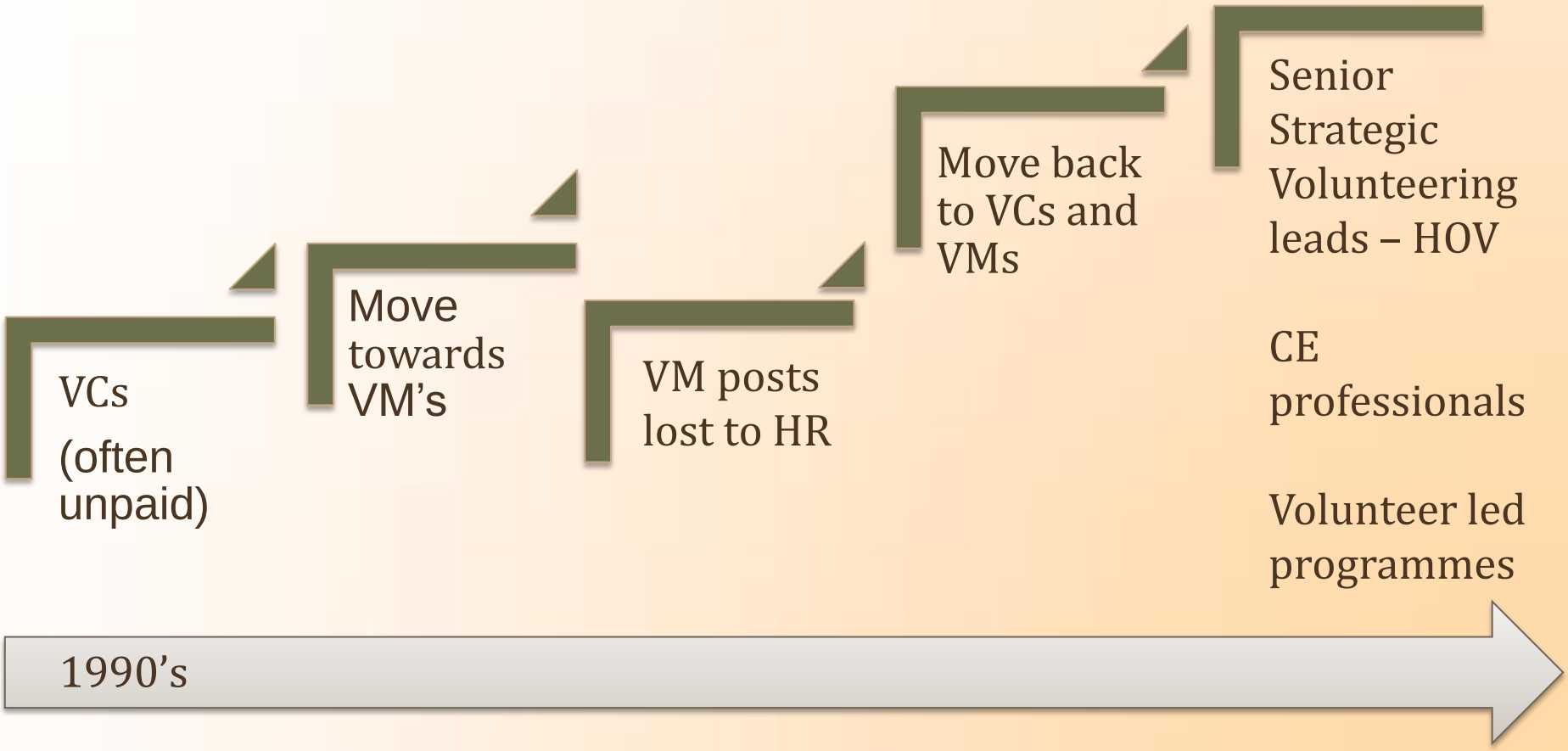
The changing face of volunteering in hospice and palliative

Dr Ros Scott, Honorary Research Fellow, University of Dundee
Co-chair EAPC Task Force on Volunteering

- What is changing and why?
- HPC volunteering in other countries
- The need for evidence
- Emerging tensions

Volunteer management journey



Influencing change

Volunteering in the community

Research round up

‘The encouragement of new models of volunteer-led volunteer services at the end of life bringing knowledge and continuity to a system of care that is all too often fragmented’.

(Volunteers Vital to the Future of Hospice Care. The Commission into the Future of Hospice Care 2013, p6).

‘Hospices could do more with volunteering to develop more inclusive community links’

(Morris et al, 2015 Volunteers bridging the gap to the community?)

