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# The UK Biobank

A project to support long-term prospective studies of genes and the environment and their relationship to health and illness in 500,000 participants

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# The “New Genetics”

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# The post-genome challenge

"We should be interested in humanity's genes rather than the human genome, moving from the individual towards the population"

*Sydney Brenner*

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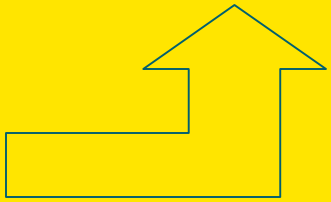
21st Century question:

Which HRT users will develop breast cancer and why?

20th Century knowledge:

Smoking causes lung cancer

Genome sequences



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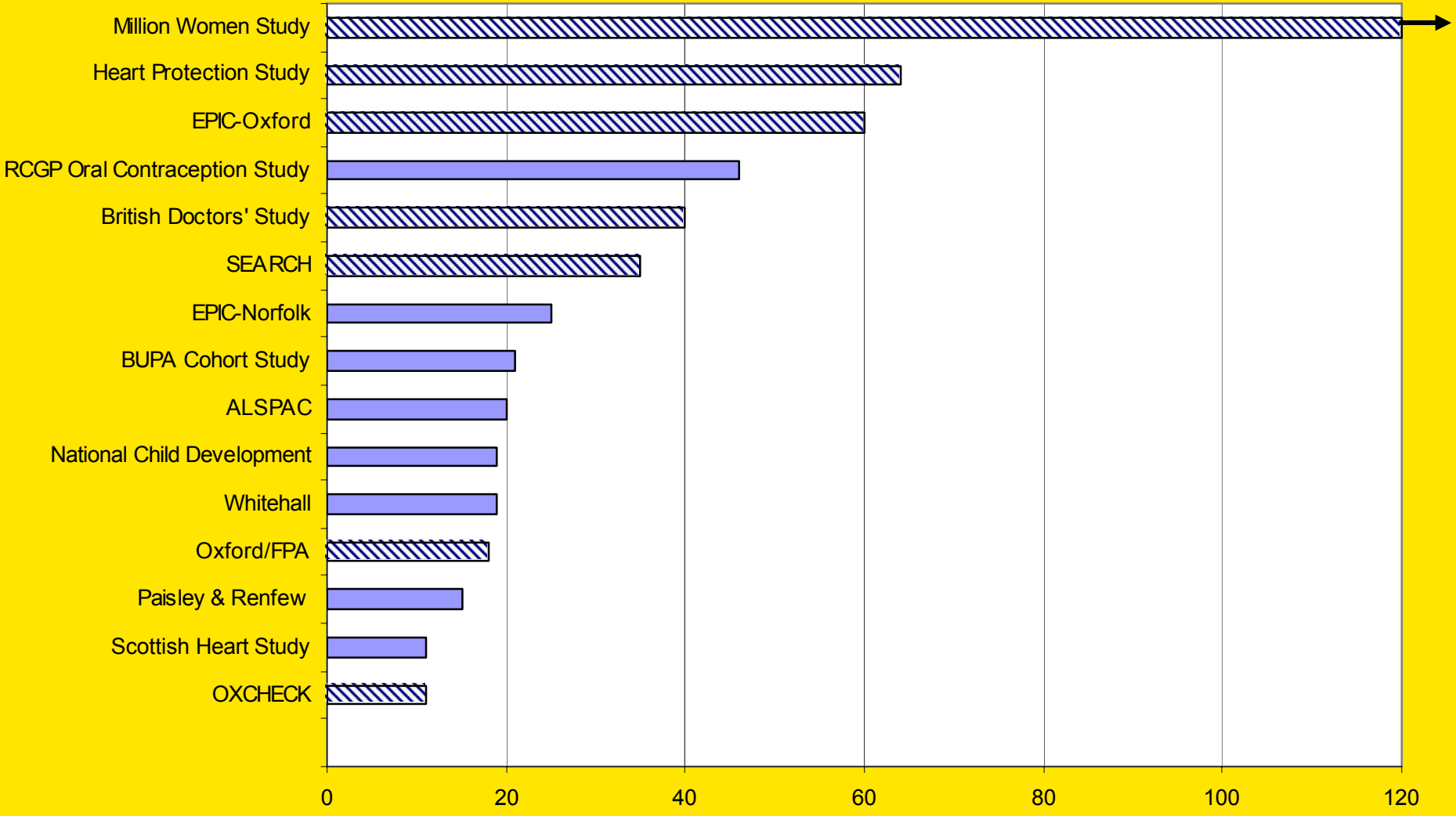
“Quantity has a quality all of its own”

