

Good Life, Good Death, Good Grief

Improving people's experiences of death, dying and bereavement



QUIZ

Q1: Of all deaths in Scotland, what percentage are due to:

a) Cancer?

b) Organ Failure?

c) Frailty/dementia?

d) Other causes?



Q2: Where do most people die?

a) Hospices

b) Hospitals

c) Care Homes

d) At home

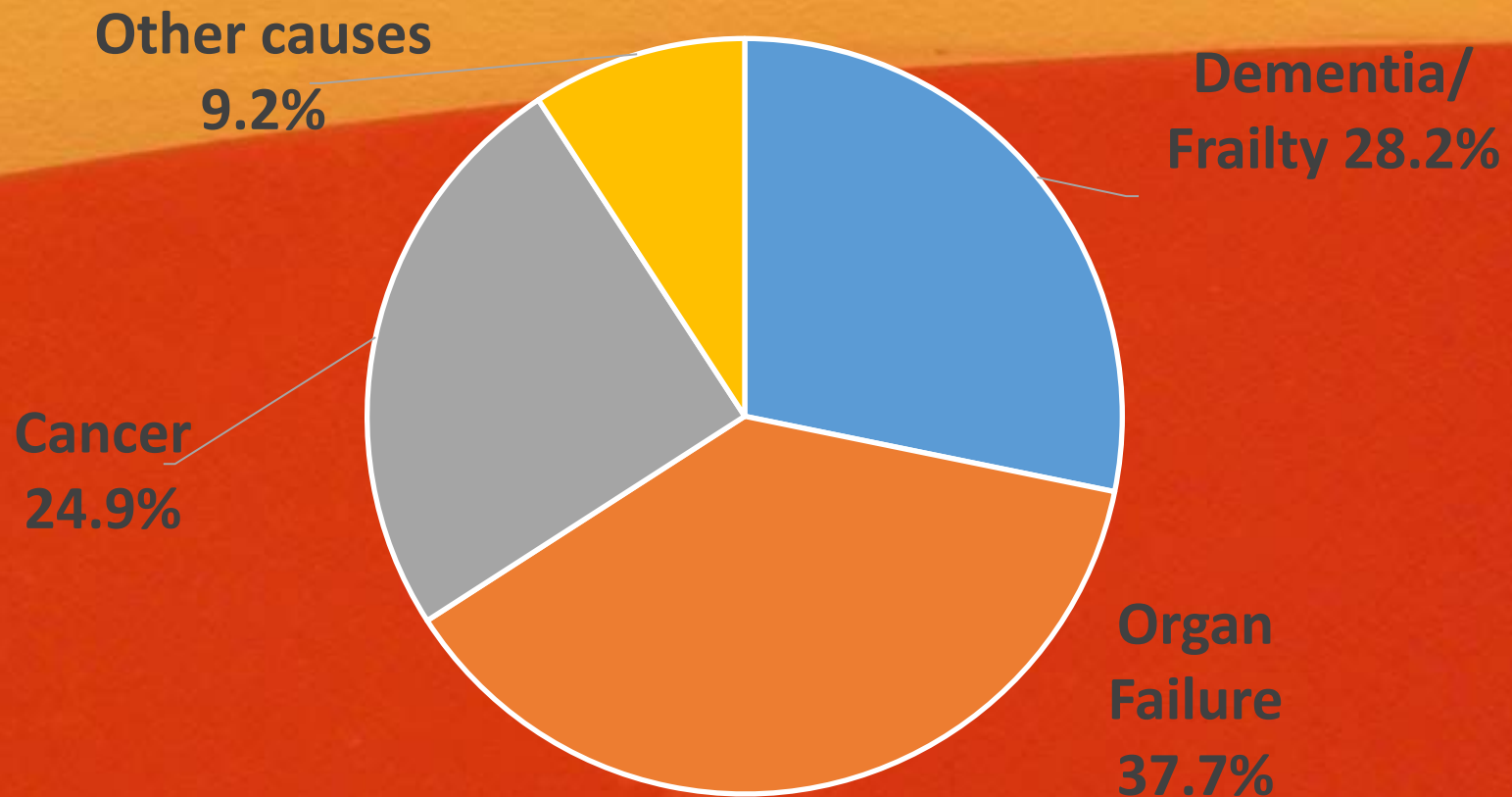


Who looks after
people who are
dying?

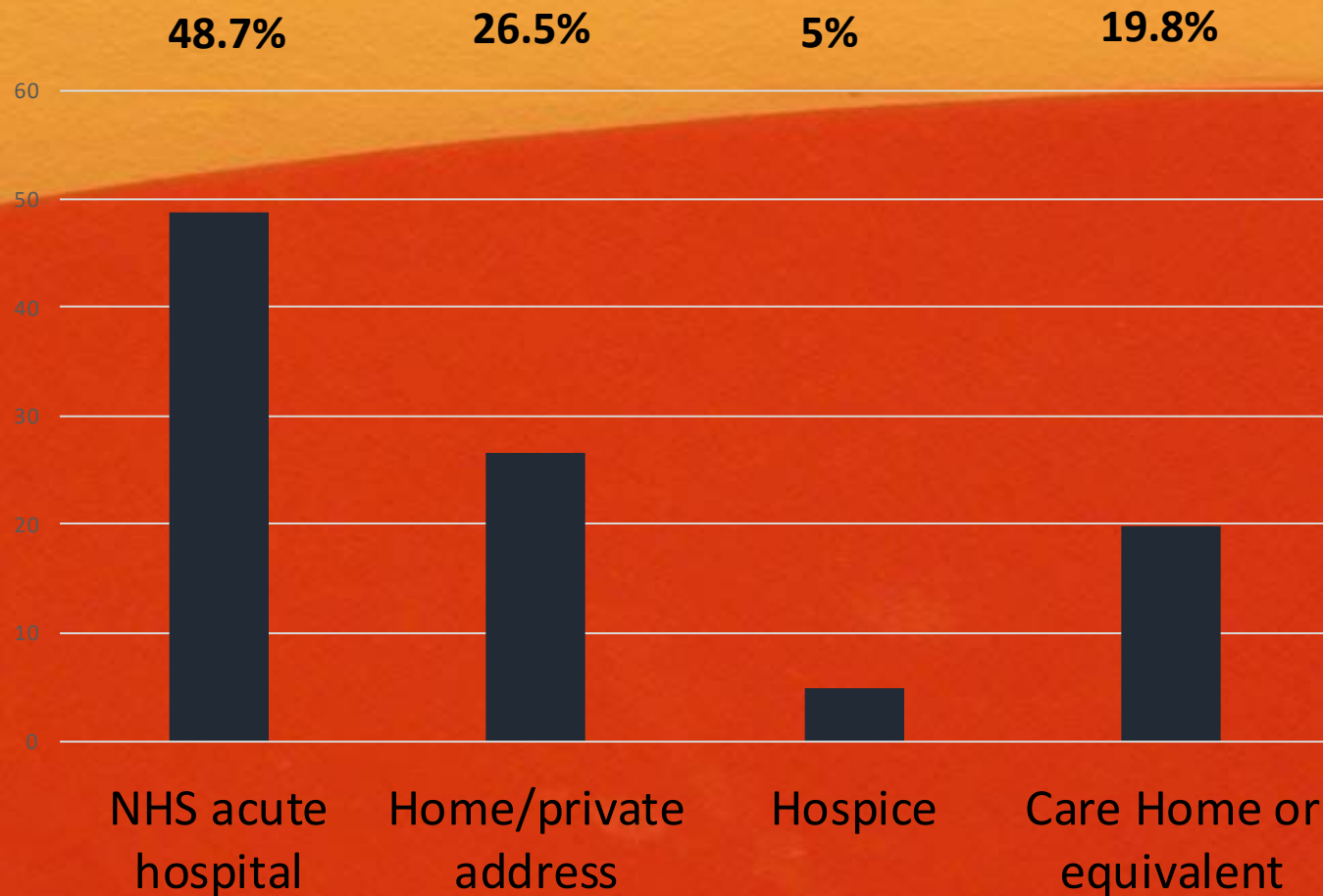
Free text response...



