

Developing compassionate communities

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EAPC Reference Group on Public health and Palliative Care

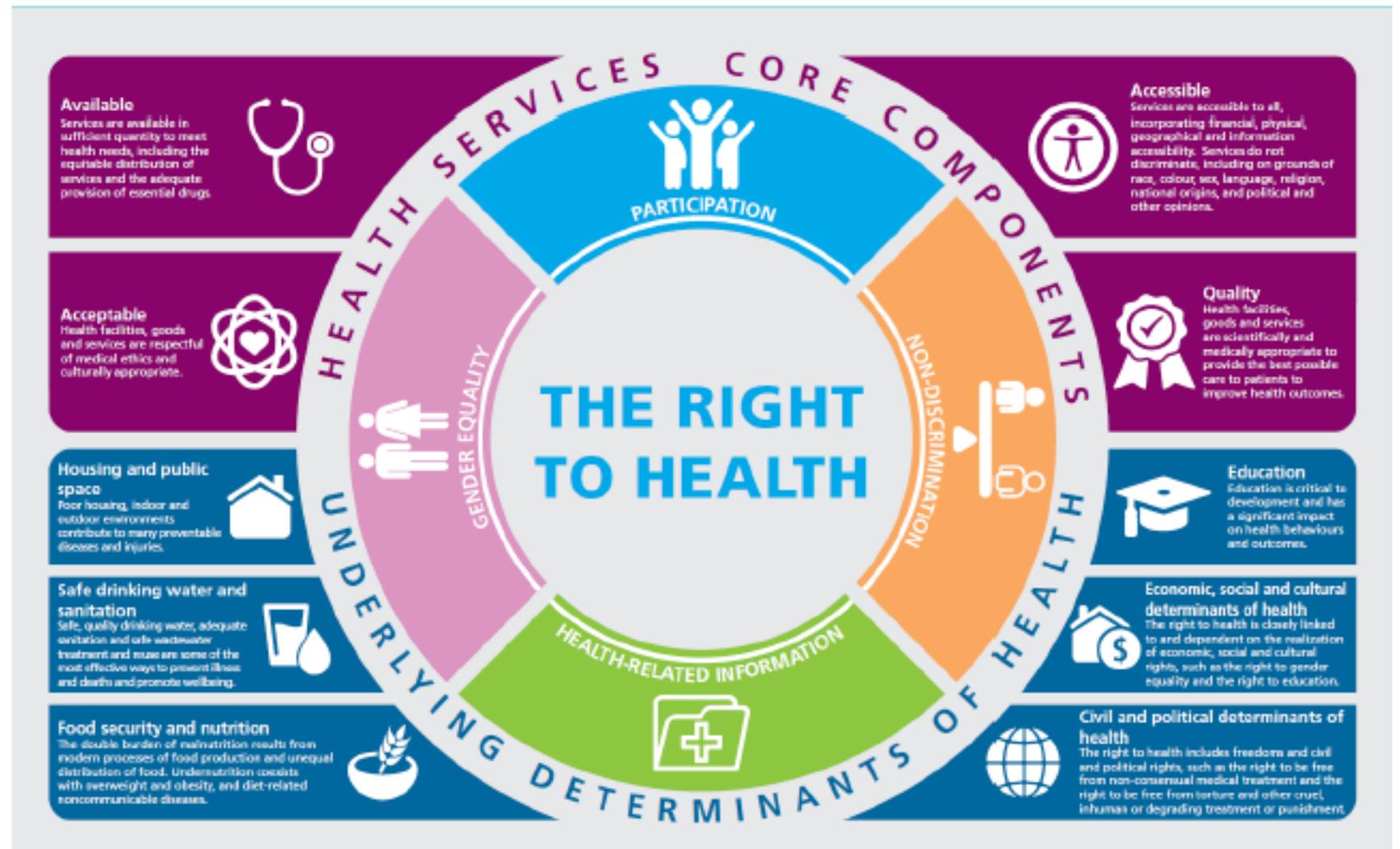
Vice President, Public Health and Palliative Care International

Aims

- Why are we talking about compassionate community approaches?
- What these approaches look like in practice?
- How can we understand their impact?