Henry Ford

# UK COHORT STUDIES (>10,000 participants)




Smaller UK studies: Regional Heart Study 8000; 1946 Birth Cohort 5000; Caerphilly & Speedwell 4000; Ely study 2000

## Recruitment

500,000

participants

aged 40-69

## Data & Sample storage

- Environmental exposure
- Physiological variables
- Neuropsychiatric evaluation
- Biochemical markers
- DNA, plasma, urine

## Follow-up

- Record linkage
- Registries
- GP records
- Hospital admissions
- Cancer registries
- Prescriptions
- Death

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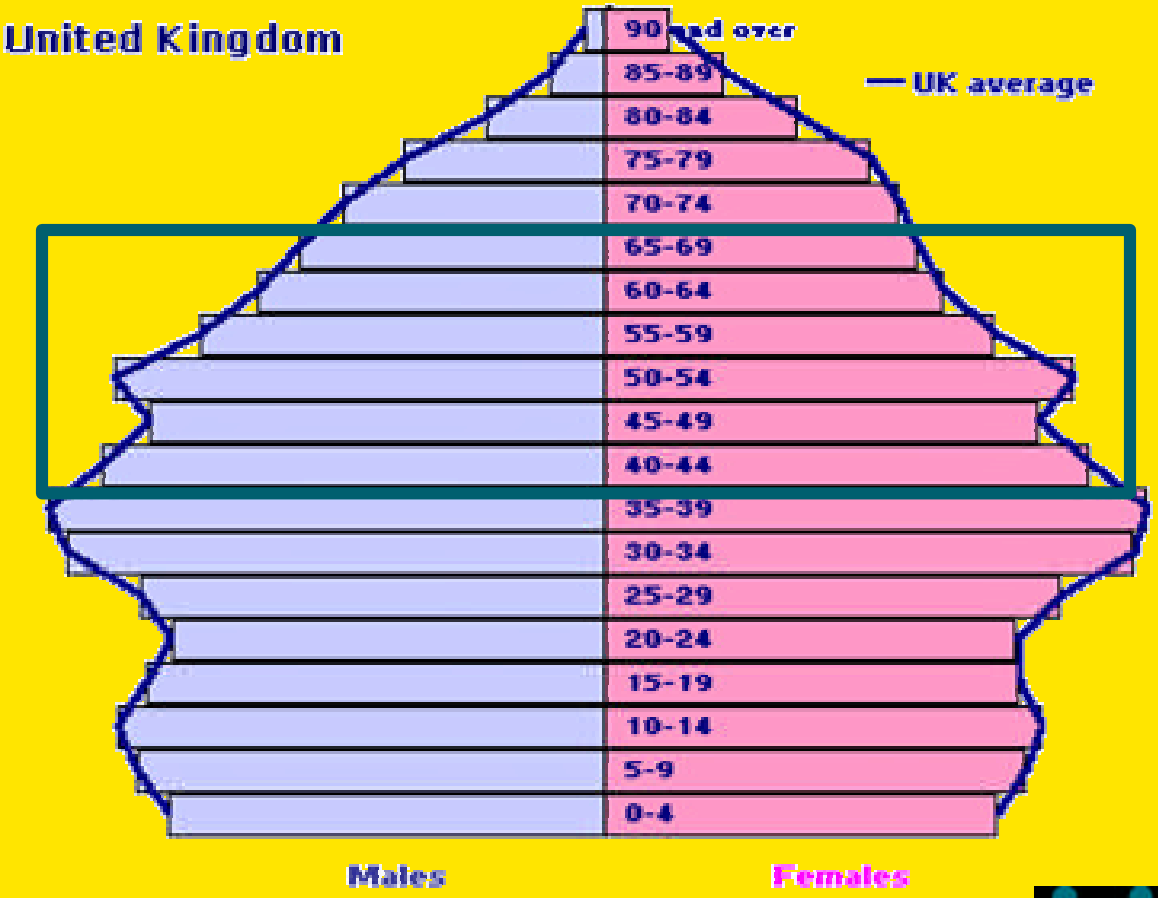
# UK population 2001




