



**National Institute for  
Health Research**

## **BEST RESEARCH FOR BEST HEALTH**

### **IMPLEMENTATION PLAN 1.2**

## **THE NIHR INFORMATION SYSTEMS PROGRAMME**

*Best Research for Best Health*<sup>1</sup> set out a 5-year Research and Development Strategy for the NHS in England. This Implementation Plan provides more details on one of the key components of that strategy: the NIHR Information Systems Programme, a cross cutting programme for the entire NIHR. This document will be regularly updated. The latest version should be used. This Implementation Plan subsumes Implementation Plan 4.2.

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### **Aim**

- To provide systems, services and the technical framework through which the Department of Health can position, maintain, support and manage the health research systems including research staff and research infrastructure of the NHS in England as a national research facility.
- To support a vibrant and efficient research environment that commands public confidence and protects research participants through:
  - world class networks for research management and governance; and
  - action to simplify processes that use research time.

### **Purpose**

- To create, with partners where appropriate, an integrated set of national systems for health research and research management that will:
  - unify and simplify the administrative procedures associated with regulation, governance, reporting and research administration;
  - enable procedures and input of data to take place once only, recognising the interdependency of systems and processes;
  - make information supporting regulatory approvals and permissions available via secure systems and processes to everyone who needs to act on it; and
  - support and integrate the operational functions of the National Institute for Health Research.

<sup>1</sup> *Best Research for Best Health*: A New National Health Research Strategy. The NHS contribution to health research in England. Department of Health. 2006.

**Nature**

The programme:

- Has launched and will continue to develop the NIHR Portal.
- Is developing the national R&D information management systems (RDMIS) architecture and application components and has delivered the first phases of those systems.
- Is working with relevant bodies and stakeholders to define data standards and processes for NIHR research, to facilitate the exchange of information within the NIHR and with its partners.
- Has delivered systems to support a streamlined process leading to permission to begin a study.

**The NIHR Portal currently:**

- Provides the internet and intranet facilities for the NIHR.
- Supports people in the NIHR research networks and other NIHR organisations.

**The NIHR Portal will:**

- Act as the first point of entry for researchers into a range of secure services and applications to support and develop research.
- Support individuals who are involved, or want to become involved, in health and social care research, including researchers, R&D managers, policy makers, patients, service users and the public.
- For research which is to be supported through the NIHR, to provide a unified interface for all the information required for ethics review, NHS site-specific permissions and regulatory authorisation of clinical trials.
- Give easy access to information, documents, guidance and people to help investigators and R&D managers work efficiently and consistently.
- Offer a central resource of information on each study's design, organisation and progress to facilitate R&D management and inform the public.
- Provide access to a national repository (or network of repositories), where all NIHR investigators can archive protocols, data and conclusions.
- Provide the public internet facility for all NIHR organisations thereby achieving the objectives of transformational government.
- Be the primary on-line communications channel for the whole of NIHR.

**The R&D information management systems (RDMIS) will:**

- Enable the provision of information about NIHR studies so that patients can be informed about research that is of particular relevance to them.
- Enable researchers and research managers to access and manage the information and guidance required to operate efficiently and participate in high quality patient- and people-based R&D with proper governance.
- Provide standard underpinning systems and services to support the operation of all the main elements of the NIHR including commissioning, funding, approvals, research management and outputs.
- Be the national source of information relating to NIHR studies.

- Provide web-oriented application programme interfaces and infrastructure to promote the secure integration of existing systems.
- Enable the facility for “once only” research study data-entry, thus removing the need for data to be entered multiple times in different systems and, in the process, addressing associated data integrity issues.
- Reduce the administrative burden of proposals, applications and reporting, releasing effort to manage outcomes and enable more effective monitoring and review.
- Include the provision of a Standard Application Form to provide a common gateway to NIHR funding.
- Include the development of customised modules that meet the needs of individual NIHR organisations as part of the overarching NIHR systems architecture.

