

Palliative Care Research: A clinical as well as a public health challenge

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what does the landscape of palliative care research look like?



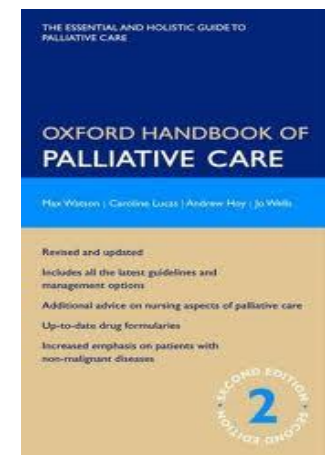
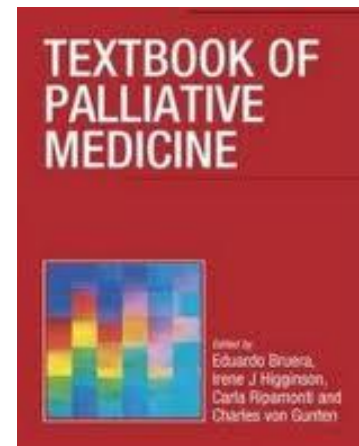
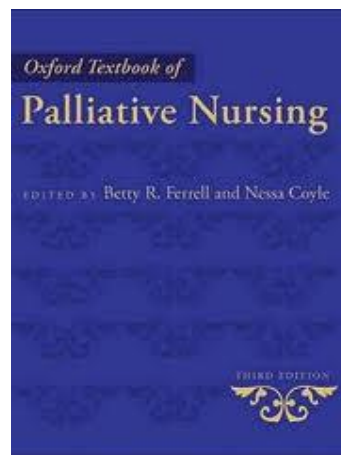
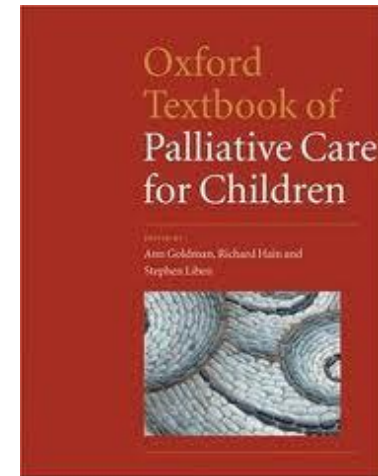
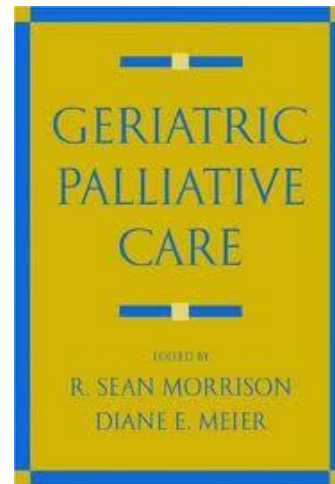
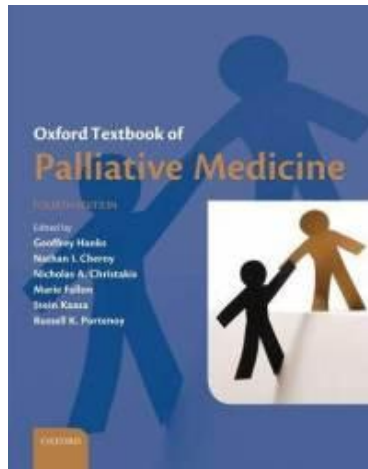
Content

- Progress in Palliative Care Research?
- Origins of the WHO public health policies?
- What is Palliative Care Research challenged with?
- How does the house of Palliative Care Research could look like?
- Conclusions

Progress in palliative care research

- substantial progress over the last decades, mainly in Europe, North America, as well as in Asia & Australia
- both within clinical research as well as HSR and public health research
- the research much better established with regard to ***funding, capacity & infrastructure***
 - chairs in Palliative Medicine, Palliative Care, Palliative Nursing, etc
 - EU FP7 increased budget for PC research ><FP6/FP5
 - academic departments of palliative care or palliative medicine
 - growing number of conferences & journals

