NHS
Connecting for Health

Research Capability Programme

Overview

Prof Alex Markham
Research Capability Programme - SRO

NHS
Connecting for Health

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
- December 2006 – Cooksey Report and OSCHR
- 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?

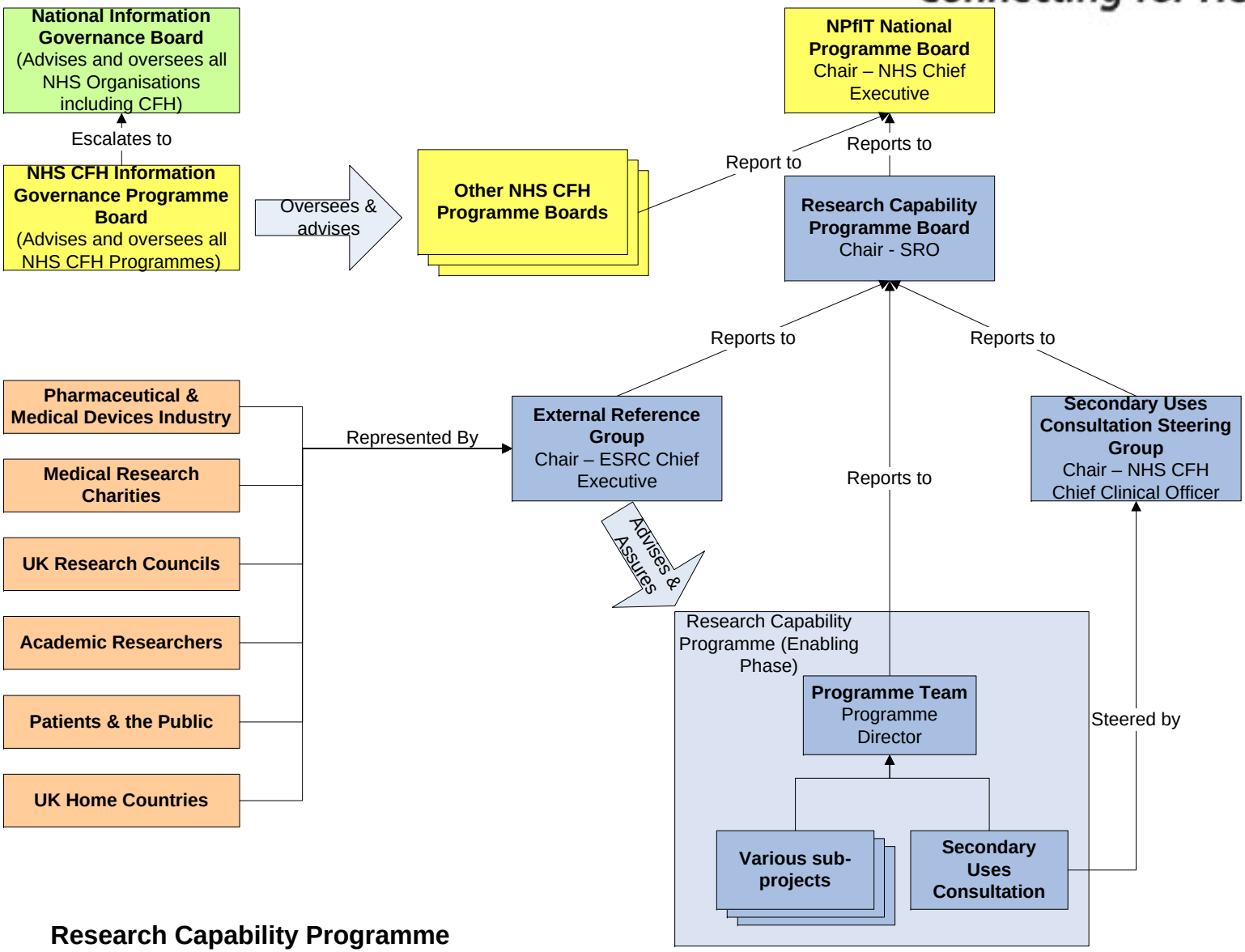
NHS Connecting for Health

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.



