HOSPIS MALAYSIA 30 years

ADVANCING EQUITY IN ACCESS TO PALLIATIVE CARE

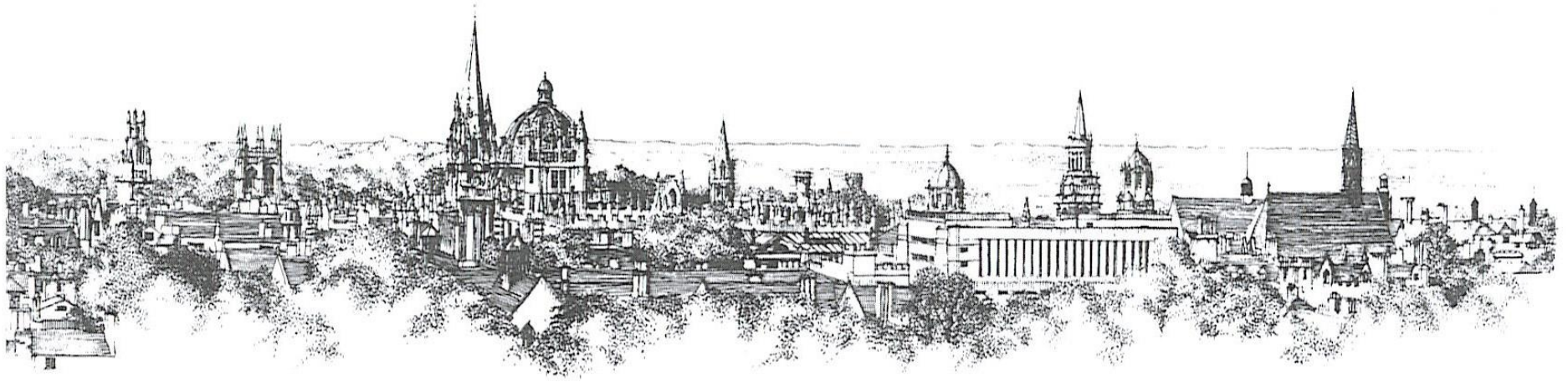
LIVE WEBINAR

PALLIATIVE CARE IN A PUBLIC HEALTH CRISIS

5 OCTOBER 2021 (5.00PM MYT)

GUEST SPEAKER: PROF. BEE WEE, CBE

National Clinical Director for End of Life Care, NHS England and NHS Improvement, UK



Palliative Care in a Public Health Crisis

Prof Bee Wee CBE
Consultant in Palliative Medicine, Oxford University
National Clinical Director for Palliative and End of Life Care, NHS England and NHS Improvement

Plan

- Concept of a public health approach to palliative care
- COVID-19 pandemic
- Palliative care in a public health crisis: UK experience
- Experience from other countries
- Learning and consequences
- Wider implications for palliative care policy and practice

Public health strategy for palliative care

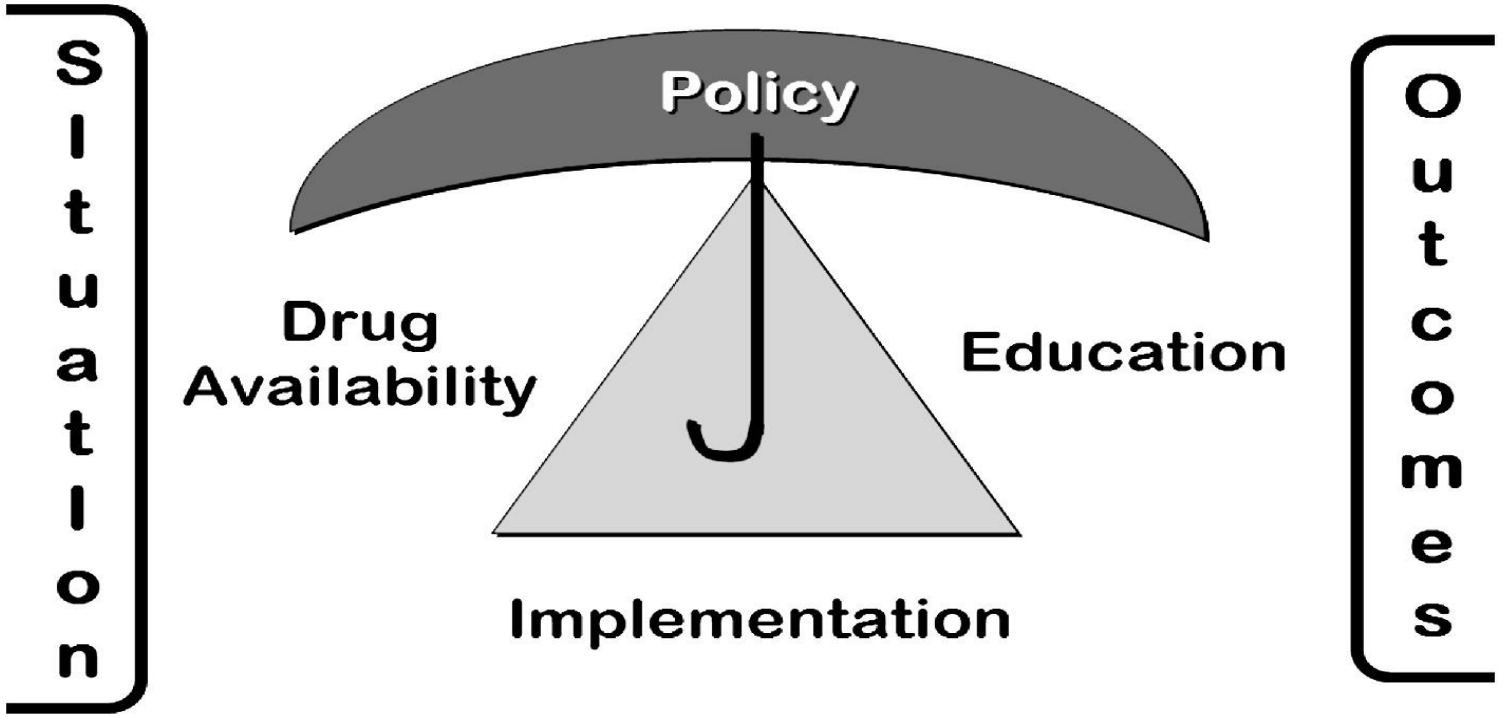
"….offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population…..

"For PHS to be effective, they must be incorporated by governments and owned by the community"

"This strategy will be most effective if it involved the society through collective and social action"

Source: Stjernsward J, Foley KM, Ferris FD, JPSM 2007

Public health strategy for palliative care



Source: Stjernsward J, Foley KM, Ferris FD, JPSM 2007

WHO approach

Policy

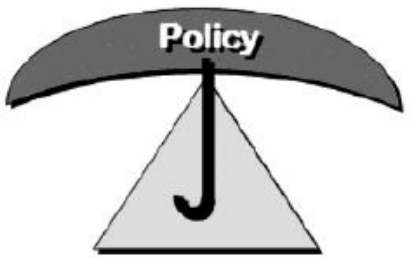
- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
- Essential medicines

(Policy makers, regulators, WHO, NGOs)

Drug Availability

- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration

(Pharmacists, drug regulators, law enforcement agents)



Implementation

- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures

(Community & clinical leaders, administrators)

