Understanding equity and inequity at the end of life

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THE UNIVERSAL DE
OF Human

PUBLIC HEALTH FACT SHEET

Palliative Care as a Human Right

Palliative care is the holistic management of physical, psychological, legal, and spiritual probl
faced by patients with life-threatening illness and by their families. Palliative care can be deliv
in a variety of settings, including hospitals, outpatient clinics, residential hospices, nursing ho
community health centers, and at home. It is fundamental to health and human dignity and
basic human right. It can and should be provided alongside curative treatment that begins a
time of diagnosis.

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Special Article

Palliative Care as an International Human Right

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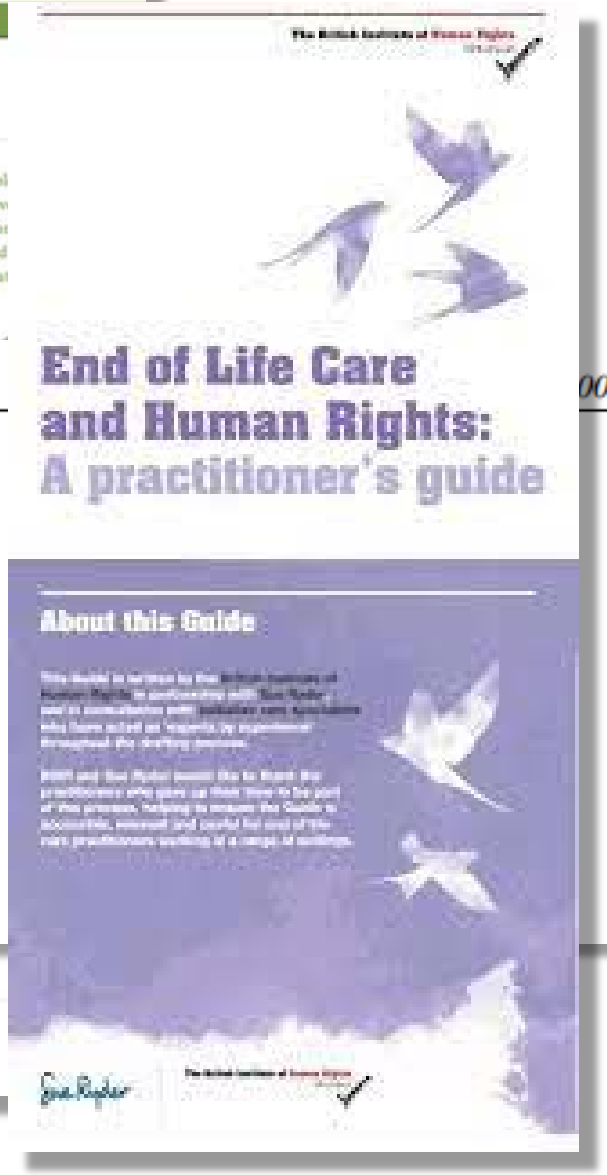
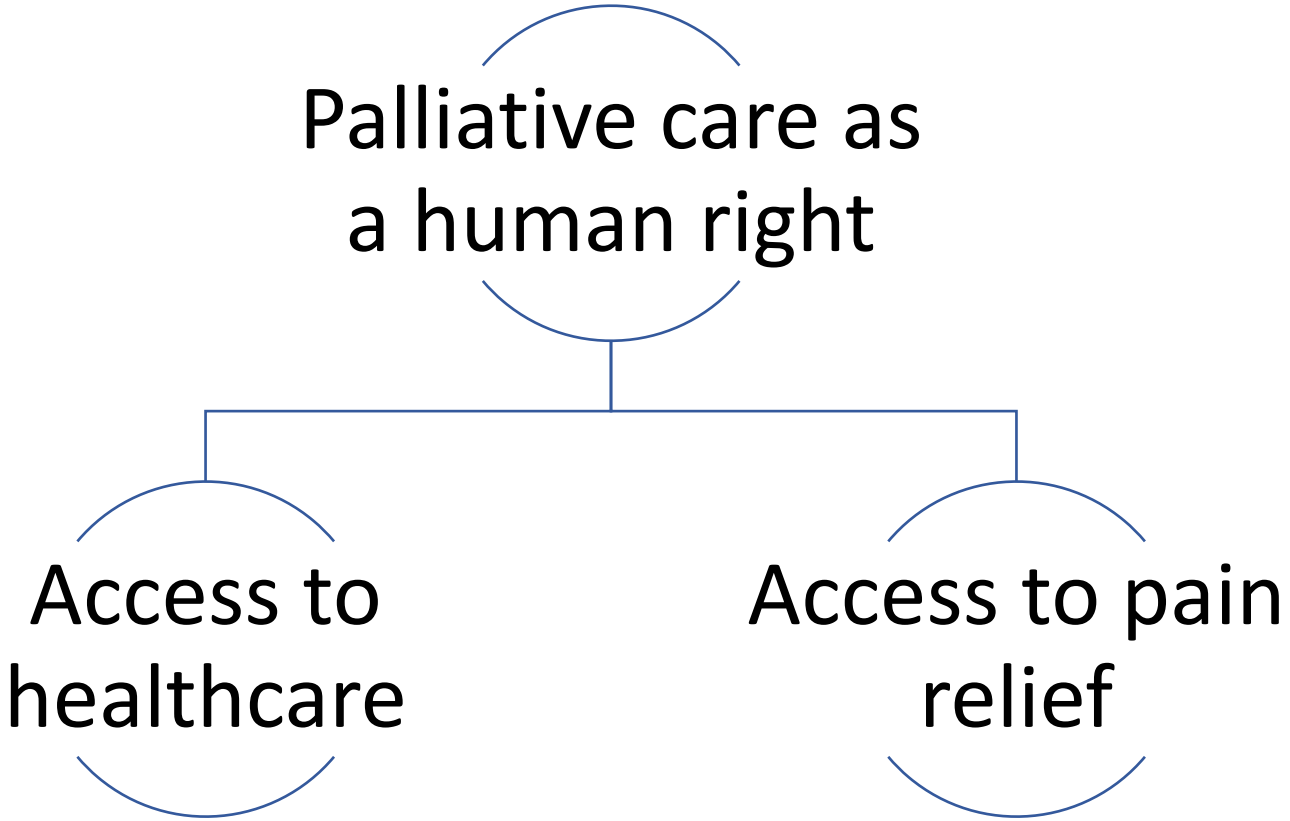



