

RESEARCH IN PUBLIC HEALTH AND END OF LIFE CARE

Building on the past and developing
the new

A background

- PHPCI conference Limerick conference 2013
- International contacts and networks
- Master class May 1, 2014
- Series of meetings in London
- PHPCI conference in Bristol (May 2015)
- Upcoming publication in Progress in Palliative Care

Aims of this session

- How do we move from curiosity to stringent research?
- How can we build on from the past to together further a research agenda for the future?
- How can this be part of wider agendas for developing public health and developing palliative care for the future?

Three key points

1. Past and current interests in palliative care (research) have virtually excluded public health approaches
 - health service and bedside approach dominant within palliative care
 - 'integrated care' paradigm it is still not addressing population health and 'hidden publics'
2. The public health approach is more appropriate to describe and address problems on a population level and of the 'hidden publics'
3. Research methodologies from new public health and classic public health can be complementary components of a public health EoL care research agenda

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key point 1

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Health service and bedside approach have been dominant within palliative care research



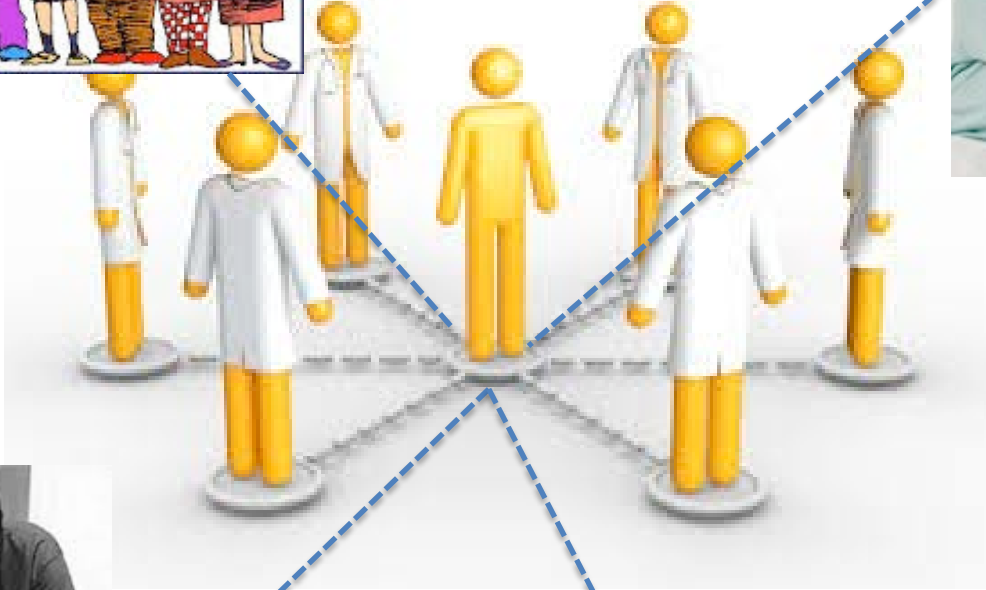
PATIENT-CENTERED CARE



Concept by Sachin Jain, Art by Matthew Hayward ©



Integrated care as the magic bullet?



A public health approach is different from a health service and bedside approach



the combination of sciences, skills and beliefs directed towards the **protection, promotion, and restoration of people's health** through organized **collective or social actions**

WHO:

state of complete physical, mental and social well-being and not merely the absence of disease or infirmity

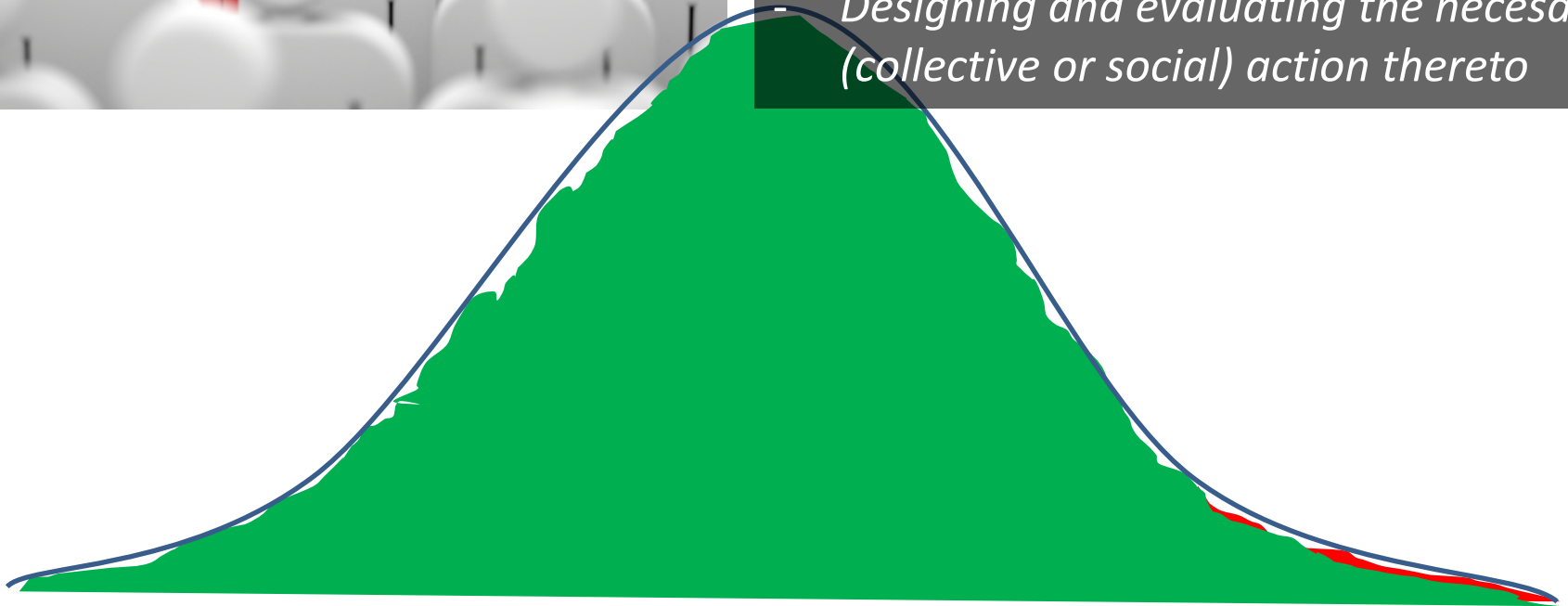
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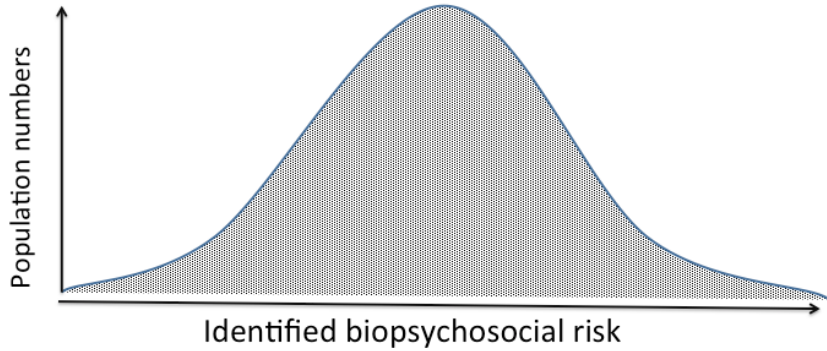
A public health approach is more appropriate to describe and address problems on a population level



