Reducing the Burden of Liver Cancer for Tasmanians

Linked Data in Action: Supporting Service Improvement

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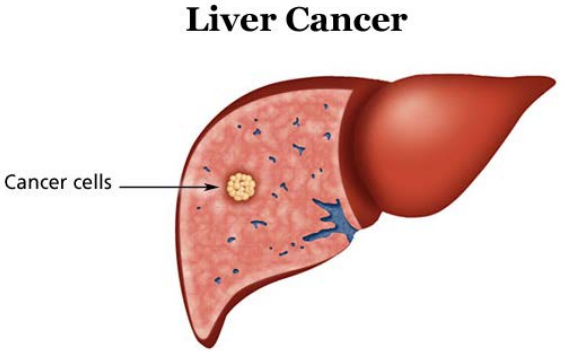
Sefton Bottomley Liver Cancer Bequest

Project overview – background

- In 2015, over 2000 Australians were diagnosed with *primary* liver cancer and almost 1800 people died from the disease
- ASR incidence has increased from a rate of ~1.6/100,000 persons in 1983 to over 7.5/100,000 in 2015
- Rates are projected to continue to increase
- Primary liver cancer is the fast growing cause of cancer-related mortality in Australia
- 5-year survival is <20%
- Survival is highly dependent on the stage of the tumour(s) at diagnosis
- It is recommended that people at high risk of developing primary liver cancer should undergo 6 monthly surveillance of liver health
- Poor 5 year survival is evidence that few people participate in this

Project Aim

- Develop an intervention to support increased participation in surveillance for primary liver cancer to reduce the burden of disease



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Project approach

Step 1 – Information gathering

- What is the situation re liver cancer in Tasmania?
  - Incidence
  - Mortality
  - Survival time
  - Staging of cancer at diagnosis and outcomes
  - Identify any geographical / regional differences

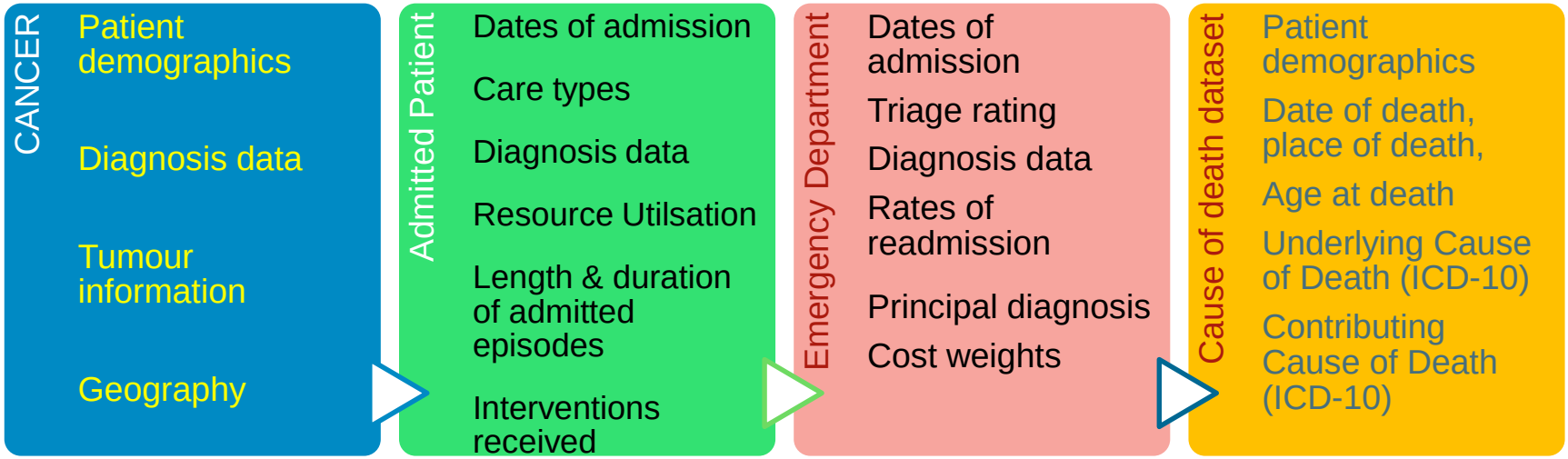
Step 2 – Work with TDLU to identify whether data-linkage can help answer questions:

- What potential datasets are available to support research?
- Are they already linked in the TDLU's Master Linkage Map (MLM)?
- What date ranges are available, quality of the data?
- Where could a research cohort be drawn from?
- What timeframes would be involved?
- What costs are involved?