Education

- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support

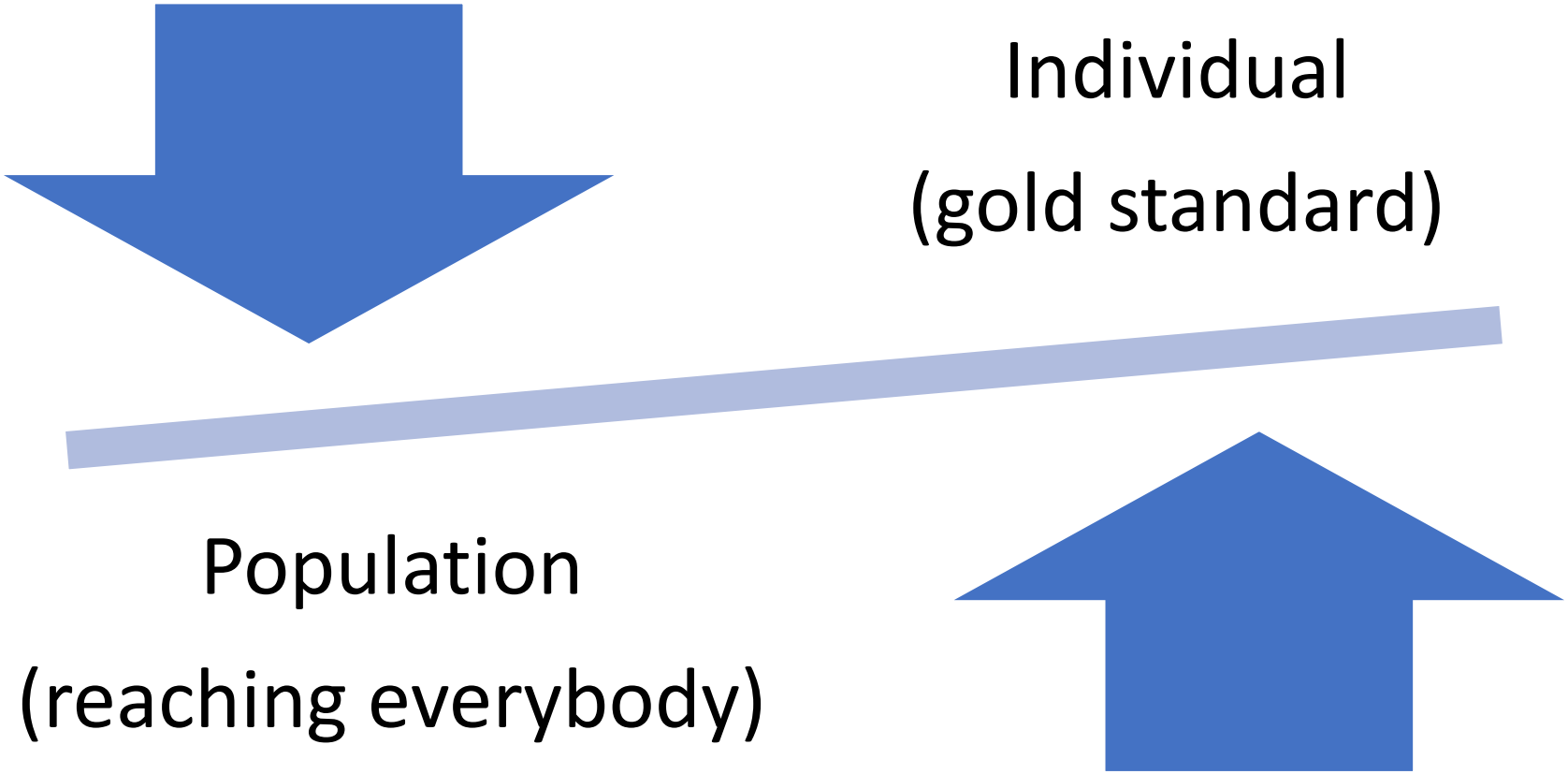
(Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Health Promotion approach

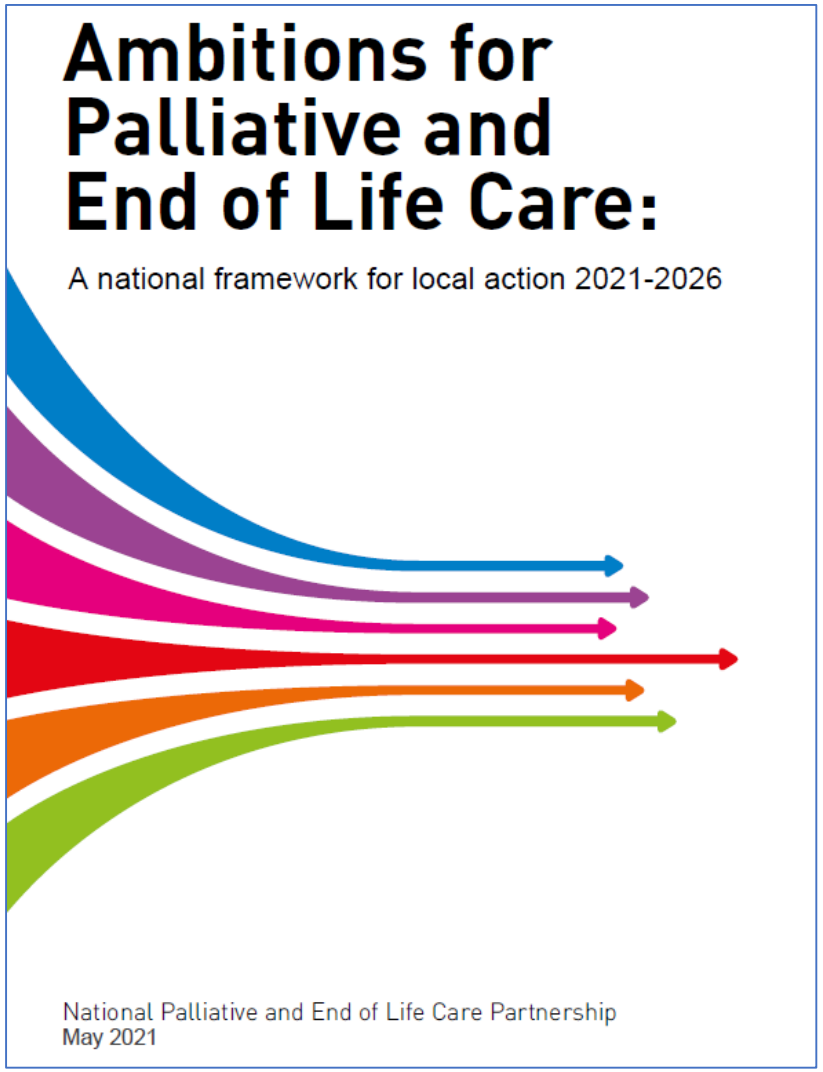
Social empowerment through:

- Compassionate communities
- Community assets
- Volunteer mobilisation
- Influencing society’s perceptions
- Public awareness and education

Population based approach



An integrated approach



Six ambitions to bring that vision about

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

06

Each community is prepared to help

The building blocks for achieving our ambition

Compassionate and resilient communities

Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.

Public awareness

Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.