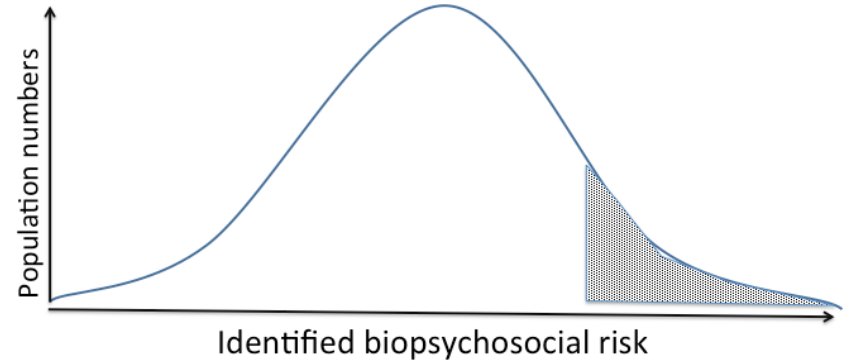
- Public health approach to EOLC:
- *Aimed at describing, understanding and optimizing the circumstances of the full population of persons facing life-shortening illness and all those involved, and*
 - *Designing and evaluating the necessary (collective or social) action thereto*



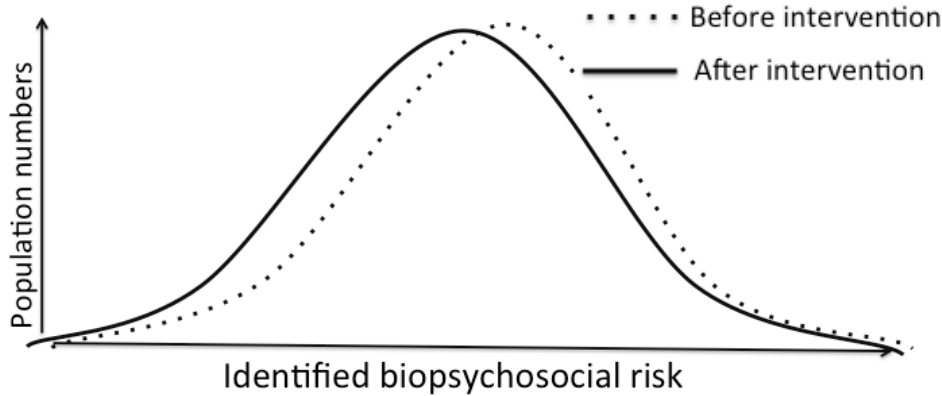
Public health research perspective



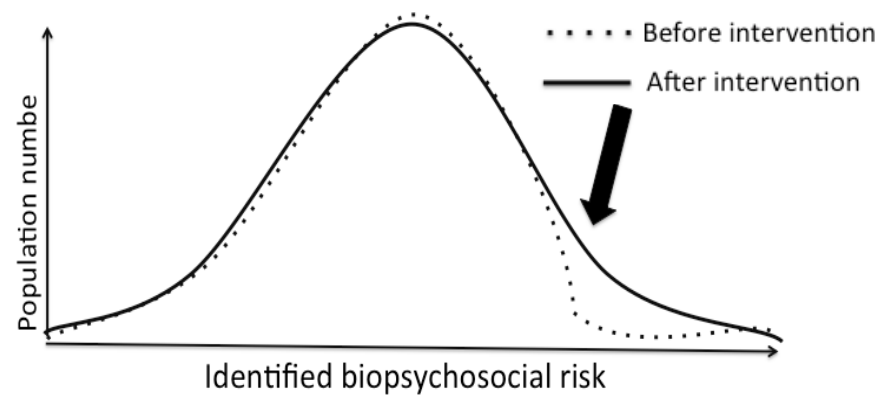
patient care/health service research perspective



Public health research perspective (interventions)



patient care/health service research perspective (Interventions)



