



iHub

Palliative & End of Life Care Delivery Group +

The Studio Glasgow, 8th November 2018

Michelle Church, Improvement Advisor

Living Well in Communities, iHub
Healthcare Improvement Scotland

Enabling health and
social care improvement

WiFi:

Twitter: @LWiC_QI

#peolcdg

Are you sitting comfortably?

- Website: [Menti.com](https://www.menti.com)
- Code: 99 85 95
- How is the temperature in the room?
- Where have you travelled from today?

Who's here today?



Today – Focus on Care Coordination

- Gain an understanding of what is going on in the test sites
- Current thinking on care coordination to develop an understanding of factors for success
- Knowledge exchange: Reflect, share and stimulate conversation that will mobilise change ideas.

Agenda:

| Time | Item | Responsible |
|---------------|---|--|
| 09:30 – 10:00 | Refreshments and Networking | All |
| 10:00 – 10:10 | Welcome / Introduction for the day | Michelle Church – Improvement Advisor, HIS |
| 10:10 – 10:45 | Test Sites – Our journey so far (5 mins) | Josaleen Connelly – East Ayrshire Hilary Provan - Dundee Maxine Jones - Fife Dianne Foster – Glasgow Susanne Gray - Renfrewshire |
| 10:45 – 12:00 | Short stories on Care Co-ordination (7 mins each) Current thinking to help develop understanding of success factors for care coordination: <ul style="list-style-type: none"> • Conversation • Regaining Narrative: Health Transitions in Human Stories • Do We Care for Carers • Bereavement • Key Information Summary (KIS) • Personal Outcomes- Towards a Shared Understanding • Double Diamond • Care Homes • Looking Beyond 2021 | Sandra Campbell Deans Buchanan Lynne Carmichael Heather Edwards Anne Finucane Ali Guthrie Trisha Hatt Jo Hockley Richard Meade |
| 12:00 – 12:40 | Lunch & Networking | |
| 12:40 – 14:50 | World Café – World Café is a simple, effective, and flexible format for hosting large group dialogue. It's a chance to exchange knowledge, reflect, share and stimulate conversation. Josaleen Connelly – East Ayrshire project Hilary Provan – Dundee project Maxine Jones – Fife project Dianne Foster – Glasgow project Susanne Gray – Renfrewshire project Ann Finucane – KIS research Paul Baughan / Sandra Campbell – Care Coordination Evidence Bundle | ALL – a chance to share your thoughts, ask your questions. |
| 14:50 - 15:20 | So What? – share your new thinking <ul style="list-style-type: none"> • What mattered to you today? | Paul Baughan |
| 15:20 – 15:30 | Close | Tim Warren |

Living Well in Communities

IMPROVEMENT SUCCESS! (?)

Michelle Church, Improvement Advisor



Plan
Do
Study
Act



Courage

Curiosity

Resilience

Determination



What's success?

- **Safe space**
- **Courageous thinking**
- **Become your leader**



Test site journey's on care co-ordination so far.....

Josaleen Connolly – East Ayrshire

Hilary Provan - Dundee

Maxine Jones - Fife

Carol Ann Duffy – Glasgow

Susanne Gray - Renfrewshire

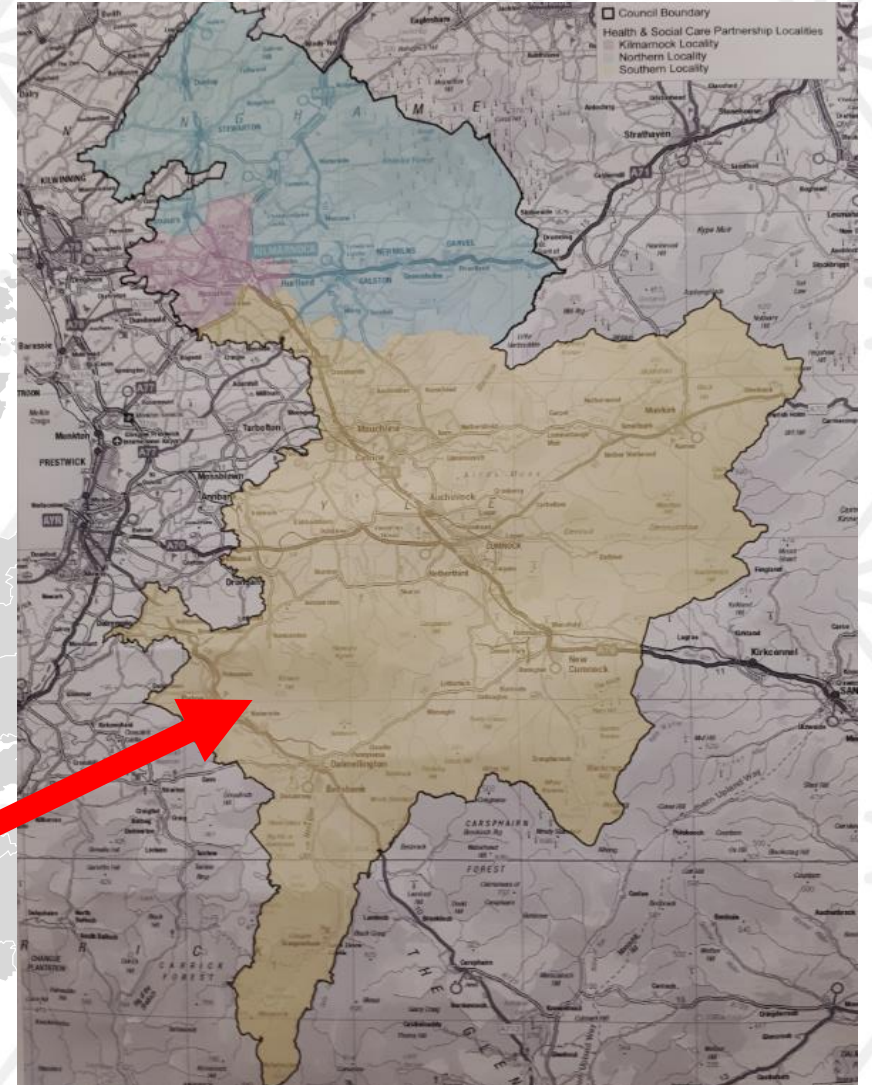
East Ayrshire - Josaleen Connolly

Palliative care bed in a care home setting

Identifying COPD for palliative care

ACP in the community

MAGICE Model



MAGICE Model – getting palliative care right every time

M

Mindful that good quality palliative care needs

A

Assessment and

G

Great conversations that are

I

Important to identify people early so that they have a

C

Care plan and know how to communicate with their care co-ordinator to

E

Enable excellence in end of life care & support in bereavement

Holistic Assessment & early identification

- Use SPICt to identify people with palliative care needs
- Assess assets already in place and what matters now
- Initiate ACP conversation
- Assess main carer needs
- Consider Realistic Medicine
- Prepare and plan for future changes
- Communicate all findings with all involved
- Early warning sent to services of changing needs

Communication & Information sharing with person and services involved

- Phone call to community team(s) involved – have knowledge of person's home situation- follow up with written information
- All teams involved need to know diagnosis/prognosis, current situation, person's preferences for care & their closest family understanding
- Clear, concise and honest communication- acknowledge uncertainty
- Explain in full, care needed during admission/significant conversations
- Care services – need informed in full of current situation/prognosis
- Timely recognition – Consider person's preferred place of care
- Prompt assessment of environment / order of equipment
- Assess needs in the present and future
- Medicines- order in advance and send 5 day supply home

Recognise symptoms

- Engage in conversation with the person and those closest to them always
- Assess and review need & outcomes with the person /with their carer
- Use Scottish palliative care guidelines (booklet, app & web site)
- Provide person with access details for help 24/7
- Access specialist support for complex issues
- Plan for pain – analgesia available always
- Symptom management – Communicate handover to teams what's current & been tried and alternative suggestions for the future

Medicines

- Assess compliance and ability to take medicines orally
- Good medicine management – prioritise most important medicines.
- Proactively anticipate Just in case medicines needed – include pain relief.
- Involve community pharmacist
- Provide/ signpost to training for social carers to give 'as required' medicines
- Assess literacy – what do people understand about their medicines?
- Improve access to anticipatory medicines

Assess/ review of Finances

- DS 1500
- Make sure income is maximised
- Share updates with those who have knowledge of person's situation ie Care Co-ordinator

Care Coordinator

- Who is key person and has most input
- Known to family
- Knowledge of referrals
- Put on Key Information Summary who Care Coordinator is
- Family/Services must know who Care Coordinator is

Role

- Keep all services up to date including ACP's
- Needs to be right person at right time
- Care Coordinator needs role to be clear
- Identify key Care Coordinator at MDT
- Document centrally

Getting it right for people with palliative care needs in East Ayrshire

Fundamental Principles

- Easy access to information and services
- Respect/caring/safe/compassion/trust at all times
- Recognise and respond to education and training needs
- Proactive planning
- Agree right person/right place/right time
- Ownership /governance/accountability
- Assess risks

Support for Carer/ Family

- Carers Assessment completed/reviewed/shared
- Provide details for a Key person contact directly 24/7
- Understanding & clear information what NHS and Social Care can/can't do.
- Involve the main carer in all planning – listen to their views
- Provide /signpost to education ie moving and handling, medicines management
- Offer information/plan respite breaks with person and their carer
- Provide time for emotional support/discussion with Carer
- Help carer build resilience/coping strategy
- Assess need for overnight care/break for carer
- Provide/signpost to social/therapeutic groups for additional support/care ie Community Connector

Utilise Community Groups

Involve support in the local area:

- Neighbours
- Volunteers i.e. foodbank, Community Connectors, compassionate communities to support people at home
- Sacred Care
- Support groups
- Spiritual care

Equipment

- Assess need and liaise with key care co-ordinator
- Risk assess area
- Order equipment promptly
- Keep family informed and consider appropriateness
- Prompt removal of equipment and aids no longer required

Transport must be

- Accessible
- Reliable
- Consistent
- booked promptly for transfer of person to another setting

Education in Palliative care

- Provide/signpost to education for all staff
- Provide/signpost to education for family, public, volunteers i.e. Moving & Handling, Medicines, Reporting symptoms, Knowing what to do and who to contact when needed

Recognising Dying

- Provide/signpost to education and communication skills for all staff
- Ensure the main carer and the person is aware of the reasons for deterioration – open and honest conversations
- Ensure additional medication/JIC meds are readily available on site
- If wanted, prepare the person/main carer for the person dying and how this is likely to be/look like
- Provide verbal and written information so that the main carer knows what to do and who to contact when death occurs

Bereavement & Loss Support

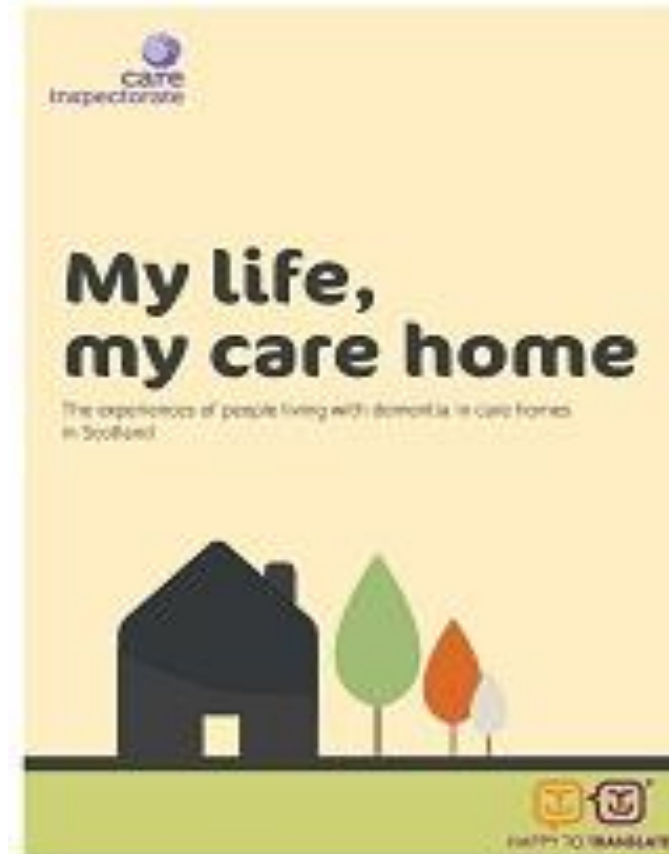
- Respect cultural differences
- Provide/signpost to appropriate support if requested/needed
- Provide written information
- Communicate to ALL services when death occurs
- Arrange a bereavement visit from most appropriate person and inform other services

Dundee – Hilary Provan



Standards of Care for Dementia in Scotland

I have the right to end of life care that respects my wishes



Improvement is needed in respect of meeting the “I have the right to end of life care that respects my wishes” standard, with 42% of care homes found to be adequate or lower. We expect to see staff who are confident and skilled in understanding their roles and responsibilities in palliative and end of life care.

Building Knowledge

Understand
current
practice, culture
and barriers

Peoples
pathways
and
experiences
of care

Carer
experience of
families care
and care
coordination

4 Care
Homes
within
Dundee

Building
knowledge
and skills of
teams

PDSA
Learning

Staff Focus
Groups



Planning for Improvement

Project Charter



Logic Model



Driver Diagram



Model for Improvement and PDSA



Measurement Plan



Change Ideas



Trial use of FAST Tool to identify deterioration and support decision making

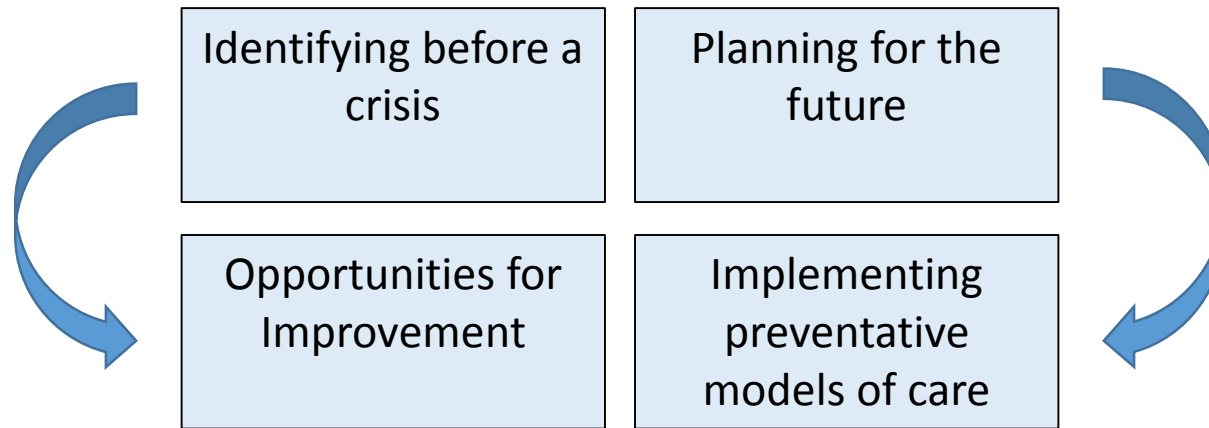
Enhance Multidisciplinary Review processes by implementing structured review document

Incorporate Care Home Team Pathway to support coordination of care

Trial use of PPP Tool to identify deterioration and support decision making

ACP thinking ahead - Preferences for care

Doing Improvement



Pay attention to...

- Organisational context, culture and capacities
- Care home setting
- Staff engagement and relationships
- Learning



Thank you

Hilary Provan
Improvement Advisor
NHS Tayside
hprovan@nhs.net

Fife – Maxine Jones

NHS Fife
Day Service Coordination Initiative

Maxine Jones

Programme Manager

Fife Specialist Palliative Care Service

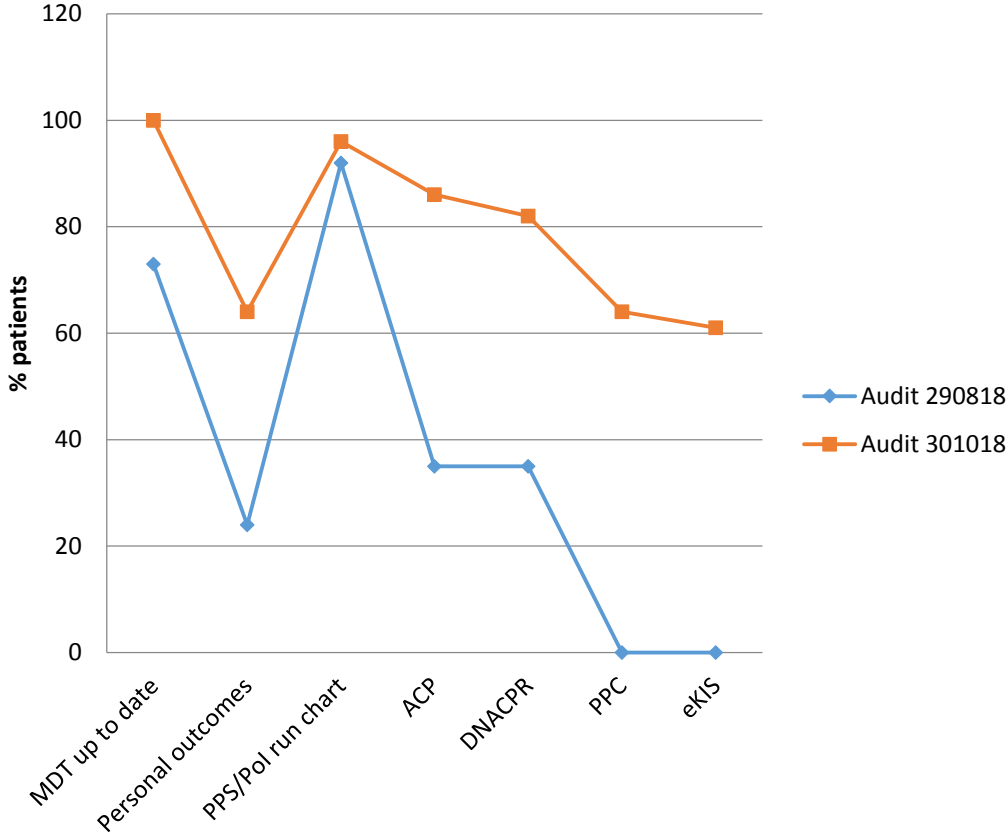
maxine.jones9@nhs.net

Driver diagram: NHS Fife, Day service coordination initiative (maxine.jones9@nhs.net)

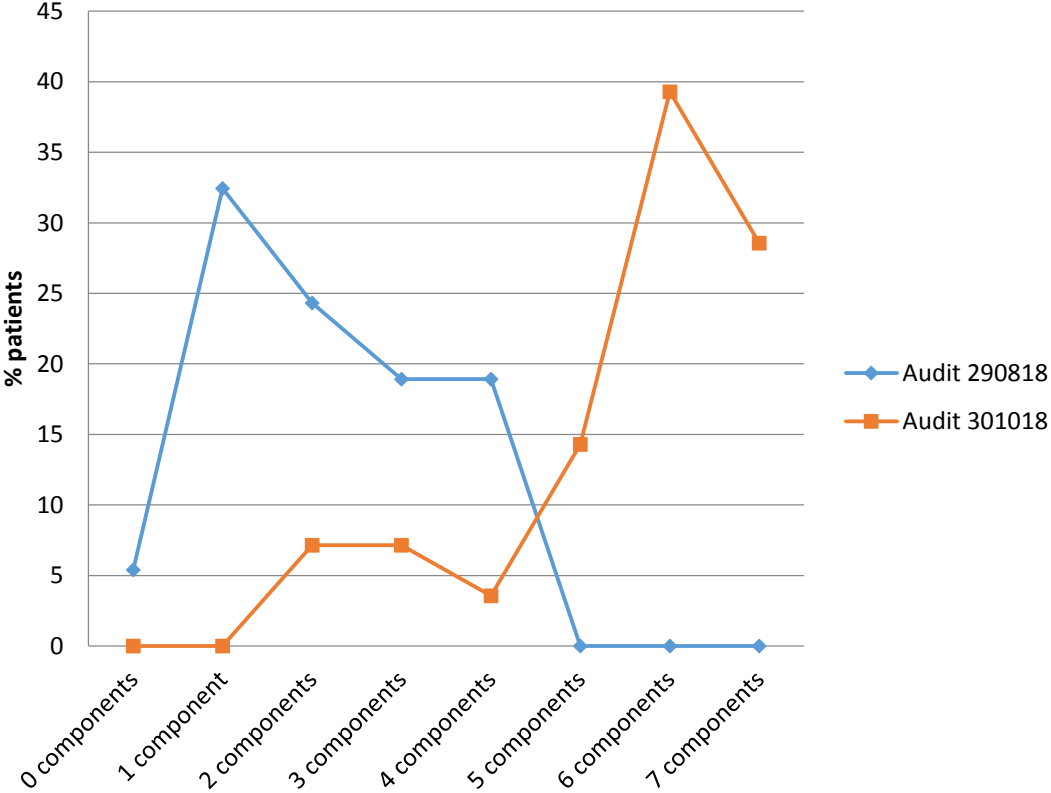
| Aim | Primary Drivers | Secondary Drivers | Change Ideas | Measures (care bundle components) |
|--|---|---|--|---|
| <p>By April 2019, to improve care coordination for all people attending day service, through introduction of a care bundle, to better support people with “what really matters” to them in their palliative journey</p> | <p>Conversations The right conversations with patients</p> | <p>Capability Staff use a personal outcomes approach</p> | <p>Bespoke personal outcomes training</p> | <p>% staff trained</p> |
| | | <p>What really matters Personal outcomes are established</p> | <p>Personal outcomes are established at first visit and reviewed at MDT</p> | <p>% with personal outcomes</p> |
| | <p>Information The right information is shared</p> | <p>Information capture The right information is captured</p> | <p>PPS/PoI is introduced at first visit and updated at each attendance</p> | <p>% with PPS/PoI run chart</p> |
| | | | <p>ACP is recorded within 4 weeks of first visit</p> | <p>% with ACP</p> |
| | | | <p>DNACPR is recorded within 4 weeks of first visit</p> | <p>% with DNACPR</p> |
| | | | <p>PPC is recorded within 4 weeks of first visit</p> | <p>% with PPC</p> |
| | <p>Coordination The right coordination mechanisms</p> | <p>MDT review People receive timely MDT review</p> | <p>MDT triggers are introduced:</p> <ul style="list-style-type: none"> – PPS 10-50% – PPS drop of 20% in 3 consecutive weeks – PoI unstable, deteriorating, dying – Due monthly review – New patient – No eKIS | <p>% with triggers reviewed at next MDT</p> |
| | | | <p>Standardised letter is sent to GP following MDT:</p> <ul style="list-style-type: none"> – Where eKIS update is needed – Where there is no eKIS | <p>% with eKIS</p> |

NHS Fife, Day service coordination initiative: Results as at 30 October 2018

Individual components: Comparison first & last audit



Care bundle: Comparison first & last audit




Glasgow City – Carol-Ann Duffy



Testing a holistic system for community palliative care

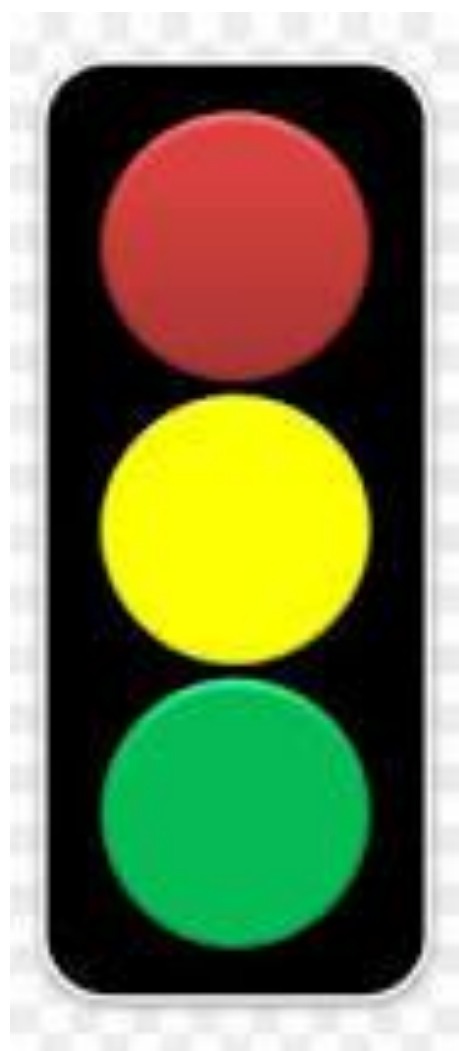
- Renfrewshire Health and Social Care Partnership
 - November 2018

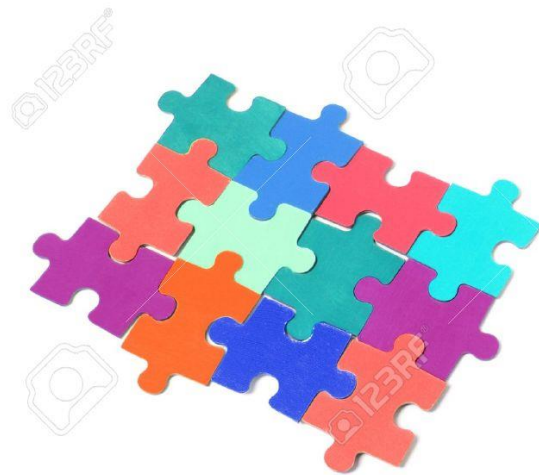


“The services offered were almost a given, whether they were right for us or not. We tweaked the edges but were not given much flexibility.”

