

Getting buy-in: Experience in setting up a work program to collect indicators

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Developing Cancer Indicators in NSW

- Why are we doing this?
- What have we learnt
- The way forward

Cancer Institute NSW

The *Cancer Institute (NSW) Act 2003* states that cancer control will be achieved by:

- reducing the incidence of cancer in NSW;
- increasing the survival rate for people diagnosed with cancer;
- improving the quality of life for cancer patients and their carers; and
- becoming a source of expertise on cancer and provide expert advice to patients, the public, health care professionals and the Government.

The Cancer Information and Registries Division (CIRD)

Responsible for

- NSW Central Cancer Registry,
- the NSW Clinical Cancer Registry,
- the Hereditary Cancer Registry

Clinical Cancer Registry

Clinical cancer registries in 6 Area Health Services. These registries contain

- detailed staging,
- treatment (surgery, chemotherapy and radiotherapy information for public hospital patients
- Referral to an MDT, clinical trial and palliative care.

2007

Different groups at the Cancer institute NSW working on

- Clinical Cancer Indicators
- Accreditation Program (pilot)
- Cancer Minimum dataset extensions

Accreditation Standards

12 Standards were developed and used for the pilot.



ACCREDITATION PILOT RESULTS

“if the program can show it will lead to improvements in patient treatments, outcomes, and experience within the cancer service then it will be accepted”.

“I don't think the doctors see the value in accreditation – most have an objection to quality programs”

Accreditation Pilot

- In general good support from the sector for an accreditation program
- Concern from clinicians on whether accreditation programs impact upon patient outcomes
- International evidence on impact on patient outcomes is limited

New Direction

- Accreditation put on hold
- Examination of cancer reporting systems used internationally
- Determination of performance measures to be utilised in NSW

Clinical Indicator

A clinical indicator is simply a measure of the clinical management and/or outcome of care. A well-designed indicator should 'screen', 'flag' or 'draw attention' to a specific clinical issue. Usually rate based, indicators identify the rate of occurrence of an event. Indicators do not provide definitive answers; rather they are designed to indicate potential problems that might need addressing, usually demonstrated by statistical outliers or variations within data results. They are used to assess, compare and determine the potential to improve care. Indicators are therefore, tools to assist in assessing whether or not a standard in patient care is being met. [ACHS]

Clinical indicator : Example areas

- **Women receiving breast conserving surgery (BCS) vs. mastectomy**
- **for invasive breast cancer**
- **Chemotherapy in colon cancer with nodal involvement**

Consultation

- Consultation with a number of different clinical advisory groups (tumour specific)
- Attempt to examine evidence /gain consensus
- In some areas evidence is not clear

- NOTE: Too much consultation or repeated consultation can lead to no agreement

Pressure from those we had consulted

- Were we going to implement?
- Who would pay?
- We would like some results – now!

Making sense of measurement

- Performance measures
 - Indicators
 - Benchmarks
 - Outcome measures
 - Dashboards/scorecards
-
- Confusion in sector about what these terms mean
 - Negative reaction to concept of “dashboard” in health sector

Step back to basics

“You can’t manage what you can’t measure”

- Deciding what is important, defining the indicator and determining how to collect the data
- Engaging clinical leaders
- Setting targets and benchmarks
- Reporting data

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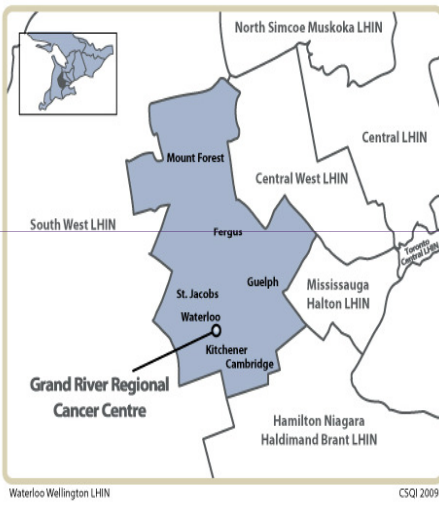
CCO Cancer Quality Council of Ontario

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 - Central LHIN
 - Central East LHIN
 - South East LHIN

