StChristopher's

C A R E

THE CENTRE FOR AWARENESS & RESPONSE TO END OF LIFE

Using outcome metrics and data to change policy

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St Christopher's Hospice

An overview of the presentation

- Why are outcomes important to policy makers?
- What are we doing at St Christopher's to help shape local and national policy through outcomes measurement?
- How could others enhance our efforts?

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Why discuss outcomes?

- Skewed attention to **experience**
- Increasing attention by regulators towards **safety**
- Hospice and palliative care services are often very expensive in the UK
- To what degree do we make any difference and if so how?

Those shaping and implementing policy want to know more

What value does hospice/specialist palliative care make in a health economy increasingly stretched?

If funded, how should hospice and specialist palliative care services be positioned in relation to other services ?

Where would investment add most value by increasing impact or extending the reach of the most effective elements?

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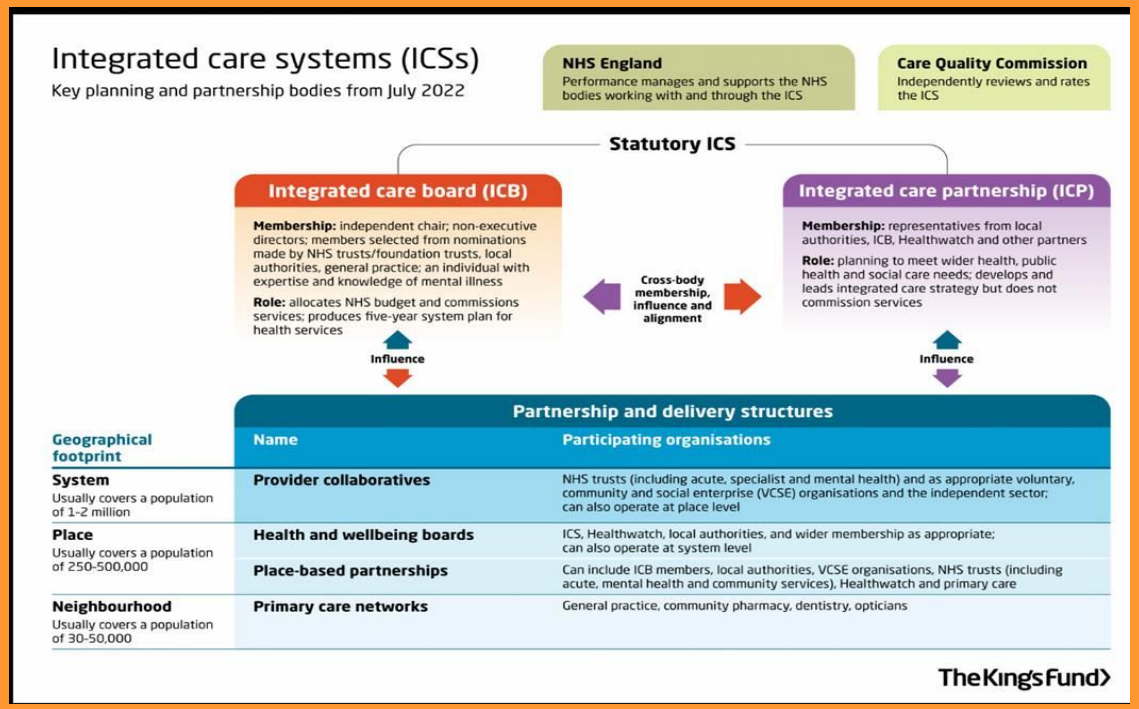
A changing national picture creates new urgency…



Integrated care systems (ICSs)

Key planning and partnership bodies from July 2022

NHS England
Performance manages and supports the NHS bodies working with and through the ICS

Care Quality Commission
Independently reviews and rates the ICS

Statutory ICS

Integrated care board (ICB)

Membership: independent chair; non-executive directors; members selected from nominations made by NHS trusts/foundation trusts, local authorities, general practice; an individual with expertise and knowledge of mental illness

Role: allocates NHS budget and commissions services; produces five-year system plan for health services

Influence

Cross-body membership, influence and alignment

Integrated care partnership (ICP)

Membership: representatives from local authorities, ICB, Healthwatch and other partners

Role: planning to meet wider health, public health and social care needs; develops and leads integrated care strategy but does not commission services