“Finding information and services is one of the most difficult parts of caring.”

“It was always up to us to ensure everyone knew what was happening, tell the DN what the GP said, tell the GP what the consultant said. It never felt like anyone other than us had the full picture.”





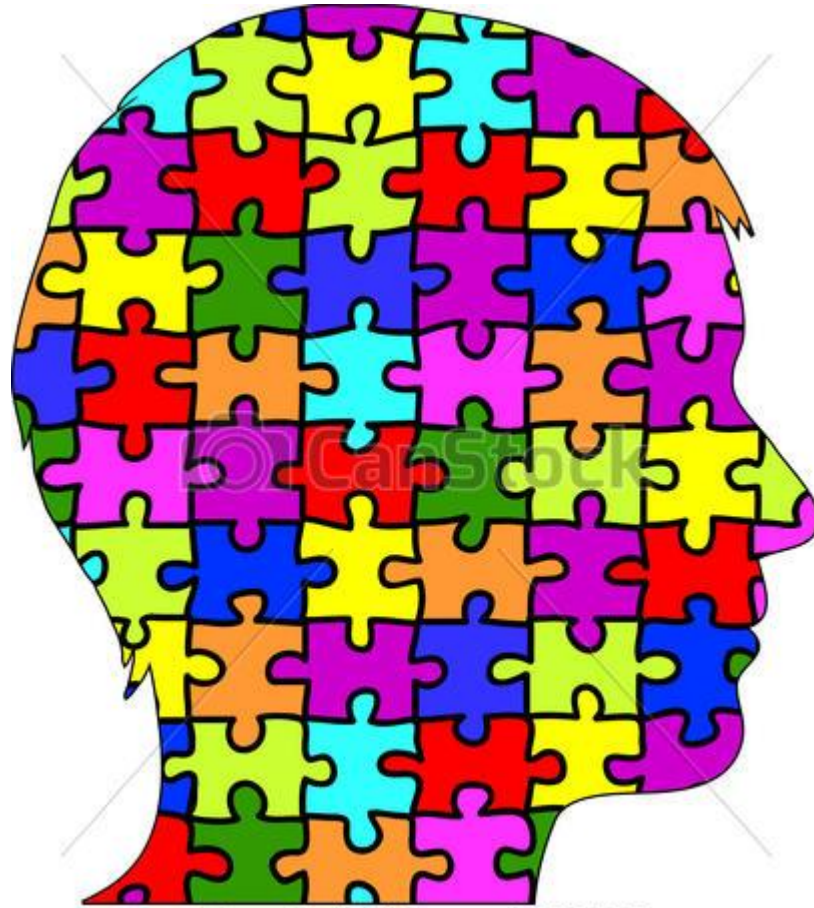
It's always the
small pieces
that make the
big picture.

QUOTEDIARY.RE





**KEEP
CALM
AND
SOLVE
PUZZLES**



© Can Stock Photo - csp18179200

Short stories on Care Co-ordination

Inter-professional and interpersonal conversations

Sandra Campbell

Care Co-ordination in PEOLC

- **WHAT** is *care coordination in PEOLC*?
- **WHY** is it important?
- **WHEN** should it be done?
- **WHO** by?
- **WHERE**?
- **HOW**?
- **Communication about planning of care**
- **To obtain optimum outcome**
- **Commence at point of identification of need/Transitions**
- **Begins with whoever identifies need**
- **Central point/ may vary**
- **Through good communication/conversations and systems**

Cs of Communication in Care Co-ordination in PEOLC

- Care planning following holistic assessment, including practical components of care & comfort
- Common language
- Consistency in approach
- Collaboration
- Clear understanding of roles
- Critical and central to PPC
- Compassion
- Correct
- Challenges addressed
- Creative & credible
- Continuity
- Culture
- Confidence
- Complete the circle of communication
- Consequences...

Conversations in care Co-ordination in PEOLC

What do I need to know about you as a person to give you the best care possible ?
Patient Dignity Question (PDQ) by Prof. Harvey Chochinov

NHS SCOTLAND

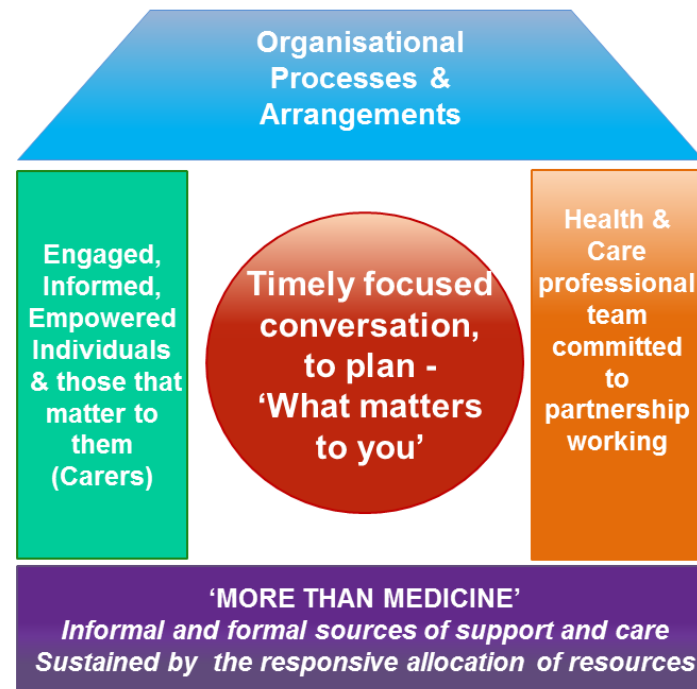
PRACTISING REALISTIC MEDICINE

- CHANGE OUR STYLE TO SHARED DECISION MAKING?** (Icon: Two people talking)
- BUILD A PERSONALISED APPROACH TO CARE?** (Icon: Network of people)
- REDUCE HARM AND WASTE?** (Icon: Biohazard symbol)
- REDUCE UNWARRANTED VARIATION IN PRACTICE AND OUTCOMES?** (Icon: Syringes)
- MANAGE RISK BETTER?** (Icon: Scales)
- BECOME IMPROVERS AND INNOVATORS?** (Icon: Lightbulbs)

Chief Medical Officer's Annual Report 2016-17

REALISTIC MEDICINE

Healthier Scotland Scottish Government



ihub
living well in communities

Palliative care identification tools comparator

Combination of skills and tools!!

FIRST IMPRESSIONS

HUMAN THERAPEUTIC ENCOUNTER

LEADERSHIP

SAGE & THYME

5Ps

GOOD CONVERSATION

COACHING



10 MINUTE CBT
EC4H

SPIKES

RAPPORT

SBAR

MOTIVATIONAL
INTERVIEWING

KIND MODEL

What do I need to know about you as a person to give you the best care possible ?
Patient Dignity Question (PDQ) by Prof. Harvey Chochinov



Short stories on Care Co-ordination

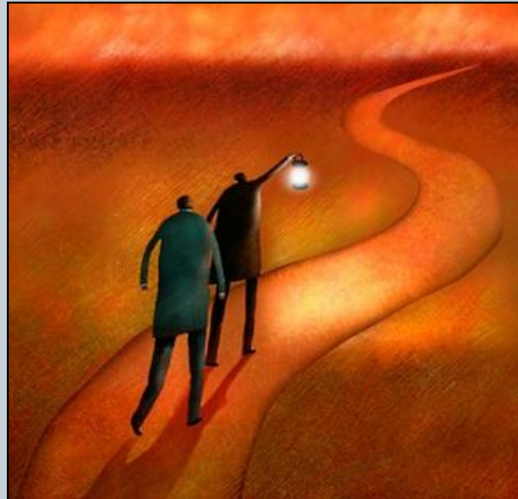
Transitions

Dr Deans Buchanan

Regaining narrative: health transitions in human stories



DEANS BUCHANAN



*'WE LIVE BY STORIES, AND THEY'RE WHAT
GIVE SENSE TO OUR LIVES.'*

Narrative



- “*Stories or narratives* are at the centre of human understanding, memory systems, and communication. Memories and information are not just **stored**; they are **storied**”
- “But patients’ stories will have been **disrupted** by their illness; this experience of **discontinuity**, of not feeling settled in the story of their lives exacerbates the illness experience and can affect their attitude and response to treatment.”
- Why do people attend doctors?

'My story is broken, can you
help me fix it?'

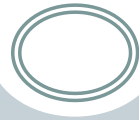
Shared decision making: co-authorship



- Who's is sharing with who?
- What is the context for the decision?
 - Relationship
 - Shared humanity and common mortality
 - Knowledge of who and knowledge of what
 - Reality-perception-reality
- What is the story, how is it broken and how will it proceed

Knowledge building, "the **social activity** by which communities create new knowledge through a process of collaborative, iterative idea improvement"

The story begins.....?



Some info



- Distressed person who may not be aware of surroundings....but might be
 - Family present - distressed
 - Risk of dying at that moment, in that hour, or that night is high
- Professionals: thinking, acting, speaking professional
- Approach....
 - A - Attitudes
 - B - Behaviour
 - C - Compassion
 - D- Dialogue

Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochinov**, and the A, B, C, and D of dignity conserving care can reinstate them

An abrupt end to a story?

A new chapter, kind of





From

Identification

to

Co-ordination

From

|

to

Co

From

Alone

to

Together

Short Stories on Care Co-ordination

**Do we care for Carers?
Lynne Carmichael**



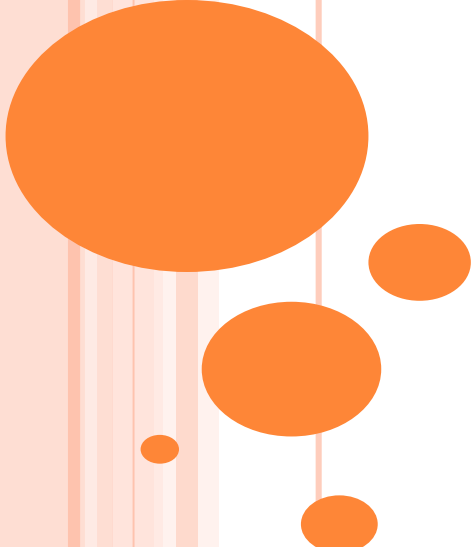
DO WE CARE FOR “CARERS”???

Lynne Carmichael


Respite and Response Team Manager

Ayrshire Hospice





“CARERS/FAMILIES ANXIETY IS RATED ALONGSIDE PATIENTS SYMPTOMS AS THE MOST SEVERE PROBLEMS TO BE EXPERIENCED BY BOTH PATIENTS AND THEIR FAMILIES”



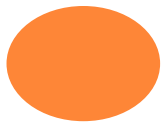
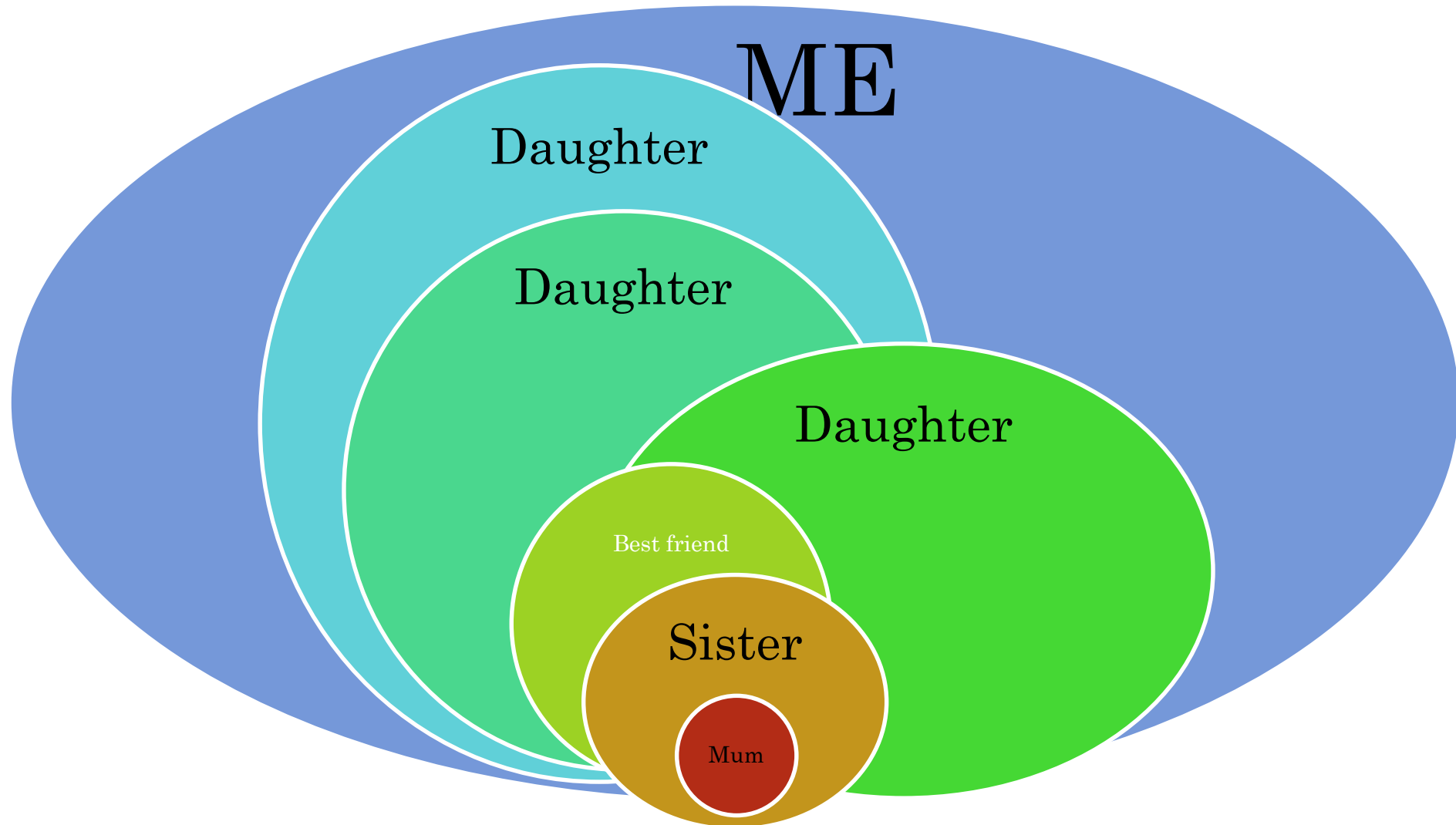
THE 1ST BARRIER????

Its all in a name.....

What is a “CARER”.....do I see myself as a carer????



WHO IS IN MY INNER CIRCLE?



- **A CARER IS A PERSON – with their own lives and aspirations**



- **Often slipping away**
- **Often not their choice**
- **Often because there is no-one else to do it**



JOB ADVERT: FAMILY/CARER

Length of contract: unknown Hours:

24hrs/day, 7 days/wk

An unexpected opportunity has arisen for a job caring for your relative who has a life-limiting condition.

This will be in addition to all other aspects of your current life responsibilities. You must be able to multi-task and have a multitude of skills including:

- **Household tasks** – cooking, cleaning, laundry, gardening
- **Caring** – nursing, bathing, dressing, lifting, using medical equipment
- **Pharmacy** – administering meds, ordering/collecting prescriptions
- **Co-ordinator / PR / Secretary** – organise, co-ordinate medical appointments
- **Counselling** – emotional support, listening, advice, confidante
- **Taxi driving** – or transport organiser
- **Financial Management** – managing bills when income may have stopped
- **Create memories** – spend quality time with your loved one

You may need to be able to do some or all of these skills, however this is what can be expected from you.

You need to manage your own emotions and at times, go without sleep.

The terms and conditions for this role are ever fluctuating and you have to manage that accordingly.

A job description is not available as this role is too big and the individual nature of each situation would make this impossible to create.



DO YOU ASSESS CARERS NEEDS?

- How do you do that?
 - On the doorstep?
 - At the bedside?
 - In the corridor?
- Does the carer know you are assessing their needs?
- How is the carer considered when we think “care coordination”?



CARERS ASSESSMENT?

- Should be considered equally to the needs of the patient?
- Consistent?
- Co-ordinated?
- Consent?
- Everyone's role? How do the team know who has assessed the carers needs?
- The CSNAT - Carer Support Needs Assessment Tool – A consistent Approach?



SUPPORTING THE NEEDS OF CARERS OF THOSE WITH A TERMINAL ILLNESS RESEARCH STUDY MARIE CURIE

- **Not knowing who to call**

'And I don't know why I had got it into my head that, you know, it was the[hospital] now and the doctors and staff there and not my surgery. So I sort

of, went for several days, floundering I suppose. Not knowing what to do.' [Glioma Interview]

- **Seeking information**

'They advise you to take a notepad when you're talking to the consultant. But you don't even, when I looked at what I'd wrote , it wasn't even legible...It was like shorthand. And she was saying, "What did they say?" and I'm saying, "Aye well it's okay, you've got to go"...I hadn't a clue.' [Primary Focus Group]



- **What to expect in the future**

'...I was told he had a tumour, a glioblastoma or whatever it was, aggressive, blah, blah, blah. But nobody ever sat me down and said, you can expect this to happen or you can expect that to happen.'
[Glioma Interview]

- **Crisis**

'It's the bashing your head against a brick wall, it's going from crisis, to crisis, to crisis. And knowing, not knowing when the next crisis is coming, not knowing what that crisis is going to be, but knowing that it's coming. And just expectations are high that it's gonna be there.' *[Primary Focus Group]*

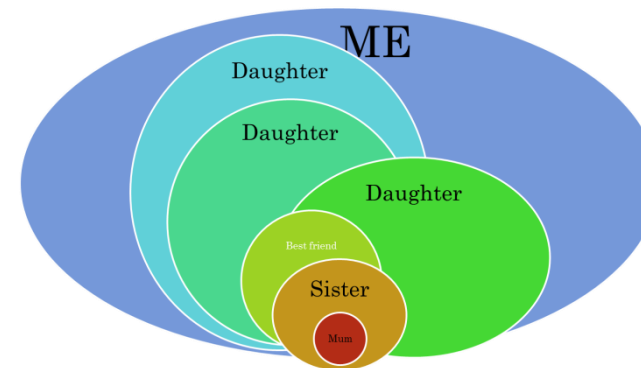
- **Failures**

'...just slipped through the system three times, they hadn't even a record of her name. That's how important she was.' *[Primary Focus Group]*



CARE CO-ORDINATION

Truly person centred – inner circle ?



Research

- **The Real-World Problem of Care Coordination: A Longitudinal Qualitative Study with Patients Living with Advanced Progressive Illness and Their Unpaid Caregivers** Barbara A. Daveson et al
- **Providing comprehensive, person-centred assessment and support for family carers towards the end of life - 10 recommendations for achieving organisational change** Gail Ewing, University of Cambridge, Gunn Grande, University of Manchester
- **Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach** Gail Ewing , Lynn Austin, Debra Jones and Gunn Grande



ONE CHANCE TO GET IT RIGHT?



Sometimes we need someone



Fb.com/MinionQuote

to simply be there...

Not to fix anything

or do anything

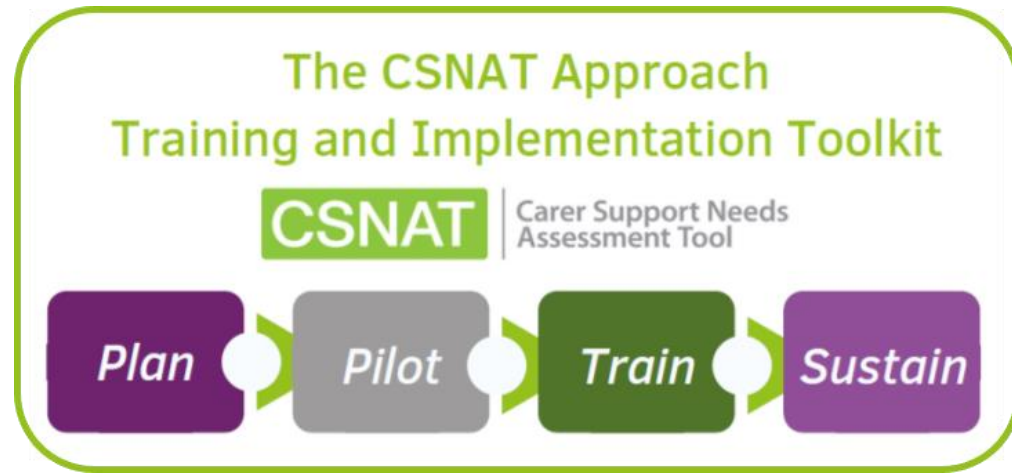
in particular,

but just to let

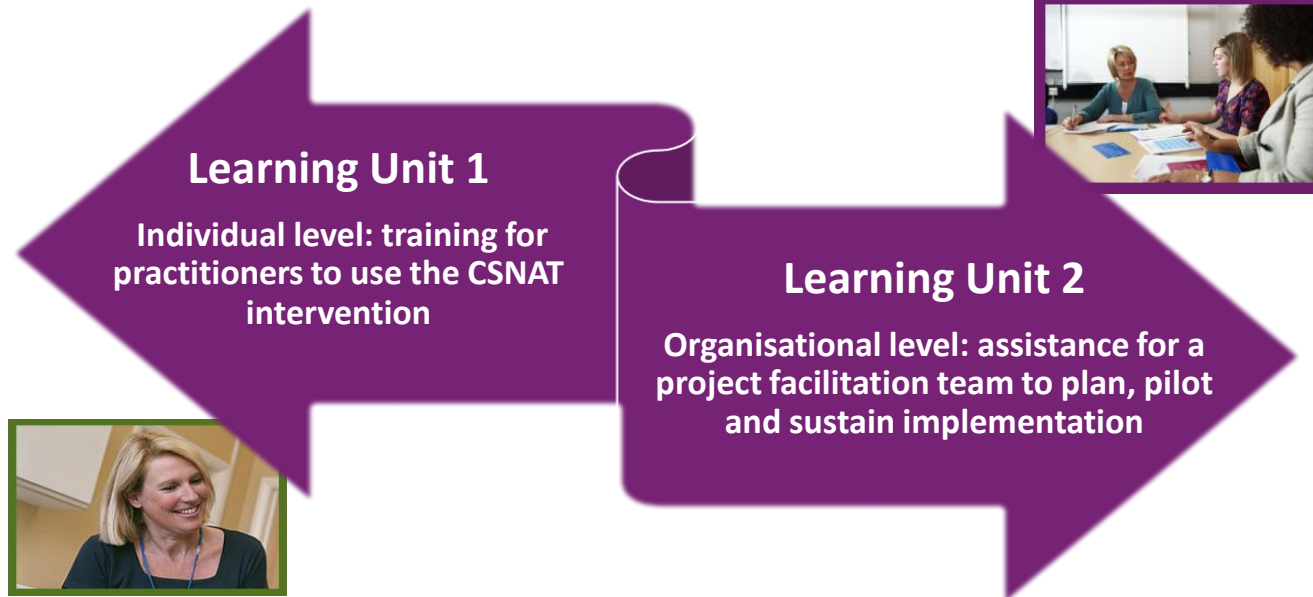
us feel we are

supported and cared about





Two learning units



[Further details on csnat.org](https://www.csnat.org)

Bereavement



Heather Edwards

Dementia Consultant
Care Inspectorate

Short Stories on Care Co-ordination

Key Information Summary (KIS) **Anne Finucane**

Key Information Summary generation for people who died in Scotland in 2017

Dr Anne Finucane

Research Lead, Marie Curie Hospice Edinburgh
Honorary Fellow, University of Edinburgh



**Care and support
through terminal illness**



Study team

Anne Finucane – Research Lead, Marie Curie Hospice Edinburgh

Scott Murray – Chair of Primary Palliative Care, University of Edinburgh

Deborah Davydaitis – Palliative Care Speciality Doctor and Researcher

Zoe Horseman – Nurse Researcher

Emma Carduff -Research Lead, Marie Curie Hospice Edinburgh

Paul Baughan – GP and National Clinical Lead for Palliative Care

Sandra Campbell - National Clinical Lead for Palliative Care - Nursing

Richard Meade – Head of Policy for Scotland - Marie Curie

Tim Warren – Palliative Care Lead - Scottish Government

Julia Tapsfield – GP, NHS Lothian (led previous KIS study in 2014)

Juliet Spiller – Consultant in Palliative Medicine, Marie Curie Hospice Edinburgh

Ian Thompson – Primary Care Clinical Lead in Digital Health and Care, Infrastructure and Digital Division, Scottish Government

Background

Vision

By 2021, everyone in Scotland who needs palliative care will have access to it.

