D-CRIS Programme for Dementia
Clinical Record Interactive Search

1 What is your specific offer to industry for CRIS & D-CRIS?

Clinical Records Interactive Search (CRIS) unlocks and transforms clinical data held in Trust systems to provide a rich and pseudonymised data resource allowing researchers to swiftly investigate hypotheses and identify patient cohorts. CRIS also provides an invaluable tool for service evaluation and clinical audit.

Trust Electronic Patient Record (EPR) systems hold a wealth of rich clinical patient data. CRIS transforms these data into a pseudonymised database appropriate for research use. This includes data recorded in coded and structured form, for example dates and scores, plus data held in unstructured free text form, for example, within written assessments, progress notes and correspondence.

The transformation process uses the patient's unique identifier to derive a research ID for each patient in the database. This ID does not allow researchers to identify patients. However, where appropriate consent has been given by the patient, the ID can be used by authorised personnel to contact patients who have been identified as potential recruits to an ethics approved research project.

The D-CRIS programme enables partnership working through the implementation of a federated CRIS solution across the programme partners. This creates the opportunity for extended research collaboration across the partnership drawing on the vast clinical record resources of the participating Trusts. The federated model brings together researchers from participating BRUs/BRCs in collaborative research projects.

2 What are the benefits to industry of working with CRIS & D-CRIS?

CRIS provides rapid, indexed access to vast numbers of pseudonymised clinical records and enables searching of unstructured, freeform clinical data.

CRIS delivers the following benefits:

Increases efficiency

- Faster delivery of results from research initiatives leads to earlier improvements in patient care.
- Supports strategic and service quality reviews to improve business planning.
- Efficient studies protect the reputation of both the Trust and the NHS.

Reduces costs

- Quicker and more efficient identification of viable studies ensures better targeting of Research and Development funding.
- Reduces researcher time spent on study feasibility.

Promotes collaboration

- Enables industry sponsored collaborations, from trials feasibility and planning, through to clinical trials, including recruitment to post-licensing effectiveness studies.
- Builds closer working relationships between practising clinicians and academics.

The D-CRIS Programme, initially implemented as separate stand-alone instances at each Trust, will rapidly move towards the second phase of the programme which will develop a federated data integration framework to enable querying across multiple datasets thus allowing access to over one million pseudonymised mental health records. The programme will also establish a governance and data-security framework for the pseudonymised use of EMR data and de-pseudonymisation with consent from the data subjects allowing researchers, where consent is given, to contact patients for recruitment in medical trials and studies.

3 Please provide a case study of how the CRIS solution has worked with an industry partner.

In 2012, the CRIS team were funded by Roche to produce a report on the prevalence and impact of 'negative' symptoms of schizophrenia. These symptoms (including emotional and social withdrawal, and loss of emotional expression) are widely believed to be strong predictors of the profound disability and loss of life expectancy experienced by people with this mental disorder. However, they are not routinely recorded in any structured field on electronic health records and so have been unmeasurable to date outside specific research projects. Over a four month period the CRIS team were able to develop applications which ascertained ten negative symptoms from clinical correspondence which were both accurate with respect to the source text and strong predictors of adverse outcomes such as hospitalisation and length of stay. These remain internationally unique data. The report (prepared to time and specification) has led to a collaborative research paper (in submission) and further commissioned work to expand automated information extraction on symptoms and other important variables.

CRIS also benefits shorter projects such as a contract set up with Roche to allow rapid-response requests for CRIS data. This has been used on two occasions to date: i) a report in March 2013 on lifetime and current clozapine use and dosage; ii) a report in September 2013 on the prevalence of apathy and poor motivation symptoms ascertained from free text in depressive episode cases.