Waterloo Wellington LHIN



Quick Statistics	
Total Population	
Waterloo Wellington:	724,260
Ontario:	13,035,870
Percentage of population over 50	
Waterloo Wellington:	30.0%
Ontario:	31.9%
Projected new cancer cases	
Waterloo Wellington:	3,372
Ontario:	64,447
Projected # of deaths from cancer	
Waterloo Wellington:	1,383
Ontario:	26,581

Measurement	CSQI 2009	Ontario	Min	Max	Target
*Stage capture rate: Percentage of valid new "stageable" cases / visits	97.7%	91.2%	51.5%	99.9%	90%

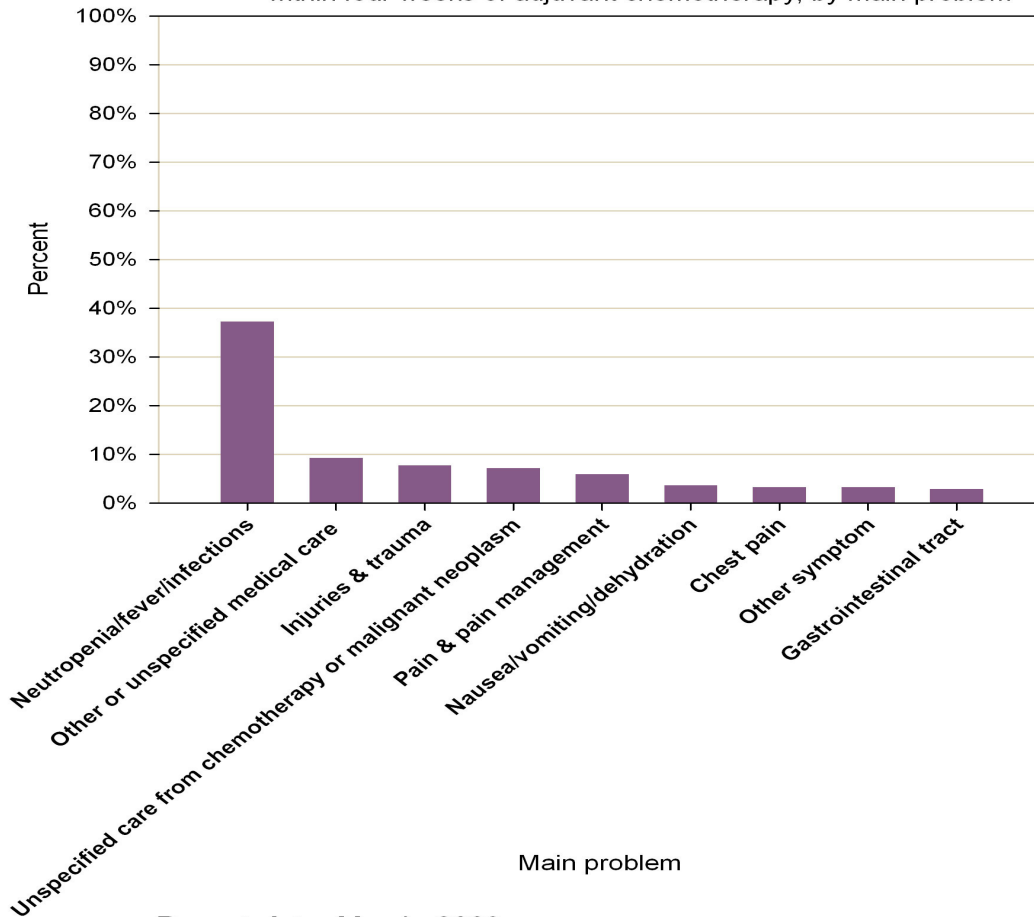
Prevention	CSQI 2009	Ontario	Min	Max	Target
Obesity: Percentage of adults (aged 18+) self-reporting obesity	23.2%	16.8%	10.4%	23.2%	10%
Smoking: Percentage of adults (aged 20+) who are current smokers	23.5%	22.6%	17.4%	29.2%	5%



Examples of reports used in Ontario

Patient Visits to Emergency Department After Adjuvant Chemotherapy

Percentage of breast cancer patient visits to the emergency department or admitted to hospital within four weeks of adjuvant chemotherapy, by main problem



