StChristopher's

KING'S College LONDON
University of London

Improving end of life care for older people with frailty in the community-

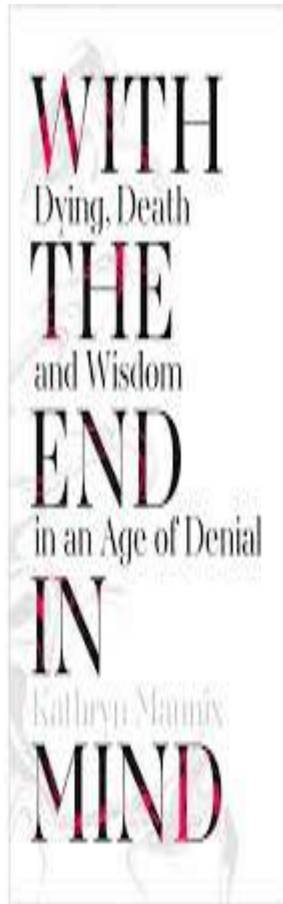
Attending to Living **AND** Dying

BGS FRAILTY 2018

Dr Caroline Nicholson
Senior Clinical Lecturer: Supportive and End of Life Care (Nursing)
St Christopher's Hospice/Kings College London
c.nicholson@stchristophers.org.uk

@DrCarolineN

Attending to people…



Page 293

BGS FRAILTY 2018

What Frailty means to those living in late old age ?

(Nicholson 2012)

Seeing in a different way:

"But my confidence in life in general has gone, you know because you can't do things. I'm frightened to an extent, to a certain extent but it might be the wrong word but in a general sense, the way the world is going everything. I haven't got the confidence anymore" *(Jack)"*

Being seen in a different way:

"I hate it, I hate being treated differently I am the same on the inside as I have always been" *(Maureen)*

A state of imbalance

- Dis-connects (Losses)

Loss of the future: more obviously inhabiting the space between living and dying-
"And then he doesn't seem to be so strong-once we got nearly as far as nearly the pillar box (on a walk) but now I don't know he doesn't want to go as far as that. I'm just terrified he's going to die." *(Betty wife of Jo)*

- Retaining connections and anchorage through the work of daily routines

- Creating connections- the creativity of older people with frailty relating to their worlds in a different way

BGS FRAILTY 2018

Understanding what matters to older people Living and Dying with Frailty in Old Age

Social Science & Medicine 75 (2012) 1426–1432

Contents lists available at SciVerse ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Living on the margin: Understanding the experience of living and dying with frailty in old age

C. Nicholson [a,*], J. Meyer [b], M. Flatley [c], C. Holman [b], K. Lowton [d]

[a] King's College London, National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, London, UK
[b] City University, London, School of Community and Health Sciences, UK
[c] St Joseph's Hospice, Hackney, London, UK
[d] King's College London, Institute of Gerontology, UK

BGS FRAILTY 2018

Maintaining Continuity-

Maintaining Personhood-

The continual work of balancing and adaptation to loss

The social networks/community "the glue" through which and in which lives are lived

The VIP Bundle http://youtu.be/Qj_YOXjL6Ws

Learnings- The Frailty Paradox

- Frailty- encompasses more than deficit No-one in my doctoral study referred to themselves as frail-Older people with frailty living at home are the survivors- outliving the majority of their birth cohort. These are important considerations when considerable capability and resilience were evidenced as well as the difficulties of living with an increasing unreliable body

- Valuing continuity The ritualised and regulated practices that older people in this study undertook to create a sense of stability in their uncertain worlds were universally cut across when health and social care became involved- potentially leaving an older person feeling more frail

- Allowing yourself to be cared for as well as cared about revalidation of the hidden work of intimate care giving for older people

- The importance of Families

- Keeping the future in mind The prolonged period of living with increasing dependency and limited function can mean deterioration is missed and dying is unrecognised and unsupported- There is unnecessary suffering for older people of over and under treatment in ignoring or fighting against dying in old age

BGS FRAILTY 2018

Improving End of Life Care
Learning through doing- Bromley Care Coordination (BCC) @ St Christopher's Hospice

Commissioned by Bromley Clinical Commissioning Group. BCC is a nursing led service, with the GP taking medical responsibility for the patient. The team consists of Clinical Nurse Specialists, health Care Assistants and administrators. Other St Christopher's services are available as necessary to meet patient needs. Those using the service can access advice and help 24 hours a day.

