Medical Research Council e-Science overview

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UCL

Overview

- The current scene
- Initiatives
  - health research
  - national infrastructure
- Barriers to progress
- Future directions

The current scene

- Biomedical science is being transformed
  - ‘bioinformatics is core discipline of biology’ – Royal Society 2005
  - Imaging technology is central to diagnostic investigation
- Health care and research are increasingly information intensive (and costly)
  - ‘information is the heart of medicine’ – BMA 1994
- Multiple legacy information systems are in use
  - supporting and linking health care, research and industry
- CfH is creating pervasive and standardised new ICT infrastructure and core services for the NHS
- Other relevant national & international scientific infrastructures and standards are emerging

But, from patients' perspectives, quality of information is still elusive

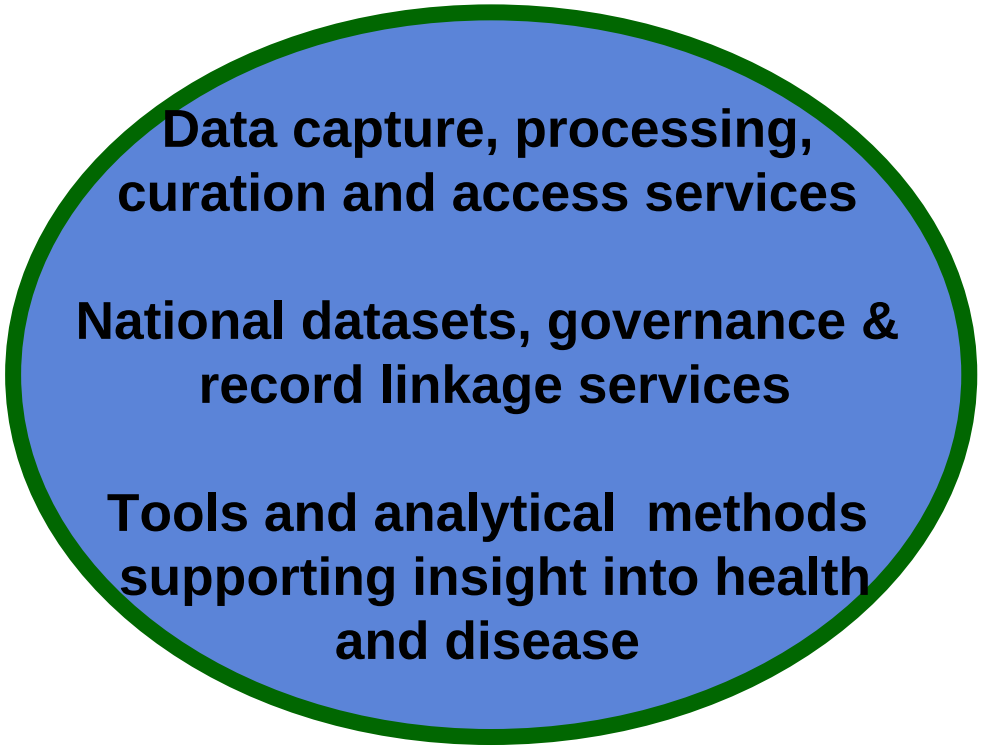
Survey of 750 patients with chronic conditions in each of USA, UK, Canada, Australia, New Zealand

- UK: 2/3 of patients not engaged in discussion about own treatment and care; 40% did not have goals of treatment made clear; 20% received conflicting information from different professionals
- UK: 20% were victims of medical error in past 2 years, 9% with serious consequences
- UK: 13% (US 22%) sent for duplicate tests, 1/2 have to repeat health history for different professionals, medical records not reaching consultation on time

