Meeting the challenges of end of life care in care homes using the Gold Standards Framework

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What if ….Bill

Current

- In care home – condition worsening
- Poor quality of life and crisis admissions to hospital
- Ad hoc visits -no future plan discussed
- Staff and family struggling to cope
- No advance care planning, no life closure discussion
- Crisis- worsens at weekend - calls 999 paramedics admit to hospital- A&E- 8 hour wait on trolley-dies on ward alone
- Family given little support in grief - staff feel let family down
- No reflection by teams- no improvement
- Expensive for NHS - inappropriate use of hospital

3 Challenges in care homes

1. Improving quality of care –
   - staff confidence and competence
   - Alignment of wishes - advance care planning

2. Reducing hospitalisation
   - Enabling more to die where they wish
   - Cost effectiveness

3. Improve teamwork and cross boundary care
   - working with GPs and others

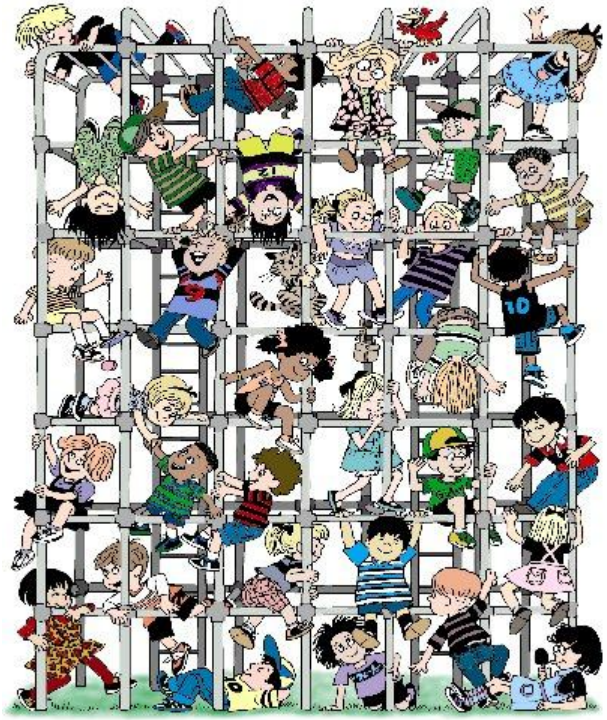
What is the Gold Standards Framework ?

Enabling generalists in end of life care

Frameworks 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



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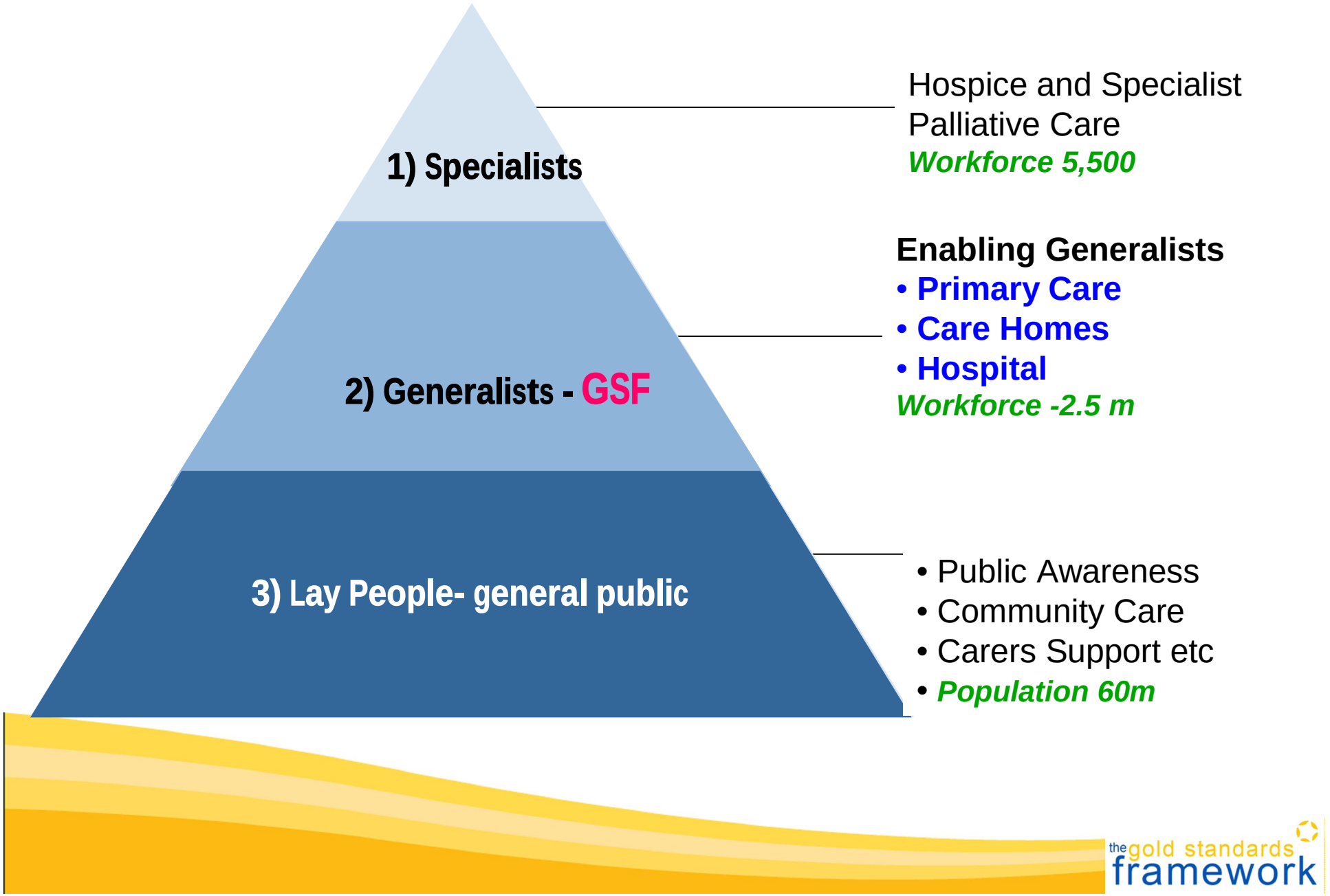
1) Specialists
2) Generalists - GSF
3) Lay People- general public
Hospice and Specialist Palliative Care
Workforce 5,500
Enabling Generalists
• Primary Care
• Care Homes
• Hospital
Workforce -2.5 m
• Public Awareness
• Community Care
• Carers Support etc
• Population 60m
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Different places of change

