Pilot study of patient reported outcome measures (PROMs) in primary care

Report to the Department of Health

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Contents

EXECUTIVE SUMMARY

Improving health care outcomes for all is the primary purpose of the NHS according to the White Paper Equity and Excellence: Liberating the NHS (Department of Health 2010) and the recent NHS Outcomes Framework (Department of Health 2011) reflected this vision by outlining five outcome domains that should be improved. The second domain is enhancing quality of life for people with long-term conditions (LTCs) by means of patient-reported outcomes (PROMs). Approximately 15.4 million of the population in England report having at least one LTC, with a third reporting multiple LTCs (Department of Health 2012). It is believed that the number of people with multilple LTCs will rise(Department of Health 2012). People with limiting LTCs are the most intensive users of the most expensive health care services and the average cost of health care for someone with a LTC is higher than for those without an LTC.

Since 2009, PROMs are used to assess outcomes in four elective surgical procedures on a routine basis in the NHS. The PROMs are used to help assess the effectiveness of single, discrete surgical procedure. The role of PROMs in LTCs is more challenging to identify as LTCs are complex to manage due to the multiple physical, social and emotional problems they pose and the diverse service providers and interventions involved over long time lines. Often the objectives of services are to maintain or avoid deterioration in function, autonomy and well-being rather than achieve major health gains.

The purpose of this pilot study was to evaluate the feasiblity and usefulness of using PROMs in LTCs in a primary care setting. The main aim of this pilot was to provide estimates of response rates to PROMs in six LTCs (asthma, COPD, diabetes, epilepsy, heart failure and stroke). Secondary aims were to to assess the differences in response rates and PROMS scores between alternative strategies of data collection (cohort vs. cross-sectional survey), LTCs and practices; to assess data quality; to assess the feasibility of recruiting LTC patients through primary care practices; to gain insight into stakeholders' views on the feasibility of collecting PROMs data and the usefulness of such data and to estimate the costs of collecting PROMs data in LTCs.

The project used both quantitative and qualitative approaches. The quantitative approaches were two surveys; the first a cohort survey and the second a one-off cross-sectional survey. The cohort survey included two points of data collection, one year apart. The cross-sectional survey was conducted at the same time as the cohort follow-up survey. This meant that the cohort baseline survey (conducted one year earlier) could serve as a first cross-sectional survey to draw a comparison between a cohort approach vs. a repeated cross-sectional approach. The qualitative approach was based on semi-structured interviews with stakeholders to gain insight into their views of collecting PROMs data for LTCs. Finally, a cost analysis was conducted to estimate the resources needed to routinely collect data in LTCs.

For the surveys, a generic and a disease-specific PROM were sent to patients. The generic PROM was the EQ5D and the disease-specific PROMs were the Mini Asthma Quality of Life Questionnaire (AQOL), the Clinical COPD questionnaire (CCQ), the Diabetes Health Profile (DHP), the Quality of Life in Epilepsy

Inventory (QOLIE-31), the Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the Stroke Impact Scale (SIS). Eligible patients were identified through an automatic database search by a subcontracted IT company. Practices were able to exclude any patients whom they did not consider suitable to be invited into the study. Participating practices mailed the survey for the cohort baseline and (second) cross-sectional surveys. The cohort follow-up was mailed from the Oxford team. All questionnaires were returned to Oxford. Thirty-three practices participated in the cohort and 7 in the cross-sectional survey. The data was entered and verified by a professional data entry company. Analyses were carried out in SPSS 18.0.

In the qualitative part of the pilot, 19 stakeholders (5 GPs, 5 nurses, 2 commissioners, one manager and 6 patients) were interviewed about their views on the feasibility and usefulness of collecting PROMs data for LTCs. Stakeholders were asked to read a summary of the cohort baseline findings prior to the interview. Semi-structured interviews were conducted and transcribed verbatim. A framework analysis was conducted using a qualitative software package (NVivo V.9).

The costs of mailing PROMs were estimated based on expenses of the PROMs pilot, apart for postage which was estimated on the recent increased postage. Estimated costs are given for each LTC and type of survey; and by questionnaires sent and returned.

Key findings on the response rates

- The overall response rate to the cohort baseline was 38.4% (1721 respondents out of 4485). The response rate varied significantly between LTCs ($p<0.001$), with heart failure achieving the highest response rate (50.4%, n=262) and asthma the lowest (30.0%, n=400).
- Cohort baseline response rates varied significant by practice ($p=0.018$), region ($p=0.002$), the practices' deprivation score ($p=0.024$), QOF (Quality and Outcomes Framework) score ($p=0.013$) and the adjusted EQ5D mean score ($p=0.004$).
- 93.1% (n=1603) cohort baseline respondents patients consented to be sent a follow up questionnaire, with the lowest rate of consent for heart failure (90.5%) and the highest for COPD (95.3%). There was no difference in whether consent to follow-up was given by LTC, age, region, ethnicity, number of comorbidities or time since diagnosis for the overall sample. However there was a difference between practices ($p=0.008$) (consent ranging from 78.6% to 100%). Furthermore there were some disease-specific differences in consent.
- The overall response rate to the cohort follow up was 71.5%. There was a significant difference in response rate by LTC ($p=0.015$), with epilepsy achieving the lowest response rate (62.7%) and diabetes the highest (75.7%). Furthermore, there were significant differences in the completion rate at follow-up between age ($p<0.001$), ethnicity ($p=0.008$) and region ($p=0.007$) and the mean baseline EQ5D score. When entered into a logistic regression, only some age groups and EQ5D remained significant.
- The overall response was 44.0% for the cross-sectional survey (7 practices).

Key findings on other aspects of feasibility

- Out of 61 practices who expressed an interest to participate, 33 participated for the cohort baseline. Some practices were not able to participate because their clinical system was not compatible with the search.
- The search identified approximately the correct number of patients (according to QOF prevalence) for asthma and heart failure. A lower proportion of patients than expected were extracted for COPD (20.3%), diabetes (13.4%), and stroke (53.4% but QOF numbers also include TIA), and higher than expected proportion of patients were identified for epilepsy (28.7%).
- After the search, practices excluded 18.1% of asthma, 5.6% COPD 5.6%, 3.8% diabetes 3.8%, 46.7% epilepsy, 24.2% heart failure and 20.2% stroke patients from being sent a questionnaire. Reasons were co-morbidities such as dementia, cerebral palsy; learning difficulties (particularly for epilepsy); blindness; patient left practice or died; or the diagnosis was unclear.
- In terms of data quality, there were few problems with internal consistency and a low rate of missing data on EQ5D. Furthermore, there were mostly no problem on individual items and few problems on disease-specific dimension scores for asthma, COPD and diabetes. However, rates of missing data were high (>10%) for multiple individual items and dimensions for epilepsy, heart failure and stroke.

Key findings from the PROMs scores

- For the cohort survey, no significant differences between baseline and follow-up scores were found on the EQ5D apart for the VAS in heart failure. Only 1 (out of 5) asthma and one (out of 9) disease-specific dimension were found to be significantly different between baseline and follow-up, and none for the other four LTCs.

- At cohort baseline, significant differences between practices for EQ5D (York tariff and VAS) only found for asthma. Significant differences between practices for disease-specific questionnaires were found for 4 out of 5 dimensions in asthma, 2 out of 4 in COPD, all 3 dimensions for diabetes, 2 out of 7 dimensions in epilepsy, 0 out of 3 for heart failure and 0 out of 9 for stroke.

- The relationship between the follow-up score and self-reported change of health (improved, stable or deteriorated) was not significant relationships for the EQ5D apart for the VAS for heart failure. Significant relationships were found for the disease-specific PROMs and change of health for all 5 asthma dimension, all 4 COPD dimensions and 2 (out of 9) stroke dimension. They were not significant on any of the diabetes, epilepsy and heart failure dimensions.

Key findings from the qualitative interviews

- Views about the response rates were mixed. Some participants thought the response rates were reasonable and as would be expected. Other participants believed that only the response rates for some LTCs were acceptable and raised concerns about how the low response rates affect the representativeness of the findings.
- The majority of stakeholders thought the collection of PROMs data was positive, but they raised concerns about necessary resources (time, staff and/or money). Some stakeholders also raised concerns about the benefits of collecting PROMs data.
- Views on the value of PROMs data were mixed, with some stakeholders viewing it as useful data as it provided a different method to assess individual or population health and may consequently lead to health improvements, and be useful for quality control and commissioning. Others did not feel they knew enough about PROMs to know whether they are of value.
- All participants agreed that the way to present the findings from the cohort baseline survey was too long. Having said this, they acknowledged that the graphs were useful. Some commented that the level of statistics was too extensive and advised that it may be better to produce a different summary of results for different stakeholders.
- Not everyone was able to make suggestions on how PROMs data may be used, but some believed they may be used for monitoring individual patients or population, benchmarking, performance monitoring and commissioning.

Key findings of the cost analysis

- Conducting a cohort survey costs between £34.65 and £56.23 per completed questionnaire (based on the response rates from this pilot) depending on the LTC.
- Conducting a cross-sectional survey costs between £14.96 and £24.42 per completed questionnaire (based on the response rates from this pilot) depending on the LTC.

Conclusions

The main conclusion to be drawn from this pilot study is that it is possible to obtain responses to PROMs from individuals with long-term conditions via general practice clinical systems at rates that are very similar to those observed for the General Practice Patient Survey (GPPS). The logistics of doing so via remote access is not straightforward and further work would be necessary to make such a system feasible across all practices' clinical systems. It is likely that many of the logistic problems encountered in this research study would eventually be overcome in a larger roll-out or mandated system.

To provide more complete (in terms of coverage) evidence of health-related quality of life of individuals with long-term conditions, the invitation to respondents to contribute self-reports of health needs to be more engaging. A greater sense of point or purpose to completing PROMs in the context of primary care could emerge in three distinct – not mutually exclusive - ways, firstly patients could find the information

valuable and useful, secondly the information may be used as part of patients' annual reviews and thirdly, PROMs may provide evidence on the quality of services. Experiments are needed to test whether PROMs can better inform patients about their progress, support communication of need or facilitate contributions to quality assessment.

PROMs for long-term conditions also need to be valued in the sense of supporting decisions made by healthcare professionals and providers. Initially trials to evaluate the benefits to health professionals of patient feedback via PROMs were negative, but recently some more encouraging evidence is beginning to emerge. Demonstration studies are needed to test benefits to both healthcare providers as well as patients of regular collection of health status via PROMs.

Even if PROMs could be made more relevant to patients and their healthcare providers, in long-term conditions PROMs scores cannot easily be as easily traced to inputs of services as can be achieved with elective surgical procedures. Because of the range, diversity and intermittent nature of services to individuals with long-term conditions, it will be challenging to use evidence from PROMs in a diagnostic way to high-light specific aspects of services requiring improvement. Instead it may be more realistic to see PROMs high-lighting or drawing attention to matters of concern to patients and stimulating discussion and debate within whole local health economies about options to bring about change.

PROMs are well established methods of capturing what matters to patients. Experiments are needed to test whether and how they can better support decision-making by patients, healthcare providers and commissioners. The form and content of PROMs may also require experiment and change. It might be argued that the PROMs included in this study were not specifically developed for the uses currently being considered in government policy. PROMs which included domains such as sense of control and confidence in self-management may need to be developed. They might be more relevant to policies for long-term conditions and hence more responsive to changes over time. Above all, given the evidence of increased multi-morbidity amongst those with long-term conditions, forms of PROM are needed that are neither the very broad-brush aspects of health of generic measures nor the very specialized disease-specific measures that will not work for the growing numbers coping with multiple conditions.

Introduction

Improving health care outcomes for all is the primary purpose of the NHS according to the White Paper Equity and Excellence: Liberating the NHS (Department of Health 2010). The NHS Outcomes Framework (Department of Health 2011) reflected this vision by outlining five outcome domains that the NHS should aim to improve. The second of these domains is enhancing quality of life for people with long-term conditions. Patient-reported outcomes are to be used to measure effectiveness and care provided (Department of Health 2010).

Patient-reported outcome measures (PROMs) were developed over 30 years ago in the form of questionnaires to assess aspects of health of most concern to people. Since April 2009, PROMs are used to assess outcomes in four elective surgical procedures (hip or knee replacement, varicose veins surgery or groin hernia repair) on a routine basis in the NHS. The role of PROMs in these four elective surgical procedures is relatively straightforward as they are used to help assess the effectiveness of single, discrete procedures in relation to patients with fairly clearly defined problems for which surgery is normally effective.

The role of PROMs is far less clearly understood with regard to long-term conditions (LTCs) such as COPD, diabetes and stroke. An estimated 15.4 million of the population in England reporting having at least one LTC and approximately a third reporting multiple LTCs (Department of Health 2012). People with limiting LTCs are the most intensive users of the most expensive health care services and the average cost of health care for someone with a LTC is higher than for those without an LTC. It is believed that the number of those with multiple LTCs will rise in the next few years which will have additional cost implications to the NHS (Department of Health 2012).

The use of PROMs in LTCs may present a method to gain more information on quality of life and outcomes in a similar manner to the use of PROMs in surgical procedures. However, the role of PROMs in LTCs is more challenging to identify as LTCs are complex to manage due to the multiple physical, social and emotional problems they pose and the diverse service providers and interventions involved over long time lines. Often the objectives of services are to maintain or avoid deterioration in function, autonomy and well-being rather than achieve major health gains observed in, for example, hip and knee replacement surgery.

There is broad agreement on the criteria that should apply to assess a PROM (Fitzpatrick et al. 1998) However the majority of evidence available addresses the more technical criteria: reliability, validity, responsiveness. Less is known about more practical issues concerning PROMs, particularly how acceptable are instruments to respondents, as reflected in response rates, and practical feasibility. Reviews of evidence about the performance of PROMs struggle to find adequate evidence on these more practical aspects. What evidence has emerged about more practical aspects of PROMs has tended to be in the context of randomised controlled trials, and evaluative health research. However generalisability from research contexts is problematic because respondents in clinical trials are subject to more exhortation by dedicated research staff to respond than is possible in more routine, day to day health service contexts.

The second gap in the evidence base for PROMs is their value for different potential stake-holders. A structured review of the impact of PROMs on health professionals by our group (Marshall et al. 2006) is consistent with conclusions from other reviews that feedback to health professionals of PROMs data about their patients whilst valued in general terms has had only modest demonstrable impact (Valderas et al. 2008). Lack of familiarity with PROMs and inappropriate methods used to provide PROMs-based feedback may partially explain impact. Most striking is the lack of research examining the value to patients and the public of either personally completing or seeing aggregated evidence from PROMs. The currently proposed pilot study provides an opportunity to begin to address this issue of the value to PROMs in relation to key groups concerned with LTCs.

Aim and objectives

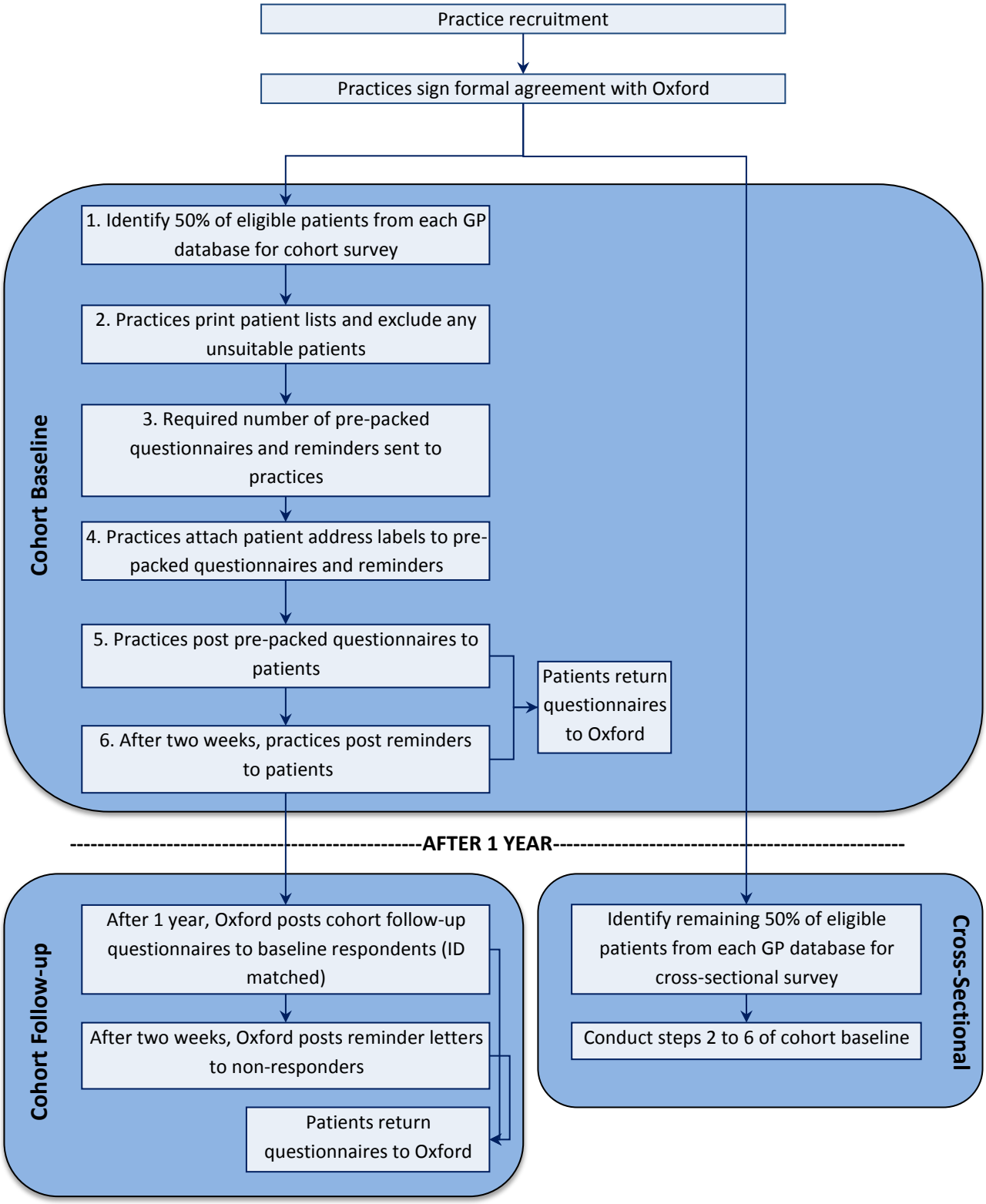
In this pilot, PROMs are tested as standardised instruments for use on a large scale population basis to assess patients' perspectives on outcomes of care to inform the quality agenda in the NHS. The main aim is to provide reliable estimates of the response rates of PROMs across contrasting LTCs. Secondary aims are:

- to assess the differences in response rates and PROMS scores between alternative strategies of data collection (longitudinal cohort vs. one-off cross-sectional survey), LTCs and practices
- to assess data quality
- to assess the feasibility of recruiting LTC patients through primary care practices
- to gain insight into stakeholders' views on the feasibility of collecting PROMs data and the usefulness of such data through a qualitative study with stakeholders
- to estimate the costs of collecting PROMs data in LTCs.

Survey methods

The survey design of the pilot aimed to inform the question of the relative advantages of PROMs being administered either as repeated cross-sectional surveys or as longitudinal cohort-type survey (**Figure 1**) (henceforth referred to a cohort survey). The pilot compared the two options in the following way. Patients were recruited into one of two ways of engaging with PROMs: either (i) to complete a single PROM or (ii) to complete two PROMs on two occasions one year apart. Feasibility, as assessed by specific indicators listed in aims and objectives, was compared for the two strategies of cross-sectional survey versus longitudinal monitoring of a 'cohort'.

Figure 1: PROMs Pilot survey methodology



In the 'cohort' study, respondents were invited to participate in a baseline survey and were followed up a year later. In the 'cross-sectional' survey, respondents are invited to participate in a single survey. The cross-sectional survey was conducted one year after the baseline sweep of the cohort study (i.e., at the same time as the one-year follow-up of the cohort study). This means that the pilot has created two cross-sectional sweeps one year apart with non-overlapping membership, approximating to the kind of data that a strategy of repeated cross-sectional surveys would generate. This design resulted in two sets of data reflecting alternative strategies for PROMs: cohort versus cross-sectional sweeps. The two data sets can be directly compared in terms of both feasibility and quality of data.

The survey was conducted with patients with one of six LTCs (asthma, chronic obstructive pulmonary disorder (COPD), diabetes, epilepsy, heart failure and stroke) in primary care. A census of all eligible patients was carried out within participating practices. An automatic and remote search was conducted to identify eligible patients from the GP databases. The questionnaire was mailed to potential participants by the GP practice. Consent was inferred from participants returning the completed questionnaire. This was followed by a reminder/thank you note two weeks later.

Recruitment of individuals with a LTCs

The recruitment of individuals with a LTC comprised two steps; first the recruitment of primary care practices and secondly the recruitment of eligible patients from each of the participating practices. The recruitment of practices and patients for the survey will be described below, and the recruitment of patients for the interviews will be described in the section on the qualitative part of the study.

The total target sample size to receive a questionnaire was 4500 patients. This meant that 175 questionnaires needed to be posted for each LTC for both the cohort baseline and cross-sectional surveys.

Practices

The practices were recruitment from two areas of England: London and North-West of England (NW). Practices were initially approached through the Primary Care Trusts (PCTs), Primary Care Research Networks (PCRN) and the Diabetes Research Network (DRN) (the latter for London only). The number of practices needed to cover each LTC depended on practice size and prevalence of the LTC. Based on an average practice size (i.e. 6500 patients) and on prevalence, it was estimated that a minimum of 2-3 practices were needed for asthma, 8 for COPD, 3 for diabetes, 20 for epilepsy, 15 for heart failure and 8 for stroke. To increase geographical spread, it was decided to recruit at least 4 practices for each LTC.

A short information sheet about the study and an expression of interest form was sent to the practices via PCTs, PCRNs or the DRN. Practices who expressed an interest were asked to complete a 'Practice Information Form'. This form collected basic information about the practice (including contact details, number of patients, clinical system) and the practices' preferences regarding which of the LTCs they were willing or particularly interested in covering. Practices were able to participate for a maximum of three LTCs to increase the number of participating practices and the geographical spread of practices. The research team selected the LTCs for each practice by taking into account the practices' preferences,

practice size and geographical location. The aim was to recruit about half the practices for each LTC from London and the other half from the NW, and to have a minimum of four practices covering each LTC. This meant that above average size practices (i.e. above 6500 patients) were asked to participate for the less prevalent LTCs (such as epilepsy) as the required sample size could have been achieved in one or two practices for the more prevalent LTCs (such as asthma). Smaller practices were asked to cover the more prevalent conditions.

Each practice was sent an information pack on the study. This pack included instructions about the study process, a letter from Apollo (role described below) reassuring the practice that no confidential data was accessed during the study, relevant service support costs information, copies of the cover and reminder letters and the questionnaires of the LTCs covered.

Patients

All adults (i.e. 18 years +) with one of the 6 LTCs were eligible to participate. The pilot aimed to be as inclusive as possible and therefore a census of all eligible patients was conducted for each practice with approximately half of the eligible patients being invited into the cohort survey, and the second half into the cross-sectional survey. Eligible patients were automatically and remotely identified by a computer search (described in more detail below). The GP practices checked the lists of eligible patients extracted and were instructed to remove any patients for whom invitation into the study would cause serious distress. Following patient exclusions, the practices contacted the research team to request the appropriate number of questionnaires for each LTC.

Identification of patients

The patients were identified according to the Quality and Outcomes Framework (QOF) criteria by an automatic and remote computer search. QOF is a voluntary reward and incentive programme for general practice in England. It details practice achievement results and rewards good practice. QOF contains four domains i.e. clinical, organizational, patient experience and additional services. Each of these consists of a set of indicators, against which practices score points according to their level of achievement. Overall, domain- and disease-specific QOF scores for each practice are available online at http://www.qof.ic.nhs.uk/search/ .

The search to identify patients was conducted by a sub-contracted company Apollo Medical Systems Ltd. (hereafter referred to as Apollo) which is a commercial company that has been developing software for the purposes of clinical audit and document management for the primary care sector since 2000. Their customer base includes for example general practitioners, the Care Quality Commission (formerly the Health Care Commission) and the Department of Health (DH). Apollo was jointly selected by the DH and the Oxford research team. Apollo was contracted to work with 5 clinical systems (EMIS LV, EMIS PCS, INPS Vision 3, iSoft Synergy and iSoft Premier). All practices received a letter from Apollo confirming that no confidential patient information was going to be accessible or to be transferred to a location other than the practice's computers or server. All practices signed a formal agreement with the University of Oxford which specified that they permitted the Apollo search to be conducted.

For the search to be conducted, practices were required to be using a clinical system that Apollo were contracted to work with. Practices were also required to have SQL Suite (Apollo software) installed on their computer. Apollo installed SQL suite where necessary. The information extracted about each patient was title, name, address and LTC as a rich text file (RTF). Although practices covered a maximum of three LTCs, the search in each practice was conducted for all 6 LTCs. Conducting the search for the two to three LTCs covered would have meant developing a separate search algorithm for each practice, which would have been very costly. The result of the search was one RTF for each LTC and practices were instructed to delete the files of the LTCs that they did not cover. This RTF was merged with a label sheet for practices to print address labels for the mail out. Additionally an aggregate data sheet was produced from the search, which contained the numbers of patients extracted for each LTC. This was used to compare the number of patients extracted to QOF estimates and to record patient exclusions by the practices.

Eligible patients were identified by using the same READ codes as those used for QOF (including the medication READ codes for asthma and epilepsy which require that patients have taken prescription medication for their asthma or epilepsy within a specified period of time). In QOF, stroke also includes transient ischaemic attacks (TIAs) but TIAs were excluded from this study and the search was conducted on stroke READ codes only. Also, QOF includes diabetes patients from age 17. This was amended to age 18 for the purposes of this study as the questionnaires have been validated for use in adult patients (i.e. 18 years or over). Patients whose records contained a 'refused consent' code were excluded. Individuals diagnosed with more than one of the relevant LTCs were only invited to participate for one LTC. The LTCs were ranked, giving preference to less frequent LTCs over more common LTCs, with patients with multiple LTCs invited to participate for their rarer LTC. The ranking (from least to most frequent) was epilepsy, heart failure, COPD, stroke, diabetes and asthma.

The aim of the pilot was to be as inclusive as possible and therefore a census of all eligible patients was conducted for each practice. A census was achieved by inviting approximately half of the eligible patients into the cohort survey, and the second half into the cross-sectional survey. The selection of patients into either survey was based on the month of birth (even vs. odd months) and the year of the search. Both types of searches (odd vs. even months) had been used to identify eligible patients for the cohort baseline, with the intention to use the opposite search to identify patients for the cross-sectional survey carried out one year later. The search results were compared to QOF estimates for each practice to ensure that the search had successfully generated the list of eligible patients.

The research team informed the practice once Apollo had completed the search. Practice staff then needed to access the aggregate data sheet through SQL suite and the patient address labels through MS Excel. The next steps were to print the label sheets of the LTCs covered and exclude any patients who the practice thought would not be suitable for inclusion. The number of exclusions were inserted into the aggregate data sheet which was returned to the Oxford team to indicate how many questionnaires were needed. The Oxford team liaised with Lynx, a professional printing company, to deliver the appropriate number of packed questionnaires and reminders to the practices. All questionnaires were numbered and Lynx provided the research team with the ID numbers that were sent to each practice. This allowed matching returned questionnaires with their practice.

Ethics and NHS permissions

Ethics approval was given by the National Research Ethics (NRES) of the Isle of Wight, Portsmouth & South East Hampshire (now the NRES South-Central Committee) in March 2010. NHS permissions were sought for 26 PCTs (6 in NW, 8 in West London and 12 in Central and East London). The study did not recruit from Central and East London due to delays in obtaining NHS permissions for some of the PCTs. Three ethics amendments were submitted at a later date. The first was submitted in July 2010 as there was a change in the diabetes PROM. The second was submitted in July 2011 to attempt to increase the response rate by making changes to the letter of invitation into the survey. The third amendment was submitted in January 2012 to include patient representatives in qualitative interviews with stakeholders. All three amendments were approved by the ethics committee and NHS approval was given by all participating PCTs.

Portfolio adoption and service support costs

The study was adopted onto the National Institute for Health Research (NIHR portfolio) (Number UKCRN ID: 8462). This meant the study was eligible for receiving support from the PCRN with recruitment and service support costs by the Comprehensive Local Research Network (CLRN) for the participating GP practices. Service support costs were paid according to the local CLRN guidelines. The research team uploaded accruals (i.e. information about the number of patients recruited into the study by each GP practice) to the NIHR portfolio website on a monthly basis.

Mailing of questionnaires

The cohort baseline and cross-sectional questionnaires were mailed from the practices, together with a cover (**Appendix 1a**) letter signed by one of the GPs, an information sheet (**Appendix 1b**) and a pre-paid return envelope. The questionnaires were provided pre-packed to the practices and address labels (printed following the Apollo search) were attached to each pack. No LTC information was printed on the label but a disease code was included to help practice staff match the labels and to the disease code printed on the questionnaires packs. Each questionnaire had a unique identifier. No record was kept of the ID number sent to individual patients, but as explained above a record was kept of the ID numbers for each practice. Completed questionnaires were returned to the Oxford team.

The cohort baseline questionnaire additionally included an address slip. Patients who were willing to complete a follow-up questionnaire were asked to provide the research team with their address. Follow up questionnaires, together with a cover letter (**Appendix 1c**) were posted by the research team rather than the practices. The ID number of the follow up questionnaire was the same as the ID number of the baseline questionnaire.

For the cohort baseline and cross-sectional surveys, the practices posted a reminder/ thank you letter two weeks after the mailing of the questionnaire to all patients (**Appendix 1d**). For the cohort follow-up, the research team posted reminders (**Appendix 1e**) two weeks after the mailing of the questionnaires to non-responders. Patients (in all three surveys) who were not willing to participate were encouraged to contact the research team to let them know their reasons for not participating.

The cohort baseline questionnaires were posted between September 2010 and May 2011, and the cohort follow-up and cross-sectional questionnaires were posted a year later. The study process was tested in 5 practices, including the search, patient exclusions and mailing of the questionnaires at the start of the cohort baseline. This led to some minor adaptations being made to instructions and the process – such as reminding practices that they only needed to review the patients' eligibility for the LTCs they were covering. Changes were made to the cover letter and information sheet following the cohort baseline in an attempt to increase response rates for the cross-sectional survey. Also, a small number of introductory questions to the PROMs questionnaire were included.

Questionnaires

The questionnaire included one generic and one disease-specific PROM, and some additional questions on basic demographics, duration of the LTC and co-morbidities. The cohort follow-up questionnaire included an additional 'transition' question i.e. the respondents' view of their health in relation to their LTC a year ago. All questionnaires were mailed out in English. A telephone translation service, with LanguageLine, was available for participants who were unable to complete a questionnaire in English.

The generic and the condition-specific questionnaires were recommended by a review of evidence by the Unit of Health Care Epidemiology under the leadership of Prof Fitzpatrick, the chief coordinator of this pilot (http://phi.uhce.ox.ac.uk/newpubs.php , accessed 13.12.12). On the basis of appraisal of the evidence, the EQ-5D, including the visual analogue scale (VAS), is recommended as the generic PROM if used in combination with a condition-specific PROM. As this pilot intends to evaluate the usefulness of both generic and disease-specific PROMs, the EQ5D was chosen as the generic PROM to be used with a disease-specific PROM for each LTC. The recommended disease-specific PROMs were the mini Asthma Quality of life Questionnaire (miniAQLQ) for asthma, the Short Form Chronic Respiratory Questionnaire (SFCRQ), the Audit of Diabetes Dependent Quality of Life (ADDQoL) for diabetes, the Quality of Life in Epilepsy (QOLIE-31) questionnaire for epilepsy, the Minnesota Living with Heart Failure Questionnaire (MLHFQ) for heart failure and Stroke Impact Scale V3 (SIS) for stroke. Licenses could not be secured for the SFCRQ, due to cost,and the ADDQoL, as the license holder did not approveit being used for the purposes of this study. Ttherefore were replaced with the Clinical COPD Questionnaire (CCQ) and the Diabetes Health Profile (DHP-18) respectively. Each of the PROMs used in this pilot is described in more detail below. A summary table of the dimensions of each PROM and their scores is given in **Appendix 2**.

Generic

EQ-5D

The EQ-5D is a generic measure of health status that provides a single-index value (Rabin and de Charro 2001). It can be used as a self or interview-administered survey and takes approximately five minutes to complete. It was developed by researchers in five European countries with the intention that it would be supplemented by other health-related questionnaires (The EuroQol Group 1990). The E Q-5D comprises five items, one each on mobility, self-care, usual activities, pain/discomfort and anxiety/depression, that are all scored on a three-point scale. A single-index value is calculated from the five items (Rabin and de Charro 2001). The single index score ranges from 1 (perfect health) to 0 (death) (NB. Scores below 0, i.e. states worse than death are possible). Additionally it includes a Visual Analogue (VAS) scale, where respondents are asked to rate their health from '0' (worst imaginable health state) to '100' (best imaginable health state).

Disease-specific

Asthma

The mini Asthma Quality of Life Questionnaire (miniAQLQ) was developed from the 32-item Asthma Quality of Life Questionnaire (AQLQ) in the US to measure both physical and emotional health (Juniper et al. 1999). The AQLQ was developed from structured interviews with patients and patients' ratings of importance of a list of items. The items that patients chose the most frequently and labelled as most important were chosen for the questionnaire. The 32 items were rated on a 1 to 7 scale (where 1 is maximum impairment and 7 is no impairment), and can be grouped into 4 domains (activity limitations, symptoms, emotional function and exposure to environmental stimuli) (Juniper et al. 1992)(Juniper et al. 1992). The shorter miniAQLQ was developed for greater efficiency of use through a number of methods (including item to item correlations from several studies, standardizing the activity domain and removing items that were of least importance to patients) (Juniper, Guyatt et al. 1999) This resulted in a 15-item miniAQLQ, which constitute the same 4 domains as the AQLQ and is also scored on a 7-point scale.

COPD

The Clinical COPD Questionnaire (CCQ) is a 10-item self-administered questionnaire developed primarily for use in clinical practice (van der Molen et al. 2003). The questionnaire was developed with input from patients and clinicians. Twelve interviews and two focus groups were conducted with COPD patients in the Netherlands, with one additional focus group carried out in the United Kingdom. The data collected, together with input from clinicians, a review of other available COPD instruments and international treatment guidelines, informed the development of an initial 16-item questionnaire covering three domains: functional state, mental state, and symptoms. A number of clinicians ranked the sixteen items in order of importance. The four most highly ranked items from the symptom and functional state domains, and the two highest ranked items from the mental state domain, were included in the final questionnaire. Each item is scored on a seven-point scale, ranging from 0 to 6 (where 0 is asymptomatic

or no limitation, and 6 is extremely symptomatic or total limitation) (Kocks et al. 2006). The CCQ has shown to be valid, reliable and responsive to change (van der Molen, Willemse et al. 2003).

Diabetes

The Diabetes Health Profile (DHP-18) (Meadows et al. 2000) was developed from the DHP-1 (Meadows et al. 1996), a 32-item self-administered questionnaire designed to measure psychosocial and behavioural dysfunction in diabetes patients requiring insulin. The DHP-1 was developed after interviews with patients, a review of the literature and other relevant instruments, and discussions with health care professionals. The DHP-1 contains 32 items in three subscales: psychological distress (14 items), barriers to activity (13 items), and disinhibited eating (5 items). All items are scored on a four-point scale, from 0 to 3. Item scores are summed to give subscale raw scores which are transformed to a common score range of 0-100 where 0 represents no dysfunction.

To adapt the DHP-1 for use in Type 2 diabetes, the DHP-1 was administered to UK and Danish patients (Meadows, Abrams et al. 2000). This led to 14 items being excluded as they failed to meet the criteria for inclusion (i.e. items related to insulin therapy, items where more than two response categories were endorsed by less than 5% of respondents and over 75% of respondents reporting never. Hence, the DHP-18 has 18 items. Following a forced 3-factor factor analysis, the 3 subscales from the DHP-1 were retained for the DHp-18: psychological distress (6 items), barriers to activity (7 items) and disinhibited eating (5 items).

Epilepsy

The Quality of Life in Epilepsy (QOLIE-31) (Cramer et al. 1998) is a self-administered questionnaire that was developed in the US from the QOLIE-89 (Devinsky et al. 1995). The QOLIE-89 was developed from the Short Form -36 (SF-36) (Ware and Sherbourne 1992) with additional generic items, epilepsy targeted items and items concerning attitudes towards epilepsy and self-esteem. Subscales from the QOLIE-89 were selected empirically for inclusion in the QOLIE-39 by asking people with epilepsy which subscales they considered most important. The QOLIE-31 has one overall item and 30 items in 7 subscales, including seizure worry (5 items), overall quality of life (2 items), emotional well-being (5 items), energy-fatigue (4 items), cognitive functioning (6 items), medication effects (3 items) and social functioning (5 items). Items are scored on a scale from 1 (all of the time) to 6 (none of the time) for all subscale items. The overall item is scored from 0 (worst possible QOL, as bad as or worse than being dead) to 10 (best possible QOL). Raw scores are converted to range values from 1 to 100 for each subscale, with higher scores reflecting better quality of life. A total score can be calculated from the seven subscales. The QOLIE-31 has been shown to be valid and reliable (Cramer, Perrine et al. 1998)(Cramer, Perrine, Devinsky, Bryant-Comstock, Meador, & Hermann 1998).

Heart Failure

The Minnesota Living with Heart Failure Questionnaire (MLHFQ), developed in the US, is a 21-item self-administered questionnaire that covers physical, socio-economic and psychological impairments in relation to heart failure (Rector et al. 1987). Items are scored on a scale of 0 to 5 (where 0 is 'not impaired' and 5 is 'very much impaired'). Item scores are summed to calculate dimensions scores including physical dimension (8 items), emotional dimension (5 items) and total impairment (overall score of 21 items) (Rector and Cohn 1992). The relevant items are summed to calculate the scores to give a score range of 0-40 for the physical dimension, 0-25 for the emotional dimension and 0-105 for the total score. A higher score means increased impairment.

Stroke

The Stroke Impact Scale (SIS) is a mail-administered outcome measure first developed in the US by Duncan and colleagues. Version 1 of the SIS was developed with patient and caregiver input and is reported only in unpublished literature (Duncan et al. 1999). SIS version 2 (SISv2) contains 64 items in 8 domains (strength, hand function, activities of daily living (ADL) or instrumental activities of daily living (IADL), mobility, communication, emotion, memory and thinking, and handicap). The four physical domains (strength, hand function, mobility and ADL/IADL) can be summed to create one score, but the remaining domains must be scored individually. Individual items are scored in the range of 1 to 5. Raw domain scores are computed to domain scores ranging between 0 (poorest impact) and 100 (highest impact). Domain scores cannot be calculated if more than 50% of responses within the domain are missing. Patients are also asked to rate their global perception of recovery on a visual analogue scale from 0 to 100 (no meaning no recovery and 100 meaning full recovery). SISv2 has been found to be valid, reliable, sensitive to change and feasible (Duncan, Wallace, Lai, Johnson, Embretson, & Laster 1999;Duncan et al. 2002). The domains of SISv2 had been derived from principal component analysis. Rasch analysis was applied to SISv2 to develop SIS version 3 (SISv3) (Duncan et al. 2003). This resulted in 5 items being deleted from 4 of the domains, but the 8 dimensions remained the same. SISv3, which has 60 items, has been shown to be reliable, and valid, and the domains are uni-dimensional.

Analysis

Response rates and feasibility information

Response rates for each LTC by practice, region (L vs. NW) and total sample were calculated in Microsoft Excel. These were entered into SPSS together with practice information (for example practice size, deprivation score, QOF scores) to analyse whether there were any differences in response rates in relation to these factors. Additional feasibility information will be presented, including information on the search, missing data, and feedback by non-participants.

PROMs scores

The questionnaire data was double-entered and verified by a professional company. SPSS version 18 was used for the analysis. Data was analyses in three different ways: cohort baseline analysis, cohort analysis and cross-sectional analysis.

Mean PROMs scores with 95% confidence interval (CI) are presented. Additionnally, the cohort baseline analyses compares mean adjusted PROMs scores by practice for each LTC. Mean PROMs scores were adjusted for age, gender, time since diagnosis and number of comorbidities. Analysis of covariance (ANCOVA) was used.

The cohort analysis focuses on the differences and change between the cohort baseline and cohort-follow up PROMs scores for each LTC. Paired t-tests were used to identify differences between baseline and follow-up. A PROMs change score (=baseline score – follow-up score) was calculated for each respondent and ANOVA was used to compare the change score between practices for each LTC and the transition question.

The PROMs scores of the two cross-sectional surveys (cohort baseline and cross-sectional surveys) were compared by t-test. Demographics data between the two surveys was also compared.

The level of significance set at 0.05 for all analyses.

Qualitative study with stakeholders

A series of individual semi-structured interviews were conducted with professional and lay stakeholders about their views on the feasibility of routinely collecting PROMs data through primary care for LTCs, and the interpretation and value of PROMs. The aim was to recruit a convenience sample of up to 30 participants including GPs, nurses, senior PCT staff, members from commissioning groups and patient representatives. Practice staff (GPs and nurses) was recruited both from practices who had participated in the surveys and practices who had not participated. Practice staff from participating practices had not necessarily been involved in the process of conducting the surveys In the NW, participants were recruited through the research team's contacts (e.g. participating practices, one commissioner) and snowball sampling. In London, participants were recruited through participating practices and the PCRN. Commissioners, covering the geographical areas in London of the participating practices, were identified through an internet search. When contact details were available, they were invited for an interview by the Principal Investigator (RF). Patient representatives were recruited through 3 practices. Two NW practices randomly selected, and subsequently invited, thirty patients who had expressed an interest in research and practice issues. One London practice invited one of the researchers (MP) to a patient forum meeting to discuss the study and invite attending patients to participate in an interview. Attempts were made to present the findings at other practices or PCRN related events, but these were not successful.

A letter, information sheet (**Appendix 3a**) and consent form (**Appendix 3b**) were sent to the invited stakeholders. Upon receipt of the signed consent form, the researchers contacted the participants to arrange the interview. Consenting participants were offered the choice of a telephone, Skype or in-

person interview arranged at their convenience. A summary of the results of the cohort baseline survey (**Appendix 4**) was sent to each stakeholder before the interview. The summary contained a short outline of the methodology and a one page summary of the main results. Detailed results on response rates and dimension scores of all the PROMs were given in an appendix. Practices were identified by code to preserve confidentiality. Participants were signposted to their relevant practice code. Commissioners were told the codes for the practices within their geographical area. This provided the basis of the discussion for the interview, along with a semi-structured interview guide (**Appendix 5**).

All interviews were recorded using Olympus DSS digital recorder and transcribed verbatim by a professional transcriber. Notes had been kept during the patient forum discussion and were also included in the analysis. A framework analysis, based around the main issues of the PROMs pilot (feasibility, and value and usefulness of PROMs results), was conducted using NVivo V.9 qualitative analysis software. All the coding was performed by the qualitative researcher (EG) and three interviews were double coded by another researcher (MP) to verify the coding frame.

Cost analysis

The costs for mailing out PROMs questionnaires for LTCs in primary care were estimated based on expenses of the PROMs pilot, apart for postage which was estimated on the recent (increased) postage. Costs are divided into 4 main categories:

1) Identification of eligible patients and sending initial questionnaires to all eligible patients in the cohort and cross-sectional study;

2) Processing of completed initial questionnaires;

3) Sending follow-up questionnaires to all patients completing the initial baseline questionnaire and who were still contactable; and

4) Processing of completed follow-up questionnaires.

A model of the cost will be presented, as well as actual costs per patient of the pilot for each LTC.

RESULTS

Feasibility of data collection

Recruitment of practices

The aim was to recruit practices from the North-West of England and London. In the NW, four PCTs expressed an interest to participate, but practices were only recruited from three PCTs. Recruitment in London was attempted from both the 'North-West London' (covering 8 PCTs) and 'Central and East London' (covering 12 PCTs) areas. However, 'Central and East London' failed to give R&D permissions within a reasonable time frame and therefore it was not possible to include any of the 32 practices who had expressed an interest to participate in the study.

Initially, 61 practices expressed an interest to participate in the study (**Table 1**) and 33 of these practices participated in the cohort survey. Reasons for not participating after initially expressing interest are summarised in **Table 2**. At the time of recruitment, the most common reason were problems related to the practice's clinical system. There were two main reasons for this. Firstly, due to limited funds, Apollo was contracted to work with 5 out of 8 possible clinical systems only. This was deemed acceptable as the selected clinical systems were used in the majority of practices. Secondly, some practices had or were changing to a clinical system that Apollo is unable to work with. The reason not to participate was unknown in 8 practices; they failed to respond after they had expressed an interest or after agreeing to participate in the study.

Table1: Practice recruitment

	North-West	London	Total
N practices who expressed interest to participate	22	39	61
N practices who did not participate	7	21	28
N practices who participated in cohort survey	15	18	33
N practices who participated in cross-sectional survey	5	2	7

Table2: Reasons for not participating (before the start of the cohort baseline)

	North-West	London	Total
Practice no longer participates in research	1	0	1
Missed deadline for participation	0	4	4
Did not agree to Apollo search	0	1	1
Problem with clinical system	4	6	10
Unknown	0	8	8
Lack of time	2	2	4
TOTAL	7	21	28

The aim was to recruit about half the practices from London and the other half from the NW for each of the LTCs. The majority of practices covered three LTCs, whereas one NW practice only covered 2 LTCs. The number of practices for each LTC and the total number of practices are shown in **Table 3**. The number of practices for each condition differed between LTCs due to the variation in prevalence of the 6 LTCs. All but one practice (NW6) participated for 3 LTCs. The choice of LTCs covered by a practice was based on practice preference and practice size (larger practices covered the less prevalent LTCs and smaller practices the more prevalent). A larger number of practices than estimated needed to be recruited for stroke (19 rather than 8 practices) as QOF includes both patients with stroke and TIA. The latter were excluded from this study but it was not possible to know what the proportion of stroke and TIA patient was in QOF estimates until the search had been conducted in some practices. Practices varied in size (12 were small (<5800 patients), 13 medium (5800-10,500 patients) and 8 large (>10,500 patients). A slightly larger number of practices were recruited from more deprived areas (**Table 4**). A full description of the practices is given in **Appendix 6**.

Table 3: Number of practices by region for the cohort baseline survey

LTC	London	NW	Total
Asthma	5	5	10
COPD	8	8	16
Diabetes	5	5	10
Epilepsy	13	10	23
Heart failure	11	9	20
Stroke	12	7	19
Total	18	15	33

Table 4: Number of practices per social deprivation quartile (cohort baseline)

	Quintile	Range (IMD rank 2010)	London	NW	Total
Most deprived	**Q1**	1 – 6496	4	4	8
	Q2	6497 - 12992	4	6	10
	Q3	12993 - 19488	5	1	6
	Q4	19489 - 25984	4	2	6
Least deprived	**Q5**	25985 - 32482	1	2	3

Of the 33 practices included in the cohort baseline, only 7 proceeded to mail questionnaires for the cross-sectional survey (**Appendix 6**). Eight practices were no longer able to participate as they had changed to a clinical system (usually a web-based system) not supported by Apollo. One practice withdrew due to lack of time. The Apollo search was conducted in the 24 remaining practices. However, questionnaires were posted in only 7 practices as there was a search problem (explained below) in 16 practices and 1 practice (L4) sent the cross-sectional surveys to the patients extracted in the cohort baseline search. Additionally, one practice (NW2) did not cover COPD; this was also due to a search problem (but it did not affect the other two LTCs covered). This meant that a census was only conducted 2 practices covered asthma, 4 COPD, 1 diabetes, 6 epilepsy, 4 heart failure and 3 stroke.

Identifying eligible patients

Eligible patients were identified through a remote and automatic search of the practices' databases. The aim was to identify approximately half of the eligible patients for inclusion in the cohort baseline. A second search was conducted after one year to identify the remaining patients for inclusion in the cross-sectional survey. Two different search algorithms had been developed, the first to select half the patients into the cohort baseline survey and the second half into the cross-sectional survey one year later.

To test the search algorithms developed by Apollo, the search to identify cohort baseline patients was first conducted in five of the thirty-three practices of the cohort baseline. The number of patients extracted from each search was compared to QOF numbers for each practice throughout the pilot to ensure that the correct number of patients was identified. Only when the research team confirmed that the search had led to the approximate number of patients expected, were the practices able to proceed with the next steps of the study.

In early cohort baseline searches, a higher than expected number of asthma and epilepsy patients, and a lower than expected number for COPD, were identified. The original asthma and epilepsy search did not include the medications codes required by QOF. The search for asthma and epilepsy was repeated in 3 practices and 5 practices chose to manually exclude ineligible patients (i.e. those who had not taken medication within the specified time period). In the first practice (NW15), the asthma questionnaires had already been posted when the problem was identified and it was no longer possible to exclude ineligible patients. The problem with COPD affected one clinical system only (EMIS PCS), as Read codes needed to be expressed differently in the search for this clinical system. These problems were resolved

before the searches in the remaining practices were conducted. The search for COPD patients was repeated in one practice (NW2).

Approximately one year after the cohort baseline search, a second search was conducted to identify the remaining patients for the cross-sectional survey. Two different search algorithms, one for each survey, had been developed. It emerged that in 16 practices, the cohort baseline search algorithm had been used rather than the cross-sectional search algorithm. This meant that the same patients had been extracted in both searches. The only way to send the cross-sectional survey to the appropriate patients was to conduct another search, this time using the correct (cross-sectional) search algorithm. To conduct another search would have caused a delay of the study of approximately three months. Furthermore, response rates for the 7 practices in which the search had been conducted successfully for the cross-sectional study were not substantially different to those from the cohort baseline. It was not expected that collection of data in further practices would lead to a substantial increase in response rate. Therefore it was decided not to re-conduct the searches for the cross-sectional survey.

There were some further problems with the searches, such as the label sheets with the patient addresses not having been extracted successfully or no patients being extracted for one of the LTCs. This meant that the search had to be re-run. This placed additional burden on practices. In total, for 41 successful search (33 baseline and 8 cross-sectional), 58 searches (46 baseline and 12 cross-sectional) had been conducted or in other words the search needed to be repeated in 16 practices (12 cohort baseline and 4 cross-sectional). According to Apollo, these problems arise due to practice differences in software and tend to predominantly affect early-stage searches. Generally, they expect an extraction failure rate of up to 20%. Some practices also had difficulties working with the unfamiliar Apollo software or printing labels from the lists. Practices had been given written instructions and these were further refined by Apollo and the research team to help the practices with these problems. Furthermore contact details for a named person at Apollo were provided rather than practices needing to contact Apollo's general helpline. This helped to facilitate the process when problems occurred.

When all the searches had been completed, a total QOF estimate was calculated to draw an overall comparison with the number of patients extracted for the pilot. QOF numbers were estimated from 2009/2010 QOF prevalence rates (http://www.qof.ic.nhs.uk/search/). Search data was available for 25 practices for the cohort baseline only and for 8 practices for both the cohort baseline and the cross-sectional surveys. A total QOF estimate was calculated by summing the 50% QOF estimate for the 25 cohort baseline practices and the 100% QOF estimate for the other 8 practices. The QOF estimates, number of patients extracted in the PROMs pilot search, the overall difference and range of difference between the practices are presented in **Table 5**. A positive score on the difference means that a higher number of patients was extracted from the PROMs pilot search, whereas a negative number means that a lower than expected number was extracted.

Table 5: Numbers of eligible patients extracted in PROMs pilot search compared to QOF estimates

LTC	QOF estimate (n)	PROMs pilot search (n)	Difference		Range of difference for practices (%)	
			n	%		
Asthma	9833	9900	67	+0.67	-55.4	+62.7
COPD	2566	2045	-521	-20.3	-62.3	+42.1
Diabetes	7457	6460	-997	-13.4	31.4	+19.0
Epilepsy	1039	1337	+298	+28.7	-80.0	+348.3
Heart failure	1193	1184	-9	-0.8	-37.5	+15.9
Stroke	3027	1382	-1645	-54.3	-73.2	-30.0

Although these results give an indication of how well the searches worked, they need to be interpreted with caution. The extracted numbers for diabetes and stroke were expected to be lower than the number of patients in QOF. Diabetes patients aged 17 upwards are included in QOF, whereas this study only included diabetes patients aged 18 or over. However, it was reasonable to assume that this difference would be minimal. Stroke on the other hand presented more of a challenge as QOF also includes TIA which was not included in this pilot. Therefore, it was unlikely that the numbers from the PROMs pilot would closely match the QOF estimates. Furthermore, it has to be noted the method to conduct the two searches conducted (i.e. by the month of birth) and the second search not having been completed in all practices may have influenced the difference between PROMs pilot numbers and QOF estimates.

