

COLLABORATIONS FOR LEADERSHIP IN APPLIED HEALTH RESEARCH AND CARE

Progress Report for Second Award Year

Note: The accompanying *NIHR Collaborations for Applied Health Research & Care – Guidance on Completion of Progress Reports for Second Award Year* contains essential guidance on the information you need to provide when completing this proforma.

**Please complete the form using a font size no smaller than 10 point (Arial).
The completed form should be no longer than 10 pages in total.**

1. CLAHRC DETAILS

Name of the NIHR Collaboration for Leadership in Applied Health Research & Care:

NIHR CLAHRC for Leicestershire, Northamptonshire and Rutland

Name, job title, address, email and telephone number of an individual to whom any queries on this Progress Report will be referred:

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2. DECLARATIONS AND SIGNATURES

Name and address of the NHS Organisation administering the NIHR CLAHRC award:

University Hospitals of Leicester NHS Trust

Name of the Chief Executive of the NHS organisation:

Mr Malcolm Lowe-Lauri
University Hospitals of Leicester NHS Trust
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I hereby confirm, as Chief Executive of the NHS organisation administering the NIHR Collaboration for Leadership in Applied Health Research & Care award, that this Progress Report has been completed in accordance with the guidance issued by the Department of Health and provides an accurate representation of the activities of the NIHR CLAHRC:

Signature of Chief Executive: **Date:**

3. OVERVIEW OF ACTIVITIES

Please provide an overview of the activities undertaken by your NIHR CLAHRC for the first award year, describing any changes to the strategy for your CLAHRC, any significant developments in implementing the strategy, and any highlights of applied health research and implementation activity supported by the NIHR CLAHRC award:

Overview of Activity and Progress

The second year of the NIHR CLAHRC for Leicestershire, Northamptonshire and Rutland (LNR) has been one of considerable activity, with the launch of 36 new applied research or implementation studies and considerable progress on established projects. During the year, there were 53 publications, 2880 people were recruited to studies, 2014 people took part in training, and externally funded research expenditure amounted to over £1m.

Potentially important findings are emerging and the CLAHRC is beginning to share these with partner organisations and the wider health and research communities across LNR. Local implementation of evidence generated by the CLAHRC is escalating and implementation projects are emerging in research themes. In this report, we summarise our strategy, and outline progress in each field of activity.

Changes to the Strategy of NIHR CLAHRC for LNR

The broad strategy of the CLAHRC, involved four inter-related applied research themes and an implementation theme, collectively focused on improving the management of long term conditions, remains unchanged. Our applied research seeks to develop, evaluate and implement improved ways of delivering effective health care interventions. However, there were some changes to aspects of our strategy following a review in September, 2010 by an invited team of international experts in knowledge translation. Professors John Ovretveit, Jonathan Lomas, Huw Davies and Dr Alison Powell spent a week with the CLAHRC to appraise our strategy and assess our progress. They concluded that the CLAHRC had “effectively expanded a portfolio of investigator-driven applied healthcare research of strong local relevance about long-term conditions”. However, the team recommended that we expand the role of social and management sciences within the CLAHRC and target greater resource on knowledge translation. They made a number of detailed suggestions on knowledge translation to help us to improve our partner organisations’ ability to value, assimilate and apply existing evidence in patient care. The review team recommendations were enormously helpful as they provided a clear, coherent and authoritative voice for making changes we were already contemplating.

The CLAHRC is responding to the recommendations with a range of activities to increase the capacity of our NHS partners to acquire and make productive use of research evidence. New educational programmes are being developed and methods of summarising and disseminating clinical knowledge are being piloted. We are expanding our investment in ‘knowledge brokers’ – NHS staff with a specific role to promote the dissemination and use of evidence. Management and behavioural science expertise is being strengthened through a new organisational psychologist post and by extending our network of advisors to include Professors Graeme Currie (Warwick), Kieran Walshe (Manchester), and Naomi Fulop (Kings College London).

A lesson that has shaped our approach is the increased recognition of the importance of meaningful engagement of Trust staff in our efforts to accelerate knowledge generation, dissemination and use. We better understand and value the role of ‘co-production’ in implementation and in applied health research, and genuine partnership is now a feature of all new projects. The appointment of ‘boundary spanning’ CLAHRC Co-ordinators in trusts has supported this principle. Their networking role has proved invaluable in topic prioritisation, project scoping and partnership development. We are mindful in all our activities of the need to identify development opportunities for Trust staff, so that their engagement with projects provides both service improvement and capability development.

An internal evaluation, led by Graham Martin (Senior Lecturer in Social Science applied to Health), has been commenced, and is currently moving towards the end of the first round of fieldwork. This first phase has involved qualitative interviews and social-network questionnaires with core members of CLAHRC staff, focusing in particular on their theories of change for the CLAHRC, challenges and achievements to date, and their views on some of the organisational innovations implemented by the CLAHRC. In addition to this part of the evaluation, which will soon be analysed and then repeated at annual intervals, a doctoral student (Sarah Chew) is carrying out a study of the realisation of the role of CLAHRC Co-ordinators, using

interviews, ethnographic work and reflexive diaries being kept by the Co-ordinators. Further evaluation work will focus on the development of 'research mindedness' in partner NHS organisations, and will include a comparative content analysis of strategic NHS documents in CLAHRC LNR trusts and non-CLAHRC trusts. We are also fully engaged in the NIHR SDO-funded evaluation projects.

To illustrate the activities undertaken by the Coordinators, a brief summary of recent work by one Coordinator is set out here (we have seven Coordinators in total): raising awareness through communication article in Trust newsletter and securing a presence on the Trust website, plus posters, targeted emails and meetings. A R&D drop in surgery has been organised for people to meet the team and find out more about what do and the other networks. Information has been collected on current research capacity/capability and use of evidence through interviews of staff, the results of which are shaping the R&D action plan of the Trust. Training for staff has been organised, beginning with 'finding the evidence', with over 60 people booked on and a large waiting list. Future sessions will cover funding, ethics and approval, evaluation, and others are planned. Leaflet/guides have also been produced to accompany the sessions and for use as set of R&D resources locally.

The Coordinator has ensured representation from the Trust on CLAHRC projects. Informal feedback indicates positive views on this engagement and how it has helped and brought lots of people together table who wouldn't usually have been able to contribute. The Coordinator is also setting up a process for research ideas to be gathered, prioritised, carried out and fed back. More than 30 research ideas have been collected thus far, and she is now looking at ways to take this forward, engaging other members of CLAHRC/universities/awards and external funding. This will hopefully lead to increase bids for funding and more research activity.

Developments

1. Implementation Theme

The focus of the Implementation Theme was initially on approaches to tailoring implementation interventions to identified barriers and enablers to appropriate care as summarised, for example, in clinical guidelines or policies. We anticipated undertaking a number of pilot studies, followed by one or two larger studies that would evaluate a practical approach for use in the NHS. During the course of the year, elements of this strategy were delivered, for example, our review of tailoring was completed and published in the Cochrane Library (Baker et al, 2010) and a project to implement the NICE guidelines on obesity in primary care completed recruitment and initial data collection.

The primary aim of this initial work was to develop readily applicable methods for identifying barriers and enablers to evidence use, and for selecting implementation interventions to address them (tailored implementation). This approach is a key component of knowledge translation models, including the Canadian Health Research Institute's (CIHR's) knowledge-to-action (KTA) cycle that is a key component of our approach to knowledge translation (Baker et al, 2009). In keeping with our new strategy, we now focus less on research into implementation methods and more on direct implementation activities. Research in this field is continuing, but in the context of a new, major, four year project funded by the EU (3.84m Euro), with collaborators in the Netherlands, Norway, Germany, Poland and Canada. This study, received as a consequence of CLAHRC funding, involves investigation and evaluation of methods and theories to improve tailored implementation, and is intended to lead to improved approaches to identifying barriers and enablers and selecting implementation strategies to address them.