Starting point

- Palliative care increasingly recognised as part of universal health care
- How are health and wellbeing created?
 - By more than clinical care alone



Starting point

- Palliative care increasingly recognised as part of universal health care
 - Palliative care plays a role in health and wellbeing
- How are health and wellbeing created?
 - By more than clinical care alone
- Focusing on one dimension will not achieve change
- Taking this broader perspective is a public health approach

Assuming a public health perspective

- Prevention
- Early intervention
- Harm reduction

*What are our end
of life public health
strategies?*

Ottawa Charter (WHO 1986)

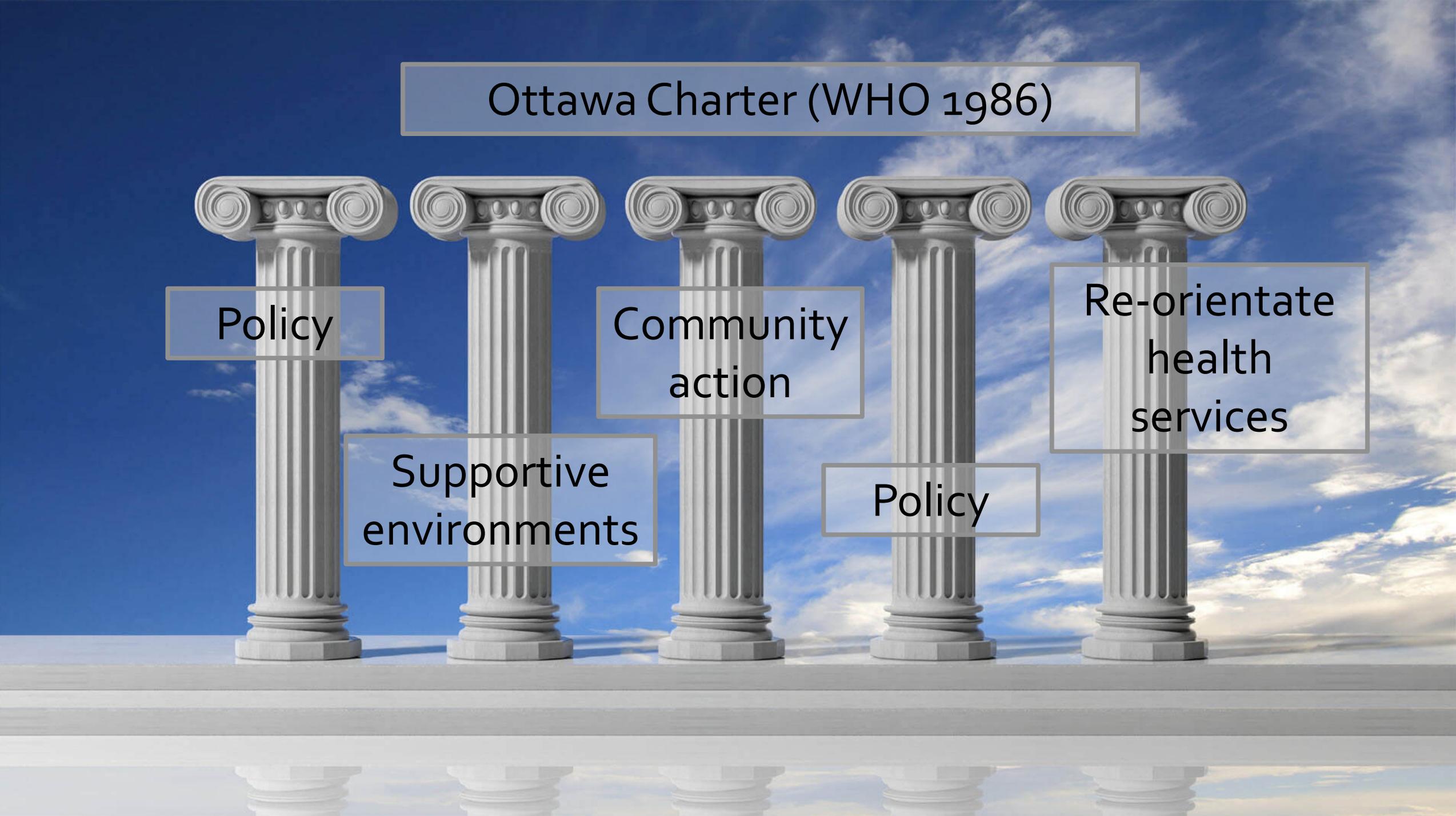
Policy

Community
action

Re-orientate
