

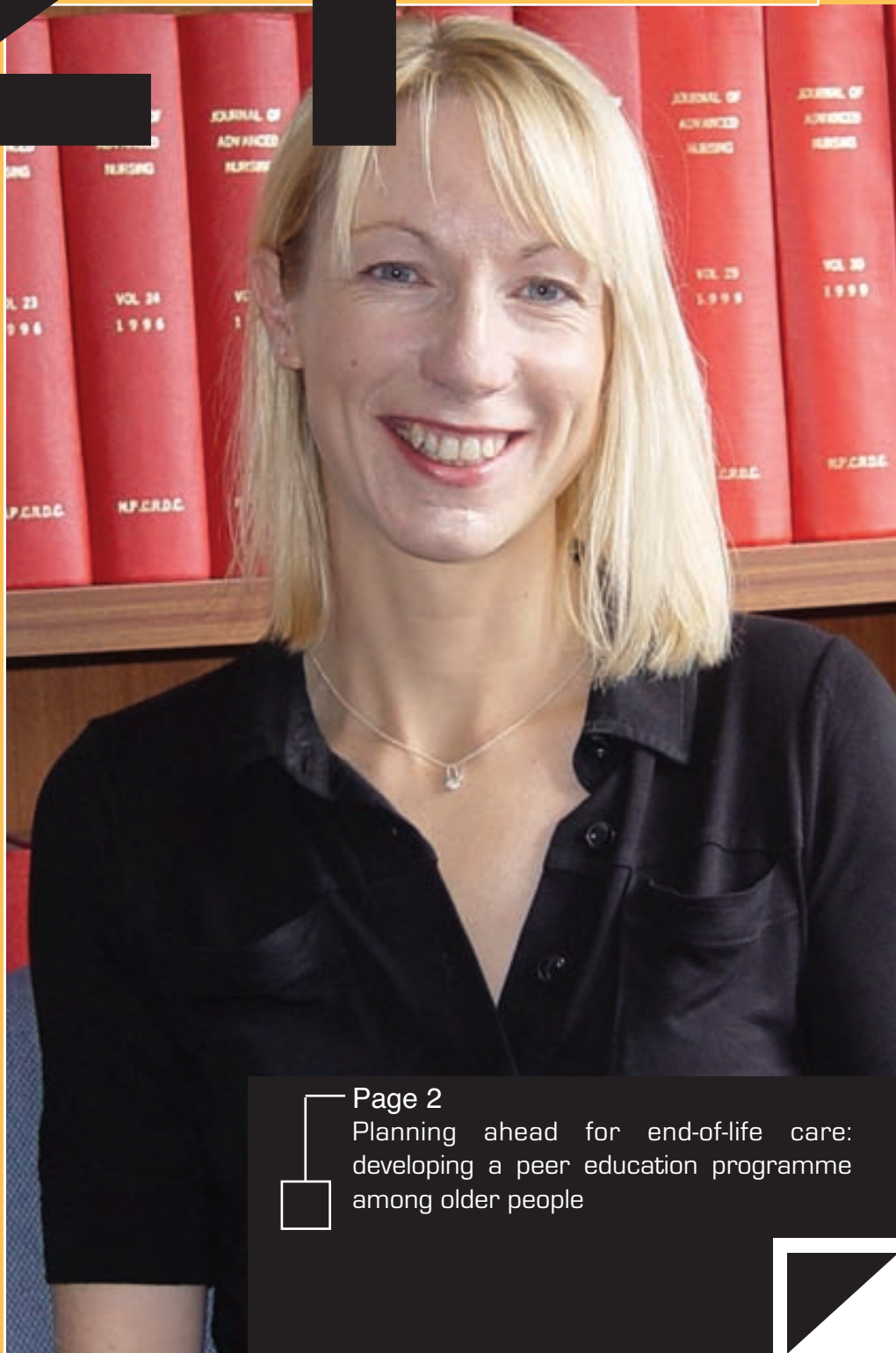


Welcome to **frontline**, the newsletter of the
National Primary Care Research and Development Centre.

frontline 21

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Planning ahead for end-of-life care:
developing a peer education programme
among older people

Planning ahead for end-of-life care: developing a peer education programme among older people



In the last months and years of life good quality palliative care is often inaccessible for older adults with complex care needs and chronic illness, and many older people often do not die in a place they would choose. To promote equity and choice in access to services, there is a growing policy emphasis on improving palliative and end-of-life care, particularly for older adults and those with non-cancer related chronic conditions.

In recent years, some organisations, including the World Health Organisation, have called for a public health approach to palliative care. This is based on the notion that we have become a 'death denying' society in which it is increasingly difficult to communicate about, and plan for, death and dying. Communication and planning are seen as crucial in improving the quality of end-of-life. The NHS End of Life Care Programme has promoted the implementation of a number of tools to aid planning and partnership working amongst staff in community and institutional care settings (e.g. the Gold Standards Framework, the Preferred Place of Care Plan, and the Liverpool Care Pathway for the Care of the Dying).

Previous research indicated that some older people wanted more information about end of life issues, but did not have access to appropriate information. The research team carried out a pilot project (funded by the Health Foundation) to develop and evaluate a peer education programme aimed at enabling older people to obtain information about treatment and care options at the end of life, and to exchange expertise about how to record and/or discuss these issues with their families and health professionals.

We worked alongside older people involved in community groups to produce a guide aimed at encouraging discussion about issues such as treatment and care options at the end of life, decision making, caring and coping, loss and bereavement.¹ Some older community volunteers took part in a 'peer education' training programme to enable them to facilitate small group discussions using the guide among their peers. Participants found the guide acceptable and easy to read² and felt that the peer education approach was an appropriate format. This view was confirmed by participants of a further series of workshop events funded by Help the Aged.³



Peer educators discussing the programme.

For further information visit:

<http://www.nottingham.ac.uk/nursing/research/centres/sueryder/projects/3.php>

We have now received a grant from the Burdett Trust for Nursing to adapt the peer education programme and evaluate its suitability and applicability in a range of settings (including care homes and extra care settings). (<http://www.burdettnursingtrust.org.uk/recent.htm>) We will also evaluate educational needs of nursing staff on this subject.