More recently, the CLAHRC has broadened responsibility for implementation to encompass the applied research themes. Applied themes are engaging staff to drive the dissemination and local adoption of findings from their respective research programmes. The Implementation Theme will coordinate this activity in the light of our overall strategy.

Ongoing and completed Implementation Theme projects are:

- Implementation of NICE guidelines on Teenage pregnancy
- Implementation of NICE guidelines on Obesity
- Health Education Reaching Out project (HERO)
- Implementing NICE guidelines on Falls in the Elderly in the emergency department (new project)
- Primary-secondary care collaboration on follow-up of older people who fall (externally funded)
- Performance of general practices
- Enhanced GP role in Cardiology Management
- Evaluation of Implementation of Matching Michigan (externally funded)
- Evaluation of Implementation of High Quality Care for All (externally funded)

- Acute Admissions: Northants
- Acute Admissions: Leicester
- Variation in Cardiovascular Mortality

Highlights

Implementation Theme highlights include work on outcomes, which showed that the success of primary care in detecting hypertension is a strong predictor of mortality rates from coronary heart disease in England (Levene et al, 2010). This finding is important in showing how a simple health care intervention – detection of hypertension - can reduce population mortality. We are now exploring with primary care organisations approaches to improving detection of hypertension in the context of the national *Health Checks* scheme.

Our obesity guideline implementation project showed that patients and practitioners experienced lack of access to weight management services. This finding has been presented to primary care Trusts (PCTs) and regional service planners, an educational package for primary care has been developed, and educational outreach delivered to primary health care teams. Building on this work, the EU funded programme of studies in implementation (see above) will concentrate in the UK on obesity management.

Our work with primary care and acute Trusts on acute admission rates has shown how patient reports of access predict acute admission and emergency department attendance rates (two papers currently submitted for publication). The findings have been used by local Trusts to develop processes to contain admission rates. These include the provision performance data to practices, meetings with practices to discuss potential improvements, and targeted activities in practices with poor patient-reported access. We are also working with a PCT to evaluate and improve the use of clinical guidance on steps to reduce the risk of admission in a small number of conditions. Work with Nene Commissioning, a pathfinder consortium, has demonstrated the value of a scheme to deliver, through trained GPs, enhanced care to people with heart failure in the community in place of referral to specialist clinics. A decision has now been taken to roll out the scheme.

The work to develop systems and processes to increase the use of research evidence in trusts is in its early stages (Parent et al, 2007). Trusts have research departments, library services, and clinical effectiveness processes, but they are often insufficiently integrated to support the systematic application of evidence. We are exploring ways of bringing these activities together, or to foster networks that enable effective interaction, to help Trusts in their decision-making. For example, we have engaged with one Trust about the use of evidence to inform the selection of CQUINS and target setting. This has involved the observation of the current process and will involve meetings to review and suggest improvements that make better use of research evidence. In addition, we are working with the same Trust to routinely include the use of evidence to inform business cases for allocation of resources. We will be looking to extend this work in other Trusts.

The HERO (Health Education Reaching Out) programme has continued to work with schools, charities, university students and other public groups and organisations to educate and inspire people to take responsibility for their own health, diet and well-being. Through interactive quizzes and public awareness lectures, HERO provides people of varied social and cultural backgrounds with the insight to prevent and reduce their risk of developing chronic diseases, such as heart disease, diabetes, arthritis and cancer. HERO is committed in this sense to providing adults, families, students and schoolchildren with a basis to appreciate the long-term benefits of regular exercise, a healthy diet and a stress-free lifestyle. Further information about HERO activities is given in the section on patient and public involvement.

References

Baker R, Robertson N, Rogers R, Davies M, Brunskill N, Khunti K, Steiner M, Williams M, Sinfield P. The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Leicestershire, Northamptonshire and Rutland (LNR): a programme protocol. *Implementation Science* 2009;4:72

Parent R, Roy M, St-Jaques D. A systems-based dynamic knowledge transfer capacity model. *Journal of Knowledge Management* 2007; 11(6):81-93.

2. Prevention Theme

The Theme has made considerable progress in conducting applied research relevant to the local

population of LNR. Theme studies bridge the primary-secondary care boundary and bring high-quality evidence to NHS efforts to prevent long term conditions. Intervention activities within the Theme are highly relevant to local and national service frameworks for chronic kidney disease (CKD) and diabetes management. Considerable local and national need has driven early implementation of the CKD audit tool and the Walking Away structured education programme.

Walking Away from Type-2 Diabetes: A Cluster Randomised Trial to Investigate the Effects of Structured Education on Walking Activity in Those with a High Risk of Developing Type 2 Diabetes

The 'Walking Away' study is an assessment of a primary care based structured education intervention package for the promotion of physical activity and prevention of type-2 diabetes. It involves more than 800 individuals from eight GP practices across Leicester, Leicestershire and Rutland. The study is assessing whether provision of an educational programme results in a change in physical activity. The study will report in September, 2013.

Work is already underway to implement structured education programmes locally and nationally as part of the national service framework for diabetes. With the support of the CLAHRC, the study team have trained a total of 36 educators to deliver the intervention to patients at high risk of diabetes. The project team were delighted to secure a *Regional Innovation Funding Award* to extend the evaluation of this early implementation work in Northamptonshire.

A Primary-Secondary Care Partnership to Prevent Adverse Outcomes in Chronic Kidney Disease (the PSP-CKD Study)

This cluster controlled trial involves around 50 general practices across Northamptonshire and compares an intensive CKD management programme in primary care to normal CKD care. The aims of the study are to determine whether reinforcement of best practice in the management of CKD care improves clinical outcomes. Anticipated study outcomes include better CKD care; improved coding of CKD; more accurate chronic disease registers; and increased research capacity in Northamptonshire. Additionally, the study is testing and evaluating a new model of partnership working between partners in commissioning, provider and academic organisations and across primary and secondary care. Nene Commissioning, a pathfinder commissioning group, is a partner in the study, and the study findings will be used by Nene in making decisions about the commissioning CKD care. The final project report will be available in September, 2013.

As a practical extension to the study, and an example of an implementation approach arising from the study and the associated network that has been created, the project team will use a MIQUEST driven extraction/audit tool to help general practices with low CKD recording to identify at risk patients and to populate their CKD registers. Opportunities for commercialisation of the data extraction tool are being explored.

In addition, Dr. Ahmad Moukli of *The Practice plc* has been appointed as a visiting Research Fellow and is working with the CLAHRC Prevention Theme to promote applied research within his organisation. In particular, Dr Moukli is implementing a strategy to improve CKD management and patient care within the 50 practices of *The Practice plc* using the PSP-CKD study extraction and audit tool.

A Psychological Approach for Preventing Perinatal Depression Antenatally – A Pilot of a Cluster RCT of Community Midwifery Training (the Pregnancy and Wellbeing Study - PAWS)

The PAWS pilot involves a partnership between the University Hospitals of Leicester NHS Trust, Leicestershire Partnership Trust, NHS Leicester City and NHS Leicestershire County and Rutland. It will establish the feasibility of a definitive trial to assess whether midwife training in a cognitive behavioural approach (CBA) reduces cases of perinatal depression. Although there is evidence to support the effectiveness of CBA, evidence is needed on how this intervention can be routinely delivered in a practical, cost-effective way. The study involves 300 pregnant women from across Leicestershire and Rutland, and subject to the findings of the pilot, an application for external funding for a full multi-centre trial will follow. The pilot study will report in late 2011.

Detection and Management of Chronic Kidney Disease in Primary Care: a Qualitative Study of the Experience of General Practitioners

A preliminary analysis of Quality Outcome Framework (QOF) reports from 2007/8 found that the detection of chronic kidney disease (CKD) in primary care was significantly lower in practices in the East Midlands and the rest of the UK compared to findings from large population studies based in the UK and the US.

