

Community Engagement:

in support of individuals with serious illness,
their families, and caregivers.

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● Outline:



Explore 'Community Engagement' in this context:

What?

Why?

How?



List current challenges and opportunities.



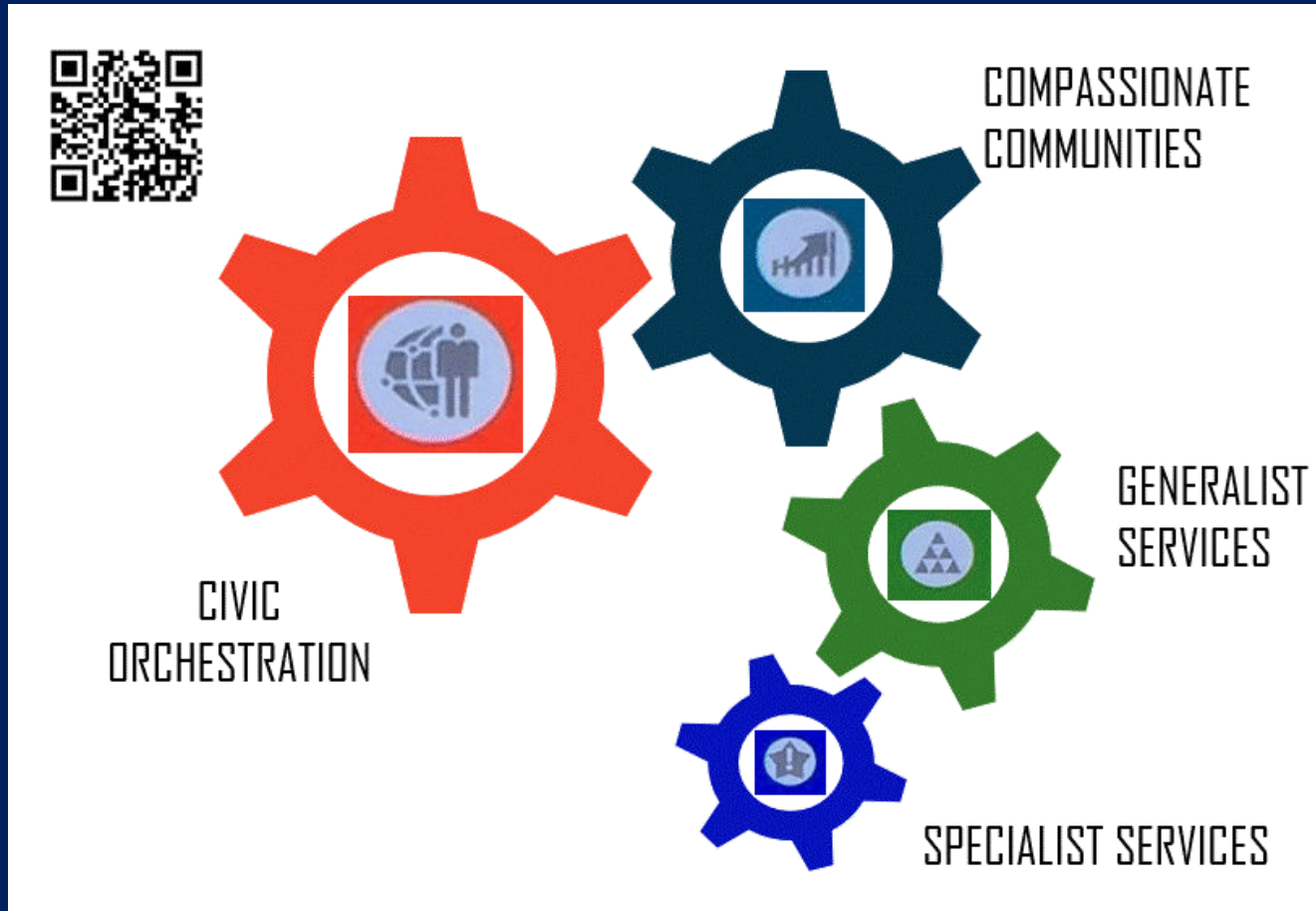
Provide key recommendations for building more **compassionate and equitable communities** for people living with serious illness, their families, and caregivers.

● What do we mean by 'Community Engagement' in this context?



1. 'Active and Systematic' interface within and between social networks.
 2. Civic engagement and collaborative partnerships.
 3. Focal importance of local knowledge and cultural practices.
- **Goal:** to create a compassionate, inclusive environment where accessible, equitable, and responsive EoL care is integrated into the community's way of life.

● Active and Systematic Civic Engagement



.....through facilitating Social Capital:

Building social relationships ,

Bridging social relationships,

and Linking social relationships

..... within and across a
Complex Adaptive **Human** System

Why is this especially important in the current context?