Q1: Of all deaths in Scotland, what percentage are due to a) cancer; b) organ failure; c) frailty/dementia; d) other causes?



Q2: Where do most people die?



Q3: Who looks after people who are dying?

- Family members – including spouses, daughters, sons, siblings, parents.
- Neighbours and friends.
- Community members.
- Homecare and care home support workers.
- Nurses , doctors and other professionals working in the community.
- Staff in hospitals.
- Staff in hospices.



Scottish Partnership for Palliative Care

Brings together health and social care professionals from **hospitals, social care services, primary care, hospices and other**

charities, to find ways of improving people's experiences of declining health, death, dying and bereavement.



We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement.





Coming up...

- Improving care and care culture in acute hospitals
- Empowering communities to provide informal support
- Project ECHO: Building a Community of Practice for Highland Care Homes
- Building resilience around bereavement in communities

Good Life, Good Death, Good Grief

An approach to improving care and care culture in acute hospitals

Partners



- Funded by Macmillan Cancer Care
- Scottish Partnership for Palliative Care
- NHS Tayside
- NHS Lothian
- NHS Greater Glasgow and Clyde

Funded by

MACMILLAN
CANCER SUPPORT



The acute hospital landscape of Good Life, Good Death, Good Grief

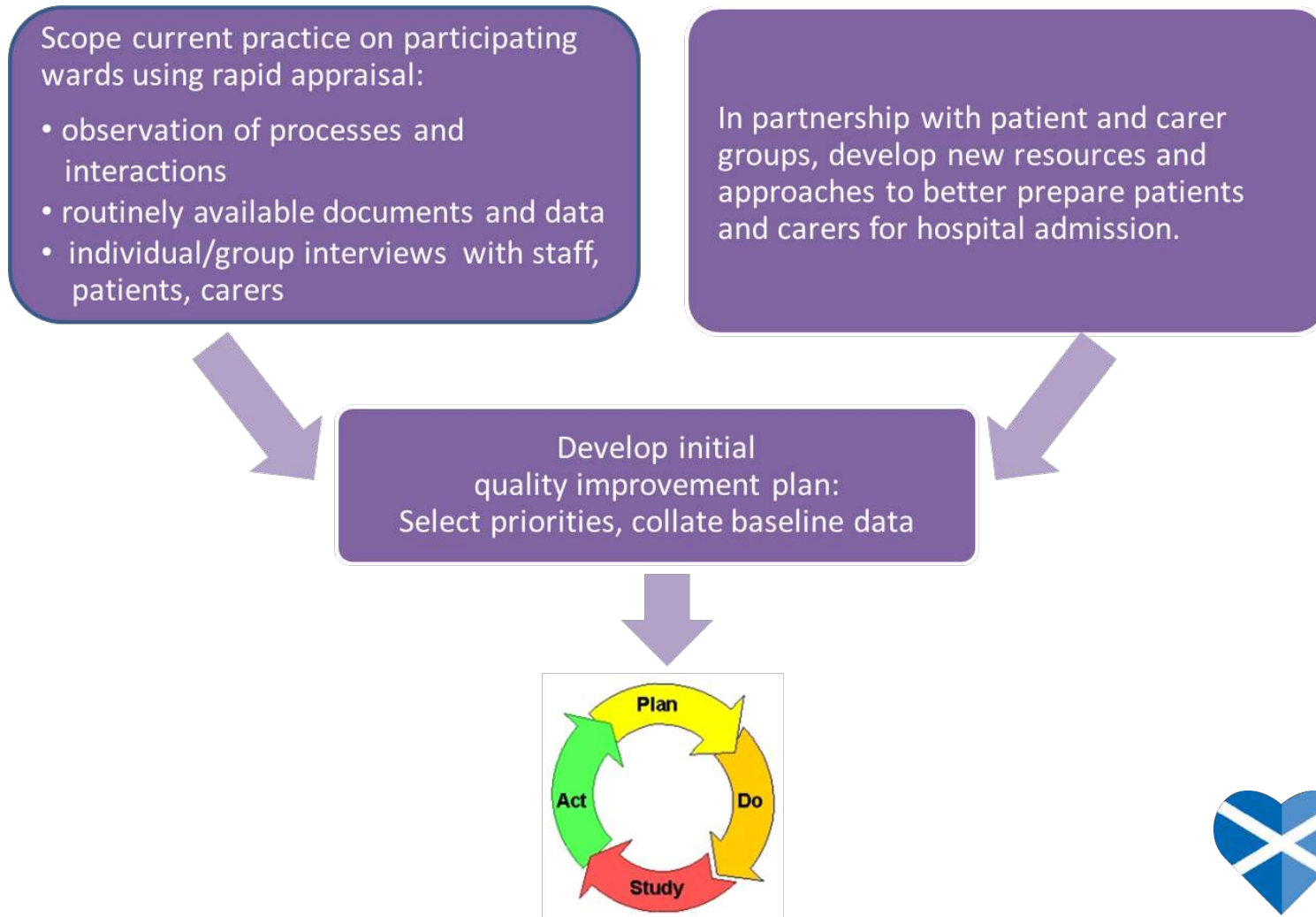
- On a given day:
 - 10, 743 people were in-patients in the acute setting
 - 28.8% (3,093) of those who had been admitted died within the next year
 - 9.3% (1,027) died during the admission studied

Clark et al, Pal Med 2014

- In Scotland
 - 56,736 deaths in 2017/18
 - 12.1% of last 6 months (i.e. 22 days on average) spent in hospital
 - More than half of the Scottish population die in hospital



Project Approach



Findings from Scoping and Baselineing

1. No systematic identification of people who may benefit from anticipatory care planning.
2. Levels of staff expertise and confidence regarding discussing deteriorating health with patients and families vary greatly, but there is enthusiasm for learning and improvement by all ward staff, including experienced consultants.
3. Anticipatory care planning (ACP) conversations with patients and families are typically conducted by senior staff, with only occasional involvement by junior doctors and nursing staff.
4. The role of nursing and auxiliary staff in Shared decision making (SDM) through their formal and informal contact with patients and families is largely overlooked.
5. Poor patient awareness and readiness to discuss their future treatment and care is a key barrier to effective SDM.
6. As a result of system pressures nurses are rarely able to join medical ward rounds, thus limiting their critical contribution to SDM processes.
7. Conversations and their outcomes are often poorly documented in notes.
8. Discharge letter templates do not encourage inclusion of ACP-related information or prompts for community-based care professionals, leading to such information being omitted.
9. Staff currently do not make good use of existing information resources, e.g. the Scottish national DNACPR leaflet.

