# *How to hold crucial conversations around the end of life*

# *- Advance Care Planning discussions*

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# Plan- Advance Care Planning (ACP)

1. Why  and what it is?
2. How to do it
3. Our experience as part of GSF programmes

# 1.ACP- Why is it important ?

- Research evidence that it is of benefit to patients, (with some caveats )
- A key means to improve  end of life care .
- Pre-planning of care important
- Close relation to UK Mental Capacity Act
- Used extensively across the world
- Enables better provision of service, related to patient needs
- Empowers and enables patient and family
- Some find increases ‘realistic hope’ and resilience
- Encourages deeper conversations/ spiritual discussions  at an important time
- The process is as important as the outcomes or the tools

# Research evidence 1

- **Associated with death in place of choice and with use of palliative care[1-3]**
- **May increase a sense of control [4]**
- **May increase congruence between preferences and treatment [5,6]**
- **Narrow interventions focusing on AD completion not as successful as complex, multiple interventions.**


1.Ratner E, et al *J of the American Geriatrics Society* 2001;49:778-78.
2.Degenholtz HB et al *Annals Of Internal Medicine* 2004;141: 113-117.
3. Caplan GA et al. Age and Ageing 2006; 35: 581-585.
4.Morrison RS et al *J of the American Geriatrics Society* 2005;53(2):290-294.
5. Hammes B, Rooney B. *Archives of Internal Medicine* 1998;158:383-390.
6. Molloy DW et al et al. *JAMA* 2000; 283(102):1437-1444.

# Research evidence 2

ACP may improve patients' quality of life by contributing to:

- Mutual understanding
- Enhancing openness
- Enabling discussion of concerns
- Enhancing hope
- Relieving fears about the 'burden' of decision making
- Strengthening family ties

# Benefits of ACP discussions in care homes

- Natural transition on admission to home- acceptable
- Longer term relationships- can review often
- Discussion with families - some gave informatin to prospective residents and families before
- Improves planning -helps prevent crises + admissions
- Systematic plan with GP helped formalise discussion-
- ACP with patients with dementia

# Families and carers

- Involved early in discussions
- Helps prepare them
- Significance of time remaining
- Has been helpful trigger to deeper discussions
- Reduces distress
- Bereavement issues

# But…Cultural and Psychological Challenges

- Sensitive to cultural interpretations
- Changing views over time
- Clash of viewpoints
- The impact of a ‘bad news’ interview
- A desire to ‘live for the moment’ or ‘take one day at a time’

# Some caveats and sensitivities –

- Some decline - ‘live for the moment’ or ‘take one day at a time’
- Changing views over time
- Clash of viewpoints- patient, family
- Sensitive to cultural interpretations
- Staff resistance -who best to do it? Time consuming
- When to begin? How to do it ? Communication skills
- Consistency and communication - coordinated strategic plan
- Raising expectations –delivering care in line with wishes may be impossible ?
- And others……

