norwich research park
BioRepository

Biorepositories:
something new, or tissue banking rebranded?

Prof M. J. Wilkinson

Norfolk & Norwich University Hospital Foundation Trust

&

Norwich Medical School

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

UEA University of East Anglia
NORWICH MEDICAL SCHOOL

Historical

- Tissue banking as a research enterprise started as an adjunct to large cohort studies such as the Nottingham Tenovus breast cancer study commenced in early 1970's.
- The Human Tissue act 2004 (implemented 2006) brought so me uniformity to the system as each bank had to meet HTA standards, but there was still great variation in style and approach

The historical model

Single disease.

- Collected by enthusiasts.
- Sometimes, but not always linked to accurate demographic and lifestyle data
- Access to clinical data.

OR

Single hit

- Opportunistic less structured collection of samples
- Limited, if any demographic data
- Access to clinical data.

2013

- there were 215 biobanks holding samples for research purposes licensed under the HTA
  - 58 hospitals;
  - 98 academic and
  - 59 industrial biobanks.
- Probably an underestimate as
  - each licensed institution may have a number of individual collections, (Cambridge had 57 separate collections in 2003)
  - not all samples collections require a HTA license

UK Biobank

single hit healthy

- recruited 500,000 people aged between 40-69 years in 2006-2010 from across the country to take part in this project.
- They have had basic data collected (BP etc.),
- provided blood, urine and saliva samples for future analysis,
- detailed information about themselves (i.e. their understanding NOT accurate medical data)
- and agreed to have their health followed.

https://www.ukbiobank.ac.uk/about-biobank-uk/

GEL

Single hit Disease

- 100,000 Genomes Project launched late 2012.
- Genomics England, a company wholly owned and funded by the Department of Health,
- sequence 100,000 whole genomes from NHS patients by 2017.
- focus on patients with a rare disease and their families and patients with cancer.
- Cancers - Collected Blood and tumour tissue
- Rare Diseases – collected blood index patient and parents

NOAR STUDY

Longitudinal study single disease

- To establish and follow a large and dynamic cohort of patients with IP.
- To collect medical and questionnaire data on relevant risk factors for development of IP.
- To collect samples of serum, plasma and DNA for serological & immunological study.
- To identify co-morbidly and mortality outcomes.
- To establish the risk of cardiovascular disease in comparison with the general population
- funded by Arthritis Research UK Centre of Excellence in Epidemiology grant renewed 2016 (£134,215.85)

www.uea.ac.uk/documents/9330206/9333495/Protocol_Version+7.1_NOAR_20170110.pdf/973f90e5-0c53-4ff7-8e90-5652334d4321
www.arthritisresearchuk.org/research/grant-tracker-items/2016/support-for-the-norfolk-arthritis-register-noar-as-part-of-the-arthritis-research-uk-centre-for-epid.aspx

Costing

UK Biobank

Phase	Funding source	Time period	Income (£M)
Planning & Pilot	DoH, MRC, WT, Scottish Exec,	2002-2006	15
Recruitment, sample & Data Collection	NW Regional Development Agency, Welsh assembly & BHF	2006-2010	47
Extra Analyses	DoH, MRC, WT	2012-2014	6
Storage & sample Distribution	MRC, WT	2012-2017	25
total			93

100,000 genomes

source	Funding source (£M)
Ilumina	162
Genomics England	78
Welcome	27
MRC	24
NHS England	20
Total	311

Financing UK biobanks: rationale for a National Biobanking Research Infrastructure STRATUM
https://www.sciencemag.org/news/2014/08/uks-100000-genomes-project-gets-300-million-finish-job-2017

Costs

- Infrastructure
  - Consent – 30 min - GEL used band 7 nurse
  - Sample collection – 5-10 min additional if clinical
  - Sample processing – varies
  - Sample handling – 10 min
- Thus each sample can take an hour of staff time

Funding

- Typical UK funders include
  - government departments,
  - research councils,
  - the NHS,
  - academia,
  - industry,
  - non-profit organizations including charities

