PATIENT-CENTRED PROFESSIONALISM:
DEFINING THE PUBLIC’S EXPECTATIONS OF
DOCTORS

FINAL REPORT TO PICKER INSTITUTE INC.

MAY 2008
Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient’s perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients’ views count. There are three key strands to our work:

- Measurement - researching and evaluating patients’ experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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## CONTENTS

1. **Introduction**  
   - Page 3

2. **Research Objectives**  
   - Page 4

3. **Research Achievements**  
   - Page 5
   - 3.1 To explore the meaning of patient-centred professionalism  
   - 3.2 To examine patient-centredness in medical education  
   - 3.3 To examine patient-centredness in doctors' professional standards  
   - 3.4 To examine patient-centredness in the regulation of doctors  
   - 3.5 To examine patient-centredness in doctors' working practices  
   - 3.6 To examine the benefits to patients of a patient-centred approach  

4. **Forum Programme Objectives**  
   - Page 9

5. **Achievements**  
   - Page 10
   - 5.1 To develop an international network  
   - 5.2 To disseminate news on patient-centred professionalism  
   - 5.3 To encourage debate and make recommendations  

6. **Programme Outputs**  
   - Page 12
   - 6.1 Advances in knowledge  
   - 6.2 Influence on policy and practice  
   - 6.3 Tangible outputs  

7. **Funding Sources**  
   - Page 14

8. **Staffing**  
   - Page 14
1 Introduction

The purpose of the Patient-Centred Professionalism project as described in the contract with Picker Institute Inc. USA was “to define patient-centred professionalism in medicine, and to help embed the essential principles in the culture of the medical profession so that in due course these will be reflected in the practice of every doctor and in the institutional arrangements for medical education and regulation.”

It was a three-year research and development programme designed to improve patient care by enhancing understanding of the patient’s perspective on doctors and medical care. The aim was to ensure that medical practice standards, education and regulation are truly patient-centred.

The programme’s goals were to improve patient care by:

- clarifying and defining the concepts of patient-centredness and professionalism and the connection between the two
- bringing together and summarising existing evidence on patient and public views on, and potential contribution to, doctors’ professional standards and medical regulation
- carrying out original research to fill gaps in knowledge about patient and public views about professional standards
- collaborating with researchers elsewhere to facilitate comparative studies of patient and public views about professional standards
- promoting an active international network of interested individuals and organisations to share relevant information, debate and policy recommendations.

Respect for and support of patient autonomy in its various forms is at the root of patient-centredness: for example, respecting patients’ preferences, providing effective information and risk communication, supporting patient education and self-care, sharing decisions, and treating patients with empathy and understanding. The project aimed to define more clearly and precisely patients’ expectations of doctors and their regulatory bodies, to examine how far these expectations are currently being met, and to identify the factors that ease or impede a patient-centred approach.

Our work is described through a comparison between objectives and achievements. Although the research programme and the development programme were very closely linked, their activities are shown separately in the following report. The development work is discussed under the heading of the ‘PCP Forum’.

Please note that this is the last of our summary reports as the project has now ended (at least in this, its first phase).
2 Research Objectives

We set the following objectives for the research programme:

1. To explore and define the meaning of patient-centred professionalism
2. To examine the extent to which a patient-centred perspective is incorporated within medical education
3. To examine the extent and nature of patient-centredness in doctors’ professional standards and to carry out new research where necessary
4. To examine the extent to which the regulation of doctors includes a patient-centred focus and to carry out new research where necessary
5. To examine the extent to which doctors’ working practices and environment encourage or inhibit a patient-centred approach
6. To examine the evidence about the benefits to patients of a patient-centred approach/patient-professional partnership.
3 Research Achievements

Over the course of the project we made progress on all objectives, through reviews of existing evidence as well as the development of new research tools and original research. Some of this new research was externally funded, as had been intended when the original grant was made.

3.1 To explore the meaning of patient-centred professionalism

Achievements on this objective:

- A conceptual review was carried out and published, as Patient-Centred Professionalism: Towards an Agenda for Research and Action.
- The concepts developed in this paper were used throughout the programme to inform further work.

