

# NIHR Information Systems Programme

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**NHS HE Forum, London  
09 November 2006**



**Justin Riordan-Jones, R&D Information Manager, Department of Health**

## Best Research for Best Health: A New National Health Research Strategy

*The NHS contribution to health research in  
England: a consultation*



**Consultation 2005**

## Best Research for Best Health

*A new national health research strategy*

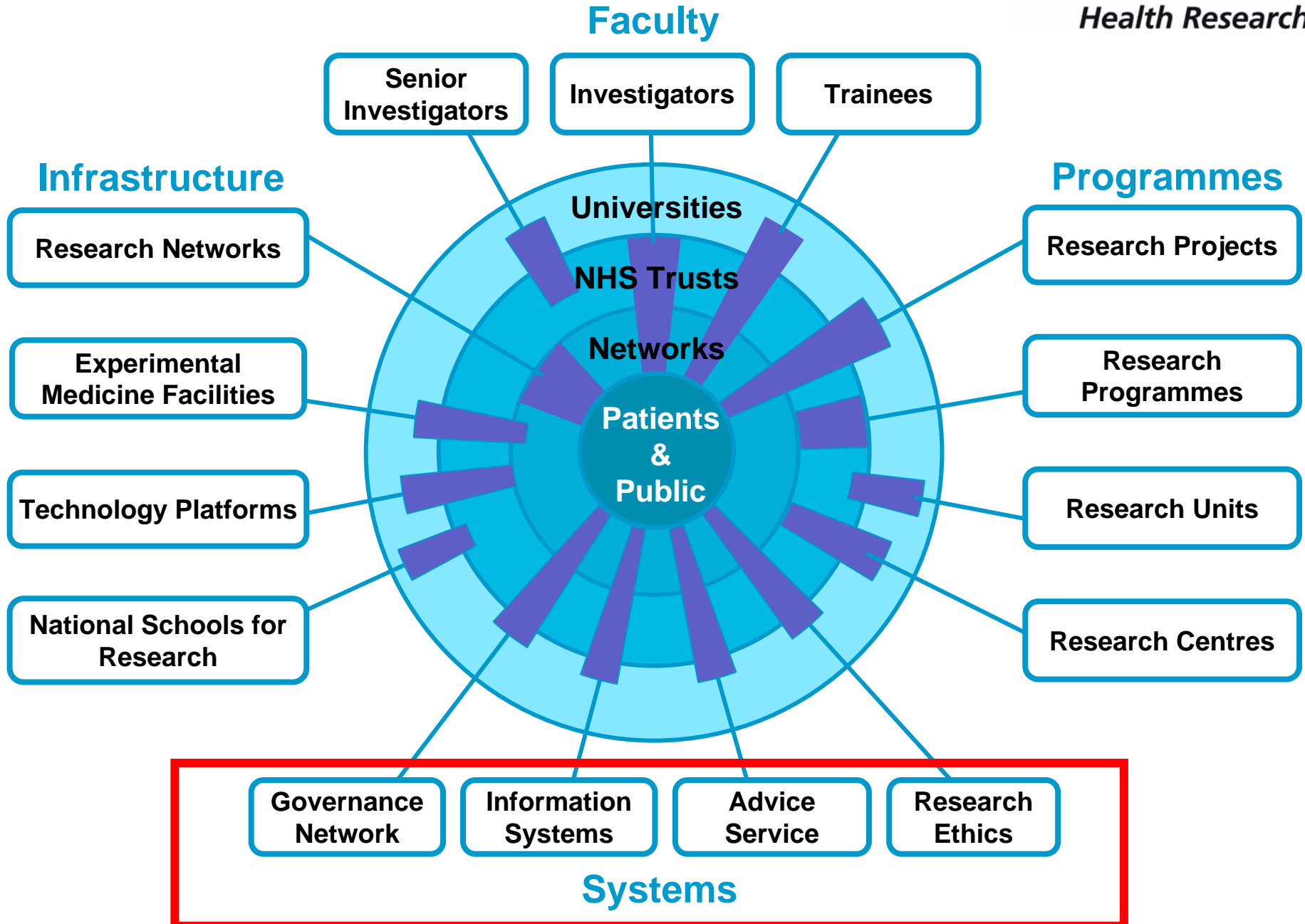




**New Government Strategy 2006**

# National Institute for Health Research



National Institute for  
Health Research



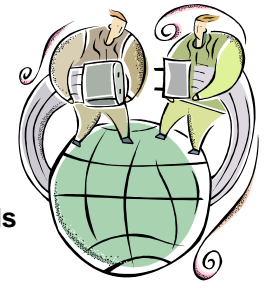
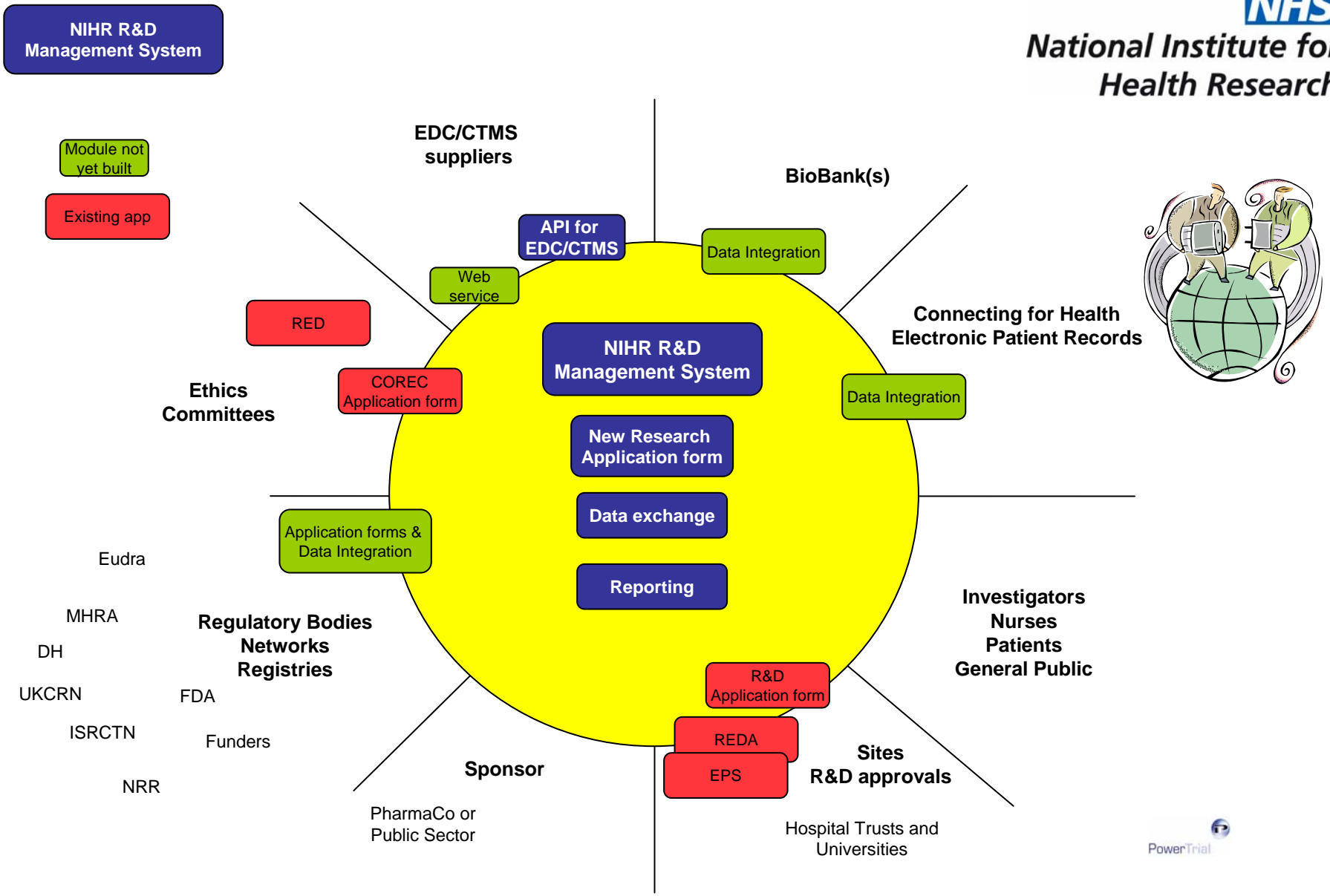
<b>Faculty</b>	 <p>Improving the health and wealth of the nation through research</p>	<b>Latest updates from NIHR</b>
<b>Programmes</b>		
<b>Systems</b>		
<b>Infrastructure</b>		
<b>Patient &amp; Public Awareness</b>		
<b>Working with Industry</b>		
<b>About us</b>		
<b>News</b>	<p>The National Institute for Health Research is now established as a part of the Government's strategy, 'Best Research for Best Health'. <a href="#">The Advisory Board</a> is complete and we are preparing for our first formal meeting in May 2006. Together we are committed to establishing the NHS as 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.</p> 	<b><u><a href="#">The Cooksey review &gt;</a></u></b>
<b>Publications</b>		
<b>Links</b>		
<b>Contact us</b>		

An illustration showing two hands, one from a person in a white lab coat and another from a person in a grey suit, holding a white ribbon that contains binary code (0s and 1s). The background is a grid of various colored squares (yellow, green, grey, blue).