GSF mainly as organisational change

- **Individual**- workforce staff

- **Organisation**- team **GSF**
  – practices, care home, ward

- **Community-** local area

- **National**- regulation + policy

GSF Training Programmes

- GSF Primary Care
  - From 2000- foundation GSF mainstreamed (QOF)
  - 90% GP practices have palliative care register and meeting
  - June 09 Next Stage GSF launched updated GSF
  - New training programme + quality recognition

- GSF Care Homes
  - From 2004 -Over 1500 care homes trained
  - Developed training and accreditation programmes
  - 100 / year accredited

- GSF Acute Hospitals
  - From 2008 -Phase 1 pilot 15 hospitals
  - Phase 2 Spring 2011
  - Improving cross boundary care

Cross boundary care

GSF Primary Care

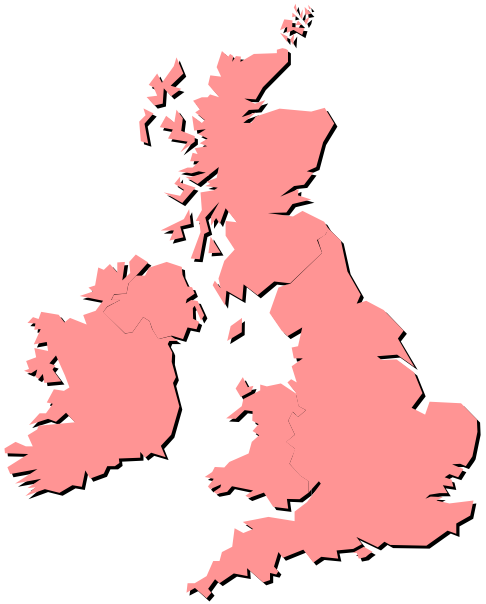
GSF Hospitals

GSF Care Homes

GSF Primary care

most GP practices in UK using GSF basic level

•90% practices – QOF pall care points basic GSF Level 1 (register and planning meeting) - mainstreaming



• 60%+ practices using GSF in UK, covering almost 3/4 of the population -(2 surveys)

10-15% Estimated using deeper GSF Level

BUT….need to build on current GSF to meet 4 challenges

- **Consistency,**
- **Effectiveness,**
- **Equity for non-cancer pts,**
- **Quality provision**

Launch of Next Stage GSF Primary Care June 09

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The Gold Standards Framework in Care Homes Training Programme

Goals

1. To improve the **quality** of end of life care

2. To improve **collaboration** with primary care and palliative care specialists

3. To **reduce hospitalisation**- and enable more to live and die at home

the gold standards framework in acute hospitals

GSF Acute Hospitals- the ‘missing link’

- Using GSF principles adapted for hospitals
- Cross boundary care and in-patient care
- Pilot Phase 1 Sept 09- Phase 2 Nov 2011
- 15 hospital wards – elderly COPD cancer, whole hospital
- Assess
  - Hospital admissions, length of stay and deaths
  - Confidence of staff
  - Coordination of care

GSF Care Homes Training and Accreditation

"the biggest, most comprehensive end of life care training programme in the UK" RNHA

Training

Over 1500 care homes trained programme

- Structured curriculum + workshops
- Learning outcomes linked to standards
- Work based changes – action plans

Accreditation

Up to 100/year accredited

- Rigorous process
- Consistency of practice
- Findings go to independent panel supported by Age UK
- Awards Presentation twice a year