The mean detection of CKD stage 3-5 in the East Midlands was 2.9% whereas the UK population studies found the prevalence to be 8.5% (Walker et al, JRCGP, in press). This qualitative study involves interviews with general practitioners to determine their experiences of detection and management of CKD in primary care and explores barriers to the use of current evidence-based guidance for CKD, and reasons for the difference between detection rates and prevalence. A detailed analysis of study findings is due to be completed by May, 2011. This will be used to improve CKD recording and patient care across LNR.

Screening Adults for Social and Communication Disorders, including Autism Spectrum Disorders

Adults with Autism Spectrum Disorders (ASDs) are one of the most under diagnosed groups in mental health services. The study will screen approximately 1500 adult users of mental health services throughout Leicestershire, Northamptonshire and Rutland (LNR) in order to assess the validity of the Ritvo Autism and Asperger's Diagnostic Scale (RAADS) self-assessment tool as a method for screening adults for autism spectrum disorders who are not self referred. The study will also assess other self-completion questionnaires, including the AQ-50. The study is due to report in September, 2012.

Implementation and Evaluation of Care Pathways in Adults with Intellectual Disability

This project will implement and evaluate eight stakeholder-identified care pathways for adults with learning disabilities in order to (a) reduce barriers to access, (b) reduce waiting times, (c) improve patient experience and outcome, and (d) improve the cost efficiency of service delivery. The project team plan to establish an initial structured assessment process to decide the most appropriate care pathway; identify 'trigger points' for high risk patients within each care pathway so that they can be prioritised and referred immediately to appropriate services; and assess the impact of the implementation of pathways. The study will report in Autumn, 2011.

3. Early Detection Theme

The overall strategy of the theme has remained consistent, with a focus on delivering world class applied health research of strong local relevance. The Theme's expanded portfolio of research activity is set out below:

Assessment of Response Rates and Yields for Two Tools for Early Detection of Non-diabetic Hyperglycaemia and Diabetes (ATTEND)

The ATTEND study assesses the feasibility and utility of two screening strategies (based on risk factor assessment) for identifying people in an ethnically diverse UK population at high risk of type 2 diabetes mellitus. It will determine the specificity and predictive power of these strategies and, to support future implementation, will also assess patient and practitioner acceptability. The study will report in March 2012.

Early Detection of Impaired Glucose Regulation Post Myocardial Infarction – The SWEETHeart Study

The SWEETHeart study compares the prevalence of diabetes and non-diabetic hyperglycaemia post MI in South Asians and Europeans and assesses whether early detection of abnormalities using OGTT and HbA1c in the course of acute coronary syndrome (ACS) can help to identify high risk patients. It will evaluate the profile of biomarkers in the post ACS period and investigate their correlation to short- and long-term prognosis. A predictive risk score model will then be developed to help screen high risk patients likely to have adverse clinical outcomes following ACS. Better knowledge of risk factors determining adverse clinical outcomes post MI will help early identification of high risk people from a mixed ethnic population following an MI, and help in the development of interventions for at-risk groups. The final study report will be available in December 2012.

Interventions to Reduce Strain in Carers of Ethnic Minority Stroke Victims

The study is determining predictors of carer strain in ethnic minority populations surviving at least one month post-stroke and with an identified carer. The results from this will then be used to develop a culturally-sensitive patient and carer intervention that will be introduced and compared to standard care in a pilot randomised controlled study based in primary care for carers of South Asian stroke patients. This study will investigate the differences between levels of carer strain between South Asian and White populations; establish the predictors and consequences of increased carer strain in a South Asian population; and develop and test a population-targeted intervention to reduce carer strain. The study will report in December 2012.

Pharmacy Based Screening of High Risk Individuals Using Stepwise Methods: The PRISM Study

This pragmatic trial is assessing pharmacy-based screening methods for impaired glucose tolerance (IGT) and type 2 diabetes mellitus (T2DM) in line with the recently implemented NHS 'health check' programme. The hypothesis is that screening using a self assessed risk score followed by near patient HbA1c testing in pharmacies and general practices increases uptake of a second stage blood test conducted at the GP surgery compared to screening with a risk score alone. To support possible widespread implementation, the study also assesses the patient, pharmacist and general practitioner acceptability of the screening methods. The study will report in March 2012.

The Use of Dynamic Plaque Indices to Predict Risk in (A)symptomatic Carotid Artery Stenosis

This study is recruiting 175 patients undergoing carotid endarterectomy for asymptomatic (35 patients) and symptomatic (140 patients) stenosis from the University Hospitals of Leicester. Non-invasive imaging techniques are being used to assess carotid plaque dynamics in order to develop and evaluate a revised risk assessment service. The aim is to prevent future disabling or fatal stroke in people with transient ischaemic attack (TIA) or minor (non-disabling) stroke as part of a strategy to reduce subsequent morbidity and mortality. The study will report in December 2011.

Leicester Diabetes Self-Assessment Risk Score

This project further developed the Leicester Diabetes Self-Assessment Risk Score (LSA) to ready it for use in practice. The LSA tool has been designed to be used by anyone to establish their risk of diabetes. Trials have found it to be more accurate in minority ethnic communities than existing tools. The work was part-funded by Diabetes UK and the LSA features on their web site where it has been used by more than 70,000 people. The tool is also a key assessment tool for the ATTEND and PRISM studies. This study reported in 2010

Leicester PCT Pharmacy Based Cardiovascular Disease Pilot Study Evaluation

This study was an evaluation of a pharmacy-based pilot that combined computer-based risk scores and personalised risk information to identify people who might develop cardiovascular disease. It involved analysis of participant risk data, referral response data and qualitative interviews with a sample of pharmacists and participants. On the basis of the evaluation, pharmacists were identified as a 'research naïve' community and studies to involve them, such as PRISM, have been developed. The evaluation findings were reported to NHS Leicester City in October 2010.

Improving Early Presentation of TIA/Stroke Patients to Specialist Services

This cluster-randomised study in primary care is focusing on the recommended interventions arising from another local research study (Barriers to the Early Assessment of TIA and Stroke, BEATS). These educational interventions are applied to patients, the public and health care professionals to support local protocols for assessment, investigation and management of TIA/stroke. The study will report in March 2012.

Exploring the Feasibility, Acceptability and Effectiveness of Screening and Management for Depressive Symptoms and Diabetes Distress for the Prevention of Deteriorating Glycaemic Control in People with Type-2 Diabetes

This study examines ways of screening people with diabetes for depression and distress and of providing effective management to control their diabetes. The study explores the views and experiences of patients and healthcare professionals in order to inform a screening and management programme suitable for delivery in general practices. A pilot study will subsequently explore the effectiveness of the programme. The study will report in March 2013.

Barriers to Participation in Bowel Cancer Screening

Through a series of focus groups with participants recruited from three of Northamptonshire's larger towns, this study assesses participants' understandings of bowel cancer, the perceived benefits and disadvantages of testing, and how and why individuals choose to return the screening test or decline to do so. The project will determine how patient participation in the NHS bowel cancer screening programme might be improved through changes to its structure, content or delivery. The study will report in March 2011.

Other Highlights

The release of the Leicester Diabetes Self-Assessment Risk score, co-funded by CLAHRC and Diabetes UK, has been a success with more than 75,000 taking the on-line version and it is a core element of the PRISM study (see below).

The Danes Camp practice in Northamptonshire is one of five in the county participating in the ATTEND study. Dr Azhar Zafar, one of the partners there, said "*Working with CLAHRC LNR has opened my eyes to the contribution that research can make to primary care. You sometimes are so busy you can overlook how important it is to look at different ways of doing things; ATTEND has been a great opportunity for me and my colleagues in Northamptonshire.*"

The theme has displayed posters from CLAHRC LNR at a number of national and international events including Diabetes UK, British Stroke Association and the European Association for the Study of Diabetes (EASD), the leading international event for diabetes research.

4. Education and Self-Management Theme

The Theme supports three CLAHRC directly funded studies: DESMOND Foundation, DESMOND Ongoing and Quality Development for Educators. All have made excellent progress during the reporting year. The Foundation and Ongoing studies involve highly productive collaborations with neighbouring CLAHRCs (Birmingham and the Black Country and South Yorkshire).