# NIHR Information Systems

# Programme Scope

- Initially we will focus on developing:
  - NIHR Portal for Researchers and Research Managers
  - National R&D (Project) Management System(s) to support and manage the whole study lifecycle
- Bigger Picture
  - Devising an IS Strategy for NHS R&D



**Developing a whole systems approach to R&D information management to underpin implementation of BRfBH**

# NIHR IS Programme Objectives

Implement integrated systems that will:

- Enable streamlined and seamless management of R&D projects;
- Ensure a common approach via national system components;
- Enable easy, secure, personalised and dynamic input and retrieval of all information required for R&D and R&D Management;
- Have a research network and devices focus





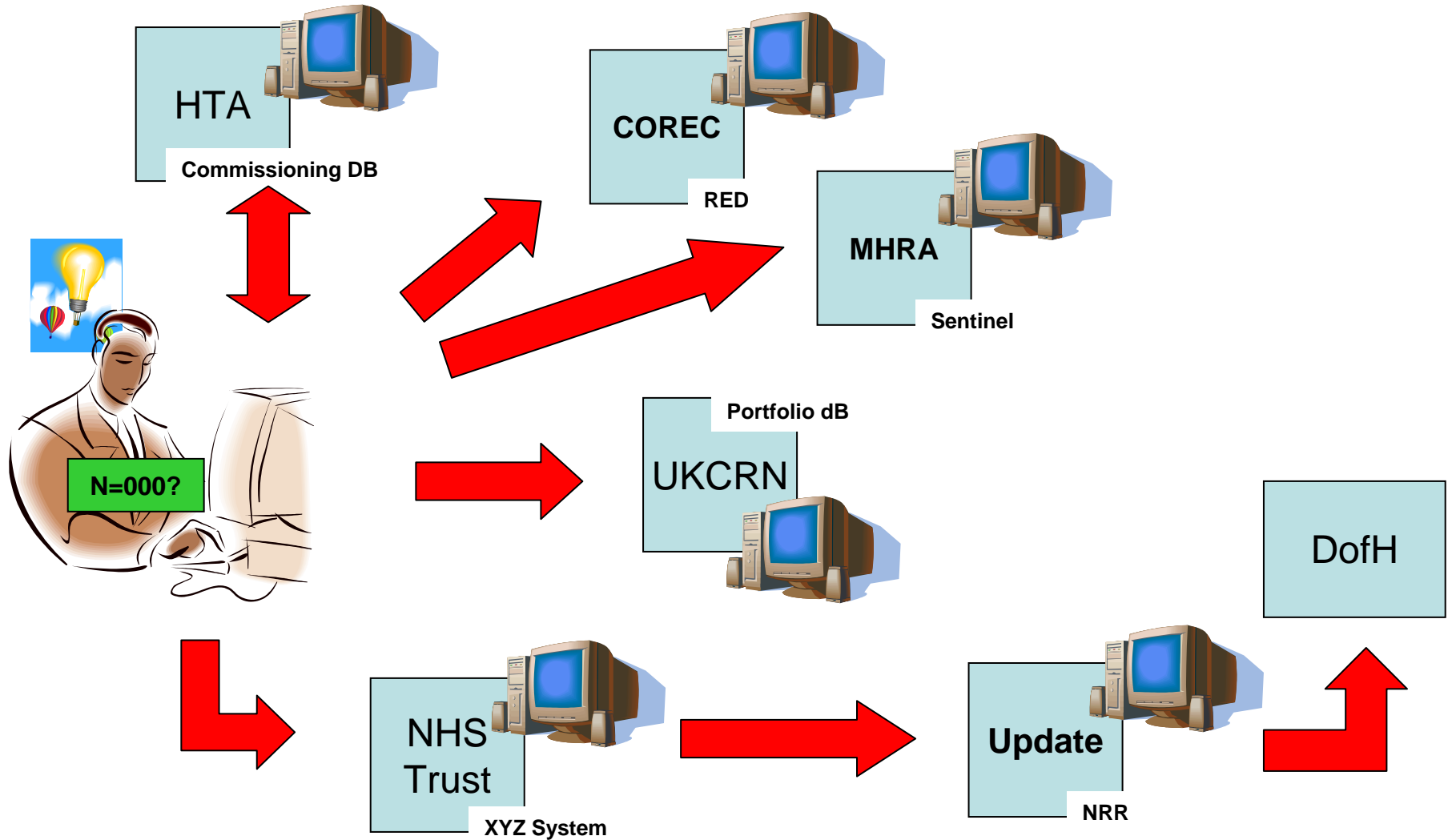
# R&D Information Management

## – What's the Problem ?

- Current management systems and processes are OK but they are:
  - Slow
  - Poorly understood
  - Inconsistent
  - Duplication – effort and information
  - Forms and “messaging” based
  - Inefficient
  - Misleading
  - Ridiculously complicated