Service Aims

- Enable older people with advanced illness or frailty thought to be in their last year of life to receive timely and well co-ordinated care
- Help people die with dignity in a place of their choice
- Provide support to their families and carers
- Reduce unnecessary hospital admissions

Activity

- **Daily caseload** averaging 260
- **Home death rates** increased 23% to 67%
- **Time in service** 16% of patients die within 7 days of referral- 2% on the books for over 2 years
- **Not known to other** services - 56 % in year one- 86% in year three

BGS FRAILTY 2018

BCC Referral Criteria

StChristopher's Bromley Care Coordination

Mainly GP's
Local Hospital's
Integrated Care Networks

BGS FRAILTY 2018

Any older person thought to be in the last year of life.

Indications for referral include:

People with an EFI of severe frailty

Multiple admissions to hospital in the last year

- Increasing uncertainty
- Deterioration
- Long term comorbidities

e.g.

- Dementia
- Endocrine (e.g. diabetes)
- Neurological (e.g. MND, multiple sclerosis, Parkinson's)
- Renal failure
- Respiratory
- Cancer
- Cardiac disease

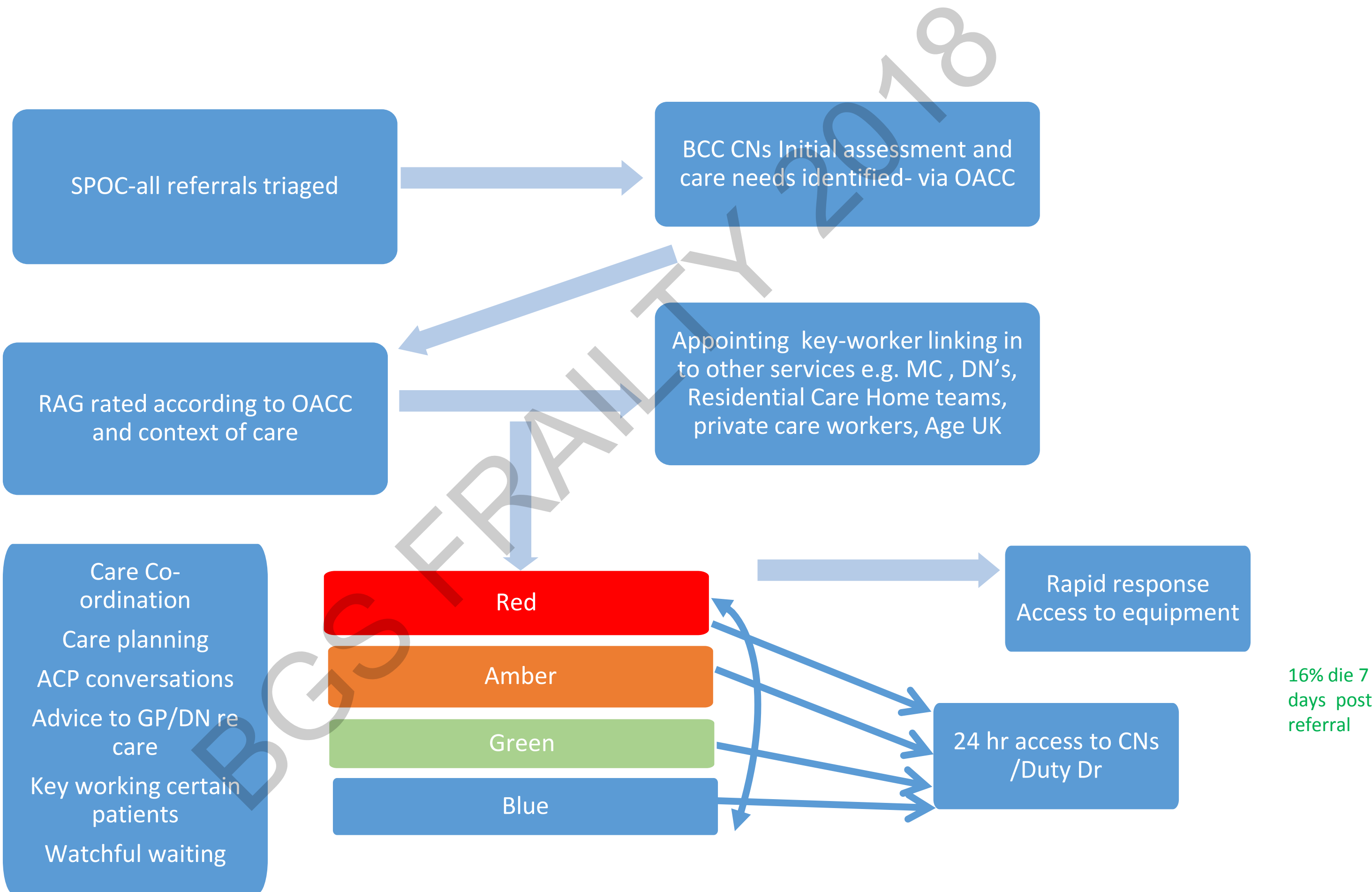
Precarious social support network/carer burden and escalation of concern