Report date: March, 2009

Data source: CIHI, NACRS, DAD

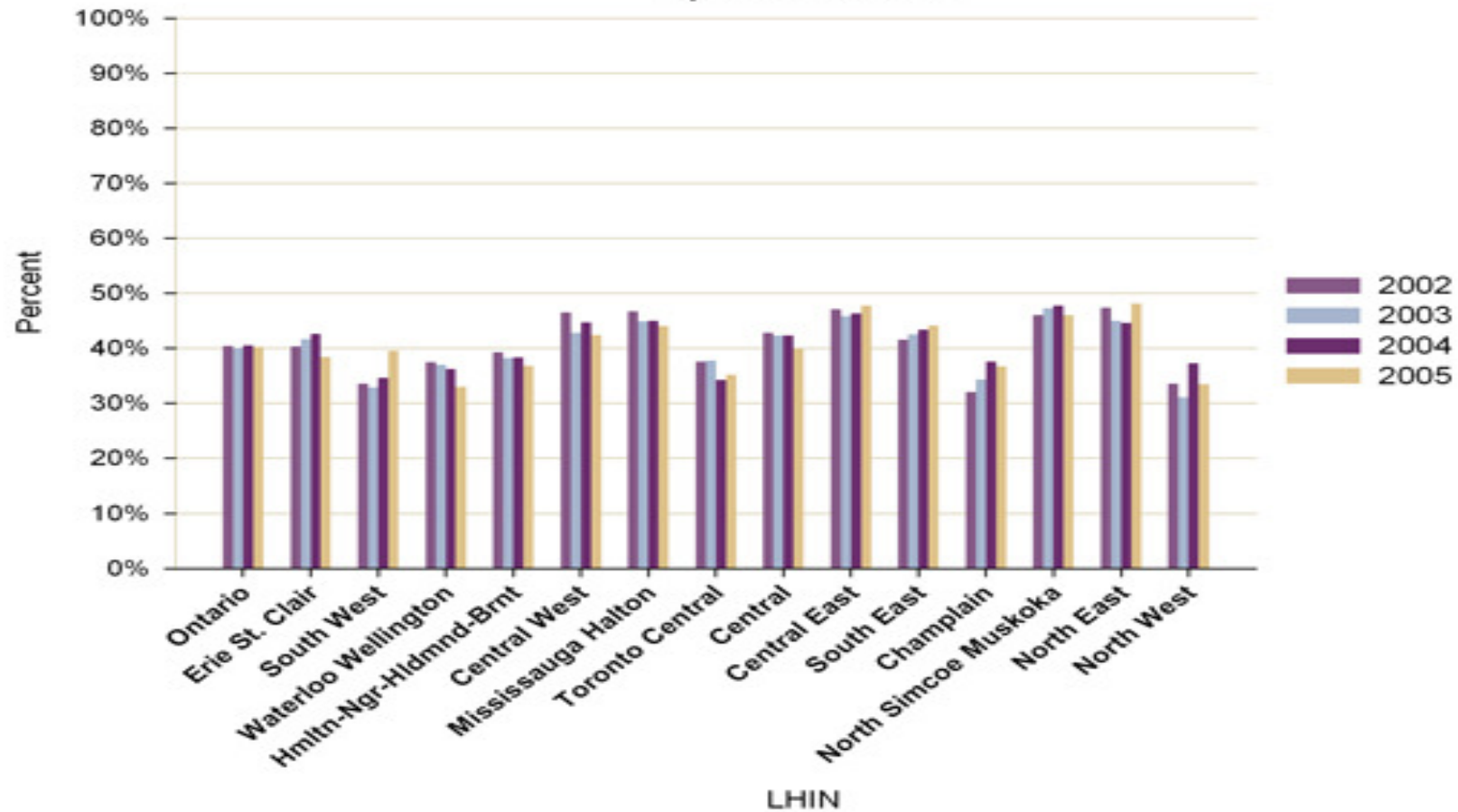
Prepared by: Cancer Informatics

Notes: Admissions/visits during the fiscal years 2006/07 and 2007/08

These are the top 9 reasons for emergency department visits or admissions to hospital
Data only include patients through the New Drug Funding Program

End-of-Life Care

Percentage of cancer patients in Ontario who visited the emergency department in the last 2 weeks of life, by LHIN, 2002-2005