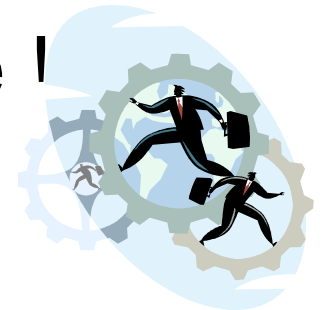


# Bureaucracy Busting



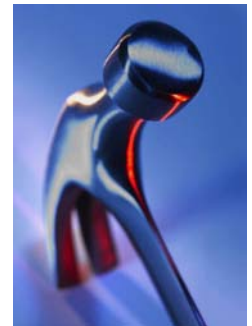
# We Need

- Data based systems to support the new BRfBH environment
- Clearly defined work flows with work flow management
- Integrated information systems to underpin the “whole system”
- Common systems used by everyone !

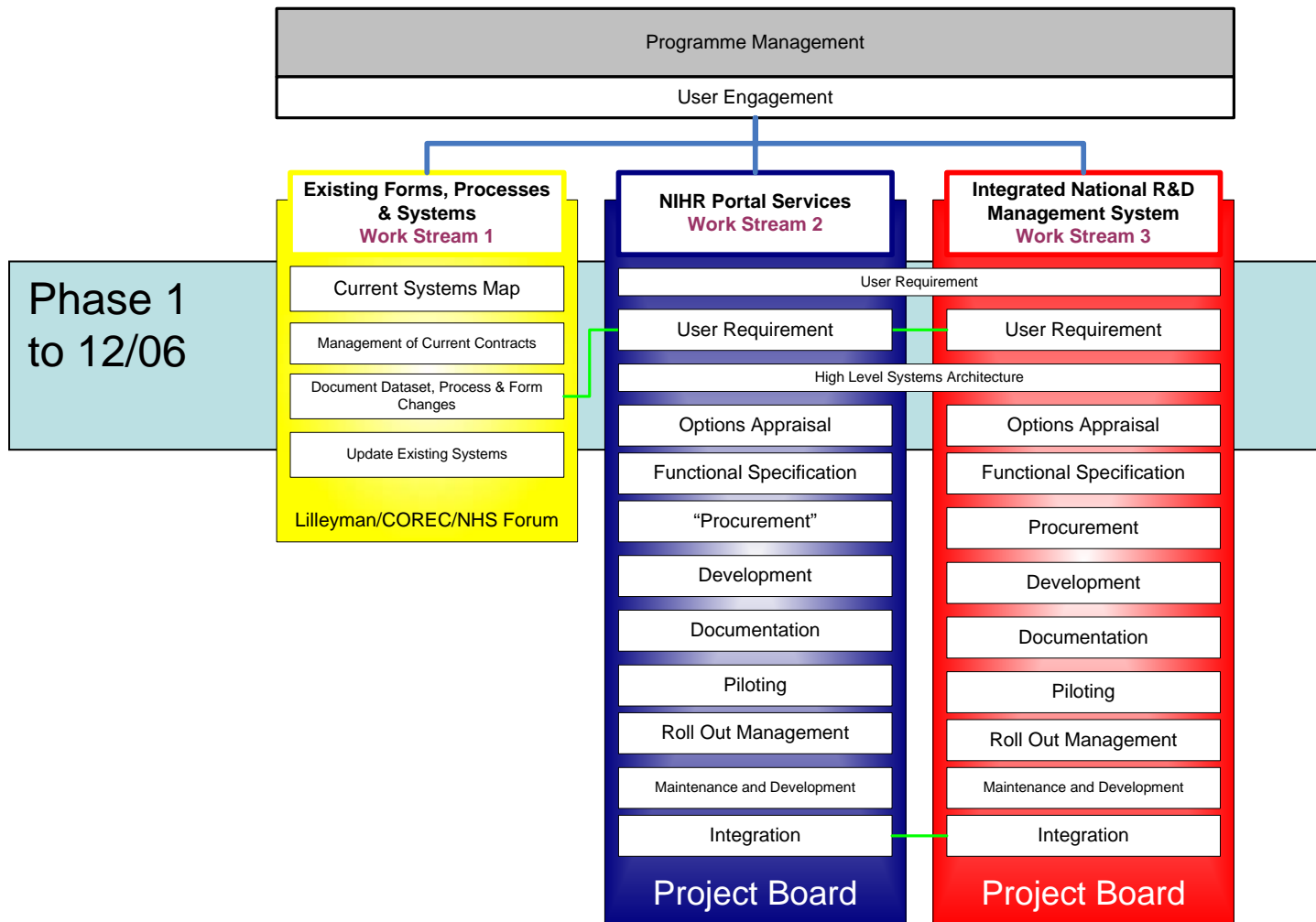


# NIHR IS Programme Approach

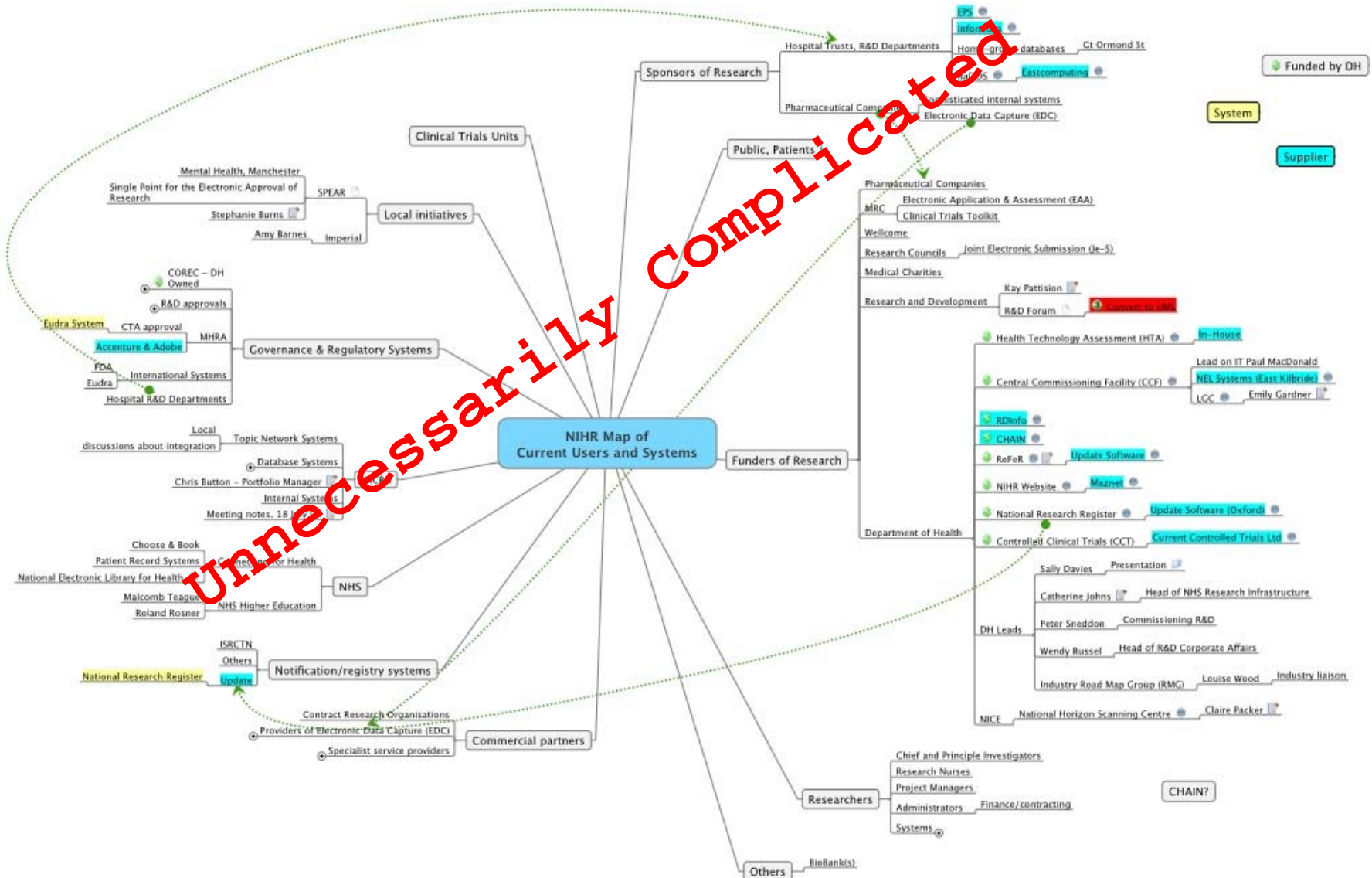
- Define and implement core national systems infrastructure:
  - NIHR Portal Services;
  - NIHR R&D Management Application with a clinical network focus;
- Involve users
- Take a **data** not a **forms** driven approach;
- Publish interface standards;
- Integrate with external systems at application and portal levels;
- Documents published on [www.nihr.ac.uk](http://www.nihr.ac.uk)