On home ground, researchers and members of the Education and Self-Management Theme worked seamlessly across Themes in LNR CLAHRC resulting in major contributions to other Themes, particularly Prevention and Early Detection. The Quality Development study, with its focus on improving educator skills has produced rich data from its service development phase, involving several hundred educators employed by health authorities across the UK, with learning already being disseminated through submitted international and national conference abstracts. The subsequent phases of this project are now the subject of a CLAHRC sponsored PhD, and will report in due course.

During the reporting period, the CLAHRC team have generated further externally funded activity, which is demonstrated in CLAHRC-associated studies: A Safer Ramadan, (education and self-management for safer observance of Ramadan); Treat for Ramadan (an RCT comparing the effectiveness of new therapies with traditional treatment regimens for patients wishing to fast); national implementation of Walking Away from Diabetes (patient education for those at risk of diabetes); service innovation in Northampton around local implementation of Walking Away from Diabetes).

Activity in the theme has spearheaded various initiatives around dissemination of research knowledge, skills and shared learning from specific projects both within and without LNR CLAHRC. Using resident expertise in national implementation, the Education and Self-Management Theme have supported implementation in diabetes prevention through early adoption of the Walking Away from Diabetes programme (see Prevention Theme). Other activity derived from the DESMOND Ongoing project is likely to facilitate capacity building initiatives for delivering structured education nationally.

Members of this Theme have continued to be active in influencing policy at all levels: The Theme leader, Prof Melanie Davies, is a member of the NICE Quality Standards for Diabetes Committee. She is also the clinical lead in the East Midlands SHA for quality standards, and has shaped the QIPP agenda for diabetes care both nationally and regionally. Other theme members have contributed to NHS working parties (on patient structured education) and on Department of Health initiatives to raise quality standards in patient education, such as the QISMET (Quality Institute for Self Management Education and Training).

In summary, the Theme has progressed core studies while taking opportunities to extend its work into related areas. It has secured substantial additional external funding, developed and put into practice dissemination strategies for shared learning, and has supported early implementation wherever possible.

DESMOND Foundation: A Randomised Controlled Trial of the DESMOND Foundation Programme for People With Established Type 2 Diabetes in a Multi-Ethnic Population in Leicester and South Birmingham

The Leicestershire, Northamptonshire and Rutland CLAHRC are collaborating with Birmingham and Black Country CLAHRC to establish whether a structured education module in diabetes with proven effectiveness in a white, newly diagnosed population can be modified for use in a multi-ethnic population with established diabetes (> 12 months < 10 years duration), to improve biomedical, lifestyle and psychological patient outcomes 6 and 12 months post intervention. This is a CLAHRC funded study.

The study is being conducted across two sites, Leicester City and South Birmingham involving approximately 8 practices from each site, and due to report in Summer 2012.

Studies and highlights

DESMOND Ongoing: To Test an Integrated Approach for Promoting Effective Self-Management in People With Established Type 2 Diabetes Mellitus (T2DM) – A Cluster Randomised Controlled Trial of the Ongoing DESMOND Education Programme

The DESMOND Ongoing Study is testing an integrated approach to diabetes care in which patients with Type 2 diabetes will be encouraged to work in partnership with their health care professionals. Practice nurses and GPs will be trained to consult in a way which values the patient's contribution and encourages them to participate in every aspect of their care. Patients will attend a rolling programme of education sessions during their 2 years in the study. This is a collaboration between LNR and SY (South Yorkshire) CLAHRCs, and is due to complete in Spring 2013. This is a core CLAHRC funded study.

DESMOND QD: Quality Development for Educators Delivering Structured Diabetes Education as Part of the DESMOND Programme

The aim of this study is to evaluate the current DESMOND Quality Development (QD) processes and produce a generic QD framework that provides a reliable and valid means of ensuring consistency between Educators and those assessing them. The developed QD process will provide the means of achieving a level of acceptable competency for the delivery of the programme. It is being conducted as part of a CLAHRC funded PhD, with the support of the DESMOND National Programme Team. This is a core CLAHRC funded study.

A Safer Ramadan: Group Education to Support Safer Fasting and Feasting for Those With Diabetes Who Wish To Observe the Holy Month of Ramadan

Although observance of Ramadan is one of the Pillars of Islam, there is currently no education package uniquely tailored to fit the needs of people with diabetes who wish to meet this particular religious obligation. Both fasting and feasting can have a negative impact on glucose control and many people with diabetes would benefit from changes in their medication to accommodate glucose excursions, both high and low. In future years Ramadan will fall in summer months with increased daylight hours and longer periods of fasting. Our current feasibility pilot will satisfy this potentially critical unmet need enabling individuals to have a greater understanding and choice whilst working more closely with healthcare professionals to safely manage their diabetes. It will be based on the DESMOND model of structured education, its philosophy and principles, combined with evidence-based research successfully conducted in Brent PCT. This is a CLAHRC-associated study.

Treat for Ramadan: A Randomised Controlled Trial for People With Established Type 2 Diabetes During Ramadan Liraglutide vs. A Sulphonylurea or Pioglitazone

This trial will investigate if Dual therapy with metformin and liraglutide is more effective at helping people with established type 2 diabetes mellitus (T2DM) observing Ramadan achieve a composite endpoint of weight maintenance, reduction/maintenance of HbA1c and elimination of severe hypoglycaemic events. This is an investigator-led, industry sponsored study. It is CLAHRC-associated.

STAND: An Intervention to Decrease Sedentary Behaviour In Young Adults At Risk of Type 2 Diabetes Mellitus: Project STAND (Sedentary Time and Diabetes)

The rising prevalence of obesity and sedentary behaviour has led to an epidemic of T2DM in the young. As the health and economic costs of T2DM in the young continue to increase, there is an urgent need for an effective lifestyle intervention to prevent the development of T2DM. Our proposed study will assess the effect of theory driven structured education, facilitated using automated technology, on sedentary behaviour and health outcomes in young people at risk of T2DM. This is a CLAHRC-associated study.

SUCCESS: Structured Education Programme to Improve Glucose Tolerance in Women With Polycystic Ovary Syndrome (SUCCESS Study)

The aim of this study is to develop and evaluate a cost effective structured education programme to target lifestyle modification in women with polycystic ovary syndrome from a multi ethnic population. The development of this will be based on the MRC framework for complex clinical interventions and using a mixed methodology of qualitative and quantitative research. This is a CLAHRC-associated study.

EXPEDITION: Early Detection Of Cardiac Dysfunction And Health Behaviours in the Young With Type 2 Diabetes Mellitus

This study aims to characterise health behaviours and beliefs and document early cardiovascular dysfunction in the young with type 2 diabetes (T2DM). This is a pilot study to extensively phenotype young people with T2DM. Biochemical markers and objective measures of metabolic and vascular dysfunction and measures of health behaviours and beliefs will be assessed. These data will be used to design an appropriate lifestyle intervention and early risk reduction and structured education programme. This is a CLAHRC-associated study.

PUCOSA: Predicating Usage of C-PAP in Obstructive Sleep Apnoea

Obstructive sleep apnoea (OSA) is a common, chronic disorder occurring in 2-4% of the middle-aged population in Western societies. OSA is characterized by sleep-induced partial and/or complete obstruction of the upper airway which results in recurrent hypoxemia and repetitive arousal from sleep, causing excessive daytime sleepiness and is associated with Type 2 Diabetes, cardiovascular disease and thus early mortality.

Continuous Positive Airway Pressure (CPAP) is the gold standard treatment for people with moderate-severe OSA. CPAP therapy has been found to improve cognitive function, reduce hypertension, reduce daytime sleepiness, and improve mood, emotional well being and insulin sensitivity. Despite this 29-83% of patients do not use their CPAP machines for as many hours a night as required to benefit the most from this treatment. The reason for poor patient compliance with CPAP therapy is not well understood.