Three key points

3. Research methodologies from new public health and classic public health can be complementary components of a public health EoL care research agenda

Combining new public health and classic public health research approaches in EOLC research

Commonalities:

1. focus on total populations
2. challenge of dominance of biomedical approaches
3. recognition of non-professional actors in healthcare alongside professional healthcare services
4. importance of social and economic determinants of health
5. support of action and policy change

NEW PUBLIC HEALTH APPROACHES

Drivers for the interest in a new public health approach

- Recognition of limitations of professional knowledge
- Communities possess answers too
- Demographic and funding pressures
- Appreciation of the impact of social factors on health and wellbeing
- Top-down approaches often do not lead to sustainable change
- Upstream interventions can have significant impact
- Health is everyone's responsibility

The principles of a new public health approach

- Focuses on equity, participation and a broad understanding of health and wellbeing
- Social capital, resilience etc. assessed along with mortality rates
- Acknowledges the limitations of the biomedical model
- Social determinants of disease recognised
- Interventions done ***with*** not ***to*** people

Declaration of Alma Ata

(WHO 1978)

“Primary health care is essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.”

The Ottawa Charter (WHO, 1986)

- Build healthy public policy
- Create supportive environments
- Strengthen community action
- Develop personal skills
- Re-orientate health services

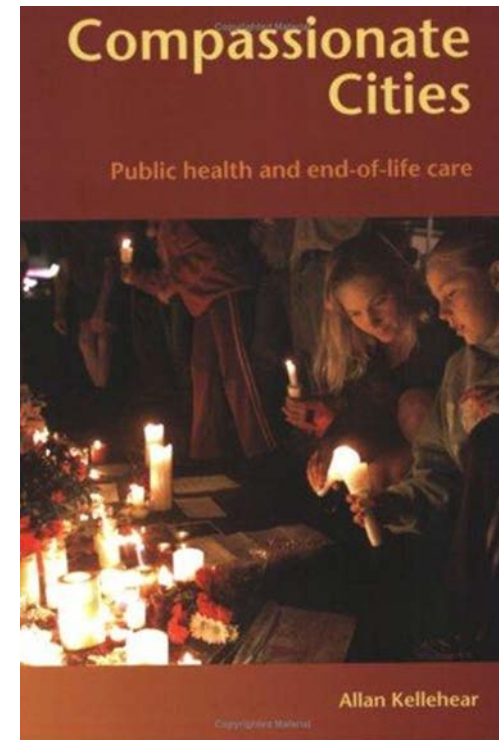


New public health and end-of-life care

- Kellehear first described the 'public health approach to end of life care' (1999)
- Aligned the two apparently paradoxical disciplines

Compassionate Communities are community development initiatives that actively involve citizens in their own end-of-life care

Build partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them with professional care



Research in this field

- What does the literature tell us?
 - Difficult to use traditional methods to understand or measure health promotion or community development
 - Outcomes and impacts often hard to determine in advance
 - Time frames can be long
 - Beneficiaries can be unexpected

Research in this field

- Methods should be congruent with the principles of the approach
 - Participatory
 - Focused on equity
 - Sharing of knowledge
 - Not disempowering for participants
 - Support capacity building

Tensions

- Participant voice is silent
- Much work is professionally led
- Risk of romanticisation
- Risk of professionalisation of community
- Community and professional knowledge – issues of privileging
- Are hospices and HCPs the right organisations to be taking this forward?
- Lack of skills in this area
- Who decides on outcomes
- How can they be determined in advance
- Relevance of studies in different contexts
- Issues of power and research
- Issue of being a professional conducting research 'on' people – who owns the research agenda?

Community Engagement

Sallnow & Paul 2014

Community engagement in end-of-life care is an umbrella term for a process which enables communities and services to work together to understand, build capacity, and address issues to improve their experience of end-of-life and bereavement and their related well being. It exists on a spectrum of engagement that extends from informing through to empowering, depending on a range of factors such as the degree of participation from the local community and the intention of the work. Community engagement activities by end-of-life care services go beyond working in the community to working with the community to improve its experience of end-of-life care.