Palliative care as a human right
Access to healthcare
Access to pain relief

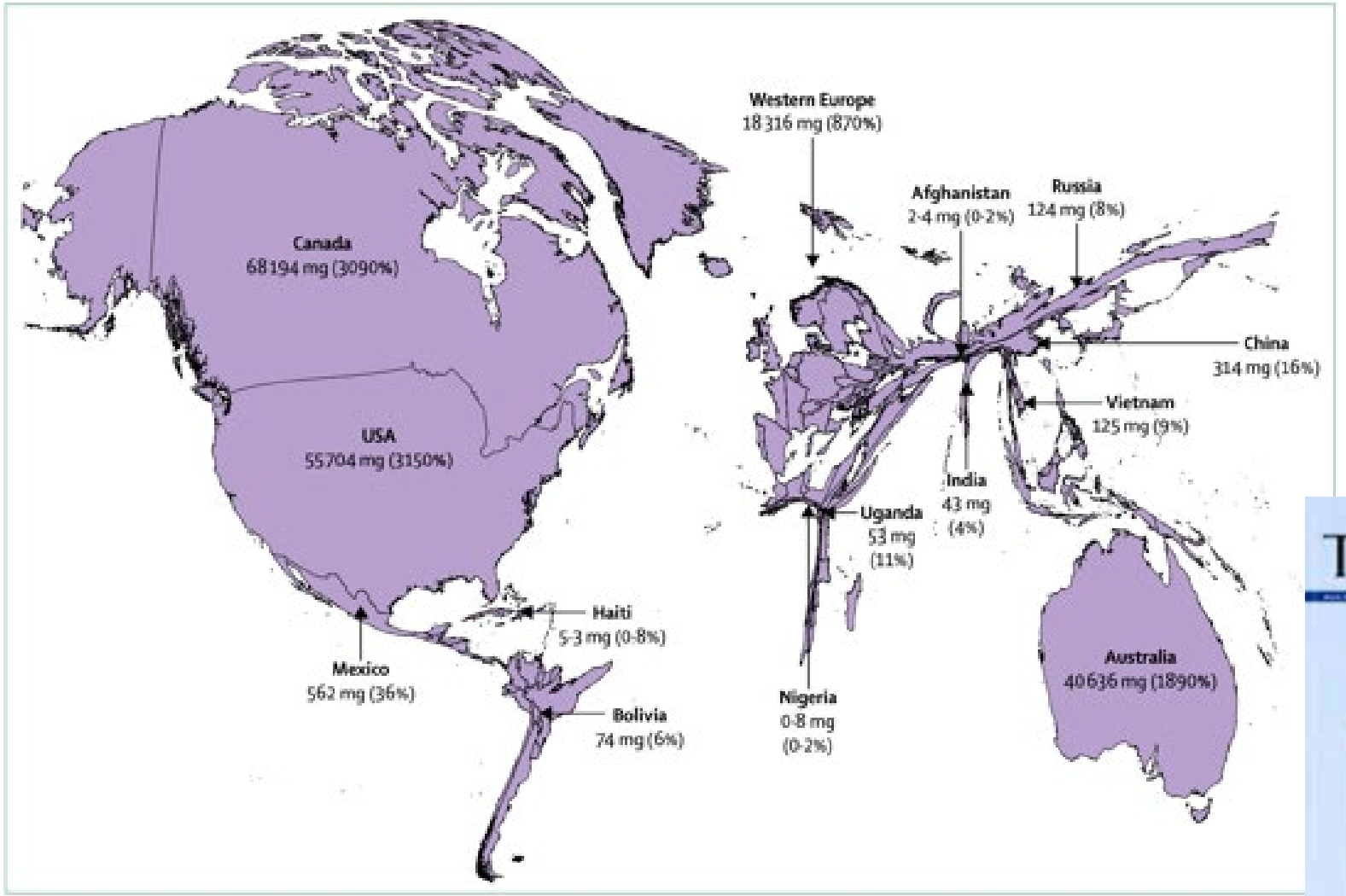
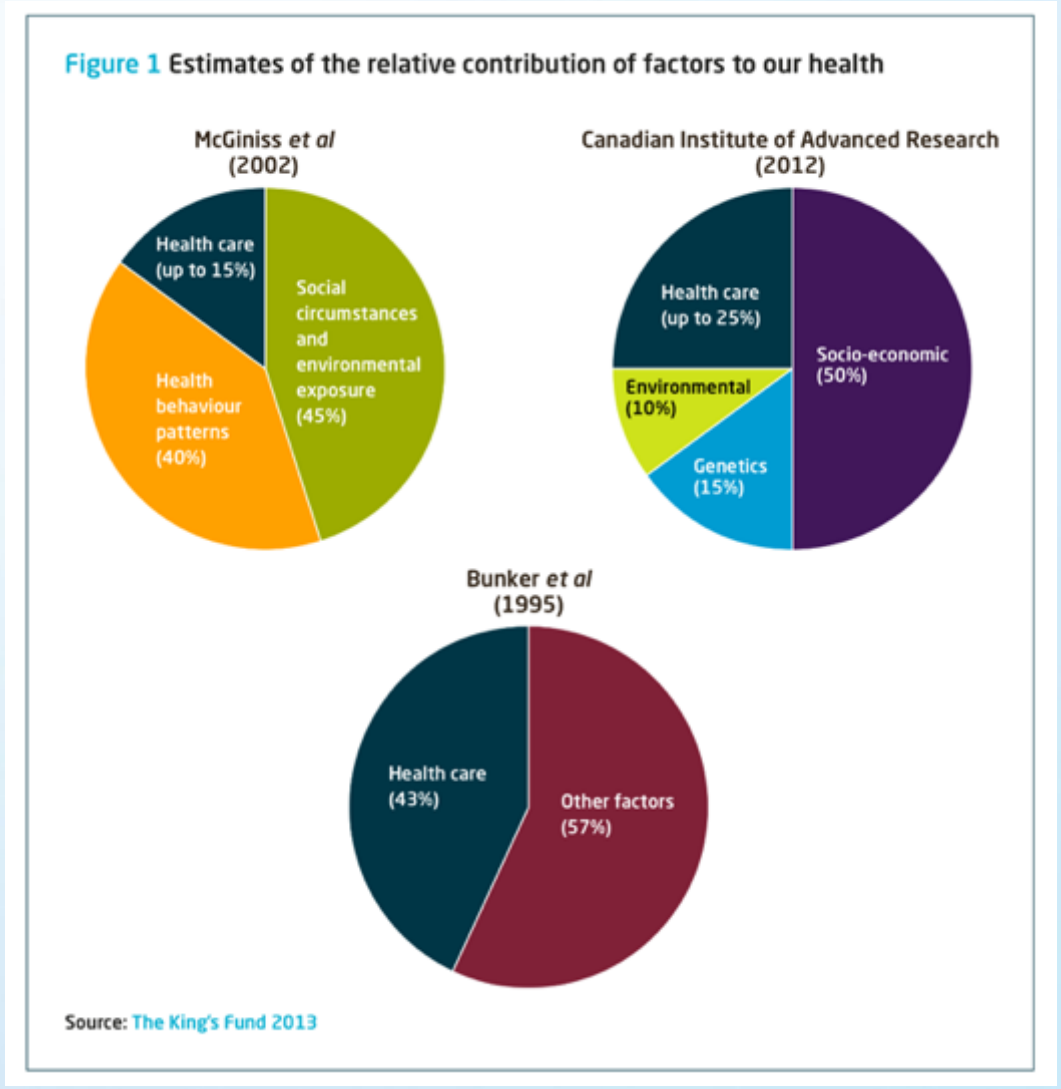