Health Affairs, May 2003

Emerging scope of research infrastructure for biomedicine

Biological Structure and Function



Clinical Dysfunction and Disease

Health Care Delivery

Personal Health, Performance and Well-Being - Contexts and Determinants

Emerging scope of health care information infrastructure

Population: health, performance and well-being

Health and social care systems

Safety and quality of services

Family and community care

Outcomes: effectiveness, efficiency

Interventions: protocol / evidence

Personal (& individualised) care

Differing perspectives

Policy, Law

Health & Disease

System

Patient

Clinical e-Science initiatives

- National e-Science Programme (MRC)
  - e.g. CancerGRID, CLEF, NeuroGRID, PsyGRID, VOTES
- UKCRC and UKCRN (DH)
- Biobank (MRC, Wellcome, DH)
- NCRI informatics initiative (CRUK, Wellcome, DH,..)
- Many more such initiatives, nationally and internationally – EU, NIH, …

SR2002 Investments

Strategy

- £13.1m to develop a comprehensive UK grid around clinical trials and longitudinal studies - a clear gap in the MRC e-Science portfolio
- Scoping workshop held to draw up the call for proposals

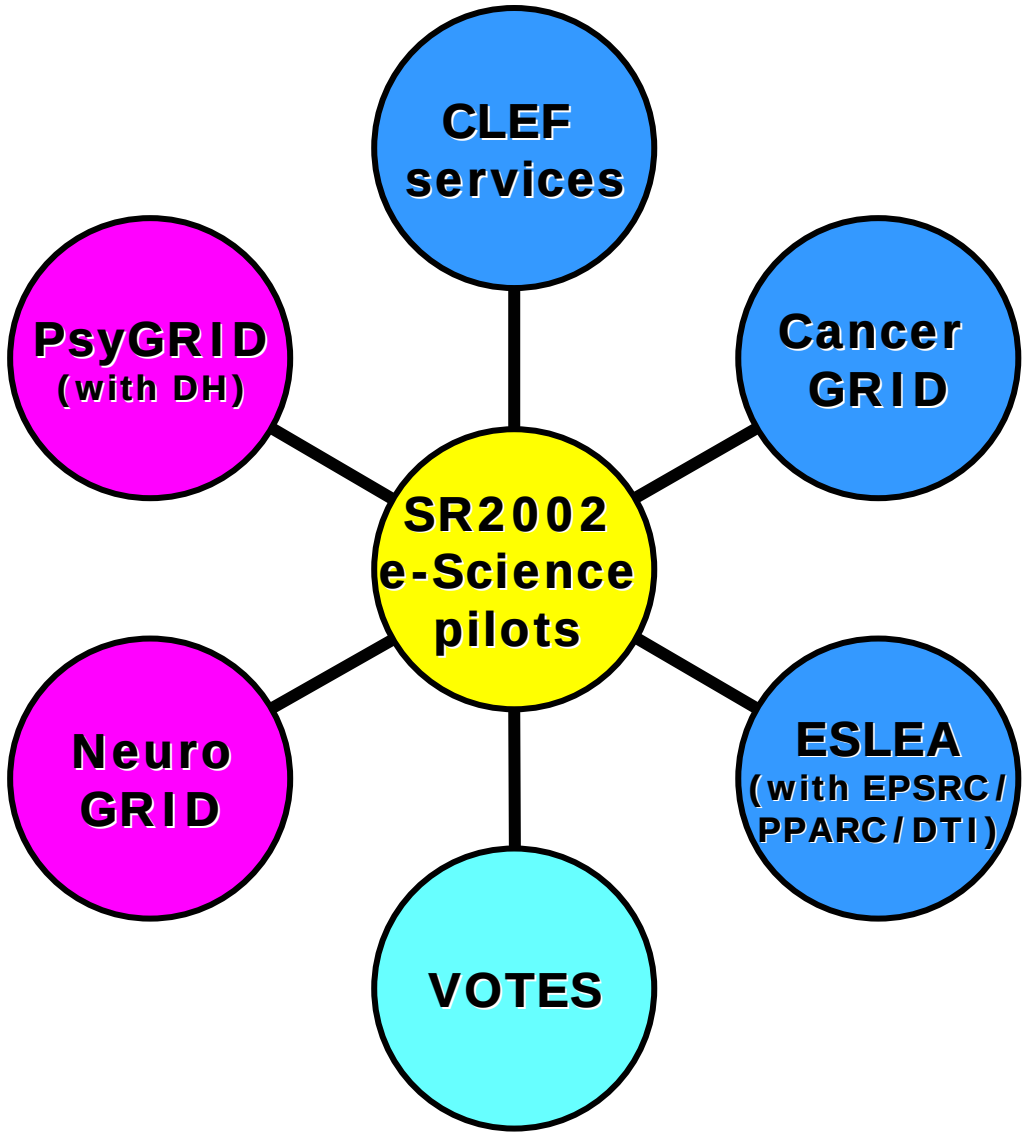
Call issued seeking:

- up to 5 large multidisciplinary networked consortia
- mix of discipline-led and tools-led consortia (ie vertical/horizontal)
- engagement of key national/international stakeholders
- development of grid architecture to access multiple/diverse datasets
- solutions to problems: ethics, confidentiality, security of patient data
- ambassadors to explain aims and encourage take up of grids
- interfaces with SR2000 pilots, core prog. and e-Science Centres

SR2002 Pilot Projects

5 SR2002 Pilot Projects to grid clinical trials / longitudinal studies (plus ESLEA) in:

- Cancer
- Primary Care
- Neuroscience



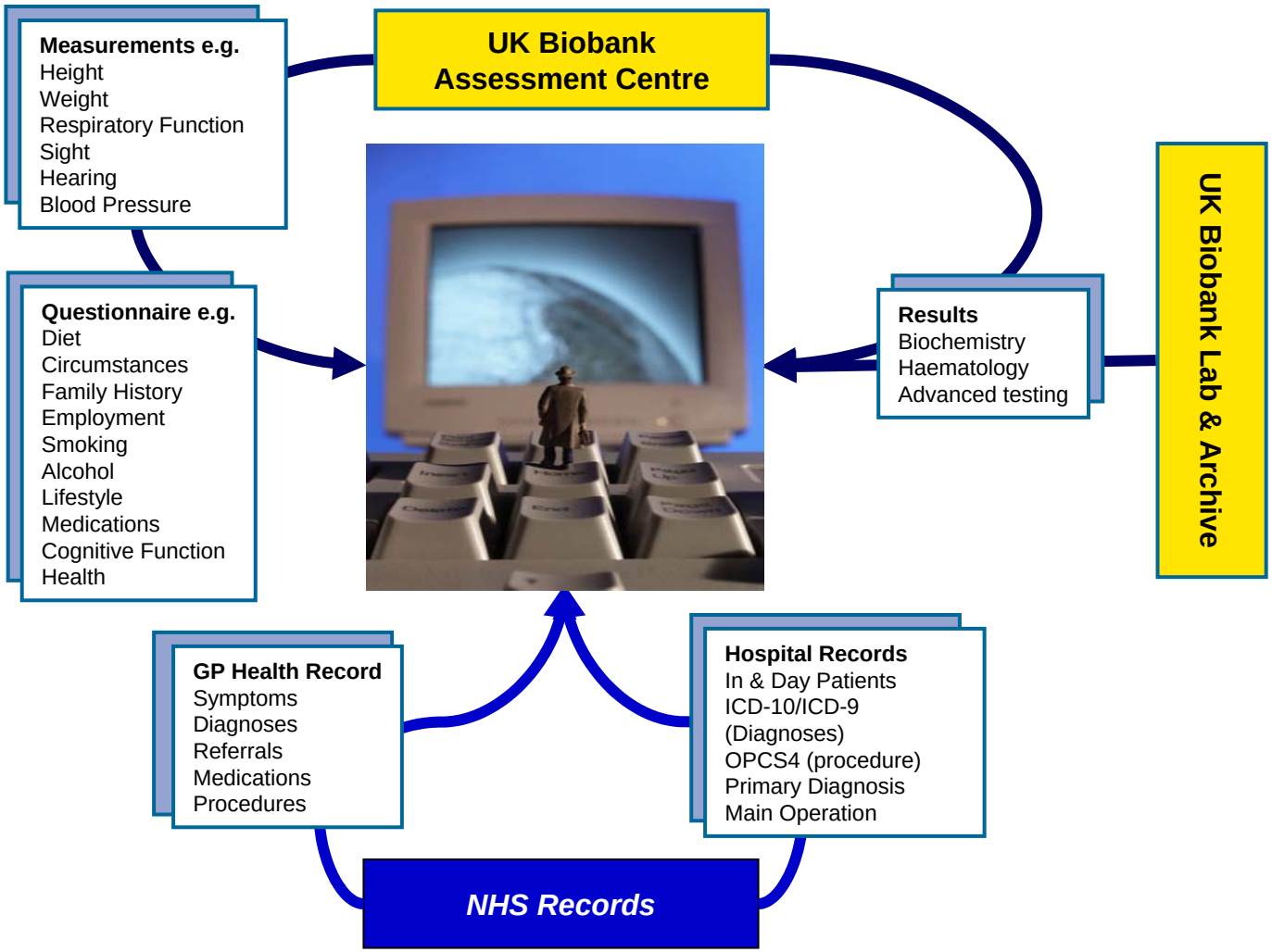
e-Science : UK Clinical Research Network synergies