All textbooks contain PH/HS chapters



Progress of PRC & EAPC RN research

- clinical research
- public health oriented research

3 ongoing PH related EU FP7 funded projects

- **ATOME** (S Payne & L Radbruch)
 - **A**ccess **T**o **O**pioids **M**edication in **E**urope
- **EURO IMPACT** (L Van den Block & L Deliens)
 - **E**uropean **I**ntersectorial & **M**ulti-disciplinary **P**alliative **C**are Research **T**raining
- **IMPACT** (Y Engels & K Vissers)
 - **I**mplementation of quality indicators in **P**alliative **C**are **s**Tudy

Other ongoing international EAPC RN projects (“national” funding)

- **IPoD** (J Cohen & L Deliens)
 - **I**nternational **P**lace **o**f **D**eath study
- **NEED IT** (S Juenger & L Radbruch)
 - **N**eeds Assessment on **I**nformation **T**ransfer in Eastern Europe and Central Asia
- **UNBIASED** (J Seymour & J Rietjens)
 - **U**K **N**etherlands **B**elgium **I**nternational **S**edation Study

However, much can be improved...

- in many parts of the world PC & PC research is poorly developed
- when it comes to “Evidence Based Palliative Care”, much more progress has to be made
- quality of the delivered care is poorly measured, mainly on process level and not on patient outcomes
- we lack a core set of generic, reliable and valid outcome measures
- the research is scattered
- interdisciplinary research is poorly developed

However, much can be improved...

Regarding funding, capacity and infrastructure

- no standard PhD curriculum in PC research training
- most chairs in PC are “clinical” chairs, very few in social sciences
- very few research teams in palliative care are embedded in a public health environment
- main textbooks in PC lack a multidisc. edit. board
- research too much dependent on charity funding
- too few PC research get funded by main stream scientific funding (e.g. national funds for scientific research, EU grants, ERC grants, etc)

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History of a new public health: **key events**

- 1974, the Lalonde report initiating the “community approach” – *A New Perspective on the Health of Canadians*
- WHO (1978), Alma-Ata Declaration on *Primary Health Care*
- WHO (1981), “*Health for All by 2000*” *Strategy*
- WHO (1986), *Healthy Cities Project*
 - //Allan Kellehear (2005) ***Compassionate Cities.*** Public Health and end-of-life care. London: Routledge

History of a new public health

- Central elements of these policies:
 - the need to reorientate medical services and health systems
 - promotion of primary care, community health, prevention and health promotion
 - importance of involving the public
 - bridging between the public, private and voluntary sector
 - put forwards very concrete health targets

History of a new public health: lessons for the palliative care?