Figure 1: **Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of nee that is met for the health conditions most associated with serious health-related suffering**

Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. See additional online material for methods.

But ‘health’ is determined by more than access to healthcare services



Health services contribute only 15-25% health outcomes

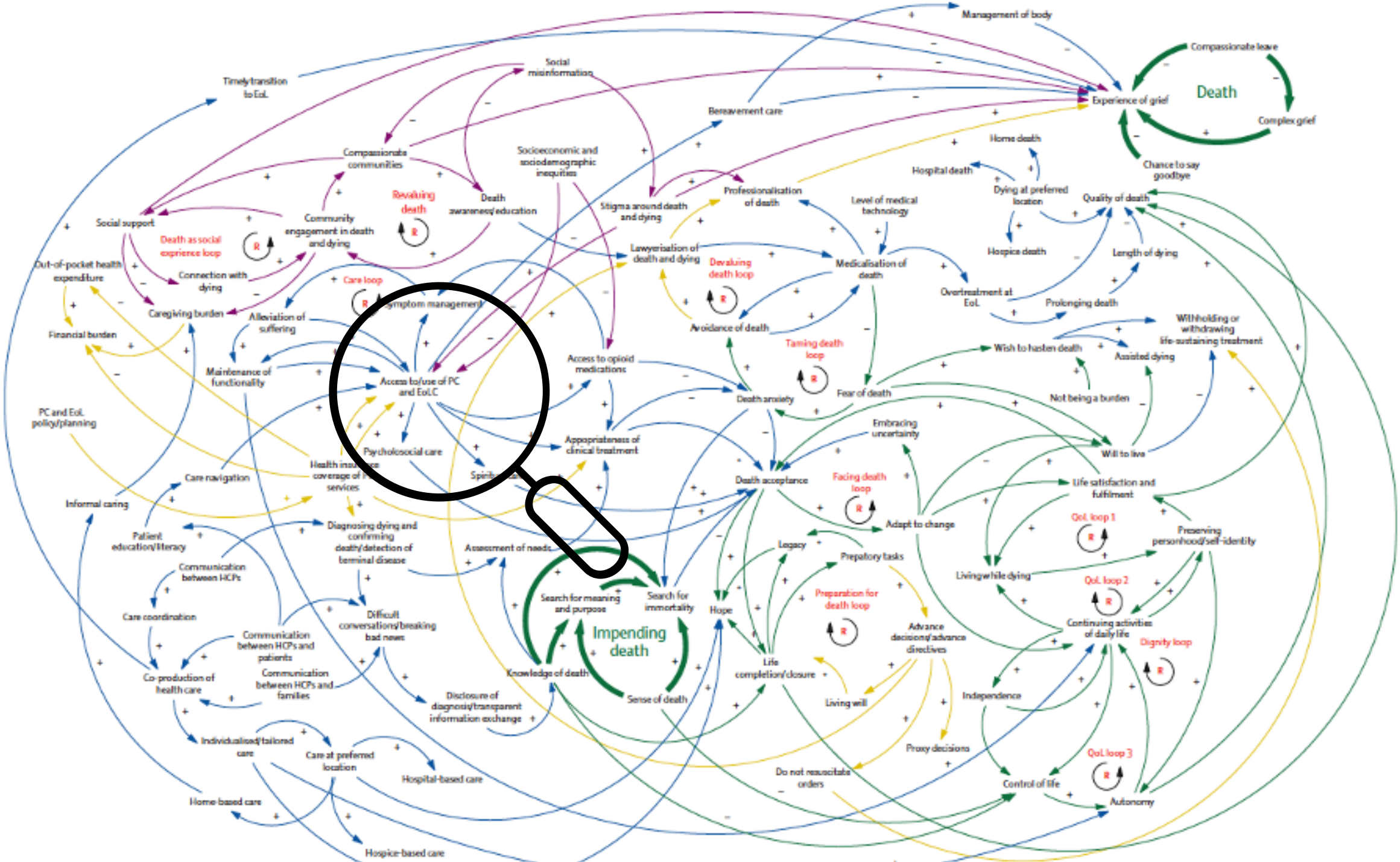
The social and structural determinants of health

