

Registries – Putting Theory into Practice

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Registries

- To be effective
 - Must have reliable, unbiased data (complete)
 - Clear aims and outcomes
 - Agreed Definitions
 - Capable of benchmarking/adjusting for risk
 - Governance structure
 - Accessible data

Registries

- Can look at trends over time
- For systems monitoring and research
 - can assess impact of interventions
 - Organisational change
 - Policy change
- Outcomes must be reliable
- Data must be complete

The Balance

- Registries provide summary data
 - Can't give reasons for change
 - "Hypothesis generating"
- RCTs provide answers to a question
 - don't tell you whether intervention will improve overall system performance
- Post Trial performance
 - Monitor compliance and effect on outcome

Administrative data systems

- Potential use for high level data
- Can use to Cross-validate some clinical data
- So far data has been a duplication of clinical data – therefore high likelihood of error
- Issues with privacy/linkage
- Generally seen as unreliable by clinicians
- Data often manipulated for admin. purposes
- Often too broad to interpret
- ? Electronic Clinical record

Using Data bases

- Admin Data Bases
 - National
 - Evaluation/monitoring of hospital performance
 - Organisational level
 - Pt Safety monitoring – eg Lab Results
- Registries
 - National/State Level
 - Evaluation and monitoring
 - Organisational Level
- Clinical Microsystems
 - Individual treatments and patients