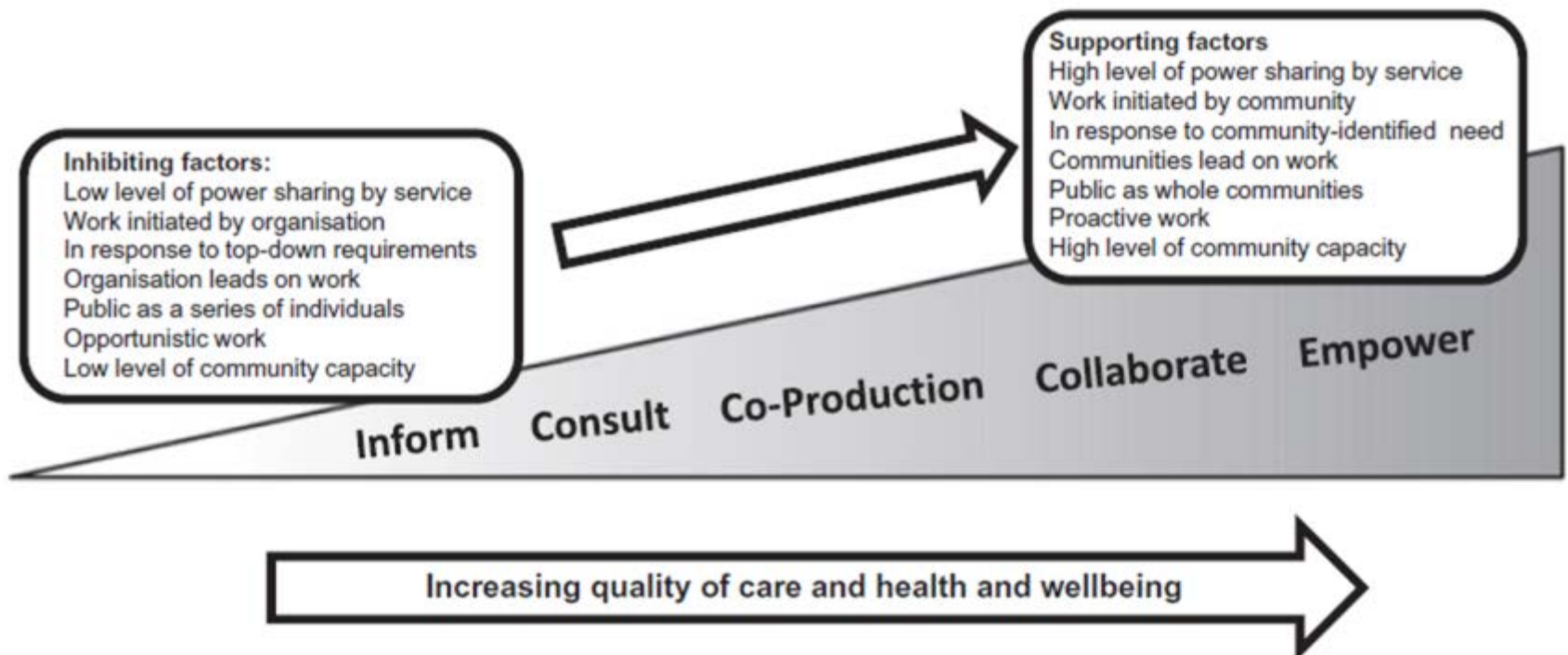
Conceptual clarity

Understanding community engagement in end-of-life care: developing conceptual clarity

Libby Sallnow^{a,b*} and Sally Paul^{b,c}

Critical Public Health, 2015

Vol. 25, No. 2, 231–238, [http](#)



Research studies

- Narrative exploration of experiences in community practice (hidden publics)
- Case studies of services implementing a health promoting approaches
- Action research studies
- Social network analysis

Systematic Review

Sallnow, Richardson, Murray, Kellehear (2015)

The impact of a new public health approach to end of life care

- Three themes from meta-ethnography
 - Making a practical difference
 - Individual learning and personal growth
 - Developing community capacity
- Quantitative results mapped to ME
 - Decreased fatigue and isolation for carers, increased size of networks and influence over place of death, involvement of EOLC services

Theme 1: Making a practical difference

- Meeting basic needs
- Education
- Tackling social isolation
- Relationship with mainstream services

Theme 2: individual learning and personal growth

- Knowledge, skills and attitudes to death and dying
- Personal reflection and confidence

Theme 3: Developing community capacity

- Changes in social capital
- Influencing professional practice
- Developing community activists
- Embedding sustainable change

The gap: impact analysis

How do themes 1 & 2 contribute to theme 3?

- Record process and outcomes of activities
- Ask permissions for follow-up
- Recruit researchers (volunteers, students)
- Partner with research teams

Towards a new way forward

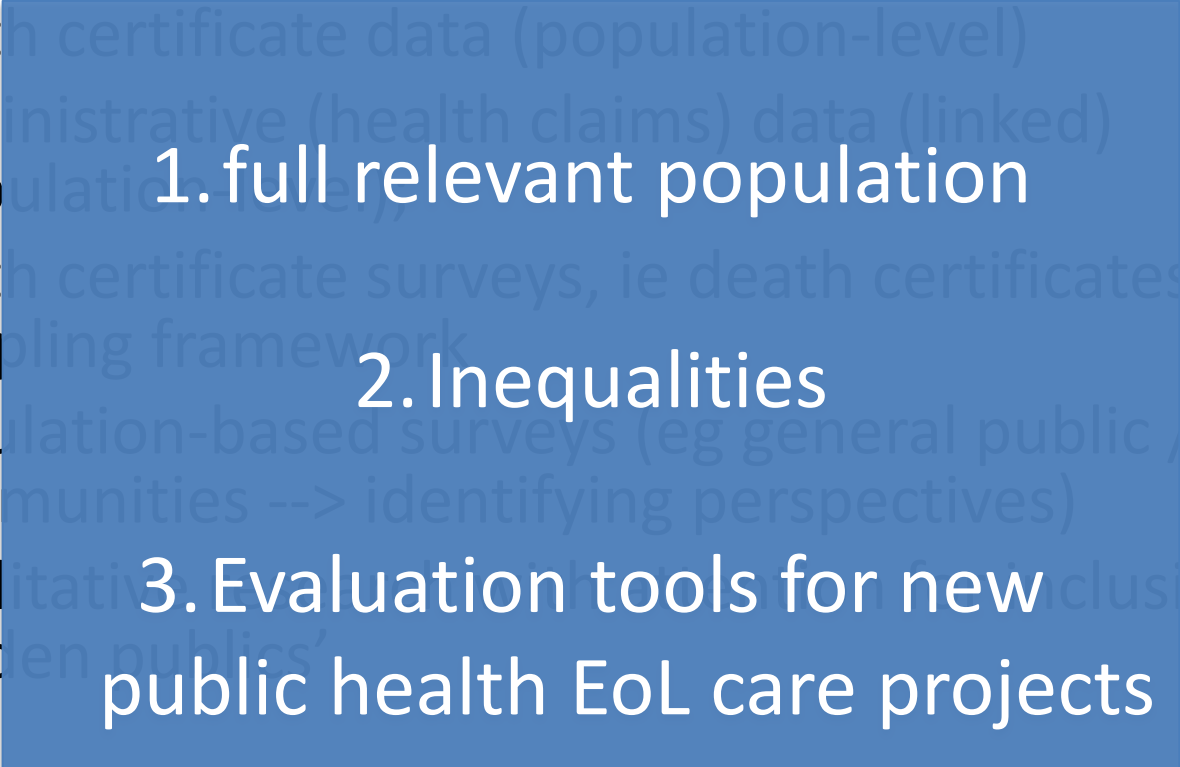
- New questions are being asked of palliative care and related research
- Increasingly complex interventions
- Patient-centred or bedside approaches being complemented by community or population level approaches
- Innovative or mixed methods have always been important and increasingly so today
- Classical and new public health research methodologies together have much to contribute