# Fears -Pandora's Box

# Hope and ACP

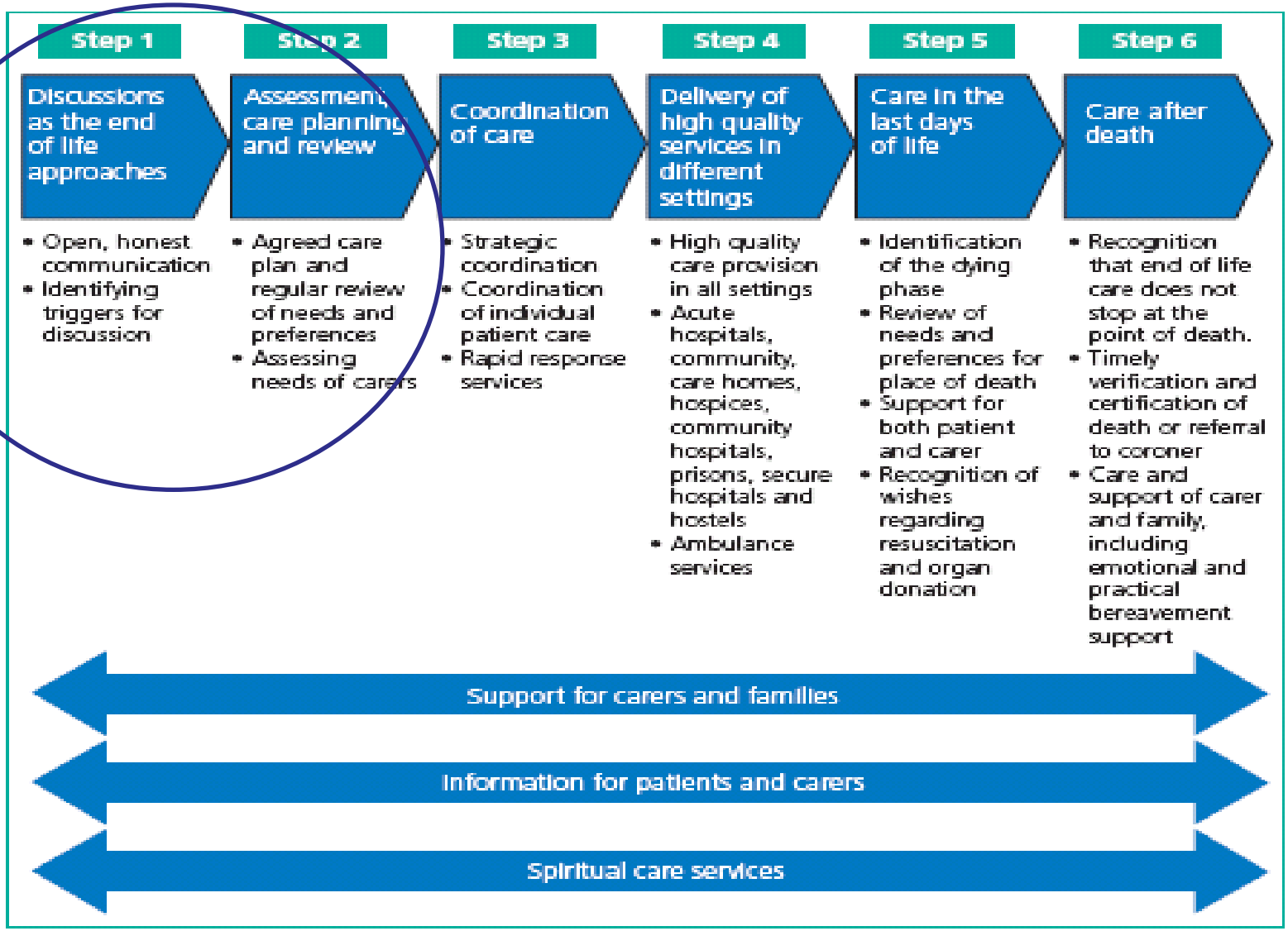
## Davison Simpson BMJ

- ACP can enhance hope not diminish it
- Hope helps determine future goals and provide insight
- Information leads to less fear and more control
- Helps maintain relationships, preserve normality, reduce feeling of being a burden, encouraging sense of being in control,
- Empowering and enabling
- Current practice is ethically and psychologically inadequate

**But…barriers**

- Left to HCP to initiate discussion
- Busying over routine clinical issues

# Wide recognition and adoption of ACP at policy levels- DH End of Life care Strategy 08

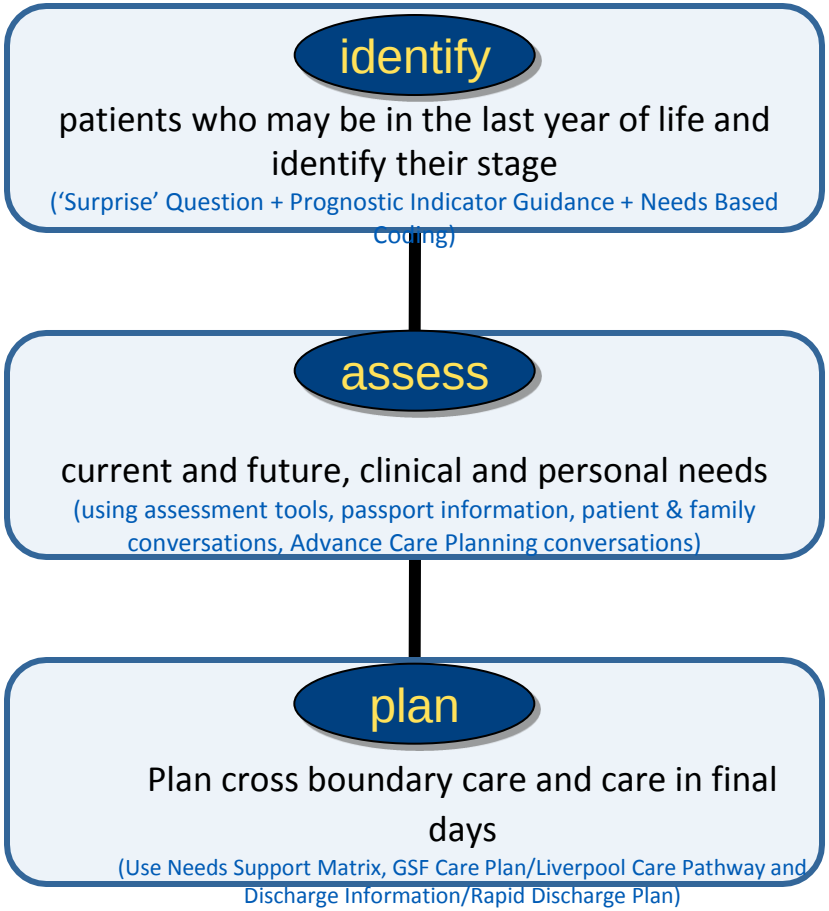


# NICE Standards

- ACP discussions -offered to every appropriate person
  - Every resident offered an ACP discussions
  - Every person on GP palliative care register