Exclusion of patients by practices

The practices had the option to exclude any patients extracted from the search if they believed that the patients were not suitable to be included in the study. The rates of exclusions varied between LTCs and practices (**Table 6**). The highest rate of exclusion was for epilepsy. In some practices, there were also high levels of exclusions for asthma. Both the asthma and epilepsy exclusions were higher in the five practices that underwent the search at an early stage. A problem with the search meant that ineligible patients (i.e. those who had not taken medication within a specified period of time) had been extracted in the search. The five practices preferred to exclude the patients manually rather than having the search run a second time.

The rate of inclusions tended to be lower in the NW than in London, although this difference was small for asthma, COPD and diabetes. However, the difference was substantial for epilepsy (43% in NW vs. 90.0% in London), heart failure (71.5 NW vs. 87.1% London) and stroke (75.2% NW vs. 83.2% London). The difference in epilepsy inclusions was influenced by the above mentioned search problem, however it was not the only explanation as the inclusion rate was as low as 34.6% in a practice where the search had been conducted correctly.

Table 6: Exclusions of patients by practices (cohort baseline data)

LTC (n practices)	N patients extracted		N patients excluded		% included	
	Total	Practice range	Total	Practice range	Total	Practice range
Asthma (10)	1628	64-684	294	0-197	81.9	63.5-100.0
COPD (16)	602	8-88	35	6-80	94.2	81.5-100.0
Diabetes (10)	1169	63-185	48	0-13	95.9	90.2-100.0
Epilepsy (23)	985	4-260	460	4-78	53.3	19.2-100.0
Heart failure (20)	687	5-143	167	4-81	75.7	56.6-100.0
Stroke (19)	525	4-69	107	0-19	79.6	52.4-100.0

Feedback from the practices suggests that the reasons for excluding patients were death, blindness, co-morbidities (such as dementia or cerebral palsy) or learning difficulties, patients had moved, patients without clear diagnosis, patients on extended holiday or who recently had a traumatic life event, epilepsy patients who were in a care home because of head injury. Comorbidities and learning difficulties were of particular relevance for excluding patients from being sent the epilepsy survey. Additionally, some practices excluded a small number of patients from receiving a reminder because the patient had left the practice or had died, the patient had contacted the research team as they did not feel the study was relevant to them (e.g. wrong diagnosis) or they did not want to be involved in the study.

Response rates

Cohort baseline

Thirty-three practices participated in the cohort baseline. A total of 4485 questionnaires were sent and 1721 were returned. The overall response rate was 38.4%. The response rate varied between LTCs, with heart failure achieving the highest response rate (50.4%, n=262) and asthma the lowest (30.0%, n=400) (**Table 7**). There variation in response rates was significant between LTCs ($p<0.001$), by practice ($p=0.018$) and by region ($p=0.002$). Additionally there were significant non-linear relationships between response rates and the practices' deprivation score (0.024, **Table 8**) and the adjusted EQ5D mean score ($p=0.004$). Practices who had a QOF score of 100 (maximum score) had significantly ($p=0.013$) higher response rates across all LTCs (mean response rate 42.9, SD 11.9) than those who did not (mean 35.5, SD 14.3).

Table 7: Cohort baseline survey numbers sent and returned, and response rates (%) for each LTC (overall, by region and practice range).

LTC (n practices)	N		Overall RR (%)	Regional RR (%)		RR by practice (range) (%)
	Sent	Returned		London	NW	
Asthma (10)	1334	395	30.0	22.7	33.0	14.3-50.0
COPD (16)	567	279	49.2	43.0	54.3	32.1-66.7
Diabetes (10)	1121	448	40.0	30.5	50.1	28.1-61.3
Epilepsy (23)	525	180	34.0	35.5	33.6	0-53.9
Heart failure (20)	520	262	50.0	48.8	51.1	30.6-71.4
Stroke (19)	418	152	36.4	30.0	44.0	7.7-63.2

Table 8: Mean response rate by deprivation score (N refers to practice and LTC)

Deprivation quintile	N	Mean	SD
Most deprived	23	34.2	13.5
2	29	43.6	13.5
3	18	39.7	10.2
4	18	43.2	9.8
Least deprived	9	48.0	14.1

Cohort follow-up

The cohort follow-up questionnaire was sent to consenting participants one year after the baseline. Overall, 93.1% patients (1603 of 1721 baseline respondents) had consented to be sent a follow up questionnaire. The lowest rate of consent was achieved for heart failure (90.5%) and the highest for COPD (95.3%). Thirteen patients were excluded from receiving a follow up survey, as they had indicated in the baseline survey that they had not been diagnosed with the LTC that they were sent a survey for. For the total sample, there was no difference in whether consent to follow-up was given by LTC, age, region, ethnicity, number of comorbidities or time since diagnosis. However there was a difference between practices (p=0.008) with the proportion of cohort baseline respondents giving consent ranging from 78.6% to 100%. There were some disease-specific differences in consent, including gender (96.1% of men consented vs. 90.1% of women, p=0.029) and practice (consent ranged from 79.1%-100% in 10 practices, p=0.010) in asthma, and number of comorbidities for epilepsy (mean 1.17 SD 1.30 for those who consented vs. 2.14 SD 2.00 for those who did not consent, p=0.017) and heart failure (mean 1.92 SD 1.62 for those who consented vs. 2.60 SD 1.71 for those who did not consent p=0.049) respectively. The overall response rate to the cohort follow up was 71.5%. The distribution of surveys sent and the response rates by LTC are given in **Table 9**.

Table 9: Cohort follow-up survey numbers sent and returned, and response rates (%) for each LTC (overall, by region and practice range).

LTC (n practices)	N		Overall RR (%)	Regional RR (%)		RR by practice (range) (%)
	Sent	Returned		London	NW	
Asthma (10)	366	267	73.0	65.4	75.1	53.9-82.4
COPD (16)	262	187	71.4	68.9	73.1	44.4-82.9
Diabetes (10)	424	321	75.7	67.9	80.7	60.4-87.8
Epilepsy (23)	166	104	62.7	69.8	58.3	25.0-100.0
Heart failure (20)	234	155	66.2	60.6	68.7	25.0-100.0
Stroke (19)	137	102	74.5	70.5	77.6	0-100.0

Differences in completion rates to the follow-up survey were examined by means of baseline characteristics of respondents who had consented to the follow-up. For the overall sample, there were significant differences in the completion rate at follow-up between the LTCs (p=0.015), age (p<0.001), ethnicity (p=0.008) and region (p=0.007). The baseline mean EQ5D score was significantly lower (p<0.001) in non-responders to follow-up (mean 0.66 SD 0.33) compared to follow-up responders (mean 0.73 SD 0.29). **Table 10** shows that epilepsy and heart failure patients were less likely to respond than patients with one of the other LTCs, as were younger patients, those based in London and those from ethnic minority backgrounds. There were no significant differences in the response rate at follow-up for gender, time since diagnosis, number of comorbidities or practice.

Table 10: Factors significantly related to the number of questionnaires completed at cohort follow-up

		% responders
LTC (p=0.015)	Asthma	72.9
	COPD	71.4
	Diabetes	75.7
	Epilepsy	62.7
	Heart failure	66.2
	Stroke	74.5
Age (years) (p<0.001)	18-24	37.5
	25-34	48.4
	35-44	63.4
	45-54	70.1
	55-64	78.8
	75-84	71.7
	85+	65.2
Region (p=0.007)	London	67.2
	North-West	73.7
Ethnicity (p=0.008)	White	72.9
	Other	63.0

When analyses were performed of prediction of return of the follow-up questionnaire for each of the six LTCs, significant differences were observed for some factors, including age (p<0.001) and ethnicity (p=0.009) in asthma; age (p=0.012) in COPD, gender (p=0.032) and region (p=0.003) in diabetes; age

(p=0.011) in epilepsy; and ethnicity (p=0.003) in stroke. The direction of these differences was the same as for the overall sample (i.e. lower completion rate in younger patients and ethnic minorities), with the additional finding that in diabetes, women were less likely to complete the follow-up than men. When entered into a logistic regression (follow-up not completed =0 vs. follow-up completed =1), only some age groups and EQ5D remained significant (**Table 11**). Asthma and age 18-24 served as reference categories.

Table 11: Factors related to completion of the follow-up questionnaire

		p	Odds ratio
LTC	**Asthma**	NS	--
	COPD	NS	1.07
	Diabetes	NS	0.80
	Epilepsy	NS	1.06
	Heart Failure	NS	0.75
	Stroke	NS	0.66
Age (years)	**18-24**	<0.001	--
	25-34	0.001	0.24
	35-44	0.005	0.37
	45-54	NS	0.71
	55-64	NS	1.04
	65-74	NS	1.68
	75-84	0.035	1.70
	85+	NS	1.23
	Region	NS	1.20
	EQ5D	<0.001	2.11
	Ethnicity	NS	0.77
	Gender	NS	0.88
	Constant	NS	1.32

Cross-sectional

As explained above, the cross-sectional survey was mailed for 7 practices only. The overall response was 44.0%. The response rates by LTC are given in Table 12.

Table 12: Cross-sectional survey numbers sent and returned, and response rates (%) for each LTC (overall, by region and practice range).

LTC (n practices)	N		Overall RR (%)	Regional RR (%)		RR by practice (range) (%)
	Sent	Returned		London	NW	
Asthma (2)	726	257	35.4	N/A	35.4	32.7-36.4
COPD (4)	285	170	59.7	64.5	58.3	49.5-66.2
Diabetes (1)	76	42	55.3	N/A	55.3	N/A
Epilepsy (6)	187	70	37.4	36.4	37.7	14.3-52.6
Heart failure (4)	105	58	55.2	58.0	52.7	52.0-64.7
Stroke (3)	90	49	54.4	40.0	63.6	40.0-64.7

Data quality

Missing data

Missing data analysis was conducted for all the PROMs and the 3 datasets. The rates of missing data for the cohort baseline and cross-sectional surveys were similar and are presented in **Table 13**. The rates of missing data are presented as a range i.e. the item/dimension with the lowest rate of missing data to the item/dimension with the highest rate of missing data. For the EQ5D, the rate of missing data on the EQ5D was low for individual items, including the VAS, for each of the LTCs. When no data imputation was performed, the EQ5D York tariff could not be derived for 3.10% of the cohort baseline participants and 5.6% of the cross-sectional survey participants. For the disease-specific PROMs, rates of missing data were low for the Mini-AQOL (asthma), the CCQ (COPD) and the DHP (diabetes), meaning that dimension scores could be calculated for the majority of participants (i.e. >90%) apart from the CCQ total score (13.5% and 15.8% missing for the cohort baseline and the cross-sectional surveys respectively). For cohort baseline participants, high rates of missing data (>10%) were found on some individual items for the QOLIE (epilepsy) (n=3, Q1, Q20 and Q27), MLHFQ (heart failure) (n=2, Q10 and Q8) and SIS (stroke) (n=9, Q1a, Q1b, Q1c, Q1d, Q8a, Q8b, Q8c, Q8d and Q8f) which had a serious impact on the calculation of some dimension scores, including overall quality of life and social scale for epilepsy, total score for heart failure; and strength and handicap scales for stroke. Further problems with dimensions of the stroke scale (despite <10% missing data on individual items) were identified for hand function, mobility, ADL, emotion and the physical scale.

Table 13: Rates (%) of missing data for the EQ5D and disease-specific PROMs for the cohort baseline (CB) and cross-sectional (XS) surveys

		Individual Items			Dimensions		
	PROM	**N items**	**% missing (CB)**	**% missing (XS)**	**N dimensions**	**% missing (CB)**	**% missing XS**
Asthma	Mini-AQOL	15	0 - 3.3	1.8 – 5.5	5	1.5 - 7.1	3.1-8.6
	EQ5D	5	0.3 – 1.0	0.2 – 0.8	1	3.3	3.7
	EQ5D VAS	1	4.3	1.2	N/A	N/A	N/A
COPD	CCQ	10	1.5 - 4.0	5.3 - 7.6	4	5.1 - 13.5	8.6-15.8
	EQ5D	5	0.4 – 1.8	0.7 – 1.7	1	3.3	5.6
	EQ5D VAS	1	6.3	4.0	N/A	N/A	N/A
Diabetes	DHP	18	0.2 - 3.6	2.4 - 5.9	3	2.2 - 6.9	4.7-10.6
	EQ5D	5	0.9 – 2.0	0 – 1.3	1	2.9	3.5
	EQ5D VAS	1	6.3	1.2	N/A	N/A	N/A
Epilepsy	QOLIE	31	0 - 28.3	3.9 - 30.7	8	1.7 – 45.0	6.3-44.9
	EQ5D	5	0.6 – 2.2	0.8 – 2.4	1	3.3	7.1
	EQ5D VAS	1	8.9	4.7	N/A	N/A	N/A
Heart failure	MLHFQ	21	1.5 - 14.7	5.0 - 21.5	3	8.1 – 30.5	10.7-35.5
	EQ5D	5	0.4 – 3.9	0.8 – 1.7	1	5.4	4.1
	EQ5D VAS	1	5.0	3.3	N/A	N/A	N/A
Stroke	SIS	60	4 - 34	4.6 - 31.0	10	2.6 – 35.1	11.5-46.0
	EQ5D	5	2.0 – 4.0	2.3 – 5.7	1	4.0	10.3
	EQ5D VAS	1	10.6	6.9	N/A	N/A	N/A

The rates of missing data for the cohort baseline and follow-up surveys are presented in **Table 14**. Data includes only participants who participated both in the baseline and follow-up. The rates of missing data are presented as a range i.e. the item/dimension with the lowest rate of missing data to the item/dimension with the highest rate of missing data. A change score was computed between the baseline and follow-up and missing data rates for the change score are also presented. Overall the rate of missing data was slightly higher for the follow up than at baseline. However, missing data rates were low for the EQ5D and slightly higher, although still acceptable, for the EQ5D VAS. The Mini-AQOL (asthma), the CCQ (COPD) and the DHP (diabetes) also had little missing data at either baseline or follow-up, although the cumulative effect of missing data meant that a change score between baseline and follow up was slightly high (>10%) for some dimensions. As already shown by **Table 13** (cross-sectional data), rates of missing data were high for some items and dimensions of the QOLIE (epilepsy), the MLHFQ (heart failure) and SIS (stroke), leading to high rates of missing data on the change score.

Table 14: Rates (%) of missing data for the EQ5D and disease-specific PROMs for the cohort baseline (CB) and follow-up (CF) surveys (only respondents who participated in both the CB and CF).

		Individual Items			Dimensions			
LTC	**PROM**	**N**	**% missing (CB)**	**% missing (CF)**	**N**	**% missing (CB)**	**% missing (CF)**	**% missing change score**
Asthma	Mini-AQOL	15	0-3.8	0.8-6.8	5	1.1-7.1	3.4-11.7	4.1-15.0
	EQ5D	5	0.4-0.8	0.8-1.9	1	1.1	3.0	4.1
	EQ5D VAS	1	3.4	3.8	N/A	N/A	N/A	6.8
COPD	CCQ	10	1.6-3.7	0-3.7	4	4.3-9.1	2.1-8.6	5.9-14.4
	EQ5D	5	0-1.1	1.1-2.1	1	2.1	4.8	5.3
	EQ5D VAS	1	5.0	4.4	N/A	N/A	N/A	7.8
Diabetes	DHP	18	0-2.8	1.2-3.1	3	1.6-6.2	2.8-7.5	4.4-12.1
	EQ5D	5	0.9-2.5	1.6-2.2	1	3.4	3.7	6.2
	EQ5D VAS	1	5.0	4.4	N/A	N/A	N/A	7.8
Epilepsy	QOLIE	31	0-27.9	1.0-30.8	8	0-42.3	2.9-50.0	2.9-61.5
	EQ5D	5	0-1.9	1.0-4.8	1	1.9	6.7	8.7
	EQ5D VAS	1	9.6	5.8	N/A	N/A	N/A	12.5
Heart failure	MLHFQ	21	0.6-11.0	3.2-21.3	3	5.8-28.4	9.0-36.1	14.8-48.4
	EQ5D	5	0-3.9	1.9-4.5	1	4.5	7.7	11.6
	EQ5D VAS	1	2.6	5.2	N/A	N/A	N/A	6.5
Stroke	SIS	60	2.9-23.5	2.0-22.5	10	5.9-36.3	5.9-38.2	9.8-52.9
	EQ5D	5	1.0-3.9	2.0-4.9	1	3.9	5.8	8.8
	EQ5D VAS	1	11.8	10.8	N/A	N/A	N/A	19.6

A summary of dimensions and items with more than 10% of missing data for the disease-specific PROMs are presented in **Table 15** and **Table 16** respectively.

Table 15: Dimensions with more than 10% of missing data for the disease-specific PROMs (dimensions in italics are those where more than 20% of data is missing)

		Cohort		Cross-sectional	
		Baseline	**Follow-up**	**Cohort baseline**	**XS**
Asthma	Mini AQOL	--	Total score	--	--
COPD	CCQ	--	--	Total score	Symptoms Total score
Diabetes	DHP	--	--	--	Activity limitations
Epilepsy	QOLIE	QoL Scale *Social Scale* *Overall score*	QoL Scale *Social score* *Overall score*	QoL Scale *Social scale* *Overall score*	Seizure worry Cognitive scale *Social scale* *Overall score*
Heart failure	MLHFQ	*Total score*	Physical score *Total score*	*Total score*	Physical score Emotional score *Total score*
Stroke	SIS	*Strength* Hand function Mobility ADL Emotion *Handicap* *Physical domain*	*Strength* Hand function Mobility ADL Emotion *Handicap* *Physical domain*	*Strength* Hand function Mobility ADL Emotion *Handicap* *Physical domain*	*Strength* *Hand function* Memory Mobility *ADL* Communication Emotion *Handicap* *Physical domain*

Table 16: Items with more than 10% of missing data for the disease-specific PROMs

		Cohort		Cross-sectional	
		Baseline	**Follow-up**	**Cohort baseline**	**XS**
Asthma	**Mini AQOL**	None	None	None	None
COPD	**CCQ**	None	None	None	None
Diabetes	**DHP**	None	None	None	None
Epilepsy	**QOLIE**	1, 20	20	1, 20, 27	1, 20, 27
Heart failure	**MLHFQ**	10	8, 9, 10	8, 10	8, 10
Stroke	**SIS**	1a-d, 7a-e, 8a-d, 8f	1a-d, 7b, 8a, 8f	1a-d, 8a-d, 8f	1a-d, 4d-g, 5b-f, 5j, 6a, 6g, 6h, 7a-d, 8a-g

Reliability

Internal consistency of each dimension for all PROMs was assessed by Cronbach's alpha. A low Cronbach's alpha was found on two dimensions only, i.e. asthma environmental stimuli (0.62) for the (second) cross-sectional survey and stroke emotion (0.60) for the cohort follow-up survey. For all other dimensions, Cronbach's alpha was over 0.7. For the majority of items and dimensions, the scores were skewed towards a more positive end of the scale, which may have contributed to the internal consistency of the dimensions.

Impact of data imputation

The amount of missing data for asthma, COPD and diabetes were negligible and hence it was not considered necessary to impute data. No author instructions have been given for imputing missing data for the QOLIE (epilepsy) and the MLHFQ (heart failure). The SIS (stroke) had a high rate of missing data and authors' instructions on data imputation were available and therefore, data imputation was carried out on the stroke scale for the cohort baseline dataset. Imputing data on the stroke scale did not lead to substantial differences in the mean scores. (**Table 17**) The main difference was it was possible to include a larger number of participants in the analysis.

Table 17: Stroke mean PROMs score with and without data imputation

	Without imputation			With imputation		
	N	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**
Stroke Strength	120	65.31	60.39 - 70.23	132	64.99	60.18 - 69.80
Stroke Hand Function	131	70.11	64.60 - 75.63	139	70.19	64.88 – 75.50
Stroke Mobility	129	74.81	70.42 - 79.20	145	72.81	68.67 - 76.94
Stroke Memory	137	78.47	74.40 - 82.54	145	78.71	74.82 - 82.60
Stroke ADL	124	79.54	75.37 - 83.71	144	77.83	73.91 - 81.76
Stroke Communication	138	84.21	80.44 - 87.99	144	84.20	80.55 – 87.85
Stroke Emotion	128	68.40	65.18 - 71.63	143	67.20	64.09 – 70.31
Stroke Handicap	98	68.24	62.09 - 74.39	137	68.82	63.70 - 73.94
Stroke Physical Dimension	99	73.45	68.41 - 78.49	130	71.09	66.74 - 75.43

Feedback on patient participation

A free telephone helpline and a study email address were set up to enable patients to contact the researchers with any queries. In the reminder letter, patients who preferred not to participate were invited to contact the researchers to give feedback on their reasons for non-participation.

Over the course of the surveys, 334 patients or someone on behalf of the patient (usually a family member) contacted the research team, predominantly by telephone. A total of 108 called with a general query such as to enquire how the data will be used or asking if they could participate if their current health state was different to usual. Sixty-three contacts were made to request a new questionnaire and 163 to explain a patient's non-participation (**Table 18**).

Additionally, 29 questionnaires were returned as undeliverable and 18 questionnaires were received after the cut-off date. No one called to get help with translation of the questionnaire.

Table 18: Reasons for non-participation in the surveys

Reason	Cohort baseline	Cohort follow up	Cross-sectional	Total
Patient has died	0	26	1	**27**
Does not or is not aware of having condition	20	1	7	**28**
Not enough time	4	1	0	**5**
Too ill	12	5	5	**22**
Don't want to participate in research	4	0	0	**4**
Don't like completing questionnaires	3	0	3	**6**
Don't think the study is worthwhile	3	0	0	**3**
No personal benefit	1	0	0	**1**
Concerns about confidentiality	3	0	0	**3**
Questions not relevant/few symptoms	15	1	3	**19**
Difficulty understanding or answering questions	7	2	7	**16**
Dislike questionnaire – other reason	4	0	0	**4**
Other reason/don't know	12	2	10	**24**
Questionnaire completed by proxy	0	0	1	**1**

PROMs scores

Cohort baseline

Asthma

A total of 395 asthma patients, from 10 practices (5 NW and 5 London), were included in the analysis. The majority of the respondents were female, under 65 years of age, in employment, white and from the NW (**Table 19**). The mean time since diagnosis was 22.5 years (SD 16.3). Two hundred and twenty-six patients (57.2%) did not report any comorbidities whereas 105 (26.6%) reported one comorbidity and 64 (16.2%) reported two or more comorbidities. There were no significant differences between practices for gender, age, number of comorbidities and time since diagnosis. However, employment was significantly different between practices ($p<0.001$), as was ethnicity ($p<0.001$).

Table 19: Demographics for asthma patients (cohort baseline)

		n	%
Gender	Male	154	39.7
	Female	234	60.3
Age (years)	18-44	127	32.6
	45-64	160	41.1
	65-74	59	15.2
	75+	43	11.1
Employment	Full-time	148	39.1
	Part-time	61	16.1
	Full-time education	7	1.8
	Unemployed	14	3.7
	Permanently sick/ disabled	16	4.2
	Retired	89	23.5
	Looking after home	34	9.0
	Other	10	2.6
Ethnicity	White	352	91.7
	Other	32	8.3
Region	London	85	21.5
	North-West of England	310	78.5
		Mean	**SD**
Time since diagnosis (years)		22.5	16.3
N comorbidities		0.6	0.9

Mean PROMs scores for all dimensions are presented in **Table 20**. When comparing practice-level PROMs scores significant differences were found for the adjusted means of both the EQ5D (York Tariff and VAS) (**Table 21**) and four out of the five dimensions of the asthma-specific AQOL (**Table 22**). It was predominantly one practice (NW3) that scored lower than the other practices on all of these.

Table 20: Mean PROMs scores for asthma

	N	Mean	95% CI
EQ5D	390	0.82	0.80 -0.85
EQ-5D VAS	378	73.13	71.18 – 75.08
Symptoms	389	5.24	5.11 – 5.36
Activity Limitations	380	5.97	5.85 – 6.09
Emotional Functioning	386	5.32	5.16 – 5.47
Environmental Stimuli	389	5.15	5.00 – 5.30
Total QOL	367	5.49	5.37 – 5.61

Table 21: Adjusted asthma EQ5D by practices

	York Tariff (p=0.002)			VAS (p=0.002)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	10	0.88	0.74 - 1.02	11	73.74	63.40 - 84.08
L6	20	0.81	0.71 - 0.90	22	71.03	63.58 - 78.48
L9	22	0.84	0.75 - 0.93	22	75.416	67.99 - 82.84
L13	11	0.73	0.60 - 0.86	11	77.31	67.12 - 87.50
L14	7	0.75	0.59 - 0.90	8	67.12	55.00 - 79.23
NW1	38	0.85	0.78 - 0.92	41	75.77	70.48 - 81.05
NW3	8	0.57	0.44 - 0.70	11	52.15	41.95 - 62.35
NW9	140	0.84	0.80 - 0.88	142	72.35	69.20 - 75.51
NW14	20	0.94	0.84 - 1.04	20	81.23	73.62 - 88.84
NW15	58	0.86	0.80 - 0.92	57	76.72	72.20 - 81.23

Table 22: Adjusted asthma disease-specific PROMs scores by practice (AQOL score range is 1-7 where 1 is 'severe impairment' and 7 is 'no impairment')

	Symptoms (p=0.001)			Activity limitations (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	10	4.61	3.83 - 5.39	22	6.07	5.59 - 6.55
L6	22	5.29	4.75 - 5.83	8	5.40	4.62 - 6.19
L9	24	5.10	4.59 - 5.61	9	4.78	4.05 - 5.52
L13	11	5.32	4.58 - 6.06	11	5.95	5.29 - 6.61
L14	8	4.92	4.04 - 5.79	11	5.76	5.10 – 6.43
NW1	39	5.52	5.12 - 5.91	143	6.07	5.86 - 6.28
NW3	11	3.70	2.97 - 4.44	21	5.83	5.34 - 6.32
NW9	150	5.40	5.18 - 5.62	59	6.02	5.73 - 6.31
NW14	20	5.62	5.07 - 6.17	40	5.82	5.48 - 6.17
NW15	59	5.49	5.17 - 5.82	20	5.76	5.27 - 6.25
	Emotional functioning (p<0.001)			**Environmental stimuli (p<0.001)**		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	10	4.24	3.29 - 5.19	11	4.35	3.45 - 5.26
L6	22	5.61	4.96 - 6.27	21	4.96	4.29 - 5.63
L9	24	5.33	4.69 - 5.97	24	4.99	4.37 - 5.61
L13	11	5.13	4.23 - 6.03	11	5.29	4.39 - 6.18
L14	8	4.85	3.71 - 5.99	8	4.10	3.04 - 5.16
NW1	39	5.42	4.95 - 5.89	40	5.31	4.84 - 5.78
NW3	11	3.22	2.32 - 4.12	9	4.49	3.50 - 5.48
NW9	150	5.58	5.30 - 5.85	149	5.57	5.30 - 5.84
NW14	20	5.39	4.72 - 6.06	20	5.33	4.66 - 6.00
NW15	59	5.59	5.20 - 5.98	60	5.19	4.80 - 5.57

	Total QOL (p=0.027)		
Practice	**n**	**Mean**	**95% CI**
L2	10	4.83	4.12 - 5.54
L6	20	5.51	5.00 - 6.03
L9	22	5.47	4.97 - 5.96
L13	11	5.44	4.77 - 6.11
L14	7	4.80	3.94 - 5.65
NW1	38	5.52	5.16 - 5.88
NW3	8	4.23	3.44 - 5.02
NW9	140	5.65	5.43 - 5.87
NW14	20	5.54	5.04 - 6.04
NW15	58	5.58	5.28 - 5.88

COPD

Two hundred and seventy-five patients from 16 practices (8 in NW and London respectively) participated in the cohort baseline survey. Forty-six percent were male and 54.0% were female. The majority were aged above 65 years, retired, white and from the NW (**Table 23**). The mean time since diagnosis was 8.6 years (SD 9.6). Sixty-three (22.9%) participants did not report any comorbidities, 87 (31.6%) reported one comorbidity and 125 (45.5%) reported 2 or more comorbidities. No significant differences were found between practices for age, employment and number of comorbidities. Significant differences between practices were found for gender ($p<0.001$), ethnicity ($p=0.018$) and time since diagnosis ($p=0.008$).

Table 23: Demographics for COPD patients (cohort baseline)

		n	%
Gender	Male	125	46.0
	Female	147	54.0
Age (years)	18-44	3	1.1
	45-64	58	21.1
	65-74	87	31.6
	75+	127	46.2
Employment	Full-time	19	7.3
	Part-time	18	6.9
	Unemployed	2	0.8
	Permanently sick/ disabled	35	13.4
	Retired	160	61.3
	Looking after home	22	8.4
	Other	5	1.9
Ethnicity	White	270	98.5
	Other	4	1.5
Region	London	108	39.3
	North-West of England	167	60.7
		Mean	**SD**
Time since diagnosis (years)		8.6	9.6
N comorbidities		1.6	1.4

Mean PROMs scores for all dimensions are presented in **Table 24**. There were no significant differences for the EQ5D between practices (**Table 25**). Two out of the four disease-specific dimensions were found to be significantly different between practices (**Table 26**).

Table 24: Mean COPD PROMs scores

	N	Mean	95% CI
EQ5D	266	0.64	0.61 – 0.68
EQ-5D VAS	257	60.78	58.37 – 63.18
Symptoms	251	2.70	2.52 – 2.89
Functional State	261	2.30	2.11 – 2.48
Mental State	260	2.18	1.96 – 2.40
Total QOL	238	2.39	2.21 – 2.57

Table 25: Adjusted COPD EQ5D scores by practice

	EQ5D (NS)			VAS (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L4	5	0.58	0.35 - 0.81	5	61.52	43.85 - 79.19
L8	11	0.59	0.42 - 0.76	10	72.48	59.97 84.99
L10	2	0.69	0.34 - 1.04	2	62.16	35.04 - 89.28
L11	10	0.72	0.56 - 0.88	10	55.60	42.37 68.82
L12	28	0.66	0.54 - 0.78	26	63.65	54.15 - 73.15
L13	3	0.54	0.25 - 0.84	3	59.35	36.49 - 82.21
L15	9	0.50	0.32 - 0.67	8	55.23	40.94 – 69.51
L18	6	0.52	0.29 - 0.74	5	62.42	44.83 - 80.01
NW1	11	0.58	0.42 - 0.74	10	57.60	44.34 - 70.86
NW2	12	0.68	0.52 - 0.85	11	58.51	45.97 - 71.06
NW3	6	0.66	0.45 - 0.87	7	58.25	42.05 - 74.46
NW4	15	0.54	0.41 - 0.68	14	51.54	40.69 - 62.39
NW5	12	0.38	0.22 - 0.54	11	51.17	38.49 - 63.86
NW9	31	0.67	0.55 - 0.78	28	57.89	49.31 - 66.47
NW10	31	0.56	0.45 - 0.67	32	60.57	51.91 - 69.23
NW12	8	0.52	0.33 - 0.70	8	59.50	45.11 - 73.89

Table 26: Adjusted COPD-specific scores by practices (score range 0-6 where 0 is 'very good health status' and 6 is 'extremely poor health status)

	Symptoms (p=0.001)			Functional state (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L4	5	2.36	1.21 - 3.51	5	1.83	0.62 - 3.05
L8	11	2.32	1.49 - 3.16	11	1.99	1.11 - 2.87
L10	2	2.77	1.01 - 4.54	2	1.17	-0.70 - 3.03
L11	10	2.21	1.39 - 3.02	10	1.72	0.86 - 2.58
L12	24	2.48	1.85 – 3.12	27	1.73	1.08 - 2.37
L13	3	3.39	1.90 - 4.88	3	2.53	0.95 - 4.10
L15	9	3.75	2.87 - 4.64	8	2.67	1.69 - 3.66
L18	6	3.26	2.13 - 4.40	6	1.84	0.73 - 2.96
NW1	11	1.67	0.82 - 2.51	11	2.40	1.53 - 3.26
NW2	11	3.51	2.69 - 4.33	12	1.64	0.78 - 2.51
NW3	6	2.82	1.77 - 3.88	7	2.13	1.02 - 3.24
NW4	14	3.67	2.96 - 4.38	15	2.93	2.20 - 3.67
NW5	11	3.46	2.64 - 4.29	12	2.84	1.99 - 3.68
NW9	29	2.48	1.90 - 3.06	30	2.61	2.03 - 3.19
NW10	30	3.43	2.88 - 3.98	31	2.02	1.42 - 2.62
NW12	7	3.38	2.40 - 4.37	8	2.48	1.50 - 3.47
	Mental state (NS)			**Total QOL (p=0.038)**		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L4	5	1.84	0.27 - 3.40	5	2.05	0.94 - 3.17
L8	11	1.54	0.40 - 2.67	11	2.03	1.22 - 2.83
L10	1	0.83	-2.53 - 4.18	1	1.94	-0.45 - 4.33
L11	10	1.80	0.70 - 2.91	10	1.96	1.17 - 2.75
L12	26	2.13	1.30 - 2.97	23	2.16	1.53 - 2.78
L13	3	1.41	-0.61 - 3.43	3	2.63	1.19 - 4.08
L15	9	3.64	2.43 - 4.84	8	3.14	2.24 - 4.04
L18	5	2.52	0.82 - 4.23	5	2.90	1.68 - 4.11
NW1	11	2.79	1.67 - 3.90	11	1.65	0.83 - 2.47
NW2	12	1.62	0.50 - 2.73	11	2.91	2.12 - 3.70
NW3	6	1.76	0.32 - 3.20	6	2.22	1.20 - 3.24
NW4	15	3.07	2.13 - 4.01	14	3.19	2.51 - 3.88
NW5	12	2.61	1.52 - 3.69	11	2.94	2.14 - 3.73
NW9	30	2.80	2.06 - 3.55	28	2.23	1.66 - 2.80
NW10	31	2.16	1.38 - 2.93	28	2.93	2.39 - 3.47
NW12	7	2.66	1.31 - 4.00	7	2.91	1.96 - 3.87

Diabetes

A total of 448 diabetes patients from 10 practices (5 in London and NW respectively) were included in the cohort baseline analysis. A little over half of the respondents were male, nearly half were retired and just over a quarter were in employment (**Table 27)**. The majority were white, with the most represented ethnic minority being Asian/Asian British (n=80, 18.6%). A total of 272 (60.7%) respondents came from the NW. Twenty-nine (6.7%) were aged 18 to 44 years, 153 (35.3%) 45 to 64 years, 124 (28.6%) 65 to 74 years and 127 (29.3%) 75 years or more. The mean time since diagnosis was 9.6 years (SD 8.6). One hundred and four (23.2%) did not report any comorbidities, 151 (33.7%) reported one comorbidity and 193 (43.1%) reported two or more comorbidities. No significant differences between practices were found for gender, number of comorbidities and time since diagnosis. Significant differences between practices were found for age ($p<0.001$), employment ($p=0.009$) and ethnicity ($p<0.001$).

Table 27: Demographics for diabetes patients (cohort baseline)

		n	%
Gender	Male	243	56.6
	Female	186	43.4
Age (years)	18-44	29	6.7
	45-64	153	35.3
	65-74	124	28.6
	75+	127	29.3
Employment	Full-time	88	20.9
	Part-time	26	6.2
	Full-time education	1	0.2
	Unemployed	20	4.7
	Permanently sick/ disabled	34	8.1
	Retired	204	48.3
	Looking after home	39	9.2
	Other	10	2.4
Ethnicity	White	330	76.6
	Other	101	23.4
Region	London	176	39.3
	North-West of England	272	60.7
		Mean	**SD**
Time since diagnosis (years)		9.6	8.6
N comorbidities		1.6	1.4

The mean PROMs scores for diabetes are presented in **Table 28**. When comparing practice-level PROMs scores, the adjusted mean scores for the EQ5D were not significantly different between practices (**Table 29**). However, the adjusted means of all three dimensions of the disease-specific PROM were significantly different between practices (**Table 30**).

Table 28: Mean PROMs scores for diabetes

	N	Mean	95% CI
EQ5D	435	0.72	0.69 – 0.75
EQ-5D VAS	420	68.46	66.61 – 70.32
Psychological Distress	433	16.69	14.79 – 18.59
Barriers to Activity	419	21.88	19.96 – 23.80
Disinhibited Eating	438	31.80	29.80 – 33.79

Table 29: Adjusted diabetes EQ5D scores by practice

	EQ5D (NS)			VAS (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	42	0.67	0.60 - 0.75	40	63.5	58.1 - 68.9
L4	18	0.72	0.61 - 0.84	18	65.8	58.0 - 73.7
L8	39	0.75	0.67 - 0.83	39	72.9	67.3 - 78.6
L10	21	0.76	0.65 - 0.87	21	71.6	64.2 - 79.0
L11	22	0.74	0.64 - 0.85	22	71.1	63.8 - 78.4
NW1	30	0.67	0.58 - 0.77	30	65.5	59.2 - 71.9
NW2	39	0.78	0.70 - 0.87	37	71.5	65.8 - 77.2
NW8	62	0.71	0.64 - 0.77	61	64.5	59.9 - 69.1
NW11	65	0.71	0.65 - 0.78	65	67.7	63.4 - 72.0
NW12	39	0.70	0.62 - 0.78	36	66.5	61.0 - 72.1

Table 30: Adjusted diabetes-specific scores by practice (score range 0-100 with a higher score meaning higher dysfunction)

	Psychological distress (p=0.001)			Barriers to activities (p<0.001)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	42	26.92	21.67 - 32.17	43	35.03	29.43 - 40.64
L4	18	14.41	6.60 - 22.21	18	20.59	12.18 - 29.00
L8	37	28.87	23.41 - 34.33	40	30.61	24.93 36.28
L10	21	20.22	12.83 - 27.61	20	22.75	14.61 - 30.89
L11	21	12.57	5.24 - 19.90	19	18.12	9.81 - 26.43
NW1	30	23.04	16.73 - 29.36	28	22.46	15.43 - 29.49
NW2	39	17.22	11.63 - 22.81	37	15.63	9.46 - 21.80
NW8	65	18.79	14.33 - 23.26	61	22.35	17.40 - 27.30
NW11	64	18.88	14.58 - 23.18	63	23.04	18.37 - 27.71
NW12	39	14.34	8.82 - 19.85	37	18.54	12.45 - 24.63

	Disinhibited eating (p=0.004)		
Practice	**n**	**Mean**	**95% CI**
L1	44	41.89	36.00 - 47.77
L4	19	38.69	29.99 - 47.38
L8	40	36.90	30.89 - 42.92
L10	20	28.87	20.24 - 37.50
L11	21	26.43	18.06 - 34.81
NW1	29	35.72	28.40 - 43.03
NW2	39	27.73	21.35 - 34.11
NW8	65	34.31	29.21 - 39.40
NW11	65	37.81	32.93 - 42.69
NW12	38	27.52	21.14 - 33.89

Epilepsy

One hundred and eighty participants from 23 practices (13 in London and 10 in the NW) participated. Slightly more women than men participated, but approximately equal proportions were in employment, permanently sick/ disabled or retired (**Table 31**). The majority were aged under 65 years, white and from the NW. The mean time since diagnosis was 22.8 years (SD 16.3). Seventy-seven (42.8%) did not report any comorbidities, 41 (22.8%) reported one comorbidity and 62 (34.4%) two or more comorbidities. There were no significant differences between practices for gender and number of comorbidities. There were significant differences between practices for age (p=0.006), employment (p<0.001), ethnicity (p=0.002) and time since diagnosis (p=0.049).

Table 31: Demographics of epilepsy patients (cohort baseline)

		n	%
Gender	Male	83	46.6
	Female	95	53.4
Age (years)	18-44	54	30.2
	45-64	67	37.4
	65-74	36	20.1
	75+	22	12.3
Employment	Full-time	41	24.3
	Part-time	11	6.5
	Full-time education	5	3.0
	Unemployed	13	7.7
	Permanently sick/ disabled	39	32.1
	Retired	46	27.2
	Looking after home	11	6.5
	Other	3	1.8
Ethnicity	White	164	93.2
	Other	12	6.8
Region	London	67	37.2
	North-West of England	113	62.8
		Mean	**SD**
Time since diagnosis (years)		22.8	16.3
N comorbidities		1.2	1.5

Mean PROMs scores for epilepsy are presented in **Table 32**. When comparing practice-level PROMs scores, no significant differences in the adjusted mean scores were found for the EQ5D between practices (**Table 33**). Significant differences on the epilepsy-specific PROM were found for four out of the eight dimensions (**Table 34**).

Table 32: Mean PROMs scores for epilepsy

	N	Mean	95% CI
EQ5D	174	0.70	0.65 – 0.74
EQ-5D VAS	164	65.41	62.00 - 68.83
Seizure Worry	169	60.97	55.85 – 66.09
Overall QOL	149	64.78	61.61 – 67.95
Emotional well-being	170	64.09	60.89 – 67.30
Energy / Fatigue	174	51.84	48.64 – 55.03
Cognitive	169	58.84	54.79 – 62.89
Medication Effects	177	61.47	56.76 – 66.18
Social Function	122	68.02	62.51 – 73.54
Total QOL	99	63.31	59.18 – 67.44

Table33: Adjusted EQ5D scores by practice

	EQ5D (NS)			VAS (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	1	0.80	0.28 - 1.31	1	58.45	22.01 - 94.89
L3	3	0.49	0.19 - 0.79	3	47.87	26.64 - 69.10
L5	4	0.55	0.29 - 0.81	4	39.59	21.51 - 57.66
L7	11	0.79	0.63 - 0.96	10	78.32	66.52 - 90.11
L8	6	0.62	0.41 - 0.84	5	65.90	49.72 - 82.07
L9	1	0.88	0.37 - 1.40	1	92.62	56.53 - 128.72
L10	2	0.56	0.20 - 0.93	2	69.60	44.03 - 95.17
L11	4	0.81	0.55 - 1.07	4	61.14	42.78 - 79.50
L12	10	0.80	0.63 - 0.96	11	74.04	62.96 - 85.12
L15	4	0.88	0.61 - 1.14	5	71.65	55.00 - 88.29
L16	4	0.59	0.33 - 0.85	3	60.04	39.32 - 80.76
L17	3	0.74	0.45 - 1.04	3	63.77	42.81 - 84.73
L18	7	0.58	0.38 - 0.78	7	57.57	43.69 - 71.46
NW4	9	0.73	0.55 - 0.90	7	70.01	56.07 - 83.95
NW6	26	0.72	0.61 - 0.82	24	64.53	56.89 - 72.18
NW7	10	0.72	0.56 - 0.88	10	67.22	55.56 - 78.89
NW8	5	0.70	0.46 - 0.93	4	58.31	39.89 - 76.72
NW9	12	0.85	0.69 - 1.00	10	71.06	59.38 - 82.75
NW10	4	0.83	0.56 - 1.10	4	80.47	61.52 - 99.41
NW11	8	0.70	0.51 - 0.88	8	76.99	63.82 - 90.15
NW13	12	0.68	0.53 - 0.83	12	67.46	56.93 - 78.00
NW15	8	0.84	0.65 -1.03	8	68.98	55.61 - 82.34

*NB no questionnaires were returned for NW5

Table 34 : Adjusted epilepsy-specific PROMs scores by practice

	Seizure worry (NS)			Epilepsy overall QOL (p=0.019)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	1	41.10	-21.71 – 103.91	1	61.60	27.48 - 95.71
L3	3	84.62	48.18 - 121.06	2	53.79	29.46 - 78.11
L5	3	43.89	6.99 - 80.78	3	41.56	21.43 - 61.68
L7	11	71.03	51.55 - 90.51	10	78.73	67.59 - 89.87
L8	5	45.35	17.51 - 73.19	6	43.66	29.61 - 57.72
L9	1	84.90	22.81 - 146.98	1	65.24	31.48 - 98.99
L10	2	71.47	27.46 - 115.48	2	64.80	40.85 - 88.75
L11	4	67.00	35.36 - 98.64	4	68.13	50.89 - 85.36
L12	11	83.71	64.64 - 102.78	8	76.84	64.26 - 89.42
L15	4	55.63	24.45 - 86.80	3	58.50	38.65 - 78.36
L16	4	23.52	-8.10 - 55.14	2	61.99	38.30 - 85.68
L17	2	70.21	26.45 - 113.98	2	56.03	32.28 - 79.77
L18	7	68.39	44.56 - 92.23	6	70.25	56.15 - 84.35
NW4	9	54.67	33.16 - 76.19	8	62.78	50.41 - 75.16
NW6	26	56.87	44.21 - 69.53	20	64.01	55.96 - 72.05
NW7	10	56.79	36.90 - 76.67	10	68.27	57.52 - 79.02
NW8	5	54.71	26.28 - 83.15	3	43.57	23.73 - 63.42
NW9	11	76.75	57.58 - 95.93	10	73.83	62.87 - 84.79
NW10	4	73.82	41.25 - 106.39	3	85.78	65.66 - 105.91
NW11	8	68.59	45.95 - 91.23	7	63.71	50.63 - 76.79
NW13	11	68.29	49.47 - 87.11	11	61.54	51.26 - 71.82
NW15	8	83.45	60.42 - 106.47	6	66.35	52.08 - 80.62

*NB no questionnaires were returned for NW5

Table 34 (continued): Adjusted epilepsy-specific PROMs scores by practice

	Emotional well-being (p=0.013)			Energy and Fatigue (p=0.012)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	1	87.48	50.75 - 124.21	1	48.32	11.52 - 85.13
L3	3	77.23	55.86 - 98.60	3	40.80	19.38 - 62.22
L5	3	36.34	14.72 - 57.97	3	41.96	20.34 - 63.58
L7	10	69.54	57.53 - 81.55	11	54.46	43.03 - 65.88
L8	5	51.06	34.72 - 67.40	5	35.41	19.05 - 51.76
L9	1	62.14	25.70 - 98.58	1	49.09	12.60 - 85.57
L10	2	70.07	44.27 - 95.87	2	49.65	23.81 - 75.50
L11	4	71.73	53.19 - 90.28	4	55.78	37.22 - 74.35
L12	10	77.85	66.07 - 89.63	11	68.02	56.83 - 79.22
L15	5	81.44	64.75 - 98.14	5	65.90	49.16 - 82.65
L16	4	47.76	29.27 - 66.26	4	37.92	19.37 - 56.48
L17	3	70.76	49.59 - 91.92	3	65.73	44.55 - 86.91
L18	5	64.94	48.45 - 81.43	7	57.35	43.34 - 71.37
NW4	10	54.83	42.91 - 66.74	9	46.46	33.83 - 59.08
NW6	26	67.62	60.22 - 75.01	25	57.08	49.57 - 64.60
NW7	11	66.85	55.74 - 77.96	10	61.28	49.67 - 72.89
NW8	5	56.89	40.23 - 73.55	5	28.83	12.12 - 45.55
NW9	11	73.23	62.00 - 84.45	12	55.72	44.96 - 66.47
NW10	4	84.52	65.38 - 103.65	4	64.95	45.84 - 84.05
NW11	8	72.10	58.84 - 85.37	8	61.17	47.89 - 74.44
NW13	12	57.15	46.52 - 67.78	12	44.31	33.68 - 54.95
NW15	8	72.10	58.62 - 85.59	8	41.52	28.02 - 55.02

*NB no questionnaires were returned for NW5

Table 34 (continued): Adjusted epilepsy-specific PROMs scores by practice

	Cognitive (NS)			Medication effects (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	1	24.85	-22.21 - 71.91	1	21.19	-37.14 - 79.52
L3	3	66.34	39.03 - 93.64	3	49.31	15.42 - 83.19
L5	3	39.62	11.98 - 67.26	4	22.96	-5.97 - 51.89
L7	11	70.17	55.59 - 84.75	11	65.11	47.08 - 83.14
L8	5	51.47	30.61 - 72.33	6	74.68	50.83 - 98.53
L9	1	67.83	21.30 - 114.36	1	74.16	16.41 - 131.92
L10	2	55.16	22.19 - 88.13	2	87.20	46.31 - 128.09
L11	4	67.61	43.93 - 91.29	4	71.37	42.01 - 100.72
L12	11	66.88	52.60 - 81.16	11	64.17	46.45 - 81.89
L15	4	77.40	54.06 - 100.75	4	88.19	59.20 - 117.19
L16	4	47.04	23.37 - 70.71	4	64.78	35.39 - 94.17
L17	3	62.98	35.95 - 90.01	3	46.72	13.19 - 80.26
L18	7	74.13	56.28 - 91.99	7	57.88	35.70 - 80.05
NW4	8	52.63	35.71 - 69.54	10	61.63	42.71 - 80.54
NW6	26	54.97	45.49 - 64.46	26	71.29	59.55 - 83.03
NW7	11	64.75	50.53 - 78.96	11	66.52	48.88 - 84.17
NW8	4	74.28	50.56 - 97.99	5	52.27	25.88 - 78.65
NW9	12	58.35	44.63 - 72.07	12	70.37	53.32 - 87.42
NW10	3	84.84	57.18 - 112.50	4	70.02	39.72 - 100.33
NW11	8	58.47	41.50 - 75.43	8	78.82	57.78 - 99.87
NW13	11	57.53	43.34 - 71.72	12	74.55	57.73 - 91.37
NW15	8	74.32	57.10 - 91.53	8	76.38	55.07 - 97.69

*NB no questionnaires were returned for NW5

Table 34 (continued): Adjusted epilepsy-specific PROMs scores by practice

	Social function (NS)			Total QOL (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L2	0	N/A	N/A	0	N/A	N/A
L3	3	46.08	10.92 - 81.24	2	53.38	25.46 - 81.31
L5	2	10.84	-35.52 - 57.19	2	34.20	3.61 - 64.79
L7	9	91.72	70.87 - 112.56	8	80.46	66.02 - 94.91
L8	3	73.11	38.61 - 107.61	3	58.47	36.02 - 80.91
L9	1	96.51	37.05 - 155.98	1	76.38	38.05 - 114.71
L10	2	64.02	21.87 - 106.17	2	62.82	35.52 - 90.12
L11	2	100.07	58.20 - 141.94	2	82.51	55.54 - 109.48
L12	8	84.06	62.75 - 105.37	5	75.91	58.13 - 93.70
L15	2	81.37	39.39 - 123.36	1	56.71	17.73 - 95.70
L16	4	73.11	42.68 - 103.55	2	51.07	24.28 - 77.87
L17	2	64.30	22.43 - 106.16	2	63.51	36.61 - 90.40
L18	2	27.57	-15.92 - 71.05	2	55.59	27.39 - 83.80
NW4	5	56.22	29.05 - 83.38	3	63.00	40.70 - 85.30
NW6	20	71.96	57.86 - 86.06	16	64.06	53.55 - 74.58
NW7	7	65.44	42.61 - 88.26	6	67.39	51.50 - 83.27
NW8	4	78.08	47.43 - 108.73	3	66.19	43.38 - 88.99
NW9	10	71.98	52.63 - 91.32	7	69.39	54.55 - 84.24
NW10	2	50.83	7.67 - 93.99	1	61.94	23.62 - 100.25
NW11	7	79.63	56.28 - 102.98	7	65.31	50.28 - 80.35
NW13	9	78.70	58.85 - 98.56	8	63.89	50.47 - 77.32
NW15	7	88.65	64.79 112.51	5	81.41	63.34 - 99.48

*NB no questionnaires were returned for NW5

Heart failure

A total of 259 patients, from 20 practices (11 in London and 9 in the NW) were included in the analysis. The majority of respondents were male, retired, aged 65 years or over, white and from the NW (**Table 35**). The mean time since diagnosis was 11.4 years (SD 11.0). Fifty-one (19.7%) respondents did not report any comorbidities, 67 (25.9%) reported one comorbidity and 141 (54.4%) reported two or more comorbidities. There were no significant differences between practices for gender, age, employment, number of comorbidities or time since diagnosis. There were significant differences between practices for ethnicity ($p<0.001$).

Table 35: Demographics for heart failure patients (cohort baseline)

		n	%
Gender	Male	161	63.6
	Female	92	36.4
Age (years)	18-44	5	2.0
	45-64	32	12.5
	65-74	73	28.5
	75+	146	57.0
Employment	Full-time	9	3.8
	Part-time	9	3.8
	Unemployed	5	2.1
	Permanently sick/ disabled	34	14.2
	Retired	160	66.9
	Looking after home	19	7.9
	Other	3	1.3
Ethnicity	White	235	92.9
	Other	18	7.1
Region	London	77	29.7
	North-West of England	182	70.3
		Mean	**SD**
Time since diagnosis (years)		11.4	11.0
N comorbidities		2.0	1.6

The mean PROMs scores for heart failure are presented in **Table 36**. No significant differences were found for the adjusted mean on either the EQ5D (**Table 37**) or the heart failure-specific MLHFQ (**Table 38**) between the practices.

