

# Knowledge about Palliative Care - mapping, user involvement (and development of practice)

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# Knowledge Centre and knowledge

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# The Knowledge Centre of Rehabilitation and Palliative Care

- The Danish Knowledge Centre of Palliative Care (PAVI), 2009 – 2013
- The Danish Knowledge Centre of Rehabilitation and Palliative Care (REHPA), 2014 –
- The purpose of the national centre is to gather, to produce/construct and to share knowledge about rehabilitation and palliative care for people suffering from life threatening diseases
- Target groups; mainly professionals, but also lay-people, civil servants, politicians etc.
- Publically financed, part of the University of Southern Denmark, situated in Copenhagen and Nyborg, Funen

# The way, we work

Mappings - of services and knowledge	Research and development - rehabilitation and PC	Communication and dialog
<ul style="list-style-type: none"><li>• Mappings of services<ul style="list-style-type: none"><li>- Descriptive (surveys)</li><li>- Explorative (interviews, observations)</li></ul></li><li>• Litteratur studies and reviews</li></ul>	<div data-bbox="720 415 1224 625" style="border: 1px solid #0056b3; padding: 10px; text-align: center; margin-bottom: 20px;"><p>Cancer rehabilitation program – in Nyborg</p></div> <ul style="list-style-type: none"><li>• Intervention research<ul style="list-style-type: none"><li>- RCT</li><li>- Action research</li><li>- Development projects</li><li>- Evaluations</li></ul></li><li>• Register studies</li></ul>	<ul style="list-style-type: none"><li>• Professional-, research-, citizens and media-related</li><li>• Publications</li><li>• Websides</li><li>• Presentations, education</li><li>• Arrangement of konferences, seminars, workshops</li><li>• Networking, boards</li><li>• Press</li><li>• Information, flyers</li></ul>

# Modes of Knowledge

Mode 1	Mode 2	Mode 3
Defined by researchers	Defined by users	Defined by political/governmental strategies
Hierarkical diffusion	Social diffussion	Commercial established
Oriented towards sciencific knowledge	Oriented towards the use in society	Oriented towards evaluation, documentation
Disciplinary organization	Trans-diciplinariry	Monoparadigmatic dominated

Nowotny H, Scott P & Gibbons M (2003): Introduction. 'Mode 2' Revisited: The New Production of Knowledge. *Minerva* 41: 179-194

Hjort K (2012): Det affektive arbejde.(The affektive work) Samfundslitteratur.

# Mapping

# On mapping palliative care (PC) - and ranking the quality of PC

- The Economist Intelligence Unit 2015: DK No 19 out of 80 countries
- WPCA/WHO 2014: Global Atlas of Palliative Care at the End of Life
- Centeno et al, 2013: EAPC Atlas of Palliative Care i Europe 2013
- The Economist Intelligence Unit 2010: DK No 22 out of 40 countries
- EU rapport 2003: DK No 13 out of 52 countries
- EAPC White Paper 2009 + 2010



# Purposes and challenges in mapping PC

*"...to categorize hospice-palliative care development, country by country, throughout the world, and then depict this development in a series of world and regional maps."*

(Wright et al, 2008)

- Absence and quality of data?
- Counting by type of service or by providers?
- The quality of care, the cultural, social and economical meaning and context of care?



