

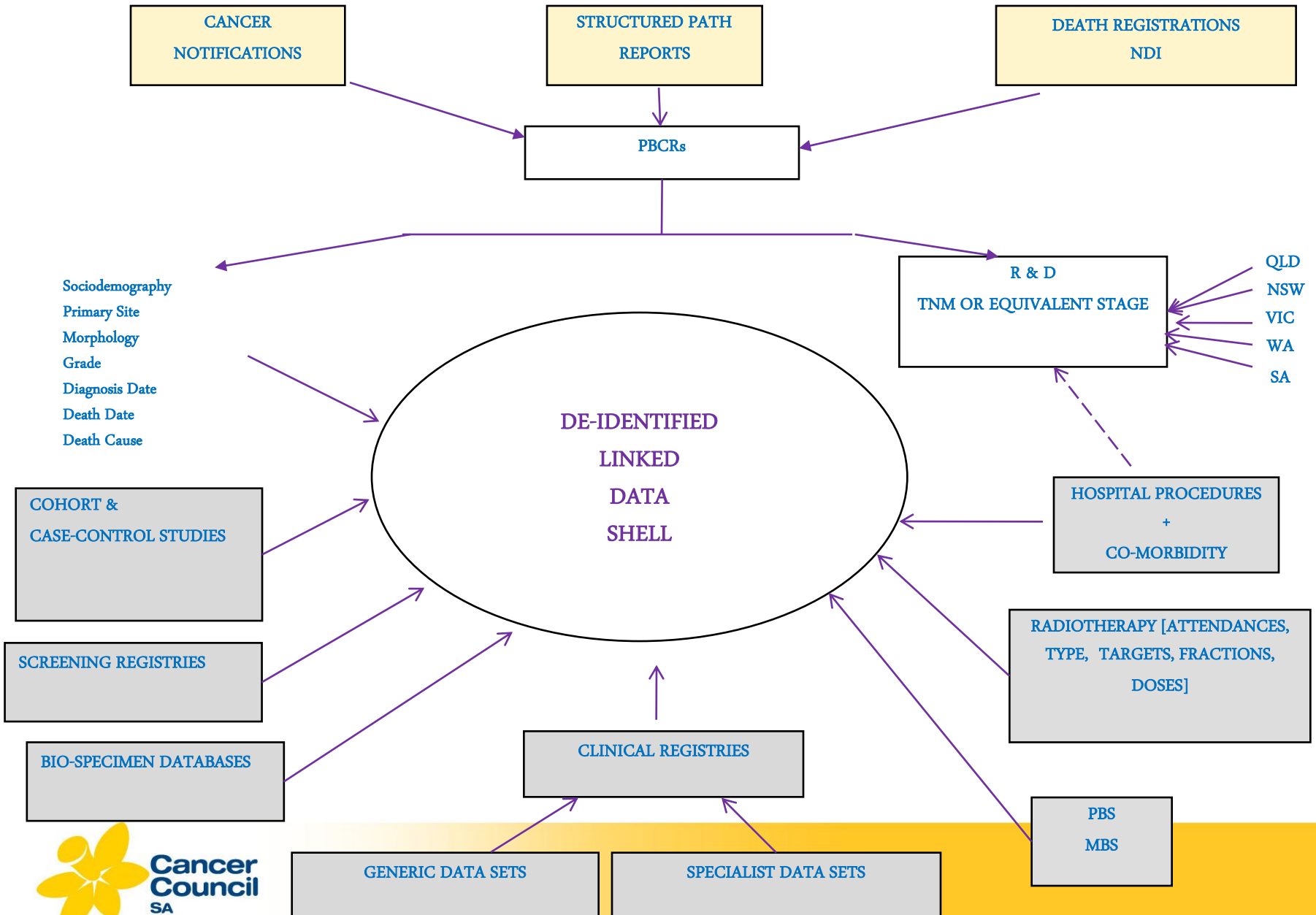
SA CANCER INFORMATION STRATEGY

with reference to

Colorectal Cancer Linkage Project Data Collection for Paediatric & AYA Cancers

David Roder
Cancer Council South Australia
September, 2010

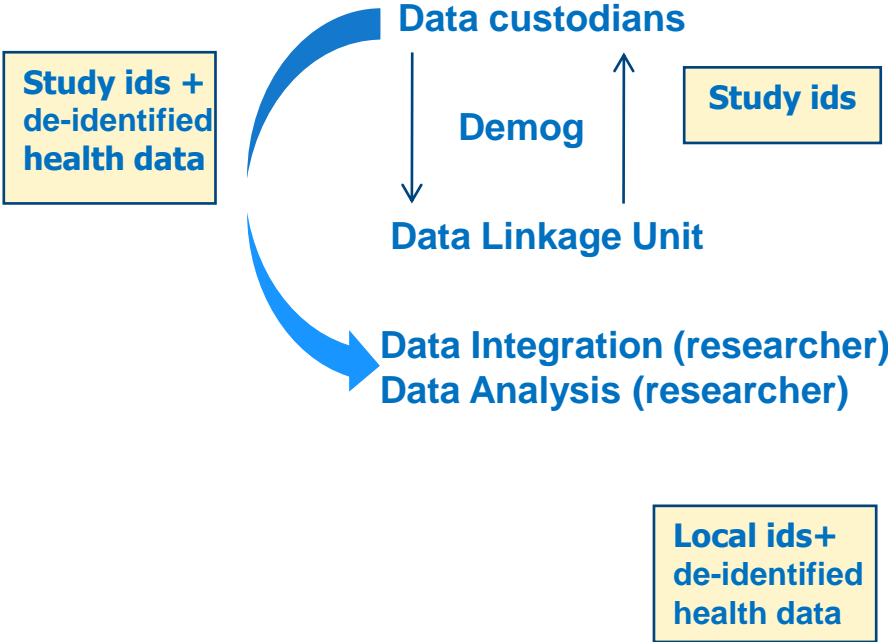
LINKED CLINICAL CANCER DATA: A PROPOSED PATHWAY



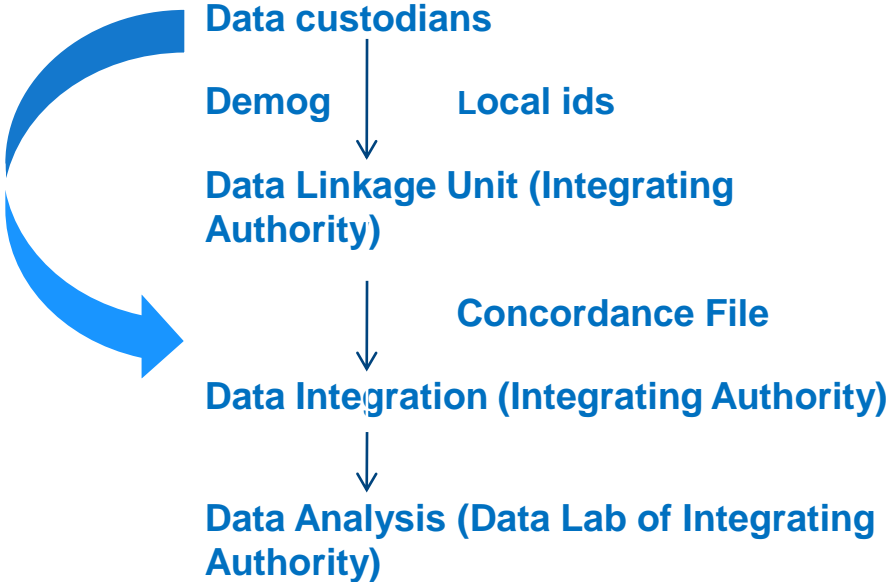
DATA LINKAGE MODELS

- EXISTING MODEL -

(WADL, NSW CHeReL, NCRIS PHRN)



PROPOSED MODEL -



AYA DSS Development (Clinic)

	Generic	WG+
1. PERSON	Names Address Sex DOB Indigenous Medicare Number Date of death Cause of death	Country of Birth
2. HISTORY TAKING		Familial cancers Genetically related events
3. PATIENT JOURNEY		Date of symptom onset Date of initial GP/primary health care consultant Date of initial medical specialist consultant
4. PROVISION OF CARE	Establishment number	Establishment type Shared care arrangement Youth treatment centre involved Care co-ordinator assigned Fertility counselling Fertility preservation Assessed by MDT Involvement of AYA specialist team If planned and delivered care differed-reasons

AYA DSS Development (Clinic)

	Generic	WG+
5. DIAGNOSIS	<p>Most valid basis</p> <p>Date</p> <p>Primary site</p> <p>Morphology</p> <p>Grade</p> <p>Laterality</p> <p>UICC TNM</p> <ul style="list-style-type: none">- clinical- pathological <p>Other staging system</p> <ul style="list-style-type: none">- name- stage grouping <p>Tumour size</p> <p>Number of nodes examined</p> <p>Number of nodes positive</p>	<p>Performance status</p>