**CLASSIC PUBLIC HEALTH
APPROACHES IN EOL CARE RESEARCH**

Public health research challenges

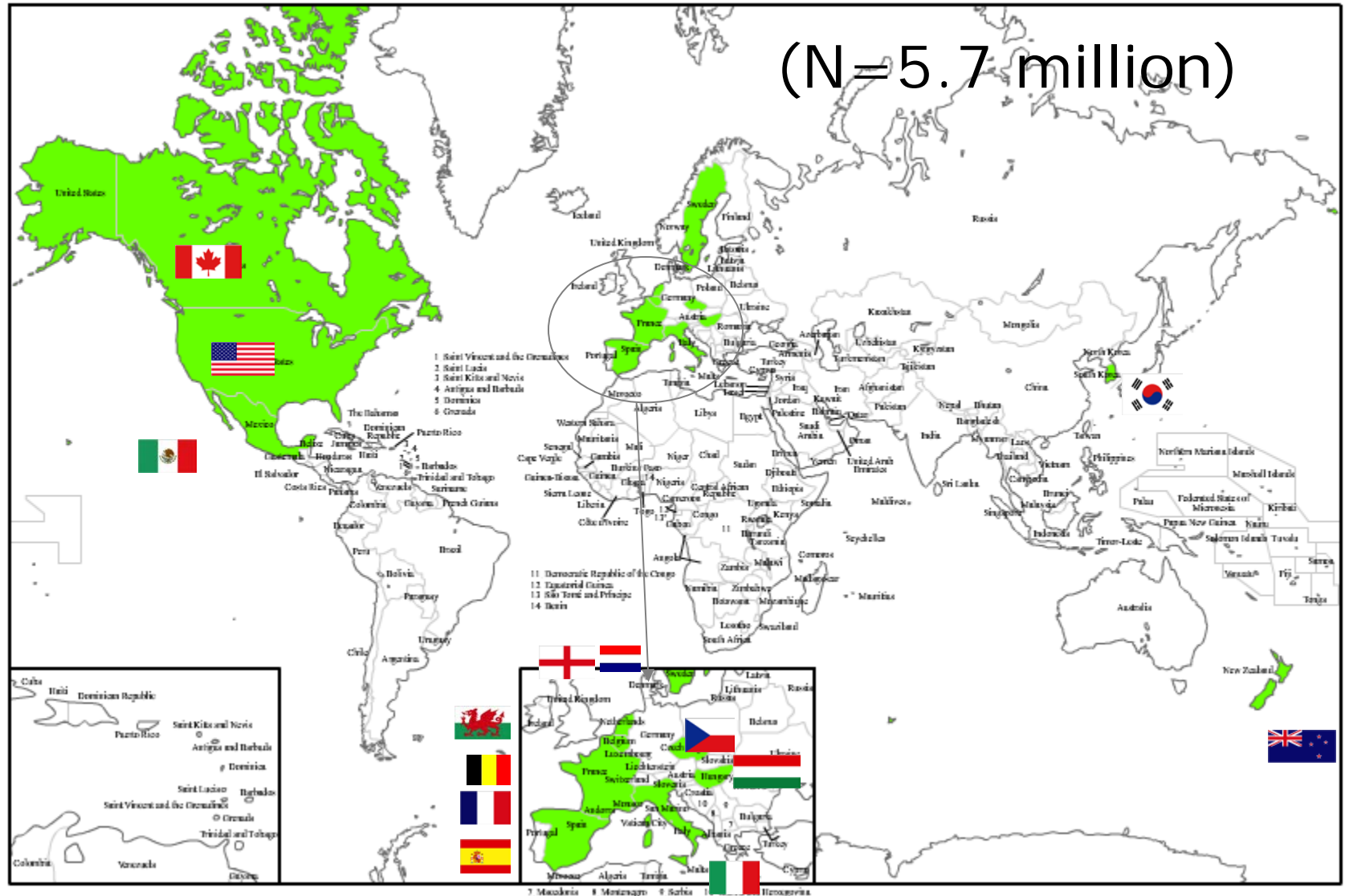
- 1) Assessment and monitoring of the health of communities and populations to identify health problems and priorities
- 2) Assure that all populations have access to appropriate and cost-effective care (incl health promotion and disease prevention services)
- 3) Public policies to solve identified local and national health problems and priorities

Different classic public health research methods can address these research challenges

1. death certificate data (population-level)
 2. administrative (health claims) data (linked) (population-level)
 3. death certificate surveys, ie death certificates as sampling framework
 4. Population-based surveys (eg general public / specific communities --> identifying perspectives)
 5. Qualitative research (eg inclusion of 'hidden publics')
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1. full relevant population
 2. Inequalities
 3. Evaluation tools for new public health EoL care projects