**The *data standards and handling processes* will:**

- Review, define and publish standards and workflow processes.
- Maintain a repository of data standards for the NIHR and its partners, and adopt international standards where relevant.
- Enable researchers to exchange standard data sets and documents with organisations that require reports and outputs for regulation, accountability, or the administration of grants and contracts.
- In particular, enable exchange of standard data sets between:
  - NIHR research networks/organisations in them;
  - NIHR programmes;
  - research funders;
  - research ethics service;
  - MHRA/EUdraCT;
  - other regulators; and
  - recognised trial registers and other registers of relevant studies.
- Enable standard data sets and documents to be linked to UK Pubmed, and to the relevant elements of the NHS National Knowledge Service and other systems providing access to research outputs.

**Benefits**

The programme seeks to enable the following benefits:

- Improved efficiency and effectiveness of research commissioning and initiation by giving policy makers, commissioners and researchers a clearer view of research requirements; and by supporting researchers and research networks.
- Reduced time taken in seeking ethical and regulatory review by simplifying, clarifying and integrating processes; implementing web-based submission systems, research passports, advice and other services.
- To make the UK more attractive internationally as a site for research.
- Increased recruitment by enabling clinicians, patients and the public to gain easy access to information about current trials and other well-designed studies.
- Improved uptake of findings by increasing the visibility of NIHR research findings:

- supporting the principle of open access to health research outputs by making NIHR outputs readily available through systems used by decision-makers; and
- working with partners to contribute to international collaboration.

## Approach

The programme is being delivered by the NIHR Information Systems team. Working closely with the RCP Programme it will include the development, integration and standardisation of previous investments in NHS R&D management information systems.

The programme director and his team will:

- engage with stakeholders (including local NHS communities through the Comprehensive Local Research Networks) to define needs and priorities;
- undertake business and technical analysis to define and maintain requirements, system architecture and standards;
- undertake the development of IS applications to meet researcher and research management requirements, within the framework of an overarching strategic technical architecture;
- explore opportunities for integration with NIHR and other key technical stakeholders in the NHS, HE, RCUK, charities, industry, UK government and international research community; and
- undertake quick expert studies to take stock of developments in electronic research management, identifying opportunities, limitations and barriers to integration;
- Establish a Business Change workstream and External Reference Groups that enable stakeholders and users of NIHR systems to participate in the development of those systems and ensure that benefits are identified and realised.

## Activities

- Working with all NIHR organisations including Clinical Research Networks, Programmes (NETSCC, TCC and NIHR-CCF), the NIHR Faculty and NIHR Research Centres to ensure that:
  - a consistent and comprehensive approach to information systems underpins R&D management in the NIHR; and
  - shared systems used for local R&D management are linked to integrated national information management systems.
- In particular, delivering the products and services described in the:
  - Programme Mandate;
  - Programme Brief;
  - Outline Business Case.

These and other related documents are available on the NIHR website:  
[www.nihr.ac.uk/systems/Pages/systems\\_research\\_information\\_systems.aspx](http://www.nihr.ac.uk/systems/Pages/systems_research_information_systems.aspx)

## Scope

- The NIHR Portal and research information systems will be designed primarily to support and manage the activities of researchers, and research managers preparing and conducting studies for which the NIHR is to accept or has accepted responsibility. The systems will support the overall functions of the National Institute for Health Research.
- All organisations and individuals in England that provide care, fund research, employ researchers or review or regulate research will be eligible for access related to their needs.
- The main aim will be to provide specialist information services for research and not services to the public or to business. Summaries of the information will be publicly accessible, subject to exemptions provided by the Freedom of Information Act and the Data Protection Act.

## Governance, Monitoring and Performance Management

- A NIHR IS Executive Board oversees the delivery of the planned systems. It reports to the Department of Health through the NIHR. Programme Boards have been established for the NIHR Portal and the RDMIS development. Individual project boards and external reference groups with appropriate stakeholder representation are established as required.
- The performance of the information management system(s) will be reviewed regularly against process performance and user satisfaction metrics.
- The programme board will report annually to the NIHR.
- The implementation and use of the information management systems will be monitored to ensure they are being used as required and delivering the intended benefits.

## Implementation Timetable

The programme board will confirm programme deliverables, planned benefits and implementation plans after discussion with stakeholders. Progress reports are available on the NIHR website at:

[www.nihr.ac.uk/systems/Pages/systems\\_research\\_information\\_systems.aspx](http://www.nihr.ac.uk/systems/Pages/systems_research_information_systems.aspx)

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