

Live electronic feeds and HL7

Area-based Clinical Cancer Registry
Northern Sydney & Central Coast
Live electronic feeds and HL7
Registries Interest Group
February 6, 2009

Neil Heron, Cancer Information Manager

Northern Sydney & Central Coast Area Health Service

- The Cancer Institute NSW funds the NSCCAHS Clinical Cancer Registry program
- Sponsor: Dr Chris Arthur, Area Director of Cancer Services



Neville Board

Information Strategy Manager

Australian Commission on Safety and Quality in Health Care

AUSTRALIAN COMMISSION ON
SAFETY AND QUALITY IN HEALTH CARE

What do we know? (direct feeds)

- Incidence & mortality
- Inpatients statistics (mostly surgical)
 - Dx, procedures, morphology
 - AKA “Admitted Patient Data collection”
- Radiotherapy statistics
 - Dx, beam, fractions, **stage**
 - AKA “LANTIS and VARiS data”

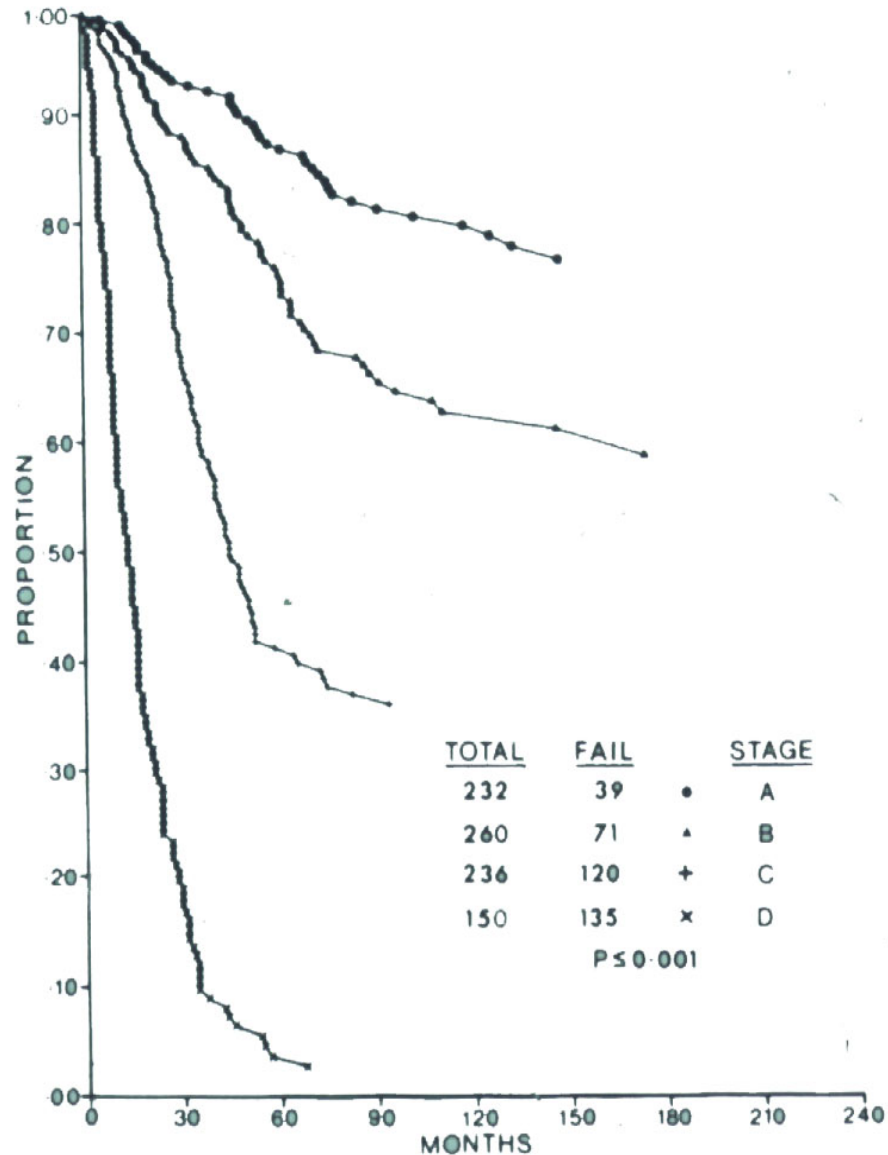
What don't we know?

- Stage
- Chemotherapy
 - Cases, Dx, regime, cycles
- Haematology treatments
 - Cases, Dx, regime, cycles
- Intermediate outcomes
- Quality of care
- Patient-centric view

