SUDI New Research Plans

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Cross Departmental Research Project

Session structure

- Introduction to the CDRP
- Coronial response project proposal
- SUDI case control study proposal
- Open discussion – your comments/involvement welcome

What is a CDRP?

Cross Departmental Research Fund administered by the Ministry of Research, Science and Technology (MoRST)

- to fund high quality cross-departmental research
- to catalyse new relationships within and between departments
- to develop research which will provide key building blocks for Government decision making.

- MOH CDRP funded by MoRST in 2003

MOH CDRP

Original objectives:

1. Conduct a SUDI case-control study
2. Establish standardised, relevant and accurate Coronial information collection systems
   - Initial focus SUDI and Youth Suicide
3. Establish a sensitive process for investigation which leads those that need and want it into appropriate health and family support services.

Why is the project needed?

- Forensic focus of current investigation – unusual for any health-trained personnel to involved with families at the death scene
- Inconsistent, incomplete information currently available to coroners, government agencies including Mortality review committees, policy makers and funders.

What's already happening?

- Coroners Bill – chief coroner, fewer coroners.
- Coronial Information System for coroners, government agencies and approved researchers.
- National Forensic Pathology Service – SUDI protocol.

Need to work collaboratively with Ministry of Justice, Police and the Forensic Pathology service and with the many other stakeholders and experts.

How the project is being organised

Clearer separation of the two elements

1. HTAs in the Coronial response project
    - HTAs
        - Better co-ordination
        - Better information
2. SUDI case-control study

Why separate the two elements?

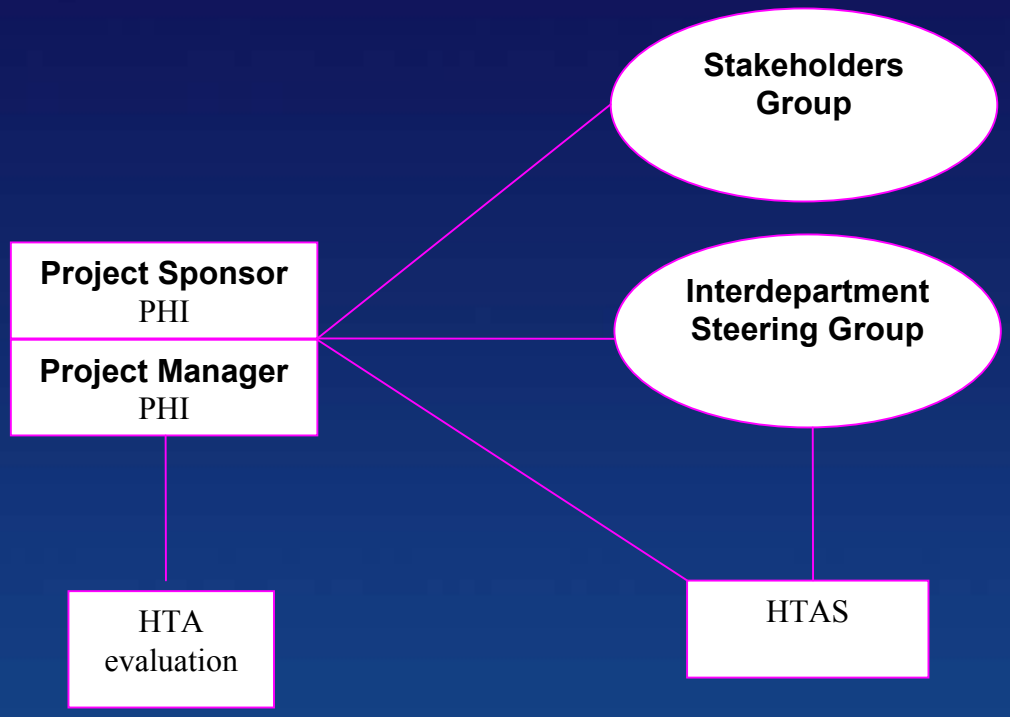
Advantages for the HTAs in the Coronial Response project

- Legal status of HTAs clear – Crown legal opinion
- Makes it clear that HTAs are being promoted as a service needed on an ongoing basis and not just for the duration of a research project
- Easier to develop data collection protocols – 1 page NCIS vs. 8 page research protocols.
- No impact on HTA assessment.

