

COLLABORATIONS FOR LEADERSHIP IN APPLIED HEALTH AND CARE SPECIFIC THEME - DETAILS

Note: The accompanying “Collaborations for Leadership in Applied Health Research and Care Invitation to Submit Application” contains essential guidance on the information you need to provide when completing this form.

Please use this form to provide details on one of the specific Research, Implementation or Mixed Themes to be conducted with the funding provided through this scheme. **If the Theme contains a mix of research and implementation, all sections need to be completed within the page limit.**

Please use a separate form for each Theme. Please complete no more than five pages for each Theme; only information submitted up to this page limit can be assessed.

Please note this should be completed in a font no smaller than 10-point Arial and margins should not be adjusted.

Host Organisation

1.1 Name of proposed Host Organisation (NHS Trust or Provider of NHS services)

Liverpool Clinical Commissioning Group

Theme – to be completed for all Themes

2.1 Name of Theme

Long term conditions: Addressing Complex Needs

2.2 Percentage of Research and Implementation

Research:	60 %
Implementation:	40 %

2.3 The specific short (1-2 years), medium (2-3 years) and long term (4-5 years) aims and objectives of the Theme:

The **overall aim** of this theme is to implement a step change in the delivery of care for people with complex needs arising from long term conditions (LTCs); resulting in services that are more person centred, cost effective and improve quality of life and ability to undertake gainful employment. This will be achieved through collaboration across the NW AHSN footprint, undertaking research that utilises quantitative, qualitative and health economic research methods to inform best commissioning and optimal services .

Objectives:

Short (1-2 years)

- Identify the patient’s journey, experience, expectations, preferences and shortfalls in holistic care of young people with epilepsy & juvenile idiopathic arthritis (JIA) transferring from paediatric to adult care
- Develop measures to assess outcomes associated with routine care in long term neurological and musculoskeletal conditions
- Determine unmet transition needs in chronic disease management in community & secondary settings

- Determine patient preferences and experience of secondary care and community based adult services.
- Complete a systematic review of the prevalence and current management strategies for co-morbidities in epilepsy and rheumatoid arthritis.
- Determine the efficacy of training for clinicians in enhancing quality of fit notes for people with LTCs

Medium (2-3 years)

- Develop informed, evidence-based, integrated, holistic patient-centred management pathways of transition from paediatric to adult services including primary and secondary settings for epilepsy and JIA
- Pilot & evaluate (healthcare provider and patient perspectives), new models of equitable & effective provision of transitional care for young people with epilepsy and JIA between paediatric & adult settings
- Implement and evaluate (including patient perspectives) interventions empowering young adults with complex needs to acquire key skills in maintaining work ability, integration and productivity.
- Develop new risk stratification Health as a Resource for Living (HARL) tool with patient involvement
- Identify current burden associated with comorbidities through analysis of routine data sources (eg HES) and develop measures to assess key and relevant outcomes of routine care
- Pilot patient held health passport/care pathway for comorbidity management in LTCs.
- Initiate 4 new projects within the theme

Long term (4-5 years)

- Develop informed, evidence based, integrated, holistic patient management pathways for transition of young adults to adult care across an extended range of conditions across the NWC AHSN
- Establish evidence based person-centred services nearer home for patients with LTCs
- Implement health passport/ care pathway for co-morbidity in standard care across the NWC AHSN.

2.4 The strategy for the Theme, providing a description of how the aims and objectives will be achieved:

Initially the theme focuses on epilepsy and JIA/RA as exemplar LTCs that may run throughout life and which are associated with the development of complex physical, psychological and social needs arising from the diseases themselves or as a consequence of therapy. Both conditions have a serious negative impact on health and quality of life, need long term therapy with a variety of medicines each with many potential major side effects, and require care to be delivered between hospitals and the community. Lessons learnt about the organisation and delivery of services for these conditions will directly inform changes needed in service delivery for other complex neurological and rheumatological LTCs that will then be addressed.

The broad strategy is to: 1) Identify complex needs that require service assessment, redesign and implementation and assessment of new service structure or elements thereof; 2) Undertake systematic review and evidence synthesis as required to inform service change; 3) Use mixed methods approaches (qualitative and quantitative) to assess existing services and develop metrics with which to monitor changes using routinely available data wherever possible; 4) Work with all key stakeholders to reconfigure services; 5) Implement new or changed services and assess using mixed methods; 6) Feedback results to stakeholders and roll out successful models into routine care within the NWC AHSN;

The four projects that have synergy with each other and complement the other work streams in this CLAHRC application (Health Inequalities, Delivering Personalised Care, and Evidence Synthesis) have been chosen to be pursued in the first two years of funding.

