

Population Based Clinical Data for Gynaecological Cancers

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HIC 09
Canberra

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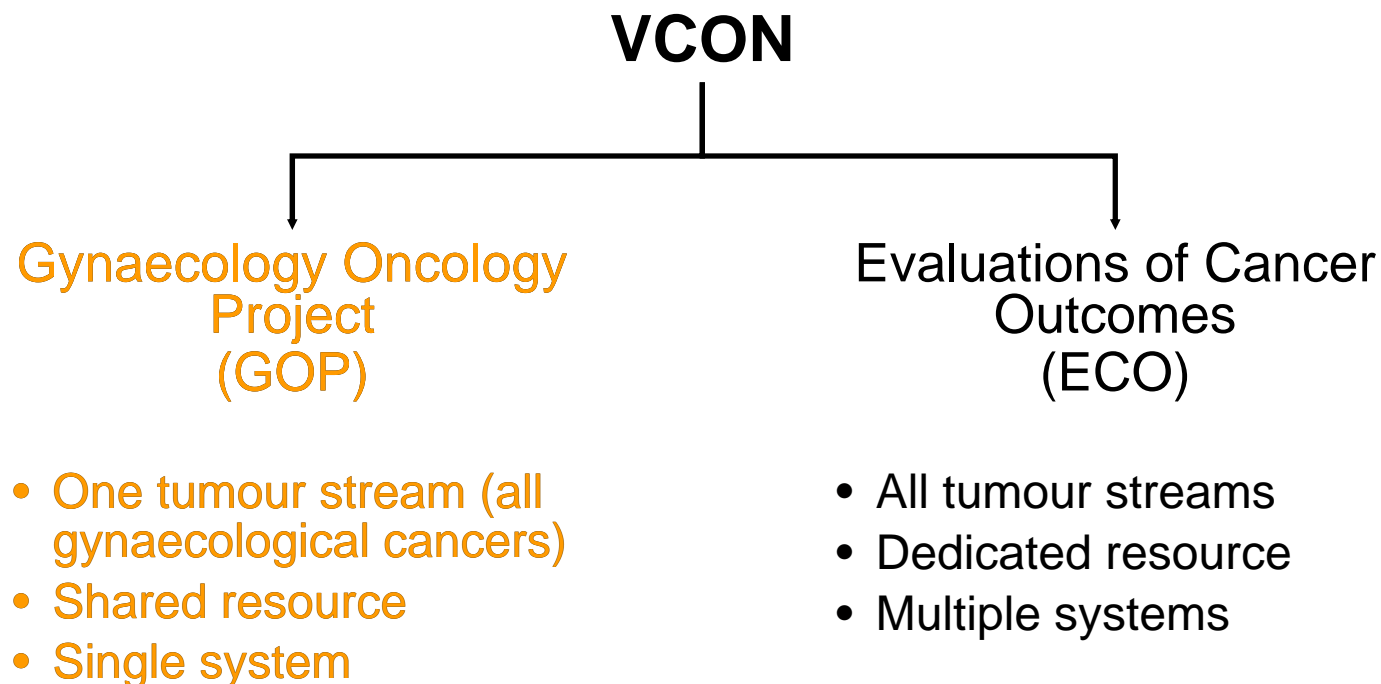
Presentation overview

- Overview
- Collection criteria
- Processes implemented
- Learnings
- Future considerations

Victorian Cancer Outcomes Network (VCON)

- Ministerial Task Force for Cancer
- Minimum standard clinical dataset
- Augment Victorian Cancer Registry incidence data
- Staging, treatment, outcomes, recurrence
- Mandatory cancer reporting - *Cancer Act (Vic)*

VCON Projects



GOP – pre-trial

- Royal Women's Hospital (RWH)
- 1 tumour stream (gynaecology cancer)
- 1 data source (CONTRO/GeMMA)
- Test capacity and workload/resource evaluation
- Identify practicalities of clinical data collection
- Data transfer model (XML)

GOP - objectives

- Major gynaecology cancer services
- Selected private clinics
- 12 months collection (Jan – Dec 2008)
- 6 months follow-up (Jan – Jun 2009)
- Statewide population data on gynaecology cancers
- Public and private patient data
- Under *Cancer Act* and ethical approval

GOP – dataset

- National cancer clinical dataset specifications (NHDD)
- Re-defined as Victorian Clinical Cancer Registration Dataset (VCCRD)

GOP - application

- **CONTRO/GeMMA software**
- **Developed by Oncology Department, RWH with Thunderbird Software**
- **Used by RWH to clinically manage patients since 2001**
- **IP own by Cancer Council Victoria**

