

**International Palliative Care Family-Carer  
Research Collaboration  
(IPCFRC)  
Meeting**

**EAPC Budapest  
Thursday 7 June 2007  
15.30 – 16.30  
Paris Hall – Building A**

# **International Palliative Care Family-Carer Research Collaboration (IPCFRC) Meeting**

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## **AGENDA**

**Chairs : Peter Hudson and Sheila Payne**

**Minutes: Karen Quinn**

- 1 Welcome**
- 2 Minutes of meeting at EAPC Congress Venice 26 May 2006 (enclosed)**
- 3 Feedback on discussion paper (enclosed)**
- 4 Update on short term objectives (a) – (e)**
  - a) Lobby relevant organization(s) for seeding funding for IPCFRC.
  - b) Establish administrative support to assist in developmental work.
  - c) Establish vehicles for communication (eg website, newsletter, letterhead/logo, meetings etc).
  - d) Promote the establishment of the IPCFRC (eg via conferences, websites, journals).
  - e) Determine how similar groups were established (eg International work group on death, dying and bereavement) and adopt one approach.
- 5 Discuss strategies for achieving short term objectives (f) – (h)**
  - f) Confirm roles of steering committee (eg chair, vice chair, secretary etc) and consider need for a program committee.
  - g) Confirm current membership and process for joining the IPCFRC. (refer list of current members enclosed.
  - h) Develop mission statement, formal terms of reference, organisational structure and constitution (including recognition of potential intellectual property issues).
- 6 Issues arising**
- 7 Next meeting**

# 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	<b>Welcome and thanks</b>	Peter thanked people for staying back so late in the day.
2	<b>Why are we here?</b>	Explore the notion of establishing an international collaboration. Brainstorming exercise.
3	<b>Introductions</b>	Peter Hudson and Sheila Payne were introduced.
4	<b>Introduction people who attend</b>	Allison Worth, Carol Davis, David Oliviere, Ebnun 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	<b>Apologies</b>	Kelli Stajduhar, Kevin Brazil, Karen Quinn, Robin Cohen and Amanda Johnson.
6	<b>Permission to take notes</b>	No objections
7	<b>Background/rationale</b>	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	<b>Definition of terms</b>	Family caregiver(s) = relative/friend identified by a person requiring palliative care as their key support person.
9	<b>Purpose</b>	Explore ways in which a more streamlined and strategic approach to family caregiver research might be achieved.
10	<b>Specific objectives</b>	<ul style="list-style-type: none"> <li>a) Ascertain interest in this area</li> <li>b) Brainstorm what might be possible</li> <li>c) Consider establishment of a core group of international researchers to take responsibility for managing the ongoing development of this initiative.</li> </ul>

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

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

## DISCUSSION PAPER (23 May 2007)

### Formalising establishment of the: International Palliative Care Family-Carer Research Collaboration (IPCFRC)

#### Background

In June 2006 a meeting was held in Venice, Italy at the European Association of Palliative Care Research Congress to obtain consensus about establishing an International Palliative Care Family-Carer Research Collaboration. Approximately 35 researchers from several countries attended and endorsed the initiative. Outcomes of the inaugural meeting were published in the European Journal of Palliative Care.

It was agreed that a steering committee be established to guide the developmental phase and prepare a report for the next face to face meeting in June 2007 at the EAPC congress in Budapest. A steering committee has been established with representatives (from a variety of disciplines and countries). Please refer to the following table:

Name	Position/Role	Employer	Country
FIRTH, Pam	Head of Family Support	Isabel Hospice	UK
GIVEN, Barb	Associate Dean for Research, College of Nursing	Michigan State University	USA
GIVEN, Bill	Professor, Dept. of Family Practice	Michigan State University	USA
GRANDE, Gunn	Lecturer in Palliative Care, School of Nursing, Midwifery & Social Work	The University of Manchester	UK
HUDSON, Peter	Associate Professor and Director, Centre for Palliative Care Education & Research	St Vincent's Hospital & The University of Melbourne	Australia
OLIVIERE, David	Director of Education and Training	St Christopher's Hospice	UK
PAYNE, Sheila	Help the Hospices Chair in Hospice Studies	Lancaster University	UK
STAJDUHAR, Kelli	Assistant Professor, School of Nursing and Centre on Aging	University of Victoria	Canada
TENO, Joan	Professor of Community Health and Medicine	Brown Medical School	USA

#### What is the purpose of this current discussion paper?

An earlier version of this paper prepared by the steering committee was circulated to the wider group prior to the Budapest meeting in order to obtain consensus on the objectives and developmental priorities. A few minor amendments were suggested and have been accommodated in this version which will be the main reference point for discussion at the EAPC Budapest meeting.