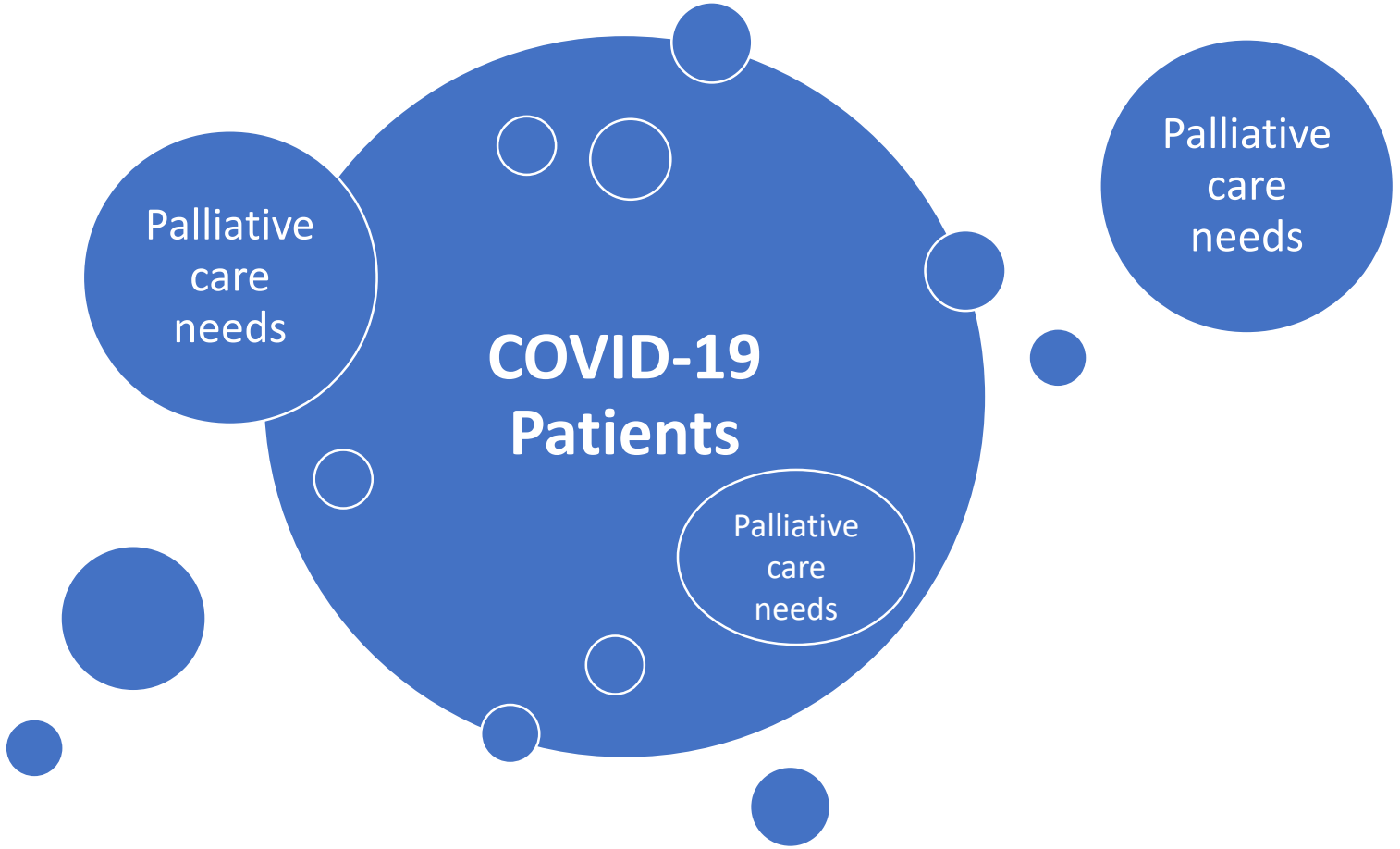
Practical support

Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.

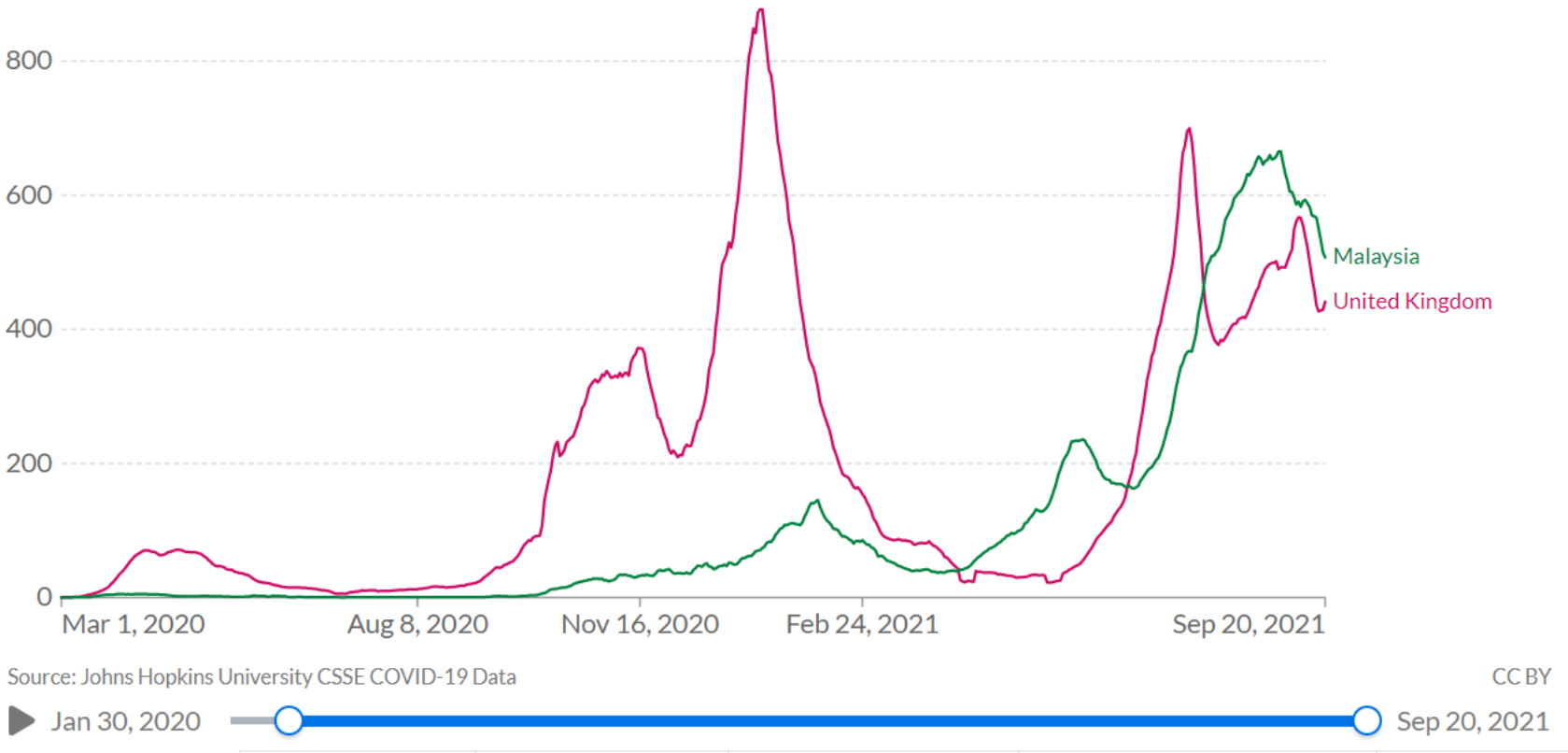
Volunteers

To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.

