

The DIAdIC End-of-project Conference (EAPC Pre-conference)

Improving quality of life and wellbeing for patients with a serious illness AND their carers

(Towards a family-centered approach to care)

The DIAdIC project, the EAPC Reference Group for Family Carers and the EAPC Reference Group for Public Health and Palliative care are organising a preconference on <u>Wednesday 15 May</u> before to the <u>13th World Research Congress</u> of the European Association for Palliative Care (EAPC) in Barcelona (16-18 May) on the theme of patient and family oriented care.

Date: Wednesday, 15 May 2024, 09.00-17.45

Venue: Aula Magna (160 places), University of Barcelona, Gran Via de les Corts Catalanes, 585 08007 Barcelona

Organisation committee:

- DIAdIC Coordination Team*
- EAPC: Cathy Payne

Scientific committee:

- DIAdIC Coordination Team*
- Peter Hudson
- Clare Gardiner & Nick Odom (EAPC reference group family caregiving)

Aims of the conference:

1) To **stimulate a paradigm shift** in policymakers, professional healthcare providers and other stakeholders towards dyadic care (addressing both the patient and the caregiver as a unit of care);

2) To inform about the outputs and results of the DIAdIC project;

3) To **collectively create strategies** to advance the implementation of dyadic approaches to care.

Target audience

- European and national professional bodies
- Researchers
- Policymakers (local, national and transnational)
- Healthcare professionals
- Representatives from patient/family carer advocacy groups
- Health insurance companies
- Civil society representatives

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Conclusion: People with scientific/political/professional background who attend these conferences for new insights and networking with the <u>intent</u> to take back these insights to inform or enhance their work/policy development.

<u>Additional materials:</u> We will provide all attendees with a booklet containing essential information about the DIAdIC program, including details about participating partners and hospitals, development process, and links to relevant available resources and materials.

Program

9:00 AM	Registration
10:00 AM	Welcome
	Speaker: Jesus Gonzalez-Barboteo (Catalan Institute of Oncology, Consultant
	Palliative Care Physician. Palliative Care Department)
10:15 - 11:15	Setting the keynote
AM	- Joachim Cohen, DIAdIC project Coordinator, (20 minutes): Introduction: what
	lies ahead: describing the care needs and potential of patients with serious
	illness and their carers, and presentation of the conference.
	- María Lasierra Losada - WHO Regional Office for Europe, the Cancer team (SNI/
	NCD), (20 minutes): Patient-family centered care as attention points in policy
	and practice.
	- Stecy Yghemonos – Director of EuroCarers (20 minutes): What are the
	challenges we would like to see addressed? What do we see as solutions?
11:15 AM - 1:00	The dyadic philosophy of care
PM	- Clare Gardiner (25 minutes): Family caregiving in palliative and end of life care:
	challenges and policy solutions (11:15-11:40)
	- Nick Odom (25min): State of the Science in Interventions for Serious Illness
	Family Carers: How far have we come? Where do we go next? (11:40-12:05)
	- Laurel Northouse (25 minutes): FOCUS - a dyadic program of care: history,
	evidence, challenges, and lessons learned over 20 years (12:05-12:30)
	- Katherine Bristowe (20 minutes): But I don't have a family carer: risks,
	limitations and solutions in dyadic approaches of care (12:30-12:50)
	Q&A: 10min (12:50-1:00)
1:00 - 2:00 PM	LUNCH
2:00 - 3:15 PM	Outputs and findings from the DIAdIC project
	- Aline De Vleminck (20 minutes): Comparing a nurse-led face to face and a self-
	administered web-based dyadic intervention with standard care: development
	and results of the FOCUS+ and iFOCUS programs (2:00-2:20)
	- Suzanne Guerin (20 minutes): understanding what works, how and why in
	FOCUS and iFOCUS (mixed methods) (2:20-2:40)

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	 Peter May (15 minutes): The costs and benefits FOCUS and iFOCUS: results of the economic evaluation (2:40-2:55) Peter Hudson (10min): The effectiveness-implementation trial of a dyadic digital health intervention in Australia (FOCUSau) (2:55-3:05) Q&A : 10 mins (3:05-3:15)
3.15-3.30 PM	Coffee break
3.30-4.45 PM	 The perspective of the patient-carer dyad and the healthcare professional Presentation/video by a patient and/or caregiver about the meaning and impact of the FOCUS+ and iFOCUS interventions (10 min) <i>Kevin Brazil</i> (20 minutes: meaning and impact of psychoeducation dyadic programs to nurses who delivered the FOCUS+ program Orphé Matthys (20 minutes): The implementation of a psychoeducation dyadic program in practice: a case example Vincent Van Goethem (20 minutes): Promise and pitfalls of eHealth and mhealth as methods to deliver psychoeducational support to patients and their carers (discussing findings from DIAdIC and other programs)
4:45 - 5:30 PM	Panel discussion : Translating knowledge into societal change (panel will discuss different elements that were presented during the day and address a number of questions (will be provided ahead of the discussion) regarding implementation, policy, etc.)
	<u>Moderator</u> : <i>Richard Harding</i> <u>Panel</u> : Clare Gardiner, Laurel Northouse, María Lasierra Losada, Julie Ling (EAPC), <i>Charles Normand (TBC)</i> , Peter Hudson, Stecy Yghemonos
5:30-5:45PM	Closing

*Please address your questions to the DIAdIC Coordination Team: Joachim COHEN <u>Joachim.Cohen@vub.be</u>; Aurelie Joos <u>Aurelie.Joos@vub.be</u>; Yuliana Gatsolaeva <u>Yuliana.Gatsolaeva@vub.be</u>; Vincent Van Goethem <u>Vincent.VanGoethem@UGent.be</u>).

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