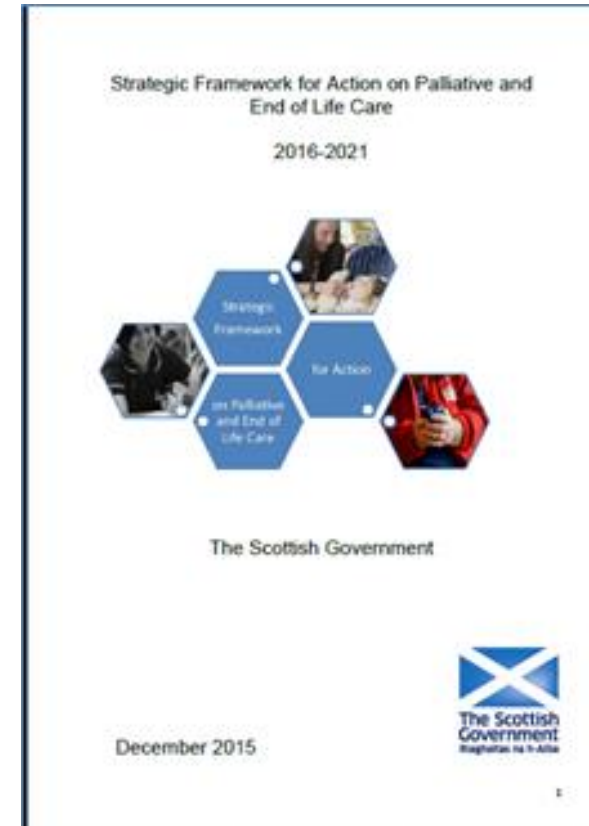
Palliative and End of Life Care Aims

- Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.

Palliative and End of Life Care Objectives

We will achieve this by:

- Improved identification of people who may benefit from palliative and end of life care.



Strategic Framework for Action on Palliative and End of Life Care 2016-2021

Background

Tapsfield et al (2016)

Data collection in 2014

- 9 general practices in Lothian
- 605 patient records

Findings

- 60% had a KIS
- 18 weeks before death
- Only 41% with organ failure had KIS
- Overall improvements compared with 2011 (Zheng et al. 2013)



OPEN ACCESS

Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners

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For numbered affiliations see end of article.

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ABSTRACT

Background Key Information Summaries (KIS) were introduced throughout Scotland in 2013 so that anticipatory care plans written by general practitioners (GPs) could be routinely shared electronically and updated in real time, between GPs and providers of unscheduled and secondary care.

Aims We aimed to describe the current reach of anticipatory and palliative care, and to explore GPs' views on using KIS.

Methods We studied the primary care records of all patients who died in 2014 in 9 diverse Lothian practices. We identified if anticipatory or palliative care had been started, and if so how many weeks before death and which aspects of care had been documented. We interviewed 10 GPs to understand barriers and facilitating factors.

Results Overall, 60% of patients were identified for a KIS, a median of 18 weeks before death. The numbers identified were highest for patients with cancer, with 75% identified compared with 66% of those dying with dementia/frailty and only 41% dying from organ failure. Patients were more likely to die outside hospital if they had a KIS. GPs identified professional, patient and societal challenges in identifying patients for palliative care, especially those with non-cancer diagnoses.

Conclusions GPs are identifying patients for anticipatory and palliative care more equitably across the different disease trajectories and earlier in the disease process than they were previously identifying patients specifically for palliative care. However, many patients still lack care planning, particularly those dying with organ failure.

INTRODUCTION

Anticipatory and advance care planning is about 'thinking ahead'. It encourages practitioners to work with patients, carers and relatives to plan for the right person to do the right thing, at the right time, to achieve patient goals, facilitating shared decision-making and person-centred care in the appropriate setting. Planning ahead is recognised as being central to the provision of palliative care.¹

With ageing populations and rising multimorbidity, general practitioners (GPs) are caring for increasing numbers of patients with complex conditions approaching the end of life. Even in countries where palliative care is relatively well developed, most people still do not benefit from palliative care before they die. We previously reported that only around 20% of people with non-malignant illnesses were identified for generalist palliative care in 2011 in Scotland, and that this varied greatly from 75% in cancer to 20% in dementia/frailty and 19% in organ failure.² Such patients were identified just weeks before death. This is illustrated in figure 1. Considerably fewer than this received specialist palliative care. These findings illustrated the need for the WHO resolution published in 2014, that palliative care should be integrated into the care of people with all advanced conditions from an early stage.³

Since 2012, the Scottish Government has funded two new initiatives which together aim to extend generalist

Study Aims

- To estimate the extent of KIS generation for people who died with an advanced progressive condition in **2017**
- To explore GP perspectives of commencing and updating a KIS; what works well and what can be improved.

Methods

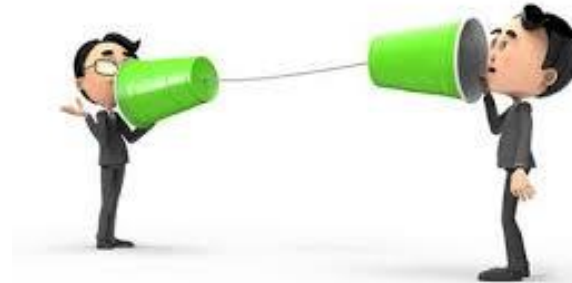
Retrospective review of the records of all patients who died in **18** Scottish general practices across four NHS Board areas in 2017

The screenshot shows a software window with several sections:

- KIS upload decision:** Includes a dropdown for 'Send key information summary (KIS) upload' and a date field set to '14/03/2013'.
- Patient consented?:** Includes a dropdown for 'Consent for key information summary upload' and a date field set to '14/03/2013'.
- Patient aware?:** Includes a dropdown for 'Patient aware?' and a date field set to '14/03/2013'.
- Legal Requirement:** A checkbox.
- Vulnerable Person:** A checkbox.
- Risk to Self:** A checkbox.
- Risk to Others:** A checkbox.
- Special Notes (shared with ePCS Screen):** A section with a checked 'Apply Special Note' checkbox and a text area containing 'This is the special note.'.
- Apply Expiry Date:** A checkbox with the text 'Special Note will not expire' and a character count '(29 of 2048 characters used)'.
- KIS Review Date (Practice Use Only):** A checked 'KIS Review Date' checkbox and a date field set to '15/03/2013'.

Buttons for 'OK' and 'Cancel' are visible at the bottom right.

Telephone interviews with one healthcare professional in each general practice.

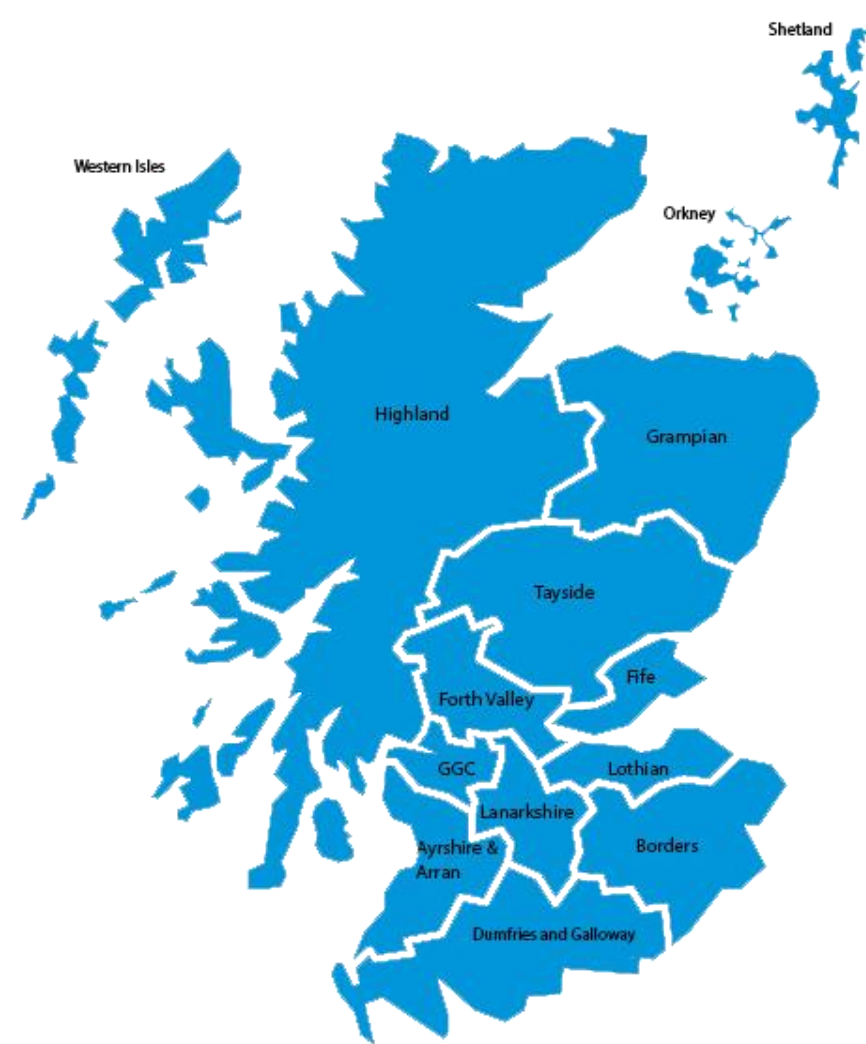


Results

| Practices | No. | Records |
|-------------------|-----------|-------------|
| Ayrshire & Arran: | 4 | 300 |
| Lothian: | 4 | 304 |
| Tayside: | 4 | 368 |
| Fife: | 6 | 332 |
| Total | 18 | 1304 |

Telephone Interviews

- 17 GPs and 2 practice nurses

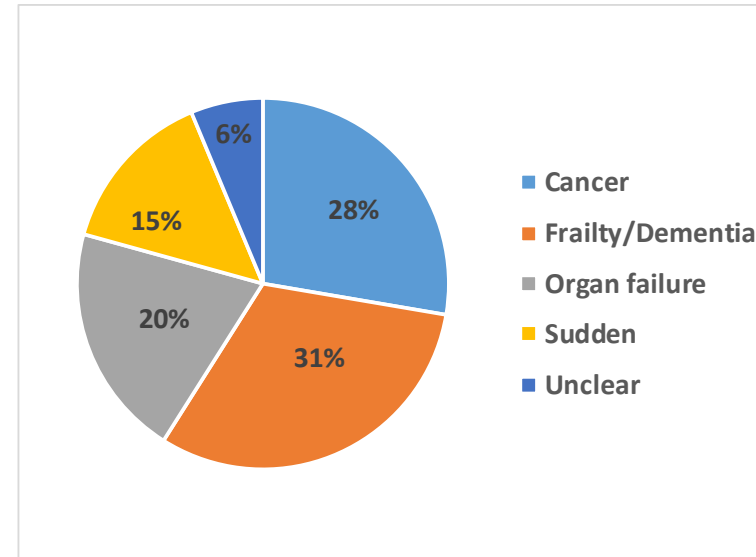


Results

Sample

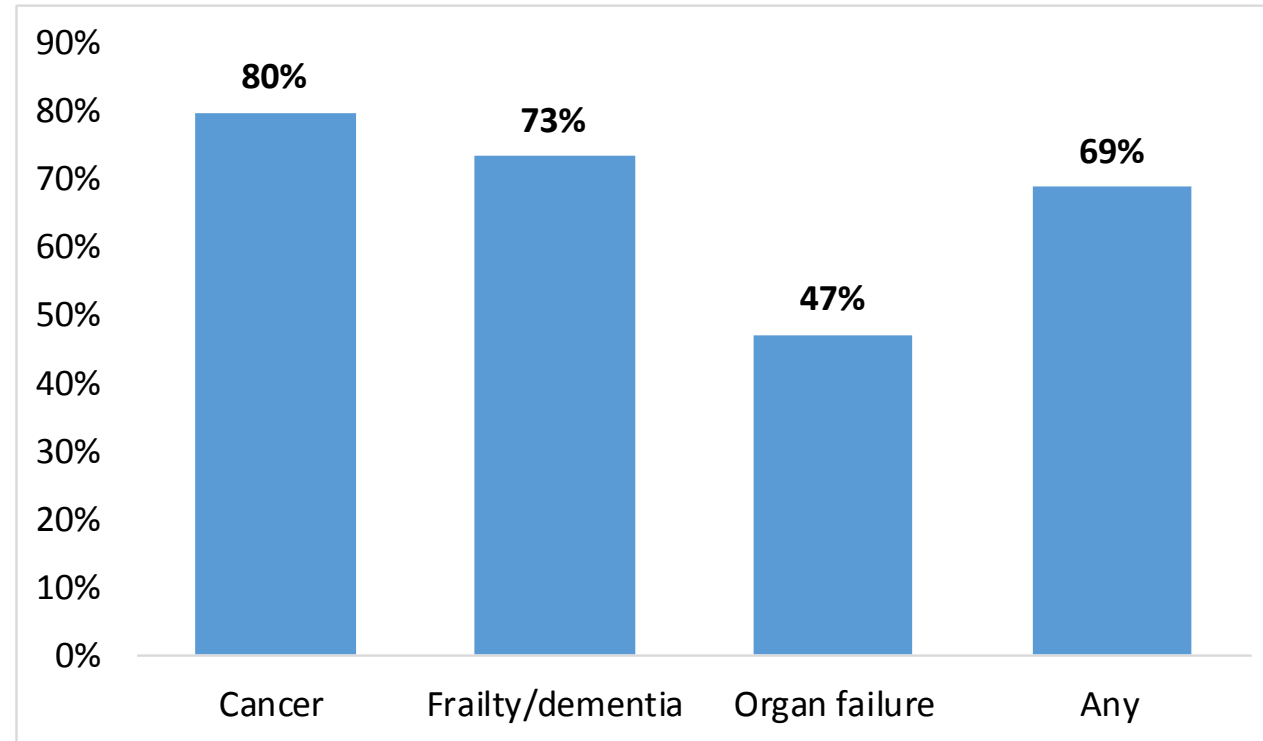
- 1304 patients
- 49% female, 51% male
- Median: 79 years
- 1,034 had an advanced progressive condition at time of death (79%)

Illness trajectory (n=1304)



Results

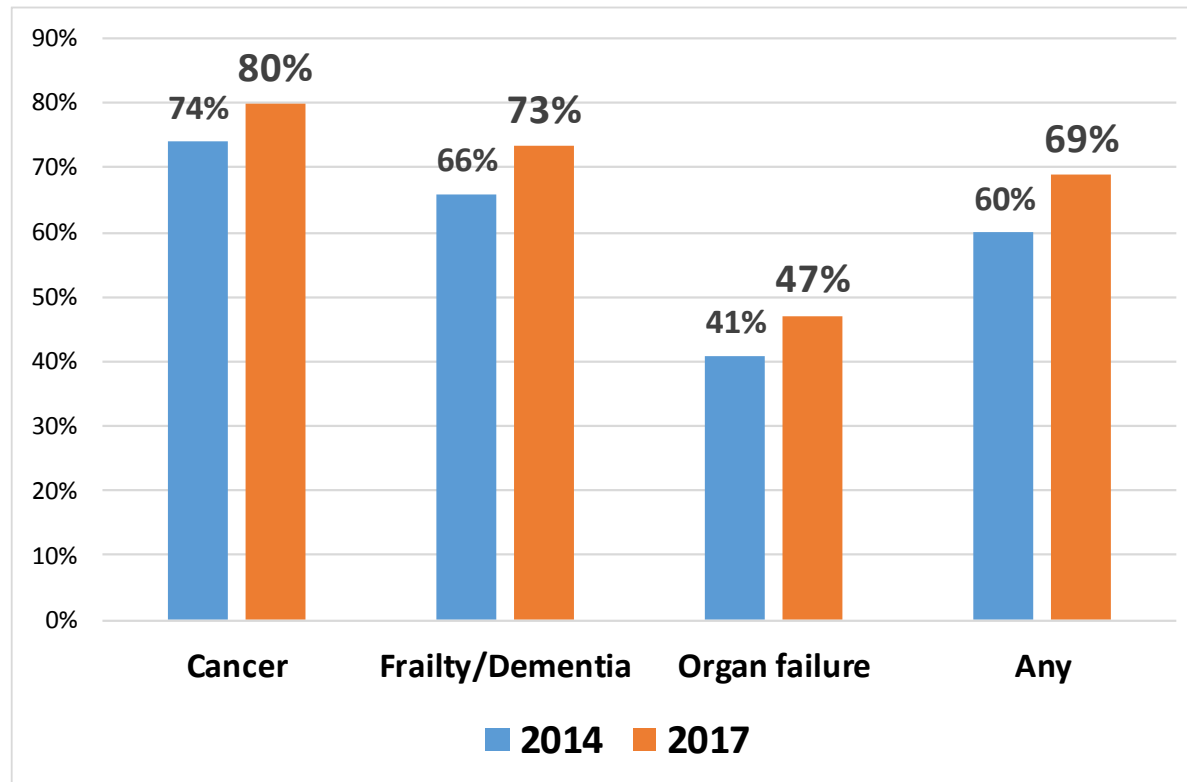
Proportion of patients with a KIS at the time of death (n=1034)



Results

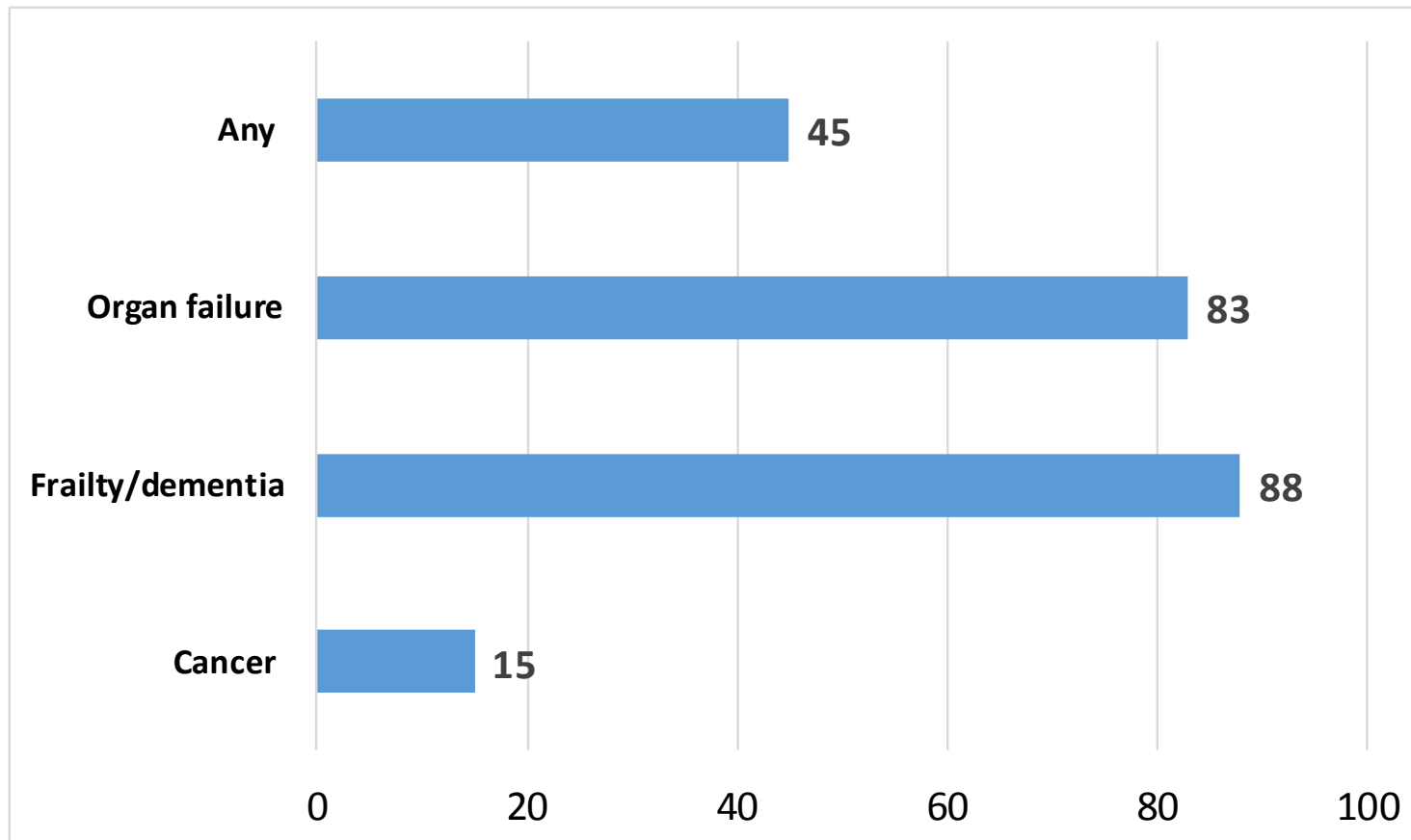
Proportion of patients with a KIS at the time of death

2014 versus 2017 (%)