## **Objectives (in order of priority) for the IPCFRC**

### **Short term (by mid 2008)**

- a) Lobby relevant organization(s) for seeding funding for IPCFRC.
- b) Establish administrative support to assist in developmental work.
- c) Establish vehicles for communication (eg website, newsletter, letterhead/logo, meetings etc).
- d) Promote the establishment of the IPCFRC (eg via conferences, websites, journals).
- e) Determine how similar groups were established (eg International work group on death, dying and bereavement) and adopt one approach.
- f) Confirm roles of steering committee (eg chair, vice chair, secretary etc) and consider need for a program committee.
- g) Confirm current membership and process for joining the IPCFRC.
- h) Develop mission statement, formal terms of reference, organisational structure and constitution (including recognition of potential intellectual property issues).

### **Medium term (by end 2008)**

- a) Develop consensus based priorities for family carer research
- b) Promote international opportunities for interdisciplinary research collaboration and publications.
- c) Communicate: new studies or new papers in process that have commenced, outcomes of recent family carer research studies (including methodological insights).
- d) Communicate opportunities for research funding.
- e) Consider formal alliance with a particular group(s) (eg WHO, Help the Hospices, EAPC etc) and possible avenues for ongoing financial support.
- f) Develop a plan to convene an international conference or state of the science meeting focused on family carer research.
- g) Consider appointing a well known person to be patron for the IPCFRC.

### **Longer term (by mid 2009)**

- a) Develop a strategic plan including financial plan.
- b) Foster informal partnerships with key research groups, policy makers, carer advocacy/consumer groups and service delivery planners.
- c) Consider establishment of research working groups (from the wider membership) eg policy, sociological and cultural, interventions, needs/experience (consumer perspectives), assessment/tools/measures and bereavement.
- d) Develop educational resources for carers. (e.g Web based, hard copy )
- e) Provide mentorship for developing family carer researchers.
- f) Promote opportunities for international research visits/exchanges amongst members
- g) Lobby relevant organisations for enhanced services/supports for family carers.

**Summary of achievements to date, time lines and *proposed* future meetings (to end 2008)**

<b>Tasks</b>	<b>Date</b>
Inaugural meeting EAPC Venice	May 2006
Report from Venice meeting circulated	June 2006
Article about the group published in European Journal of Palliative Care	July 2006
Steering committee established	December 2006
Discussion paper for steering committee	March 2007
Steering Committee teleconference	March 2007
Revised discussion paper circulated among steering committee	April 2007
Discussion paper circulated among wider group	May 2007
Face to face meeting Budapest	7 June 2007 (15.30 – 16.30)
Minutes from Budapest circulated	July 2007
Steering committee teleconference	August 2007
Steering committee teleconference	December 2007
Steering committee teleconference	March 2008
Face to face meeting & symposium (to confirm) EAPC Research congress Norway	May 2008
Steering committee teleconference	July 2008
Face to face meeting & symposium (to confirm) International Congress of Palliative Care Montreal, Canada	September 2008

## Current Members

S/N	Name	Attending Budapest	Employer	Country
1	ADDINGTON-HALL, Julia	Yes	University of Southampton	UK
2	BENKEL, Inger	Yes	Sahlgrenska University Hospital	Sweden
3	BRAZIL, Kevin	Yes	St. Joseph's Healthcare Hamilton	Canada
4	BUSH, Shirley	Yes	Southern Health & Southeast Palliative Care	Australia
5	CHANG, Esther		University of Western Sydney	Australia
6	CHOWNS, Gillian	Yes	Oxford Brookes University	UK
7	COHEN, Robin		McGill University	Canada
8	DAVIS, Carol	Yes	Southampton University Hospitals	UK
9	FIRTH, Pam	Yes	Isabel Hospice	UK
10	GIVEN, Barb		Michigan State University	USA
11	GIVEN, Bill		Michigan State University	USA
12	GRANDE, Gunn	Yes	The University of Manchester	UK
13	GREAVES, Judi		Monash University School of Nursing and Midwifery	Australia
14	HUDSON, Peter	Yes	Centre for Palliative Care Education & Research, St Vincent's & University of Melbourne	Australia
15	JACKSON, Debra		University of Western Sydney	Australia
16	JOHNSON, Amanda		University of Western Sydney	Australia
17	LLOYD-WILLIAMS, Mari		University of Liverpool	UK
18	MILNE, Donna		Peter MacCallum Cancer Centre	Australia
19	NEWMAN, Rachel		Royal Cornwall Hospitals NHS Trust	UK
20	OLDHAM, Lynn		Curtin University of Technology	Australia
21	OLIVIERE, David	Yes	St Christopher's Hospice	UK
22	PAYNE, Sheila	Yes	Lancaster University	UK
23	POWAZKI, Ruth	Yes	Cleveland Clinic	USA
24	QUINN, Karen	Yes	Centre for Palliative Care Education & Research, St Vincent's & University of Melbourne	Australia
25	SEYMOUR, Jane	Yes	University of Nottingham	UK
26	STAJDUHAR, Kelli		University of Victoria	Canada
27	TENO, Joan		Brown Medical School	USA