South London and Maudsley NHS
NHS Foundation Trust

Using Electronic Health Records to Support Patient Empowerment

Mike Denis
CIO, South London and Maudsley NHS Foundation Trust

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An Academic Health Sciences Centre for London

Pioneering better health for all

History

- Bethlem Royal Hospital **Founded in 1247**
- Oldest psychiatric institution in the world
- Bethlem Royal Hospital, for a long time the only mental health institution in the country

Moorfields 1676

Imperial War Museum site 1815

Henry Maudsley

A HOSPITAL FOR MENTAL DISEASES.

At the weekly meeting of the London County Council, held on February 18th, Mr. H. P. Harris, Chairman, read the following letter:

"13, Queen Street, Mayfair, W.,
"February 14th, 1908.

"Dear Mr. Harris,—In December last you kindly allowed me to put before you a scheme for the establishment in London of a fully-equipped hospital for mental diseases. I said then that should the London County Council be willing to carry it into effect, I should be pleased to contribute £30,000 towards the cost of it. In the hope that the Council may look favourably on the scheme, I venture to ask its acceptance of that sum for the purpose. As a physician who has been engaged in the study and treatment of mental diseases for more than half a century I have been deeply impressed with the necessity of a hospital the main object of which would be (1) the early treatment of cases of acute mental disorder, with the view, so far as possible, to prevent the necessity of sending them to the county asylums; (2) to promote exact scientific research into the causes and pathology of insanity, with the hope that much may yet be done for its prevention and successful treatment; and (3) to serve as an educational institution in which medical students might obtain good clinical instruction. (1) It is believed that many cases of acute insanity, in which recovery usually occurs within a few weeks, or under three months—notably, cases of puerperal insanity—would be cured, and the persons thus saved from much of the prejudice which is sometimes a lasting injury to them when they have been sent to an asylum; and it is hoped that, in a small institution, with several medical and other attendants, the patient and apt

Maudsley's letter to London County Council
Published in the British Medical Journal 1908

Soldiers during World War I, Maudsley Hospital

South London and Maudsley NHS
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The Maudsley Hospital today

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SLaM today

Largest provider of specialist mental health services in Europe

Operates a specialist Biomedical Research Centre with Institute of Psychiatry, KCL

Member of Kings Health Partners Academic Health Sciences Centre

South London and Maudsley NHS
NHS Foundation Trust

King's Health Partners
Academic Health Science Centre

King's College London

Guy's and St Thomas' NHS Foundation Trust

King's College Hospital

South London and Maudsley NHS Foundation Trust

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Academic Health Sciences Centres in England

- Manchester AHSC
- Cambridge University Health Partners
- UCL Partners, London
- Imperial College, London
- King's Health Partners, London

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South London and Maudsley NHS
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The Institute of Psychiatry
Kings College, London

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Clinical Academic Groups

Addictions	Behavioural and Developmental Psychiatry	Child and Adolescent Mental Health	Mental Health of Older Adults and Dementia	Mood, Anxiety and Personality	Psychological Medicine	Psychosis
Allergy, Respiratory, Critical Care and Anaesthetics	Cancer, Haematology, Palliative Care and Therapies	Cardiovascular	Child Health	Clinical Neurosciences	Dental	Diabetes, Endocrinology, Nutrition, Obesity, Vision and Related Surgeries
Genetics, Rheumatology, Infection, Immunology and Dermatology	Imaging and Biomedical Engineering	Liver, Renal, Urology, Transplant, Gastro/Gastro Intestinal Surgery	Medicine	Orthopaedics, Trauma, Emergency, ENT (Ear, Nose and Throat) and Plastics	Pharmaceutical Sciences	Women's Health

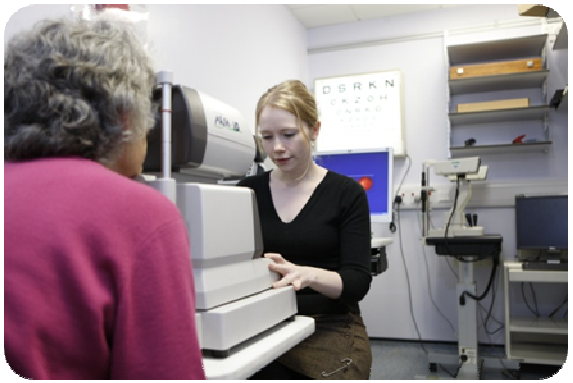
Our vision –
a radical change in healthcare

King's Health Partners is pioneering better health and well-being, locally and globally, through integrating excellence…

in research

in education/training

in patient care



The overall vision

- “The best care,
  delivered by the best people,
  in the best place,
  at the earliest opportunity”

The vision –
a radical change in healthcare

To advance health and well-being by integrating world-class research, care, education and training through:

- **Translating research more rapidly** into clinical practice and effectively disseminating these advances through education and training

- **Integrating physical and mental healthcare** to deliver a holistic approach to patient care

- **Harnessing the power of discovery science** to transform the nature of healthcare by moving from treatment towards population screening and disease prevention

- **Developing a workforce that will transform healthcare** – delivering innovation through education

As the two friends wandered through
the snow on their way home, Piglet
grinned to himself, thinking how lucky
he was to have a best friend like Pooh.

As the two friends wandered through the snow on their way home, Piglet grinned to himself, thinking how lucky he was to have a best friend like Pooh.
Pooh thought to himself:
"If the pig sneezes,
he's f****** dead.

Translational Research ?

- Translating scientific discoveries into practical applications
- “bench to bedside”
- Personalised medicine

Accessing data from electronic medical records is one of the top 3 targets for research