Would benefit from advance care planning or discussions about the future

Requires a joined-up approach – currently falling between services and requires care co-ordination.

BCC- Model of Care (current)

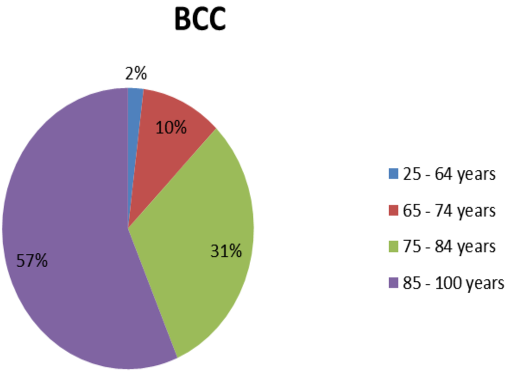
StChristopher's Bromley Care Coordination



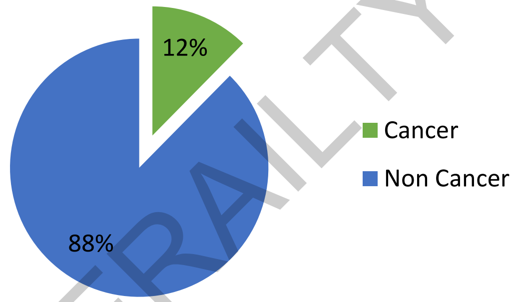
BGS FRAILTY 2018

The BCC population compared to conventional community palliative care patients

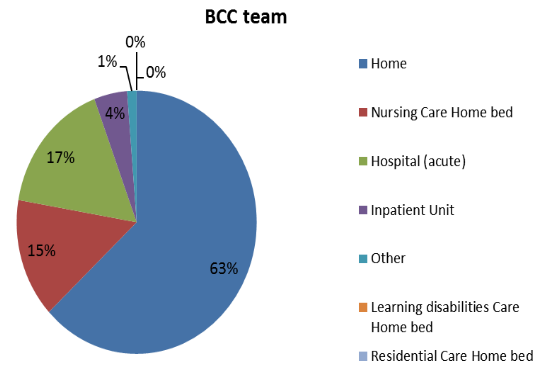
Age

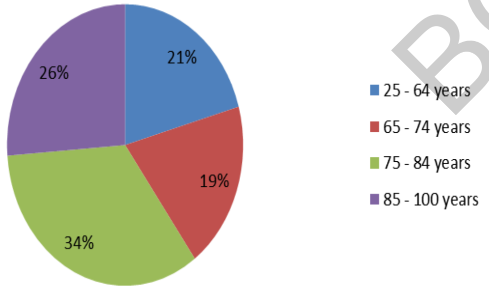


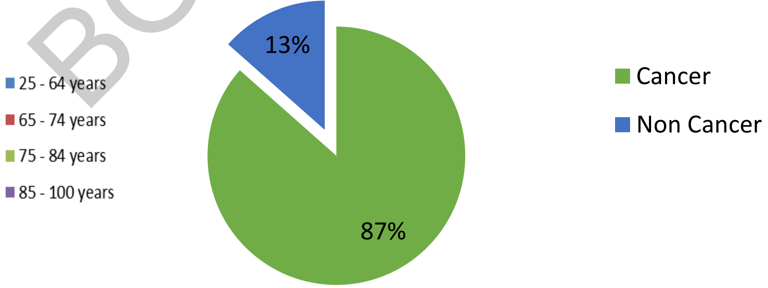
Diagnosis

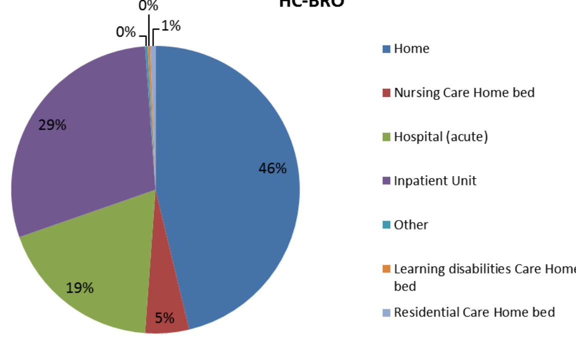


Place of Death









BGS FRAILTY 2018

Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London)

NHS National Institute for Health Research

Using Patient Reported Outcomes to improve our understanding of need in older people with frailty