health
services

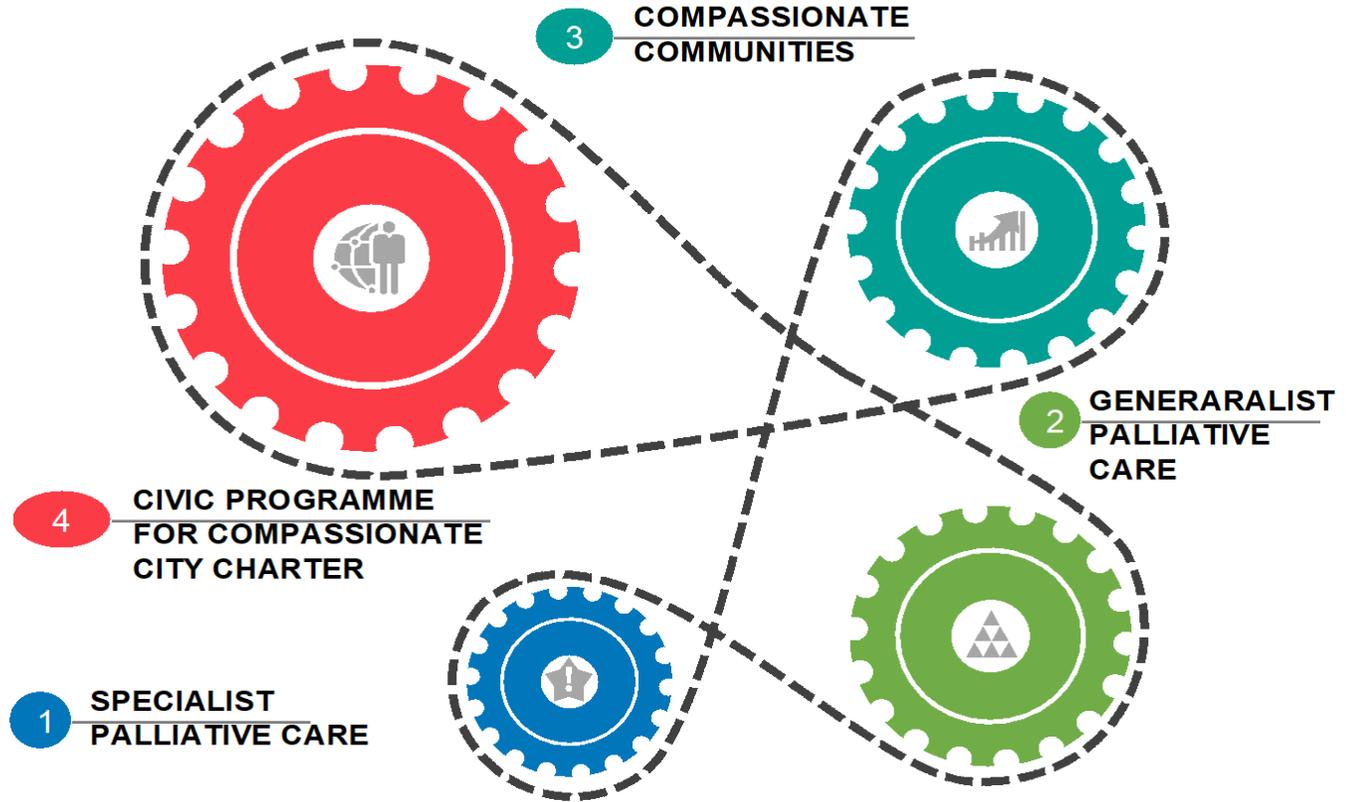
Supportive
environments

Policy



Returning to
end of life care
and public
health

Palliative Care – The New Essentials



Abel, Kellehear and Karapliagou 2018

Compassionate communities

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



PHPCI

HOME

MEMBERS

ABOUT

NEWS

COMPASSIONATE CITIES

CONFERENCE

JOIN NOW

RESOURCES

Public Health Palliative Care International

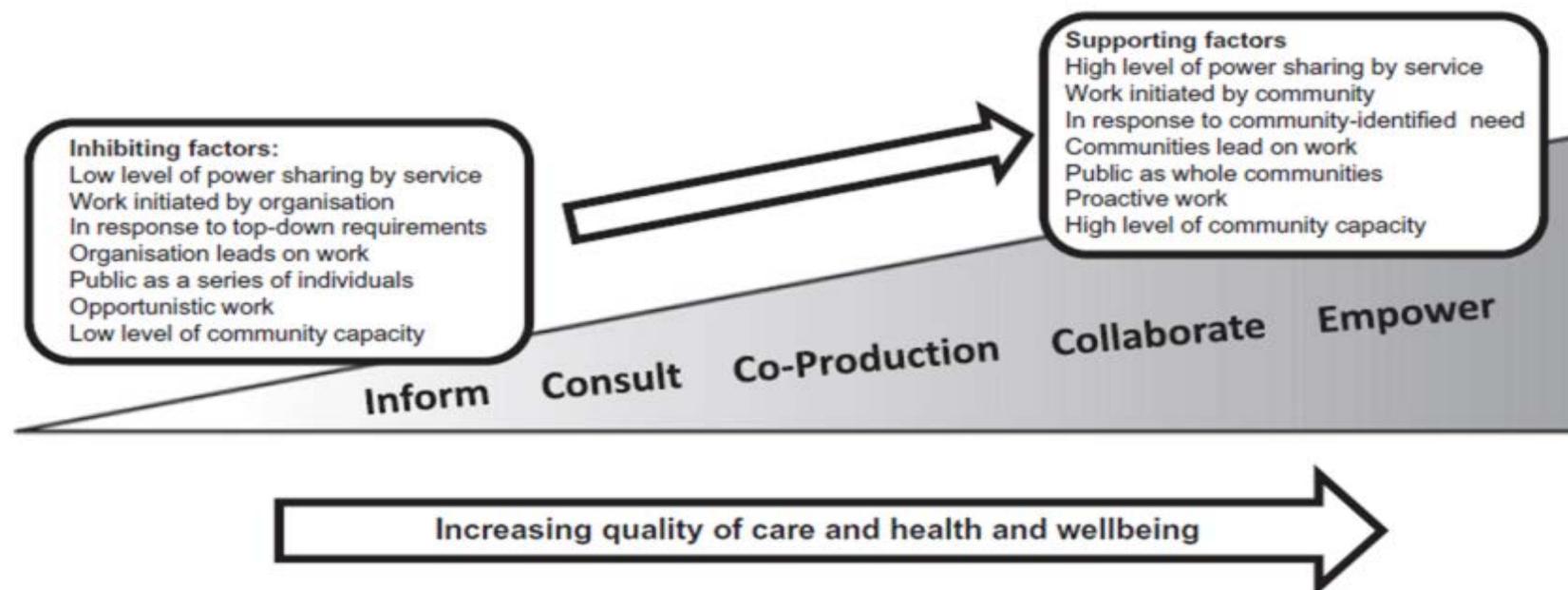
Creating Compassionate Communities

Welcome to Public Health Palliative Care International

www.phpci.info

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://dx.doi.org/10.1080/17445019.2015.1058888>

The need for
conceptual
clarity & to
understand
the principles

A growing
evidence base

PALLIATIVE
MEDICINE

Review Article

The impact of a new public health approach to end-of-life care: A systematic review

Libby Sallnow^{1,2}, Heather Richardson³, Scott A Murray² and Allan Kellehear⁴

Palliative Medicine
2016, Vol. 30(3) 200–211
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216315599869
pmj.sagepub.com


Research

Julian Abel, Helen Kingston, Andrew Scally, Jenny Hartnoll, Gareth Hannam, Alexandra Thomson-Moore and Allan Kellehear

Reducing emergency hospital admissions:

a population health complex intervention of an enhanced model of primary care and compassionate communities



OPEN ACCESS

Identifying changes in the support networks of end-of-life carers using social network analysis

