A cost-effective model for the detection of coeliac disease

What is the problem and why is it important?
Coeliac disease is an inflammation of the small bowel caused by individuals own immune system attacking the small bowel in response to eating gluten (which is present in wheat, barley or rye). This is a common disease affecting up to 1% of all adults. Patients who are diagnosed with coeliac disease report having an improved quality of life on a gluten free diet. They have many non-specific symptoms which often resolve once they are diagnosed.

Most cases go undetected (4 out of 5). The diagnosis is made by having a positive blood test and the presence of ‘flat small bowel’ on a biopsy. The biopsy is taken at the time of performing a gastroscopy. Our group and others have reported that individuals with undetected coeliac disease may present with non-specific gut symptoms – for this reason they are referred for a gastroscopy but often a small bowel biopsy is not taken. This means cases of adult coeliac disease are often missed at endoscopy.

The average delay in diagnosis for coeliac disease in the UK is 13 years (Coeliac UK data 2005). For this reason many people have suggested that a routine small bowel biopsy should be taken when any individual is referred for endoscopy. This strategy has significant cost implications.

Research plan
We are suggesting that using a novel ‘pin prick’ test may allow us to immediately detect which individuals have coeliac disease and in these selected cases then a biopsy can be performed.

We initially want to study a group of 5000 patients referred for endoscopy using the conventional methods of testing and comparing this against our new pin prick tests.

Impact of research
The research will
• reduce the number of patients requiring a small bowel biopsy
• speed up the time to diagnosis
• increase the diagnostic accuracy
• improve patient outcomes
To understand and enhance how people with dementia can provide meaningful feedback on their experience of dementia specific services.

**What is the problem and why is it important?**
NHS services are increasingly being expected to involve users in seeking feedback and developing services. Usual methods of feedback and involvement, such as surveys and large forums, can be a challenge for people with dementia due to short term memory, thinking and communication difficulties. Understanding the best ways to include people with dementia in these processes is not fully understood and yet it is essential that people with dementia are enabled to use their experience of living with the condition to influence how NHS services develop.

**The overarching research aims are to:**
- To understand how services engage people with dementia in gathering patient experience data
- To explore whether such data is gathered in a meaningful way from the perspective of the person with dementia
- To understand the barriers and facilitators to gathering patient experience data
- To explore and test out ways to overcome such challenges

**Research plan**
The research will be qualitative in nature and an action research methodology will enable the research to understand in-depth the complexity of understanding and implementing approaches to seek feedback from people with dementia in NHS practice.

**Impact of research**
The research will extend the knowledge on which methods work best in what circumstances and how they can be best implemented into practice. Findings will be examined for their relevance to other user groups with communication or cognitive difficulties.

Guidance will be developed for organisations on the best ways to ‘involve’ and gain meaningful patient experience feedback from people with dementia in order to develop person-centred services.

People living with dementia will be offered more opportunities to have their voices and experiences heard within the NHS and improved opportunities to influence future service delivery.
SMuRFS: Sheffield MUltiple Rib Fractures Study

What is the problem and why it is important?
Over 9,000 patients are admitted to hospital each year with multiple rib fractures. Multiple rib fractures equate to a serious injury, with a significant burden of pain and resulting considerable impact on resumption of prior activities and return to work.

Rib fractures may be “simple”, with one fracture per rib. A “flail” segment is where three or more adjacent ribs are fractured in two or more places, giving rise to gross instability and dysfunction.

In the past, early surgical techniques were used with varying degrees of success to manage selected cases of flail chest. Surgery did not become established for a number of reasons. Recent technological and organisational advances have led to rib fracture fixation being implemented across the UK.

However, there are no evidence-based guidelines available for the surgical management of multiple rib fractures, particularly where the pattern of injury falls short of a displaced flail segment, due to the lack of inclusion of patients in most of the trials conducted to date.

The aim of study is to investigate whether patients benefit from surgical fixation of multiple rib fractures.