Research Capability Programme Governance Structures & Organisation

Version 0.3 20/11/07

NHS Connecting for Health

Research Capability Programme
Programme Board Membership

Professor Sir Alex Markham (Chair)	University of Leeds
Professor Ian Diamond	Economic and Social Research Council
Professor Michael Thick	NHS Connecting for Health
Dr Louise Wood	Department of Health
Jeremy Thorp	NHS Connecting for Health
Richard Jeavons	NHS Connecting for Health / DH
Marc Taylor	Department of Health
Peter Knight	NHS Connecting for Health
Dr Paula Whitty	North East SHA Chief Information Officer

NHS Connecting for Health

Research Capability Programme
External Reference Group Membership

Professor Ian Diamond	ESRC (Chair)
Dr Richard Barker	ABPI
Rob Thwaites	GSK
Dr Alan McDougall	Astra Zeneca
Dr Charles Brigden	Amgen
Dr David Roblin	Pfizer Global R&D
Dr Paul Cload	GE Healthcare
Dr John Parkinson	PGRD, MHRA
Professor Ronan Lyons	HIRU
Professor Tony Avery	University of Nottingham
Professor Frank Sullivan	University of Dundee
Professor Rory Collins	UK Biobank / Oxford
Professor Carol Dezateux	ICH, UCL
Professor Paul Elliot	Imperial College
Professor John G Williams	University of Swansea
Dr Louise Wood	NIHR
Dr Tim Hubbard	Wellcome Trust
Dr George Sarna	MRC
Christine Vial	Patient / Public Member
Tony Sargeant	Patient / Public Member
Nick Partridge	INVOLVE

Why is it needed?

NHS Connecting for Health

"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

Guide to Acronyms

UKCRC – United Kingdom Clinical Research Collaboration

CRDB – Care Record Development Board (superseded by the NIGB)

NIGB – National Information Governance Board (established October 2007)

NHS CRS – NHS Care Records Service

SCR – Summary Care Record

DCR – Detailed Care Record

SUS – Secondary Uses Service

R&D – Research and Development

OSCHR – Office for the Strategic Coordination of Health Research

NHS
Connecting for Health

RCP Aspiration

- Improve access to existing NHS data and reduce need for using identified data, i.e. create infrastructure to:
  - Provide access to centrally or federally managed healthcare datasets.
  - Support effectively anonymised linkage of independently managed data sources.
- Develop the data sources within the NHS, i.e. develop point of care data collections into NHS CRS systems (i.e. support the overall aspiration of NPfIT).
- Disseminate knowledge, i.e. inform NHS best practice using the results of research.

NHS
Connecting for Health

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

NHS
Connecting for Health

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

RCP Data Sources?

- Assessing feasibility of:
  - Demographic Data (NHS patient index)
  - Vital events (births, deaths)
  - Primary care clinical records (GP system extracts, research collections)
  - Secondary care clinical records (Hospital system extracts, research collections)
  - NHS National Data Collections (HES/MHMDS)
  - NHS CRS National Systems (Summary Care Record, Choose and Book, Electronic Prescription Service)
  - Disease Registries (National and Regional)
  - Diagnostic data (Laboratory tests)
  - NHS Specialist Collections (Clinical Audit)
  - Other data collections (research datasets, education, social care, deprivation, socio-economic)

Timelines

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

Phase 1 has determined the timelines and milestones for phase 2

NHS
Connecting for Health

Enabling Phase (to June 2008)

- Define the scope of work for the new Programme and for related initiatives
- Prepare programme initiation documents
- Identify a programme director
- Establish a programme board
- Agree terms of reference for an external reference group operating under the aegis of the Office for Strategic Co-ordination of Health Research (OSCHR)
- Make substantial progress on the recommendations identified in the UKCRC report
- Engage with stakeholders to create a common vision
- Establish the subsequent phases of the Programme ready for commencement in June 2008.

NHS
Connecting for Health

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

Key Deliverables (1):

NHS Connecting for Health

- Technical
  - PD01: Architecture Options Appraisal
  - PD02: Preferred Technical Architecture & Specification
  - PD03: Proof of Concept Approach
  - PD04: End to End Proof of Concept Report
  - PD05: Technical Data Access Report
  - PD09: High Level Non-Functional Requirements

Key Deliverables (2):

NHS Connecting for Health

- Functional Scope & Business Case
  - PD06: Functional Requirements
  - PD07: Functional Scope and Feasibility
  - PD08: High Level release Schedule
  - PD10: Business Case

- Data Quality, Standards and Linkage
  - PD11: Approach to Data Quality, Standards and Linkage
  - PD12: Data Quality, Standards and Linkage Report

Key Deliverables (3):