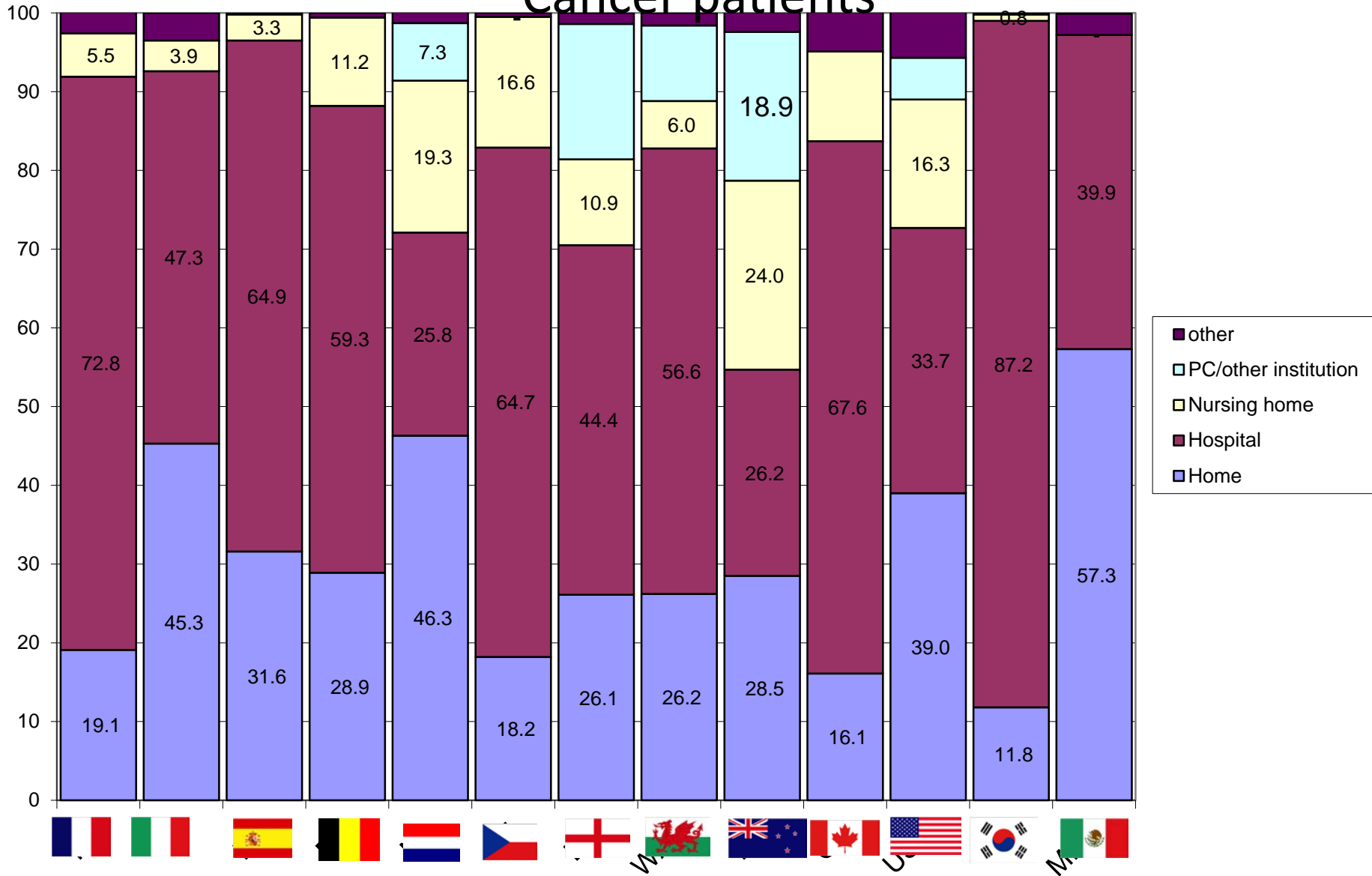
Example 1: death certificate data

International Place of Death (IPoD study)