- CancerGRID : National Cancer Research Network
- PsyGRID : Mental Health Research Network
- NeuroGRID : Neurodegenerative Diseases Research Network
- CLEF-services : UKCRN-coordinating centre
- VOTES : Primary Care Research Network

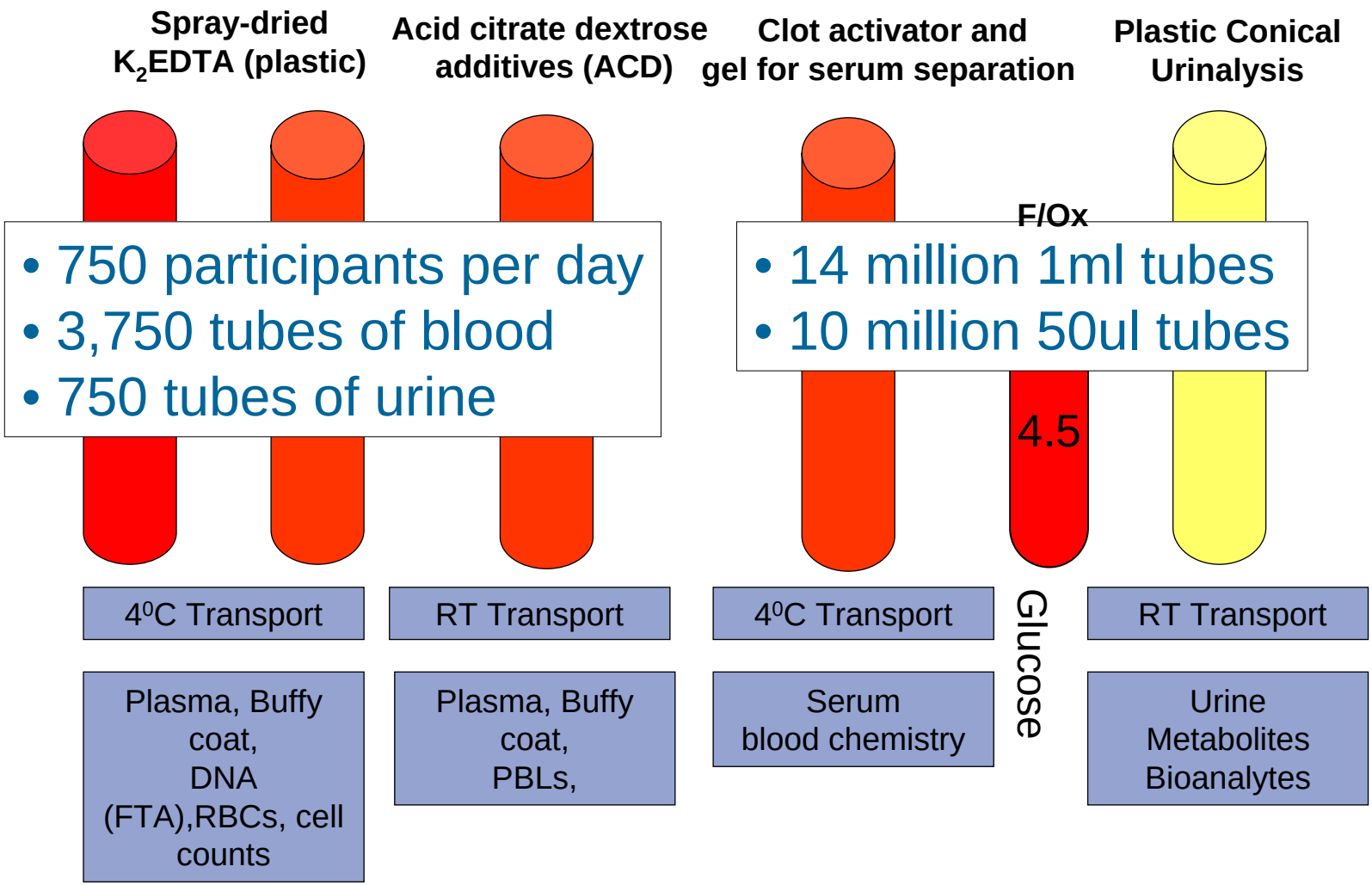
Plus

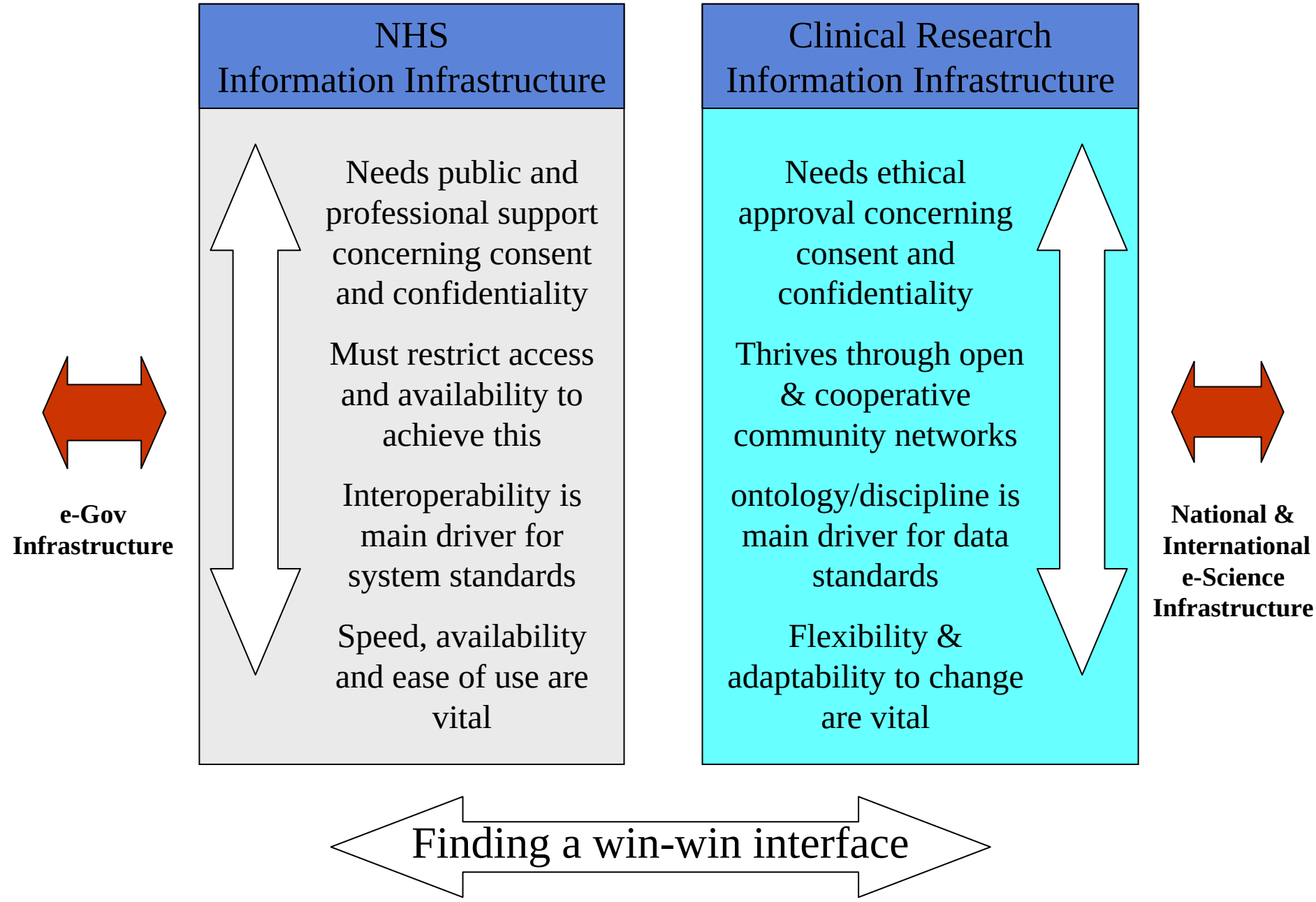
Children's Medicines, Stroke, Primary Care (GPRF, GPRD), …. Networks; infectious diseases surveillance

