

Power to the people: do public health campaigns improve awareness and quality of palliative care?

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Overview

- **Brief context**
- **Awareness campaigns: some examples**
- **What do people think? Findings from public awareness research**
- **Findings from other research**
- **Summary and implications**



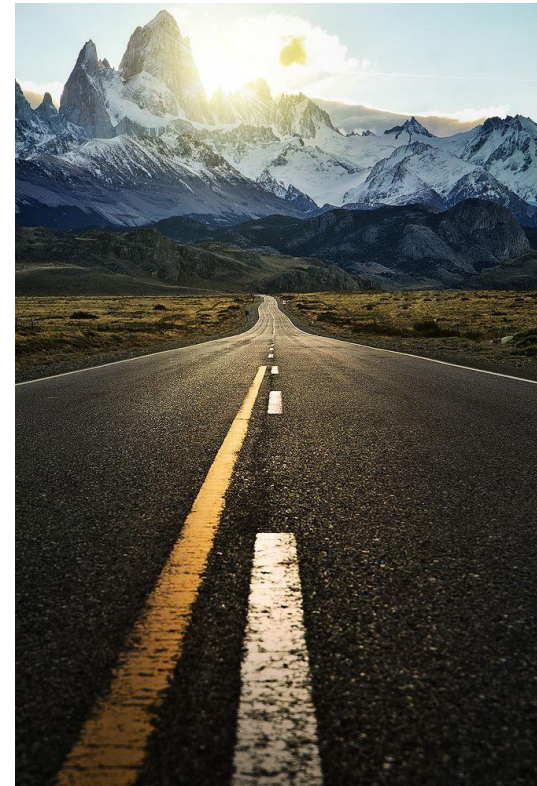
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**'Death, like the sun cannot be
looked at steadily'**

**(Francois de la Rochefoucauld-
1678)**

Why is awareness important?

- **Changing patterns of illness, ageing and dying**
- **Social justice and human rights**
- **Palliative care involves:**
'...social, economic and personal challenges stretching far into the future'



(Cox K, Bird L, Arthur A, et al. BMJ Supportive & Palliative Care 2013;3:37–45)

Examples of campaigns internationally

‘Project on Death in America’ (PDIA) -

<https://www.opensocietyfoundations.org/publications/transforming-culture-dying-project-death-america-1994-2003>

‘Dying Matters’ campaign in England and Wales-

<http://www.dyingmatters.org/overview/about-us>

‘Dying to know’ day in Australia

The ‘Speak up’ Campaign in Canada:

<http://www.advancecareplanning.ca/>



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An All Ireland Campaign



THE PALLIATIVE HUB

An All Ireland Gateway to
Palliative Care Information



HOME ABOUT US WHAT IS PALLIATIVE CARE PUBLIC AWARENESS



AIHPC

All Ireland Institute of
Hospice and Palliative Care

Public Awareness Campaign 2016

6 December 2016

PALLIATIVE
CARE WEEK
3-8
OCTOBER

Palliative Care Enabling Living

Find out how Palliative Care
can enable living
www.thepalliativehub.com

Emma, Age 2 years
Living with a serious genetic disorder

'She felt safe and secure
surrounded by everyone and
everything that she loved'

PALLIATIVE
CARE WEEK
3-8
OCTOBER

#pallcareweek

World Hospice & Palliative Care Day 8 October 2016

PUBLIC AWARENESS

Public Awareness

Palliative Care Week

Add your voice to Palliative Care Week 2016

www.thepalliativehub.com



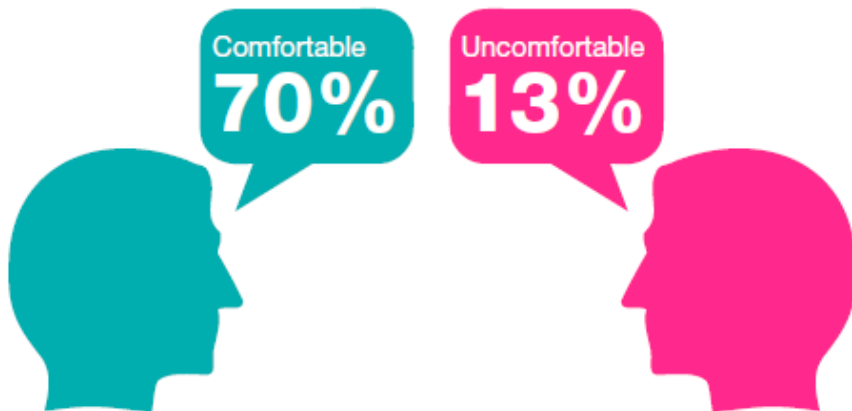
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What do people think about palliative care related issues?