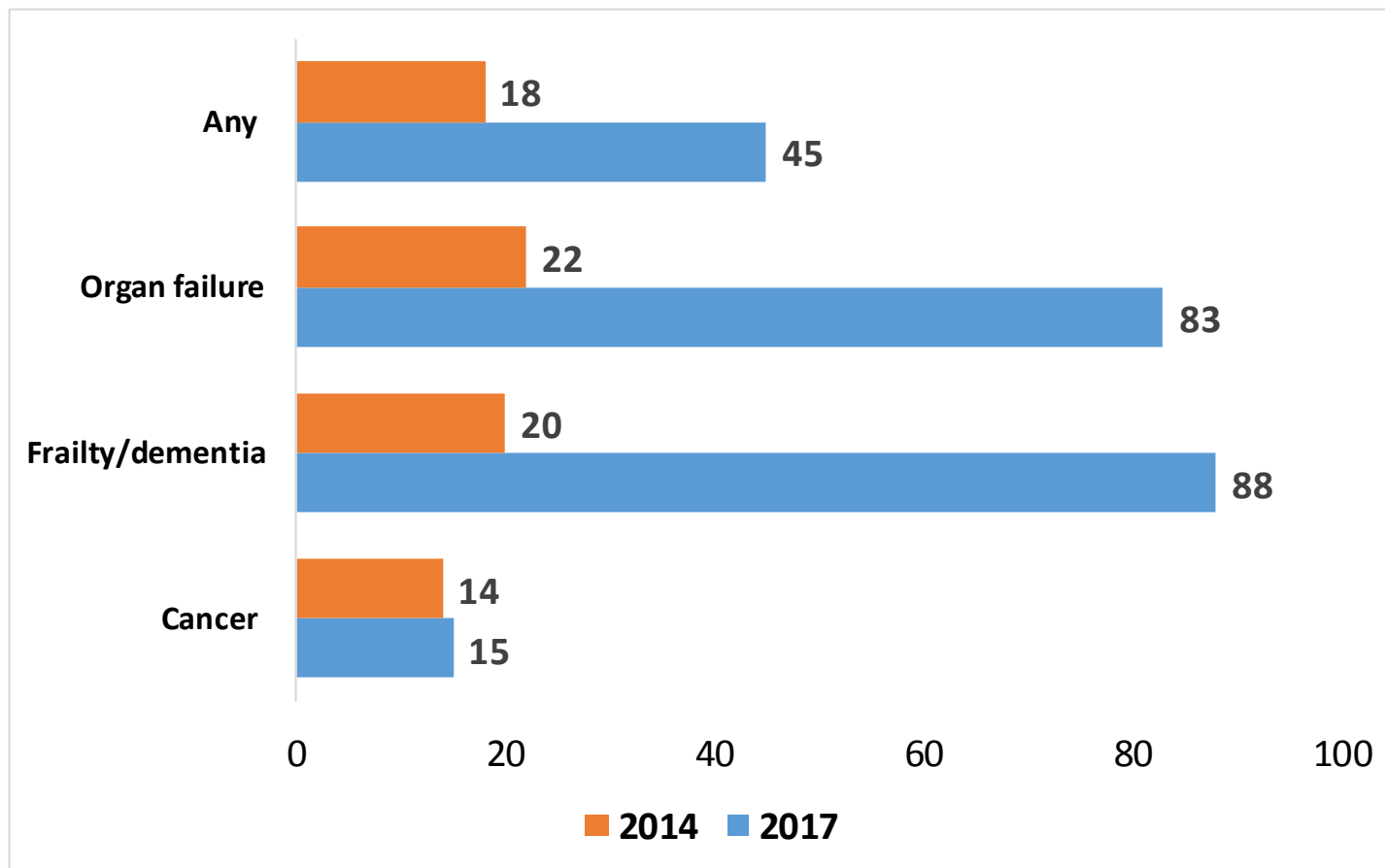
Results

Timing of KIS generation (median weeks before death)



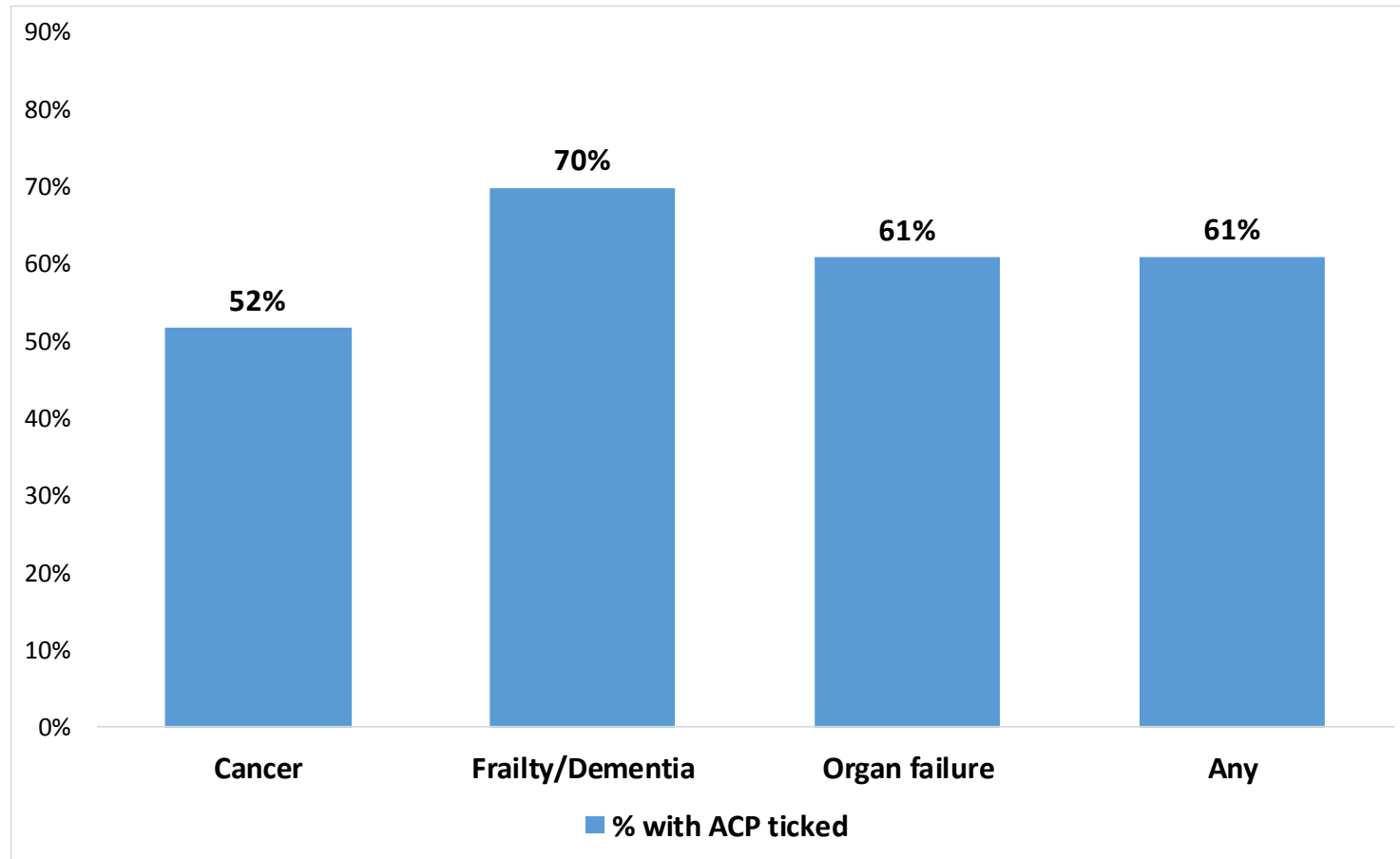
Results

Timing of KIS generation (median weeks before death)



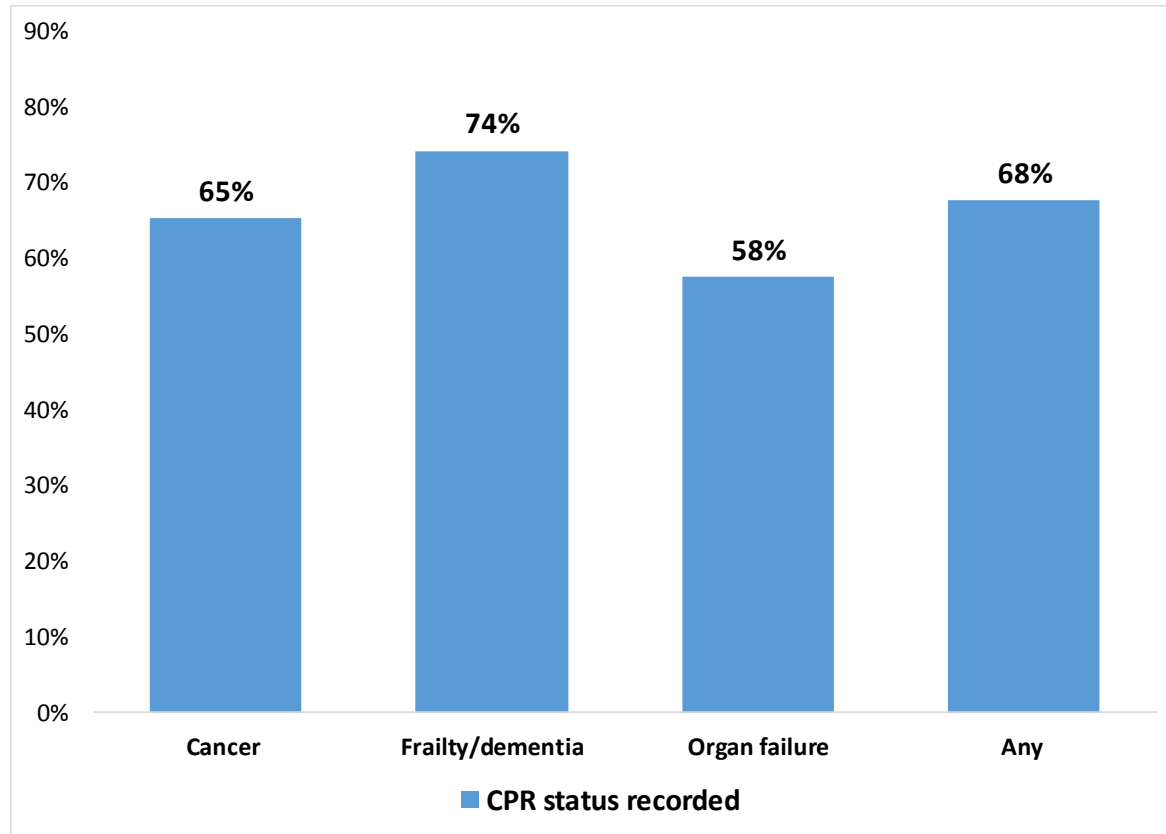
Results

Proportion of patients with ACP box ticked



Results

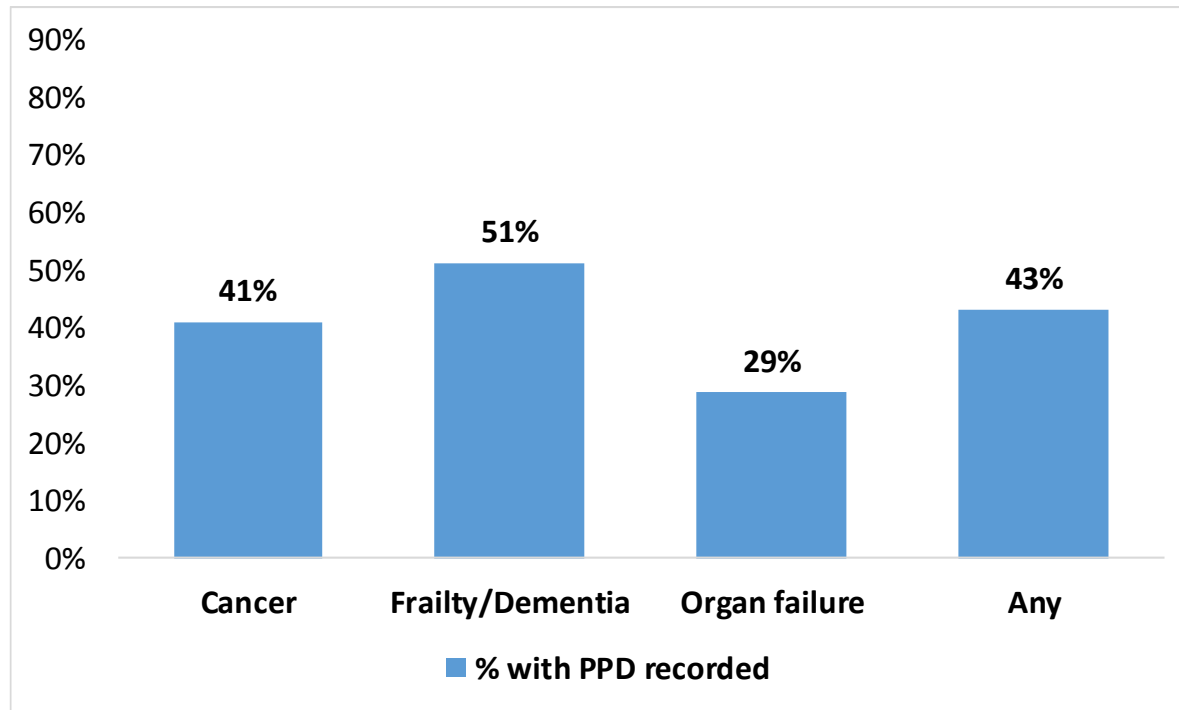
Proportion of patients with resuscitation status recorded in KIS (n=712)



→ Increase from 42% in 2014

Results

Proportion of patients with preferred place of death recorded in the KIS (n=712)

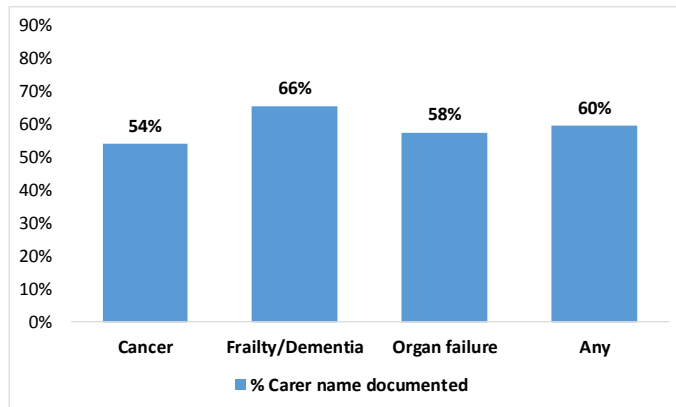


Increase from 29% in 2014

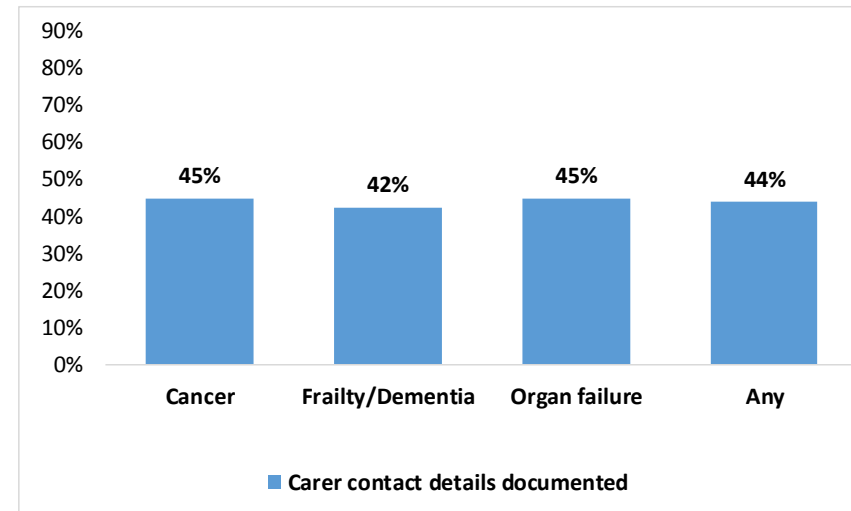
Results

Proportion of patients carer details documented in the KIS (n=712)

Carer name documented (%)



Carer contact details documented (%)



Results

KIS Usefulness

Highly useful

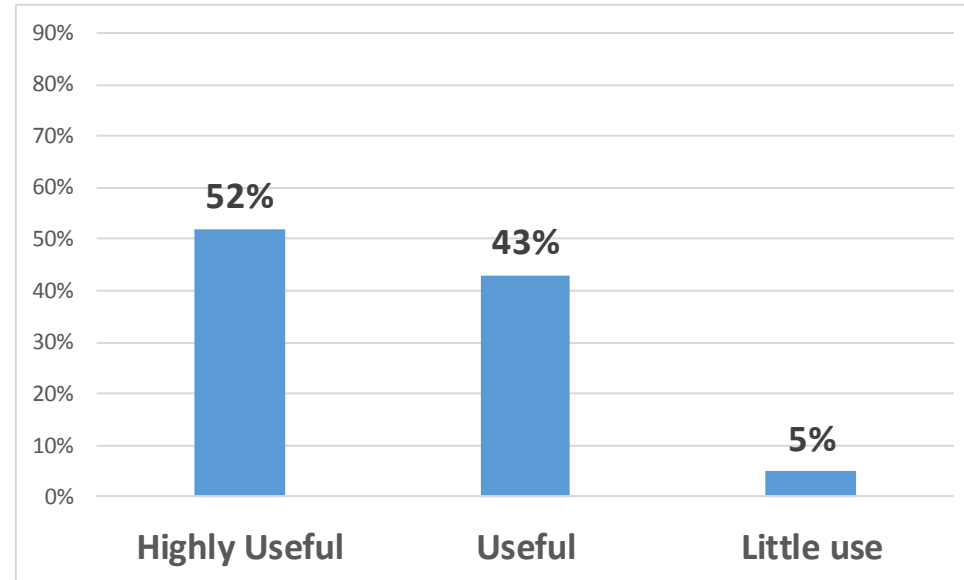
- Clear plan regarding patient (and ideally family) wishes regarding current care and future planning.

Useful

- Some additional useful clinical information, but no clear wishes regarding current care or future planning.

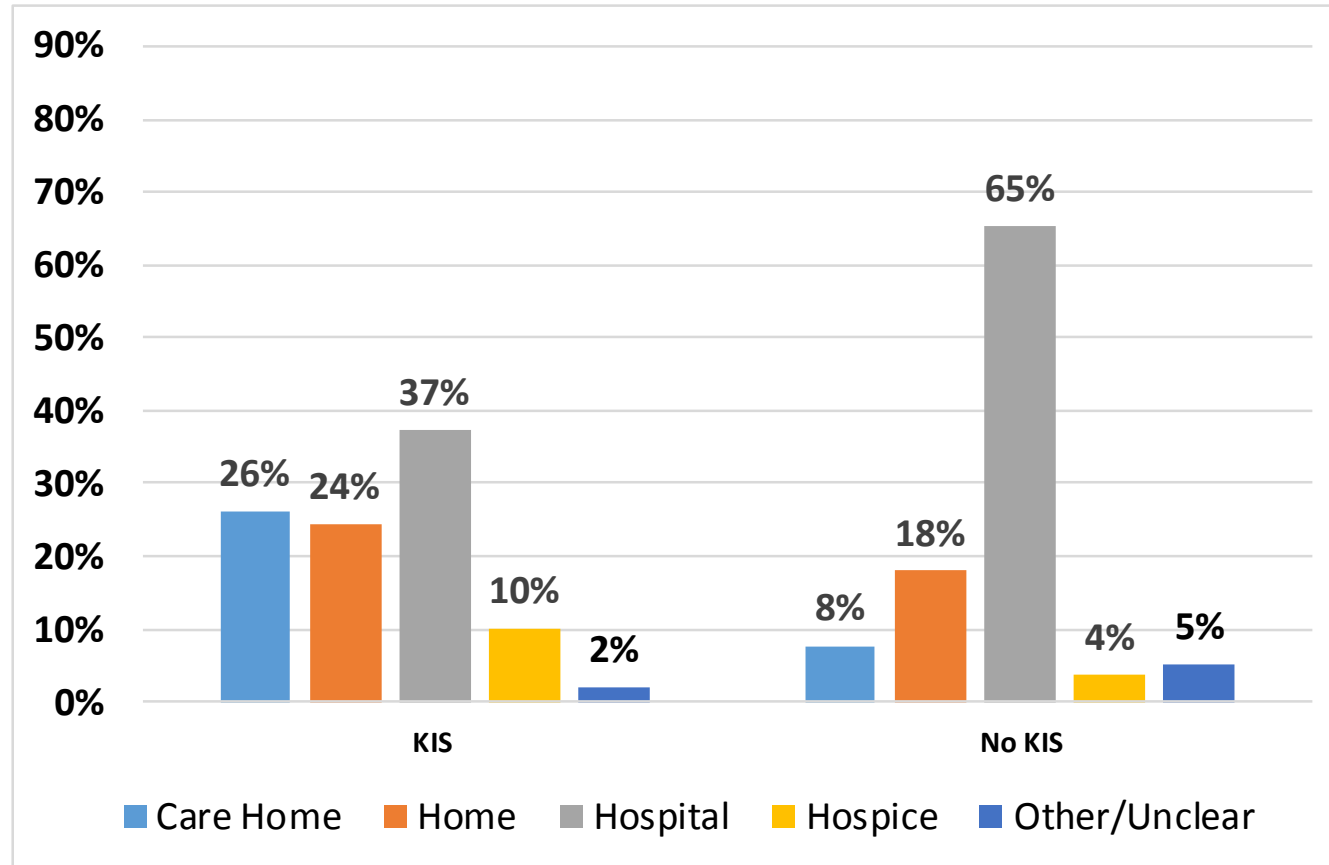
Little use

- KIS present but no additional information added, no relevant boxes ticked, no special note.



Results

KIS and place of death (n=712)



Qualitative findings

Special note is considered most useful section



...out-of-hours [it's] the special notes box that I go for, the most useful bit because of clinical information and ceiling of care...really useful information.



And one of the things I think the KIS has been useful for , and does appear to get read by the out-of-hours service, is where the patients ceiling of care is set at staying in the nursing home.. I've seen that ...that has swayed the out-of-hours services



Qualitative findings

Perception that NHS24 don't access the KIS



NHS24 are dire at noticing they are in place and it has a negative impact on patient care if they fail to notice that.



Patients and carers could ask for a KIS



[Patients and carers] should come and ask 'I need a KIS'.. do people know [to ask]



Conclusions

- The proportion of people with an advanced progressive illness who have a KIS has increased significantly since 2014.
- KISs are being generated earlier, and over half of all KISs are generated at least a year before the person dies.
- The ACP tick box has limited value.
- The vast majority of KISs are useful or highly useful and KIS completion is regarded as important by GPs.
- Renewed focus on triggers for KIS completion for people with organ failure is warranted
- Better information regarding carers/next of kin is recommended

Conclusions

- Consider how to ensure greater use of KIS by NHS 24 to enhance clinical decision-making out-of-hours.
- Could we rebrand the KIS to make it so that it is easier for patients to understand, and empower people to request a KIS?
- Strong and sustained progress towards improved identification of patients for a supportive and palliative approach, and sharing of key patient information across settings in Scotland.