Report date: March, 2009

Data source: Ontario Cancer Registry, NACRS

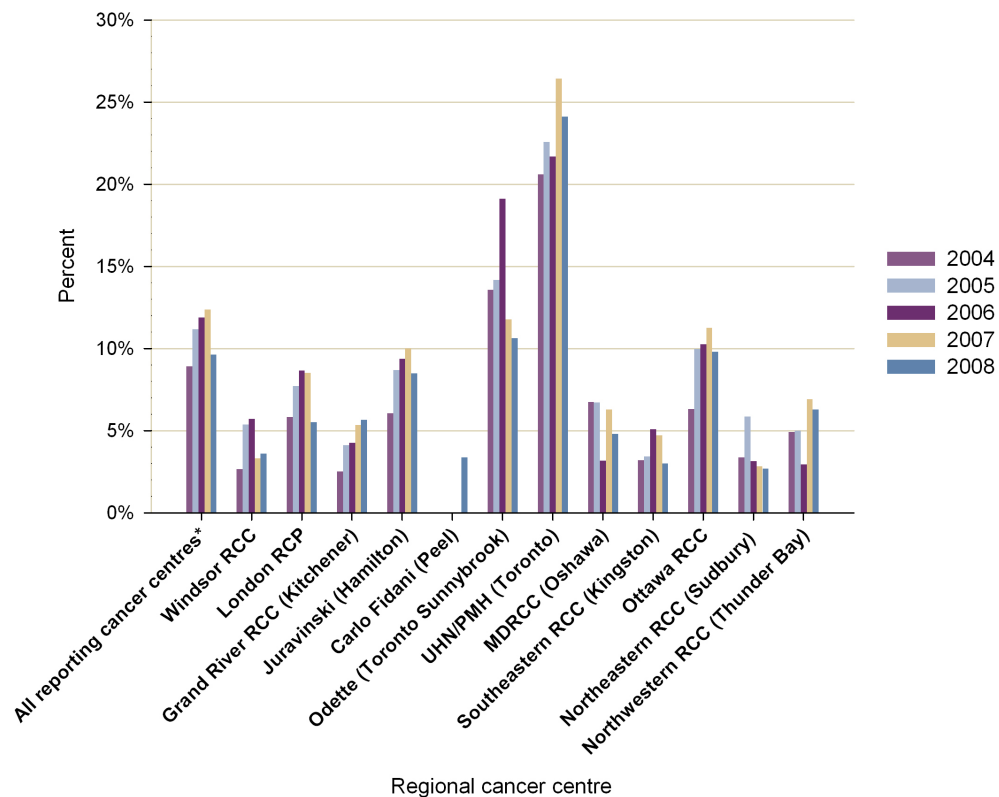
Prepared by: ICES

Notes: Crude rates shown

Calendar years

Cancer Patient Participation in Clinical Trials

Percentage of cancer patients treated at cancer centres recruited to treatment-based clinical trials,
Ontario, 2004-2008



Report date: March, 2009

Data source: Ontario Institute for Cancer Research, Clinical Trials Program; Princess Margaret Hospital Cancer Program Scheduling System; Cancer Care Ontario, Activity Level Reporting

Prepared by: OCRN / OICR

Notes: Excludes clinical trials for prevention, screening and diagnosis. Hospital affiliation to cancer centres may change. These changes will affect the cancer centres' (and affiliates') reporting.

Initial identification of 100+ possible cancer indicators

Gradual reduction in number through internal evaluations

- Meaningful
- Removing duplications
- Evidence
- Not able to be collected

External organisations looking at variety of quality/safety and other health indicators

- COAG Agreement
- AIHW National Safety and Quality work
- CEC hospital performance measures
- Garling Report

Consultation Issues

How to consult with a workforce that lacks a clear understanding of what can/should be monitored/benchmarked?

MDTs and “Outcome measures”

- Funded individual MDT to develop an outcome measures
 - Team satisfaction surveys
 - Level of staff participation
 - Were treatment plans generated
 - Clinical outcomes
 - Were supportive care needs discussed
 - Patient waiting times
 - Minimum data set collection

Results orientation – Freidman approach

- Plain English
- Results logic demonstrating how agencies services contribute to results
- Demonstrate link between agency results and government priorities
- Integration with agency planning process

Internal debate

- What are we attempting to measure?
- How do we do this
- Is the measurement meaningful?

