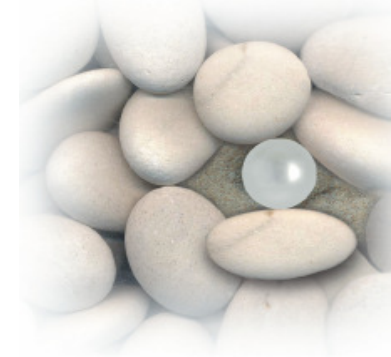


# Research Governance in Hospices

Wendy Fisher

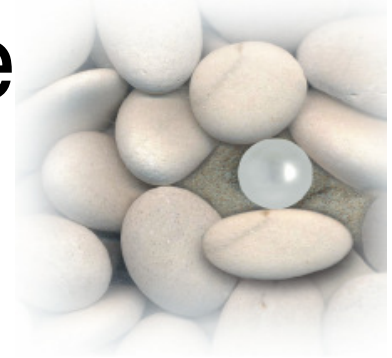
Wendy Fisher Consulting  
R&D Forum conference 2008.

# Why should we be interested?



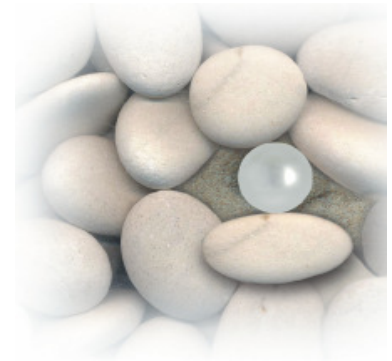
- Patients have a right to be involved in research
- A rich source of research information:
  - Pain control
  - Palliative care
  - Effects of previous and current treatments
  - Psychological aspects of disease
  - Service improvement

# Types of research carried out in hospices



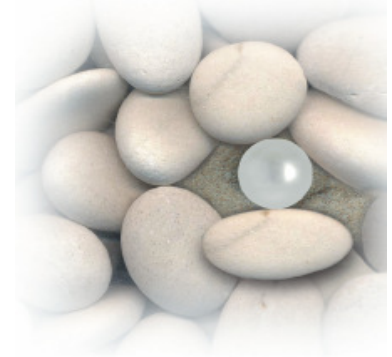
- Quality of life questionnaires
- Service improvement surveys
- Services for carers – impact
- Attitudes of staff – to patient/family
- Experiences of treatment
  - Syringe drivers, etc.
- Experiences of care
  - Community, transfers from home/hospital

# Some want to:



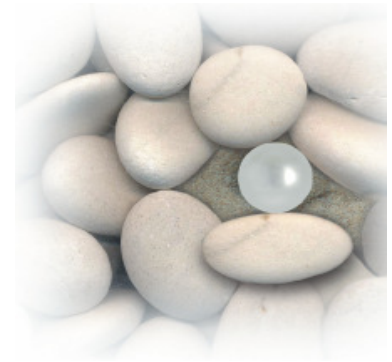
- Conduct trials of drugs in recognised use
- Take part in commercial trials
- Be part of multi-centre trials with HEIs
- Support MSc and PhD students who want to conduct research in palliative care

# What happens at the moment



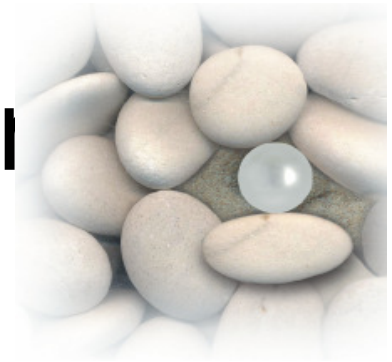
- A lot of confusion and uncertainty from NHS and hospices.
- Very difficult for anybody to collaborate with hospices if they can't be assured systems are in place to protect patients.
- Equally difficult are issues around monitoring, indemnity and peer review.

# Scenario



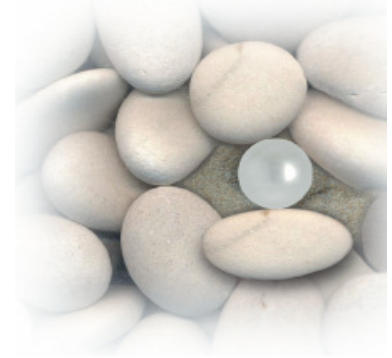
- A London hospice involved in a multi centre trial unable to move forward due to the lack of a research governance system.
- Have been carrying out their own in house mainly qualitative research.
- Want to instigate their own drug trials.

# What needs to happen

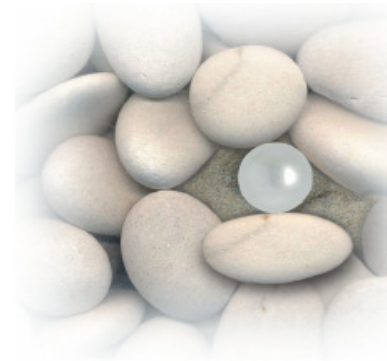


- The hospice needs to set up governance systems that will assure themselves that any research conducted in the hospice is ethically and scientifically sound and appropriate for their population.
- The system needs to be robust enough for Trusts and HEIs to be able to collaborate with them – the system needs to be recognisable

