

An all-Ireland Biobank Network:  
The vital link between cancer research  
and better care

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# Frequently asked Questions

- What exactly *is* a biobank?
- How does a frozen tissue sample help fight cancer?
- Will anyone know who the sample is from?
- Will the patient know the sample has been taken?
- Who will have access to the samples?
- Who will decide who has access to samples?
- What information about me will be released to researchers?
- Will samples be sold to pharmaceutical companies?

# Background

- Cancer affects 1 in 3
- Poor prognosis in Ireland
  - Delayed diagnosis
  - Inefficiencies, inequities
  - Inconsistent treatment
  - *Despite excellent personnel*
- We must replace fear with hope

# What We Can Do

- The fight against cancer depends on research
- ***Develop a hospital-based cancer biobank network as a bridge between research and care***
  - Will raise (nearly) all boats
  - No losers

PATIENT in HOSPITAL

*Tests*

Consent

Cancer  
Removed

Pathology

? More treatment

Cancer  
Diagnosis,  
assessment

Freeze samples  
For Research  
Database  
coded data

Biobank



# High Street Bank vs Biobank Network

- High Street Bank

- Money is safe
- Added Value
- Withdraw anytime
- For my gain

- Biobank Network

- Samples are safe
- Increasingly valuable
- Approval for Withdrawal
- *For the benefit of everyone*

# Cancer Tissue Sample - How Does it Fight Cancer?

- Surplus from cancer operation specimen
- Size: 2 cent coin
- With coded patient data on database
- Precious resource (otherwise wasted)
  - Research on cancer genes, proteins
  - Large collaborations -> meaningful results
  - New understanding of how cancers work
  - Academic-Industry partnership -> new tests and better less toxic treatments *after many years*

# Biobank Ireland Trust





- Founders: E Gaffney, C Flanagan
- *To promote development of an All-Ireland Cancer Biobank Network*
- Spanish Network Model: hospital biobanks, shared database
- NCI Ireland-NI Cancer Consortium
- Promotion, consultation, education, fundraising
- Incentive for all-Ireland, international cancer research collaborations
- Immediate research facilitation -> better treatment *in long-term*
- Biobanking to be standard of care, government-funded



[www.biobankireland.com](http://www.biobankireland.com)