3.2 To examine patient-centredness in medical education

Achievements on this objective:

- We carried out a small-scale study and reviewed existing evidence about patient-centredness in medical education. This was published as a think-piece entitled Education for Partnership.
- We were commissioned to write a report for the ASME series, Understanding Medical Education, jointly with Professor John Spencer of Newcastle University, on the role of patients and users in medical education (due for completion summer 2008)

3.3 To examine patient-centredness in doctors’ professional standards

Our achievements on this objective:

- A systematic comparison of professional standards or codes of practice from UK, USA and Canada was carried out, examining similarities and differences, and focusing particularly on the extent to which they reflect
patients’ concerns. The output was a report entitled: A Review of Professional Codes and Standards for Doctors in UK, USA and Canada.

- We were awarded a research grant by the British General Medical Council to investigate patients’ and doctors’ views of standards for the medical profession. The aim of this qualitative study was to understand more fully what patients and the public think about the standards of care and practice they expect of doctors. The report of this study was published as: Setting Standards

- A further research grant was awarded to us by the General Medical Council for qualitative research on the potential use of Good Medical Practice by patients and service users. This work has been carried out and the report published as Patients’ Use of Good Medical Practice.

3.4 To examine patient-centredness in the regulation of doctors

Our achievements include:

- A critical review of questionnaires from UK, USA and Canada used to gain patient feedback on the communications skills and other aspects of a doctor’s practice was carried out, and published as What do you think of your doctor?.

- The development of a new patient feedback questionnaire was completed and piloted. The construction of this tool arose out of our review of other patient feedback questionnaires and was closely tied to the revised version of Good Medical Practice. We expect this tool to be accepted for use in the appraisal and/or revalidation of doctors in the UK.

- We carried out a population survey using our new patient feedback instrument. This has been completed and results are available.

- A meeting has been held with key staff from the Consumers’ Union in USA and with colleagues from the USA’s National Board for Medical Education in hopes of a comparative USA survey of patients’ experiences of doctors, assessed against standards of Good Medical Practice. The negotiations were promising but not in the end successful due to funding limitations.

3.5 To examine patient-centredness in doctors’ working practices
We made the following progress with this objective:

- We carried out a qualitative interview study to examine doctors’ own views of patient-centred professionalism and the factors they saw as easing or impeding their ability to deliver patient-centred practice. From this exploratory research we developed a survey instrument for examining these issues with a larger sample of doctors.

- Funded by the Health Foundation, we analysed survey data gathered by the Commonwealth Fund on patient engagement from UK, USA, Canada, Australia, New Zealand, and Germany. The results showed that patients’ role as active participants in their healthcare is still insufficiently recognised and supported by health professionals.

- A questionnaire for a self-completion survey of doctors has been drawn up. This survey examines doctors’ views on patient-centredness and on what helps and hinders them in delivering patient-centred care. We are in negotiation with the organisers of an online database of doctors to carry out the survey, after piloting.

- We were awarded a research grant by the NHS Modernisation Agency to evaluate the implementation of a decision-support programme for men with prostate conditions. This project was a collaboration between the UK and North America: the decision support aids and training were provided from USA and Canada and implemented in the UK. Whilst the benefits of decision-support were already known, research was needed to examine how such programmes can be incorporated into healthcare practice. This research showed how challenging such implementation is in practice.

3.6 To examine the benefits to patients of a patient-centred approach

We carried out the following work to address this objective:

- A series of six reviews commissioned by the Health Foundation to examine international research evidence on the efficacy of patient-focused interventions and their impact on healthcare quality. We examined interventions tackling one or more of the following six quality improvement goals:
  
  - Improving health literacy
  - Improving clinical decision making
  - Improving self-care
  - Improving safety
  - Improving access
  - Improving patients’ experience
The reports were published by the Health Foundation and are also available on the Picker Institute website, as Patient-Focused Interventions: A Review of the Evidence.
4 Forum Programme Objectives

We set the following objectives for the PCP Forum:

1. To promote an active international network of people who share an interest in patient-centred professionalism

2. To disseminate news, research findings and examples of good practice

3. To encourage debate and make recommendations to promote patient-centred professionalism.
5 Achievements

Forum objectives were addressed through informal and formal networking, liaising, speaking engagements and writing.

5.1 To develop an international network

We made the following progress with this objective:

- Leaflets and postcards describing the PCP project were produced and widely disseminated.