# Adopt a recognised system

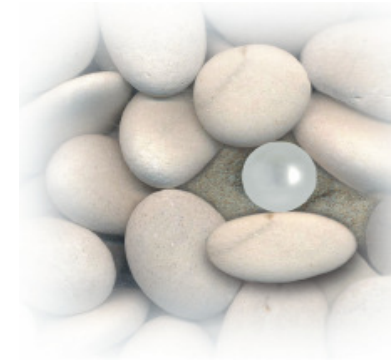


- Take the Research Governance Framework
  - Adapt it to a small unit – treat it like a PCT
- Need a form for researchers to complete for permission to carry out research
- Leave scientific quality and ethics to the ethics committee – unless self generated



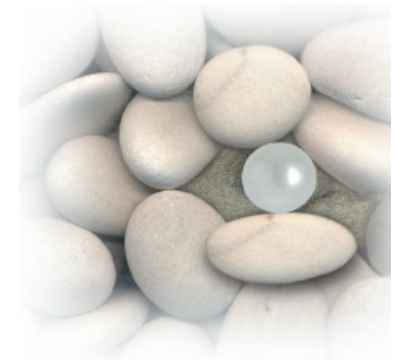
- Form a research committee to consider:
  - Capacity
  - Is there a cost involved
  - Is the population going to be over researched
  - Is the research in line with their strategy and direction
  - Documentation complete

# Indemnity Considerations

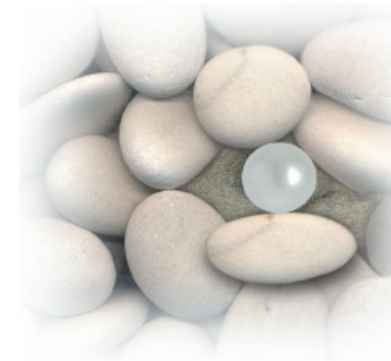


- Hospices are insured already to provide care
- Contact their insurers to extend to research
  - Consider the population of a hospice, often very limited life expectancy.
  - May have to insure on a study by study basis

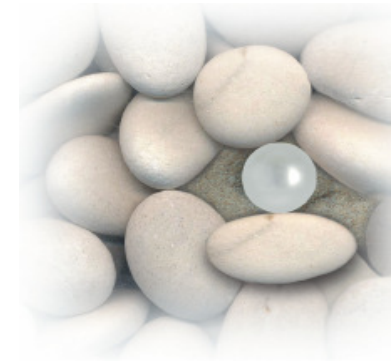
# Action Plan



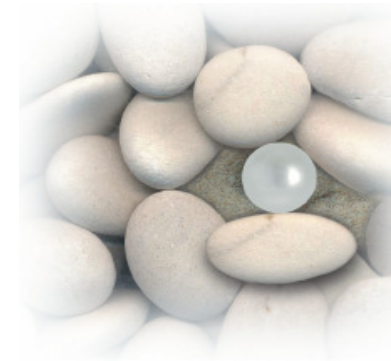
- Advise on what research governance means and what it covers – the hospices role
- Provide help and support to understand the role of the sponsor
- Advise on the role of ethics committees
- Provide a sensible and user friendly on line form



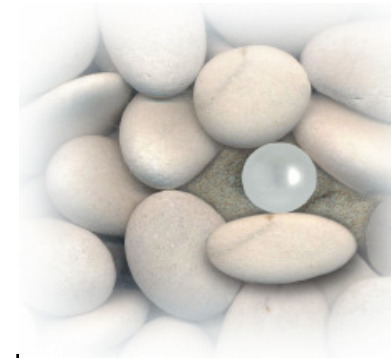
- Facilitate the formation of an RM&G committee
- Provide terms of reference
- Facilitate the conduct of the group and what they should consider – provide decision criteria – attend meetings to support and advise
- Liaise with insurers



- Help with staff recruitment
- It may not be sensible for each hospice to appoint an R&D manager/coordinator but:
  - Does the hospice want to become very research active and develop bids to major funders
  - Is there a fairly constant stream of researchers wanting to come to the hospice
  - Are there opportunities to collaborate with other organisations that need to be developed

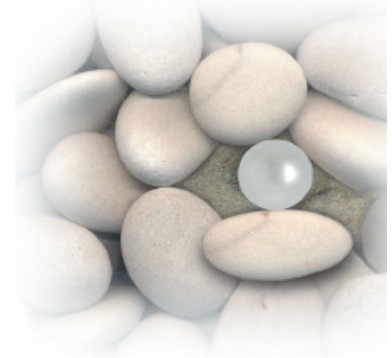


- Facilitate collaboration with local PCT for governance advice – if not employing staff
- Attend meetings with other hospices to discuss options for sharing services and collaboration
- Facilitate GCP training with local NHS Trust or on line
- Provide training session for hospice staff to explain research governance and their role

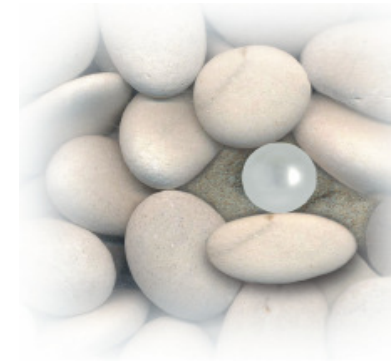


- Facilitate buy in of pharmacy services from NHS Trust
- Facilitate buy in of monitoring expertise between hospices or from NHS Trust
- Support hospice for up to 1 year with issues they experience.

# Is it worth it?



- Yes
- Labour intensive to start with but will allow hospices to play an active role in research with the confidence they are acting appropriately and within the law.
- Will provide the assurance required to collaborators, patients, families and staff.



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