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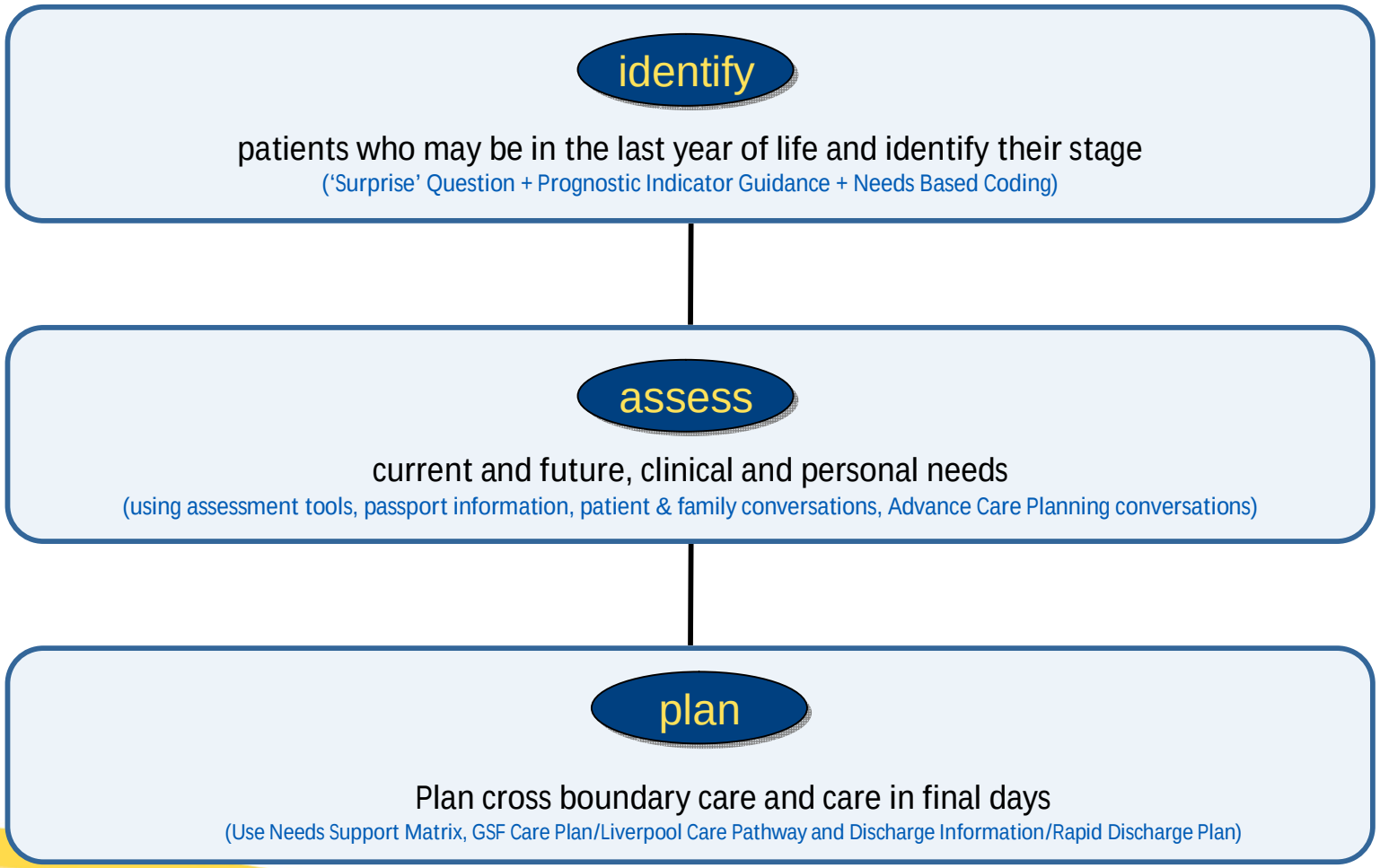