COVID-19 Pandemic: Public health crisis

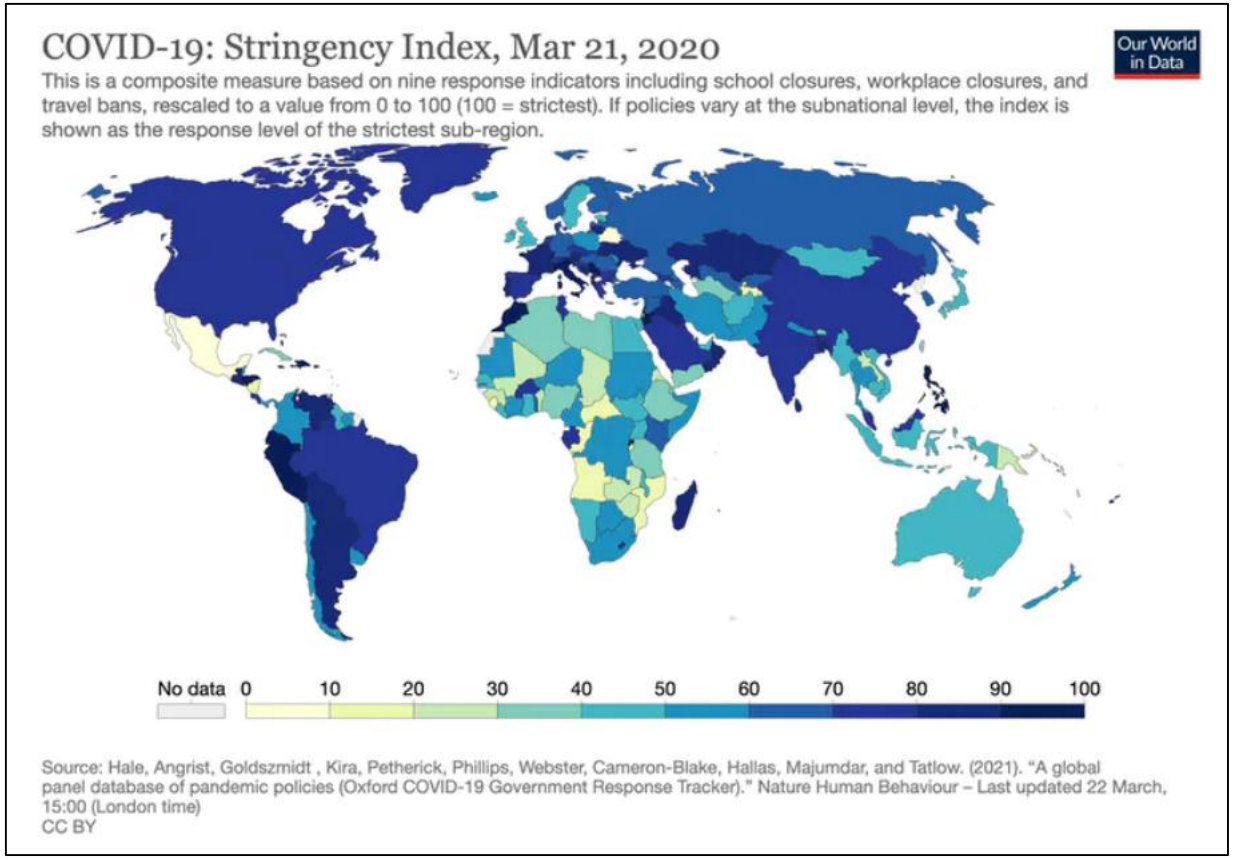


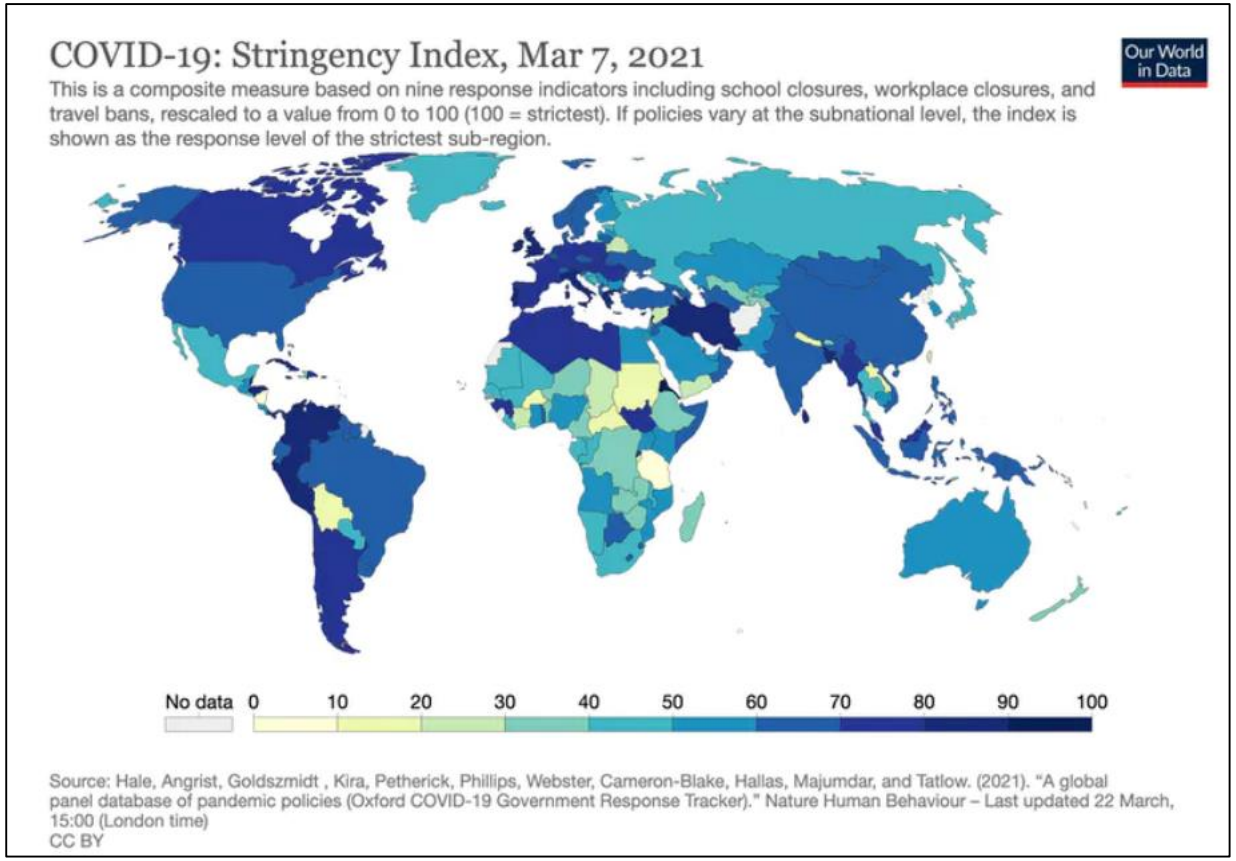
Daily new confirmed COVID-19 cases per million people