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

The social and structural determinants of **dying**?

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

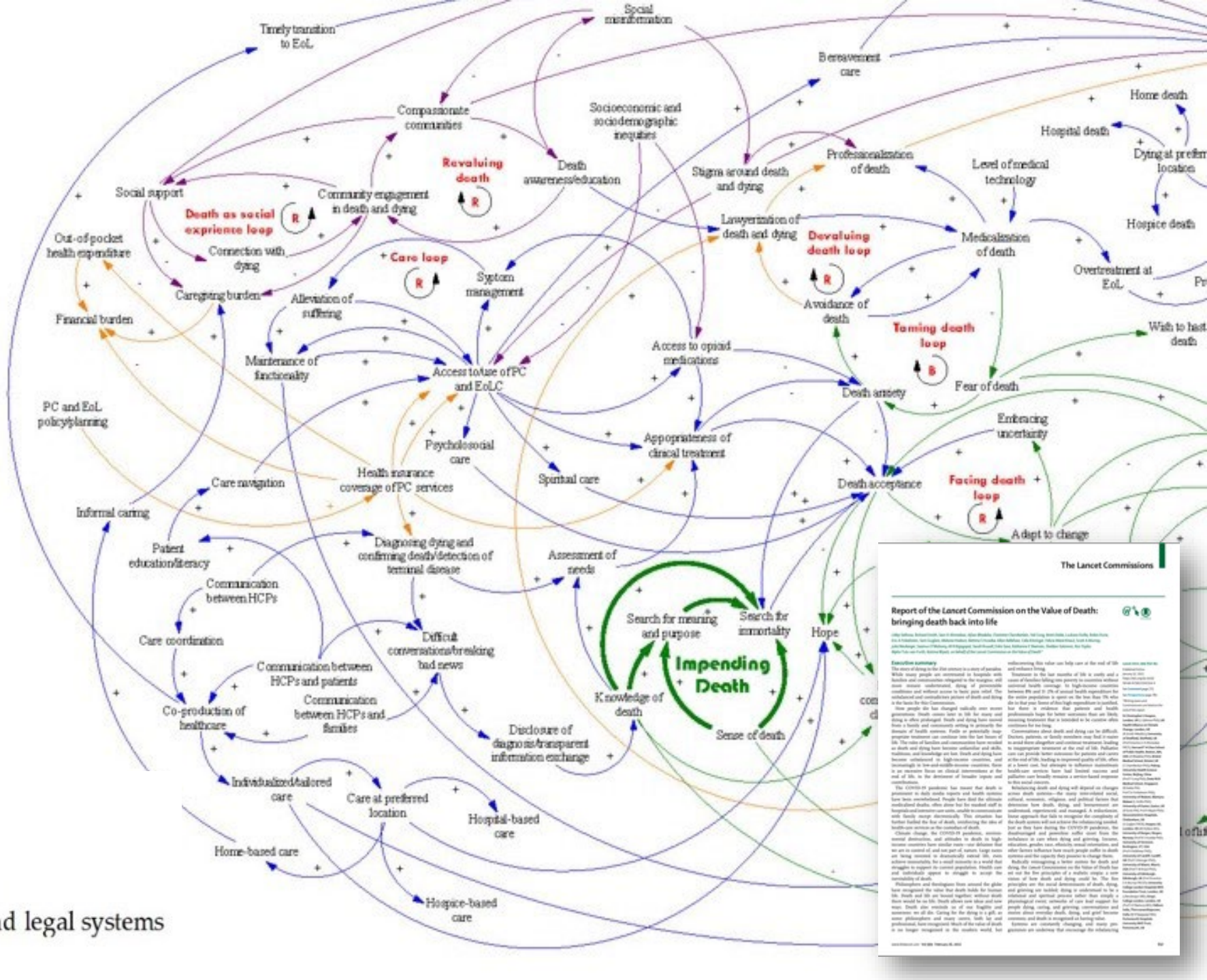
Symptom management
Access to/use of PC and EoLC
Psychosocial care
Spiritual care
Health insurance coverage of PC services