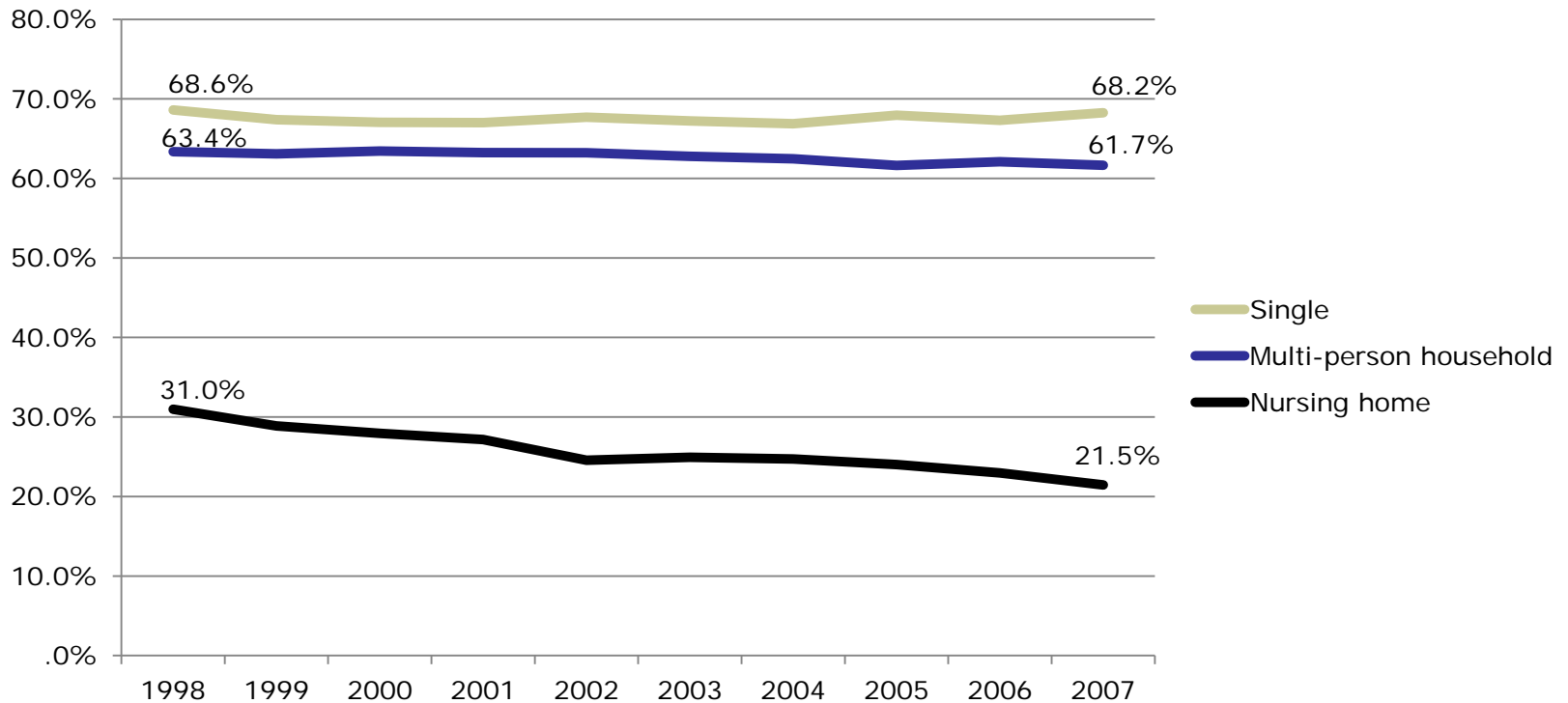
EXAMPLE 1: DEATH CERTIFICATE DATA

Cancer patients



EXAMPLE 1: DEATH CERTIFICATE DATA

- Decrease in hospital death in people living in care homes
- All deaths ≥ 65 year, Belgium (Flanders +BCR), 1998-2007





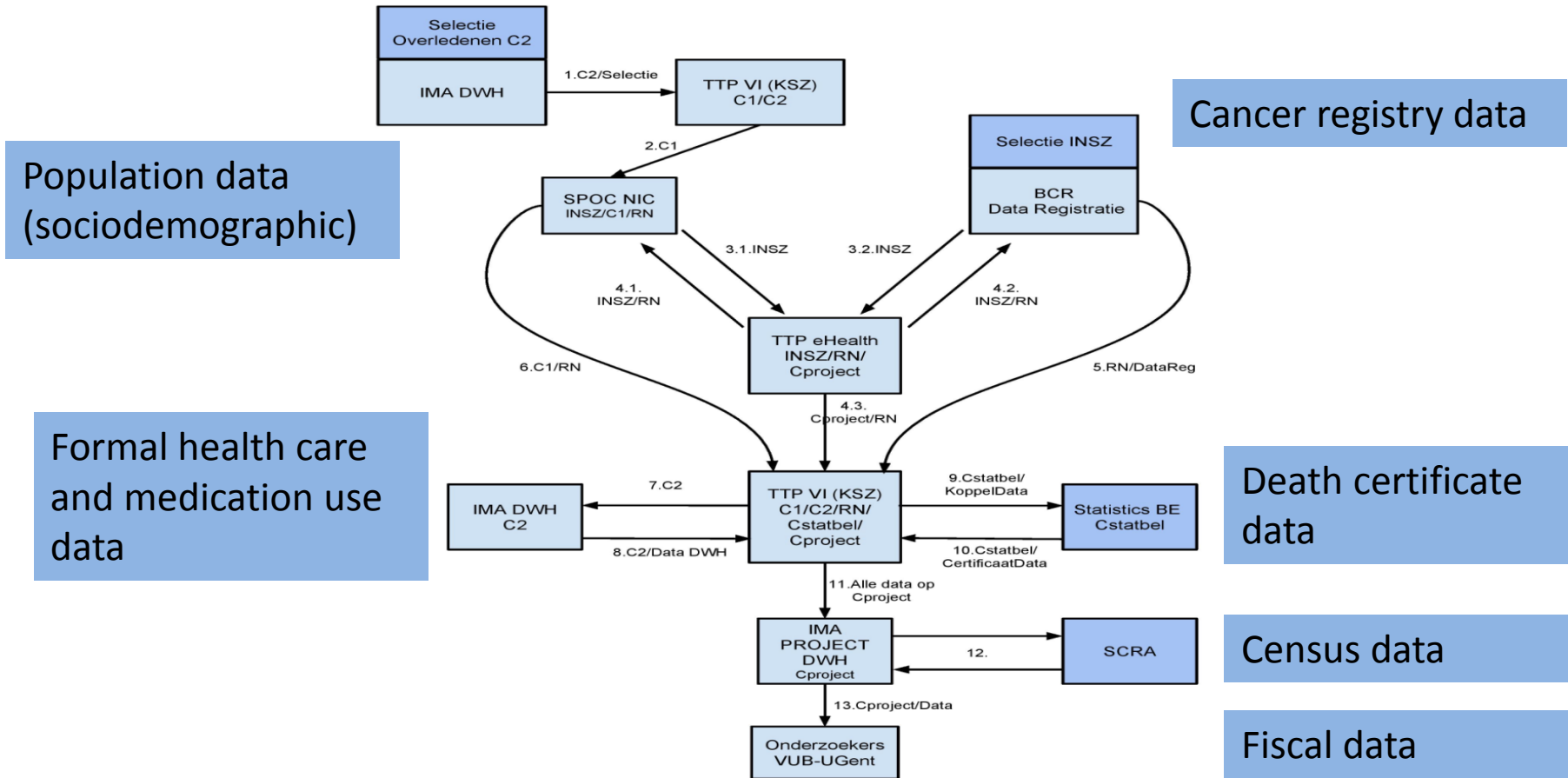
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Example 2: Linking various administrative datasets