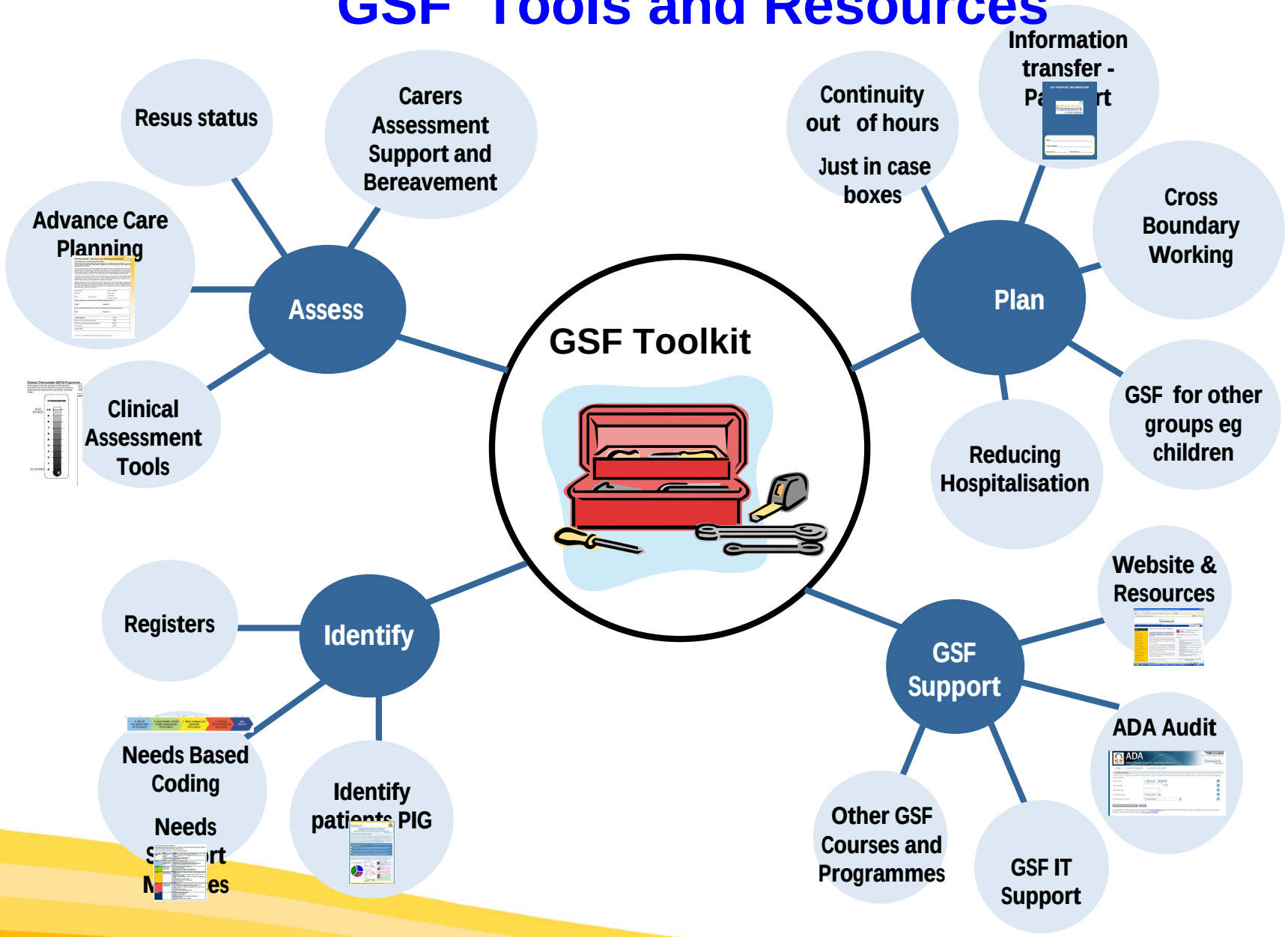
GSF 3 Steps