Source: https://ourworldindata.org/covid-deaths

Oxford COVID-19 Government Response Tracker





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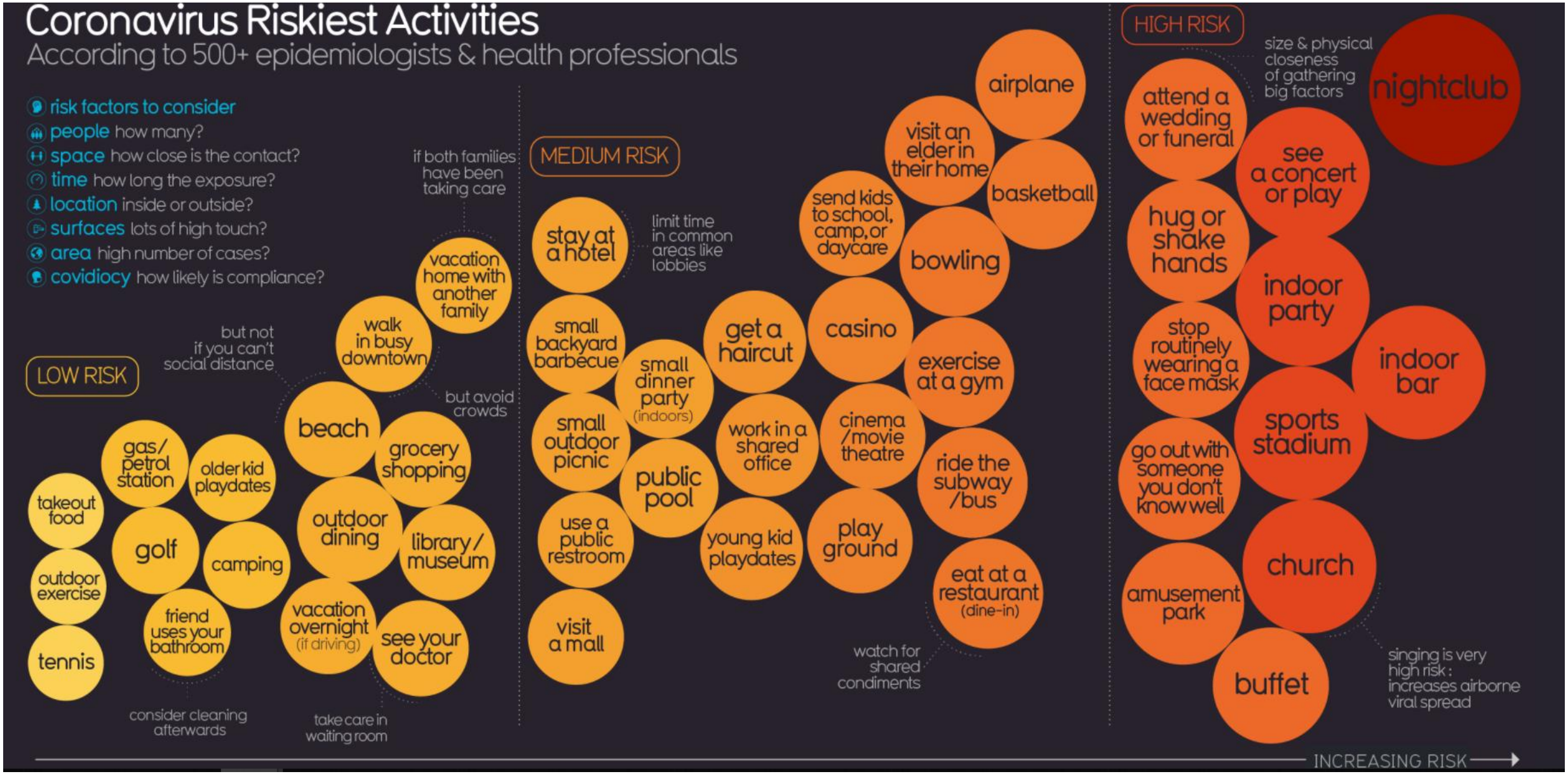
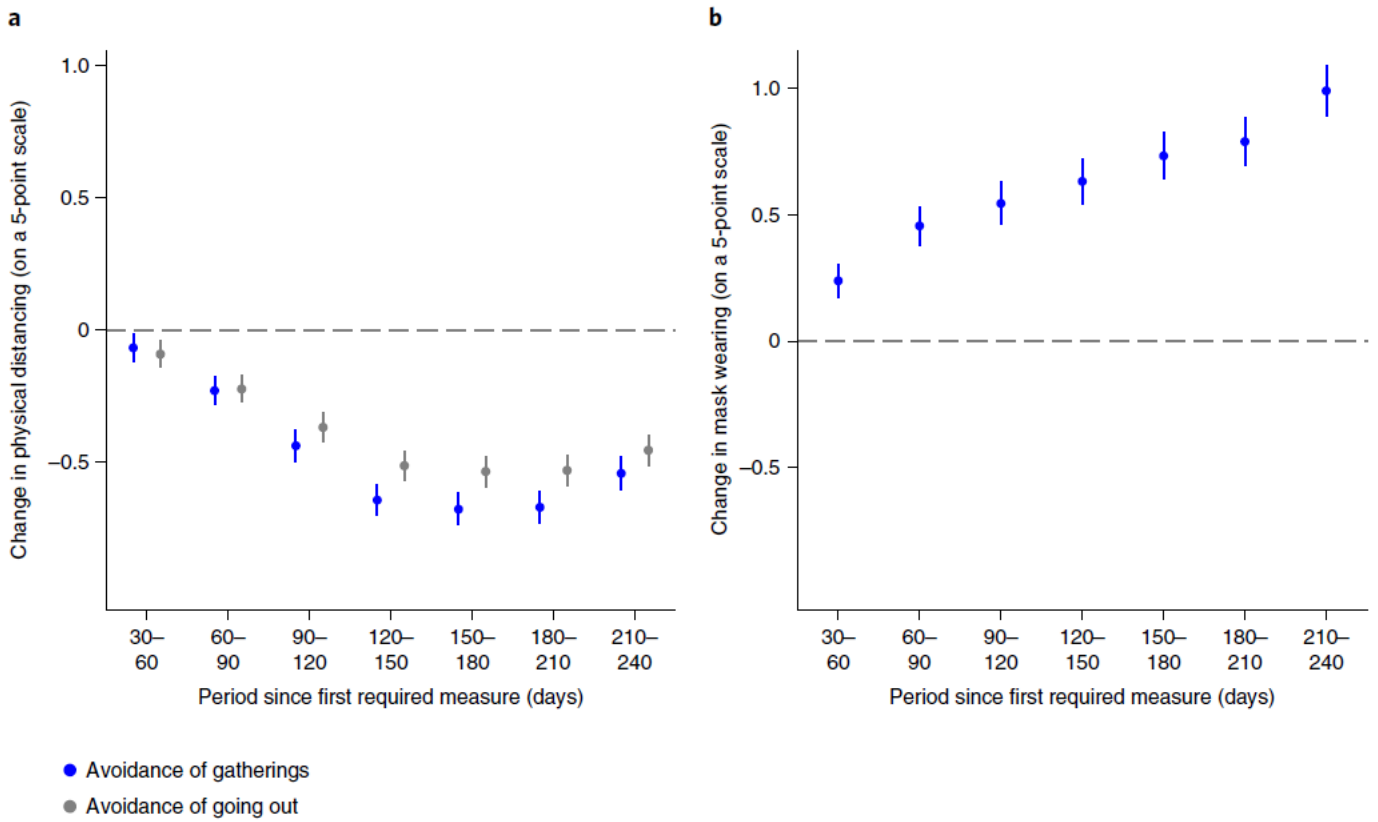


