

BIOBANKS SUPPORTING RESEARCHERS WITH PROJECT SPECIFIC CINICAL DATA COLLECTION:

Challenges encountered with the Gastric Study at Peter Mac

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Genome-wide expression analysis in gastric cancer

Principle Investigator: Alex Boussioutas

Study Commenced: 1999

Funded by: NHMRC grants

Currently: 318 participants

208 Gastric & 110 Oesophageal adenocarcinomas

Data captured for Gastric Study

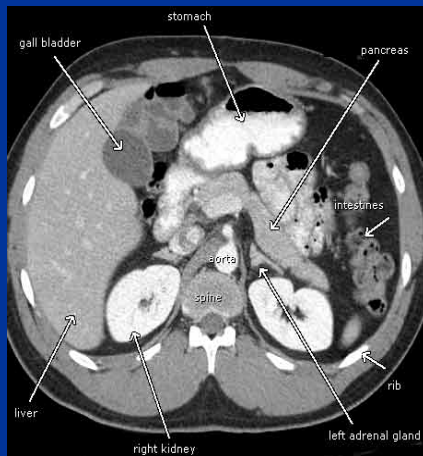


Collected on one occasion:

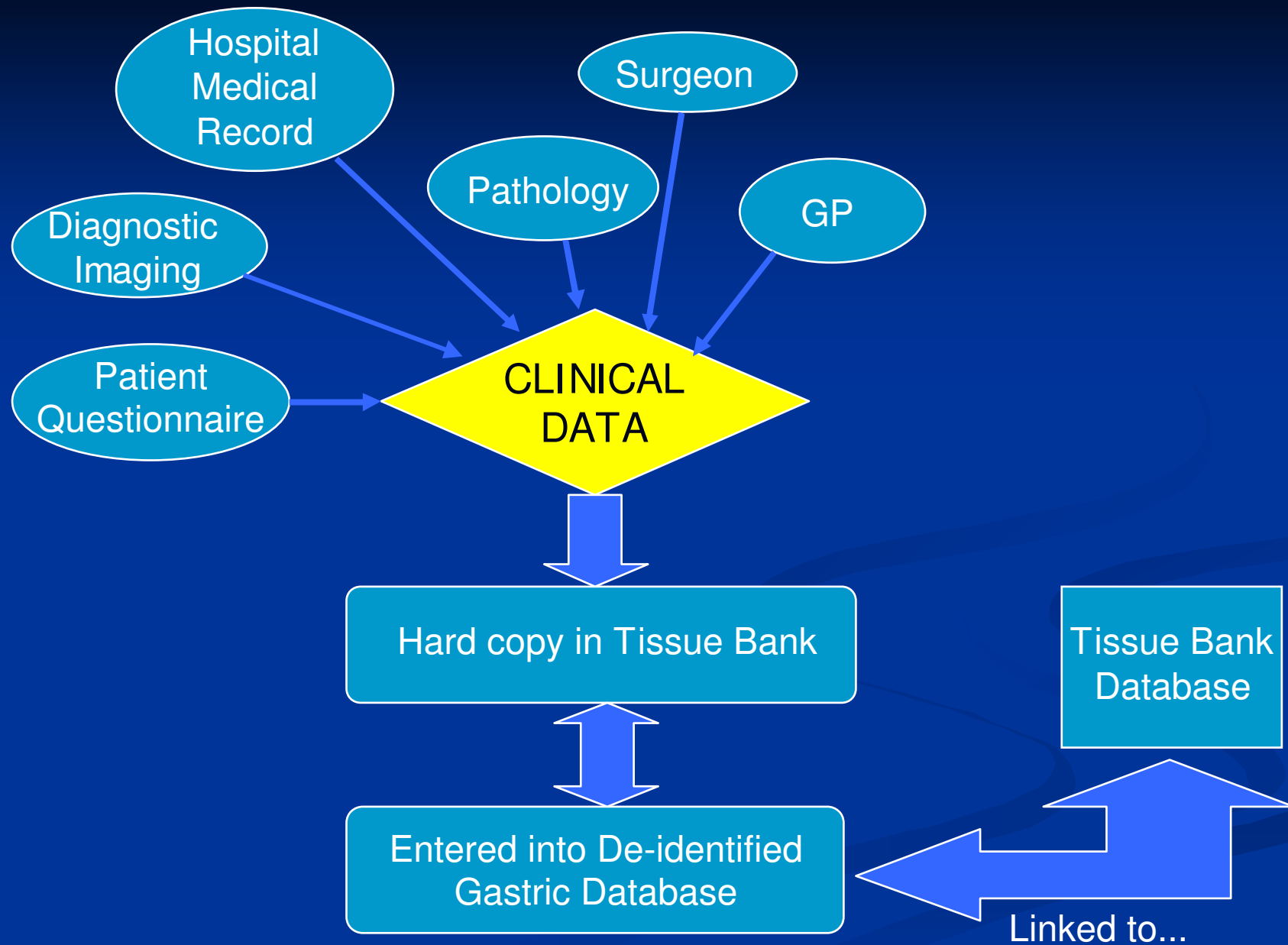
- Country of birth
- Diet
- Alcohol and Smoking history



Collected Pre-Op & Post-Op at 3 or 6 monthly intervals:



- Medications
- Clinical symptoms
- Copy of Investigation Reports (eg: gastroscopy & biopsy, CT, PET, EUS)
- Neoadjuvant, Adjuvant and Palliative Chemo/RT details
- Recurrence (date & details)
- Date and Cause of Death



Types of Follow Up / Patient Involvement

	Total Cases	Verbal Follow up	Passive Follow up	Lost to Follow up	'drop out'
Gastric	208	145	57	6	13
Oesophageal	110	95	13	2	4
TOTAL	318	240 (75.5%)	70 (22%)	8 (2.5%)	17 (5%)

Patient's consented and willing for future contact.

Patient's who did NOT consent for future contact, and/or Patient's who have withdrawn from verbal follow up "drop out".

Unable to continue collecting clinical data

KEY FACTORS FOR GOOD FOLLOW UP DATA

- Contacting consented patients regularly in a friendly and accommodating manner
- Developing and maintaining good relationships with surgeon receptionists and medical records staff.
- Good detective work



OTHER CHALLENGES:

- Post Op progress NOT monitored by treating hospital and/or surgeon
- Patient care involving more than one physician
- Detail in medical record
- Funding
- Prospective versus Retrospective



CONCLUSION

- Biobanks can provide researchers with de-identified clinical data on a project specific basis.
- Most challenges in collecting follow up data have been overcome.
- Integration of our database with BioGrid's informatics platform should reduce the time and staff required to obtain clinical data in the future.



Acknowledgments:

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Gastric Study Co-Investigator: David Bowtell

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Victorian Cancer Biobank

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