identify
patients who may be in the last year of life and identify their stage
('Surprise' Question + Prognostic Indicator Guidance + Needs Based Coding)
assess
current and future, clinical and personal needs
(using assessment tools, passport information, patient & family conversations, Advance Care Planning conversations)
plan
Plan cross boundary care and care in final days
(Use Needs Support Matrix, GSF Care Plan/Liverpool Care Pathway and Discharge Information/Rapid Discharge Plan)

20 Key standards- Accreditation checklist

1. Leadership + support
2. Team-working
3. Documentation
4. Planning meetings
5. **GP Collaboration**
6. **Advance Care Planning**
7. Symptom control
8. **Reduce hospitalisation**
9. DNAR +VoD policies
10. Out of hours continuity
11. Anticipatory prescribing
12. Reflective practice+ audit
13. Education + training
14. Relatives
15. **Care in final days**
16. Bereavement
17. Dignity
18. Dementia
19. Spiritual care
20. Sustainability

GSF Tools and Resources



1. Identify- GSF Prognostic Indicator Guidance-

identifying pts with advanced disease in need of palliative/ supportive care/for register

Three triggers:

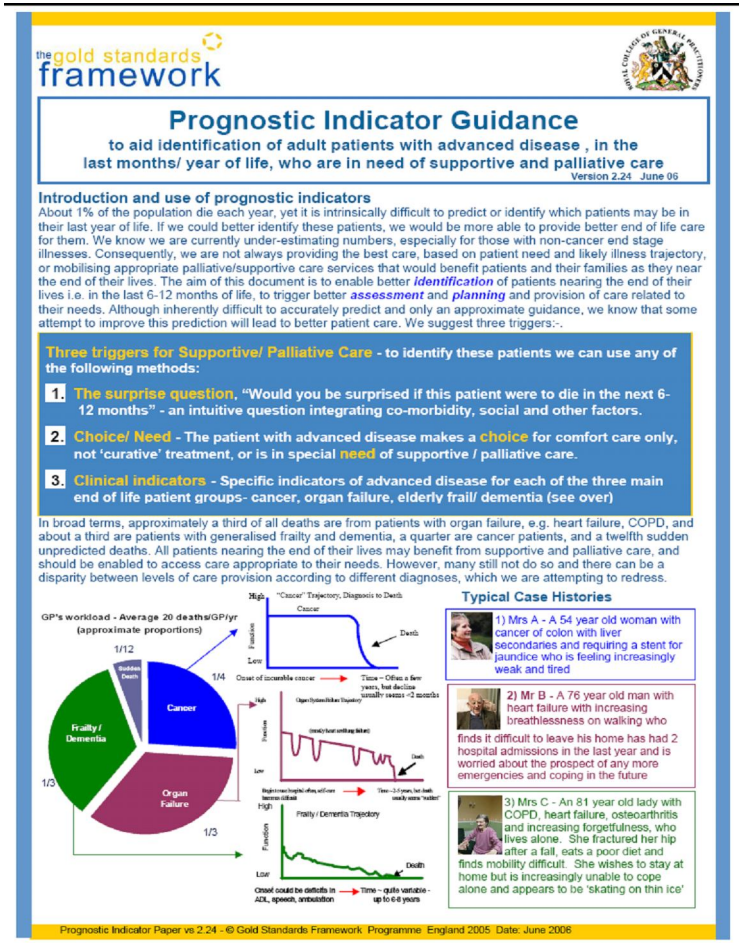
1. **Surprise question-**

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

2. **Patient preference** for comfort care/need

3. **Clinical indicators**

Suggested that all pts 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)

Typical Case Histories

1) Mrs A - A 54 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

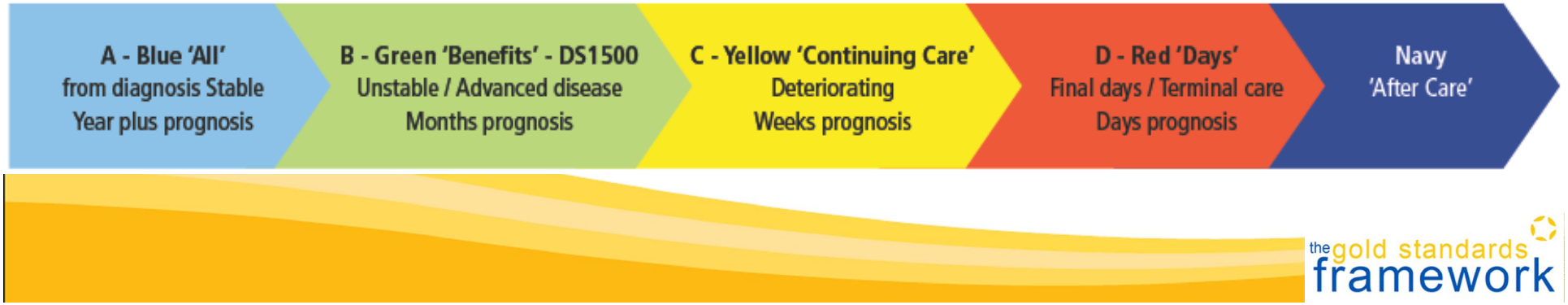
3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be ‘skating on thin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

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

Needs Based Coding

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

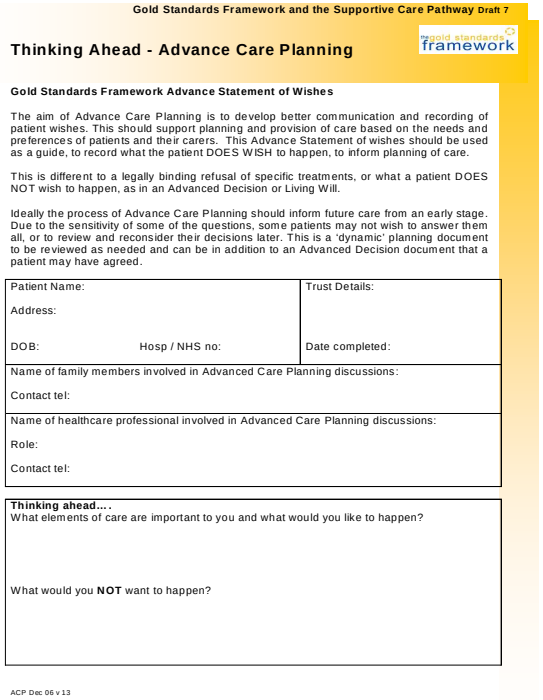
- **A - All – stable from diagnosis** **years**
- **B – Unstable, advanced disease** **months**
- **C** – Deteriorating, exacerbations **weeks**
- **D** - Last days of life pathway- **days**



2. Assess – Advance Care Planning

GSF Thinking ahead includes:

- - open questions
  - what matters to you
  - what you wish to happen and what not to happen
- Proxy - who else involved (LPOA) +Who to call in a crisis
- Preferred place of care & death, options
- Other requests eg special instructions



Gold Standards Framework and the Supportive Care Pathway Draft 7

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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 involved in Advanced Care Planning discussions: Role: Contact tel:	

Thinking ahead... ,
What elements of care are important to you and what would you like to happen?

What would you **NOT** want to happen?

