

**AN INTERNATIONAL COLLABORATION FOR FAMILY CARER
RESEARCH INITIATIVE: MAKING THE DESIRABLE POSSIBLE**

26 May 2006

EAPC Research Congress, Venice

MINUTES

No	Agenda Item	New Discussion
1	Welcome and thanks	Peter thanked people for staying back so late in the day.
2	Why are we here?	Explore the notion of establishing an international collaboration. Brainstorming exercise.
3	Introductions	Peter Hudson and Sheila Payne were introduced.
4	Introduction people who attend	Allison Worth, Carol Davis, David Oliviere, Ebum Abarshi, Gillian Chocons, Gunn Grande, Inger Benkel, Jane Seymour, Jean Clarke, Jean Jacques Georges, Joanne Reeve, Judi Greaves, Julia Addington-Hall, Koen Herwegers, Lucie Hacpille, Mari Lloyd-Williams, Marjan Westerman, Pam Firth, Rachel Newman, Samar Aoun, Sander Borgsteede, Shirley Bush, Sriram Yennurajalingam, Suzanne Quin, Vida Kennedy, Walter Rombouts
5	Apologies	Kelli Stajduhar, Kevin Brazil, Karen Quinn, Robin Cohen and Amanda Johnson.
6	Permission to take notes	No objections
7	Background/rationale	Support for family caregivers is a core tenet of palliative care philosophy. Family caregivers are prone to negative psychological, physical, financial and social outcomes yet there is a dearth of evidence based interventions to guide health professionals. Given the seemingly limited pool of researchers who are focusing on family caregiver research and the scarcity of funding opportunities, a strategic and collaborative approach to map out future research directions seems wise.
8	Definition of terms	Family caregiver(s) = relative/friend identified by a person requiring palliative care as their key support person.
9	Purpose	Explore ways in which a more streamlined and strategic approach to family caregiver research might be achieved.
10	Specific objectives	<ul style="list-style-type: none"> a) Ascertain interest in this area b) Brainstorm what might be possible c) Consider establishment of a core group of international researchers to take responsibility for managing the ongoing development of this initiative.

11	Potential advantages of the initiative	<ul style="list-style-type: none"> • Join together to collaborate • Bigger and better grants • Vehicle for information sharing • Avoid duplication • United voice re: policy • Peer support • Map out programs of research
12	Potential disadvantages of the initiative	<ul style="list-style-type: none"> • Managing the group • Structure needed • Cultural differences • Communication definitions
13	Main challenges	<ul style="list-style-type: none"> • Language • Time to plan research studies • Keep small and simple – focus • Intellectual property • Using an existing conference – WUN
14	Precedents/models in other areas of research	Bereavement network
15 & 16	Potential strategies for funding & Potential collaborators	Funding sources <ul style="list-style-type: none"> • Charities • EAPC • Other networks eg IAHPC • Corporate support • Carer groups
17	Potential patron	Ester Ranson
18	Key family caregiver research priorities	Family Research Initiatives <ul style="list-style-type: none"> • Interventions • After death experience – employment • Information provision • Carer specific assessment • Policy for carers • Cross cultural compassion • Positive experiences • Migrant patterns – people caring • Differences in carers characteristics • Education for health and social care • Risk factors for poor outcomes • Young carers • How do people become caregivers? Do they have a choice? Lived experience of caregiving • Families negotiate caring, whole family – children • Resource poor countries and caring

19	Potential research domains	Leader for each stream eg theoretical frameworks, assessment, user groups, intervention research (pilot, embryonic & advanced), advanced cancer, care for older people, pediatrics, bereavement, neurodegenerative, organ failure, policy, service development.
20	Survey to canvas interest in those unable to attend	Group agreed we have enough people for now.
21	Governance issues	Need to establish a steering group.
22	Recommendations for developing the group in the short to medium term	<ul style="list-style-type: none"> • Unanimous support to develop the initiative • Develop terms of reference • State of the Science meeting moving things forward • Involved interdisciplinary and involved users
23	Volunteers to become part of a steering committee	Agreed that Peter and Sheila would coordinate and aim to get interdisciplinary groups representatives from major countries/continents.
24	Contact details of people who attended	See attached contact list.
25	Next meeting	Budapest 2007 – Pam Firth to arrange time and venue.
26	Summary	Peter provided a summary.
27	Issues arising	Nil
28	Conclusion	