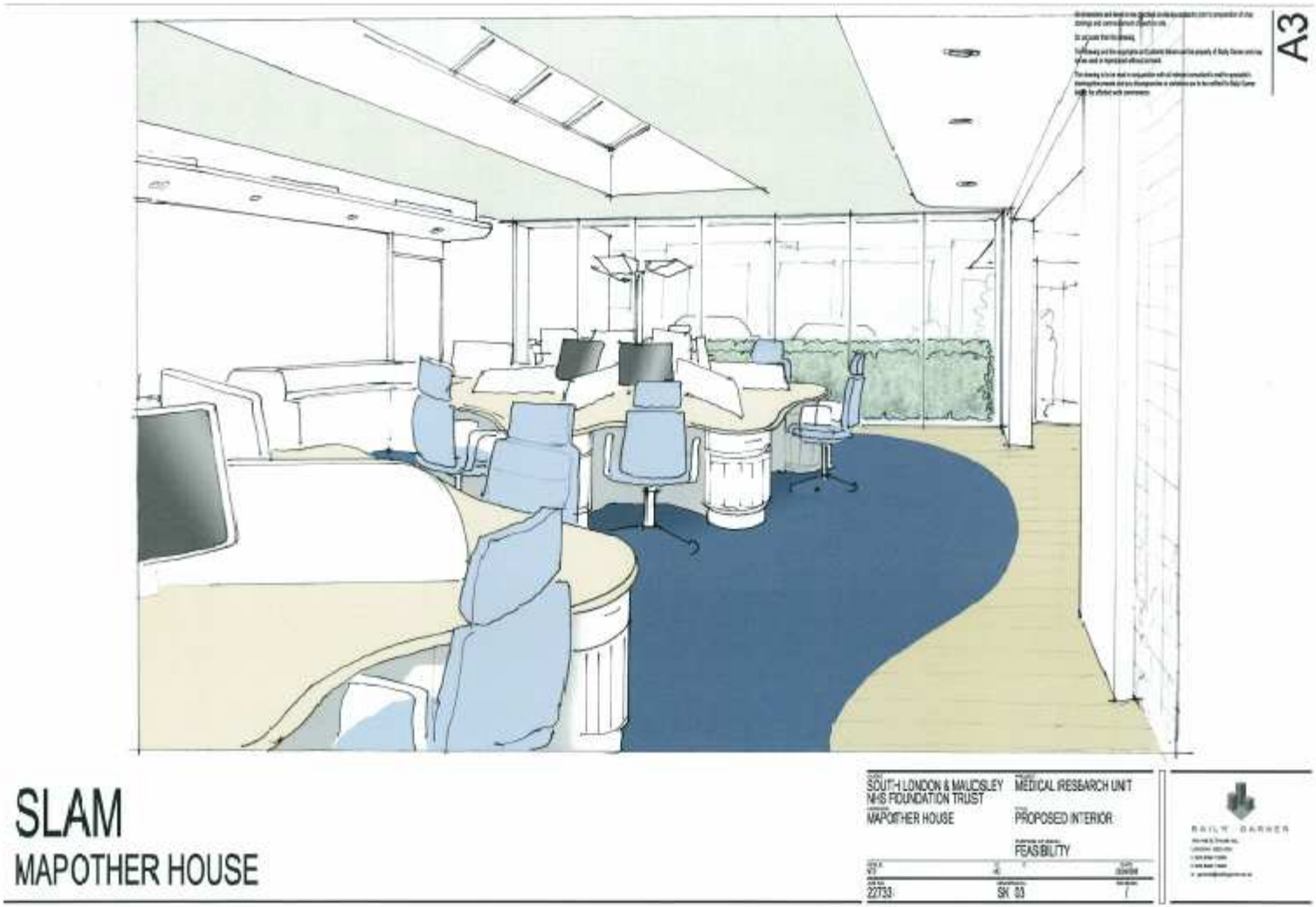
Sir William Castell, Chairman Wellcome Trust

Case Register

Provides information on specific disorders that is readily obtainable and available for meaningful analysis

Derived from EPR or local study data from recruited clients

10
11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Intended Use

Short term:

Observational research

Alerting

Recruitment (finding potential participants in BRC research projects)

Medium term:

Linking with other BRC databases (Imaging, genomics, proteomics….)

External data Linkage

Challenges for the Case Register

- Data protection, ethics, governance
- Quality of the data
- Complexity of the data
- Volume of the data

Headline Functionality

Search one or more specified PJS fields

search structured and indexed unstructured (free text) fields

use arithmetic, date range, thesaurus, spell-checking, synonyms, word-stemming and other modern search strategies

Identify one or more fields to be returned

export the results dataset to other applications for further analysis, e.g. SPSS (but within SLAM firewall)

Set up proactive searches

whereby the CR will actively inform a researcher when a particular value has been entered or when there has been a particular change in circumstance for one of a specified cohort of participants

Save search parameters for future use

Technical Security Model – 6 elements

1. Pseudonymisation: – NHS Number = BRC Number

   Identifiable information (names, DOB, address, carer details etc.) ‘ZZZZZZ’-ed out in free text field returns

2. Role-based access

- Administrator – manage access control and audit log
- Research 1 – can convert BRC number to NHS number
- Research 2 – BRC number only

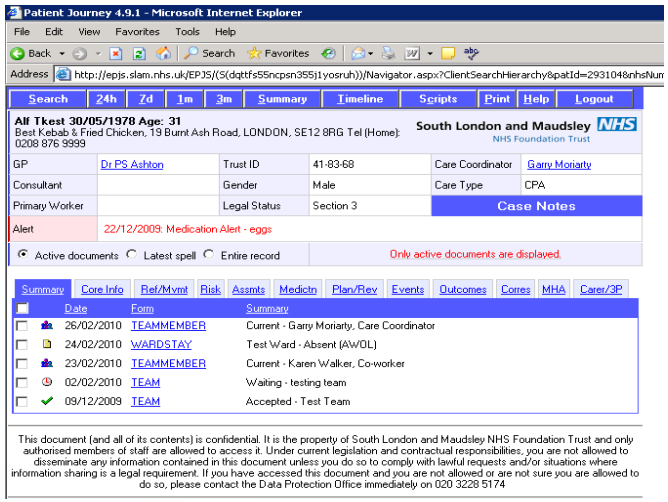
3. NHS number cannot be revealed without explicit assent in PJS