What People Did

- Process changes
- Education activities
- Development and testing of conversation guides

RED-MAP

R eady	Can we talk about your health and care?
E xpect	What do you know/ want to ask/ expect?
D iagnosis	We know.../ We don't know... Your questions?
M atters	What matters to you now?
A ctions	What can help... Pros and cons of options... This does not work well / help when...
P lan	Let's plan ahead for when/ if....

ACP-Talk 1 (Starting Anticipatory Care Planning)

Let's think ahead

Can we talk about your health and care?

What do you know/ want to ask/ expect?

We know.../ we don't know... Your questions?

Do say...

When would be a good time to talk? Who should join us?

Can we talk about how you are doing.../ what has changed?

Have you thought about making plans for the future?

How do you see things going in the next months/ years...?

Do you have questions or worries you'd like to talk about?

What do you like doing/ would you like to go on doing?

Do you have questions or worries you'd like to talk about?

It's good that you are well just now, but can we talk about what might happen when/ if...?

If you got less well/ seriously ill, what would be important?

Are there any things you'd like or wouldn't want for you?

Clear language Short sentences Pauses

ACP-Talk 2 (Getting less well)

Let's think ahead

Can we talk about your health and care?

What do you know/ want to ask/ expect?

We know.../ we don't know... Your questions?

Do say...

How have you been doing recently? What has changed?

I wish we could..., but we don't know if...

We hope..., but we are worried that/about...

It's possible you might not get better because...

Do you have questions or worries you'd like to talk about?

Are there things you'd like or wouldn't want for you?

This can help.../This does not work well for people with...

Clear language Short sentences Pauses

Don't talk about...

Treatment limits/calling, withdrawal, futile, distressing, chance of, try...

ACP-Talk 3 (Talking about dying)

Let's think ahead

Can we talk about your care?

What do you know/ want to ask/ expect?

We know.../ we don't know... Your questions?

Do say...

We hope..., but we are worried that/about...

It is possible you will not get better this time...

Can we talk about what might happen if you get more ill?

Do you have questions or worries you like to talk about?

Are there things you'd like or wouldn't want for you? (e.g. CPR)

This can help by.../This does not work when... (e.g. CPR)

We don't know exactly what will happen or when...

Clear language Short sentences Pauses

Don't talk about...

Treatment limits/calling, withdrawal, futile, nothing more we can do...

Talking about treatment and care when people are ill in hospital

NHS SCOTLAND



The team looking after you want to find out about what matters most to you. When a person is ill and in hospital, it is important to talk about what is happening now and what might happen if the person's condition changes so we can plan good care together.

Here are some things you might want to ask us:

- What is what we are doing?
- What is what we are planning to do?
- Can we talk about what is important to me and the things I want to do?
- Can we talk about what I am worried about?
- Can we talk about what I am worried about?
- Can we talk about what I am worried about?

Put up a leaflet and talk to the staff on the ward

Building on the ward

One acute area's change actions

- Effective Communication for Healthcare (EC4H) training
- More structured Treatment Escalation Plan
- Improved learning opportunities for junior medical staff
 - e-Learning
 - Role play
 - Test communication guides
- Updating of ward information resources to include Provincial Palliative and End-of-Life Care (PEoLC) issues
- Audit on people for whom Acute Medical Unit (AMU) admission was not in their best interest
- Culture change – purposeful, deliberate attention to SDM



Evaluation of Interventions (What People Said)



“The freedom of communication is so much better between staff now...This has been a great way of enriching what we do here...It feels like it works.”

“The nurses didn’t used to be involved in this, and as a result some information would be missed, or picked up wrongly by other members of the team. Now everyone is involved in the conversations, so everyone is working from the same page.”

“I think even just reading through the resources has helped me with how I speak with patients. I’m using some of the conversation prompts already, even though we’ve not implemented them across the ward. There is definitely a gap for using the RED-MAP cards...these resources give control back to the patients, which is really important.”



Evaluation of Interventions (What People Said)

“Each hospital has come up with a different approach to improvement, and for us here that has fostered a sense of ownership related to the changes we’re making.
That’s a really important approach to take.”

“We’re working at over 100% capacity just now, our winter beds crisis is still impacting on us. So in terms of getting other things done, without additional resources it’s really difficult.

“BotB has impacted on us as staff, because we talk about the concept of optimal care now, and we didn’t before.”

Key Learning 1

- Evidencing activity and impact is a big challenge
- Timescales are long
- Competing priorities (and crises)
- Many ward staff are very interested and engaged
- The programme has been a catalyst for change
- Evidence of positive impact for people and their families

Key Learning 2

- Channel more resources to ward level
- Extra resources needed to measure change and evidence impact.
- Value and measure cultural change as well as process and activity change.
- Availability of local resources should be conditional on clearly identified local leadership and plan
- Increase input and feedback from the public, patients and families.
- Sustain activity for a longer period

Phase 2

- 3-year programme, again funded by Macmillan
- One post (hosted by SPPC)
- Some £ resource for local improvement work
- Three strands:-
 - Establish and support a national network for palliative care in acute hospitals
 - Local improvement work on general wards
 - Public engagement
- **Get in touch – we want you to be involved!**

Resources and references

- Effective Communication for Healthcare
<http://www.ec4h.org.uk/>
- 4 videos for professionals about using the RED-MAP communication guide.
<https://www.spict.org.uk/other-resources/>
- Hospital doctors' experiences of caring for dying patients
https://www.rcpe.ac.uk/sites/default/files/jrcpe_48_4_gray.pdf

Good Life, Good Death, Good Grief

Empowering communities to support each other

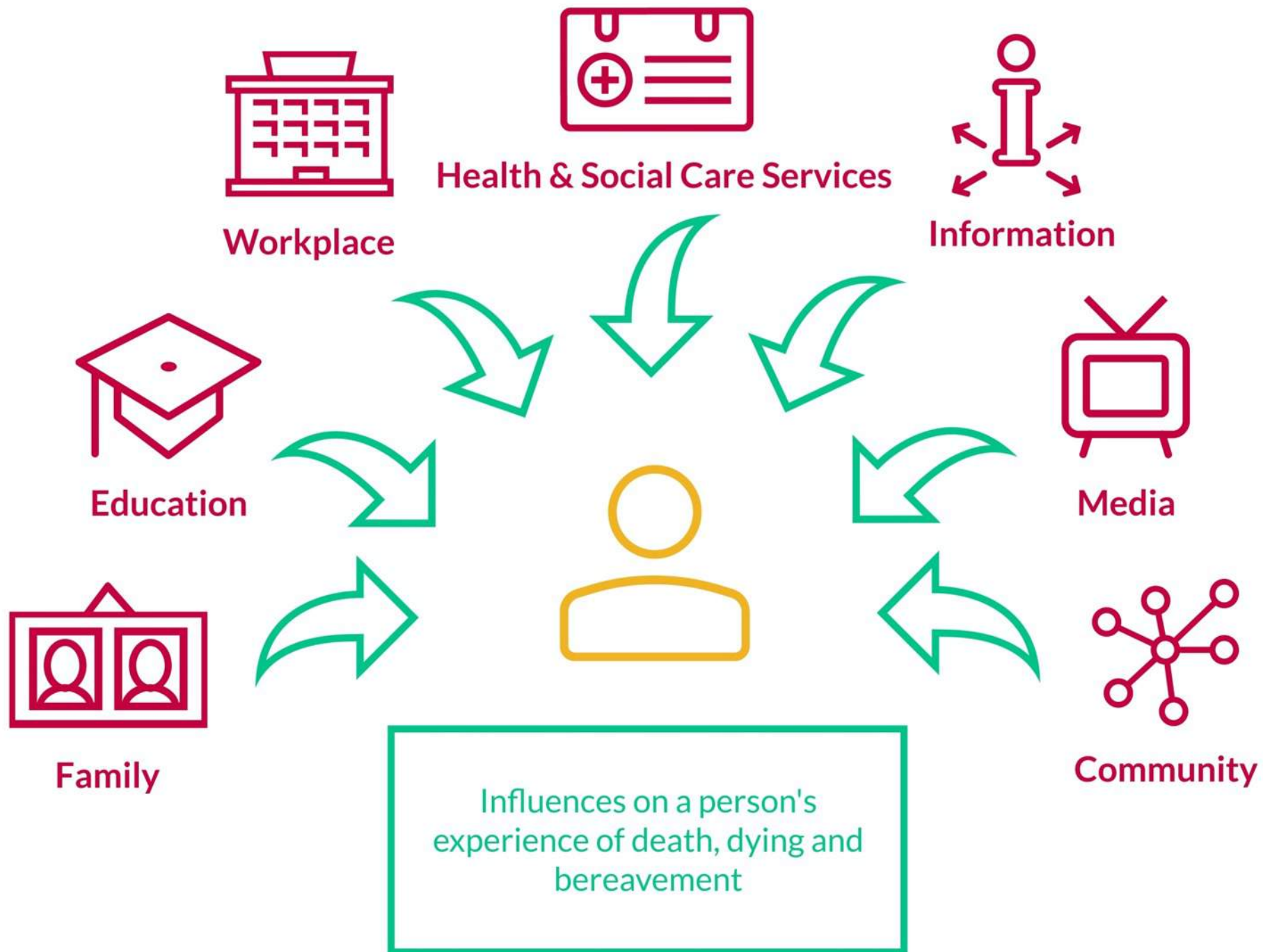
Mark Hazelwood, Chief Executive, Scottish Partnership for Palliative Care