Biobank target population

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# Likely Prevalence at baseline

8,000 IHD

7,000 Diabetes

6,500 CerebroVascD

3,500 COPD

1,600 Parkinson's

1,700 RA

131,000 Chol >5

75,000 High BP

46,000 Obese

20,000 Low $FEV_1$

19,000 low GHQ12

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# Scientific Objectives

- Determine separate and combined effects of genes and environment on common causes of health and illness
  - Nested case-control studies
  - Prevalence studies
  - Cohort studies (exposure based)

- Genotype-driven clinical investigation

- Biomarker detection as markers or risk factors

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# Scientific Justification for Prospective Studies

- Genetic information is available for all cases regardless of severity
- Measurement of blood based molecular and proteomic factors using samples collected prior to onset
- A resource where investigation of unforeseen outcomes and relationships is possible
- A resource for studying the determinants of health as well as disease

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# General Benefits of UK Biobank

1. Public Health - Measure the effect of environmental, lifestyle and genetic risk factors in populations
2. Clinical Medicine - Understand heterogeneity within disease groups
3. Bioscience - Identify important biomarker-disease associations

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# Additional benefits

Promote high standards for ethics and governance in this field

Broaden access to expensive research resources

Opportunities to collaborate internationally

Efficient and economic approach

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# How is UKBiobank funded?




# How has UK Biobank been established?

EGC

UK Biobank science committee

UK Biobank board

UK Biobank management group

RCCs

RCCs

RCCs

RCCs

RCCs

RCCs

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# The Approach

- Modern, efficient methodology in patient recruitment, data collection, IT, genotyping, LIMS and genomics

- Industrial scale processes,  process and project planning, and quality assurance

- Distributed scientific collaboration – strong central co-ordination and quality control

