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Research Capability Programme

Peter Knight
Group Programme Director
and
Kerrie Woods
Pilot Programme Manager

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RESEARCH FOR PATIENT BENEFIT WORKING PARTY

FINAL REPORT

"For us, science and research constitute a front-line service, as they too, reduce distress and pain and save lives".

(Dr John Reid, Secretary of State for Health, 22 March 2004)

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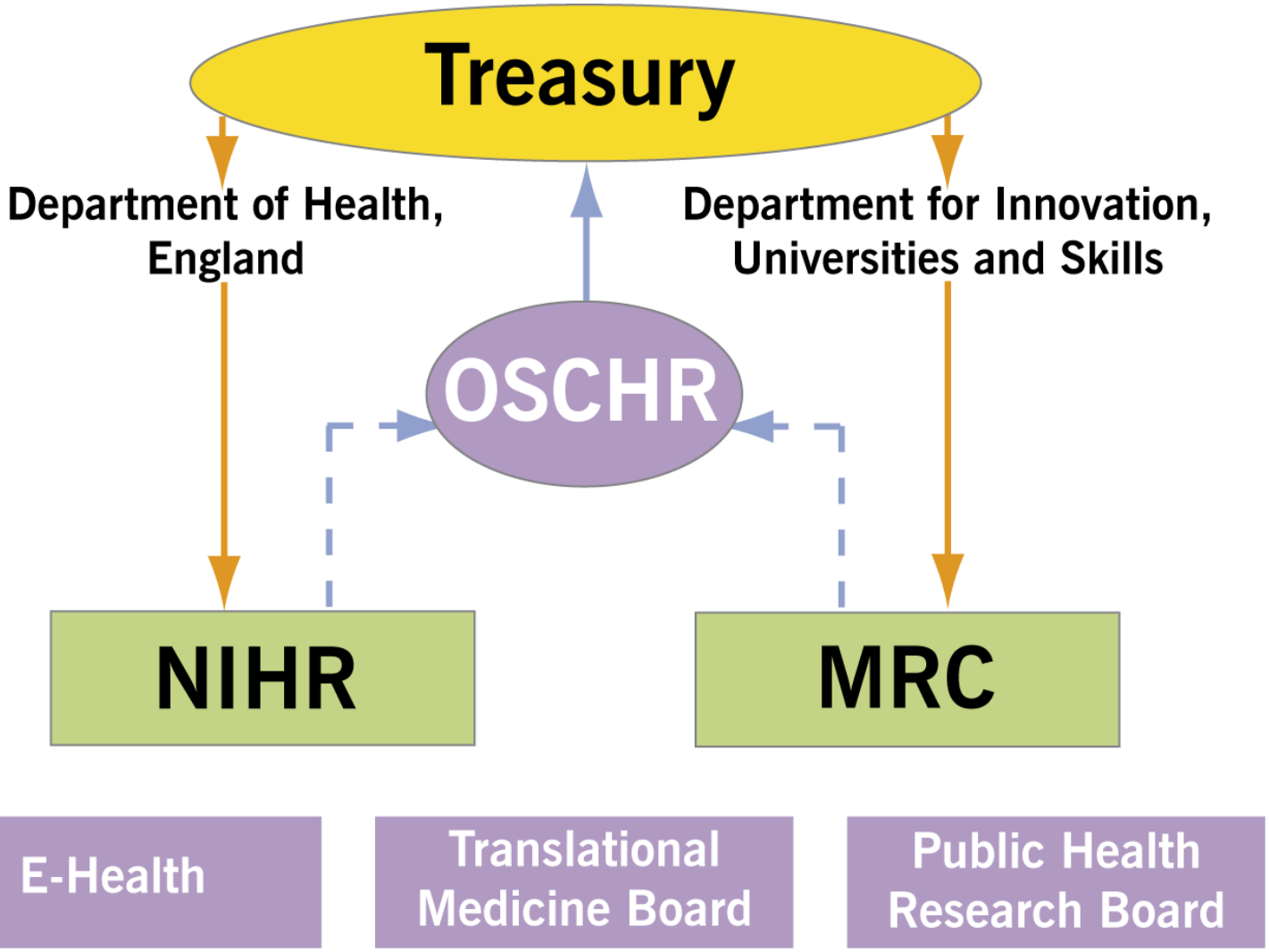

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Background

- Dec 2005 – Chancellor's 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 – CRDB SUS working group report
- August 2007 – Research Capability Programme initiated
- September 2007 – Health Select Committee Report

What is the Research Capability Programme?