Management of body
Timely transition to EoL
Social misinformation
Compassionate leave
Death
Experience of grief
Complex grief
Bereavement care
Compassionate communities
Socioeconomic and sociodemographic inequities
Home death
Hospital death
Dying at preferred location
Chance to say goodbye
Social support
Revaluing death
Death awareness/education
Stigma around death and dying
Professionalisation of death
Level of medical technology
Quality of death
Community engagement in death and dying
Death as social exprience loop
Lawyerisation of death and dying
Devaluing death loop
Medicalisation of death
Hospice death
Length of dying
Out-of-pocket health expenditure
Connection with dying
Care loop
Symptom management
Overtreatment at EoL
Prolonging death
Caregiving burden
Alleviation of suffering
Avoidance of death
Financial burden
Taming death loop
Withholding or withdrawing life-sustaining treatment
Wish to hasten death
Assisted dying
Access to opioid medications
Maintenance of functionality
Access to/use of PC and EoLC
Death anxiety
Fear of death
Not being a burden
PC and EoL policy/planning
Embracing uncertainty
Will to live
Psychosocial care
Appropriateness of clinical treatment
Health insurance coverage of services
Death acceptance
Facing death loop
Life satisfaction and fulfilment
Care navigation
Informal caring
Adapt to change
QoL loop 1
Preserving personhood/self-identity
Patient education/literacy
Diagnosing dying and confirming death/detection of terminal disease
Assessment of needs
Legacy
Preparatory tasks
Living while dying
Communication between HCPs
Search for meaning and purpose
Search for immortality
Hope
QoL loop 2
Care coordination
Difficult conversations/breaking bad news
Impending death
Preparation for death loop
Advance decisions/advance directives
Continuing activities of daily life
Communication between HCPs and patients
Knowledge of death
Life completion/closure
Dignity loop
Co-production of health care
Communication between HCPs and families
Disclosure of diagnosis/transparent information exchange
Sense of death
Living will
Independence
Individualised/tailored care
Care at preferred location
Proxy decisions
Hospital-based care
Do not resuscitate orders
QoL loop 3
Control of life
Home-based care
Autonomy
Hospice-based care

Death, dying and grieving systems:

"the many inter-related social, cultural, economic, religious, and political factors that determine how death, dying, and bereavement are understood, experienced, and managed."

The Lancet Commission on the Value of Death (2022)



Legend

- Human system
- Health system
- Sociocultural system
- Political, economic, and legal systems

Social and structural determinants in my practice

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care? For if we are focusing on the comfort of a patient with a life-limiting illness, surely that must include water, food, a habitable environment, warmth, bedding, and sanitation as much as symptom control. Indeed, it would be artificial to separate a "right to palliative care" from a general right to health, housing, water, and sanitation. All are interconnected. All determine good health, even and including at the end of life. That interconnectedness was made expressly by the General Comment on the Right to Health.[24]

A human rights based approach

A means for promoting and protecting human rights

Recognises a system of ‘rights holders’ and ‘duty bearers’