Rebecca Patterson, Director of Good Life, Good Death, Good Grief

20 Takes on Death and Dying

To play the video please click here:

<https://vimeo.com/347469980/0f54fdf445>



Have we become disempowered?

- Medicalisation and institutionalisation
- Disparate society
- Most people die in extreme old age



1. **End of Life Aid Skills for Everyone (EASE):** a public education course
2. **Nurturing Compassionate Communities:** support communities to take local action relating to death, dying, loss and care.
3. **Bereavement-friendly Workplaces:** working to support employers to support employees during bereavement.





End of Life Aid Skills for Everyone (EASE)



The EASE course aims
to enable ordinary people to be more comfortable and
confident supporting family/community members with
issues they face during dying, death and bereavement.



Module 1: An Introduction to Death in Scotland





Module 2: Serious Illness and Frailty



Module 3: The Reality of Caring and Dying

Module 4: Caring for the Carer





The Truacanta Project



Helping each other with
death, dying, loss and care

...will work with communities to develop local projects aimed at improving local people's experiences of death, dying, loss and care.

Up to four communities from across Scotland will receive dedicated community development advice and support for two years.

Scottish Compassionate Communities Toolkit

A collection of resources providing ideas and information aiming to of practical use to people wishing to make their local community more supportive of people going through difficult times that can come with death, dying, loss and care.



scottish compassionate communities toolkit

YOU ARE HERE: [HOME](#) > [TOOLKIT](#)

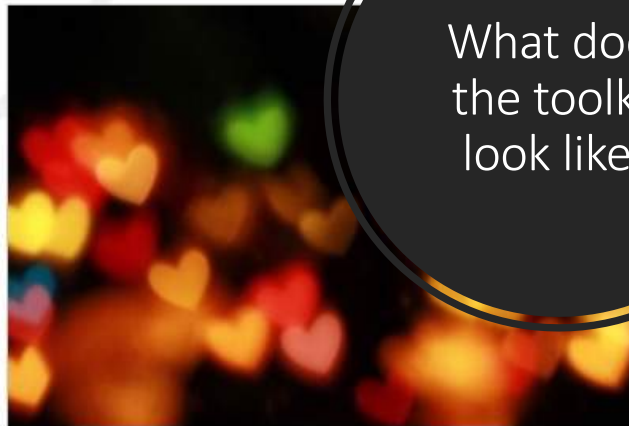
welcome to the toolkit

This collection of resources provides ideas and information that will be of practical use to people wishing to make their local community more supportive of people going through difficult times that can come with death, dying, loss and care.

Since communities are all different, not all of the ideas in the toolkit will appeal to everyone, or seem appropriate for every community.

However, hopefully they will provide a starting point and help to stimulate thought and new ideas in communities.

Click on the links below for more information...



What does
the toolkit
look like?

[getting started](#)

Some ideas on starting a new project and gathering support for local action from across the community.

[creating opportunities](#)

How might you create opportunities for people to talk about, plan for, give support and receive support relating to ill health, death, dying and bereavement?

[encouraging supportive environments](#)

How might you encourage institutions (eg schools and workplaces) and neighbourhoods to have cultures/structures/networks which enable people to give and receive support in the face of death, dying and bereavement?

[increasing knowledge and skills](#)

How might you increase people's knowledge, skills and information, enabling them to respond to and support each other through the difficult times that can come with death, dying and bereavement?

Search this site ...



Text size: [A](#) [A](#) [A](#)

browse the toolkit

[welcome](#)

[welcome to the toolkit](#)

[getting started](#)

[practicalities - learning from others](#)

[what is a compassionate community?](#)

[compassionate cities](#)

[networking](#)

[knowledge, skills & information](#)

[end of life aid skills for everyone \(ease\)](#)

[create an online directory of local activities and services](#)

[become a dementia friend](#)

[pushing up the daisies](#)

[coach 4 care](#)

[creating opportunities](#)

[to absent friends](#)

[death revue](#)

[monthly gathering](#)

[good death week](#)

[planning ahead workshop](#)

[back home boxes](#)

[encouraging supportive environments](#)

[nurture neighbourliness](#)

[supportive workplaces](#)

[supportive schools](#)

What does the toolkit cover?

Creating Opportunities

Increasing knowledge and Skills and Information

Encouraging supportive environments



**WORLD'S
BEST
BOSS**

Supportive Workplaces

Helping employers to
become more
“bereavement-friendly”

For more information on any of this, please
email:
rebecca@palliativcarescotland.org.uk