Table 36: Mean PROMs scores for heart failure

	N	Mean	95% CI
EQ5D	245	0.62	0.58 -0.66
EQ-5D VAS	246	60.21	57.60 – 62.83
Total QOL	180	39.03	34.91 – 43.16
Physical Dimension	238	19.38	17.74 – 21.01
Emotional Dimension	238	8.42	7.41 – 9.44

Table 37: Adjusted heart failure EQ5D scores by practice

	EQ5D (NS)			VAS (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	0.68	0.30 - 1.05	2	70.62	45.30 - 95.95
L3	6	0.78	0.57 - 0.99	6	56.85	42.53 - 71.16
L4	2	0.67	0.30 - 1.04	2	71.16	45.98 - 96.34
L5	10	0.56	0.39 - 0.74	10	54.58	42.74 - 66.42
L6	2	0.53	0.15 - 0.90	2	54.14	29.10 - 79.17
L7	7	0.57	0.37 - 0.77	8	55.99	43.29 - 68.69
L9	2	0.92	0.55 - 1.30	2	74.58	49.43 - 99.74
L12	17	0.62	0.47 - 0.76	17	62.10	52.22 - 71.98
L14	2	0.77	0.39 - 1.15	2	63.59	38.20 - 88.99
L16	1	0.50	-0.03 - 1.02	2	54.76	29.59 - 79.93
L17	5	0.56	0.32 - 0.80	5	45.24	28.99 - 61.49
NW4	9	0.48	0.30 - 0.67	9	53.42	40.96 - 65.89
NW6	26	0.57	0.44 -0.69	28	58.54	50.51 - 66.57
NW7	27	0.49	0.36 - 0.61	27	61.01	52.85 - 69.16
NW8	15	0.56	0.41 - 0.71	15	57.53	47.30 - 67.77
NW10	21	0.64	0.51 - 0.77	22	67.93	59.43 - 76.43
NW11	12	0.65	0.48 - 0.81	13	68.45	57.73 - 79.18
NW12	11	0.54	0.37 - 0.71	10	59.77	47.79 - 71.75
NW13	22	0.64	0.50 - 0.77	21	59.21	50.05 - 68.37
NW14	4	0.44	0.18 - 0.71	5	67.97	51.73 - 84.21

Table 38: Adjusted disease-specific PROMs scores by practice (score range 0-105 for total QOL, 0-40 for the physical dimension and 0-25 for the emotional dimension with a higher score representing more impairment)

	Total QOL (NS)			Physical dimension (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	32.37	0.08 - 64.67	2	16.43	1.60 - 31.26
L3	14	44.93	31.28 - 58.59	7	19.35	11.54 - 27.17
L4	2	40.10	7.64 - 72.57	2	17.08	2.34 - 31.81
L5	1	40.98	-3.82 - 85.77	11	18.68	12.03 - 25.32
L6	4	54.09	30.97 - 77.21	2	17.31	2.66 - 31.96
L7	7	40.41	23.46 - 57.36	8	20.58	13.15 - 28.02
L9	2	45.48	13.45 - 77.51	2	21.87	7.16 - 36.58
L12	8	39.86	23.22 - 56.50	17	19.60	13.81 - 25.39
L14	1	43.92	-0.92 - 88.75	2	16.44	1.57 - 31.30
L16	7	44.60	27.14 - 62.05	2	22.05	7.33 - 36.78
L17	2	56.27	24.31 - 88.22	5	22.79	13.27 - 32.31
NW4	11	44.20	29.85 - 58.56	9	29.75	22.45 - 37.04
NW6	9	41.10	25.22 - 56.97	26	22.42	17.61 - 27.22
NW7	8	53.93	37.32 - 70.54	27	24.08	19.31 - 28.85
NW8	16	39.56	26.59 - 52.52	15	22.08	16.09 - 28.07
NW10	3	48.51	22.15 - 74.87	19	17.30	11.95 - 22.64
NW11	7	58.20	40.53 - 75.86	13	20.18	13.90 - 26.46
NW12	19	45.58	33.86 - 57.29	9	21.80	14.48 - 29.12
NW13	23	58.34	47.16 - 69.53	21	18.45	13.11 - 23.80
NW14	13	45.46	31.65 - 59.27	5	23.47	13.96 - 32.97

Table 38 (continued): Adjusted disease-specific PROMs scores by practice (score range 0-105 for total QOL, 0-40 for the physical dimension and 0-25 for the emotional dimension with a higher score representing more impairment)

	Emotional dimension (NS)		
Practice	**n**	**Mean**	**95% CI**
L1	2	5.72	-3.71 - 15.14
L3	7	8.82	3.85 - 13.79
L4	2	7.97	-1.39 - 17.33
L5	11	8.31	4.08 - 12.53
L6	2	12.69	3.38 - 22.00
L7	8	9.69	4.96 - 14.41
L9	2	13.23	3.87 - 22.58
L12	17	10.28	6.60 - 13.96
L14	2	10.51	1.07 - 19.95
L16	2	4.97	-4.40 - 14.33
L17	5	13.79	7.74 - 19.84
NW4	9	14.82	10.19 - 19.46
NW6	25	12.18	9.07 - 15.28
NW7	27	13.09	10.06 - 16.13
NW8	14	11.19	7.29 - 15.09
NW10	20	10.85	7.58 - 14.12
NW11	12	9.33	5.22 - 13.44
NW12	10	13.04	8.59 - 17.49
NW13	21	9.50	6.11 - 12.89
NW14	3	11.62	3.91 - 19.33

Stroke

A total of 151 stroke patients, from 19 practices (12 in London and 7 in the NW) were included in the analysis. The majority of respondents was male, aged 65 years or over, retired; white and from the NW (**Table 39)**. The mean time since their stroke was 7.3 years (SD 6.1). Eighteen (11.9%) did not report any comorbidities, 53 (35.1%) reported one comorbidity and 80 (53.0%) reported two or more comorbidities. There were no significant differences between practices for gender, age, employment, number of comorbidities or time since diagnosis. Significant differences between practices were found for ethnicity (p=0.006).

Table 39: Demographics for stroke patients (cohort baseline)

		N	%
Gender	Male	88	61.1
	Female	56	38.9
Age (years)	18-44	4	2.7
	45-64	45	30.4
	65-74	41	27.7
	75+	58	39.2
Employment	Full-time	14	19.7
	Part-time	15	10.3
	Unemployed	6	4.1
	Permanently sick/ disabled	19	13.0
	Retired	84	57.5
	Looking after home	7	4.8
	Other	1	0.7
Ethnicity	White	133	93.0
	Other	10	7.0
Region	London	68	45.0
	North-West of England	83	55.0
		Mean	**SD**
Time since diagnosis (years)		7.3	6.1
N comorbidities		2.0	1.5

The mean PROMs scores for stroke are presented in **Table 40**. No significant differences between practices have been found for the EQ5D (**Table 41**) or the disease-specific dimensions (**Table 42**) between practices.

Table 40: Mean PROMs scores for stroke

	N	Mean	95% CI
EQ5D	145	0.63	0.58 – 0.69
EQ-5D VAS	135	70.72	67.04 – 74.40
Strength	120	65.31	60.39 – 70.23
Hand Function	131	70.11	64.60 – 75.63
Mobility	129	74.81	70.42 – 79.20
Memory	137	78.47	74.40 – 82.54
ADL	124	79.54	75.37 – 83.71
Communication	138	84.21	80.44 – 87.99
Emotion	128	68.40	65.18 – 71.63
Handicap	98	68.24	62.09 – 74.39
Physical Dimension	99	73.45	68.41 -78.49

Table 41: Adjusted stroke EQ5D scores by practice

	EQ5D (NS)			VAS (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	0.81	0.39 - 1.22	2	71.66	42.21 - 101.12
L2	1	0.21	-0.37 - 0.78	1	48.28	7.54 - 89.02
L3	3	0.39	0.05 - 0.73	3	57.26	33.32 - 81.20
L5	10	0.48	0.28 - 0.69	9	59.09	44.25 - 73.92
L6	3	0.59	0.26 - 0.93	2	61.92	33.12 - 90.71
L7	6	0.45	0.21 - 0.70	6	69.89	52.52 - 87.25
L13	3	0.51	0.17 - 0.86	2	67.32	36.48 - 98.15
L14	5	0.69	0.42 - 0.96	4	68.16	46.75 - 89.56
L15	5	0.45	0.18 - 0.72	5	48.41	29.44 - 67.39
L16	4	0.63	0.33 - 0.92	4	65.06	44.09 - 86.03
L17	5	0.72	0.47 - 0.97	5	67.22	49.38 - 85.06
L18	9	0.53	0.31 - 0.74	7	75.51	58.48 - 92.53
NW2	9	0.65	0.43 - 0.86	9	72.27	57.02 - 87.53
NW3	4	0.44	0.16 - 0.73	4	42.99	22.84 - 63.14
NW5	9	0.45	0.24 - 0.66	9	61.76	46.84 - 76.69
NW7	13	0.49	0.31 - 0.67	14	64.37	51.85 - 76.89
NW13	21	0.51	0.35 - 0.66	18	58.87	47.53 - 70.20
NW14	3	0.59	0.25 - 0.94	3	81.06	56.55 - 105.57
NW15	11	0.71	0.53 - 0.89	12	64.30	51.89 - 76.70

Table 42: Adjusted stroke specific scores by practice (score range 0-100 with a higher score meaning higher disability)

	Strength (NS)			Hand Function (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	75.16	35.97 - 114.35	2	104.55	61.16 - 147.94
L2	1	32.12	-22.20 - 86.44	1	18.17	-41.96 - 78.30
L3	3	56.70	24.77 - 88.64	3	64.21	28.89 - 99.53
L5	8	51.45	30.48 - 72.43	8	62.52	39.49 - 85.55
L6	3	62.26	30.88 - 93.64	3	57.48	22.74 - 92.23
L7	6	59.97	36.84 - 83.11	7	65.56	41.57 - 89.55
L13	2	72.77	31.46 - 114.08	2	65.80	20.10 - 111.50
L14	3	70.09	37.56 - 102.61	3	74.06	38.20 - 109.92
L15	5	44.30	18.95 - 69.65	5	38.40	10.38 - 66.42
L16	3	74.15	42.46 - 105.84	4	69.88	39.06 - 100.70
L17	4	68.05	41.37 - 94.73	4	55.99	26.49 - 85.49
L18	6	72.75	48.37 - 97.13	8	78.46	54.27 - 102.65
NW2	5	78.72	53.07 - 104.38	6	85.58	59.53 - 111.64
NW3	3	51.57	20.45 - 82.69	4	63.39	33.71 - 93.06
NW5	9	65.76	45.75 - 85.76	9	52.79	30.78 - 74.79
NW7	13	59.59	42.36 - 76.81	14	60.40	41.88 - 78.91
NW13	19	57.23	42.26 - 72.20	20	62.11	45.91 - 78.31
NW14	2	64.92	24.24 - 105.59	2	67.19	22.10 - 112.28
NW15	11	56.75	39.60 - 73.90	10	75.49	55.81 - 95.18
	Mobility (NS)			**Memory (NS)**		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	88.41	55.91 - 120.92	2	81.44	46.80 - 116.08
L2	1	48.19	3.22 - 93.15	1	62.26	14.35 - 110.17
L3	3	73.82	47.37 - 100.28	3	64.25	36.04 - 92.46
L5	9	74.40	57.96 - 90.83	10	63.59	46.71 - 80.47
L6	3	68.08	41.98 - 94.18	3	68.49	40.67 - 96.31
L7	7	71.39	53.40 - 89.38	6	75.96	55.48 - 96.45
L13	2	85.15	51.11 - 119.20	2	72.87	36.57 - 109.16
L14	5	89.75	68.40 - 111.11	4	69.95	44.73 - 95.18
L15	5	60.40	39.43 - 81.37	5	79.15	56.78 - 101.52
L16	3	87.02	60.72 - 113.33	4	65.51	40.81 - 90.21
L17	4	74.69	52.84 - 96.55	4	80.61	57.31 - 103.91
L18	6	91.84	71.46 - 112.22	8	78.86	60.01 - 97.72
NW2	8	83.24	65.81 - 100.68	8	79.61	61.01 - 98.22
NW3	4	59.07	36.83 - 81.32	4	53.03	29.33 - 76.72
NW5	9	67.75	51.23 - 84.27	9	55.74	38.15 - 73.33
NW7	14	74.36	60.51 - 88.21	14	70.06	55.31 - 84.81
NW13	18	68.28	55.67 - 80.88	19	66.98	53.82 - 80.14
NW14	3	83.17	56.09 - 110.26	3	75.30	46.41 - 104.19
NW15	10	80.83	66.20 - 95.46	11	75.09	60.04 - 90.14

Table 42 (continued): Adjusted stroke specific scores by practice (score range 0-100 with a higher score meaning higher disability)

	ADL (NS)			Communication (NS)		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	103.16	72.30 - 134.02	2	95.06	58.47 - 131.65
L2	1	34.81	-7.53 - 77.15	1	75.05	24.75 - 125.36
L3	2	85.73	55.71 - 115.75	3	77.48	47.52 - 107.44
L5	8	67.77	50.92 - 84.62	10	71.15	52.59 - 89.71
L6	2	70.01	39.92 - 100.09	2	66.58	30.79 - 102.38
L7	7	76.25	58.80 - 93.70	6	86.29	64.18 - 108.40
L13	2	82.83	50.39 - 115.26	2	86.46	47.96 - 124.95
L14	4	87.62	65.01 - 110.24	4	88.13	61.18 - 115.09
L15	4	54.79	32.46 - 77.11	5	90.36	66.28 - 114.43
L16	3	96.44	71.48 - 121.41	4	84.26	57.97 - 110.55
L17	5	77.25	58.89 - 95.62	5	81.71	59.83 - 103.59
L18	7	89.97	71.43 - 108.50	8	92.31	71.45 - 113.16
NW2	7	92.76	74.81 - 110.71	8	85.64	65.39 - 105.88
NW3	4	64.49	43.68 - 85.29	4	78.22	53.54 - 102.90
NW5	9	71.08	54.81 - 87.35	8	76.18	56.04 - 96.32
NW7	12	84.17	69.71 - 98.63	14	78.42	61.95 - 94.89
NW13	18	79.52	66.87 - 92.17	20	75.21	60.56 - 89.86
NW14	3	88.16	62.33 – 114.00	3	92.04	61.35- - 122.73
NW15	9	85.92	69.82 - 102.03	10	82.45	64.05 - 100.85
	Emotion (NS)			**Handicap (NS)**		
Practice	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**
L1	2	80.57	54.41 - 106.74	2	53.26	5.83 - 100.69
L2	1	94.60	58.38 - 130.83	0	N/A	N/A
L3	3	59.30	37.97 - 80.64	2	90.76	44.59 - 136.92
L5	9	56.05	42.72 - 69.38	6	62.97	33.87 - 92.06
L6	2	71.37	45.78 - 96.95	1	37.46	-27.74 - 102.67
L7	6	69.64	54.16 - 85.11	3	70.77	32.02 - 109.51
L13	2	74.37	46.65 - 102.09	2	71.05	19.64 - 122.46
L14	4	69.69	50.57 - 88.81	1	25.32	-39.93 - 90.57
L15	5	66.57	49.64 - 83.50	3	39.99	-0.66 - 80.64
L16	4	53.62	34.99 - 72.24	4	83.39	49.17 - 117.61
L17	5	79.43	63.60 - 95.27	3	47.35	10.78 - 83.91
L18	8	65.63	51.20 - 80.06	7	86.45	57.78 - 115.12
NW2	7	72.60	57.70 - 87.50	6	73.47	43.33 - 103.61
NW3	4	51.42	33.51 - 69.32	3	45.20	8.22 - 82.19
NW5	9	54.83	41.56 - 68.10	7	66.14	38.15 - 94.13
NW7	12	62.64	50.88 74.40	8	69.96	43.28 - 96.64
NW13	19	58.74	48.83 - 68.66	16	68.74	47.92 - 89.56
NW14	3	69.21	47.37 - 91.05	2	78.92	28.28 - 129.55
NW15	9	68.81	56.25 - 81.37	8	84.33	58.09 - 110.57

Table 42 (continued): Adjusted stroke specific scores by practice (score range 0-100 with a higher score meaning higher disability)

	Physical dimension (NS)		
Practice	**n**	**Mean**	**95% CI**
L1	2	96.95	62.32 - 131.58
L2	1	34.75	-13.01 - 82.52
L3	2	87.97	54.27 - 121.67
L5	6	65.14	43.66 - 86.61
L6	2	69.28	35.45 - 103.10
L7	6	74.70	53.73 - 95.66
L13	2	81.07	44.38 - 117.75
L14	3	81.10	52.15 - 110.06
L15	4	45.44	20.09 - 70.78
L16	3	89.01	60.94 - 117.09
L17	3	68.53	41.83 - 95.24
L18	4	83.72	56.23 - 111.21
NW2	4	90.89	65.33- 116.45
NW3	3	59.83	32.71 - 86.96
NW5	9	66.95	48.27 - 85.62
NW7	11	72.98	55.96 - 90.01
NW13	17	72.64	57.83 - 87.45
NW14	2	77.29	41.21 - 113.37
NW15	7	80.37	60.36 - 100.38

Cohort survey

Thirty-three practices had completed a cohort baseline survey (results reported above), and the majority of cohort baseline respondents had given consent to be sent a follow-up questionnaire after one year. This section presents that data of patients who completed both the baseline and follow-up questionnaires. **Table 43** presents the number of participants for each LTC.

Table 43: Number of respondents to both the baseline and follow-up

LTC	N
Asthma	266
COPD	187
Diabetes	321
Epilepsy	104
Heart failure	155
Stroke	102
Total	1135

Disease-specific health in comparison to a year ago

Follow-up participants were asked to rate their disease-specific health in comparison to a year ago, scored on a five-point scale (much better, a little better, about the same, a little worse and much worse). Due to the small numbers, this was recoded to improvement (i.e. much better and a little better), stable (i.e. about the same) and deterioration (i.e. a little worse and much worse). Overall, the largest proportion (53.0%) reported to have stayed stable, with approximately a quarter reporting improvement or deterioration (**Table 44**). There was a significant difference in the change in health status reported after one year between LTCs ($p<0.001$).

Table 44: Change in disease-specific health at follow-up

	Much better		A little better		About the same		A little worse		Much worse	
	n	%	n	%	n	%	n	%	n	%
Asthma	35	13.4	35	13.4	142	54.2	46	17.6	4	1.5
COPD	13	7.1	17	9.3	79	43.4	63	34.6	10	5.5
Diabetes	36	11.8	37	12.1	181	59.3	47	15.4	4	1.3
Epilepsy	17	17.0	13	13.0	58	58.0	8	8.0	4	4.0
Heart failure	13	8.5	11	7.2	76	49.7	47	30.7	6	3.9
Stroke	25	25.3	10	10.1	48	48.5	11	11.1	5	5.1

PROMs scores

The PROMs scores (EQ5D and disease-specific) were compared between the baseline (Time 1) and the follow-up (Time 2) one year later. Furthermore, the change scores (=score at Time 1 – score at Time 2) was examined in relation to the self-reported change in disease-specific health. These data, together with demographics data, are presented for each LTC.

Asthma

A total of 267 asthma patients from 10 practices (5 NW and 5 London) were included in the analysis. The majority of respondents were female, under the age of 65, in employment, white and from the NW (**Table 45**). There was a small increase in the number of comorbidities reported at follow up, but this was not significant compared to the number of comorbidities reported at baseline. There were no significant differences between practices for gender, age, employment, comorbidities (at baseline or follow up) and time since diagnosis; but there were for ethnicity ($p<0.001$).

Table 45: Demographics for asthma patients (cohort)

		n	%
Gender	Male	109	41.0
	Female	151	56.8
Age (years)	18-44	69	26.4
	45-64	118	45.2
	65-74	42	16.1
	75+	32	12.3
Employment	Full-time	91	35.7
	Part-time	42	16.5
	Full-time education	3	1.2
	Unemployed	7	2.7
	Permanently sick/ disabled	13	5.1
	Retired	70	27.5
	Looking after home	23	9.0
	Other	6	2.4
Ethnicity	White	242	94.2
	Other	15	5.8
Region	London	52	19.5
	North-West of England	214	80.5
		Mean	**SD**
Time since diagnosis (years)		23.8	16.8
N comorbidities (baseline)		0.66	0.93
N comorbidities (follow up)		0.69	16.8

No significant differences between the baseline and follow up PROMs scores were found for the EQ5D (**Table 46**). For the asthma-specific PROM, a significant difference was found on only one dimension (activity limitations) (**Table 46**). The change scores were significantly related to the health change question for all the disease-specific dimensions, although it was not significant for the EQ5D (**Table 47**).

Table 46: Difference in asthma PROMs scores between baseline and follow-up

		Cohort baseline (Time 1)		Cohort follow-up (Time 2)		Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**Mean**	**95% CI**		
York A1 tariff	255	0.83	0.80 - 0.86	0.84	0.81 - 0.87	-0.01	NS
VAS	248	73.77	71.31 - 76.23	74.33	71.94 - 76.72	-0.56	NS
MINI-AQOL							
Symptoms	252	5.29	5.14 - 5.45	5.29	5.13 - 5.45	0.001	NS
Activity Limitations	240	6.08	5.92 - 6.23	5.92	5.75 - 6.09	0.15	0.004
Emotional Functioning	253	5.37	5.18 - 5.57	5.28	5.09 - 5.48	0.09	NS
Environmental Stimuli	255	5.30	5.11 - 5.48	5.24	5.06 - 5.43	0.05	NS
Total QOL	226	5.60	5.45 - 5.75	5.52	5.36 - 5.68	0.08	NS

Table 47: Asthma change scores in relation to question on health in comparison to one year ago

		N	Mean	95% CI		p
				Lower	Upper	
EQ5D York Tariff	Improvement	69	-0.02	-0.04	0.01	NS
	Stable	137	0.00	-0.01	0.01	
	Deterioration	47	-0.01	-0.04	0.02	
EQ5D VAS	Improvement	64	-0.89	-4.31	2.53	NS
	Stable	132	-0.91	-3.02	1.20	
	Deterioration	49	1.90	-1.74	5.53	
Mini AQOL						
Symptoms	Improvement	66	-0.42	-0.62	-0.23	<0.001
	Stable	136	0.03	-0.12	0.17	
	Deterioration	48	0.52	0.18	0.85	
Activity Limitations	Improvement	66	-0.12	-0.29	0.05	<0.001
	Stable	131	0.11	-0.01	0.23	
	Deterioration	41	0.74	0.40	1.07	
Emotional Functioning	Improvement	68	-0.32	-0.58	-0.06	<0.001
	Stable	136	0.11	-0.06	0.28	
	Deterioration	47	0.60	0.22	0.98	
Environmental Stimuli	Improvement	67	-0.29	-0.53	-0.06	0.001
	Stable	139	0.12	-0.03	0.28	
	Deterioration	46	0.35	0.04	0.65	
Total Quality of Life	Improvement	62	-0.27	-0.43	-0.10	<0.001
	Stable	126	0.09	-0.02	0.21	
	Deterioration	36	0.60	0.32	0.88	

COPD

A total of 187 patients from 16 practices (8 NW and 8 London) were included in the analysis. The majority of respondents were female, over the age of 65, retired, white and from the NW (**Table 48**). There was a small increase in the number of comorbidities reported at follow up, but this was not significant compared to the number of comorbidities reported at baseline. There were no significant differences between practices for age, employment, ethnicity, comorbidities (at baseline or follow up) but there were for gender (p=0.029) and time since diagnosis (p=0.0013).

Table 48: Demographics for COPD patients (cohort)

		n	%
Gender	Male	84	45.4
	Female	101	54.6
Age (years)	18-44	2	1.1
	45-64	44	23.5
	65-74	65	34.8
	75+	76	40.6
Employment	Full-time	16	9.0
	Part-time	14	7.9
	Unemployed	2	1.1
	Permanently sick/ disabled	18	10.1
	Retired	107	60.1
	Looking after home	16	9.0
	Other	5	2.8
Ethnicity	White	184	98.4
	Other	3	1.6
Region	London	73	39.0
	North-West of England	114	61.0
		Mean	**SD**
Time since diagnosis (years)		8.1	9.1
N comorbidities (baseline)		1.58	1.31
N comorbidities (follow-up)		1.68	1.29

No significant differences between the baseline and follow up PROMs scores were found for the EQ5D or any of the COPD-specific dimensions (**Table 49**). The change scores were significantly related to the health change question for all the disease-specific dimensions, although it was not significant for the EQ5D (**Table 50**).

Table 49: Difference in COPD PROMs scores between baseline and follow-up

		Cohort baseline (Time 1)		Cohort follow-up (Time 2)		Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**Mean**	**95% CI**		
York A1 tariff	177	0.67	0.63 - 0.71	0.67	0.63 - 0.71	0.002	NS
VAS	173	62.29	59.31 - 65.27	62.14	59.13 - 65.15	0.15	NS
CCQ							
Symptoms	171	2.60	2.38 - 2.81	2.60	2.38 - 2.83	-0.007	NS
Functional State	176	2.03	1.81 - 2.24	2.14	1.91 - 2.36	-0.11	NS
Mental State	174	2.11	1.84 - 2.37	2.20	1.94 - 2.46	-0.10	NS
Total QOL	160	2.22	2.01 - 2.43	2.28	2.06 - 2.50	-0.06	NS

Table 50: COPD change scores in relation to question on health in comparison to one year ago

		N	Mean	95% CI		p
				Lower	**Upper**	
EQ5D York Tariff	Improvement	28	-0.02	-0.07	0.04	NS
	Stable	75	-0.01	-0.02	0.01	
	Deterioration	70	0.02	-0.01	0.05	
EQ5D VAS	Improvement	30	-0.30	-9.27	8.67	NS
	Stable	73	-3.18	-6.02	-0.34	
	Deterioration	66	3.61	-1.71	8.93	
CCQ						
Symptoms	Improvement	30	0.34	-0.09	0.77	0.032
	Stable	72	0.05	-0.16	0.26	
	Deterioration	66	-0.22	-0.47	0.03	
Functional State	Improvement	29	0.41	0.10	0.73	0.001
	Stable	73	-0.07	-0.22	0.08	
	Deterioration	70	-0.33	-0.60	-0.07	
Mental State	Improvement	28	0.50	0.01	0.99	0.005
	Stable	73	0.01	-0.26	0.27	
	Deterioration	69	-0.41	-0.73	-0.08	
Total QOL	Improvement	28	0.42	0.08	0.75	<0.001
	Stable	66	0.02	-0.13	0.17	
	Deterioration	63	-0.32	-0.55	-0.09	

Diabetes

A total of 321 patients from 10 practices (5 NW and 5 London) were included in the analysis. The majority of respondents were male, over the age of 65, retired, white and from the NW (**Table 51**). There was no significant difference between the number of comorbidities reported at baseline and at follow up. There were no significant differences between practices for gender, age, comorbidities (at baseline or follow up) or time since diagnosis, but there were for age (p=0.004), employment (p=0.020) and ethnicity (p<0.001).

Table 51: Demographics for diabetes patients (cohort)

		n	%
Gender	Male	187	60.3
	Female	123	39.7
Age (years)	18-44	17	5.4
	45-64	107	34.1
	65-74	94	29.9
	75+	96	30.6
Employment	Full-time	60	19.7
	Part-time	21	6.9
	Full-time education	1	0.3
	Unemployed	9	3.0
	Permanently sick/ disabled	23	7.6
	Retired	154	50.7
	Looking after home	28	9.2
	Other	8	2.6
Ethnicity	White	247	78.7
	Other	67	21.3
Region	London	112	34.9
	North-West of England	209	65.1
		Mean	**SD**
Time since diagnosis (years)		9.88	8.96
N comorbidities (baseline)		1.64	1.40
N comorbidities (follow up)		1.66	1.34

No significant differences between the baseline and follow up PROMs scores were found for the EQ5D or any of the diabetes-specific dimensions (**Table 52**). Similarly, no significant differences were found for the change scores in relation to the health change question for the EQ5D and all the disease-specific dimensions (**Table 53**).

Table 52: Difference in diabetes PROMs scores between baseline and follow-up

		Cohort baseline (Time 1)		Cohort follow-up (Time 2)		Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**Mean**	**95% CI**		
York A1 tariff	301	0.73	0.69 - 0.76	0.72	0.69 - 0.76	0.002	NS
VAS	296	68.16	65.84 - 70.48	69.76	67.53 - 71.99	-1.60	NS
DHP							
Psychological distress	301	16.35	14.05 - 18.66	16.59	14.25 - 18.94	-0.24	NS
Barriers to activity	282	22.17	19.84 - 24.51	22.39	19.96 - 24.82	-0.22	NS
Disinhibited eating	307	30.16	27.81 - 32.52	30.08	27.77 - 32.38	0.09	NS

Table 53: Diabetes change scores in relation to question on health in comparison to one year ago

		N	Mean	95% CI		p
				Lower	**Upper**	
EQ5D York Tariff	Improvement	67	0.00	-0.03	0.02	NS
	Stable	175	0.01	-0.01	0.02	
	Deterioration	48	0.00	-0.04	0.03	
EQ5D VAS	Improvement	67	-2.46	-6.00	1.07	NS
	Stable	171	-1.48	-3.94	0.98	
	Deterioration	49	0.39	-3.81	4.59	
DHP						
Psychological distress	Improvement	66	1.09	-2.00	4.19	NS
	Stable	172	-0.55	-2.20	1.10	
	Deterioration	49	-0.68	-4.73	3.37	
Barriers to activity	Improvement	62	-0.61	-4.00	2.77	NS
	Stable	160	0.18	-1.46	1.81	
	Deterioration	47	-0.81	-5.69	4.07	
Disinhibited eating	Improvement	70	-0.19	-3.65	3.26	NS
	Stable	175	0.15	-2.02	2.32	
	Deterioration	49	1.77	-2.63	6.17	

Epilepsy

One hundred and four epilepsy patients from 23 practices (10 NW and13 London) were included in the analysis. The majority of respondents were female, under the age of 65, white and from the NW (**Table 54**). There was no significant difference between the number of comorbidities reported at baseline and at follow up. There were no significant differences between practices for gender, age or number of comorbidities (at baseline or follow up), but there were for employment (p=0.009), ethnicity (p<0.001) and time since diagnosis (p=0.047).

Table 54: Demographics for epilepsy patients (cohort)

		n	%
Gender	Male	44	43.1
	Female	58	56.9
Age (years)	18-44	22	21.4
	45-64	42	40.8
	65-74	24	23.3
	75+	15	14.6
Employment	Full-time	24	24.7
	Part-time	9	9.3
	Full-time education	3	3.1
	Unemployed	5	5.2
	Permanently sick/ disabled	15	15.5
	Retired	33	34.0
	Looking after home	5	5.2
	Other	3	3.1
Ethnicity	White	95	93.1
	Other	7	6.9
Region	London	44	42.3
	North-West of England	60	57.7
		Mean	**SD**
Time since diagnosis (years)		23.73	17.26
N comorbidities (baseline)		1.11	1.32
N comorbidities (follow up)		0.98	1.29

No significant differences between the baseline and follow up PROMs scores were found for the EQ5D or any of the epilepsy-specific dimensions (**Table 55**). Furthermore, no significant differences were found for the change scores in relation to the health change question for the EQ5D and all the epilepsy-specific dimensions (**Table 56**).

Table 55: Difference in epilepsy PROMs scores between baseline and follow-up

		Cohort baseline (Time 1)		Cohort follow-up (Time 2)		Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**Mean**	**95% CI**		
York A1 tariff	95	0.76	0.71 - 0.82	0.76	0.71 - 0.81	0.001	NS
VAS	91	71.40	67.12 - 75.68	73.59	69.68 - 77.50	-2.20	NS
QOLIE							
Seizure worry	95	64.49	57.69 - 71.30	65.32	58.19 - 72.44	-0.08	NS
Overall QOL	79	68.26	63.97 - 72.55	68.58	64.49 - 72.66	-0.32	NS
Emotional well-being	95	67.58	63.25 - 71.91	67.24	63.08 - 71.40	0.34	NS
Energy	98	54.34	50.10 - 58.57	51.99	47.50 - 56.48	2.35	NS
Cognitive	89	63.92	58.66 - 69.18	64.69	59.34 - 70.05	-0.77	NS
Medication effects	98	62.59	56.28 - 68.89	61.65	55.47 - 67.83	0.94	NS
Social function	53	79.25	72.88 - 85.61	79.04	72.53 - 85.55	0.21	NS
Total QOL	40	69.92	64.16 - 75.67	70.13	64.25 - 76.02	-0.22	NS

Table 56: Epilepsy change scores in relation to question on health in comparison to one year ago

		N	Mean	95% CI		p
				Lower	Upper	
EQ5D York Tariff	Improvement	28	-0.01	-0.04	0.02	NS
	Stable	53	0.00	-0.02	0.03	
	Deterioration	12	0.02	-0.07	0.11	
EQ5D VAS	Improvement	25	-4.68	-9.41	0.05	NS
	Stable	54	-1.76	-5.73	2.21	
	Deterioration	10	-0.80	-18.98	17.38	
QOLIE						
Seizure worry	Improvement	26	-1.53	-9.58	6.52	NS
	Stable	53	-0.28	-5.69	5.13	
	Deterioration	12	-3.72	-15.07	7.63	
Overall QOL	Improvement	20	0.13	-5.50	5.75	NS
	Stable	50	-0.60	-4.33	3.13	
	Deterioration	7	-4.29	-25.17	16.60	
Emotional well-being	Improvement	27	0.74	-5.74	7.22	NS
	Stable	55	-0.07	-4.60	4.45	
	Deterioration	9	-2.22	-16.49	12.04	
Energy	Improvement	22	-3.50	-10.25	3.26	NS
	Stable	52	-0.07	-3.75	3.60	
	Deterioration	11	4.17	-6.07	14.40	
Cognitive	Improvement	28	2.08	-8.84	13.01	NS
	Stable	55	-0.45	-6.08	5.17	
	Deterioration	12	4.86	-13.34	23.07	
Medication effects	Improvement	12	4.08	-7.71	15.88	NS
	Stable	37	-2.41	-8.32	3.51	
	Deterioration	2	14.00	-113.06	141.06	
Social function	Improvement	28	0	0	0	NS
	Stable	57	0	0	0	
	Deterioration	12	0	0	0	
Total QOL	Improvement	8	-0.77	-7.71	6.16	NS
	Stable	30	-0.69	-4.15	2.77	
	Deterioration	1	8.06	N/A	N/A	

Heart failure

One hundred and fifty-five heart failure patients from 20 practices (9 NW and 11 London) were included in the analysis. The majority of respondents were male, over the age of 65, retired, white and from the NW (**Table 57**). There was a significant difference between the number of comorbidities reported at baseline and at follow up (mean difference 0.2, p=0.022). There were no significant differences between practices for gender, age, employment, number of comorbidities (at baseline or follow up) or time since diagnosis, but there were for ethnicity (p<0.001).

Table 57: Demographics for heart failure patients (cohort)

		n	**%**
Gender	Male	97	63.8
	Female	55	36.2
Age (years)	18-44	2	1.3
	45-64	24	15.6
	65-74	47	30.5
	75+	81	52.6
Employment	Full-time	6	4.1
	Part-time	7	4.8
	Unemployed	4	2.7
	Permanently sick/ disabled	18	12.3
	Retired	98	67.1
	Looking after home	12	8.2
	Other	1	0.7
Ethnicity	White	144	94.1
	Other	9	5.9
Region	London	43	27.7
	North-West of England	112	72.3
		Mean	**SD**
Time since diagnosis (years)		11.12	11.30
N comorbidities (baseline)		1.83	1.47
N comorbidities (follow up)		2.01	1.55

The EQ5D VAS score was found to be significantly different between baseline and follow up with a mean difference of 3.53 (p=0.029). No significant differences between the baseline and follow up scores were found for the EQ5D York Tariff or any of the heart failure-specific dimensions (**Table 58**). A significant relationship was found between the EQ5D VAS and the health change question (p=0.0024). No significant differences were found for the change scores in relation to the health change question for the EQ5D York Tariff and all the heart failure-specific dimensions (**Table 59**).

Table 58: Difference in heart failure PROMs scores between baseline and follow-up

		Cohort baseline (Time 1)		Cohort follow-up (Time 2)		Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**Mean**	**95% CI**		
York A1 tariff	137	0.64	0.59 - 0.69	0.64	0.59 - 0.69	0.005	NS
VAS	145	62.20	58.93 - 65.47	58.67	55.10 - 62.24	3.53	0.029
MLHFQ							
Total QOL	80	36.91	30.96 - 42.87	35.10	29.32 - 40.88	1.81	NS
Physical dimension	125	18.44	16.23 - 20.65	18.02	15.84 - 20.20	0.42	NS
Emotional dimension	132	7.79	6.44 - 9.14	7.48	6.16 -8.79	0.31	NS

Table 59: Heart failure change scores in relation to question on health in comparison to one year ago

		N	Mean	95% CI		p
				Lower	**Upper**	
EQ5D York Tariff	Improvement	20	0.01	-0.04	0.06	NS
	Stable	68	0.00	-0.02	0.02	
	Deterioration	48	0.01	-0.03	0.04	
EQ5D VAS	Improvement	22	-6.45	-13.18	0.27	0.024
	Stable	71	5.34	1.09	9.59	
	Deterioration	51	3.69	-1.41	8.78	
MLHFQ						
Total QOL	Improvement	9	5.00	-2.41	12.41	NS
	Stable	46	2.52	-1.56	6.61	
	Deterioration	25	-0.64	-4.10	2.82	
Physical dimension	Improvement	19	1.84	-0.73	4.41	NS
	Stable	61	1.03	-0.84	2.91	
	Deterioration	45	-1.00	-2.91	0.91	
Emotional dimension	Improvement	19	-0.68	-2.24	0.87	NS
	Stable	66	0.65	-0.42	1.72	
	Deterioration	46	0.24	-0.81	1.29	

Stroke

A total of 137 stroke patients from 19 practices (7 NW and 12 London) were included in the analysis. The majority of respondents were male, over the age of 65, retired, white and from the NW (**Table 60**). There was no significant difference between the number of comorbidities reported at baseline and at follow up. There were no significant differences between practices for gender, age, employment, ethnicity, number of comorbidities (at baseline or follow up) or time since diagnosis.

Table 60: Demographics for stroke patients (cohort)

		n	%
Gender	Male	62	63.9
	Female	35	36.1
Age (years)	18-44	2	2.0
	45-64	30	29.7
	65-74	32	31.7
	75+	37	36.6
Employment	Full-time	12	12.1
	Part-time	8	8.1
	Unemployed	3	3.0
	Permanently sick/ disabled	11	11.1
	Retired	60	60.6
	Looking after home	4	4.0
	Other	1	1.0
Ethnicity	White	94	96.9
	Other	3	3.1
Region	London	43	42.2
	North-West of England	59	57.8
		Mean	**SD**
Time since diagnosis (years)		7.70	6.43
N comorbidities (baseline)		2.00	1.41
N comorbidities (follow up)		1.95	1.30

The ADL dimension of the stroke-specific PROM was found to be significantly different between baseline and follow up with a mean difference of 2.56 (p=0.009). No significant differences between the baseline and follow up scores were found for the EQ5D or the other 8 stroke-specific dimensions (**Table 61**). Significant relationships were found between two stroke-specific dimensions (hand function p=0.048 and ADL p=0.042) and the health change question. No significant differences were found for the change scores in relation to the health change question for the EQ5D and the remaining 6 stroke-specific dimensions (**Table 62**).

Table 61: Difference in stroke PROMs scores between baseline and follow-up

		Cohort baseline (Time 1)		Cohort follow-up (Time 2)		Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**Mean**	**95% CI**		
York A1 tariff	93	0.67	0.61 - 0.74	0.67	0.60 - 0.73	0.01	NS
VAS	82	73.84	69.26 - 78.42	71.96	67.17 - 76.75	1.88	NS
SIS							NS
Strength	72	66.75	60.15 - 73.36	65.97	59.81 - 72.13	0.78	NS
Hand function	76	73.22	66.14 - 80.31	72.17	64.81 - 79.53	1.05	NS
Mobility	79	78.83	73.42 - 84.24	76.72	70.90 - 82.54	2.11	NS
Memory	91	81.32	76.48 - 86.16	81.04	76.20 - 85.89	0.27	NS
ADL	80	82.22	77.42 - 87.02	79.66	74.20 - 85.12	2.56	0.009
Communication	92	86.88	82.72 - 91.04	85.05	80.54 - 89.57	1.83	NS
Emotion	77	72.08	67.99 - 76.17	71.90	67.47 - 76.33	0.18	NS
Handicap	48	72.20	63.21 - 81.19	72.92	64.19 - 81.65	-0.72	NS
Physical dimension	52	78.08	71.32 - 84.83	76.35	69.42 - 83.28	1.72	NS

Table 62: Stroke failure change scores in relation to question on health in comparison to one year ago

		N	Mean	95% CI		p
				Lower	Upper	
EQ5D York Tariff	Improvement	33	-0.01	-0.03	0.01	NS
	Stable	44	0.02	-0.01	0.06	
	Deterioration	13	0.02	-0.06	0.10	
EQ5D VAS	Improvement	30	1.27	-3.67	6.20	NS
	Stable	38	3.32	-0.77	7.40	
	Deterioration	12	-1.67	-16.76	13.43	
SIS						
Strength	Improvement	24	-3.65	-10.29	3.00	NS
	Stable	37	2.20	-2.84	7.23	
	Deterioration	11	5.68	-16.25	27.62	
Hand function	Improvement	27	-1.11	-4.28	2.06	0.048
	Stable	37	0.27	-3.81	4.35	
	Deterioration	12	8.33	-0.27	16.94	
Mobility	Improvement	34	0.42	-2.76	3.60	NS
	Stable	43	0.91	-3.83	5.66	
	Deterioration	13	-2.47	-15.10	10.15	
Memory	Improvement	32	0	-2.79	2.79	NS
	Stable	38	3.22	-0.70	7.13	
	Deterioration	8	7.29	-1.99	16.58	
ADL	Improvement	29	0	-1.82	1.82	0.042
	Stable	38	3.03	-0.04	6.09	
	Deterioration	12	7.29	-0.17	14.76	
Communication	Improvement	34	0.21	-2.65	3.07	NS
	Stable	44	1.95	-2.01	5.90	
	Deterioration	13	6.04	-3.13	15.22	
Emotion	Improvement	30	-0.93	-7.37	5.52	NS
	Stable	35	0.63	-4.03	5.30	
	Deterioration	11	1.52	-7.60	10.63	
Handicap	Improvement	16	-6.25	-15.55	3.05	NS
	Stable	27	1.74	-3.32	6.79	
	Deterioration	5	3.75	-21.75	29.25	
Physical dimension	Improvement	19	-0.37	-3.59	2.85	NS
	Stable	29	3.44	0.74	6.15	
	Deterioration	4	-0.79	-9.37	7.79	

Cross-sectional surveys

Seven practices participated in both the cohort baseline (Time 1) and in the one off cross-sectional survey (Time 2) one year after the cohort baseline. The cohort baseline data of these 7 practices serves as a first cross-sectional survey and the PROMs scores from the two surveys (cohort baseline and cross-sectional) are compared in this section.

Asthma

A total of 231 and 257 asthma patients from 2 North-West based practices participated in the cohort baseline and cross-sectional survey respectively. There were no significant differences in terms of gender, age, employment, ethnicity, time since diagnosis or number of comorbidities between participants from the two surveys (**Table 63**). No significant differences were found in the generic and asthma-specific PROMs scores between the two surveys (**Table 64**).

Table 63: Demographics for asthma cohort and cross-sectional survey participants (7 practices)

		Cohort baseline (Time 1)		**Cross-sectional (Time 2)**	
		n	**%**	**n**	**%**
Gender	Male	91	40.3	107	42.0
	Female	135	59.7	148	58.0
Age (years)	18-44	77	33.9	94	36.9
	45-64	93	41.0	111	43.5
	65-74	32	14.1	29	11.4
	75+	25	11.0	21	8.2
Employment	Full-time	91	41.4	115	46.0
	Part-time	38	17.3	35	14.0
	Full-time education	4	1.8	7	2.8
	Unemployed	8	3.6	10	4.0
	Permanently sick/ disabled	11	5.0	13	5.2
	Retired	45	20.5	53	21.2
	Looking after home	16	7.3	12	4.8
	Other	7	3.2	5	2.0
Ethnicity	White	220	98.2	252	98.8
	Other	4	1.8	3	1.2
Region	North-West of England	231	100.0	257	100.00
		Mean	**SD**	**Mean**	**SD**
Time since diagnosis (years)		22.61	15.58	20.05	14.79
N comorbidities		0.60	0.85	0.63	1.01

Table 64: Differences in asthma PROMs scores between Time 1 and Time 2

	Cohort baseline (Time 1)			Cross-sectional (Time 2)			Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**		
York A1 tariff	228	0.84	0.81 - 0.87	255	0.83	0.80 - 0.87	0.006	NS
VAS	218	73.94	71.49- 76.38	253	73.59	70.83 -76.35	0.34	NS
MINI-AQOL								
Symptoms	228	5.36	5.20 - 5.52	245	5.40	5.23 - 5.56	-0.004	NS
Activity Limitations	222	6.10	5.95 - 6.26	239	6.07	5.90 - 6.23	0.04	NS
Emotional Functioning	227	5.50	5.31 - 5.69	245	5.62	5.43 - 5.80	-0.12	NS
Environmental Stimuli	229	5.33	5.14 - 5.53	245	5.39	5.22 - 5.56	-0.06	NS
Total QOL	216	5.62	5.48 - 5.77	231	5.67	5.52 - 5.82	-0.05	NS

COPD

A total of 133 and 170 COPD patients from 4 practices participated in the cohort baseline and cross-sectional survey respectively. No significant differences between the two groups were found for gender, age, employment, ethnicity, time since diagnosis or number of comorbidities between participants from the two surveys (**Table 65**). No significant differences were found in the generic and COPD-specific PROMs scores between the two surveys (**Table 66**).

Table 65: Demographics for COPD cohort and cross-sectional survey participants (7 practices)

		Cohort baseline (Time 1)		Cross-sectional (Time 2)	
		n	**%**	**n**	**%**
Gender	Male	58	43.6	83	49.1
	Female	75	56.4	86	50.9
Age (years)	18-44	2	1.5	0	0.0
	45-64	29	21.8	34	20.0
	65-74	42	31.6	57	33.5
	75+	60	45.1	79	46.5
Employment	Full-time	7	5.6	12	7.5
	Part-time	10	8.0	5	3.1
	Unemployed	0	0.0	1	0.6
	Permanently sick/ disabled	20	16.0	17	10.7
	Retired	74	59.2	108	67.9
	Looking after home	11	8.8	13	8.2
	Other	3	2.4	3	1.9
Ethnicity	White	131	99.2	167	99.4
	Other	1	0.8	1	0.6
Region	London	35	26.3	40	23.5
	North-West of England	98	73.7	130	76.5
		Mean	**SD**	**Mean**	**SD**
Time since diagnosis (years)		8.03	6.93	10.13	14.58
N comorbidities		1.77	1.44	1.82	1.46

Table 66: Differences in COPD PROMs scores between Time 1 and Time 2

	Cohort baseline (Time 1)			Cross-sectional (Time 2)			Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**		
York A1 tariff	129	0.65	0.60 - 0.70	162	0.62	0.57 - 0.67	0.03	NS
VAS	124	60.60	57.25 - 63.96	162	59.35	56.14 - 62.55	1.26	NS
CCQ								
Symptoms	119	2.78	2.51 - 3.05	145	2.94	2.71 - 3.17	-0.16	NS
Functional state	125	2.40	2.12 - 2.68	152	2.61	2.36 - 2.87	-0.21	NS
Mental state	124	2.33	2.01 - 2.66	153	2.38	2.11 - 2.66	-0.05	NS
Total QOL	112	2.50	2.23 - 2.77	143	2.68	2.45 - 2.91	-0.18	NS

Diabetes

Forty-three and 42 diabetes patients from 1 practice of the North-West participated in the cohort baseline and cross-sectional survey respectively. No significant differences between the two groups were found for gender, age, employment, ethnicity, time since diagnosis or number of comorbidities between participants from the two surveys (**Table 67**). One dimension (disinhibited eating) was significantly different between the two surveys (p=0.029), but no other significant differences were found in the generic and diabetes-specific PROMs scores (**Table 68**).

Table 67: Demographics for diabetes cohort and cross-sectional survey participants (7 practices)

		Cohort baseline (Time 1)		Cross-sectional (Time 2)	
		n	**%**	**n**	**%**
Gender	Male	26	65.0	23	59.0
	Female	14	35.0	16	41.0
Age	45-64	14	35.0	15	38.5
	65-74	13	32.5	10	25.6
	75+	13	32.5	14	35.9
Employment	Full-time	7	18.4	8	22.2
	Part-time	2	5.3	2	5.6
	Unemployed	1	2.6	0	0.0
	Permanently sick/ disabled	3	7.9	2	5.6
	Retired	19	50.0	22	61.1
	Looking after home	3	7.9	0	0.0
	Other	3	7.9	2	5.6
Ethnicity	White	40	100.00	37	94.9
	Other	0	0.0	2	5.1
Region	North-West of England	43	100.00	42	100.0
		Mean	**SD**	**Mean**	**SD**
Time since diagnosis (years)		8.65	9.09	8.28	6.59
N comorbidities		1.33	1.34	1.33	1.16

Table 68: Differences in diabetes PROMs scores between Time 1 and Time 2

	Cohort baseline (Time 1)			Cross-sectional (Time 2)			Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**		
York A1 tariff	42	0.81	0.74 - 0.88	42	0.78	0.70 - 0.86	0.03	NS
VAS	41	75.34	70.15 - 80.53	41	73.22	67.64 - 78.80	2.12	NS
DHP								
Psychological distress	42	10.85	6.27 - 15.42	39	12.39	6.02 - 18.76	-1.55	NS
Barriers to activity	41	12.08	8.11 - 16.05	35	17.41	12.07 - 22.76	-5.34	NS
Disinhibited eating	43	22.17	16.92 - 27.42	38	32.11	24.92 - 39.30	-9.93	0.029

Epilepsy

Fifty-seven and 70 epilepsy patients from 6 practices participated in the cohort baseline and cross-sectional survey respectively. No significant differences between the two groups were found for gender, age, employment, ethnicity, time since diagnosis or number of comorbidities between participants from the two surveys (**Table 69**). No significant differences were found in the generic and epilepsy-specific PROMs scores between the two surveys (**Table70**).

Table 69: Demographics for epilepsy cohort and cross-sectional survey participants (7 practices)

		Cohort baseline (Time 1)		**Cross-sectional (Time 2)**	
		n	**%**	**n**	**%**
Gender	Male	28	49.1	28	40.6
	Female	29	50.9	41	59.4
Age (years)	18-44	19	33.3	25	35.7
	45-64	17	29.8	24	34.3
	65-74	10	17.5	11	15.7
	75+	11	19.3	10	14.3
Employment	Full-time	11	21.2	16	23.5
	Part-time	5	9.6	9	13.2
	Unemployed	5	9.6	1	1.5
	Permanently sick/ disabled	8	15.4	12	17.6
	Retired	17	32.7	23	33.8
	Looking after home	5	9.6	3	4.4
	Other	1	1.9	4	5.9
Ethnicity	White	52	94.5	66	94.3
	Other	3	5.5	4	5.7
Region	London	16	28.1	12	17.1
	North-West of England	41	71.9	58	82.9
		Mean	**SD**	**Mean**	**SD**
Time since diagnosis (years)		23.73	18.02	19.28	16.39
N comorbidities		1.30	1.24	1.01	1.29

Table 70: Differences in epilepsy PROMs scores between Time 1 and Time 2

	Cohort baseline (Time 1)			Cross-sectional (Time 2)			Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**		
York A1 tariff	54	0.75	0.68 - 0.82	67	0.67	0.59 - 0.75	0.08	NS
VAS	51	67.51	61.81 - 73.21	67	70.03	65.38 - 74.68	-2.52	NS
QOLIE								
Seizure worry	53	67.77	59.31 - 76.24	61	66.06	59.05 - 73.06	1.72	NS
Overall QOL	46	67.12	61.23 - 73.01	63	68.81	64.74 - 72.88	-1.69	NS
Emotional well-being	53	65.21	58.74 - 71.68	63	68.44	63.42 - 73.47	-3.24	NS
Energy / fatigue	55	52.09	46.10 - 58.08	61	53.11	47.40 - 58.83	-1.02	NS
Cognitive	52	58.40	50.73 - 66.06	59	64.03	57.72 - 70.34	-5.63	NS
Medication effects	56	60.12	51.45 - 68.79	63	62.57	55.21 - 69.92	-2.45	NS
Social function	38	66.58	56.91 - 76.25	45	69.16	60.98 - 77.33	-2.58	NS
Total QOL	27	64.94	56.60 - 73.28	43	65.14	59.09 - 71.20	-0.21	NS

Heart failure

Sixty-three and 58 heart failure patients from 4 practices participated in the cohort baseline and cross-sectional survey respectively. No significant differences between the two groups were found for gender, age, employment, ethnicity, time since diagnosis or number of comorbidities between participants from the two surveys (**Table 71**). Furthermore, there were no significant differences in the generic and heart failure-specific PROMs scores between the two surveys (**Table 72**).

