

Developing collaborative research: A study of public awareness in end of life issues

Katherine Froggatt, Senior Lecturer
Gail Capstick – Research Partner
Lancaster University

Lancaster Research Partner Forum

- Developed within the Older Adult theme portfolio of work.
- Initiated by CECO supported researchers at Lancaster University

Aims of Research Partner Forum

1. To support individuals to become involved in the development of CECo initiated projects;
2. To develop new research proposals, seek funding and undertake user-led studies.

Processes

- Monthly meetings
 - facilitated by university staff;
 - rotating chair
- Further involvement through:
 - attendance at specific project meetings and training events.
- Annual review undertaken
 - to identify the work achieved, benefits and challenges of this work.

Membership

- The forum currently has 11 members (has ranged from 5 to 12)
- Range of backgrounds:
 - personal experiences of life-threatening illnesses
 - caring responsibilities
 - professional health and social care roles
 - research experience, knowledge and skills

Development of own research

1. Friends and cancer

- 2 outlines submitted and shortlisted but unsuccessful

2. Public awareness around end of life care

- 1 grant successfully obtained

Improving public awareness of end of life issues among older people in North Lancashire: A peer education approach

End of Life Peer Education Group : Gail Capstick
Oliver Coles, Katherine Froggatt, Deirdre Jacks,,
Susan Lockett, Irene McGill, Jill Robinson, Janet
Ross-Mills

c/o International Observatory on End of Life Care,
School of Health and Medicine,
Lancaster University

Background

- End of Life Care Strategy (DH 2008)
 - Public Awareness work
 - Dying Matters National Coalition
- Knowledge about public awareness is limited
- Previous studies
 - Peer education and older people
 - Understanding older people's perspectives
 - Revisions to educational resources
 - Development and piloting of peer education training

Aims and Objectives

Aim:

- To pilot a locally appropriate peer education programme on end of life issues for older adults;

Objectives

- To design a personal portfolio to hold individually tailored end of life resources and information;
- To undertake public end of life workshops for older members of the general public and their advocates;
- To identify future partnerships for ongoing end of life public awareness work.

Research design

- Based upon participatory action research approach
- Key principles
 - Working with
 - Incorporating different forms of knowledge
 - People's experiences
 - Practical impact
 - Bringing about a change
 - Both action and review

User Involvement

- Integral to study
 - Designed and undertaken by End of Life Peer Education group,
 - Comprises members of general public , retired and/or active in working with older adults about issues of learning, plus researcher
 - All members of Lancaster Research Partner Forum

Methods

- ***Strand 1: Development of personal end of life information and resources portfolio***
- Monthly meetings – September 2009 to March 2010 and ongoing
 - Record of meetings - notes
 - Personal reflections

Strand 2: Development of a community workshop on end of life issues

- Two workshops
 - Older adults
 - Advocates
- Preparation facilitated by external adviser Mary Mattheisen “Cumbria Conversations for Life”