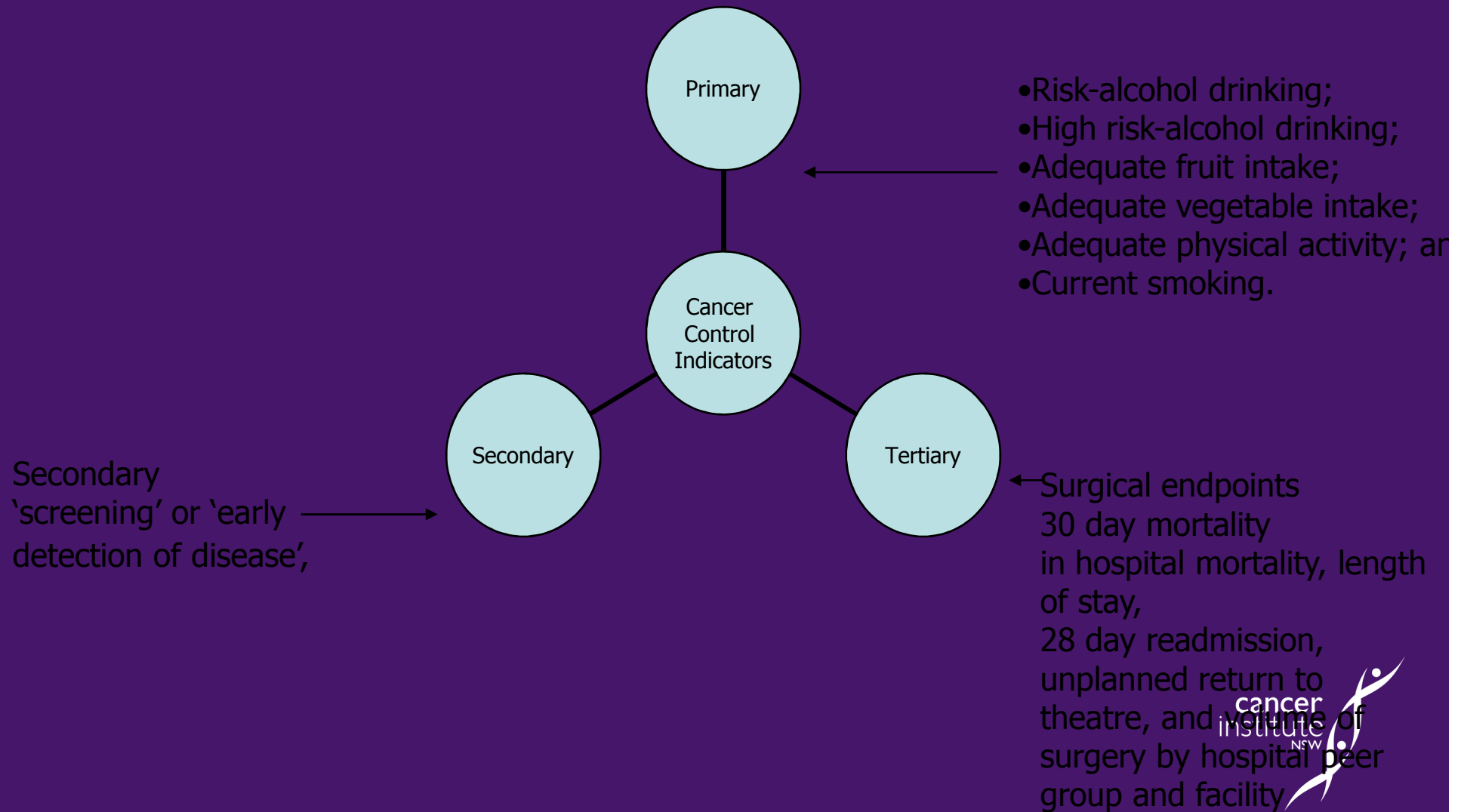
Cancer Control

- Survival
- Morbidity/Quality of Life

Risk factors for cancer

- Risk-alcohol drinking;
- High risk-alcohol drinking;
- Adequate fruit intake;
- Adequate vegetable intake;
- Adequate physical activity; and
- Current smoking.
- Obesity