Table 71: Demographics for heart failure cohort and cross-sectional survey participants (7 practices)

		Cohort baseline (Time 1)		Cross-sectional (Time 2)	
		n	**%**	**n**	**%**
Gender	Male	37	58.7	29	50.0
	Female	26	41.3	29	50.0
Age (years)	18-44	1	1.6	0	0.0
	45-64	11	17.5	7	12.1
	65-74	9	14.3	17	29.3
	75+	42	66.7	34	58.6
Employment	Full-time	2	3.4	4	7.7
	Part-time	3	5.2	1	1.9
	Unemployed	1	1.7	1	1.9
	Permanently sick/ disabled	7	12.1	6	11.5
	Retired	40	69.0	34	65.4
	Looking after home	5	8.6	5	9.6
	Other	0	0.0	1	1.9
Ethnicity	White	58	92.1	51	87.9
	Other	5	7.9	7	12.1
Region	London	29	46.0	29	50.0
	North-West of England	34	54.0	29	50.0
		Mean	**SD**	**Mean**	**SD**
Time since diagnosis (years)		11.30	9.56	12.34	14.03
N comorbidities		1.83	1.49	1.98	1.41

Table 72: Differences in heart failure PROMs scores between Time 1 and Time 2

	Cohort baseline (Time 1)			Cross-sectional (Time 2)			Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**		
York A1 tariff	60	0.64	0.57 - 0.72	57	0.62	0.54 - 0.70	0.03	NS
VAS	61	61.85	56.79 - 66.92	55	56.98	50.47 - 63.49	4.87	NS
MLHFQ								
Total QOL	42	36.52	29.38 - 43.66	36	35.81	27.66 - 43.96	0.72	NS
Physical dimension	59	18.58	15.38 - 21.78	46	20.54	16.85 - 24.24	-1.97	NS
Emotional dimension	59	7.71	5.91 - 9.52	49	9.57	7.27 - 11.87	-1.86	NS

Stroke

Thirty-eight and 49 stroke patients from 3 practices participated in the cohort baseline and cross-sectional survey respectively. No significant differences between the two groups were found for gender, age, employment, ethnicity, time since diagnosis or number of comorbidities between participants from the two surveys (**Table 73**). Furthermore, there were no significant differences in the generic and heart failure-specific PROMs scores between the two surveys (**Table 74**).

Table 73: Demographics for stroke cohort and cross-sectional survey participants (7 practices)

		Cohort baseline (Time 1)		Cross-sectional (Time 2)	
		n	**%**	**n**	**%**
Gender	Male	19	54.3	21	44.7
	Female	16	45.7	26	55.3
Age (years)	18-44	1	2.8	2	4.3
	45-64	7	19.4	8	17.0
	65-74	9	25.0	11	23.4
	75+	19	52.8	26	55.3
Employment	Full-time	2	5.9	3	6.8
	Part-time	4	11.8	3	6.8
	Unemployed	1	2.9	1	2.3
	Permanently sick/ disabled	3	8.8	5	11.4
	Retired	22	64.7	29	65.9
	Looking after home	1	2.9	3	6.8
	Other	1	2.9	0	0.0
Ethnicity	White	34	94.4	43	89.6
	Other	2	5.6	5	10.4
Region	London	11	28.9	14	28.6
	North-West of England	27	71.1	35	71.4
		Mean	**SD**	**Mean**	**SD**
Time since diagnosis (years)		6.28	5.42	7.25	5.87
N comorbidities		2.21	1.47	1.63	1.37

Table 74: Differences in stroke PROMs scores between Time 1 and Time 2

	Cohort baseline (Time 1)			Cross-sectional (Time 2)			Mean difference	p (2-tailed)
EQ5D	**N**	**Mean**	**95% CI**	**N**	**Mean**	**95% CI**		
York A1 tariff	35	0.67	0.56 - 0.79	46	0.66	0.56 - 0.76	0.01	NS
VAS	34	71.38	63.37 - 79.39	44	68.66	61.23 - 76.09	2.72	NS
SIS								
Strength	28	60.94	49.64 - 72.24	32	70.12	59.27 - 80.96	-9.18	NS
Hand function	28	76.07	63.31 - 88.84	38	70.66	59.80 - 81.52	5.41	NS
Mobility	32	75.00	66.44 - 83.56	42	71.83	62.99 - 80.66	3.18	NS
Memory	33	80.84	71.89 - 89.80	44	83.93	77.05 - 90.81	-3.08	NS
ADL	28	79.02	69.01 - 89.03	41	81.28	73.05 - 89.51	-2.26	NS
Communication	33	83.87	75.59 - 92.16	41	86.76	81.19 - 92.32	-2.89	NS
Emotion	30	69.91	61.99 - 77.83	43	66.41	61.04 - 71.78	3.50	NS
Handicap	24	74.74	61.97 - 87.51	27	79.75	70.10 - 89.39	-5.01	NS
Physical	19	71.19	58.05 - 84.33	28	73.21	62.51 - 83.92	-2.02	NS

Qualitative interviews with stakeholders

The multiple routes of recruitment resulted in a minimum of 78 stakeholders (35 GP practices, 35 patients and 8 commissioners) being invited for an interview. The exact number of stakeholders contacted is unknown as a snowballing technique was used and there was no feedback from the London PCRN on how many stakeholders were contacted. Overall recruitment was challenging as many stakeholders did not respond to the invitation (or reminder) and commissioners were difficult to identify. A total of 20 consented to participate, although one withdrew before the interview. Thus 19 interviews were conducted, 15 by telephone and 4 by Skype. Fourteen participants were from the NW. Fifteen participants had been recruited from practices who had participated in the survey but not everyone had been aware of the surveys (in particular the patient representatives). Of the 10 participants who knew about the surveys, 5 had been actively involved in some aspect of collecting the survey data. **Table 75** provides summary details on the participants (full details in **Appendix 7**).

Table 75: Interview participants

Participant	***North West***	***London***
Research nurses	3	0
Practice nurses	2	0
GPs	3	2
Commissioners	1	1
Managers	0	1
Patient representatives	5	1
TOTAL	14	5

Issues discussed during the interviews focused on feasibility and the PROMs data itself. Aspects of feasibility included the process of collecting PROMs data, response rates and the wider implementation of PROMs data collection. The discussions on the PROMs data comprised comments on the questionnaires used, presentation of data and the value and usefulness of data collection. All of these will be reported in more detail in this section of the report.

Feasibility

Process of collecting PROMs data

Five of the participants had been actively involved in conducting the surveys in their practice and talked about their experiences. Overall, they reported that the pilot caused no significant problems to their practices and generally had little impact on practice staff, apart from those actively involved in facilitating the research. It was thought that the procedures outlined by the research team had been clear and easy to follow. A nurse stated that they could have included all six LTCs as the process was simple enough.

"… The instructions were very clear and very easy to follow. That was all made very easy by the team who sent through the information. I was able to follow that quite easily, that was great. In fact prior to joining the study, we had restricted the number of conditions that we would consent to being involved with. Afterwards, after we had been through the process, I thought to myself that we could easily have done asthma and epilepsy and heart failure as well…" (Practice nurse_16_NW)

Mostly participants did not report problems with the Apollo searches to identify patients. However, two practices (NW 8; L 1) reported technical challenges with the search, for example in practice NW8 there had been problems with the COPD search. Additionally, minor practical problems were highlighted. Two participants from different practices described difficulties with printing the address labels. Furthermore, sealing and posting the volume of envelopes was reported to be burdensome.

Questionnaires

The PROMs used in the surveys had been provided to the stakeholders prior to the interviews. Several participants, in particular the patients, had looked at them in detail and mostly felt positive about their content and the PROMs approach of data collection. Two patients made reference to the EQ-5D-VAS; that it was easy to complete and could act as a trigger for discussion.

"… Those forms [PROMs] give that initiative to people, so people can think about their own health and what they should be doing…" (Patient_13_NW)

"… It's a means of bringing them [GPs] up to date with the patient's history. You know the headings are good, the questions are good. I mean just as a small example, I am not quoting these accurately, but one of the questions concerning breathlessness – are you having difficulty climbing stairs? Answers on a scale of 1-10. Well you know, you tick 4, the GP should say perhaps in a year's time I will look at that – are you still 4? ..."(*Patient_12_NW)*

However, some negative comments were also made, such as about the length of the questionnaires, the unavailability of translated versions or the actual questions asked.

"… Did you particularly want the outcome for every single question you asked there? If you are looking at an overall outcome measure, could you get it with far fewer questions?..." (Patient_18_NW)

"… I had a brief look at, which one did I have a look at, I think it was asthma. I thought it was actually quite long, but I don't see how you could do it any shorter…" (Commissioner_11_L)

Response rates

The main aim of the pilot was to evaluate feasibility by assessing response rates. The response rates to the cohort baseline were outlined in the summary document that had been provided to participants before the interview and participants were asked to comment on these. Suggestions for maximising responses to questionnaires were also sought.

Views about the response rates were mixed with some participants feeling that the response rates were reasonable and as would be expected. Other participants believed that only the response rates for some LTCs were acceptable and some raised concerns about the low response rate from the patients within their practice. Those who found response rates low commented on how this would affect the representativeness of the sample and ultimately the PROMs scores. Others believed that it was important to ensure a wide spread in terms of demographic and disease severity amongst respondents rather than staying too fixated on actual response rates.

"… I suppose getting a 30% response rate wasn't too bad for a postal survey…" (GP_08_NW)

"… the response rate is 19% [for the practice], I would be looking at that and thinking well is that the 19% who are really sick or the 19% who are quite well…" (GP_09_L)

"… I notice on the epilepsy one that 50% of people with epilepsy were excluded. So you have only got 50% of them and of those 50% only 30% responded, so you are only looking at 15% of people with epilepsy. Those responses statistically weren't worth very much …" (Patient_18_NW)

"… I think population based approaches are fine, providing that the response rates if you are looking for people's opinions is big enough to demonstrate that you have captured enough breadth and I think someone might criticise you for saying how do you know you have captured all the different types of asthma? How do you know these are not just the really well ones…" (GP_09_L)

Various stakeholders attempted to explain the response rates and highlighted barriers to participation. Some believed that often it was more difficult to engage with men for both health monitoring and data collection. Participants also felt that the lower response rates related to diverse populations (including large proportion of ethnic groups and different languages spoken in London) or a lack of perceived benefit to the participant.

"… I suppose some people might not want to participate, because they might not see the point of it, that's the thing. Um, see people are very strategic and are obviously very busy, so if they see that their opinion is going to change something, a bit like voting, then they are much more likely to offer their opinion. A lot of them might think that this is an academic exercise and actually isn't going to change anything and also I think if you've got people with relatively mild asthma, who don't access services, are less likely to think that views are valid or less useful, so it might be that they select themselves out inappropriately because they think well I am not bad enough to warrant comment…" (GP_09_L)

Some suggestions were made to improve response rates. There was consensus that to maximise response rates a personalised approach was necessary and a stamped return address was essential. Overall, endorsement from the practice was considered vital. A letter from a GP/nurse informing patients about a forthcoming survey or together with the survey was thought be an acceptable approach. The latter was used in the surveys.

> *"…What you have to do is tell people you were going to receive the questionnaires about their condition and the practice would be reinforcing the value of responding….please take the time to fill it in as it is intended to help people in a similar condition to get the best out of the NHS…that sort of message…" (GP_19_NW)*

Others suggested that the questionnaires could be completed while the patient was at the surgery waiting for appointments. Telephone administration was considered to be an option to potentially increase response rates in addition to other methods such as postal.

Wider implementation

If considered successful, the methods of collecting PROMs data piloted in this study were going to be implemented on a national basis, as part of the national PROMs programme. Therefore, stakeholders were asked about their views on collecting PROMs data for LTC on a regular basis. Although PROMs data was often viewed as positive, most participants expressed concerns in relation to time.

> *"…I am sure of it [be enthusiastic about implementation], it's always with that sort of caution of how much extra time is it going to take. But really when we look at it and see well yes there is value in it, then that's ok. It's if you can a value to the patient or a value to the service, then you think well ok it's worthwhile. It's just with the recognition that it takes time…" (Practice nurse_16_NW).*

> *"…It's not about money in the back pocket, its more about more nurse time or doctor time, as there are only so many hours in the day and patients still have to be seen…" (GP_08_NW)*

Concerns were raised about costs and there were strong opinions about the need for incentives or adequate financial resources for implementation. Participants were more open towards wider implementation of PROMs data collection if resources were specifically allocated to this and it did not mean diverting funds from existing projects.

> *"…There has to be enough remuneration to cover costs of applying it. Those costs might be medical costs, which are extensive, or it might be health care assistant costs, or training people to collect the information. But within the system as a practice, I hear this from many people I work with; there is not the capacity to take on additional work. They want to do things at a higher level, but there isn't the capacity or time to do it, for people to come on board, initially it has to be doctors. But their costs one way or another has to be covered…" (GP_14_L)*

> *"…If you want practices to do anything, you need to incentivise it…" (Manager_01_L)*

There were concerns though about the benefits of implementing a national PROMs programme for LTCs. One participant expressed that it seemed that benefits were marginal for the amount of work involved and another felt that the issues covered in the PROMs questionnaires were part of the annual review and therefore already covered. A GP felt it had to fit in with everything else that was happening in practices.

> *"… what I mean is, they are kind of the things that you should be doing at the annual review anyway. Um-in most of these conditions and actually getting the patient to fill out a form, hand it in. If we have to, um I presume it will have to be us that has to look at the data if it was in an individual patient, I am not sure that we would get a lot more out of it than we would hopefully be doing at the annual review..." (GP_08_NW)*

> *"…I think it's right to have transparent services; it's not that its wrong, but I do worry about the political push about how we must have all this information available for all the patients…" (Commissioner_03_NW)*

If PROMs data collection for LTCs is implemented on a national basis, participants thought that data should be collected once a year. It was acknowledged that patient's views of their LTC may not change a lot over a year. Some participants believed that PROMS data could be part of the annual QOF indicators, whilst others thought it could be feasible to collect data in conjunction with a patient's annual review. However, concerns were raised that this latter approach may increase consultation time.

> *"…I suppose if it was done at an annual review, they do an awful lot of them so it could be that each person that came in that day would have an annual review and that would mean extra time for the practice and I don't know if that would be practical really…" (Research_nurse_05_NW)*

Different methods of administration were seen as favourable such as postal; telephone; during consultations or annual reviews or by email from the practice. It was suggested that patients be provided with alternative methods of completing PROMs; this could engage the hard to reach. A research nurse suggested that if PROMs were to be collected a poster could be displayed for patient information.

PROMs data

The participants had been provided with a summary of the findings from the cohort baseline, including PROMs scores by practice for each LTC. They were invited to consider the findings prior to the interview as the interview questions focussed on the presentation and the value of the data. The majority of participants had read at least part of the report; two GPs reported that they had not read the report because of time constraints.

The value of the data

Overall, engagement with the results presented reflected the level of interest in and knowledge of PROMs data collection. Those with favourable interest and prior knowledge provided more positive comments than those who had little knowledge. Where relevant, participants were signposted to the results of their practice, and they generally focused on these. Some participants compared their practice's results to those of other practices, whilst other participants focused on the report generally. Patients tended to be positive about data being collected from their perspective.

> *"… from my perspective I actually find it quite interesting but I was participating, but I was part of the study so yes to me it was quite interesting. I can imagine showing it to the other nurses and them probably thinking oh fine and not particularly interested…" (Research_nurse_06_NW)*

> *"… these kind of reports are very good stuff and the more we can do on it, the better our services will become and more relevant they will become to patients…" (Commissioner_11_L)*

> *"…It was very clear and I was pleased to read it, I thought how good to have the beginnings of a new approach…" (Patient_13_NW)*

When questioned about the value of PROMs data, there was a mix of enthusiasm, interest and scepticism. Many participants believed that collecting PROM data was valuable as it captures the patients' perceptions of their LTC, and as such 'the right thing to do'. One participant suggested the PROMs data could be used in conjunction with other data.

> *"…it was very clear and I was pleased to read it, I thought how good to have the beginnings of a new approach…" (Patient_13_NW)*

> *"…Probably this kind of data that we tend to get is sometimes about highlighting a disease or process that was previously considered to be well tolerated so like acne is a classic one. So I think even if it just raises a profile of how debilitating some conditions are, that would be a useful exercise and it makes people think more about patients living with a particular process. Yes so it will be very interesting to see the data put into the same data sheet almost so you get your mortality/morbidity data within all that and in that is the patient's perspective and how they feel…" (GP_08_NW)*

> *"… As somebody who would be the person who would be helping to implement this with my practices I couldn't unpick whether they are a good thing or not to do of it…… I think it feels like the right thing to do, but I am not sure that we have the evidence to say it's definitely the right thing to do…" (Commissioner_03_NW)*

Presentation of findings

The general view of all the participants, including those who found the results interesting, was that the document presenting the results was too long and therefore difficult to navigate. This deterred some participants from reading it in full.

"…This is not a summary document it is a five course meal. It is not accessible to me. Far too much information…. main point is that the document is impenetrable to your average audience of people who are trying to do a good job but just deluging them with more data is not going to be helpful.." (GP_19_NW)

Beyond the length of the report, the views of the participants were mixed with both positive and negative, and even sometimes contradictory, comments from the participants. The PROMs data had been presented in graphs, some of the stakeholders liked the graphs whereas others, in particular the patients, found them too complicated. Some believed that there was too much technical and/or statistical information, whilst others thought this information was necessary. It was suggested that different reports may be needed for different audiences.

"… I liked the graphs – the graphs were nice and clear – I always like graphs…" (Commissioner_03_NW)

"…Well it's complicated. Anybody who is not familiar with statistical information and standard deviations and the like it would have been meaningless. There is a lot of information in there that perhaps isn't relevant to all patients…" (Patient_17_NW)

Another problem was that some participants found the PROMs scoring methods difficult to interpret as they varied between PROMs.

"…. I found it quite difficult to read and quite confusing in places, particularly around the scores and basically results for each one and then when you are reading the results like the average score was 5.33 and then for others it was 0.5 and I found that quite difficult to interpret…"(GP_10_NW)

There were suggestions for improvement including giving more explanations of the graphs and figures; producing shorter versions and an overall summary; presenting a small report for one condition; and condensing the report into a large poster. It was acknowledged that this would be a considerable challenge. The overall comments suggested that there should be different version for different audiences such as a summary targeted at patients or a conditions-specific summary.

"…no-one now has any more time to look at anything that's more than two pages, and actually given the fact that it would probably be the asthma commissioner or diabetes commissioner would probably look at the relevant pages and they are actually about two pages long…" (Commissioner_11_L)

Uses of the data

For a wider implementation of PROMs data collection in LTCs to be supported, it would be necessary to know what the benefits are of collecting the data as explained by one of the commissioners.

"…I think practices will want to see what they get out of it. I suppose it's the obvious thing, if they see that they get something out of it, they see a benefit to them, and then they will probably buy into it. There is the other problem of some practices will do it anyway because it's the right thing

to do, some will obviously expect to be paid to do it, saying it's not in our contract. So it depends on if it's in their contract then they will be expected to do it. And actually I would assume that this kind of monitoring should be in their contract anyway …" (Commissioner_11_L)

Some participants found it difficult to make suggestions how the data may be used, as they did not feel they knew enough about PROMs.

"…The report assumes I have a working knowledge of PROMs which I haven't. I am not even sure what a PROMS report would look like…" (GP_19_NW)

Participants who were able to make suggestions could see PROMs data being used for different purposes. Participants frequently had an opinion on how other stakeholders could use the data. The uses most frequently referred to monitoring individual patients or monitoring practice performance. There were mixed views on whether the results would help improve services or be useful for commissioning services.

Although the data presented to the stakeholders were population-based data, some participants talked about the use of PROMs for individual patient monitoring. One patient with a LTC thought PROMs data would enable personal benchmarking and monitoring. It was also thought to be an approach that might promote self-management and responsibility for one's health.

"…I think it then gives you a personal benchmark about how I felt, how I am feeling now and I can look back at it in a year's time and think maybe my condition has improved, although the reasons for that might be that my doctor gave me a different type of inhaler, but yeah and so on and so forth, but I think it would be interesting for me if I was to fill out one of those …" (Patient_04_L)

The patient representative group believed it would be helpful if PROMs results for individual patients were fed back to the GP as this might help communication between the GP and the patients. Furthermore, a patient's perception of their illness does not always compare to the GPs opinion.

"…This would be of most value as a tool in a properly organized chronic disease set-up…such as we run at this practice…so that the patient attended with the agenda of discussing this particular condition…it would help to identify what was relevant to them. …a patients point of view which perhaps we don't get at when we just sit down and talk to people…facilitates a more structured discussion……..it is becoming more acknowledged I think that the long term outcomes in chronic conditions are likely to be more driven by the patient if the patient is the one that sets the particular agenda and say what they want to discuss… "(GP_19_NW)

Furthermore, the questionnaires were regarded as a method whereby patients could think about their condition and raise issues that perhaps wouldn't be discussed during a normal consultation but also enable monitoring of health overtime. However, one GP felt it was not providing any information that would not be discussed during a clinical consultation. Healthcare professionals could see the value of PROMs data to facilitate discussion with patients and aid with clinical decision making but concerns were expressed about increasing consultation time.

Population-based data was thought be helpful in particular to GPs as this may contribute to monitoring their and their practices' performance, benchmarking and identifying outliers. This was believed to potentially lead to improvements in services. However some of the professional stakeholders were concerned about comparing practice scores. Patients on the other hand showed some enthusiasm for collecting PROMs data as it may open the dialogue with practices on their performance.

> *"…I think they [GPs] would like it – at a population level, it's very useful information. It's something GPs if they see what is out there they start questioning themselves and questioning integrity and everything else, but it's useful information if you take it on board and then work with it. I can't see how they wouldn't take that role. Some would take it in a positive sense and develop their practice with it and note that population level is as important as anything* else…" *(GP_14_L)*

> *"… think there are issues about the meaningfulness of the data but I suppose if you are a practice struggling with a high level of, you know in a really deprived area, multiple co-morbidities and you know lots of sick people um you know and then you are being compared with a leafy suburb. Alright people will still have morbidity, but they may have one illness and will generally feel not too bad. I suspect that I would feel quite threatened by that (GP_08_NW)*

To compare the health of different disease groups was thought to be difficult as quality of life may be different in specific locations for example, some affluent areas of the NW compared to more deprived areas. A nurse thought that using generic health questionnaires and comparing between different conditions would be interesting to observe the impact on the patient living with that LTC.

> *"…It would be to look at the generic questions, which were presented to all the people with chronic disease, to compare the chronic diseases to say – if you live with epilepsy is that going to have more of an impact on your life than living with a stroke. In terms of then looking where you target your resources that might have been an interesting thing to look a…" (Practice nurse_16_NW)*

Other respondents were more sceptical and raised concerns about whether the data is informative about the quality of the services receive or the representativeness of the data in relation to the low response rates and the demographics of the participants. Some felt it needed to be proved that PROMs data is helpful for benchmarking practices. Questions were raised with regards to the usefulness of the data when small populations of people with a particular LTC were registered at a practice.

> *"…I suppose that's a little bit of my concern about it, I am not totally sure that the questions and the answers actually tell you whether they are telling you they are getting a good service and in practice I think it tells you more about how ill patients are…" (GP_08_NW)*

The views on using the data for commissioning services were similar to those of using the data for service improvement. Some felt that PROMs data might provide important information to target resources where quality of life is low for specific conditions within practices.

> *"…So we see in stroke, we didn't perform very well in terms of function, and being in a rural setting, we do not have a brilliant set up for the acute management of stroke, whereas if you live*

in London, if you get there within an hour you can have the treatment to reduce the clot and all of that. So that's interesting information to the PCT and to the Government to look at services and what impact you can have…" (Practice nurse_16_NW)

One GP (NW) wasn't convinced that commissioners were in a position to use PROM data for commissioning decisions due to the subjectivity of the data but also because clinical commissioning groups were currently in a development phase. However, commissioners could see the value of using PROMs data.

"… we are developing a local quality dashboard with a lot of different indicators to develop the breadth of quality and I could see that would fit in if we had it for each practice.." (Commissioner_03_NW)

"… I do think it's very useful, I think if you can get a long period of data collected on a regular basis, once every six months or regular enough to show progression over, say three years. If it's once a year that would make that progression slightly harder to see. Um, I would also like to be able to link it to what is it an outcome of. Are there any activities practices or services have done with those patients in order to get those outcomes? So if there are any outliers then I suppose we can go and interrogate it ourselves to find out if anything has happened. I think particularly with CCG commissioning coming in, increase people's care and they are increasingly trying to move care back out to them and this gives them a chance to compare themselves and each other and benchmark the CCG. So the CCG has a better level of control and this can be particularly useful for a CCG commissioner..." (Commissioner_11_L)

Cost analysis

A model of cost was developed on the basis of actual expenses of the PROMs pilot, with the exception for postage. The cost of stamps had increased since data had been collected and estimates for postage were based on current cost rather than on actual expenses. Furthermore, many of the costs included as part of this model, including print runs, stationary, envelopes and data entry services will vary depending on quantity. Therefore, if purchasing were to be co-ordinated nationally rather than locally there may be opportunities to reduce the costs presented in **Table 70**. In addition, the model does not take into account some of the costs incurred as part of the pilot study, including:

a) The search algorithm required to identify patients from computerised records in general practices. These costs, which were estimated at approximately £660 per general practice, were not included as it is not possible to determine, at this stage, how often the search algorithm would have to be updated and the costs for each update.
b) Translation services.
   The set-up costs for the translation service were estimated at £180. These costs were not included in the model as they are assumed to be one-off fixed costs. The costs per contact with the translation service, estimated at £19.80 per contact, were not included as no patient made use of the service.
c) Set-up costs set by the firms printing questionnaires, letters, or responsible for data entry.
   These costs were not included in the model as they are assumed to be one-off fixed costs.
d) Data analysis.
   The cost of data analysis was not included because it is unknown how frequently the analyses will take place, what analyses will be undertaken, and whether the analyses will be the same in each occasion.

Table 70: Cost model for PROMs in LTCs

	Activity	Condition	Cost	Unit of measurement	Cost includes:
	Sending initial questionnaire (either baseline cohort or cross sectional)				
1.	Identification of eligible patients	Asthma COPD Diabetes Epilepsy Heart failure Stroke	£1.52 £1.93 £1.96 £2.01 £2.29 £2.66	Eligible patient identified	a. Meetings with general practice staff and on-going communication; b. Identification of potential patients through searches of computerised patient lists; and c. Double checking of eligibility and final approval of eligible patients.
2.	Questionnaires	Asthma COPD Diabetes Epilepsy Heart failure Stroke	£4.42 £4.93 £4.70 £5.22 £5.15 £5.40	Eligible patient identified	a. Envelopes, return envelopes, information sheets, letters, reminders and study questionnaires; b. Delivery of questionnaire packs to primary care practices; and c. Stuffing and addressing envelopes.
3.	Postage	All	£1.50	Eligible patient identified	a. Postage for questionnaire (£0.90 for 1st class large letter) b. Postage for reminder (£0.60 for 1st class letter)
	Processing of completed initial questionnaires				
4.	Postage	All	£0.66	Patient completing initial questionnaire	a. Postage for large reply paid envelope
5.	Data entry	Asthma COPD Diabetes Epilepsy Heart failure Stroke	£0.32 £0.30 £0.38 £0.45 £0.39 £0.68	Patient completing initial questionnaire	a. Data entry by data processing company (excludes setup costs)

Table 70 (continued): Cost model for PROMs in LTCs

	Sending follow-up questionnaires (only for patients in the cohort study)				
6.	Questionnaires	Asthma COPD Diabetes Epilepsy Heart failure Stroke	£3.64 £3.88 £3.55 £4.71 £3.93 £5.01	Patient completing initial questionnaire & contactable at 1 year	a. Envelopes, return envelopes, information sheets, letters, reminders and study questionnaires; and b. Stuffing and addressing envelopes.
7.	Postage	All	£1.11	Patient completing initial questionnaire & contactable at 1 year	a. Postage for questionnaire (£0.66 for 1st class franked large letter) b. Postage for reminder (£0.45 for 1st class franked letter)
	Processing of completed follow-up questionnaires				
8.	Postage	All	£0.66	Patient completing follow-up questionnaire	a. Postage for large reply paid envelope
9.	Data entry	Asthma COPD Diabetes Epilepsy Heart failure Stroke	£0.23 £0.24 £0.25 £0.32 £0.26 £0.51	Patient completing follow-up questionnaire	a. Data entry by data processing company (excludes setup costs)

The costs included in **Table 70** vary with respect to:

- The number of eligible patients identified (N),
- The proportion of eligible patients completing a baseline cohort or cross-sectional questionnaire (α). For the cohort study, response rates were: 30% for asthma, 49% for COPD, 40% for diabetes, 34% for epilepsy, 50% for heart failure, and 36% for stroke. For the cross-sectional study, response rates were: 35% for asthma, 60% for COPD, 55% for diabetes, 37% for epilepsy, 55% for heart failure, and 54% for stroke.
- The proportion of patients completing a baseline cohort questionnaire and still contactable at the 1 year follow-up (μ). For the cohort study, the proportion of patients who were sent a follow-up questionnaire one year after completing the baseline questionnaire was: 92% for asthma, 94% for COPD, 95% for diabetes, 92% for epilepsy, 89% for diabetes, and 90% for stroke.
- The proportion of patients completing a follow-up cohort questionnaire (β), which was: 73% for asthma, 71% for COPD, 76% for diabetes, 63% for epilepsy, 66% for heart failure, and 74% for stroke.

Table 71 presents a set of formulas allowing estimation of the expected average cost per eligible patient (number of patients following the search and the practice's exclusions) identified using the costs observed in the pilot study.

Table 71: Average cost per eligible patient identified

Condition	Average cost	Comment
Cohort study		
Asthma	£7.44 + £0.98α + £4.74αμ + £0.89αμβ	Costs 1. + 2. + 3. in Table 1 = £7.44 Costs 4. + 5. in Table 1 = £0.98 Costs 6. + 7. in Table 1 = £4.74 Costs 8. + 9. in Table 1 = £0.89
COPD	£8.35 + £0.96α + £4.99αμ + £0.90αμβ	Costs 1. + 2. + 3. in Table 1 = £8.35 Costs 4. + 5. in Table 1 = £0.96 Costs 6. + 7. in Table 1 = £4.99 Costs 8. + 9. in Table 1 = £0.90
Diabetes	£8.16 + £1.04α + £4.66αμ + £0.91αμβ	Costs 1. + 2. + 3. in Table 1 = £8.16 Costs 4. + 5. in Table 1 = £1.04 Costs 6. + 7. in Table 1 = £4.66 Costs 8. + 9. in Table 1 = £0.91
Epilepsy	£8.73 + £1.11α + £5.81αμ + £0.98αμβ	Costs 1. + 2. + 3. in Table 1 = £8.73 Costs 4. + 5. in Table 1 = £1.11 Costs 6. + 7. in Table 1 = £5.81 Costs 8. + 9. in Table 1 = £0.98
Heart failure	£8.95 + £1.05α + £5.04αμ + £0.92αμβ	Costs 1. + 2. + 3. in Table 1 = £8.95 Costs 4. + 5. in Table 1 = £1.05 Costs 6. + 7. in Table 1 = £5.04 Costs 8. + 9. in Table 1 = £0.92
Stroke	£9.56 + £1.34α + £6.12αμ + £1.17αμβ	Costs 1. + 2. + 3. in Table 1 = £9.56 Costs 4. + 5. in Table 1 = £1.34 Costs 6. + 7. in Table 1 = £6.12 Costs 8. + 9. in Table 1 = £1.17

Table 71 (continued): Average cost per eligible patient identified

Condition	Average cost	Comment
Cross-sectional study		
Asthma	£7.44 + £0.98α	Costs 1. + 2. + 3. in Table 1 = £7.44 Costs 4. + 5. in Table 1 = £0.98
COPD	£8.35 + £0.96α	Costs 1. + 2. + 3. in Table 1 = £8.36 Costs 4. + 5. in Table 1 = £0.96
Diabetes	£8.16 + £1.04α	Costs 1. + 2. + 3. in Table 1 = £8.16 Costs 4. + 5. in Table 1 = £1.04
Epilepsy	£8.73 + £1.11α	Costs 1. + 2. + 3. in Table 1 = £8.73 Costs 4. + 5. in Table 1 = £1.11
Heart failure	£8.95 + £1.05α	Costs 1. + 2. + 3. in Table 1 = £8.95 Costs 4. + 5. in Table 1 = £1.05
Stroke	£9.56 + £1.34α	Costs 1. + 2. + 3. in Table 1 = £9.56 Costs 4. + 5. in Table 1 = £1.34

Using the values of α, μ and β identified in the pilot study, and the formulas depicted in **Table 2,** the average expected cost per eligible identified patient with asthma, diabetes, epilepsy, heart failure or stroke (**Table 72**) is estimated. To account for the uncertainty in response rates, we also evaluate the average costs for different values of α (baseline/cross-sectional questionnaire completion rate), and β (follow-up questionnaire completion rate), assuming that μ (proportion of patients who were sent a follow-up questionnaire one year after completing the baseline questionnaire) remained the same as that observed in the pilot study.

Table 72: Expected average cost per eligible patient identified for the: a) cohort study and b) cross-sectional study

α	β	Asthma	COPD	Diabetes	Epilepsy	Heart failure	Stroke
Cohort Study							
Observed		**£9.22**	**£11.43**	**£10.60**	**£11.14**	**£12.02**	**£12.34**
30%	50%	£8.87	£9.81	£9.63	£10.24	£10.36	£11.46
40%	60%	£9.38	£10.32	£10.15	£10.77	£10.85	£12.13
50%	70%	£9.89	£10.84	£10.68	£11.32	£11.36	£12.81
60%	80%	£10.42	£11.37	£11.23	£11.87	£11.87	£13.51
70%	90%	£10.96	£11.92	£11.79	£12.44	£12.40	£14.23
Cross-sectional Study							
Observed	**n/a**	**£7.79**	**£8.93**	**£8.73**	**£9.14**	**£9.53**	**£10.29**
30%	n/a	£7.74	£8.64	£8.47	£9.06	£9.26	£9.96
40%	n/a	£7.84	£8.74	£8.58	£9.17	£9.37	£10.10
50%	n/a	£7.93	£8.83	£8.68	£9.28	£9.47	£10.23
60%	n/a	£8.03	£8.93	£8.78	£9.39	£9.58	£10.36
70%	n/a	£8.13	£9.03	£8.89	£9.50	£9.68	£10.50
80%	n/a	£7.79	£8.93	£8.73	£9.14	£9.53	£10.29

The costs presented in **Table 72** represent the expected average cost per eligible patient identified with one of the 6 LTCs under study. However, if estimating the average cost per patient completing either the

two questionnaires in the cohort study, or the one for the cross-sectional study, the average cost per patient is considerably higher (**Table 73**). Again, to account for the uncertainty in response rates, we also evaluate the average costs for different values of α and β, assuming that μ remained the same as that observed in the pilot study.

Table 73. Average cost per patient completing: a) baseline and follow-up cohort questionnaire; and b) cross-sectional questionnaire

α	β	Asthma	COPD	Diabetes	Epilepsy	Heart failure	Stroke
Cohort Study							
Observed		£46.06	£34.65	£37.01	£56.23	£40.32	£50.56
30%	50%	£64.66	£69.62	£67.86	£74.05	£77.29	£84.76
40%	60%	£42.70	£45.77	£44.70	£48.68	£50.61	£56.06
50%	70%	£30.89	£32.98	£32.25	£35.06	£36.33	£40.61
60%	80%	£23.73	£25.23	£24.72	£26.82	£27.70	£31.24
70%	90%	£19.02	£20.15	£19.77	£21.41	£22.05	£25.07
Cross-sectional Study							
Observed	n/a	£22.01	£14.96	£15.81	£24.42	£17.25	£18.90
30%	n/a	£25.79	£28.81	£28.24	£30.20	£30.87	£33.21
40%	n/a	£19.59	£21.84	£21.44	£22.93	£23.42	£25.24
50%	n/a	£15.87	£17.67	£17.36	£18.56	£18.94	£20.46
60%	n/a	£13.39	£14.88	£14.64	£15.65	£15.96	£17.27
70%	n/a	£11.62	£12.89	£12.70	£13.58	£13.83	£15.00

Discussion

Since 2009, PROMs have been used to assess outcomes in four elective surgical procedures in the NHS. This initiative has greatly increased the potential evidence and scope for understanding and improving quality and outcomes for these four surgical procedures. The current government is committed to extending the role of PROMs wherever feasible. This report describes a pilot of one such potential extension. Long-term conditions (LTCs) represent one of the largest major challenges to the health service in terms of the number of individuals concerned and the complexities and costs of providing and improving services. The majority of contact with and care for LTCs happens in primary care. The pilot reported here therefore aimed to investigate the feasibility and potential meaningfulness of collecting PROMs data on LTCs in primary care. The six LTCs were asthma, COPD, diabetes, epilepsy, heart failure and stroke. Patients were recruited through primary care practices in the North West of England and London and were invited to participate in a survey including a generic (EQ5D) and a disease-specific PROM. This discussion summarises the results obtained regarding the feasibility and the meaningfulness of the PROMs data in LTCs and considers the implications of results.

Feasibility

Response rates

The main aim of the pilot was to assess response rates of patients with LTCs to PROMs. Overall the response rate was 38.4% for the cohort baseline, 71.5% for the cohort follow-up and 44.0% for the cross-sectional survey. Although the response rates are not ideal, other NHS based surveys achieve similar response rates. The GP patient survey achieved 39% response rate in 2008/09 (Campbell et al. 2009) and 38% in 2009 (Roland et al. 2009).

Due to ethical constraints on access to non-respondents, no demographic information was available for the majority of non-responders (cohort baseline and cross-sectional surveys) in this pilot and it is not possible to know if there was a non-response bias. However, at cohort baseline, response rates were significantly related to the type of LTC, practice, geographical region, the practice's deprivation and QOF scores. In addition, demographic information from cohort baseline respondents was analysed to identify any differences in response rate at follow up of the cohort. The analyses showed differences in those who consented to follow up for gender, LTC and number of co-morbidities, as well as differences in actually achieved response rates between LTCs, age, ethnicity, region and EQ5D scores. The PROMs programme in elective surgery similarly found differences in response rates for gender, younger patients, deprivation and poorer pre-operative health (Hutchings et al. 2012).

Following the low response rate at cohort baseline (38%), some changes were introduced to the questionnaires, cover letters and information sheets in an attempt to increase response rates for the cross-sectional survey (the second cross sectional survey, carried out one year later on a sub-sample of practices). A slightly higher response rate (44%) was achieved. It was difficult to determine whether modifications to the survey were responsible for the slightly increased response rate compared to other factors. This group of patients were invited into a one off survey rather than a repeated cohort survey

(with reduced burden to them). The practices in the second cross sectional survey were predominantly from the NW, where a higher response rate had been achieved at cohort baseline.

Follow-up rates in the cohort sample were higher. However it is difficult to know to what extent this reflected selection effects in the sense that this group may have been more highly motivated by agreeing to enter the initial survey.

As is discussed below, there were few obvious incentives for patients to participate in the PROMs survey. It had to be made clear to participants that the reason for the study was to assess the feasibility of such data collection. It was therefore clear to patients that their answers played no role in either their own healthcare or in providing evidence about the quality and outcomes of their services.

Overall, the low participation rates in the PROMs survey are a concern. While the achieved results provide information about the health status and health-related quality of life of individuals with long term conditions, the low response rates and observed and other potential influences on participation make it difficult to believe that major inferences about quality of services could be made on the basis of such evidence. It is even less likely that decisions about resources or reimbursement would be acceptable based on evidence from such low response rates.

Participation of practices

This study was carried out via general practice, one of the most likely sources for any future collection of evidence about the health status and health-related quality of life of people with long-term conditions. Some of the challenges encountered in this study may be specific to the methods of recruiting practices into a research study and would not arise if the NHS mandated participation in PROMs collection.

Considerable time and resource was spent in the recruitment of practices. Thirty-three practices had agreed to participate in the cohort baseline. Recruiting practices was supported by the London and North-West PCRNs, the DRN and in London and research nurses in the NW. Nearly half of the practices who initially expressed an interest in the study, did not participate. For the pilot, practices were able to decide whether they participated and could also express an interest in which LTCs they wished to cover.

All but one practice were willing to participate in the second cross-sectional survey, one year after they had participated in the first survey for the cohort study. However, not all practices were able to participate as their clinical system had changed to one that was not compatible with the Apollo search. A number of practices offered to run their own search to identify the patients, but this was not accepted as the Apollo search was one aspect that this pilot aimed to evaluate. Only a small number of practices were affected by this problem at cohort baseline but it was an increasing problem for the cross-sectional survey. Recently, there has been a move to web-based clinical systems and at the time of the study Apollo was not able to work with these. This particularly affected the NW where 7 practices were lost for the cross-sectional survey. Finally, a mistake in the search meant that patients had not been identified correctly for the cross-sectional survey. Although it would have been possible to re-run the search in the affected practices, it would have caused a delay of several months. A joint decision was

made between Oxford and the Department of Health to not repeat the searches as the information provided would have been of limited additional value.

If PROMs are to be used more widely in LTCs following this pilot, further research is needed to improve the logistics and resource required remotely to extract patient identifiers from GP databases. Given on-going modifications and improvements to clinical systems it is likely that logistic and practical considerations of accessing the full range of clinical systems in a more wide-spread mandated system would not be trivial.

Recruitment of patients

To reduce the practices' burden of participating in the pilot, remote search via clinical systems was set up to identify patients diagnosed with one of the LTCs. As outlined in the results, there were problems with identifying eligible patients. First, some mistakes had been made in the search algorithms and the numbers of identified patients were not within the expected QOF estimates. The searches needed to be re-conducted added to the burden of the practices and in some cases, the PROMs were sent to patients who were not eligible. In a more general system, and given the likelihood of a more inclusive approach to long-term conditions, effort would need to be invested further to specify codes, search terms and definitions relating to long-term conditions.

Furthermore, there were additional problems when practices needed to access the lists of identified patients. Hence, any such remote search needs to be piloted thoroughly before being applied on a wider basis. Although effort was made to limit practice work as much as possible, practices did have to send out letters of invitation and initial PROMs for this research study. A more generalizable or mandated system could probably further reduce burden to practices by agreement to release patient information to survey providers.

Once patients had been identified through the search, practice staff checked the lists to exclude any patients who were not thought to be suitable to be sent a survey. The rate of exclusions varied by LTC i.e. 18.1% for asthma, 5.8% COPD, 4.1% diabetes, 46.7% epilepsy, 24.3% heart failure and 20.4% stroke. The particularly high rate of exclusion for epilepsy was related to a high proportion of epilepsy patients having learning difficulties. Only in COPD and diabetes were the levels of exclusions within acceptable limits, the rate of exclusions of the other four LTCs show that conducting a census is a challenging prospect. The feasibility to exclude any unsuitable patients would need to be investigated if PROMs were to be collected on a routine basis in LTCs. The Health Survey for England considers individuals who are not able to give consent or to understand questions and give coherent answers (through language or mental health problems) as non-responders (Mindell et al. 2012). This approach would further reduce the response rate for collecting PROMs data in the LTCs where a high rate of patients was excluded. It is not clear that such a system of exclusion of patients would be required in a more mandated system, compared to a research study.

In this pilot, patients with more than one of the six included LTCs were sent a survey for their rarest LTC only as it was considered too burdensome to ask patients to complete multiple PROMs. A large proportion of patients for each LTC at baseline (42.8% asthma, 77.1% COPD, 76.8% diabetes, 57.2%

epilepsy, 80.3% heart failure and 88.1% stroke patients at cohort baseline) reported one or several additional morbidities. In a sample of people registered at a medical practice, 42.2% of patients had at least one morbidity and 23.2% were multi-morbid, thus challenging the single-disease framework by which most health care operate and suggesting the need for a complementary strategy to provide personalised and comprehensive continuity of care (Barnett et al. 2012). LTCs are not a series of disconnected health problems (Epping-Jordan 2005) and it may be difficult for patients to answer disease-specific questions meaning that a more common approach to assess outcomes may be necessary.

It is likely that a more general or mandated system would not target specific selected long-term conditions and in this sense could be logistically simpler. The target is more likely to be individuals with any of an inclusive list of long-term conditions. Even so, thought and testing of methods would need to be dedicated to how relevant conditions per respondent were captured and linked to survey responses, given the problem of multiple morbidities and the relevance of multiple morbidities to patient experience and quality of services.

Meaningfulness of PROMs for long-term conditions

Data quality

A key issue is how well PROMs are completed amongst those who return questionnaires. The EQ5D performed well with regards to the rate of missing data. It is a short instrument that has been widely tested. Some of the disease-specific measures (particularly QOLIE for epilepsy, MHLFQ for heart failure and SIS for stroke) had high rates of missing data (>10%) on at least one item. This meant that there was a high rate of missing data for some dimensions. A cumulative effect meant high rates of missing data on several dimensions of the QOLIE, MHLFQ and SIS. Data imputation made no difference to the PROMs scores, thus the main effect of missing data was a reduction in the sample size and therefore a reduction of statistical power.

The disease-specific PROMs had been selected on the basis of extensive literature reviews of alternative available PROMs for each of the long term conditions. The best available instruments, in terms of the psychometric properties, were used for asthma, epilepsy, heart failure and stroke in this pilot. The second best instruments were used for diabetes and COPD as the licenses could not be secured for the psychometrically strongest measures. The rates of missing data for three of the disease-specific PROMs may be an indication that these measures are not suitable for this kind of population-based survey.

PROMs scores

In designing the study, an important consideration had been that any more widespread use of PROMs in relation to long-term conditions would be particularly focused on changes in health-related quality of life. Such changes over time could in principle be analysed in relation to services and the role of services in contributing to changes. The survey included long-term conditions which might be expected to vary in their trajectories over time; the natural history of conditions such as COPD and heart failure being more

likely to decline compared to conditions such as asthma and epilepsy, expected to be more stable over long periods of time.

Two approaches to change were built into the study. The cohort component provided evidence of whether there was intra-individual change in health status over one year. The base-line of the cohort and the re-administration of the PROMs survey to a separate but comparable group of individuals in the participating practices provided a kind of simulation of changes over time that might be observed via repeated cross-sectional surveys. The evidence of change revealed by the two approaches are separately considered.

Cohort approach

Differences between cohort baseline and follow-up PROMs scores were found for single sub-scales in the disease-specific PROMs scores for asthma and stroke, and the EQ5D VAS for heart failure. For the majority of other PROMs measures for these three conditions and for all scales and PROMs of the other three conditions no changes were observed over one year. On average the health-related quality of life of all six conditions appeared stable. There may be non-response bias, as between 24.3% (diabetes) and 37.3% (epilepsy) of baseline respondents did not return the follow-up questionnaire. It may be possible that respondents who deteriorated were less likely to participate in the follow-up. For example, in this pilot, epilepsy and heart failure patients who had comorbidities were less likely to consent to follow-up.

It is possible that the absence of change over time in some of the LTCs is due to the PROMs used in the pilot not being sensitive enough to detect change. This seems unlikely. It is commonly observed that for any given condition, disease-specific instruments are more likely to be sensitive to change compared to a generic measure. In this study disease-specific PROMs were more likely than the generic EQD to detect a change in the case of asthma and COPD, when compared to patients' retrospective transition judgements. Similarly, there is evidence on responsiveness for the majority of the disease-specific questionnaires e.g. the DHP for diabetes (Goddijn et al. 1999), the QOLIE-31 for epilepsy (Birbeck et al. 2000) questionnaires and the MHLFQ for heart failure (Harrison et al. 2002). No information on responsiveness has been identified for the SIS (stroke). The PROMS used had been selected on the basis of extensive review work prior to the pilot and responsiveness was one amongst a range of psychometric criteria that were considered in the selection of the instruments. At the time of the reviews, information on responsiveness was available for the majority of the instruments; however the evidence was more mixed and limited for diabetes (DHP), epilepsy (QOLIE-31) and stroke (SIS).

Two disease-specific instruments, those for asthma and COPD, showed the strongest and most consistent correlations with respondents' simple, single transition judgements in the cohort study. It might be argued that, for this environment at least, the min-AQOL for asthma and Clinical COPD Questionnaire for COPD received particular support as being appropriate for population surveillance.

The EQ5D has been shown in previous studies to be responsive to change, although either the time periods for follow-up were longer (Grandy and Fox 2012), participants were at a more advanced stage of disease at the time of the study (Goossens et al. 2011; Wilke et al. 2012), participants were hospitalized (Menn et al. 2010) or had been given a drug intervention (Selai et al. 2005).

For all conditions, in response to a simple retrospective transition question about their condition compared to a year before, substantial proportions of respondents did identify a positive (23.8%) or negative (23.2%) change. Individuals with COPD were particularly likely (40%) to notice deterioration, compared with respondents with asthma diabetes and epilepsy who were more likely to view their condition as stable (59.3% and 58.0% respectively). Stroke respondents were the most likely to have experienced improvement (35.4%). Given modest or limited scope for improvement, compared with say the dramatic improvement in health status observed via PROMs for elective orthopaedic surgical procedures, more work is needed to identify changes that are meaningful changes for PROMs for long term conditions.

Repeated surveys approach

The study was designed to produce two cross-sectional surveys one year apart, the first produced by one half of the individuals with long-term conditions recruited into a cohort study and the second survey from the cross-sectional survey carried out a year later on the other half of eligible individuals with long-term conditions from the same practices. The two surveys to some extent provided a simulation of what might occur if, in any larger scale exercise, samples of individuals with long-term conditions were surveyed via PROMs on an annual basis. For practical reasons that have been explained, the second cross-sectional survey was collected one year later in only 7 practices.

For all scales of all PROMs across conditions, with the one exception of a single sub-scale of the diabetes PROM, no significant difference was observed between the two samples taken from the 7 practices, one year apart. Given the evidence of substantial stability in the health-related quality of life of individuals observed over time, differences observed via two separate surveys in the same practices would have been surprising and might have indicated problems with sampling strategy.

Thus overall both approaches yielded similar results. As earlier argued, it is likely that over the period of a year mean health-related quality of life scores were stable for the six long-term conditions. One possible conclusion is that the interval of a year is too short to expect to detect changes. If so, it may also be an unreasonable period in which to expect the health and social care services to have a detectable impact.

The other possible conclusion would focus on the fact that clearly some individuals across all conditions did report changes in PROMs. More effort is needed to identify what represents a meaningful change amongst such changes and what is merely measurement error. A common method for exploring meaningful change is to relate change scores in PROMs to other judgements of what is valued or noticed by patients. As already noted, in this study, two instruments mini-AQOL and the CCQ had consistent and significant correlations with respondents' judgements of change. These may be more promising candidates by means of which to explore further meaningful change in asthma and COPD.

Exploring differences between practices

It was explicitly not the objective of this study to examine differences between practices in their patients' PROMs. Nevertheless it is an opportunity in a purely exploratory way to examine the

differences that might be observed. The baseline results of the cohort of respondents provided the largest cross-sectional sample within the study. Analyses of these cross-sectional data showed a significant difference on the EQ5D only for asthma, and differences for some or all of the disease-specific PROMs dimensional scores for 4 LTCs (asthma, COPD, diabetes and epilepsy) between practices. However, no significant differences were found for heart failure and stroke between practices. The fact that no significant differences were found for heart failure and stroke may be related to the small sample size and the high rate of missing data. However it is also possible that there were no differences in health status between the practices that participated for heart failure and stroke.

Overall, the majority of the disease-specific PROMs revealed differences between practices not observed via the EQ5D. This may be due to higher sensitivity of disease-specific PROMs.

Although these data show that it is possible to detect at least some differences between practices, it is not possible to know why these differences have occurred. The scores were adjusted for patient-related factors (age, gender, length of time with diagnosis and number of comorbidities) but it was not possible to adjust PROMs scores for practice factors as there was no variation between practice and practice-related factors such as deprivation or QOF scores. Furthermore, no data was available on services received by patients. Data on services received may be necessary to assess whether PROMs data is a useful way of assessing quality of services, for instance whether patients attending an annual review or having a care plan have a better outcome.