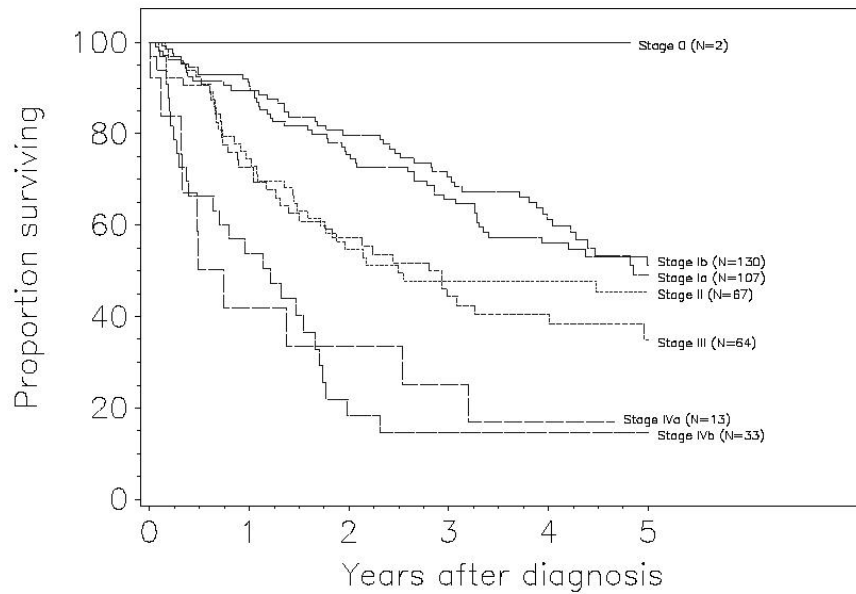
WHERE DO WE WANT TO BE?



NATIONAL
CANCER
CONTROL
INITIATIVE

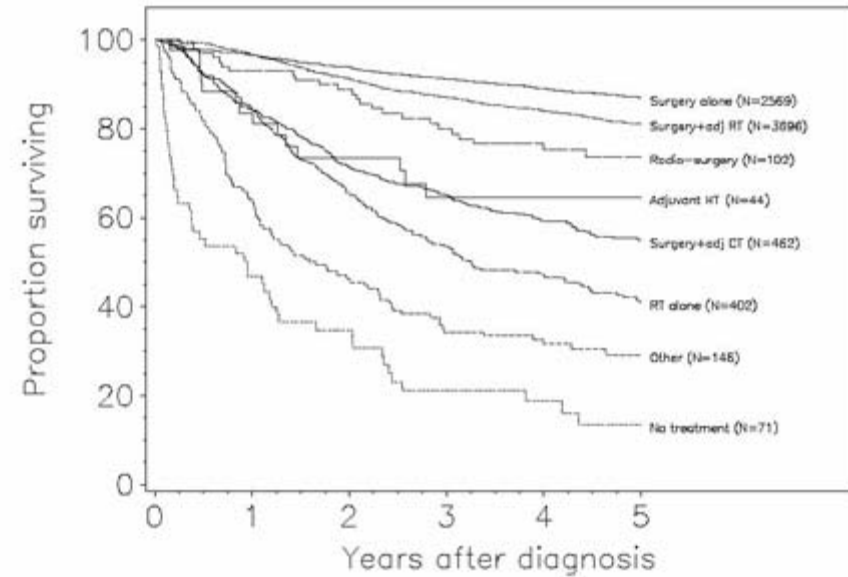


WHERE DO WE WANT TO BE?



Stage	Patients (n)	Mean age (yr)	Overall survival (%) at					Hazards ratio ^a (95% CI)
			1 year	2 years	3 years	4 years	5 years	
0	2	67.5	100.0	100.0	100.0	100.0	—	—
Ia	107	70.6	89.6	79.8	70.6	61.3	49.6	Reference
Ib	130	72.0	91.1	75.3	65.7	55.7	51.0	0.9 (0.6–1.4)
II	67	72.9	75.2	55.1	48.2	48.2	45.8	1.2 (0.8–2.0)
III	64	69.7	72.8	57.4	44.6	40.7	35.4	1.8 (1.1–2.9)
IVa	13	64.8	44.0	35.2	26.4	15.8	—	6.6 (2.7–16.2)
IVb	33	66.1	53.8	20.2	16.2	16.2	16.2	4.4 (2.6–7.4)

^aHazards ratio and 95% Confidence Intervals obtained from a Cox model adjusted for age, stage and country.



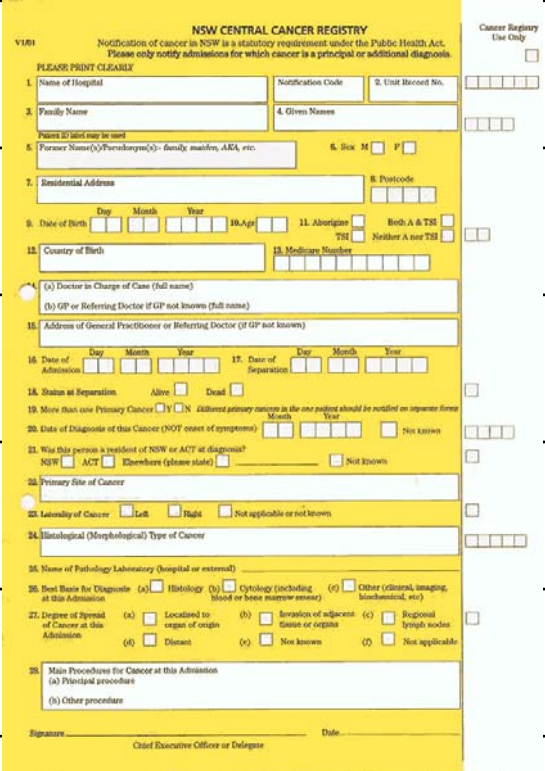
Treatment	Patients (n)	Mean age (yr)	Overall survival (%) at					Hazards ratio ^a (95% CI)
			1 year	2 years	3 years	4 years	5 years	
No treatment	71	73.2	47.8	35.1	21.5	19.3	12.9	5.5 (4.0–7.7)
Surgery alone	2569	62.0	96.5	93.8	91.2	88.9	86.9	Reference
RT alone	402	73.6	84.6	65.7	53.5	46.8	40.9	1.6 (1.2–2.0)
Radio-surgery	102	61.8	93.0	88.7	79.9	75.0	73.2	1.1 (0.7–1.7)
Surgery + adj RT	3696	63.7	96.8	91.3	87.1	84.0	81.0	0.8 (0.7–1.0)
Surgery + adj CT	462	59.6	84.0	71.5	65.1	59.2	54.9	1.4 (1.2–1.8)
Adjuvant HT	44	65.7	83.5	73.1	64.3	64.3	64.3	1.2 (0.7–2.1)
Other	146	65.9	64.3	46.5	34.7	32.1	29.8	3.0 (2.3–3.9)