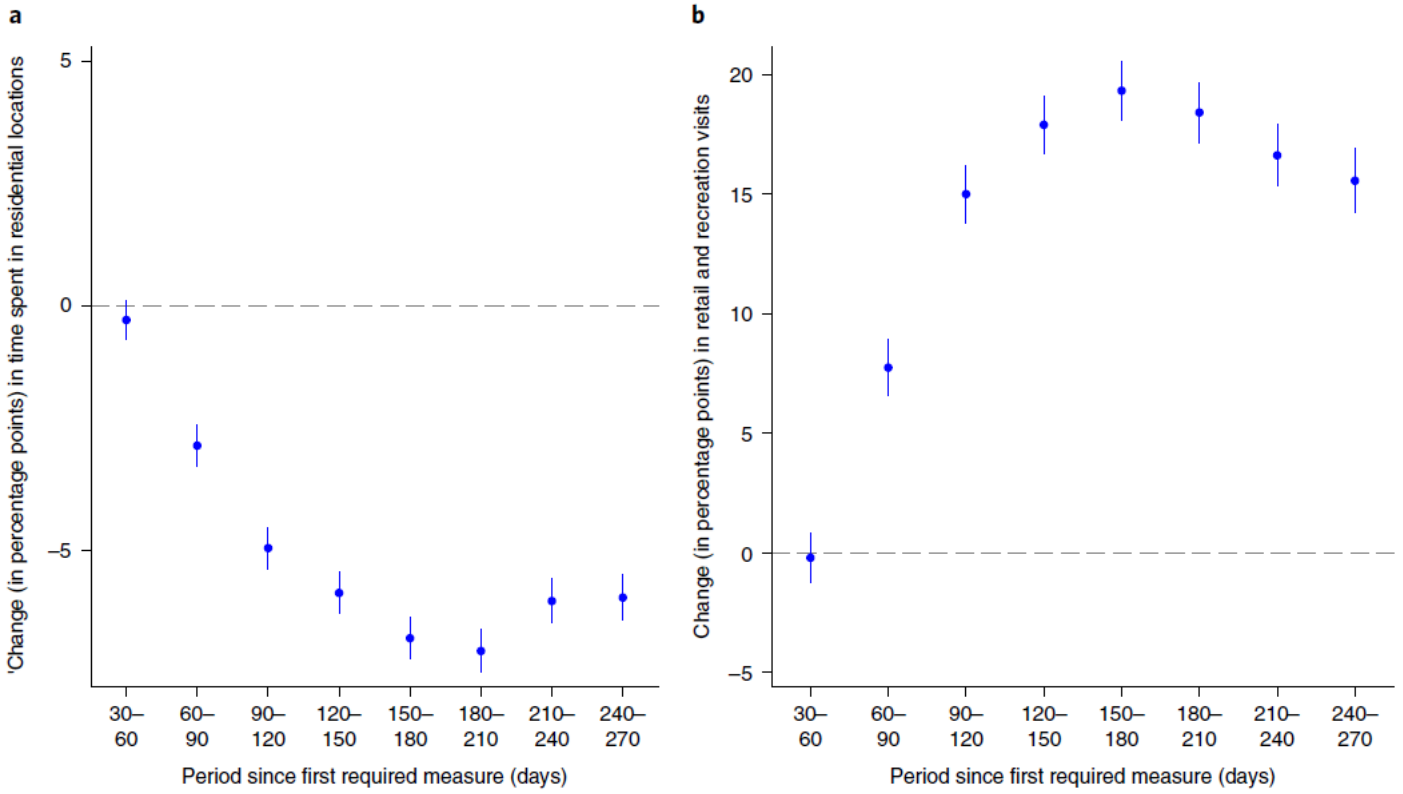
Source: Informationisbeautiful.net

Adherence to high-cost, sensitising vs low-cost habituating behaviours



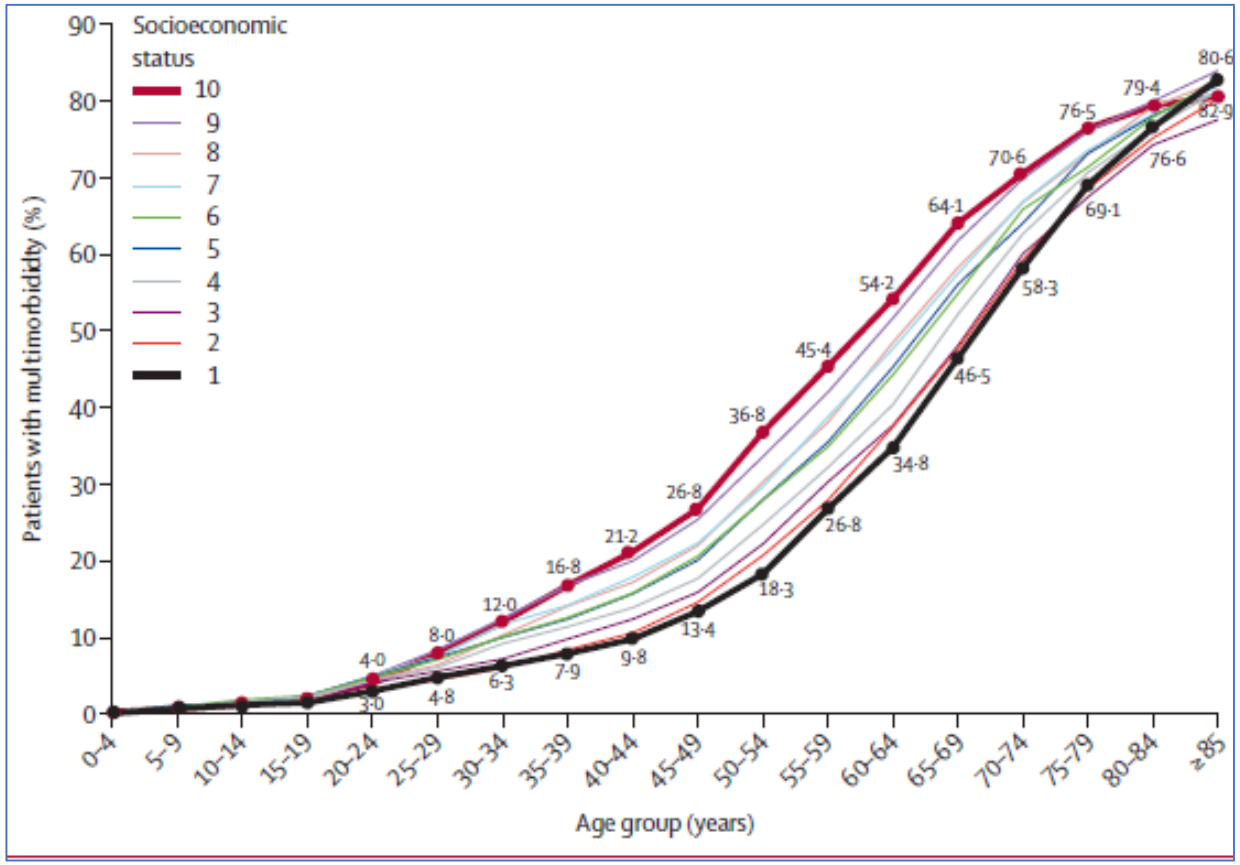
Source: Petherick et al, Nature Human Behaviour, 2021: www.nature,com/nathumbehav

Time spent in residential vs retail/recreation locations

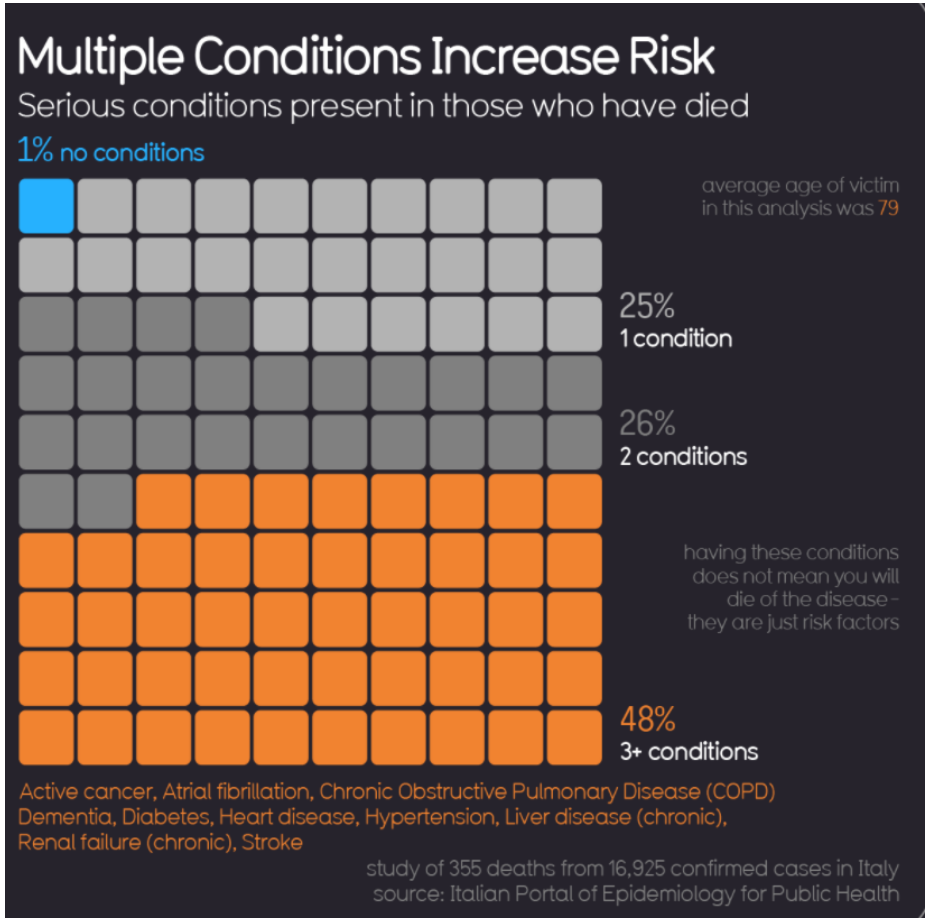


Source: Petherick et al, Nature Human Behaviour, 2021: www.nature,com/nathumbehav