Research plan
A number of work streams are required to identify the size of the problem; to characterise the state of equipoise according to different classifications of injury; to assess outcomes in different groups; to gain data for proposed primary and secondary study outcomes. The work streams include a

• retrospective dataset of 792 Sheffield cases over 5 years will characterise the service with an economic analysis of outcomes.
• novel radiological classification of multiple rib fractures will be created and piloted to determine whether it has predictive as well as prognostic value.
• retrospective patient reported outcome measures (PROMs) of the late effects of rib fractures.
• prospective study to collect PROMs to test the relevance to the research.

Impact of research
The research will provide evidence-based guidelines available for the surgical management of multiple rib fractures, where the pattern of injury falls short of the current consensus indications for surgical fixation.
Sheffield CRA Fellow – Dr Steve Brown

'What is an optimal treatment strategy for perianal Crohn's disease and what individual factors determine this'

What is the problem and why it is important?
Estimates suggest 1 in 650 people in the UK is affected by Crohn's disease (CD). Up to 80% will be affected by fistulating perianal disease presenting with pain and discharge affecting normal daily activities. Patients seek help from different sources; either GP, a Nurse Specialist or via A&E.

Management of the condition has been identified as a research priority by the Association of Coloproctology (ACPGBI) and by Crohn's and Colitis UK. There are many grey areas in the treatment pathway e.g. the role and timing of medical therapy, the effect of antibiotics, which cohort of patients will benefit from biological therapy and for how long therapy should be continued.

Whilst surgical drainage is routinely practiced, it is not certain that all require surgery before commencing medical therapy. Multiple classification systems exist to assess disease activity but their role in decision making is unclear. The impact of the condition on patients is also unknown.

Research plan
In order to test our hypothesis that the care of patients with perianal CD can be improved by optimisation of the patient care pathway we plan to:
• Undertake a systematic review of the literature around key decision-points in the acute perianal Crohn’s pathway
• Use data from the literature to develop a decision model to assist in the care of patients.
• Validate any model derived on an independent population from our case load.
• Investigate the psychosocial impact of perianal CD on this population before and after introduction of a novel treatment pathway.

Impact of research
This research will provide evidence based guidance on the optimal treatment strategy for patients with CD.
Sheffield CRA Fellow – Dr Anthony Hart

BRAIN (Brain abnormalities and aetiological investigations for neurodevelopmental difficulties) study.

What is the problem and why it is important?
Neurodevelopmental difficulties are common in paediatrics, affecting up to 10% of children consuming a large portion of paediatric clinic time and resources. Early developmental impairment (EDI) is one type, where a child does not reach their milestones in two areas of development at the appropriate time and affects 2-3% of UK children.

There are hundreds of causes for EDI. They include genetic, metabolic or hormone disorders; structural brain abnormalities, or acquired brain injury in the womb. Most have no treatment. Nevertheless, parents report knowing the cause is important. Some paediatricians do very few tests; others do a lot. Our pilot work shows there is no consistent approach throughout the UK. Over 80% of UK clinicians who responded to a questionnaire wanted evidence-based guidelines on the investigation of children with EDI. Investigations for EDI are expensive and could be directed more efficiently, giving a cost saving to the NHS.

Research plan
We aim to enroll 650 children aged 2-6 years with suspected EDI of unknown cause from paediatric clinics in 4 major centres and their surrounding district general hospitals.

The children will be phenotyped using a standardised history, examination and the Griffiths Mental Development Scales. We will screen them for autistic features using the Childhood Autism Rating Scale-2. A second appointment will be arranged for a battery of investigations, including MRI and genetic tests.

A classification tree analysis will assess how phenotypic features affect the diagnostic rate of specific tests. From this data, an algorithm can be created for the most efficient and cost effective diagnostic approach to the different phenotypes.

Impact of research
This study will
- create an effective and cost-efficient guideline for investigating children with EDI
- save the NHS money by not performing expensive, unnecessary tests
- reduce the number of unpleasant and unnecessary tests done in children
- ensure all children with EDI in the UK have equity of access to the most appropriate aetiological tests.