4. All searches to be labelled, e.g. with CRT, project, ethical approval code

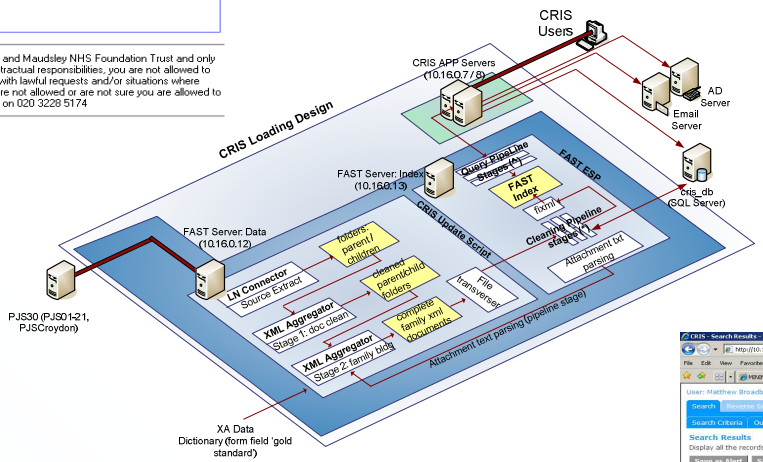
5. Audit log

6. Firewalled

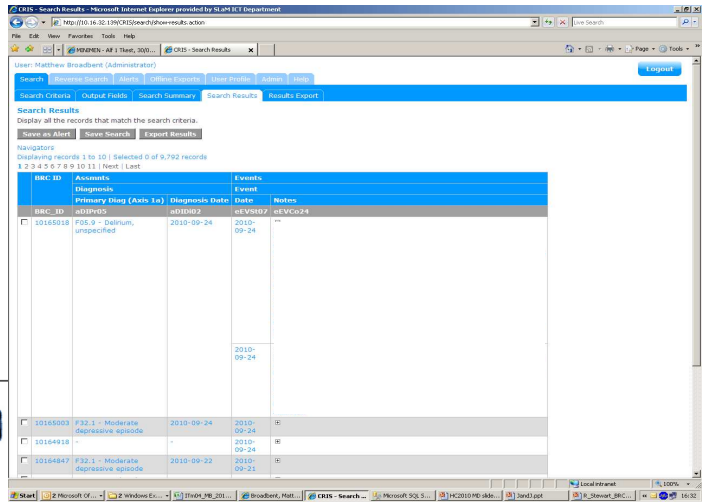
SLaM BRC Case Register



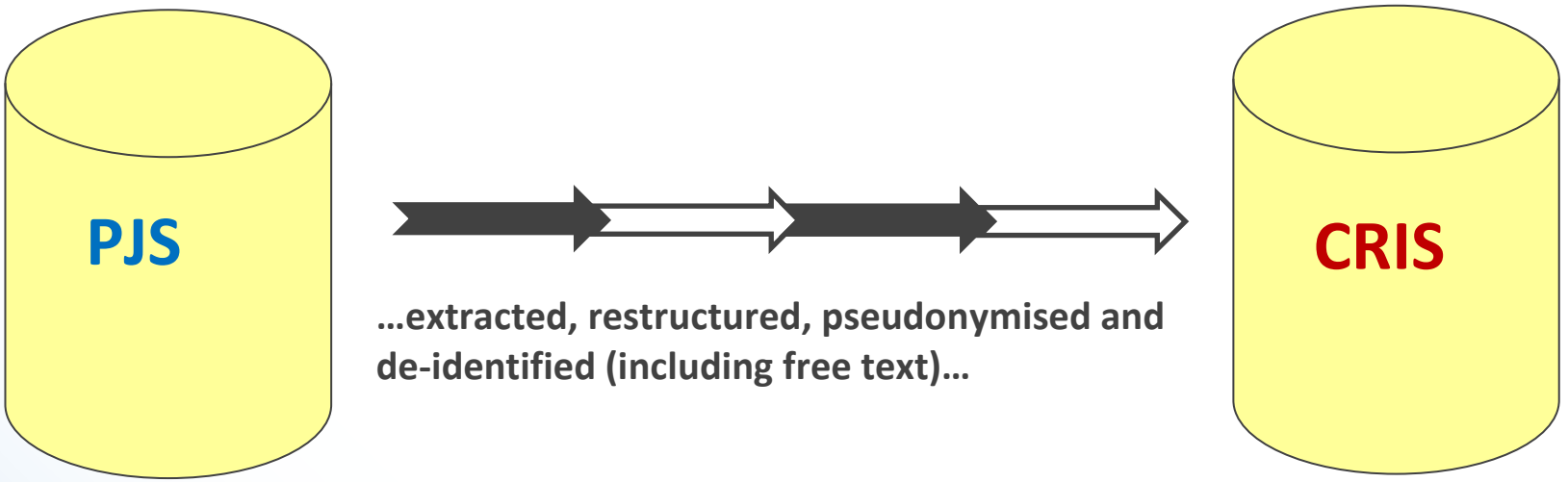
SLaM Patient Journey System (PJS)



Case Register Interactive Search (CRIS)



ALL data from ALL 170000+ records in the source EHR are…



CRIS - Case Register Interactive Search - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Search Favorites