Rosemary Leonard,¹ Debbie Horsfall,² Kerrie Noonan²

Leonard R, et al. *BMJ Supportive & Palliative Care* 2013;0:1–7. doi:10.1136/bmjspcare-2012-000257

A growing
evidence base

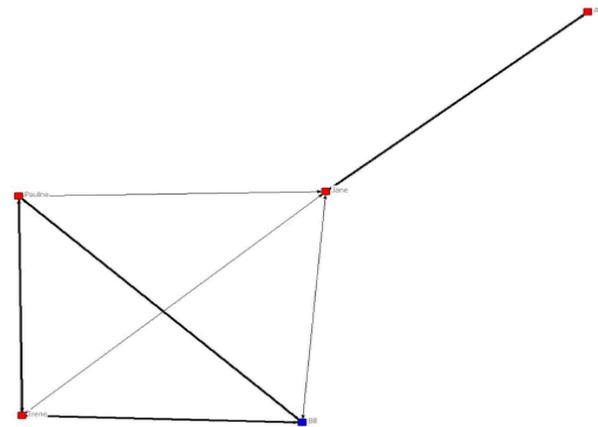


Figure 1 Jane's network at Time 1.

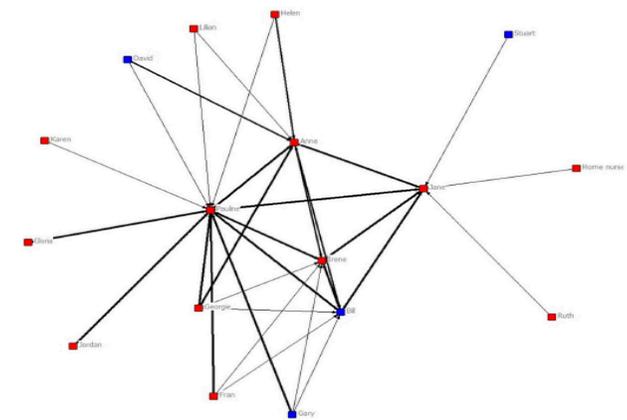


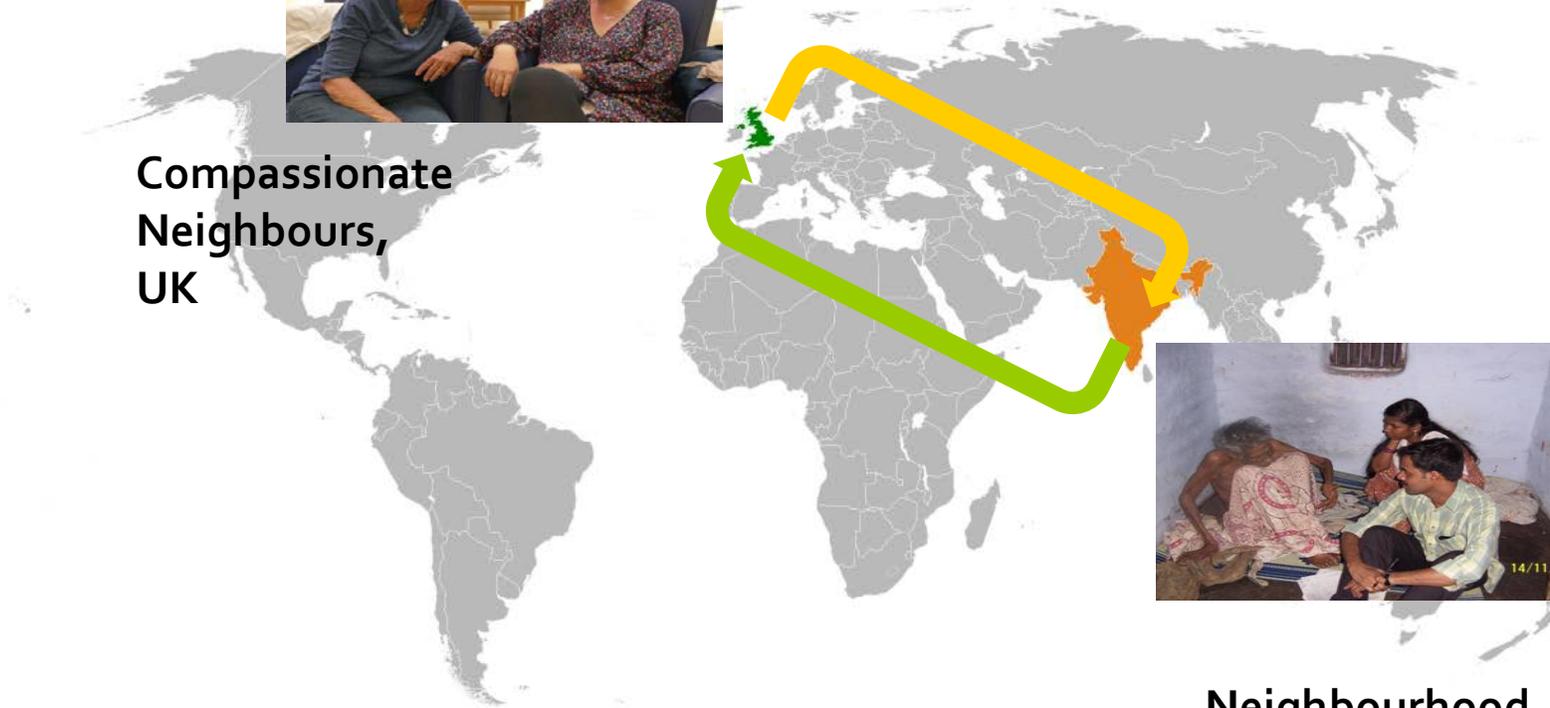
Figure 2 Jane's network at Time 2.