This new work is being led by Professor Jane Seymour from the Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham in collaboration with Dr Amanda Clarke (University of Sheffield), Dr Caroline Sanders (National Primary Care Research and Development Centre, The University of Manchester), Dr Katherine Froggatt (University of Lancaster), Dr Merryn Gott (University of Sheffield), and Maddie Welton (Northern General Hospital, Sheffield). We gratefully acknowledge the support from the Burdett Trust for Nursing.

Publications from initial pilot work:

1. Seymour,J.; Sanders,C., Clarke,A., Welton,M., Gott,M. & The Peer Education Project Group (2006) Planning for Choice in End-of-Life Care. Educational Guide. London: Help the Aged.
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3. Clarke,A., Seymour,J., Welton,M., Sanders,C., Gott,M. & The Peer Education Project Group (2006) Listening to Older People. Opening the door for older people to explore end-of-life issues. London: Help the Aged.

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Professor Helen Lester

Background

In January 2005, the NHS Employers advertised for an Expert Panel to review the evidence base underpinning the Quality and Outcomes Framework (QOF) within the GP contract. Collaboration between the Society for Academic Primary Care (SAPC), the Royal College of General Practitioners (RCGP) and a group of leading Universities was successful and awarded the tender. In 2006, the NHS Employers and British Medical Association (BMA) reappointed the Expert Panel, led by Professor Helen Lester from NPCRDC, to continue their role until 2009. The Panel consists of over 40 leading academic primary care health professionals, who review the existing and emerging evidence base in current and potential new areas of the QOF.

Increasing patient and public involvement in QOF

The content of the QOF has, to date, been largely professionally driven. This is unsurprising given the complexity of developing and operationalising evidence based performance measures within primary care. However, in 2007 NPCRDC has helped to make the process of developing new areas within QOF more transparent to patients and the public, and to actively engage patient groups in developing QOF.

In February 2007, Helen, and the communications unit at NPCRDC produced a leaflet explaining the aims and content of QOF for the general public and inviting ideas for developing new areas within the Framework. This was disseminated to thousands of health professionals and patient groups through Primary Care Trust (PCT) intranets and patient group mailing lists held by NHS Employers, the RCGP, BMA and the Long Term Medical Conditions Alliance. Over 150 ideas were submitted, including eighty from patient groups or national organisations with a strong patient focus.

Professor Lester and members of the Expert Panel have since met up with over 20 of these patient groups, all of whom submitted ideas about issues that are common in primary care and have a significant morbidity or mortality. These meetings enabled the groups to highlight issues that are most important to them and think through how they might be turned into meaningful performance measures within QOF. These discussions will help inform the Expert Panel reports for the negotiating teams later this year. All reports will also be seen and commented on by members of the RCGP patient participation group. We hope this more open and inclusive process will increase public understanding of QOF and enable the development of indicators that are seen as relevant by both patients and health professionals. For more information please visit:

[http://www.npcrdc.ac.uk/QualityandOutcomesFramework\(QOF\).htm](http://www.npcrdc.ac.uk/QualityandOutcomesFramework(QOF).htm) .

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National Institute of Health Research (NIHR) School for Primary Care Research



Professor Martin Roland

The first NIHR School in England comprises five partners: the Universities of Birmingham, Bristol, Cambridge, Manchester and Oxford, all 5 or 5* rated academic research centres. Professor Martin Roland is Director of the School, and in addition to Manchester's academic contribution, the School's core administrative staff are based in Manchester.

Professor Helen Lester has been nominated as Head of the NIHR School for Manchester to support Martin as the Head of the Department in Manchester. Dr Julia Miller as Senior Scientific Administrator is setting up the systems and processes needed for the development of the School with the support of Gillian Leavy, School Administrative Officer, and Lynda McIntosh, the Communications Officer. Julia, Gillian and Lynda have been spending a lot of time establishing relationships with our academic partners to ensure that we have good communication processes to develop effective working relationships within the School.

The School's research focuses on applied clinical research with the aim of increasing the evidence base for primary care research and we have established five cross-organisational research programmes (<http://www.nspcr.ac.uk/OurResearch.cfm>).

NPCRDC's Professor Bonnie Sibbald convenes a programme on Co-morbidity and Patient Focused Outcomes (<http://www.nspcr.ac.uk/ThemeDetails.cfm?ID=3>).

This programme focuses on how the delivery of health care and the assessment of health outcomes need to move away from the traditional single disease approach and adapt to the rise in primary care patients presenting with multiple morbidities. Colleagues from Cambridge and Bristol are also involved in the development of this programme. Our research in this area has important implications for the delivery of health services, the assessment of quality of care and patient outcomes.

Professor Helen Lester is leading the Befriending in Mental Health project as part of programme 2, (Monitoring and managing patients with long term conditions).

(<http://www.nspcr.ac.uk/ThemeDetails.cfm?ID=2>) This programme aims to examine how befriending schemes might offer an alternative approach to addressing common mental health problems in primary care. The limited evidence in the area suggests that these schemes benefit women and older people with depression and new mothers with emotional problems. If befriending is found to be an effective intervention, it would offer an alternative to the traditional approaches to individuals with these problems.

The School website (www.nspcr.ac.uk) provides detailed information about our research programmes, projects, activities and events. Visitors to the site may sign up for our e-newsletter which will deliver new developments directly to their in-box.

We have also recently produced a small leaflet outlining our activities (www.nspcr.ac.uk/publications/nih_r_leaflet.pdf) and our first newsletter, NIHR School for Primary Care Research News (www.nspcr.ac.uk/publications/nih_r_newsletter.pdf).

For more information or for general queries about the School please contact Dr Julia Miller julia.miller@manchester.ac.uk or visit: www.nspcr.ac.uk

Health Scrutiny – past and future

Since 2003, social services local authorities have been required to maintain an Overview and Scrutiny Committee (OSC). The OSC, composed of elected non-executive councillors, responds to proposals from the NHS to changes in services and has the discretion to set their own agendas for undertaking more detailed scrutiny of health issues (including the NHS).

NPCRDC has been involved since 2002 in investigating the implementation and operation of health scrutiny, via two major projects:

- Research into the implementation of local authority scrutiny of primary health care: 2002-2005¹ and
- The national evaluation of health scrutiny on behalf of the Centre for Public Scrutiny (2004-2007)^{2,3}.