Funding 2

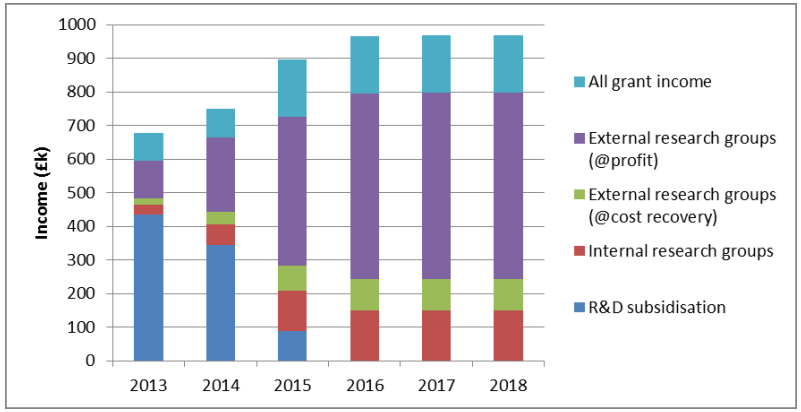
- However, there is discussion (involving the scientific community, funders and policy makers) on the potential for biobanking to become self-sufficient, i.e. moving to a cost-recovery model.
- biobanks should not make financial gains from selling tissue,
- they are allowed to make gains from data about samples or through the provision of services.

Evers, K., Forsberg, J. and Hansson, M. (2012) Commercialization of Biobanks, *Biopreservation and Biobanking,* vol. 10 (1) p 45-47.

Self Funding ??
Bank = Single hit Disease

- The self-funding model motivated the biobank to accurately evaluate the costs associated with biobanking. Costs were calculated primarily on the time taken for a given activity, and based on the minimum salary band of personnel required to undertake that activity.
- actual costs significantly higher than recognised by most researchers and funding bodies. (5-10 times the amount estimated by the MRC)

- Consent – members of the public are recruited as volunteers to approach potential donors.
- Sampling –
  - Most solid tissue is collected by NHS pathologists during routine tissue handling.
  - Blood (serum and plasma) and other body fluids collected by phlebotomy or clinical staff during routine patient treatment
- Handling – biobank staff carry out processing and storage.