Thank you

Short Stories on Care Co-ordination

Personal outcomes – Towards a shared understanding
Ali Guthrie

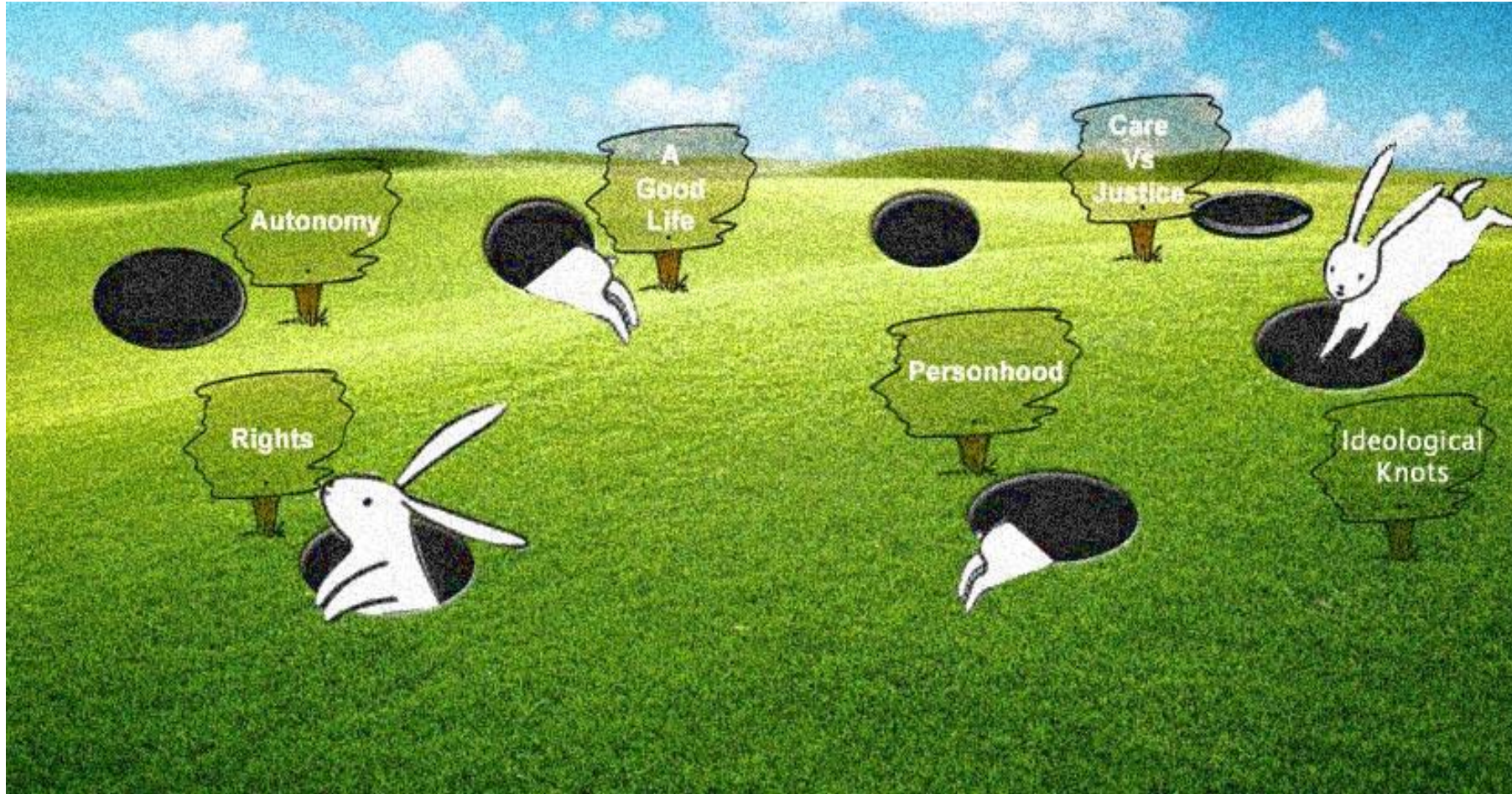


Personal Outcomes: Towards a shared understanding – Personal Outcomes Resources for you and your role

Healthcare Improvement Scotland 08/11/18

Alison Guthrie Learning & Development Adviser, SSSC



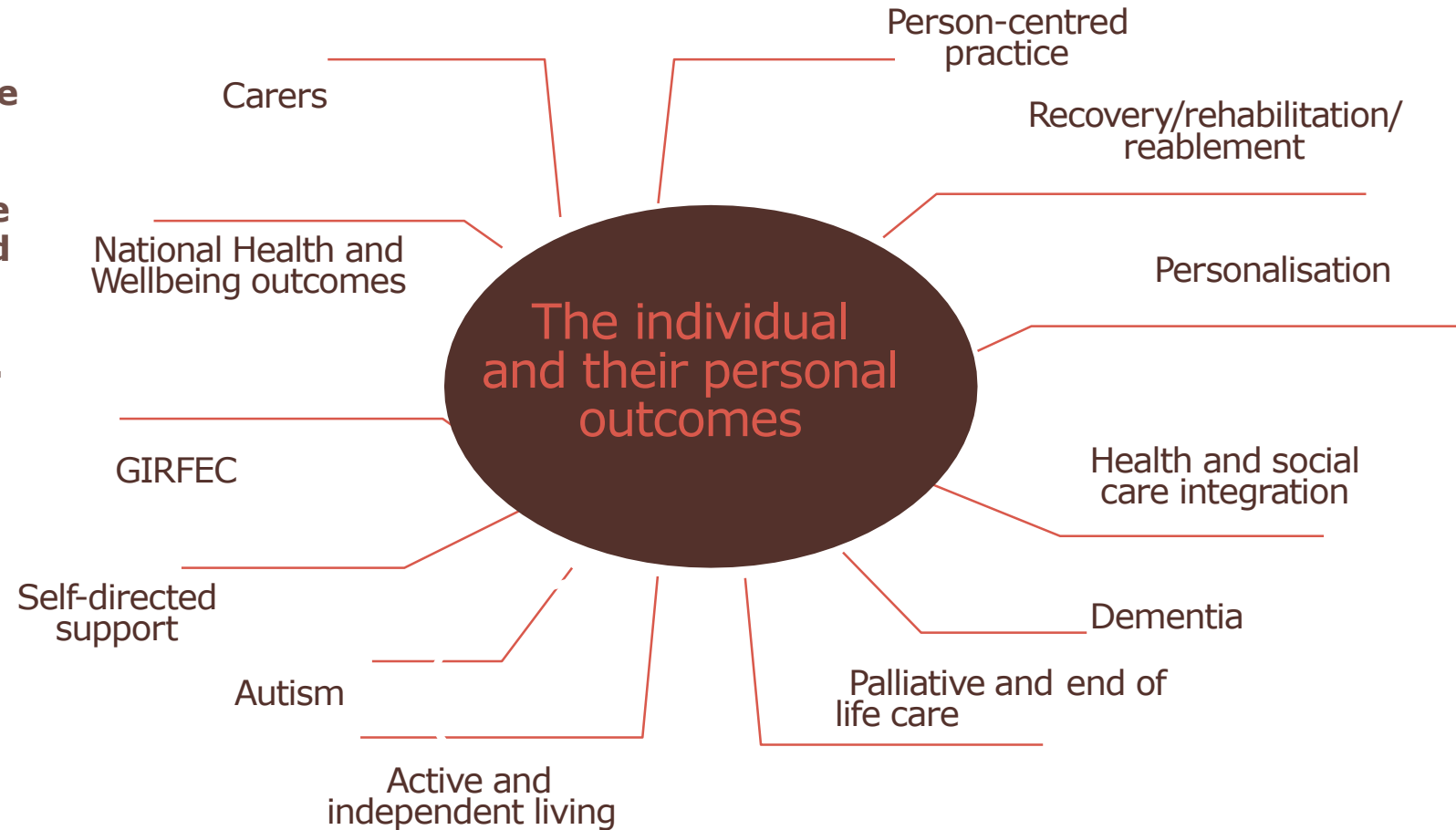




- The Christie report on public service reform in Scotland in 2011 highlighted the need to work closely with individuals to understand their needs, maximise their talents and resources, support self-reliance and build resilience.
- Since then, focusing on what matters to people by adopting personal outcomes approaches has moved beyond the 'nice to do' category of service improvement to being understood as fundamental to transforming and sustaining public services in Scotland.
- Many services across health, social care, housing and beyond have now developed good practice around personal outcomes.
- Evidence shows this approach leads to better outcomes for the individuals being supported and for organisations adopting this approach.
- Workers across all sectors have identified the need to raise awareness of personal outcomes approaches and to share experience and evidence.



A wide range of policy areas in Scotland are underpinned by personal outcome approaches.





What are personal outcomes?

When we talk about personal outcomes we mean the things that are important to people in their lives.

“I want help with getting my confidence back in the kitchen. Home cooking makes a house into a home and the smell of soup on the stove makes me feel I am making a home for my husband and me.”

Iris, 82

Home from hospital after breaking her leg in a fall

Personal outcomes often relate to maintaining or improving wellbeing.





What does a personal outcomes approach mean for you?



For you as a worker, a personal outcomes approach involves **active listening, good conversations and engagement; recording personal outcomes in a meaningful way; reviewing and monitoring progress towards achieving personal outcomes.**

“What I like about this way of working is that we are engaging with people about what is important to them, instead of processing them through the system.”

Eileen, 37
Social worker

The Health and Social Care Standards

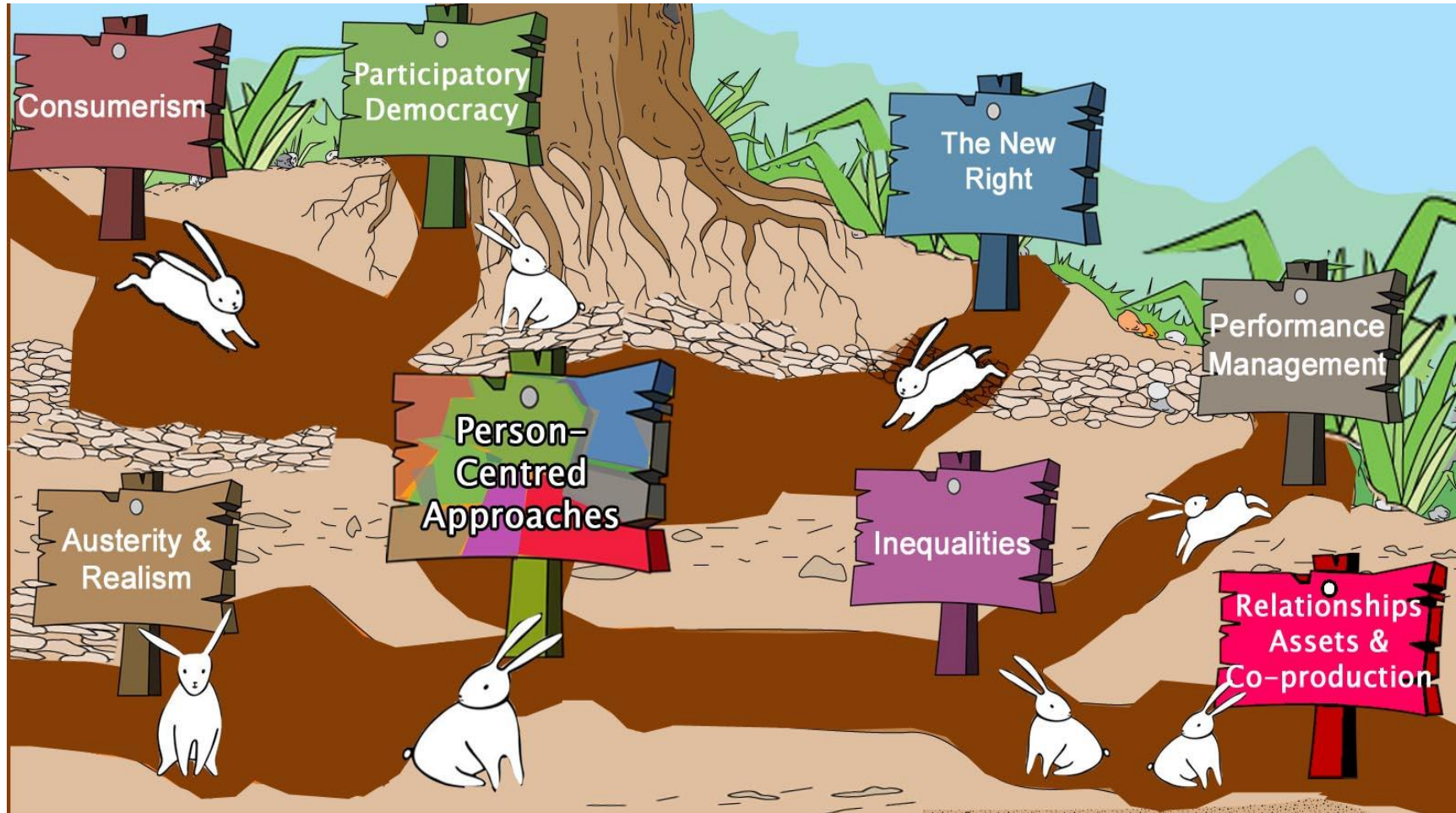


Principles

- Dignity and respect
- Compassion
- Be included
- Responsive care and support
- Wellbeing

Standards

1. I experience high quality care and support that is right for me.
2. I am fully involved in all decisions about my care and support.
3. I have confidence in the people who support and care for me.
4. I have confidence in the organisation providing my care and support.
5. I experience a high quality environment if the organisations provides the premises.



Background

- ❖ Co-design - Using Appreciative Inquiry principles
- ❖ Connecting with existing evidence and personal outcomes materials
- ❖ Building on what already exists
- ❖ Sharing learning and experience through collaborative development
- ❖ Grounded in the everyday realities, complexities, diversity and dynamics of people's lives
- ❖ In recognition that improving personal outcomes is everybody's business



Understanding personal outcomes

Background
information

Understanding
outcomes

Engaging and
conversation

Recording and
measuring

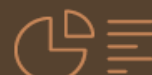
Working with
people

Working with
other
professionals

Leadership and
system change

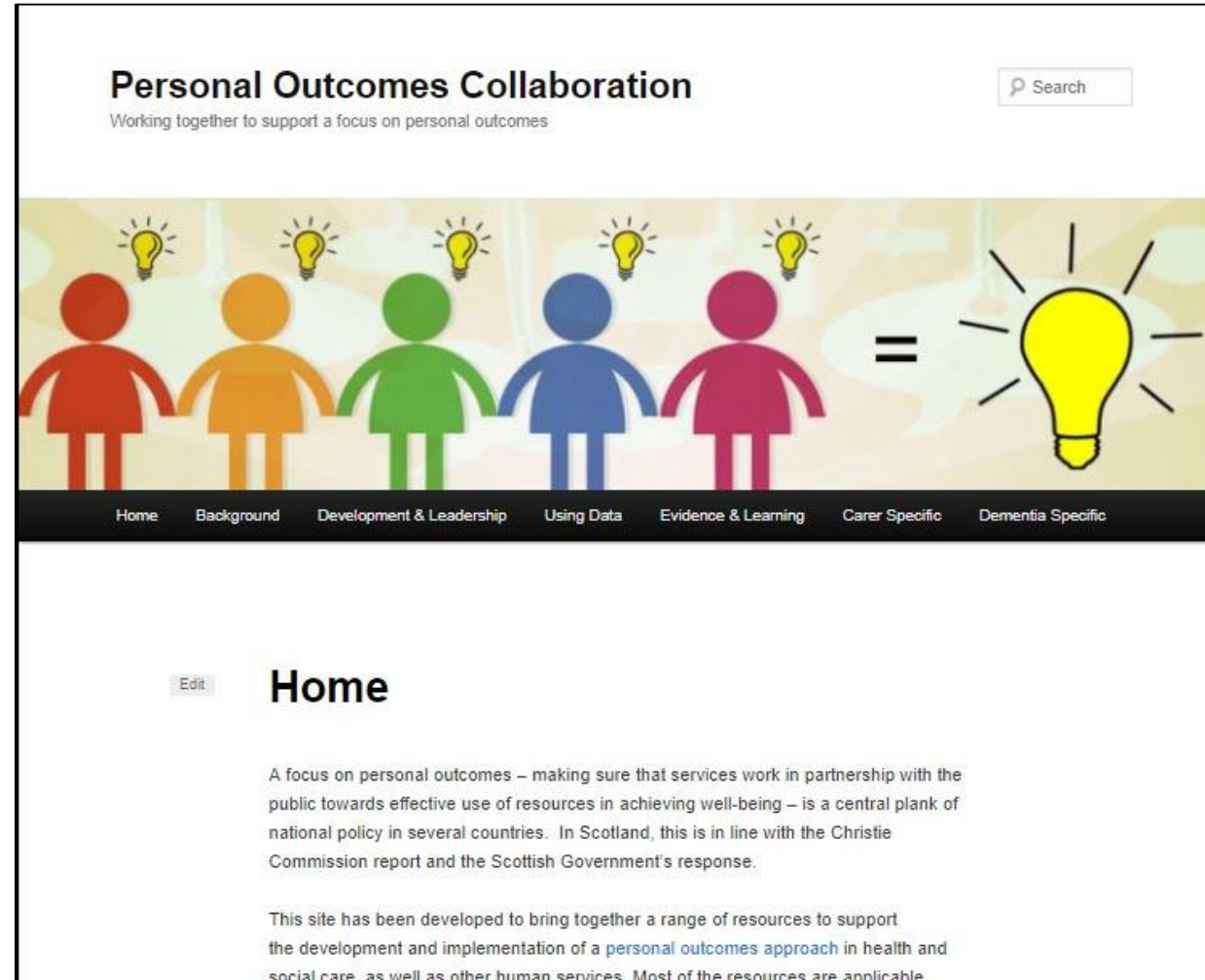
Risk and
challenges

Evidence and
learning




Updating the Personal Outcomes Collaboration Website

<https://personaloutcomescollaboration.org/>



Personal Outcomes Collaboration
Working together to support a focus on personal outcomes

Search



Home Background Development & Leadership Using Data Evidence & Learning Carer Specific Dementia Specific

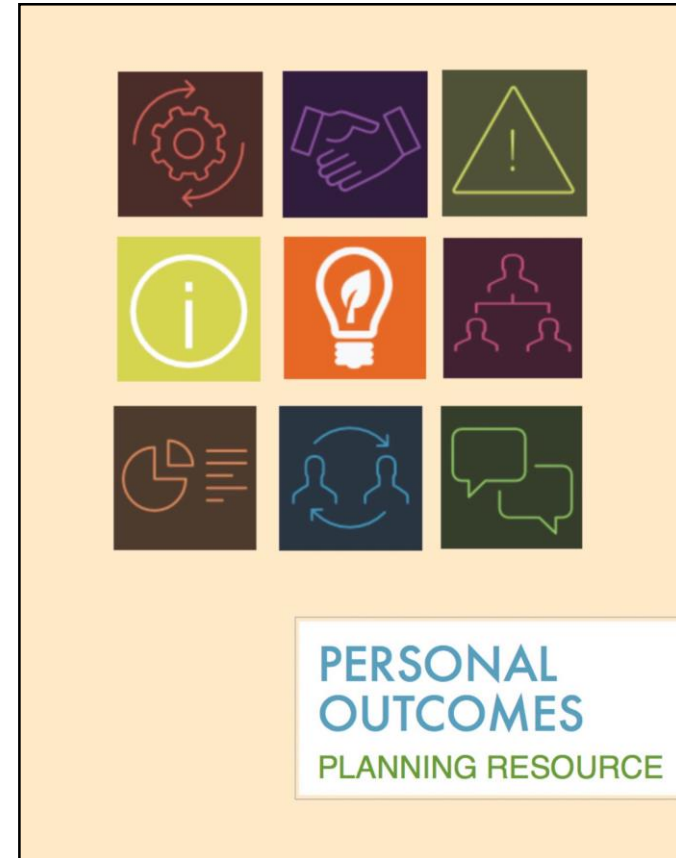
Edit **Home**

A focus on personal outcomes – making sure that services work in partnership with the public towards effective use of resources in achieving well-being – is a central plank of national policy in several countries. In Scotland, this is in line with the Christie Commission report and the Scottish Government's response.

This site has been developed to bring together a range of resources to support the development and implementation of a [personal outcomes approach](#) in health and social care, as well as other human services. Most of the resources are applicable

Personal Outcomes E-books

- ❖ Interactive learning resource
- ❖ Includes videos and internet links
- ❖ Also has internal bookmarks to enable easy and quick navigation between sections
- ❖ Users are able to write their own notes to develop individualised resource



Personal Outcomes E-books



worker and the carer spend time together trying to work out what the priorities are:

'I don't necessarily know the purpose of it until they're there. Because I think, for some people, it is about a sounding board and... you know, someone to listen... In the first session you tend to get more, sort of, offloading in that sense... Often you don't really know what they're wanting to get out of it until you're, kind of, having that conversation. And sometimes people are... using you to kind of, refine down their situation a little bit for them... and reflect back'. (interview with VOCAL practitioner)

Conversations with the carer about what matters



The Meaningful and Measurable project found that good conversations which allow people to reflect on their situation and possible ways forward can build confidence, restore identity and improve wellbeing.

In this example, Christeen describes the impact of having an outcomes focused conversation with a practitioner called Josephine. As this conversation predates the Carers Act, she talks about an outcome focused assessment rather than a plan. The benefits are significant.



You can read a transcript of Christeen's story [here](#).

Personal Outcomes E-books

Study Notes

7 Leadership and system change


Leadership and system change

Today at 17:00 44

For many practitioners it will be a requirement of their registration body to maintain a record of continuing professional development or post registration training and learning... This is a test note to show what you can do

Today at 17:01 44

While it may not be possible to iron out all the contradictions that exist in complex systems, good leadership facilitates conversations within organisations that allow people at all... Another test note that can be cross-referenced



culture where individuals can use and enhance their leadership skills. This includes empowering people working in and using social services, and encouraging professional autonomy, creativity, measured risk-taking and initiative.


For many practitioners it will be a requirement of their registration body to maintain a record of continuing professional development or [post registration training and learning \(PRTL\)](#).

The [Step into Leadership](#) also encourages citizen leadership for people who use services and carers. There are examples of different citizen leaders and of most relevance to this resource, material about young carers as citizen leaders

<http://lx.iriss.org.uk/content/skye-and-lochalsh-young-carers>

Leading for outcomes

There are six leadership capabilities that underpin the leadership strategy and leadership development activity in the sector.



Leadership and risk

There is widespread recognition that risk averse cultures in both health and social services can mean that people are unnecessarily prevented from taking reasonable risks as part of everyday life; another reason why embedding personal outcomes requires a whole system approach. While it may not be possible to iron out all the contradictions that exist in complex systems, good leadership facilitates conversations within organisations that allow people at all levels to name tensions and negotiate consistent ways of navigating through them.

Open Badges

- Open badges available to recognise learning
- Learners will need to write short reflective account
- More badges to be developed including over-arching badge



Immediate impact: Reactions, awareness

**Do you feel that the resource is useful to your role and practice context?
99% of respondents to local launch events questionnaires to date
answered Yes.**

'I am going to introduce the resource in Practitioner training –particularly 'Carers Act'

'Will check out with Voluntary sector colleagues and Children's Services'



'I plan to look at project group with practitioners and how we can collaboratively use the resources'



Immediate impact: Reactions, awareness

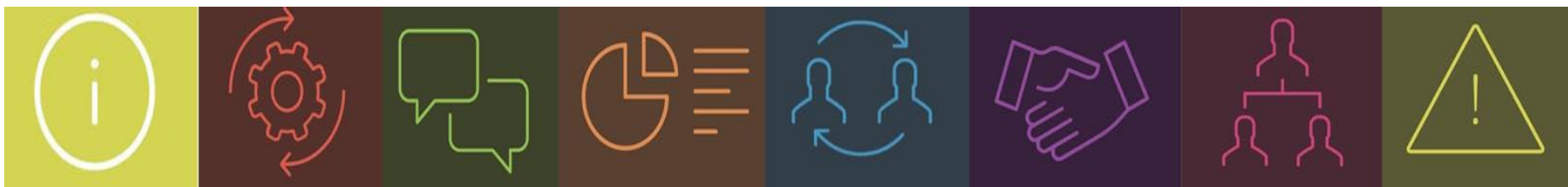
'Great new book on Personal Outcomes, fantastic resource'

'I am going to explore further with Children's Services'

'Also worth mentioning you can use the approach beyond client/practitioner relationships and include team meetings, student/clinical supervision. Let's really shift the culture of care!'