Both projects combined national (English) surveys with in-depth case studies to gain data at different levels. Research has begun to suggest some of the benefits and difficulties of the operation of health scrutiny over the past four years. Findings include:

- Scrutiny structures have been successfully established and review topics now include cross-cutting, health improvement issues as well as specific organisations and services;
- Health scrutiny has generally suffered from a lack of resources, training and officer support (especially in the context of a high volume of statutory consultations from the NHS) and recognition of the process by council executives, NHS bodies and the public;
- the non-prescriptive nature of overview and scrutiny guidance and an ambiguity in some of the requirements have resulted in different structures, ways of working and outcomes across England;
- there is little evidence of systematic direct involvement of patients and the public in the health scrutiny process;



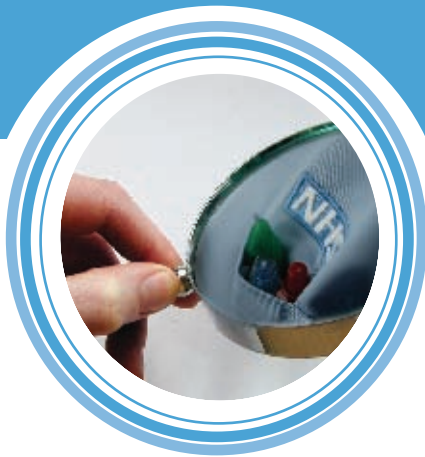
- health scrutiny has been employed less as a vehicle for rigorous scrutiny of the NHS than as the means for building networks between health and local government agencies.

During 2006 three major consultation documents were published by the Government which will potentially have far reaching impacts on local authority scrutiny of health:

- Our Health, Our Care, Our Say⁴
- A Stronger Local Voice⁵
- Strong and prosperous communities⁶

Chapter seven of the White Paper *Our health, our care, our say*⁴ discussed issues of accountability, influence and public involvement. The White Paper aimed to create health and social care services which are, regardless of who provides them, user centered, responsive, flexible, open to challenge, accountable to communities and constantly open to improvement. The chapter suggested that there are advantages to doing this and ideas for its achievement include:

- Placing a duty on commissioners and providers to “systematically and rigorously” discover what people want, especially difficult to reach groups;
- Establishing a Patient and Public Involvement Resource Centre;
- Elected local councillors acting as advocates for their local communities (‘Community call for action’);
- Local triggers requiring Primary Care Trusts to take action relating to public satisfaction and service quality.



The *Stronger Local Voice*⁵ consultation set out plans to abolish Patient and Public Involvement Forums and in their place establish Local Involvement Networks (LINks) for every Social Service Local Authority area (i.e. area based as opposed to organisation based). It is proposed that LINks will “establish special relationships” with Overview and Scrutiny Committees and will have the power to refer matters to the OSC and expect an appropriate response. The co-terminosity of LINks with Local Authority boundaries may help facilitate relationships with health OSCs. However, once again the quality and capacity of all the proposed processes will be dependent upon the resources made available.

It is proposed that Health OSCs will be encouraged to focus their attention on service commissioners, which will be especially important in terms of developing practice based commissioning (PBC) processes locally.

Proposals in the *Strong and prosperous communities*⁶ White Paper are made to strengthen overview and scrutiny by:

- extending scrutiny's remit to other service providers;
- extending the Community Call for Action;
- encouraging more use of "area" OSCs;
- extending the use of co-option onto OSCs: and
- encouraging councils to dedicate resources to support scrutiny.

Many public service providers will be covered by a duty to co-operate to agree relevant targets in the Local Area Agreement and there are requirements to appear before an OSC or provide requested information (in relation to service delivery) within 20 days of a request. Health OSCs will also have the right to recommend an independent inspection of services where necessary and will be encouraged to scrutinise the responses of local authorities and Primary Care Trusts (PCTs) to annual reports of the Directors of Public Health.

The strong message from government is one of involving and responding to the demands of the local population. At a practical level, any enhanced role for overview and scrutiny will need to overcome current challenges, as councillors (and their supporting officers) already have demanding roles and limited capacity and resources. From a more strategic perspective, the proposals summarised above seem to imply a shift in interpretation of the overview and scrutiny role from one of network building between agencies to one more directly concerned with scrutiny and challenge.

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6. Secretary of State for Communities and Local Government (2006) Strong and prosperous communities: the local government White Paper. Cm 6939-I London, Stationery Office.

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News from the Institute of Health Sciences

The Institute of Health Sciences is a networked organisation of health science research groups in The University of Manchester and its local NHS trusts - acute, primary care and mental health. Our aims are to:

- Improve health and health care practice through high quality research in the health sciences;
- Promote new alliances, enabling people to work across disciplines and organisational boundaries, and so generate new knowledge and more effective approaches to health care;
- Support and co-ordinate the research and strategic development of member groups; and
- Promote the prestige of the health science community, making Greater Manchester an internationally esteemed centre of excellence.

We are a research institute of The University of Manchester. With more than 500 academic staff the health science community in Manchester is one of the largest in the UK. In the last RAE in 2001 the community based medical sciences, nursing, pharmacy, management and social science disciplines all achieved a top rating of 5 or 5*. Research income for university members of the IHS has risen from £8 million in 2000/1 to more than £43 million in 2004/5 (£106m over five years).

Bonnie Sibbald steps down as IHS Chair after six successful years

Professor Bonnie Sibbald stepped down in December 2006 as Chair of the Institute of Health sciences after six years in order to devote more time to her research in primary care, not least to support the new NIHR School for Primary Care Research. Bonnie said *'My first love has always been research and it's been great to have more time to explore new research opportunities and support my research team. I have thoroughly enjoyed being Chair of the Institute and I think this is an appropriate time to give someone else the opportunity to take the Institute forward'*.



Professor Bonnie Sibbald

Professor Colin Sibley, the Associate Dean for Research in the Faculty of Medical and Human Sciences has been Interim Director of IHS since January while there has been a strategic review of the Institute and its activities. This has now been completed and funding has been secured for at least the next three years. We advertised for a new director of the Institute in July 2007.