Makes explicit power and discriminatory practices

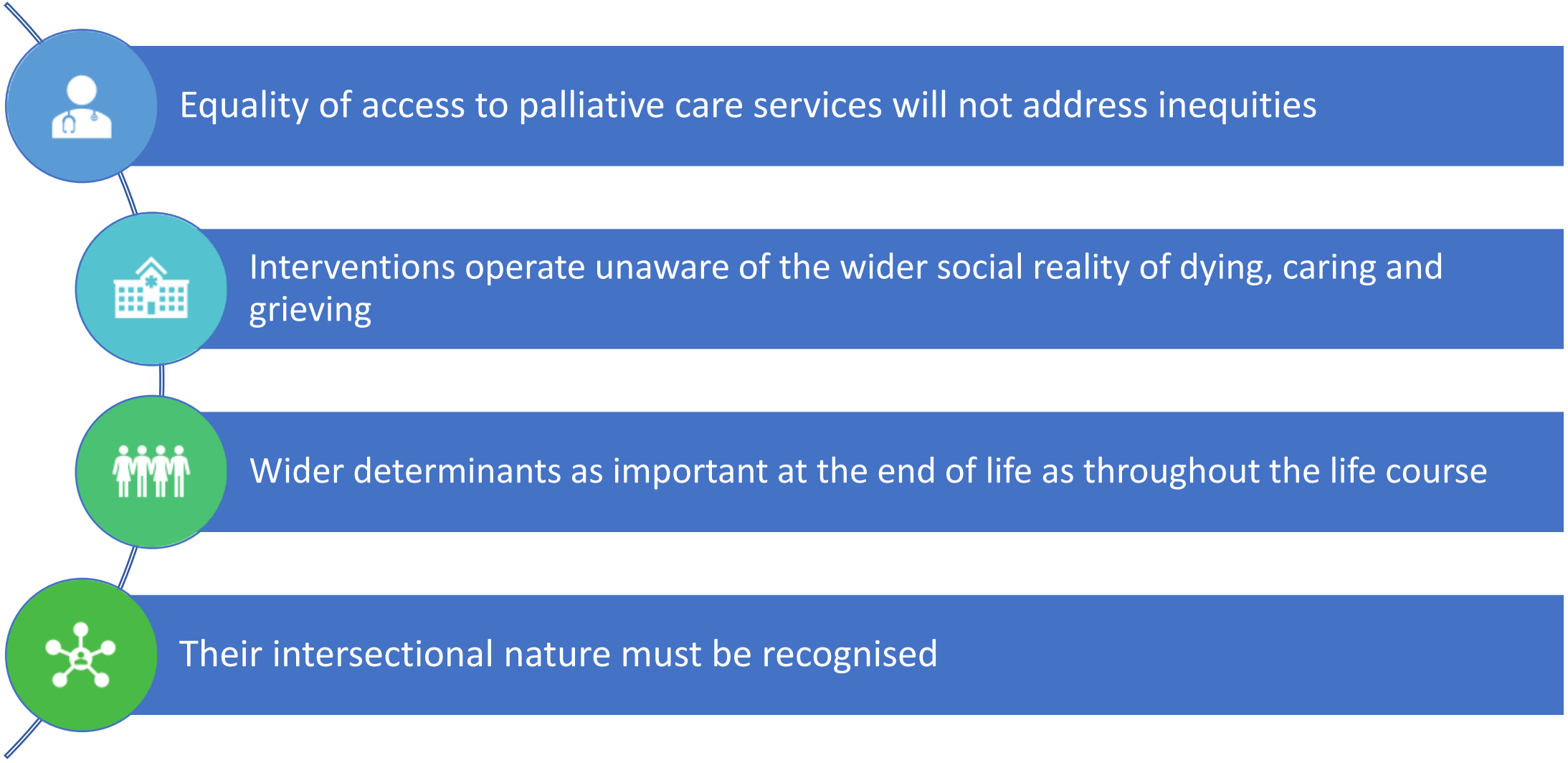
Based on core principles:

- Universality
- Accountability
- Participation
- Indivisibility & interdependence
- Equality and non-discrimination

Principles of compassionate communities and new public health approaches

- Participatory
- Look beyond biomedical perspectives
- Beyond the absence of symptoms
- Focus on social justice, social change and equity
- Beyond patient or family focus and beyond ‘choice’
- Palliative care services are essential but only one part
- Partnerships between professionals and communities
- Recognise death, dying and grieving as universal, social issues
- Take a whole systems approach