Discussing death

Most people express a considerable degree of confidence around discussing death and planning for the end of life.



70% say they feel comfortable **talking about death**; just 13% feel uncomfortable doing this.



The majority express confidence about **planning** in relation to one or more aspects of the end of life; 73% feel confident about making financial plans for the end of life, while 79% feel confident about planning for the right sort of support and care.

British Social Attitudes Survey data, 2013



Planning for end of life

Yet this expressed comfort and confidence is not always translated into actual discussions and practical planning, largely because death is seen as far off – even among many older people.

Not discussed their wishes as death seen as far off



Less than half (45%) have discussed what their wishes would be in relation to one or more aspects if they didn't have long to live. 43% have **not discussed their wishes because death seems far off**; this is the case for around one in five (23%) of those aged 75+.

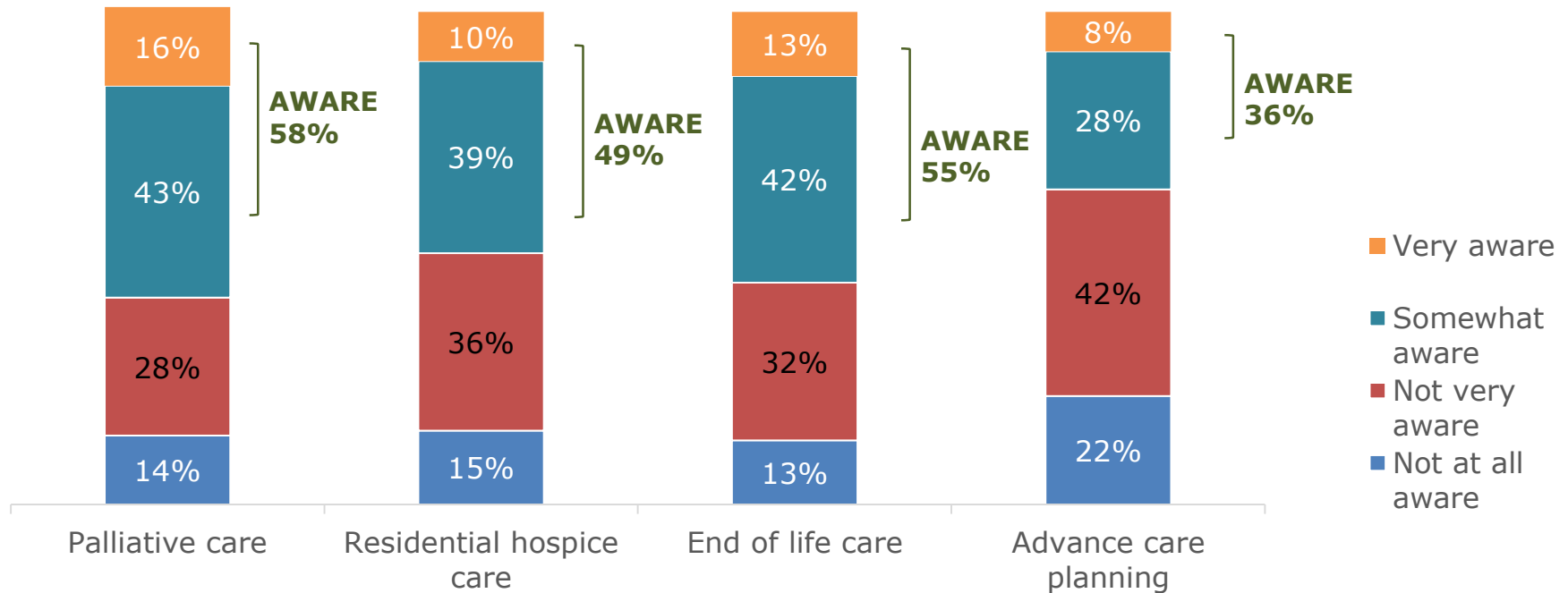


5% have living will/advance care plan

11% have written funeral plans

Only 5% report having a **living will or advance care plan**, while 11% have written plans in place for their funeral.

