

# Evaluation of the Local Palliative Care Grants Program Care Planning Sub-Program

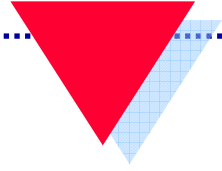
Professor Kathy Eagar

Director

Centre for Health Service Development (CHSD)

# Issues to be covered

- ◆ Role of the National Evaluation Team (NET)
- ◆ The National Evaluation Framework
  - Why evaluate?
  - Measuring impacts and outcomes at three levels
  - Establishing a common language for the evaluation
- ◆ Evaluating your project – some practicalities
- ◆ Ethics – why and how?



# Role of the National Evaluation Team

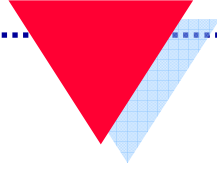
# Role in the evaluation - CHSD

Role is to:

- ◆ design overall evaluation framework
- ◆ provide a set of evaluation tools
- ◆ support and assist projects to undertake their own evaluations
- ◆ synthesise local project evaluation findings and combine with the program evaluation to form a national evaluation.

# Support and assistance

- ◆ Site visit to each project over the next few months
- ◆ Potential for a follow up visit if you need help
- ◆ Key contact person for each State
- ◆ List server
- ◆ Website
- ◆ Information bulletins as needed
- ◆ Ongoing training and support as you need it



# National Evaluation Framework

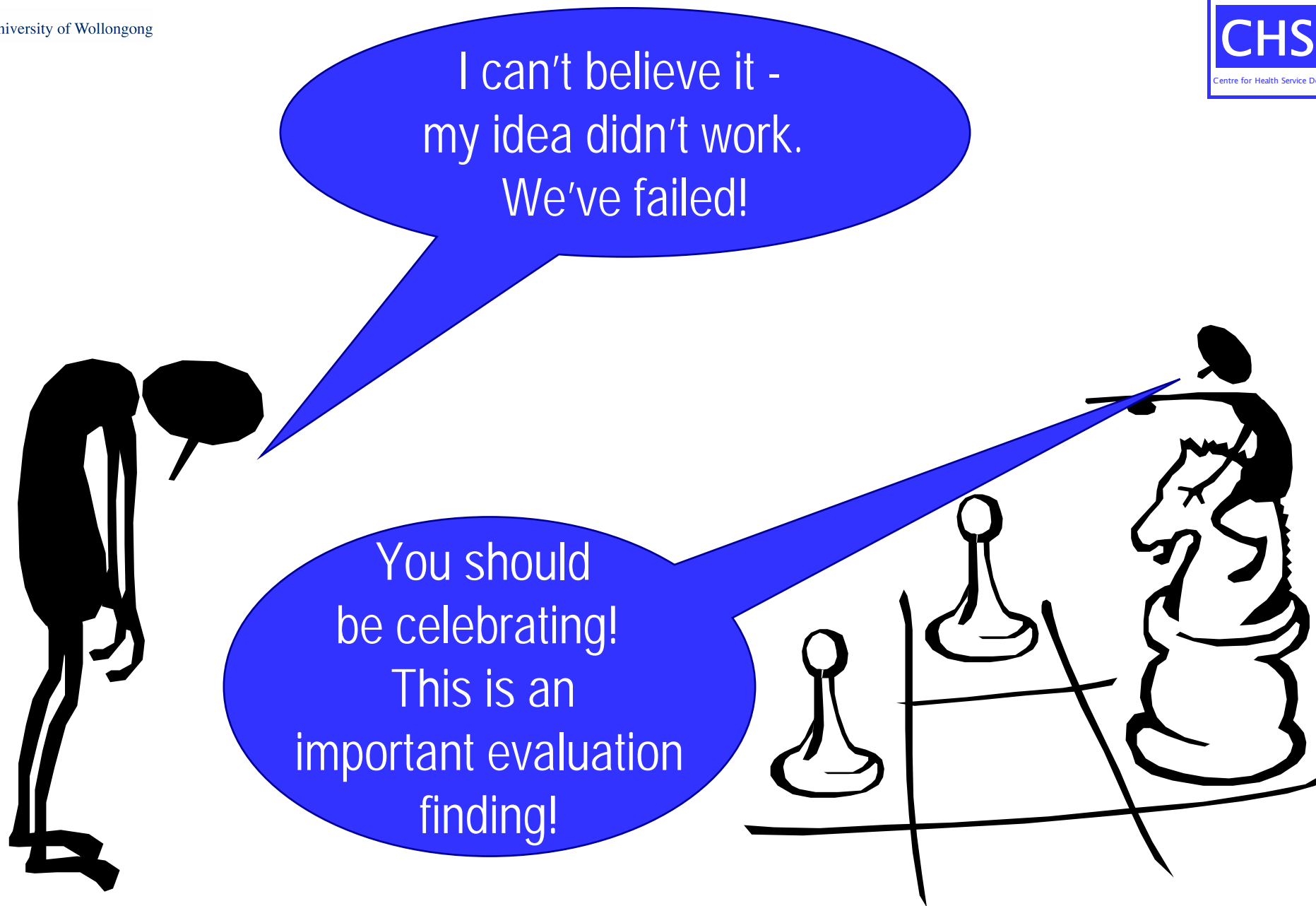
# Why evaluate?