Address http://10.16.32.139/CRIS/login Go

KING'S College LONDON

Institute of Psychiatry

at The Maudsley

South London and Maudsley NHS

NHS Foundation Trust

NHS

National Institute for Health Research

Specialist Biomedical Research Centre Mental Health

CRIS

Case Register Interactive Search

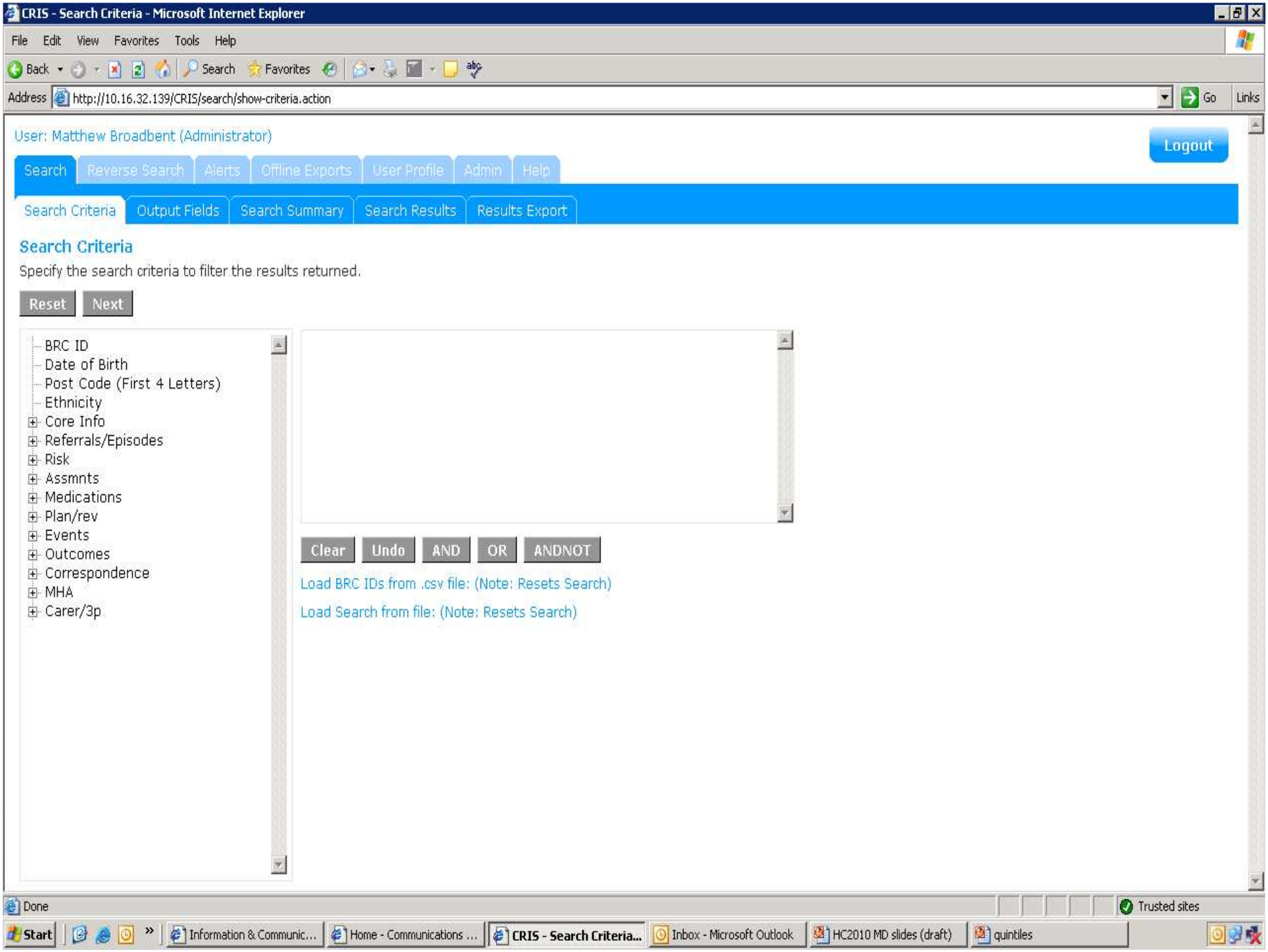
Login

Username:

Password:

Login Clear

Register


CRIS - Search Criteria - Microsoft Internet Explorer
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HC2010 MD slides (draft)
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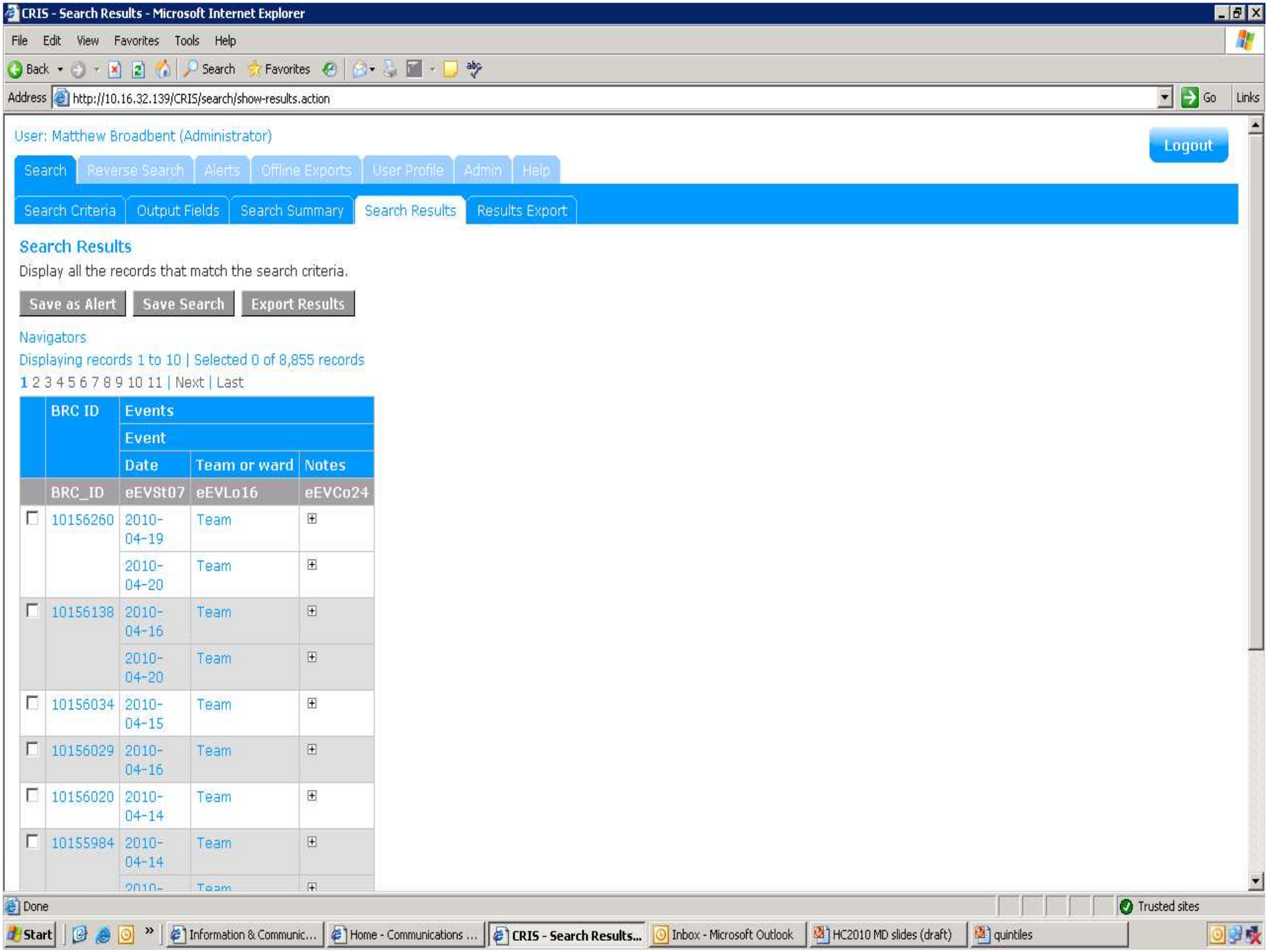
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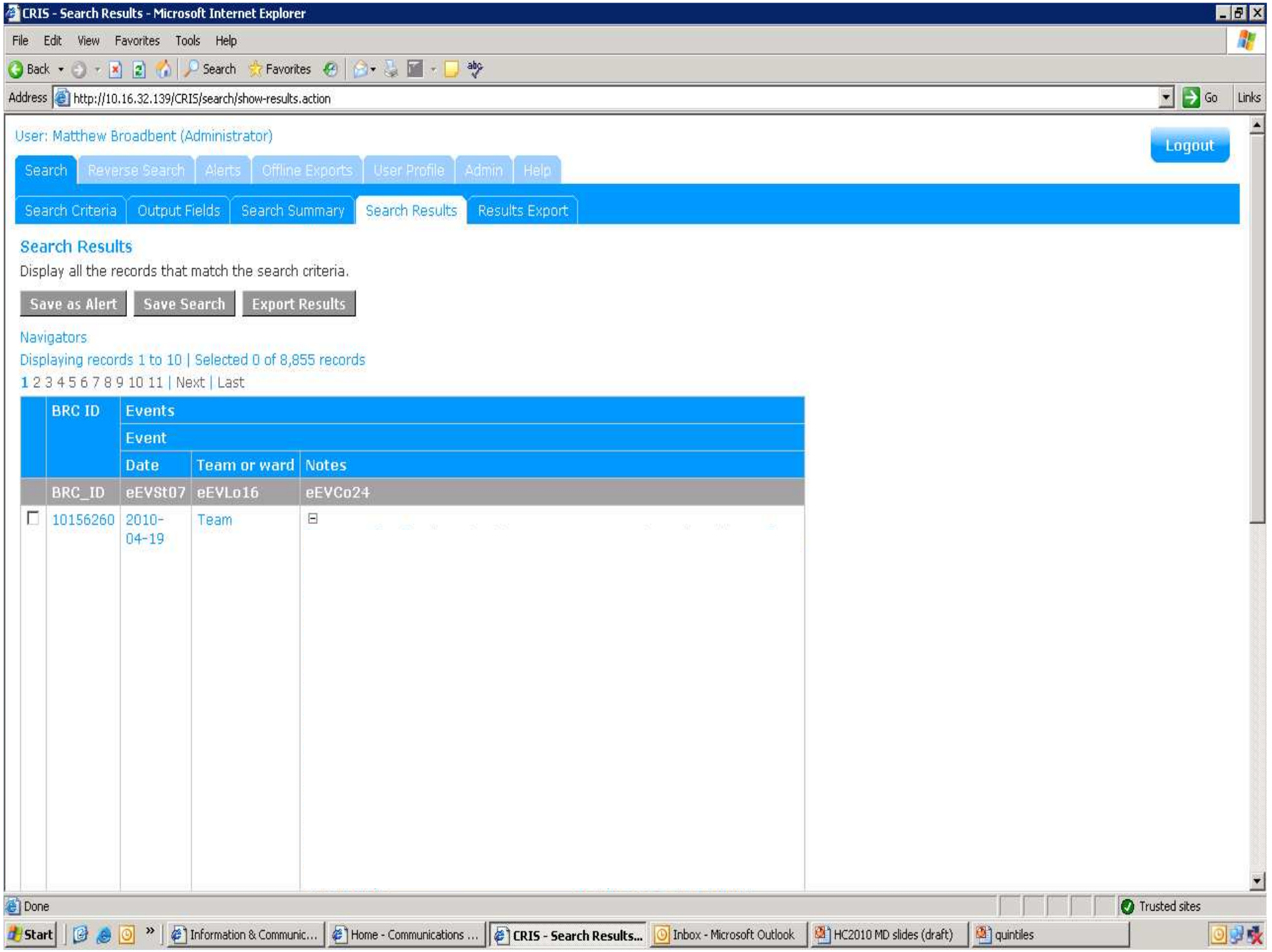
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quintiles