Awareness of Palliative Care in Canada (n=1540)

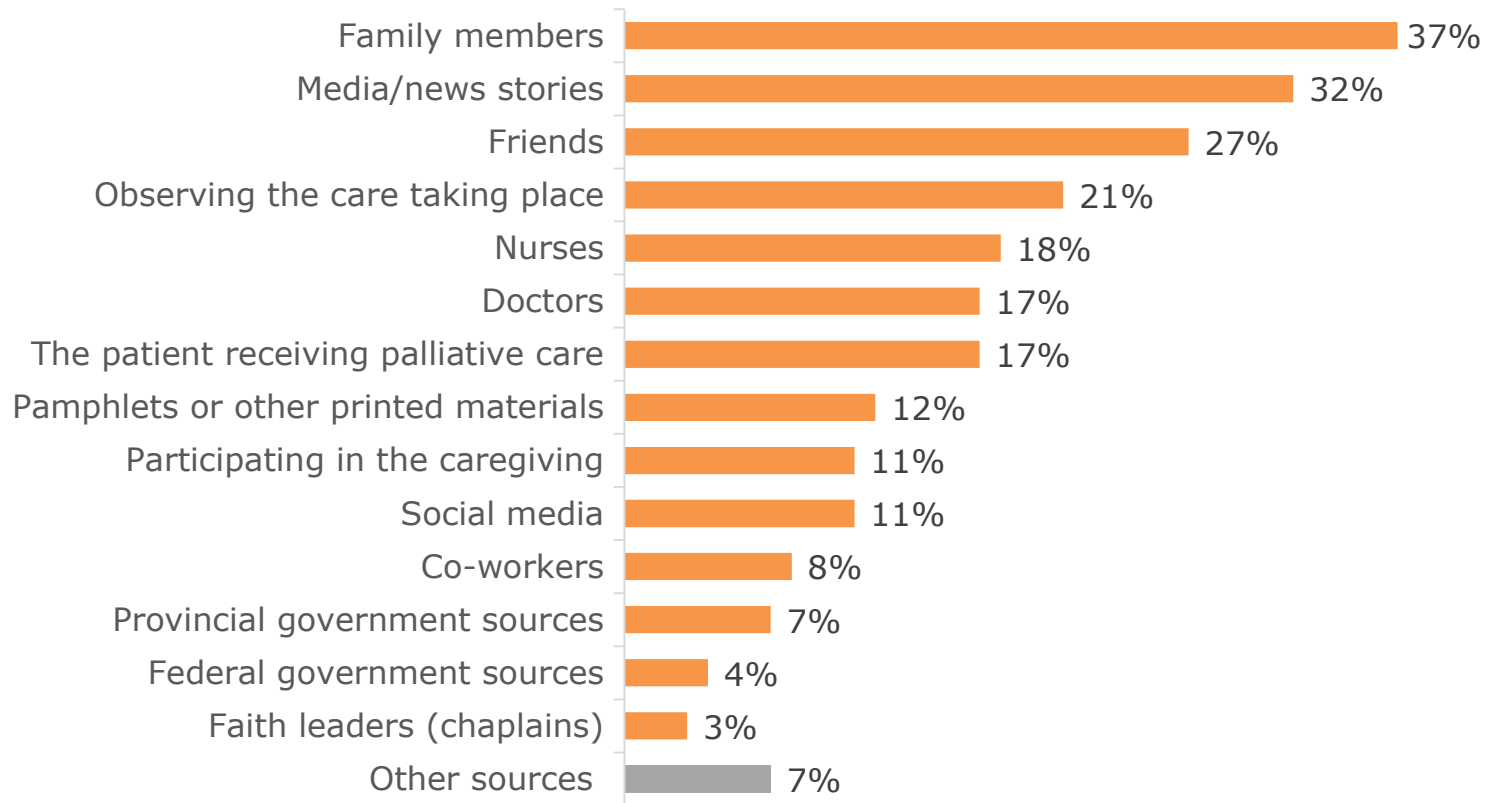


Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national

IPSOS survey 2016, <http://www.palliativecarematters.ca/home/>

Sources of Information

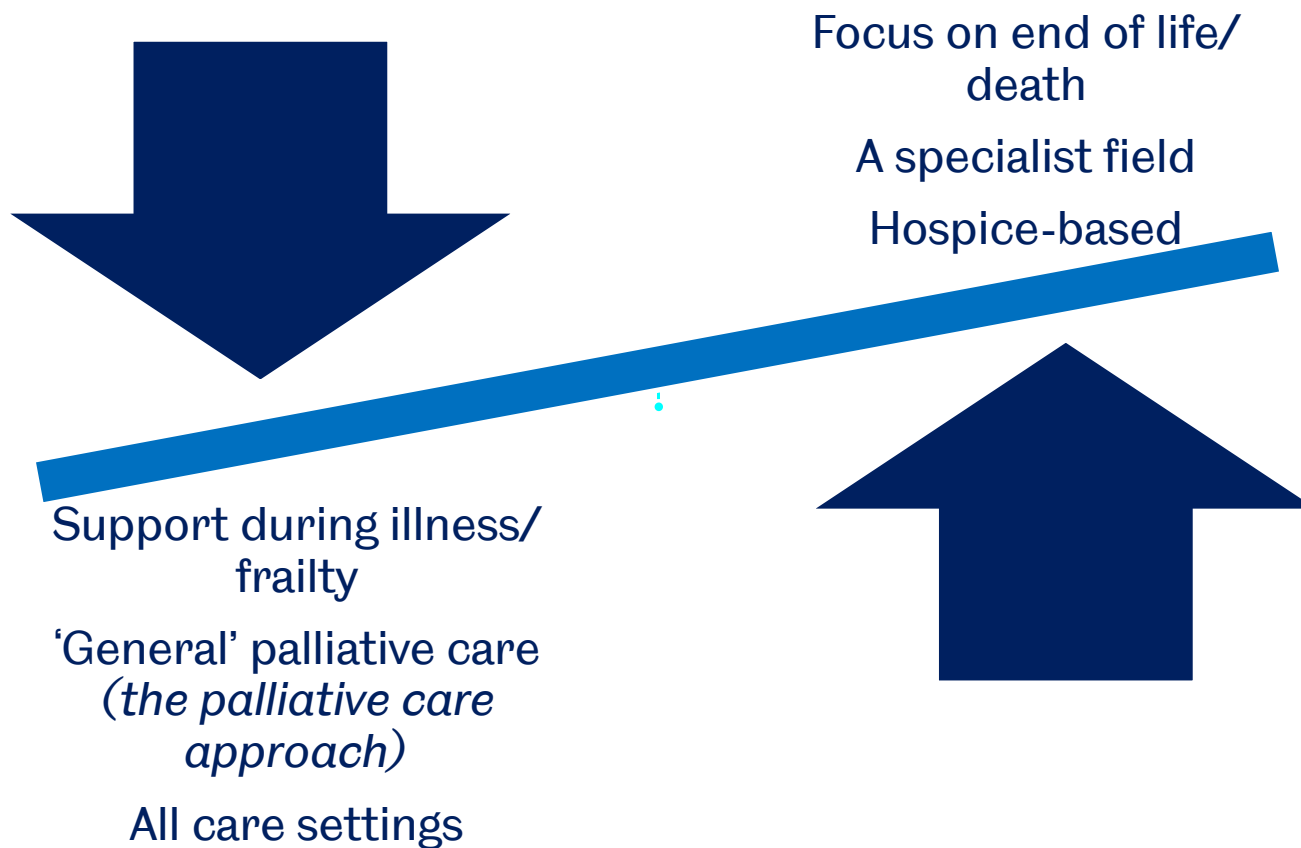


Palliative Care Matters | Building National Consensus

L'importance des soins palliatifs | Forger un consensus national



Ambivalence in palliative care



One inclusive definition

- Palliative care provides comfort and support to patients and families:
 - During a life limiting illness,
 - At the end stages of life, and
 - When dealing with grief and loss
- Relieving pain and other symptoms is an important part of palliative care. It prevents and relieves psychological and spiritual suffering.
- Palliative care improves the quality of life for people of any age and at any stage of a serious illness.

Palliative Care Matters, Canada

<http://www.palliativecarematters.ca/faq/#FAQ1>

Four questions:

1. What techniques are effective in raising public awareness and promoting engagement in **general health issues**?
2. What techniques are effective in raising public awareness of **palliative care issues** and **helping people talk to their families**?
3. What are the best ways of raising awareness of **advance care planning** and what is the impact on quality of care?
4. What are the **key features of successful campaigns**?

Question 1- raising awareness of general health issues: what works?