Event Data Maintenance

*Event Type Description	Redundant	
Admission	No	
Breast Clinic	No	
Breast Nurse Admission Review	No	
Chemo Assessment	No	
Death	No	
Discharge from Oncology Clinic	No	
Fail to Attend (FTA)	No	
First Visit	No	
Follow-up Visit	No	
Initial Cancer Treatment	No	
Initial Referral	No	
Investigation	No	
Lost to Followup	No	
Lymphoedema Clinic	No	
Multidisciplinary Meeting	No	

*Field	Description	Type	Sub Type	Mandatory	
1	Tumour Link	Tumor		Yes	▼
2	Treatment Received	Boolean	Yes/No	Yes	▼
3	Surgical Treatment	Boolean	Yes/No	No	▼
4	Intention of Surgery	List Item	Intention of Treatm...	No	▼
5	Radiation Therapy	Boolean	Yes/No	No	▼
6	Intention of Radiotherapy	List Item	Intention of Treatm...	No	▼
7	Systemic Therapy	Boolean	Yes/No	No	▼
8	Intention of Systemic Therapy	List Item	Intention of Treatm...	No	▼
9	Hormone Therapy	Boolean	Yes/No	No	▼
10	Intention of Hormone Therapy	List Item	Intention of Treatm...	No	▼
11	Other Treatment	Boolean	Yes/No	No	▼
12	Details of Other Treatment	Text		No	▼
13	Intention of Other Treatment	List Item	Intention of Treatm...	No	▼
14	Overall Outcome	List Item	Outcome of Initial T...	No	▼
15	Date of Outcome Assesment	Date	Non-future Date	No	▼
16	Date of Entry	Date	Non-future Date	No	▼

Event List Maintenance

*Event List Name	Redundant	
Adequacy	No	▼
Age Range	No	▼
Death Notifiers	No	▼
Employment Status	No	▼
Follow-Up	No	▼
Intention of Treatment	No	▼
Life Stressors	No	▼
Marital Status	No	▼
Menopausal Status	No	▼
Outcome of Initial Treatment	No	▼
Reasons for Admission	No	▼
RECIST Criteria	No	▼
Referral Options	No	▼
Referral Reasons	No	▼
Smoking Status	No	▼
Social Support	No	▼
Source of Referral	No	▼
Support Program Outcome	No	▼
Support Program Type	No	▼
Treatment Plan	No	▼
Y/N/NA	No	▼

Item Description	*Sequence	Redundant	
Complete Response	1	No	▼
Partial Response	2	No	▼
Stable Disease	3	No	▼
Progressive Disease	4	No	▼
Not assessed	5	No	▼

GOP – CONTRO/GeMMA

- Gynaecological configuration of CONTRO
- Designed for multi-team use
- ‘Real-time’ data collection
- Information used at multi disciplinary meetings
- Correspondence letters

**Chemotherapy
Day Center**



Data Analyst

**Clerical
Office**



**Data Managers &
IT Developer**



Outpatient Reception



Outpatient Clinic

Resident Doctors



Research Lab



Theatre



Booking Office



GOP – CONTRO/GeMMA

- Gynaecological configuration of CONTRO
- Designed for multi-team use
- ‘Real-time’ data collection
- Information used at multi disciplinary meetings
- Correspondence generation module

Main Window

File Search Chemotherapy Window Reports Options Internet About

Case Explorer (084425 - TEST, Data)

REGISTRATION
CORRESPONDENCE
EVENTS

- ⇒ First Visit
- ⇒ Admission
- ⇒ Follow-up Visit
- ⇒ Tumor Board Review
- ⇒ Chemo Assessment
- ⇒ Initial Cancer Treatment
- ⇒ Support Program Participation

NOTES
ALLERGIES
TUMOR(S)

- ▼ 15/06/2006: Ovary (evident)
 - ⇒ Prognostic Factors
 - ⇒ Recurrent/Secondary Tumors

OTHER TREATMENT
CHEMOTHERAPY

- ▶ Doxorubicin Pegylated Liposomal 40mg/m2 [Current]
- ▶ Carboplatin and Paclitaxel combination regimen [Complete]

COMPLICATIONS
DIAGNOSTIC TESTS

- ⇒ Radiology
- ⇒ Tumour Markers

SURGERY

- ⇒ 06/09/2006

Created	Sent	Author	Description	Addressee
30/04/2007	30/04/2007	Martha BLUESPEAR	Imported letters	
30/04/2007	30/04/2007	Dr. Ken MAINCRAY	Clinic Letters 8.5.07	Dr. Suresh Jain
			Tumour Board	Dr. Suresh Jain
			Clinic Letters 22.5.07	Dr. Suresh Jain
			Chemo letters 5.6.07	Dr. Suresh Jain

date

 <*a=1*>
 <*a=2*>

Dear <*a=3*>,

 Re: <*p=2*> <*p=1*>, <*p=8*>
 DOB: <*p=6*> RWH UR: <*p=5*>

 I am writing to you about your patient, <*p=2*> <*p=1*> who has failed to attend her last several appointments made here at the
 I enclose a copy of our recent letter to her.