We know:

- End of life care and supporting people with loss is emotional.
- Long-term caring and grief can be exhausting and lonely.
- These experiences can have significant impacts on health.
- Each person's experience is unique to them.
- The most effective support comes from the people who know us best.

Challenges in the Current Context: “Uncertain Times, Unsettled Lives”

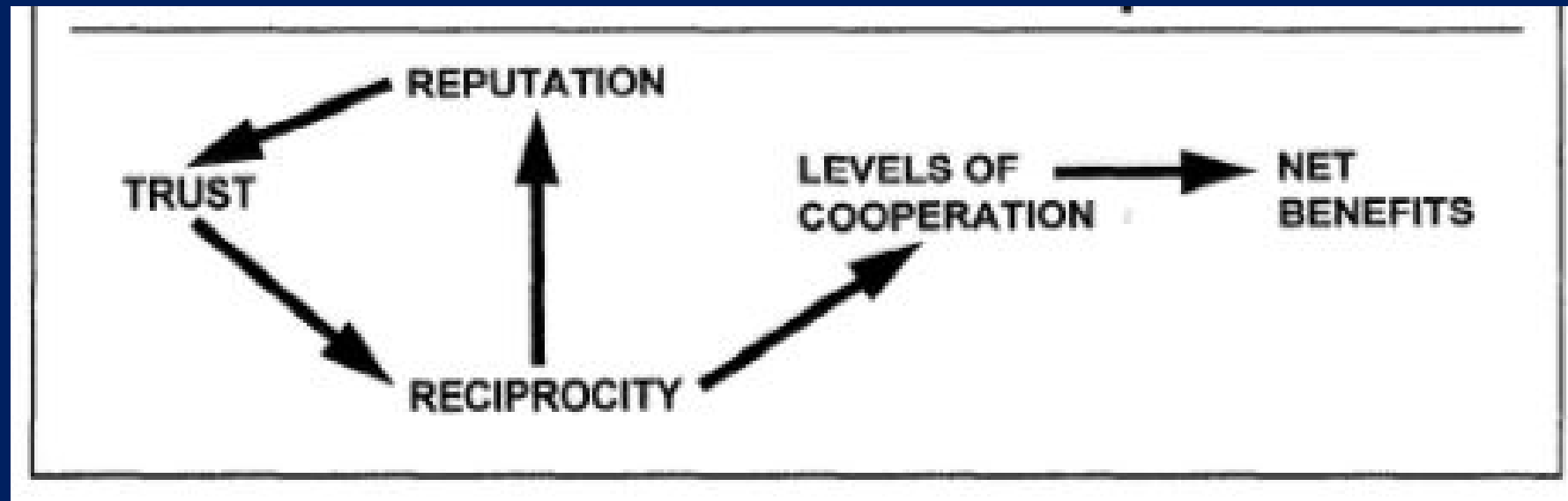


- Demands on end-of-life care services.
- Resource constraints.
- Complexity of care system.
- Complexity of care needs.
- **We need Collective Action!**

● Death and Dying represent a Social Dilemma

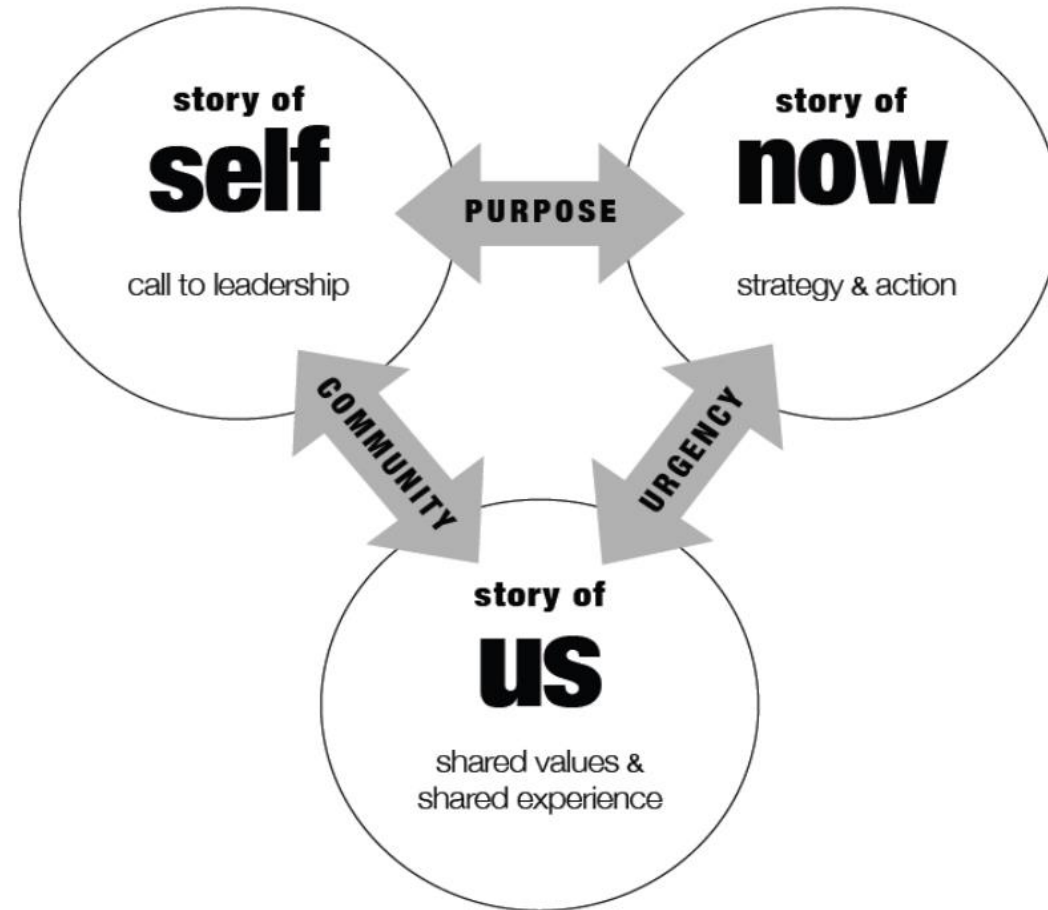
...we must balance individual interests with collective need.