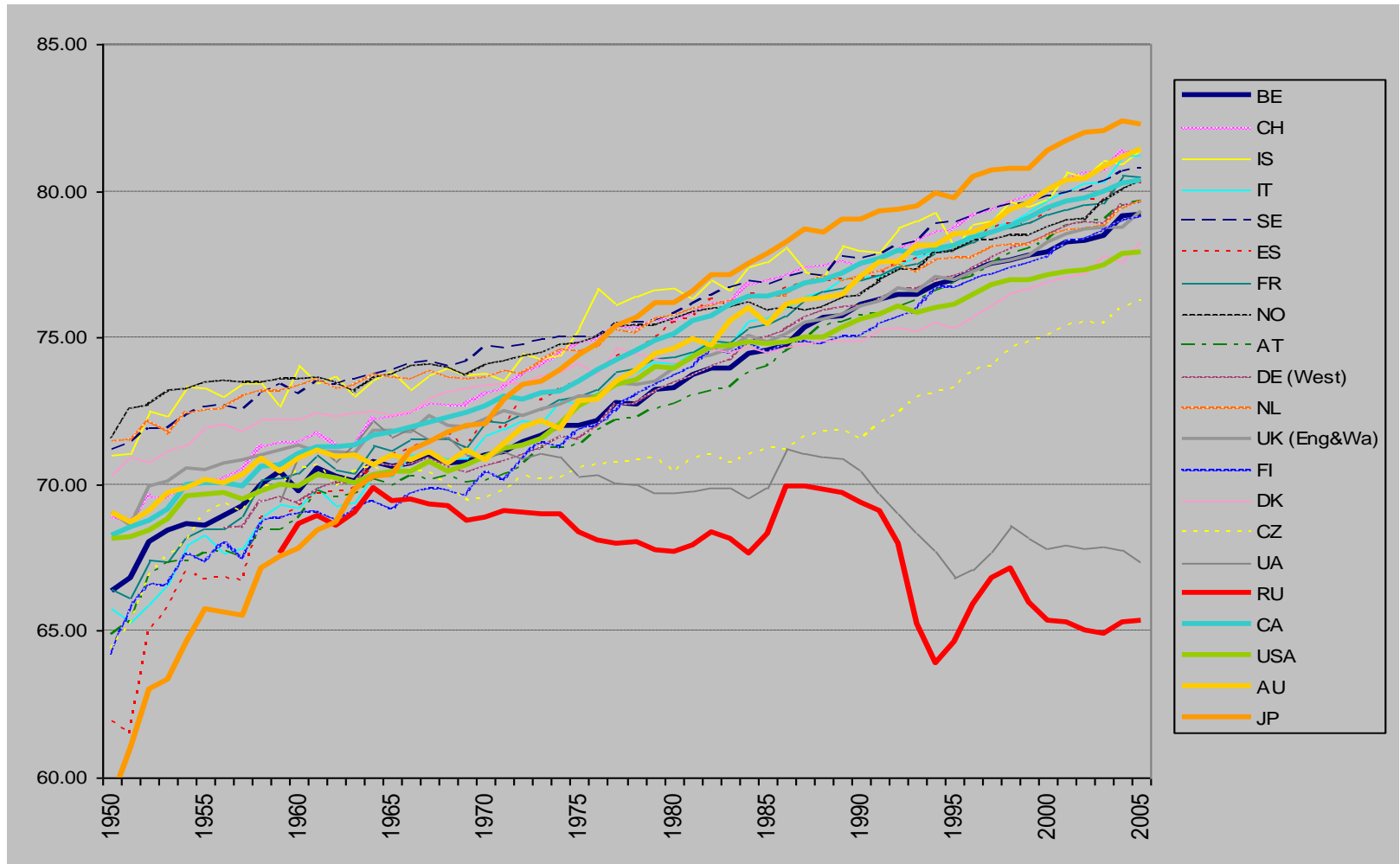
- the present PH policies have been developed over a century as a **global response to global problems**
- also PC is facing the global problem of aging in societies and many more challenges
- why don't we learn from that experience and see how we can adopt this in the benefit of PC developments and PC research?

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What is PC challenged with?

Increasing life expectancy



What is PC challenged with?

A change in dying

- length of illness process has substantially increased in last 100 years
- people die at an older age
- facing longer period of illness before death => prolonged dying process
- strong medicalization of society and of dying in 20th century

=> health care interventions can make a difference in the quality of dying!



What is PC challenged with?

A changing social context

- >50 million people worldwide die each year
 - 40% to 60% of them could benefit from some form of palliative care
- ⇒ ensuring that these people have (equal) access to adequate palliative care presents a major public health challenge
- ⇒ safeguarding good quality of life at the end of life for eligible patient groups essentially requires not only a clinical approach but also a public health approach

What is PC challenged with?

A changed culture

- societal values are changing:
 - secularisation
 - self-determination

- in health care:
 - Focus on “quality of life” vs quantity
 - Patient autonomy vs physicians’ paternalism (cfr patients rights)

Socio-economical context?

Troubling times for PC

- recognition of the importance of PC is peaking at a time when governments are faced with reductions of their budgets
- desire of policy makers and practitioners to embrace the holistic ideals of PC comes face-to-face with an ever-diminishing financial capacity to do so
- most resources are allocated to physical care, more specifically to *curative* and *therapeutic/life prolonging* treatments (95%)

How can we take up and win these challenges?

- *"Evidence Based Palliative Care"* (EBPC)
 - micro level: Clinical Practice research
 - meso level: Health Services and Health Systems research
 - macro level: Population based research
- EBPC is a necessary, but **not a sufficient, condition!**
- we need a complementary *"strategic public health plan"* as well !