2.5 A brief description of proposed projects that will be pursued within the first two years of the contract:

Each project will commence during the first 2 years with milestones by that time that will inform their further development and implementation during years 3-5. In the early phases we will identify key measurable indicators of outcome (including patient-reported) that can be measured, which will be used to assess whether implemented changes make a useful difference. Some outcomes are easier to define (e.g. admissions or attendances), but others will require effort from the collaborators to find markers that reflect both patient expectation and health service efficiency.

1) Transition care for young adults with long term condition. Transition from paediatric to adult care poses many challenges, as the ethos of adult and paediatric services differ, the teams are usually separate and often based on different sites. Young people with complex problems often require transition from, and to, a multiplicity of different services. As a result, transition between services causes significant anxiety amongst patients and their families and, if not coordinated correctly, can result in harm. This project will build on recent "Alder Hey Research into Transition" (ART) projects including the "Knowledge of Epilepsy at Transition" study. These include mapping exercises of general transitional care resources & structures across specialties and resilience and knowledge transfer determinants. Focusing further, this project will initially determine perspectives from professionals, young people with epilepsy & JIA, their carers, primary and secondary care clinicians, NHS managers, commissioners and other stakeholders. Particular

consideration will be given to the contrasting demographics, geography and wealth of the population of the NWC, together with the provision of health care that varies from that delivered in an internationally renowned children's hospital to community care-based provision in other parts of the region. From this we will derive a comprehensive understanding of the structural systems facilitating (or not) transition, identify strengths and weaknesses between existing specialty models, and obtain a rich narrative of the experience of families and healthcare professional perspective. In parallel, a systematic review of complex transition services will be undertaken. Results will be fed back to clinicians, patient representatives, managers and commissioners tasked with recommending how services should be changed. Subsequently an optimal system approach will be developed using the findings of the structural & qualitative studies and systematic review. Changes will then be implemented and re-assessed, including outcomes and cost. Findings will then be fed back, enabling further service changes as appropriate and implementation across the NWC AHSN.

2) Optimal Provision of Specialist Care in the Community. The National Service Framework for LTCs identified the need for services to be provided closer to where patients live, yet many people with LTCs still receive much of their care in secondary care, which may be costly and inconvenient for patients who may have mobility problems or be unable to drive. Also, when flares of LTCs occur, it may be difficult to re-access services, resulting in expensive admissions in secondary care. The focus in this project will be on services for people with MSK or neurological diseases. Whilst some community based services are available, such as musculoskeletal clinical assessment services, neurology clinics, GPs with a special interest, community based epilepsy nurses, services are poorly coordinated and patchy across the region. We will use qualitative methods and linkage of routine data sources from primary and secondary care to develop measures of outcome of routine care, describe baseline demand, activity and outcome (at the level of CCGs, hospitals and/or general practices) and assess variation according to geography, case-mix and other factors and assess temporal trends. Mirroring project 1, a mixed methods approach will be used to assess stakeholders' experience and view of existing services and a systematic review undertaken. Results will be fed back to clinicians, stakeholders and commissioners, tasked with recommending how services should be changed. Changes to services will be implemented and assessed again, including assessment of outcomes and cost. Findings will then be fed back to enable further service changes as appropriate.

3) Maximising Work Productivity in Complex Needs. Patients with LTCs often experience long periods of unemployment and find it difficult to return to paid employment. This project will commence with an evaluation of the impact of providing enhanced training to primary and secondary care clinicians on completion of fit notes (utilising CHAWKT website and RCGP programme resources). In parallel we shall: (1) Develop an intervention to support patients with inflammatory arthritis (IA) in self-managing issues around their work capacity and productivity. This will focus on practical issues regarding self-management in work-place settings and around knowledge and skills for negotiating with employers. The aim is to develop an intervention which could be embedded within existing programmes to support self management of IA delivered by multidisciplinary teams in the NHS. The initial phase will involve working with patients and health professionals across the NWC to shape the intervention, using mixed methods approaches and building upon our work to identify barriers to work in people with inflammatory arthritis. This will identify key issues and inform the generic content of the intervention, as well as identifying the feasibility for personalised approaches within the overall framework. The next phase will be to undertake an evaluation of the utility and efficacy of the intervention from patient and health professional perspectives, using a mixed methods approach. (2) Extend the scope of the Work Foundation's existing partnerships with large companies to develop exemplars of employer led-schemes for supporting work capacity and productivity for people with IA.