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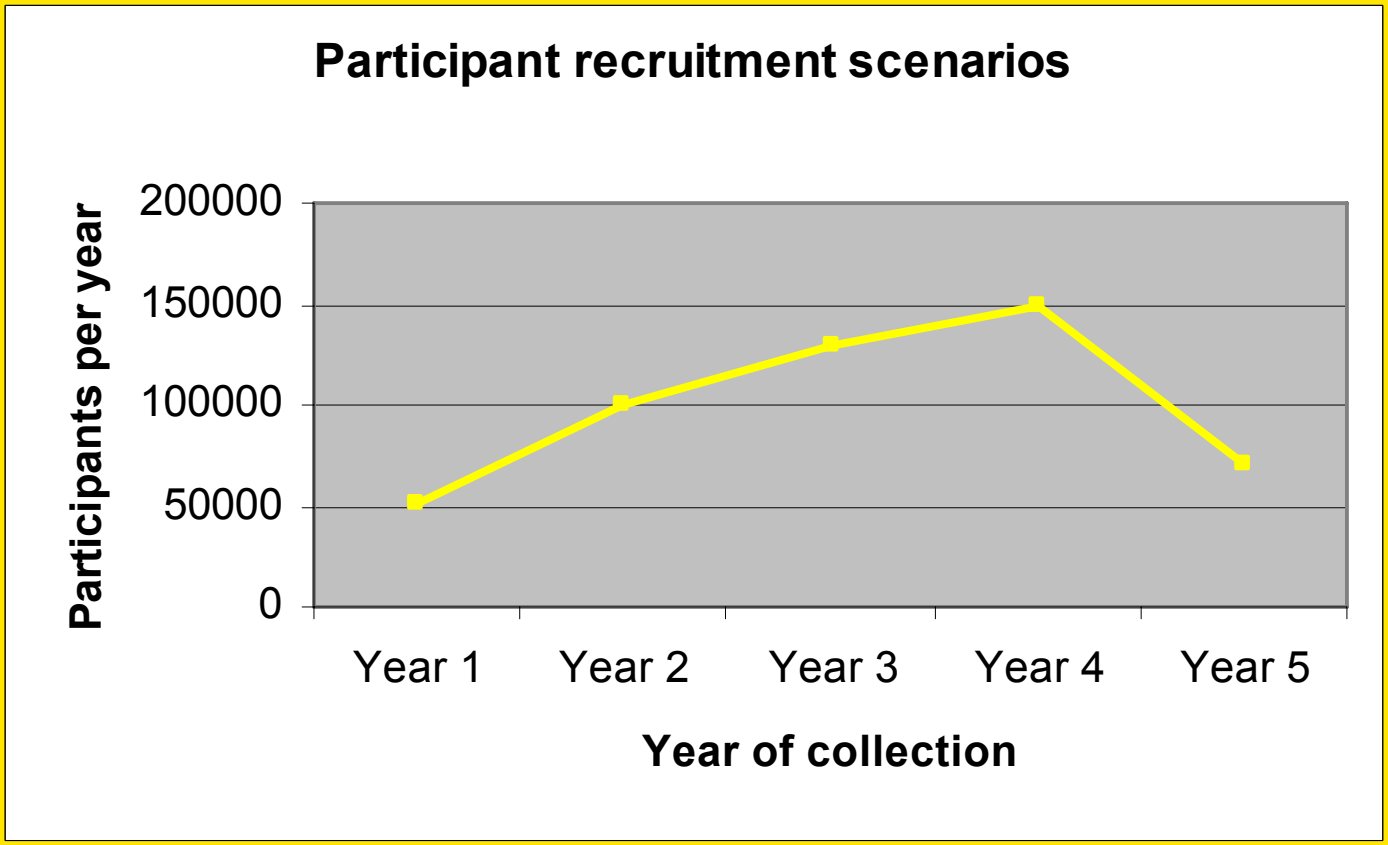
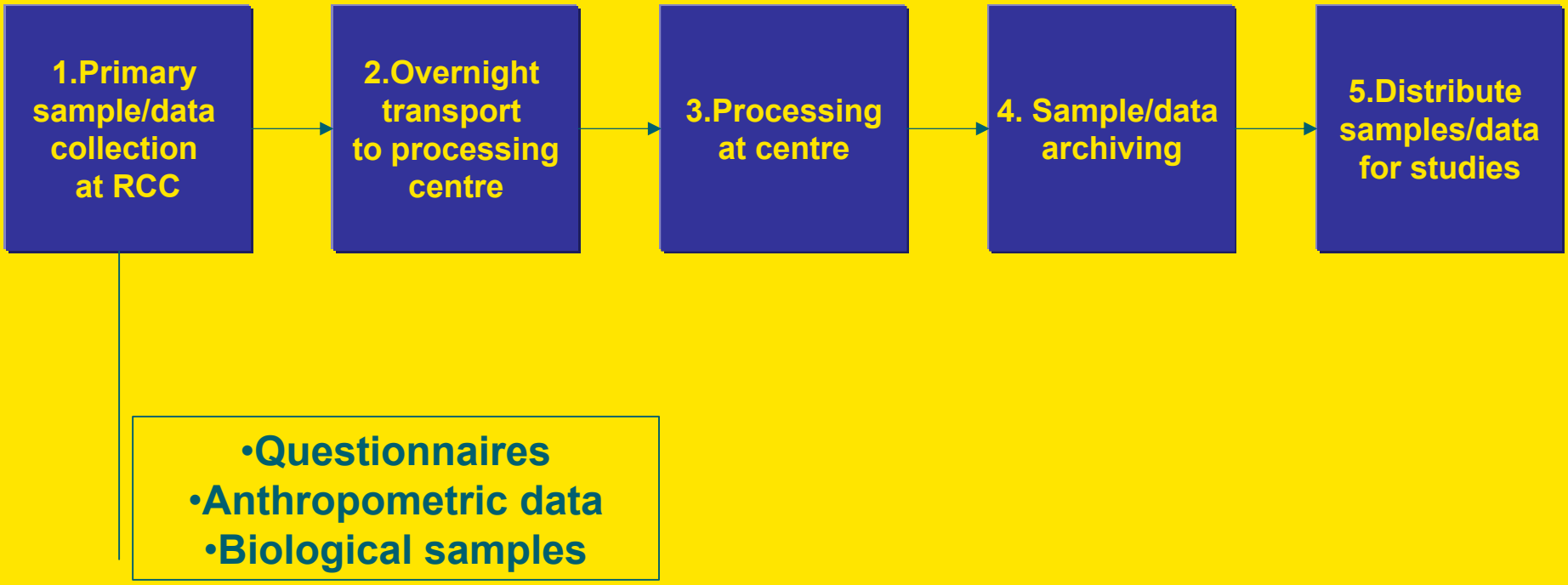
# The project is being designed with an accelerating recruitment plan….