Workshop Content

Three sections

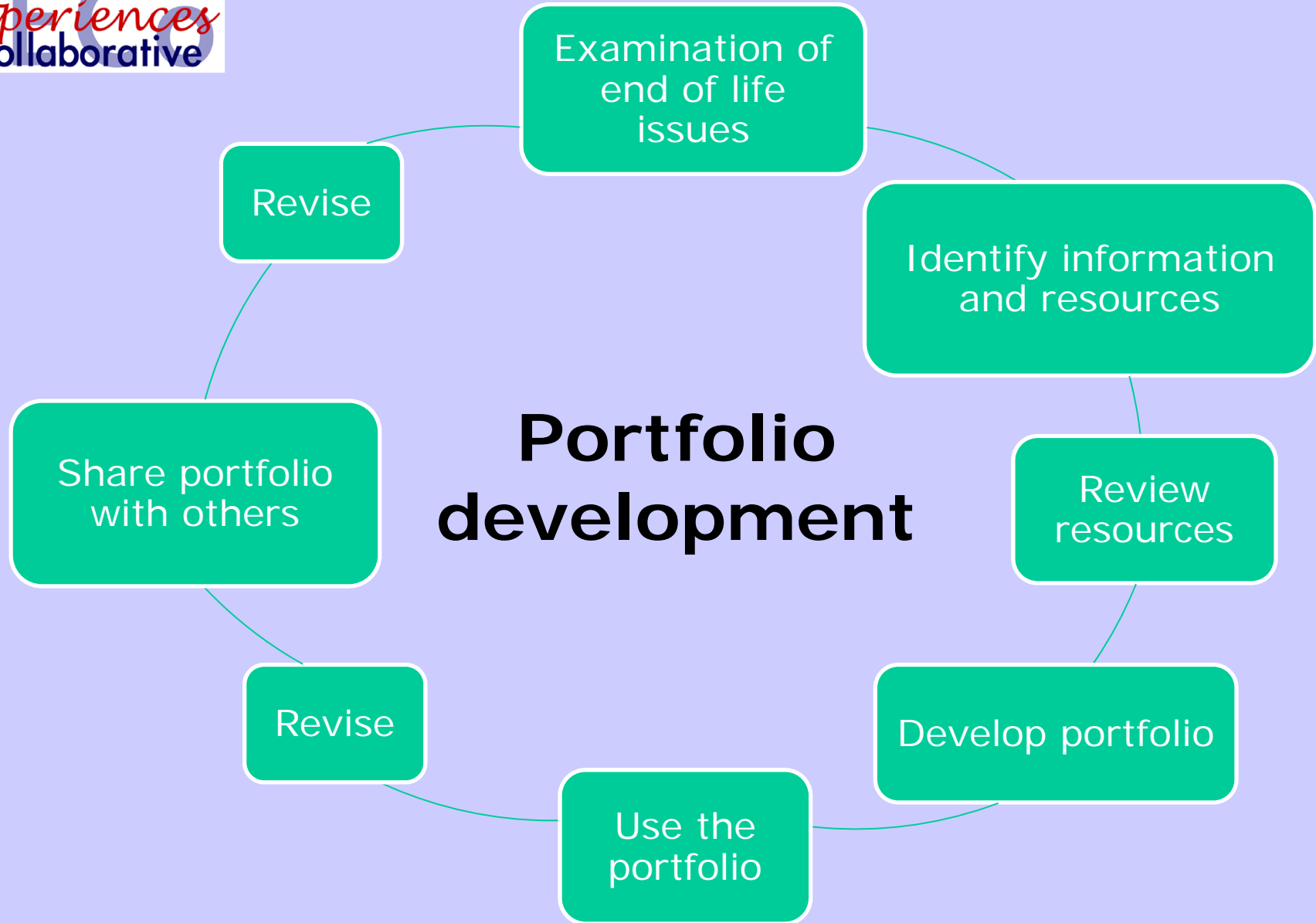
1. *What are some things to think about?*
2. *How to begin planning*
3. *How to talk about these issues*

Structure

- Personal stories
- Facilitated table discussions
- Feedback and wrap up

Findings

- Portfolio development
- Community Workshops



Looking to the Future portfolio

- Introduction to the Portfolio
 - Who am I?
 - Personal Details
 - Life Contacts
 - Health Information
 - Important Documents
 - How I want to be cared for now and in the future
 - Anticipating Future Changes
 - After I Die
- Further Information
- Resources
- Background

Portfolio evaluation

- 8 workshop participants sent feedback.
- Overall positively reviewed
 - Clear and comprehensive
 - Identified as useful
- Some issues
 - How to ensure someone knows about it
 - How to keep information safe
 - How to access to resources for people without *web* access
 - Too much to address all at once

Workshops

Attended by 35 participants

Workshop 1 – 21 older participants

- 18 women; 3 men
- Age
 - All participants were over 55 years old,
 - 17 (85%) over 65 years old
 - 7 (35%) over 75 years old

Workshop 2 – 14 professional and advocate participants

- 11 women; 3 men
- (1 older women)
- Hospital, hospice, care home and voluntary sector backgrounds
- Nurses, doctors, social workers

Workshop Evaluation

- Valued recognition of:
 - Shared concerns
 - Importance of doing this work
 - Identification of practical ways to plan and talk to others
 - Importance of timing

Information Needs Identified

- Frameworks for advanced care planning
- Local resources for support and end of life care
- How to communicate about these issues
- General information about services and resources

Discussion (1)

- Public awareness work
 - Interest and need
 - Emotional work
- Portfolio
 - How to develop further
 - How to best communicate about it

Discussion (2)

- Community workshops
 - How to reach a broader population of older people
 - Are other ways of presenting these issues needed?
 - Going to people
 - Small group work
 - 1:1

In summary

- Met our aims and objectives
 - Piloted a local peer education initiative
 - Designed a personal portfolio
 - Undertaken public end of life workshops
 - Identified future partnerships and further work
- Publication submitted to journal

Where next?

- Funding obtained:
 - Small Sparks grant (Lancashire County Council)
 - Series of 6 workshops (February – July 2011)
 - Two part sessions:
 - External expert speakers
 - Discussions around portfolio development
- Links with other regional initiatives –
Conversations for Life

Reflections

- What is required to develop user involvement in research?
 - Funding
 - Time
 - Commitment
- Where a clear idea and passion resonates with national priorities, user led research can be undertaken.