Wales Cancer Bank (WCB)

Aim

- To provide a population based collection of tissue and blood samples from all patients in Wales undergoing an operation where cancer is a possible diagnosis.
- In the hope that, eventually, the provision of a standardised, quality assured collection of tissue samples, linked to clinical outcome, will help identify novel profiles for prediction and prognosis which will lead to individualised treatment, thereby avoiding unnecessary or ineffective treatments for patients.

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R² (recruitment and regulation)

- Started consenting patients in February 2005
- 3190 patients so far, from 7 hospitals
- 17 different tumour types, variety of sample types
- Licensed by the Human Tissue Authority
- Approval Wales MREC

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Patient perspectives

- The Patient advocates have varied backgrounds.
- Each brings a unique perspective.
- A Living Library!
- Patient involvement is varied, with each having a different way of getting involved.

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How are patients involved?

Patient Involvement

Patients as advisers

Patients as advocates

Patients as donors

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Patients as Advisers

- Patients were full members of the founding Steering Committee set up in 2002
- Patient Liaison group formed in 2003
  - Patient information sheets
    - Easy to understand, NO acronyms
  - Consent forms
  - MREC submission
    - Protocols and pathways

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Patient Involvement today

- Reformatted into Lay Liaison & Ethics group in 2007
  - Communication Strategy
    - Informing public, patient groups, policy makers, healthcare professionals and funding bodies
  - Review patient documentation

- Patient representative on Advisory Board and Executive group
Patients as Advocates

- Public launch in Cardiff in 2004
  - 42% attendees patients/patient representatives
- Patients giving press interviews
  - Support and training
- Lobbying politicians
- Patient forum and newspaper articles
- Attending conferences

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Patients as Donors

- 98.7% patients agree to consent when approached pre-surgery
- 99.5% patients agree retrospectively
- 57% of WCB donors are female, 43% male
  - Breast largest collection
- 68% are over 60
- Men more reluctant to act as control
Patients as Donors 2

- No common reason for not consenting
- Pharmaceutical company involvement not an issue
- Gathering refusal reasons:
  - ‘I’ve got cancer and I don’t want to help anyone else’
  - ‘The arm of the chair is sticky’
  - ‘I don’t want my wife cloned!’

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What have we learnt?

- Patients are at the heart of bio banking.
- They want to get involved and they make the conscious decision to do so.
- Patients are very strong advocates.
- Patient groups are good information forums.
- Patients bring a different, but positive perspective to projects.

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BUT ………

- Biobanks must not let patients down
  - They expect their samples to be collected, processed and stored to assure quality
  - They expect their samples to be used responsibly for good quality, reproducible research that will:
    - further knowledge
    - lead to new drug discovery
    - help future generations

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