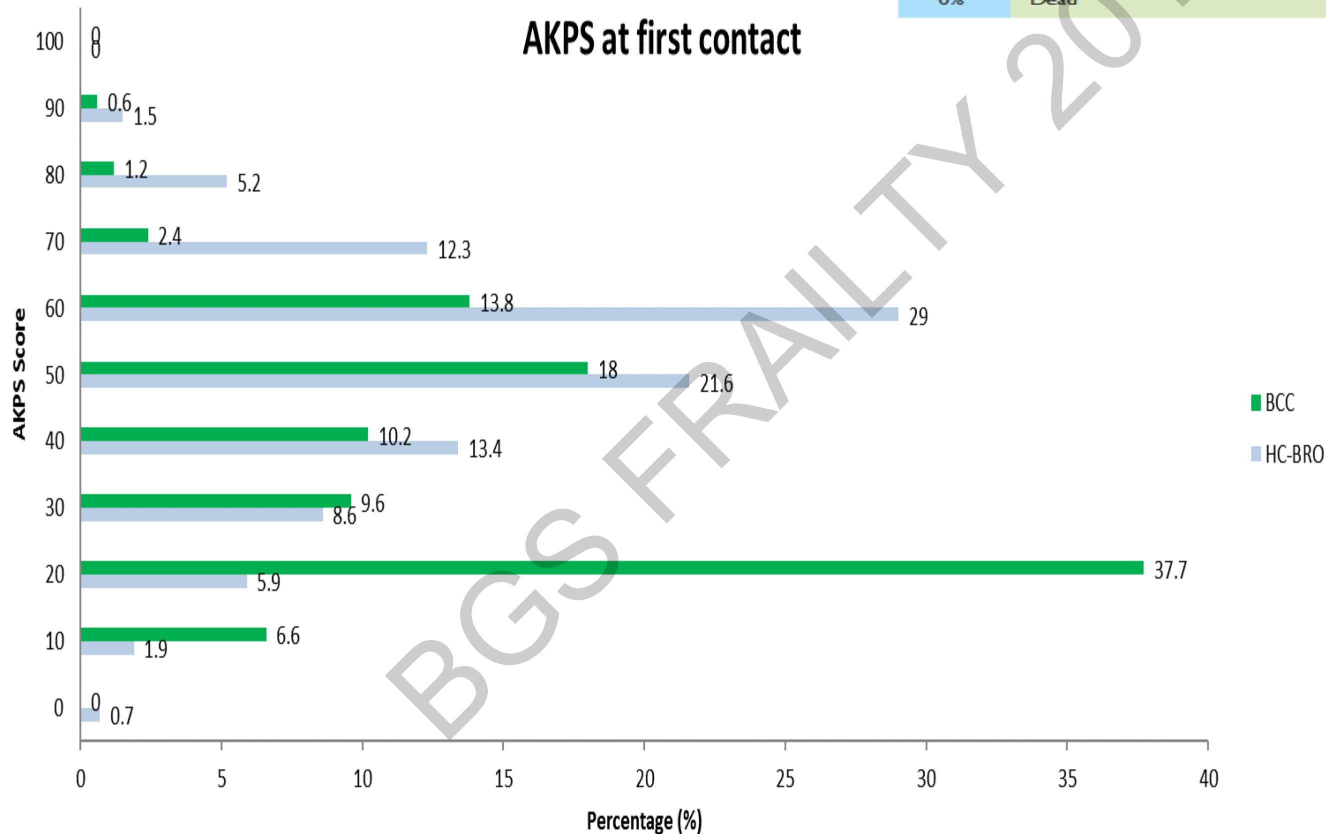
BGS FRAILTY 2018

The Outcome Assessment and Complexity Collaborative (OACC) project-
www.kcl.ac.uk/nursing/departments/cicelysaunders/research/studies/oacc/index.aspx

- **AKPS:** measure of functional status; 0-deceased to 100 best possible function
- **Phase of Illness** –describes four distinct clinical stages of a palliative patient's illness: stable, unstable, deteriorating, and dying (and deceased).