Influence

Partnership and delivery structures

Geographical footprint	Name	Participating organisations
System Usually covers a population of 1–2 million	**Provider collaboratives**	NHS trusts (including acute, specialist and mental health) and as appropriate voluntary, community and social enterprise (VCSE) organisations and the independent sector; can also operate at place level
Place Usually covers a population of 250-500,000	**Health and wellbeing boards**	ICS, Healthwatch, local authorities, and wider membership as appropriate; can also operate at system level
	Place-based partnerships	Can include ICB members, local authorities, VCSE organisations, NHS trusts (including acute, mental health and community services), Healthwatch and primary care
Neighbourhood Usually covers a population of 30-50,000	**Primary care networks**	General practice, community pharmacy, dentistry, opticians

The Kings Fund

"Our big challenge is pulling through national aspirations around outcomes into local conversations with integrated systems"

"And vice versa. We need to take local insights and translate into regional and national policy to shape priorities and investment"

Jonathan Ellis, Hospice UK

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The picture is changing at local level too

We are working in different times

- Health and social care systems are under stress
- New groups of people who need palliative care are emerging
- Staff report increased complexity as the new norm
- Individuals present with increased/different manifestations of need post - pandemic
- Organisations beyond the sector are adopting new/ increased roles in end of life care which require hospices and palliative care services to work differently

Reflecting on our efforts at St Christopher's

The good, the bad and the ugly….

- We have been collecting outcomes data related to our patients since 2015
- It spans home and inpatient care; now input to care home residents too
- The quality of the data varies. Second and subsequent measurements are not always available
- We have not always given enough time or effort to patient reported outcomes
- How consistent we are across teams and services is uncertain

BUT –

- Persistence has started to pay off
- Conversations with the ICS, commissioners, attendees on training events focuses increasingly on outcomes to shape end of life care in SE London and beyond.

A quick introduction to what we mean by outcomes measurement

Based on seminal work generated by the OACC programme

- **Phase of Illness** – definitions related to stability of illness and proximity to death
- **AKPS:** measure of functional status; 0-deceased to 100 best possible function
- **IPOS:** 17 items, common symptoms & problems in palliative population, 5 point scale, 0 absent to 4 overwhelming
- **Barthel:** measure of function on main Activities of Daily Living
- **Views on Care (VoC):** 4 questions about QoL and service
- **Zarit Carer interview:** 6 questions for carers

Why is this important for us to do?

1. It confirms our role in providing holistic care at the end of life

This is important because:

- It challenges the increasingly reductionist nature of the health system
- It expands key performance indicators used to represent “quality”
- It confirms users views of what is important at EOL
- It allows us to protect what we think is most important moving forward

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How are you?

At St Christopher's we do our best to meet your needs by listening to you, your family and your carers. One way we do this is by asking all our patients to complete a St Christopher's questionnaire each time we see them in a clinic or in their own home.

We know that when our patients and their carers complete this questionnaire, we are able to focus on what is most important to them, rather than focusing on what we think is important. Therefore, each time we meet with you, you will be asked to complete the questionnaire.

If you would rather not complete it, then please do not hesitate to hand it back to the member of staff or volunteer who gave it to you. They will be happy to complete the form with you, or on your behalf if you prefer.