In the elective PROMs pilot and the now fully implemented programme, hospitals are used as the main unit of analysis (Browne et al. 2007). The collection of PROMs data in LTCs is only feasible through the involvement of primary care practices, however the size of practices can considerably vary (PROMs pilot example), meaning that sample sizes can be very small in particular for the rarer LTCs. This reduces statistical power and the ability to detect any differences.

If PROMs in LTCs are used to compare practices, possible uses for this type of information would need to be considered as well as the best methods for data presentation. The PROMs data collected in the elective programme is thought to potentially be useful for patient information and choice, managing clinical quality in hospital, commissioners in relation to provider performance and value-for-money and regulation, quality and NHS productivity (Devlin and Appelby 2010). For LTCs, it is unlikely that the data can be used for patient choice of a GP practice. PROMs data may have uses for monitoring practice performance. In the qualitative interviews, stakeholders thought that PROMs may be used for individual patient monitoring or population-monitoring. Some participants believed the latter may help identify problems with care through identifying outliers, and help make commissioning decisions to ultimately improve health care. However, other participants were more sceptical and not sure that PROMs scores are able to reveal problems with quality of care. Only one study could be identified where the effect of giving population level feedback to physicians was compared to a group of physicians (control) who received general information (Weingarten et al. 2000). Both the control and intervention group deteriorated significantly over the course of the study but there was no significant difference in deterioration between the two groups. Given the limited information on the usefulness of population-level data, research is needed to build an evidence base for the value of using PROMs in this way.

Cost of data collection

The estimated cost per completed questionnaire ranged from £34.65 (COPD) to £56.23 (epilepsy) for the cohort survey and £14.96 (COPD) and £24.42 (epilepsy). This assumes that cohort patients have completed both the baseline and the follow-up questionnaires. The cross-sectional survey is a one off survey and therefore cheaper than the cohort. However, the estimated cost in LTCs, even for a cross-sectional type of survey, is considerably higher than for elective surgery (range for the upper estimate per completed questionnaires £6.16 to £9.42 (Browne, Jamieson et al. 2007)). If a cohort type of survey was conducted, the costs would rise if patients were to be followed up for a period longer than 12 months.

Conclusions

The main conclusion to be drawn from this pilot study is that it is possible to obtain responses to PROMs from individuals with long-term conditions via general practice clinical systems at rates that are very similar to those observed for the General Practice Patient Survey (GPPS). The logistics of doing so via remote access is not straightforward and further work would be necessary to make such a system feasible across all practices' clinical systems. Compared to the GPPS, the strength of such a system would be the potential of greater reliability of diagnoses of long-term conditions obtained from GPs' records although the scale of the greater reliability over self-reported diagnoses in GPPS would need to be assessed. It is likely that many of the logistic problems encountered in this research study, for example difficulties with changes in practices' clinical systems, the burden on practices of checking extracted lists and overseeing dispatch of questionnaires, would eventually be overcome in a larger roll-out or mandated system.

Some more broader considerations arise from conducting the current pilot study.

To provide more complete (in terms of coverage) evidence of health-related quality of life of individuals with long-term conditions, the invitation to respondents to contribute self-reports of health needs to be more engaging in the sense of serving a purpose. A greater sense of point or purpose to completing PROMs in the context of primary care could emerge in three distinct ways, not mutually exclusive. Firstly patients could find the information valuable and informative, for example by providing feedback of their progress over time or in comparison with other patients. Secondly, they could find the information in PROMs helpful in preparing for consultations with healthcare providers or as a part of regular review or assessment. Thirdly, it is conceivable that patients would value providing information if it were truly the case that PROMs data were used to provide evidence of quality or performance of services. The NHS and indeed all other healthcare systems are a long way from being able to support any of these possible uses of PROMs for long-term conditions that might enhance patient engagement. Experiments are needed to test whether PROMs can better inform patients about their progress, support communication of need or facilitate contributions to quality assessment.

PROMs for long-term conditions also need to be valued in the sense of supporting decisions made by healthcare professionals and providers. Initially trials to evaluate the benefits to health professionals of extra feedback from patients via PROMs were negative. More recently some more encouraging

evidence is beginning to emerge. Demonstration studies are needed to test benefits to both healthcare providers as well as patients of regular collection of health status via PROMs.

It is apparent that even if PROMs could be made more relevant to patients and their healthcare providers, in the context of long-term conditions PROMs scores cannot be as easily traced to inputs of services as can in principle be achieved with elective surgical procedures. Because of the range, diversity of sources and intermittent nature of services to individuals with long-term conditions, it will be challenging to use evidence from PROMs in a diagnostic way to high-light specific aspects of services requiring improvement. Instead it may be more realistic to see PROMs high-lighting or drawing attention to matters of concern to patients and stimulating discussion and debate within whole local health economies about options to bring about change.

PROMs are well established methods of capturing what matters to patients. Experiments are needed to test whether and how they can better support decision-making by patients, healthcare providers and commissioners. In the same way the form and content of PROMs may also require experiment and change. It might be argued that the PROMs included in this study were not specifically developed for the uses currently being considered in government policy. PROMs which included domains such as sense of control and confidence in self-management may need to be developed. They might be more relevant to policies for long-term conditions and hence more responsive to changes over time arising from creative development of services for long term conditions. Above all, given the evidence of increased multi-morbidity amongst those with long-term conditions, forms of PROM are needed that are neither the very broad-brush aspects of health of generic measures nor the very specialized disease-specific measures that will not work for the growing numbers coping with multiple conditions.

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Disclaimer

The views and opinions expressed in this are those of the authors and do not necessarily reflect those of the NHS or the Department of Health.

Appendices

Appendix 1: Letters and information sheets for each survey

a) Cohort baseline cover letter

{Address GP surgery}

Dear Patient,

Our practice has been asked to take part in a study called '*Asking you about your health*' which is being undertaken by the University of Oxford. The purpose of this study is to assess how helpful questionnaires are as a way of asking people with a long-term condition about their health. You are invited to participate in this study as you have been identified from the general practice database as having {relevant LTC}.

If you are willing to take part in the study, please complete the enclosed questionnaire and return it to the research team in the pre-paid envelope. Your name and address have not been made available to the research team by our practice. If you participate, the research team will ask you for your name and address, to be able to send you a follow-up questionnaire in a year. Your decision concerning whether or not you will participate in the study is entirely voluntary and will not affect the medical care you receive. You have the right to withdraw from the study at any point without giving a reason.

Further information about the study can be found in the enclosed information sheet. If you have any questions, please contact the research team on freephone 0800 9151 664 or email YourHealth@dphpc.ox.ac.uk.

Thank you very much for taking the time to read this letter.

Yours sincerely,

{GP}

Version 2, 14.04.2010
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/10

b) Cohort baseline information sheet

UNIVERSITY OF OXFORD
Department of Public Health
Old Road, Oxford OX3 7LF

Asking you about your health
{relevant LTC}

INFORMATION SHEET

What is the '*Asking you about your* health' study about?

This study aims to assess whether questionnaires are a useful way of collecting health information. If this approach is found to be acceptable, it may be used to inform the NHS about the quality of its services. Individuals with one of six different long-term conditions are included in the study. The conditions are asthma, chronic obstructive pulmonary disease (COPD), diabetes, epilepsy, heart failure and stroke.

Who is conducting the study?

The research is carried out by the Department of Public Health, University of Oxford. The team is led by Professor Ray Fitzpatrick, and the project manager is Dr Michele Peters. The study is funded by the Department of Health (London) under their Policy Research Programme.

Why have I been invited to participate?

You have been invited to participate in this study as you have been identified from the database of your general practitioner practice as having {relevant LTC}. The process of identifying you as a potential participant has been conducted by a computer program, which identifies you without making any of your details known to anyone apart from the staff at your GP practice. This means that your details have not been made available to the research team by your practice.

How do I participate?

To participate, you need to complete and return the enclosed questionnaire to the research team in the enclosed pre-paid envelope. The questionnaire will take about 20 minutes to complete. If you agree to participate in the survey, you will be asked to give your name and address in order to be sent a second questionnaire in a year's time. On your questionnaire, there will be a unique identifier number, which allows the research team to compare your responses from the two questionnaires. You have the right to withdraw from the study at any point without giving a reason.

What will happen to the information I give?

Any personal information (such as your address) will be stored securely, and computer data will be password protected. Any personal information will only be accessible to the research team. Once your participation in the study is completed, the files containing your personal information and the unique identifying number linking you to your replies will be destroyed. This means that it will not be possible to identify you in any of the reports.

(please turn over)

Version 2, 14.04.2010
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/10

The results of the study will be used to assess how helpful questionnaires are as a way of asking people about their health. The findings will be reported back to the Department of Health (London), published in the scientific literature and presented at conferences.

It is possible that authorised members of the University of Oxford may audit the study to ensure compliance with the NHS research governance framework.

As a result of the questionnaire, there will be no feedback to individuals about their health. However, a summary of the findings will be sent to participating GP practices to display. You will also be able to view a summary of the study findings online at http://www.publichealth.ox.ac.uk/research/hsru/asking-you-about-your-health.

What do I do if there is a problem?

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part. However, the University of Oxford has arrangements in place to provide for harm from participation in the study for which the University is the Research Sponsor. If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact the research team or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 857939 or the head of CTRG, email heather.house@admin.ox.ac.uk.

Who can I contact if I have any questions?

If you have any questions or would like any further information before you agree to take part, please contact the research team (freephone 0800 9151 664 or email YourHealth@dphpc.ox.ac.uk). Further information can be found at http://www.publichealth.ox.ac.uk/research/hsru/asking-you-about-your-health.

c) Cohort follow-up cover letter

UNIVERSITY OF OXFORD
Department of Public Health
Old Road, Oxford OX3 7LF

Asking you about your health
{relevant LTC}

«ParticipantTitle» «ParticipantForename» «ParticipantSurname»
«ParticipantAddressLine1»
«ParticipantAddressLine2»
«ParticipantAddressLine3»
«ParticipantTown»
«ParticipantCounty» «ParticipantPostcode»

«QuestionnaireSentDate2012»

Dear «ParticipantTitle» «ParticipantSurname»,

A year ago, you completed a questionnaire for the '*Asking You About Your Health*' study conducted by the University of Oxford. As you may recall, the study involves you completing questionnaires about your health in relation to your {relevant LTC} at two separate times. We are now sending you the second questionnaire. Completing the questionnaire twice allows us to find out whether your health has changed. We hope that you will be able to participate, as your answers will help us decide whether questionnaires are a useful way of asking people about their health.

Enclosed you will find the questionnaire and a pre-paid return envelope. Further information about the study and how to take part is on the front of the questionnaire. Each questionnaire has a unique number, which allows us to link your answers from the two questionnaires. Any link between your personal information and this number will be kept confidential during the study and will be deleted at the end of the study.

A summary of the findings will be made available on our study webpage http://www.publichealth.ox.ac.uk/research/hsru/asking-you-about-your-health and will also be sent to your GP practice for display.

If you have any further questions, please do not hesitate to contact us on freephone 0800 9151 664 or email YourHealth@dph.ox.ac.uk .

Yours sincerely,

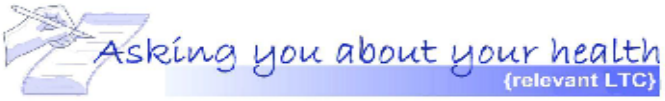
Dr Michele Peters

Version 2, 14.04.2010
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/10

«QuestionnaireNo»

d) Reminder letter (cohort baseline and cross-sectional)

{Address GP surgery}



Dear Patient,

I wrote to you recently inviting you to take part in the '*Asking You About Your Health*' study being conducted by the University of Oxford. The purpose of the study is to assess how helpful questionnaires are as a way of asking people with one of a number of long-term conditions about their health. You were invited to participate in this study as you have been identified from the general practice database as having {relevant LTC}.

If you have already returned the completed questionnaire, I would like to thank you for your participation. If you have not yet returned the completed questionnaire, there is still time to do so by returning your completed questionnaire. For another copy of the questionnaire, please contact the research team on freephone 0800 9151 664 or email YourHealth@dph.ox.ac.uk.

If you would prefer not to participate, the research team would be very interested in the reasons for your decision. If you are happy to discuss this decision with the research team, please call freephone 0800 9151 664 or email YourHealth@dph.ox.ac.uk.

Your name and address have not been made available to the research team by our practice. Your decision concerning whether or not you participate will not affect the medical care you receive. You have the right to withdraw from the study at any point without giving a reason.

If you have any questions, please contact the research team (freephone 0800 9151 664 or email YourHealth@dph.ox.ac.uk).

Thank you very much for taking the time to read this letter.

Yours sincerely,

{GP}

Version 2, 14.04.2010
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/10

e) Cohort follow-up reminder

UNIVERSITY OF OXFORD

Department of Public Health
Old Road, Oxford OX3 7LF

Asking you about your health (relevant LTC)

«ParticipantTitle» «ParticipantForename» «ParticipantSurname»
«ParticipantAddressLine1»
«ParticipantAddressLine2»
«ParticipantAddressLine3»
«ParticipantTown»
«ParticipantCounty» «ParticipantPostcode»

Dear «ParticipantTitle» «ParticipantSurname»,

A year ago, you completed a questionnaire for the '*Asking You About Your Health*' study conducted by the University of Oxford. As you may recall, the study involves you completing a questionnaire about your health. Your answers will help us decide whether questionnaires are a useful way of asking people with one of a number of long-term conditions about their health. You were invited to participate in this study as you were identified from your general practice database as having «ConditionName».

Two weeks ago, we sent you a questionnaire to complete and a pre-paid return envelope. If you have returned your completed questionnaire, we would like to thank you for your participation. If you have not yet returned the questionnaire, there is still time to do so.

Please contact us if you have any questions or if you need another copy of the questionnaire (freephone 0800 9151 664 or email YourHealth@dph.ox.ac.uk).

Yours sincerely,

Dr Michele Peters

Version 2, 14.04.2010
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/10

«QuestionnaireNo»

Appendix 2: Dimensions and scores of the PROMs

Table 1 Appendix 2: Dimensions and scores of the PROMs used

Generic PROM		
PROM	**Dimensions (n items)**	**Score**
EQ-5D (5 items)	EQ5D Health status	0-1 where 0 is 'worst health state' and 1 is 'full health'
	EQ5D Visual Analogue Scale (VAS)	0-100 where 0 is 'worst health state' and 100 is 'full health'
Disease-specific PROMs		
PROM	**Dimensions (n items)**	**Score**
Mini Asthma Quality of Life Questionnaire (AQOL) (15 items)	Total score (all 15 items)	1-7 where 1 is 'severe impairment' and 7 is 'no impairment'
	Activity limitations (4 items)	
	Symptoms (5 items)	
	Emotional function (3 items)	
	Environmental stimuli (3 items)	
Clinical COPD questionnaire (CCQ) (10 items)	Total score (all 10 items)	0-6 where 0 'very good health status' and 6 'extremely poor health status'
	Symptoms (4 items)	
	Functional state (4 items)	
	Mental state (2 items)	
Diabetes Health Profile (DHP) (18 items)	Psychological distress (6 items)	0-100 with a higher score representing higher dysfunction
	Barriers to activity (7 items)	
	Disinhibited eating (5 items)	

Table 1 Appendix 2 (continued): Dimensions and scores of the PROMs used

PROM	Dimensions (n items)	Score
Quality of Life in Epilepsy Inventory (QOLIE) (31 items) NB we used 30 items as the VAS scale was not included	Total score (all 31 items)	0-100 with higher scores reflecting better quality of life
	Overall quality of life (2 items)	
	Seizure/ worry (5 items)	
	Emotional well-being (5 items)	
	Energy/ fatigue (4 items)	
	Cognitive (6 items)	
	Medication effects (3 items)	
	Social function (5 items	
Minnesota Living with Heart failure Questionnaire (MLHFQ) (21 items)	Total score (all 21 items)	0-105 with a higher score meaning more impairment
	Physical dimension (8 items)	0-40 with a higher score meaning more impairment
	Emotional dimension (5 items)	0-25 with a higher score meaning more impairment
Stroke Impact Scale (SIS) (60 items)	Strength (4 items)	0-100 with higher score meaning higher disability
	Memory (7 items)	
	Emotion (9 items)	
	Communication (7 items)	
	ADL (10 items)	
	Mobility (9 items)	
	Hand function (5 items)	
	Handicap (8 items)	
	Physical dimension (hand function, strength, mobility and ADL, i.e. 28 items)	
	Recovery scale (1 item, VAS)	

Appendix 3: Letter and consent form for qualitative interviews

a) Cover letter

Department of Public Health

Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel: +44 (0)1865 289428, email: michele.peters@dph.ox.ac.uk

Asking you about your health
long-term conditions

PROMs pilot on long-term conditions in primary care

Dear {Stakeholder name}

I am writing to invite you to participate in our research study '*Asking You About Your Health*' which is being conducted by the University of Oxford. The study is funded by the Department of Health as part of their Policy Research Programme. The purpose of the study is to assess how helpful patient reported outcome measures (PROMs), in the form of short questionnaires, are as a way of asking people with a long-term condition about their health. We are interested in your views on the process of collecting PROM information and the usefulness of the data.

I am writing to ask if we could talk to you briefly about the study by means of an interview. The interview would be arranged at your convenience and can be conducted either by telephone or in person. Your views would be very valuable to us. We will produce a summary of the study and results for you to read prior to the interview.

If you are willing to take part, please complete and return the enclosed consent form. You will be contacted by Elizabeth Gibbons the research interviewer to arrange the interview.

Further information about the study can be found in the enclosed information sheet or can be found at http://www.publichealth.ox.ac.uk/units/hsru/Askingyouaboutyourhealth . If you have any questions, please contact Elizabeth Gibbons on telephone number 01865 289405 or email Elizabeth.gibbons@dph.ox.ac.uk).

Thank you very much for taking the time to read this letter.

Yours sincerely,

Dr Michele Peters
Project manager

Version 1, 25.01.2012
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/101

b) Consent form

UNIVERSITY OF OXFORD

Department of Public Health
Old Road, Oxford OX3 7LF

Asking you about your health
long-term conditions

CONSENT FORM

PROMs pilot on long-term conditions in primary care

Names of researchers: Prof. Ray Fitzpatrick, Prof. Crispin Jenkinson, Dr Michele Peters, Dr Helen Doll, Ms Elizabeth Gibbons, Ms Helen Boyce

Please initial each box

1. I confirm that I have read and understand the invitation letter dated 25/01/2012 (version 2) and have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I confirm that I have read and understand the information sheet dated 25/01/2012 (version 2) and have had the opportunity to ask questions. ☐
3. I understand that my participation in the interview is voluntary and that I am free to withdraw at any time without giving a reason, without my legal rights being affected. ☐
4. I understand that any personal information shared with the research team will be kept confidential. Authorised members of the University of Oxford may audit the study to ensure compliance with the NHS research governance framework. ☐
5 I agree to the interview being audio-recorded ☐
6 I agree to take part in the above study ☐

Version 1, 25.01.2012
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/101

My preferred way to be interviewed would be (please tick): By telephone ☐

In person ☐

If you agree to be interviewed, please sign this form and return it to the research team in the enclosed pre-paid envelope.

So we can contact you, please provide us with

a telephone number _____ Best time to telephone _____

OR an email address _____

Name {_____} Signature _____

Date ___/___/___

Version 1, 25.01.2012
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/101

Appendix 4: Cohort baseline summary of findings (qualitative interviews)

Pilot study of patient-reported outcome measures (PROMs) in long-term conditions in primary care

A Department of Health funded research project

Michele Peters, Crispin Jenkinson, Elizabeth Gibbons and Ray Fitzpatrick

May 2012

Department of Public Health

Old Road Campus

Oxford OX3 7LF

Background

Ensuring positive outcomes for patients is a key feature of current government policy and improving quality of life of patients with long-term conditions (LTCs) is a key domain of the Department of Health Outcomes

Framework. The use of short questionnaire in the form of patient-reported outcome measures (PROMs) may present a method to gain more information on quality of life and outcomes in LTCs.

The study is funded by the Department of Health and carried out by the Department of Public Health, University of Oxford. The team is led by Professor Ray Fitzpatrick, and the project manager is Dr Michele Peters.

Aim

The aim is to investigate the feasibility and acceptability of using PROMs in people with LTCs in primary care. This is achieved by assessing the response rates between practices and conditions, assessing completeness of data and comparing PROMs scores between practices. The LTCs are asthma, chronic obstructive pulmonary disease (COPD), epilepsy, diabetes, heart failure and stroke.

Methods

This pilot study involves two surveys in which PROMs are administered either as repeated cross-sectional surveys or as cohort-type surveys. The data for the cohort survey is collected twice, one year apart. The data presented in this report presents a summary of the findings from the cohort baseline survey which was conducted September 2010 and June 2011.

Thirty-three practices from London and the North-West of England (NW) participated. A total of 4485 patients (1334 asthma, 567 COPD, 1121 diabetes, 525 epilepsy, 520 heart failure and 418 stroke patients) were invited into the cohort baseline survey. Eligible patients were identified by a remote and automatic search of the GP databases conducted by Apollo Medical Systems Ltd. Patients were eligible if they were aged 18 years or over and had a diagnosis of either asthma, COPD, diabetes, epilepsy, heart failure or stroke according to Quality and Outcomes Framework (QOF) criteria. Patients with multiple LTCs were sent a questionnaire for the rarest of LTC. The search generated a list with eligible patients for each condition on the practices computer. The practices had the opportunity to exclude patients whom they did not consider suitable to receive a questionnaire. The practices sent the remaining patients practice were sent a questionnaire consisting of a core of two PROMs instruments, one generic and one disease-specific and a small number of additional demographics and comorbidity questions. A reminder was sent two weeks after the mailing of the questionnaire.

The data analyses compare response rates and mean adjusted PROMs scores for each LTC. Mean PROMs scores were adjusted for age, gender, time since diagnosis and number of comorbidities. Analysis of covariance (ANCOVA) was used with the level of significance set at 0.05.

This report outlines the results for the six LTCs including information about participating practices, response rates, missing data and PROMs scores. First, a short summary of the results is given for each LTC. More details on the methods and the full results can be found in the appendices.

Results- Asthma

- The questionnaires used were the EQ5D and the Asthma Quality of Life Questionnaire (AQOL).
- Ten practices (5 in London and 5 in the NW) participated for asthma, and 1334 questionnaires were sent to achieve an overall response rate of 30% (n=400). The response rate in the NW was higher (33%, n=313) than in London (23%, n=87). Five respondents were excluded from the analysis as they reported not having asthma.
- The rate of missing data for both the EQ5D and most of the AQOL dimensions was below 5%. The 'total quality of life' dimension of the AQOL was missing for 7.1% (n=28) of participants.
- Demographics
    - 234 respondents were female (60.3%), 209 (55.2%) in employment, 352 (91.7%) white and 310 (78.5%) from the NW.
    - 127 (32.6%) were aged between 18 and 44 years, 160 (41.1%) between 45 and 64 years, 59 (15.2%) between 65 and 74 years and 43 (11.1%) 75 years or above.
    - Mean time since diagnosis was 22.5 years (sd 16.3).
    - 226 (57.2%) did not report any comorbidities, 105 (26.6%) reported one comorbidity and 64 (16.2%) reported two or more comorbidities.
- Generic health status assessed by EQ5D
    - The majority reported no problems with walking, self-care, usual activities, pain or discomfort, or feeling anxious or depressed.
    - The most commonly reported problem was pain or discomfort (moderate / severe) by 133 patients (33.7%).
    - The overall adjusted mean score for the EQ5D York tariff was 0.83 (CI 0.81-0.87) and for the VAS 73.74 (CI 71.52-76.00). (score range for York tariff is 0-1 and VAS 0-100, with a higher score meaning lower quality of life).
    - The adjusted mean scores of the York Tariff and the VAS were significantly different by practice (p=0.002 for both).
- Asthma-specific health status assessed by AQOL
    - The three most commonly reported problems occurring at least 'a good bit of the time' were 'bothered or avoiding cigarette smoke' (n=113, 28.8%), 'bothered by or avoiding dust' (n=100. 25.4%) and 'experienced wheeze in the chest' (n=61, 18.2%).
    - The overall adjusted mean scores were 5.33 (CI 5.17-5.50) for 'symptoms', 5.39 (CI 5.20-5-59) for 'emotional functioning', 5.29 (CI 5.09-5.48) for 'environment', 5.93 (CI 5.79-6.08) for 'activity limitations' and 5.51 (CI 5.36-5.67) for 'total quality of life'. (score range 1 = severe impairment to 7 = no impairment).
    - The adjusted mean scores were significantly different between practices for four AQOL dimensions, including 'symptoms' (p=0.001), 'emotional functioning' (p<0.001), 'environmental stimuli' (p<0.001) and 'total quality of life' (p=0.027).
    - Only 'environmental stimuli' was significantly different between London and the NW (p<0.001).

Results COPD

- The questionnaires used were the EQ5D and the Clinical COPD Questionnaire (CCQ).
- Sixteen practices (8 in London and 8 in the NW) participated for COPD and 568 questionnaires were sent to achieve an overall response rate of 49% (n=279). The response rate in the NW was higher (54%, n=169) than in London (42%, n=110). Four participants were excluded from the analysis as they reported not to have been diagnosed with COPD.
- The rate of missing data was below 5% for individual items of the EQ5D and the CCQ. Dimensions scores could be calculated for the majority of participants (i.e. <10% missing), with the highest missing rated being 13.5% (n=37) for 'total quality of life' on the CCQ.
- Demographics
    - 125 (46.0%) were male and 147 (54.0%) were female
    - 160 (61.3%) were retired, 270 (98.5%) white and 167 (60.7%) from the NW.
    - 61 (22.2%) participants were aged between 18 and 63 years, 87 (31.6%) 65 to74 years and 127 (46.2%) 75 years or more.
    - Mean time since diagnosis was 8.6 years (SD 9.6).
    - 63 (22.9%) participants did not report any comorbidities, 87 (31.6%) reported on comorbidity and 125 (45.5%) reported 2 or more comorbidities.
- Generic health status assessed by the EQ5D
    - The majority of patients reported no problems with self-care (n=196, 71.3%), or feeling anxious or depressed (n=152, 55.3%).
    - 177 (64.6%) reported some problems with walking
    - 171 (63.3%) reported at least some problems with usual activities
    - 170 (62.0%) reported at least moderate pain or discomfort.
    - The overall adjusted mean score for the EQ5D York tariff was 0.59 (CI 0.52-0.67) and for the VAS 59.29 (CI 53.57-65.01) (score range for York tariff is 0-1 and VAS 0-100, with a higher score meaning lower quality of life).
    - The adjusted mean scores of the York Tariff and the VAS were not significantly different by practice or by region.
- COPD-specific health status assessed by the CCQ
    - The three most commonly reported problems occurring at least 'many times' were 'sort of breath doing physical activity' (n=129, 48.9%), 'concerned about getting a cold or breathing getting worse' (n=105. 39.5%) and 'coughing' (n=106, 39.1%).
    - The overall adjusted mean scores were 3.00 (CI 2.59-3.40) for 'symptoms', 2.30 (CI 1.89-2.70) for 'functional state', 2.44 (CI 1.92-2.96) for 'mental state' and 2.58 (CI 2.20-2.96) for 'total quality of life' (score range between 0 =very good health status and 6 =extremely poor health status).
    - The adjusted mean scores were significantly different between practices for two CCQ dimensions, including 'symptoms' (p=0.001), and 'total quality of life' (p=0.038).
    - Only 'functional status' was significantly different between London and the NW (p=0.035).

Results Diabetes

- The questionnaires used were the EQ5D and the Diabetes Health Profile (DHP)
- Ten practices (5 in London and 5 in the NW) participated for diabetes and 1121 questionnaires were sent to achieve an overall response rate of40.0% (n=448). The response rate in the NW was higher (50.1%, n=272) than in London (30.4%, n=176).
- There was a low rate of missing data for both the EQ5D and the DHP with less than 5% missing for all individual items and dimensions apart from the DHP 'barriers to activity' dimension (n=31, 6.9%).
- Demographics
    - 243 (56.6%) respondents were male and 186 (43.4%) were female.
    - 204 (48.3%) were retired and 114 (27.1%) were in employment (n=114, 27.1%).
    - 330 (76.6%) were white. The most represented ethnic minority was Asian/Asian British (n=80, 18.6%).
    - 272 (60.7%) respondents came from the NW.
    - 29 (6.7%) were aged 18 to 44 years, 153 (35.3%) 45 to 64 years, 124 (28.6%) 65 to 74 years and 127 (29.3%) 75 years or more.
    - Mean time since diagnosis was 9.6 years (SD 8.6).
    - 104 (23.2%) did not report any comorbidities, 151 (33.7%) reported one comorbidity and 193 (43.1%) reported two or more comorbidities.
- Generic health status assessed by the EQ5D
    - The majority of patients reported no problems with walking (n=245, 55.4%), with self-care (n=374, 84.4%), performing usual activities (n=276, 62.6%) or feeling anxious or depressed (n=292, 66.5%).
    - The most commonly reported problem was at least moderate pain or discomfort (n=240, 54.0%).
    - The overall adjusted mean score for the EQ5D York tariff was 0.72 (CI 0.69-0.75) and for the VAS 67.60 (CI 65.46-69.74) (score range for York tariff is 0-1 and VAS 0-100, with a higher score meaning lower quality of life).
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS by practice
- Diabetes-specific health status assessed by the DHP
    - The three most commonly reported problems were 'quite likely or very likely to eat more' (n=211, 47.6%), and feeling 'usually or always' that 'food controls life' (n=129, 29.2%) or that they are 'tied to meal times' (n=111, 25.1%).
    - The overall adjusted mean scores were 20.15 (CI18.00-22.30) for 'psychological distress', 23.94 (CI 21.60-26.28) for 'barriers to activities' and 34.65 (CI 32.23-37.08) for 'disinhibited eating. (score range from 0 to 100 with a higher score representing higher dysfunction)
    - The adjusted mean scores were significantly different between practices for all three DHP dimensions, including 'psychological distress' (p=0.001), 'barriers to activities (p<0.001)) and 'disinhibited eating (p=0.004)
    - Significant differences were found between London and the NW for 'barriers to activities' (p=0.001) 'psychological distress' (p=0.021).

Results Epilepsy

- The questionnaires used were the EQ5D and the Quality of Life in Epilepsy Inventory (QOLIE).
- 23 (13 in London and 10 in the NW) participated for epilepsy and 525 questionnaires were sent to achieve an overall response rate of 34.3% (n=180). The response rates in London and the NW were similar (35.4%, n=67 and 33.6%, n=113 respectively).
- There was a low rate of missing data for the EQ5D (<5% for both the York Tariff and VAS). The rate of missing data on the QOLIE was low except for 3 items ('medication caused trouble with driving' (28.3%), the 'quality of life scale' (15.0%) and 'bothered by work limitations (10.6%)). This led to a high rate of missing scores for 'social function' (n=58, 32.2%) and for 'overall quality of life' (n=31, 17.2%). The rate of missing data for the other 5 QOLIE dimensions was below 10%.
- Demographics
  - 83 (46.6%) participants were male and 95 (53.4%) were female. 64 (93.2%) were white and 113 (62.8%) were from the NW.
  - 52 (30.8%) participants were in employment, 39 (32.1%) permanently sick/ disabled (n=39, 32.1%) and 46 (27.2%) retired.
  - 54 (30.2%) were aged 18 to 44 years, 67 (37.4%) 45 to 64 years, 36 (20.1%) 65 to 74 and 22 (12.3%) 75 years or more.
  - Mean time since diagnosis was 22.8 years (SD 16.3).
  - 77 (42.8%) did not report any comorbidities, 41 (22.8%) reported one comorbidity and 62 (34.4%) two or more comorbidities.
- Generic health status assessed by the EQ5D
  - The majority reported no problems with walking (n=108, 61.0%), with self-care (n=142, 80.7%), performing usual activities (n=100, 56.2%) or pain/ discomfort (n=91, 50.8%).
  - The most commonly reported problem was at least moderate anxiety or depression (n=91, 51.1%).
  - The overall adjusted mean score for the EQ5D York tariff was 0.74 (CI 0.68-0.77) and for the VAS 67.25 (CI 63.96-70.54) (score range for York tariff is 0-1 and VAS 0-100, with a higher score meaning lower quality of life).
  - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS by practice or between London and the NW
- Epilepsy-specific health status assessed by the QOLIE
  - The three most commonly reported problems were feeling bothered by 'memory difficulties' (n= 69, 39.2%) or by 'work limitations' (n=61, 37.9%); and 'having a lot of energy' only 'a little or none of the time' (n=59, 33.6%).
  - The overall adjusted mean scores were 65.09 (CI59.55-70.62) for 'seizure worry', 65.95 (CI62.55-69.36) for 'overall quality of life', 66.64 (CI63.22-70.01) for 'well-being', 54.06 (CI 50.67-57.45) for 'energy / fatigue', 61.74 (CI57.60-65.87) for 'cognitive functioning', 66.45 (61.41-71.49) for 'medication effects', 71.19 (CI 64.73-77.66) for 'social functioning' and 66.00 (CI 61.59-70.41) for 'total quality of life' (score range from 0 to 100 with higher scores reflecting better quality of life).

- The adjusted mean scores were significantly different between practices for 3 QOLIE dimensions, including ‘overall quality of life (p=0.019), ‘emotional well-being’ (p=0.013), ‘energy / fatigue’ (p=0.012).
- No significant differences were found between London and the NW on any of the QOLIE dimensions.

Results Heart Failure

- The questionnaires used were the EQ5D and the Minnesota Living with Heart Failure Questionnaire (MLHFQ)
- Twenty practices (11 in London and 9 in the NW) participated and 520 questionnaires were sent to achieve an overall response rate of 50.4% (n=262). The response rate was similar in London and the NW (28.8%, n=79 and 50.4%, n=183 respectively). Three questionnaires were excluded from the analysis as the respondents reported not having been diagnosed with heart failure.
- The rate of missing data for the EQ5D York Tariff and VAS were 5.4% and 5.0% respectively. The rate of missing data for individual was low except for 'difficulty with sexual activities' (14.7%) participants and 'difficulty working to earn a living' (12.7%).This meant that dimensions scores were missing for 30.5% on the 'overall quality of life' dimension. Missing data for the other dimensions was below 10%.
- Demographics
    - The majority of respondents were male (n=161, 36.4%), retired (n=160, 66.9%), white (n=235, 92.9%) and from the NW (n=182, 70.3%).
    - The mean time since diagnosis was 11.4 years (SD 11.0).
    - 37 (14.5%) were aged between 18 and 64 years, 73 (28.5%) 65 to 74, and 146 (57.0%) 75 years or more.
    - 51 (19.7%) did not report any comorbidities, 67 (25.9%) reported one comorbidity and 141 (54.4%) reported two or more comorbidities.
- Generic health status assessed by the EQ5D
    - The majority of heart failure patients reported no problems with self-care (n=178, 69.8%) or feeling anxious/ depressed (n=132, 53.0%)
    - At least some problems were reported for walking (n=186, 72.1%), usual activities (n=179, 70.2%) and pain and discomfort (n=145, 57.3%).
    - The overall adjusted mean score for the EQ5D York tariff was 0.59 (CI 0.53-0.66) and for the VAS 59.46 (CI 54.94-63.98) (score range for York tariff is 0-1 and VAS 0-100, with a higher score meaning lower quality of life).
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS between practices or regions (London vs. NW).
- Heart failure-specific health status assessed by the MLHFQ
    - The three most commonly reported problems were shortness of breath (n=142, 56.1), difficulty with walking about or climbing stairs (n=140, 55.0%) and difficulty with going places away from home (n=133, 53.0%). (NB a problem was interpreted as a score of 3 or more on a scale that asked participants to rate how much heart failure prevented them from living the life they wanted. The scale ranged from 1 to 5 where 1 was 'no' and 5 was 'very much').
    - The overall adjusted mean scores were 46.62 (CI40.74-52.50) for 'total quality of life' (score range 0-105), 20.96 (CI18.31-23.63) for the 'physical dimension' (score range 0-40) and 10.91(9.22-12.60) for the 'emotional dimension' (score range 0-25). A higher score means more impairment.
    - No significant differences were found for the adjusted mean scores between practices and regions (London vs. NW).

Results Stroke

- The questionnaires used were the EQ5D and the Stroke Impact Scale (SIS)
- 19 practices (12 in London and 7 in the NW) participated for stroke and 419 questionnaires were sent to achieve an overall response rate of 36.4% (n=152). The response rate in the NW was higher (44.0%, n=84) than in London (30.0%, n=68). One questionnaire was excluded from the analysis as the respondent reported not having had a stroke.
- There was a low rate of missing data for the EQ5D York Tariff (4.0%) but the VAS item was missing for 13.3% of respondents. The rate of missing data on the SIS was low except for 'limited in work' (22.5%), 'limited participation in religious activities'(21.2%),four strength items (13.2 -18.5%) and for three social items (10.6-11.3%). This meant that dimensions scores could not be calculated for 35.1% of participants for 'handicap', 20.5% for 'strength', 17.9% for 'emotion', 14.6% for 'mobility', 13.2% for 'hand function', 9.3% for memory, 8.6% for 'communication', and34.4% for the 'physical domain'.
- Demographics
    - The majority of respondents was male (n=81, 61.1%), retired (n=84, 57.5%) or in either full-time or part-time employment (n=29, 30%); white (n=133, 93.0%) and from the NW (n=83, 55.0%).
    - The mean time since their stroke was 7.3 years (SD 6.1).
    - 49 (33.1%) were aged 18 to 64 years, 41 (27.7%) 65 to 74 years and 58 (39.2%) 75 years or more.
    - 18 (11.9%) did not report any comorbidities, 53 (35.1%) reported one comorbidity and 80 (53.0%) reported two or more comorbidities.
- Generic health status assessed by the EQ5D
    - The majority reported no problems with self-care (n=104, 70.7%), and being anxious/ depressed (n=75, 51.0%).
    - The majority reported at least some problems with walking (n=88, 59.4%), usual activities (n=77, 53.1%) and pain and discomfort (n=85, 57.8%).
    - The overall adjusted mean score for the EQ5D York tariff was 0.56 (CI 0.48-0.65) and for the VAS 62.29 (CI 56.01-68.57) (score range for York tariff is 0-1 and VAS 0-100, with a higher score meaning lower quality of life).
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS between practices or regions (London vs. NW)
- Stroke-specific health status assessed by the SIS
    - The three most commonly reported problems were enjoying things only a little or none of the time (n=71, 50.0%), difficulty with walking fast (n= 59, 40.7%) and difficulty with climbing several flights of stairs (n=57, 40.1%). (NB the latter two were interpreted as a problem if they were rated 'could not do at all' or 'very difficult' on the questionnaire).
    - The overall adjusted mean scores were 60.41 (CI52.24-68.59) for 'strength', 64.85 (CI55.46-74.24) for 'hand function', 74.02 (CI67.01-81.04) for 'mobility', 69.92 (CI 62.66-77.17), 77.51 (CI 69.34-85.68) for 'activities of daily living', 80.45 (CI71.65-89.25) for 'communication', 64.60 (CI 58.85-70.36) for 'emotion', 63.97 (CI 52.19-75.75) for 'handicap', 70.98 (CI 62.12-79.84) for the 'physical dimension' (score range from 0 to 100 with higher scores meaning higher disability.
    - No significant differences were found for the adjusted mean scores between practices and regions (London vs. NW).

Appendices (Cohort baseline summary of findings)

Background

Ensuring positive outcomes for patients is a key feature of current government policy and improving quality of life of patients with long-term conditions (LTCs) is a key domain of the Department of Health Outcomes Framework. The use of patient-reported outcome measures (PROMs) in LTCs may present a method to gain more information on quality of life and outcomes in a similar manner to the use of PROMs in surgical procedures. Since April 2009, PROMs are used to assess outcomes in four surgical procedures (hip or knee replacement, varicose veins surgery or groin hernia repair) on a routine basis in the NHS. The role of PROMs in these four elective surgical procedures is relatively straightforward as they are used to help assess the effectiveness of single, discrete procedures in relation to patients with fairly clearly defined problems for which surgery is normally effective.

The role of PROMs is far less clearly understood with regard to LTCs such as COPD, diabetes and stroke. LTCs are complex to manage as they pose multiple physical, social and emotional problems, with diverse service providers and interventions involved over long time lines. Often the objectives of services are to maintain or avoid deterioration in function, autonomy and well-being rather than achieve major health gains observed in, for example, hip and knee replacement surgery. This means that their role is more challenging to identify but potentially even more positive, particularly if they facilitate patient-involvement and personalised care.

This study is a pilot study to investigate the feasibility to use PROMs in people with LTCs in primary care. The LTCs include asthma, chronic obstructive pulmonary disease (COPD), epilepsy, diabetes, heart failure and stroke. If the use of PROMs is feasible in LTCs, their application can be extended to a broader use than the current programme for four elective surgical procedures.

The study is funded by the Department of Health and carried out by the Department of Public Health, University of Oxford. The team is led by Professor Ray Fitzpatrick, and the project manager is Dr Michele Peters.

Aims and objectives

The primary aim of the study was to assess the feasibility and acceptability of collecting patient-reported outcome measures (PROMs) data through primary care for one of six LTCs (asthma, COPD, diabetes, epilepsy, heart failure and stroke). This is achieved by assessing the response rates between practices and conditions, assessing completeness of data and comparing PROMs scores between practices.

Methods

The study involves two surveys in which PROMs are administered either as repeated cross-sectional surveys or as cohort-type surveys. The data for the cohort survey is collected twice, one year apart. The data presented in this report presents a summary of the findings from the cohort baseline survey which was conducted September 2010 and June 2011.

A total of 33 practices from London and the North-West of England (NW) agreed to participate. A total of 4485 patients were invited into the cohort baseline survey, including 1334 asthma, 567 COPD, 1121 diabetes, 525 epilepsy, 520 heart failure and 418 stroke patients. Eligible patients were identified by a remote and automatic search of the GP databases was conducted by Apollo Medical Systems Ltd. Patients were eligible to participate if they were aged 18 years or over and had a diagnosis of either asthma, COPD, diabetes, epilepsy, heart failure or stroke according to Quality and Outcomes Framework (QOF) criteria. Patients with multiple LTCs were sent a questionnaire for the rarest of LTC. The search generated a list with approximately half of the eligible patients for each condition on the practices computer. Once patients had been selected, practices had the opportunity to exclude patients whom they did not consider suitable to receive a questionnaire. Patients considered suitable for the study by the practice were sent a baseline questionnaire consisting of a core of two PROMs instruments, one generic and one disease-specific (**Table 1**), and a small number of additional demographics and comorbidity questions. A reminder was sent two weeks after the mailing of the questionnaire.

Table 1: Description of the PROMs used

Generic PROM		
PROM	**Dimensions (n items)**	**Score**
EQ-5D (5 items)	EQ5D Tariff	0-1 where 0 is 'worst health state' and 1 is 'full health'
	EQ5D Visual Analogue Scale (VAS)	0-100 where 0 is 'worst health state' and 100 is 'full health'
Disease-specific PROMs		
PROM	**Dimensions (n items)**	**Score**
Mini Asthma Quality of Life Questionnaire (AQOL) (15 items)	Total score (all 15 items)	1-7 where 1 is 'severe impairment' and 7 is 'no impairment'
	Activity limitations (4 items)	
	Symptoms (5 items)	
	Emotional function (3 items)	
	Environmental stimuli (3 items)	
Clinical COPD questionnaire (CCQ) (10 items)	Total score (all 10 items)	0-6 where 0 'very good health status' and 6 'extremely poor health status'
	Symptoms (4 items)	
	Functional state (4 items)	
	Mental state (2 items)	
Diabetes Health Profile (DHP) (18 items)	Psychological distress (6 items)	0-100 with a higher score representing higher dysfunction
	Barriers to activity (7 items)	
	Disinhibited eating (5 items)	

Table 1 (continued): Description of the PROMs used

Disease-specific PROMs

PROM	Dimensions (n items)	Score
Quality of Life in Epilepsy Inventory (QOLIE) (31 items) NB we used 30 items as the VAS scale was not included	Total score (all 31 items)	0-100 with higher scores reflecting better quality of life
	Overall quality of life (2 items)	
	Seizure/ worry (5 items)	
	Emotional well-being (5 items)	
	Energy/ fatigue (4 items)	
	Cognitive (6 items)	
	Medication effects (3 items)	
	Social function (5 items	
Minnesota Living with Heart failure Questionnaire (MLHFQ) (21 items)	Total score (all 21 items)	0-105 with a higher score meaning more impairment
	Physical dimension (8 items)	0-40 with a higher score meaning more impairment
	Emotional dimension (5 items)	0-25 with a higher score meaning more impairment
Stroke Impact Scale (SIS) (60 items)	Strength (4 items)	0-100 with higher score meaning higher disability
	Memory (7 items)	
	Emotion (9 items)	
	Communication (7 items)	
	ADL (10 items)	
	Mobility (9 items)	
	Hand function (5 items)	
	Handicap (8 items)	
	Physical dimension (hand function, strength, mobility and ADL, i.e. 28 items)	
	Recovery scale (1 item, VAS)	

Data was double entered and verified by a professional company. The data analysis was conducted in SPSS 18.0. Analyses compare response rates and mean adjusted PROMs scores for each LTC. Mean PROMs scores were adjusted for age, gender, time since diagnosis and number of comorbidities. Analysis of covariance (ANCOVA) was used with the level of significance set at 0.05. Figures with mean adjusted PROMs scores are presented if significant differences were found between practices.

This report outlines the results for the six LTCs including information about participating practices, response rates, missing data and PROMs scores.

Results

Participating practices

Thirty-three practices participated in the cohort baseline (table 2). The number of practices participating for each condition differed between LTCs due to the variation in prevalence of the 6 LTCs. Practices varied in size (12 were small (<5800 patients), 13 medium (5800-10,500 patients) and 8 large (>10,500 patients) and in deprivation (table3).

Table 2: N of practices covering each LTC

	Total	London	NW
Asthma	10	5	5
COPD	16	8	8
Diabetes	10	5	5
Epilepsy	23	13	10
Heart Failure	20	11	9
Stroke	19	12	7
TOTAL	33	18	15

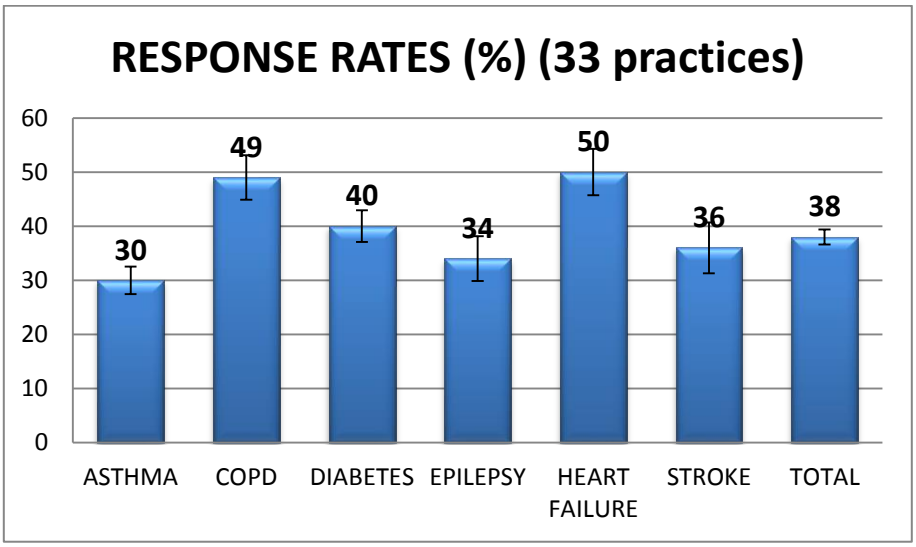
Table 3: N of practices by deprivation quintiles

	Quintile	Range (IMD rank)	Total (n)	London (n)	NW (n)
Most deprived	1	1 – 6496	8	4	4
	2	6497 - 12992	10	4	6
	3	12993 - 19488	6	5	1
	4	19489 - 25984	6	4	2
Least deprived	5	25985 - 32482	3	1	2

Overall Response rates

A total of 4485questionnaires was sent and 1721 were returned. The response rate varied between LTCs (Figure 1), with heart failure achieving the highest response rate (50.4%, n=262) and asthma the lowest (30.0%, n=400).

Figure 1: Response rates by LTCs

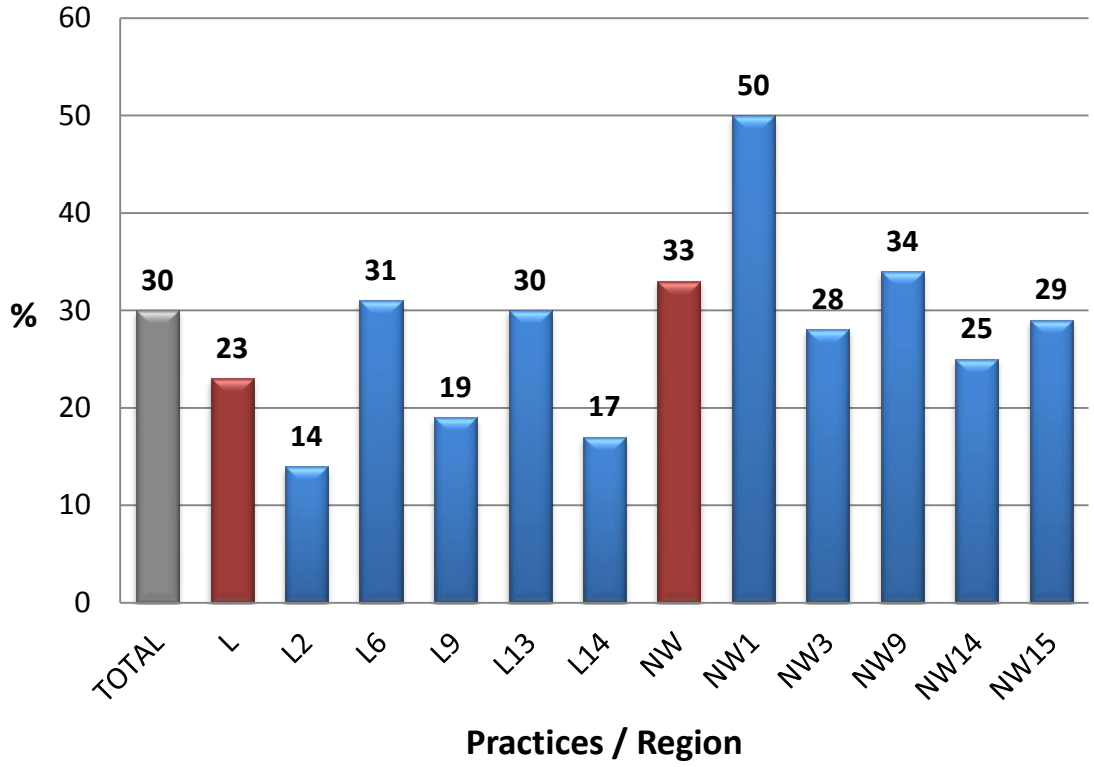


Asthma

Participating practices and their response rates

Ten practices (5 in London and 5 in the NW) participated for asthma. A total of 1627 patients were extracted from the search (London n=443 and NW n=1184) and 294 (18.1%) were excluded by the practices from being sent a questionnaire. Hence, 1333 questionnaires were sent to achieve an overall response rate of 30.0% (n=400) (Figure2). The response rate in the NW was higher (33%, n=313) than in London (23%, n=87). Five questionnaires were excluded from the analysis as the respondents reported not having been diagnosed with asthma.

Figure 2: Asthma response rate (%) for total sample, by region and practice



Missing data

There was a low rate of missing data for both the EQ5D and the asthma-specific questionnaire (AQOL). The EQ5D York tariff could not be calculated for 5 patients (1.27%) and the VAS was not available for 17 patients (4.3%). Between 0 and 3.3% (n=13) of data were missing on individual AQOL items. The highest rate of missing data was for the question on Limited work-related activities (n=13, 3.3%). As data was not imputed, it was not possible to calculate the dimension scores for some patients i.e. 15 patients (3.8%) for 'activity limitations', 9 (2.3%) for 'emotional function', 5 (1.5%) for 'symptoms', 6 (1.5%) for 'environmental stimuli' and 28 (7.1%) for the overall score.