- **IPOS:** 17 items, common symptoms & problems in palliative population, 0 absent to 4 overwhelming

AKPS: measure of functional status

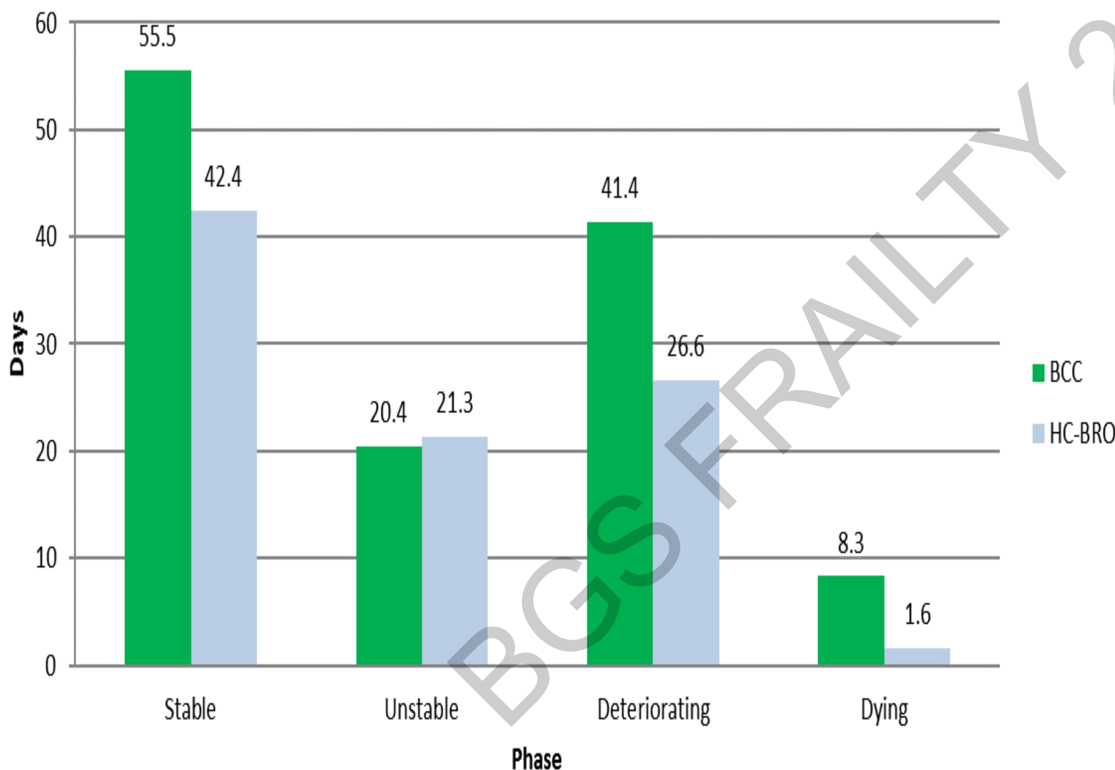
AKPS Score	Description of performance status
100%	Normal, no complaints, no evidence of disease
60%	Able to care for most needs, but requires occasional assistance
20%	Totally bedfast and requiring extensive nursing care by professionals and/or family
10%	Comatose or barely arousable, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly
0%	Dead