We hypothesise that psycho-social factors play an important role in determining CPAP use. Therefore, our key aim is to identify the psycho-social predictors of CPAP use by a comprehensive assessment of these factors, and develop an education intervention to address them. This is a CLAHRC-associated study.

Walking Away from Diabetes: National Implementation

The DESMOND National Programme Team has already worked with a small number of early adopter PCTs to test the logistics of implementing the Walking Away from Diabetes Programme. They are now finalising arrangements to facilitate national implementation through the established infrastructure for delivering training, resources and support throughout the UK. This is a CLAHRC-associated study.

Walking Away from Diabetes in Northamptonshire

Through a regional innovation fund grant, the DESMOND National Programme team will be collaborating with NHS Northamptonshire and LNR CLAHRC colleagues in the Prevention Theme to train practice nurses in the county to deliver the Walking Away from Diabetes programme. This is a CLAHRC-associated study.

5. Rehabilitation Theme

The Rehabilitation Theme continues to conduct its novel and ambitious programme of applied research in the field of rehabilitation for patients with chronic cardiopulmonary diseases. The benefits of pulmonary and cardiac rehabilitation are well established and enshrined in national and international guidelines and service strategies. Our research philosophy has been to design and test tailored rehabilitation interventions that target difficult to reach patient groups and clinical settings where we believe rehabilitation will be effective but challenging to deliver.

The REACH and SPACE for COPD trials are recruiting participants and progressing well. During the year, we have been able to realise our plans to widen the scope of our projects in line with the Theme's overarching strategy to embrace both chronic respiratory and cardiac disease.

Operational steering groups have been established for all the trials to deal with day-to-day issues, reporting to an overarching Theme Steering Committee. Staff recruitment has continued during the year and we now have a full complement of research and managerial staff. The Clinical Trials Unit at the University of Leicester provides a randomisation and data management service for the REACH and SPACE for COPD trials, as well as supporting other CLAHRC trials.

An important element of the Theme's strategy is to run research seminars designed to promote and stimulate the development of applied research in cardiopulmonary rehabilitation. These seminars attract a

multi-professional audience from a wide range of healthcare and academic organisations in LNR. They provide a useful forum for meeting others with similar interests and for fostering a community of practice and building partnerships for future research. The programmes include brief presentations by investigators within the Rehabilitation Theme with plenty of time for discussion.

Now that the applied research programme is well established, we have started to develop an implementation plan. We envisage that implementation activities will increase during the second half of the CLAHRC funding period. Specific objectives of the implementation programme include:

- Implementation of the SPACE manual in four GP practices within the GP Commissioning Consortia in Northamptonshire.
- Implementation of “Activate your Heart” in Kettering and Northampton General Hospitals.
- Programme to assist partner Trusts in meeting CQUIN standards relating to unscheduled hospitalisation for patients with COPD.
- Development of a database tool to gather information on COPD management in primary care in collaboration with the prevention theme (IMPACT).

Information about Rehabilitation Theme Studies is set out below:

Can REhabilitation Delivered Immediately on Hospitalisation for an Acute Exacerbation of Chronic Respiratory Disease Improve Long Term Health Outcomes? (REACH Trial)

This study assesses whether early and proactive rehabilitation delivered immediately on hospitalisation for an acute exacerbation of chronic respiratory disease can prevent decline in physical function, improve clinical outcomes, and reduce the risk of subsequent hospitalisation. The primary outcome is all-cause unplanned admission rate at the end of the 12 month follow up period. Secondary outcomes include assessment of muscle strength, exercise performance, physical activity, markers of systemic and muscle inflammation, health status, anxiety and depression and health care utilisation. The study will report in March, 2013.

A Self-Management Programme for Chronic Obstructive Pulmonary Disease (COPD): Is it Effective in Primary Care? (SPACE for COPD Trial)

The study aims to evaluate the effectiveness of self-managed rehabilitation compared with usual GP care. It will also determine the acceptability of self-management in COPD. It will involve assessment of lung function, exercise capacity, information needs and health status in 184 patients. The primary outcome measure is the dyspnoea component of the Chronic Respiratory Disease Questionnaire at 6 months after introduction of a self-management manual compared to the usual care group. Secondary outcomes include information needs, physical activity and exercise performance. The study will report in March, 2013.

Activate Your Heart (www.activateyourheart.org.uk)

CLAHRC is developing and evaluating a secure, interactive web-based cardiac rehabilitation programme. Through this, patients can receive a tailored programme of cardiac rehabilitation with access to healthcare specialists through discussion forums, blogs and “Ask the Expert” sections. The project is being developed within the cardiac rehabilitation department at University Hospitals of Leicester. This project is expected to increase patient choice for cardiac rehabilitation and increase uptake of cardiac rehabilitation in East Midlands and nationally. The study will report in April, 2011.

Training for Healthcare Professionals to Deliver a Self-Management Manual (SPACE) for Patients with COPD

This project is developing an interactive web-based training and learning package for healthcare professionals to enable them to deliver the SPACE manual to patients with COPD. It complements the SPACE for COPD trial (described above). A face-to-face training programme for healthcare professionals is also being developed to outline physical activity strategies for the individual with COPD and identify the skills required to promote behaviour change. The project will assess the learning needs of users of the training package and evaluate its acceptability and effectiveness. The study will report in July, 2011.

Training initiatives

During the year, we launched an MRes in Research Translation, and a CLAHRC leadership fellow has

started the course. He is a respiratory medicine trainee, and is acquiring the skills to lead service design and implementation. An MSc in Diabetes also launched this year, and is heavily subscribed. It builds on our extensive expertise in this field. Our MRes in Applied Health Research continues, and remains popular among clinical and non-clinical staff. The number of PhD students has increased, and we continue to support the development of FY1, FY2 and ST2 doctors in various disciplines. A wide range of less formal training has also been provided (see the attached database).

Management arrangements

There have been no important changes to the management arrangements of the CLAHRC. However, Professors Fulop and Walshe have joined the Management Board, and now contribute high level management science expertise to our strategic thinking.

4. IMPACT ON HEALTHCARE PROVISION

Please provide descriptions of impacts/benefits to patients arising from work undertaken by the CLAHRC. You should provide examples of impacts that the Collaboration's work has had on health services or health policy, detailing how research findings have led to changes in the way services are delivered to patients, both locally and further afield.

Given the timelag associated with the translation of research findings into patient benefit, it is legitimate to include examples from previous work undertaken by the members of the CLAHRC in the relevant research area with support from DH/NIHR (eg via NHS R&D Support Funding), which made an impact in the past year, provided that the source of support is made clear:

There have been impacts at both local and national levels. These are summarised below.

1. Implementation Theme support for the implementation of NICE guidelines on obesity has improved the management of overweight and obese adults in local general practices by providing practices with information about referral opportunities for overweight patients. An educational package (an e-learning tool) for healthcare professionals has also been made available. Professor Baker is a member of NICE's Implementation Strategy group, and therefore has been able to keep NICE informed of lessons emerging from the CLAHRC's experience. This has included participation in a workshop hosted by the Implementation Strategy Group, interaction with NICE's regional implementation consultant, and with local NICE scholars.
2. The Walking Away for Diabetes programme is being implemented in seven regions in the UK and Ireland as part of usual care. The initiative has had a major impact on patient care and usual health care practice in these regions. Furthermore, several investigators from the project are currently involved in drafting NICE guidance around the prevention of diabetes in high risk population.
3. The CLAHRC has supported further development of the Leicester Self-Assessment risk score (originally funded by Diabetes UK). This has had a significant impact on the numbers of people assessing their risk of diabetes and more than 75,000 people have, so far, taken the on-line self-assessment test. An agreement has also been reached with Sandwell PCT, part of Birmingham and the Black Country CLAHRC, to use the risk score in their activities.
4. The *Quality Development for Educators Delivering Structured Self-Management Education for Diabetes* project has provided training to more than 800 people in 105 primary healthcare organisations around the UK and Ireland. This is an ongoing process, with additional training sessions held every month. The project has supported more robust assessment of educators, and has increased the level of consistency between assessors and assessments.
5. The Education and Self-Management Theme leader, Professor Melanie Davies, is a member of the NICE Quality Standards for Diabetes Committee. She is also the clinical lead in the East

Midlands SHA for quality standards, and has shaped the QIPP agenda for diabetes care both nationally and regionally.