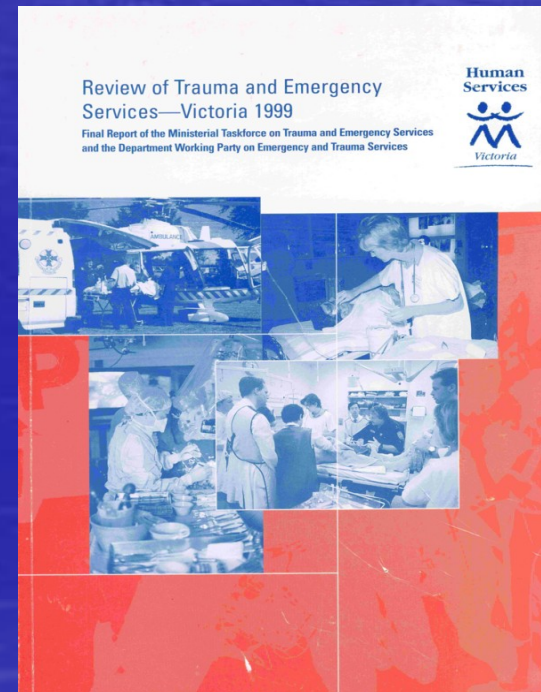
A Case Study of Registries in Action

- The Victorian trauma System

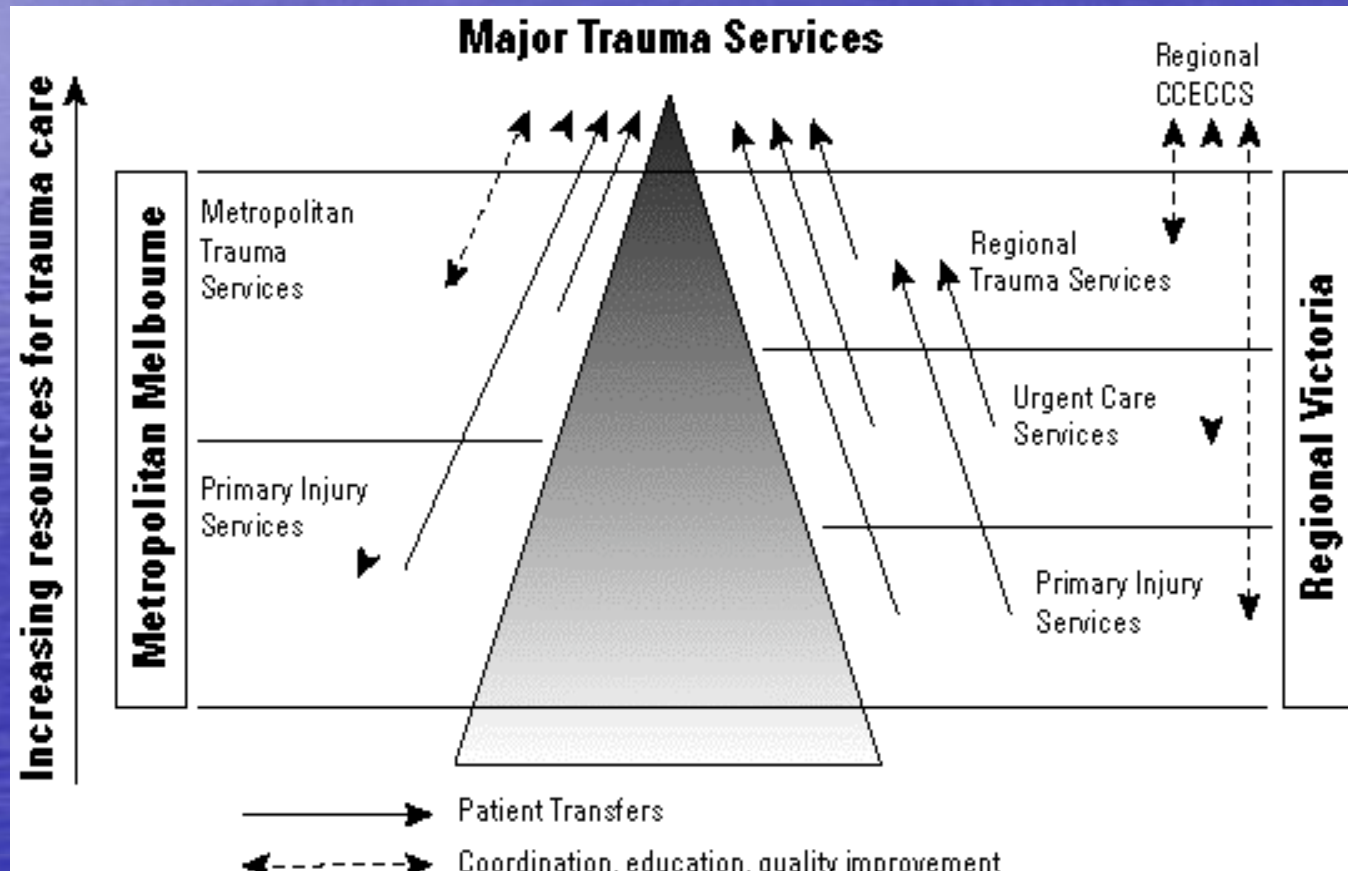


The Trauma System

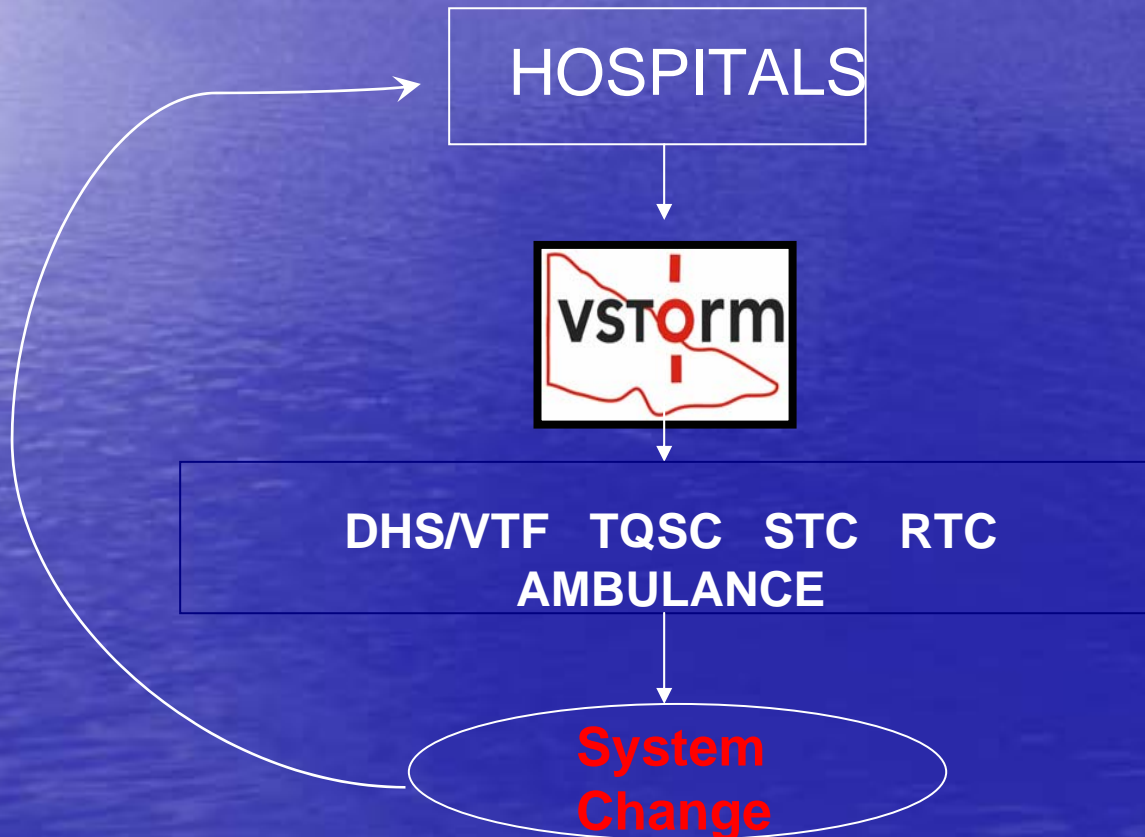
- Introduced in 2000 after ministerial report suggested a major restructure
- Recognised need for monitoring the new system
 - Focus on major trauma patients
- Major issues
 - Wrong patients to wrong hospitals
 - Long transfer times
 - Preventable deaths
 - Process issues eg long time to theatre