Step 3 – Datasets Identified

1. **Tasmanian Cancer Registry**
    - *High quality, coded data (ICD-10), some clinical variables, data available since 1982*
2. **Tasmanian Public Hospital Admitted Patients Dataset**
    - *Coded discharge events, comprehensive data, clinical and administrative data – up to 10 years of admitted events*
3. **Tasmanian Public Hospital Emergency Department presentations**
    - *Coded data, comprehensive, clinical and administrative data – up to 15 years of admitted events*
4. **Coded cause of death**
    - *Accurate coded data (ICD-10) primary, antecedent causes, other contributing factors – data back to 2006*

Types of data important to research team



Step 4 – Cohort defined

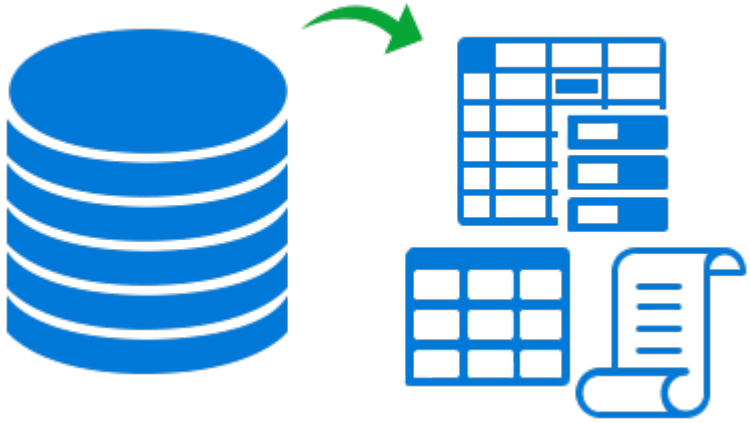
1. **Tasmanian Cancer Registry**
    - *Adults aged 18 years and older*
    - *All persons diagnosed with a primary Liver Cancer –* ICD 10 AM code C22.*
    - *Diagnosed between 2007 – 2015*

Step 5 – Approvals

1. **Design research plan / study protocol**
2. **Identify desired research variables**
3. **HREC Application**
4. **TDLU Application**
5. **Data Custodian Approvals (Managed by TDLU)**
    1. *Tasmanian Cancer Registry – Director Public Health*
    2. *Public hospital admitted patient – Dept. of Health*
    3. *Emergency Department Presentations – Dept. of Health*
    4. *Death Registrations – Australian Coordinating Registry / Menzies*

Step 6 – Data Linkage / Extraction

1. TDLU links cohort extracted by Tasmanian Cancer Registry
2. Data linked with other datasets in MLM
3. TDLU assigns linkage keys to linked data
4. Linkage keys returned to each data custodian
5. Data returned to researcher by each custodian
6. 4 datasets combined into 1 using the PPID



Step 7 – Data Management / Analysis

1. Data combined into single researchable dataset
2. Data cleaning by researcher
    - I.e., multiple hospital admissions in separate rows, needed to be moved so each individual has a single row of data
    - Missing data items identified
- Data exported to statistical software

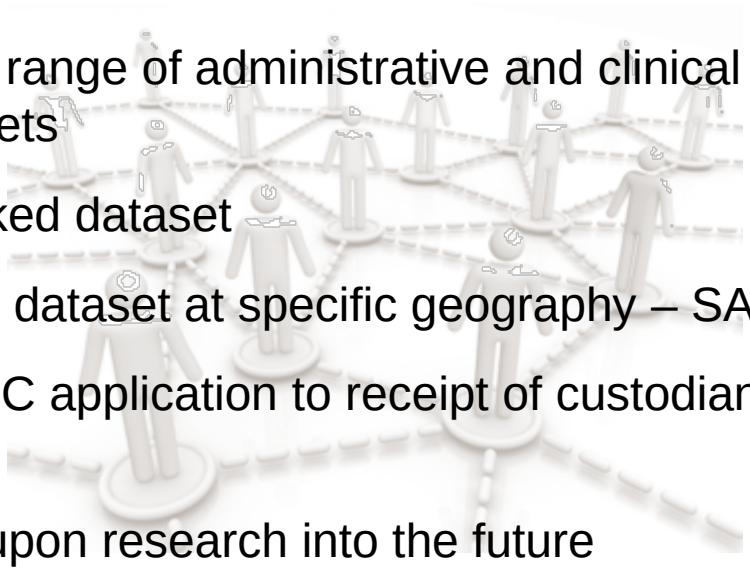
Preliminary results

	N=299 N (%)
Male	220 (74%)
Age	69 years (range 28-93) (SD 11)
Average survival time	14 months (SD 0.9)

- Incidence and mortality rates similar in Tasmania to Australia
- The absence of having stage at diagnosis a limiting factor in greater depth of analysis

Why data linkage?

1. Ready access to relevant datasets, already linked in TDLU's MLM
2. Cost effective
3. Access to wide range of administrative and clinical data derived from four datasets
4. High quality linked dataset
5. Able to analyse dataset at specific geography – SA2 in this case
6. Time from HREC application to receipt of custodian data relatively short
7. Ability to build upon research into the future
    1. ie, new questions, more data, more datasets



Next steps

1. Continue to analyse linked dataset
2. Investigate opportunity for TCR to stage liver cancer for some or all years of research
3. Discuss initial findings with ‘expert’ clinicians
4. Publish findings in relevant journals
5. Investigate opportunities to replicate research in another jurisdiction