Multimorbidity, risk and socio-economic status

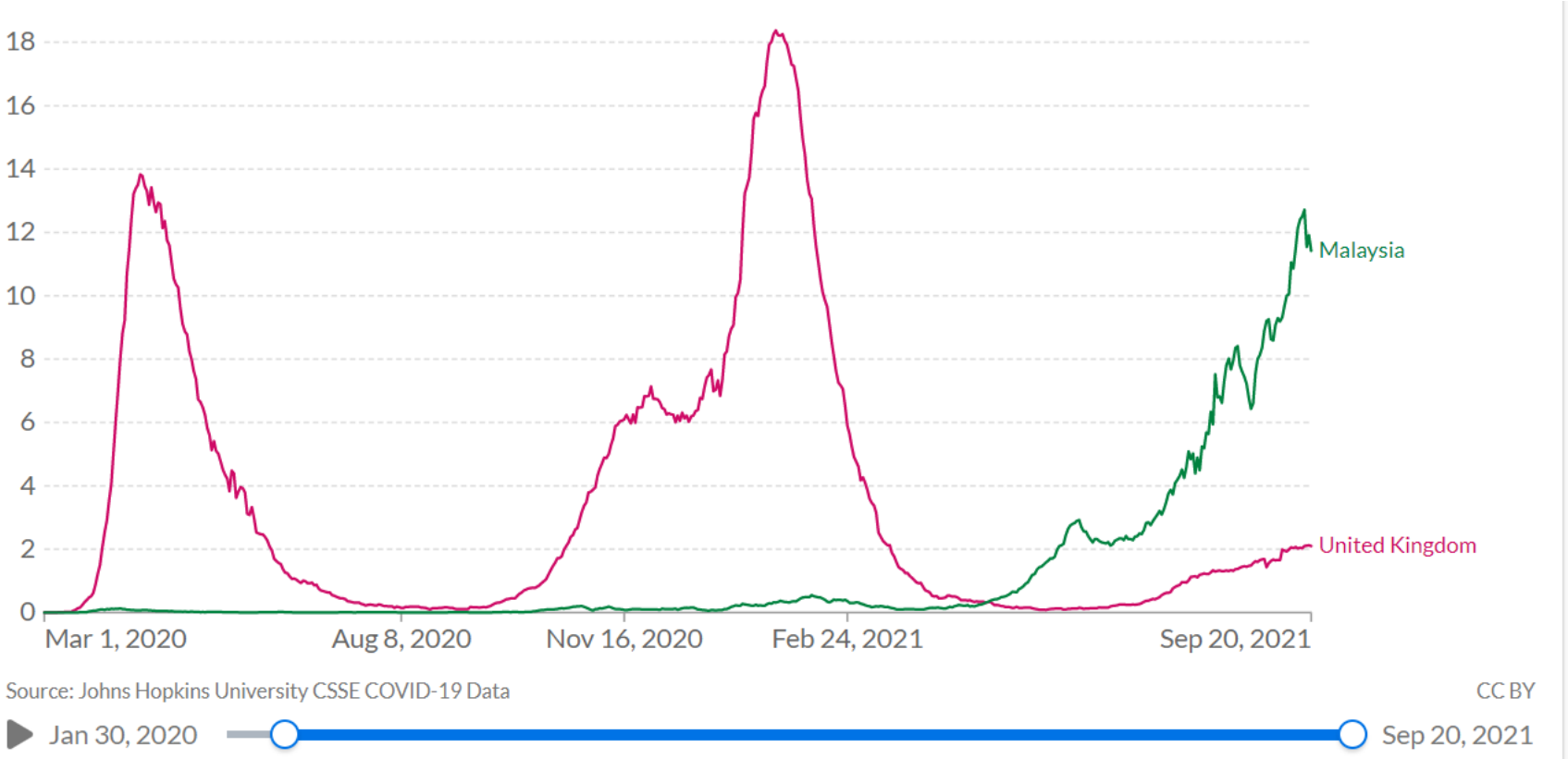


Source: Barnett et al, Lancet 2012



Source: Informationisbeautiful.net

Daily new confirmed COVID-19 deaths per million people



Source: https://ourworldindata.org/covid-deaths

UK experience

- National
  - Recognition of role of ‘end of life care’
    - Pandemic planning
    - ‘Cell’ within the National Incident Response Board
    - Involvement in other cells of relevance – medicines and other supplies, Nightingale hospitals, testing, vaccination, hospital discharge, verification of death
    - Continuing involvement – hibernation of cell
  - Support for hospice funding
  - Provision of guidance
  - Essential list of medication – prioritisation against critical care and others
  - Security of other supplies relevant to palliative care
  - Communication – weekly calls with clinical leaders and with stakeholders, weekly webinars

UK experience: service response vs experience

- Hospital teams
  - Palliative care teams
  - Some dedicated pall care beds
- Community
  - Telemedicine
- Day services:
  - Attendance suspended
  - Volunteer led telephone response
- Hospices
  - Increase capacity
  - COVID-19 hospices

- Hospital teams
  - Severe pressure
  - Most visible – not always recognised
- Community
  - patients fearful of staff visiting
  - less ‘eyes’ on the patient
  - complex needs unrecognised or under-reported
- Day services
  - Virtual services better received than expected
- Hospices
  - drop in demand – faster turnaround times
  - Isolation areas needed to be built in

UK experience: response vs experience

- System coordination and collaboration:
  - Single point of access
  - Daily check-ins across services
- Workforce:
  - Training and education suspended
  - Virtual meetings
  - Technology to support non-specialist areas
- Academia:
  - Research activity suspended

- System coordination and collaboration:
  - Single point of access works
- Workforce:
  - Different ways of working – psychological impact
  - Self-isolation and sickness including long COVID
  - Free resources for education and training
- Academia:
  - Publication bonanza

Online survey of specialist palliative care providers (CovPall)

- 458 respondents – half UK, a quarter Europe and a quarter rest of the world
- 23rd April 2020 – 31st July 2020

Changes	Enablers	Barriers
• streamlining, extending and increasing outreach services • technology to facilitate communication • Implementing staff wellbeing measures	• fear and anxiety • duplication of effort • information overload • funding	• collaborative teamwork • staff flexibility • pre-existing IT infrastructure • strong leadership.

Source: Dunleavy et al, Pall Med 2021

“Palliative care services responded actively but most felt ignored by national health systems during the COVID-19 pandemic, despite supporting patients who were dying or had severe symptoms, supporting their families/carers, and supporting other professionals to deliver care.

Services provided expertise in symptom management and holistic care while facing shortages of equipment, staff and medicines.

The crucial role of palliative care during pandemics must be better recognized and integrated. This is particularly the case for charity managed services and those providing care in people’s homes.”

