

Building a Health Research Support Service

Research Capability Programme

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Background

- Dec 2005 – Chancellors commitment
- Jan 2006 – DH strategy “Best Research for Best Health”
- July 2006 – R&D advisory group to NHS CFH established by UKCRC
- June 2007 – UKCRC R&D advisory group report
- August 2007 – Research Capability Programme initiated
- September 2007 – Health Select Committee report
- November 2008 – Wellcome Trust and RCGP report

What is the Research Capability Programme? (i)

- Its primary objective is to enable research to achieve its full potential as a “core” activity for healthcare.
- The Research Capability Programmes vision is to:
 - Enable better health outcomes for the public and patients achieved at best value for the taxpayer; and
 - Support the ambition to make the UK the preferred place to carry out medical research, by building a nationwide health data and information platform that will enable research to achieve its maximum potential benefit.
- It will do this by developing and implementing the Health Research Support Service (HRSS)

What is the Research Capability Programme? (ii)

- It is a National Institute for Health Research (NIHR) programme within the systems work stream
- It has a Senior Responsible Owner, who is a nominee of the DH Director-General of R&D. A programme board and advisory board provide strong governance
- Within the Research Capability Programme there are 5 work streams:
 - Sourcing and Approvals
 - HRSS Pilot Programme
 - Communications
 - Information Governance
 - Patient and Public Involvement

The Health Research Support Service (HRSS)

- The HRSS will link together data for researchers to use for research studies or clinical trials
- It will increase the data routinely available to health research
- Patient data and confidentiality will be protected by strict controls
- It will enable researchers to carry out studies that lead to more effective treatments and improved health outcomes, patient safety and quality of life

What is the Health Research Support Service (HRSS)?

- Technology (hardware, software and development)
- Services (helpdesk, users guidance, analytical, research informatics expertise)
- Information Governance services (assistance, guidance and audit)
- Data sources (ONS, IC, Cancer, Heart disease etc)
- Data processing (meta-data, linkage etc)
- Secure tools and environment for researchers to access data and work

Benefits of HRSS

The HRSS will:

- Use research evidence much more efficiently to improve health and healthcare for all
- Provide greater capacity to invite right kind of patients to take part in clinical trials and conduct the trials more efficiently
- Enhance the thriving research culture within the UK
- Increase industry investment in clinical research in the NHS

The HRSS Pilot Programme

- The HRSS Pilot Programme has been developed to implement the *initial* Health Research Support Service capability
- The objectives of the HRSS Pilot Programme are to:
 - Prove the functionality and feasibility of the Pilot HRSS
 - Demonstrate some initial benefits of the service
 - Create useful lessons learned and provide feedback for the development of the main service

