Information and the Research Agenda

Peter Knight
Programme Director
CfH Research Capability Programme

Core Objective #5:
Enabling use of cancer information to support audit and research programmes

Electronic Health Records for Research

Research Capability Programme

Overview

Peter Knight

Programme Director

Research Capability Programme

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
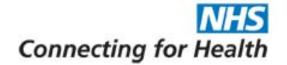
What is the Research Capability Programme?

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.

Why is it needed?

"The development of the SCR and DCR [NHS Care Records Service] will offer the SUS access to clinical data which are more timely, better integrated and of a significantly higher quality than those currently available. This is likely to transform the SUS and offers significant benefits, most notably for health research. ……. more should be done to ensure that these opportunities are maximised. We make several recommendations for improving access to data for research purposes."

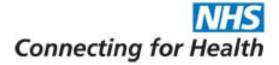Health Select Committee Report

September 2007

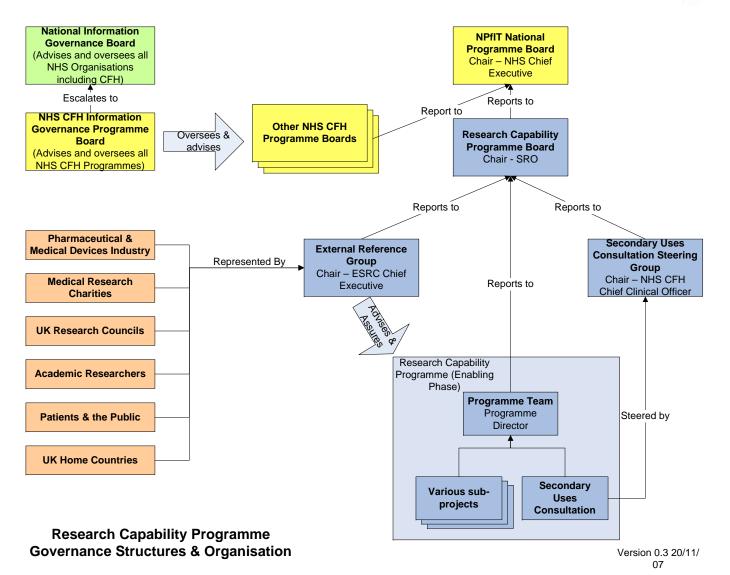# *What are the potential benefits for research*

- 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

What challenges do we face?

- Ensuring the opportunities are maximised

- Developing better linkage between new and existing databases

- Data quality and standards

- Information Governance:
    - Patient confidentiality;
    - Access – who, when, where, what, how, why;
    - Pseudonymisation / anonymisation;
    - Patient consent.

- Consolidating different stakeholder views e.g. professional Vs patient groups or across different professional groups

NHS
Connecting for Health

National Information Governance Board
(Advises and oversees all NHS Organisations including CFH)

Escalates to

NHS CFH Information Governance Programme Board
(Advises and oversees all NHS CFH Programmes)

Oversees & advises

Other NHS CFH Programme Boards

NPfIT National Programme Board
Chair – NHS Chief Executive

Reports to

Report to

Reports to

Research Capability Programme Board
Chair - SRO

Reports to

Reports to

Pharmaceutical & Medical Devices Industry

Medical Research Charities

UK Research Councils

Academic Researchers

Patients & the Public

UK Home Countries

Represented By

External Reference Group
Chair – ESRC Chief Executive

Advises & Assures

Secondary Uses Consultation Steering Group
Chair – NHS CFH Chief Clinical Officer

Reports to

Research Capability Programme (Enabling Phase)

Programme Team
Programme Director

Steered by

Various sub-projects

Secondary Uses Consultation

Research Capability Programme Governance Structures & Organisation

Version 0.3 20/11/07

Timelines

Phase 1   Enabling phase   Complete

Phase 2   Full programme   June 08 onwards
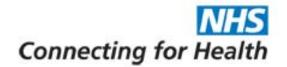   Stage 1 underway

Enabling Phase

- **Has achieved**:
  - Appointment of Programme Chair (SRO) and Director
  - Establishment of a programme board
  - An agreed phase 1 Programme Initiation Document
  - Agreed terms of reference for an external reference group operating under the aegis of the Office for Strategic Co-ordination of Health Research (OSCHR)
  - Engagement with stakeholders to create a common vision
  - Substantial progress on the recommendations identified in the UKCRC report
  - A defined scope of work for the Programme and for related initiatives
  - Production of a high level requirements documentation
  - An approved Strategic Outline Case
  - A draft Programme Initiation Document Phase 2
  - Development of the genesis of an Outline Business Case
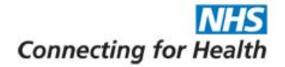
Delivered by six work-streams

- Technical Architecture
- Functional Scope and Business Case
- Data Quality, Standards and Linkage
- Information Governance and Threat Assessment
- Infrastructure
- Communications and Stakeholder Engagement

RCP - Next Steps Jun to Dec 08

Jun/Jul	Aug/Sep	Oct to Dec
Outline Business Case (OBC)		Public Procurement of services using catalogues suppliers where possible.
Input/Output Based Specification (I/OBS)1	I/OBS 2	
Procurement Strategy (PS) 1	PS 2	
Service Model (SM) 1	SM 2	Full Business Case
Informal Industry Soundings	Further Industry Soundings	
Approval of OBC	Approval of Final OBC	

Jan 09 approvals and mobilisation

In summary

We are making good progress on the journey

Much work is ahead before the full benefits can be realised

Some good preparatory work has already been undertaken and this continues but…..

….. don't underestimate the challenges ahead

We will continue at a safe and steady pace

We will thoroughly engage stakeholders to ensure a common vision and agreement on the way forward

We are committed to maximising research to achieve its full potential to improve the quality and safety of care

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 NHS CFH
- The report of the CRDB SUS Working Group

Contact us via the following email address:

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