- ◆ The need for palliative care will continue to grow over the next decade
  - in your own community/region/State/Territory
  - across Australia
- ◆ We need to:
  - learn what works (and what doesn't)
  - build palliative care capacity so that the need can be met
- ◆ The Care Planning program provides a great opportunity to do this

# What is evaluation?

- ◆ A process of continuous learning.
- ◆ NOT a test in which you pass or fail.
- ◆ NOT DIFFICULT.
- ◆ A continuous process of asking questions, reflecting on the answers and reviewing your ongoing strategy and action.
- ◆ An opportunity to learn from both 'successes' and 'failures'.





# 2 purposes

## ◆ Formative evaluation

- evaluation for learning
- 'how can we learn and get better as we go?'

## ◆ Summative evaluation

- evaluation for judgement
- 'how did we do?'

# 33 Care Planning projects

- ◆ With different goals, needs, resources and stakeholders
  - but lots of overlaps and similarities too
- ◆ The evaluation will be tailor-made to each project, but with as many common tools as possible

# Six key evaluation questions

- ◆ What did you do? (PROGRAM & PROJECT DELIVERY)
- ◆ How did it go? (PROGRAM & PROJECT IMPACT)
- ◆ What's been learned? (CAPACITY BUILDING)
- ◆ Will it keep going? (SUSTAINABILITY)
- ◆ Are your lessons useful for someone else? (GENERALISABILITY)
- ◆ Who did you tell? (DISSEMINATION)

# How did it go? Evaluation hierarchy

- ◆ 'Process, Impact and Outcome' not enough
- ◆ Level 1: Impact on, and outcomes for, consumers
  - patients, families, carers, friends, communities
- ◆ Level 2: Impact on, and outcomes for, providers
  - professionals, volunteers, organisations
- ◆ Level 3: Impact on, and outcomes for, the system
  - structures and processes, networks, relationships

Different projects are aiming for different impacts and outcomes - some at all 3 levels, some at only 1 or 2