'Will use to develop further learning resources and to work with staff'





THANK YOU

For more information on the personal outcomes resources and to request copies of the personal outcomes booklet please contact:

sdsandintegration@sssc.uk.com

@SSSCnews | www.sssc.uk.com | 0345 60 30 891

Short Stories on Care Co-ordination

Care homes
Jo Hockley

Care coordination and care homes

Jo Hockley RN PhD

Primary Palliative Care Research Group

Centre for Population Health Sciences

The Usher Institute, University of Edinburgh

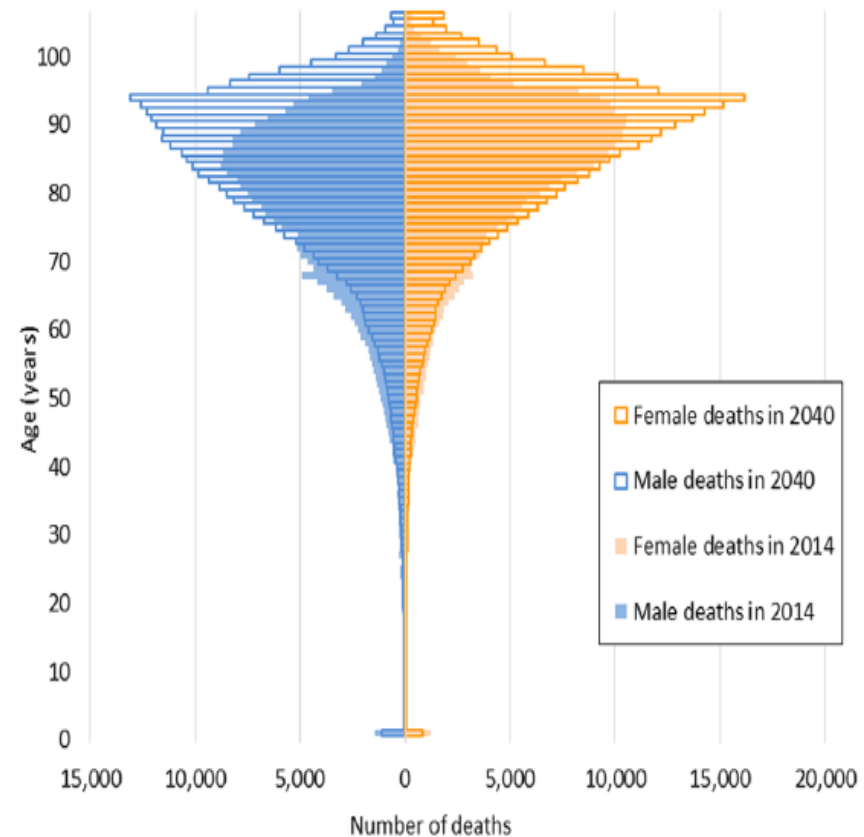
Jo.hockley@ed.ac.uk

Over the last 10 years:

- People over 80+ years is the fastest segment of our UK population
- Care home residents now increasingly frail with multiple co-morbidities and increasing dependency
 - 80% of residents in care homes have diagnosis of dementia or severe memory loss
 - Multiple co-morbidities
 - One fifth of Scottish population die in care homes
- Care home workforce
 - Is overlooked compared with its NHS counterpart – lack of career structure
 - High turnover of staff + difficulties in recruitment
- Increasing pressure for external healthcare professionals to support to care homes

Impact of population ageing

- The disabled older population will increase by over 80% and those with dementia by 50% by 2030 (Jagger et al 2009)
- By 2040, it is predicted that 40% UK population will die in care homes (Bone et al, 2017)



Gaining a better hold on palliative care in care homes – what are the main issues

- Lack of recognising dying
- Lack of external healthcare support in relation to palliative care
- Lack of support of staff
- CIRC tool
- Monthly palliative care m/disciplinary meetings in the care home
- Reflective debriefing

Gaining a better hold on palliative care in care homes – what are the main issues

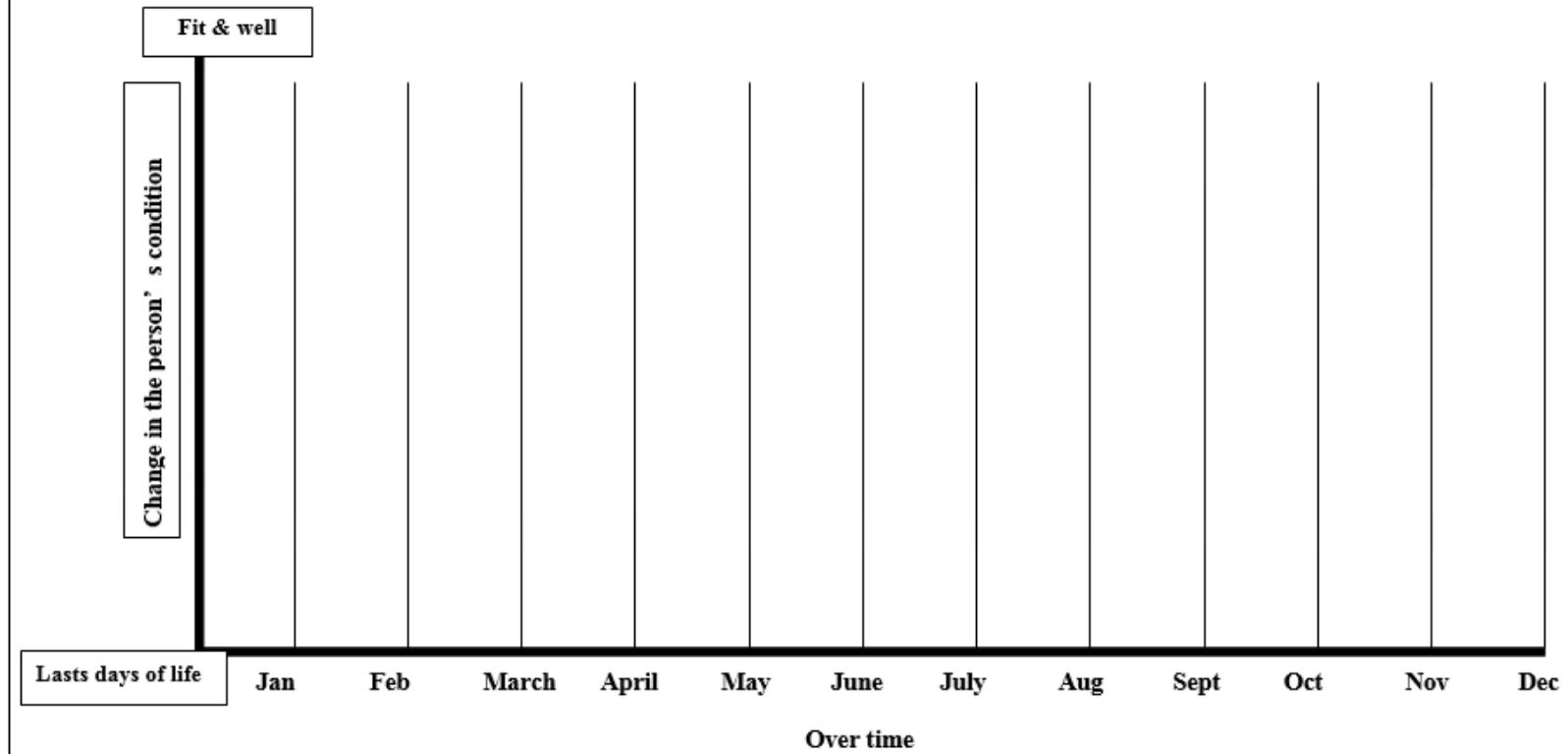
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'Changes in a Resident's Condition Chart' (CIRC)

(adapted from Macmillan 2011 – Foundations in Palliative Care)

Person's name:
Date commenced:

Use this graph at your palliative care review meetings to plot change in the person's condition.



▲ Main Diagnosis: _____

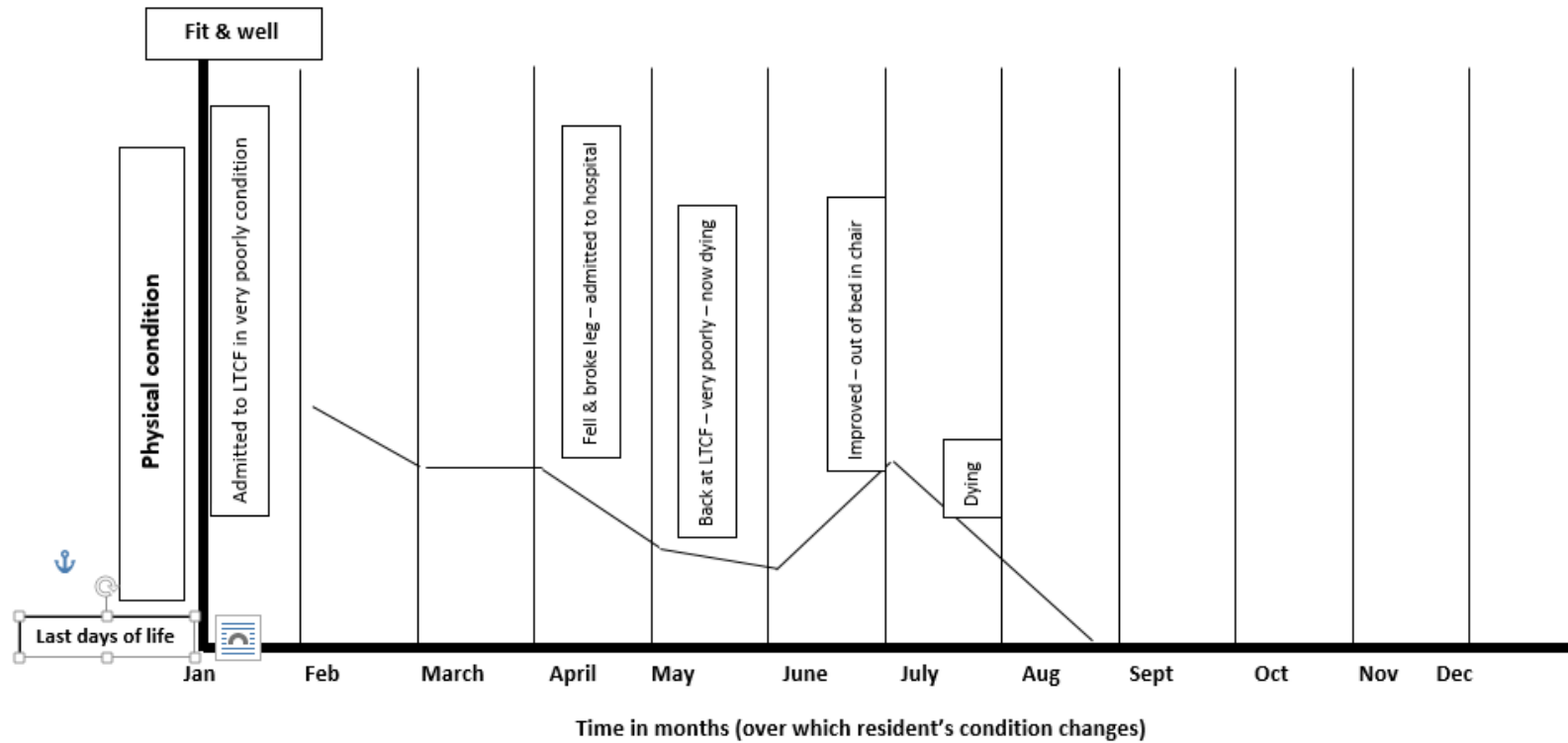
(Copyright; Hockley et al
University of Edinburgh)

Changes in Resident's Condition Chart – an exemplar

Resident's name:

Date commenced:

Use this graph at your MONTHLY multi-disciplinary palliative care review meetings to indicate change in the resident's physical condition in order to anticipate dying and the necessary quality care in the last phase of life.



Gaining a better hold on palliative care in care homes – what are the main issues

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Gaining a better hold on palliative care in care homes – what are the main issues

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REFLECTIVE DEBRIEFING TOOL (Hockley 2014)

Initial of resident :

Date of reflection:

Reflective debriefing is the process whereby clinical practice can be re-examined to foster the development of critical thinking for improved practice. The process is on-going with each debriefing and should be viewed as an aid to lifelong learning rather than single processes.

1. Describe the person/event.

For no more than five minutes, encourage all staff to recall their memory about the person who has died/event – such as Person: What were they like, what did they like to do? Did they have family? Who was important to them? What did they like/dislike? Were they humorous/serious/sad/angry? What were their perspective on what was happening? Were their fears/anxieties?

Event: What was the event? who was involved?

2. What happened leading up to the death/event?

Describe what happened for individuals on the various shifts that led up to the death/event

3. How do staff feel things went?

What went well? What didn't go so well? How did people feel?

Both positive and negative feelings should be described and owned. Feelings can be a useful guide to how learning is possible whilst it is important to be honest it is also important to respect others feelings.

Look at the decisions that were made – this will help you to understand what else could/could not have been done. Opinions of others will help this process. Remember to reflect on what was hoped and planned for, the original aims and objectives in the event of death in the care home: Was the documentation for the last days of life used? Were anticipatory drugs in place? Were symptoms controlled? Were family supported and informed? Were spiritual needs addressed? Were they in the place of choice? Was a decision made that cardio-pulmonary resuscitation was inappropriate if heart stopped suddenly? Was an care plan completed?

4. What could have been done differently?

Existing knowledge can be built on by theorising about what could have been done differently. In order for this to be effective critical thinking in a safe learning environment is essential with a 'no blame' attitude.

5. What do we need to change as a result of this reflection?

Key learning points can be listed and any action plans needed to enhance learning/more appropriate care. This might be in the form of re-writing of a policy, further chats with GP/nurse specialist in order that in the future the problem being discussed does not occur again, or it may highlight a need for training. It is essential that these learning points are not just logged but acted upon.

Each reflection can inform practice and should be used not only as a building block to learning but as a celebration of good practice. Reflection is not a passive contemplation but an active, deliberate process that requires commitment, energy and a willingness to learn as a team.

1. Pen portrait of person or event

2. What happened leading up to the death?

3. How do staff feel things went?

a) What went well?

b) What didn't go so well?

5. What do we need to change as a result of this reflection?

4. What could we have been done differently?



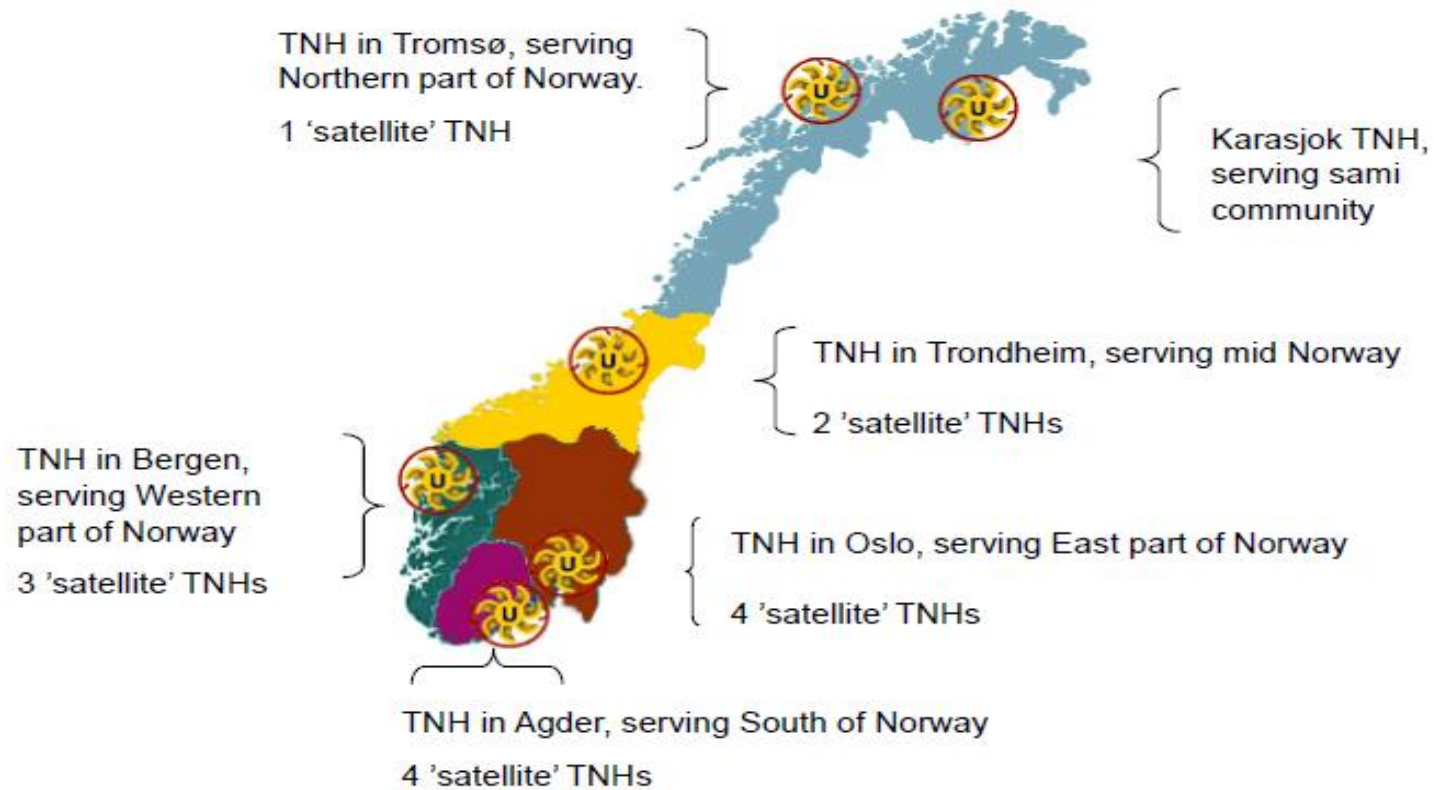
Update [2015-2017]

- 2015-2017
 - Scoping of the international literature + visited TNHs in Norway, the Netherlands & Australia
 - Visioning Day
 - Undertook a FEASIBILITY STUDY
 - Reported to NHS Lothian + local IJBs
- 2018
 - Support
 - all universities in Lothian (QMU, EN, UoE & HW) + local 'not-for-profit' care home/housing organisation
 - Scottish Government support



THE
VISION
FOR A TEACHING/
RESEARCH-BASED
CARE HOME

Norwegian Teaching Nursing Home Program (2004-2007)



Linking care homes into the system

- Eight 'satellite' care homes:
 - Undertake 'tests of change' to inform the Centre
 - Form a relationship together across care home companies
 - Once Centre is built, they will help disseminate to CHs in their region
- Hospital-based 'older people medicine'
- Hospital-at-home
- Community services

- Linking CHs with each other
 - clusters

In summary – we want to:



- Bring a sea-change in local public/professional perception of care homes
- Be the sustainability initiative behind practice development and quality improvement
- Support/work with 100+ care homes across Lothian in quality improvement initiatives and research
- Encourage a career pathway in care home work for health and social care professionals and so increase the workforce
- Encourage training in CHs for a variety of student interests
- Establish volunteerism and community engagement in care of frail older people

Thank you
jo.hockley@ed.ac.uk



Short Stories on Care Co-ordination

Looking beyond 2021
Richard Meade



**Marie
Curie**

**Care and support
through terminal illness**

Beyond 2021: thinking about the future

Richard Meade, Head of Policy and Public Affairs, Scotland

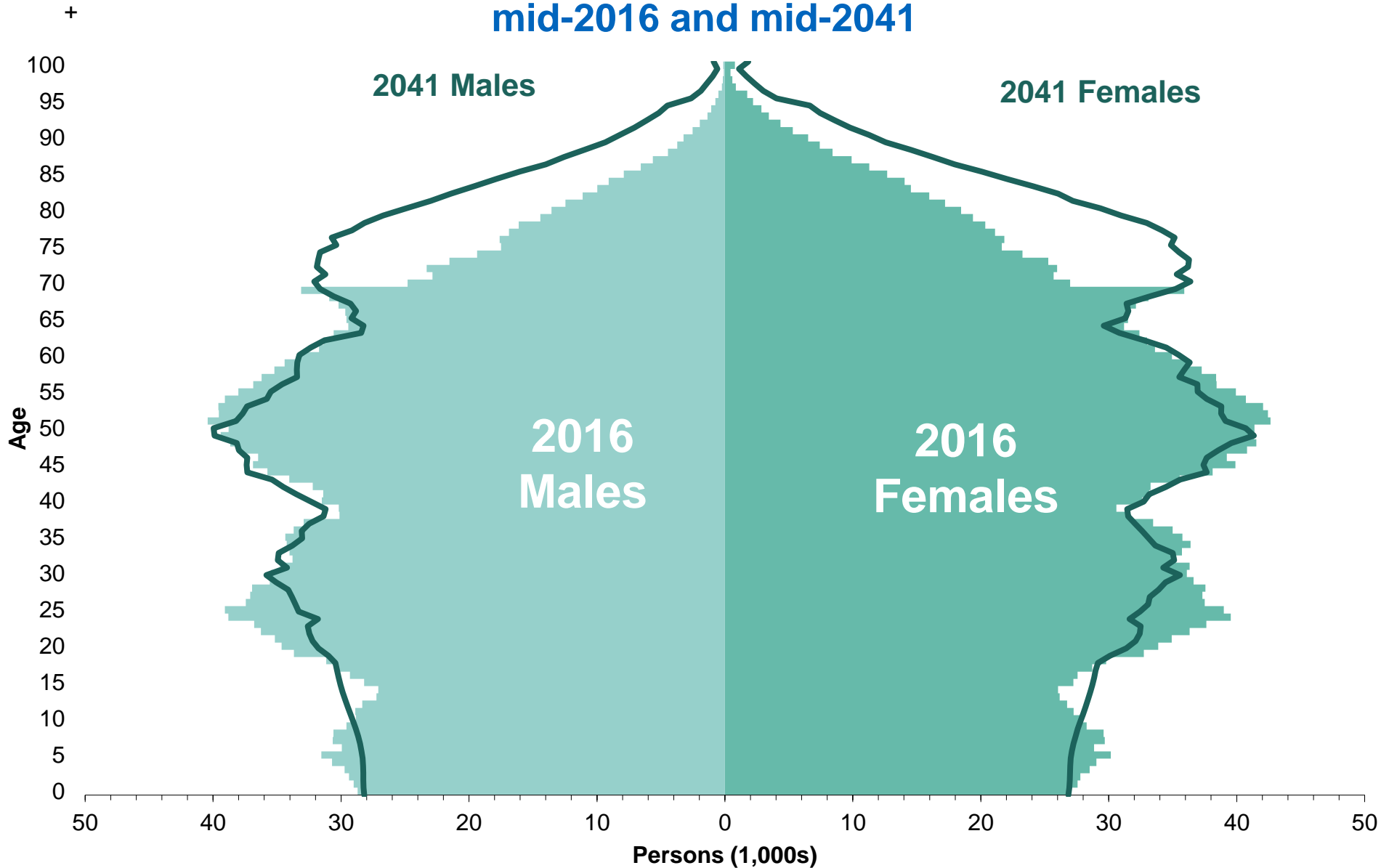


Beyond 2021: thinking about the future

- Are we thinking about tomorrow or just for today?
- What does tomorrow look like?
- What are the challenges we know about?
- What are the challenges we do not know about?
- How can we prepare for the future?