Good Life, Good Death, Good Grief

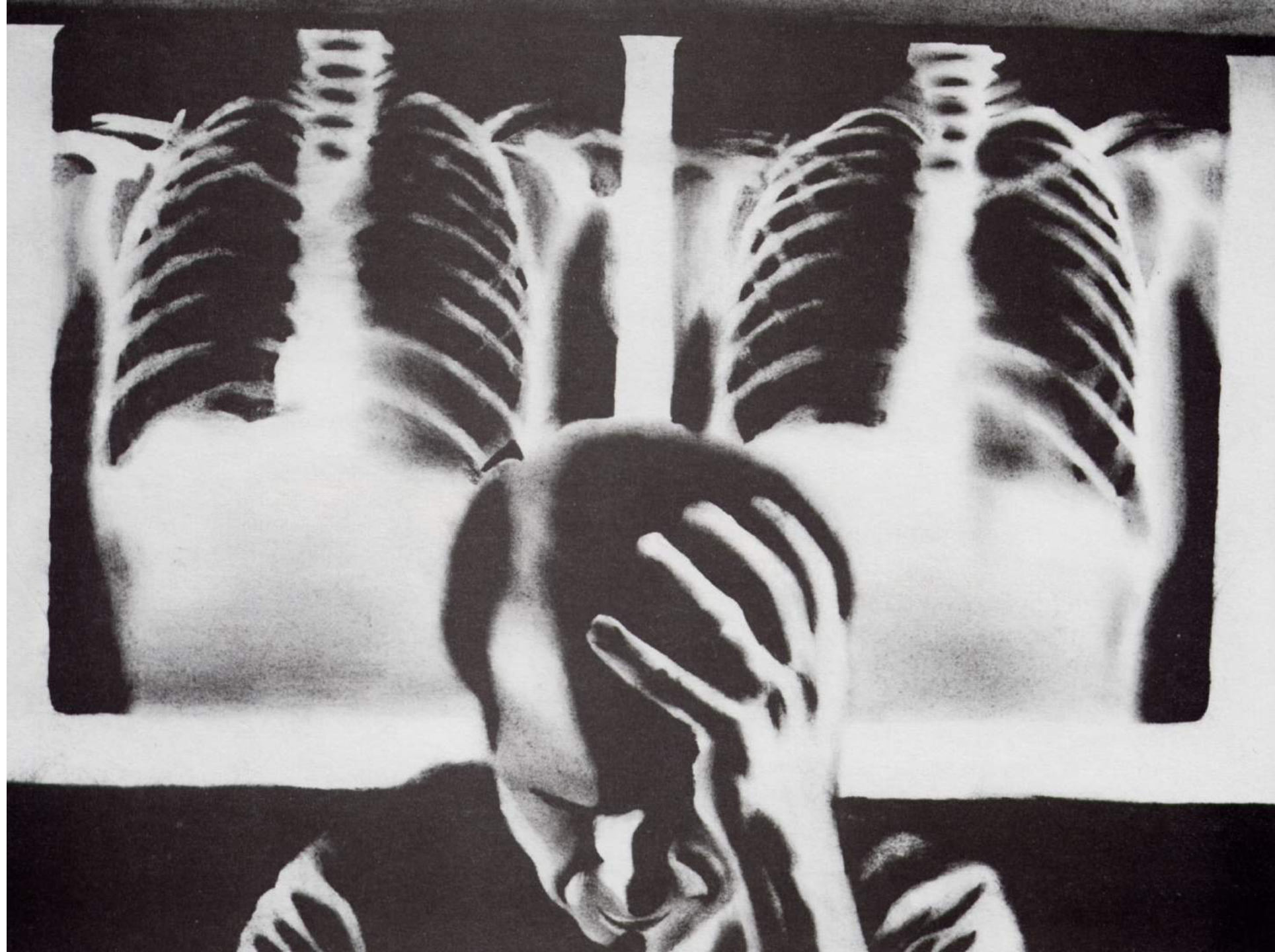
Project ECHO: Building a Community of Practice for Highland Care Homes

Partners



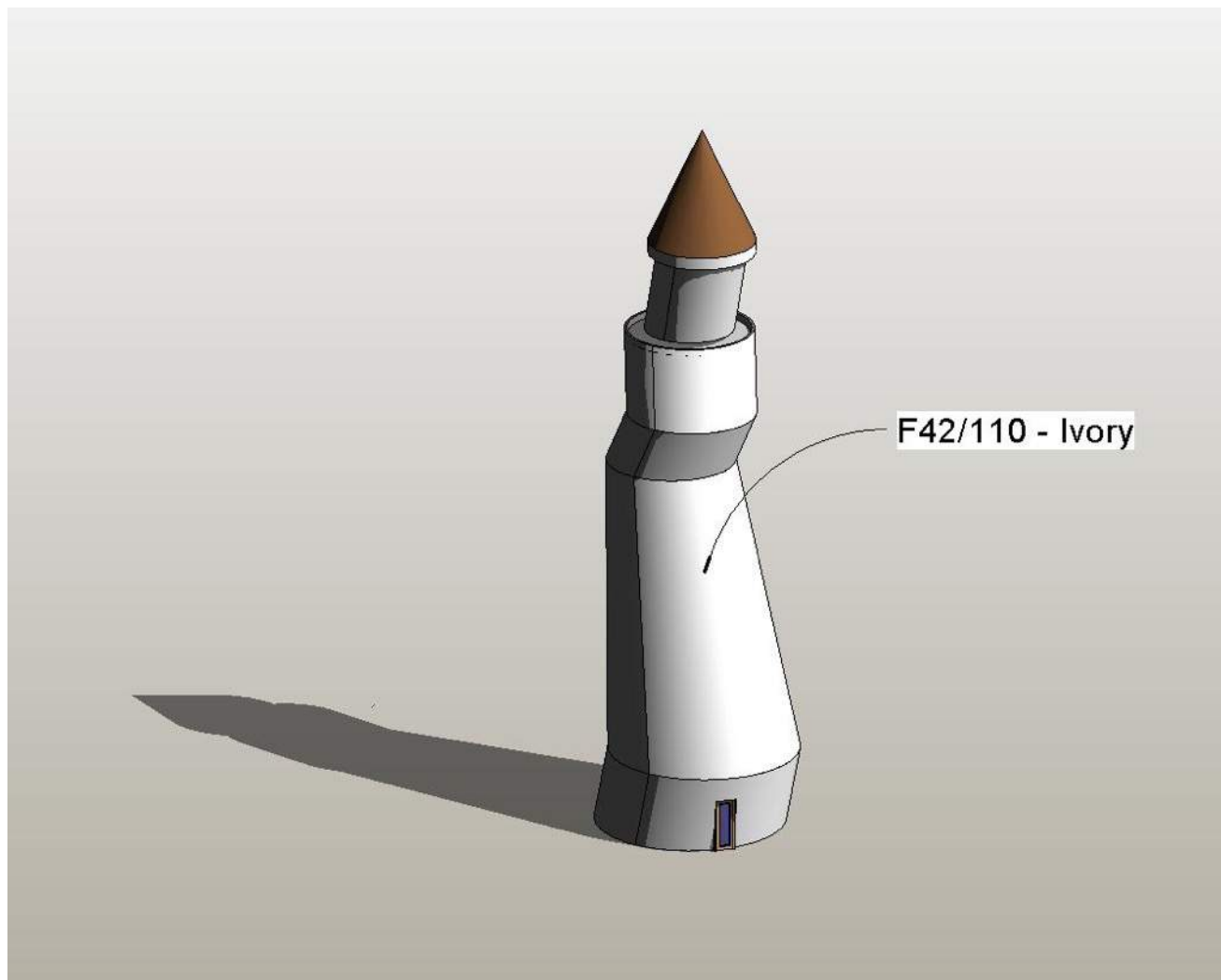
- Project ECHO University of New Mexico
- Project ECHO Northern Ireland
- Hospice UK
- NHS Highland
- UHI
- Scottish Government