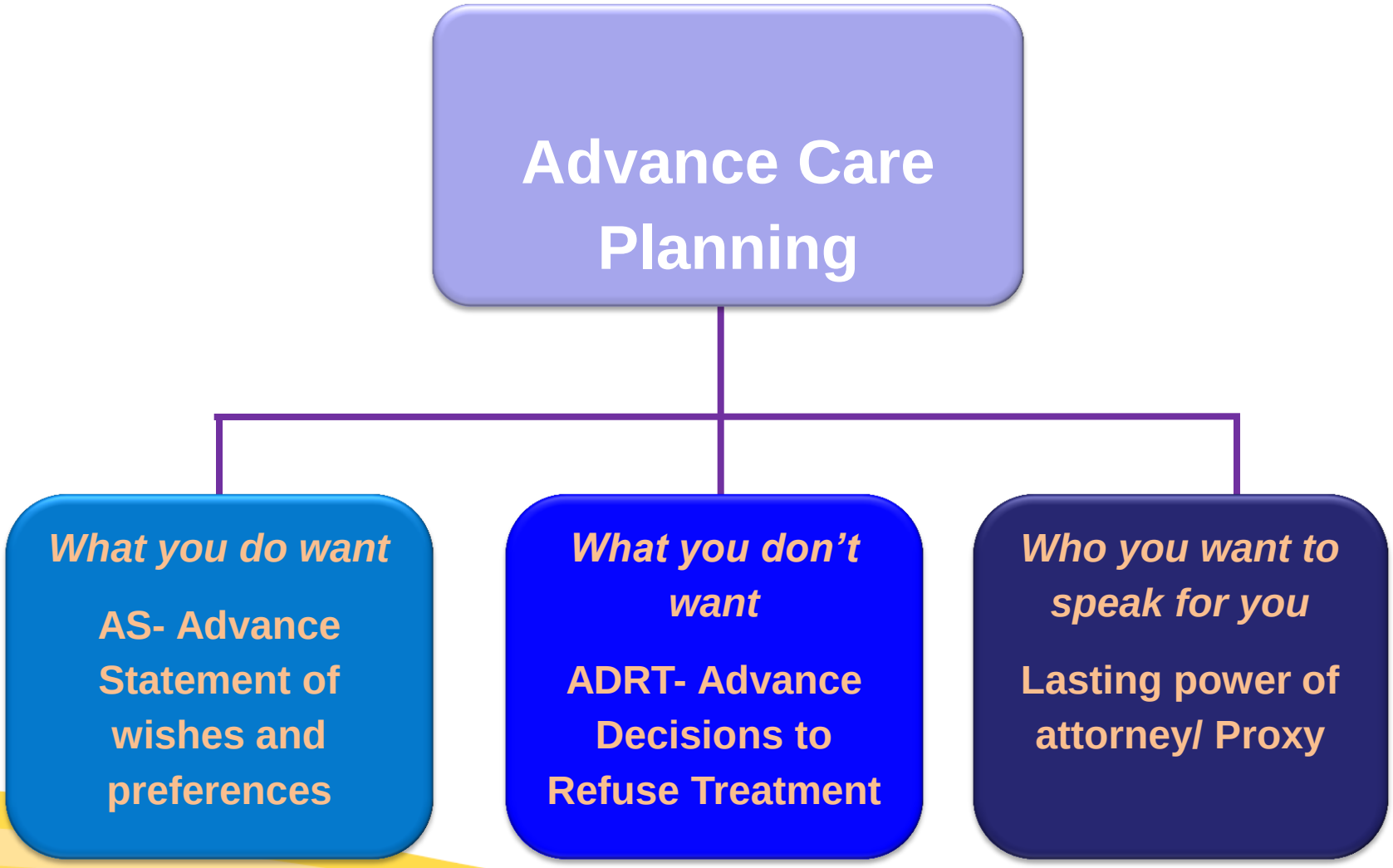
# Three key bottlenecks for generalists that GSF helps w

- **Identify the right patients** particularly non-cancer
- **Assess needs with crucial conversations**
- **Effective team work** - proactive care, coordinating and collaborating



# 2. ACP- What it is ?

## In the context of the Mental Capacity Act (2005)



# Advance Care Planning Discussion

## How?

- Opportunistic informal conversations
- Formalised systematic

## What?

- What matters to you?
- What do you wish to happen?
- What do you do not want to happen?

## Who?

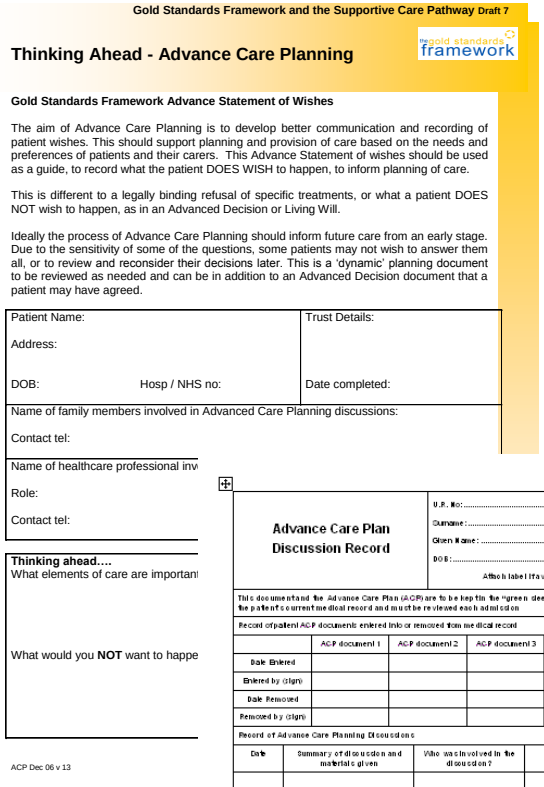
- Named spokesperson (informal)
  Can tell those who act in best interests what sort of person you are
- Lasting Power of Attorney (formal)
  Can make legal decisions regarding your health

## Where?

- Preferred Place of Care
- Carer's Preferred Place of Care

## Other?

- Special instructions-Organ/tissue donation



Gold Standards Framework and the Supportive Care Pathway Draft 7

**Thinking Ahead - Advance Care Planning**

**Gold Standards Framework Advance Statement of Wishes**

The aim of Advance Care Planning is to develop better communication and recording of patient wishes. This should support planning and provision of care based on the needs and preferences of patients and their carers. This Advance Statement of wishes should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care.

This is different to a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, as in an Advanced Decision or Living Will.

Ideally the process of Advance Care Planning should inform future care from an early stage. Due to the sensitivity of some of the questions, some patients may not wish to answer them all, or to review and reconsider their decisions later. This is a 'dynamic' planning document to be reviewed as needed and can be in addition to an Advanced Decision document that a patient may have agreed.