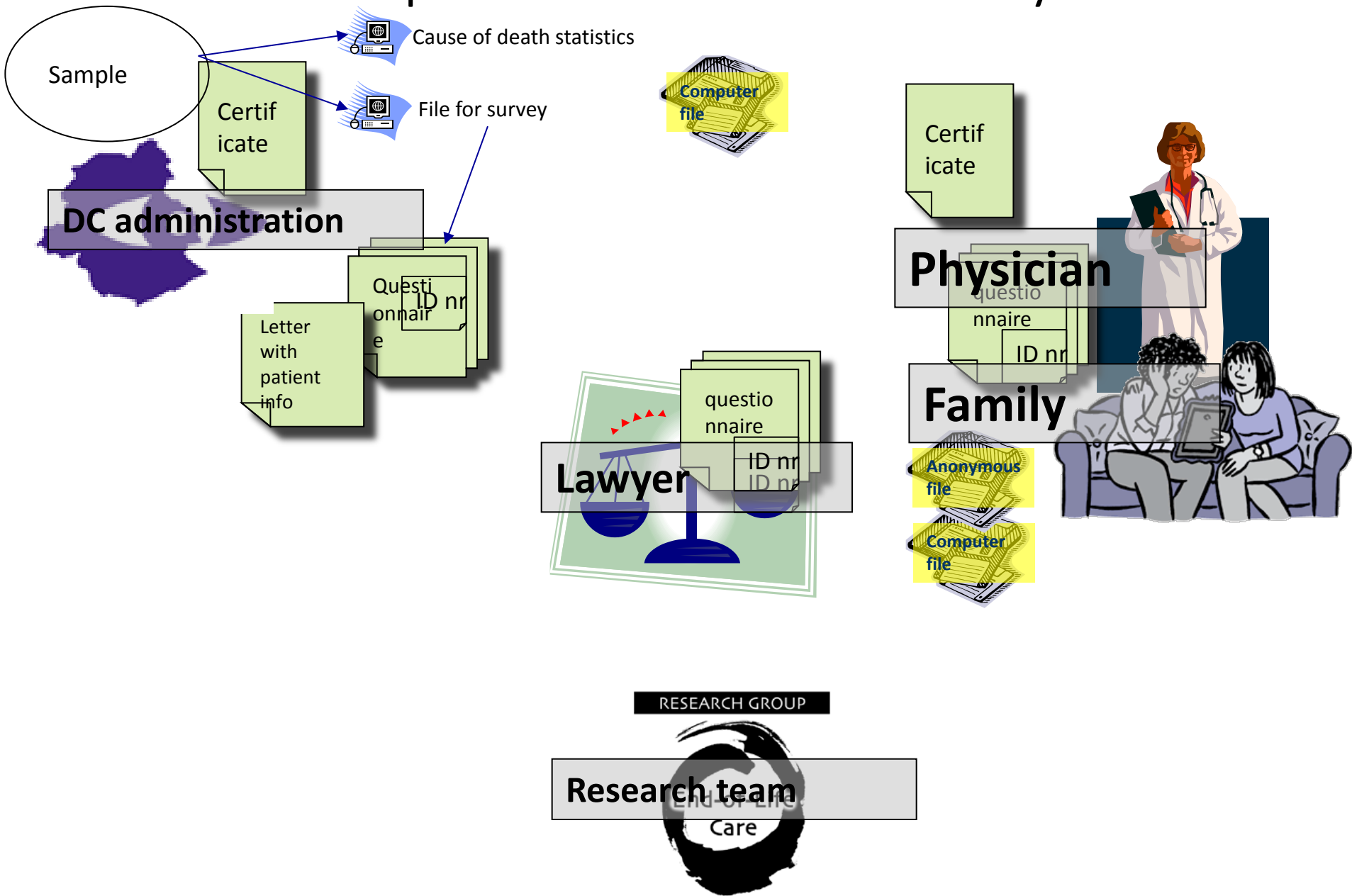
VUB - UGent
 Studie Levensinzorg
 Data Traject




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Example 3: death certificate surveys





First national VOICES survey of bereaved people: key findings report

'How people die remains in the memory of those who live on'

Dame Cicely Saunders

Founder of the Modern Hospice Movement

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Important aspects are missing in past classical public health research in EoLC

1. post-mortem/retrospective methods advantaged
2. Some 'publics' remain hidden
3. Do not capture complex interactions between community, dying person, environment and health services
4. Not aimed at community intervention?

Moving forward: combining the old and the new

NPH and CPH complementary components of the public health EoL care research agenda

Identifying relevant populations

Evaluating impacts of new public health work

Provide rigorous population-based measures reflective of NPH ideals

Include new perspectives re: health-related wellbeing and involving the community as partners

Towards collaborative partnerships

Combine and reconcile epistemological or paradigmatic differences

Enriching but challenging

DISCUSSION

Questions

- What types of knowledge/research approaches do we need to enhance public health/PC agendas?
- How do can the public be part of public health agendas in meaningful ways?
- Communities of the future: From local and geographic to global and virtual?
 - Possibilities and challenges for research?

What are the next steps in taking this agenda forward?

- Visibility?
 - E.g. Dublin EAPC research conference
 - How to reach public health forums and agencies?
- Collaboration?
 - International Association for Public Health and Palliative Care
 - Research forum? Coordination
- Exchanging knowledge and experience?
 - Publication
 - Funding difficulties

Thank you

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