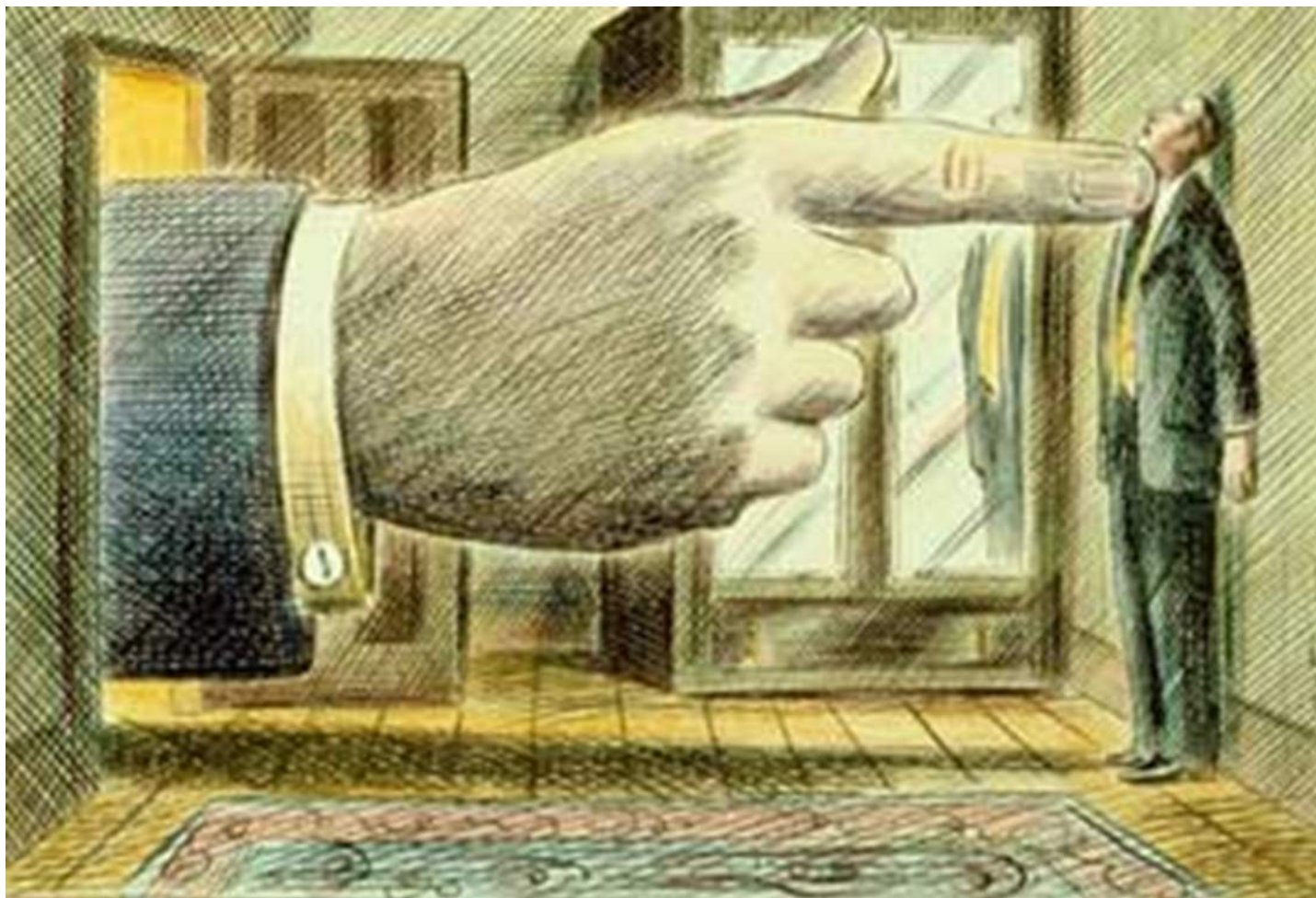
















"I'll need plenty of hot water."



What is ECHO?

Extension of **C**ommunity **H**ealthcare **O**utcomes

A not for profit movement to improve care by gathering a ***community of practice*** together for learning and support with the goal of improving decision-making by collaborative problem solving.



ECHO is.....Telementoring

Origins of Project ECHO



What is ECHO?

ECHO :

- A. Provides **A**mplification – using technology to leverage scarce resources
- B. Shares **B**est **P**ractice to reduce disparity
- C. Using **C**ase-Based Learning to master complexity and
- D. a **D**atabase to **M**onitor **O**utcomes

What is ECHO?

ECHO is :

- a community of the willing
- democratisation of specialist knowledge
- the building of communities of practice
- tele-mentoring

REALISING REALISTIC MEDICINE

'REALISTIC'

1. HAVING OR SHOWING A SENSIBLE AND PRACTICAL IDEA OF WHAT CAN BE ACHIEVED OR EXPECTED.
2. REPRESENTING THINGS IN A WAY THAT IS ACCURATE AND TRUE TO LIFE.

CREATING CONDITIONS

COMMUNICATE



CONNECT



COLLABORATE



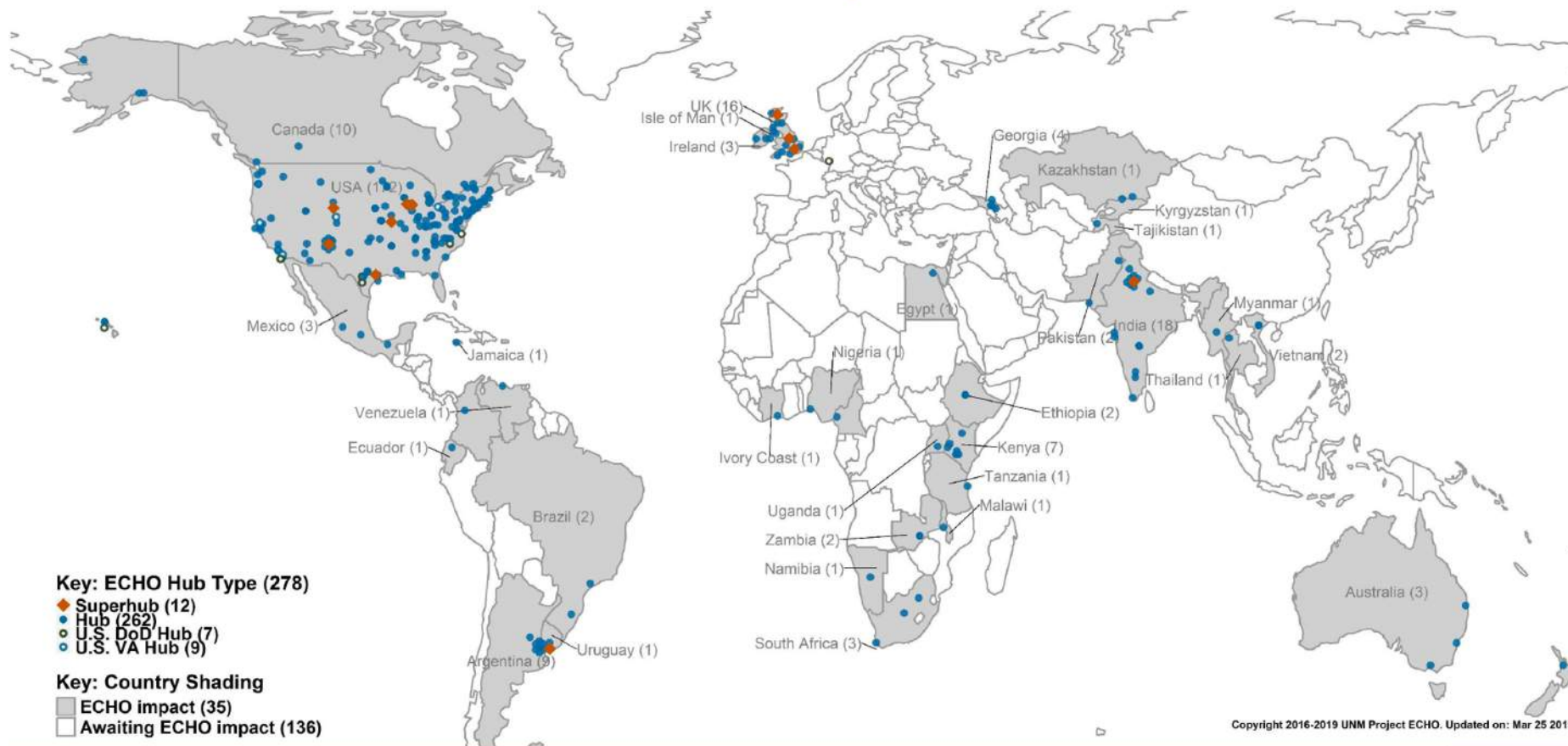
CULTURE



THE VISION

BY 2025, EVERYONE WHO PROVIDES HEALTHCARE IN SCOTLAND WILL DEMONSTRATE THEIR PROFESSIONALISM THROUGH THE APPROACHES, BEHAVIOURS AND ATTITUDES OF REALISTIC MEDICINE

