

UK Primary Care Research Portfolio Review

Background

In the decade since the Mackenzie II¹ and Mant² reviews of primary care research there has been considerable development in academic primary care in the UK. The breadth and depth of primary care research, summarised in this review of research registered on the UK Clinical Research Network database, is striking. A broad, generalist perspective is inevitable in primary care research but recent years have seen a step change in the depth, quality and international standing of research in primary care in the UK: well-exemplified in the results of the 2008 Research Assessment Exercise^{3 4}.

Research in community settings has its roots in the discoveries of William Withering⁵ (digitalis) and Edward Jenner (smallpox and vaccination)⁶. More recent exponents of general practice epidemiology include William Pickles, the Wensleydale GP who delineated the mode of transmission of infectious hepatitis and Edgar Hope Simpson, a Gloucestershire practitioner, who was the first to show that shingles represented a re-activation of the varicella virus⁷. Julian Tudor Hart, working in the Welsh valleys in Glyncoed was a pioneer of interventional cardiovascular epidemiology, whilst John Fry, John Howie and David Morrell laid the foundations of practice based research into people as well as patients.

Epidemiology provides an understanding of the processes by which people turn into patients, with Morrell showing that only one in forty of symptoms experienced in the community ever become the subject of a medical consultation⁸ and David Hannay elaborating the concept of the illness iceberg⁹. Respiratory¹⁰ and Gastrointestinal disorders¹¹ were an early target for general practice epidemiology, with important work on conditions such as heart failure¹² and chronic pain¹³ as well as cross cutting themes such as deprivation and multiple morbidity have appeared more recently¹⁴.

Research into **health beliefs and expectations** is essential for understanding why a particular patient has chosen to consult on a particular day. Studies of patients' attributions of health and illness and their health locus of control began with the pioneering work of Roisin Pill and Nigel Stott in Cardiff in the 1980s¹⁵, and an important series of studies undertaken by Britten and her team on expectations, misunderstandings and concordance with management and therapy¹⁶.

Screening and health prevention are important opportunities in the general practice consultation and studies such as OXCHECK, the Family Heart Study, ProActive UK and SAFE42-44 have carefully looked at the role of screening, the identification of cardiovascular risk and the value of interventions. Excessive alcohol consumption and smoking have also been the subject of a number of influential trials undertaken in general practice¹⁷¹⁸.

Diagnosis is, as Osler recognised, at the heart of the consultation and this has been recognised as a key issue in Primary Care Research for a long time¹⁹. The diagnosis needs to be made early, accurately and safely and general practice research has contributed across all three dimensions. The detailed work on meningitis from Mant's group in Oxford²⁰ has acted as a template for studying the detailed natural history of disease onset, with individual symptom prevalence and trajectory being followed in different age groups of children hour by hour. Harold Hin's work on coeliac disease²¹ has greatly raised the profile

of this condition, stimulating widespread attempts to ensure that patients at risk are appropriately identified and treated. A number of innovative approaches to making an accurate diagnosis have appeared in the general practice research literature, including Hobbs' studies of N-terminal pro-brain natriuretic peptide²² and the influential work on the use of two or three screening questions for depression by Bruce Arrol and colleagues from Auckland, New Zealand²³. Using the General Practice Research Database, Jones and colleagues have evaluated the significance of alarm symptoms in terms of making a safe diagnosis,²⁴ and Hamilton, Sharp and colleagues in Bristol have studied in detail symptoms in patients diagnosed with colorectal cancer²⁵ and lung cancer²⁶.