# SPANISH TUMOUR BANK NETWORK OF NETWORKS – SEPTEMBER 2005

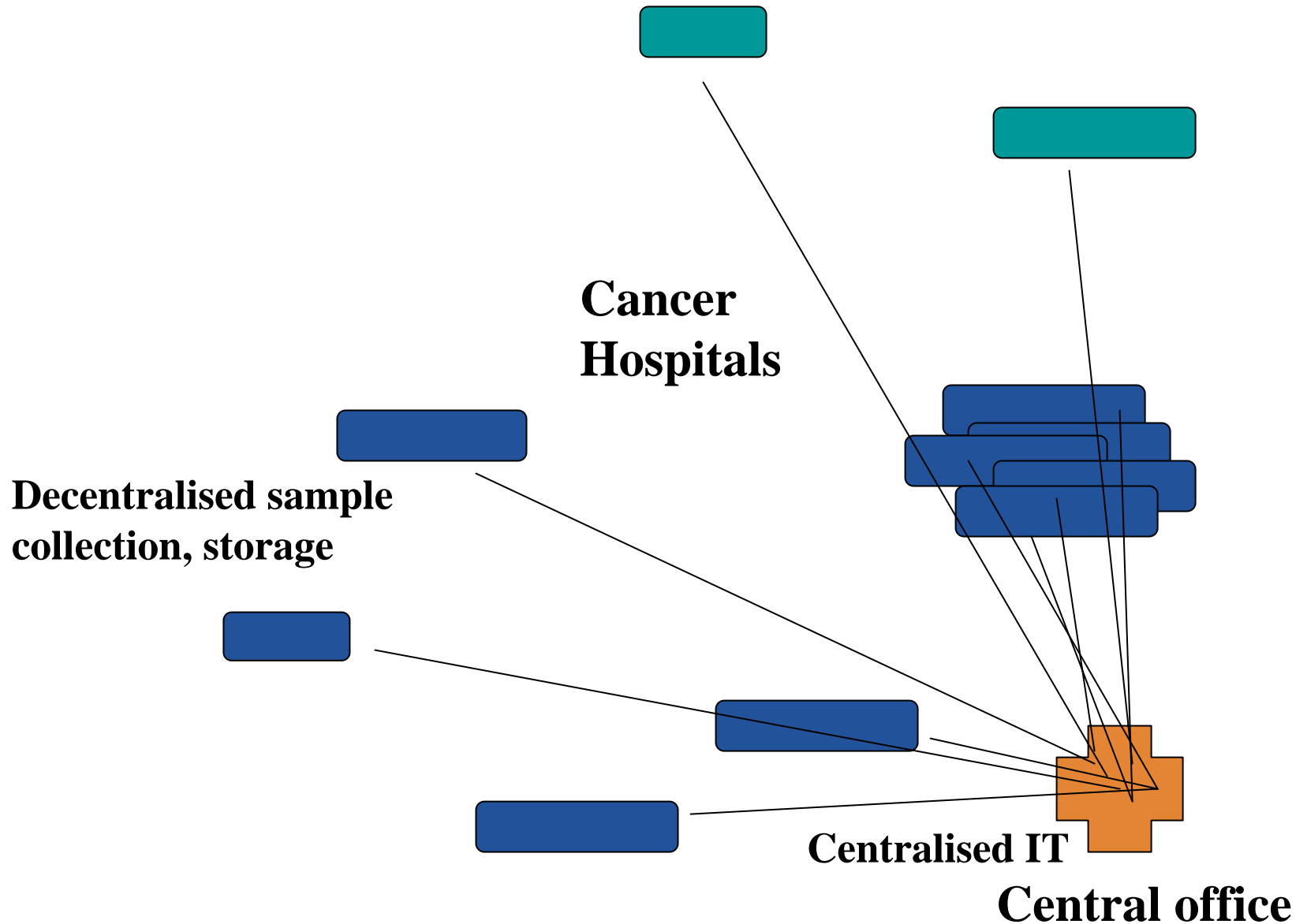


-  CNIO NETWORK: CURRENT ASSOCIATED HOSPITALS ... 19
-  CNIO NETWORK: FORTHCOMING ASSOCIATED HOSPITALS ... 4
-  ANOTHER REGIONAL NETWORKS WITH COLLABORATIVE AGREEMENTS
-  ANOTHER LOCAL HOSPITAL TUMOUR BANK WITH COLLABORATIVE AGREEMENTS

# Irish Cancer Biobank Network

- Pathology-centred biobanks for frozen/fixed cancer research samples; Quality Assurance
- Biobank staff work with other hospital staff
- Same procedures, shared online database
- Consent, confidentiality, privacy
- Fair researcher access, incentive to collaborate
- Maximise expertise and resources
- Must be properly resourced and staffed

# All-Ireland Cancer Biobank Network



# Biobank Networks: People Communicating and Co-operating

- **Patient donor**
- Nurse, surgeon, biobank technician, pathologist, database manager, hospital CEO, researcher.....Minister for Health and Children
- See [www.biobankireland.com](http://www.biobankireland.com) for many more



[www.biobankireland.com](http://www.biobankireland.com)

# Communication



# And Attitudes

- *Patient group & public - consultation and input*
- Communication, Enthusiasm
- Openness, Trust, Confidence
- Help researchers share samples and overall results
- New treatments take 10 years or more
  - Accelerate research if more samples available
- We cannot justify doing nothing
  - Must start now for our children, but.....

# The Interested Parties

Cork Cancer Centre  
Medical scientists  
Industry  
Nat Cancer Reg  
DOHC  
ICORG  
NI R&D Office  
Minister Health & Children  
Public  
Marble Arch International  
Surgeons  
Cancer nurses  
Patient advocate groups  
Western Cancer Alliance  
International Advisors  
ISSP  
Patient  
Hospital Management  
GPs  
Media  
DMMC  
NCI  
Ent Ireland  
HSE  
Irish Cancer Soc  
Biobank Ire Trust  
Nat Cancer Forum  
HRB  
Ethicist  
IACR  
Business  
Hospital staff  
Faculty  
Path RCPI  
Action Cancer NI  
al.