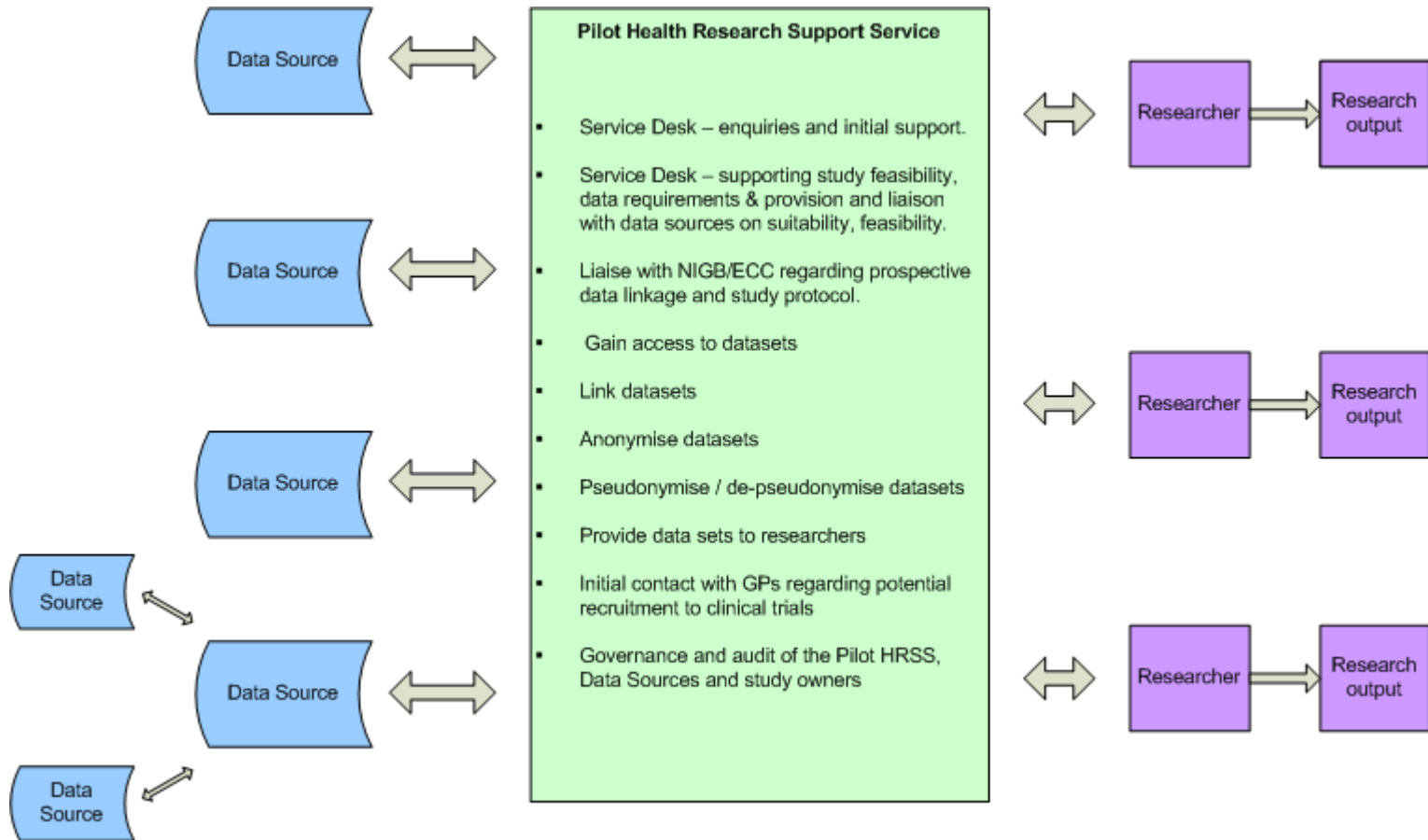
What will the Pilot HRSS do? (i)

- Link to a number of (initial) data sources through a single point of access
- Link datasets and analyse data and linkage quality
- Anonymise / pseudonymise / de-pseudonymise data
- Provide data to health researchers (within the agreed regulatory framework) to support observational studies and clinical trials

What will the Pilot HRSS do? (ii)

- Forge initial working relationships and business processes between HRSS and other bodies, in order reduce the volume of administration associated with research
- Work within the agreed Information Governance (IG) Framework and subject to independent IG audit (created by the IG and Compliance Programme of the NHS IC)

How will the Pilot HRSS work?



Planned Pilot HRSS Studies

| Organisation | Area of study |
|---|---|
| Kings College, London | Mental disorder and cancer |
| National Cancer Intelligence Network | Post colonoscopy complications |
| Imperial College, London | Migratory movements amongst births in England |
| Health Protection Agency | Monitoring Hepatitis C related care |
| | Gynaecological complications following Chlamydia diagnoses |
| GlaxoSmithKline | Paediatric Pilot Study: The Utility of Linking Additional Patient-Level Data Sources in England for Epidemiological Studies |
| UK Renal Registry | Measuring quality and driving change in renal services using routinely collected data |
| MEMO/Hypertension Research, University of Dundee | The Standard care versus Celecoxib Outcome Trial (SCOT): A Large Streamlined Safety Study |
| University of Oxford Clinical Trial Service Unit & Epidemiological Studies Unit | ASCEND (A Study of Cardiovascular Events in Diabetes) |
| | Study of Heart and Renal Protection (SHARP) |
| General Practice Researcher Database | Evaluating the comparative effects of Statins |
| | Evaluating antibiotics to treat chronic lung disease (COPD) |