^aHazards ratio and 95% Confidence Intervals obtained from a Cox model adjusted for age, stage and country.

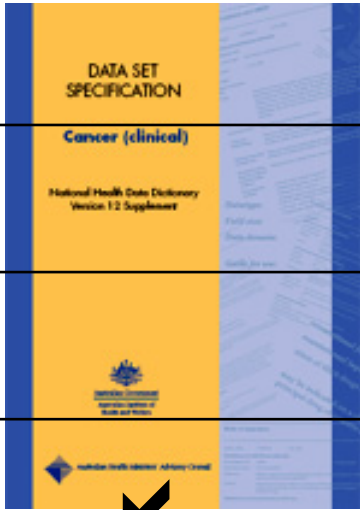
Fig. 8. Carcinoma of the cervix: patients treated in 1996–98. Survival by clinical stage. *n* = 416.

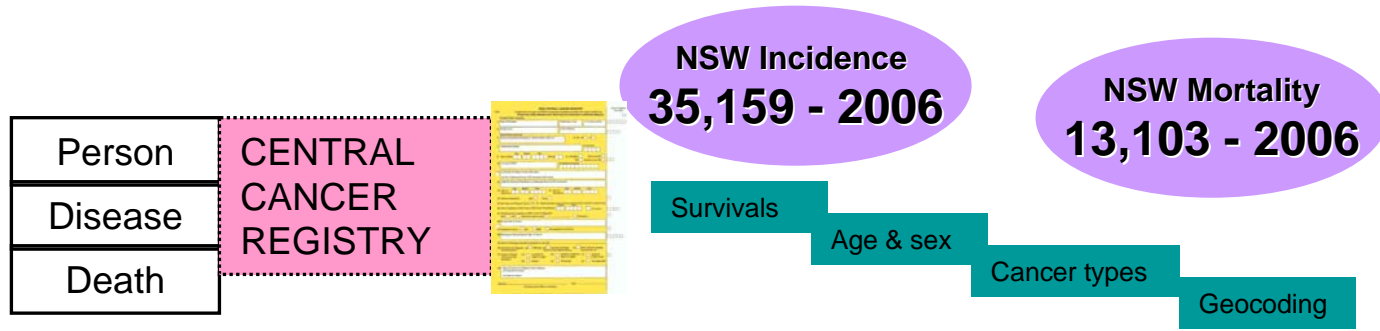
Fig. 23. Carcinoma of the corpus uteri: patients treated in 1996–98. Survival by mode of treatment, *n* = 7492.

CANCER REGISTRIES

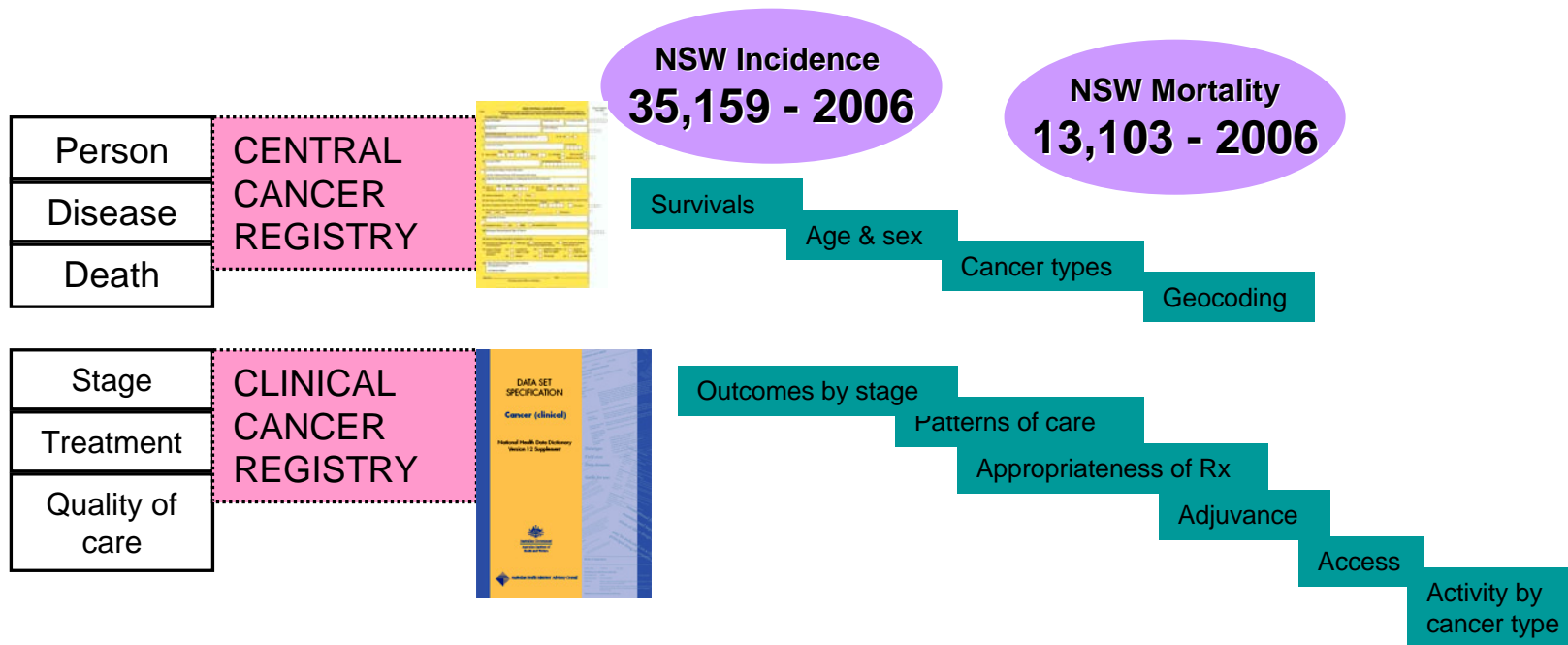
	Central	Clinical
Demographic	✓	 <p>The image shows the NSW Central Cancer Registry form, which is a detailed notification form for cancer in NSW. It includes sections for patient demographics (name, address, date of birth), clinical information (date of diagnosis, stage, treatment), and administrative details (referring doctor, hospital, date of admission). The form is divided into numbered sections and includes checkboxes for various options like 'Primary Site of Cancer' and 'Main Procedure for Cancer at this Admission'.</p>
Dx	✓	
Stage		
Rx		
Quality of care		
Death	✓	