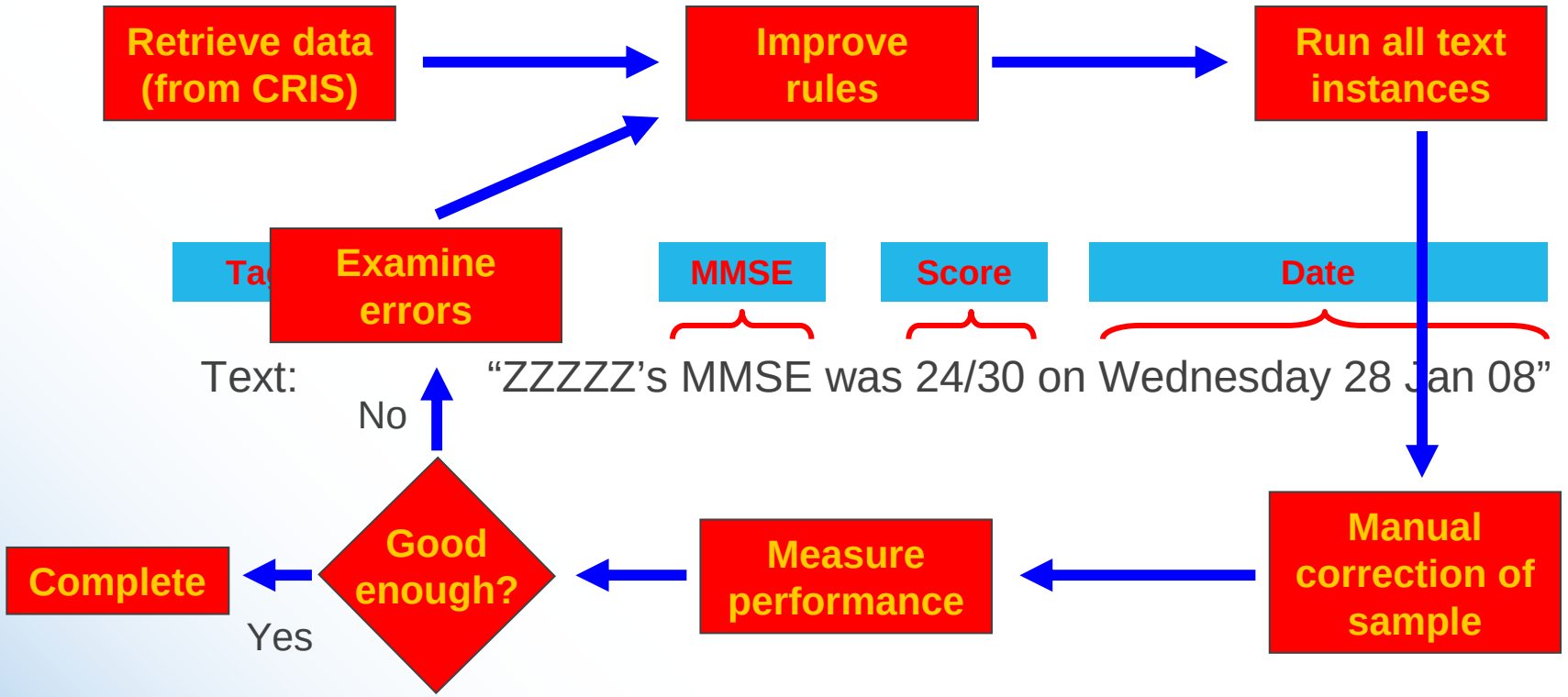
GATE – Text Parsing

FAST enables **information retrieval**, i.e. search and retrieval by matching against user defined strings;