Planned Pilot HRSS Data Sources

| | |
|---|--|
| IMS Hospital Prescribing (NHS IC) | UK Renal Registry |
| Hospital Episode Statistics (NHS IC) | Socio-economic reference data |
| Death Registrations (ONS) | Medical Research Information Service (NHS IC) |
| Primary Care (Multiple physical source acquisition strategy) | Birth Registrations (ONS) |
| National Cancer Register (ONS) | Address point (via Imperial) |
| Coronary Care Audit Database (CCAD): British Cardiovascular Intervention Society (BCIS) | Thames Cancer Registry |
| Coronary Care Audit Database (CCAD): Myocardial Infarction Audit Project (MINAP) | Demographics (NSTS) |
| Local CTSU Recruited Cohort: ASCEND | NHS Cancer Screening Programme: Bowel |
| Local CTSU Recruited Cohort: SHARP | SLAM BRC Case Register |
| Master Patient Index | British Isles Network of Congenital Abnormalities Register (BINOCAR) |
| Local Dundee Recruited Cohorts | |

Governing the Pilot HRSS (i)

- Created and agreed an Overarching Governance Framework (OGF) for the Service, including principles, policies and operating procedures centred around:
 - Scientific Governance
 - Information Governance
 - Ethical Governance
 - Patient Public Involvement
- Scientific Governance: Working with the MHRA Independent Scientific Advisory Committee (ISAC) - commenced with first 2 study protocols

Governing the Pilot HRSS (ii)

- Information Governance (IG):
 - Working with National Information Governance Board (NIGB) to gain endorsement of the IG mechanisms that will be part of the Pilot HRSS
 - Working with the Ethics and Confidentiality Committee (ECC) to gain class support for the Pilot studies and design specific support for the RCP moving forwards
 - Conforming to the Information Governance Framework (IGF) and subject to independent audit by the IG Compliance Unit (IGCU)

Governing the Pilot HRSS (iii)

- Ethical Governance: Working with the National Research Ethics Service (NRES) and the South East Coast Research Ethics Committee (SEREC) to gain ethical endorsement for the Pilot study protocols
- Patient and Public Involvement (PPI): Working to incorporate patient and public input to the research process via a PPI co-ordination group