ACP Dec 06 v 13

3. Plan

- Cross boundary care
  - primary care teams
  - hospitals
  - others

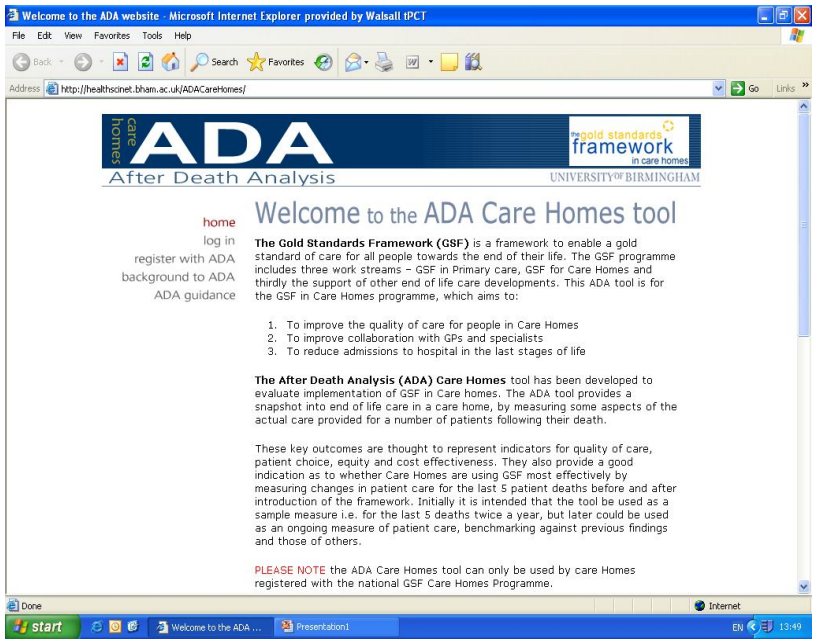
- Care in final days
  - Use of care pathway eg LCP
  - Use of Minimum Protocol

ADA Evaluation- before and after

ADA Care Homes

Electronic Format – Register on line

- Background information
- Last 5 patient deaths before and after GSF introduction
- What went well, what didn't go so well, what could we do better.
- Feed back of information.



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3 Challenges in care homes

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1. Quality -Staff confidence

Successes with GSF Care Homes Training Programme

- Open attitude to death and dying
- All residents offered advance care planning discussions
- Improved confidence of staff
- Better working with GPs

*"GSF has made my work **simple** to care for my residents**.** It has drawn m**e closer** to my residents and relatives, given me **confidence** in discussing end of life care**."***

(Nursing Home RN Accreditation Round 3)

GSF in Care Homes also helps ….

- Relates to CORE VALUES of staff
- Improve staff confidence
- Develop strong team-spirit
- Enable conversations about death and dying
- Share best practice and releases creativity

"Its been life changing for us! ….

Before we were just fire-fighting! Its changed everything we do, from life stories for our long term residents, to getting weekend drugs ready with our GPs to avoid admissions, to memorial books after death. We all know what we are doing and less is left to chance."

Yorkshire Care Home Lead GSF Nurse

"Its released us to be creative and we all feel we have grown in confidence and compassion - and we really love this work "