BGS FRAILTY 2018

Whilst indicative of care need and possibly carer distress this data suggests AKPS as a predictor of decline in BCC patients is of limited value

Phase of illness

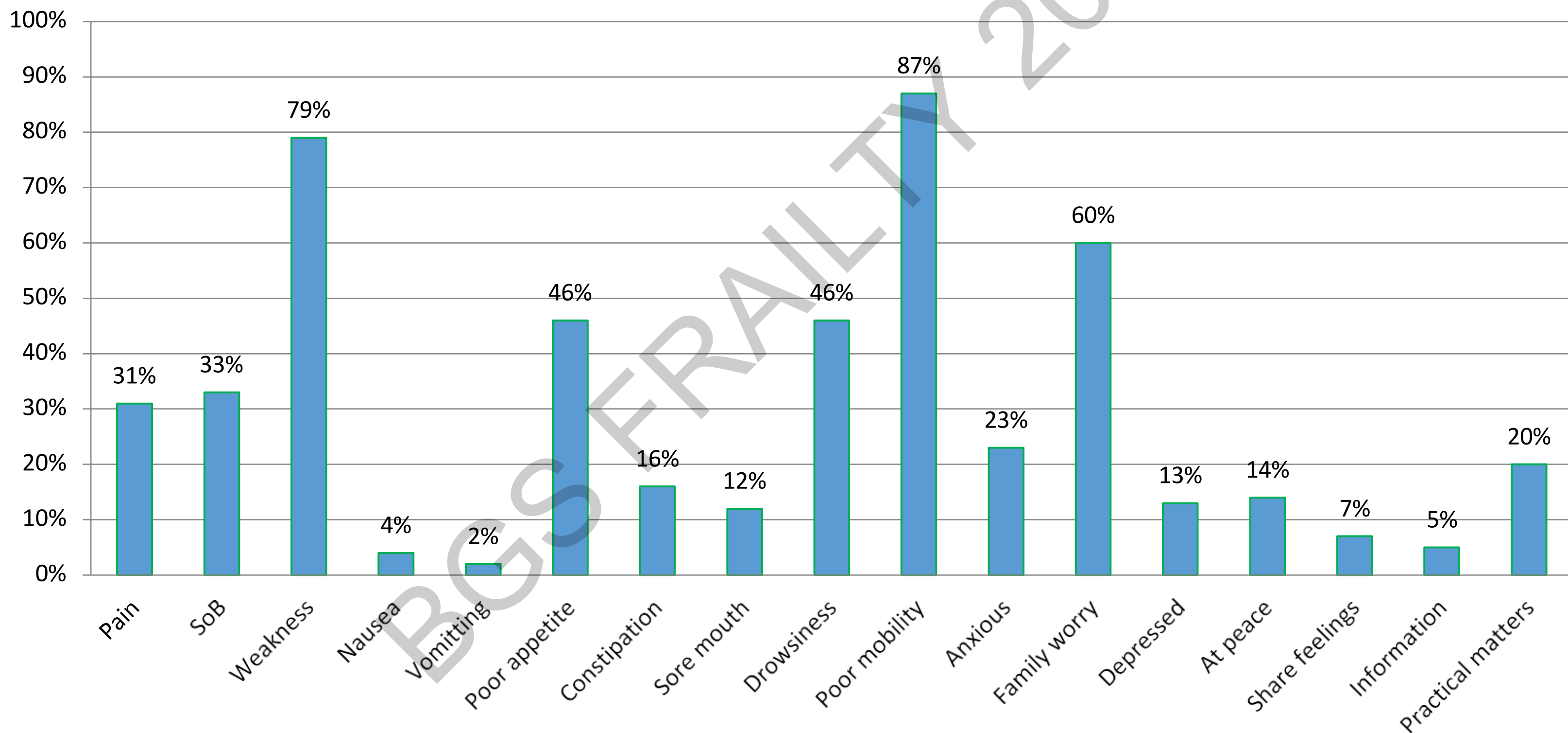


Phase	This is the current phase if...	This phase ends when...
Stable	Patient's problems and symptoms are adequately controlled by established plan of care* **and** further interventions to maintain symptom control and quality of live have been planned **and** family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required **because** the patient experiences a new problem that was not anticipated in the existing plan of care **and/or** the patient experiences a rapid increase in the severity of a current problem **and/or** family/ carers circumstances change suddenly impacting on patient care.	The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crises has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and/or** death is likely within days (i.e. patient is now dying).
Deteriorating	The care plan is addressing anticipated needs, but requires periodic review, **because** the patient's overall functional status is declining **and** the patient experiences a gradual worsening of existing problem(s) **and/or** the patient experiences a new, but anticipated, problem **and/ or** the family/carer experience gradual worsening distress that impacts on the patient care.	Patient condition plateaus (i.e. patient is now stable) or and urgent change in the care plan or emergency treatment **and/or** family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** death is likely within days (i.e. patient is now dying).
Dying	Dying death is likely within days.	Patient dies **or** patient condition changes and death is no longer likely within days (i.e. patient is now stable and/or deteriorating).
Deceased	The patient has died; bereavement support provided to family/carers is documented in the deceased patient's clinical record.	Case is closed.

BGS FRAILTY 2018

Over 6 months – deterioration phase seems slower -The nurses in BCC express this as a different momentum and pace – can be hard to know what we are doing and register change, – Care pathways and management pathways not so clear. ACP can be harder as people do not identify as ill (er) or dying. Variation in POI "practice dying".

"Keeping Going"



BGS FRAILTY 2018

Specialist Palliative care focus is often on disease rather than on disability and resilience- importance of functionality and rehabilitation and falls prevention.