AYA DSS Development (Clinic)

	Generic	WG+
6. TREATMENT (Initial course)	<p>Type</p> <p>Surgery</p> <ul style="list-style-type: none"> - date - type <p>Radiotherapy</p> <ul style="list-style-type: none"> - start/stop date - site - type - fractions - dose <p>Chemotherapy</p> <ul style="list-style-type: none"> - start/stop date - agent/protocol - cycles <p>Immunotherapy</p> <ul style="list-style-type: none"> - start/stop date - type <p>Systemic therapy procedure</p> <ul style="list-style-type: none"> - start/stop date - type <p>Other treatment</p> <ul style="list-style-type: none"> - start/stop date - type <p>Treatment response</p>	<p>Intent</p> <p>Trial enrolment</p> <p>Psychosocial referral</p> <p>Outcome (CR, PR, SD, PD, etc.)</p> <p>Grade 3+ treatment complications</p>

AYA DSS Development (Clinic)

	Generic	WG+
7. RECURRENCE	Date Region Basis of diagnosis	Trial offered/enrolled
8. FOLLOW-UP	Last contact date Cancer status	Follow-up content type

AYA DSS DEVELOPMENT (Other)

- General stress thermometer
- Areas of distress
 - Practical : Living situation, education, work, money etc.
 - Family : Parents, siblings, partner, children etc.
 - Emotional : Anxiety, anger, depression etc.
 - Social : Isolated, relationships etc.
 - Physical : Appearance, fitness, sexual, pain etc
 - Information : Comprehension, privacy, feel involved in decisions etc.