- **Short mass media campaigns:** 'trustworthy' sources; old and new media
- **Public deliberation methods-** e.g. citizens' panels
- **eHealth interventions**
- Social media (Twitter etc)- but some risks



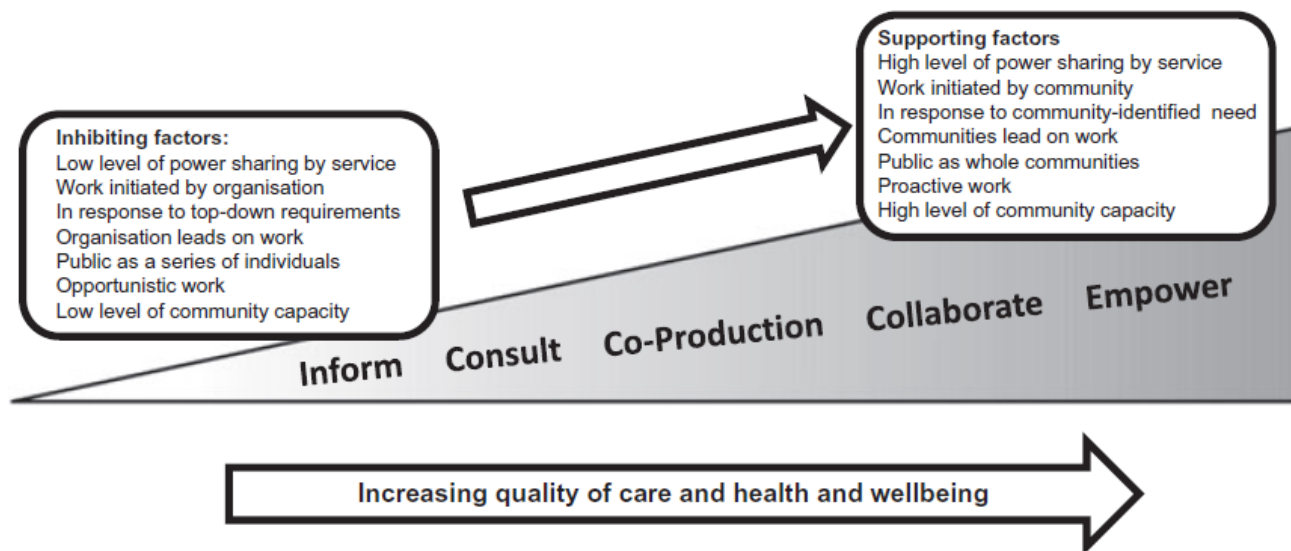


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Question 2- raising awareness of palliative care and talking to your family: what works?



The spectrum of engagement



Sallnow, L. and S. Paul, *Understanding community engagement in end-of-life care: developing conceptual clarity*. Critical Public Health, 2015. **25**(2): p. 231-238

Collaborative and empowering interventions: peer education and /or community projects

Mixed media campaigns- radio, social and print media

Use of stories

'Top down' interventions less successful:
lectures or materials not previously road tested

[A thank you letter to David Bowie from a palliative care doctor](#)

15 Jan, 16 | by BMJSPCblog



Question 3- raising awareness of advance care planning: what works?

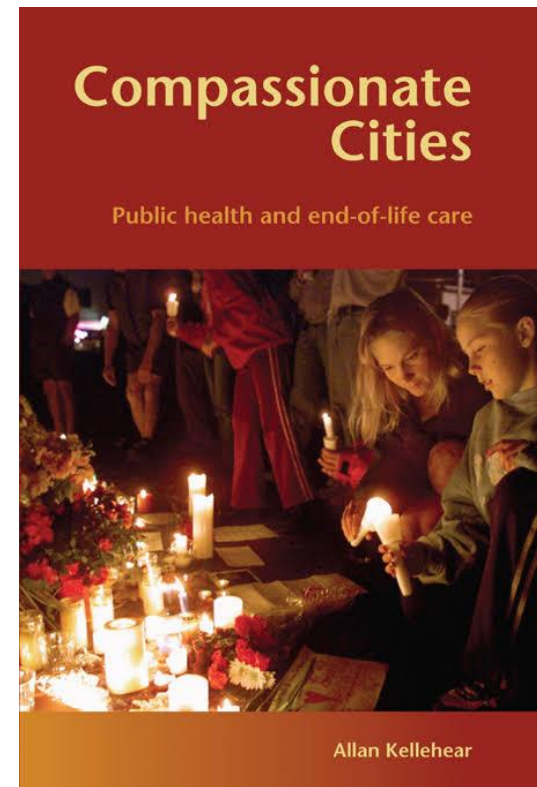
- Ensure materials are culturally appropriate and piloted
- Pay special attention to some groups
- Start young
- Involve the community and build coalitions



“I’m a firm believer in starting them young.”

