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For more information about the Research Capability Programme or to request further copies of this brochure please visit:

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



Health Research Support Service

Improving health through research

Introduction



The Health Research Support Service (HRSS) is a ground-breaking service to help researchers analyse a wide range of healthcare and other data. The service is being developed by the National Institute for Health Research's Research Capability Programme.

The Health Research Support Service (HRSS) will allow researchers to carry out studies and clinical trials that lead to more effective treatments and improved health outcomes, patient safety and quality of life.

This will be achieved by analysing and understanding trends in patient and other data. The service will safeguard patient confidentiality by anonymising data wherever possible or ensuring any approvals, required in some cases by the regulatory authorities or governance structures, have been provided before any data is processed for researchers. This mechanism will be an improvement on the current situation as it will allow better control over governance of data usage.

Researchers will be able to review health data sets such as disease registries, primary care, death registries, hospital episodes and birth registries, augmented by other data sets such as demographic, socio-economic and geo-spatial data, to analyse emerging trends and potential solutions. Having a single National Health Service across the country puts the UK and UK researchers in a unique position to be able to do this, for the benefit of patients and the public.



The Service

The HRSS will link together data for researchers to use for research studies. The service will allow researchers to use patient data (while protecting patient confidentiality and identity) for health research studies or clinical trials. The HRSS will allow health researchers to access high quality patient data quickly and efficiently.

The HRSS will support and promote health research in the UK by:

- Increasing the data routinely available to support health research
- Providing services and functions to prepare for and support research; and
- Providing services and functions to protect personal information.

How can the HRSS be used by researchers?

The Health Research Support Service will give researchers approved access to information, for them to analyse as part of their research studies.

Researchers wanting to use the HRSS will first need to have their research approved by independent groups who assess regulatory, ethical, scientific and confidentiality compliance.

www.nres.npsa.nhs.uk
and www.nigb.nhs.uk/ecc

Researchers likely to use the service will be NHS health professionals, academic researchers, or those working in the pharmaceutical, biotechnology or medical device industries who are developing important new treatments and ways of delivering improved care.

The service is likely to be of most use to:

- Observe trends in infectious diseases
- Monitor the safety and efficacy of prescribed drugs
- Assess occupational, environmental and other risks to public health
- Evaluate new treatments and interventions through clinical trials
- Carry out audits to help to inform healthcare management
- Evaluate pioneering new medical devices, surgical procedures and treatments.



The HRSS Pilot Programme

An HRSS Pilot Programme has been set up to prove the service works and realise some initial benefits of the proposed full Health Research Support Service. Running the Pilot HRSS allows NIHR to learn more about the challenges of acquiring, processing, linking and de-identifying data so clinical researchers have timely access to high quality data.

The Pilot HRSS will allow a limited number of research studies to use the Service for their research. The Pilot HRSS will be able to access a small but significant number of data sources relevant to the studies and link those data sources together. Datasets could even be analysed at the person level so researchers can track a single individual's medical history without ever knowing who that person is. The Pilot HRSS will demonstrate these processes, create useful lessons learned and provide feedback for the development of the main service.

Researchers need to be confident that data is robust and of known quality in order to generate accurate predictions for new trends in illnesses and find new treatments and clinical solutions. Poor quality data can make research results less meaningful and in some cases, inaccurate.

Data is often linked together from a number of different sources. The Pilot HRSS will test how to best link these different systems together to enable high quality research outcomes. This could reduce the number of steps researchers need to go through to access various data sources, allowing them more time to spend on the analysis of the data and their findings, and to answer new research questions.

The Pilot HRSS is due to begin in Autumn 2010.

Protecting patient confidentiality

Keeping patient data safe is a top priority for the Health Research Support Service. All data will be protected by strict controls:

- The vast majority of data supplied to researchers will be anonymised (i.e. it will not identify individuals in any way)
- If and when data which identifies individuals is requested, it will only be provided when patient consent procedures have been fully satisfied, including any approvals required from regulatory authorities.

- Data will only be provided for research projects which have ethical, scientific and information governance endorsement
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- Data will only be supplied to legitimate research organisations.
- And finally, the Health Research Support Service itself will be independently audited against the Information Governance Framework.



Benefits to patients and researchers

The Health Research Support Service is not a research body. It is being set up to support researchers and enable their research.

The new system will:

- Use research evidence much more effectively to improve health and healthcare for all
- Allow more patients and health professionals to participate in health research with high-quality protocols, enabling early access to new intervention and prevention strategies

- Provide greater capacity to invite the right type of patients to take part in clinical trials and to conduct the trials efficiently, which in turn leads to safer, more effective treatments
- Enhance the thriving research culture within the NHS
- Increase industry investment in clinical research in the NHS.

The research enabled by the HRSS will help:

- Find more effective ways of preventing, treating and managing illness
- Allow better use of NHS resources for curing and managing illness
- Improve prioritisation in NHS services and healthcare research as researchers begin to analyse and quantify the patterns of disease across the UK.

What do researchers need to do now?

The HRSS will be a valuable service for researchers providing unprecedented opportunities to carry out innovative research using health research data. More information about the HRSS can be found at:

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



About the NIHR Research Capability Programme

The Research Capability Programme is a National Institute for Health Research (NIHR) programme within the Systems work stream. The NIHR was established as a part of the "Best Research for Best Health" strategy. It is committed to ensuring

the NHS is an internationally recognised centre of research excellence through supporting outstanding individuals, working in world-class facilities, conducting leading-edge research focused on the needs of patients and the public.

The Research Capability Programme's 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 health research to achieve maximum potential benefit.

It will achieve this by providing a Health Research Support Service that enables high quality research directed towards improving health outcomes, effective treatment, patient safety and quality of life.