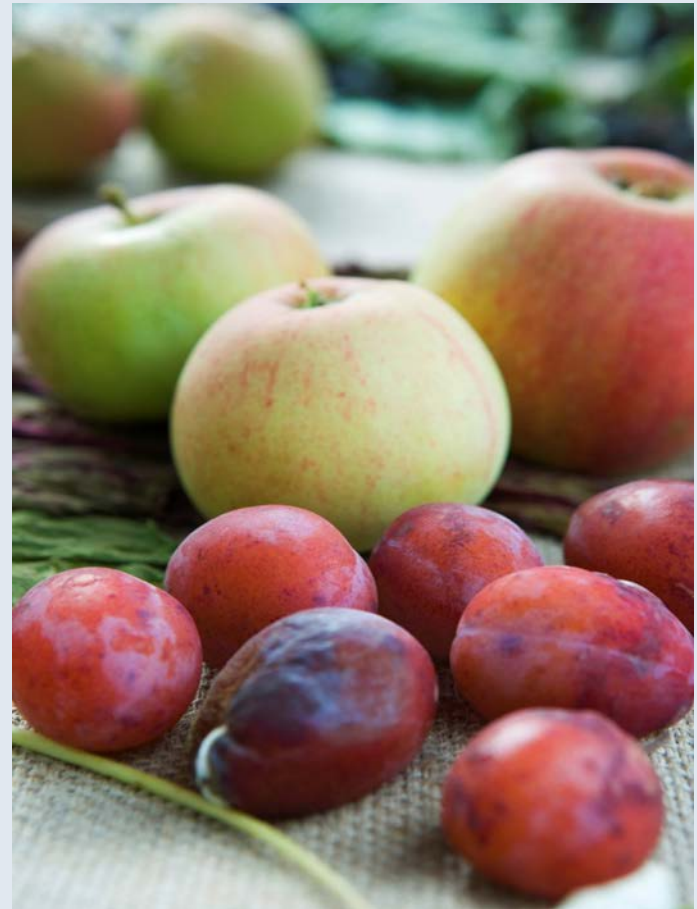


# References

- Clark D & Centeno C: Palliative care in Europe: an emerging approach to comparative analysis. *Clinical Medicine*, Vol 6, No 2, March/April 2006
- Wright M et al: Mapping Levels of Palliative Care Development: A Global View. *J of Symptom and Pain Management*, Vol 35, No 5, May 2008
- Lynch T, Connor S & Clark D: Mapping Levels of Palliative Care Development: A Global Update. *J of Symptom and Pain Management*, Vol 45, No 6, June 2013
- Woitha et al: Policy on palliative care in the WHO European region: an overview of progress since the Council of Europes (2003) recommandation. *Eur J of Public Health*, Nov 6, 2015
- Timm H & Vittrup R: Mapping and comparison of palliative care nationally and across nations: Denmark as a case in point. *Mortality*, Vol 18, No 2, 2013

# The purposes and outcomes of mapping PC?

- Policy making – how is it working (in what sense)?
- Measuring quality of PC – how is it working (in what sense)?



# User involvement

# On user involvement

(background)

- In a historical perspective
- As a concept and as methods
- In the our centre



# User involvement historically, as a concept and as methods (why, how and where)

Theoretical approaches	Why? User involvement	How? User involvement	Where? User involvement
Radical/critical	Conflict of interests, inequality in power	Empowerment of users	Macro, meso and micro level
Philosophical/ Phenomenological	Differences in perspectives	Exploration of and collaboration from the users' perspective	Meso and micro level
Consensus, policy making	Democracy/voice	Evaluation Opinion surveys satisfaction surveys	Meso and micro level
Consensus, policy making	Consumerism/choice	Dissemination of professional knowledge, sharing informations, PROMS	Meso and micro level

# User involvement in the field of palliative care

- A radical and critical approach?
- A philosophical approach?
- A democratic approach?
- A consumer approach?



# Sharing knowledge with Danish Citizens and Patient Organizations (theoretical assumptions)

- Knowledge is transformed/constructed information, therefore knowledge is always grounded in a specific perspective
- The construction of knowledge has to do with methods (e.g. methods for investigating suffering, palliation or quality of life)
- Knowledge is connected to power
- For empowerment, for using a voice and for making a choice – you need to know about the options for care
- To share knowledge with the public, the centre needed a baseline
- Macro (society and population) and meso level (organisations and units) – while normally in the field the meso and micro level (individuals)

# Sharing knowledge with Danish Citizens, and Patient Organizations (intro)

- 1. The Citizen Project 2012-2013: What do the Danes know about life threatening diseases (LD), death and dying – and do they want to know more?
- 2. The Knowledge Sharing Project 2013 – 2015: How do Danish patient organizations (PO) communicate about palliative care and how can this communication be developed?
- 3. The mourning support project (elderly spouses) 2013 – 2015: Sharing knowledge about new mourning theory and the experiences of elderly spouses – with the public, the professionals and a group of spouses.



# Sharing knowledge with Danish Citizens and Patient Organizations (definitions)

- **Knowledge** = all kinds of information, that has been “...processed or systematized by thought” (Peter Burke, A Social History of Knowledge, 2000, p. 11)
- **Sharing** = exchanging in person and/or disseminating (knowledge) by means of communication
- **Citizens** = all Danes and the public, but mainly lay-people in general and patients and relatives in particular
- **Patient Organisations** = Private organisations, associations/NGOs concerned with the situation of patients and relatives living with life threatening diseases
- **User involvement** =