An example

UK and Kerala

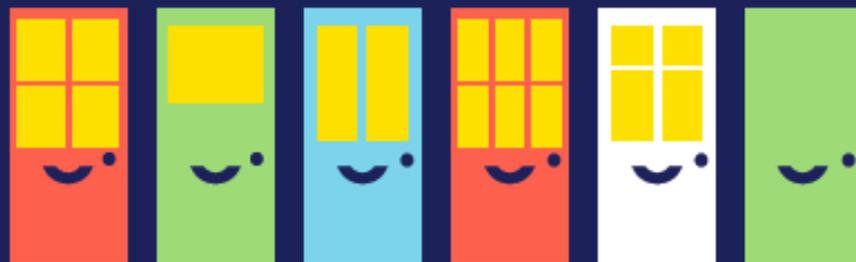


Compassionate
Neighbours,
UK



Neighbourhood
Network in
Palliative Care,
Kerala

Compassionate
Neighbours
in East London



St Joseph's
Hospice

Understanding the impact of a new public health approach to end of life care:

A mixed methods study of a compassionate community

Compassionate Neighbours

- Recruit and train community members to become 'Compassionate Neighbours'
- Support people emotionally, socially, practically in their homes
- Role of a neighbour, not professional
- Supporting people as friends rather than delivering an intervention
- Aims to make communities more compassionate places to live and die
- Community development model
- Partnership between hospice and community advocacy charity



Methods

- Exploratory mixed methods study (QUAL/quant)
 - Congruent with the principles of the project
 - Flexible – open to unanticipated outcomes
 - Engaging a wide range of stakeholders
 - Participatory
- Ethical approval through University of Edinburgh
- Participant researcher perspective
- Analysis: modified grounded theory (Charmaz 2014)

Method	Sample	Participants
21 interviews	7 compassionate neighbours 4 community members 4 hospice staff 3 external staff	19
2 focus groups	FG1 – 15 FG2 - 16	31
Participant observation	19 events: Training, selection events, supervision, public events, home visits	450
Documentary analysis	Training, marketing materials, meeting minutes, evaluation forms	11 documents

Method	Sample	Participants
Observational longitudinal data	Compassionate neighbours Community members	180
		80