Demographics

A total of 395 patients were included in the analysis. The majority of the respondents were female (n=234, 60.3%), in employment (either full-time or part-time) (n=209, 55.2%), white (n=352, 91.7%), from the NW (n=310, 78.5%). About a third (n=127, 32.6%) were aged between 18 and 44 years, 160 (41.1%) between 45 and 64 years, 59 (15.2%) between 65 and 74 years and 43 (11.1%) 75 years or above. The mean time since diagnosis was 22.5 years (sd 16.3). Two hundred and twenty-six patients (57.2%) did not report any comorbidities whereas 105 (26.6%) reported one comorbidity and 64 (16.2%) reported two or more comorbidities.

PROMs Results

Individual items

- Generic health status assessed by EQ5D
    - The majority of respondents reported no problems with walking (n=309, 78.6%), self-care (n=369, 93.7%), usual activities (n=291, 73.9%), pain or discomfort (n=259, 66.1%), or feeling anxious or depressed (n=268, 67.8%).
    - The most commonly reported problem was pain or discomfort (moderate and severe) by 133 patients (33.7%).
- Asthma-specific health status assessed by AQOL
    - The three most commonly reported problems occurring at least 'a good bit of the time' were 'bothered or avoiding cigarette smoke' (n=113, 28.8%), 'bothered by or avoiding dust' (n=100. 25.4%) and 'experienced wheeze in the chest' (n=61, 18.2%).

PROMs scores

Adjusted mean scores of the EQ5D (York 1 Tariff and VAS) and the5 dimensions of the AQOL were calculated for total sample, by practice and by region. The EQ5D York Tariff ranges between 0 (worst health) and 1 (full health), the EQ5D VAS between 0 (worst health) and 100 (full health) and the AQOL dimensions between 1 (severe impairment) and 7 (no impairment).

Key findings:

- Generic health status assessed by the EQ5D
    - The overall adjusted mean score for the EQ5D York tariff was 0.83 (CI 0.81-0.87) and for the VAS 73.74 (CI 71.52-76.00)
    - The adjusted mean scores of the York Tariff and the VAS were significantly different by practice (p=0.002 for both).
- Asthma-specific health status assessed by the AQOL
    - The overall adjusted mean scores were 5.33 (CI 5.17-5.50) for 'symptoms', 5.39 (CI 5.20-5-59) for 'emotional functioning', 5.29 (CI 5.09-5.48) for 'environment', 5.93 (CI 5.79-6.08) for 'activity limitations' and 5.51 (CI 5.36-5.67) for 'total quality of life'.
    - The adjusted mean scores were significantly different between practices for four AQOL dimensions, including 'symptoms' (p=0.001), 'emotional functioning' (p<0.001), 'environmental stimuli' (p<0.001) and 'total quality of life' (p=0.027).

- Only 'environmental stimuli' was significantly different between London and the NW ($p<0.001$).

Figures 3- 11 illustrate that significant differences between the practices' mean scores for the EQ5D and the four AQOL dimensions were predominantly influenced by one practice (NW3). The figures also display the sample size for each practice.

Figure 3: Adjusted mean Asthma EQ5D scores with confidence intervals for each practice (p=0.002)

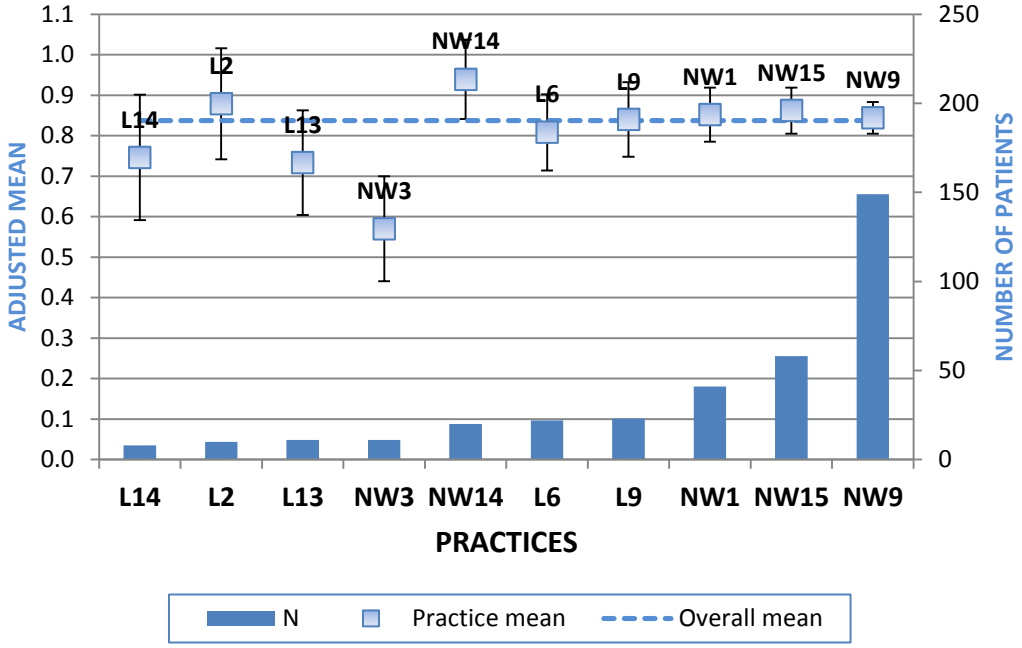


Figure 4: Adjusted mean Asthma EQ5D VAS scores with confidence intervals for each practice (p=0.002)

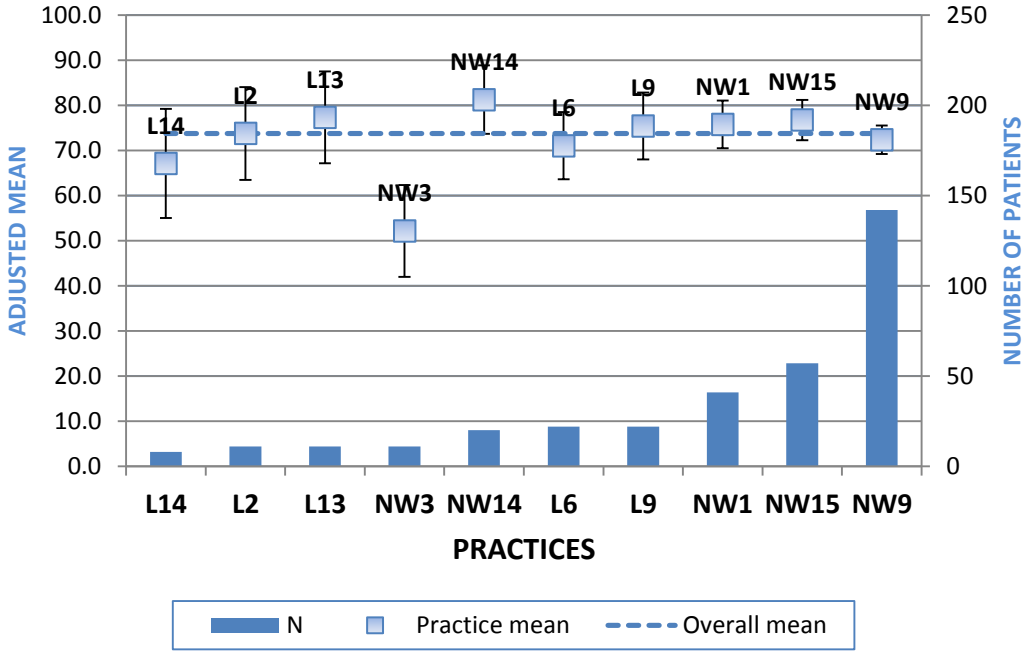


Figure 5: Adjusted mean Asthma Symptoms scores with confidence intervals by practice (p=0.001)

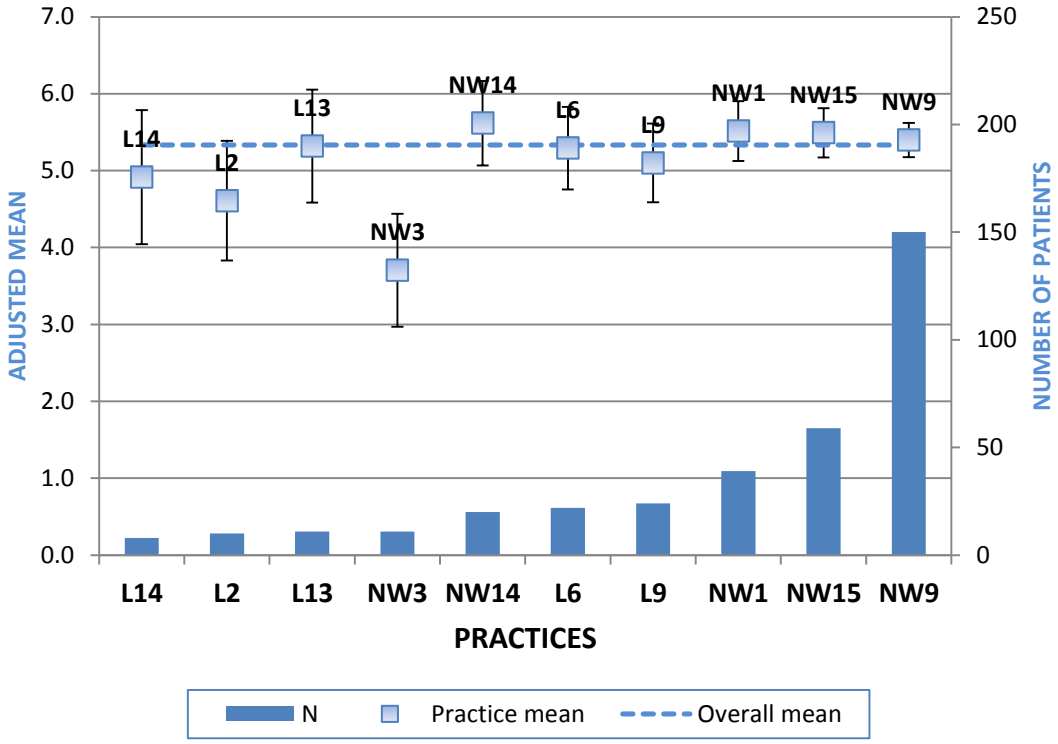


Figure 6: Adjusted mean Asthma Emotional Functioning scores with confidence intervals by practice (p<0.001)

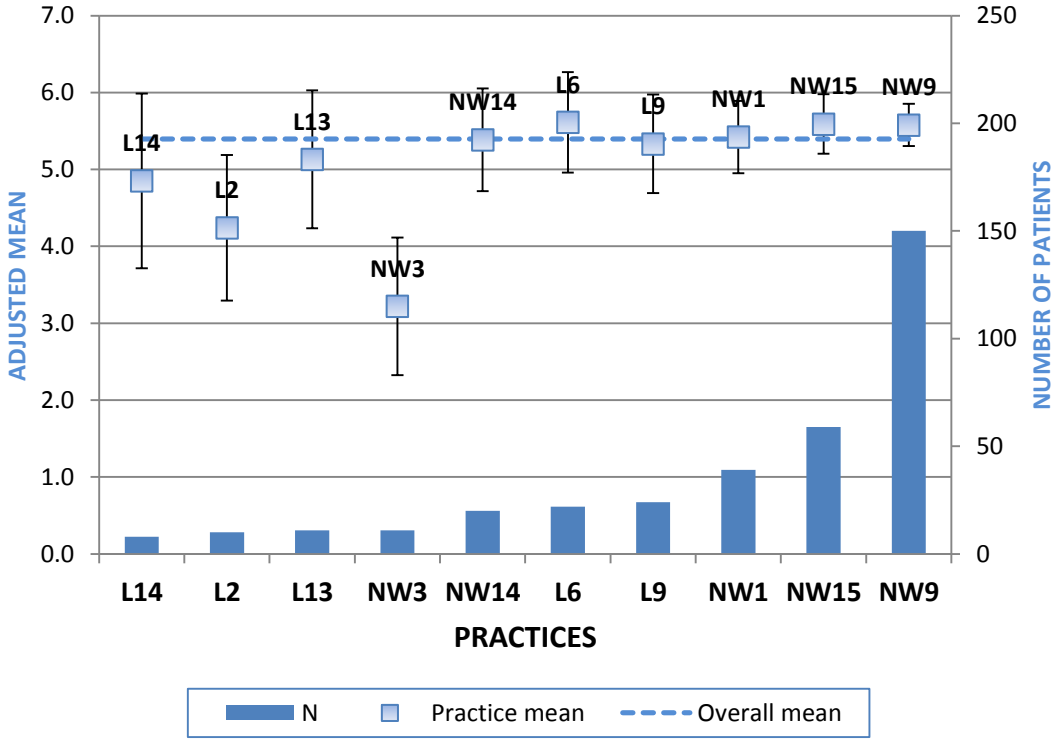


Figure 7: Adjusted mean Asthma Environment scores with confidence intervals by practice (p<0.001)

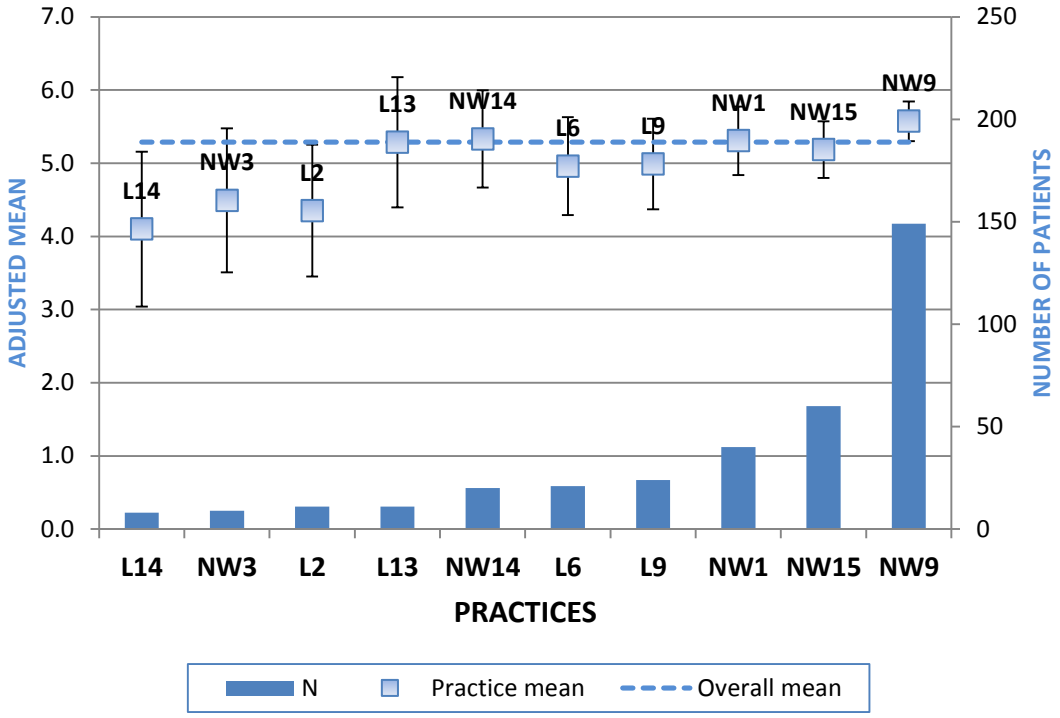


Figure 8: Adjusted mean Asthma Activity Limitations scores with confidence intervals by practice (not significant)

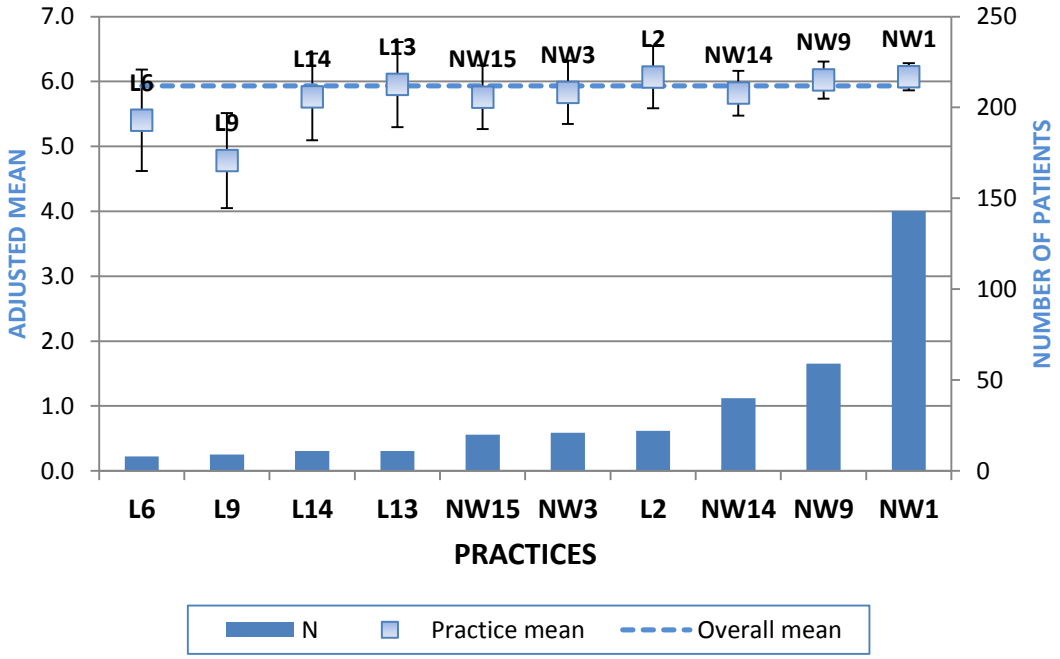
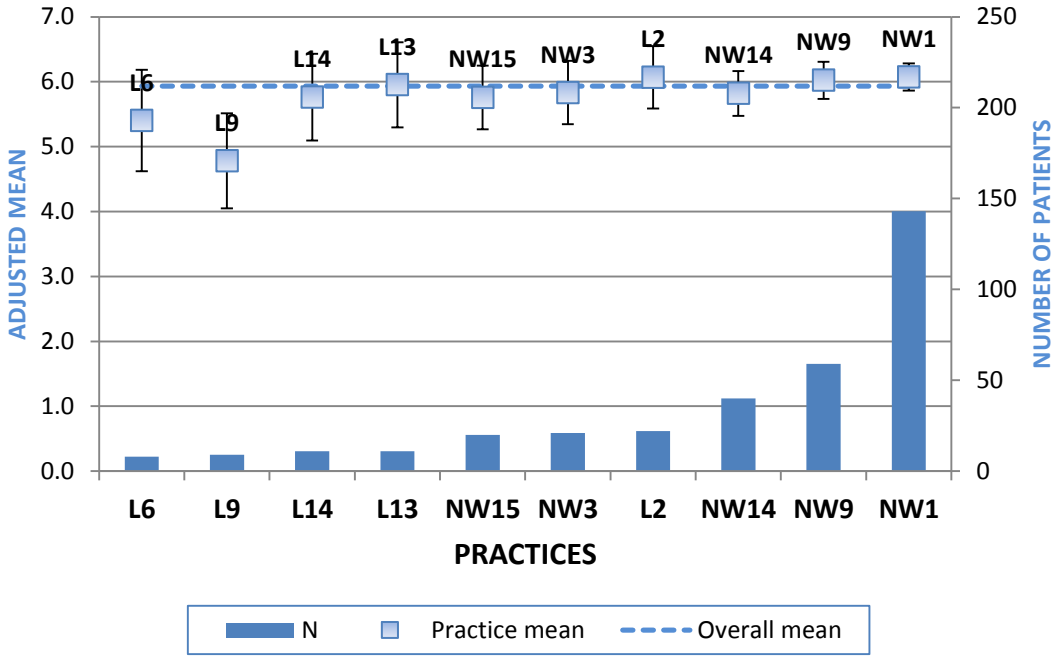


Figure 9: Adjusted mean Asthma Total Quality of Life scores with confidence intervals by practice (p=0.027)

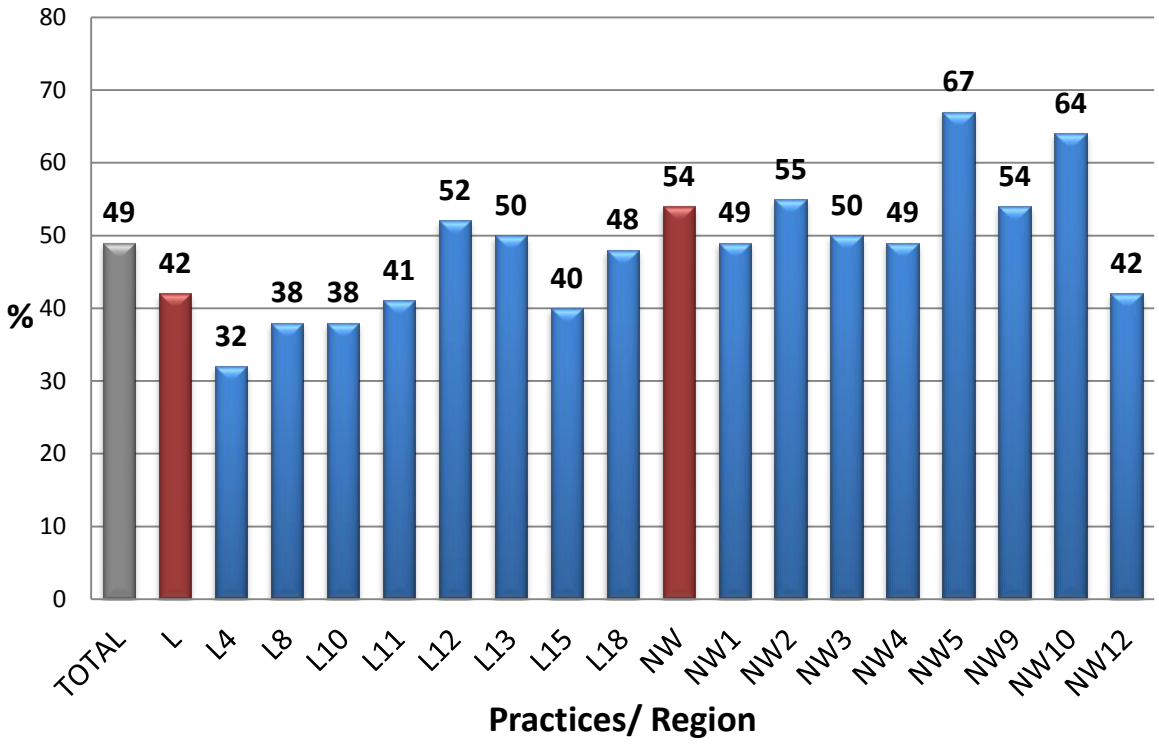


COPD

Participating practices and their response rates

Sixteen practices (8 in London and 8 in the NW) participated for COPD. A total of 602 patients were extracted from the search (London n=271 and NW n=331) and 34 (5.6%) were excluded by the practices from being sent a questionnaire. Hence, 568 questionnaires were sent to achieve an overall response rate of 49% (n=279) (Figure 10). The response rate in the NW was higher (54%, n=169) than in London (42%, n=110). Four questionnaires were excluded from the analysis as the respondents reported not having been diagnosed with COPD.

Figure 10: COPD response rate (%) for total sample, by region and practice



Missing data

There was a low rate of missing data for both the EQ5D and the COPD-specific questionnaire (CCQ). The EQ5D York tariff could not be calculated for 9 participants (3.3%) and the EQ5D VAS was not available for 26 participants (9.5%). Between 4 (1.5%) and 11 (4.0%) of data was missing for individual items, with the highest rate (4.0%) for the items 'short of breath doing physical activity' and 'depressed because of breathing problems'. As no data imputation was performed, it was not possible to calculate the dimensions scores for some participants, i.e. 24 (8.7%) for 'symptoms', 14 (5.1%) for 'functional state', 15 (5.5%) for 'mental state' and 37 (13.5%) for 'total quality of life'.

Demographics

A total of 275 patients, of which 125 (46.0%) were male and 147 (54.0%) were female, were included in the analysis. The majority were retired (n=160, 61.3%), white (n-270, 98.5%) and from the NW (n=167, 60.7%). Sixty one (22.2%) participants were aged between 18 and 63 years, 87 (31.6%) 65 to74 years and 127 (46.2%) 75 years or more. The mean time since diagnosis was 8.6 years (SD 9.6). Sixty-three (22.9%) participants did not report any comorbidities, 87 (31.6%) reported on comorbidity and 125 (45.5%) reported 2 or more comorbidities.

PROMs Results

Individual Items

- Generic health status assessed by the EQ5D
    - The majority of patients reported no problems with self-care (n=196, 71.3%), or feeling anxious or depressed (n=152, 55.3%).
    - 177 (64.6%) reported some problems with walking
    - 171 (63.3%) reported at least some problems with usual activities
    - 170 (62.0%) reported at least moderate pain or discomfort.
- COPD-specific health status assessed by the CCQ
    - The three most commonly reported problems occurring at least 'many times' were 'sort of breath doing physical activity' (n=129, 48.9%), 'concerned about getting a cold or breathing getting worse' (n=105. 39.5%) and 'coughing' (n=106, 39.1%).

PROMs scores

Adjusted mean scores of the EQ5D (York 1 Tariff and VAS) and the4 dimensions of the CCQ were calculated for the total sample, by practice and by region. The EQ5D York Tariff ranges between 0 (worst health) and 1 (full health), the EQ5D VAS between 0 (worst health) and 100 (full health) and the CCQ dimensions between 0 (very good health status) and 6 (extremely poor health status).

Key findings:

- Generic health status assessed by the EQ5D
    - The overall adjusted mean score for the EQ5D York tariff was 0.59 (CI 0.52-0.67) and for the VAS 59.29 (CI 53.57-65.01)
    - The adjusted mean scores of the York Tariff and the VAS were not significantly different by practice or by region.
- COPD-specific health status assessed by the CCQ
    - The overall adjusted mean scores were 3.00 (CI 2.59-3.40) for 'symptoms', 2.30 (CI 1.89-2.70) for 'functional state', 2.44 (CI 1.92-2.96) for 'mental state' and 2.58 (CI 2.20-2.96) for 'total quality of life'.
    - The adjusted mean scores were significantly different between practices for two CCQ dimensions, including 'symptoms' (p=0.001), and 'total quality of life' (p=0.038).
    - Only 'functional status' was significantly different between London and the NW (p=0.035).

Figures 11-16 illustrate the sample size and adjusted mean scores for each practice.

Figure 11: Adjusted mean COPD EQ5D scores with confidence intervals for each practice (NS)

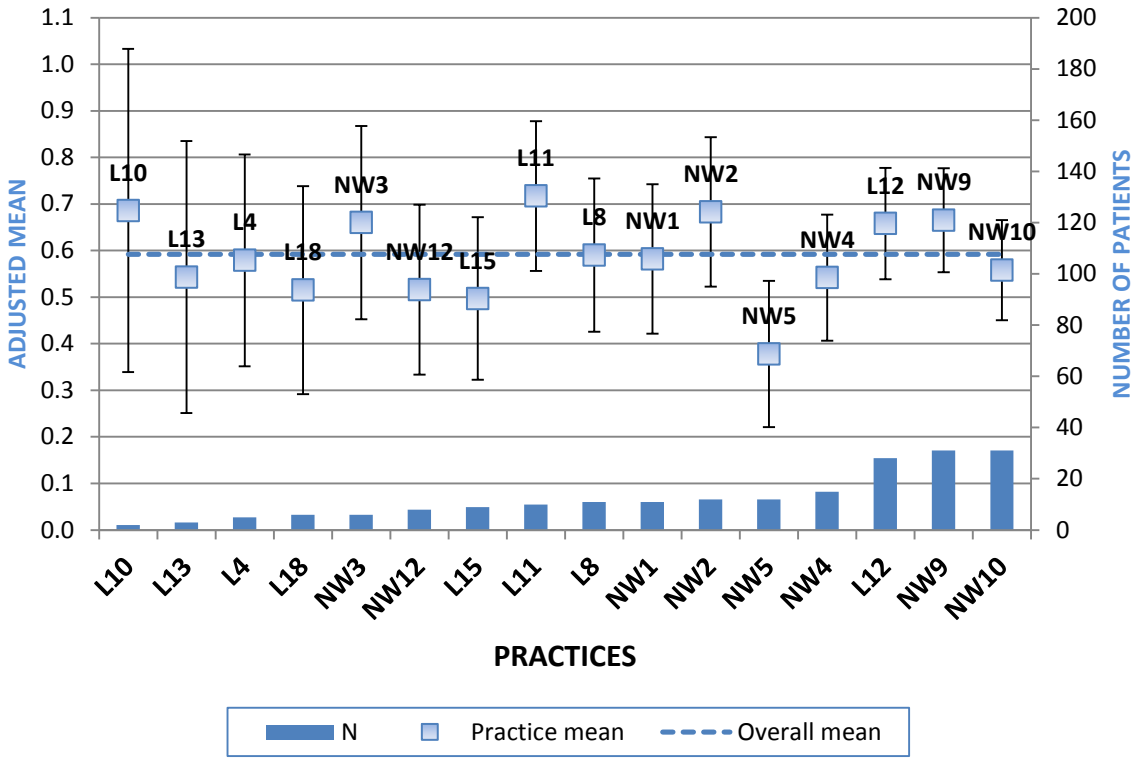


Figure 12: Adjusted mean COPD EQ5D VAS scores with confidence intervals for each practice (NS)

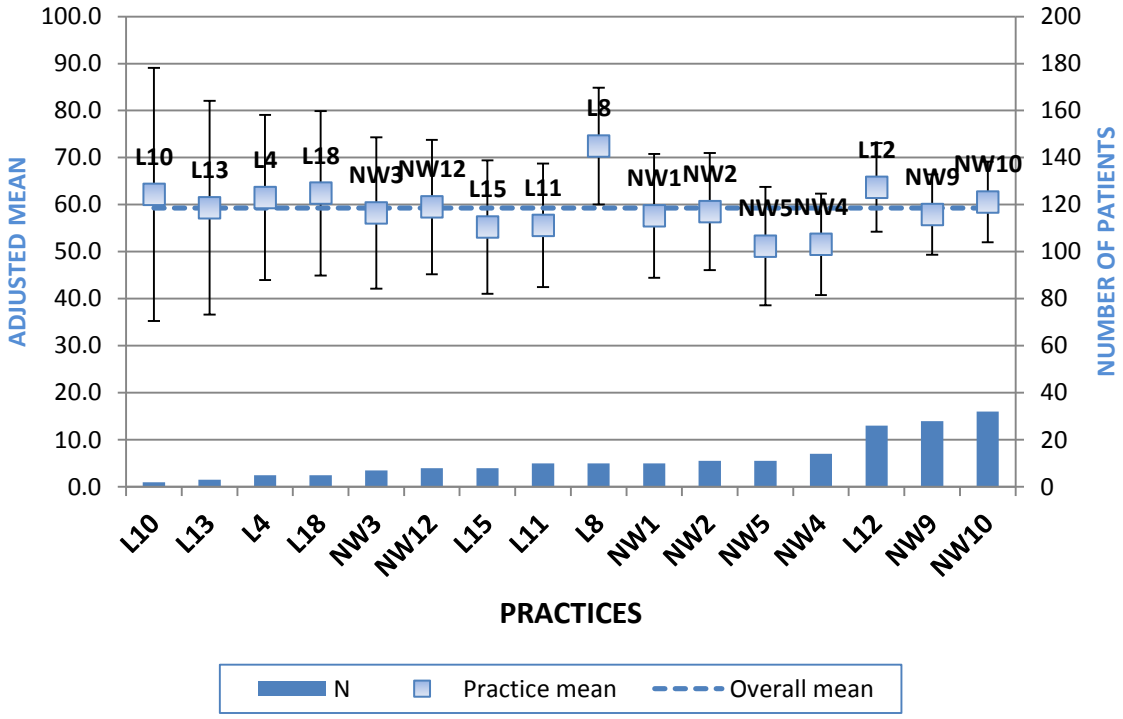


Figure 13: Adjusted mean COPD Symptoms scores with confidence intervals for each practice (p=0.001)

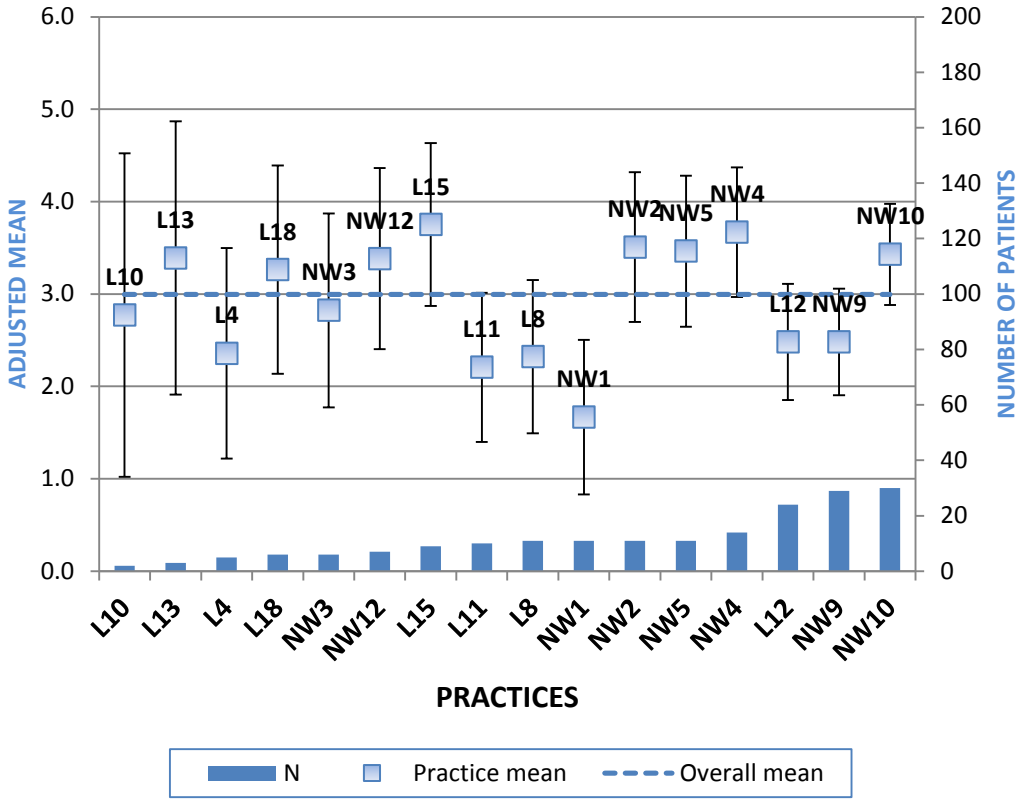


Figure 14: Adjusted mean COPD Functional State scores with confidence intervals for each practice (NS)

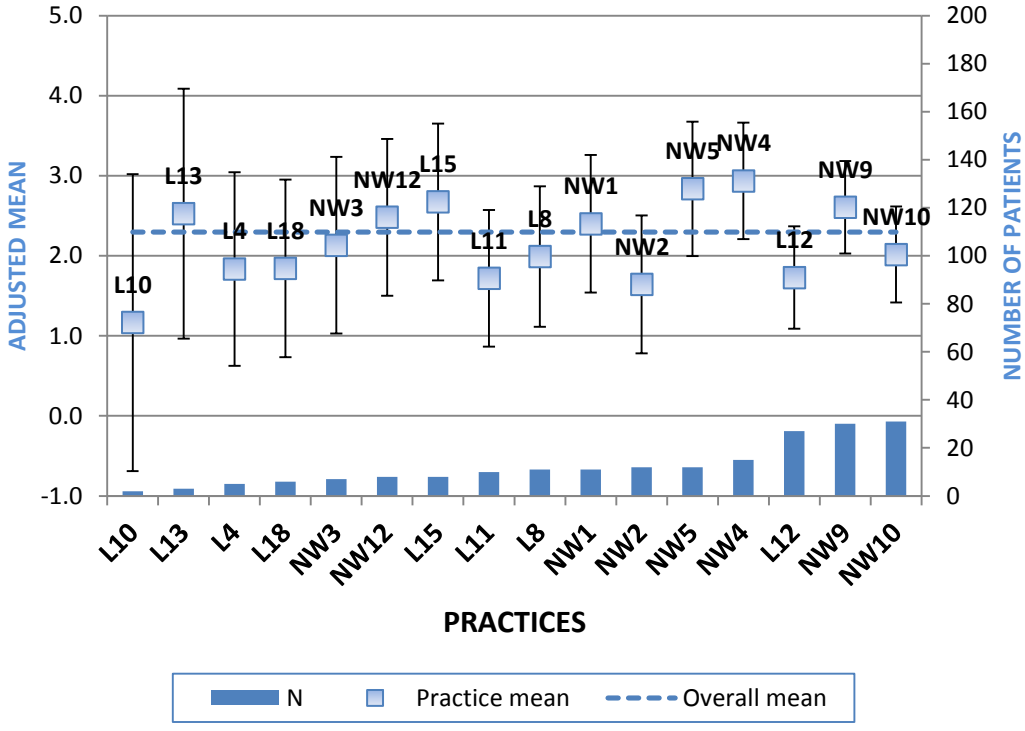


Figure 15: Adjusted mean COPD Mental State scores with confidence intervals for each practice (NS)

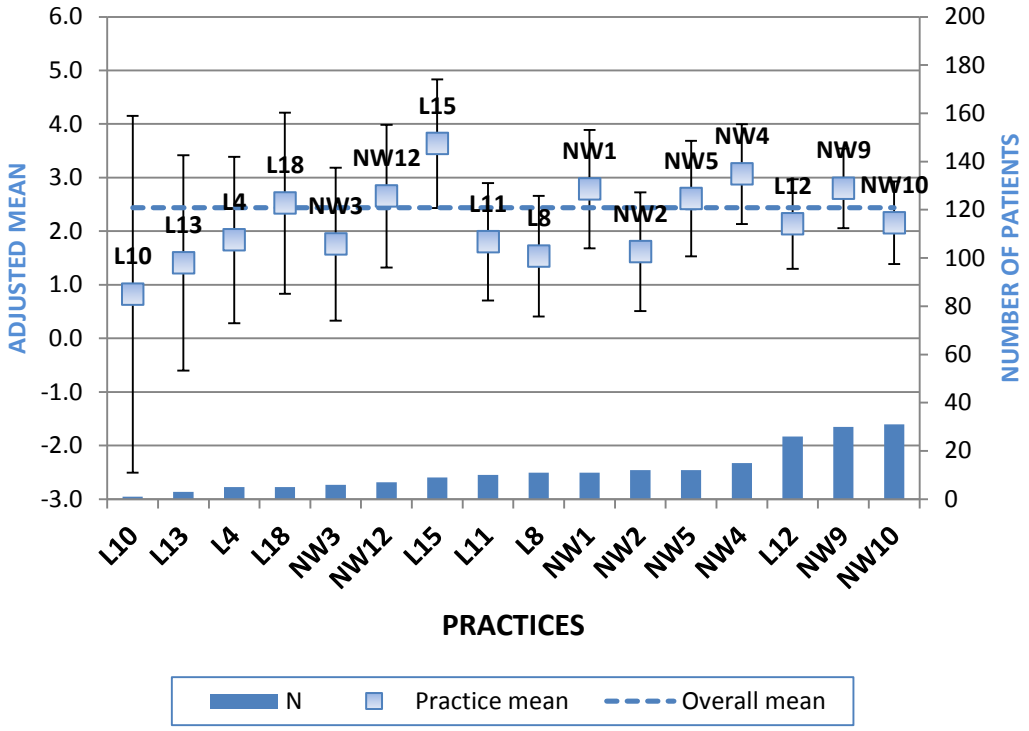
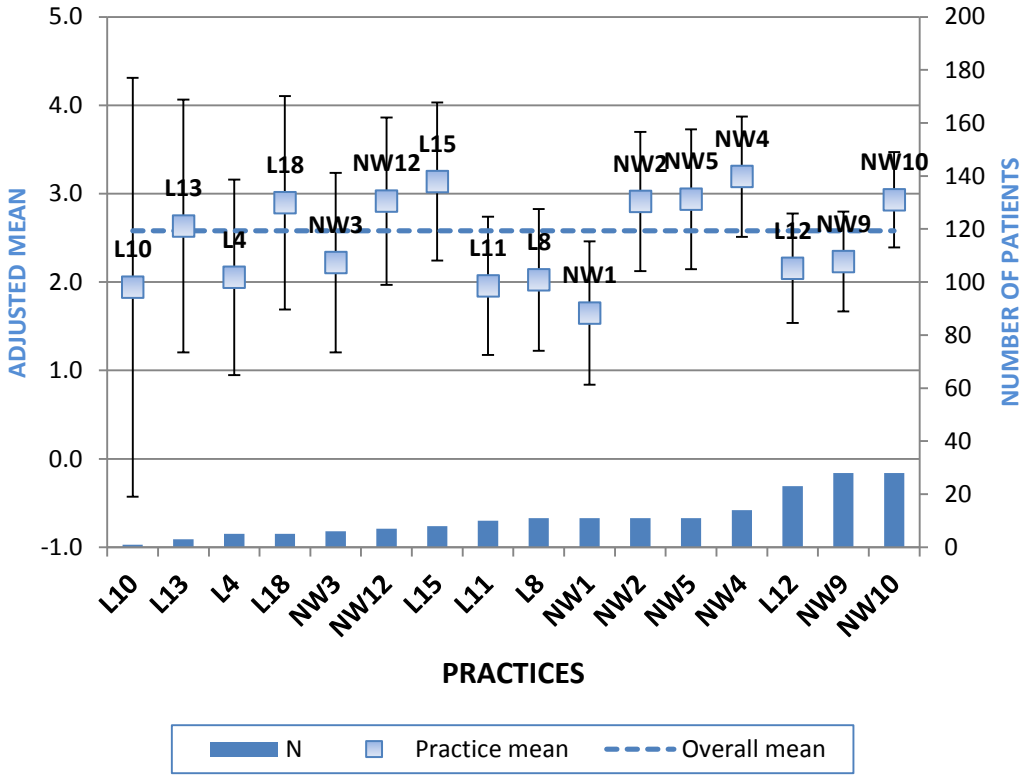


Figure 16: Adjusted mean COPD Total Quality of Life scores with confidence intervals for each practice (p=0.038)

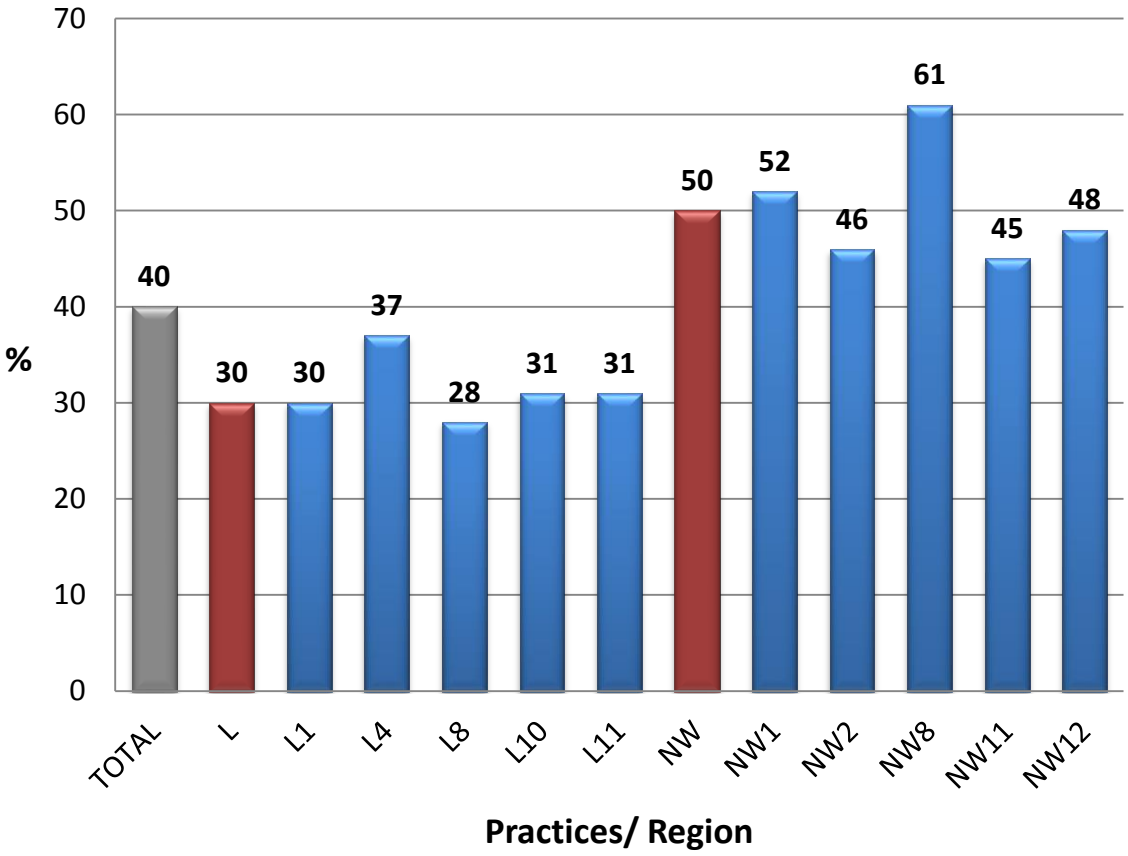


Diabetes

Participating practices and their response rates

Ten practices (5 in London and 5 in the NW) participated for diabetes. A total of 1169 patients were extracted from the search (London n=596 and NW n=573) and 48 (4.1%) were excluded by the practices from being sent a questionnaire. Hence, 1121 questionnaires were sent to achieve an overall response rate of40.0% (n=448) (Figure 17). The response rate in the NW was higher (50.1%, n=272) than in London (30.4%, n=176).

Figure 17: Diabetes response rate (%) for total sample, by region and practice



Missing data

There was a low rate of missing data for both the EQ5D and the diabetes-specific questionnaire (DHP). The EQ5D York tariff could not be calculated for 13 (2.0%) of participants and the EQ5D VAS was missing for 18 (6.5%) participants. Between 1 (0.2%) and 16 (3.6%) of data was missing for individual items. The highest rate of missing data was on the item 'avoid going out if sugars are low' (n=16, 3.6%). No data imputation was performed, therefore it was not possible to calculate the dimensions scores for 31 (6.9%) participants for 'barriers to activity', 16 (3.6%) for 'psychological distress' and 10 (2.2%) for 'disinhibited eating'.

Demographics

A total of 448 diabetes patients, of which 243 (56.6%) were male and 186 (43.4%) were female, were included in the analysis. Nearly half were retired (n=204, 48.3%) and just over a quarter were in employment (n=114, 27.1%). The majority were white (n=330, 76.6%) and the most represented ethnic minority was Asian/Asian British (n=80, 18.6%). A total of 272 (60.7%) respondents came from the NW. Twenty-nine (6.7%) were aged 18 to 44 years, 153 (35.3%) 45 to 64 years, 124 (28.6%) 65 to 74 years and 127 (29.3%) 75 years or more. The mean time since diagnosis was 9.6 years (SD 8.6). One hundred and four (23.2%) did not report any comorbidities, 151 (33.7%) reported one comorbidity and 193 (43.1%) reported two or more comorbidities.

PROMs Results

Individual Items

- Generic health status assessed by the EQ5D
    - The majority of patients reported no problems with walking (n=245, 55.4%), with self-care (n=374, 84.4%), performing usual activities (n=276, 62.6%) or feeling anxious or depressed (n=292, 66.5%).
    - The most commonly reported problem was at least moderate pain or discomfort (n=240, 54.0%).
- Diabetes-specific health status assessed by the DHP
    - The three most commonly reported problems were 'quite likely or very likely to eat more' (n=211, 47.6%), and feeling 'usually or always' that 'food controls life' (n=129, 29.2%) or that they are 'tied to meal times' (n=111, 25.1%).

PROMs scores

Adjusted mean scores of the EQ5D (York 1 Tariff and VAS) and the3 dimensions of the DHP were calculated for total sample, by practice and by region. The EQ5D York Tariff ranges between 0 (worst health) and 1 (full health), the EQ5D VAS between 0 (worst health) and 100 (full health) and the DHP dimensions between 0 and 100 with a higher score representing higher dysfunction

Key findings:

- Generic health status assessed by the EQ5D
    - The overall adjusted mean score for the EQ5D York tariff was 0.72 (CI 0.69-0.75) and for the VAS 67.60 (CI 65.46-69.74)
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS by practice
- Diabetes-specific health status assessed by the DHP
    - The overall adjusted mean scores were 20.15 (CI18.00-22.30) for 'psychological distress', 23.94 (CI 21.60-26.28) for 'barriers to activities' and 34.65 (CI 32.23-37.08) for 'disinhibited eating.
    - The adjusted mean scores were significantly different between practices for all three DHP dimensions, including 'psychological distress' (p=0.001), 'barriers to activities (p<0.001)) and 'disinhibited eating (p=0.004)

- Significant differences were found between London and the NW for 'barriers to activities' (p=0.001) 'psychological distress' (p=0.021).

Figures 18- 22 illustrate the practices' sample size and adjusted mean scores for the EQ5D and the 3 DHP dimensions.