- Different recruitment settings will be used throughout the project
- We will balance coverage vs. cost vs. quality control

# Participants will come to assessment centres……

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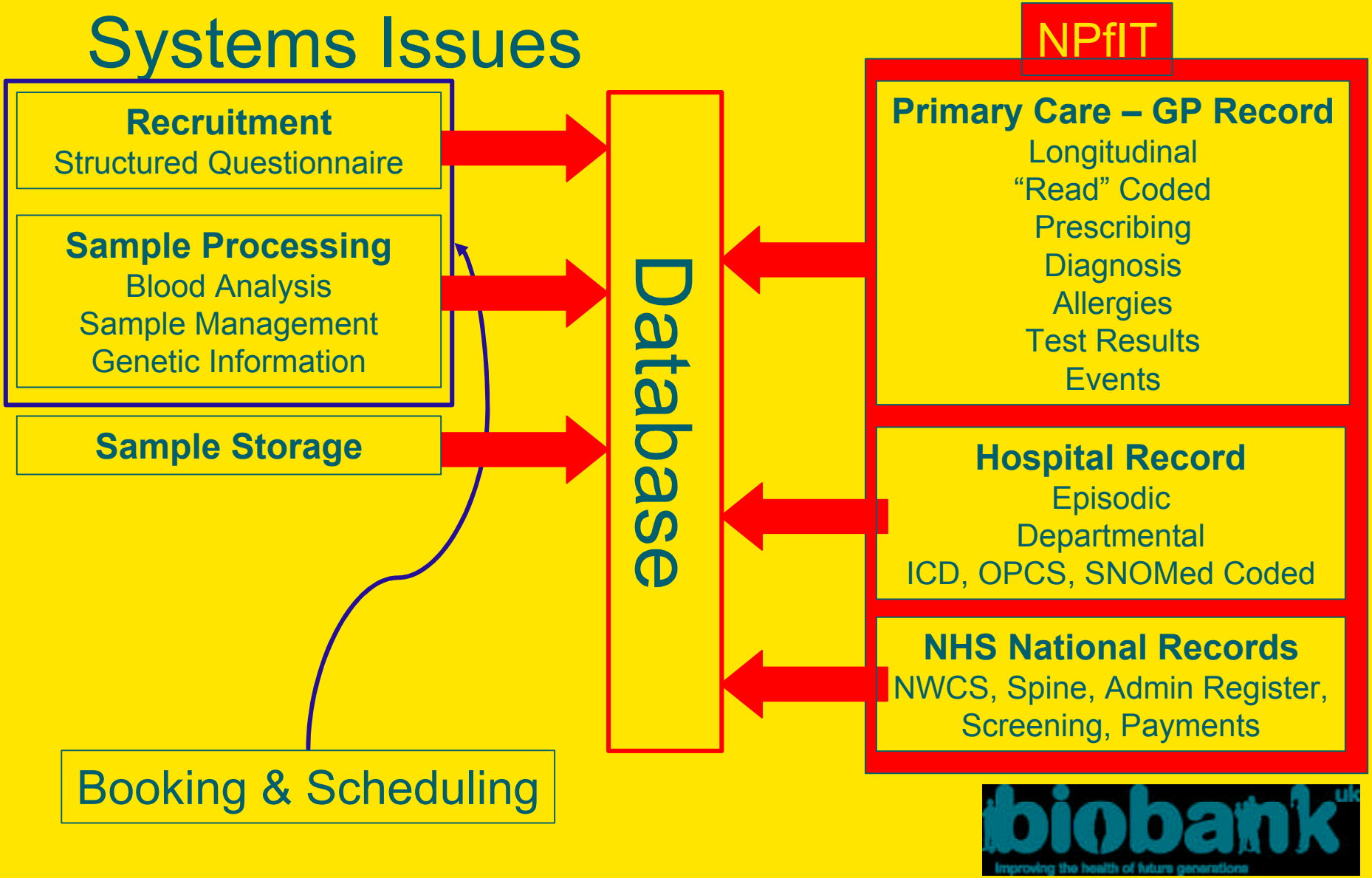
# Data Management & Systems Issues