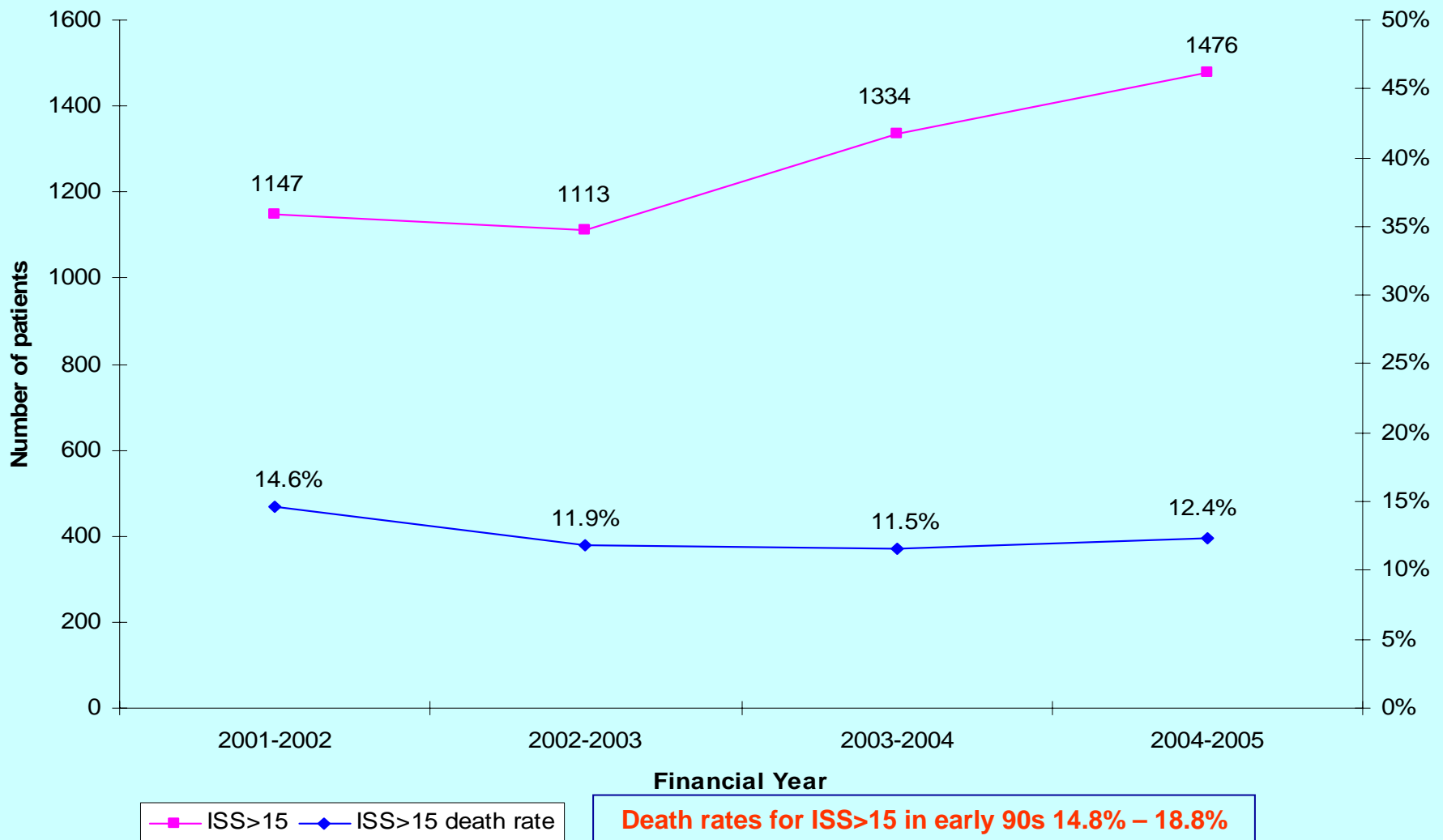
Transfers of major trauma patients



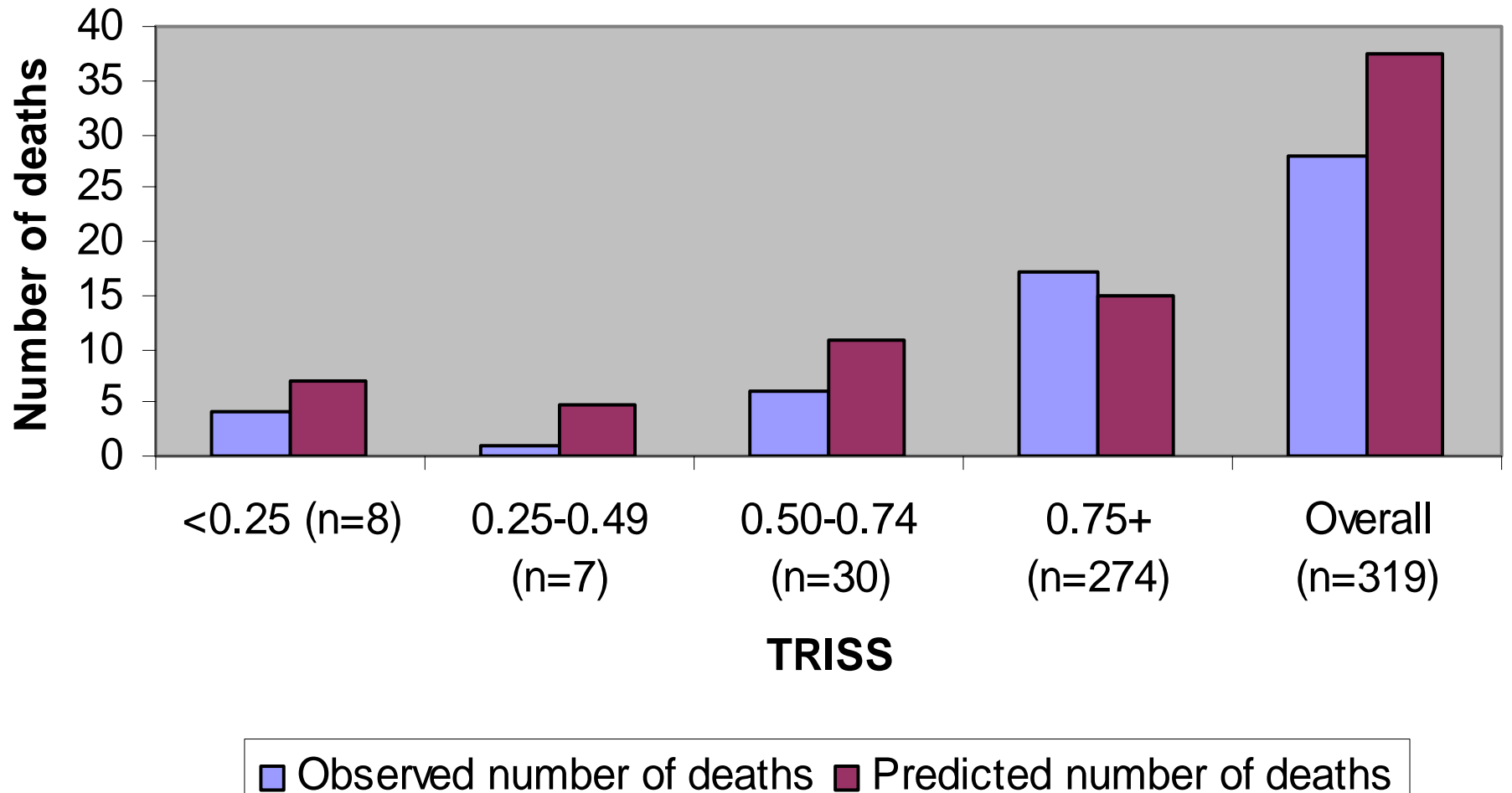
Feedback Loop



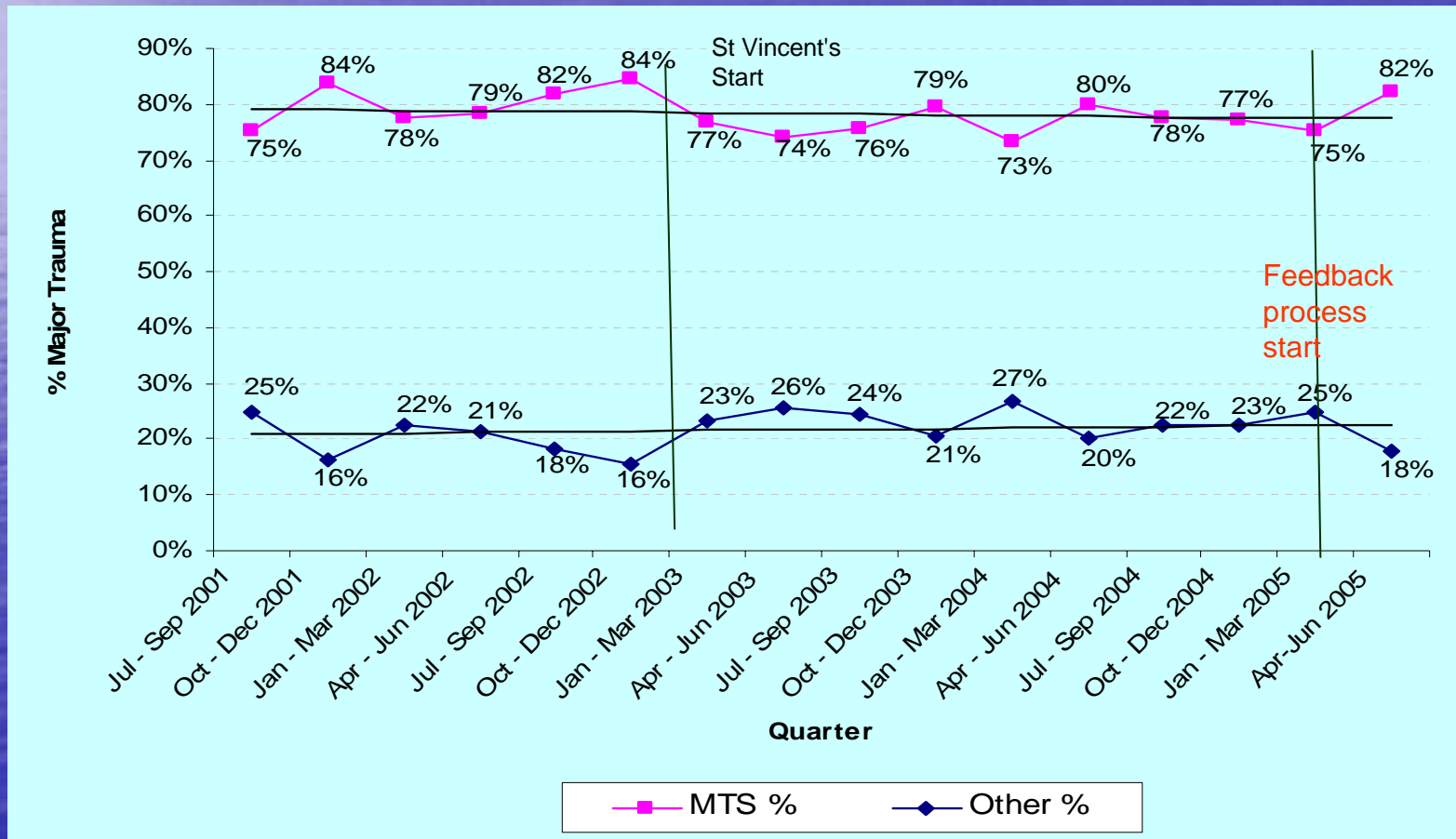
VSTORM ISS > 15 (severe injury) and Death Rate



Observed and expected deaths according to TRISS (risk adjustment)



VSTORM Definitive Care at MTS



Other feedback to Trauma Coordinators

- Comatose on arrival hospital and no intubation
- **Transfer time > 6 hours**
 - Ongoing issue, needs further monitoring
- Trauma team not activated
- Serious head injury and >2 hours to CT scan
- Penetrating torso trauma >1 hour to operation

Feedback to Ambulance Service

- Pre-hospital time > 1 hour (non-entrapped)
- Pre-hospital time > 1 hour (entrapped)
- Pre-hospital scene time > 20 minutes
- Hypotensive on arrival and scene time > 10 minutes (Non-entrapped penetrating injury)
- Comatose at scene and low oxygen Sat after 20 minutes (Head Injured patients)
- Comatose and Hypotensive after 10 minutes (Head Injured Patients)

Systems of Care

- You can't have a system if you don't monitor it
- Registries essential part of this
- Must agree on
 - Governance
 - Summary measures
 - reliable data items
 - Not too many!
 - desired outcomes
- Data that is not "used" is useless
- Cost high but....
 - Imagine a factory without numbers
 - Process times
 - Defects
 - etc