Treatment in general practice has been researched in a number of ways, from the description of the 'rule of halves' by Ritchie and Currie in 1983²⁷ (whereby only half of patients with a certain condition are identified, only half are treated and only half of them are treated adequately) and Griffith, Kinmonth and others identifying the key components of effective interventions in terms of the provision of patient information, adequate communication skills, and attention to emotional content²⁸. Prescribing strategies, including the use of the 'deferred prescription', have been elegantly researched by Little's group in Southampton²⁹. In cardiology the IMPROVE programme described the variation in quality of care provided by general practitioners in Europe³⁰, and a similar survey undertaken by the European Society for Primary Care Gastroenterology has emphasised the range of treatment strategies being taken for the management of common gastrointestinal disorders in ten European countries³¹. Clarification of the value of testing for and treating *Helicobacter pylori* infection in dyspepsia³² and the role of cognitive behavioural therapy in the treatment of irritable bowel syndrome³³ have been subjects of influential randomised controlled trials in general practice. In the field of acute diseases general practice research has helped to define the role of interventions in common conditions such as Bell's palsy³⁴ and conjunctivitis³⁵.

The care of chronic disease is a major component of the work of general practice and the principles of chronic disease management in primary care have been explored and refined for cardiovascular, respiratory, gastrointestinal, genitourinary, musculoskeletal, neurological problems and diabetes. The key elements of registration, recall and regular review of the key components of care have been studied³⁶. Measuring and assuring the **quality of care** in general practice is essential and the internationally-recognised work of Roland's group in Manchester in developing quality indicators, culminating in the introduction of the Quality and Outcomes Framework, a pay-for-performance system within the GP Contract, has received widespread international attention³⁷. The QOF Database provides rich opportunities for an exploration of demographic, practice and other factors associated with the attainment of quality markers for disease management in general practice³⁸.

Beyond these topics and methods, general practice research has also embraced mental health problems, musculo-skeletal disorders and, recently and importantly, various aspects of genetics (risk, early diagnosis, genetic counselling) in primary care. In terms of methodology generic health services research, epidemiological studies and trials have been complemented by a good deal of work on complex interventions, using the MRC Framework as a guide, and a range of sophisticated qualitative methods to explore beliefs, understandings and behaviours.

Research in primary care has greatly benefited by the registration system of patients in the NHS, providing a unique and rich data source. The commitment of the National Health Service to research and development has been strengthened in recent years, with the establishment of the National Institute for Health Research, the National School of Primary Care Research, the UK Clinical Research networks and Primary Care Research Networks across the country. The Research for Patient Benefit programme has provided a substantial boost to research funding in primary care and the applied community-based sciences.

The UK Primary Care Research Portfolio Review and Development Group was set up in 2007 comprising representatives from MRC GPRF, NSPCR (England), PCRN(England) Primary Care Research leads from N. Ireland, Scotland and Wales, RCGP and SAPC (Appendix 1) The remit of the group is to develop an oversight of the primary care research portfolio in the UK and to facilitate the development of a programme of high quality primary care research. At the first meeting of the group on 27/11/07 it was agreed that there was the need to map current primary care research activity throughout the UK in order to identify areas of strength and important potential activity gaps.

Methods

Phase 1: Identify an appropriate classification framework

Potential Frameworks for mapping of current UK primary care research portfolio

Options considered included the MRC Topic Review Framework, the European Definition of Family Medicine³⁹, the Mackenzie 2 Classification¹, RAE2008 UoA8 declared research topics⁴⁰ (Appendix 2). UKCRC Health Research Classification System⁴¹ (Appendix 3)

Testing classification frameworks

1st classification exercise-UKCRN, Mackenzie (Modified) and RAE

Four reviewers were asked to classify 20 abstracts from the Society for Academic Primary Care (SAPC) Annual meeting 2007 using the UKCRC, Modified Mackenzie and RAE classification frameworks. Reviewers were provided with copies of the abstracts and an algorithm for each classification framework describing how they should be use

Observer variability was determined by calculating kappa scores which were low so after consultation with members of the UK Primary Care Research Portfolio Review and Development Group, it was decided to drop the RAE classification and substitute the Modified Mackenzie with European Definition of Family Medicine (WONCA) classification. Rather than choosing one classification per framework, it was agreed that multiple categorisation should be used in future which would allow inter and intra-rater reliability to be ignored. This means that a study about depression in diabetes would be classified in Mental Health as well as Diabetes.

