JOHNS HOPKINS MEDICINE

POPULATION HEALTH ANALYTICS

Improving End of Life Care in Dorset –

A Focus on the last 1,000 days

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Paul Molyneux

Wednesday, 17 May 2023

AGENDA

- Introductions
- What's happening in Dorset?
- What is the opportunity?
- How to find people?
- Engagement and management – what does good look like?
  - How to Access Recordings and Slides
  - Next Session
  - Questions & Answers

END OF LIFE ACTIVITIES IN DORSET

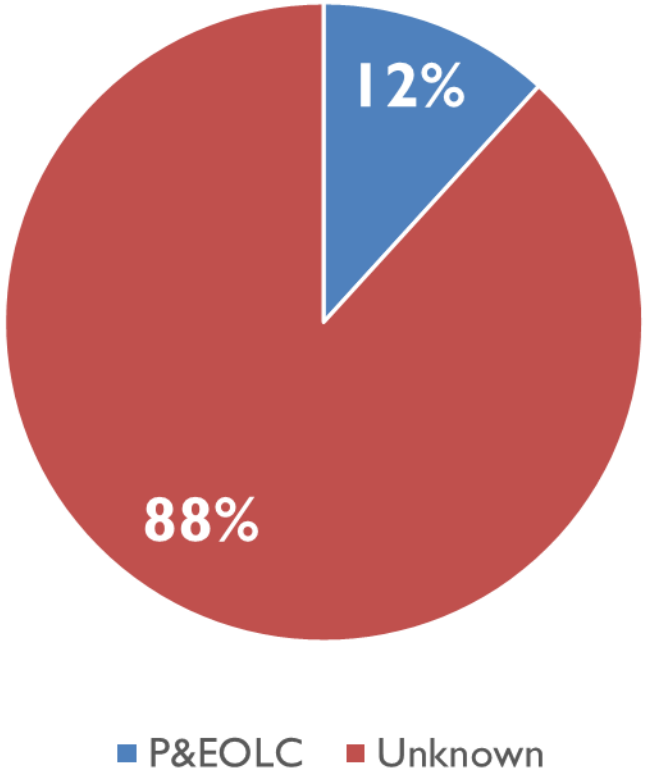
DORSET LANDSCAPE

- **Results through relationships**
  - Collaboration to improve last years of life in Dorset
- **Getting to Outstanding**
  - National quality improvement programme hosted and funded by NHS England
  - Programme (November 2021 – May 2022).
  - Purbeck PCN
- ~~What's the matter with you?~~
- **What matters TO you?**
  - Understanding what matters July 2022 – Present
- **CCLIP – local incentivised improvement plan**
  - End of life care
  - System Wide – All PCNs
- **PHM Ambassador Program**