Core relationships in mobilising Collective Action.



[from Ostrom, 1998]

● The Power of Story: Marshall Ganz

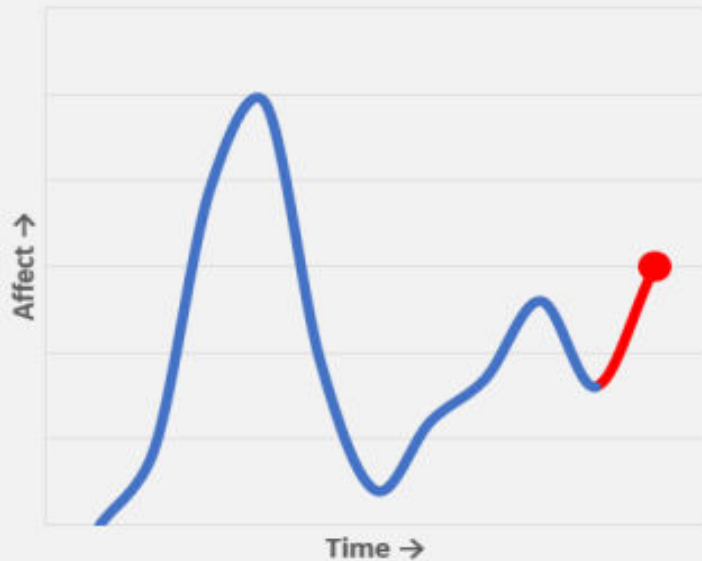


● Why me?

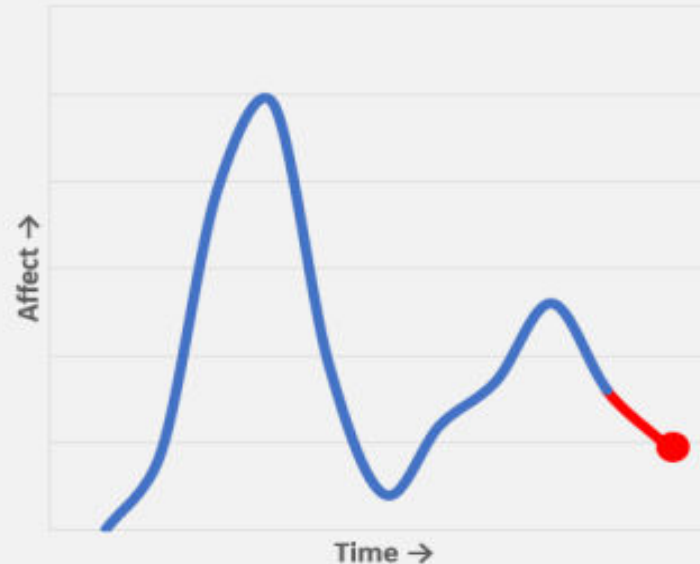
The trend at the end

An improving trend at the end improves the memory of the experience compared to a worsening trend at the end.