Research round up 2

‘Increasing contact with volunteers as part of a social action befriending service appears to significantly improve quality of life for people in their last year of life’.

‘Outcomes of quality of life, loneliness and perception of social support were improved. Improvements did not reach statistical significance, but all trends were consistently in favour of the befriending service.’

(Walshe et al. (2016) What is the benefit of social action befriending services at the end of life? ELSA Study)

Research round up 3

'There is a strong link between hospice volunteering and UK hospice sustainability'.

(Scott, Jindal Snape and Mainwaring. (2018) Exploring the relationship between volunteering and hospice sustainability in the UK: A theoretical model. International Journal of Palliative Nursing 24 (5) 212-219

'Volunteers '…use practical tasks to initiate psychological, social and existential care'
'Volunteer role… 'being there' – presence, time, combating loneliness and engaging the patient's direct needs and wishes.'

Vanderstichelen, S. et al (2018) The liminal space volunteers occupy and the roles they perform. International Seminar of EAPC RN and EAPC Reference Group on Public Health and Palliative Care. Brussels, Belgium 25-26 October 2018.

Together for Short Lives FSV pilot evaluation

Project aims:

- Improve wellbeing/QOL
- Help families to cope
- Positive volunteer experience
- Feasibility of volunteer support
- Partnerships

Volunteer activity:

Five pilot sites

Practical/emotional support

- Household tasks
- Transport to appointments
- Outings
- Play with siblings/homework

Family support outcomes

Family outcomes:

Improved wellbeing/QOL 100%
Families coped better 95%
Reduction in stress 95%
More time important tasks 68%
Less time on household tasks 55%

Further outcomes:

Volunteers: confidence/skills, keen to continue 92%
Organisations: greater capacity
"Model has huge potential"
Together We Can – free resources, community of practice
https://www.togetherforshortlives.org.uk/changing-lives/developing-services/developing-volunteering-services/__about/

Hospice UK Survey: Adult services

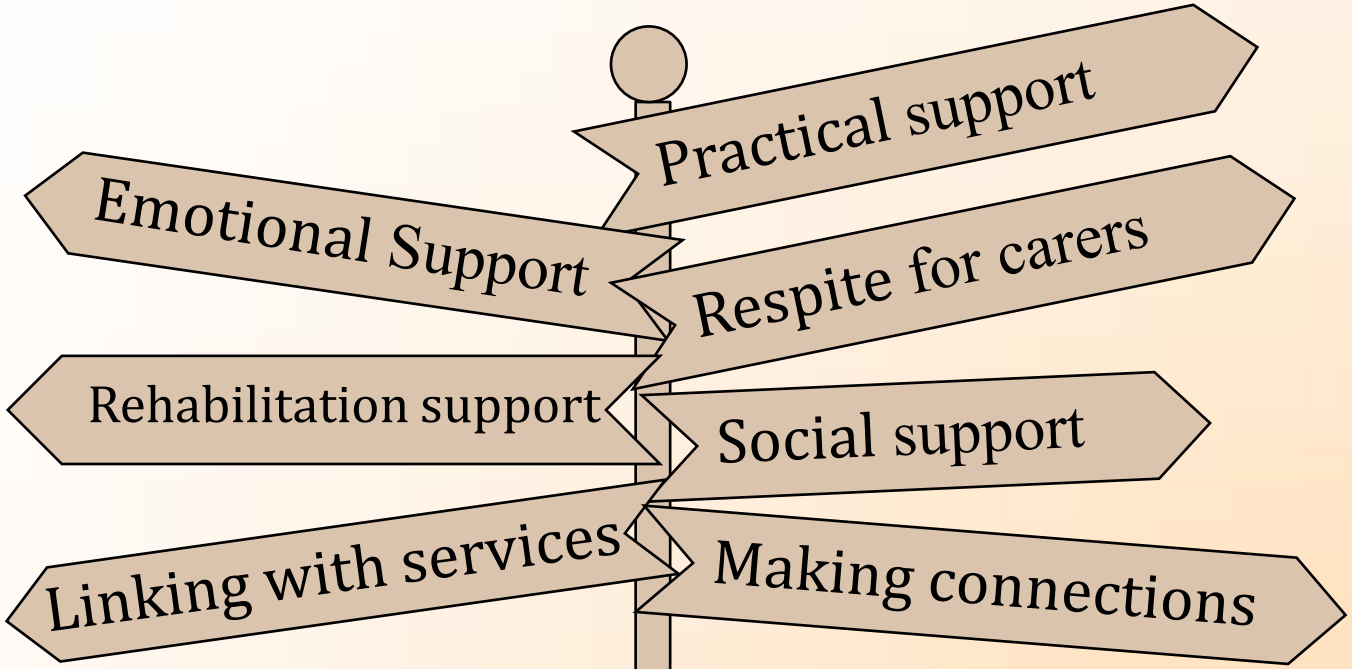
Hospice community volunteering

Project aims:

- Map the extent
- Understand structures/approach
- Understand benefits/drawbacks
- Evidence for new resource hub

Initial findings:

- Online survey and interviews
- Responses from 121/225 hospices
- 70% had cv programmes
- 60% (n=21) without keen to develop
- Commitment towards less structured models



People outcomes

Reduced isolation
Improved wellbeing
Improved care/access
'Doing with not to'

Hospice outcomes

Reaching new people
Improved capacity/services
Engaging communities
Staff focus – complex care

Other countries

- Context, funding, influences and change
- National approaches: legislation, training, data
- Country examples: Germany, Poland, Netherlands, France
- “Being there”- presence, time, connection, sensing and responding to person’s needs and wishes
- What volunteers tell us

EAPC Madrid Charter on Volunteering in HPC

- Background EAPC and Task Force
- EAPC Madrid Charter 'Voice of Volunteering':
  - Promote successful development of volunteering
  - Recognise volunteering as a third resource
  - Promote research and best practice
- Implementation
  - Publicise, support through signing and implementation
  - Research evidence to develop practice guidance
  - Report on impact

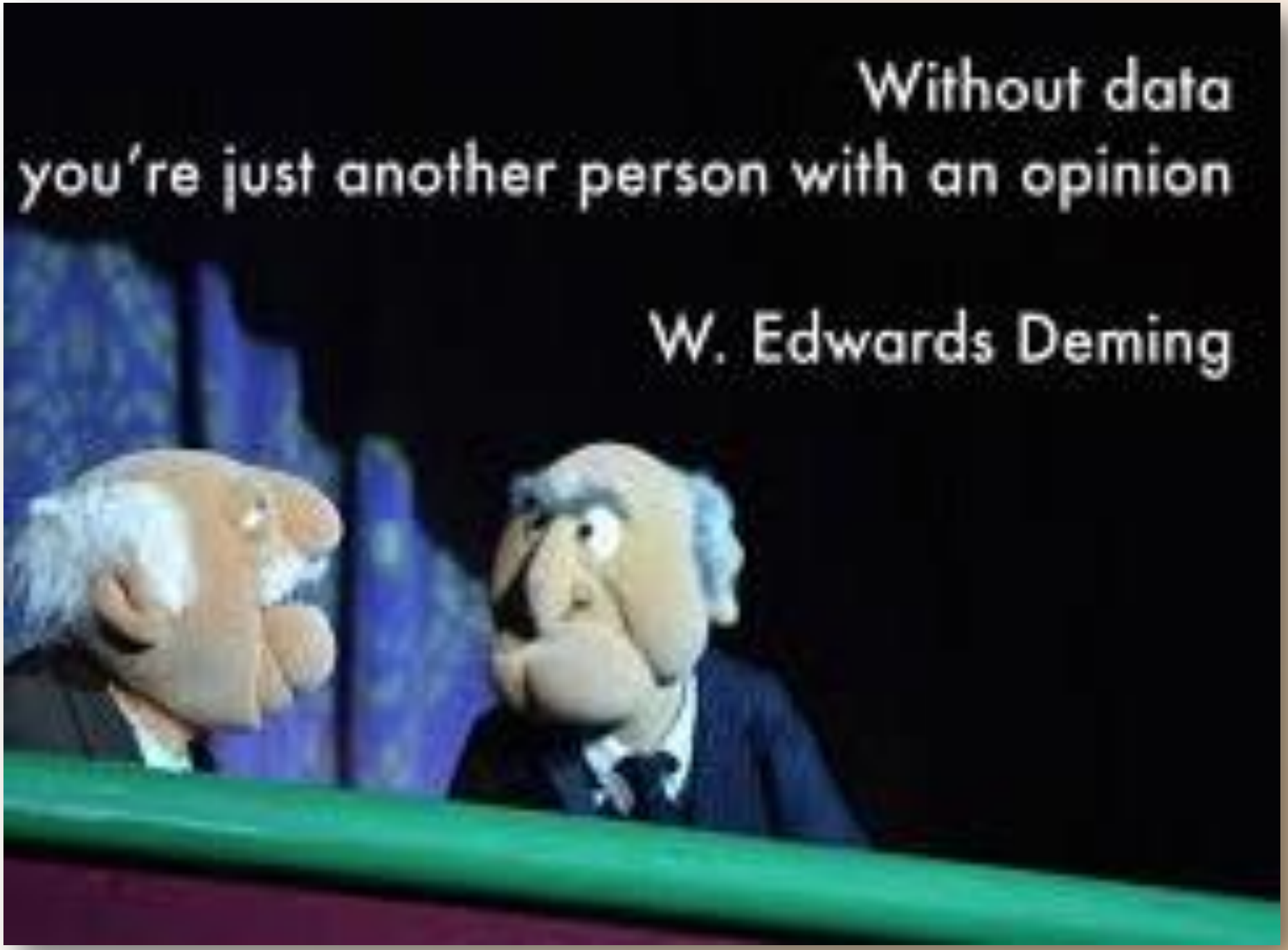
Please sign: http://bit.ly/EAPCVolunteeringCharter