Challenges

- Macro – national:
  - balance between national guidance and local contextualisation
  - supplies – medicines, syringe drivers, oxygen, PPE
  - communication and guidance – ‘Goldilocks effect’
- Meso – local system/provider
  - swamped – managing numbers: focused on hospital beds
- Micro – individual:
  - under-treatment as opposed to over-treatment
  - anxiety about infection over-rides help seeking behaviours
  - treatment escalation plans

Adaptations

Immediate crisis response?

- Provision by non-specialists in palliative care
- ‘Distanced’ or remote working
- Working outside normal ‘comfort zone’
- Dropping ‘other’ normal activity

After the first wave?

- Trying to be ‘normal’ – rhetoric about ‘new normal’ but also trying to ‘get back on track’
- Emotional cost – patients, families, staff, public

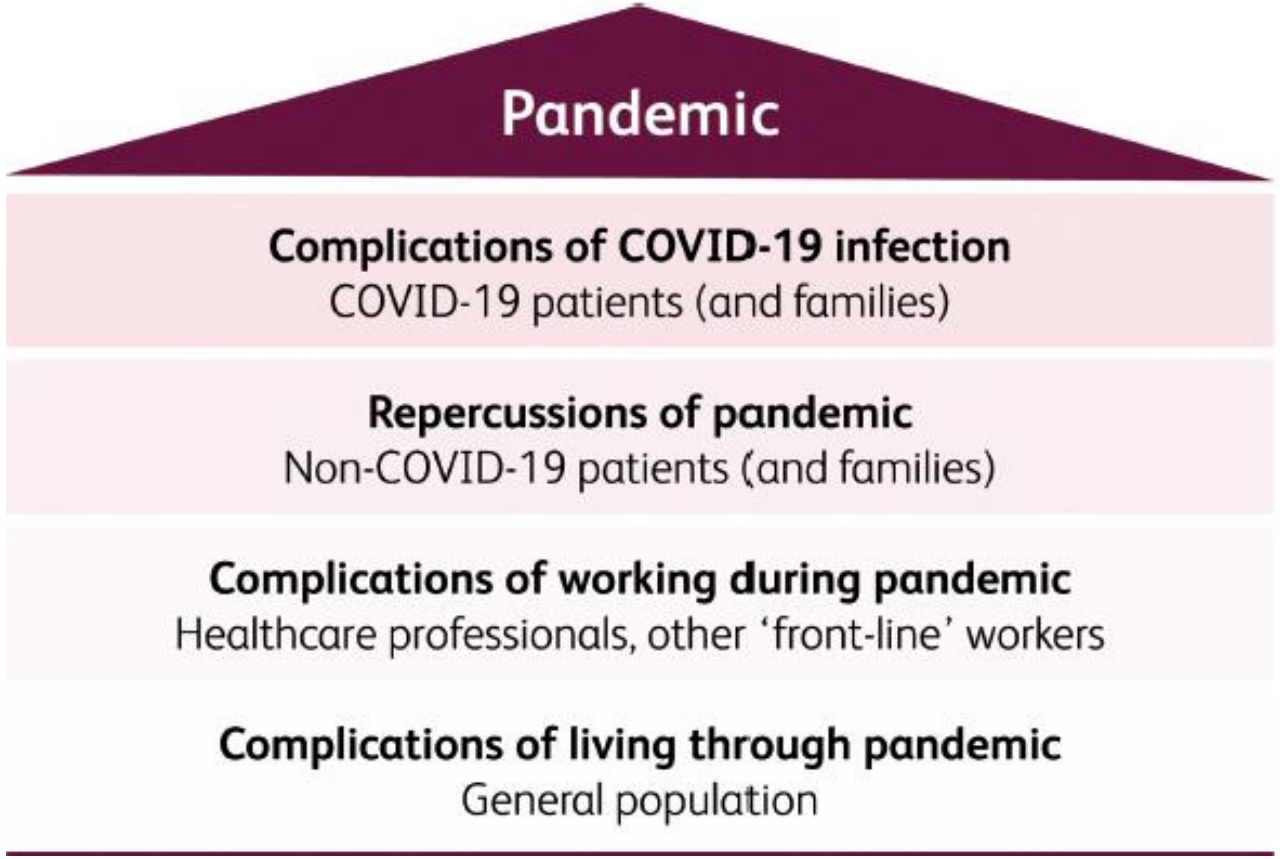
Consequences

- Post-COVID or Long COVID
  - Psychological stress
  - Physical consequences
- Delays to diagnosis and treatment
- Highlighting health inequalities
- Reflections on changes to services and public attitudes
  - Learning, sustainability, funding
- Must re-scrutinise evidence and incorporate new learning
- Holding on to innovations – reviewing, re-planning, re-invigorating

Role of digital technology

- Avoid false dichotomy between ‘high tech’ and ‘high touch’
- Benefits of digital technology:
  - Geographical barriers to access:
    - Professional-patient distance
    - Patient-family distance
  - Supports more home based care
  - Supports informal carers less intrusively
  - Empowers through virtual communities
  - Enables other family members to join in virtual consultations
- Beware digital exclusion:
  - Seeing the technology as an enhanced and empowerment not a barrier
  - Intergenerational help

Iceberg scenario



Source: Davies and Hayes, RCP 2020

Palliative pandemic plan

"Stuff"	Staff	Space	Systems
Stockpile medications for common symptoms: • Opioids for dyspnea and pain • Haloperidol or methotrimeprazine for nausea and delirium • Scopolamine for secretions Stockpile equipment to deliver medications: • Subcutaneous butterflies • Continuous drug delivery pumps Prepare kits including medications and equipment to deliver medications for long-term care facilities and home care services.	Identify all clinicians with palliative care expertise: • Physicians • Nurse specialists Provide focused education sessions to frontline staff for symptom management and end-of-life care for H1N1 patients. Develop standardized order sheets and protocols for symptom management and end-of-life care for H1N1 patients. Involve specialist allied health care workers to provide psychosocial support and grief and bereavement counseling. • Social workers • Spiritual care staff	Identify wards and nonclinical areas in all health care facilities that would be appropriate to accommodate lar ge numbers of patients expected to die. Maximize the use of identified palliative care unit, hospice, and ward beds.	Create a triage system to identify patients in need of specialist palliative care management (see text). Create a triaging system for intrafacility, interfacility, and community transfers to dedicated palliative care units, hospices and wards. Create a system for direct consultation support for staff in hospitals, long-term care facilities, and the community by telephone or telemedicine. Ensure that all patients currently admitted to health care facilities have clear and updated advance care plans.

Source: Downar et al, JPSM, Feb 2020

WHO Briefing Note:
The COVID-19 Pandemic, Palliative Care and Human Rights

Major challenges for enjoyment of the right to palliative care as a component of the right to the highest standard of physical and mental health:

- Significant new palliative care need
- Major challenges to palliative care for existing patients
- Infection risk for providers and patients
- Increased need for psychosocial and spiritual care
- Scarcity of resources

WHO Briefing Note:

Recommendations to UN member states and civil society organisations

- Frame all national responses within a human rights perspective
- Ensure availability, accessibility and quality of basic palliative care services and essential palliative care medicines
- Provide testing, treatment and palliation free of charge
- Avoid interfering with existing palliative care services
- Mitigate negative impacts of infection restrictions on palliative care
- Develop and distribute guidance on palliative care for COVID-19
- Train healthcare workers in basic palliative care techniques
- Protect provider safety
- Ensure transparency and clarity around any rationing of treatment in emergencies

Thank you

HOSPIS MALAYSIA

SUPPORTING PALLIATIVE CARE

For any enquiries about the webinar, please send an email to education@hospismalaysia.org