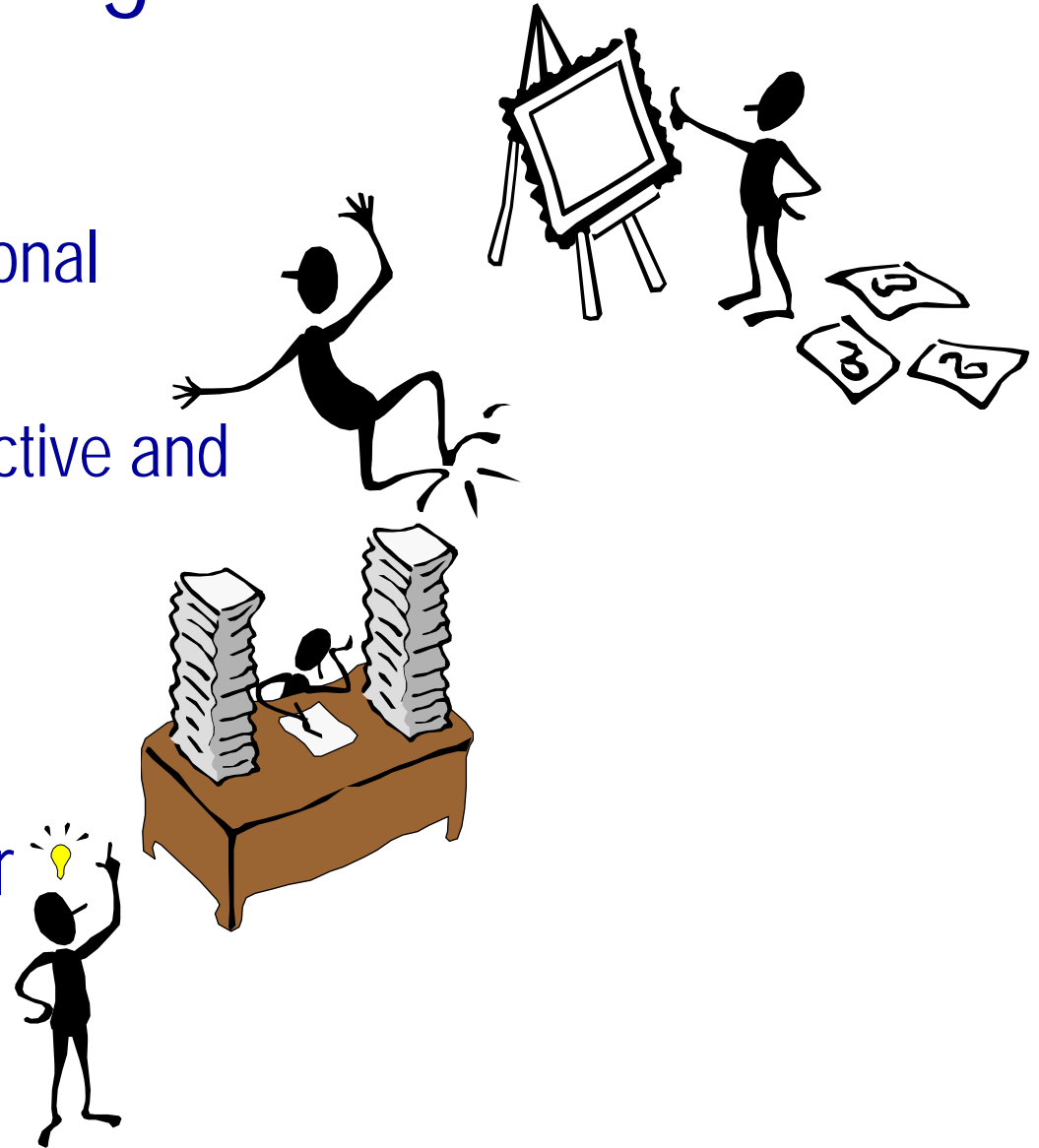
# How did it go? Evaluation hierarchy

- ◆ 'Process, Impact and Outcome' not enough
- ◆ Level 1: Impact on, and outcomes for, consumers
  - patients, families, carers, friends, communities
- ◆ Level 2: Impact on, and outcomes for, providers
  - professionals, volunteers, organisations
- ◆ Level 3: Impact on, and outcomes for, the system
  - structures and processes, networks, relationships

CHSD  
will work  
with each  
project to  
help identify  
what it is  
aiming to  
achieve