Information Governance Framework (i) National Institute for Health Research

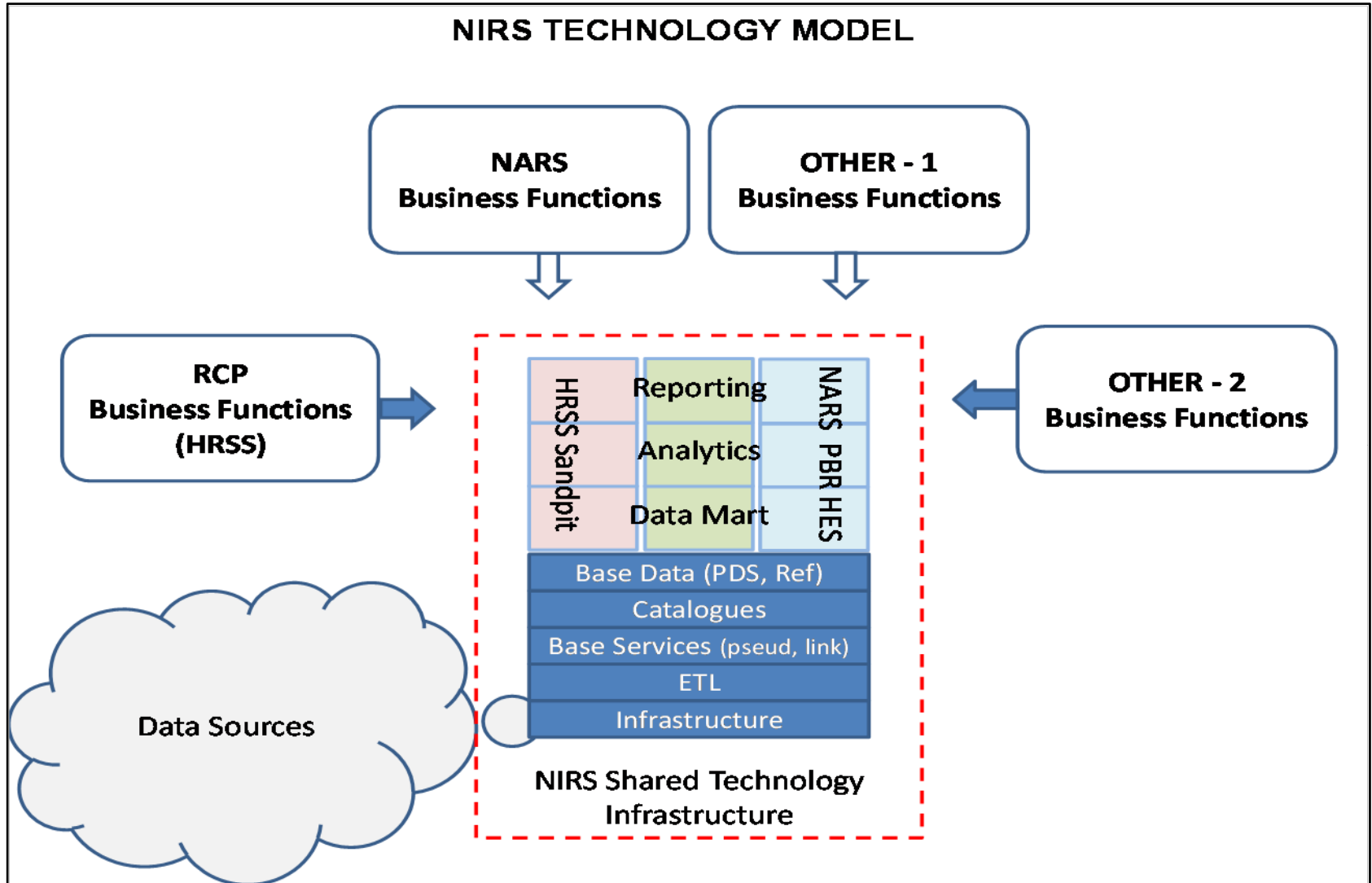
- The Information Governance Framework (IGF) brings together the relevant legislation, standards, and best practice guidance in information governance that apply to the processing of patient information for secondary purposes
- The framework has been produced by the NHS Information Centre for health and social care in collaboration with the Research Capability programme

Information Governance Framework (ii)

- The IGF endeavours to make it easier for relevant organisations to identify the information governance requirements that apply to their processing of patient information for secondary purposes and the evidence they will need to provide to demonstrate conformance to these requirements
- The Pilot HRSS and full service will be independently audited against the IGF to provide assurance of meeting the strict information governance requirements

Procuring the HRSS

- The HRSS is a unique and innovative service for which there is no direct comparator in the private sector
- Much of the expertise required to deliver the service resides in the academic sector and others with health research experience rather than in the private sector, thus decision to build in the public sector
- The publicly provided HRSS will comprise the people and processes required to deliver the services, utilising the functionality provided by the technology infrastructure