<http://www.neystadt.org/john/album/>

# How Can It Be Done?

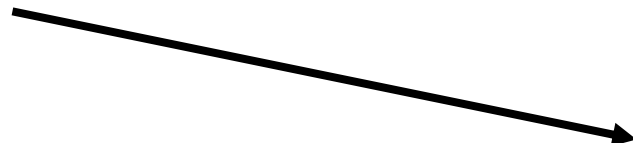
- Minister's Expert Group
  - Report -> -> -> implementation
- Wait till all the boxes are ticked?
- Wait for the next Celtic Tiger?
- Start with 2 hospitals in a “bottom-up” development
- Constant re-evaluation and *prove the concept*
- Develop cancer biobank network - 11 hospitals - in increments
- Guided by the international biobanking community



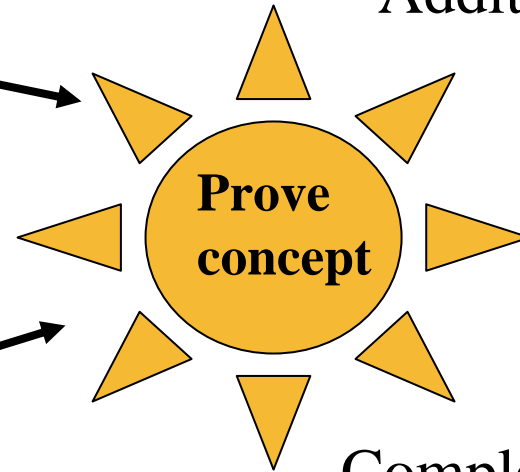
[www.biobankireland.com](http://www.biobankireland.com)

# Biobank Ireland Start-up Proposal

Hospital 1

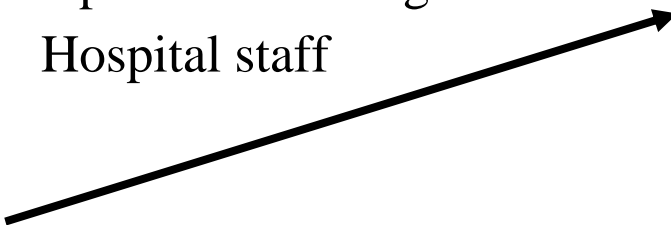


Additional hospitals



Complete Network

Biobank technicians  
Identical Procedures, IT  
Operations manager  
Hospital staff



