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Research Capability Programme: Background

A NIHR Programme, with a Senior Responsible Owner nominated by the DH Chief Medical Officer

- Its primary objective is to enable research to achieve its full potential as a “core” activity for healthcare.
- The Research Capability Programme 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)

The Health Research Support Service (HRSS): Overview

- The HRSS links together data for researchers to use for research studies or clinical trials
- The HRSS provides anonymisation and pseudonymisation services, to protect patient confidentiality and privacy
- 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

The Health Research Support Service: Benefits

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

Current status of the RCP

Research Capability Programme

- The DH is committed to completing the RCP, and to implementing the HRSS. As of 2011, there is no public capital available to support the strategic aims of the RCP. An alternative route to implementation has been identified, and due diligence is underway to explore the implications of this.
- In parallel, the Pilot sub Programme, which is implementing the initial capability, has approval from its DH sponsor (PD Sally Davies) to continue its work.

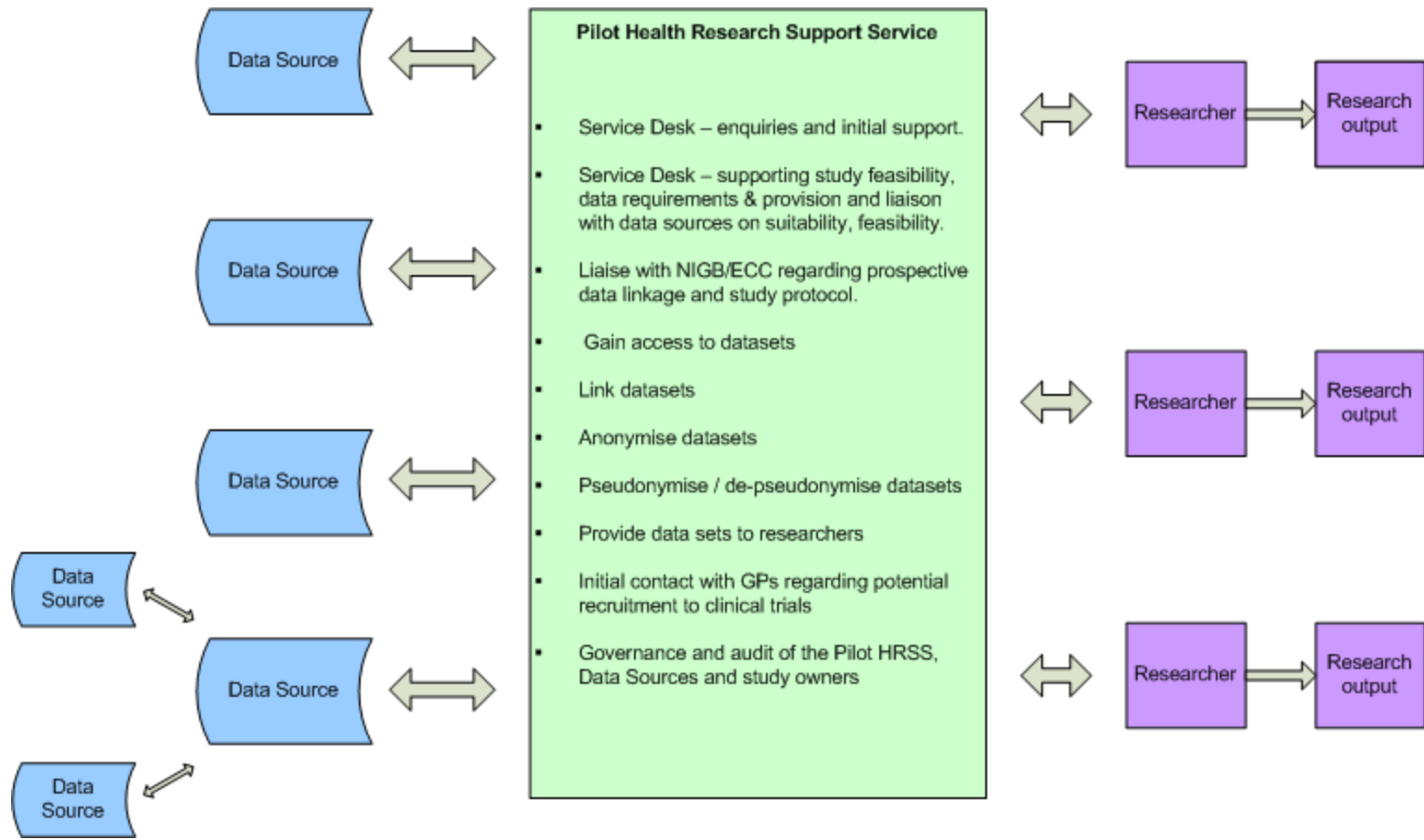
The HRSS Pilot Programme

Research Capability Programme

The HRSS Pilot Programme has been developed to implement the *initial* Health Research Support Service capability:

- 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, anonymisation etc)

How will the Pilot HRSS work?



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	

Pilot HRSS: Progress so far (i)

- Pilot HRSS overarching governance in place:
 - Overarching ethical approval (SE REC)
 - Overarching IG approval (NIGB ECC)
 - Independent scientific review of research protocols (ISAC of the MHRA)
 - Appointed a PPI Coordination Group to ensure the perspectives of patients and the public are central to the governance of the HRSS
 - IG Toolkit compliance ongoing, first formal submission due May 2011
 - Opt out process agreed and piloted in early adopter GP Practices (independent report on this process received and under review)
 - Bespoke data sharing agreements created and signed

Pilot HRSS: Progress so far (ii)

- Pilot HRSS infrastructure built, tested and delivered. The Service is now operational.
- Initial data sources loaded (TCR and SLAM)
- First data set provided to the research team:

Kings College London will now start to use the data for the research study to examine how mental disorders in patients impacts upon the diagnosis and treatment of cancer, to understand if there is any delay in cancer diagnosis and the affect it can have on a patient's survival.

The results from this study aim to influence patient care in both oncology and psychiatry and may impact policies that seek to identify and decrease inequalities in cancer incidence, outcome and choice in end of life care.

RCP and Pilot HRSS:

Next steps

- Due diligence process (to agree medium / long term future of the RCP)
- Continued delivery of Pilot research datasets (next planned study is for UK Renal Registry)
- Pilot learning, benefits etc – key input to due diligence process and any transition planning resulting from it.

Where to go for more information

- Go to our web pages:

www.nihr.ac.uk/systems/Pages/research_capability_programme.aspx

- Subscribe to our newsletter – online



**National Institute for
Health Research**

Research Capability Programme

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