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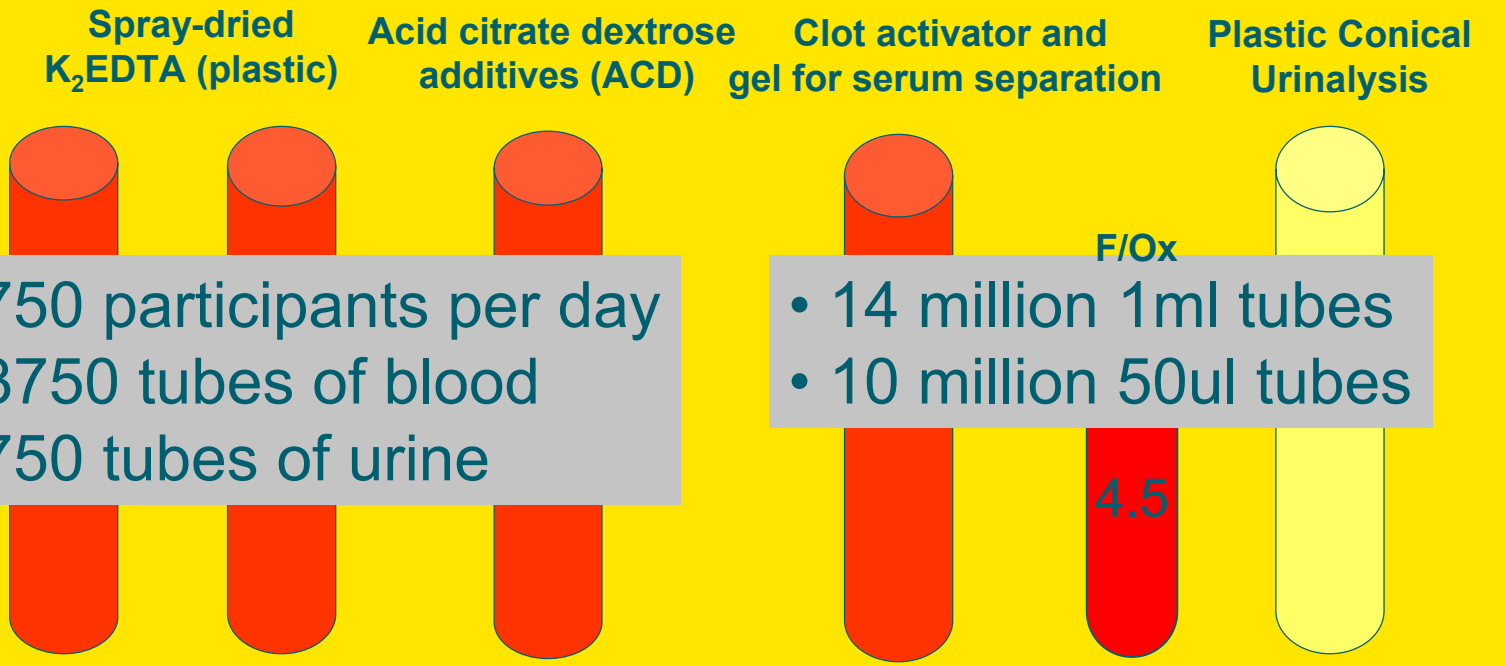
# Samples will be collected from each participant




- 750 participants per day
- 3750 tubes of blood
- 750 tubes of urine

- 14 million 1ml tubes
- 10 million 50ul tubes

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# Liquid nitrogen storage facility


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# Sample storage: automated retrieval at -80 degrees

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# Ethical and Governance Framework

- Volunteers can withdraw at anytime
- Broad consent to future use
- Data security + confidentiality assured
- Samples not released to others
- Full access for appropriate purposes
- Internal and external review of science and ethics
- Independent Ethics and Governance Council