CANCER REGISTRIES

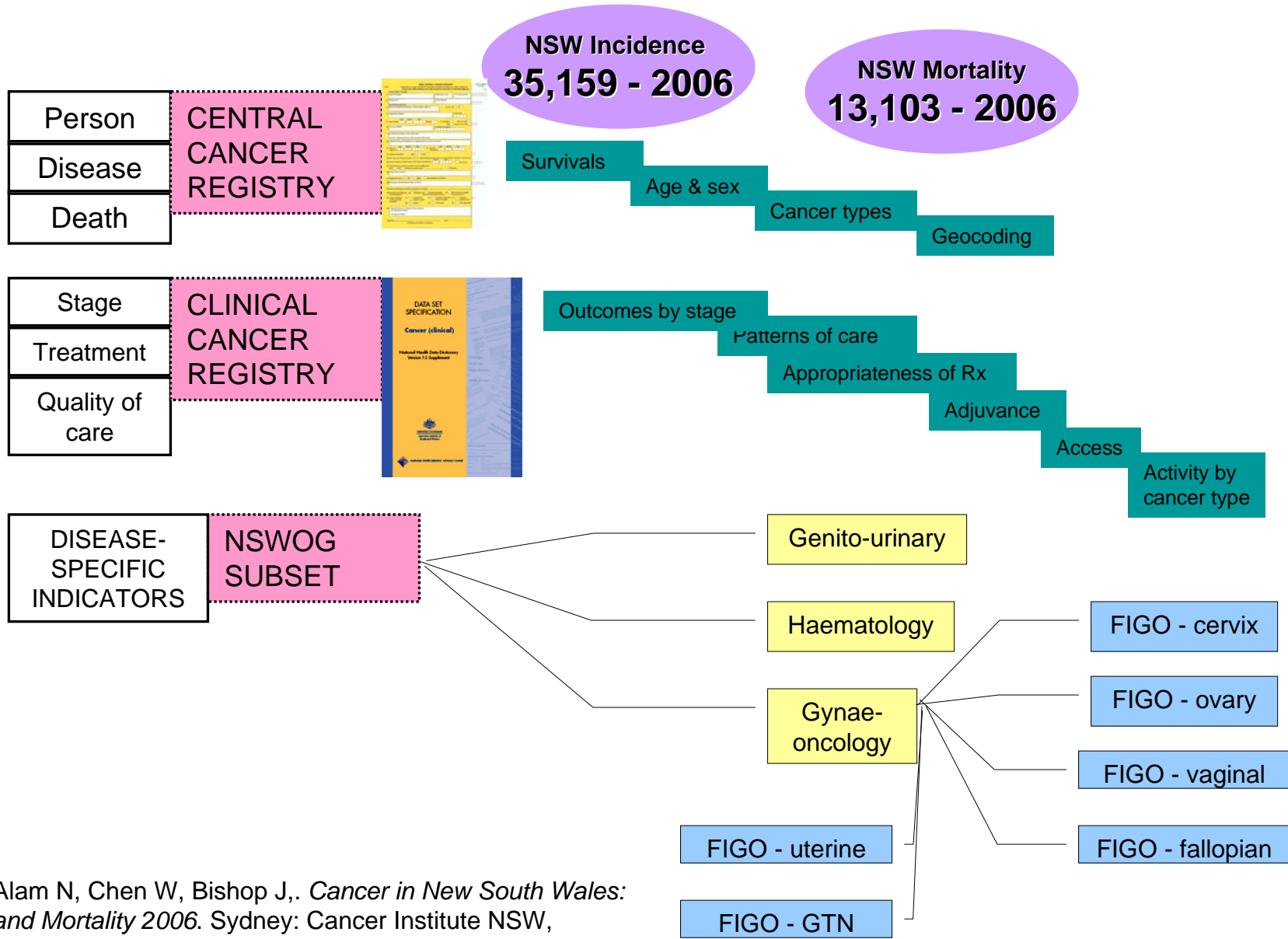
	Central	Clinical
Demographic	✓	✓
Dx	✓	✓
Stage		✓
Rx		✓
Quality of care		✓
Death		✓