The need for evidence

‘Little is currently known from a population viewpoint about how volunteers deliver care in hospice and palliative care, in particular the level of activities provided within hospice and palliative care and in what settings do these activities occur? What are volunteers’ own experiences?‘

Candy B., Low J., Scott R., Pelttari L. (2018) Volunteers in Palliative Care. In: MacLeod R., Van den Block L. (eds) Textbook of Palliative Care. Springer, Cham https://doi.org/10.1007/978-3-319-31738-0_120-1

- Lack of UK national hpc volunteering data trends, activities, impact, training
- Why it is important
- Changing the narrative


Without data
you're just another person with an opinion
W. Edwards Deming

AVSM – a key role

- Sharing your vision; sharing your work
- Changing the narrative
- Get involved in evaluation and research
  - How can you help with data?
- Working with the Task Force
  - Promoting the Charter, EAPC Atlas, Reseach
- Volunteering Symposium in Berlin May 2019

‘Hospices could do more with volunteering to develop more inclusive community link’
(Morris et al, 2015 Volunteers bridging the gap to the community?)

‘The last thing we need is more hospice volunteers’

‘Without volunteers our hospice would close’
(Scott 2013)

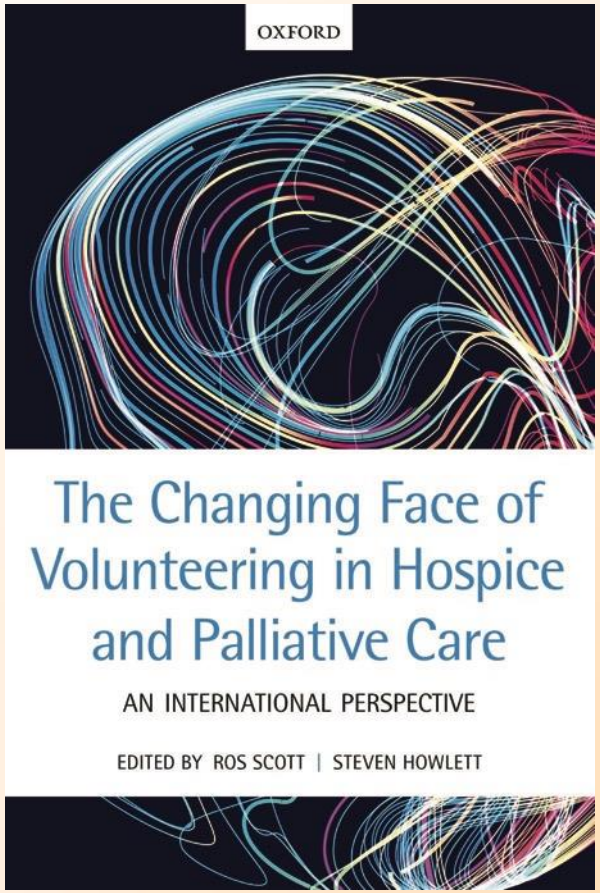
‘The people in this project are not volunteers’

Strength lies in differences

Not in similarities

Steven Covey

Thank you



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Group discussion

1. What data do you collect?

2. How do you/could you measure the impact of volunteering?

3. What will HPC volunteering look like in 2030?

4. Can/should volunteers ever be experts in their own right or will they always be 'assistants to experts' ? (Huntir, 2018)