GATE enables **information extraction**, i.e. extracts ‘meaning’ (structure) from free text context

GATE – Text Parsing

How GATE works: use case – extract MMSE score and date from free text



GATE – Text Parsing

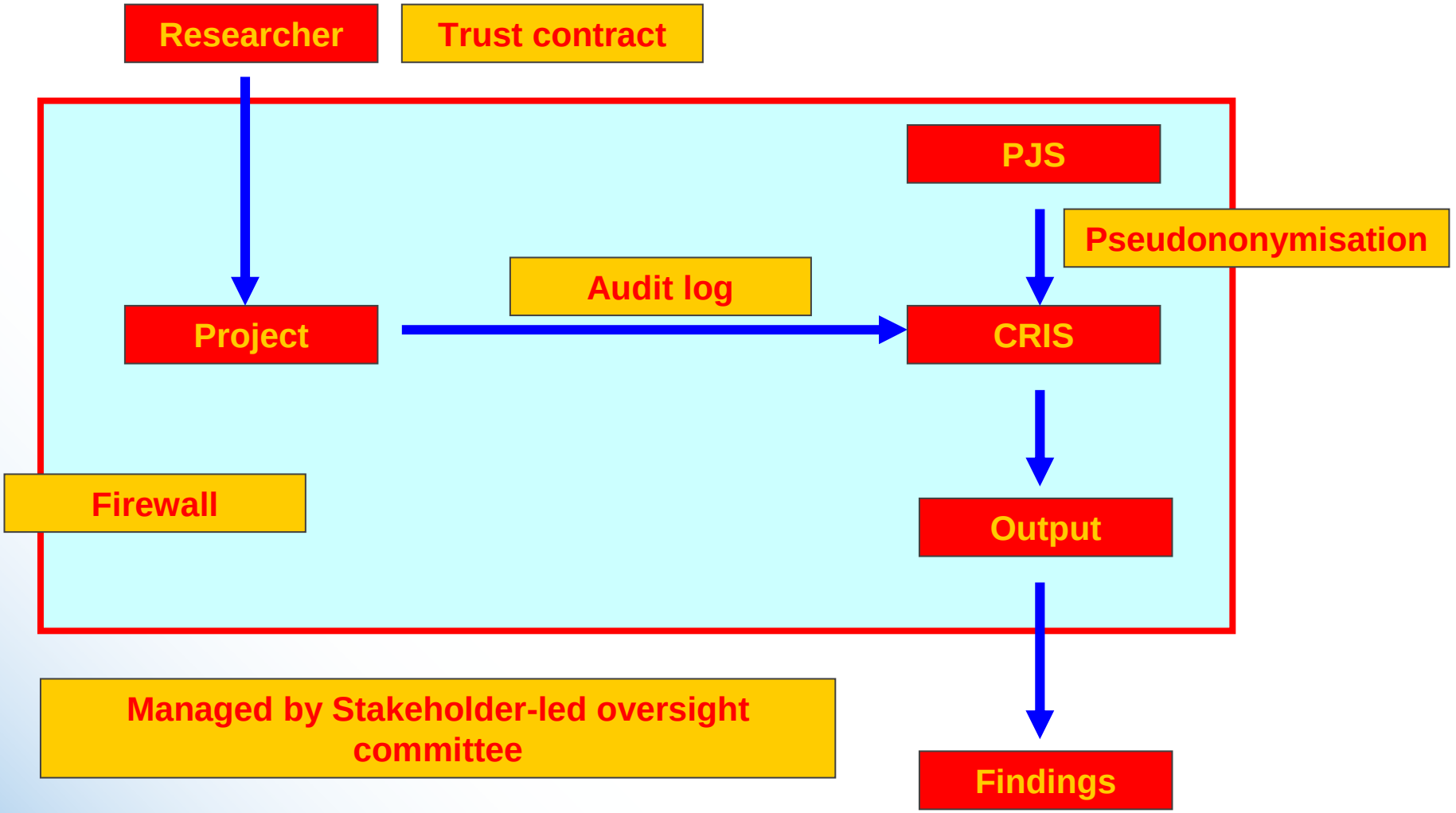
How GATE works: use case – extract MMSE score and date from free text