- Forum members were actively recruited over the course of the project, with numbers eventually reaching 1001. Subscribers included academics, healthcare professionals and managers, patient group representatives, policy makers, from European countries, USA, Canada, Egypt, Thailand, Ghana, Australia and Brazil.

5.2 To disseminate news on patient-centred professionalism

Our progress here included:

- A PCP website was set up, with details of our activities and how to become a member of the PCP Forum.

- PCP Newsletters were issued at two-three monthly intervals between autumn 2005 and late 2007. Content included news and information on our own project and that of others working on similar issues internationally. Recipients also submitted material from their own work.

- Staff have made presentations on patient-centred professionalism at numerous conferences, both national and international. A full list would be cumbersome, but some examples include: international conference on patient involvement in health professional education, Vancouver, 2005; a General Medical Council conference on regulating the future healthcare worker; international conference in Italy on developments in clinical skills training; the Osler Lecture at McGill University, Society for Shared Decision-Making conference, Boston, USA.
• Staff have published widely in journals and books on the topic of patient-centred professionalism.

• Staff have been members of groups and committees to which they have provided guidance on patient-centred professionalism. These have included professional bodies, government committees, and voluntary associations.

5.3 To encourage debate and make recommendations

We carried out the following activities:

• We published our PCP reports on the website, with a ‘rapid response’ facility to enable readers to comment.

• We contributed our recommendations to a number of public consultations, such as the Royal College of Physicians’ enquiry into professionalism; the Joint Consultants’ Committee of the British Medical Association, on patients’ expectations of doctors; the Chief Medical Officer’s consultation on medical regulation.

• We have held discussions in the USA with key medical professional organisations about the development of a new set of professional standards, Good Medical Practice USA

• A very successful PCP Conference was held. More than 80 delegates attended from UK and overseas, including Department of Health personnel; professional regulators – from the Medical Royal Colleges and the General Medical Council; educationalists, from the Deaneries and university departments; the NHS employers; patients’ organisations and lay representatives. A series of ideas and recommendations were produced from the day. These were summarised in a report circulated to all delegates after the event, and will also be taken forward through our participation in the UK government’s working groups on the Regulation White Paper, led by the Chief Medical Officer.

• Two Seminars were held with key activists, in conjunction with the Nuffield Trust, to consider the internalisation of professional standards through medical educational institutions and their teachers.

• Working with four medical schools in England we have actively encouraged local responsibility for embedding patient-centred professionalism into the practice of the clinical teaching workforce and therefore the undergraduate and postgraduate learners. This part of our work has been led by Sir Donald Irvine.
6 Programme Outputs

The PCP programme has had important outputs, which can be expressed either in the form of general advances in knowledge, or – somewhat more intangibly – in their influence on policy or practice, or as print-based outputs such as research tools, databases or research reports and papers.

The programme led to a surge of interest and cross-fertilised with other projects.

We summarise some of these key outputs as follows:

6.1 Advances in knowledge

We have achieved a much better understanding of:

- What patients want in their encounters and relationships with doctors
- The qualities, skills and environments doctors need in order to deliver patient-centred care
- Why it is not always easy to achieve patient-centred care; the tensions and complexities in this process and the factors which both inhibit and encourage patient-centred approaches on the part of doctors.

6.2 Influence on policy and practice

- We helped with the development of the USA Good Medical Practice
- We contributed to the revised version of the UK’s code of Good Medical Practice
- We contributed to the development of patient-centred medical education and training in the UK
- We have had an influence on the way doctors are appraised and regulated.

6.3 Tangible outputs

- Tools: interview guides and questionnaires
- Databases: our network list of interested individuals and organisations
- PCP reports, conference presentations and articles.
7  Funding Sources

The programme of work has been funded by the following organisations:

Picker Institute Inc., USA
Picker Institute Europe
The Health Foundation
NHS Modernisation Agency
European Union
General Medical Council
The Nuffield Trust
The Academy of Medical Royal Colleges

8  Staffing

Over the course of the programme the team has included:

Sir Donald Irvine
Prof Angela Coulter
Prof Janet Askham
Dr Alison Chisholm
Sarah Claridge
Helen Magee
Don Redding
Stephen Peckham
Dr Andreas Hasman
Liz Cairncross
Dr Jo Ellins
Dr Erica Wirrmann