2nd classification exercise-UKCRN, European Definition of Family Medicine (WONCA)

Six reviewers were asked to classify 20 study protocols for primary care studies registered on the UK Portfolio Database using the UKCRC (modified) and the WONCA classification frameworks. Reviewers were provided with copies of the study protocols and an algorithm for each classification framework describing how they should be used.

Reviewers did not find the WONCA classification suitable for the purposes of this exercise as it was not intuitive and reduced rather than enhanced meaningful output. Prof. Martin Roland suggested an alternative classification with 18 topic headings (which incorporated most of the content of the WONCA but included terms that readers would be more familiar with (see Appendix 2).

Two reviewers classified the 20 study protocols using the Roland classification framework and the results were compared with the UKCRN and WONCA classification scores.

Society of Academic Primary Care (SAPC) Annual Meeting 2008

The results of the 2nd classification exercise were the topic of a workshop at the SAPC 2008 meeting where **it was agreed by participants that the UKCRN and Roland classification frameworks should be used** to classify summaries of primary care studies on the Portfolio Database. On the basis of discussion at the SAPC workshop, the Roland classification was modified in the following way: two further categories were added ('Trial of treatment' and 'Other') and two others expanded (Whether 'Education/training' is doctor or patient and 'Health promotion' to include prevention). It was also agreed that a short classification framework should be added to the UKCRN and Roland classifications to cover **the setting** in which the research was taking place (Appendix 3).

Box 1

Agreed Classification

1. 30 UKCRN Categories
2. 20 Portfolio group Categories
3. 6 Setting categories

3rd classification exercise-UKCRN, Roland, Setting

Reviewers were requested to classify approx 20 study summaries each using the UKCRN, Portfolio group and Setting classification frameworks. Each summary was scored independently by two reviewers. Reviewers were advised that they should score in as many categories as appropriate for each of the three classification frameworks but should make a judgement regarding the areas (categories) to which the study is likely to make its main contribution to knowledge rather than have a peripheral involvement e.g. a study of depression in elderly patients with heart failure could have 3 UKCRN codes.

Pairs of reviewers were invited to reach agreement about their scores in the following way:

- 1) Reviewer A considers Reviewer B's categorisation and accepts/rejects
- 2 Reviewer B repeats for the updated list produced by Reviewer A

3) Email/telephone discussion of any outstanding discrepancies

The reviewers who participated in the UK Portfolio Review are listed in Appendix 4.

Phase 2: Create and populate a database with research studies included on the UKCRN portfolio.

Various options to define current research in primary care were considered including exhaustive surveys of all known primary care researchers in the UK. In order to expedite the process and focus on those whose quality has been assured by reference to specified criteria the primary care subset of UKCRN registered studies was chosen.

Abstracts of approximately 170 primary care studies registered on the UK Portfolio database were obtained either from the database itself where study information included a summary or by contacting the researcher named on the database and requesting a summary or protocol from which an abstract could be extracted.

It was then necessary to broaden the scope of the review in order to obtain summaries of other eligibly funded studies which are on-going across the UK but are not registered on the UKCRN Portfolio database. PCRN managers and clinical leads were requested to identify research projects which fit these criteria and forward abstracts to SSPC if possible. It was possible to obtain abstracts for approx 34 additional studies via this process and identify approx 20 more studies for which summaries were sought unsuccessfully. The basis of the report is the **204 studies** for which an abstract was available.

In order to widen the pool of reviewers to classify the additional studies identified via this process, PCRN Clinical leads were asked to nominate primary care researchers of senior lecturer grade or higher who could assist with this exercise.

Each of the four UK nations has developed specific eligibility criteria for studies that can be included in their respective portfolios.