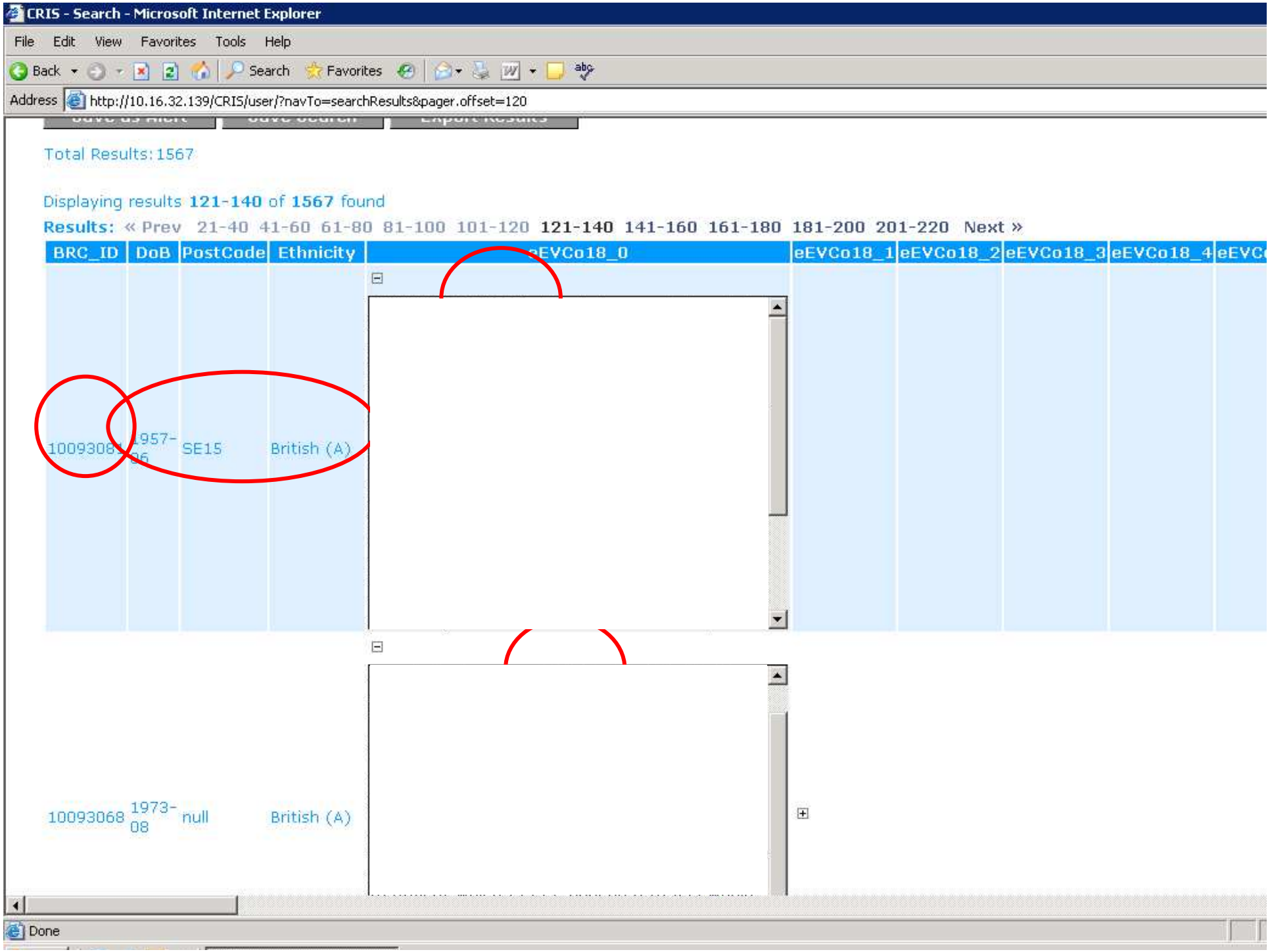
Results:

	1st iteration	2nd iteration	3rd iteration
MMSE score only	**0.90**	**0.97**	**0.99**
Score and date	**0.11**	**0.67**	**0.89**

Accuracy better than manual coding rates for large data sets

CRIS Security




CRIS - Search - Microsoft Internet Explorer
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Total Results: 1567
Displaying results 121-140 of 1567 found
Results: « Prev 21-40 41-60 61-80 81-100 101-120 121-140 141-160 161-180 181-200 201-220 Next »
BRC_ID DoB PostCode Ethnicity eEVCo18_0 eEVCo18_1 eEVCo18_2 eEVCo18_3 eEVCo18_4
10093068 1957-06 SE15 British (A)
10093068 1973-08 null British (A)
Done

CRIS Security Model - status

CRIS granted ethics approval as an anonymised data source for secondary analysis

CRIS security model signed off by Trust Caldicott and Executive committees

NIGB approval for consent to contact/recruit model

Service improvement – the next steps

- Consent →Identify → Approach → Recruit
- Personal Health Records, PROMs
- Record Linkage – Thames Cancer Registry, Primary Care
- Listen to the Users, Industry
- Direct access to clinicians, e.g. to search for key events/terms in their own caseload; identify best practice in comparable cases, profiling

Patient Empowerment ?

Patient Empowerment means that patients have the right to make their own choices about their health care

Why SLaM/IoP?

Delivering the Trust's strategic aims

Everything we do is to improve the experience of people using our services, and to promote mental health and wellbeing for all

- Working in partnership to promote mental wellbeing
- Supporting others by sharing our clinical knowledge and expertise
- We will underpin KHP's strategic objectives by working with our stakeholders to build information technology and resources to support our efforts.