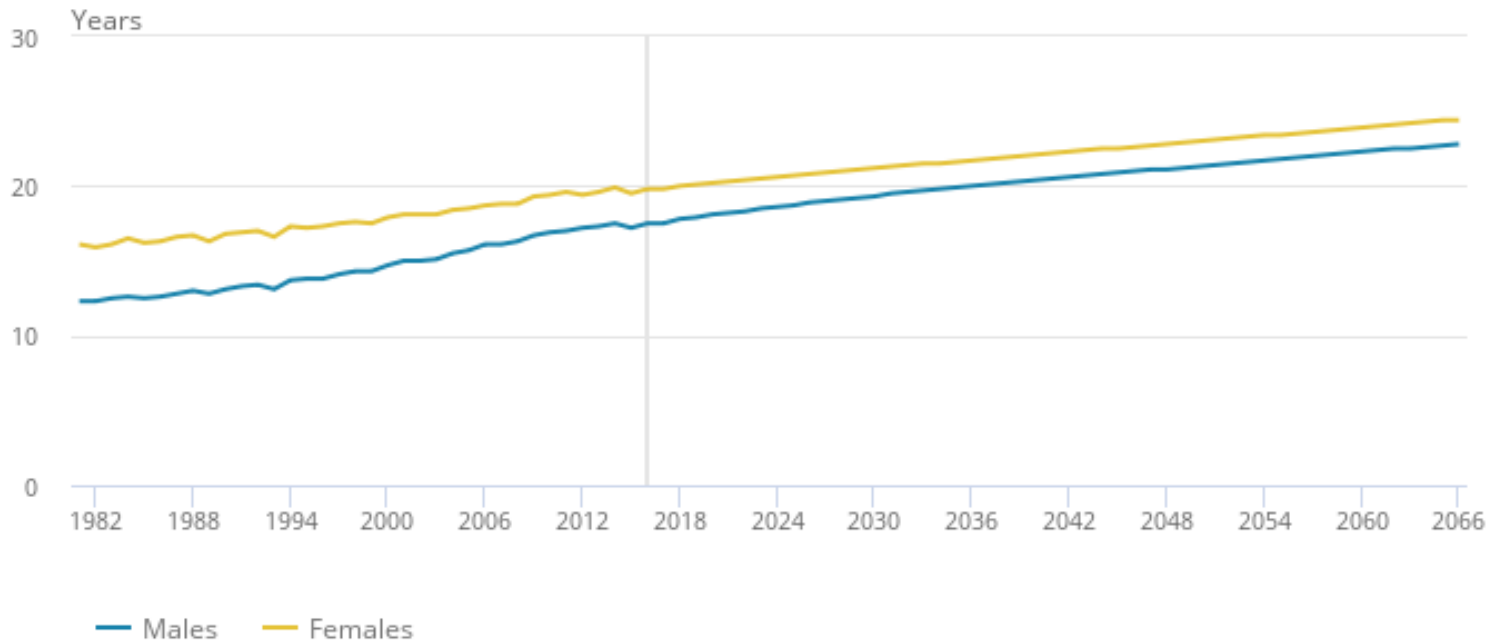


Estimated and projected age structure of the Scottish population, mid-2016 and mid-2041

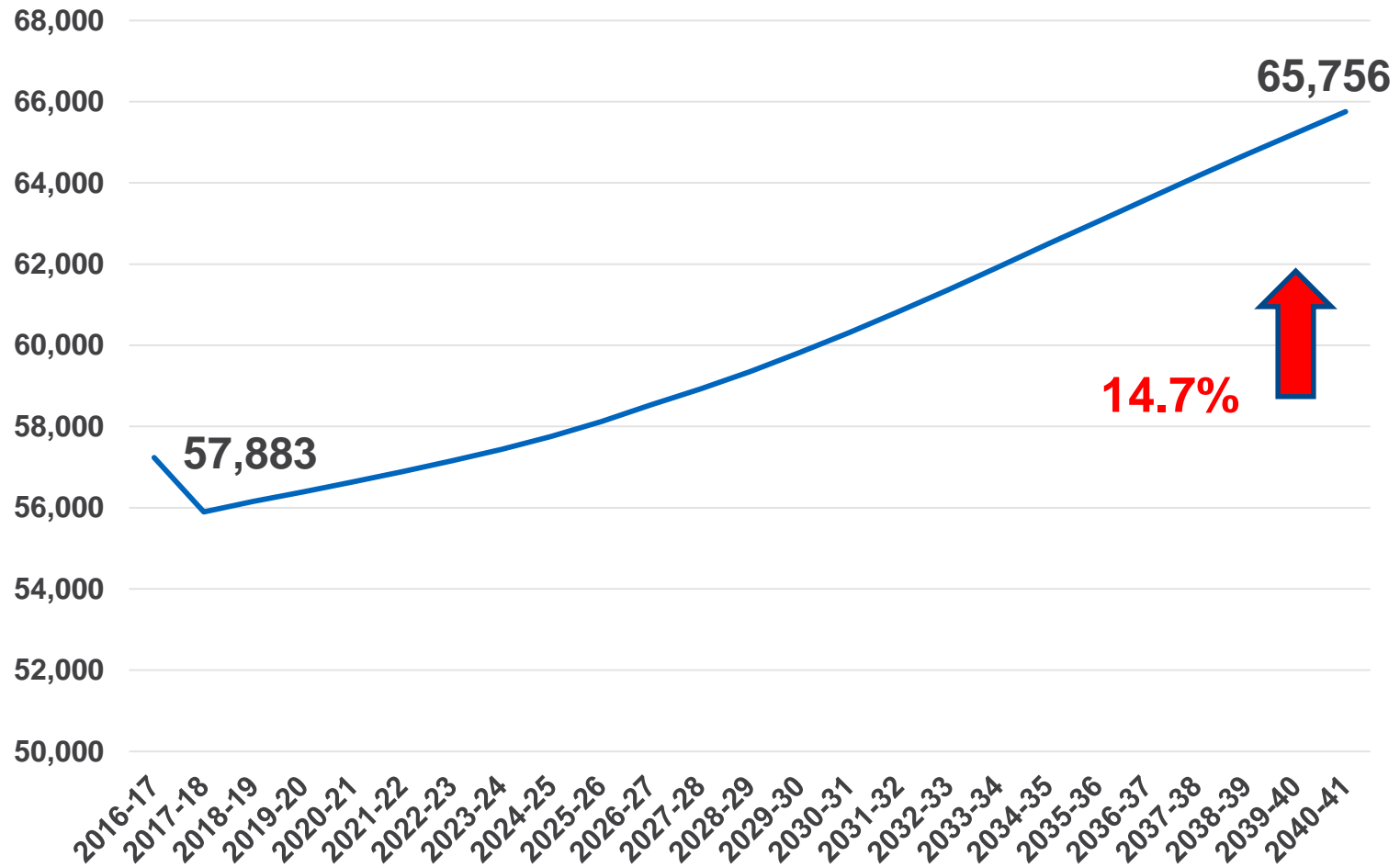


Life Expectancy at 65 – projected forward

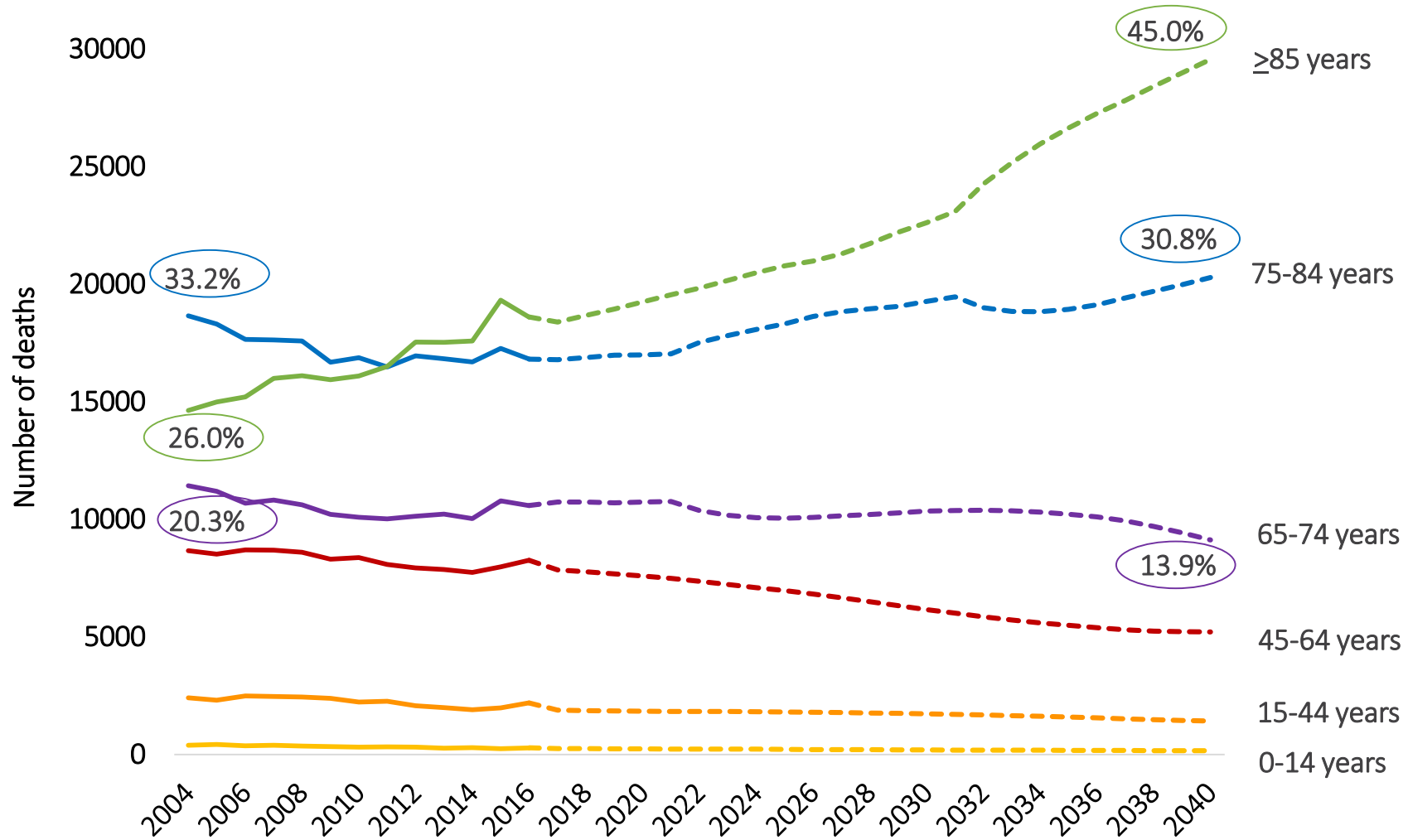
Figure 4.8b: Estimated and projected period expectation of life at age 65, Scotland, 1981 to 2066



Projected deaths in Scotland 2016-41

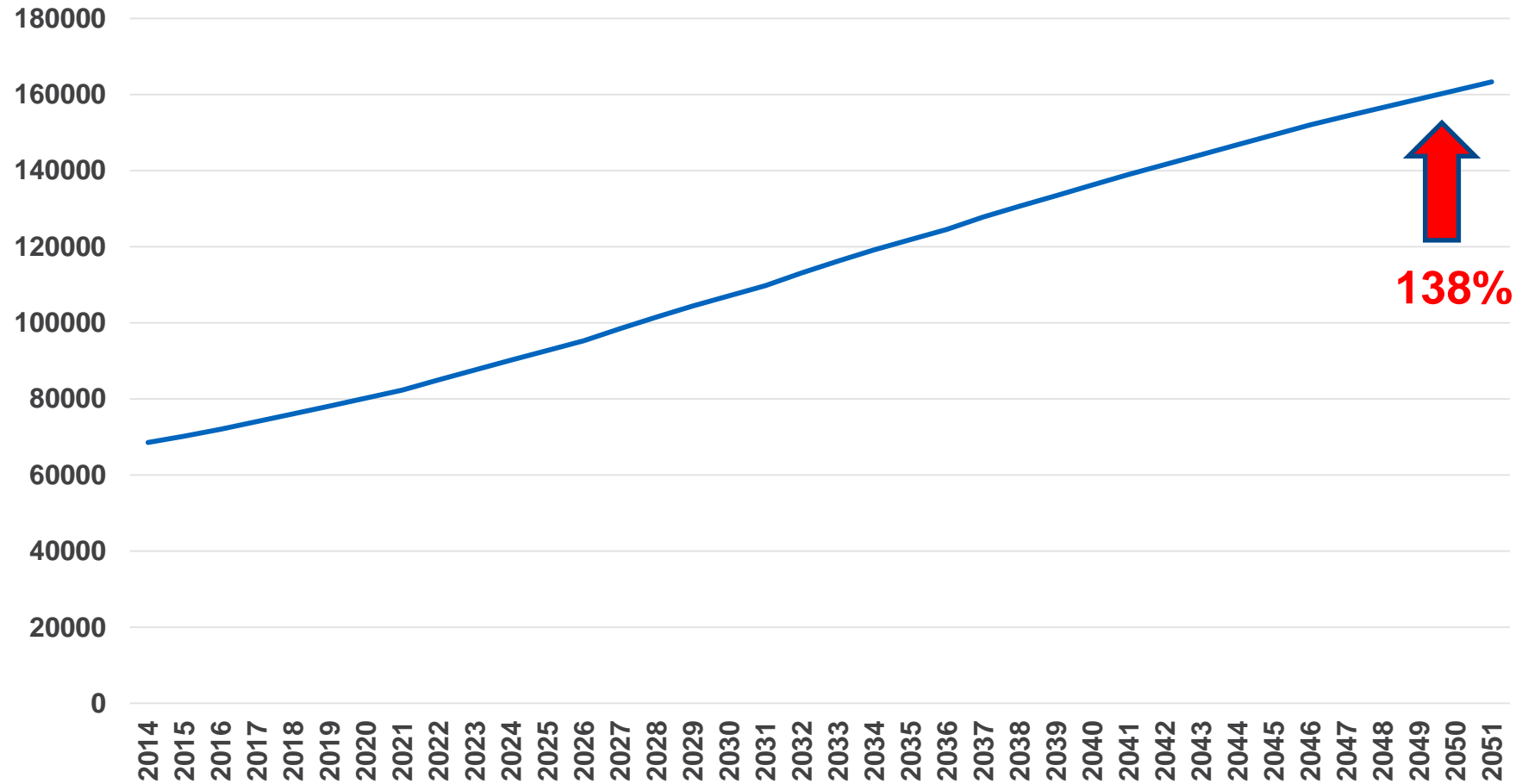


Observed and projected deaths in Scotland by age group

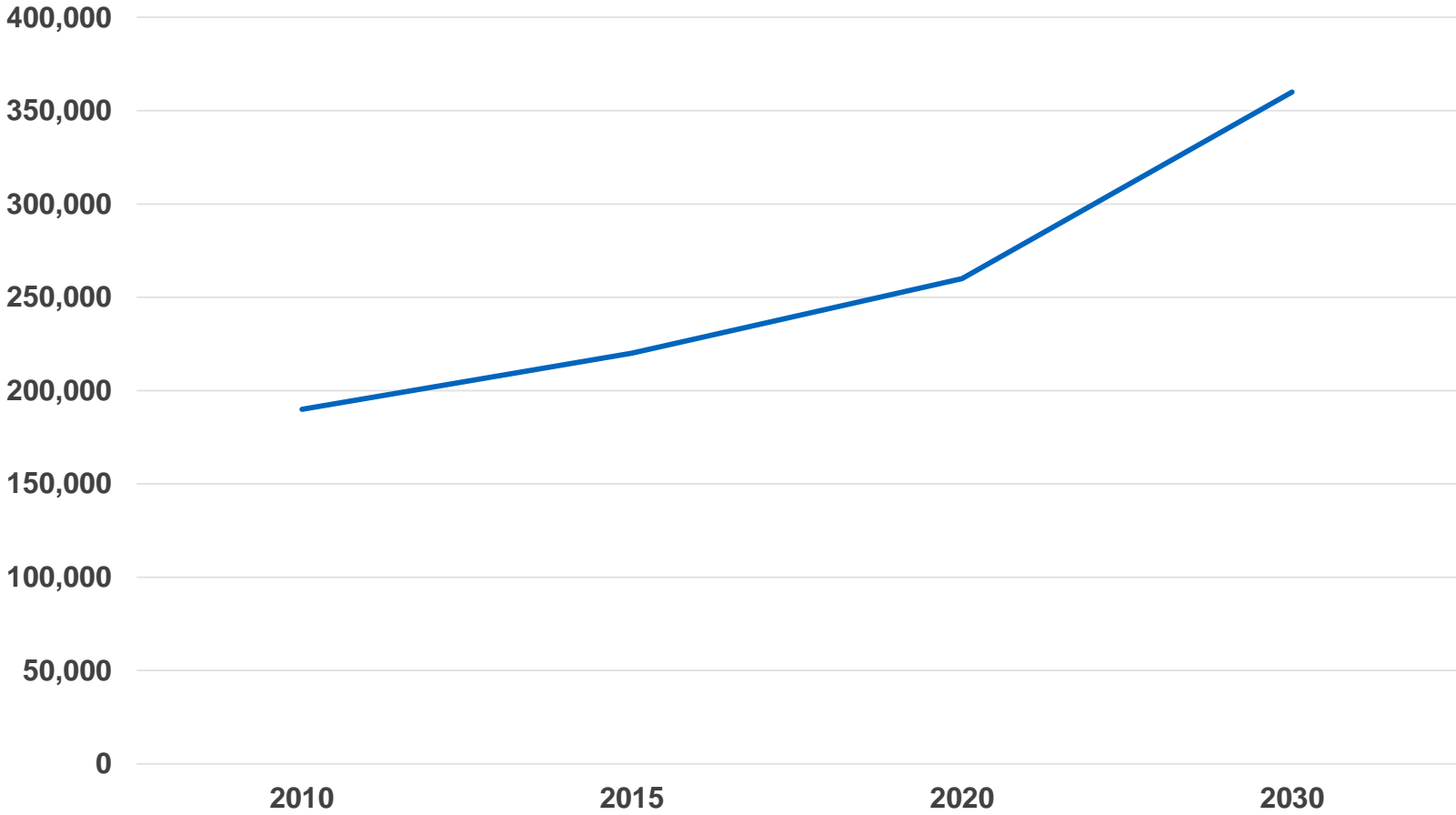


Data source:
Office for National Statistics

Prevalence of Dementia: Scotland 2014-2051



Prevalence of cancer projections: Scotland 2010-30



Source: https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf



Frailty could also rise significantly

Frailty Prevalence rises with increasing age:

- **6.5% in those >60 years**
- **30% in those >80 years**
- **65% in those >90 years**

(Longitudinal study Age & Ageing 2014)

| Frailty in over 80s | |
|---------------------|---------|
| 2016 | 91,031 |
| 2040 | 177,040 |