The UK Biobank Resource



Samples Collected from Each Participant





Bridging the gap

What's needed for research – key requirements

- Ethico-legally acceptable clinical data capture, curation and access services;
  flexible and available as close to the point of care as is practical
- Clear and workable procedures governing sharing of personal health data between the NHS and University and Medical School research groups
- Research information infrastructure that supports national and international clinical research consortia

Barriers to progress

- Data standards - bioscience, technology, clinical practice
- Security, confidentiality, privacy
- Multi-level, competing initiatives, lacking common strategy
  - ‘ a strategy is a mission pursued by a group of people ’
- IPR – much that needs to be openly shared and debated is hidden from view

Need for directed resource to target these issues, both practically and in discipline terms, with common strategy, backed at a high level

Working towards solutions

- Adopt an experimental approach, based on a limited set of important, clearly-communicated, well-specified, clinically-focused research information requirements
- Differentiate areas of these requirements that we know how to meet – get on with these
- For areas where we lack necessary knowledge, capacity and infrastructure, work to bridge the gap, in terms of:
  - Partnership – across sectors, international
  - R&D
  - Capacity
  - Infrastructure

Develop a set of path-finding projects to explore requirements, approaches and solutions, experimentally; e.g.

- Biomedical science - bioscience/health care data and record standards
- Clinical trials & experimental medicine – patient recruitment, data capture, curation and retrieval
- Health Services Research – confidentiality, information discovery/disclosure, governance
- Public Health – disease surveillance
- Epidemiology – record linkage

Policy Support

Engaging with wide range of stakeholders to…

- Develop practical guidance to support MRC researchers in the planning and execution of their data curation activities
- Identify costed options for long-term preservation for sharing to support major population data assets
- Deliver a ‘route map’ through current processes regulating use of personal data for medical research
- Commission research into public awareness of, and attitudes to, medical research using personal data
- Consider data sharing models to address MRC research community needs

Public Consultation

Exploration of public attitudes to:

- **Risks and Benefits**
- **“Necessary & Proportionate” use without consent**
- **Generic consent**
- **“Consent for Consent”**
- **Opt-in versus Opt-out**
- **Role of NHS**
- **Research Sponsorship**

Cohort Support Project

MRC Medical Research Council

"SILVER"

- Sufficient Ongoing Solution
- Focus on Enabling Wider Sharing & Use
- Up to 3 years to implement
- Bronze items plus:
  - Secondary User functions in place
  - Data & metadata in suitable release formats
  - Governance in place - access and secondary use
  - Significant Visibility - enhanced online information
  - Selected data available on-line for "bona fide" users
  - Basic but dedicated user support functions & resource