Impacts

Personal level

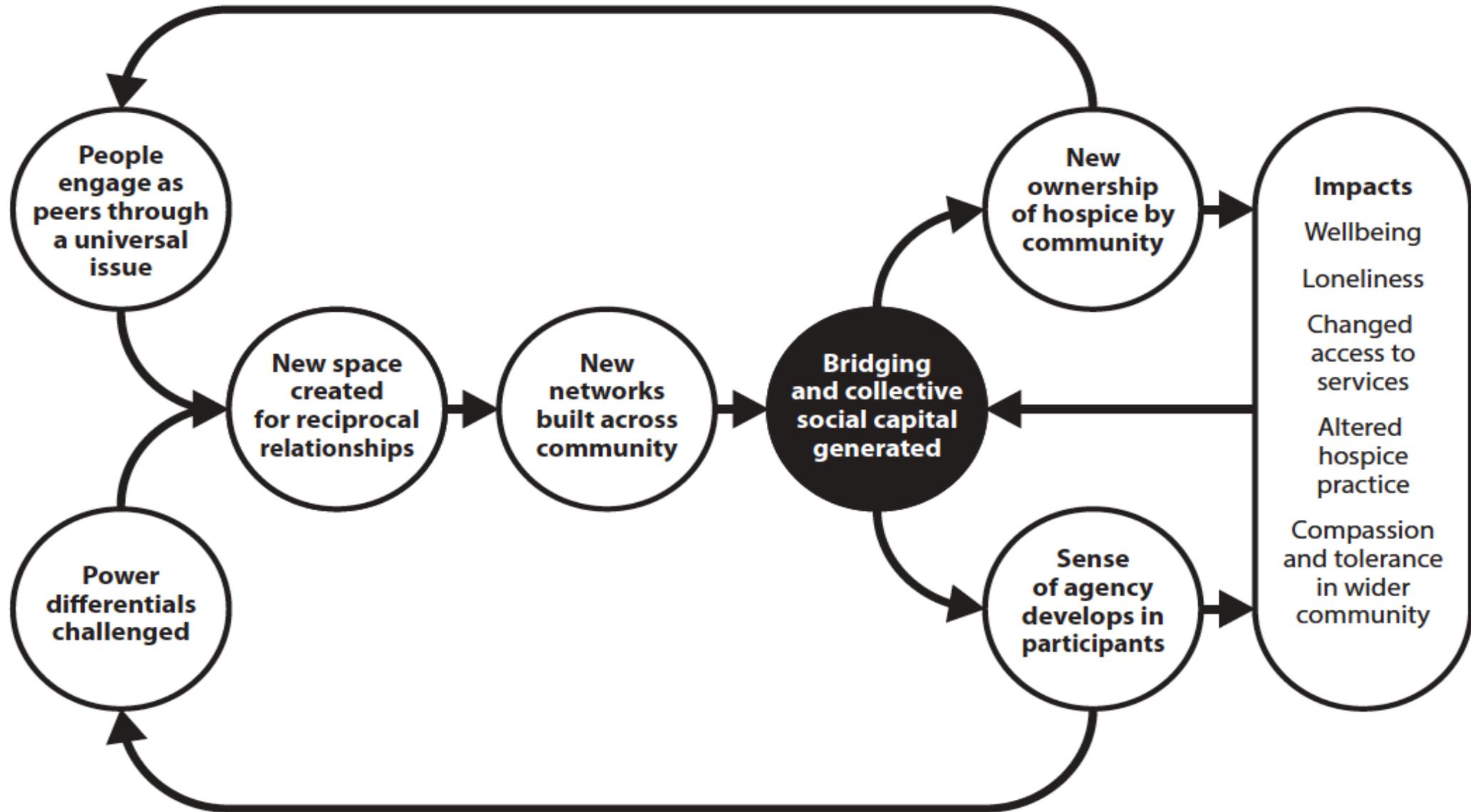
- Reduced loneliness
- Increased meaning & purpose
- Increased local connections
- Returning to employment
- Further advocacy or volunteering
- Plans and supports for own death

Organisational level

- Increased local ownership of hospice
- Changed patient access
- Changed hospice practice
- Existing boundaries challenged

Community level

- New networks of relationships
- People moved between roles
- Relationships across difference
- Independent networks developed



Sallnow, L (2017) Collective Social Capital: a new model of social capital in end-of-life care

Summary

- Public health approaches are common-place in most areas of health & social care
- End of life care must include preventative and upstream interventions
- Developing evidence to support this
- Considers social justice and equity alongside clinical care
- Participation and considerations of power are central
- These are not new services but partnerships across sectors and community

Thank you

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