Patient Name:
Address:
DOB: Hosp / NHS no:
Trust Details:
Date completed:

Name of family members involved in Advanced Care Planning discussions:
Contact tel:

Name of healthcare professional inv
Role:
Contact tel:

**Thinking ahead....**
What elements of care are important

What would you **NOT** want to happe

ACP Dec 06 v 13

**Advance Care Plan Discussion Record**

U.R. No:
Surname:
Given Name:
DOB: Age:
Affix label if available

This document and the Advance Care Plan (ACP) are to be kept in the "green sleeve" at the front of the patient's current medical record and must be reviewed each admission

Record of patient ACP documents entered into or removed from medical record

| | ACP document 1 | ACP document 2 | ACP document 3 | ACP document 4 |
|---|---|---|---|---|
| Date Entered | | | | |
| Entered by (sign) | | | | |
| Date Removed | | | | |
| Removed by (sign) | | | | |

Record of Advance Care Planning Discussions

| Date | Summary of discussion and materials given | Who was involved in the discussion? | Name of ACP consultant |
|---|---|---|---|
| | | | |
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Assess

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# Advance Care Planning
# Which document will you use?

There are many examples of ACP documents. You may already have one in your hospital or wider community. Some areas have a generic document which can be used across all settings. Some commonly used documents are:

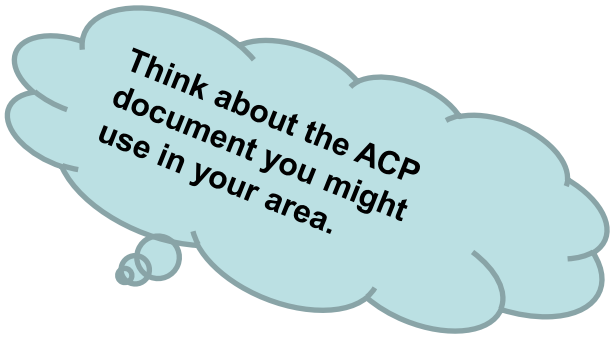
Preferred Priorities of Care Document - PPC: http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare

St. Christopher's Advance Care Plan: http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/St-Christophers-advanced-care-plan.pdf

GSF Thinking Ahead Advance Care Planning Discussion: http://www.goldstandardsframework.org.uk/Resources

NHS South Central Adult Advance Care Planning Toolkit: http://www.southofengland.nhs.uk

North East Integrated ACP documentation - Deciding Right www.northeast.nhs.uk/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# 3. How to do it ?

- Opportunistic and/or planned

- Sensitive discussion
- ‘Relationship’ questions- taken over time
- Open questions

- Communication skills training can help
- May need leaflets/ guidance materials

- Be aware of our own ‘death anxiety’.

# “…the response is amazing”

# Like a waltz

# Open questioning

- Could you tell me what the most important things are to you at the moment?
- Can you tell me about your current illness and how you are feeling?
- Who is the most significant person in your life?
- What fears or worries, if any do you have about the future?
- In thinking about the future, have you thought about where you would prefer to be cared for as your illness gets worse?
- What would give you the most comfort when your life draws to a close?

Horne, G., Seymour J.E. and Shepherd, K. (2006) *International Journal of Palliative Nursing*.12(4): 172-178.

# Communication Skills Models

## SPIKE

- **S**etting
- **P**erception
- **I**nvitation
- **K**nowledge
- **E**mpathy

Baile Buckman et al Spikes a 6 step protocol for breaking bad news Oncologist 5:302-311

## Sage and Thyme

- **S**etting
- **A**sk
- **G**ather
- **E**mpathy
- **T**alk
- **H**elp
- **Y**ou?
- **M**e?
- **E**nding

Connolly , Duck (2008)Communication Skills in end stage respiratory disease Breathe 5(2)-147-54

# Communication Skills Models

## PREPARED

- **P**repare
- **R**elate to the person
- **E**licit preferences
- **P**rovide information
- **A**cknowledge emotions and concerns
- **R**ealistic hope fostered
- **E**ncourage questions
- **D**ocument

Clayton et al (2007) Clinical Practice Guidelines Medical Journal of Australia

## Calgary Cambridge

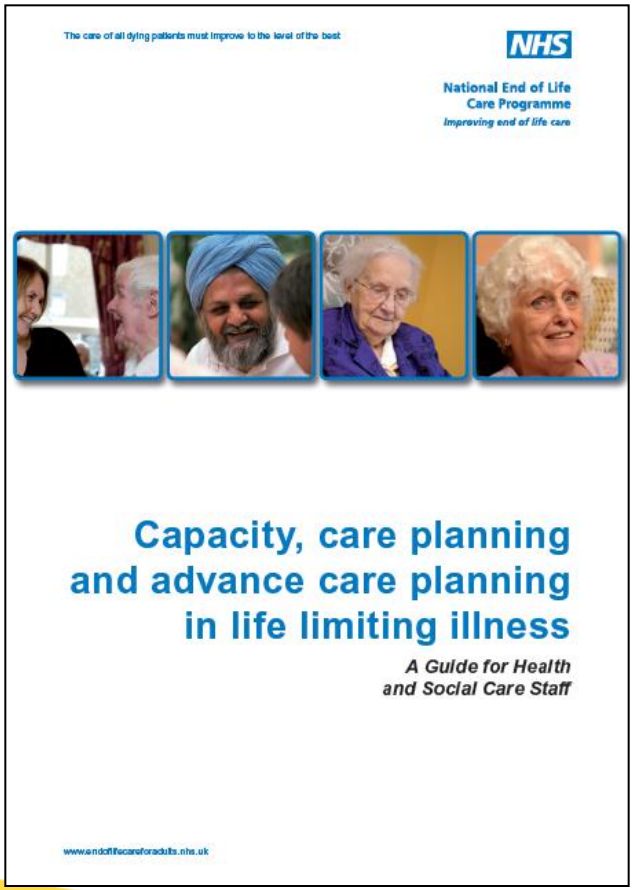
- **I**nitiate the session
- **G**ather information
- **P**rovide structure Build relationships
- **E**xplanation and planning
- **C**losing and planning