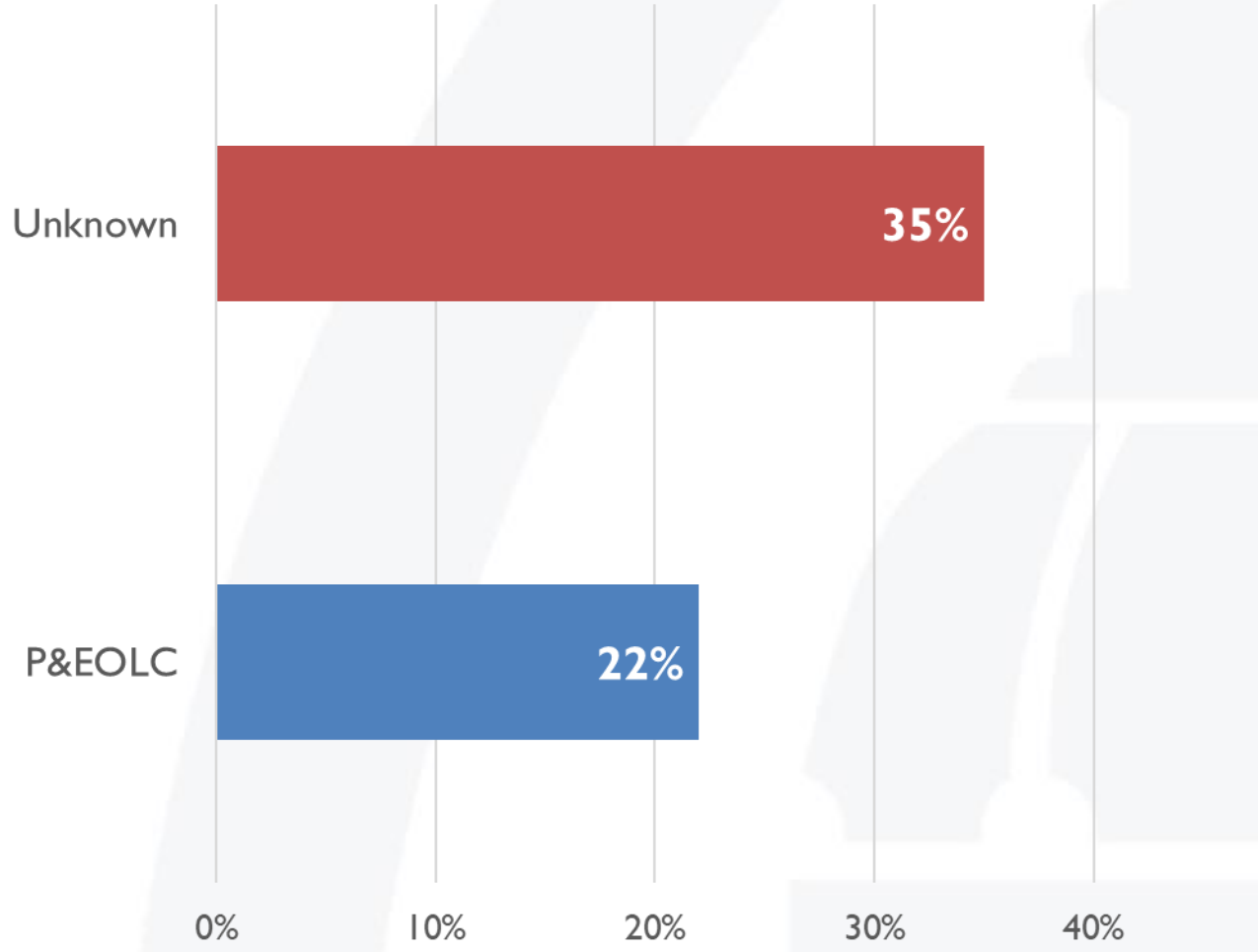
OPPORTUNITY

SYSTEM OPPORTUNITY

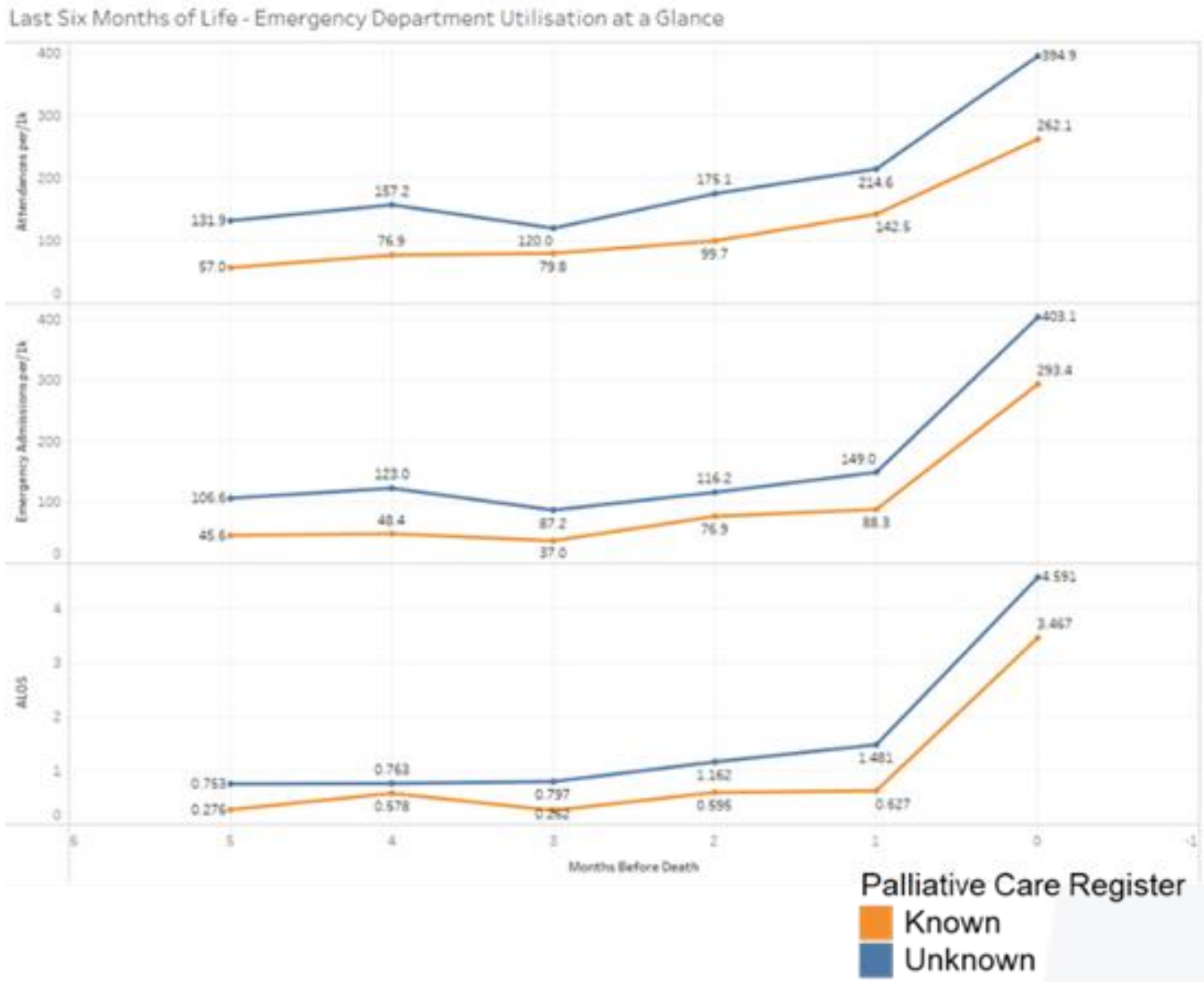
People on the Palliative & End of Life Care Register (P&EOLC) six months prior to when they died (n~8,500)



Proportion of people who died in hospital



SYSTEM OPPORTUNITY



By focusing on those in greatest need and closing the care gap to ensure people have equitable outcomes we estimate the following system savings could be achieved:

- 600+ fewer A&E visits in the last six months of life (with associated costs to the commissioners of £120k)
- 500+ fewer emergency inpatient admissions (with associated costs to the commissioners of £2m)
- 5,000 potential bed days saved
- 100+ people dying in their preferred place of death