6. The *Masters in Diabetes Care*, developed and led by CLAHRC-funded staff members, has recruited over 100 primary care clinicians (mainly GPs and practice nurses) to undertake modular study, leading to Masters degree. The modules on insulin management and new and advanced therapies in diabetes have been the most popular modules. This up-skilling of primary care practitioners will contribute to improved patient care in both the short and long term.
7. There have been a number of changes to the rehabilitation service informed by research led by members of the Rehabilitation Theme. For example a reduction to a four week rehabilitation programme for some patients (see 'A randomised controlled trial of four weeks versus seven weeks of pulmonary rehabilitation in chronic obstructive pulmonary disease. Green RH, Singh SJ, Williams J, Morgan MD. *Thorax*. 2001 Feb;56(2):143-5.')
8. Professors Mike Morgan and Sally Singh have been heavily involved in national and international guidelines and the national clinical strategy for COPD as follows:
 - COPD Outcome Strategy and Department of Health Commissioning Framework for COPD (due for publication in March 2011) (Mike Morgan and Sally Singh)
 - American Thoracic Society committee to examine integrated care in chronic respiratory disease
 - Input into the revised British Thoracic Society guidelines for pulmonary rehabilitation (in development)
 - Membership of the American Thoracic Society Pulmonary Rehabilitation Program Committee (Mike Morgan)
 - Joint Chair American Thoracic Society/European Respiratory Society Pulmonary Rehabilitation guidelines (Sally Singh)
 - Joint Chair for Nutrition in COPD guidelines (Sally Singh)
 - NICE Commissioning Committee for COPD (Sally Singh)
 - Chair of the European Respiratory Society Committee on Rehabilitation in Long Term Chronic Disease (Sally Singh)
 - Department of Health Commissioning Guidelines for Cardiac Rehabilitation (Sally Singh)
 - Chartered Society of Physiotherapists R&D Committee (Sally Singh)
9. All patients participating in the *Activate Your Heart* cardiac rehabilitation programme are asked to provide feedback. Comments about the programme include:

"Helped me in understanding the importance in reducing risk, having a healthy diet and the importance of regular exercise."

"A pity all this good information is password protected & not widely available."

"Focuses you on what you should be doing with regards to exercise."

"Really enjoyed the programme, found it easy to access."

"Lots of useful information."

"Found information useful and things I thought I knew I didn't."

"Brilliant for work circumstances and travelling."

Importantly, ten out of fifteen patients who completed the web-based cardiac rehabilitation programme said they would not have attended traditional rehabilitation. This supports the view that the website widens access to, and improves the uptake of, cardiac rehabilitation and thereby reduces the risk of subsequent cardiac events and hospitalisation.

5. PATIENT AND PUBLIC INVOLVEMENT

Please provide specific examples of how patients and the public have been actively involved in the work of your CLAHRC (e.g. in informing or developing strategy, identifying research priorities, involvement in the research process itself), detailing the nature of their contribution and the impact this has made.

CLAHRC for LNR works closely with a number of existing groups representing the interests of patients and the public, both in the strategic management of the CLAHRC programme and in the design and delivery of CLAHRC studies. Examples of relationships include with Local Involvement Networks (LiNKs) in Northamptonshire, Leicester and Leicestershire; the Breath Easy Group (a patient network for people with chronic respiratory disease); the UK Diabetes Research Network Advocacy and PPI groups; and, also within diabetes, local patient representative focus groups in Leicestershire and in Northamptonshire.

The CLAHRC has pledged to engage patients and the public in all of its work streams and structures. To reinforce this, the CLAHRC has endorsed the following commitments:

- Project and/or theme steering groups have a member (Patient and Public Involvement Champion) whose primary remit is to help to protect participant safety and ensure that public and patient perspectives inform the design, delivery and dissemination of activities;
- Meetings and associated papers avoid unexplained acronyms and jargon;
- Meetings have clear terms of reference and appropriate methods for encouraging and supporting contributions from lay members;
- Meetings involving patients and lay representatives are held at accessible times and in accessible locations;
- Patients and lay members of groups and committees are:
 - provided with a clear role description which will be regularly reviewed
 - provided with profiles of other members
 - assigned an academic or clinical mentor to support their full and active participation and be available to answer questions and address and issues or concerns
 - provided with training and other appropriate support to ensure that they can effectively contribute to all groups and committees
 - treated as full members of the group and their views and opinions given full deliberation
 - receive reimbursement for all reasonable expenses incurred
- Study participants and lay members of groups and committees are provided with information about the outcomes and impacts of research of which they are a part;
- Patient and Public Involvement in projects and other activities is documented and particular note is taken when decisions or activities are modified because of this engagement.

The CLAHRC is also committed to working with other groups, networks and organisations to support and to share good practice in patient and public involvement in research. To enable this, the CLAHRC has been instrumental in the launch of a region-wide forum (LNR Research Engaging Patients and the Public), with lay membership and representation from NHS organisations, LiNKs, UKCRN research networks, local government, universities, charities and voluntary organisations. Objectives of the forum are to:

- Raise awareness of the importance, relevance and impact of Patient and Public Involvement in research in the LNR research community and other stakeholders, including patients and carers
- Encourage LNR health care and academic groups, networks and organisations to embed meaningful and effective Patient and Public Involvement in all aspects of their research
- Develop, promote and support and share methods to encourage the widest possible level of Patient and Public Involvement in the LNR research community
- Work in partnership with research based Patient and Public Involvement initiatives in LNR to enhance sharing of knowledge and experience
- Engage with patient representative groups within LNR to encourage and facilitate the engagement of their members in the design, delivery and dissemination of LNR research projects
- Develop, deliver and signpost people to educational material and courses focusing on Patient and Public Involvement in research aimed at the LNR research community and patients and the public.

With CLAHRC support, the LNR Research Engaging Patients and the Public Forum is holding Patient and Public Involvement focused training days for healthcare researchers, providing support and training on the stages of involvement in studies and the importance of ensuring that involvement is active at all those stages.

A project recently launched in the Implementation Theme involves user-led research into the acceptability and utility of a patient involvement centre in one of our partner mental health Trusts.

Most project steering groups have service user representation. Where this is not possible, Patient and Public Involvement champions are appointed to safeguard the interests of service users and to maximise opportunities for patient and lay involvement in study design, conduct and dissemination. For example, the Walking Away study, and its predecessor PREPARE, were developed with extensive input from service users, involving members of the public identified with a high risk of type 2 diabetes. This input informed

both the content and structure of the programme and ensured the programme met the needs of those attending and delivering it.

The Education and Self-Management Theme supports the South East Midlands Diabetes Research Network Patient and Public Involvement Group, with whom CLAHRC researchers have a relationship that pre-dates CLARHC. This group are consulted as a matter of routine on all studies, both to inform them as interested stakeholders, and to canvass their opinions on general and specific issues.

The Education and Self-Management Theme also has representation from a second Patient and Public Involvement group, hosted at Northampton General Hospital under the leadership of Dr Charles Fox. This has contributed to the Theme's work, both by responding to general consultation and by contributing at Theme meetings. The group are currently developing a project looking at patient preferences and responses to completing questionnaires.