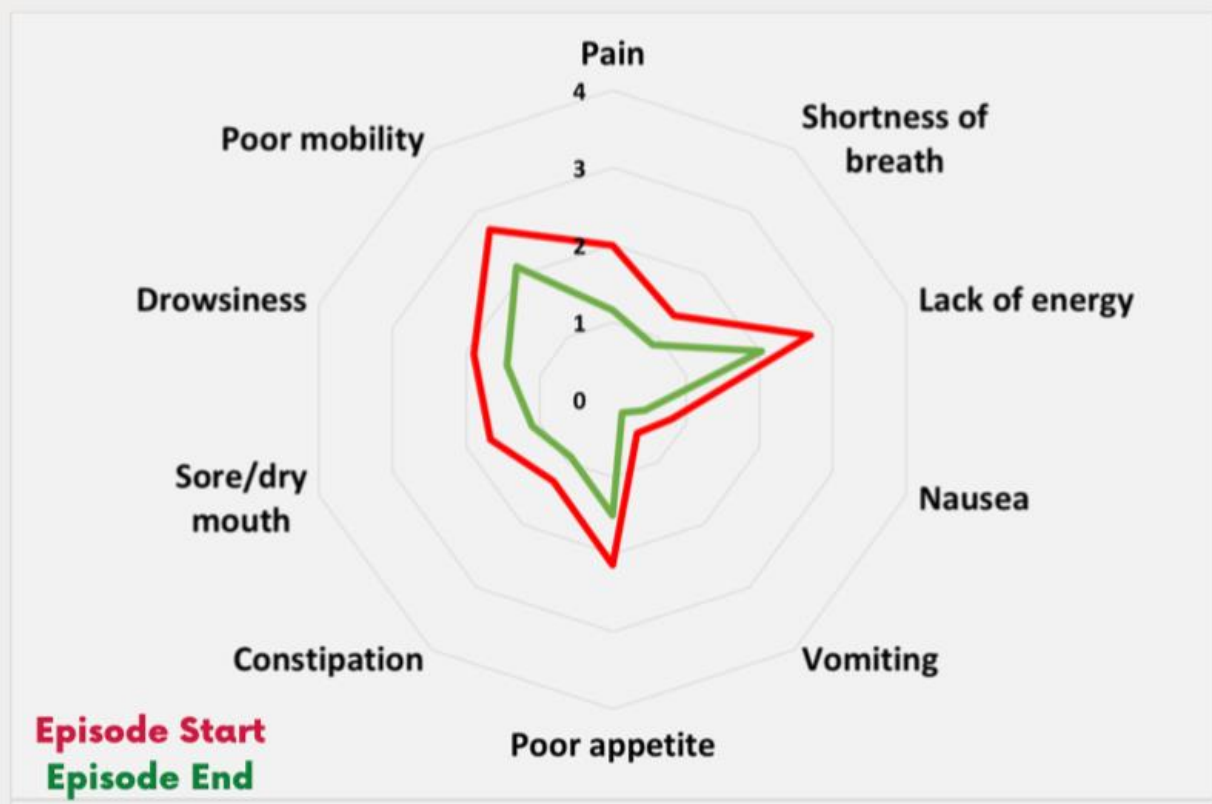
The questionnaire is designed to help us understand a number of different issues, such as:

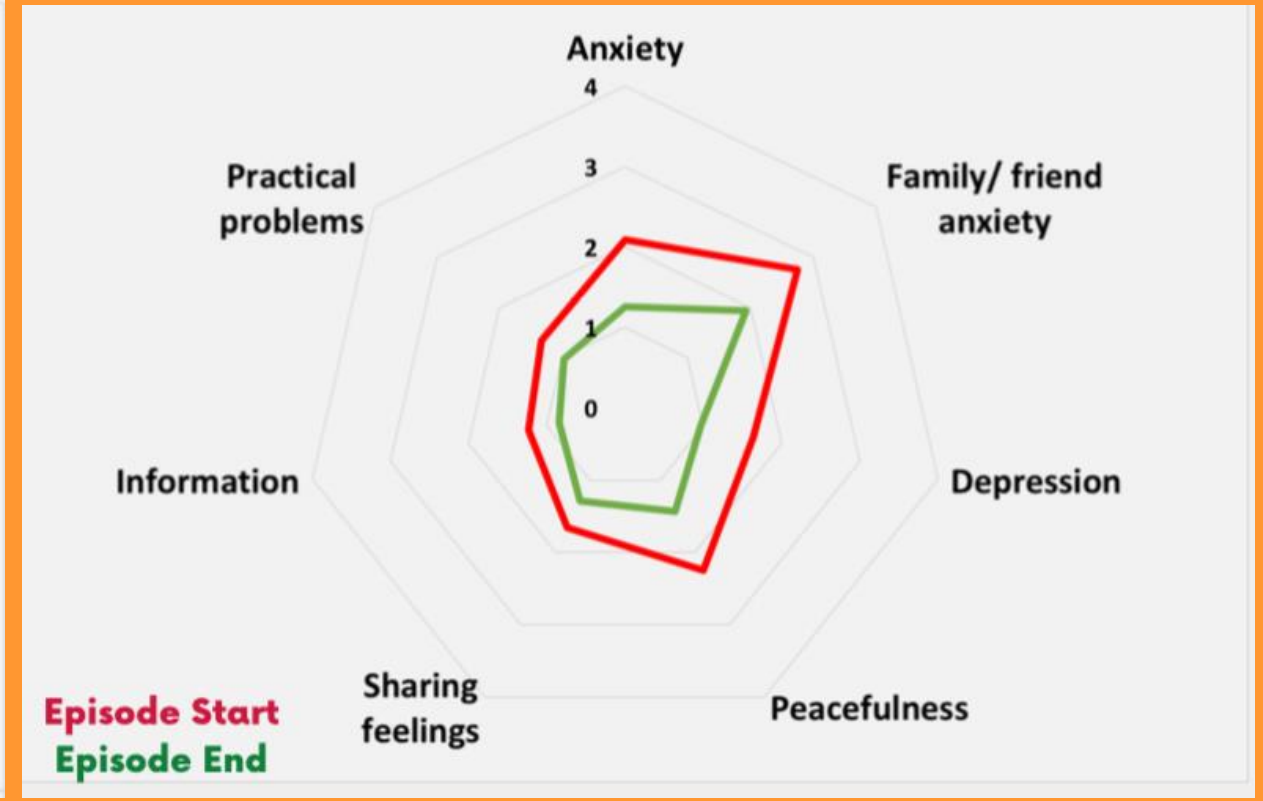
- what is important to you now, and what are your goals for the next days and weeks
- what, if any, physical symptoms are causing you trouble
- how you are feeling and coping with life
- how your family and friends are coping
- what you need to help you to manage your life
- what practical issues you might need some support with
- the needs of those supporting and caring for you.