Improving End



Worsening End

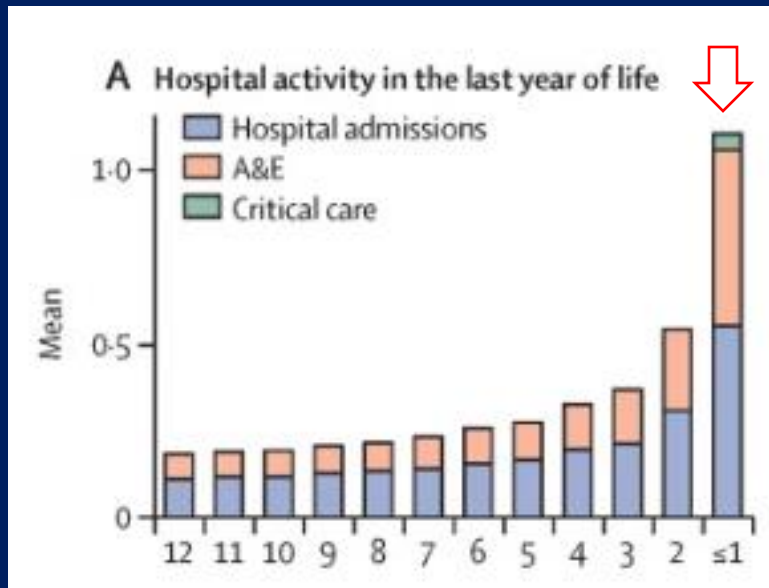


Daniel
Kahneman's
'Peak-End Rule'

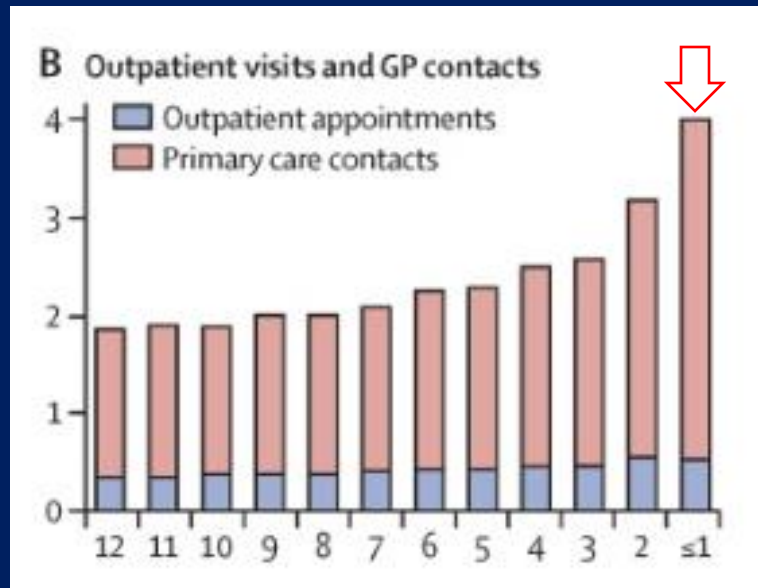
Endings
Matter

● Why us?

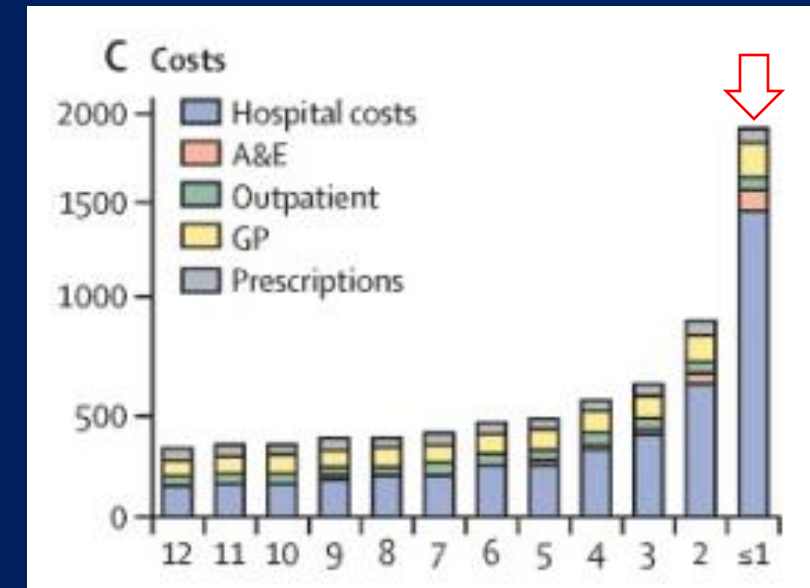
England: Healthcare Use and Costs in last 12 months of life