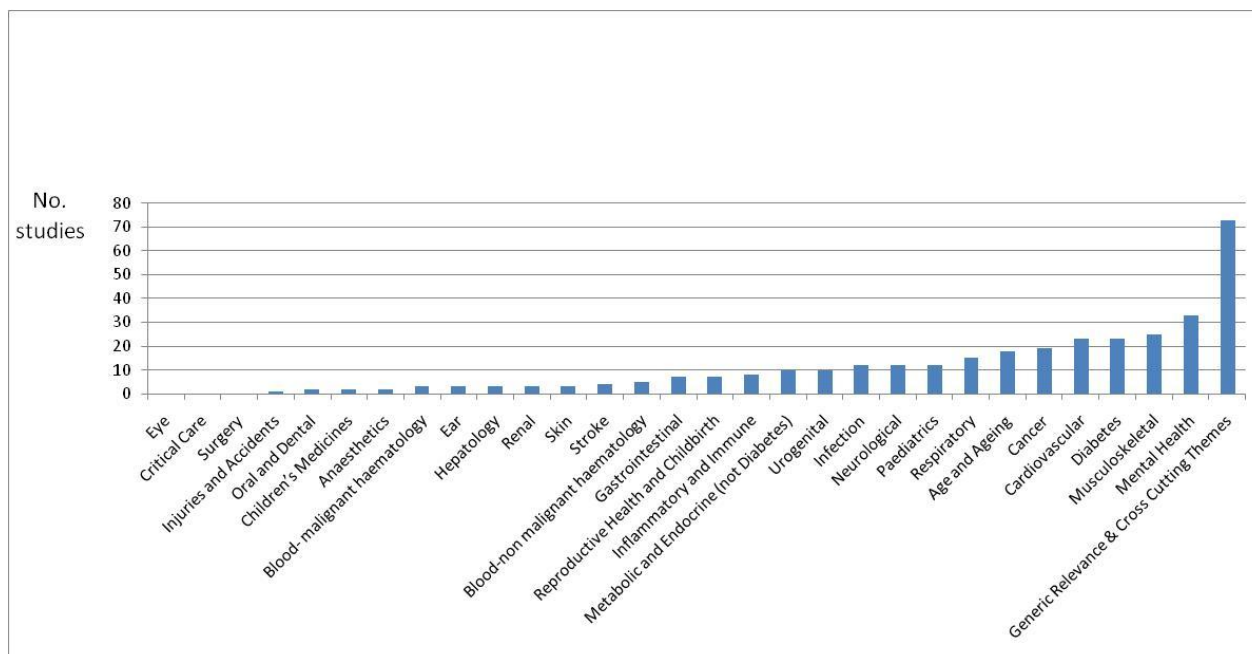
In England, the Department of Health has determined that studies (clinical trials and other well designed studies which involve the NHS) that are funded by NIHR, other areas of Government, and NIHR non-commercial Partners are automatically eligible to be included in the Portfolio. NIHR Partners are those organisations that:

- award research funds as a result of open competition across England with high quality peer review
- fund research that is of clear value to the NHS
- have strategic direction for the research that they fund.

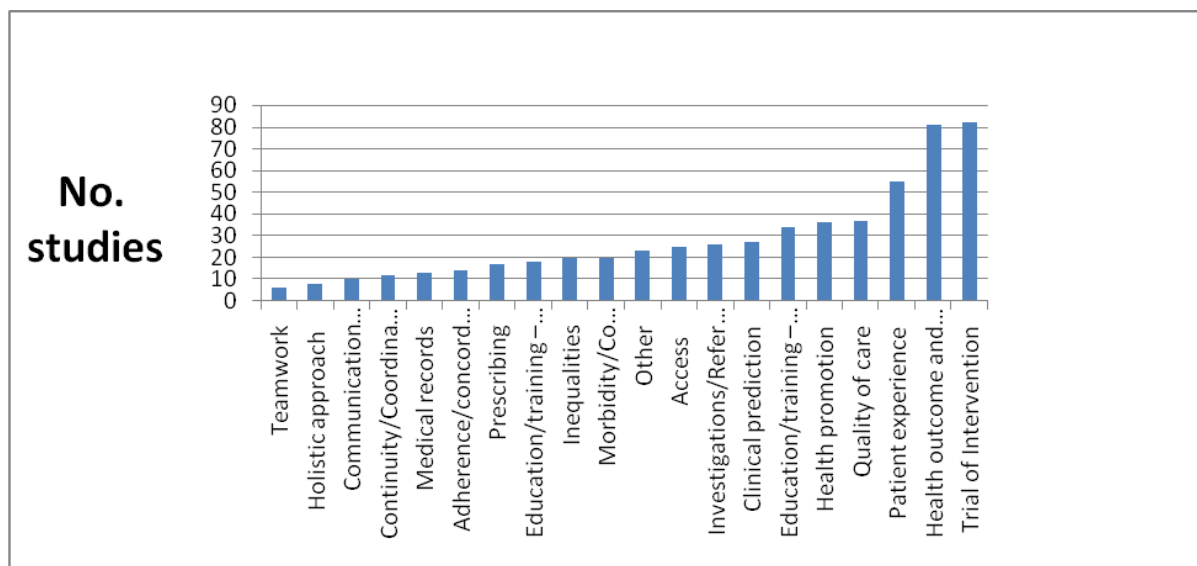
Scotland names the eligible funder organisations on the CSO website
<http://www.sehd.scot.nhs.uk/cso/index.htm>