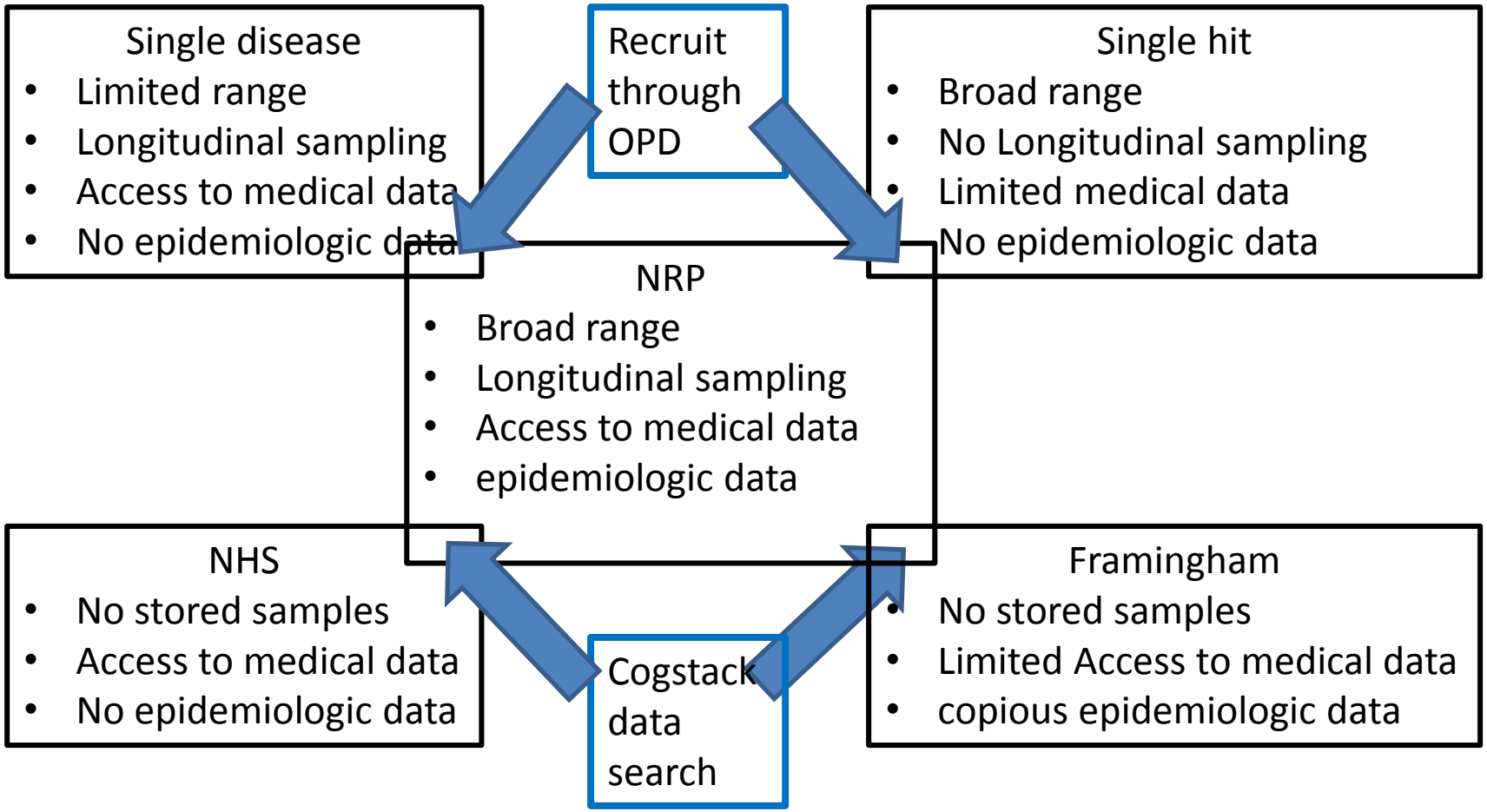
But future self financing model achieved by

- Writing off all infrastructure costs to date
- Writing off all costs related to current sample bank

The NRP Biorepository

- Is a cooperation between UEA, NNUH, Quadram Institute (a new research institute in Norwich)
- funded by BBSRC, UEA and NNUH.
- Started as the Partners in cancer research Tissue bank in 1999 collected cancer samples as a single hit bank

NRP


Single disease
• Limited range
• Longitudinal sampling
• Access to medical data
• No epidemiologic data
Recruit through OPD
Single hit
• Broad range
• No Longitudinal sampling
• Limited medical data
No epidemiologic data
NRP
• Broad range
• Longitudinal sampling
• Access to medical data
• epidemiologic data
NHS
• No stored samples
• Access to medical data
• No epidemiologic data
Cogstack data search
Framingham
• No stored samples
• Limited Access to medical data
• copious epidemiologic data

NRP

- Minimal contact consent = low cost
  - PIS in OP letters
  - Website with FAQ video etc
  - Telephone answering
  - CF posted in OP clinic (plan online ASAP)
- Enduring = longitudinal sampling
  - Demographic data
  - Residual material any clinical sample
  - All medical data

Data collection and storage

- Questionnaire on consent devised by dept nutrition UEA
- CoGstack
  - Cogstack downloads clinical information from the multiply hospital databases (n=47 for NNUH and QIE) onto a single server allowing the collected information to be searched “google-fashion”. (a data retrieval project that would normally take medical students 3 months and cost £12,000 was completed using Cogstack in 10 hours.)
  - establish links with all NHS Norfolk Core Commissioning Groups thus giving access to all a patient’s medical data from birth.
  - We will search files to answer specific questions posed by researchers and anonymise thus GDPR compliant

Sample Collection and Storage

- don’t collect blood etc until needed
- “test set” BR collection added to machine repertoire – aliquoted samples can be ordered as a “when available test”
- Automated freezer linked to LIM system
- Ultimately plan automated freezer linked to analyser so, no contact collecting

norwich research park
BioRepository

Space for 65 -85°freezers

144 draws per freezer

400 Samples per draw =

3,744,000 Samples.