Advantage to SUDI Case control study

- Reduced delays
- Simplified management structure
- Clarification of issues around consent.

Proposed HTAs in the Coronial Response Project Structure



Overlapping, flexible groups. Movement between groups as project develops.

New groups may join project, for example, DHBs or Maori Health Providers.

HTAs in the Coronial Response Project Scope

- HTA appointment and training
- HTA operation
- HTA evaluation
- Recommendations.

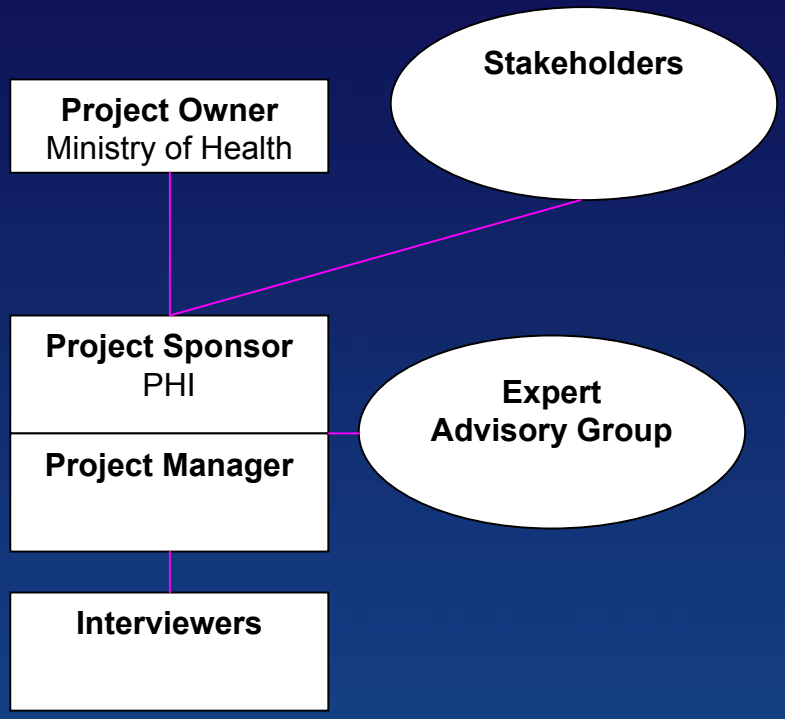
Coronial Response Project Approach

- Information sharing
- Facilitating decision making
  - who will HTAs be?
  - who will employ them?
  - how many?
  - training?
  - will they have other roles? All suicides? Other types of death? Cardiac Inherited Diseases Group project. What level of collaboration/co-ordination should there be?
- Implementation
- Data analysis – better information
- Service evaluation – qualitative research about families' experiences

Coronial Response Project Timeline

- Preplanning and consultation
- Steering group meeting June 2006
- Stakeholders meeting July–August 2006
- HTA training programme development 2006
- Coronial data collection protocols agreed 2006
- HTAs employed and trained ? 2006
- HTAs start work 2007
- HTA evaluation 2008
- HTA evaluation report 2008

Proposed SUDI Study Project Structure



SUDI Case Control Study Project Scope

- Nationwide
- Three years
- 40-60 deaths per year
- Four matched controls
- Not a randomised study
- Will build on the improved death scene investigation

SUDI case control study Timeline

- Pre-planning
  - consultation 2006
  - forming expert advisory group 2006
  - forming stakeholder group 2006
  - research protocols, ethical approval, interviewer training 2007
- Case control research 2008–2010
- Data analysis 2008–2010
- Results available
- Policy changes

Sudden Unexpected Death in Infancy Case Control Study

- Still lots of unanswered questions
- Do overseas findings apply in New Zealand?
- Different types of co-sleeping. Why is co-sleeping safe in some countries and not in others? What can be done to reduce risk in co-sleeping situations?
- Do babies who fall asleep at the breast show the same reduction in SUDI rates as babies who fall asleep using a dummy?
- What is the degree of risk associated with known and possible risk factors (need for a control group) sofas, mattress on floor.
- Need to ask the right questions in the right way – PHI will need your help.

Your Questions