# The challenge for us!

- ◆ Find the balance between:
  - the requirements of the National Palliative Care Program,
  - the need to have a cost-effective and realistic evaluation
  - what you can manage
  - what you want to achieve
- ◆ Combine realism with rigour



# Sources of data

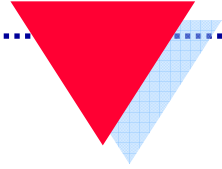
## Project evaluation

- ◆ Site visits
- ◆ Six-monthly progress reports
- ◆ Checklists
- ◆ Workshop presentations
- ◆ Final reports
- ◆ Evaluation reports
- ◆ Exit interviews

## Program evaluation

- ◆ Project data plus:
- ◆ Document review
- ◆ Stakeholder interviews
- ◆ Workshop group discussions
- ◆ Personal communication





A common language for the evaluation

# Performance Indicators and Evaluation

- ◆ Performance indicators (PI's):
  - required by the Australian Government as part of accounting for funding
- ◆ Setting and measuring PI's is not evaluation
  - but PI's can help in an evaluation because they answer two of the evaluation questions:
    - ◆ What did you do?
    - ◆ How did it go?

# Goals, objectives and strategies

## Goal

- ◆ an overarching statement about the desired outcome
- ◆ not usually directly measurable

## Examples

- ‘Improve the quality of life for dying people and their loved ones’
- ‘Build palliative care capacity in Australia’
- ‘Provide culturally appropriate palliative care services’

# Goals of the Care Planning Program

Projects support health professionals to improve care for patients who are living at home, through:

- ◆ Flexible models of service delivery
- ◆ Collaboration between services
- ◆ Smooth and appropriate transitions between services

Some projects address all three goals, some one or two

# Goals, objectives and strategies

## Objectives (sometimes called aims)

- ◆ dissect a goal into a series of action statements that say what is going to be different
- ◆ specific, with time frames and measurable
- ◆ objectives are evaluated (including the analysis of PI's) to ascertain whether a goal has been achieved, partially achieved or not achieved at all.

# Objectives of the Care Planning Program

Six types of projects, with different objectives:

1. Develop resources or tools for care planning
2. Involve carers and families in care planning
3. Trial models of care (e.g., case conferencing)
4. Address the needs of population groups
5. Support the translation of research into practice
6. Promote high-quality evaluation of current initiatives