Results

Figure 1 illustrates the variability in primary care research activity across the UKCRN categories. High levels of activity are evident in Generic & Cross-Cutting themes; Mental Health; Musculoskeletal; Diabetes and Cardiovascular Research. Much lower levels are obvious in Eye, Critical Care, Surgery, Injuries and Accidents Oral and Dental, Children's Medicines.



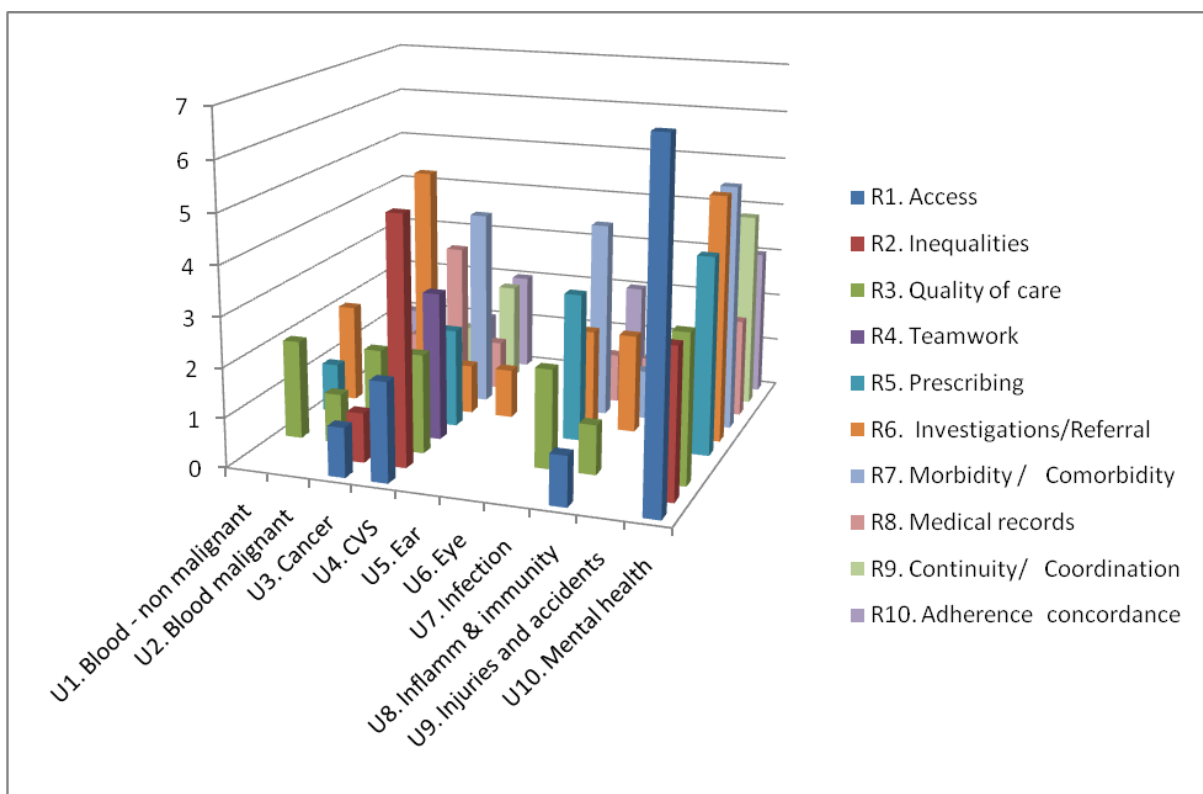
The Portfolio Group categories show activity in all areas of primary care research with an emphasis on Trials of Interventions; Health outcome and costs; Patient experience; Quality of care; Health promotion. Much less current activity is evident in Teamwork; Holistic approach; Communication skills/shared decision making; Continuity/Coordination; Medical records.