The review found that the Institute of Health Sciences is widely regarded as a successful networking organisation between The University of Manchester and the NHS in Greater Manchester. The IHS will become a wholly University funded research institute and current NHS members will be included via the Greater Manchester Research Alliance. This change of emphasis will help secure firmer funding sources and will not be a barrier to continued collaboration between the University and NHS groups.

Visitors to the Institute of Health Sciences

Professor Alan Gilbert, President of the The University of Manchester, and Professor Dame Nancy Rothwell, Vice-President for Research at The University of Manchester visited the Institute in March 2007. The senior management team of the IHS outlined the scope and scale of health sciences research in Greater Manchester, as well as the opportunities and outcomes from collaboration between the University and the NHS. Delegates heard the latest news on the review of the Institute, our forward plan, and presentations from various IHS research networks. We were commended by the President on the breadth and depth of the research undertaken in health sciences and its impact on policy and practice.



IHS Headquarters in University Place (formerly the SCAN building)

The IHS will have headquarters space in this building, co-located with the School of Nursing, Midwifery and Social Work. The IHS headquarters comprises office space for four staff (Director, Co-ordinator and administrative staff), an 11-person visiting fellows' suite, and two seminar rooms capable of holding 90 people in total. In addition, there is office accommodation for 164 health science researchers. Occupants are likely to be health economists, biostatisticians as well as groups from the new Community Based Medicine Research School (Head: Professor Martin Roland).

A visible headquarters will bring together Institute and health sciences researchers and opportunities to produce knowledge that will improve health and healthcare practice for the people of Greater Manchester, the UK, and elsewhere.

Network updates

All institute networks run regular workshops to encourage interdisciplinary research collaboration.

Patient safety research network

The Patient Safety Research Network, supported by the IHS, was founded in 2001. It has over 100 members from academia, the NHS and policy organisations.

(www.ihs.manchester.ac.uk/researchnetworks/patientsafety/)

Patient Safety Research into Practice, (www.mcgraw-hill.co.uk/html/0335218539.html) edited by Kieran Walshe and Ruth Boaden at Manchester Business School, The University of Manchester, won the Basis of Medicine Category in

the British Medical Association Medical Book Competition 2006. There were over 550 entries for this prestigious prize

(www.bma.org.uk/ap.nsf/Content/LIB2006WinnersBookCompetition).

One of the editors Kieran Walshe said; *'We are thrilled to receive this prize. The idea for the book came from our discussions at network meetings, where people from different traditions with new ideas come together to develop interdisciplinary approaches to patient safety research; we hope the book gives an overview of the current thinking'*.

The IHS Child Health Research Network held a workshop in October 2006 on the *Emotional well-being of children and young people*. They will also hold a workshop on *Accessing the Voice of Young People Challenges and Solutions* in July 2007 and plan a workshop with the outline topic of *Teenagers: risky behaviours* on 20 November 2007.

The IHS Diabetes and Obesity Research Network (DORN) held a workshop in November 2006 titled *Molecules to Metropolis - interdisciplinary research and clinical impact*. Professor Des Johnston, the Director of the National Diabetes Research Network, (part of the UK Clinical Research Network) was the keynote speaker. Their next workshop in December 2007 will focus on obesity issues (www.dorn.org.uk).

IHS Psychological Therapy Network which has 130 members, has produced a members' expertise booklet and held a workshop on *Research Methods for Psychological Therapy Practitioners* in September 2006 to encourage and support front line NHS staff who would like to undertake research. Their next workshop is on 19th October 2007 on *Working together with service users, carers and clinical researchers: Opportunities and challenges*.

If you are a Greater Manchester based researcher or clinician and would like to be involved in any of the Institute of Health Sciences Networks, please get in touch. Or visit the website for more information (www.manchester.ac.uk/ihs).

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OHU Update



To date, 2007 has been a busy year for the Oral Health Unit (OHU) starting with the publication of the results of the OHU school dental screening project in January. Led by Dr Keith Milsom, the project resulted in changes to Government policy and new guidance issued to the NHS on the national school dental screening programme.

Most recently, results from a longitudinal study of children aged three to six years old conducted in 50 general dental practices, provided new information on how caries progress in young children and the associated risk of pain and extractions. This study produced results which show that once a child develops decay, it progresses very rapidly and there is a very high chance that they will experience pain and will need to have a tooth extracted.

There have also been a number of invitations for the team to share their expertise at conferences, nationally and internationally. Most recently Professor Tickle was invited to speak at the practice-based research seminar at International Association of Dental Research (IADR) conference in New Orleans in March. He spoke on the first hand experience of the OHU of running randomised control trials in general dental practice.

In Manchester he was joined by the other OHU Directors who presented research posters on different projects to help raise the Unit's profile internationally.

In May, Professor Tickle was also invited to share the team's experiences of undertaking primary care randomised control trials and the issues and challenges involved at the Society for Clinical Trials Meeting in Montreal.

In order to accommodate the expanding workload, two new appointments have been made. Dr Vishal Aggarwal a former Wellcome Trust PhD research fellow has joined as a Walport Clinical Lecturer in Primary Care Dentistry and Dr Iain Pretty has joined the team as a Specialist Registrar in Dental Public Health. Dr Pretty is a Department of Health Clinician Scientist, who also works with Professor Ellwood at the Colgate-Palmolive Dental Health Unit.

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Oral Health Unit (OHU) Research Changes National Dental Policy



Dr Keith Milsom

Results of a recent randomised control trial undertaken by the Oral Health Unit (OHU) have led to a change in Government policy regarding the dental care of all school children in England and Wales.

Screening school children in state schools for dental disease has been a long standing statutory requirement in the UK. It is an intervention that has recently been endorsed by the World Health Organisation which has suggested that it plays an important role in the planning and provision of school dental health. However, in the UK the aims of school dental screening have always remained vague and there was little evidence to show that this dental public health intervention improved children's dental health.

Against this background, the OHU developed a study designed to ascertain whether school dental screening led to reduced levels of untreated tooth decay and increased levels of attendance in the child population. Additionally the study examined the impact of school dental screening on those children screened positive.

The results of the study showed that at the population level, there was no significant difference in decay levels between screened and unscreened groups. Furthermore, there was no evidence to indicate that school dental screening led to increased dental attendance amongst those screened positive.