PERSONAL OPPORTUNITIES

- When it doesn't go well…
- When it does go well…

IDENTIFICATION

METHODS OF IDENTIFICATION

PREDICTIVE MODELLING KLOEs

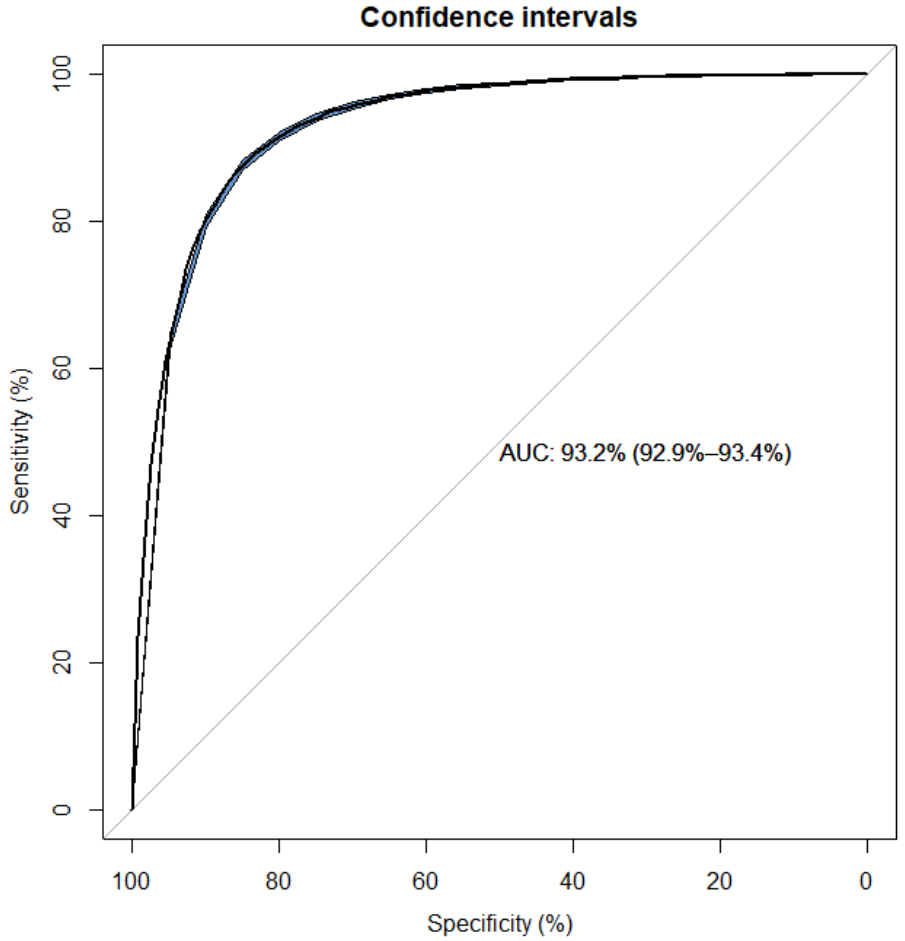
1. Is the outcome you're predicting for negative and actually predictable?
2. Can you do anything to prevent/manage it in a timely manner?
3. Is it making the best use of valuable resources when considering the incidence of the problem and the likelihood of a successful intervention?

Context:

- Dorset residents dying without having been enrolled onto a model of support
- Believed to be very predictable and an issue that scales
- Given the right model of support better outcomes are possible
- Implications for enormous quality, experience and productivity benefits