Tracey E, Alam N, Chen W, Bishop J,. *Cancer in New South Wales: Incidence and Mortality 2006*. Sydney: Cancer Institute NSW, November 2008|ISSN: 1836-4551



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Table 1

Carcinoma of the corpus uteri: **Surgical staging classification** (FIGO nomenclature, Rio de Janeiro, 1988)

Stage Ia*	Tumor limited to the endometrium
Stage Ib*	Invasion to less than half of the myometrium
Stage Ic*	Invasion equal to or more than half of the myometrium
Stage IIa*	Endocervical glandular involvement only
Stage IIb*	Cervical stromal invasion
Stage IIIa*	Tumor invades the serosa of the corpus uteri and/or adnexae and/or positive cytological findings
Stage IIIb*	Vaginal metastases
Stage IIIc*	Metastases to pelvic and/or para-aortic lymph nodes
Stage IVa*	Tumor invasion of bladder and/or bowel mucosa
Stage IVb*	Distant metastases, including intra-abdominal metastasis and/or inguinal lymph nodes

* Either G1, G2 or G3. See section on Rules for classification.

Table 2

Carcinoma of the corpus uteri: Stage grouping for corpus uteri

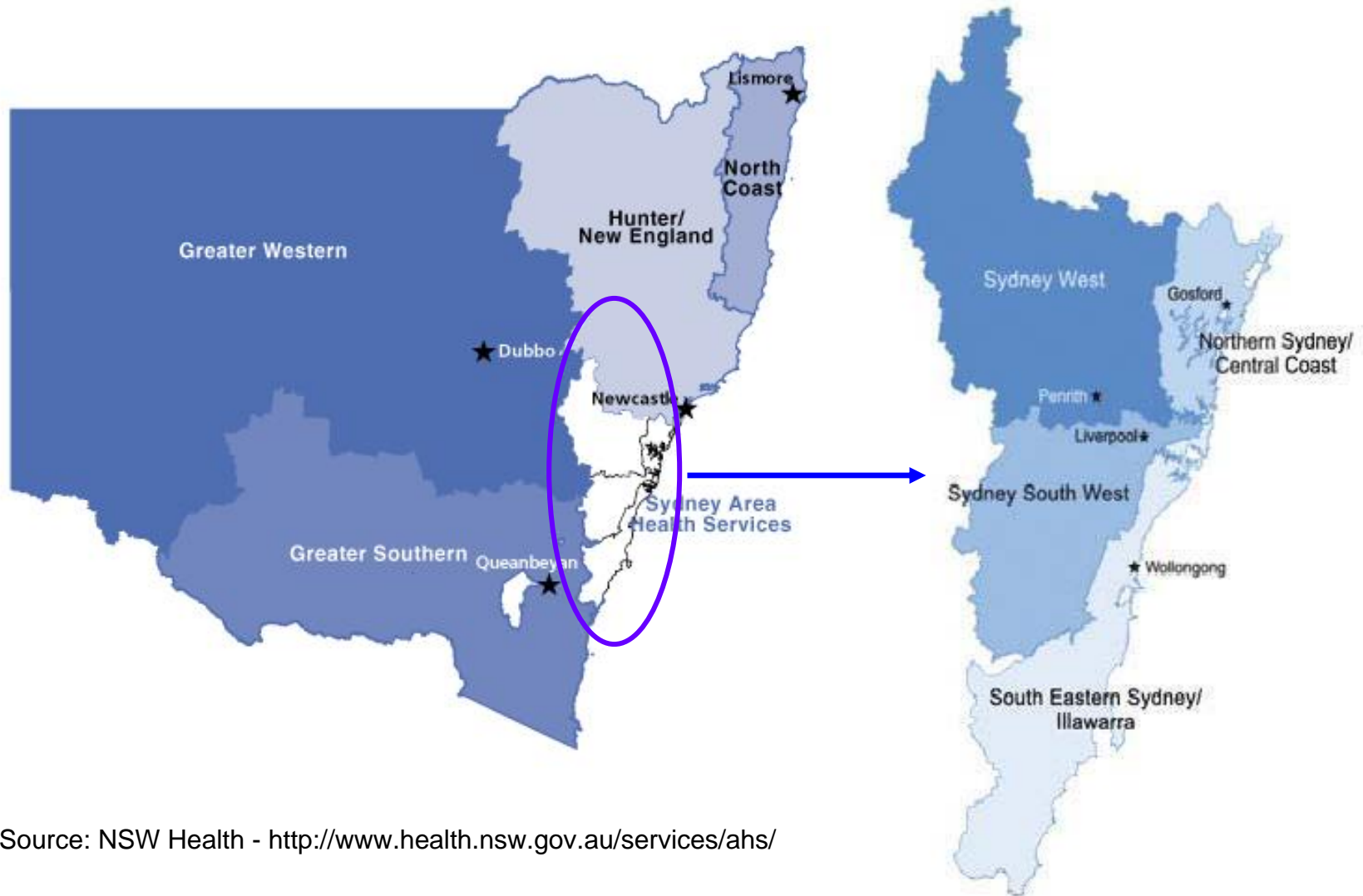
FIGO stage	UICC		
	T	N	M
0	Tis	N0	M0
Ia	T1a	N0	M0
Ib	T1b	N0	M0
Ic	T1c	N0	M0
IIa	T2a	N0	M0
IIb	T2b	N0	M0
IIIa	T3a	N0	M0
IIIb	T3b	N0	M0
IIIc	T1	N1	M0
	T2	N1	M0
	T3a	N1	M0
	T3b	N1	M0
IVa	T4	any N	M0
IVb	any T	any N	M1