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It is a formal programme of work within NHS CFH looking at how information held in the National Programme for IT systems may be used for research purposes.

It will take forward the recommendations in the “Report of Research Simulations” produced by the UKCRC Advisory Group to NHS CFH.

It has a Senior Responsible Owner, who is a nominee of the DH Director-General of R&D. A programme board and external reference group provide strong governance.

The primary objective is to enable research to achieve its full potential as a “core” activity for healthcare, alongside other uses of NHS data that lead to improvements in the quality and safety of care.

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What are the potential benefits for research?

- More timely access to better integrated information for research purposes
- More streamlined protocols for access to information
- Support for ground-breaking work on the health of the population
- Facilitation of recruitment of patients for clinical trials
- Enhance the UK as a centre for research excellence with associated economic benefits

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What is the Vision of RCP?

The vision of the NHS Research Capability Programme is:

- To enable better health outcomes for the public and patients achieved through best value for the taxpayer; and

- To 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 health research to achieve its maximum potential.

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How will the RCP Vision be realised?

It will achieve this by:

- Providing a common information infrastructure that will be adaptable and develop in response to the research process and the needs of all stakeholders (including patients);

- Providing a customer-focused set of services that both ensure information is treated and handled in a safe and secure way to protect the rights and confidentiality of patients and individuals under the law, and also meet researchers' needs efficiently. The services will enable high quality research directed towards improving health outcomes: effective treatments, patient safety and quality of life; and

- Providing access to a comprehensive range of technical resources and data sets, under strict protocols of information governance, that will aid the research community to access the data needed to conduct research of the highest methodological standard.

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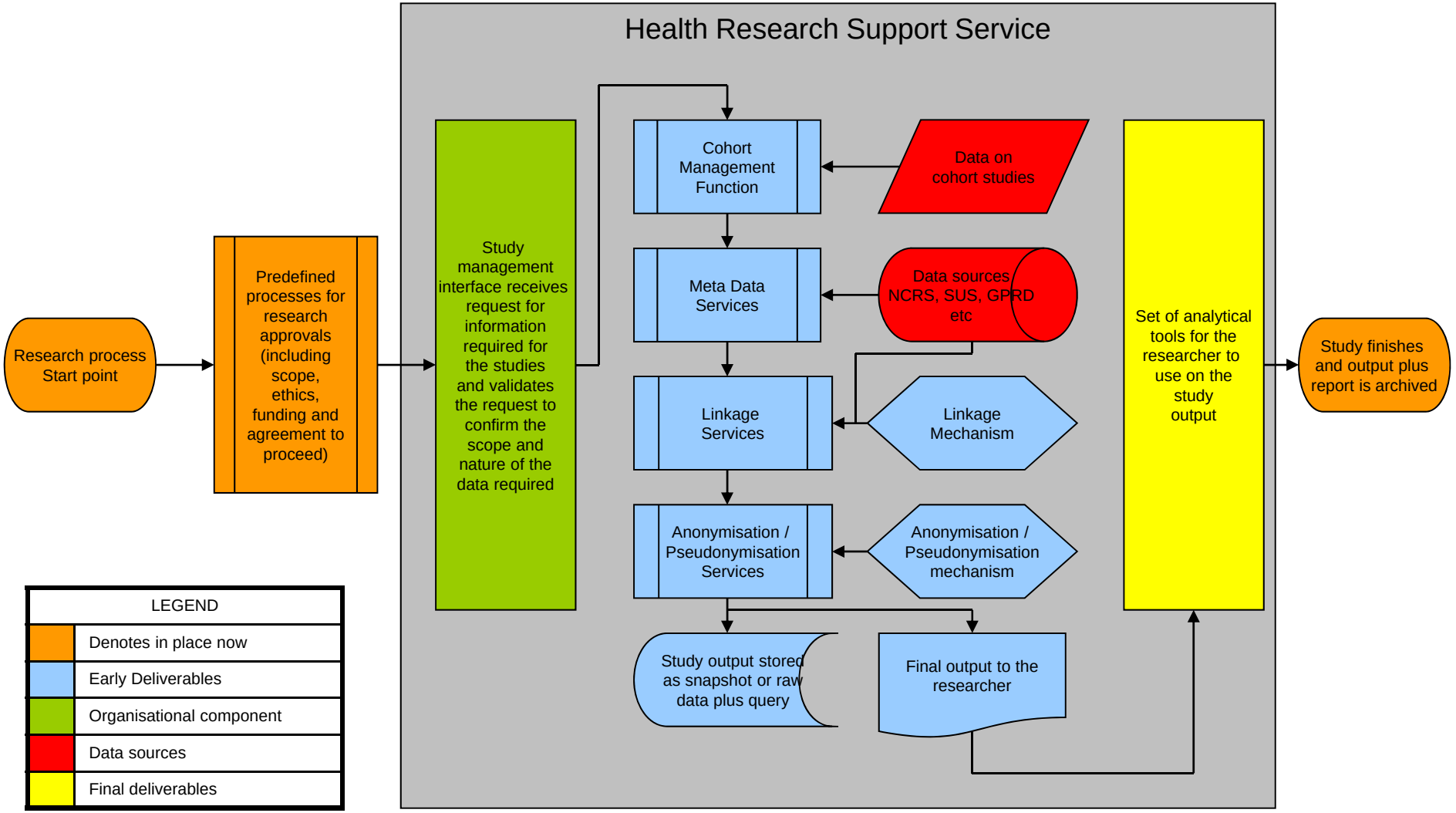