ECHO Hubs and Superhubs: Global



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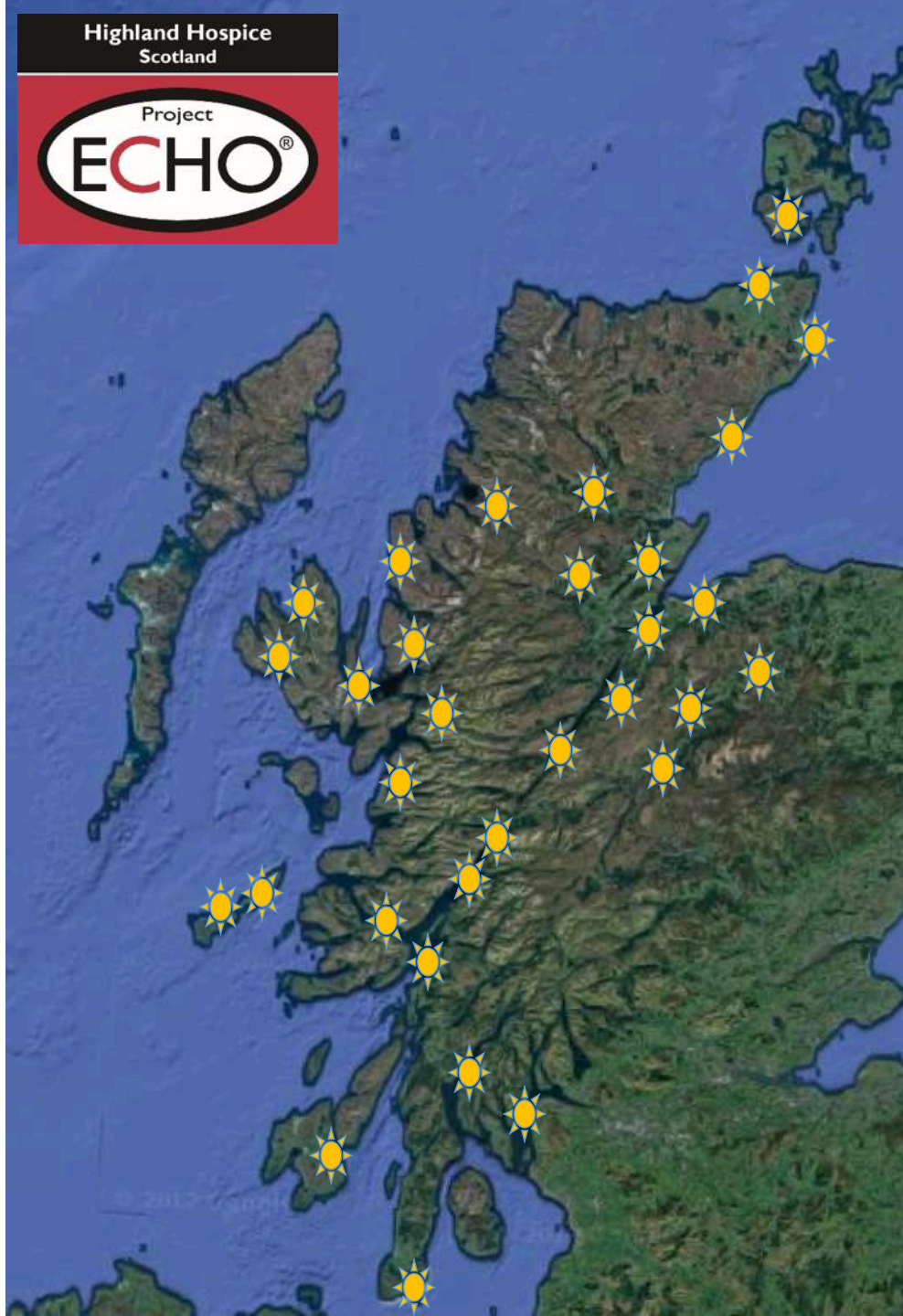


Over the last 2 years:

27 Care Homes
(63% Private, 37% NHS)
and

89 Individual members
of staff

Have taken part in
ECHO

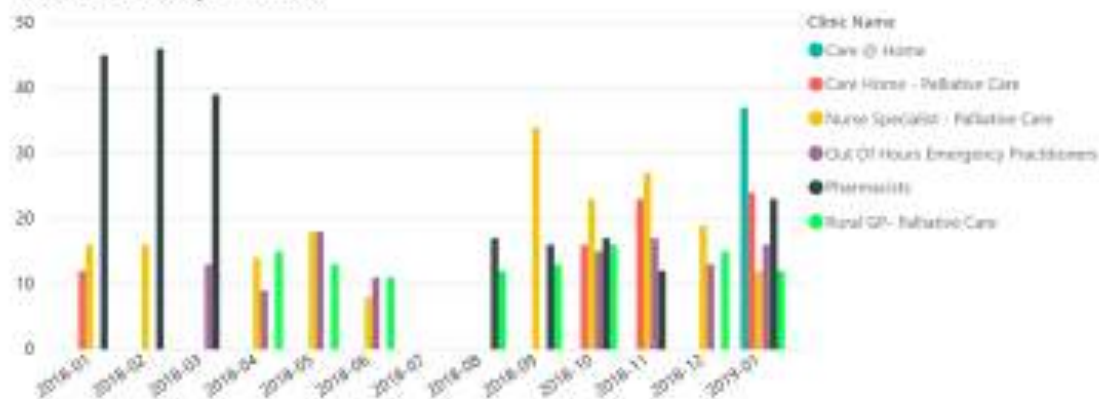


iECHO – Monitoring Outcomes

Learning Support and Mentoring

iEcho Telementoring Sessions Summary

No of Attendees by Clinic Name



Includes all Attendees including Staff & Facilitators

No of Individual Attendees in 12 month period

189

Head Count (Total)

Total Attendees for 12 month Period by Postcode Area/District



Project ECHO Immersion Training

Month	Organisations	Trainees
2018-05	St Columbas / Strathcarron	6
2018-09	CHAS	4
2018-11	NHS Tayside / NHS Dumfries & Galloway	7
Next training scheduled for March, May & September 2019		

ECHO in Practice

- Spoke and hub members have initial meeting at which is established a curriculum, times, dates, evaluation and responsibility for spokes presenting cases at each meeting.
- 60-90 minutes long, facilitated by 'Zoom' internet video conferencing.
- 20-30 minutes PowerPoint teaching from topic expert.
- 1-2 case presentations and discussions based on template.
- Sessions recorded and uploaded to secure, dedicated 'Moodle' site.