# Programme Work Structure



# Current Landscape



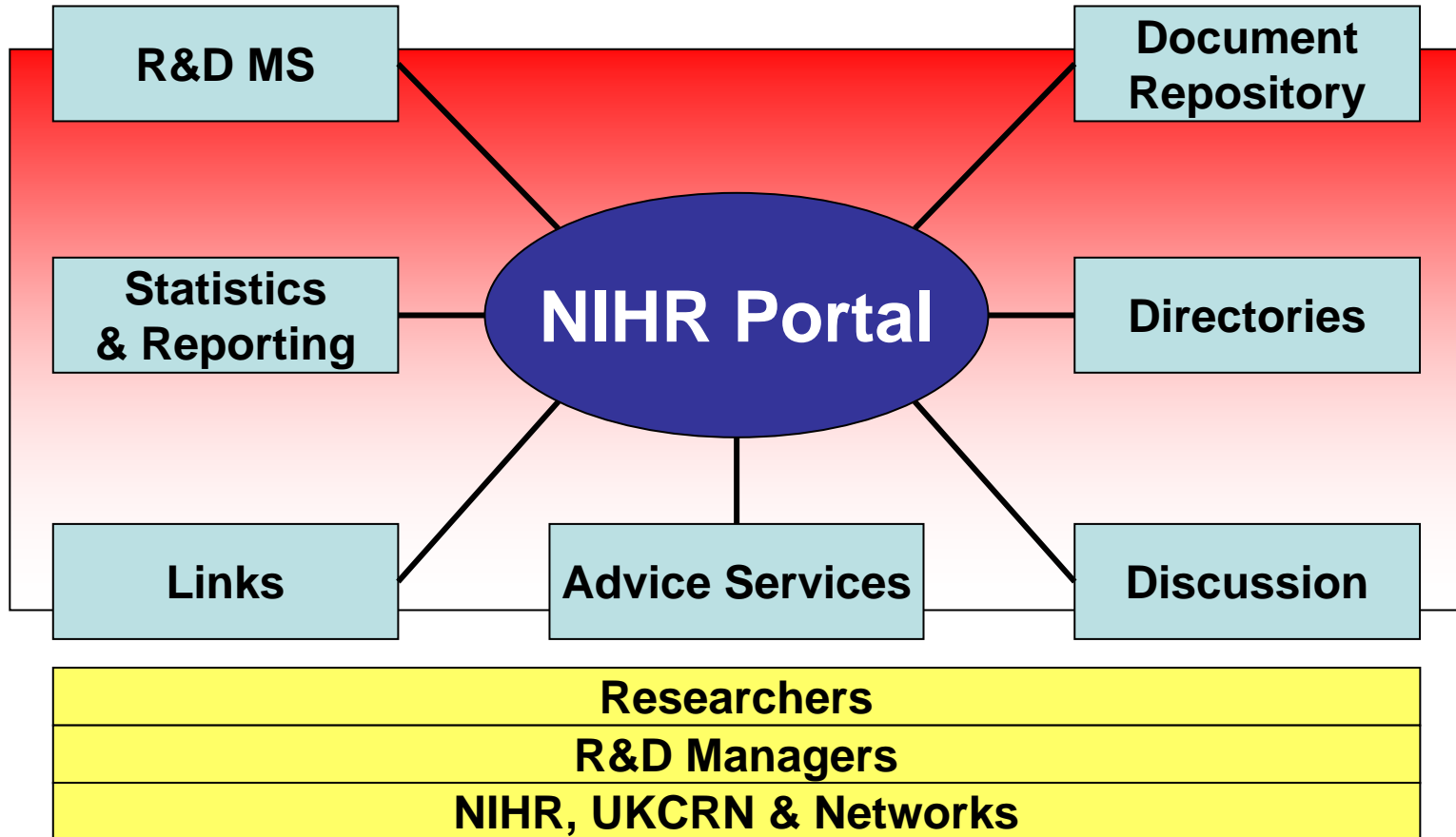
# Implementation

- Scalable, phased and flexible
- Build on what is good and best fit
- Impact on current local systems, we will:
  - Deliver national infrastructure and applications
  - Publish integration standards
  - Enrich the national infrastructure over time
- Provide strong support for users linked to strong performance management
- Consider all options for piloting
- Prioritise needs of networks





# NIHR Portal



# Key Features

- See NIHR Portal User Requirement v1.0 on [www.nihr.ac.uk](http://www.nihr.ac.uk)
- Access/search
- Classification
- Collaboration
- Personalisation
- Expertise and profiling
- Application Integration
- Security





username:   
password:   
  
[forgotten your password?](#)  
[create an account](#)

**Live Stats**

**average time to:** 32 days  
**sign-off**  
**trials in system:** 521  
**sites in system:** 211  
**users in system:** 1054  
**studies signed off in:** 5  
**last week**