Programme Phases

Phase 1	Enabling phase	Aug 07 – June 08
Phase 2	Full programme Six stage programme	Jul 08 onwards

Phase 2 the Full Programme is well underway and has six stage to complete by March 2011 before the Programme is closed and the services are handed over to business as usual. There will be functionality operational in 2009 to the research community

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RCP – Implementation Phase

The Programme structure:

- Business Cases and Procurement Project
- Commissioning of the IG Services Programme
- **Pilot Programme**
- Public Consultation Project
- Programme Communication
- Programme Assurance

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Health Research Support Service (HRSS) Pilot Programme

The HRSS Pilot Programme

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Background:

- A sub Programme of the Research Capability Programme, alongside the Strategic Procurement and IG and Compliance areas.
- Planning to implement the *initial* RCP capability – utilising a Pilot / demonstrator approach

Objectives:

- Prove the functionality
- Demonstrate some initial benefits to engender confidence (Quick Wins)
- Record and communicate useful learning on the Programme Management, DBT and live Service operations. (to mitigate some risks to the strategic procurement)

What is the Pilot HRSS

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- Will federate a (limited) number of data sources through a single point of access
- Link datasets and provide analysis of data and linkage quality
- Anonymise / pseudonymise / de-pseudonymise data
- Provide data to Health Researchers (within the agreed regulatory framework)
- Work within an agreed IG Framework and subject to independent IG audit
- Forge initial working relationships and business processes between HRSS and other regulatory bodies
- Capability to support observational studies and clinical trials

Current Programme Activities

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- Identified 10 studies to take forwards
- Identified 15 data sources to take forwards
- Created 2 x Memoranda of Understanding (MOU)
- Formally working with study and data owners towards MOU agreement
- Created Input Based Specification (IBS)
- Infrastructure Procurement documentation nearly complete (includes IBS)
- Infrastructure supplier procurement due to complete July 2009

High Level Programme Timeline

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July – November 2009

- Commence recording & communications of lessons learned (ongoing)
- Data and study owner readiness activities and pre go live testing
- DBT of infrastructure

November 2009

- Service Go Live
- Commence internal and independent IG audit (ongoing)

December 2009 – May 2010

- Implement studies
- Scope and plan additional studies / uses as appropriate
- Establish, communicate benefits (ongoing)

May 2010 – August 2010

- Implement additional studies / uses as prescribed

September 2010 – October 2010

- Plan and implement transition to strategic solution
- Complete, communicate final lessons learned and Benefits reports
- Close Programme

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More information

www.connectingforhealth.nhs.uk/systemsandservices/research

From there you will also find links to:

- The DH Strategy *Best Research for Best Health*
- The report of the UKCRC Advisory Group to CFH
- The report of the CRDB SUS Working Group