Care Home RGN London feedback

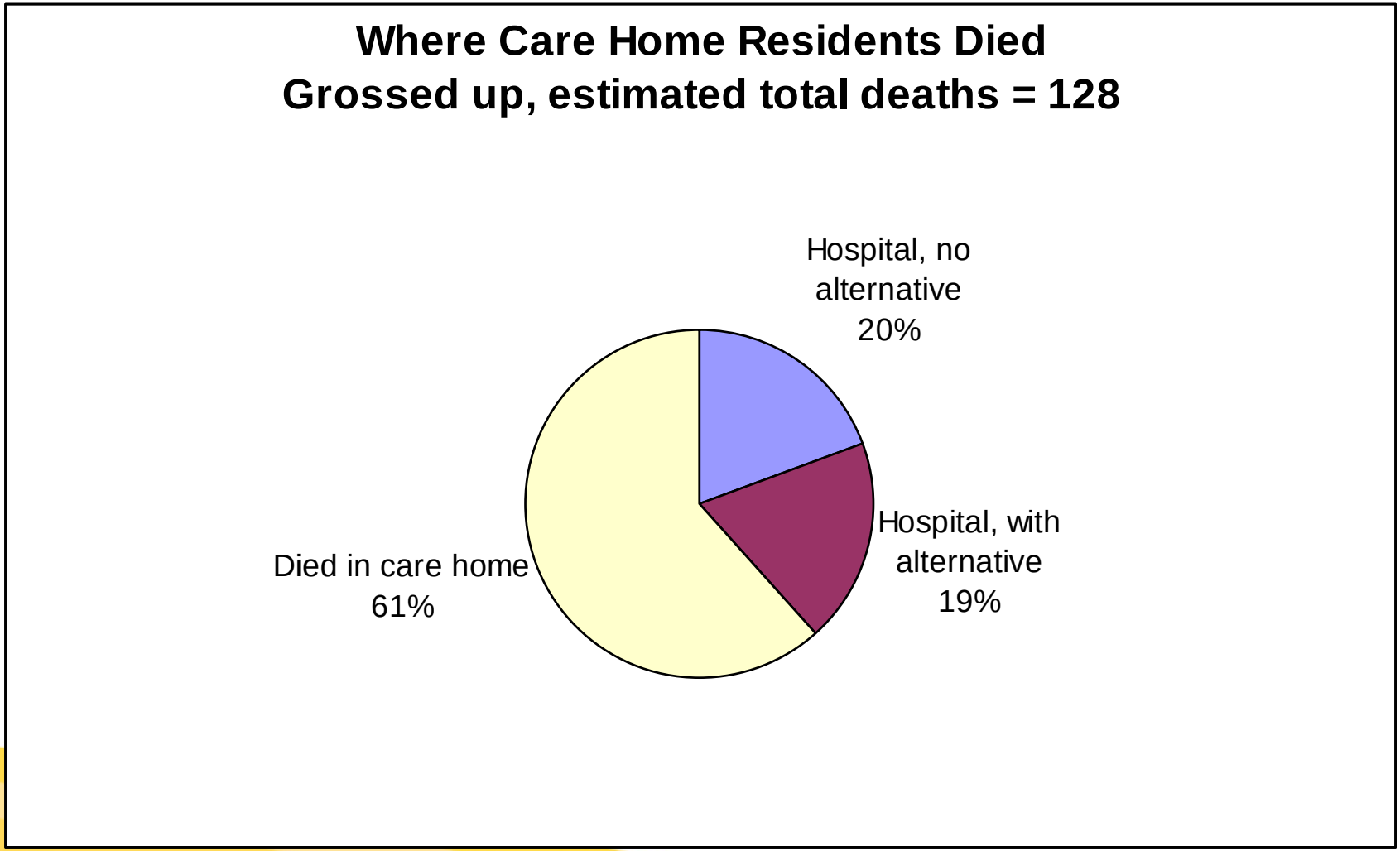
2.Quality of care- Alignment

Links to Standard 6 of accreditation checklist

- An advance care planning discussion is offered and recorded for ALL residents and their families

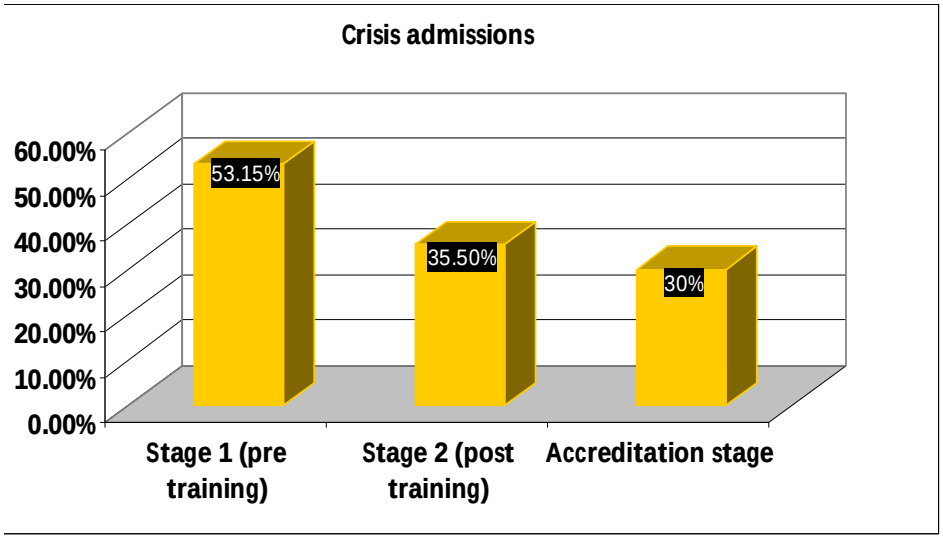
- Evidence of advance care planning discussion offered ,recorded and reviewed
- Offered to ALL residents
- Evidence of ACP influencing care provided

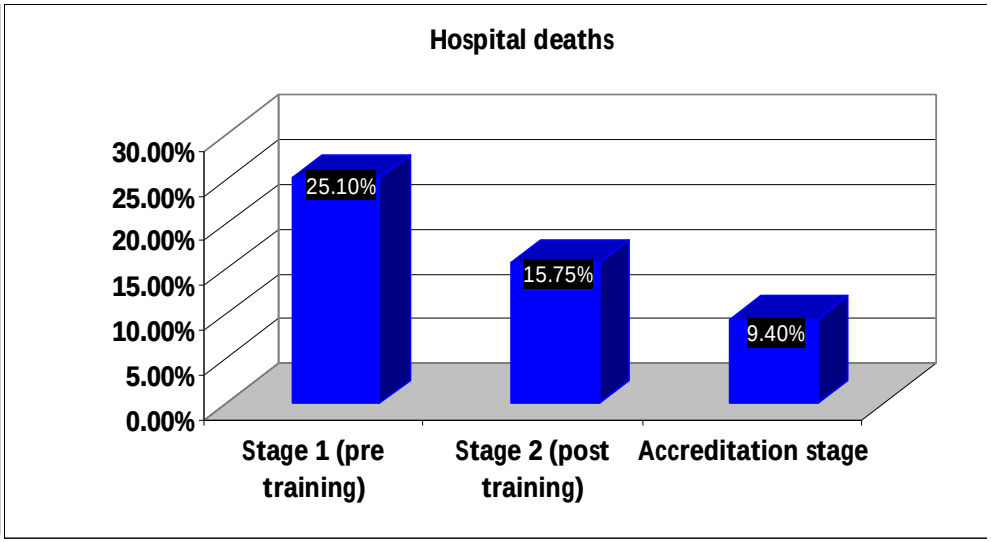
2. 50% of frail care homes residents could have died at home (NAO report 08)