CLINICAL CANCER REGISTRY PROJECT

An Area Health Service-based registry to:

- monitor service quality
- target deficiencies for remedial action
- evaluate outcomes of this action.
- provide detailed management information for cancer services planning
- Monitor Clinical programs – MDT, Psychosocial, Clinical trials, QCT

NSW AREA HEALTH SERVICES



Source: NSW Health - <http://www.health.nsw.gov.au/services/ahs/>



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Northern Sydney & Central Coast CLINICAL CANCER REGISTRY

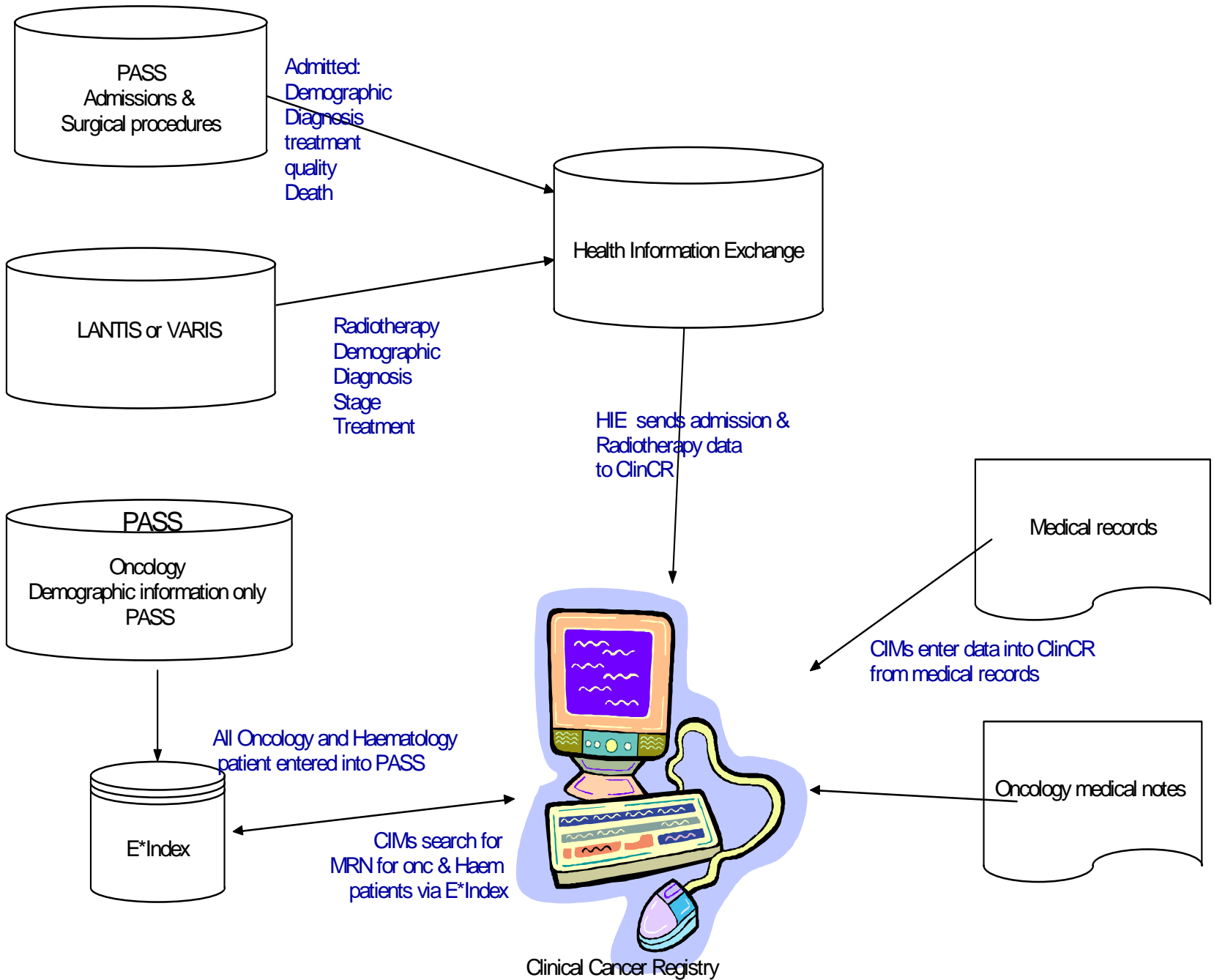
- 9 public sector hospitals, 2 of which are tertiary
- 5 Area-based staff (Project Manager and Cancer Information Data Managers)
- Funding based on clinical activity

E-DATA SOURCES

1. NSW Health Data Warehouse (Admitted Patients + Radiotherapy)
2. Patient Master Index (PMI) via HL7
3. File upload other databases