Hospital Admissions
&
A&E



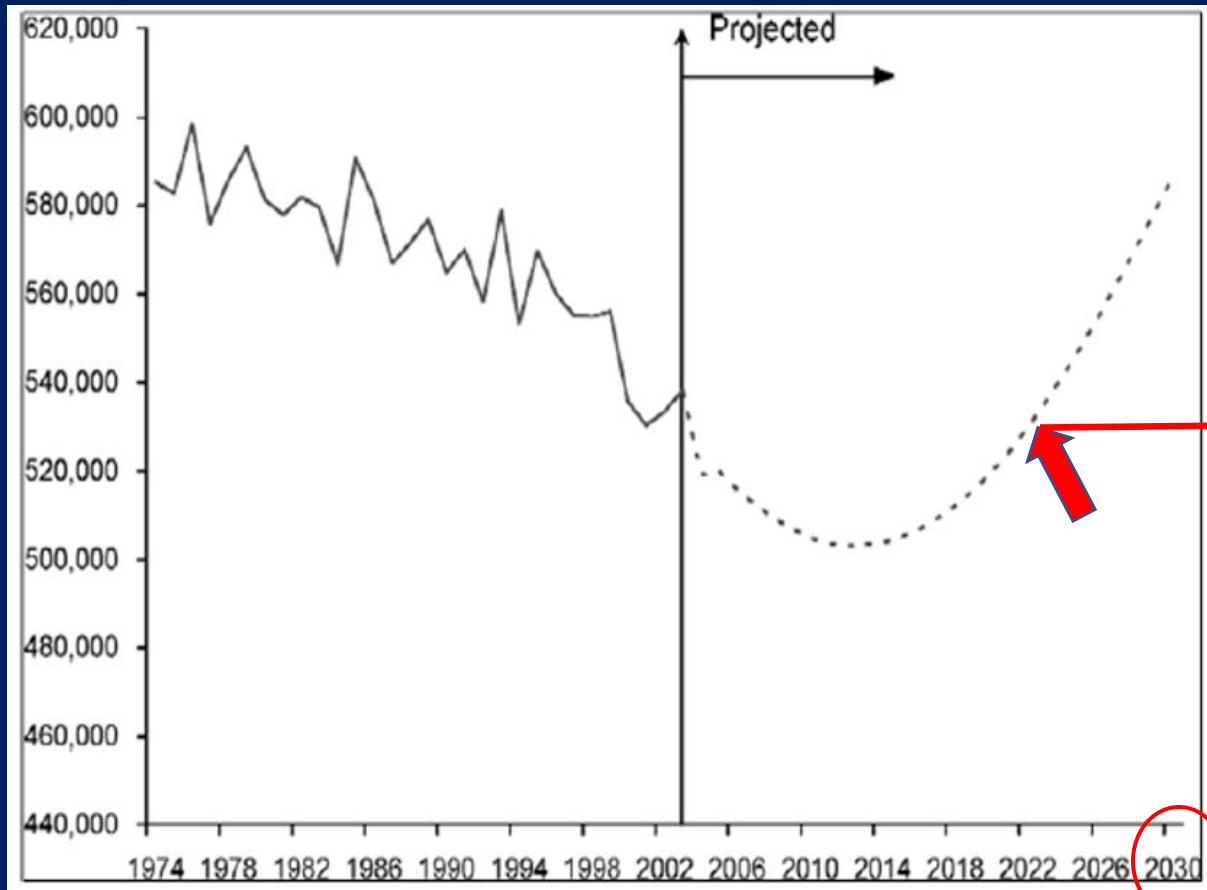
Primary Care Contacts
&
Outpatient



Costs
All sectors

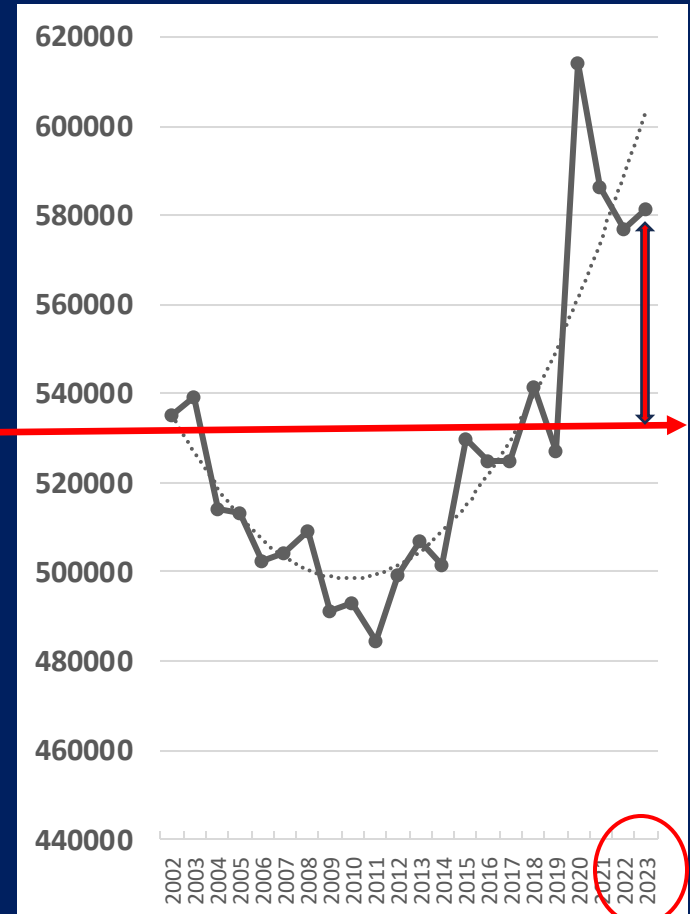
● Why now?