Figure 18: Adjusted mean diabetes EQ5D scores with confidence intervals for each practice (NS)

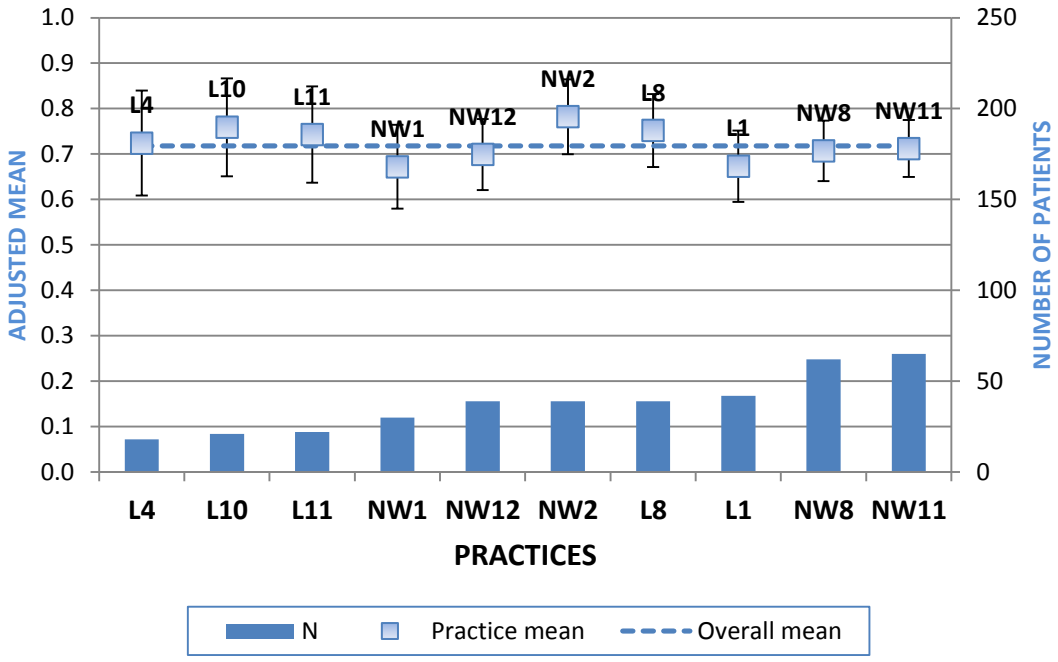


Figure 19: Adjusted mean diabetes EQ5D VAS scores with confidence intervals for each practice (NS)

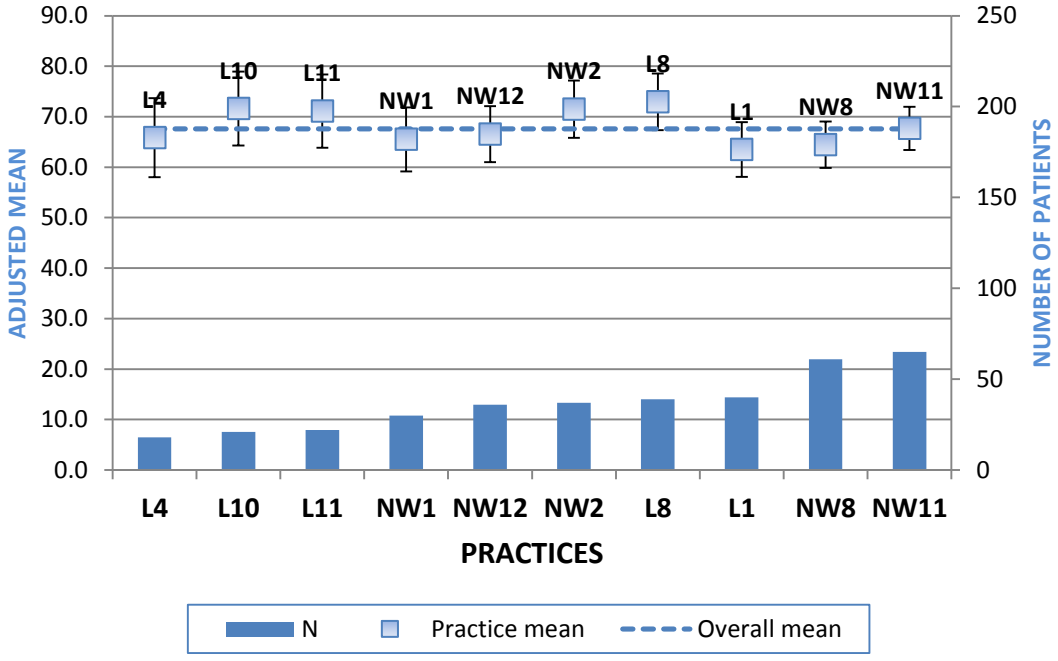


Figure 20: Adjusted mean diabetes psychological distress scores with confidence intervals for each practice (p=0.001)

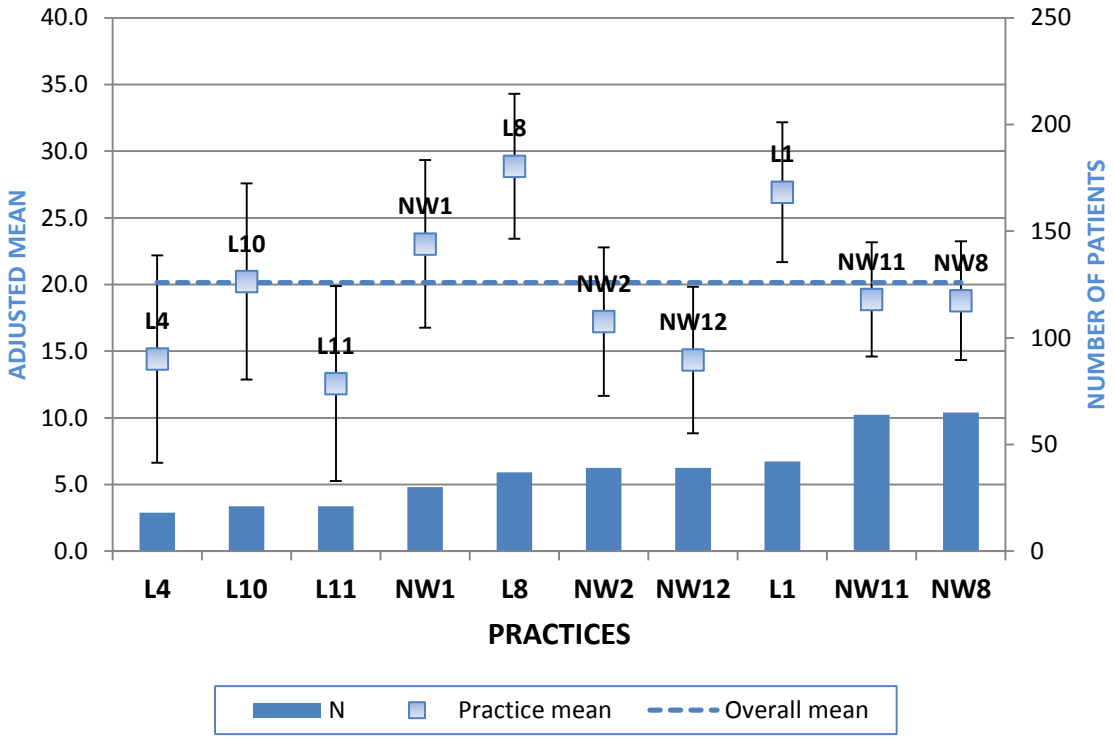


Figure 21: Adjusted mean diabetes barrier to activities scores with confidence intervals for each practice (p<0.001)

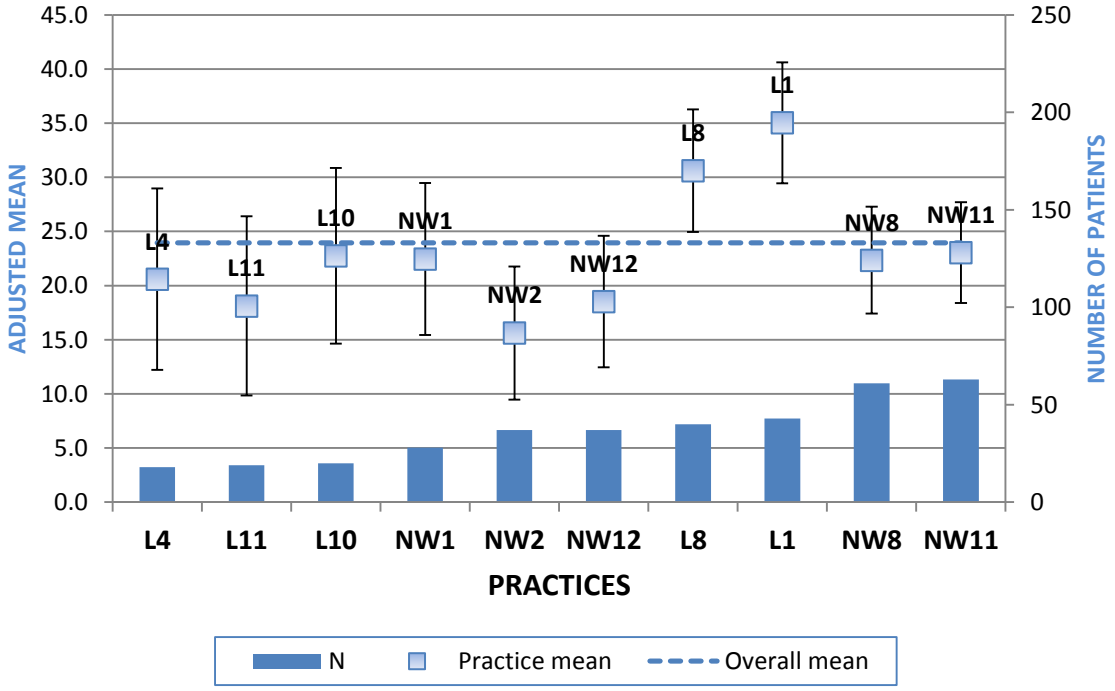
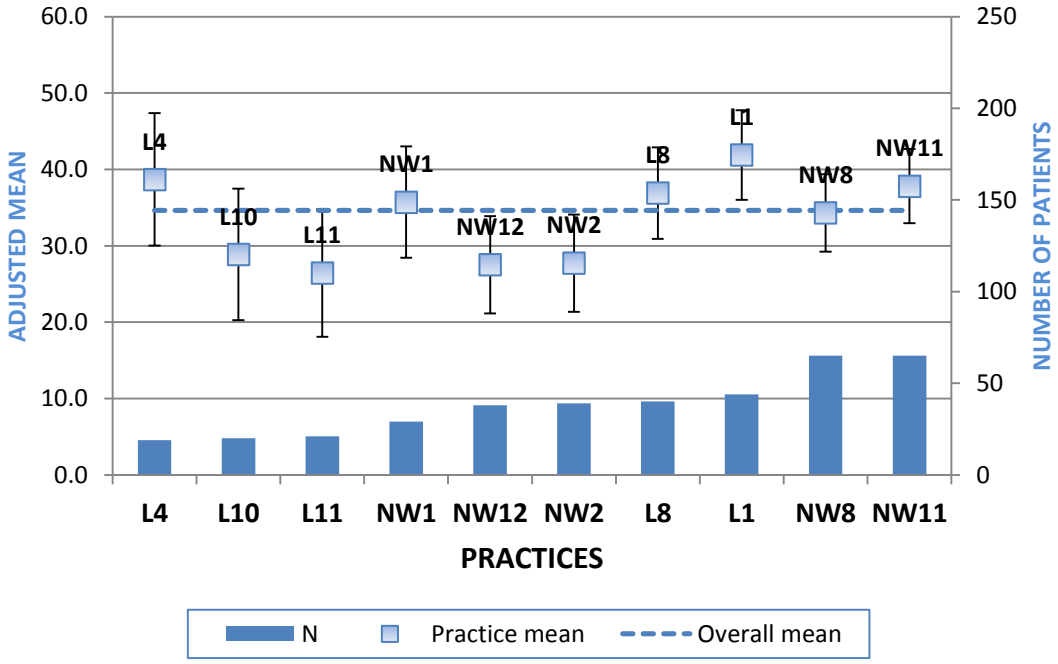


Figure 22: Adjusted mean diabetes disinhibited eating scores with confidence intervals for each practice (p=0.004)

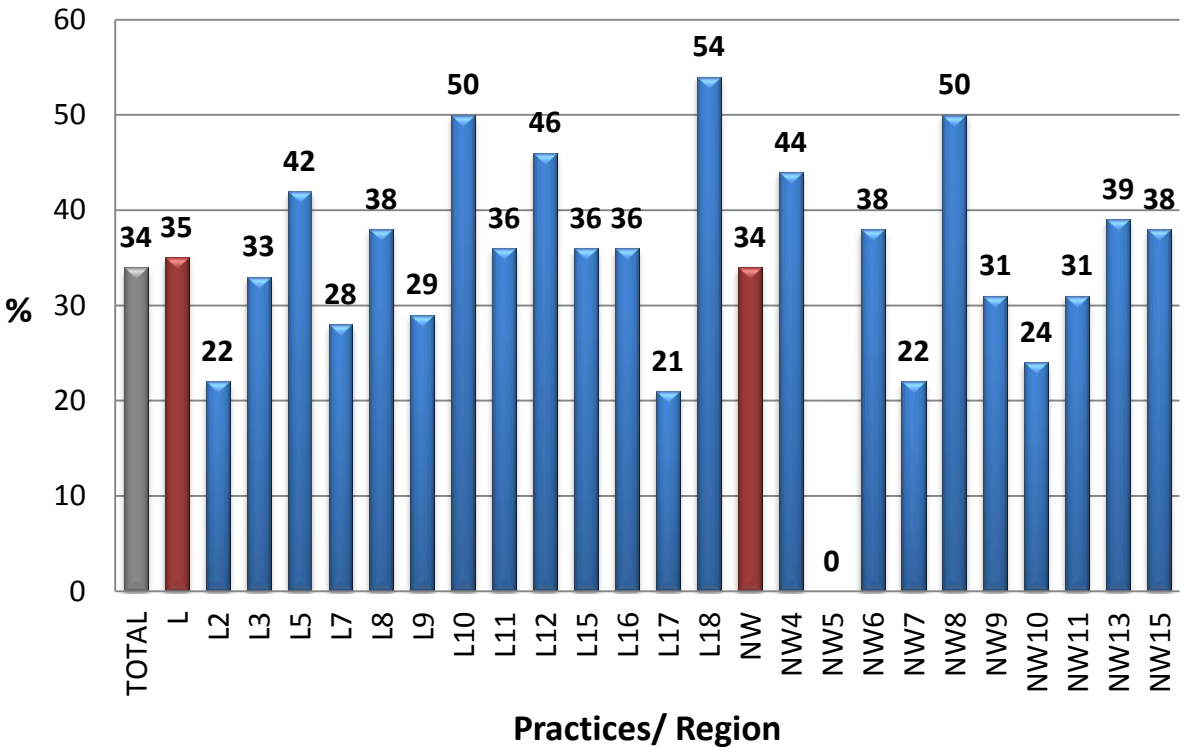


Epilepsy

Participating practices and their response rates

Twenty-three practices (13 in London and 10 in the NW) participated for epilepsy. A total of 985 patients were extracted from the search (London n=210 and NW n=775) and 460 (46.7%) were excluded by the practices from being sent a questionnaire. Hence, 525 questionnaires were sent to achieve an overall response rate of 34.3% (n=180) (Figure 23). The response rates in London and the NW were similar (35.4%, n=67 and 33.6%, n=113 respectively).

Figure 23: Epilepsy response rate (%) for total sample, by region and practice



Missing data

There was a low rate of missing data for the EQ5D. The EQ5D York tariff could not be calculated for 5 (1.3%) of participants and the EQ5D VAS was missing for 17 (4.3%) participants. The rate of missing data on the epilepsy-specific questionnaire (QOLIE) was low for most items, however three items had a high rate of missing data, including 28.3% (n=51) for 'medication caused trouble with driving', 15.0% (n=27) for the 'quality of life scale' and 10.6% (n=19) for 'bothered by work limitations). As no data imputation was performed, this meant that dimension scores could not be calculated for 58 participants (32.2%) for 'social function', 31 (17.2%) for 'overall quality of life', 11 (6.1%) for 'seizure worry', 11 (6.1%) for 'cognitive function', 10 (5.6%) for 'energy / fatigue', 3 (1.7%) for 'medication effects and 81 (45.0%) for 'total quality of life.

Demographics

A total of 180 participants were included in the analysis. Eighty-three (46.6%) were male and 95 (53.4%) were female. Approximately equal proportions were in employment (n=52, 30.8%), permanently sick/ disabled (n=39, 32.1%) or retired (n=46, 27.2%). The majority were white (n=164, 93.2%) and from the NW (n=113, 62.8%). Fifty-four (30.2%) were aged 18 to 44 years, 67 (37.4%) 45 to 64 years, 36 (20.1%) 65 to 74 and 22 (12.3%) 75 years or more. The mean time since diagnosis was 22.8 years (SD 16.3). Seventy-seven (42.8%) did not report any comorbidities, 41 (22.8%) reported one comorbidity and 62 (34.4%) two or more comorbidities.

PROMs Results

Individual Items

- Generic health status assessed by the EQ5D
    - The majority of patients reported no problems with walking (n=108, 61.0%), with self-care (n=142, 80.7%), performing usual activities (n=100, 56.2%) or pain/ discomfort (n=91, 50.8%).
    - The most commonly reported problem was at least moderate anxiety or depression (n=91, 51.1%).
- Epilepsy-specific health status assessed by the QOLIE
    - The three most commonly reported problems were feeling bothered by 'memory difficulties' (n= 69, 39.2%) or by 'work limitations' (n=61, 37.9%); and 'having a lot of energy' only 'a little or none of the time' (n=59, 33.6%). (NB. 'feeling bothered' = a score of at least 4 or a scale from 1 'not at all bothersome' to 5 'extremely bothersome').

PROMs scores

Adjusted mean scores of the EQ5D (York 1 Tariff and VAS) and the 8 dimensions of the QOLIE were calculated for total sample, by practice and by region. The EQ5D York Tariff ranges between 0 (worst health) and 1 (full health), the EQ5D VAS between 0 (worst health) and 100 (full health) and the QOLIE dimensions between 0 and 100 with higher scores reflecting better quality of life.

Key findings:

- Generic health status assessed by the EQ5D
    - The overall adjusted mean score for the EQ5D York tariff was 0.74 (CI 0.68-0.77) and for the VAS 67.25 (CI 63.96-70.54)
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS by practice or between London and the NW
- Epilepsy-specific health status assessed by the QOLIE
    - The overall adjusted mean scores were 65.09 (CI59.55-70.62) for 'seizure worry', 65.95 (CI62.55-69.36) for 'overall quality of life', 66.64 (CI63.22-70.01) for 'emotional well-being', 54.06 (CI 50.67-57.45) for 'energy / fatigue', 61.74 (CI57.60-65.87) for 'cognitive functioning', 66.45 (61.41-71.49) for 'medication effects', 71.19 (CI 64.73-77.66) for 'social functioning' and 66.00 (CI 61.59-70.41) for 'total quality of life'.

- The adjusted mean scores were significantly different between practices for 3 QOLIE dimensions, including 'overall quality of life (p=0.019), 'emotional well-being' (p=0.013), 'energy / fatigue' (p=0.012)
- No significant differences were found between London and the NW on any of the QOLIE dimensions.

Figures 24 – 33 illustrate the adjusted mean PROMs scores and sample size for each practice.

Figure 24: Adjusted mean epilepsy EQ5D scores with confidence intervals for each practice (NS)

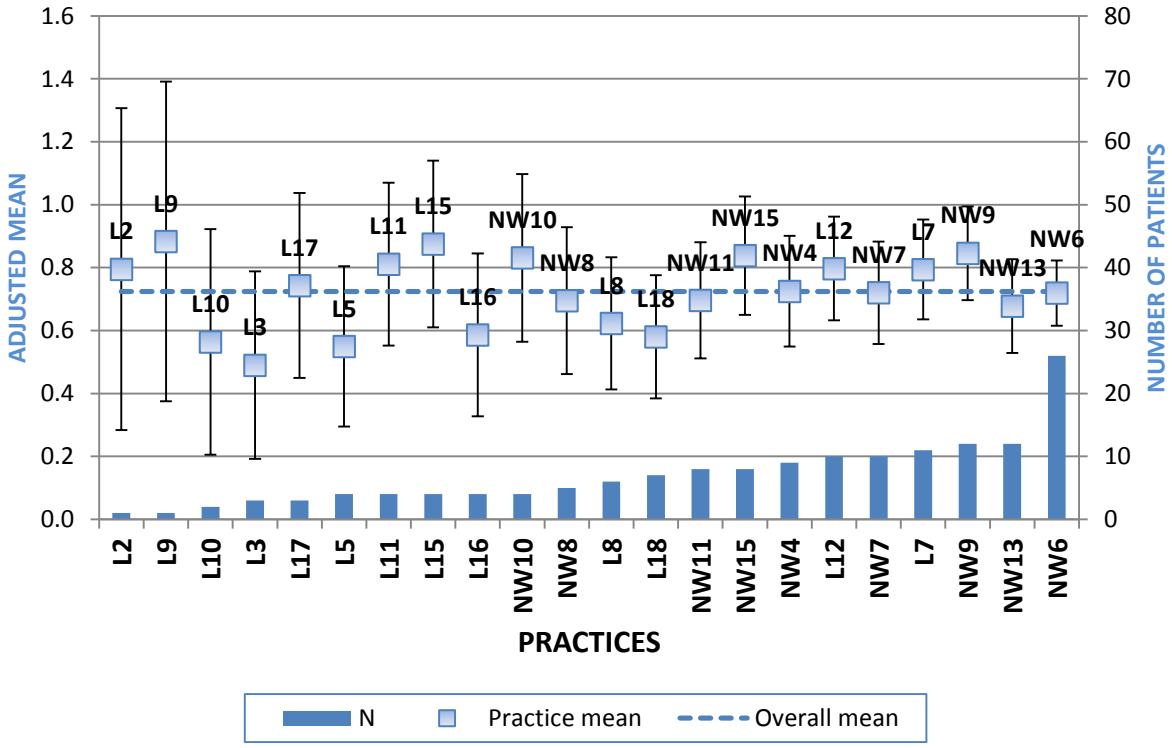


Figure 25: Adjusted mean epilepsy EQ5D VAS scores with confidence intervals for each practice (NS)

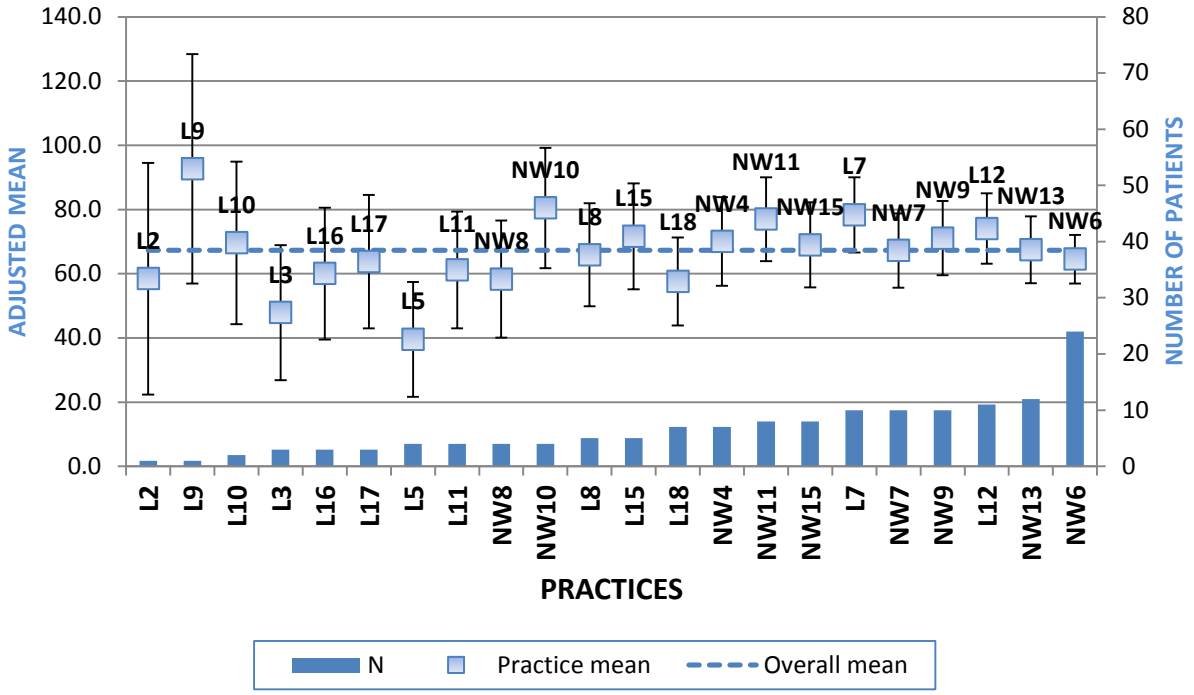


Figure 26: Adjusted mean epilepsy seizure worry scores with confidence intervals for each practice (p=)

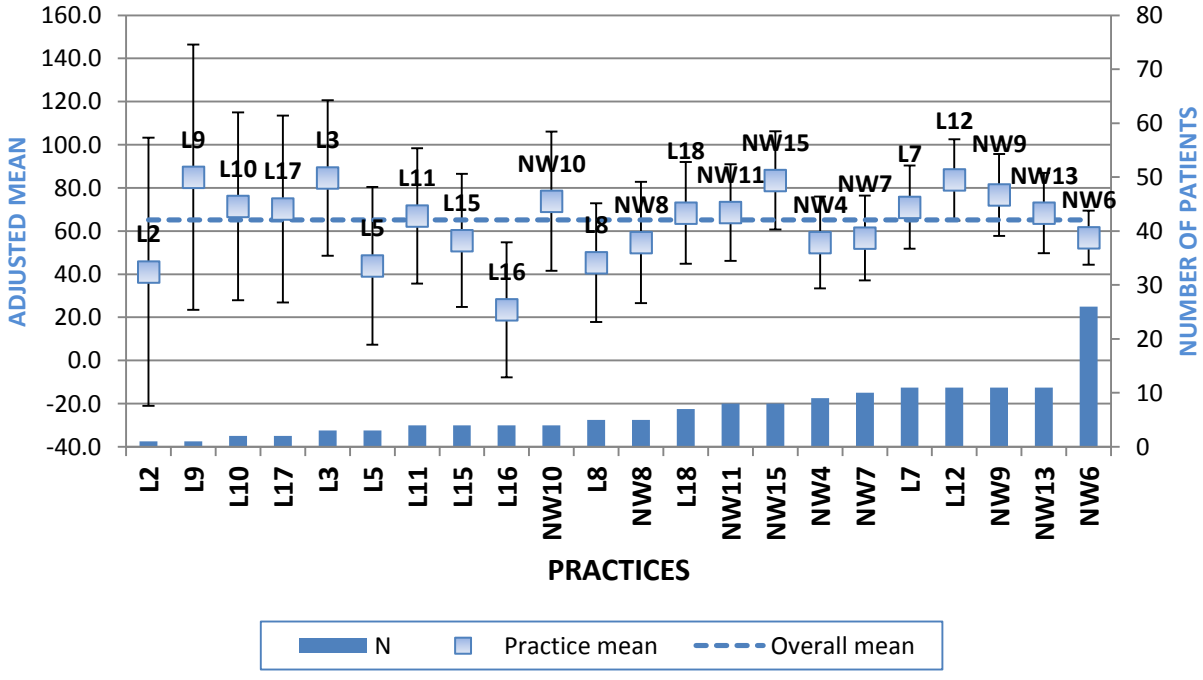


Figure 27: Adjusted mean epilepsy overall quality of life scores with confidence intervals for each practice (p=0.019)

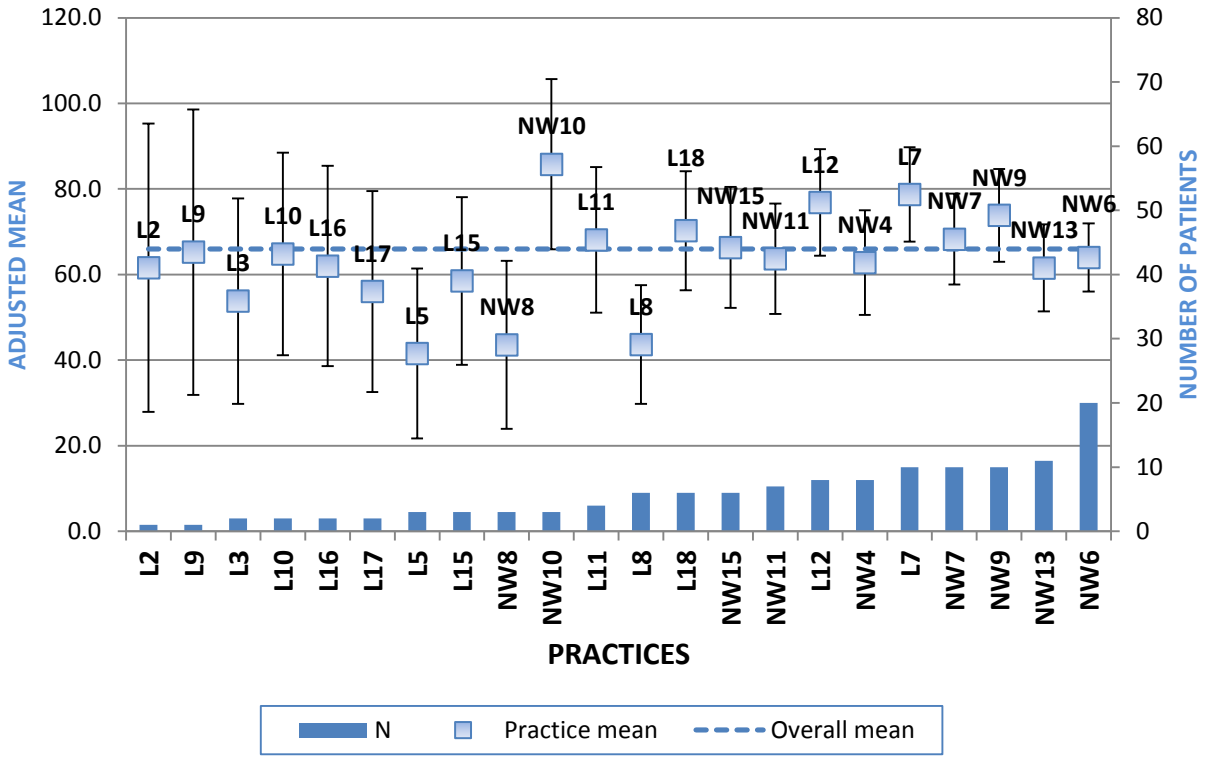


Figure 28: Adjusted mean epilepsy emotional well-being scores with confidence intervals for each practice (p=0.013)

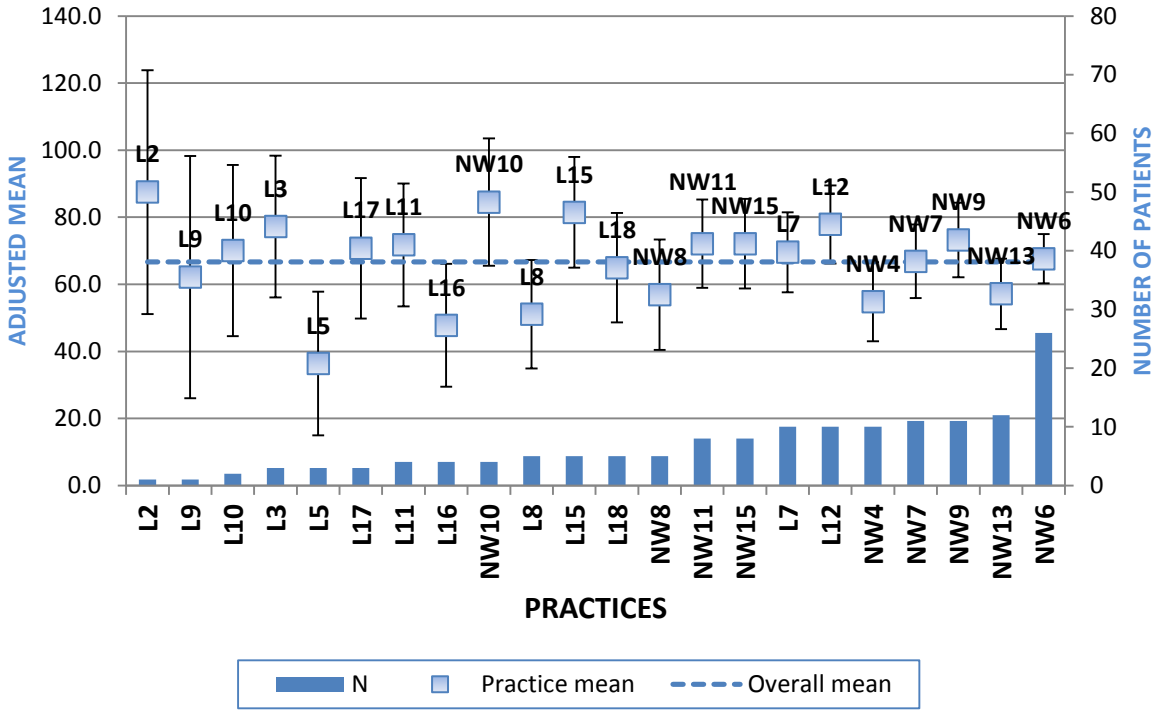


Figure 29: Adjusted mean epilepsy energy / fatigue scores with confidence intervals for each practice (p=0.012)

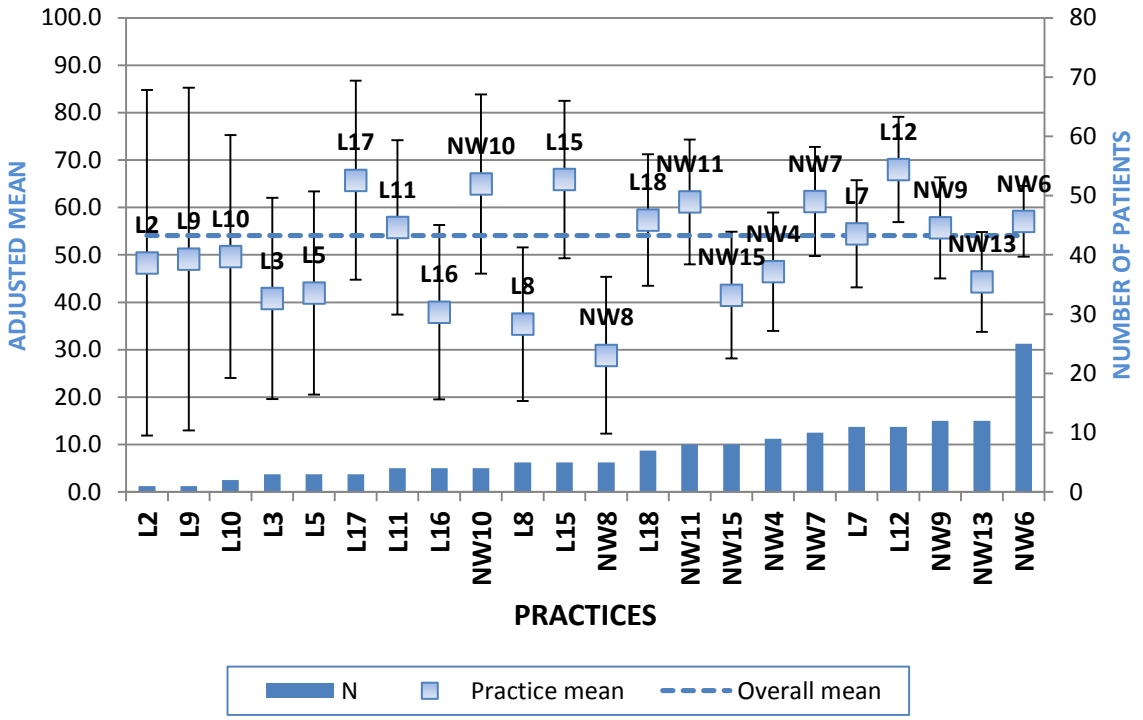


Figure 30: Adjusted mean epilepsy cognitive dimension scores with confidence intervals for each practice (NS)

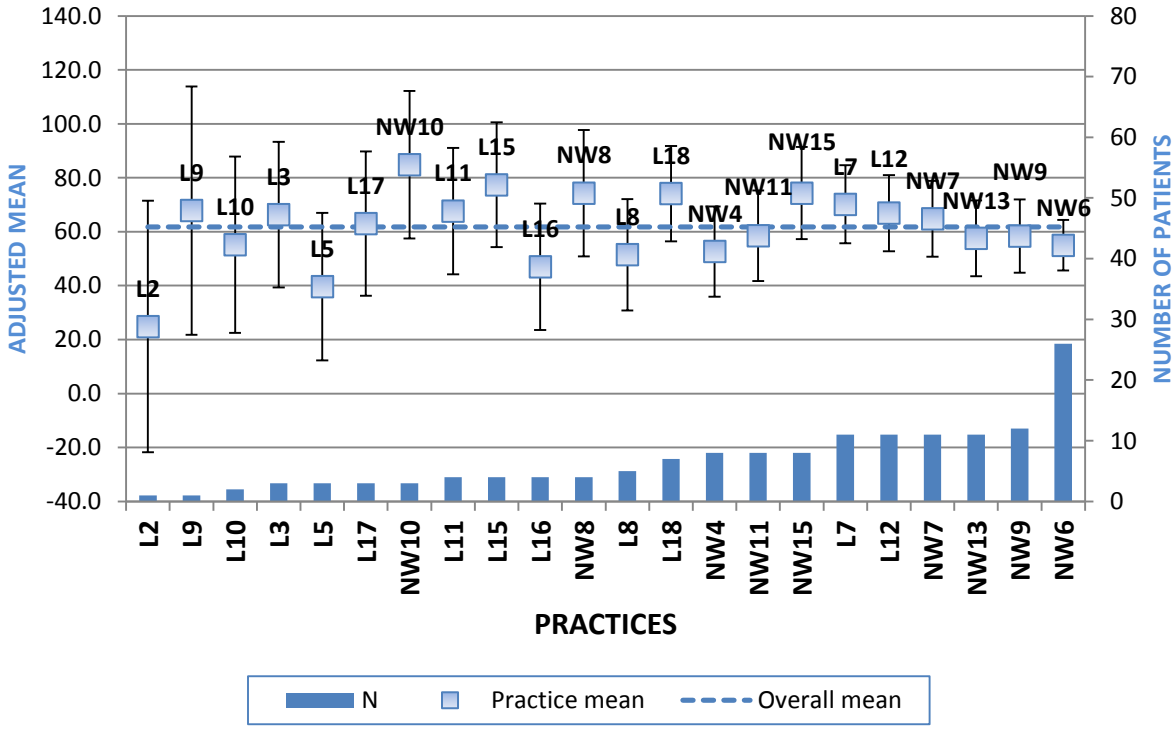


Figure 31: Adjusted mean epilepsy medication effect scores with confidence intervals for each practice (NS)

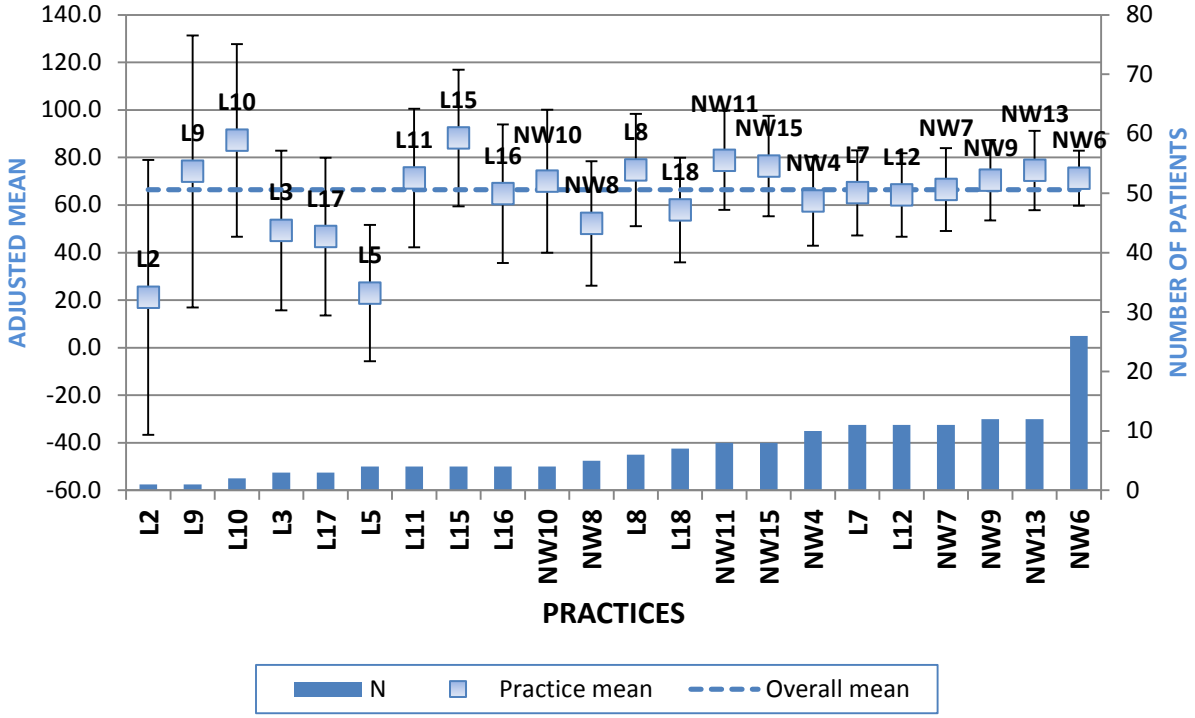


Figure 32: Adjusted mean epilepsy social functioning scores with confidence intervals for each practice (NS)

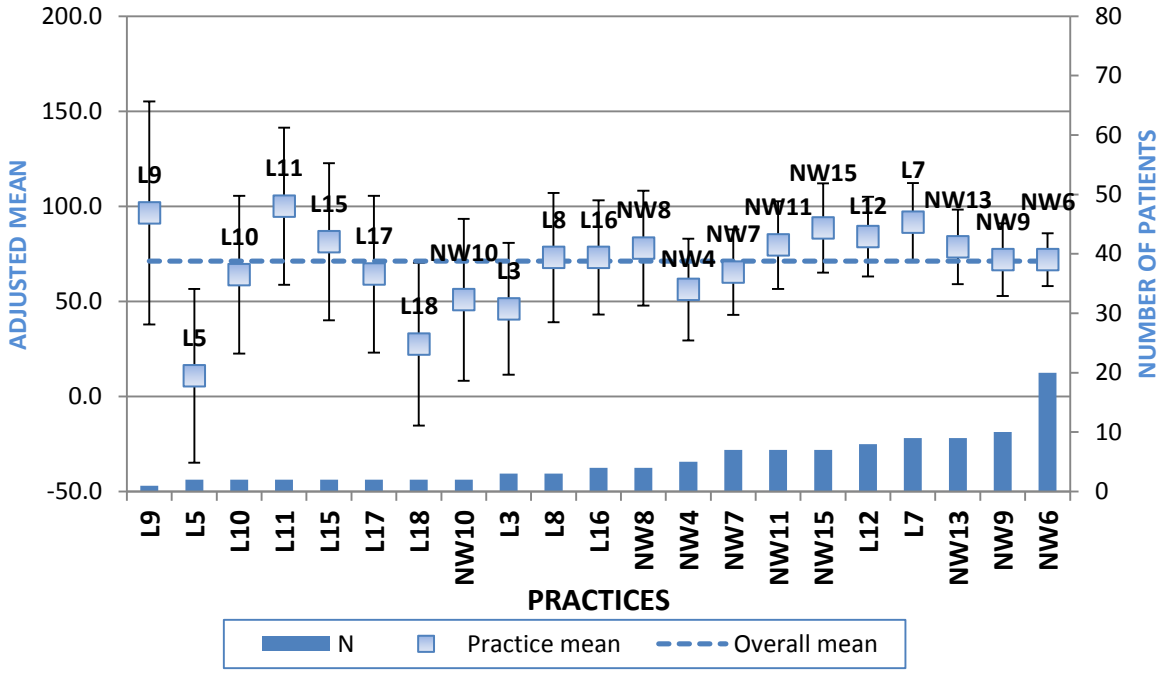
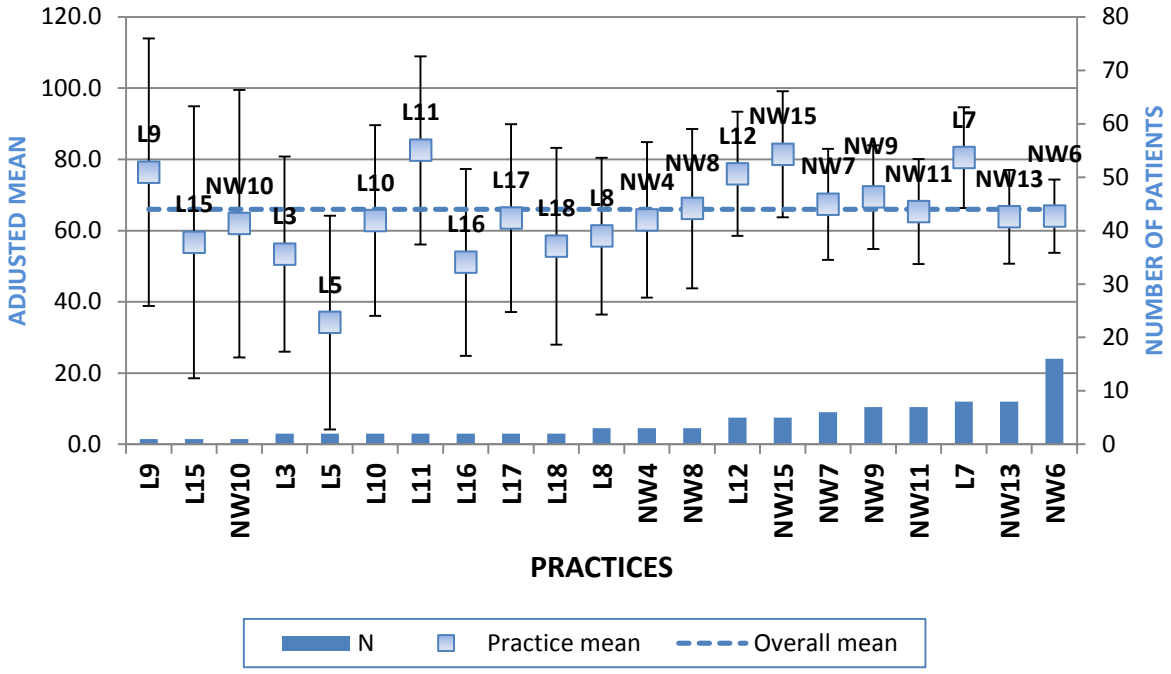


Figure 33: Adjusted mean epilepsy total quality of life scores with confidence intervals for each practice (NS)

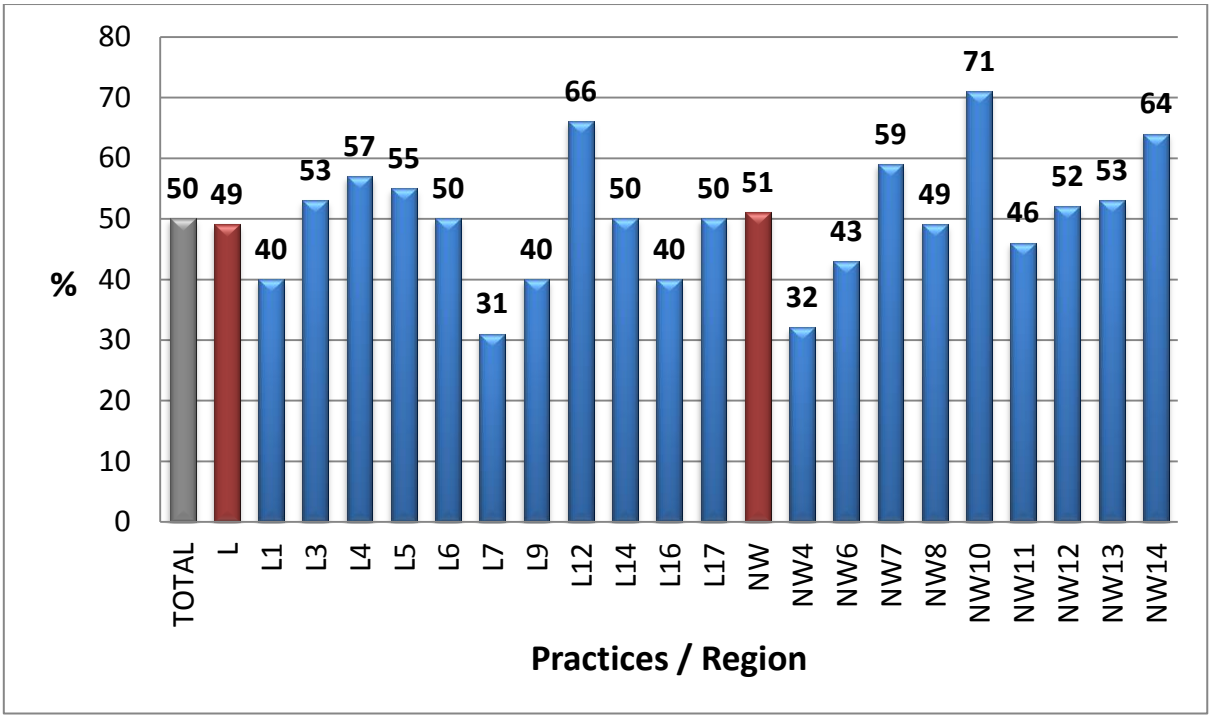


Heart Failure

Participating practices and their response rates

Twenty practices (11 in London and 9 in the NW) participated for heart failure. A total of 687 patients were extracted from the search (London n=186 and NW n=501) and 167 (24.3%) were excluded by the practices from being sent a questionnaire. Hence, 520 questionnaires were sent to achieve an overall response rate of 50.4% (n=262) (Figure 34). The response rate was similar in London and the NW (28.8%, n=79 and 50.4%, n=183 respectively). Three questionnaires were excluded from the analysis as the respondents reported not having been diagnosed with heart failure.

Figure 34: Heart failure response rate (%) for total sample, by region and practice



Missing data

There was a low rate of missing data for the EQ5D. The York Tariff could not be calculated for 14 (5.4%) of participants and the VAS was missing for 13 (5.0%) participants. The rate of missing data was low for most items of the heart failure-specific questionnaire (MLHFQ). Two items had a high rate of missing data 'difficulty with sexual activities' was missing for 38 (14.7%) participants and 'difficulty working to earn a living' was missing for '33 (12.7%) of participants. As no data imputation was performed, dimensions scores could not be calculated for 21 (8.1%) participants for the physical dimension, 21 (8.1%) for the emotional dimension and 79 (30.5%) of the overall quality of life score.

Demographics

A total of 259 patients were included in the analysis. The majority of respondents were male (n=161, 36.4%), retired (n=160, 66.9%), white (n=235, 92.9%) and from the NW (n=182, 70.3%). The mean time since diagnosis was 11.4 years (SD 11.0). Thirty seven (14.5%) participants were aged between 18 and 64 years, 73 (28.5%) 65 to 74, and 146 (57.0%) 75 years or more. Fifty-one (19.7%) respondents did not report any comorbidities, 67 (25.9%) reported one comorbidity and 141 (54.4%) reported two or more comorbidities.

PROMs Results

Individual Items

- Generic health status assessed by the EQ5D
    - The majority of heart failure patients reported no problems with self-care (n=178, 69.8%) or feeling anxious/ depressed (n=132, 53.0%)
    - At least some problems were reported for walking (n=186, 72.1%), usual activities (n=179, 70.2%) and pain and discomfort (n=145, 57.3%).
- Heart failure-specific health status assessed by the MLHFQ
    - The three most commonly reported problems were shortness of breath (n=142, 56.1), difficulty with walking about or climbing stairs (n=140, 55.0%) and difficulty with going places away from home (n=133, 53.0%). (NB a problem was interpreted as a score of 3 or more on a scale that asked participants to rate how much heart failure prevented them from living the life they wanted. The scale ranged from 1 to 5 where 1 was 'no' and 5 was 'very much').

PROMs scores

Adjusted mean scores of the EQ5D (York 1 Tariff and VAS) and the3 dimensions of the MLHFQ were calculated for total sample, by practice and by region. The EQ5D York Tariff ranges between 0 (worst health) and 1 (full health) and the EQ5D VAS between 0 (worst health) and 100 (full health). The MLHFQ dimensions score ranges vary by dimension, i.e. total score between 0 and 105, physical dimension score between 0 and 40 and the emotional dimensions score between 0 and 25. A higher score means more impairment.

Key findings:

- Generic health status assessed by the EQ5D
    - The overall adjusted mean score for the EQ5D York tariff was 0.59 (CI 0.53-0.66) and for the VAS 59.46 (CI 54.94-63.98)
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS between practices or regions (London vs. NW)
- Heart failure-specific health status assessed by the MLHFQ
    - The overall adjusted mean scores were 46.62 (CI40.74-52.50) for 'total quality of life', 20.96 (CI18.31-23.63) for the 'physical dimension' and 10.91(9.22-12.60) for the 'emotional dimension'.
    - No significant differences were found for the adjusted mean scores between practices and regions (London vs. NW).

Figures 35-39 illustrate the sample size and adjusted mean scores for each practice.