Many projects have several of these objectives

# Goals, objectives and strategies

## Strategies:

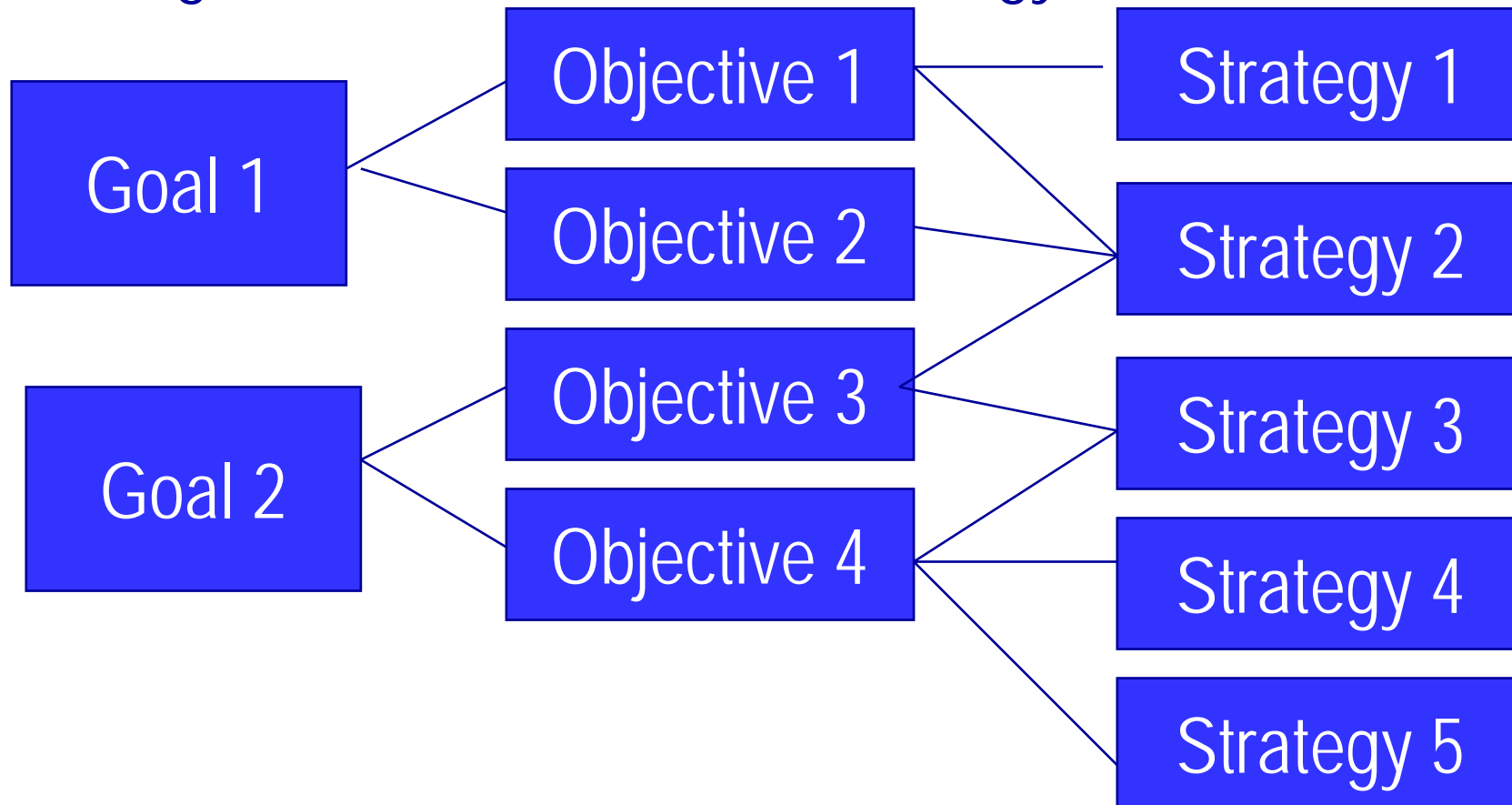
- ◆ the detail of what you need to do to achieve each objective

Example - Objective: 'Develop a case conferencing package'

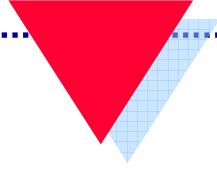
- ◆ Recruit project officer
- ◆ Undertake scoping study or literature review
- ◆ Consult stakeholders
- ◆ Develop and pilot test the package
- ◆ Analyse feedback from pilot users of the new package
- ◆ Prepare and implement a training program