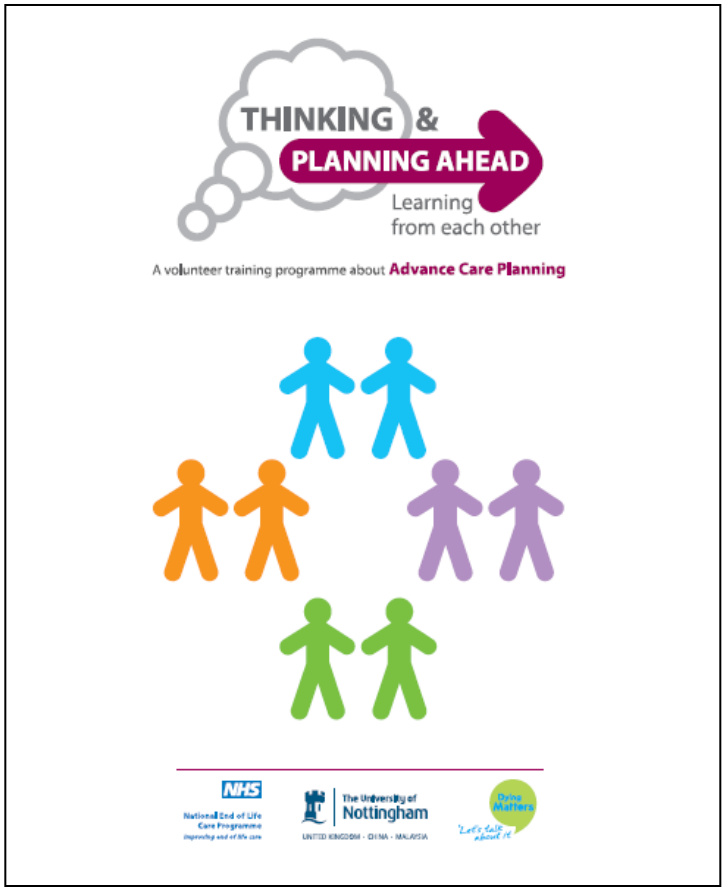
Silverman et al (2008) Skills for communicating with patients Radcliffe Medical Press

# Resources Available

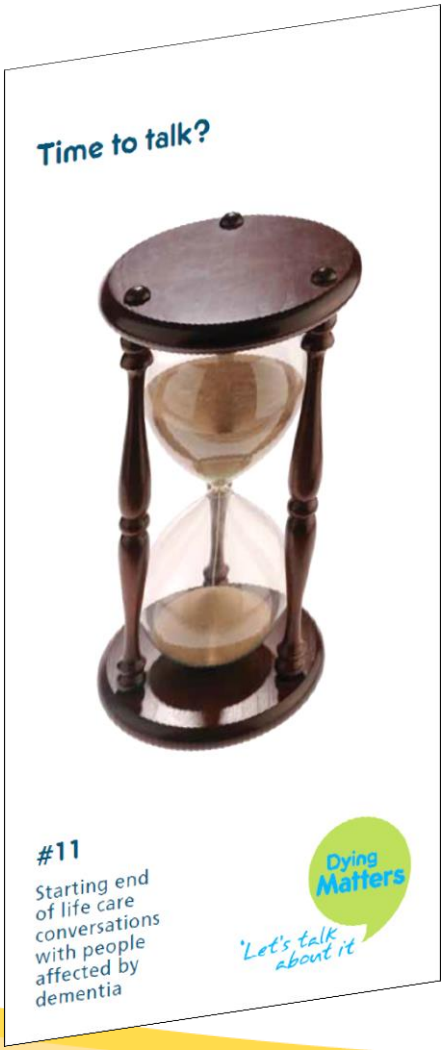
- **Textbook**
  - Oxford University Press 2011 - Advance Care Planning in End of Life Care – Ed Thomas and Lobo
- **NEoLCP**
  - core competences include ACP
  - Capacity, Care Planning and Advance Care Planning guidance
  - Planning for your future care
  - e-ELCA  ACP modules- Freely accessible health and social care
- **NCPC**
  - NEoLCP/Thinking and planning ahead resource guide
  - Communications resources e.g. Difficult conversations NEoLCP /Dying Matters resources
- **GSF**
  - ACP- used in all GSF programmes
  - GSf training Primary care, care homes hospitals
- **Local tools**
  - Deciding Right
  - St ChristophersLooking Ahead doc (EoLC planning for residents without capacity) + Thinking Ahead (EoLC planning for residents with capacity)

# NHs End of Life Care Programme



# NCPC & Dying Matters publications



www.dyingmatters.org

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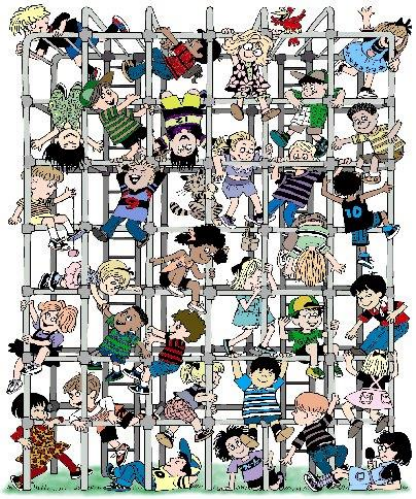
## 4. Our GSF experience

# The National GSF Centre in End of Life Care

The leading EOLC training centre
enabling generalist frontline staff
to deliver a 'gold standard' of care
for all people nearing
the end of life

*"Every organisation involved in providing end of life care will be expected to adopt a coordination process , such as the GSF"*