At the primary care level, the results were equally disappointing. Fewer than half the children screened positive went on to attend a dentist within

four months of the screening intervention, and for those children who were screened positive for dental decay in their permanent teeth, fewer than one in four went on to receive appropriate treatment for the condition.

Most tellingly, the study suggested that school dental screening, far from reducing dental inequalities has the potential to exacerbate them. The process selectively 'prompts' dental attendance from within the more affluent population groups rather than from the socially disadvantaged, where most of dental decay is found.

OHU Operations Director, Dr Keith Milsom, said, *'This research raises questions about the ethical basis of school dental screening. Furthermore, at a time when, in many parts of the country access to NHS primary dental care services is severely limited, questions must be raised about the opportunity costs of providing ineffective dental programmes'.*

The UK National Screening Committee recommended to the UK Chief Dental Officers that there is no evidence to support the continued use of dental screening for children aged 6-9 years and new guidance was issued to the NHS in January 2007 (Gateway Approved Reference Number: 7698) recommending that 'PCTs consider whether or not to continue local screening programmes and, if not, how best to address inequalities in oral health in other ways'.

For more information please visit:
www.ohu.ac.uk

Workforce changes following the new GMS contract

Since the introduction of the new GMS contract GPs are more likely to deal with chronic and prevention problems and nurses are dealing with more complex cases than before, according to NPCRDC researchers.

Workload diaries were completed by GPs and nurses for a one week period in 42 GP practices in England in 2003 and 2005 and were used to identify changes in team size, composition, workload and work allocation within general practice teams between 2003 and 2005.

The number of practice staff increased between 2003 and 2005, however there was no change in the total number of hours worked per week by nurses or doctors. After the introduction of the new GMS contract, the proportion of patient presenting problems that were classified as chronic or preventative increased for GPs but not nurses. Nurses were more likely to describe their consultations as complex or very complex in 2005 compared to 2003, but there was no difference for GPs. These findings suggest that practice activity shifted to focus on aspects of care attracting payment and that the distribution of workload in the practice also shifted after the introduction of the GMS contract.

Interdependent working among team members may have declined as highlighted by the fact that fewer referrals within the practice were made after the new contract. Practices did not seek to meet quality targets by shifting care to other health providers as overall fewer patients were referred out of practice in 2005 compared to 2003.

General practices may have responded to the 2004 GP contract by increasing the staffing levels of both GPs and nurses, with nurses absorbing a higher proportion of the extra workload than GPs.

Mental health, social exclusion and inequality

On March 20th, NPCRDC hosted the second in an ESRC funded seminar series of social science and mental health at The University of Manchester. Symposium speakers included Professor David Pilgrim (Liverpool University, UCLAN and Blackburn with Darwen PCT), Dr David Morris (Programme Director for National School Inclusion Programme - NSIP), Professor James Nazroo (The University of Manchester), Professor Justine Schneider (University of Nottingham), Professor Ian Shaw (University of Nottingham) and Martin Webber (Institute of Psychiatry, King's College London).

Over recent years, the UK has witnessed significant changes in the provision and management of mental health care, with accompanying shifts in the lives of those who directly experience mental health problems. This has acted as a catalyst for critical thinking and action with the re-emergence of a social science perspective on mental health that many commentators feel has been muted since the 1960s.

To advance this movement, a group of academics approached the UK Economic and Social Research Council to request funds for a series of four invited seminars to bring together a select group of key thinkers, clinicians, carers and service users with an interest in the social science of mental health. The aim was to encourage and capture discussion which will underpin the future direction of this movement.

The seminar series is a collaboration between National Primary Care Research and Development Centre (NPCRDC) at The University of Manchester, Durham University, Nottinghamshire NHS Trust, Essex University, the University of Dundee, the Royal College of Psychiatrists and the University of Surrey. The third session will be held in Nottingham on 28 September, 2007.

To view papers and presentations from the Manchester event, please visit <http://www.npcrdc.ac.uk/SeminarsDetail.cfm?ID=72>

Self Care Support – An NPCRDC/EPP seminar series



Three seminars on the theme of self care were jointly organised by NPCRDC and the national Expert Patients Programme (EPP) team and brought together policy makers, researchers, clinicians, others involved in service reform and those delivering self management in the health service. Chris Ham (Professor of Health Policy and Management, University of Birmingham) facilitated each of the sessions.

Self care has had a rising profile in DH policy and features strongly in the latest 2006 White Paper: 'Our health, our care, our say: a new direction for community services'.

About 50 invited participants took part at venues in Manchester, Birmingham and London. The seminars aimed to clarify the nature of the evidence about approaches to self care and the role of self care in a modern NHS and outline the benefits the public and NHS could expect from an NHS where self care support is fully integrated as part of the overall care a person receives. The seminars were designed as a series to encourage ongoing discussion and debate; we started with 'Self Care - Where are we now, evidence and key approaches', continued with 'Self care support – the role of professionals and service development' and ended on September 14th with 'The future direction of self care support for people with long-term conditions'.

Each seminar had four invited speakers who gave a short overview of their topic and then participants broke up into small discussion groups where lively debate ensued.

The following are a few points which emerged from the discussions.

1. Evidence for self management is contested and those programmes or interventions with the strongest evidence are not necessarily those that are top of the list for implementation.

2. The expectations of policy makers and clinicians may differ from those of patients.
3. One size does not fit all needs. Generic or disease specific programmes may be required at different stages or be customised to a variety of needs.
4. More should be done to persuade and train professionals about the role of self care support, and the ways in which professionals already promote self care support require more recognition.
5. The current organisation of care, especially the 10 minute consultation, is a serious constraint. Alternatives like group appointments or facilitating self management could be considered.
6. There are challenges in disseminating and spreading self care programmes. Uptake, interest and understanding in the NHS are variable, and much work remains to be done to demonstrate the benefits and the business case: what is the return on investment from self care?
7. In primary care, new GMS and QOF influence the work of clinical teams. Should there be points and targets for self care in primary care?
8. The focus needs to shift to how to promote self care in the health reform programme, especially as payment by results and practice based commissioning are becoming more important.
9. The terms of debate around self care are changing with recognition of the complexity of the issues and of challenging and critical voices.

The organisers of the seminar series plan to publish a discussion paper in the Autumn.