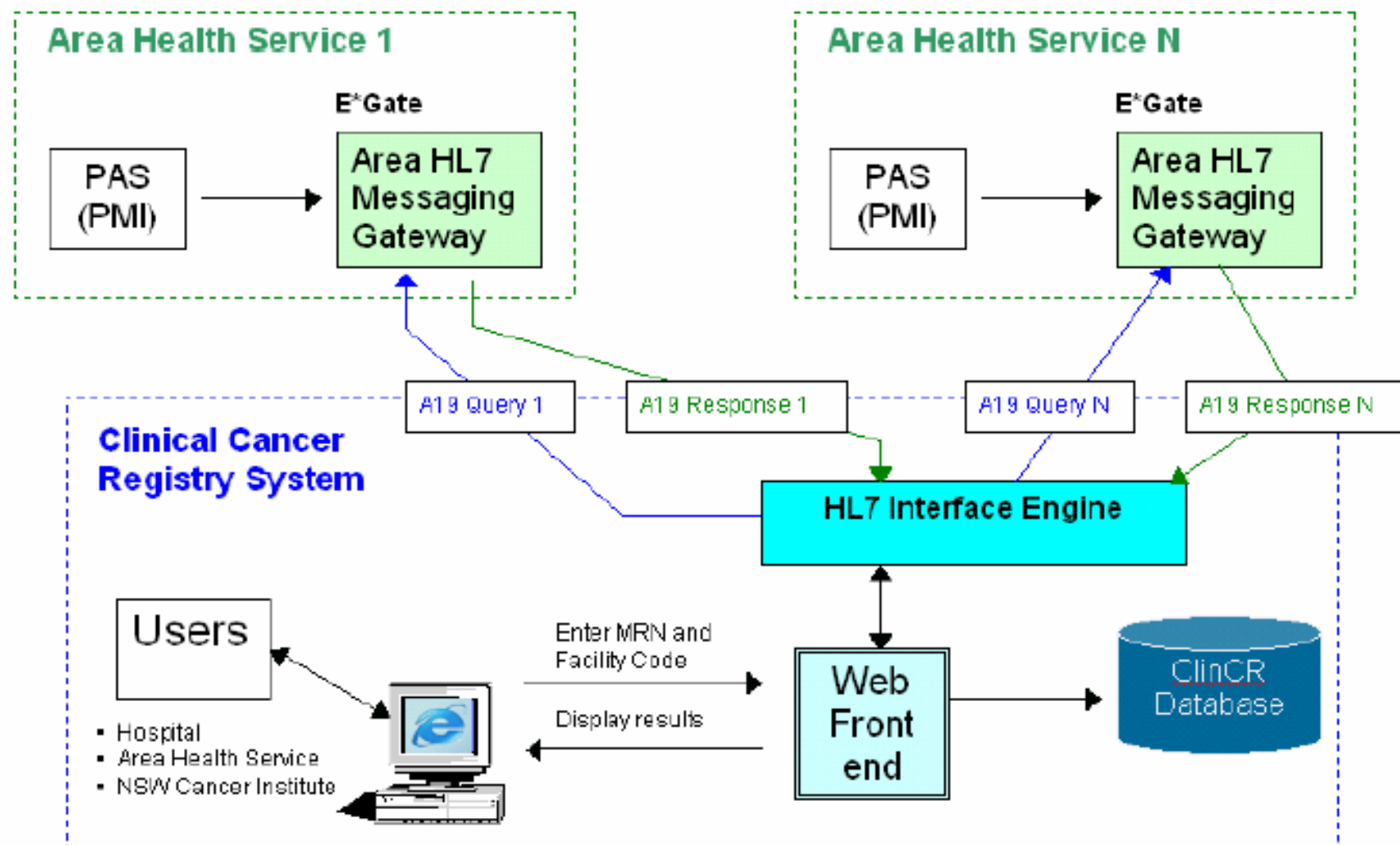
OTHER DATA SOURCES

- Labs, notes, MDT, imaging



ClinCR HL7 A19 (demographic import)

The basic data flow process can be illustrated as follows:





NSW Clinical Cancer Registry

> Welcome > About ClinCR > Data Collection > Data Set > Area Health Services > Contact Details

Welcome to NSW Clinical Cancer Registry Online Train Version 2.2

This online service provides access to the NSW Clinical Cancer Registry, and is intended for cancer services in lead Area Health Services.

As part of the NSW Cancer Plan, the Cancer Institute NSW is committed to piloting an Area-based, centrally hosted registry for the collection, collation and timely reporting of accurate cancer clinical information. The clinical cancer minimum data set is based on the national standard, and information provided by this service will enable clinicians and services to monitor and benchmark activity, appropriateness and effectiveness of cancer care.

This service is only available to Users who have login access and its main purposes are to:

- Facilitate collection and collation of Hospital Clinical Cancer Data
- Provide a means to enquire and extract Cancer Clinical record details
- Provide Ad Hoc reporting facility

USER LOGIN

Authorised users only, by logging into this system you are accepting the [terms of entry](#).

GO

The ClinCR module is funded and managed by the Cancer Institute NSW, hosted and supported on contract by HealthTechnology NSW, and used by 5 Area Health Services

Session Time Left: 30 Minutes

QUICK SEARCH

* Indicates required field

Surname *

D.O.B(Optional) **GO**

For Advanced Search [click here](#)

- > Home
- > Search
- > Enquiry
- > Patients
- > User Profile
- > Import Files
- > Export Data
- > Ad Hoc Reports
- > Audit Report
- > Change Password
- > Logout

Patient Search

Search Parameters

Patient

MRN 00..