- Safe
- Listening
- Affirming
- Respect
- Support
- All teachers
- All learners

Current ECHO Palliative Care 'Clinics'

- Community Macmillan Cancer Nurse Specialists
- Care Homes
- Home Carers
- Emergency / Out of Hours Practitioners
- Community Pharmacists
- Rural GPs
- Childhood Bereavement

Leveraging our resource

Cardiology & Palliative HF

Regional Child & Adolescent
Mental Health

Palliative Care Paediatrics

Carer Support

Palliative and end of life
care needs - SE Trust

Gynaecology

Community Pharmacy &
impact age well

Practice Based Pharmacists
via GP Federations
(Wave 1)

Diabetes

MSK

Practice Based Pharmacists
via GP Federations
(Wave 2 & 3)

Gastroenterology

Palliative care Network
Pharmacies

Nurse Training -Diabetes

Neurology

ENT

Optometry/Ophthalmology
(Macular and glaucoma)

Regional quality
improvement & patient/
Client safety

Prison Healthcare SEHSCT

Marie Curie provision of
education to registered
nurses

Dementia

Regional Child & Adolescent
Mental Health Services

Health Visitor Support -
BHSCT (Children)

NI Paediatric Network

Dermatology

Urology

Pain Management

General Surgery

Palliative Care in
Community Hospitals in
NHSCT

Rheumatology

ECHO Feedback – Care Homes

- The sense of being part of a **community**
- **Networking** – Project ECHO allows participants to get to know dispersed colleagues and other healthcare professionals including Highland Hospice staff.
- **Sharing experience** – it enables learning from peers

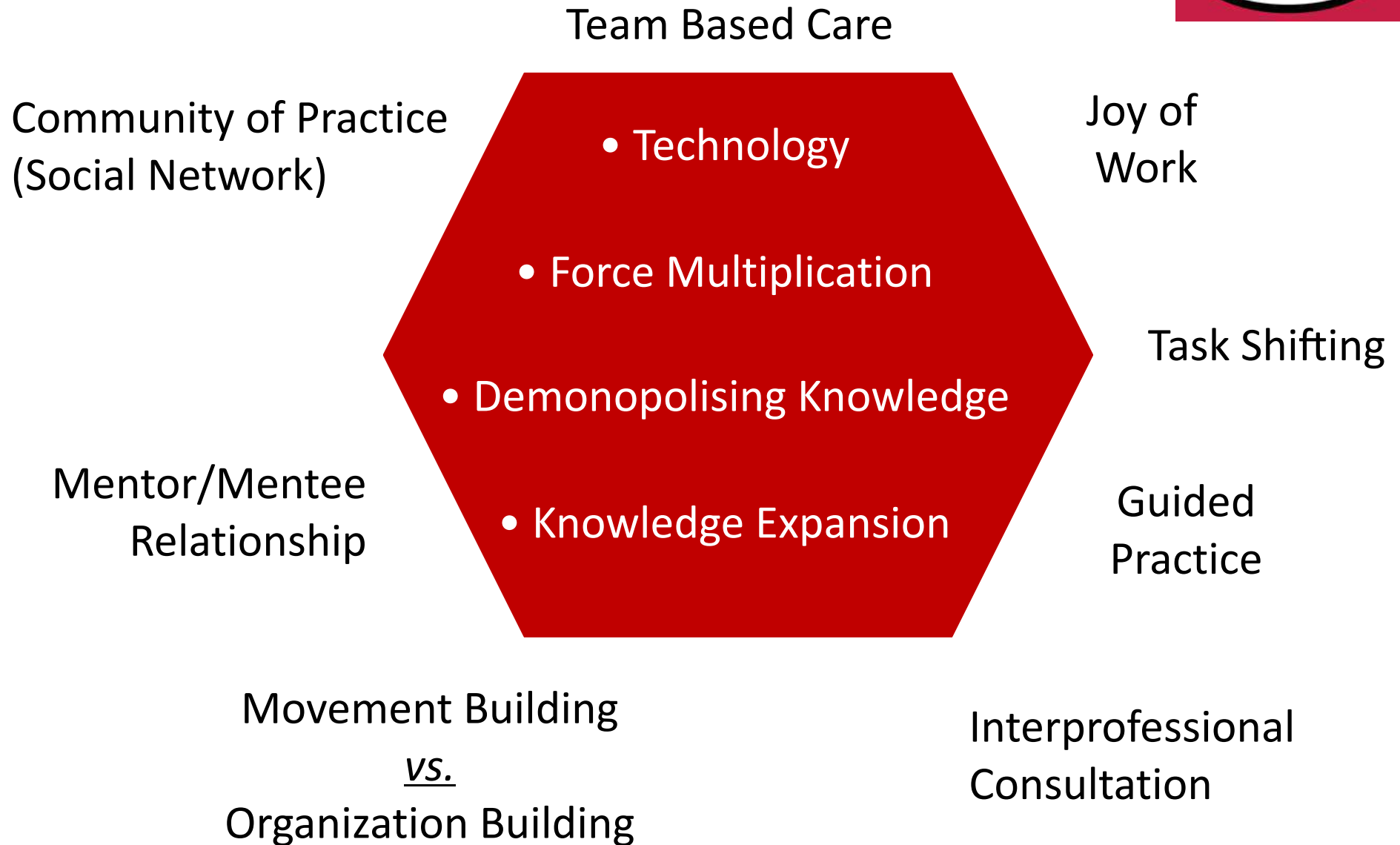
ECHO Feedback – Care Homes

- Project ECHO engendered a “level of **trust**” and “**team ethos**” which would be very difficult to replicate using any other method.
- Access to **learning** – Project ECHO is a CPD opportunity that it is possible to take up without travelling, is easy to take part in and is time efficient.

ECHO Feedback – Care Homes

- Enhanced **support** – through contact with peers and the Highland Hospice.
- Increased **knowledge** – participants reported practical learning points which can be incorporated into working practice across both clinical and care contexts.
- Increased personal and professional **confidence** – bestowing reassurance and improving communication with colleagues, patients and carers.

What makes ECHO work?



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Bottom Line.....





“ECHO just works, like an old Ford T that just takes you places”

Don Berwick, International Healthcare Quality and Improvement Guru, 2019



Good Life, Good Death, Good Grief

Building resilience around bereavement

Rebecca Patterson, Director of Good Life, Good Death, Good Grief



“If palliative care services wish to serve the majority of their bereaved clients, they should attend to developing community capacity rather than to providing specialized bereavement services of their own.”

Bereavement and palliative care: A public health perspective

Bruce Rumbold, Samar Aoun

Progress in Palliative Care, 2014, Vol 22, No.3

#TEAM MACMILLAN

macmillan.org.uk/events



FOR DAD



to absent friends ...

[home](#) [about](#) [festival](#) [storytelling](#) [remembrance](#) [get involved](#) [past festivals](#)

a people's festival of storytelling and remembrance

because dead ordinary people live on in the memories and stories we share.

Held across Scotland from 1-7 November each year.



No one
missed but
I was with love
Kia

No one
missed but
I was with love

#toabsentfriends

#toabsentfriends

#toabsentfri





www.toabsentfriends.org.uk

@2absentfriends

Good Life, Good Death, Good Grief

Improving people's experiences of death, dying and bereavement