# Goals, objectives and strategies

- ◆ Not a neat one to one relationship
- ◆ Your goal is someone else's strategy



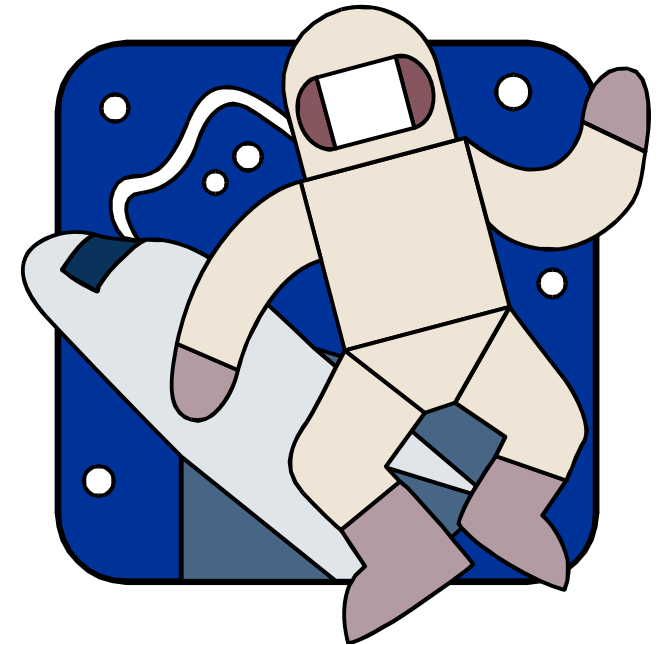




# Evaluating your project

# Project purposes and evaluation terms

- ◆ Achieve your own goals
  - during the project (**IMPACT**)
  - after it finishes (**SUSTAINABILITY**)
- ◆ Contribute to the bigger picture:
  - build knowledge and expertise in pall care across Australia (**CAPACITY BUILDING**)
  - provide lessons for other projects, regions and States/Territories (**GENERALISABILITY**)



# Evaluability Assessment

- ◆ Can your project actually be evaluated? If not, what would need to change? Includes looking at:
  - Whether objectives are well defined and quantifiable and whether data on these measures can be collected;
  - Whether the size and scope and boundary limits are clearly defined;
  - What effects (broad or specific) the program aim to achieve;
  - Whether assumptions and objectives are plausible (ie, the activities have some likelihood of meeting the objectives); and
  - Whether the intended uses of the evaluation information are well defined

# Why have an evaluation plan?

Purpose of the plan is to answer the question,

- ◆ “How will I assess whether my project has met its goals?”

Plan may encompass impacts, outcomes and processes:

- ◆ What effects are expected for each of the target groups?
- ◆ What happened during the project that may have affected its outcomes, positively or negatively?

# What is in the evaluation plan?

- ◆ Plan clearly defines the relevant processes, impacts and outcomes and how they will be measured:
  - ◆ Timing of measurement
  - ◆ Methods and tools to be used
- ◆ NET will help where needed
- ◆ We will ask you to report progress against your plan

# *Evaluation and palliative care: a guide to the evaluation of palliative care services and programs*

Kathy Eagar, Carla Cranny and Dave Fildes

available at:

[www.uow.edu.au/commerce/chsd/palliative care](http://www.uow.edu.au/commerce/chsd/palliative%20care)

[www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-publicat.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-publicat.htm)

for copies of checklists etc in word format, email:

[chsd@uow.edu.au](mailto:chsd@uow.edu.au)



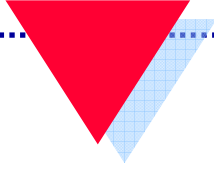
# Mix and match evaluation tools

- ◆ CHSD tool kit contains evaluation tools:
  - for each of the 3 levels (consumer, provider and system)
  - that address each of the key questions (delivery, impact, sustainability, capacity building and generalisability) and
  - that are appropriate for different types of projects
- ◆ In consultation with CHSD, projects select those tools that are right for them (can include own tools)
- ◆ At completion, CHSD synthesises the results achieved with these common tools
- ◆ We will complete some tools with you at site visits

# Six monthly reports

- ◆ 6 monthly progress report to DoHA office (cc to CHSD)
  - reporting in accordance with the schedule in your contract
    - ◆ What did you do?
    - ◆ How did it go?
- ◆ 6 monthly evaluation progress report
  - adding some information on the other evaluation questions
    - ◆ What's been learned?
    - ◆ Will it keep going?
    - ◆ Are your lessons useful for someone else?
  - format and content to be decided ... may vary by project ...