4) Co-morbidity in complex Diseases. People with LTCs, often have co-morbid conditions whether due to underlying disease, drug treatment or the psychological consequences of having a chronic illness. Both exemplar LTCs, RA and epilepsy, are associated with depression and anxiety, cardiovascular disease, and osteoporosis (the latter largely due to drug treatment). Co-morbidity is well studied in older people but, unlike heart failure or COPD, epilepsy and inflammatory arthritis affect patients of all ages and the potential gains from managing co morbidity well here, are greater. The organisation of care for people of working age is far from clear - what is the responsibility of the specialist vs the GP? When and where should services be available? What is the balance between being reactive to patient demands and being proactive? How does patient reticence to ask impact on a) service use and b) their disease? As a consequence of inadequate coordination of care, preventative or therapeutic opportunities are being missed. This project will focus on patients with RA or epilepsy, with similar design to 1 and 2 (above). Linkage of routine data sources from primary and secondary care will be used to develop metrics, baseline demand and activity for co-morbid conditions, and identify sources of variation. Evidence synthesis will be undertaken to identify detection paradigms and management strategies for co-morbidities associated with these conditions. Mixed methods approaches will be used to assess stakeholders views and experience of services. Results will be fed back to clinicians, stakeholders and commissioners who will be tasked to devise strategies to implement. Services will then be reassessed using a mixed methods approach, including assessment of outcomes and

cost and findings fed back to enable further changes as appropriate and roll out in the NWC AHSN.

2.6 The Theme's relevance to the health of patients and the public:

LTCs affect people from childhood through to old age and are a major problem to both patients and the public. The NHS currently spends up to 70% of total budget on LTCs and their effect on the UK economy as a whole is vast. Many affected people are unable to work and require either early retirement or benefit supports. They result in complex needs through an intricate interplay between disease, its treatment and co-morbidities. Care for LTCs is further complicated as it often spans many clinical disciplines, primary, secondary and social care. Because there is a substantial lack of understanding of how this links to the way care is organised across disciplines and sectors, commissioning has been uneven resulting in inequalities of provision and outcomes skewed dramatically across the country. Understanding what matters, setting up systems to get it right first time, and importantly creating new and better informatics with which to measure and monitor that provision should improve both population health and use the budget better.

2.7 The proposed Theme Leader:

Professor Anthony Marson

2.8 Three examples over the last ten-year period from the proposed NIHR CLAHRC of how previous research findings in this area have translated into improved outcomes for patients and the NHS:

- 1) The NIHR HTA SANAD trial compared standard and new antiepileptic drugs. lamotrigine (focal epilepsy) and valproate (generalised epilepsy) were identified as firstline treatments, underpinning NICE guidance.
- 2) The Liverpool-Manchester neurodevelopment group (NIH USA) assessed cognitive outcomes of in utero exposure to antiepileptic drugs. Results changed labelling of sodium valproate and underpin NICE guidance
- 3) Our work identifying that rheumatoid arthritis is a major risk factor for cardiovascular disease (CVD) has led to major changes in CVD risk calculation in primary and secondary care in the UK and internationally.

For Themes containing proposed applied health research

Research Theme Section – for research or mixed model Themes
Please leave blank if implementation-only Theme

3.1 Please describe the proposed applied health research to be undertaken within the Theme using NIHR funding and where appropriate matched funding:

The work proposed in this theme will use a range of methods: Projects 1 to 3: Qualitative semi structured interviews will be used to assess views of current transition and community based services for epilepsy or inflammatory arthritis, using purposive sampling to ensure appropriate representation. In addition to identifying patient experiences and preferences for future services, the interviews will identify barriers to care and patient preferences for outcomes of routine care that should be measured. Interviews will be recorded and transcribed verbatim. We will use constant comparative thematic analysis. A quantitative approach will be taken to map out current services, identify patient pathways, costs and outcomes of care. Similarly, a health informatics approach will be taken to analyse routine (HES, local databases, GPES and prescriptions) data, describing demand, activity and the outcome of care at the level of CCGs, hospitals and/or general practice and allow assessment of sources of variation including geography and case-mix. This work will develop outcome measures of routine care that can be used regionally and ultimately nationally, potentially including a variety of domains including outcomes of disease (eg enhanced function, less hospitalisation) and societal outcomes (eg proportions enabled to study and/or work productively despite ongoing disability). Results will be fed back to stakeholders and changes to services agreed, implemented and reassessed using outcome measures created with further analysis of routine data sources. Project 4: A systematic review will assess the prevalence of and management strategies for co-morbidities in epilepsy and RA. Quantitative and qualitative methods (as for projects 1 and 2), will be used to assess patient experience, current services, develop outcome metrics and implement improved services.