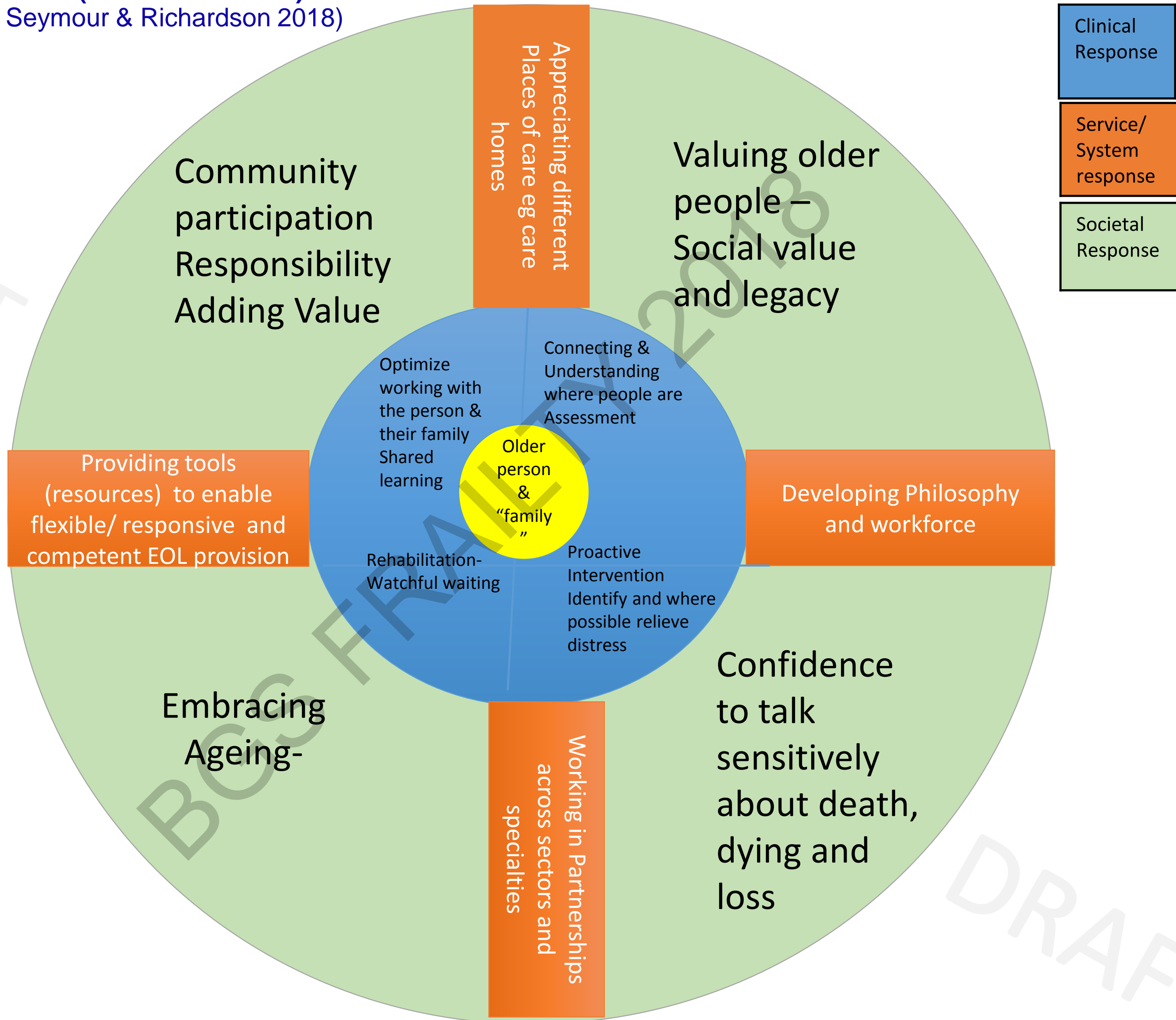
Learnings and Questions

- **Single disease focus is problematic** in determine need for this patient group- Multimorbidity - needs long term and ongoing partnerships with older people's services-
- **Care Co-ordination –** how do we maintain continuity of some low involvement
- **Advance Care Planning- perhaps a** different language-or a different focus - uncertain futures as much as care in the last few days of life. –
- **What and How are we assessing need?** E.g. **Mental health assessment -** often overlooked yet physical And mental issues together are a sign of complexity and poor outcomes, symptoms rather than functionality
- **Workforce Development-** adapting our services to be less organised around dying and more around variable episodes of crisis and need-
- **Rehabilitation/Disability Models** – Partnerships with wider community services and voluntary sector
- **Palliative Care in the community mainly provided by social care agencies and families -** Carer needs and capability- who supports this and how do we enable people to support each other?

BGS FRAILTY 2018

Age Attuned (Palliative) Care

(Nicholson, Seymour & Richardson 2018)



Balancing Continuity and Adaptation to Loss

DRAFT
BGS FRAILTY 2018
DRAFT

Summary- Older People with Frailty

- People need recognition of their capability and strengths over a life- long lived-this may help ease a conversation about their current or future vulnerabilities
- It is as important to attend to accumulated losses and distress as to death and dying- this values the ageing process and dependency/ interdependency which are often ignored
- Knowing when someone is going to die (prognostication) may be less helpful than knowing what matters to a person (preferences and needs)

BGS FRAILTY 2018

Services/Community

- Working with people in their own homes means letting go of being in charge, allowing more risk and uncertainty than is comfortable and knowing a person over time
- Communities are a hugely important and core in providing care, compassion and continuity for older people with frailty
- Know who and what "community" is for an individual older person and work with that community

BGS FRAILTY 2018

In conclusion…

Living with and dying from Frailty moves beyond the dichotomies of independent/dependent or coping/requiring care, to a person-centred approach recognising both potential needs and capability.
It seeks to recapture McCue's insight of life naturally moving towards closure in old age.
In this formulation, dying is engaged holistically and not, without careful thought, resisted biologically *(Nicholson 2017)*

BGS FRAILTY 2018