Compassionate communities

- ...community development initiatives that actively involve citizens
- Involve partnerships between services/ professionals and communities





Slide information from Dr Libby Sallnow:

http://www.togetherforshortlives.org.uk/assets/0001/0471/Libby_Sallnow_-_Compassionate_communities.pdf

St Joseph's Project

Results



Tensions within this work

- Much work is professionally led
- Participant voice is silent
- Risk of romanticisation
- Current interest – must ensure it is not rhetoric
- 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
- Confusion with marketing or traditional volunteering



The Contribution of Social Networks to the Health and Self-Management of Patients with Long-Term Conditions: A Longitudinal Study

David Reeves , Christian Blickem, Ivaylo Vassilev, Helen Brooks, Anne Kennedy, Gerry Richardson, Anne Rogers

Published: June 02, 2014 • DOI: 10.1371/journal.pone.0098340

Aim

To determine how the social networks of people with long-term conditions (diabetes and heart disease) are associated with health-related outcomes and changes in outcomes over time.

Results

Findings indicated that: (1) social involvement with a wider variety of people and groups supports personal self-management and physical and mental well-being; (2) support work undertaken by personal networks expands in accordance with health needs helping people to cope with their condition; (3) network support substitutes for formal care and can produce substantial saving in traditional health service utilisation costs. Health service costs were significantly ($p < 0.01$) reduced for patients receiving greater levels of illness work through their networks.

Conclusions

Support for self-management which achieves desirable policy outcomes should be construed less as an individualised set of actions and behaviour and more as a social network phenomenon. This study shows the need for a greater focus on harnessing and sustaining the capacity of networks and the importance of social involvement with community groups and resources for producing a more desirable and cost-effective way of supporting long term illness management.



St Joseph's
Hospice

Slide from Dr Libby Sallnow,

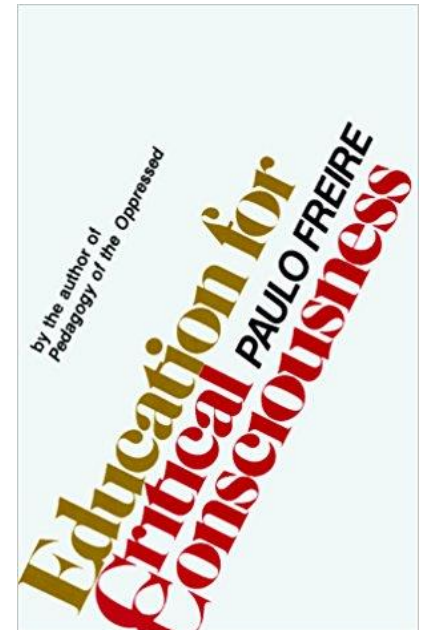
[http://www.togetherforshortlives.org.uk/assets/0001/0471/Libby_Sallnow - Compassionate communities.pdf](http://www.togetherforshortlives.org.uk/assets/0001/0471/Libby_Sallnow_-_Compassionate_communities.pdf)



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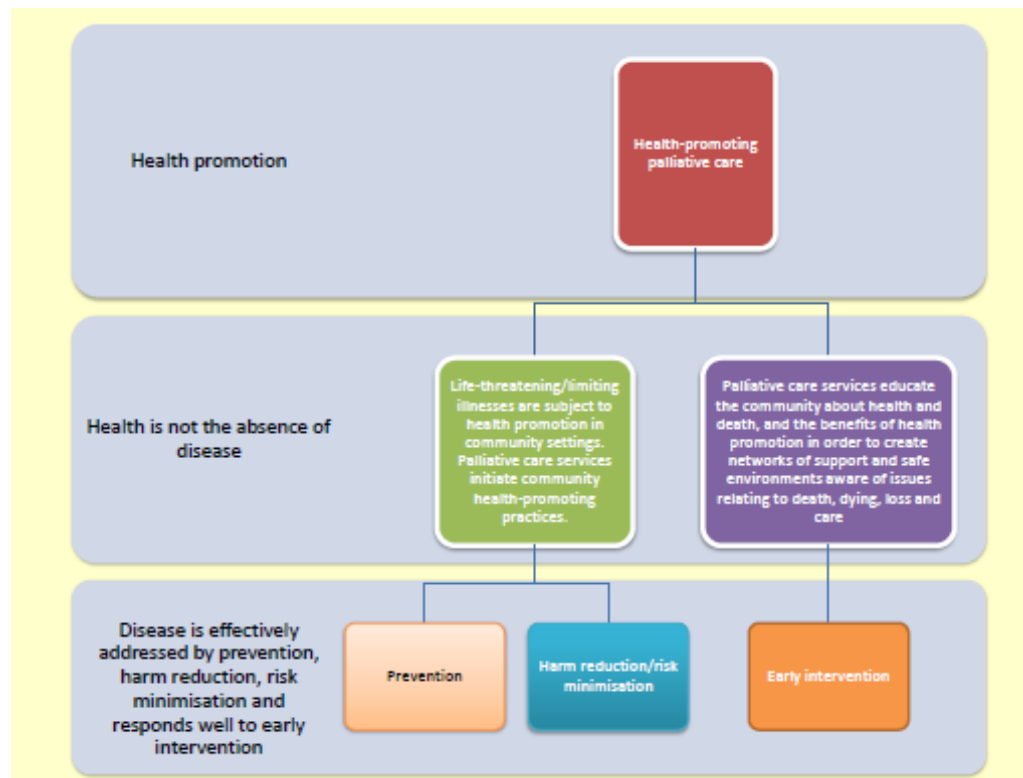
Community based interventions: mechanisms

