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# Workshop Research Methods in Palliative Care

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# Outcomes of participating in workshop

- Reflect on why research is important in palliative care and develop arguments for doing it, identify potential obstacles.
- Ethics and palliative care
- Reflect on the range of topics which might be addressed and professional groups which could be involved.
- Consider range of methods for research and appropriateness for different research questions



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# Introductions: Your professions and Research interests



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# Why is research in palliative care important?

# Why is research important?

- Better treatments
- Discover new things
- Prevention
- Influence policy and investment
  
- Research is valid if we do not know the answer



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# Who do we have to convince? Potential obstacles?

# Who do we have to convince?

Ethics committees

Research Funders

Universities

Employers (to give time)

Colleagues

Patients

Families

General Public

The Media

(Journals for Publication)

# Potential obstacles?

Fear of death

Lack of Understanding

Anxiety about harm to patients or others

Failure to understand need for research as opposed to implementation

Conflict between funders/commissioners' interests and researchers – pre-determined ideas



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# Ethics and Palliative Care Research

Is palliative care different?

# Ethics considerations

- Vulnerable population (patients and families)
- Need to know they are terminal – tell truth
- Mental Capacity (fluctuating, dementia, drugs, infections)
- Primum non-nocere
- Consent -fully informed, extra care not to give false hopes or undue pressure
- Family research subjects or decision makers
- Doctors and other staff

# Most important

Human Rights

Dignity

Welfare

# Study subjects

Patients

Family

Professionals

Volunteers

Members of the public

# Considerations

- The study's potential to benefit the participants
- The study's risks to participants
- The study's potential to benefit future subjects (patients or families) Altruism
- Decision making capacity
- True voluntariness of subject's choices
- Subjects' motivation



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# Types of Research?

# Types of research

- Literature review, systematic review, meta-analysis
- Qualitative
- Quantitative
- Interventional
- Descriptive – case studies
- Policy Analysis
- Needs Assessment
- Big data

# Funding – Challenge in Palliative Care

In the UK less than 0.3% of the £500 million spent on cancer research is allocated to palliative care

# Disciplines

- Patients, family, members of the Public (Experts through experience)
- Doctors
- Nurses
- Physiotherapists
- Occupational therapists
- Paramedics
- Psychologists
- Sociologists
- Anthropologists
- Theologians
- Behaviour change – social marketing
- Policy makers
- Political scientists
- Lawyers
- Ethicists
- Economists
- Artists/Interior designers

# Literature Review

Consideration:

Search methodology

Language

Study criteria

Analysis

Publication bias

# Analysis of documents

- Policy documents
- Media coverage
- Content analysis – themes, form of presentation within document
- Double reading

# Qualitative research

Face to face interviews

Focus Groups

Anthropological research

Observational studies

Good for identifying previously unrecognised issues

Prelude to quantitative work

Content analysis

Consider impact of interviewer

Preferential responding

Group dynamic

# Surveys

Good for identifying views on topics especially families, professionals, public

## **Methods::**

- Face to face
- Telephone
- Post
- On line

## **Considerations:**

- Access
- Response bias
- Preferential responding
- Question order
- Fatigue
- Language literacy barriers

# Big data

## **Benefits**

Large numbers – statistical significance, subgroup analysis, multivariable analysis, time trends, ecological studies

Data definitions,

Routinely collected

Lack of bias?

## **Cons**

Access

May not be comprehensive

Misclassification

Only proxy for quality

Consider purpose of collection

Biases in recording

# Trials

- Double blind RCT ideal
  - Analyse by intention to treat
  - Treatment units or geographical areas

Phase 1 studies

Before and after intervention

# Ecological studies

Geographical variation

Associations but not causation

Beware ecological fallacy

# Case - control

Compare exposure in cases and controls

Limited uses in palliative care

# Time series

Before and after

Good for assessing interventions where RCT not appropriate



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# Discussion and your research questions