**UKCRN Networks**

- Cancer
- Stroke
- Mental Health
- Diabetes
- Medicines for Children
- Dementias & Neuro-Degenerative Diseases
- Primary Care Research Network
- Comprehensive NHS Network

**User Info**

**People Online**  
Visitors: 6  
Members: 8  
Total: 14

**Membership**

New Today: 0  
New Yesterday: 1  
Overall: 427

**News**

[most recent](#) | [view all](#)



**Human Tissue Act comes into force.**  
New legislation covering the storage of human tissues has recently come into force. What are the implications for researchers? [more](#)

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**Early intervention saves lives.**

Researchers from Nottingham have discovered that early laparoscopic intervention in patients with disease x results in much better outcomes. [more](#)



| [add new comment](#)



**New malaria hope.**  
British scientists have helped to develop a new malaria treatment which they hope could save many thousands of young lives in Africa. [more](#)

| [add new comment](#)

**Guidance and Documents**

**Sources of Advice.** Find a reliable source for advice on regulatory and other issues.

**Templates.** Clinical Trial Agreements, Protocols, Site Contracts etc...

**Data Repository.** Reports from research projects.

**Knowledge.** Search our knowledge base of Sites, Trials, Investigators, Patients.

**Resources and Tools**

**Research Approval Wizard.** Online tool to help you get your research project off the ground. [More](#)

**NIHR Directory.** Find the people and groups you need in the NIHR Faculty and UKCRN. [More](#)

**Discussion Groups.** Keep up to date with the research community. [More](#)

**Collaboration Tools.** Manage your clinical trial. [More](#)

 **Manage Studies**

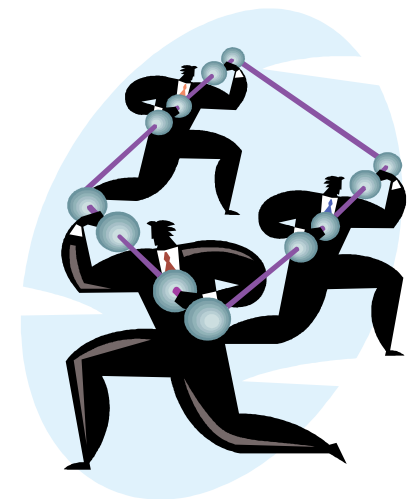
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 Current Studies	Ref No	Sites	Patients Recruited	Ethics	R & D	MHRA
<b><u>PSC831 in colonic carcinoma</u></b> Phase I/II study in patients with relapsed disease.	19128182912	8	17	✓	✓	✓
<b><u>EPIC 2</u></b> NCRN study in small cell lung cancer.	778641311664	86	436	✓	✓	✓
<b><u>INTEGRAL</u></b> Phase III multinational breast cancer adjuvant therapy study.	186721113568	12	129	✓	✓	✓
<b><u>BRCA II surveillance</u></b> Registration study on BRCA II mutation frequency.	90078182912	0	0	✗	✗	✓
<b><u>Another of my studies...</u></b> Trial to determine the effects of not drinking on a friday night.	48224141664	0	0	✓	✗	✗
<b><u>And another...</u></b> Investigation into the effects of onions on breath odour.	89752184568	0	0	✗	✗	✓

Create New Trial

# Portal Resources

- Information resources
- Events calendar
- Collaboration tools
- Document repository
- Search facilities
- Project Oriented Facilities
- Delivery anticipated via UKCRN





# R&D Management System



# Pharma Focus Group Issues

- Urgent needs:
  - Consistency of processes in NHS;
  - Speed of set up – will do anything to save a month
  - Ease of recruitment
- Systems no use if people are not forced to use them
- Very ambitious programme