3.2 Please outline the key researchers associated with the Theme including how their involvement will add depth and quality to the proposed applied health research to be conducted:

A group of researchers and stakeholders, including service users, commissioners, primary and secondary care clinicians and managers have been assembled with the skills and experience to deliver and implement findings from high quality research to inform commissioning effective, patient centred and efficient care.
Commissioners: Dr D O'Brien (General practitioner and lead commissioner for elective musculoskeletal (MSK) care, Liverpool CCG); Dr C Mimmagh (GP and Director of Strategy for Liverpool Health Partners);
Research methodology: Prof PR Williamson (Medical Statistics) Prof G Baker (Neuropsychology and

outcomes/QOL), Dr Adam Noble (Qualitative methods) Prof S Cartwright (Head, Centre for for Organisational Health and Wellbeing) Prof S Bevan (Work Foundation), Dr J Reeve (NIHR UoL SL in GP). *Clinical evaluation and Health Informatics* Prof M Pearson and Dr K Bodger *Epilepsy*: Prof AG Marson (Lead epilepsy reserch group and epilepsy service), Dr Richard Appleton (paediatric neurologist). *Paediatric Rheumatology*: Prof MW Beresford (Chair, MCRN/AR UK Paediatric Rheumatology Clinical Study Group, Joint Interim Director, NIHR Medicines for Children Research Network). Dr R Lwin (Child Neuropsychology); *Rheumatology*: Prof J Goodacre (Director, Lancashire & Cumbria Clinical Research Hub; Clinical Director NIHR Cumbria & Lancashire CLRN), Dr P Holland (Senior Lecturer, Faculty of Health & Medicine, Lancaster University), Prof RJ Moots (Clinical Academic Lead MSK theme, Liverpool Health Partners), Dr N Goodson (Rheumatologist and Epidemiologist)

3.3 Please describe the proposed outputs from the research and the impacts anticipated (including the intended audience, how the impacts will be achieved and the likely timeframe):

- 1) *Transition care for young adults with long term condition*: Identification, piloting and implementation of optimal pathways for high quality, cost effective and equitable care for young adults as they transition to adult care (2-3 years). New clinical pathways established and adopted (4-5 years).
- 2) *Optimal Provision of Specialist Care in the Community*: Description of best evidence-based and cost-effective high quality pathways for management of chronic epilepsy and RA between hospital settings and the community (2-3 years). Evidence base for optimal commissioning of these conditions as exemplar LTCs (4 years). Different services commissioned (5 years).
- 3) *Maximising Work Productivity in Complex Needs*: Validated package of training for optimal completion of fit notes (1-2 years). Evidence base for interventions delivered as part of standard clinical care across NWC footprint (4-5 years)
- 4) *Management of Co-morbidities in complex Diseases*. Preparation and publication of systematic review on management of co-morbidities in long term condition (1 year). Identification of preferred (by patient and clinican) strategies of managing co-moirbidity in epilepsy and inflammatory arthritis established (2 to 3 years). HARL tool and patient passport established with piloting in clinical practice (4-5 years),

For Themes containing implementation (to be funded by matched funding only)

**Implementation Theme Section – for implementation or mixed model Themes
Please leave blank if research-only Theme**

4.1 Please describe the proposed implementation of applied health research into clinical practice across the health community that will be pursued within the proposed Theme using the matched funding, including an overview of how these relate to the overall strategy:

The over arching aim of this theme is to implement evidence based sevicees for people with complex needs and long term conditions. Starting with an initial focus on epilepsy and inflammatory arthritis as exemplar conditions, it will widen to other neurological / rheumatological conditions, and on to LTCs more generally.

4.2 Please describe the proposals for activities to facilitate the implementation of research findings across the health community, including the rationale and an outline of the process and methodology by which this approach to implementation will be evaluated:

A collaboration of service providers, clinicians, commissioners, patient & public represenatatives & researchers will undertake this work. Service changes to implement will be informed by existing reseach, systematic review, qualitative & quantitative projects as described. Implementation will be evaluated using a number of methods using a 'before and after' approach. Outcome metrics will be created as described above to analyse routine data colleted, with further assessment using quantitative and economic methods. The experiences of patients and those providing the service will be assessed using qualitative methods.

4.3 Please outline the key individuals associated with the implementation, summarising their previous experience in the proposed approach to implementation:

Key individuals with experiences of assessing outcome and consequences of implementation and interventions include: Prof M Pearson & Dr K Bodger (clinical evaluation); Prof G Baker (outcomes/QOL), Dr Adam Noble (qualitative methods) Prof S Cartwright (Head, Centre for for Organisational Health and Wellbeing) Prof S Bevan (Work Foundation). *Clinical evaluation and Health Informatics*. Prof AG Marson (epilepsy/neurology outcomes); Prof MW Beresford (Rheumatology outcomes); Dr R Lwin (Child neuropsychology); Prof J Goodacre (Rheumatology outcomes); Prof M Gabbay, Dr J Reeve (primary care); Dr P Holland (social inequalities)

This form, together with other requested attachments, must be submitted by **1:00pm on 13 May 2013**. Any questions about the completion of the form should be directed to Claire Vaughan (claire.vaughan@nihr-ccf.org.uk).