**DH End of Life Care Strategy July 08**



**The right care, for the right people, in the right place, at the right time… everytime**

# Current GSF Training Programmes - 2013

## GSF Primary Care- 95% Foundation Level (8,500 practices)

1. From 2000- Foundation GSF mainstreamed (QOF)
2. From 2009- Next Stage GSF 'Going for Gold' training programme

Round 1 GP practices accredited Nov 2012 , Round 2 2013

## GSF Care Homes - 2300 care homes trained

From 2004 Comprehensive training and accreditation programmes
200 / year accredited – recognised quality assurance
Many re-accredited annually – recognised by CQC and commissioners

## GSF Acute Hospitals – 40 acute hospitals

2008 -Phase 1 pilot 15 hospitals + Improving cross boundary care
2011- Phase 2 9 hospitals, 2012- Phase 3 –8 ,Phase 4 -8
Accreditation in development – some whole hospital s,

## GSF Domiciliary care – 300 care workers

Phase 1-Manchester, West Mids SHA , Rotherham + others
Phase 2- Train the trainers 6 modular distance learning programme

## GSF Community Hospitals - 42 community hospitals

Phase 1 - December 2011 - Cornwall & Dorset-14 each
Phase 2 Summer 2013 - Cumbria

## GSF Dementia Care- 60 candidates

Phase 1 Pilot programme complete 2013 – evaluations underway

# GSF Primary care

the gold standards framework in primary care

## 1. First Stage - Foundation Level

Most (95%) GP practices in UK using GSF - QOF Foundation Level - having a register and a meeting

**BUT…National Primary Care Snapshot Audit 09/10**
Every death Feb March 09 in 502 practices, 4500 pts

- **25% patient deaths on register only**
- **25% non-cancer patients** on register
- **Of those on a register - better coordinated care**

## 2. Next Stage GSF - 'Going for Gold'

Practice based Distance Learning - move to Accreditation Level

Over 300 practices - first wave accreditation - Nov 12

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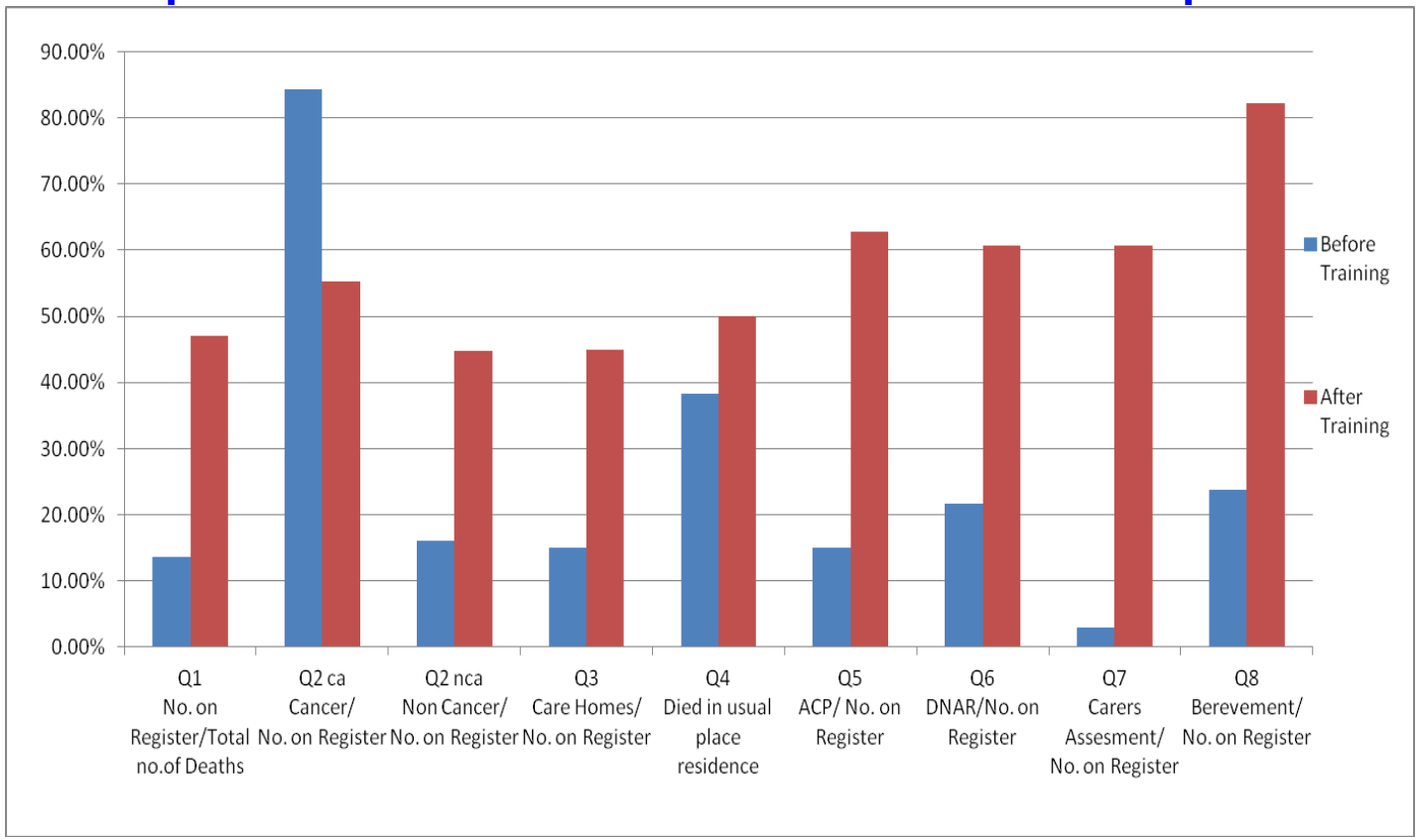
# GSF Primary Care Going for Gold Accredited GP Practices Nov 28th 12