Actual and projected deaths in England and Wales, 1974–2030



(Gomes & Higginson, 2008)

Indications of Credibility



(Office of National Statistics, 2023)

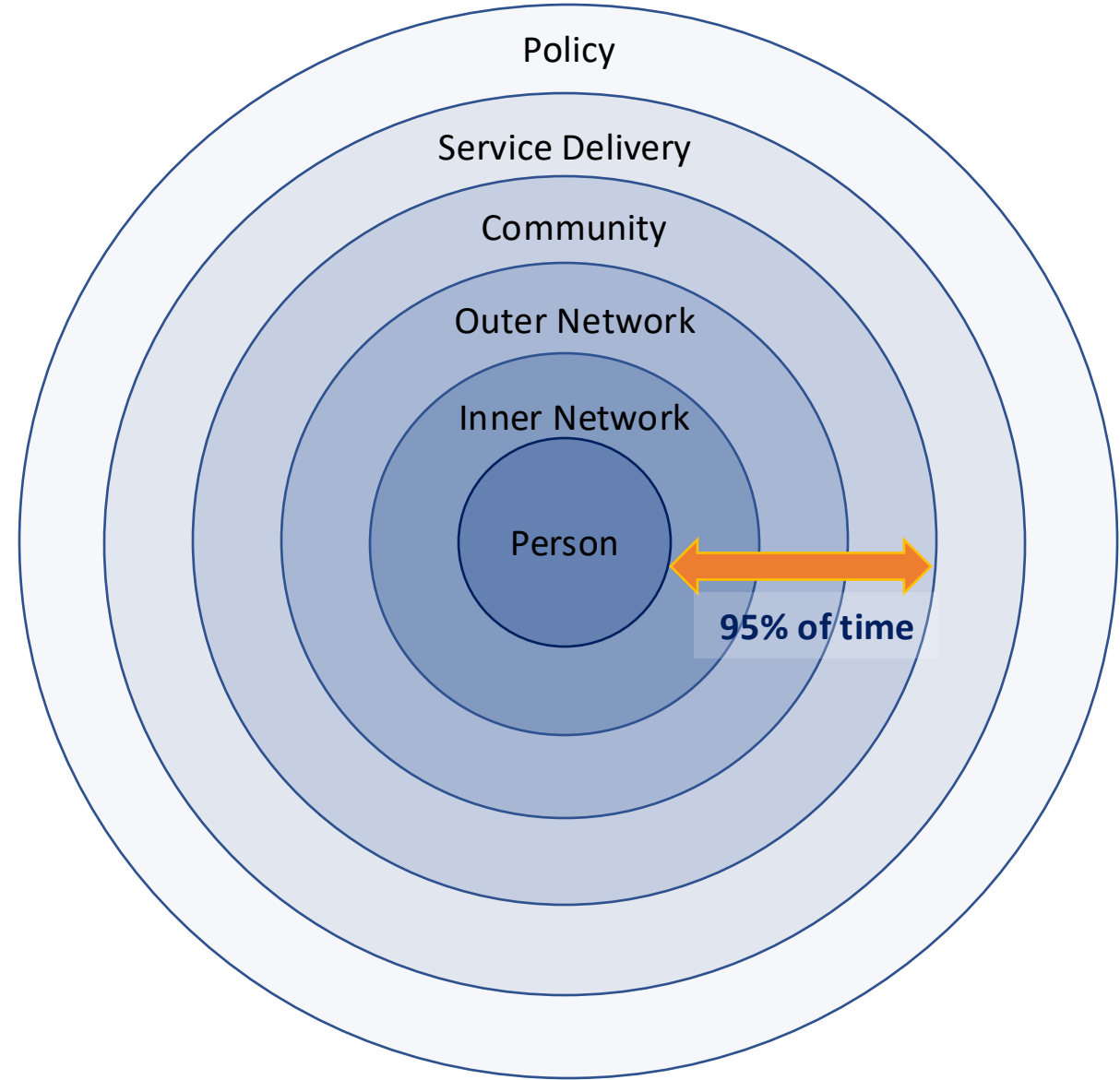
● How does this apply to Compassionate Communities?