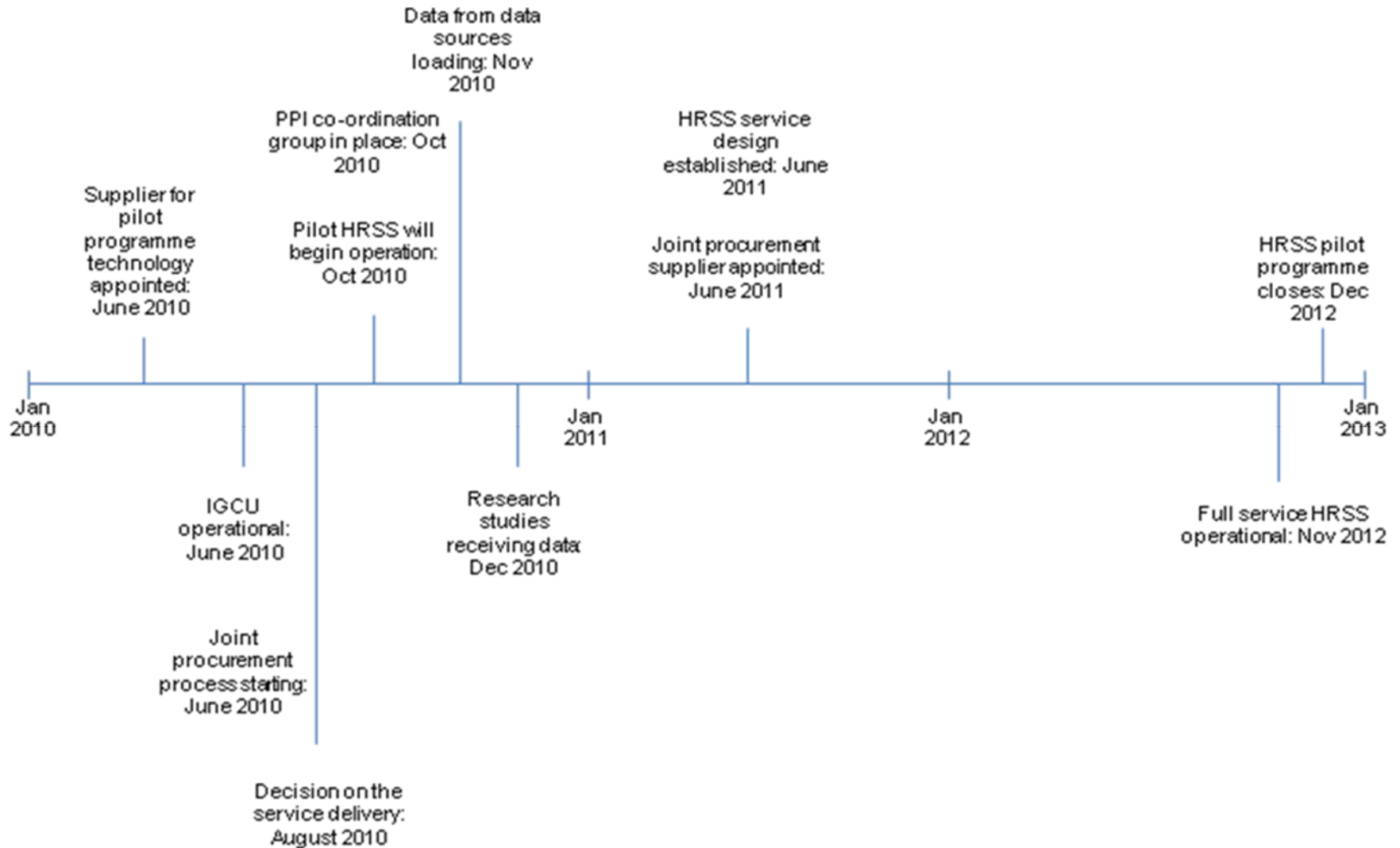
The Required Elements for our Service

- A single Shared Technology Infrastructure to serve RCP and other services
- The range of research facing services required to support RCP Business Functions – the Health Research Support Service (HRSS)
- In addition this infrastructure can support services required to support other Business Functions

The Shared Technology Infrastructure

- The Shared Technology Infrastructure is a comparatively uncomplicated set of technology that can best be sourced via a European Procurement (OJEU) using the competitive dialogue process. This procurement will be run jointly with the NARS programme.
- It will comprise a set of hardware, application software and tools, portals, plus the associated operational and support services to run them.

Where we are and next steps



Where to go for more information!

- Visit our stand in the exhibition area
- Go to our web pages:
www.nihr.ac.uk/systems/Pages/research_capability_programme.aspx
- Subscribe to our newsletter – online or at our stand

Questions