Patients in Leicestershire, Sheffield, and Rotherham have worked with trainers during the service development phase of the *DESMOND Ongoing* study to develop the structured education programme. People with diabetes have participated in education sessions, given feedback on content and learning activities and given their opinions on the structure of the programmes. This feedback has been directly responsible for revisions, additions and other amendments to the curriculum, and has allowed the team to choose and develop more appropriate resources to support the programme's learning goals. Participants have commented on the logistics and other practical aspects of courses (e.g. length and frequency of sessions, choice of venues, timings). They have also expressed their needs, expectations and wishes in relation to follow-up care from primary care doctors and practice nurses. This information has been used to inform key aspects of practice staff training programmes. Where participants have expressed a wish to continue to be involved in the programme, we are planning to develop opportunities for them as patient champions to help disseminate not only to other patients, but to GP practices, commissioners, and other relevant parties in the new NHS structure. The Theme is planning to establish a *DESMOND* 'graduate' patient reference group in conjunction with the *DESMOND* National Programme to enable participants to help us develop our current and new resources. We hope this group will eventually act as patient champions for structured education in the region in the long term.

Much of our PPI activity within the Rehabilitation Theme has been obtained from a pool of dedicated volunteers and Breathe Easy Group Members (British Lung Foundation self-help group). More recently, it has been agreed that even stronger patient and public involvement might be achieved through the establishment of a dedicated Patient and Public Involvement Advisory Panel. The aims of this will be to

- Support formal, permanent and diverse representation of patients and public who use the Cardiac and Pulmonary Rehabilitation department services or participate in Cardiac and Pulmonary Rehabilitation research.
- Advise on the topic choice, design, conduct and dissemination of high quality research.
- Advise on improving clinical provision within the Cardiac and Pulmonary Rehabilitation Services and in the development of future services.

Please also describe how you keep patients and the public informed of the work being undertaken by your CLAHRC.

The local population are kept informed of activities and outputs of the CLAHRC by a (i) a regularly updated website, (ii) a quarterly newsletter – *the SPARK*, (iii) regular email bulletins, and (iv) events and presentations from CLAHRC themes. CLAHRC also makes good use of newsletters, websites, events and other communication channels hosted by local organisations. For example, the Prevention Theme uses the Nene Commissioning newsletter to update patients and the public on progress with its research activities and outputs. Members of the CLAHRC regularly attend patient group meetings organised by local trusts or branches of national charities, such as Diabetes UK, to discuss and update the community on our research activity. Work is also underway to liaise with local NHS Trusts to contact their members to inform them of CLAHRC activities and seek to recruit them into CLAHRC studies and, where appropriate, project steering groups.

In 2009 and 2010, CLARHC researchers and Patient and Public Involvement group members joined forces to raise awareness of the public about diabetes and CLARHC studies as part of World Diabetes Day activities. In 2010, the group hosted a stand at major local shopping centre which was well supported by members of the public.

Health Education Reaching Out (HERO)

The HERO initiative aims to educate and inspire people to take responsibility for their own health, diet and well-being. Health Educating Reaching Out (HERO) is made up of a series of different areas:

- a) The HERO schools project
- b) Links with local charities including HOPE Against Cancer
- c) University open days for prospective students and the wider public
- d) Other community outreach events promoting healthy living such as a drugs and alcohol education workshop for students with special educational needs
- e) MY DIET (Macmillan working with Your Dietary needs to Improve Education on prevention of Tumours) is a collaboration between Genetics Education Networking for Innovation and Excellence (GENIE) at the University of Leicester, HERO, Macmillan and the Clinical Genetics department at the Leicester Royal Infirmary. It involves interactive educational workshops for patients and their families to discuss how they can reduce familial cancer susceptibility

In December 2009, HERO ran an *Interactive Healthy Living Event* for 150 13-14 year old school pupils from four Leicestershire County Council schools (Roundhill Community College, Thurmaston; Humphrey Perkins High School, Barrow Upon Soar; St. Martin's Catholic School, Stoke Golding; and Market Bosworth High School). The event comprised interactive and hand-on activities about healthy eating, exercise and smoking. The pupils filled in 'passport' style worksheets to take away. The event was evaluated using qualitative questionnaires and feedback from participants and their teachers.

In March 2010, a *Cancer Awareness and Healthy Living Evening* was held for 35 members of the public and sixth form students at the University of Leicester (in collaboration with Hope Against Cancer). As part of National Science and Engineering Week, members of the public and sixth form students from local schools and colleges were invited to increase their cancer awareness. The public were involved via the university website, posters around the university, through Hope Against Cancer and through the Sharma Centre (Asian women's centre). The evening event included talks and hands-on activities using exercise equipment, activity cards and laboratory equipment to:

- Learn what cancer is and how it starts
- Discover the connection between DNA and cancer
- See what a cancer cell looks like
- Find out how scientists are finding drugs to fight cancer
- Discover how your diet can affect your risk of cancer
- Ask a doctor and a dietician questions
- Learn about physical fitness and cancer risk

The event was evaluated using pre- and post-event questionnaires about the participants' perceptions of and experiences of cancer.

In May and June 2010, MY DIET (Macmillan working with Your Dietary needs to Improve Education on prevention of Tumours) events were held for adult cancer patients and family members. MY DIET is a collaboration between CLAHRC HERO, Macmillan and the Clinical Genetics Department at the Leicester Royal Infirmary. The events provide opportunities for cancer patients to attend an interactive educational workshop with their families to discuss how they can reduce familial cancer susceptibility. The workshops involve short presentations on the link between what we eat and cancer development, followed by a general question-and-answer session. They also provide the opportunity for one-to-one counselling with a dietician. Interactive hands-on activities and demonstrations using exercise equipment, card activities and displays are used to help participants understand how food and exercise can affect cancer susceptibility. The events are evaluated using pre- and post-event questionnaires to assess participants' perceptions and experiences of cancer and appreciation of the event.

In June 2010, HERO delivered hands-on healthy eating activities using exercise bikes and food displays as part of the University of Leicester 'Focus on Medicine' open day attended by 3000 potential degree course students and parents.

In September 2010, HERO delivered training to ten university students and researchers on delivering healthy living activities to school children.

Also in September 2010, 'HERO Health Lab' interactive healthy living activities were delivered to 624 13-14 year old school pupils as part of the Genetics outreach event 'Dynamic DNA'. Students learnt about the link between their genes and their lifestyle and how to reduce their risk of future chronic diseases such as diabetes, heart disease and cancer by making lifestyle changes now. Hands-on activities included using laboratory equipment to weigh out the sugar and fat found in their choices of snacks; pulse-measuring watches; and an interactive computer-based activity to help students to think about their own diet and lifestyle and about a healthier future. The event was evaluated through pupil and teacher feedback questionnaires.

6. LINKS WITH NIHR INFRASTRUCTURE

Please outline any progress in engaging with other NIHR Infrastructure funded organisations (CLAHRC, Biomedical Research Centres and Units, Clinical Research Networks etc) describing any significant successes and/or any challenges faced during the second award year. Please also outline any strategic plans for increasing engagement with other elements of the NIHR Infrastructure:

We have good links with the Leicester Cardiovascular Biomedical Research Unit, and are developing plans for collaborative projects. We also work closely with colleagues in the *Comprehensive Local Research Network* (CLRN) on issues of ethics and governance, and frequently access their expertise in patient recruitment. Theme researchers access many of the CLRN's training and education courses and networking activities. Professor Baker is a member of INVOLVE, and has promoted links between INVOLVE and the CLARHCs.

The Education and Self-Management Theme works closely with the *South East Midlands Diabetes Research Network* with support for studies and a number of shared study personnel. It also has well established links with the *NIHR Research Design Service for the East Midlands* and with the *East Midlands and South Yorkshire Primary Care Research Network*. Opportunities for collaborations with the *Leicester Cardiovascular Biomedical Research Unit* are currently being explored.

The Education and Self-Management Theme hosts two large projects in collaboration with other CLAHRCs: the DESMOND Foundation Study with *Birmingham and Black Country CLAHRC*; and the DESMOND Ongoing Study with *South Yorkshire CLAHRC*. We hold joint investigator meetings on a regular basis, and researchers have established robust communication strategies for ensuring the smooth day-to-day running of the studies.

External advisors now include Professor Naomi Fulop, Director of the NIHR King's Centre for Patient Safety and Quality Research, and Professor Kieran Walshe, Director of the NIHR Service Delivery and Organisation (SDO) research programme. Both Professor Fulop and Professor Walshe have expertise in management science and the social processes involved in translating research evidence into practice.