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The Impact of the Expert Patients Programme on Demand for Health Services



Self care support in the NHS, currently provided through the Expert Patients Programme (EPP), is intended to have a key role to play in utilisation reduction and containing health care spending (Department of Health, 2005). EPP was launched by the Department of Health in England in 2001. It was originally designed to be delivered by Primary Care Trusts (PCTs) and is now operated through new community interest companies (CICs). EPP is a group-based self care intervention designed for use with any long-term condition, led by trained lay people and delivered in community venues outside of where care is normally provided. One of the key ways of judging the success of self-management programmes such as EPP, has been their ability to impact on health service utilisation: “Confident, knowledgeable patients practicing self-management will experience improved health status and will utilise fewer health care resources” (Lorig, Sobel, Stewart, Brown, Bandura, Ritter et al. 1999).

At NPCRDC we have recently completed the REPORT trial (Research into Expert Patients – Outcomes in a Randomised Trial) to test the clinical and cost-effectiveness of the EPP with a waiting list control (Kennedy, Reeves, Bower, Lee, Middleton, Richardson et al. 2007).

Results showed that patients who took part in the EPP reported significantly greater confidence in their ability to manage their condition and their energy levels. However, they did not report significant reductions in health services utilisation. In order to better understand these results we also conducted a longitudinal qualitative study, where interviews were conducted with individuals before and after taking part in the EPP. Interviews took place between August 2003 and March 2005.

The qualitative study allowed us to explore the way patients related to services prior and subsequent to taking part in the EPP. Findings uncovered two possible reasons for the lack of change in the use of health services. The first is the possibility of a ‘ceiling effect’ relating to patients’ existing patterns of health service use. Many respondents described themselves as low service users. Some had reached a point where they had accepted there was a limit to what traditional health services could offer them. Others had experienced frustrated and failed attempts to gain support from professional services, leading them to question the benefits of service use. Consequently, they had already reduced or minimised their levels of utilisation before attending EPP.

The room for individuals to change existing utilisation patterns was also limited by ‘supply side’ organisational practices where the health professionals expected the patient to attend regular monitoring or ongoing treatment. The second concerns the disconnectedness of EPP from formal health service providers. This makes it difficult for individuals to bring into their consultations the fact



that they had attended EPP and learnt new skills. Most respondents here gave a low priority to telling their health professional of their attendance on the EPP, as they seemingly had more important issues to cover within a time-limited consultation.

The qualitative study illuminates the way in which prior to attending a self-skills training programme, utilisation is firmly established as a habitual and routinised part of living with and managing a long term condition. Participants described having multiple contacts at different points in the health care system. Accounts suggested that even before attending EPP, people were negotiating their way through the health care system on a path which had been adapted over a long period of time. Although people described enjoying taking part in EPP, many did not appear to make the connection with the implicit messages transmitted via EPP that they could reduce their need for medical care by changing their behaviour.

Current health policy encourages the facilitation of self care (NatPaCT, 2004). However, for this to happen, the way in which services are organised and health professionals interact with patients requires change. Community run self-management education such as the EPP, which is delivered outside of where most chronic care is received, is not in a position to address the structural issues and barriers which may be faced by patients coming into contact with formal health services (e.g. access to and time given for appointments). Nor does it address supply-induced demand where demand, and therefore, utilisation is generated by

health professionals and services in order to monitor and provide ongoing treatment.

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Further Self-Management Research Success



NPCRDC has recently published quantitative¹ and qualitative² papers reporting on the results of our Irritable Bowel Syndrome (IBS) self-management study – the largest primary care IBS trial in the UK. Functional abdominal symptoms such as abdominal pain, bloating, diarrhea and constipation are very common and account for nearly 2 million primary care consultations in Britain every year and produce significant morbidity. We evaluated the impact of two self-help interventions on how often people saw their GP and the severity of their symptoms. Four hundred and twenty patients from 54 primary care centres were randomised to receive self-help information in the form of a guidebook (some also attended a “self-help” group meeting) or put in a control group receiving neither intervention. Data were collected using questionnaires and primary care records.

The results showed that at one year, patients in the guidebook group had a 60% reduction in primary care consultations ($p < 0.001$) and a reduction in perceived symptom severity ($p < 0.001$) compared with controls. Allocation to the self-help group conferred no additional benefit. Actual symptom scores did not change significantly in any group. Costs per patient were reduced by £73 (confidence interval £43, £103) or 40% per year.

Patients felt that the guidebook gave them the confidence to self-manage their conditions and they no longer felt the need to have consultations with GPs and other health professionals about their condition. The use of the guidebook as an alternative way of providing primary care was based on acknowledging the suffering people experienced as a result of their condition, reinforcing the existing ways people had already found to deal with their condition, advocating new opportunities and allowing people to feel positive about self-managing.

Our research suggests that to become active partners in chronic illness management, patients need relevant information that clearly explains treatment choices. It would seem that the introduction of a self-help guidebook for IBS sufferers results in a reduction in primary care consultations, a perceived reduction in symptoms and significant health service savings. This suggests that patients seeing their GP with functional abdominal symptoms should be offered self-help information as part of their primary care management.

- 1 A randomised controlled trial of self-help interventions in patients with a primary care diagnosis of irritable bowel syndrome. Robinson A, Lee V, Kennedy A, Middleton L, Rogers A, Thompson, DG, Reeves D. Gut, 2006, 1-7
- 2 Continuity and change? Exploring reactions to a guided self-management intervention in a randomised controlled trial for IBS with reference to prior experience of managing a long-term condition. Rogers A, Lee V, Kennedy A. Trials, 2007, 8/1/6

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Building Research Capacity at NPCRDC

Developing the research capacity of the NHS is one of our core aims and our work is built around three areas.

MRes

We have worked with the School of Epidemiology and Biostatistics to develop a new web-based Masters in Public Health and Primary Care/ Masters in Research which has significant components relating to primary care and health services research. Students undertake a research project if they want to study for a Masters in Research. The course had its first intake in September 2006. Further details can be obtained from www.mphe.man.ac.uk.

