Population Based Clinical Data for Gynaecological Cancers

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HIC 09
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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

VCON

Gynaecology Oncology Project (GOP)
• One tumour stream (all gynaecological cancers)
• Shared resource
• Single system

Evaluations of Cancer Outcomes (ECO)
• All tumour streams
• Dedicated resource
• Multiple systems
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
GOP – CONTRO/GeMMA

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

Ref: RWH UR: 0000

I am writing to you about your patient [Patient Name], who has failed to attend his last several appointments made here at the clinic. I have enclosed a copy of our recent letter to him.

If she is having trouble getting to our clinic, we would suggest reviewing your transport service.

We have not made any further appointments, so please do so should you have any concerns.

With kind regards,

Yours sincerely,

[Signature]

Dr. Deborah Newsham
Surgical Oncologist
Oncology/Dysphaea Unit

Initial Referral: 424;75;dn
First visit: 31;81;82;dn
Admission: 391;69;70;71;dn
Chemo Assessment: 33;59;61;dn
Last procedure: 16;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
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