Unique ID

Medicare No.

Surname

Given Name

Sex ▼

Suburb

From To

Date of Birth

Location

Area Health Service ▼

Facility ▼

Disease & Treatment

Entry Status Incomplete Completed Blank

Primary Site of Cancer

From To

Disease Last Update

Date of Primary Diagnosis

Treatment Group Admitted Radiotherapy Oncology

Result list will be limited to 1000 records

CLEAR **SEARCH >**

The ClinCR module is funded and managed by the Cancer Institute NSW, hosted and supported on contract by HealthTechnology NSW, and used by 5 Area Health Services

Disease Staging

T Stage	3	T Stage Basis	--- Select Staging Basis ---
N Stage	1	N Stage Basis	--- Select Staging Basis ---
M Stage	X	M Stage Basis	--- Select Staging Basis ---
Other Staging Basis	Pathological		
Other Staging Scheme	TNM Classification of Malignant Tumours		
Scheme Group	Stage III DUKES C(III) (bev+cet+cap)		

Disease Data Entry Status

Disease Entry Status Incomplete Completed

Status Updated by Cannon Gavin Status Update DateTime 05/06/2007 12:37PM

Quality of Care

First Clinical Trial Name	Rofecoxib	Date of First Multidisciplinary Team Consultation	18/07/2006
Date of First Clinical Trial Enrolment	21/11/2006	Date of first referral to Palliative Care	23/01/2007
Palliative Care Status	Yes	Performance Status at first presentation	ECOG 1 Restricted in physically strenuous activity but ambulatory can perform light / sedentary work
Psycho Social Referral	Specialist nurse / nurse counsellor	Distress Thermometer Score at Diagnosis (0-10)	2

Update Status

Created By File Process Last Update By Cannon Gavin

Created Date 29/08/2006 Last Update Date 05/06/2007

Treatment

Admission/ Start Date	Primary Cancer Site	Date of Diagnosis	Treatment Type	
18/11/2005	C18.8	12/10/2005	Oncology	<input type="button" value="DELETE"/>

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- > Enquiry
- > Patients
- > User Profile
- > Maintenance
- > Import Files
- > Export Data
- > Ad Hoc Reports
- > Audit Report
- > Change Password
- > Logout

Best disease information

Definitive Primary Site of Cancer

First Valid Date of Diagnosis 21/03/2006

Definitive Morphology M8441/3 Serous cystadenocarcinoma NOS

Laterality Not applicable

Best Basis of Diagnosis Histology

Degree of Spread Distant metastases

* Indicates required field

CANCEL

SAVE >

Treatment Details - Admitted

Treatment Record ID 62558

* **Treatment Modality** Surgery

AMO Registration Number MPO336639

* **Admission Date** 19/03/2006

Discharge Date 24/03/2006

Procedures - ICD codes

Procedure Version ICD10V5

ADD PROCEDURES

No.	Procedure Code	Description	Principal Flag	Action
1	32003-01	Right hemicolectomy with anastomosis	<input type="radio"/>	DELETE
2	30396-00	Debridement and lavage of peritoneal cavity	<input type="radio"/>	DELETE
3	92514-39	General anaesthesia, ASA 39	<input type="radio"/>	DELETE
4	92062-00	Transfusion of other serum	<input type="radio"/>	DELETE
5	95550-03	Allied health intervention, physiotherapy	<input type="radio"/>	DELETE
6	95550-10	Allied health intervention, psychology	<input type="radio"/>	DELETE
7	13815-01	Percutaneous central vein catheterisation	<input type="radio"/>	DELETE
8	35653-03	Abdominal hysterectomy with bilateral salpingo-oophorectomy	<input type="radio"/>	DELETE

Access

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BENEFITS

HL7

- Case finding
- Accurate transcription (no double keying)
- Efficiency – time to register a patients

ELECTRONIC FEEDS (ADMIN DATA)

- Case finding
- Surgical coding
- Multi-facility linkage
- Build on robust systems (coding quality cycle)

FILE UPLOAD

- Leverage existing systems
- Anywhere load
- Built-in edits – distributed compliance

TRADE-OFFS

HL7

- Demands other system compliance; support to establish

FEEDS (ADMIN DATA)

- facility centric rather than patient-centric initially
- Limitations of coded data – accuracy and clinical detail
- 4-8 weeks lag (cite colorectal manual v ClinCR)
- “noise”
- Greed with free data
- Measures of function and outcome – (current admin systems – discuss clinical systems)

FILE UPLOAD

- Change control, migration and regression
- Security?

ISSUES

- Scope creep and complexity
- Integrating datasets vs separate registries
- Pros and cons of in-house vs commercial
- Suspense files and discretionary loads v live feeds
- Need for and limits of business rules
- Inter-Area and public/private data sharing

GAPS and GOAL STATE

GAPS

Absent feeds for chemotherapy

Inability to load pathology reports (diagnosis and stage, eventually nodes and margins, genetics markers)

GOAL STATE

Alignment and shared core dataset with population-based and clinical registries

LESSONS

- Independent technical expertise
- Controlled scope of versioning
- Version: resources for design and testing, migration and training (ripple effect)
- Governance
- Linkage and patient centricity – feeds are silo-ed