Decreased hospital admissions and deaths with GSFCH Training programme

as measured by ADA phases 4-6

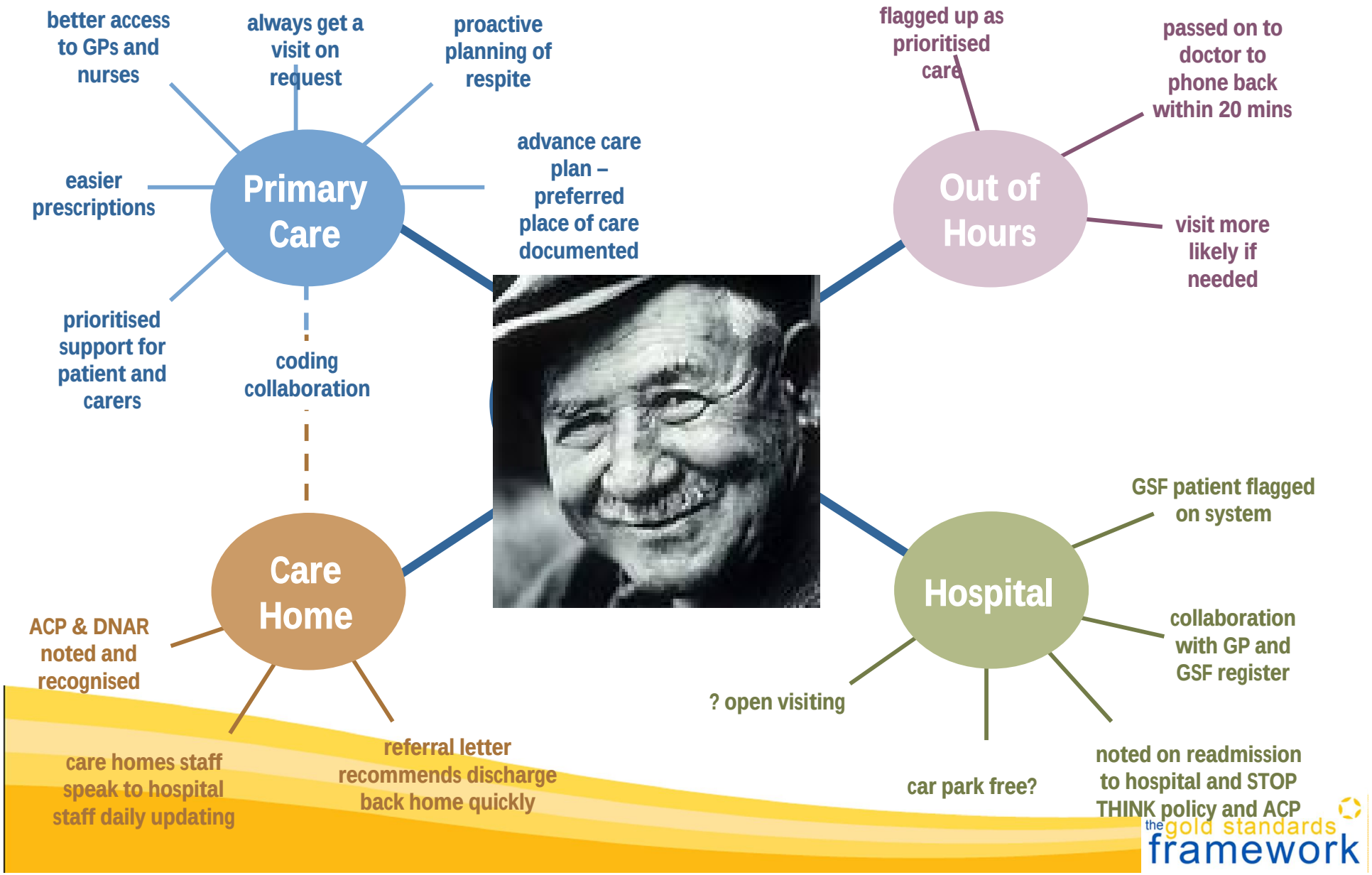




Focus on reducing hospitalisation

- Advance care planning discussions
- Needs Based Coding
- Needs Support Matrices
- Planning meetings
- Team collaboration
- DNaR/ AND discussions
- Training and education for all staff (including night staff and temp/ bank)
- Policy +guidance on reducing avoidable admissions
- Stop Think policy
- Anticipatory prescribing
- OOH handover form
- Audit/ SEA
- LCP for dying
- Communication with family re ACP

3. Better working with others
Benefits to Patients of Cross Boundary GSF



What if ….Bill

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Ideal

Using GSF Care Homes

- **Identify and code stage**
- **Assessment of clinical and personal needs**
- **Advanced care planning**
- **Planning -regular support + coordination within primary care**
- **Handover form out of hours**
- **Crisis – discussion with family+ GP**
- **Admission averted**
- **High quality care provided**
- **Dies in care home**
- **Bereavement care for family**
- **Audit (ADA),reflection**
- **Continuous Quality Improvement**

- **Better outcome for patient, family, staff**
- **Most cost effective + best use of NHS**

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Its about living well until you die

www.goldstandardsframework.nhs.uk

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