- Maximisation of social capital
- Creation of 'critical consciousness'
- Allowing communities to develop local solutions
- Promotion of health and well-being





Health promoting palliative care

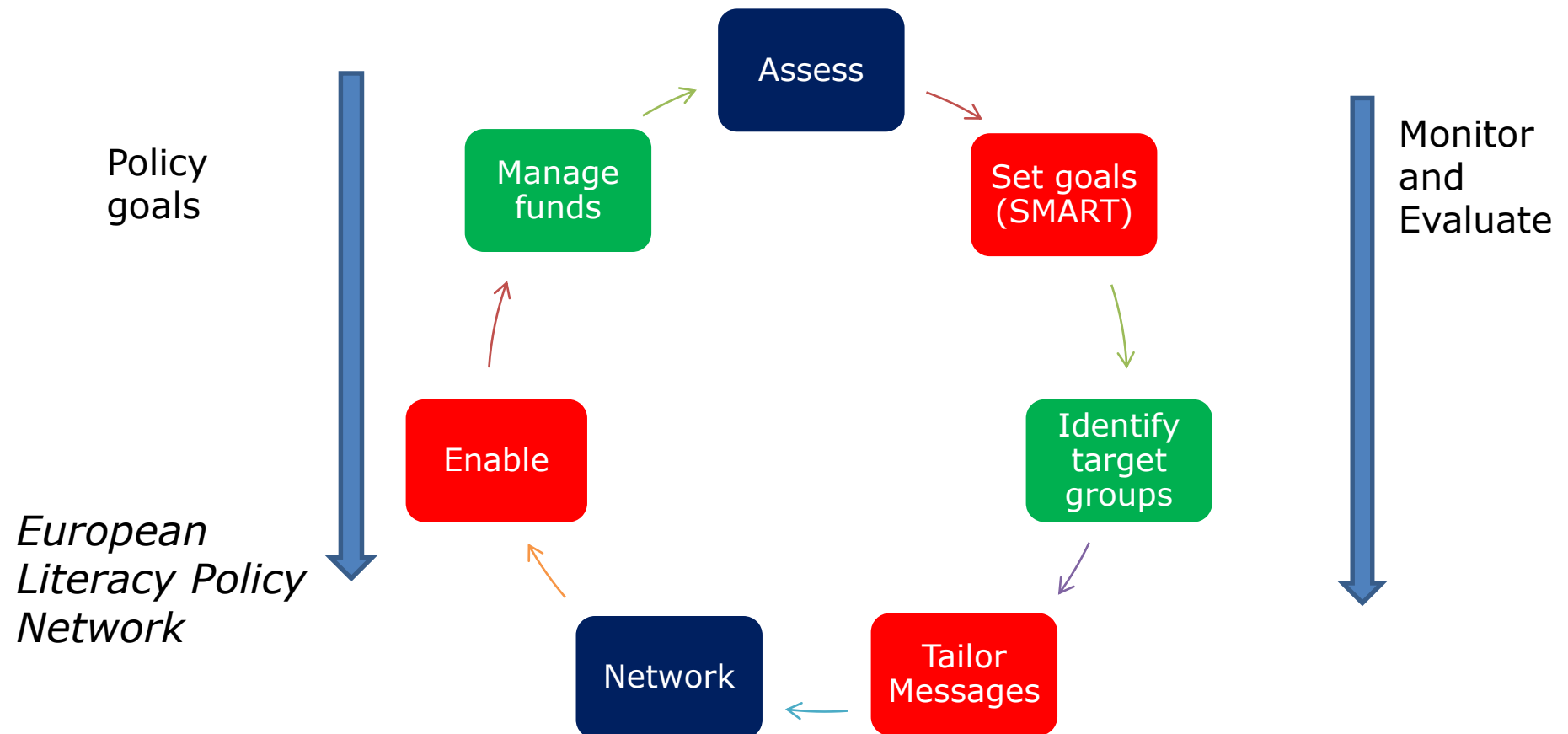


Public health approaches to end of life care: a toolkit. Public Health England.