The Compassionate Communities movement involves taking collective action to empower individuals and groups of people with the skills they need to generate solutions and effect change within their communities.

How do we go about strategic,
active, and systematic civic
engagement?

1. Family Focus

- **Reflect on the 95% rule**
- **Objective:** bolster support to people and families **outside of services**
- How do we equip inner / outer network to feel '**prepared to help**'?
- **Recommendation:** routinely assess a family's support network in standard clinical practice, including hospital and hospice care.



Circles of Care (2013)

2. Community Focus: Socioecological Approach



Systematic approach to
Knowledge
Mobilisation



Asset-based
Methods



Social Capital
Social Cohesion



Compassionate Communities: Civic Charter

Compassionate Communities is an approach to enable all of us to live well within our communities to the end of our lives. It encourages support for people and their families who are living with life limiting illness, loss, and bereavement. It recognises that care for one another is not simply a task solely for health and social services but is everyone's responsibility.

A **Compassionate Community** will advertise, collaborate and co-operate to develop and support the following 13 social changes to the community's key institutions and activities.



**Schools and
Colleges**



**Workplaces and
Trade Unions**



**Places of
Worship**



**Hospices and
Nursing Homes**



**Museums and Art
Galleries**



**Community-wide
Memorial Event**



**Incentive Schemes
and Awards**



**Promoting
and Celebrating**



**Inclusive Policies
and Practices**



**Become a
Compassionate Friend
or Champion**



**Establish a Compassionate
Community Steering
Group**

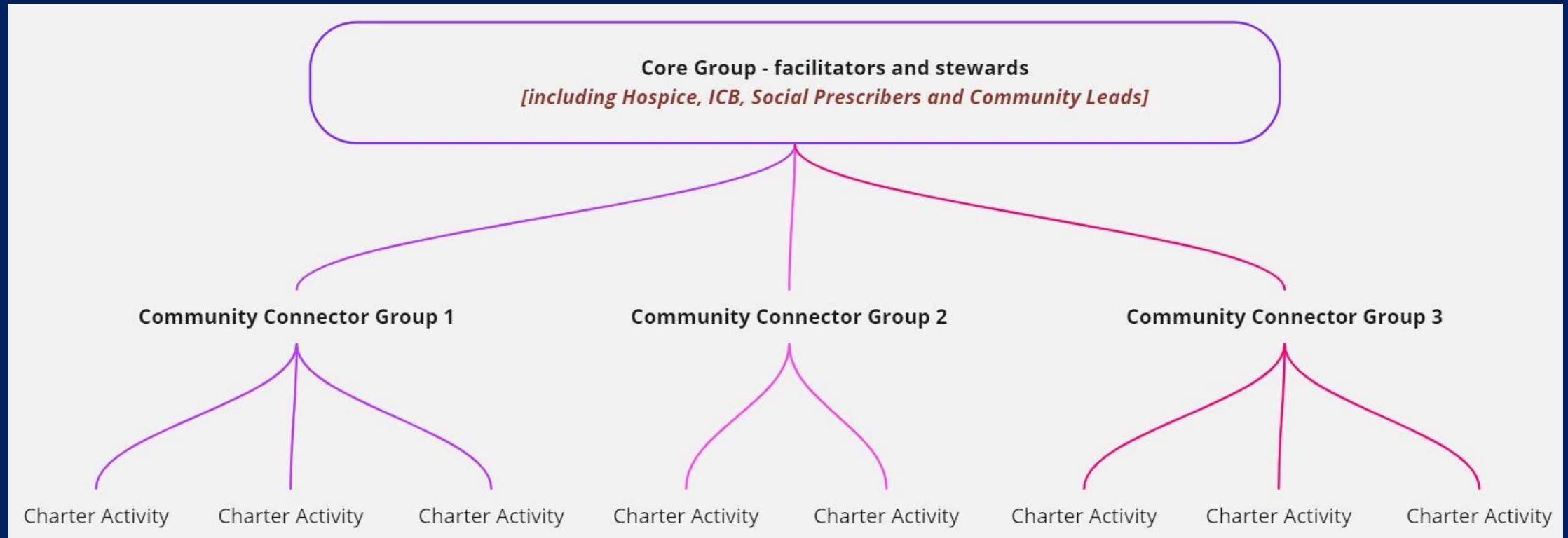
Opportunities & Recommendations

● Recommendations to stimulate **Social Learning Capability**

- **Invite** people to commune.... steward the core reason to gather
- Find out **what matters most** to people who attend
- Be alongside each other.....networks are non-hierarchical
- **Promote shared responsibility**....beware of groups developing **dependencies**.
- Use your communication resources more creatively to **celebrate good work**.
- **Money** can't be the barrier to act!