Figure 35: Adjusted heart failureEQ5D scores with confidence intervals for each practice (NS)

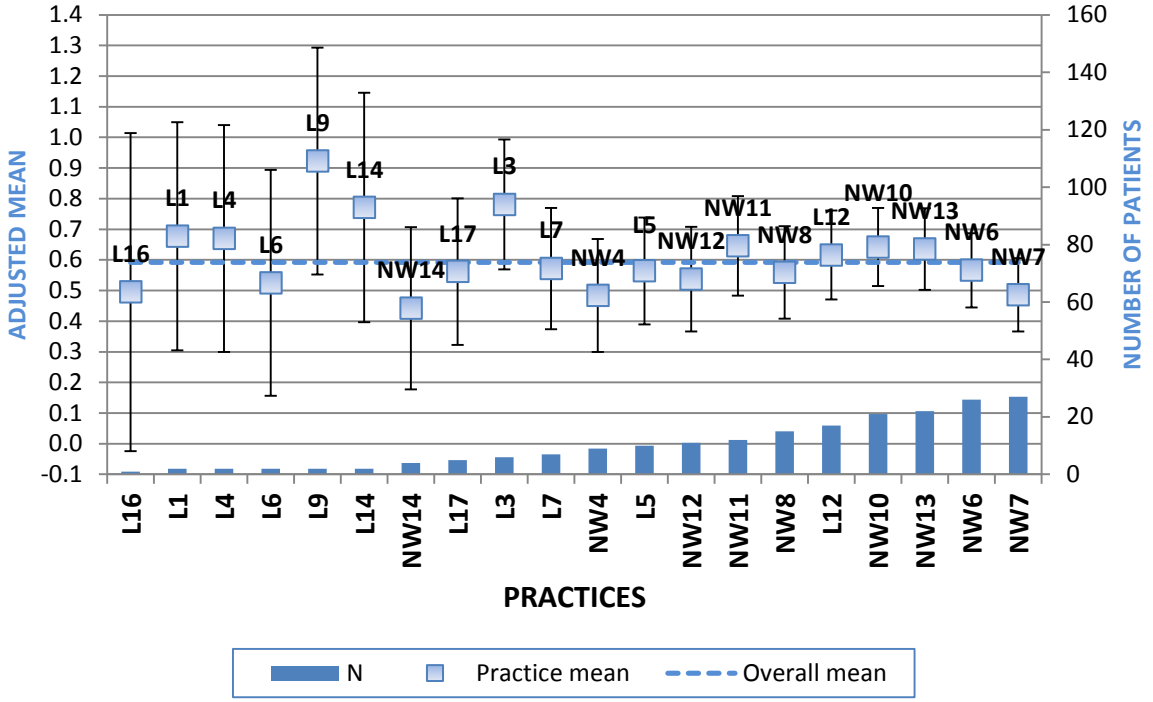


Figure 36: Adjusted heart failure EQ5D VAS scores with confidence intervals for each practice (NS)

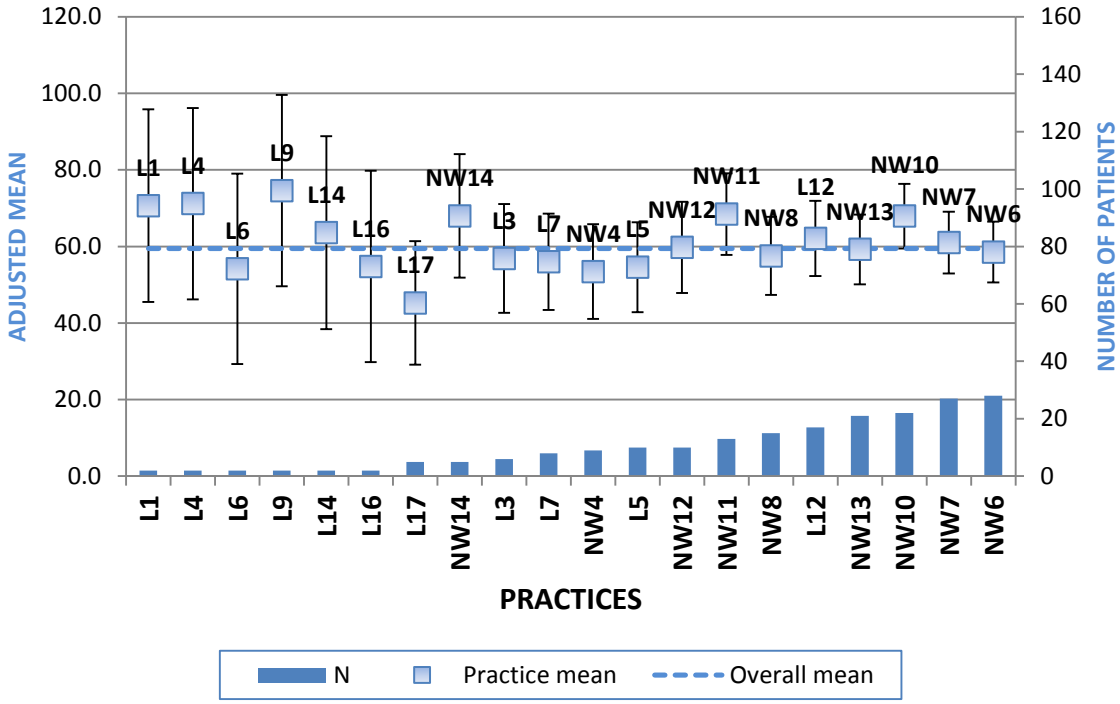


Figure 37: Adjusted heart failure total quality of life scores with confidence intervals for each practice (NS)

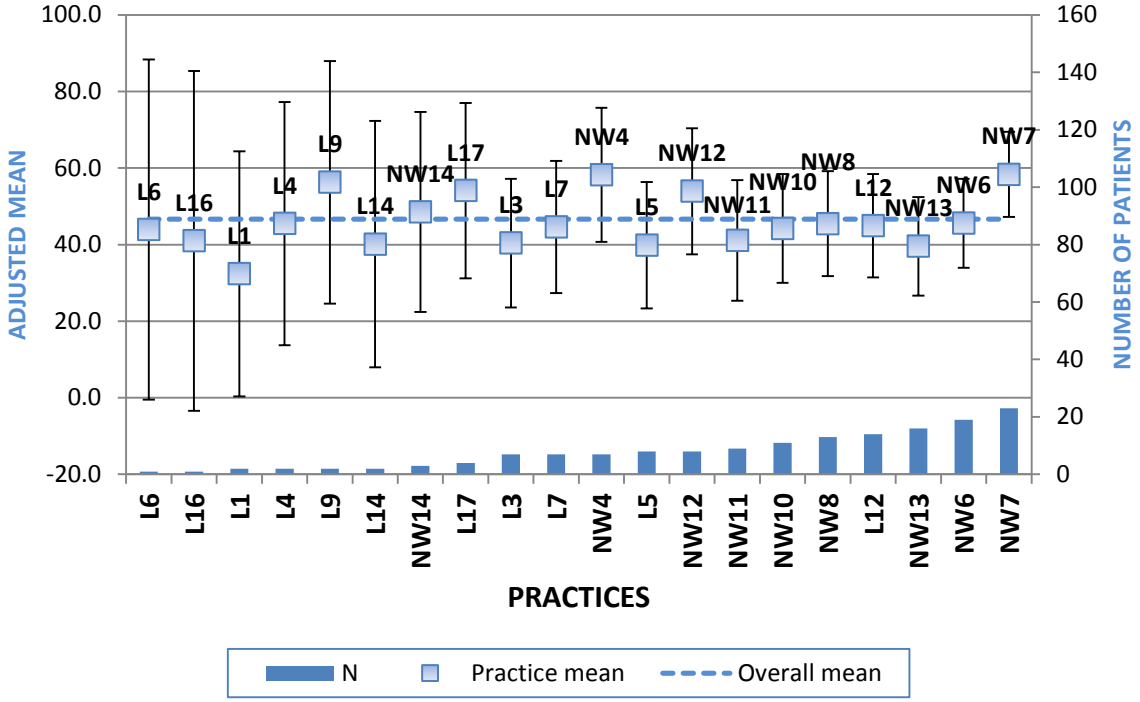


Figure 38: Adjusted heart failure physical scores with confidence intervals for each practice (NS)

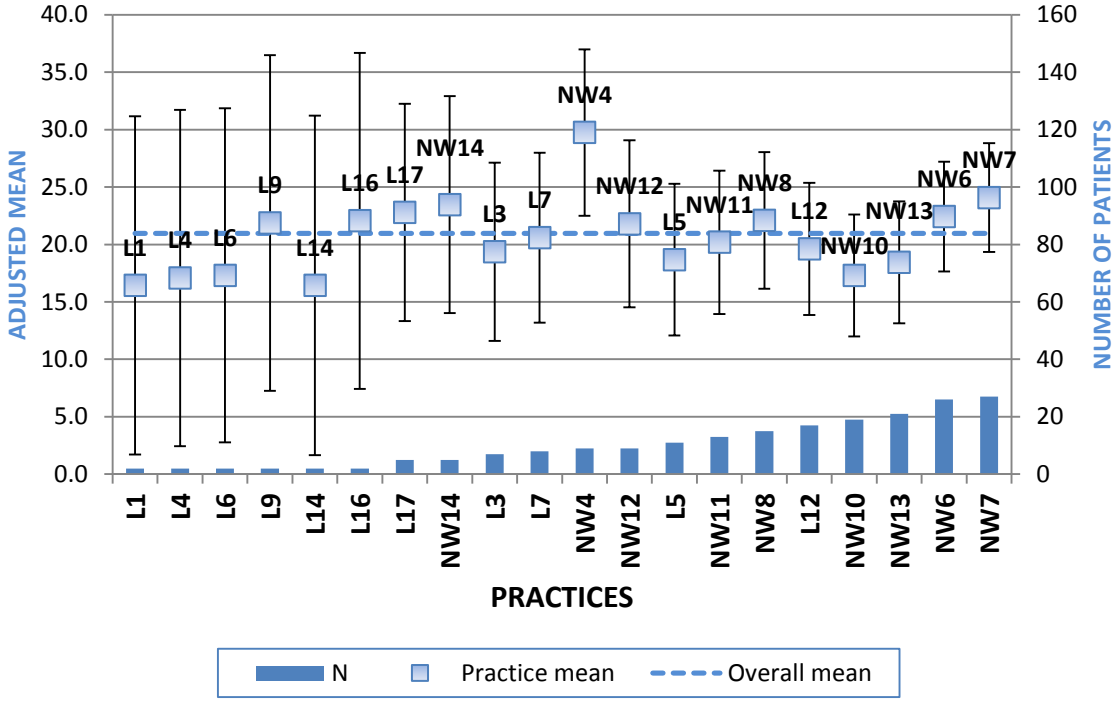
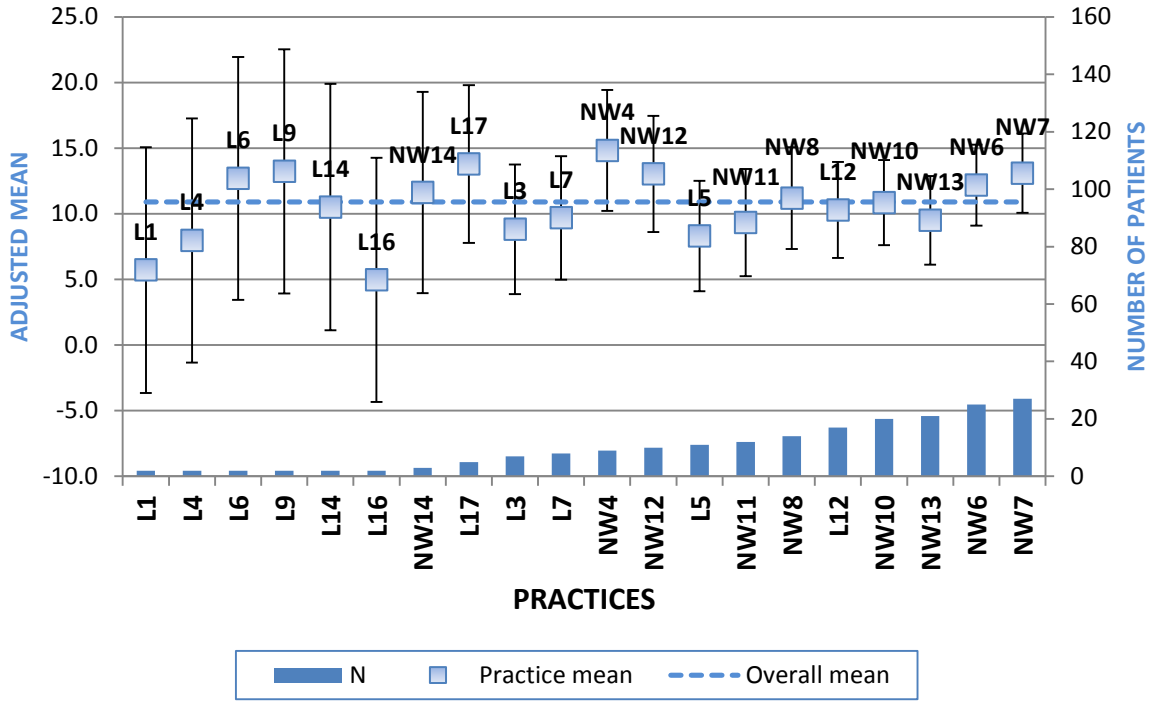


Figure 39: Adjusted heart failure emotional scores with confidence intervals for each practice (NS)

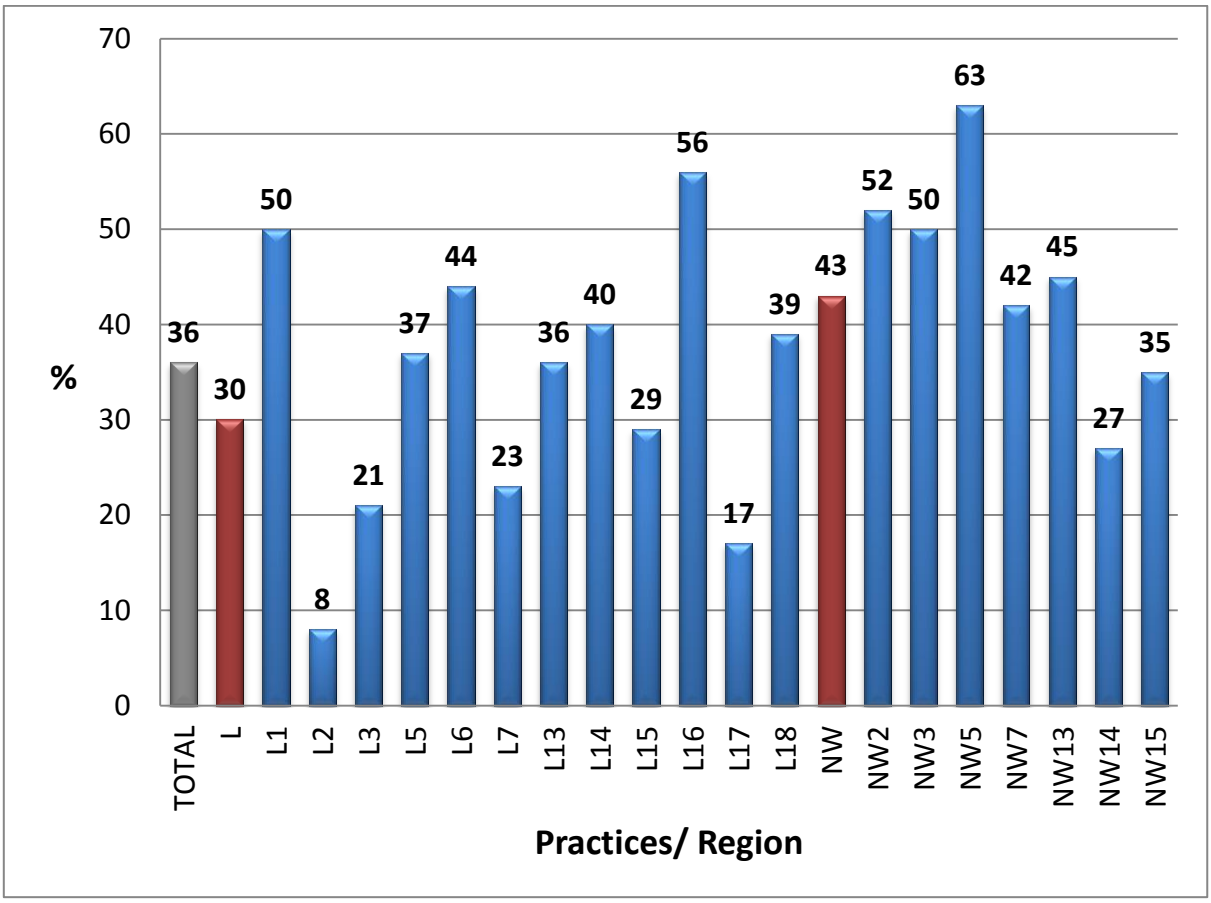


Stroke

Participating practices and their response rates

Nineteen practices (12 in London and 7 in the NW) participated for stroke. A total of 525 patients were extracted from the search (London n=273 and NW n=252) and 106 (20.2%) were excluded by the practices from being sent a questionnaire. Hence, 419 questionnaires were sent to achieve an overall response rate of 36.4% (n=152) (Figure 40). The response rate in the NW was higher (44.0%, n=84) than in London (30.0%, n=68). One questionnaire was excluded from the analysis as the respondent reported not having had a stroke.

Figure 40: Stroke response rate (%) for total sample, by region and practice



Missing data

There was a low rate of missing data for the EQ5D items to calculate the York Tariff (n=6, 4.0%) but the VAS item was missing for 20 (13.3%) of respondents. The rate of missing data on the Stroke Impact Scale (SIS) was low for the majority of items but 9 items had a high rate of missing data. Thirty-four (22.5%) of data was missing for 'limited in work', 32 (21.2%) for 'limited participation in religious activities', 20-28 (13.2 -18.5%) on the four strength items (arm, hand, leg and foot/ankle) and 16-17 (10.6-11.3%) for three social items (limited in social activities, and quiet and active recreation). As no data imputation was performed, the dimensions scores could not be calculated for 53 (35.1%) participants for 'handicap', 31 (20.5%) for 'strength', 27 (17.9%) for

'emotion', 22 (14.6%) for 'mobility', 20 (13.2%) for 'hand function', 13, (9.3%) for memory, 13 (8.6%) for 'communication', and 52 (34.4%) for the 'physical domain'.

Demographics

A total of 151 stroke patients were included in the analysis. The majority of respondents was male (n=81, 61.1%), retired (n=84, 57.5%) or in either full-time or part-time employment (n=29, 30%); white (n=133, 93.0%) and from the NW (n=83, 55.0%). The mean time since their stroke was 7.3 years (SD 6.1). Forty-nine (33.1%) were aged 18 to 64 years, 41 (27.7%) were aged 65 to 74 and 58 (39.2%) 75 years or more. Eighteen (11.9%) did not report any comorbidities, 53 (35.1%) reported one comorbidity and 80 (53.0%) reported two or more comorbidities.

Results

Individual Items

- Generic health status assessed by the EQ5D
    - The majority of respondents reported no problems with self-care (n=104, 70.7%), and being anxious/ depressed (n=75, 51.0%).
    - The majority of respondents reported at least some problems with walking (n=88, 59.4%), usual activities (n=77, 53.1%) and pain and discomfort (n=85, 57.8%).
- Stroke-specific health status assessed by the SIS
    - The three most commonly reported problems were enjoying things only a little or none of the time (n=71, 50.0%), difficulty with walking fast (n= 59, 40.7%) and difficulty with climbing several flights of stairs (n=57, 40.1%). (NB the latter two were interpreted as a problem if they were rated 'could not do at all' or 'very difficult' on the questionnaire).

PROMs scores

Adjusted mean scores of the EQ5D (York 1 Tariff and VAS) and the3 dimensions of the SIS were calculated for total sample, by practice and by region. The EQ5D York Tariff ranges between 0 (worst health) and 1 (full health) and the EQ5D VAS between 0 (worst health) and 100 (full health) and the SIS between 0 and 100 with higher scores meaning higher disability.

Key findings:

- Generic health status assessed by the EQ5D
    - The overall adjusted mean score for the EQ5D York tariff was 0.56 (CI 0.48-0.65) and for the VAS 62.29 (CI 56.01-68.57)
    - No significant differences were found between the adjusted mean scores of the York Tariff and the VAS between practices or regions (London vs. NW)
- Stroke-specific health status assessed by the SIS
    - The overall adjusted mean scores were 60.41 (CI52.24-68.59) for 'strength', 64.85 (CI55.46-74.24) for 'hand function', 74.02 (CI67.01-81.04) for 'mobility', 69.92 (CI 62.66-77.17), 77.51 (CI 69.34-85.68) for 'activities of daily living', 80.45 (CI71.65-89.25) for 'communication', 64.60 (CI 58.85-

70.36) for 'emotion', 63.97 (CI 52.19-75.75) for 'handicap', 70.98 (CI 62.12-79.84) for the 'physical dimension'.

- No significant differences were found for the adjusted mean scores between practices and regions (London vs. NW).

Figures 41-51 illustrate the sample size and adjusted mean scores for each practice.

Figure 41: Adjusted stroke EQ5D scores with confidence intervals for each practice (NS)

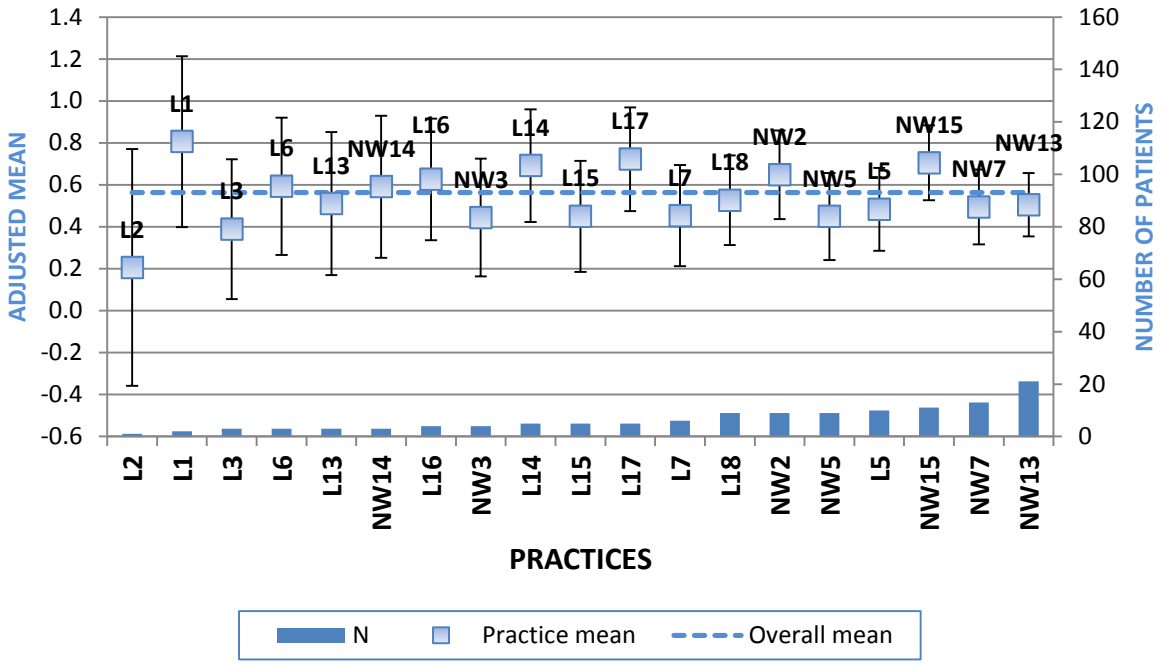


Figure 42: Adjusted stroke EQ5D VAS scores with confidence intervals for each practice (NS)

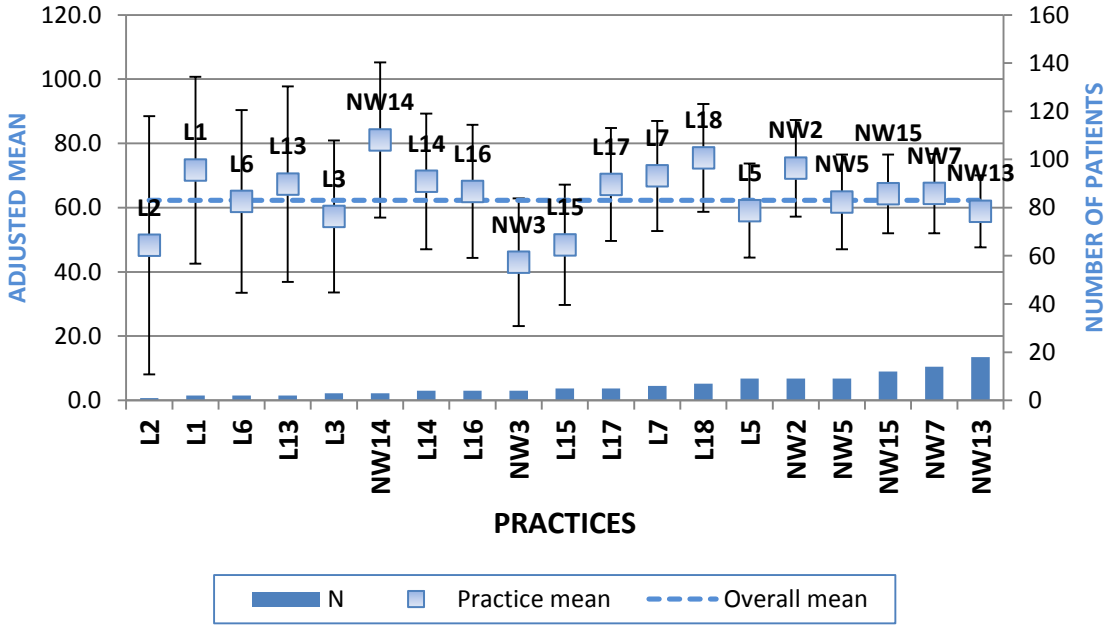


Figure 43: Adjusted stroke strength scores with confidence intervals for each practice (NS)

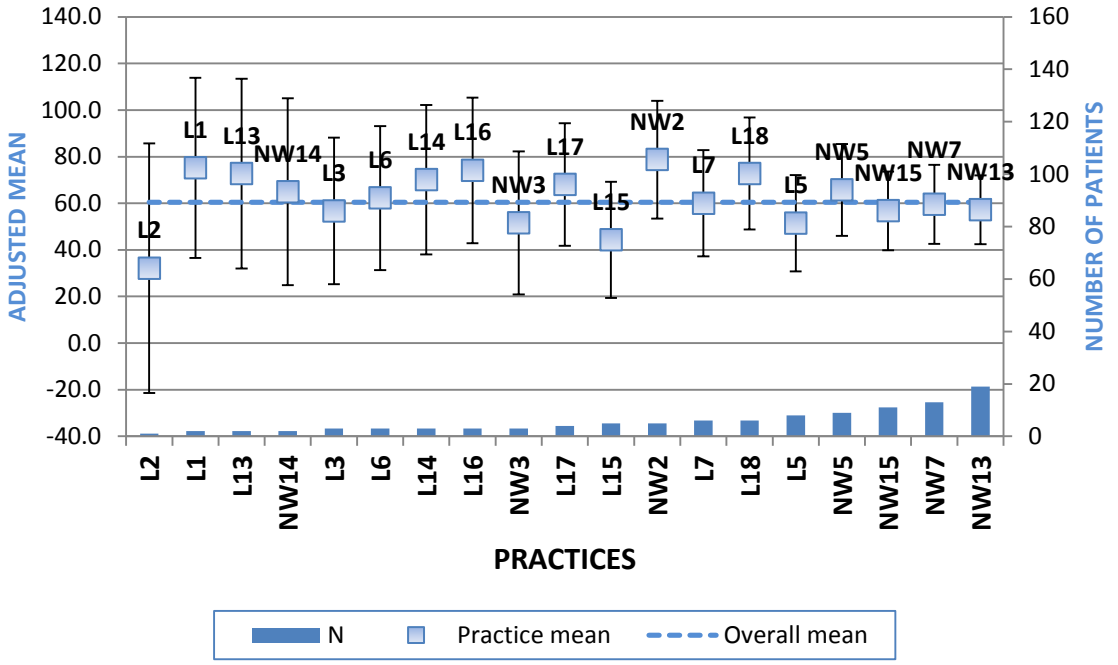


Figure 44: Adjusted stroke hand function scores with confidence intervals for each practice (NS)

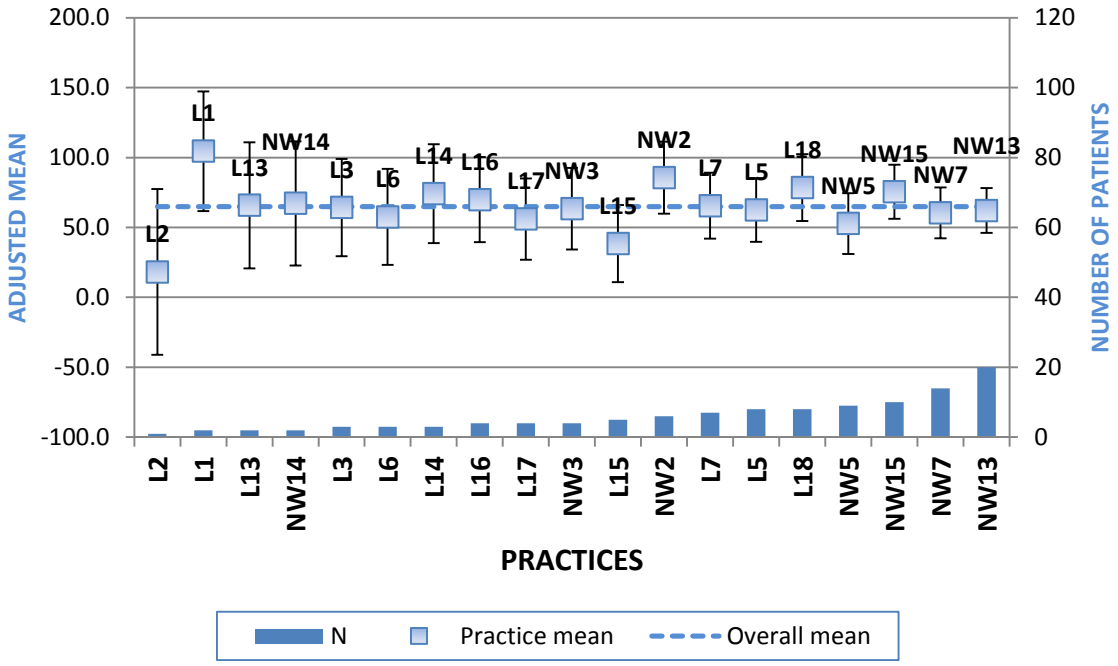


Figure 45: Adjusted stroke mobility function scores with confidence intervals for each practice (NS)

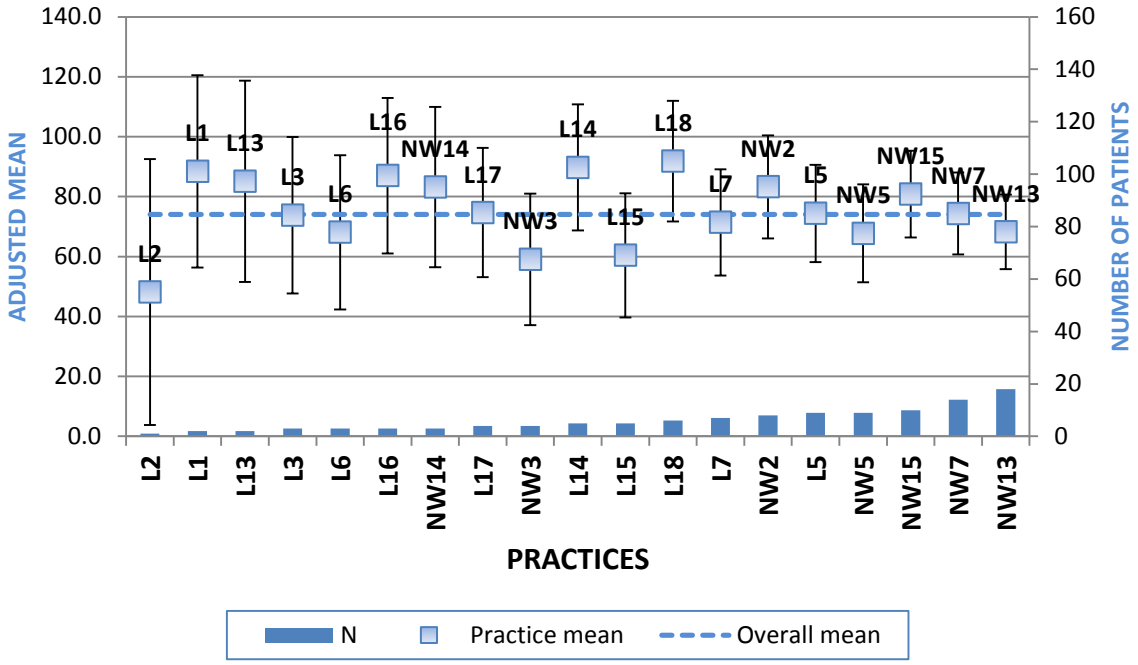


Figure 46: Adjusted stroke memory scores with confidence intervals for each practice (NS)

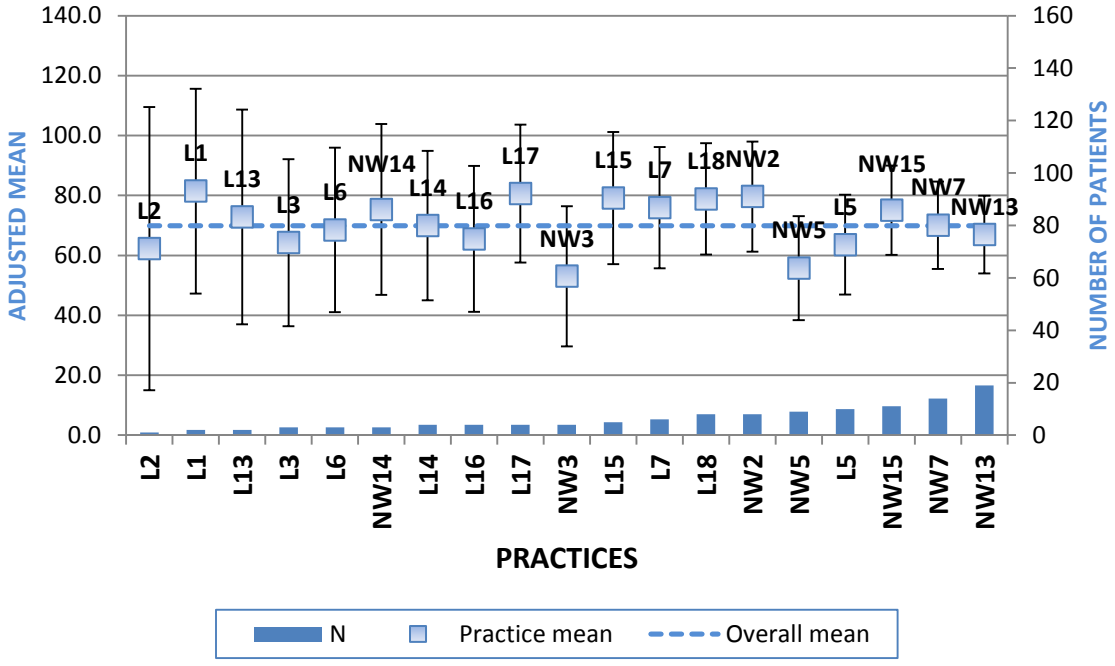


Figure 47: Adjusted stroke ADL scores with confidence intervals for each practice (NS)

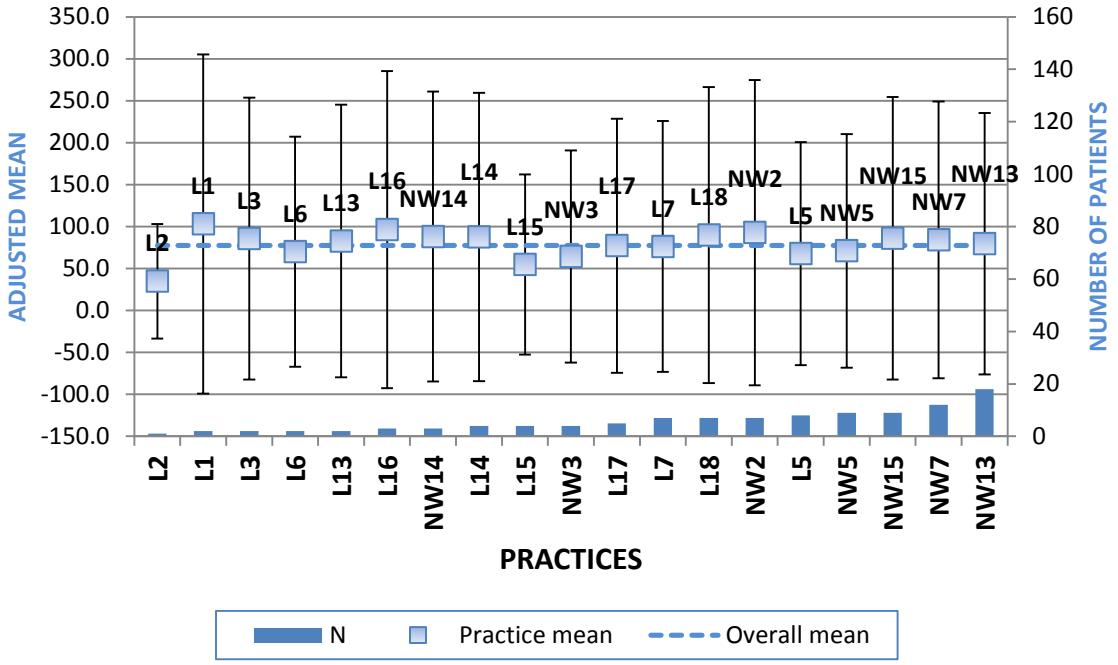


Figure 48: Adjusted stroke communication scores with confidence intervals for each practice (NS)

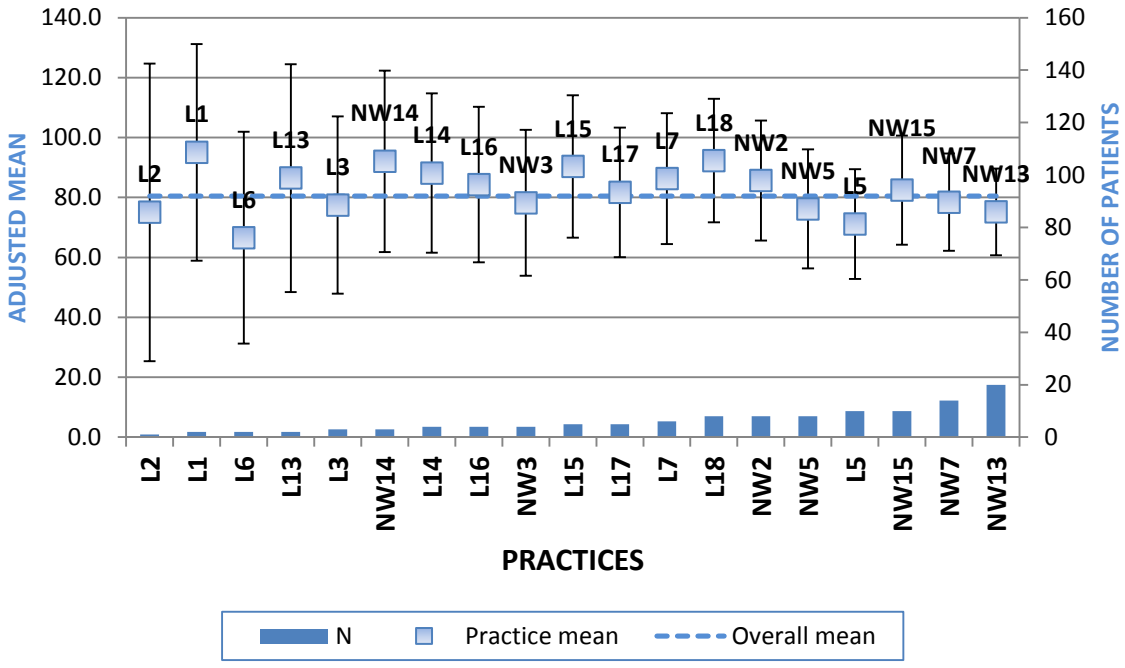


Figure 49: Adjusted stroke emotion scores with confidence intervals for each practice (NS)

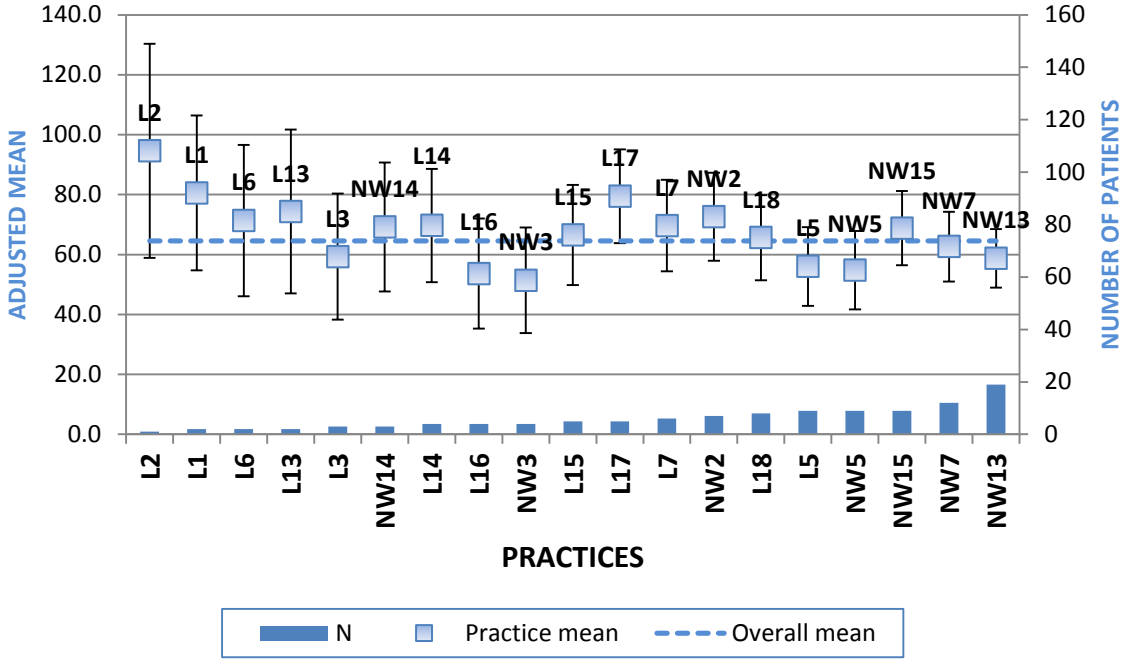


Figure 50: Adjusted stroke handicap scores with confidence intervals for each practice (NS)

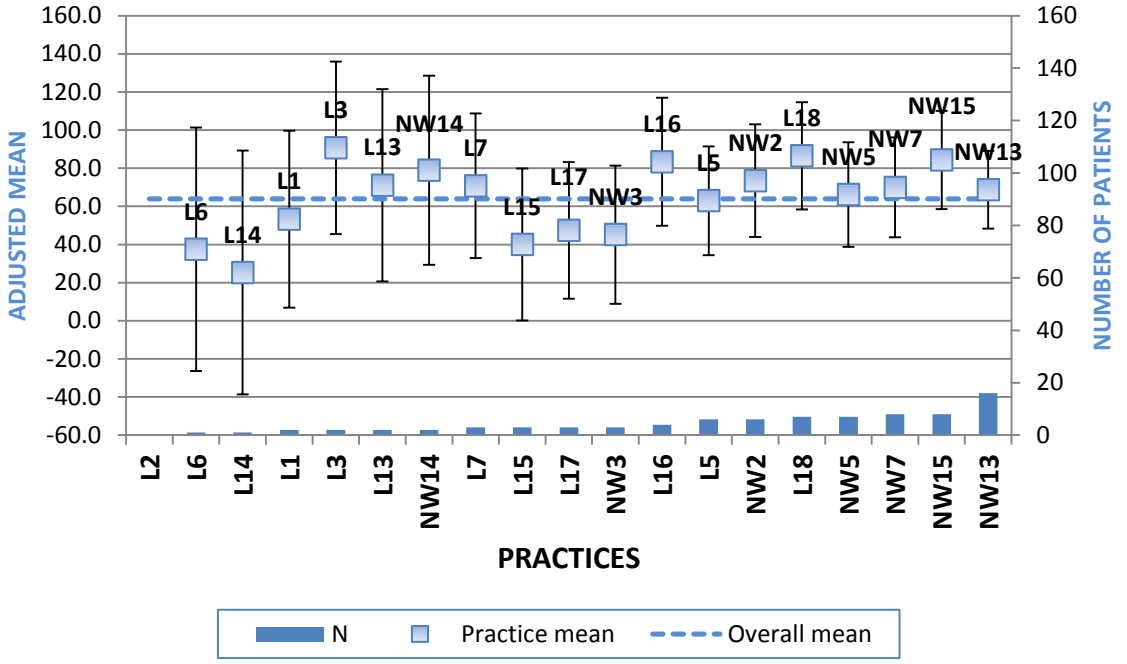
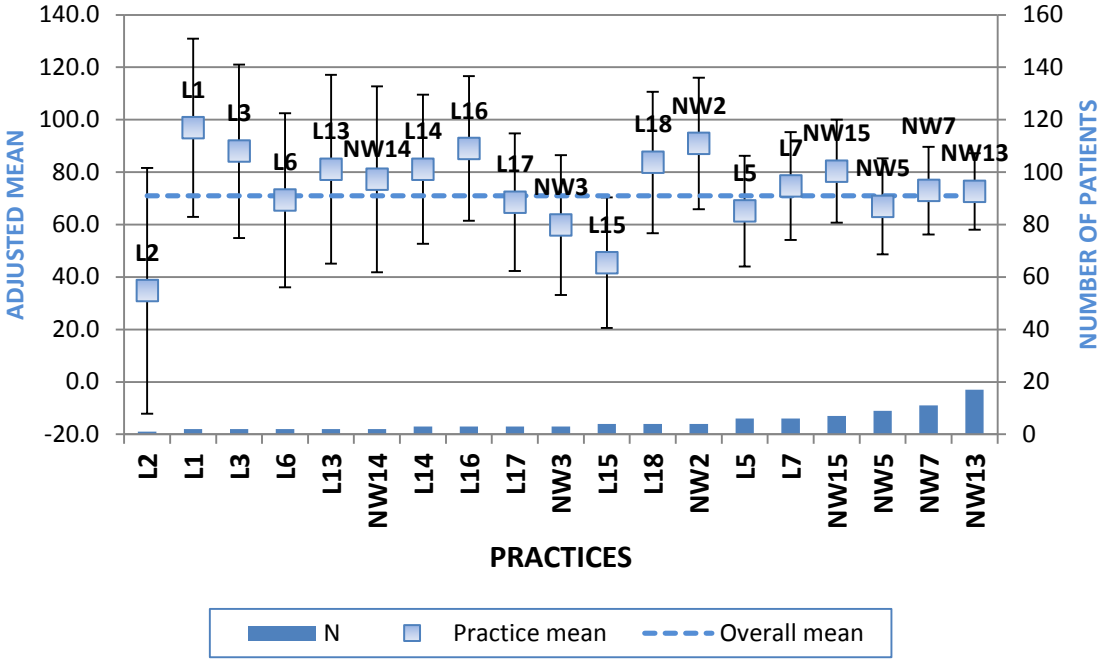


Figure 51: Adjusted stroke physical dimension scores with confidence intervals for each practice (NS)



Appendix 5: Semi-structure interview guide for qualitative interviews with stakeholders

UNIVERSITY OF OXFORD
Department of Public Health
Old Road, Oxford OX3 7LF

PROMs pilot on long-term conditions in primary care

Interview guide for stakeholders

1) How clear and meaningful are the data provided from the reports of PROMs?

2) What new or different information have the PROMs reports provided?

3) Do you have any concerns about the data reported?
Prompts:
- Does the data make sense? Is it believable?
- For example, the response rates
- Ways in which data are statistically analysed and presented?
- What are the best ways to present the data?
- Do you think there are issues that may affect the process of collecting PROM data?

4) Do you have any views about how such data should be collected?
Prompts:
- For example, how frequently should the data be collected?
- Who should collect the data?
- What are the best ways of collecting PROMs data?

5) What might be the best uses of data from PROMs?
Prompts:
- To assess health of patients in practices?
- To improve communication and relationships with patients?
- To inform commissioning or assessment of quality of services?

6) Are there any uses of PROMs that you would not support or have confidence in?

7) Which issues do you think have an effect on response rates?
Prompts:
- Relevance
- Length and complexity of questionnaire
- Clarity of what is being asked of respondents
- Problems of confidentiality
- Motivation
- Increasing demands for this type of information from patients

Version 1, 25.01.2012
Study approved by the NHS Research Ethics Committee. Title: PROMs Pilot: REC Reference Number: 10/H0501/10

Appendix 6: Participating practices

Table Appendix 6: Description of practices who participated in the surveys

North-West England								
	PCT	**N of patients**	**Clinical system**	**LTCs covered**	**IMD 2010 score**	**IMD 2010 Rank**	**Overall QOF score (%)**	**Survey**
NW1	Cumbria	3,500	EMIS PCS	Asthma COPD Diabetes	9.71	24,412	98.8	Cohort
NW2	Cumbria	5,800	EMIS LV	COPD Diabetes Stroke	8.00	26,606	96.9	Cohort XS (not COPD)
NW3	North Lancashire	2,000	EMIS LV	Asthma COPD Stroke	42.76	3,769	99.6	Cohort
NW4	North Lancashire	19,500	EMIS LV	COPD Epilepsy Heart Failure	42.76	3769	96.5	Cohort XS
NW5	North Lancashire	6,000	EMIS LV	COPD Epilepsy Stroke	28.07	9,097	95.9	Cohort
NW6	North Lancashire	36,000	EMIS PCS	Epilepsy Heart Failure	54.38	1,493	92.9	Cohort
NW7	North Lancashire	13,500	EMIS PCS	Epilepsy Heart Failure Stroke	36.67	5,629	97.5	Cohort
NW8	North Lancashire	5,600	EMIS LV	Diabetes Epilepsy Heart Failure	28.07	9,097	95.6	Cohort
NW9	North Lancashire	13,000	EMIS LV	Asthma COPD Epilepsy	15.75	17,559	96.1	Cohort XS
NW10	North Lancashire	8,000	EMIS LV	COPD Epilepsy Heart Failure	22.38	12,300	93.7	Cohort XS
NW11	North Lancashire	8,800	EMIS LV	Diabetes Epilepsy Heart Failure	22.38	12,300	96.1	Cohort

Table Appendix 6 (continued): Description of participating practices

North-West England								
	PCT	**N of patients**	**Clinical system**	**LTCs covered**	**IMD 2010 score**	**IMD 2010 Rank**	**Overall QOF score (%)**	**Survey**
NW12	Western Cheshire	4,400	EMIS LV	COPD Diabetes Heart Failure	11.31	22,340	97.8	Cohort
NW13	Western Cheshire	17,100	EMIS LV	Epilepsy Heart failure Stroke	27.35	9,453	95.1	Cohort
NW14	Western Cheshire	4,200	EMIS LV	Asthma Heart Failure Stroke	6.40	28,523	95.3	Cohort
NW15	Western Cheshire	6,200	EMIS LV	Asthma Epilepsy Stroke	33.04	6,923	99.8	Cohort XS
	London							
L1	Brent	5,100	EMIS LV	Asthma Epilepsy Stroke	17.12	16,366	96.1	Cohort
L2	Brent	3,300	EMIS LV	Asthma Epilepsy Stroke	55.76	1,296	94.1	Cohort
L3	Ealing	8,300	EMIS LV	Epilepsy Heart Failure Stroke	14.96	18,277	94.0	Cohort
L4	Ealing	4,300	EMIS LV	COPD Diabetes Heart Failure	15.77	17,543	94.6	Cohort
L5	Ealing	9,600	EMIS LV	Epilepsy Heart Failure Stroke	13.97	19,264	88.9	Cohort XS
L6	Ealing	3,800	EMIS LV	Asthma Heart failure Stroke	22.80	12,022	98.3	Cohort
L7	Hammersmith and Fulham	14,700	INPS V3	Epilepsy Heart Failure Stroke	29.80	8,279	96.4	Cohort

Table cont: Description of participating practices

	PCT	N of patients	Clinical system	LTCs covered	IMD 2010 score	IMD 2010 Rank	Overall QOF score (%)	Survey
L8	Hammersmith and Fulham	10,500	INPS Vision 3	COPD Diabetes Epilepsy	25.18	10,576	90.4	Cohort
L9	Hammersmith and Fulham	5,000	EMIS LV	Asthma Epilepsy Heart Failure	36.54	5,675	94.5	Cohort
L10	Harrow	4,000	EMIS LV	COPD Diabetes Epilepsy	13.40	19,915	93.8	Cohort
L11	Harrow	6,000	EMIS LV	COPD Diabetes Epilepsy	20.30	13.771	98.4	Cohort
L12	Hillingdon	11,500	EMIS LV	COPD Epilepsy Heart Failure	8.11	26,460	96.2	Cohort XS
L13	Hounslow	4,000	INPS Vision 3	Asthma COPD Stroke	12.75	20,684	96.1	Cohort
L14	Westminster	6,000	EMIS LV	Asthma Heart Failure Stroke	13.19	20,159	97.7	Cohort
L15	Westminster	8,250	EMIS LV	COPD Epilepsy Stroke	40.00	4,561	91.8	Cohort
L16	Westminster	8,000	INPS V3	Epilepsy Heart Failure Stroke	23.99	11,278	93.3	Cohort
L17	Westminster	8,500	INPS V3	Epilepsy Heart Failure Stroke	52.18	1,823	94.1	Cohort
L18	Westminster	10,200	EMIS LV	COPD Epilepsy Stroke	9.90	24,169	97.7	Cohort

Appendix 7: Details of stakeholders who participated in qualitative interviews

Code	Participant	Location	Survey participation	Actively involved in survey
Manager_01_L	Assistant practice manager	L14	Yes	Yes
Research manager_02_NW	Research and development manager	NW	No (but aware of surveys)	No
Commissioner_03_NW	Quality improvement manager/ commissioner	NW	No (but aware of surveys)	Yes
Patent_04_L	Patient representative	L14	Yes	No
Research nurse_05_NW	Research nurse	NW7	Yes	Yes
Research nurse_06_NW	Research nurse	NW6	Yes	Yes
Practice nurse_07_NW	Practice nurse (chronic diseases)	NW7	Yes	No
GP_08_NW	GP	NW9	Yes	No
GP_09_L	GP	L9	Yes	Yes
GP_10_NW	GP	NW13	Yes	No
Commissioner_11_L	Commissioner	Brent and Harrow PCT	No	No
Patient_12_NW	Patient representative	NW6/9	Yes	No
Patient_13_NW	Patient representative	NW6/9	Yes	No
GP_14_L	GP	London	No	No
Patient_15_NW	Patient representative	NW6/9	Yes	No
Practice nurse_16_NW	Practice nurse	NW2	Yes	Yes
Patient_17_NW	Patient representative	NW6/9	Yes	No
Patient_18_NW	Patient representative	NW6/9	Yes	No
GP_19_NW	GP	NW2	Yes	No
Patient representative group L14 - notes	Patients, GP, Manager	L1	Yes	No