*Online database*



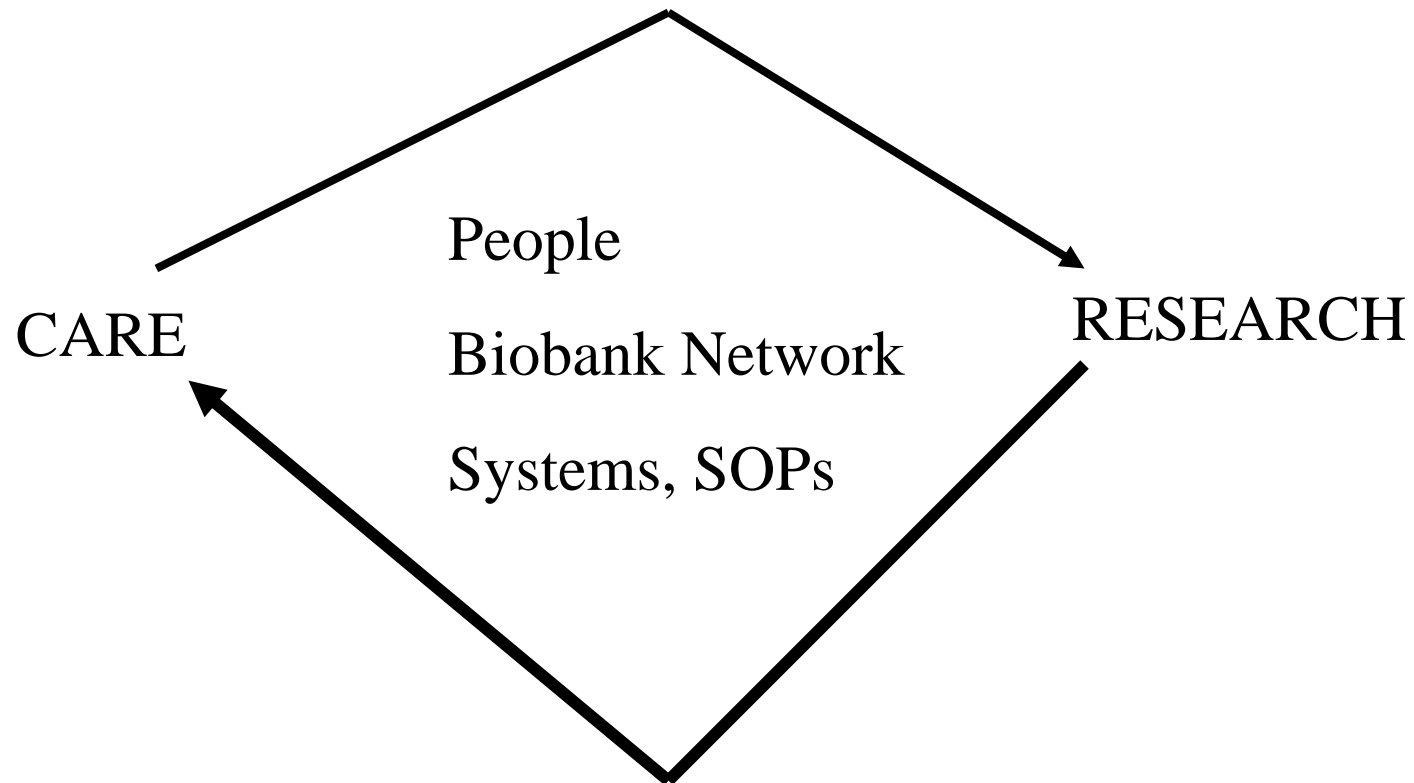
Hospital 2

*Start-up funds*

*HSE*



# Bridging Care and Research



# Selected Benefits

- *Research efficiency, quality*
  - Numerous samples - “start project running”
  - Incentive to share expertise, resources
  - Co-ordination: online access, data, re-evaluation
- National, international *collaborations*
- *Quality samples* for industry, acad / industry partnerships
- Facilitates translation of *new research findings into better patient interventions and ultimately prevention*
- Fast-track *individualised medicine*

# For Our Children



# Funding?

- Government and partnerships
  - ? other agencies e.g. Health Research Board, Enterp Ireland
  - Philanthropically-minded, industry
- Biobank Ireland, Irish Cancer Society
- Government has a huge responsibility
  - So do we all
  - Not easy *or* inexpensive - BI est. (2005): €10m. over 4 years
  - But expense is no excuse for denying diverse beneficiaries, including our children