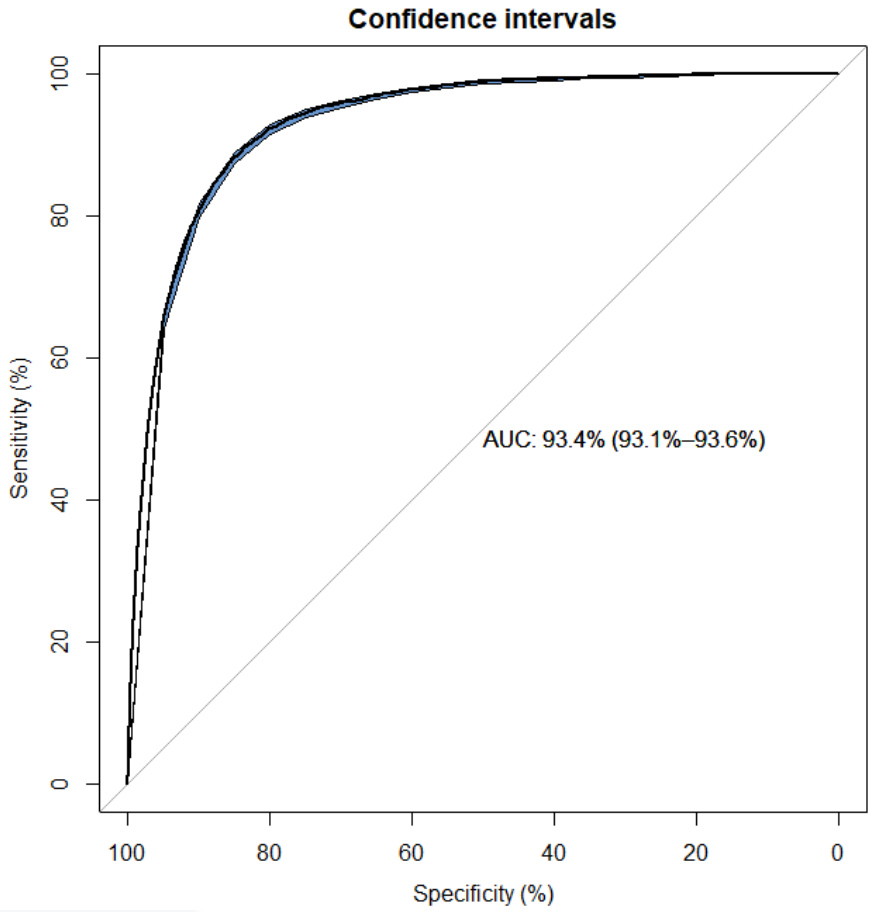
VALIDATION | CALIBRATION | GENERALISABILITY

AS PUBLISHED



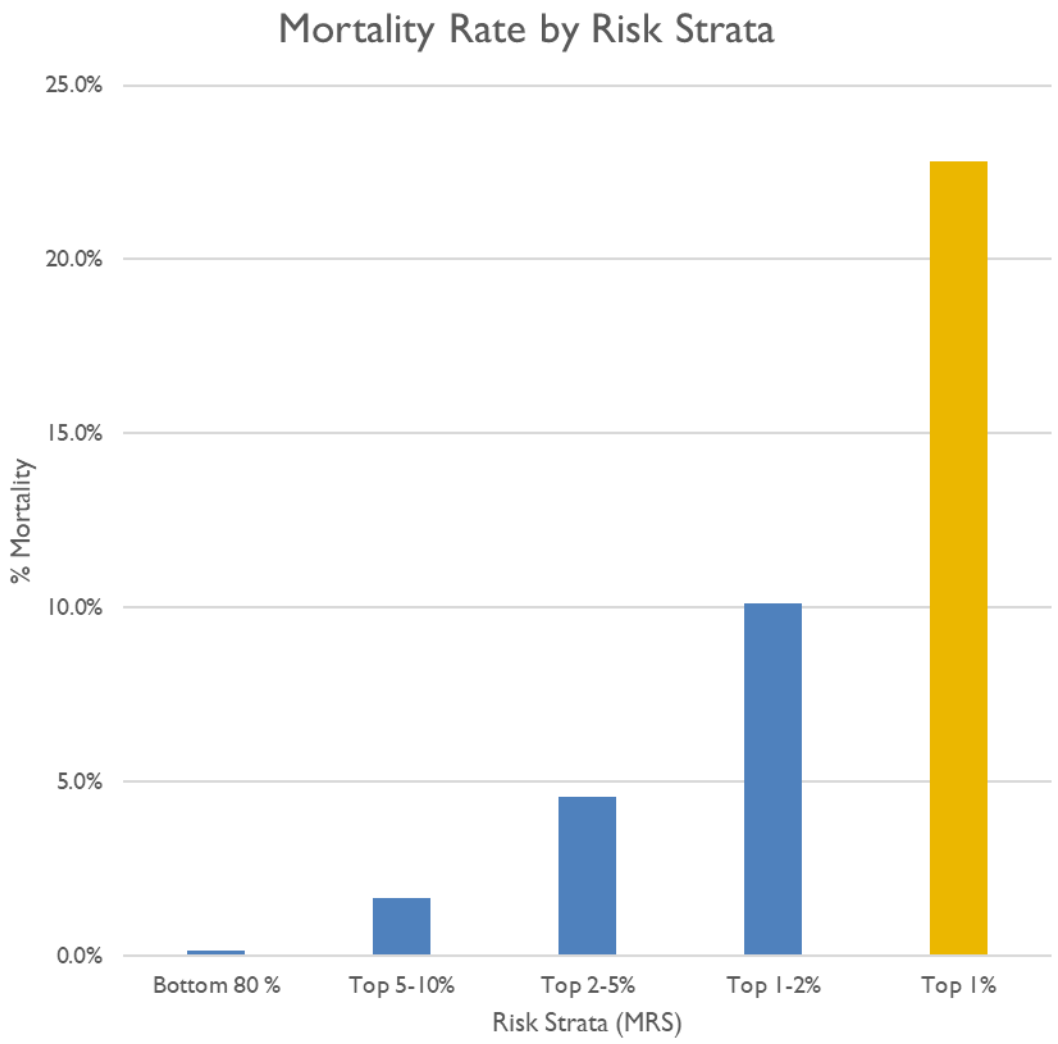
- **Accuracy:** **94.9%** | *(0.9488, 0.9498)*
- **Sensitivity:** **62.6%**
- **PPV:** **11.6%**