[http://www.ncpc.org.uk/sites/default/files/Public Health Approaches To End of Life Care Toolkit WEB.pdf](http://www.ncpc.org.uk/sites/default/files/Public%20Health%20Approaches%20To%20End%20of%20Life%20Care%20Toolkit%20WEB.pdf)



Question 4- what do successful campaigners do?





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Summary and implications

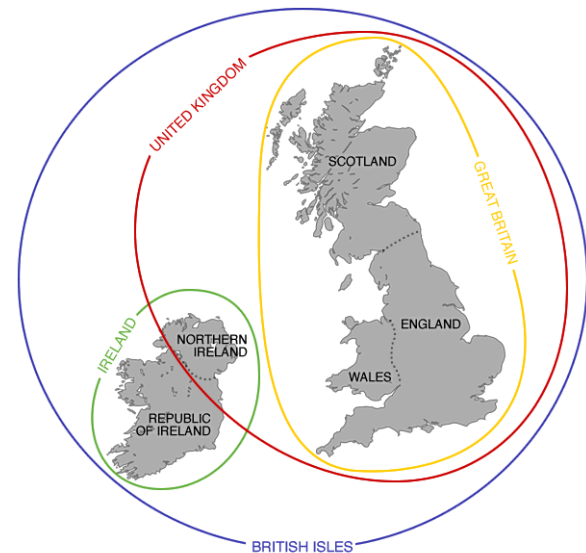
Key messages

- Public awareness campaigns are effective in palliative care/ advance care planning
- They probably improve quality of care, but evidence lacking
- Short awareness campaigns, combined with longer term community engagement, works
- Planning and evaluation essential

"A problem well stated is a problem half solved"
John Dewey, 1859-1952

What makes a good national campaign?

- **Planning and evaluation**
- **Short interventions with simple messages**
- **Piloting and clarity**
- **Mixed media: old and new**
- **Avoid 'selling' and stereotyping**



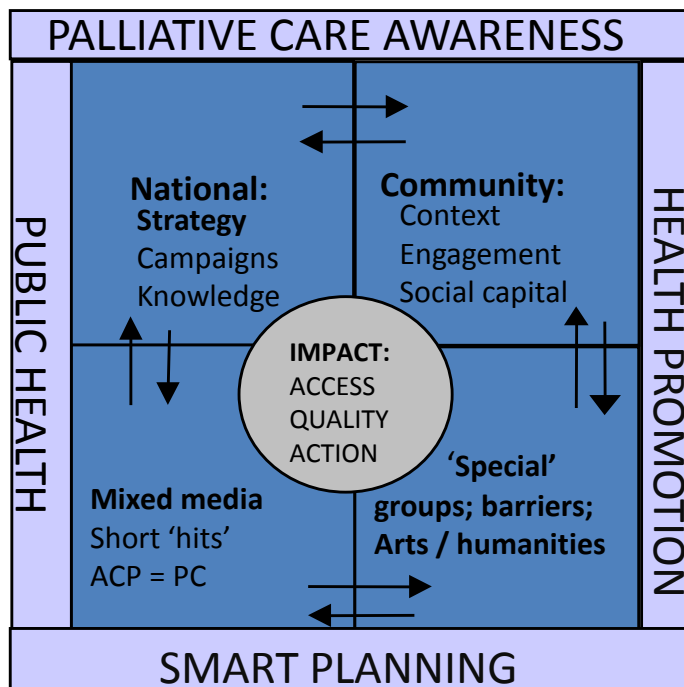
What makes a good community project?

- **Planning and evaluation**
- **Engagement to build social capital/ critical consciousness**
- **Awareness of special groups**
- **Using stories**
- **Arts and humanities**
- **Addressing barriers**





Implications





Tropfest Film Festival short film 2013
<https://youtu.be/ttA2Nk-bFog>