# Luas - San Seamas

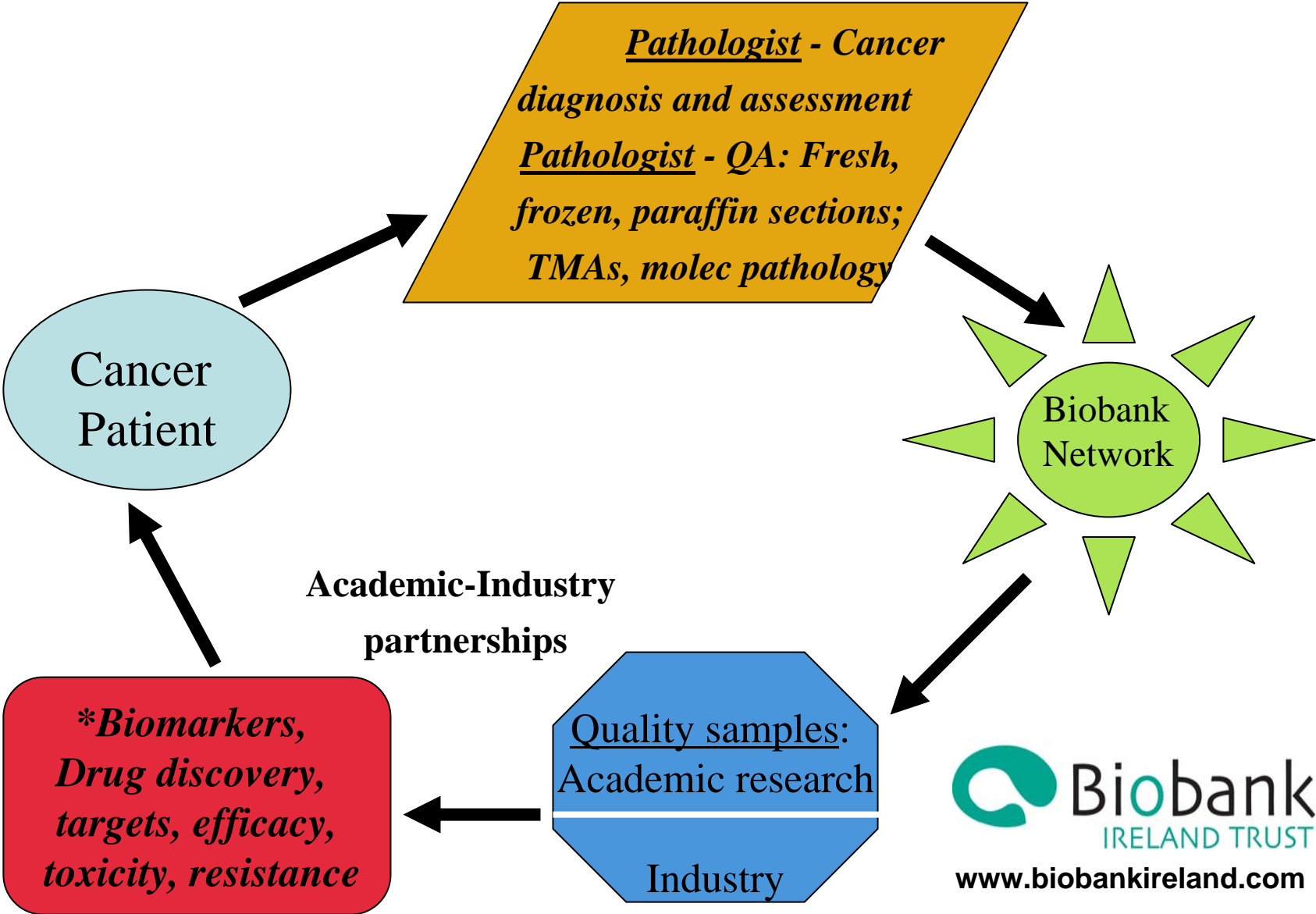


And PPARS, E-voting, Port Tunnel, NRA, Tribunals.....

# Biobank Ireland - Progress

- The interested parties
  - Proposals, promotion: HRB/NCI-Ireland Cancer Consortium, Irish Cancer Society
  - Altnagelvin Hospital, Derry; CAWT cross-border group
  - Industry
  - Patient groups, public, patrons, international presentations, media
- National Cancer Strategy 2006 -> DOHC
- Minister for Health and Children
- Network start-up proposal to CEOs and HSE
- [www.biobankireland.com](http://www.biobankireland.com)
- Central office, operations manager
- International contacts: NCI, ISBER, Marble Arch International
- Gastronomique fundraisers, Rennes, 2006, 2007

# From Patient Care to Research to Care





# Le Gastronomique

## Golf Event I

At Cice Blossac, Rennes, France  
Saturday June 9<sup>th</sup> - Tuesday June 12<sup>th</sup> 2007

In Aid of BIOBANK IRELAND TRUST





# And What is a Biobank?

Small frozen human samples  
Consent, confidential, privacy  
Cancer & normal tissue, blood  
Specialist technician, security  
Sample data, coded patient data  
Formal approval process for  
sample release - *not sold*



# I: CNIO Tumour Bank Network

*CNIO TB-Unit plays the role of central coordination office that means a guaranty for...*



- *Confidentiality*
- *Stability*
- *QA/QC policy*
- *Homogeneous protocols*
- *Stable recognition by Research Agencies and Ethic Review Boards*
- *Leadership*

*... the so-called “**HONEST BROKER**” design*



*But Hospitals are the main players in this design*