In the first year all our students have taken core subjects of biostatistics, epidemiology and evidence based practice, and many have also opted to take qualitative research methods. We receive funded studentships from the Medical Research Council to complete the MRes. The first places were taken up by Sudeh Cheraghi-Sohi, who recently completed work within the Quality theme at NPCRDC, and Nathan Whittle. We hope that this funding will provide us with a cohort of students who are well placed to go on to PhD studies, and Sudeh will now move on to complete a PhD based on our research on incentives.

PhD

PhD studies are at the core of our research capacity building. A three year PhD is a significant undertaking and to ensure students are well supported we assign them to one of our Research Themes and encourage membership of our thriving PhD support group.

In 2006, we saw four more students successfully complete their PhD studies (See page 18). Anna Coleman worked as part of a multidisciplinary team working on Local authority scrutiny of the NHS (www.npcrdc.ac.uk/ResearchDetail.cfm?ID=171). She is now part of the team evaluating practice based commissioning (www.npcrdc.ac.uk/ResearchDetail.cfm?id=177), and leading the development of a new health policy course for the MPH. Muna Ahmead completed her PhD on self help technology for depression in adolescents and has now returned to Palestine to take up a senior position in nursing education. Muna hopes to find further opportunities for research. (<http://www.npcrdc.ac.uk/r5.53>)

Nicola Walsh completed her PhD on the *Evaluation of Personal Medical Services (PMS): the impact on working arrangements and service development in primary care*. Umesh Chauhan is a GP in a PMS site in Rossendale. His PhD addressed how current approaches to structured diabetes care impacts on inequalities in care relating to ethnicity. (<http://www.npcrdc.ac.uk/r5.49>)

Tim Doran completed his thesis *Hidden Extremes: identifying health over-achievement and under-achievement in England* and received his Doctor of Medicine from the University of Liverpool. He now leads our work analysing data from the Quality and Outcomes Framework (QOF).

We also welcomed five new PhD students to NPCRDC (See page 18). Rob Owen is funded through our grant from the National Co-ordinating Centre for Research Capacity Development (NCCRCD), and his work on pre-hospital care provided by ambulance trusts promises to add a new dimension to the range of work conducted with the Quality Programme (<http://www.npcrdc.ac.uk/r5.79>).

Julia Hiscock also received a prestigious award from NCCRCD, and her PhD on social networks will complement the ongoing self-management theme. Nik Hanafi is funded by the University of Malaya, and has just returned to complete data collection in her home country in a study of health seeking behaviour in Malayan communities. (<http://www.npcrdc.ac.uk/r5.81>).

Julia Segar is funded through a strategic studentship from the Medical School, and has taken up her studies after completing the previous MRes course run by the Division of Primary Care (<http://www.npcrdc.ac.uk/r5.84>). Diane Whalley is an existing member of staff within the Workforce theme who will be doing her PhD on factors that encourage GPs to work in deprived areas (<http://www.npcrdc.ac.uk/r5.72>).

For further information about postgraduate study at NPCRDC, please contact Dr Stephen Campbell, Post-graduate Tutor, on 0161 275 7655 or email stephen.campbell@manchester.ac.uk

In 2006, we received an invitation from Professor Moira Stewart (Centre for Studies in Family Medicine, University of Western Ontario) to send a student and supervisor on a course entitled 'Transdisciplinary Understanding and Training on Research Primary Health Care: TUTOR-PHC'. The course seeks to prepare students for their PhD studies, and involves a week long residential course and ongoing online work. After an internal competition, Dr Cath Snape attended with her supervisor Dr Ruth McDonald. Both reported that they found the course useful and challenging.

Post doctoral studies

Making the transition from PhD candidate to established researcher can be difficult and to help we introduced a post-doctoral bridging fellowship to support applications for external postdoctoral training awards. We are very pleased to announce that our first two bridging fellowships have been successful in allowing researchers to move onto new challenges at NPCRDC.

Joanne Protheroe has received a five year award from the RC-UK scheme to fund research into the development of interventions to support shared decision making in disadvantaged groups. She also secured support from The University of Manchester Stepping Stones Scheme to fund a PhD student to work with her on this programme.

Katherine Checkland has now been employed on a Walport lectureship in primary medical care as part of the Modernising Medical Careers/NCCRCDC programme, to work with Professor Steve Harrison on the Organisations Programme, and is developing a portfolio of work on general practice organisations and their responses to the changing health care environment.

If this has whetted your appetite for postgraduate study we can provide support and assistance to find funding and begin studying. You may find it useful to talk to our students about their experience of studying.

Completed PhDs and MDs

Anna Coleman	Local Authority scrutiny of health 2002-2004: an empirical study
Nicola Walsh	Evaluation of Personal Medical Services: the impact on working arrangements and service development in primary care
Muna Ahmead	The use of self help technology for the management of adolescents' emotional problems: evidence base and user views
Umesh Chauhan	Diabetes Care in Ethnic Minority Groups
Tim Doran	Hidden extremes: identifying health over-achievement in England

New PhD students

Diane Whalley	Why do practitioners work in deprived areas? Identifying affinity factors for urban deprived general practice
Nik Sherina Hanafi	Self-management in primary care
Rob Owen	Quality in pre-hospital care
Julia Hiscock	Social networks supporting self care
Julia Segar	Patient choice in the health marketplace

Staff news

Goodbye to...



Muna Ahmead came to NPCRDC on a scholarship from AMIDEAST in Palestine. After successful completion of her PhD studying the use of self help technology for adolescents with depression, Muna returned to Palestine to a position in nursing education.



Andy Wagner, after more than seven years at the Centre as Manager of the National PCT Database, left to join the University's Centre for Pharmacy Workforce Studies.



Kathryn Kelly left early October to start a new job with Leeds University working as a cardiovascular risk specialist nurse as part of a research study being undertaken by the Centre for Metabolic and Endocrine Diseases and then moved on to Leeds General Infirmary as a renal research sister on the dialysis unit.



Kate Davies who left the Communications Unit in July, to take up a new post as Secretary for the University's Royal Navy Unit (URNU).



Richard Newton left the communications unit to train at the Manchester Metropolitan University as a secondary school teacher.

NPCRDC e-newsletter...

Be the first to hear about NPCRDC publications, seminars and research areas of interest when you sign up to receive the NPCRDC e-newsletter at <http://www.npcrdc.ac.uk/NewsletterRegistration.cfm>

Welcome to.....