NHS Connecting for Health

- Information Governance and Threat Assessment
  - PD13: Threat Assessment
  - PD14: Pseudonymisation Study
  - PD15: Patient Consent Approach
  - PD16: Information Governance Framework
- Infrastructure
  - PD18: The Case for a Data Custodian (Honest Broker)
  - PD19: Specification of Requirements for an “Honest Broker”
  - PD20: Implementation Plan
- Communications and stakeholder engagement
  - PD17: Consultation Report
  - Information to support programme understanding
  - Stakeholder engagement

Underpinned by programme plans, initiation documents, stakeholder engagement and strong governance controls

NHS
Connecting for Health

Progress of the Programme

- The programme is in the enabling phase, which is due to complete in June 2008
- All six work-streams have delivered products
- The External Reference Group is shaping, quality assuring and signing off the requirements
- Stakeholder engagement is underway

NHS
Connecting for Health

How are stakeholders being engaged?

Representation on the External Reference Group:

The External Reference Group has been established and has common membership with the OSCHR E-Health Research Board, as well as the same chair, in order to ensure coordination of activities. It includes representation from a wide range of stakeholders as well as patients/public and UK Home Countries.

A public consultation

To test the findings and recommendations of the CRDB SUS working group report with professionals and patients and to probe public attitudes towards the use of medical information for research purposes.

NHS
Connecting for Health

Summary of Programme Update

- Products are emerging that should be fit for purpose and will deliver the aims of the programme
- Expert input, quality assurance and sign-off is delivering the requirements
- Wider engagement with the research community, patients and the public is underway
- *Your input is vital to get the right products delivered*
- The next phase, which turns requirements into products that R&D can use

In summary

NHS Connecting for Health

We're at the beginning of 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

NHS Connecting for Health

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

NHS
Connecting for Health

Contact details

Peter Knight: peter.knight@nhs.net

NHS
Connecting for Health

The NHS Care Records Service (NHS CRS)

- The NHS in England is introducing the NHS Care Records Service. This is to improve the safety and quality of patient care.
- It will give health care staff faster, easier access to reliable information about the patient to help with treatment.

NHS
Connecting for Health

NHS CRS

There are two elements to the NHS CRS: detailed records (held locally) and the Summary Care Record (held nationally).

- The NHS CRS will enable each person's detailed records to be securely shared between different parts of the local NHS, such as GP surgery and hospital.
- Patients will also be able to have a summary of their important health information, known as their Summary Care Record, available to authorised NHS staff treating them anywhere in the NHS in England.

NHS
Connecting for Health

NHS CRS

The NHS CRS is a secure service that links patient information from different parts of the NHS electronically, so that authorised NHS staff and patients have the information they need to make care decisions.

NHS
Connecting for Health

Programme Update

Work-stream activities and progress

NHS
Connecting for Health

Programme Update

Context of the Research Capability Programme in Connecting for Health Programmes (i.e. National Care Records Service)

NHS Connecting for Health

Work-stream Progress (1)

- **Technical**
  - *Products completed:*
    - PD01: Architecture Options Appraisal
    - PD03: Proof of Concept Approach
  - *Products in production:*
    - PD02: Preferred Technical Architecture & Specification
    - PD05: Technical Data Access Report
    - PD09: High Level Non-Functional Requirements
  - *Activities underway:*
    - End to End Proof of Concept

NHS Connecting for Health

Work-stream Progress (2)

- **Functional Scope & Business Case**
  - *Products completed:*
    - PD06: Functional Requirements
  - *Products in production:*
    - PD07: Functional Scope and Feasibility
    - PD08: High Level Release Schedule
  - *Products to be initiated:*
    - PD10: Business Case

NHS Connecting for Health

Work-stream Progress (3)

- **Data Quality, Standards and Linkage**
  - *Products completed:*
    - PD11: Approach to Data Quality, Standards and Linkage
  - *Products in production:*
    - PD12: Data Quality, Standards and Linkage Report

- **Information governance and Threat Assessment**
  - *Products completed:*
    - PD15: Patient Consent Approach
  - *Products in production:*
    - PD13: Threat Assessment
    - PD14: Pseudonymisation Study
    - PD16: Information Governance Framework

NHS Connecting for Health

Work-stream Progress (4)

- **Infrastructure**
  - *Products in production:*
    - PD18: The Case for an Honest Broker
    - PD19: Specification of Requirements for an Honest Broker
    - PD20: Implementation Plan

- **Communications and stakeholder engagement**
  - *Products in production:*
    - PD17: Consultation Report
  - *Activities planned:*
    - Stakeholder engagement events
    - Public consultation

NHS
Connecting for Health

Research Capability Programme Update

Peter Knight
Programme Director