RECALIBRATED



- **Accuracy:** **95.2%** | *(0.9518, 0.9528)*
- **Sensitivity:** **61.6%**
- **PPV:** **12.1%**

RESEARCH INTO PRACTICE



- People dying without having a plan is bad and represents poor outcomes for both the individual and the system as a whole
- We have demonstrated that this is predictable and can be done at scale using routinely collected data and **ACG markers**
- There are substantial benefits that can be realised if early detection, engagement and management is achieved systematically
- The top 1% most at risk represent a natural and compelling cohort (left)
- Important to review those who have not been enrolled onto a model of support and may be at risk of care coordination issues

WHAT GOOD LOOKS LIKE

PERSONALISED ENGAGEMENT

- Good excuse to get in touch
  - Recently discharged from hospital
  - Haven't seen GP recently
  - *Data can play a role here*
- Cross functional team
  - Care coordinators
  - Frailty lead
  - Health and wellbeing coach
- Relationships are key
  - Don't want to surprise the person
  - Level of continuity
  - Capitalise on recent contacts

PERSONALISED ENGAGEMENT

- Recognising that people choose to share their views in different ways, we enabled a choice in how to participate. This included:
  - an invitation for semi-structured conversations (face to face or by phone) involving a small team:
    - two experienced nurses,
    - a doctor and
    - a chief executive of a hospice charity
  - a survey
  - we also invite people to share their experiences online via Care Opinion

KEY LEARNINGS

Conversations

- **"Was he supported to understand and anticipate what might happen in the last months, weeks and days of life?"**
- "At no stage were we sat down as a family and told what it would be like when he was dying. That would have been so helpful for all of us."
- **"Have you felt supported in these last months?"**
- "I find a real life buddying system much more supportive [than a national online forum]…. I wanted to talk with people of a similar age who knew what it was like. There's four of us who go on walks together each week, "bereavement buddies". I'd like to grow that, it's really helpful."

Survey

- **Gaps persist:** only three of 56 people said that it was recognised that the person was in their last weeks of life. The remaining 53 didn't respond.
- **Physical comfort:** 20 people felt that the person was as comfortable as possible; 11 that they were moderately comfortable; 11 not comfortable and 1 not sure.
- **Emotional comfort:** 22 people felt that the person was as comfortable as possible; 14 that they were moderately comfortable; eight not comfortable and five not sure.

FRAMEWORK OF VALUES

- Top ten values for Palliative and End of Life Care

	Care/Nurture (100) - To be physically and emotionally supported by family and friends and to value doing the same for others.
	Family/Belonging (66) - Having a place or sense of home. To be devoted to people you consider family and to experience belonging and acceptance.
	Empathy (54) - To deeply relate with others in such a way that they feel understood.
	Generosity (46) - To unconditionally share your resources, talents and skills as a way of serving others.
	Interdependence (37) - To value personal and inter-institutional co-operation above individual decision-making.
	Communication/Information (36) - The effective and efficient flow of ideas and factual information.
	Community Support (35) - To have, or to create, cooperative groups of peers with shared values that provide mutual support and enhancement of each other.
	Education/Knowledge (30) - Engaging in ongoing learning to gain new facts, truths, principles and insights.
	Health/Well-Being (30) - To practise self-awareness and healthy living in order to have physical and emotional well-being.
	Service/Vocation (30) - To use your unique gifts, skills and abilities to contribute to society through your career, profession or calling.