Multimorbidity

Age

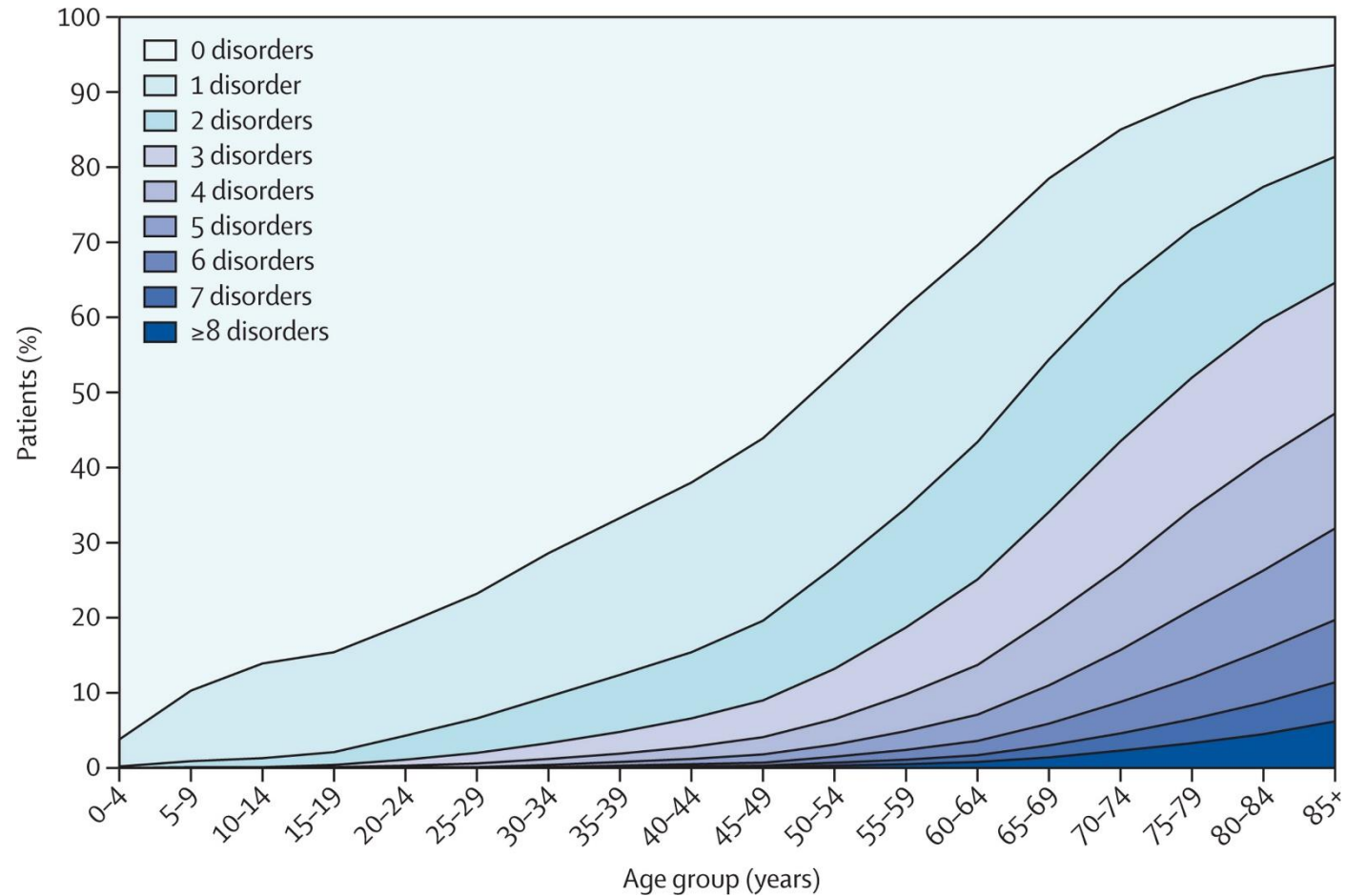
0-24 – 1.9%

25-44 – 11.3%

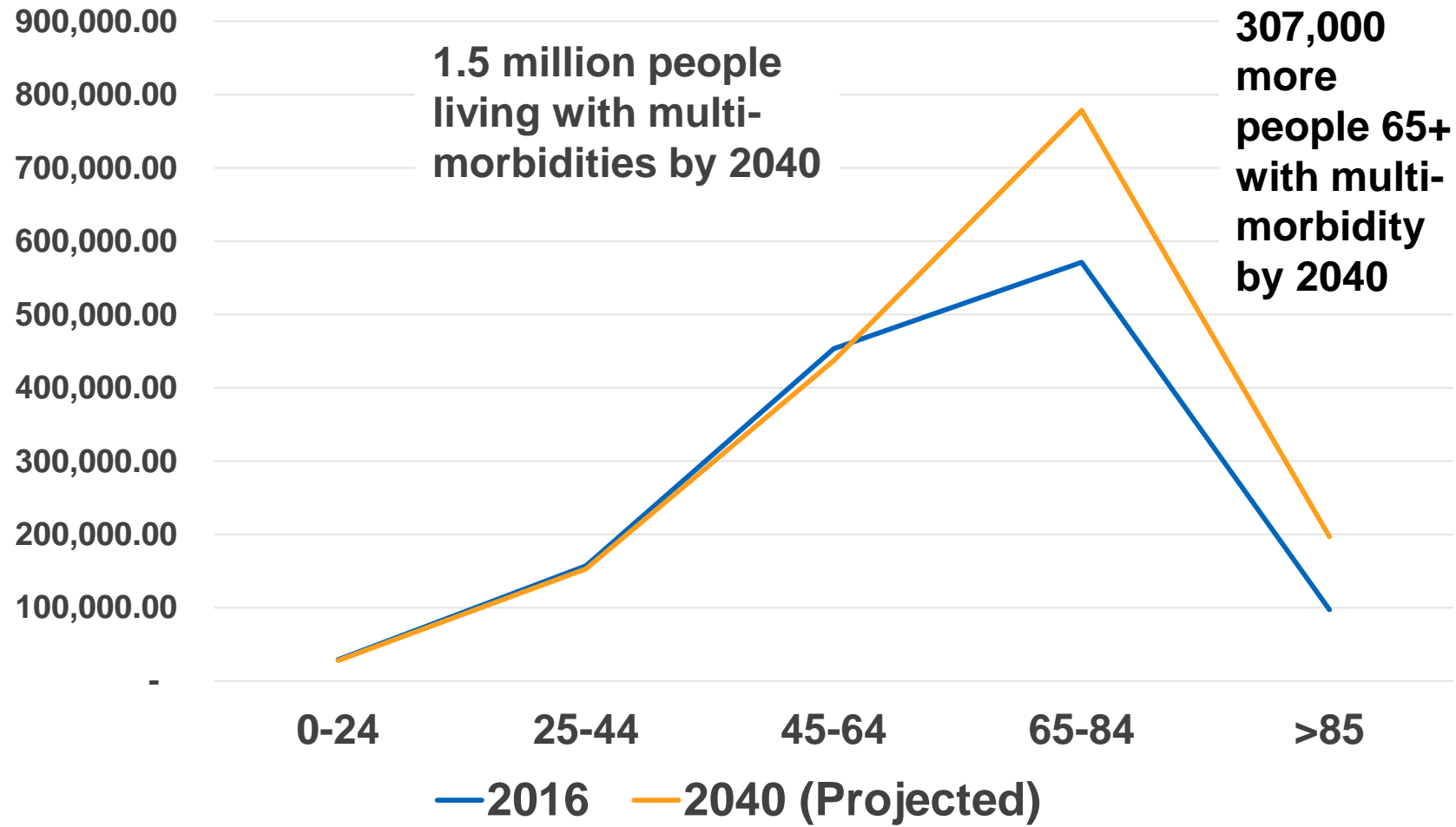
45-64 – 30.4%

65-84 – 64.9%

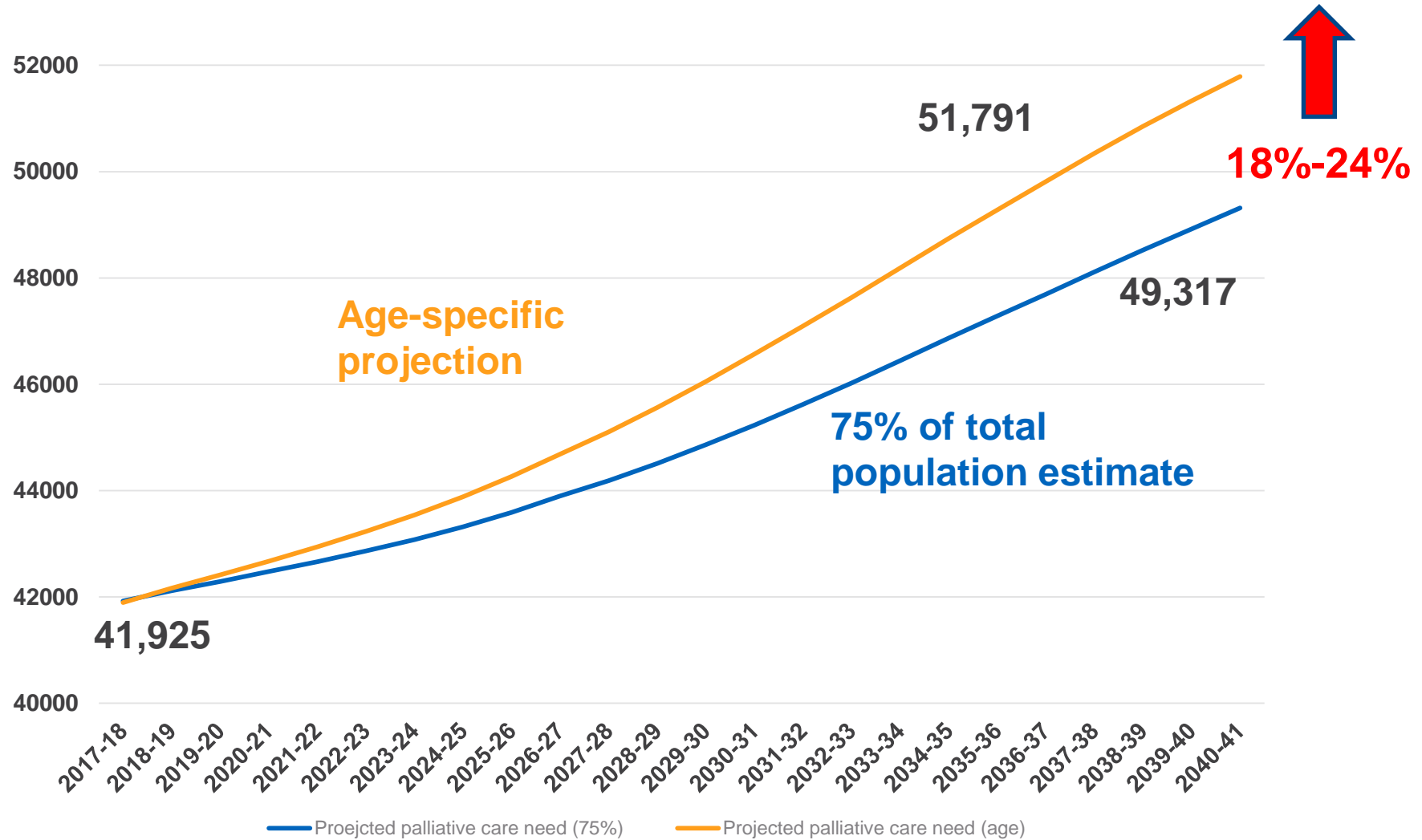
85+ – 81.5%



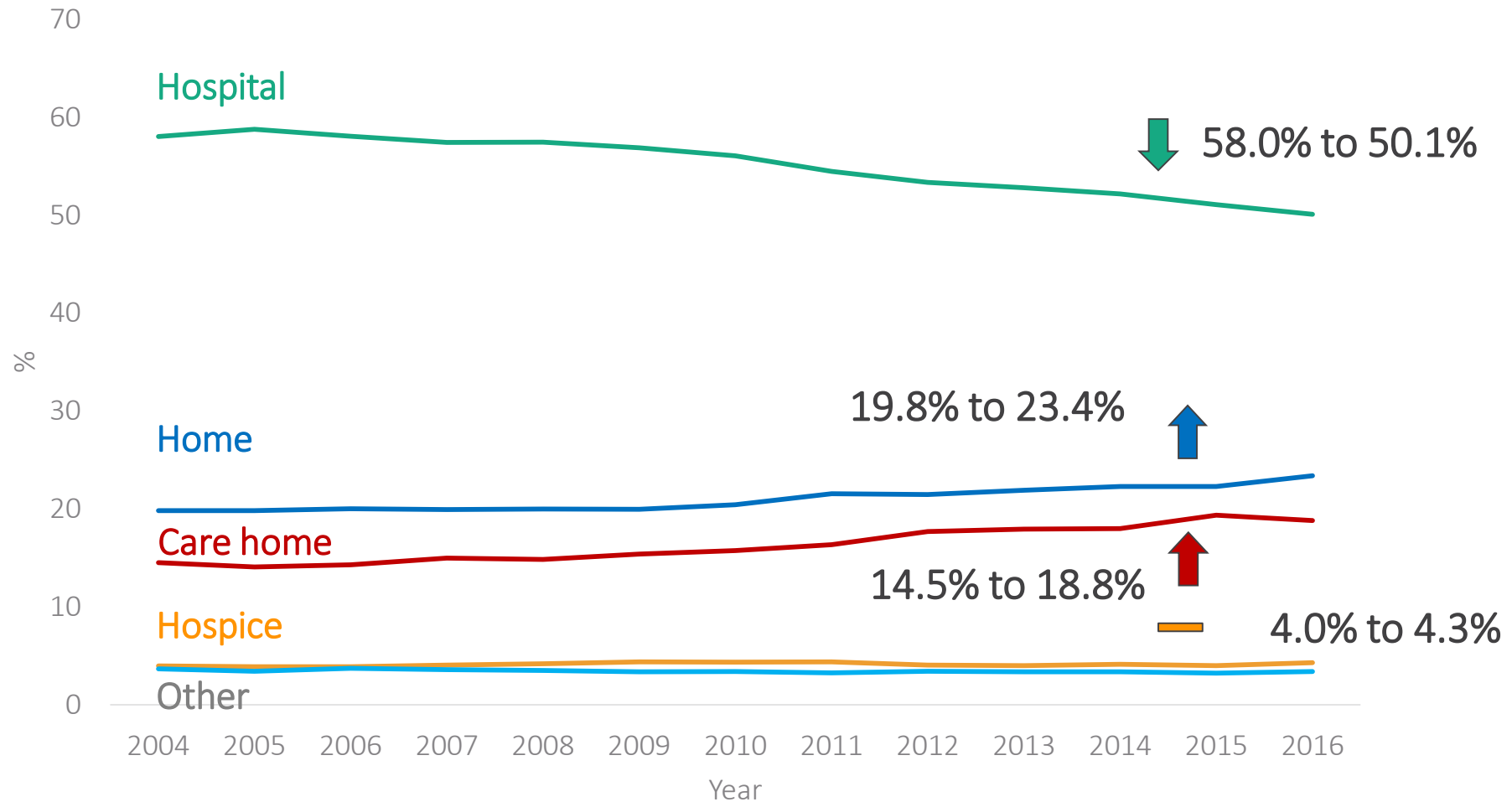
Prevalence of Multimorbidity 2016 vs 2040 (projected)



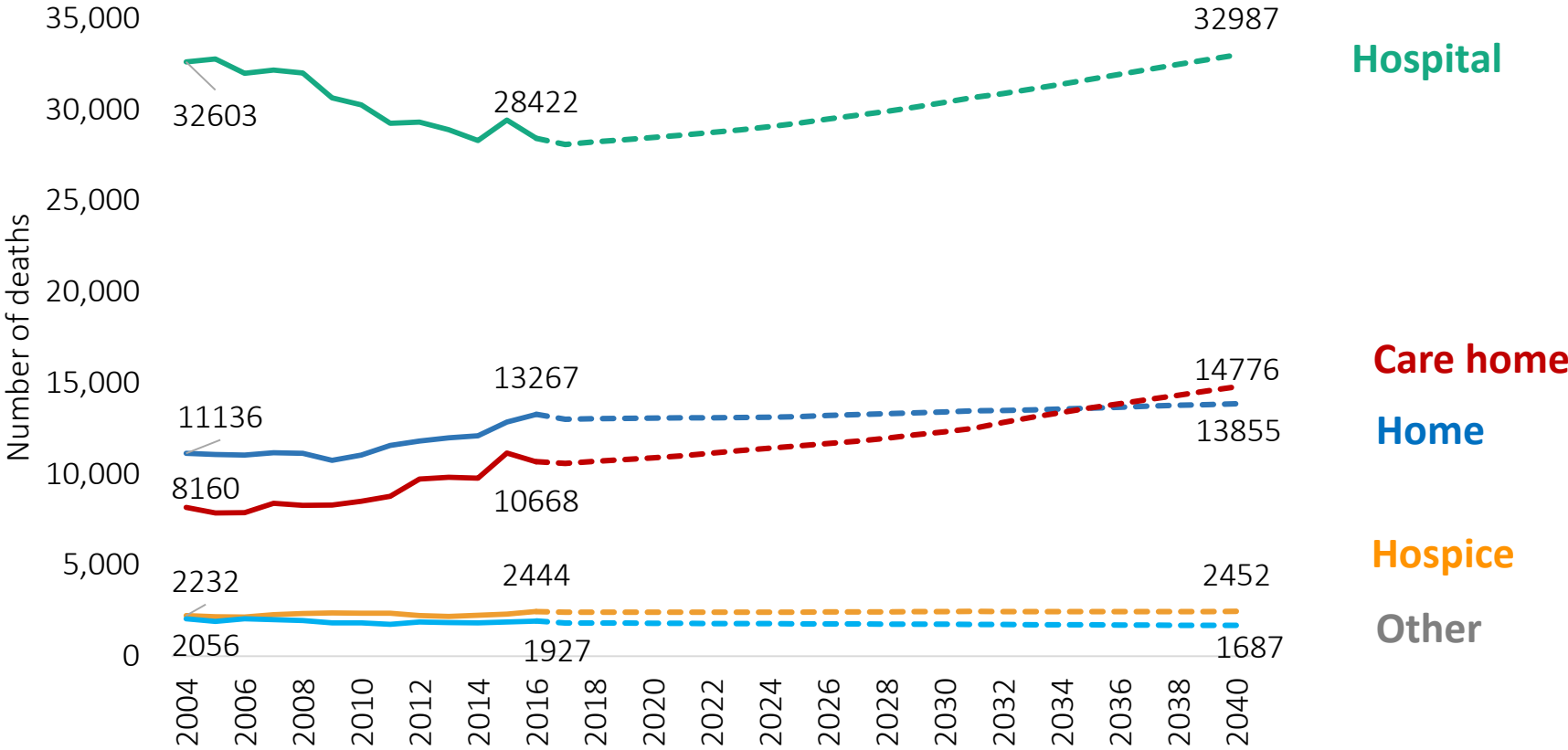
Estimated Palliative Care Need in Scotland 2017-2040



13-year trends in place of death in Scotland (2004-2016)

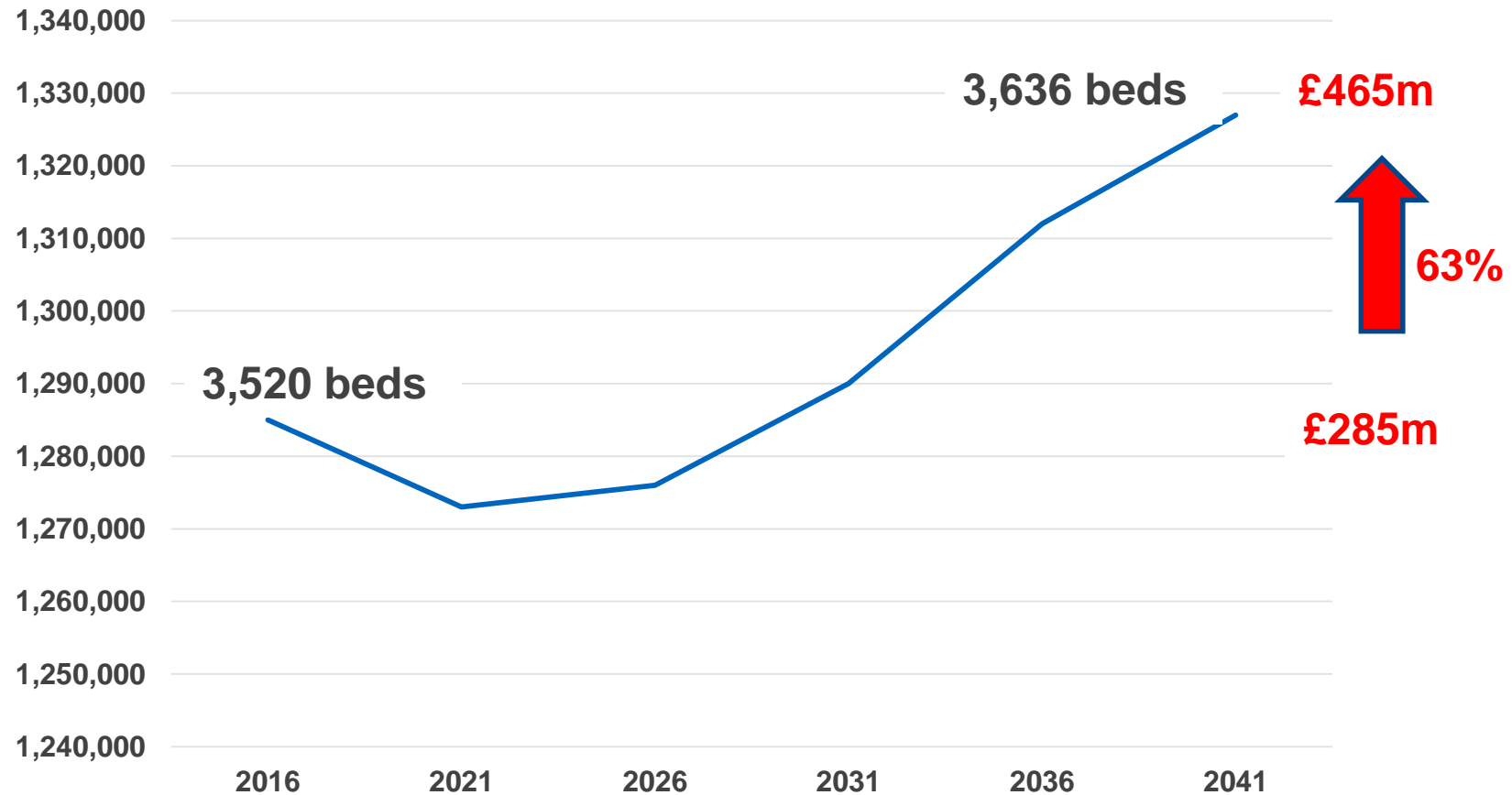


Assumes proportions of deaths in each setting in 2016 are unchanged



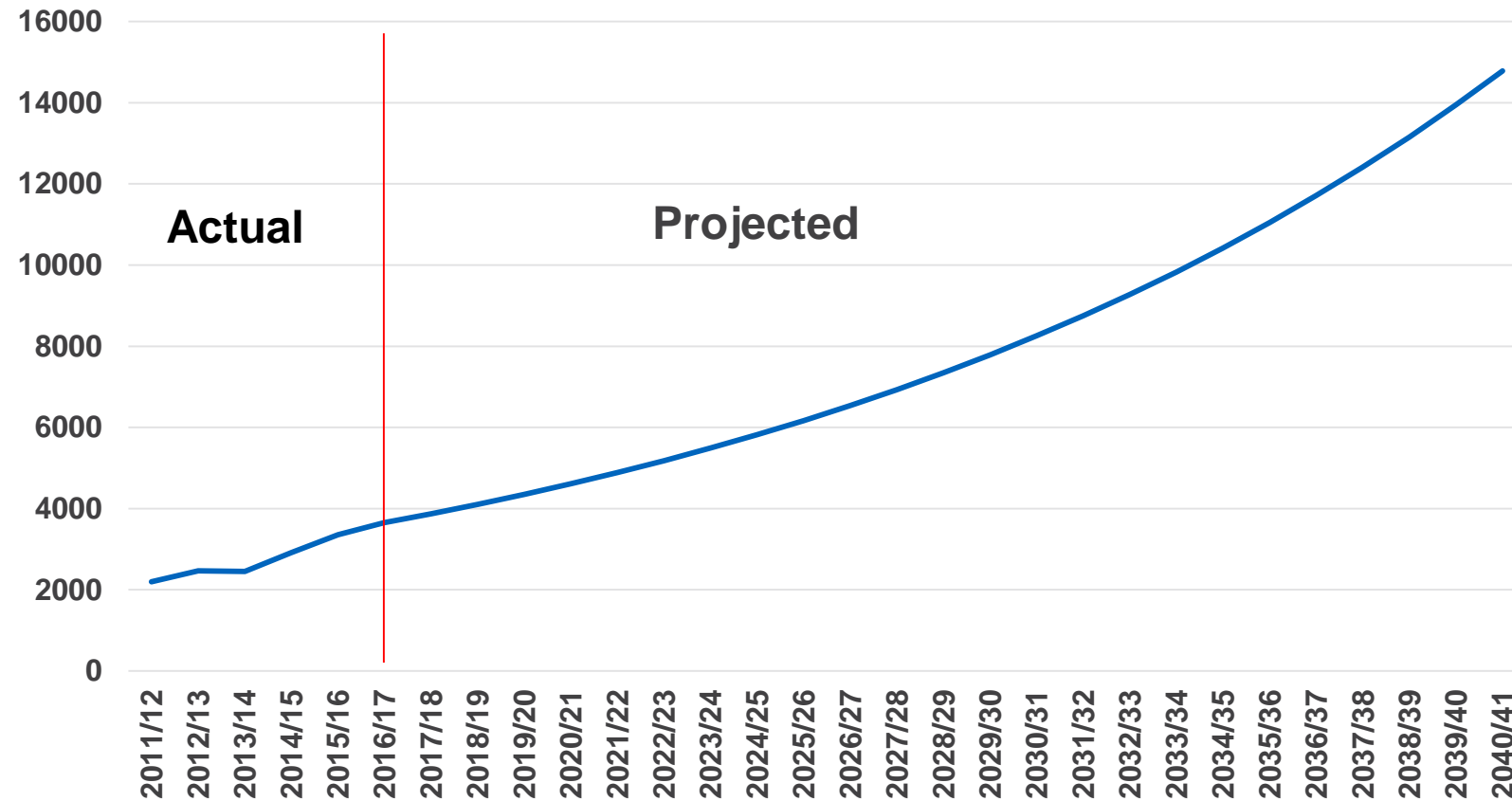
Emergency Admissions at end of life

Emergency bed days



Dementia Emergency bed days – projected 2041

(based on 6% annual increase from 2011-2016)



Source: details here (or delete)

What does all this mean

More people living longer, with multi-morbidities, most likely to include dementia, cancer and frailty.

- Increasing pressures on every care setting?
- Increasing pressures on workforce and resources
- What about informal carers?
- Changing models and ways of care?
- Are we doing enough to prevent/reduce challenges
- Specialist vs generalist palliative care



Workforce Challenges Projected forward

GP/DN nursing

Care homes

Care at home services

Palliative care services

ISD – 3700 GPs (WTE) in 2009 and now 3,575 GPs (WTE) in 2017 – 3.4% decrease

By 2042

Notes: further details here (or delete)

Source: details here (or delete)

Palliative Care Consultant Workforce

The projected population of Scotland in 2041 according to the high migration variant was previously labelled as 5.99 million.

Challenges

- Need more research and thinking to be done around the future.



Lunch & Networking



World café

World Café methodology is a simple, effective, and flexible format for hosting large group dialogue.

<http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/>

Purpose

Get talking about care coordination and the change ideas being tested and implemented. Move, oppose, bystand and follow to create generative dialogue.

Why

“Generative Relationships – occur when interactions among parts of a complex system produce valuable, new, and unpredictable capabilities that are not inherent in any of the parts acting alone”

David Lane and Robert Maxfield - Foresight, Complexity, and Strategy

What matters to you? – Paul Baughan



Final thoughts – Tim Warren

Keep in touch

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