Ella Gaehl joined NPCRDC in January 2007 as a Research Technician for the Quality and Incentives in Practice Project (QuIP).



Dr Islay Gemmell who joined us in October 2006. Islay is the course unit leader for the Biostatistics course on the Division of Primary Care MPH and within NPCRDC she is involved in research projects within the quality research group.



Julia Hiscock, who joined us in January 2007 as a Research Training Fellow on an NCCRD Personal Fellowship Award, is undertaking a study on social networks and self care which is being conducted jointly with the department of Sociology.



Professor Helen Lester joined us in 2007 having spent 10 years in the Department of Primary Care at the University of Birmingham. Helen leads Manchester's NIHR School Programme (See page 4), and currently leads the Expert Panel that advises the GP Contract Quality and Outcomes Framework group. Helen will be working with NPCRDC's Quality team and the Primary Care Mental Health Group.



Dr Julia Miller is now based in Manchester as Senior Scientific Administrator with the NIHR School for Primary Care. Her post supports School Director Martin Roland and four other University partners (Birmingham, Bristol, Cambridge and Oxford).



Rob Owen was the Clinical Director of the Surrey Ambulance Service NHS Trust. Rob joined the Centre to do a PhD on measurement of quality of care provided by transactional/episodic services such as GP out-of-hours services and the ambulance service.



Julia Segar joined the Centre as a Training Fellow after completing the MRes (Health and Community) at The University of Manchester. Her PhD research is on patients' choice of complementary and alternative medicine in the health marketplace and how such choices may run counter to the ideals of evidence based medicine.



Professor Barbara Starfield joined NPCRDC as a Visiting Professor which enables us to develop research links with her world-leading department of Primary Care in Baltimore. Recognising the importance of her appointment, the University has appointed one of her post-doctoral fellows (Chema Valderas) to a full time lecturer post in Manchester in order to develop this collaboration.



Nicola Small joined the centre in December 2006 and works as a Research Technician on the Quality and Incentives in Practice project (QuIP) with Dr Stephen Campbell.



Dr Jose (Chema) Valderas joined the Centre as Clinical Lecturer and previously worked as a research fellow at the Department of Health Policy and Management, Johns Hopkins University (Baltimore, MD).



Catherine Snape joined us to complete her PhD, "General practices as learning organisations; exploring the relationship between learning culture and performance". During her time at the centre she continues to work as a GP principal at Gillygate Surgery, in York.



Professor Doug Wholey is from The University of Minnesota and joined the Centre in September as a part-time Visiting Professor in Organisational Sociology. Doug is developing a programme of research into the organisation and function of NHS primary health care teams and networks in partnership with the leaders of NPCRDC's Workforce and Organisations research themes. His current research examines social networks in medical clinics and team management in assertive community treatment teams.

Congratulations to.....



Dr Pete Bower on his recent promotion to Reader in Health Services Research at The University of Manchester.



Dr Stephen Campbell and Dr Ruth McDonald on their recent promotions to Senior Research Fellow at The University of Manchester.



Dr Kath Checkland who recently completed her PhD on *Understanding general practice: an exploration of the impact of bureaucratic initiatives in general practice* and is now employed on a Walport lectureship in primary medical care as part of the Modernising Medical Careers/NCCRCDC programme.



Dr Umesh Chauhan on gaining his PhD on *Diabetes Care in Ethnic Minority Groups*.



Sudeh Cheraghi-Sohi who received funding from a Medical Research Council Studentship to undertake the MRes in primary care in October for one year.



Dr Anna Coleman, Dr Muna Ahmead and Dr Nicola Walsh on successful completion of their PhDs (see page 17 for details).



Dr Tim Doran on receiving his Doctor of Medicine from the University of Liverpool. His thesis was *Hidden extremes: identifying health over-achievement and under-achievement in England*.



Professor Helen Lester on being presented with the John Fry Award by the RCGP last month. This is awarded to a younger member of the College who has promoted the discipline of general practice through research and publishing as a practising GP.



Dr Joanne Protheroe who has received a five year award from the RC-UK scheme to fund research into the development of interventions to support shared decision making in disadvantaged groups, as well as support from The University of Manchester Stepping Stones Scheme to fund a PhD student to work with her on this programme.



Dr Ruth McDonald who was awarded a Harkness fellowship and is planning to spend a year in the USA, based in a University department looking at incentives for quality aimed at primary care physicians in the USA. The fellowship will also enable her to participate in high level seminars organised by the Commonwealth Fund.




Anne Rogers and David Pilgrim who won the top prize of BMA Medical Book of the year with *A Sociology of Mental Health and Illness*, 3rd edition. There was stiff competition with over 550 entries vying for 88 across a variety of categories and new awards. Anne and David also won first prize in the Mental Health category. The book was described as being “simply the best textbook in the area of mental health”.



Rosalind McNally on gaining her Postgraduate Certificate in Learning and Teaching in Higher Education



Caroline Sanders on being awarded a grant of £200,000 from the Burdett Trust to adapt and evaluate the peer education programme among older people (See page 2). The lead researcher is Jane Seymour, Sue Ryder care professor of palliative and end of life studies at the University of Nottingham.

 *Executive Summary 42 – Evaluation of the Evercare approach to case management of frail elderly people*
<http://www.npcrdc.ac.uk/es42>

Executive Summary 43 – Budgets and incentives in primary care
<http://www.npcrdc.ac.uk/es43>

Executive Summary 44 – National Evaluation of the Expert Patients Programme
<http://www.npcrdc.ac.uk/es44>

Executive Summary 45 - Partnerships: Reviewing the evidence
<http://www.npcrdc.ac.uk/es45>

Annual Report 2006
<http://www.npcrdc.ac.uk/ar2006>

Spotlight on support for self care in the NHS
<http://www.npcrdc.ac.uk/s4>

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The National Primary Care Research and Development Centre is a multidisciplinary and academically independent centre, established by the Department of Health in 1995 to undertake a programme of policy related research in primary care. It is a collaboration between the Universities of Manchester and York with our main base at the University of Manchester.

We aim to:

Deliver high quality, policy relevant research to inform the development of primary health care;

Communicate research findings to promote the development of evidence-based primary health care;

Develop research capacity in primary care through the provision of support, training and staff development.

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