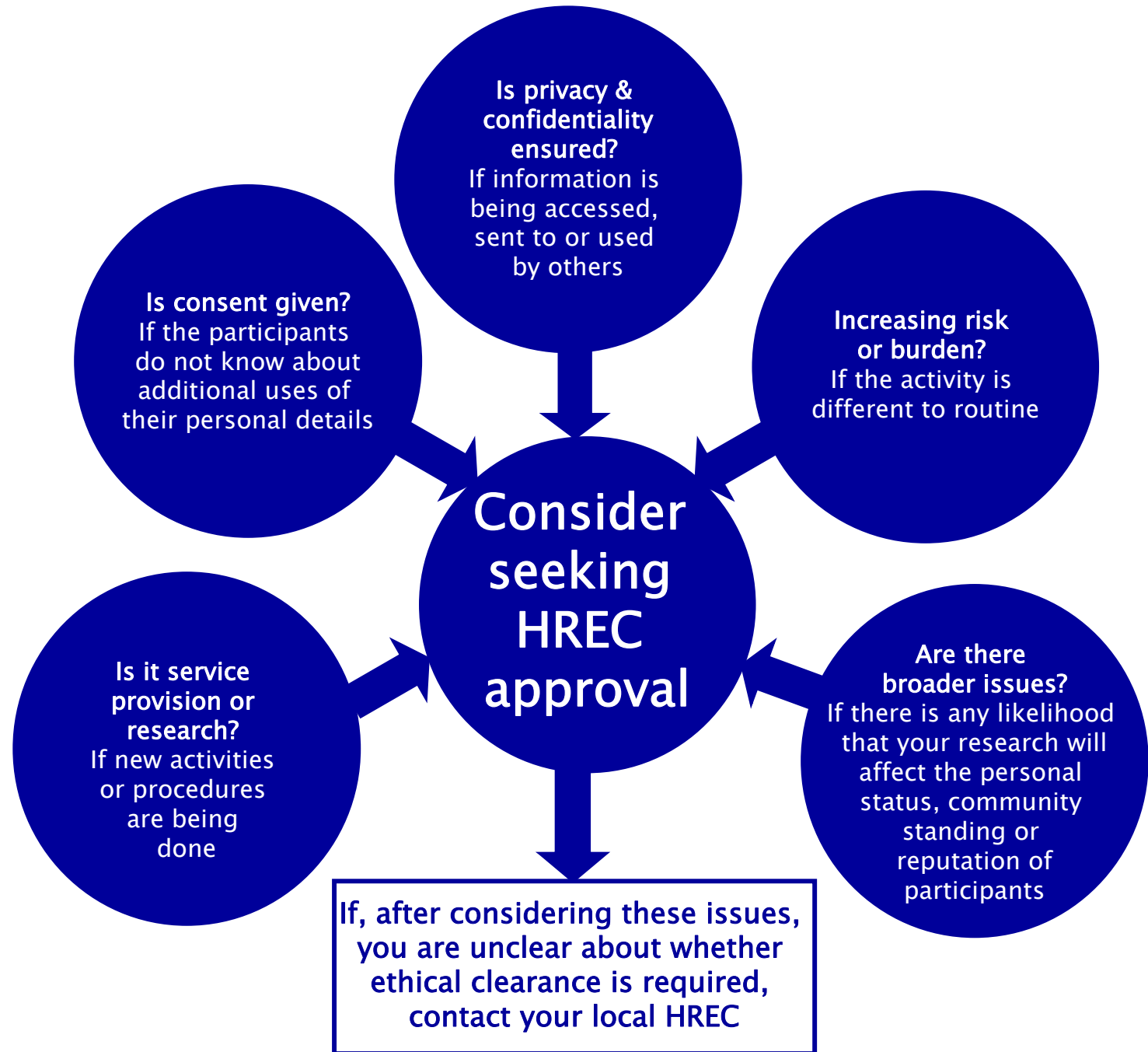


Ethics – why and how?

# Understand the “Ethical Principles”

- ◆ The National Statement identifies a number of principles of ethical conduct that HRECs are to consider in ethical evaluation of research proposals as follows:
  - Integrity and justification,
  - justice,
  - beneficence and
  - respect for persons
- ◆ The principles are not applied mechanically by HRECs. HREC members have to judge which principles have priority and how the principles apply to particular cases.