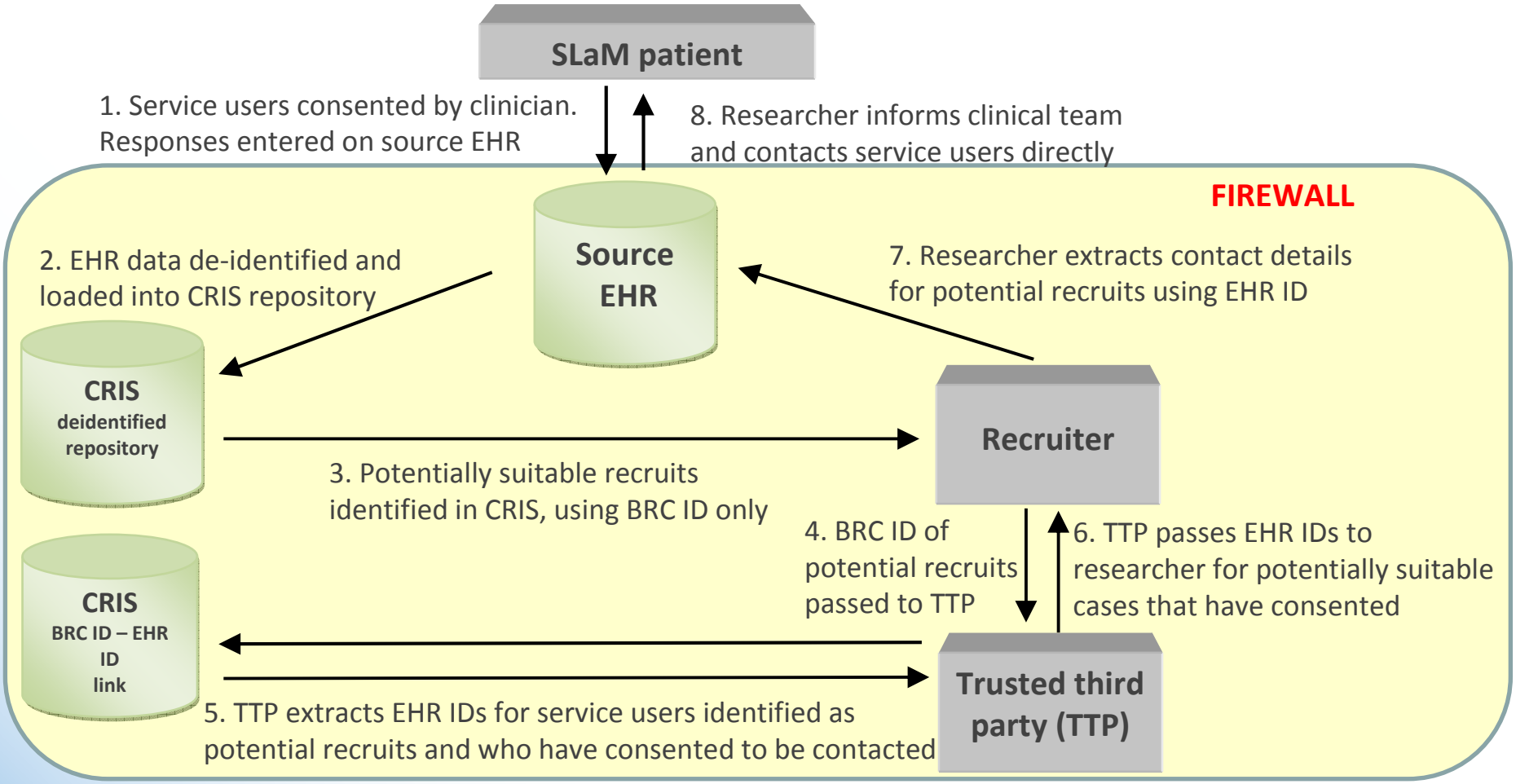
Purpose

- To develop a SLaM/IoP innovation model for service user empowerment
- To improve the use of outcome measurement across SLaM services
- To explore the development of a connected health model (between SLaM and primary care)
- To promote research for the development and use of personal health records

SLAM BRC Case Register – new application for participant recruitment

Identifying research participants using CRIS

'Consent for Consent' model enables researchers to approach potential participants directly



Identifying research participants using CRIS

'Consent for Consent' model enables researchers to approach potential participants directly

Consent-for-consent model – the main steps:

1. Service users are approached by their clinical team and asked if they would like to be approached by researchers for potentially relevant studies (capacity assessed at this time)
2. Clinicians enter responses into PJS
3. Researchers enter inclusion/exclusion criteria into CRIS to identify potential cases.
4. A Trusted Third Party de-anonymises potential cases that have consented only
5. Researchers inform the clinical team and contact the service users directly

Key components

Procedures

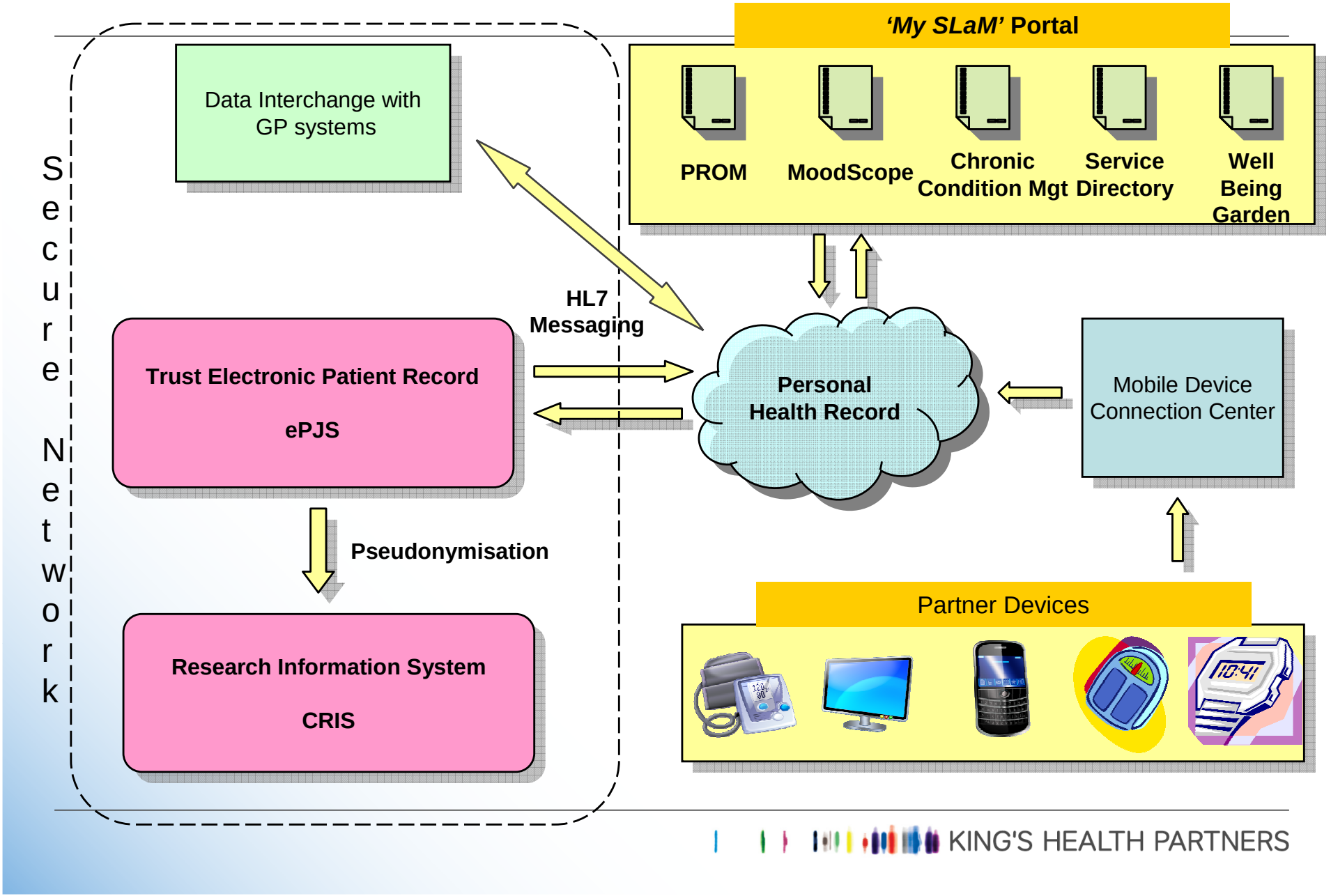
- Recording approaches and participation (PJS)
- Safeguards (e.g. re-consent at discharge)
- Reminders about participation (newsletter)
- Capacity assessment and training
- Information leaflet
- Implementation strategy

Approvals

- National Information Governance Board (NIGB) approval ✓
- Research Ethics approval ✓
- Caldicott Guardian ✓ (minor amendment)
- CAMHS ✓ (minor amendment)
- Trust Executive ✓

NIGB: "… Committee members had reiterated their view that this posed an elegant solution to the issue of participant recruitment, and noted the significant amount of work that had taken place in regard to developing this model."

SLaM *eMPOWERMENT* – Connected Health Model



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Thank You