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Palliative Care for All in need

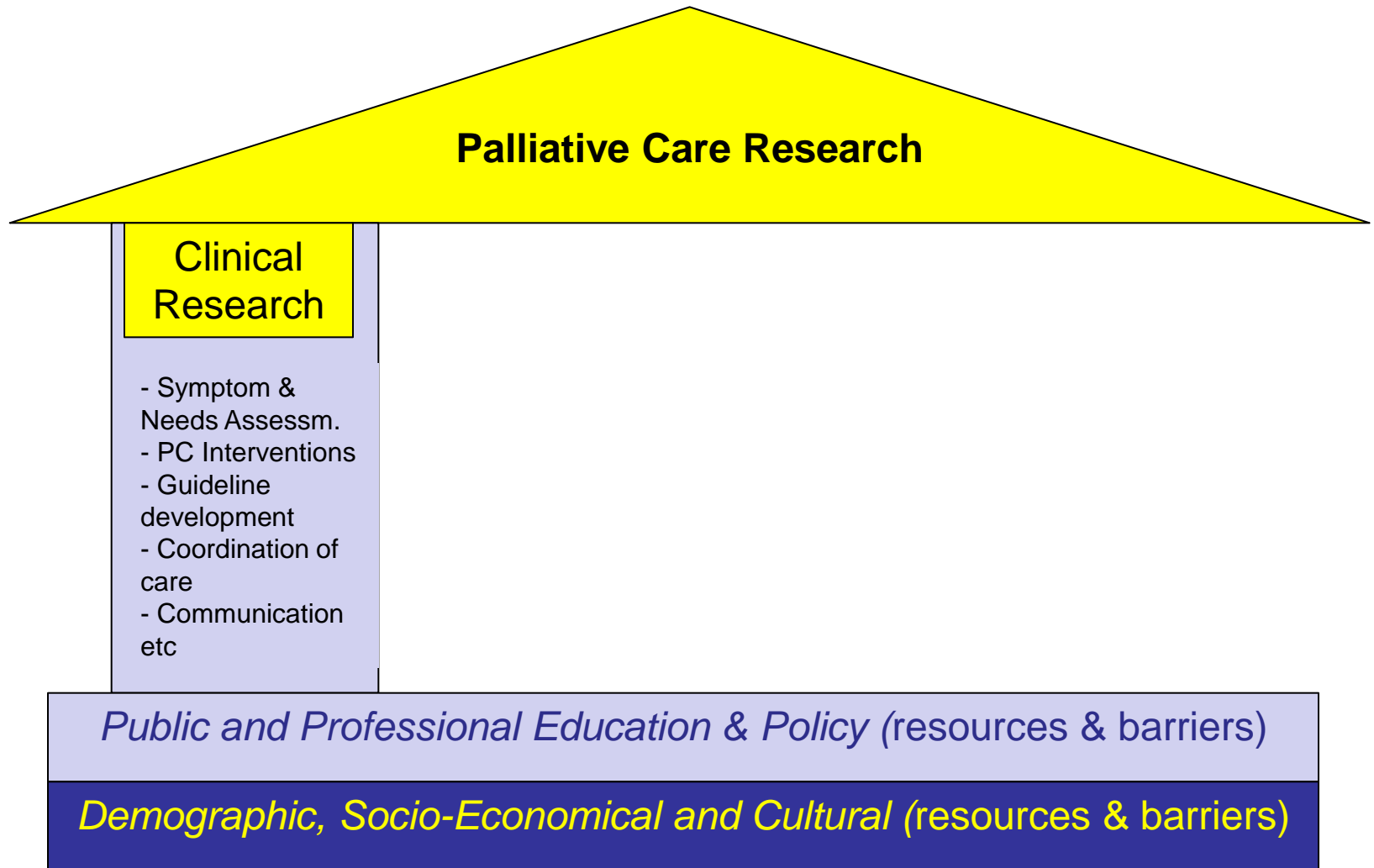


Palliative Care Research