STAFF ENGAGEMENT - RAYS OF SUNSHINE

"What matters to me about last years of life – being able to do the things that they want to do, if they're able to… and towards the very end to be comfortable, to be pain free and not to be frightened… I love my job"

Sharon Walmsley, Community Support Worker

"Personalised care to me is whatever it means to the person I'm looking after… We get to know them as a person… we get to know what matters most to them"

Jill Dowland, Specialist Practitioner, District Nurse

"When I went to look after a patient in their own home… I then realised it wasn't that scary. And it's beautiful thing to look after a patient at their last moment in their life and after they passed away…. An amazing thing to do"

Jainaba Jobe, Student Nurse

"Allison chose to die at home and her husband Dave looked after her together with the district nurses and the community support workers. They were incredibly impressed by these teams and the care they gave her"

Jane Lewis, Trustee, Allison Campbell Trust

SYSTEM ENGAGEMENT & MANAGEMENT

- **PHM Ambassadors**
  - Structured system wide program
  - Oversight of mini cycles of service improvement (PDSA)
  - Routine collaboration events
- **Support and training** can be made available to PCNs that request help (e.g. webinars)
- **Good sharing of information**
  - Dependent on information sharing – Dorset Care Record
  - Joined up systems great – but no substitute for human interaction
  - Stamped into people's consciousness as oppose to the database
- **Agency to have the conversations**

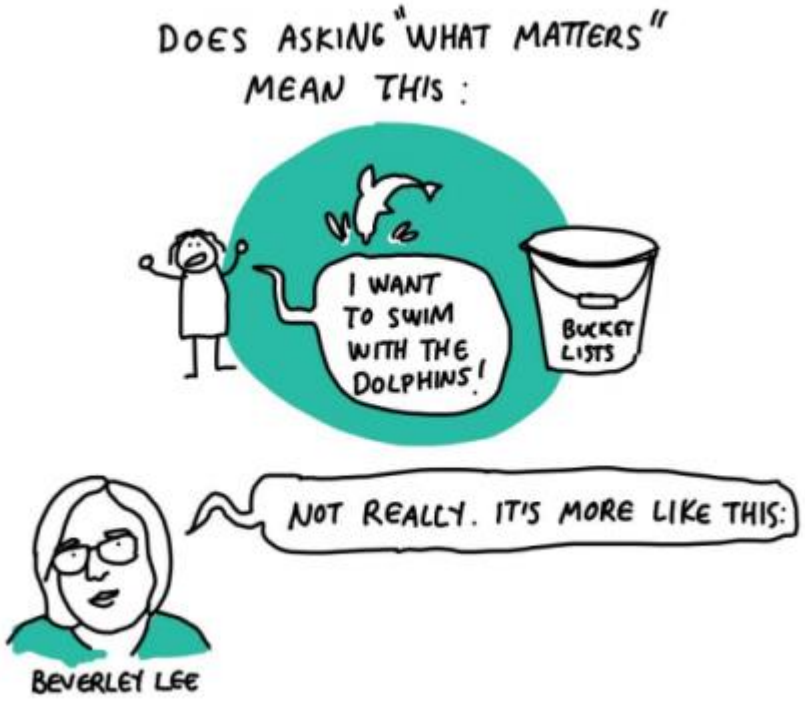
- **NHS Long term plan** – personalised care
  - Personalised care and support plan
  - Preferences recorded as part of plan
- **Associated metrics to demonstrate participation and processes (and outcomes)**