Members of the Prevention Theme are building relationships with the *NIHR CLAHRC for Greater Manchester* renal team to share learning in chronic kidney disease (CKD). There has been considerable interest in our CKD data extraction and audit tool which we hope will be implemented in the Manchester area.

The Early Detection Theme has excellent links with both the *Diabetes and Stroke Research Networks*. The *Diabetes Research Network* has provided support to the SWEETHeart study through advice on staff recruitment and use of Diabetes Specialist Nurses to support patient recruitment. Two Early Detection Theme Research Nurses are joint posts with the *Stroke Research Network* and the Network has provided practical support in staff recruitment and training. An agreement has been reached with Sandwell Primary Care Trust, part of *Birmingham and the Black Country CLAHRC*, to use the risk score in their activities. The Theme has also received support from the *Primary Care Research Network* and *Comprehensive Local Research Network* in relation to primary care recruitment and approval processes.

The Rehabilitation Theme has received support from the *Primary Care Research Network for East Midlands and South Yorkshire* to recruit general practices in Leicester and Leicestershire for the SPACE for COPD trial.

7. LINKS WITH INDUSTRY

Please outline progress of your CLAHRC in engaging with industry (pharma, biotech and devices) describing any significant successes and/or any challenges faced during the

second award year. Please also outline any strategic plans for increasing engagement with industry:

The CLAHRC has developed links with several commercial agencies, including pharmaceutical and biotech companies and providers.

1. Following a meeting between the CLAHRC and representatives of the Association of the British Pharmaceutical Industry (ABPI), four pharmaceutical and biotechnology companies have expressed interest in collaboration: NAPP pharmaceuticals are in discussion with CLAHRC members around pain care pathways and in particular the use of opiates for the management of long term pain. Merck Pharmaceuticals, Amgen UK and Bristol-Myers Squibb have shown an interest in our CKD work in primary care. The effective use of endogenous erythropoietin (EPO) and ACE-I/angiotensin receptor blockers (ARB) for the treatment of CKD have been identified as an area needing further evidence in primary care.
2. The Walking Away from Type-2 Diabetes team have worked closely with GE Healthcare and have secured the installation of a state of the art dual-emission X-ray absorptiometry machine for use in the study. This study is also supported Impeto Medical (£51,000).
3. As evidenced by industry grants and 'support in kind', the Education and Self -Management Theme has established mutually beneficial links with a number of industry partners. These relationships are also facilitating wider dissemination, particularly internationally, of CLAHRC achievements, alongside conference presentations and attendance. The Theme are working with Novo Nordisk to promote DESMOND structured education to a wider international audience with a grant of £13,000 and will be continuing the partnership with Unilever, which provides technological support to a variety of projects across CLAHRC Themes (valued at approximately £157,000).
4. The Early Detection Theme also has good relationships with industry. Merck, Sharpe and Dohme have provided equipment and training worth an estimated £75,000. This additional funding has allowed the PRISM study to be adopted on the CRN portfolio and so gain Diabetes Research Network and Primary Care Research Network support. The study examining the use of Dynamic Plaque Indices to Predict Risk in (A)symptomatic Carotid Artery Stenosis has received £90,000 of additional funding through a discount on a sophisticated ultrasound scanner.
5. The CLAHRC Rehabilitation Theme leads have been involved with the proposed MRC/ABPI COPD consortium (funding confirmed Jan 2011). This national consortium will support collaborative research between academic and pharmaceutical sectors with the overarching aim of facilitating successful drug development for COPD. Dr Steiner is co-lead for work-package 4 which will support the development of therapeutic targets to treat skeletal muscle dysfunction and other systemic manifestations of COPD. The funding is due to start March/April 2011. Biological material (blood and skeletal muscle samples) arising from CLAHRC supported studies within the theme (REACH trial and NMES study) will be made available to the consortium (subject to appropriate release and IP agreements).
6. The Implementation and Prevention Themes have developed links with The Practice PLC, a national healthcare provider that runs around 50 general practices and other facilities in England. The relationship enables a dialogue on new ways to deliver efficient care and on how use of research can help improve service delivery decisions. The Practice PLC has funded protected time for a GP as research fellow to work with the CLAHRC, for example on initiatives to improve management of people with chronic kidney disease or the detection of people with hypertension.

8. FORWARD LOOK

Please identify any significant developments (eg major research findings or planned initiatives) anticipated in the coming year, particularly those that are likely to generate media interest:

It is a busy and exciting time for NIHR CLAHRC for LNR. Following the recent external review, we have developed plans for launching revised strategies for increasing the absorptive capacity of our local Trusts.

These include training and education activities focused on obtaining and applying research evidence, dissemination of evidence summaries, and improved systems of communication. We are increasingly drawing on social science models of knowledge utilisation, and aim to build on the networks established by our applied themes to create communities of practice enabling better spread of evidence and innovation.

Coincidental with these developments, commissioning consortia are being established locally. We see re-vitalised commissioning as an important opportunity to improve the use of research evidence in decisions about the provision of services and of their configuration. We are already developing links with commissioning consortia, and aim to deepen these in the coming months.

Furthermore, implementation will be increasingly addressed by the Applied Themes. For example, the Rehabilitation Theme will be forming an implementation group to focus on knowledge management, communication, engagement, evidence synthesis and dissemination. An Implementation Manager will be appointed to develop and facilitate effective links between clinical, academic and commissioning colleagues in LNR. Of critical importance will be their ability to work collaboratively with the Implementation Theme and CLAHRC Co-ordinators. Specific Rehabilitation Theme implementation activities will focus on:

- The incorporating the SPACE manual for the management of patients with COPD in a primary care cluster within the Nene Commissioning Group
- Implementing "Activate your Heart", a web-based cardiac rehabilitation programme within partner acute trusts
- Participating in a programme to assist partner trusts meeting CQUIN standards relating to unscheduled hospitalisation for patients with COPD.

New educational programmes will be launched to support research design, finding and appraising evidence and getting research into practice. New posts - a Knowledge Manager and a Research Capacity Development Lead - are being appointed to support these activities.

Research activity will also progress and it is expected that the Early Detection Theme will appoint support personnel and begin to recruit participants to four studies.

The Education and Self-Management Theme plan to:

- Share learning from the Safer Ramadan project at the International Diabetes Federation Congress in Dubai in December 2011;
- Host a visit by a team from the Steno Centre for Education in March 2011, with a view to establishing Anglo-Danish collaboration;
- Provide support for the *Leicester Centre for Ethnic Health Research*, which will in turn provide an excellent opportunity for patient and public involvement from ethnic communities;
- Develop training for lay people as part of a new initiative, following the conclusion of the Diabetes UK funded study on this topic.

The national implementation of Walking Away from Type-2 Diabetes will take place during 2011, with local providers already booking training places.

The Rehabilitation Theme plan to launch three new projects in year three:

- The Early Rehabilitation after Hospitalisation for an Acute Exacerbation of Chronic Heart Failure: A Randomised Controlled Trial will determine the effectiveness of an early rehabilitation intervention in improving exercise capacity and health status compared with usual standard care.
- A Study to Explore Patients' Perceptions Following an Acute Exacerbation of COPD will explore illness perceptions after exacerbation of COPD in order to help to promote behaviour change (increased physical activity and attendance to pulmonary rehabilitation).
- The effects of neuromuscular electrical (NMES) stimulation on quadriceps in COPD will study the effects of NMES and voluntary resistance training on COPD patients lower limbs.

This form, together with a completed *Activity & Outputs* proforma and a publication list for the second award year, must be submitted, *via* the NIHR Portal, no later than **5:00pm on Monday 7th March, 2011**.

A signed copy of the entire Progress Report (*ie* both completed proforma) should be sent, as soon as possible after this date (**and no later than Wednesday 16th March, 2010**), to:

Dr Julian Hughes

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