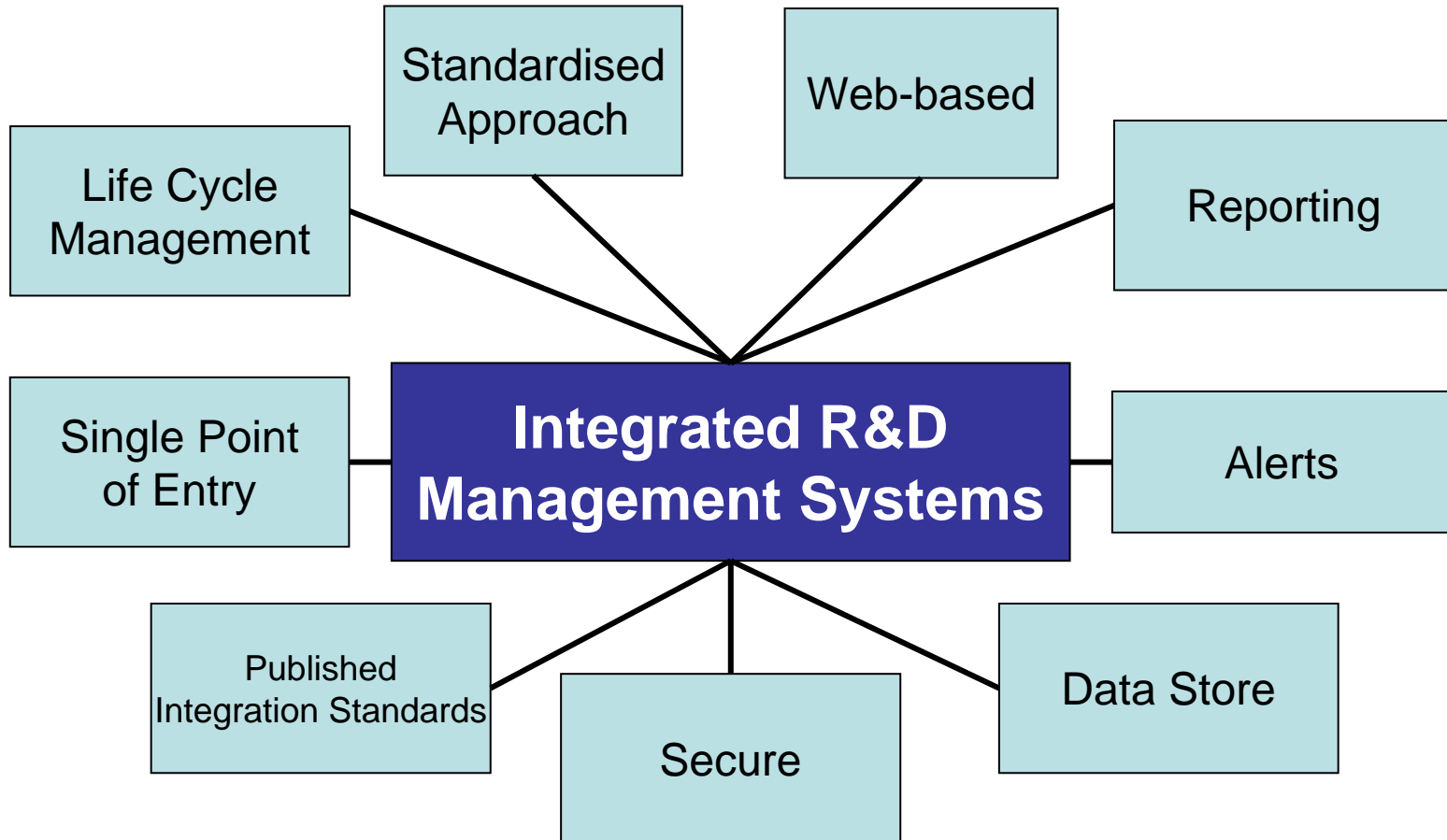
# Pharma Focus Group Expectations

- **Rapid** feasibility, set up & project delivery
  - Sites, investigators, recruitment
  - Clear, efficient, standard processes, approvals
  - Contracting, transparent costings, overheads
- **High quality** data
- **Value** for money
- **Reliability**
  - Processes, Sites, Investigators





# Integrated National R&D Management Systems



**Issues** – technology, procurement, hosting, design, functionality, integration, users, access, management, security, *how far do current systems meet the new requirements?*

# R&D MS - Key Features

- Assistance - ‘what approvals do I need?’
  - Ethics
  - R&D approval
  - MHRA, CTA
  - ISRCTN, Eudra, others
- Single point of ‘form filling’
  - Single Research Approval Form
- eFeedback on applications, eApprovals
- Monitoring/governance
- Unified reporting
  - All agencies, agreed format and scheduling
- Security and confidentiality – “FDA” compliance

# Timescales

<ul style="list-style-type: none"><li>• Decision on implementation approach for NIHR portal</li></ul>	<b>October 2006</b>
<ul style="list-style-type: none"><li>• First draft requirement specification for integrated national R&amp;D information management system available</li><li>• Decision taken on procurement and implementation approach for integrated national R&amp;D information management system</li></ul>	<b>November 2006</b>
<ul style="list-style-type: none"><li>• Establish and launch NIHR portal</li></ul>	<b>April 2007</b>
<ul style="list-style-type: none"><li>• Piloting of integrated national R&amp;D information management system begins</li></ul>	<b>September 2007</b>
<ul style="list-style-type: none"><li>• Integrated R&amp;D information system in full operation.</li></ul>	<b>April 2008</b>

# Finally

- About to move from initial analysis to implementation planning and resourcing;
- Need to establish project boards with strong research network involvement;
- Need research networks to identify systems priorities and solutions with us;
- Must be able to support and manage national systems that will become mission critical for many organisations