# When is HREC approval required?



# Special issues with palliative care research

1. Risks and benefits of palliative care research
2. Informed consent
3. Patient vulnerability
4. Qualitative research

# 1. Risks and benefits

- ◆ **Defining research risks and benefits.** The risks and benefits important to terminally ill patients may be more difficult to define because patients' goals for care change substantially as they near death.
- ◆ **Measuring risks and benefits.** There is no single agreed standard against which a researcher or an Ethics Committee can assess the risks and benefits of research.

## Strategies to minimise harm

- ◆ Frequent monitoring of participants.
- ◆ Presence of trained personnel to respond to emergencies.
- ◆ Coding of data to protect confidentiality.
- ◆ Debriefing for participants and/or availability of counselling service.
- ◆ Review and monitoring of data as it is collected to identify any risks or harms.
- ◆ Exclusion of vulnerable groups or individuals.
- ◆ Consideration of alternative methodologies

## 2. Informed consent

Informed consent occurs when patients are given sufficient information about the proposed research, are capable of understanding that information and have the power of free choice that allows them to either give or withhold consent to participate

# Information to potential participants

- ◆ Participation is voluntary.
- ◆ Right to withdraw consent at any time without reprisal.
- ◆ Why the research is being undertaken.
- ◆ Details of how the research will be conducted.
- ◆ Anticipated benefits and potential risks.
- ◆ Potential inconveniences or discomforts.
- ◆ Any costs to participants.
- ◆ How confidentiality will be maintained.
- ◆ Possible conflicts of interest.
- ◆ Institutional affiliations of the researchers.
- ◆ Possible outcomes, including publications.



## 3. Patient vulnerability

- ◆ Compulsion to participate out of a sense of desperation i.e., try anything in the hope of benefit.
- ◆ Obligation to participate because of a feeling of dependency.
- ◆ Feeling the need to 'give something back'.
- ◆ Real reduction in decision-making capacity due to illness.
- ◆ Inability or unwillingness to concentrate for a sufficiently long period of time.
- ◆ Presence of a cognitive impairment.

## Ethical response to patient vulnerability

- ◆ Emphasise distinction between clinician and researcher by delegating recruitment of subjects to a 'third' party.
- ◆ Mitigating feelings of desperation by using a 'lead in' period for the research to optimise symptom management prior to recruitment of subjects.
- ◆ Repeatedly making it clear to patients involved in research that they are free to withdraw their consent at any time.
- ◆ Sensitivity on the part of researchers to any signs that participants no longer wish to be involved.

## 4. Qualitative research

- ◆ Some HRECs may be dismissive of qualitative methodologies.
- ◆ Committees may not include members with qualitative research training and expertise.
- ◆ For some qualitative studies it may be appropriate to obtain verbal consent.
- ◆ The nature of some qualitative research requires the establishment of a level of rapport between researcher and participant. This can be problematic in certain circumstances.
- ◆ Confidentiality is difficult to guarantee in qualitative research, primarily because of the way data are collected.

# How to approach the process

- ◆ Be organised – may take 8-10 weeks for approval
- ◆ Write for an informed lay person
- ◆ Be honest about what you know and don't know
- ◆ Anticipate the issues that the HREC might be concerned about and address them up front
- ◆ Be prepared to seek a variation if something changes in the course of the research
- ◆ When all else fails, go home and have a gin and tonic!

# *Ethical research in palliative care: a guide through the Human Research Ethics Committee process*

Malcolm Masso, Sue Dodds, Dave Fildes, Heather Yeatman and Kathy Eagar

available at:

[www.uow.edu.au/commerce/chsd/palliative care](http://www.uow.edu.au/commerce/chsd/palliative%20care)

[www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-publicat.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-publicat.htm)

for copies of checklists etc in word format, email:

[chsd@uow.edu.au](mailto:chsd@uow.edu.au)