Appendix 5 tabulates the numbers of times the reviewers applied each of the three categories to each study. Tables 1-3 show these in a simple, uniaxial manner and tables 4a-4d provide the crosstabulations of UKCRN and Portfolio group categories. The detailed tables show where some disease areas which are being actively studied nevertheless have some gaps in activities e.g. Medical records in Diabetes (table 4k), Prescribing in Musculoskeletal Disease(table 4m).

Although the setting for more than half of the studies is Primary Care-General Practice there is primary care research occurring in a range of other settings. Topics where primary care research is being undertaken outwith NHS general practice include Cancer, Cardiovascular Disease, Mental Health and Diabetes.

The later tables and carpetplots of UK data (Appendix 6) highlight the detail of the types of research undertaken in each UKCRN category. Some subjects such as mental health are being addressed comprehensively across multiple Portfolio group categories whereas other UKCRN categories such as Cancer are not: there are no primary care studies on the database addressing issues of Teamwork or Prescribing and only 1 in each of Access, Inequalities, Continuity/Coordination, Adherence/concordance, Communication skills/shared decision making, Morbidity/Co morbidity and Holistic approach..



In appendix 7 the carpetplots for individual devolved nations illustrate the differences between countries and significant gaps such as musculoskeletal disease in Scotland compared to England.

Discussion

This snapshot of primary care research activity registered on the UKCRN Project Register at the end of 2008 provides a valuable but partial view of current research activity in UK primary care. The value depends on the accuracy and timeliness of the information it provides. Since the review only includes those studies which are eligible to be registered onto the UKCRN register it is necessarily only those studies which do not adhere to the stringent criteria for inclusion. Many studies which are important will not be included but all of the studies analysed for this report have satisfied strict selection criteria. If primary care research may be likened to a comet lighting up the dark sky then we are looking at the head of that comet.

The aim of this review was to map current primary care research activity throughout the UK in order to identify areas of strength and important potential activity gaps. Some of the activity gaps may be partially filled by unseen studies but the areas of strength are showing through clearly. The results of this exercise could be used by individual academics, research groups and institutions as well as funders. As it has with other research networks it could be used by funders to inform the development of Primary Care Clinical Studies Groups.

At its meeting on Monday 11th May 2009 the UK Primary Care Research Portfolio Review & Development Group considered this draft report. Modifications to the report were suggested and a decision was taken to undertake a consultation exercise, involving funders, speciality groups and relevant professional groups in workshops similar to those undertaken by the MRC Topic Review. The purpose of the workshops would be to identify priority areas for research. One proposal was for the gaps to be mapped against objective measures of likely priority, including the following:-

- workload
- health expenditure
- burden of disease
- policy priorities

A group of 15-20 experts for each specialty area will be created and asked to take part in a 3 stage process to prioritise potential research issues by email:

1. Generation of 1-6 potential research issues from each expert which will be the subject of the voting rounds.
2. Voting round 1 – All questions generated by the expert group are voted upon to determine which should be prioritised .
3. Voting round 2 – The top 20 issues identified in voting round 1 are reconsidered and voted upon to determine which are the top 10 priorities.

Frank Sullivan

Alison Hinds

Paul Wallace

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