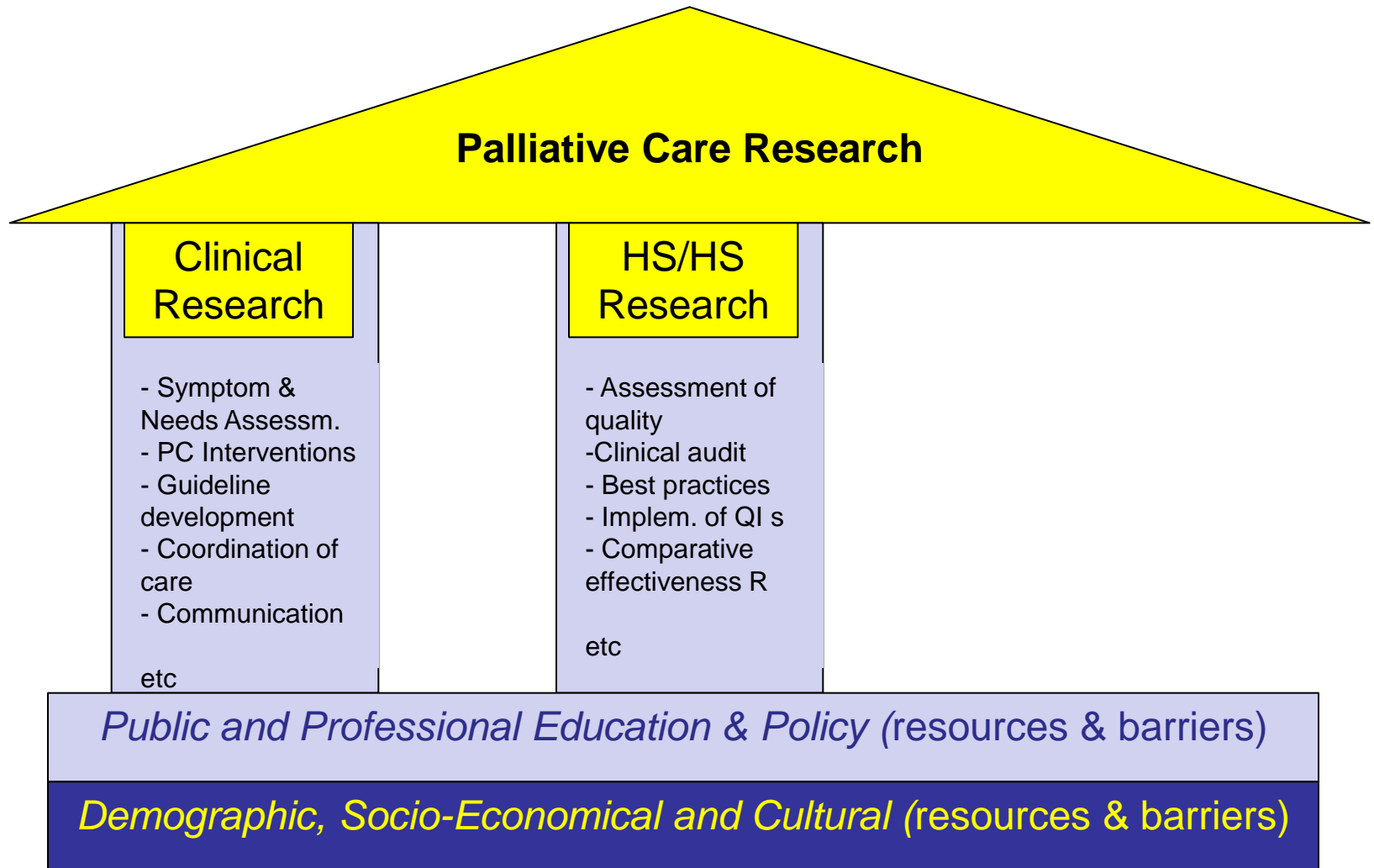
Public and Professional Education & Policy (resources & barriers)

Demographic, Socio-Economical and Cultural (resources & barriers)