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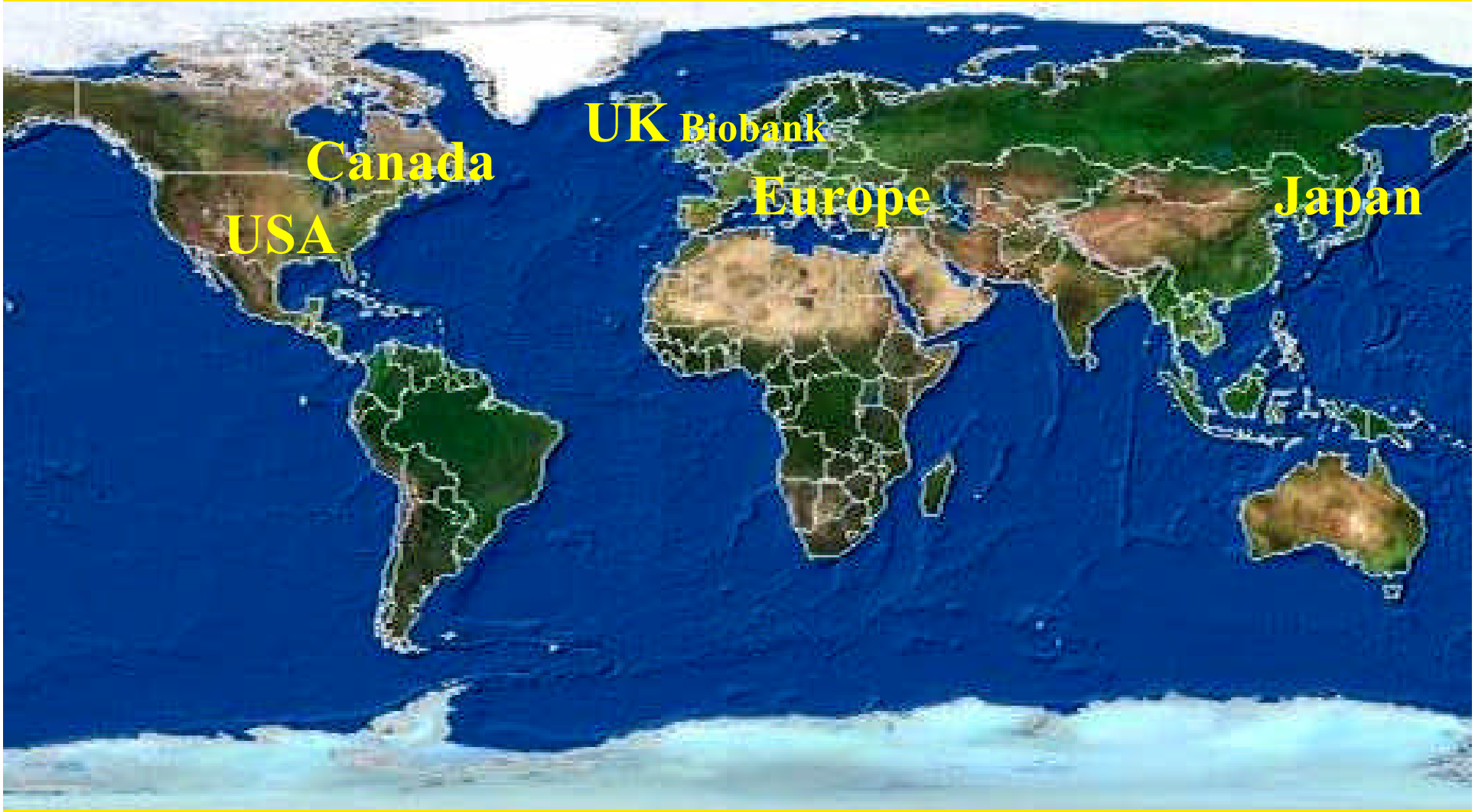
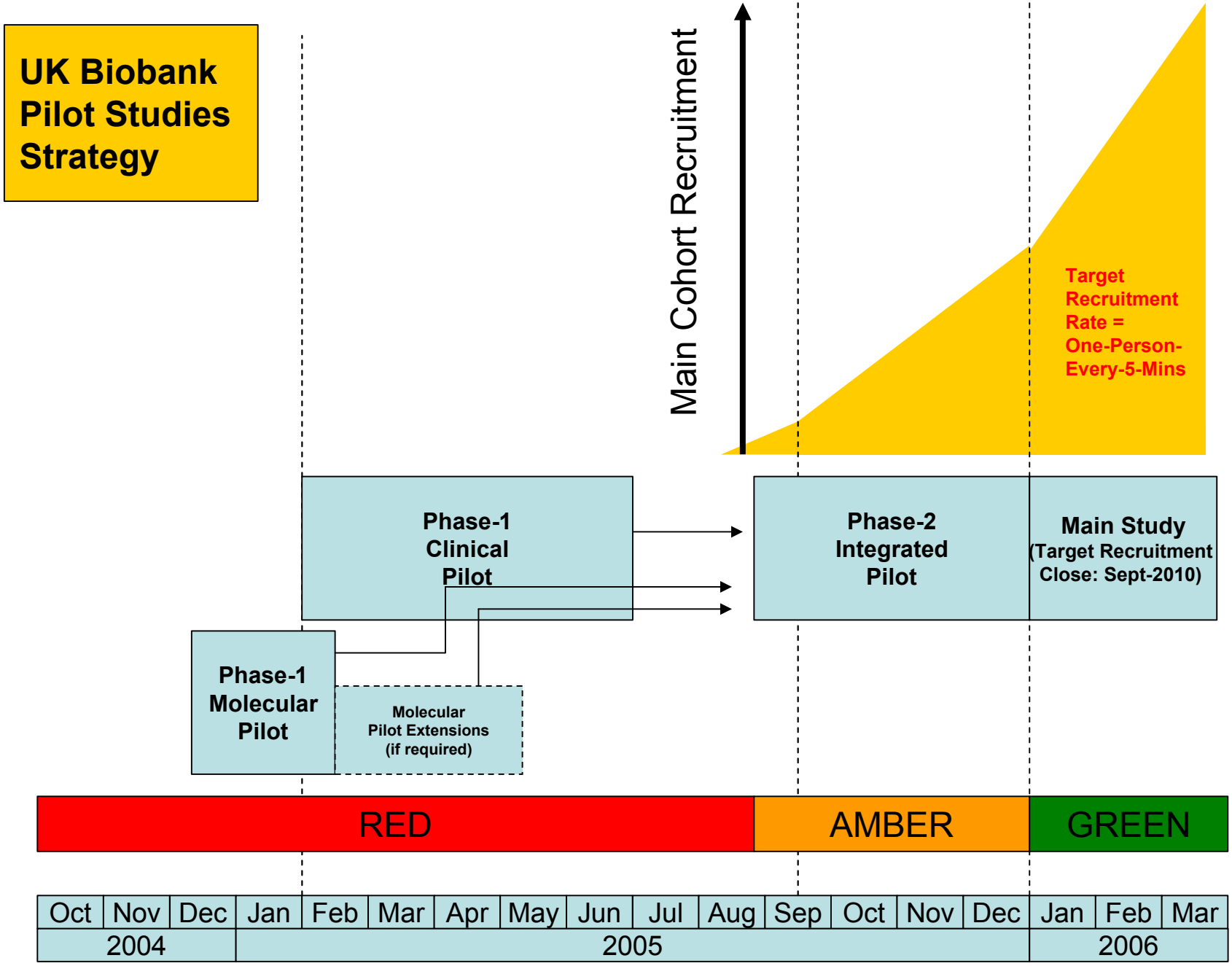
# The need for collaboration