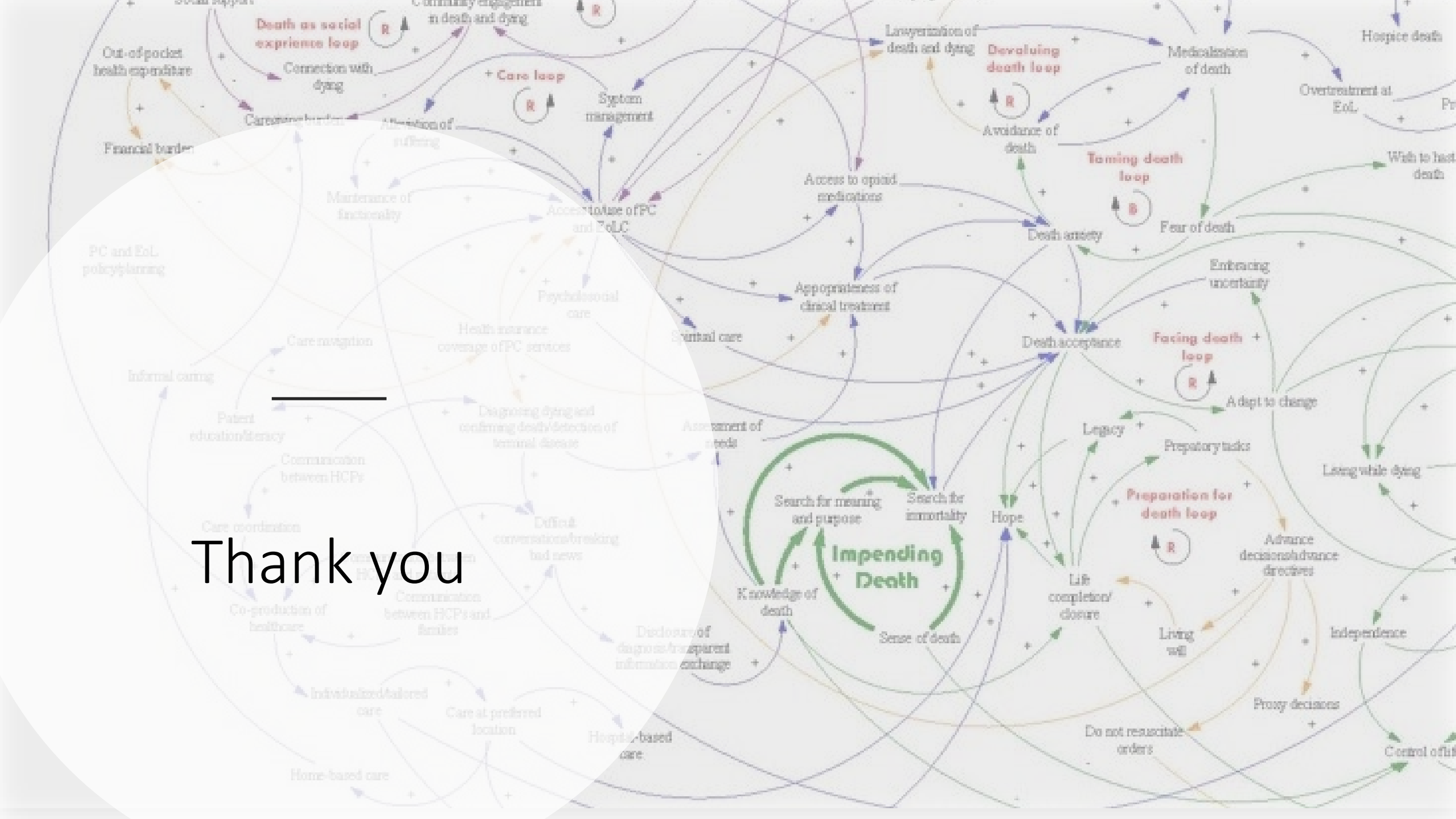
Returning to equity



Our actions

1) How holistic is our lens?
2) Recognise the limitations of a service-focus for dying, caring and grieving
3) Partner with communities, community groups, people with lived experience
4) Link with other sectors beyond palliative care
5) Integrate a human rights based approach into care when dying, caring and grieving

Examples of this approach in practice will be described in detail over the next two days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Thank you