● Where to start?

- Convene and maintain a localised Collaborative Action-Learning Network
- Develop Citizen-led Communities of Practice



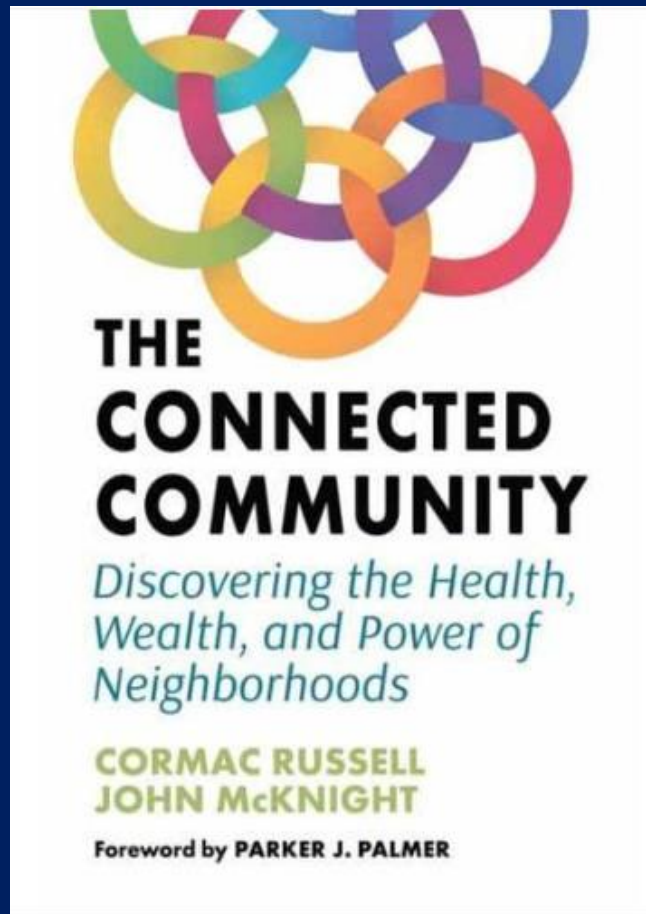
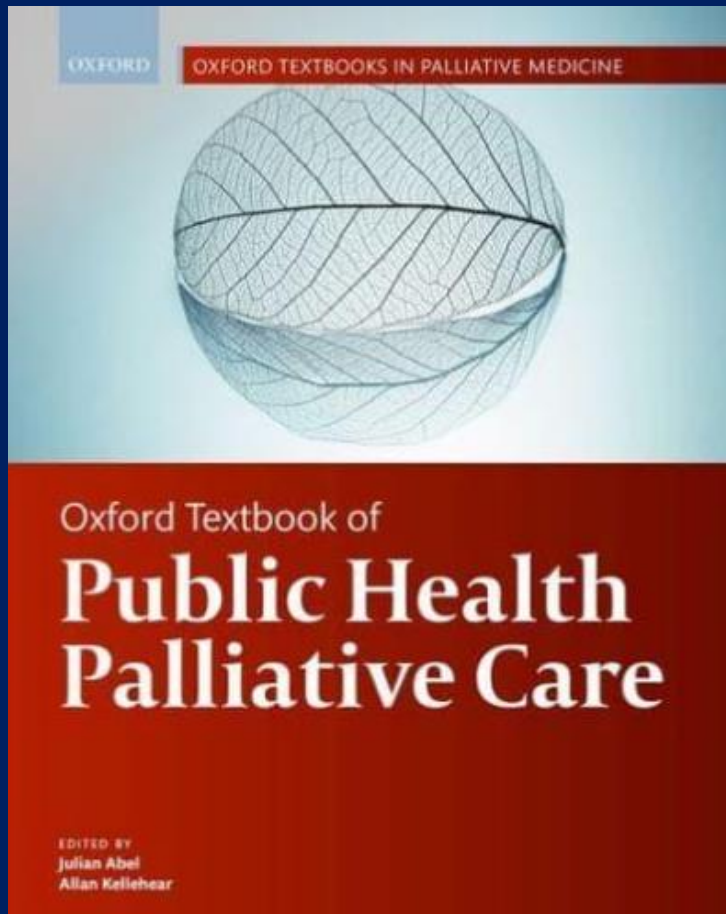
● What is the first step?

- *****Craft an invitation *****

- Pay special attention to how people gather.
- We need to provide opportunities for people to talk and share knowledge, skills and experiences.
- We need more **exposure** to hold these '**important**' conversations.



Resources



Guy Peryer

NIHR Knowledge Mobilisation Fellow

NIHR | Applied Research Collaboration
East of England



Thank you for listening