Draft Cancer Control Indicators



Other measures under consideration

- Appropriate End of Life planning
- Inappropriate chemotherapy in the last 28 days of life
- Routine pain assessment and appropriate management
- Use of evidence based practice
- The use of multidisciplinary treatment plans
- Patient satisfaction measures
- Routine Distress screening and appropriate referral
- Adverse events

System elements

- Monitor adverse incidents;
- Monitor service capacity;
- Engage in cancer service redesign activities;
- Engage consumers/patient experience;
- Monitor competencies of chemotherapy nurses;
- Review available cancer service reports;
- Death review and mortality and morbidity meetings;
- Monitor clinical variability;
- Linkage to AHS Clinical Governance Units;
- Monitor the application of evidence based practice.

Role of patient/consumer feedback

- How to utilise patient feedback to drive change

Next steps

- Finalise list
- Place into agreed format
- Publish indicators for comment
- Pilot test for ease of use , utility, effectiveness.
- Review and finalise

Provide reports to AHS

- The initial goal will be to develop a series of AHS report to aid and assist them in service planning

State-wide monitoring

- Monitoring and comparison between AHS and or facilities will be possible.

Different project areas
(2007)

Strategic unified approach
(2009)

Accreditation
Pilot

Clinical
Indicators

Morphed into

CANCER
CONTROL
INDICATORS

Primary

Secondary

Tertiary

?

Cancer
Registries

What will happen when results come in?

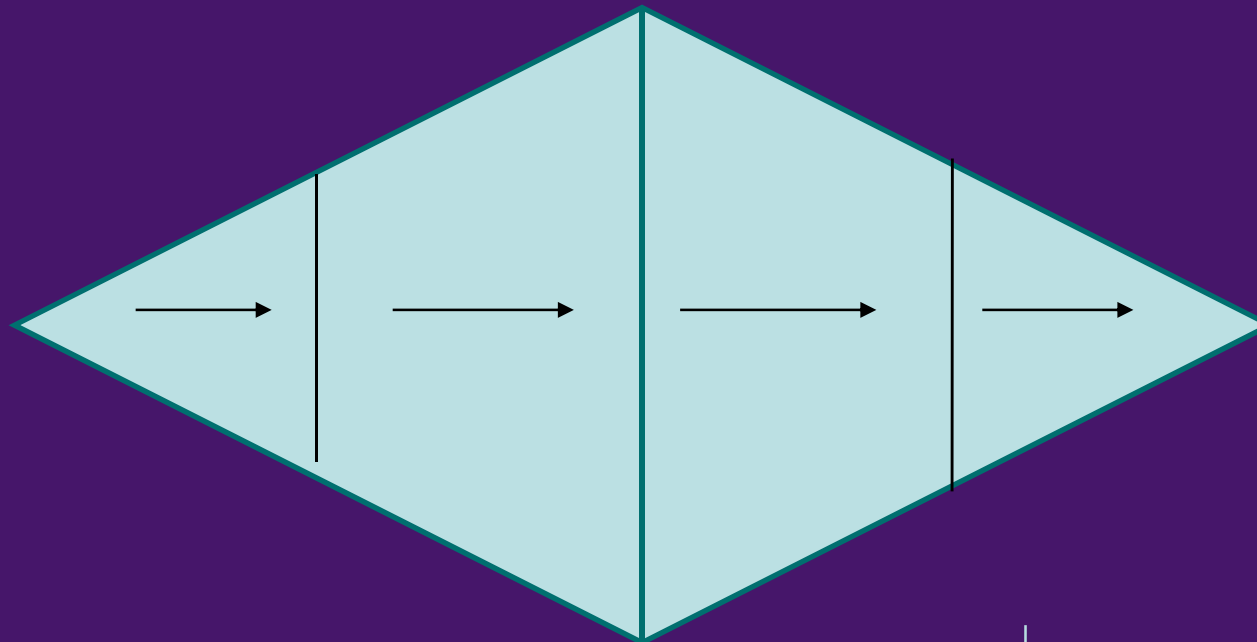
Initially people will dispute results

“data is not reliable”

“we did not answer in the way you think”

“We are different”

What have we learnt?



Initial development

Overwhelmed by complexity

What is possible/useful

cancer
institute
NSW