FRAMEWORK OF WHAT MATTERS

People in their last year of life say...
Initially...
You recognise that I am nearing the end of my life
You help me not to feel scared
You listen to me and what matters to me
You provide timely, relevant and easily understood information to help me make sense of my circumstances
You allow me to take the time I need to absorb this and ask questions
You leave me clear about what will happen and who to contact if I need to
Then...
You help me continue to make sense of what really matters to me; what a good remaining life can be and what a good death will be
You help me to do (or continue to do) what really matters to me
You help me to manage my fear/anxiety
You help me to feel prepared for my death so that I know what to expect
You help me to feel in control and listened to
In the end...
You keep listening to me, recognising that my needs and wishes may change as my death approaches
You make me comfortable within my wishes
You don't make unnecessary investigations, interventions, etc
You help me to die in the place of my choosing
You help me to die with my friends, family, pets (or whoever/whatever matters to me) around me
You help me to die with dignity

- Initially you recognise I am nearing the end of my life
- Then you help me to do what really matters to me and help me manage my fear
- In the end you make me comfortable with my wishes and die with dignity

VOICE OF THE PATIENT



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OUTCOMES

SHIFT IN SUPPORT MODEL

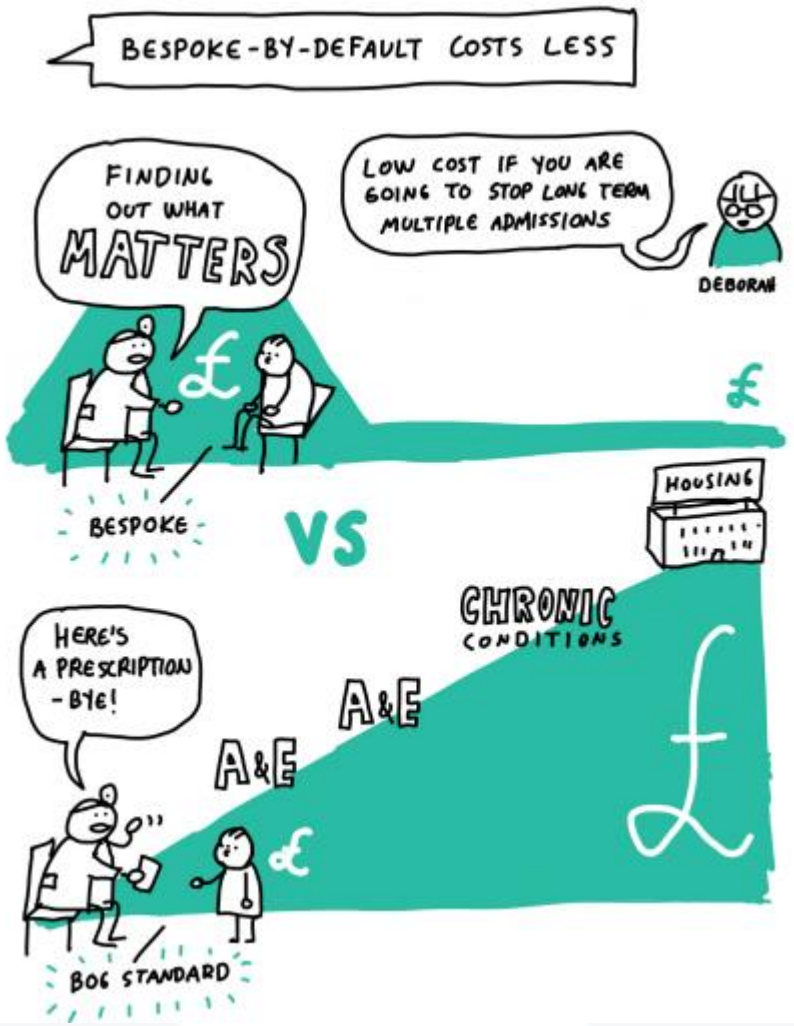
From:

OVER…

- testing
- treating
- diagnosing
- referring
- prescribing
- providing

To:

UNDER…standing



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Thank You

Questions?

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Next Webinar:

7th June 2023

Planning for Integrated Care in General Practice in LLR