UK Biobank Pilot Studies Strategy
Main Cohort Recruitment
Target Recruitment Rate = One-Person-Every-5-Mins
Phase-1 Clinical Pilot
Phase-2 Integrated Pilot
Main Study (Target Recruitment Close: Sept-2010)
Phase-1 Molecular Pilot
Molecular Pilot Extensions (if required)
RED
AMBER
GREEN
Oct Nov Dec Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec Jan Feb Mar
2004
2005
2006

# Current activities

- Piloting the clinical and molecular processes
- Establishing the IT infrastructure and clinical applications
- Developing the communications strategy to support recruitment
- Writing the scientific protocol and participant questionnaire
- Refining the Ethics and Gov. Framework
- Implementing the laboratory facilities and processes

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# Site of the automated storage facility

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# Challenges

- Delivery against project timelines in a distributed organization
- Ensuring ethical approvals for complex studies
- Negotiating access to required information
  - To invite and maintain contact with participants
  - To access longitudinal and secondary data sources
- Ensuring continuity and security of data chain over many years

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# UK Biobank special features…

- Size of project (persons x time)
- Biological resource for study of biomarkers and genes
- Recall of subsets for intensive phenotyping
- Extensive use of routine health records
- Ethical approach – public participation

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# Towards an IP and Access policy

- An open resource
- Managed to optimise its use and value for research in the public interest
- Appropriate safeguards and controls

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# Safeguards?

- Honour commitments to participants
- Ensure compliance with legal and regulatory requirements
- Prioritise access to depletable resources
- Manage IP rights appropriately

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