# Sharing knowledge with Danish Citizens and Patient Organizations (what did we do?)

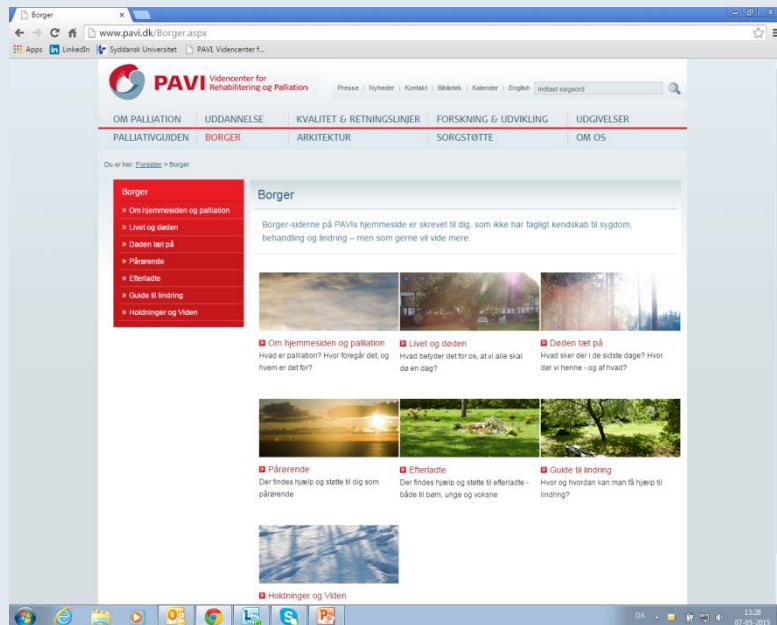
Project	Methods , purpose and results
1. The Citizen Project	<ul style="list-style-type: none"><li>• A survey (baseline 1; what do the Danes know already?)</li><li>• A web-site (sharing knowledge)</li><li>• A workshop (sharing knowledge)</li></ul>
2. The Knowledge Sharing Project	<ul style="list-style-type: none"><li>• A literature search (investigating international experiences)</li><li>• Interviews (baseline 2; how do PO share knowledge about PC?)</li><li>• A network (POs sharing and developing knowledge and communication about PC)</li><li>• Texts and articles for web-sites and the press</li><li>• A course at The Public University</li><li>• A report, an article</li></ul>
3. The Mourning Support Project	<ul style="list-style-type: none"><li>• A book</li><li>• A strategy and activities ensuring public awareness/PR</li></ul>

The Citizen Project 2012-2013: *What do the Danes know about life threatening diseases (LD), death and dying – and what do they want to know more about? (baseline 1: A survey, 51% of 2000 Danes)*

- LD, death and dying is part of most grown-ups' lives
- Death and dying is seen as private but not as a taboo
- The Danes have relevant knowledge about LD and places of death, but wish different for themselves
- The Danes have some trust in being taken care of in a physical sense by the Health Care System
- The Danes worry about LD
- They want quality before a longer life span
- They might want the possibility of euthanasia
- They do not want more knowledge – until they actually need it
- They think PO can be supportive

# The Citizen Project 2012-2013: *What do the Danes know about life threatening diseases, death and dying – and what do they want to know more about?*

## The web-site



## The workshop



The Knowledge Sharing Project 2014 – 2015: *How do Danish patient organizations share knowledge about palliative care with their members and how can this communication be improved? (baseline 2: Interviews with POs)*

15 persons:

- 5 chairmen/heads (individual)
- 6 consultants (focus-group)
- 4 patients & relatives (focus-group)

Questions:

- The Danish national strategy of PC (2011)?
- Whats is PC?
- How do you work with PC in your PO?

- Not much knowledge about the national strategy
- PC = terminal care for cancer patients
- PC = death
- Talking about PC = takes away hope

# Palliative care, patient organisations and hope



*“...you do not want to frighten them (the patients). You want them in (to the PO), and you get them in, if you can give them some hope i relation to the disease.”  
(consultant from PO)*



The Knowledge Sharing Project 2014 – 2015: *How do Danish patient organizations share knowledge about palliative care with their members and how can this communication be improved?*

## A network



## A "common cause"

- A strategy for making knowledge about palliative care "a common cause"
- Press – media
- Websites of the POs

The Knowledge Sharing Project 2014 – 2015: *How do Danish patient organizations share knowledge about palliative care with their members and how can this communication be improved (international experiences)?*

## A literature search

- Dying Matters, UK (2009-)
- The Conversation Project, US (2010 -)
- Palliative Care, Australia (1991-)

## Inspiration for "a common cause"

- Sharing knowledge, disseminating information
- Web-sites
- Awareness week, hundreds of local events (May)
- Storytelling about death & dying, guides
- Death over Dinner (January)
- PC week (May)



# Results and conclusion

- Baseline 1 – the survey
- Baseline 2 – the interviews
- Dialog and communication
- More knowledge available on web-sites, in the media, in education etc.
- In proces and in progress
- This was a way to do it
- What's next???



# User involvement within the field of palliative care in general?

## What is user involvement about in PC?

- Talking, listening and being together?
- Sharing knowledge, planning and making decisions?
- Evaluating the results of the care given?
- Quality of life?
- Governance?

## Which methods and tools should be used?

- Time, space and social relations?
- Shared decision making, Advance Care Planning
- Patient Related Outcome Measures (PROMs)? (EORTC etc?)
- Documenting outcomes AND/OR meaning of PC?!