through GP practices. They will be identified from the practices' Quality and Outcomes Framework (QOF) database. Half of the identified patients will be sent a questionnaire in 2010 and the other half will be sent a questionnaire in 2011.
- A sub-contractor (Apollo Medical Systems Ltd.) will remotely run a search on the practice's database to produce a list of participants with one of the relevant conditions. No information about the patient will be made available to the sub-contractor or the research team.
- GP practices will mail questionnaires to the identified individuals.
- Individuals who wish to participate are asked to return their completed questionnaire to the Oxford research team. Individuals invited into the study in 2010 will be asked to give their consent to be sent a follow-up questionnaire in a year's time.
- A sub-set of individuals will be asked to participate in a qualitative interview about completing PROMs questionnaires.

### **What will GP practices have to do?**

There are a number of tasks to be undertaken by the GP practice. These tasks need to be undertaken twice, one year apart.

- Give permission for a sub-contracted organisation (Apollo Medical Systems Ltd.) to run a query on their patient registers, remotely.
- Allow Apollo to generate a list of patients with the required inclusion criteria, by remotely accessing GP systems, overnight.
- GP check the lists of identified patients to exclude anyone in whom they think invitation into the study would cause serious distress.
- Take delivery of required materials (e.g. labels, pre-packed questionnaires etc).
- Print two sets of labels from the generated list (one for the pre-packed questionnaires and one for the reminders).
- Attach labels to the pre-packed questionnaires and mail. (There will be no need for practice staff to obtain informed consent from patients, as consent is implied by when the patient returns the completed questionnaire.
- Two weeks after mailing the questionnaires, attach labels to the reminders and mail.

## **What support is provided to the practices?**

- A helpline function (freephone number and email address) operated by the Oxford team, which practices and patients will be able to contact if they have enquiries about the study.
- If a participant contacts the practice for information, the practice is advised to refer the participant to the research team's helpline.

## **Will practices be paid for their participation?**

Yes, practices will be paid. The pilot has been adopted onto the NIHR portfolio, and it is anticipated that practices will get paid through the CLRN (Clinical Local Research Network).

## **What are the software requirements for practices?**

Apollo Medical Systems Ltd. work with a range of GP clinical systems. Currently compatible systems included in the pilot are (more systems may be added as the pilot progresses):

- EMIS PCS
- EMIS LV
- iSoft Premiere

Apollo will provide any necessary technical support, including uploading compatible software.

## **What will happen with the completed questionnaires and the data?**

- The completed questionnaires will be returned to the project team for data entry and analysis.
- The cross-sectional and cohort data sets will be compared in terms of acceptability (response rates and completeness of data), feasibility and quality of data (missing data). Standard analysis including means, medians and proportions will be carried out for the data sets, as well as change scores for the cohort data set.
- Qualitative data will be transcribed verbatim and analysed thematically using qualitative analysis software to identify the factors that influence completion of PROMs.
- Some headline observations on the data will be made available to participating PCTs and practices. Where feasible, a PCT or GP practice's position relative to all others will be indicated to the PCT or GP practice which owns the data, with comparator data remaining anonymised. Best endeavours will be made to make the data as useful to participating sites as possible. Confidentiality will be offered to individual participants in the pilot and therefore it will not be possible to share individual level data with PCTs or GP practices.