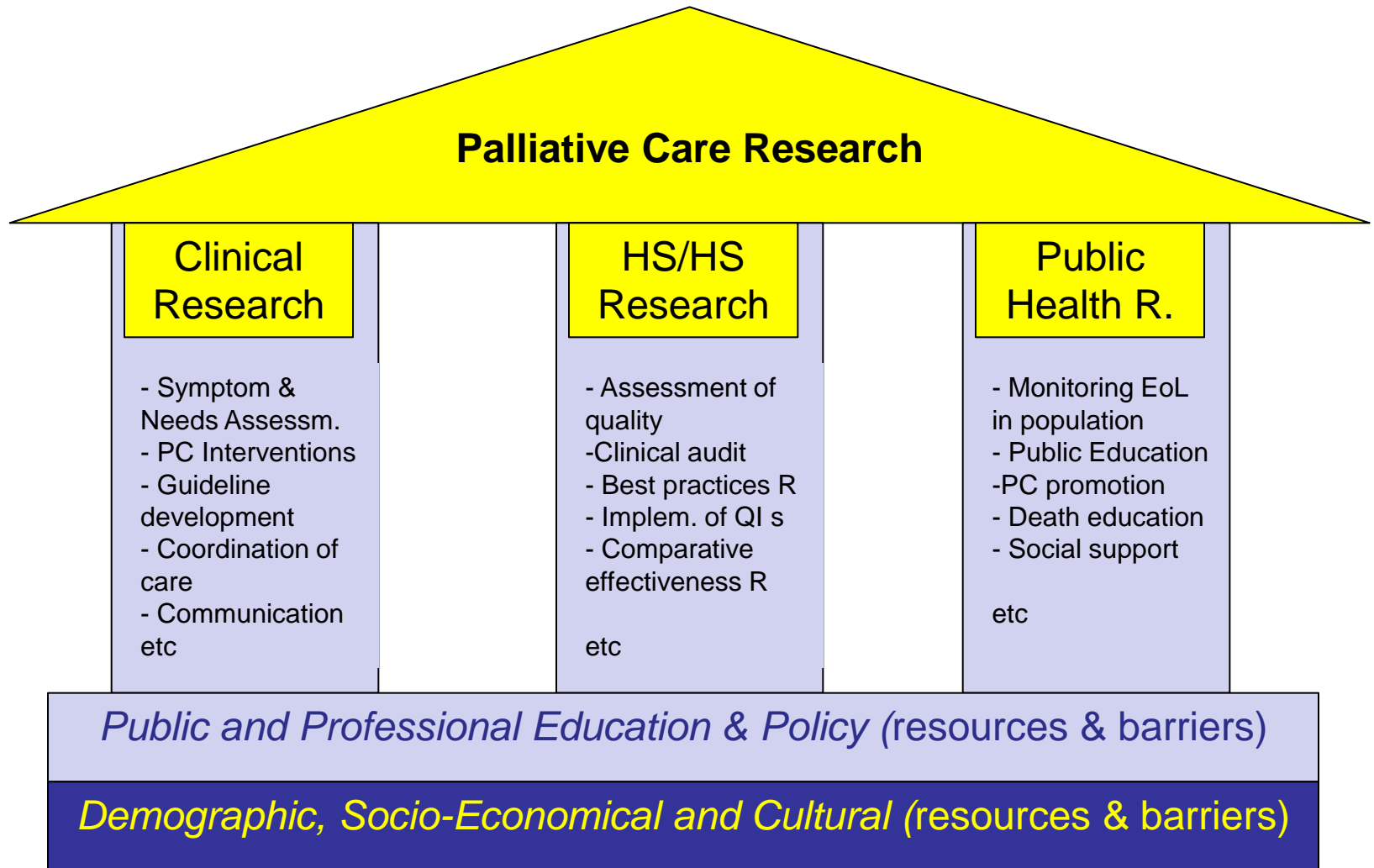
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Conclusions

- beyond the clinical research agenda, we need a global multidisciplinary research agenda
- in order to generate more research, we have to link up with other faculties outside the medical faculty
- next to clinical researchers we need to recruit and involve more (social) scientists into palliative care research
 - broaden the scope of the research
 - stimulate real interdisciplinary research
 - introduce new methodologies and theories

Conclusions

- where possible, between clinicians and public health researchers we can set up collaborative projects
- we need a global research strategy in palliative care
 - integrating clinical, HSR and PH research
 - clear vision on a multidisciplinary research agenda
- in order to gain societal impact (and more resources) we need to develop a palliative care public health strategy
 - ***"Palliative Care for All in Need by 2020"***

Ghent, October 18 - 19, 2012

I wish you all a nice and
challenging seminar

2nd International Seminar of the PRC and EAPC RN