If she is having trouble getting to our clinic over her care. We would suggest review a vault smear.

We have not made any further appointments too pleased to do so should you have any

 With kind regards
 Yours sincerely

 Dr Deborah Neesham
 Gynaecological Oncologist
 Oncology/Dysplasia Unit

Patient Name: <*p=2*> <*p=1*>

Initial Referral <*e=424;75;dn*>

First visit <*e=31;81;82;dn*>

Admission <*e=393;69;70;71;dn*>

Chemo Assessment <*e=33;59;61;dn*>

Last procedure <*p=16*><*p=18;nst*>

GOP – collection process

- Shared Data Manager
- Site deployment of CONTRO/GeMMA
- Major public gynaecological cancer sites
- Private patient data from private hospitals and clinician consulting rooms

GOP – process implementation (public hospital)

- Deploy CONTRO/GeMMA or legacy database
- In-patient data in medical records
- Data extraction by site data managers
- Extraction support by Clinical Data Coordinator

GOP – process implementation (private hospital)

- In-patient data from medical records
- Extraction by Clinical Data Coordinator
- Health Information Services support

GOP – process implementation (clinician private rooms)

- Deploy CONTRO/GeMMA or legacy database
- Private patient data in clinical notes including correspondences
- Cooperation of clinician and clinic staff
- Ethical approval

GOP – learnings

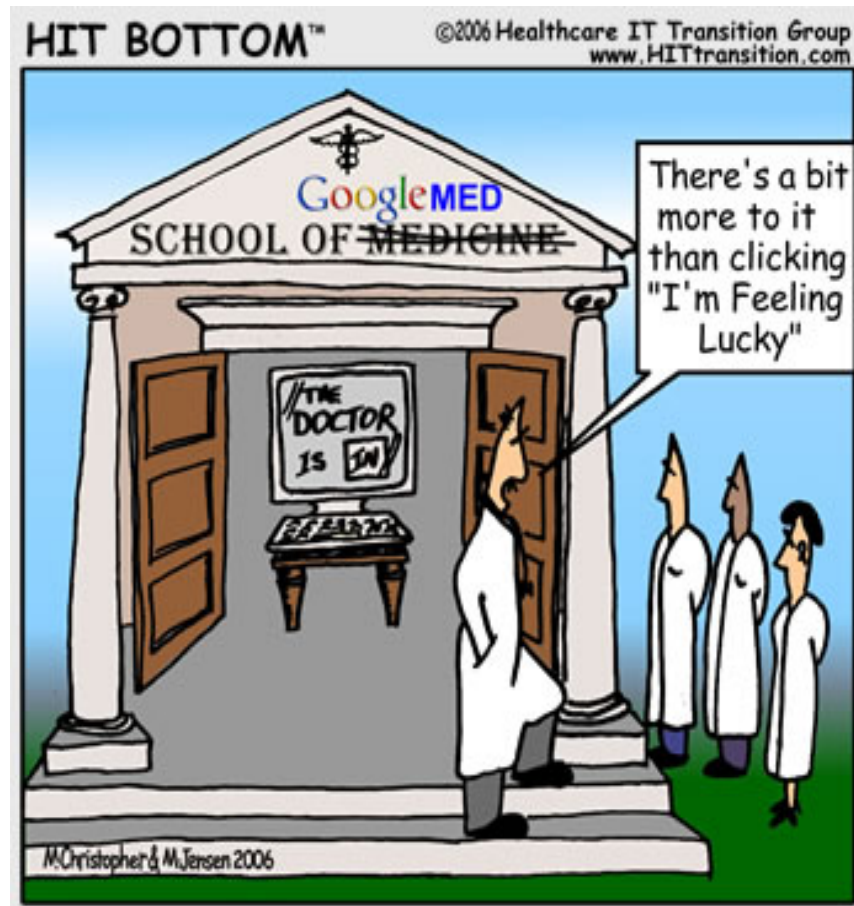
- How to collect data
- Multiple data collection solutions and sites
- Lack of software options necessitated use of Interim software solution (CONTRO/GeMMA)
- Support of clinician and department staff
- Supplement with shared Data Manager
- Resources required
- Availability of standards

GOP – complexity

- Private patients in public setting
- Private patients in private setting
- Follow-up after initial treatment
- Where is most efficient location to collect treatment information?

GOP – exceptions

- Small tumour stream (~ 1,300 new cancers)
- Handful gynaecological cancer specialists
- Specialists health services
- Within metropolitan boundaries





www.cancervic.org.au