# GSF Accreditation practices

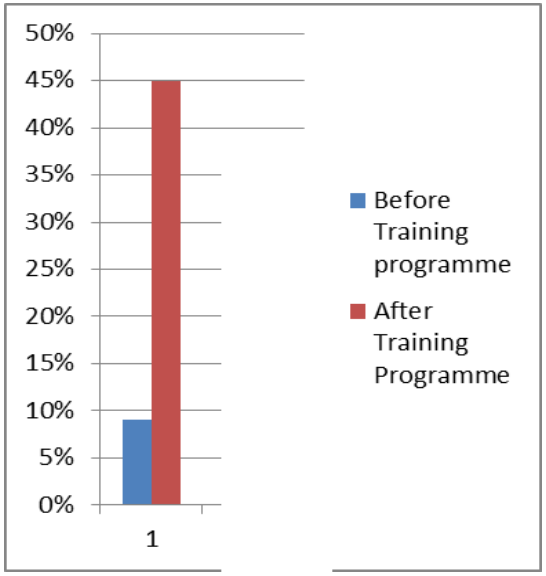
## 7 practices in GSF Accreditation pilot

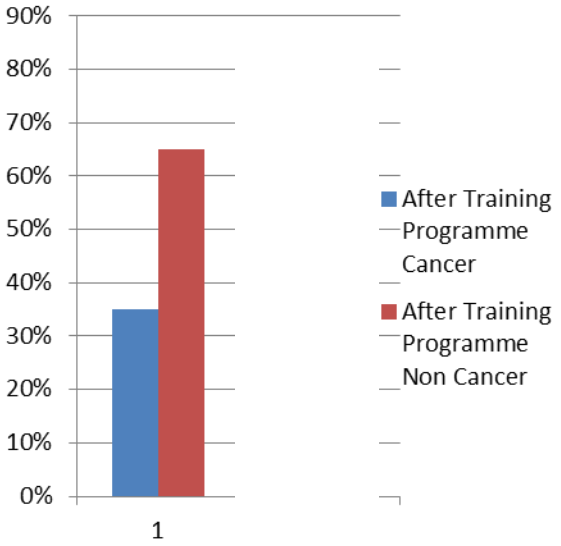


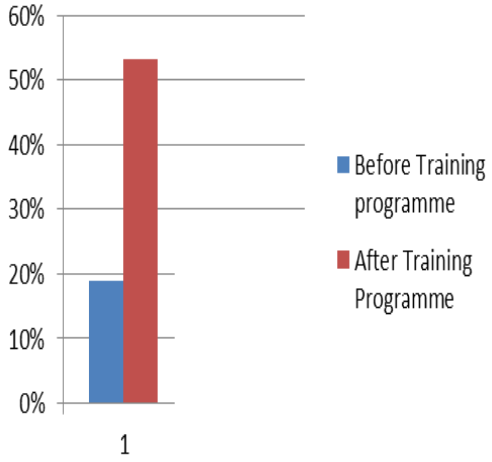

- *Trebling numbers on register, non-cancer, care homes residents*
- *Significantly increasing key ratios for ACP discussions, cares support, bereavement, dying in usual place of residence*

# Coastal Medical Group- Areas of Excellence

- **Key ratios- Increased early identification**
of patients for the register (9%-45%) especially non-cancer (5%-65%) and from care homes (19%-53%)




- **Key ratios - halving hospital deaths** (35%-16.6%) , almost doubling dying in usual place of register (40.5%-72.9%) , bereavement support increased (5.4%-76.5%)

- **ACP-** Impressive total offered ACP discussions (83%) and acceptance and confidence of team

- **Practice protocol** with clinical guidance

- **Impressive coordination** of big numbers in a large practice and coordination with care homes and community resources

# 1. Identify – the right patient

## GSF Prognostic Indicator Guidance

identifying patients with advanced disease in need of palliative / supportive ca

Three triggers:

1. **The surprise question**

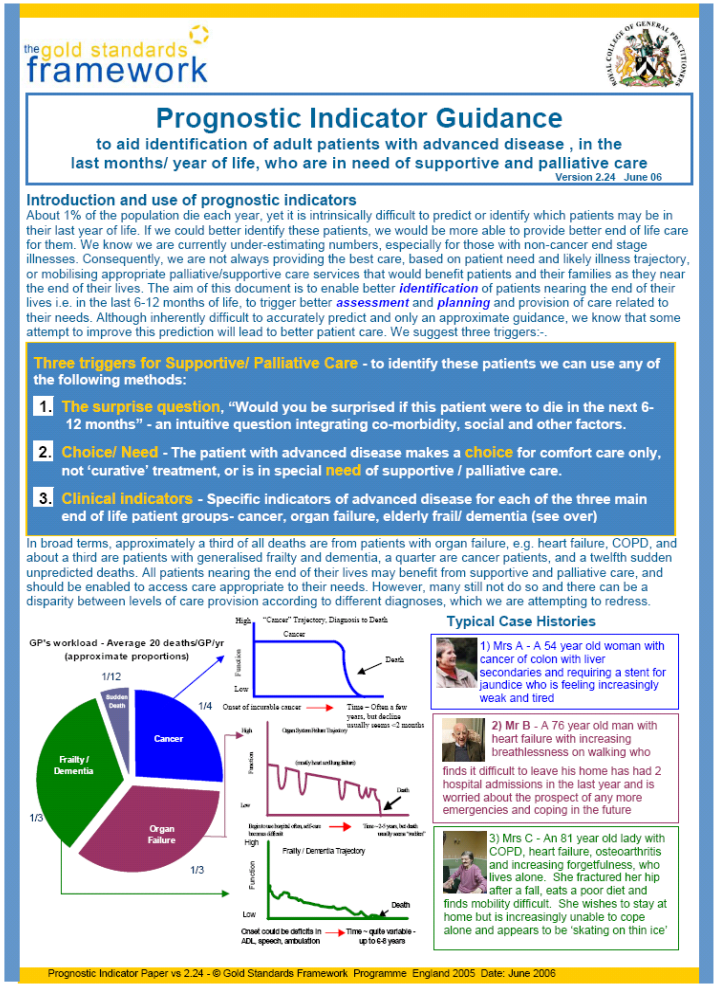
   'Would you be surprised if this person was to die within the next year?'

2. **General Indicators**

   for decline + comfort care/need

3. **Clinical indicators**

   Suggested that all patients on register are offered an ACP discussion



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**Prognostic Indicator Guidance**

to aid identification of adult patients with advanced disease , in the last months/ year of life, who are in need of supportive and palliative care

Version 2.24 June 06

**Introduction and use of prognostic indicators**

About 1% of the population die each year, yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If we could better identify these patients, we would be more able to provide better end of life care for them. We know we are currently under-estimating numbers, especially for those with non-cancer end stage illnesses. Consequently, we are not always providing the best care, based on patient need and likely illness trajectory, or mobilising appropriate palliative/supportive care services that would benefit patients and their families as they near the end of their lives. The aim of this document is to enable better ***identification*** of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better ***assessment*** and ***planning*** and provision of care related to their needs. Although inherently difficult to accurately predict and only an approximate guidance, we know that some attempt to improve this prediction will lead to better patient care. We suggest three triggers:-.

**Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:**

1. **The surprise question, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.**
2. **Choice/ Need - The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive / palliative care.**
3. **Clinical indicators - Specific indicators of advanced disease for each of the three main end of life patient groups- cancer, organ failure, elderly frail/ dementia (see over)**

In broad terms, approximately a third of all deaths are from patients with organ failure, e.g. heart failure, COPD, and about a third are patients with generalised frailty and dementia, a quarter are cancer patients, and a twelfth sudden unpredicted deaths. All patients nearing the end of their lives may benefit from supportive and palliative care, and should be enabled to access care appropriate to their needs. However, many still not do so and there can be a disparity between levels of care provision according to different diagnoses, which we are attempting to redress.

GP's workload - Average 20 deaths/GP/yr (approximate proportions)



"Cancer" Trajectory, Diagnosis to Death





Frailty / Dementia Trajectory



**Typical Case Histories**



1) Mrs A - A 64 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired



**2) Mr B** - A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the future



3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'

Prognostic Indicator Paper vs 2.24 - © Gold Standards Framework Programme England 2005 Date: June 2006

Overview

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# 1. Identify- Needs Based Coding

Surprise question

Used of Needs based coding

Use of Needs Support Matrices

Identify stage of illness
- ✓deliver the right care
- ✓at the right time
- ✓for the right patient

- **A - All - stable from diagnosis** **years**
- **B - Unstable, advanced disease** **months**
- **C - Deteriorating, exacerbations** **weeks**
- **D - Last days of life pathway** **days**

# GSF IT Solutions - e-PIG


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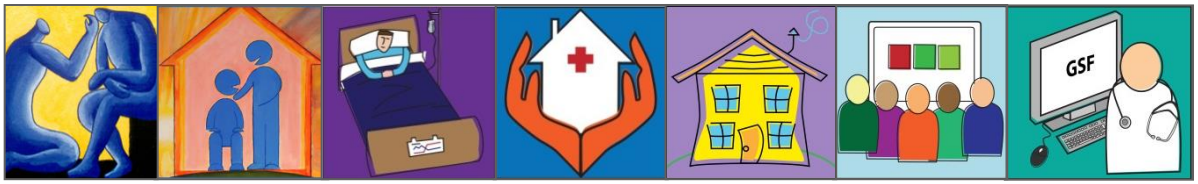
IT Solutions

***"Making it easy to do the right thing"***

1. *Early Alerting -* ***e-PIG***
2. *Trigger actions - GSF Care Plan/ Needs Support Matrix*
3. *Audit care - ADA and other measures*
4. *Communicate to others - EPaCCs/Locality Registers*

# GSF enables a gold standard of care for all people nearing the end of life

## 1.Spread




**GSF Quality Improvement provides full package of support for many different settings**

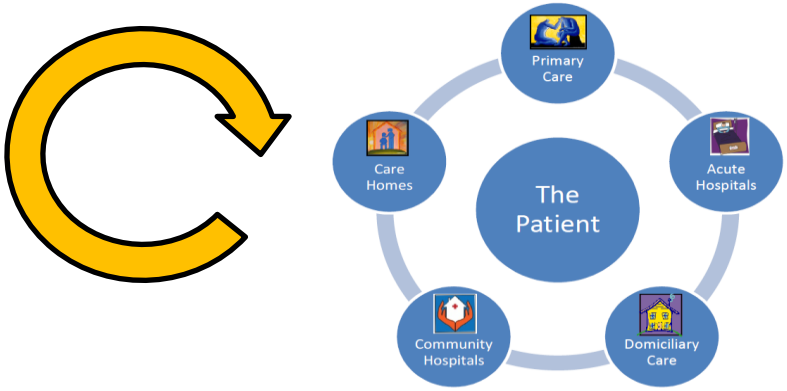
## 2. Depth

**Quality assurance**
through accreditation
eg Primary Care and care homes


Depth also in **compassionate** or heart care

## 3. Joined-up

**Integrated Cross boundary care**
GSF can be a common language to help improve coordination of care

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**“When your time comes to die**

**make sure that dying**

**is all you have left to do”**

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