If you need help to complete the questionnaire, please do not hesitate to ask one of the team. There are no right and wrong answers – its purely how you feel.

We hope that you will be able to see that using the forms can help you to be involved in your care here at St Christopher's.

Inpatient data June 2019- June 2021 (1,264 patients)





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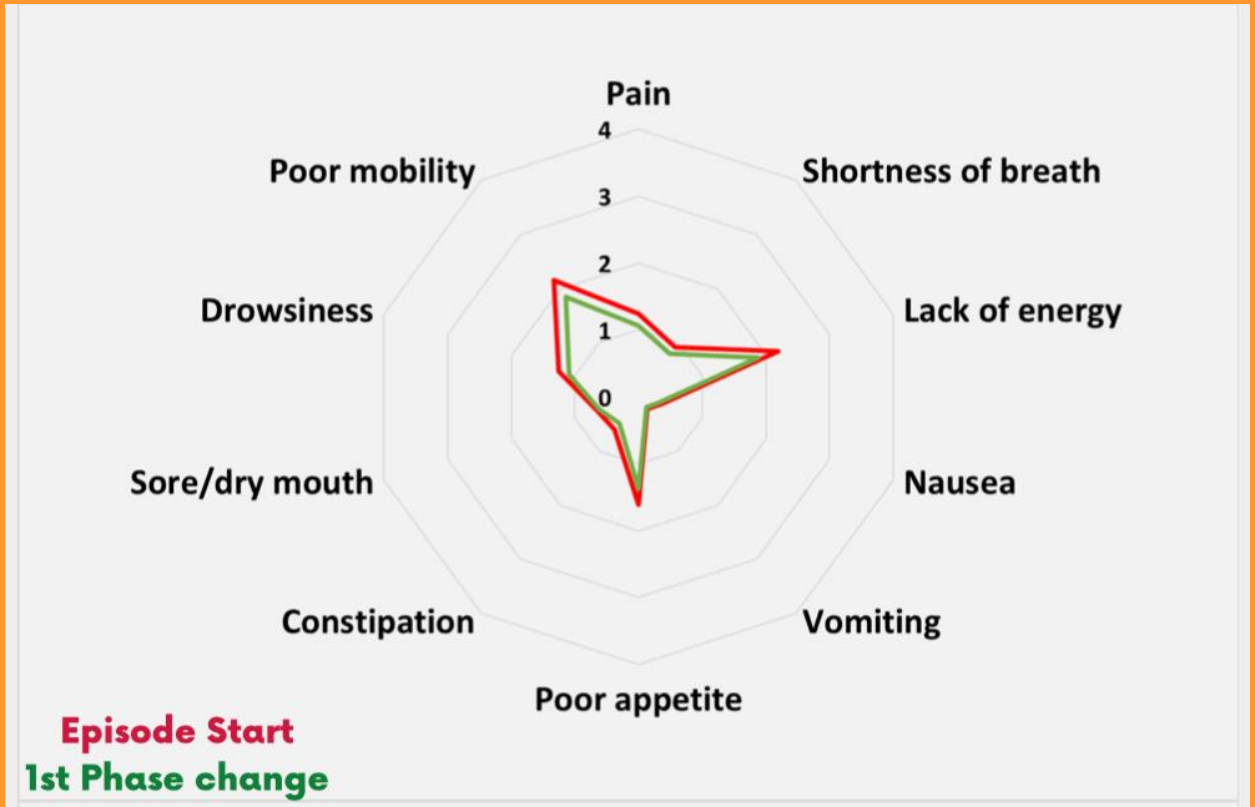
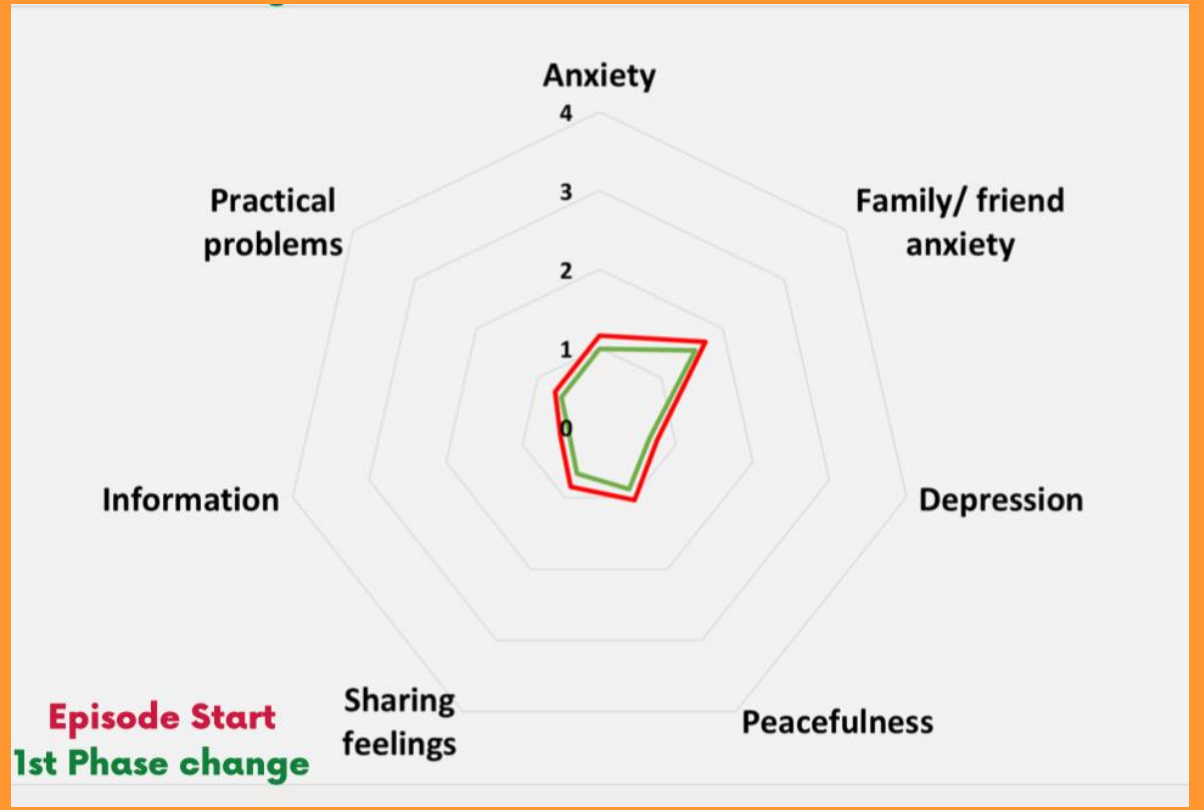
Community patients data June 2019- June 2021 (5,223 patients)





2. We can be clear we add value as a key player in the system

This is important because:

- There are mixed views about whether St Christopher's brings anything more or different to other providers
- We often talk solely in terms of experience / emotional value which policy makers can easily dismiss
- Our local CCGs vary in terms of the degree to which they want to invest in areas of innovation/service development or EOL more generally

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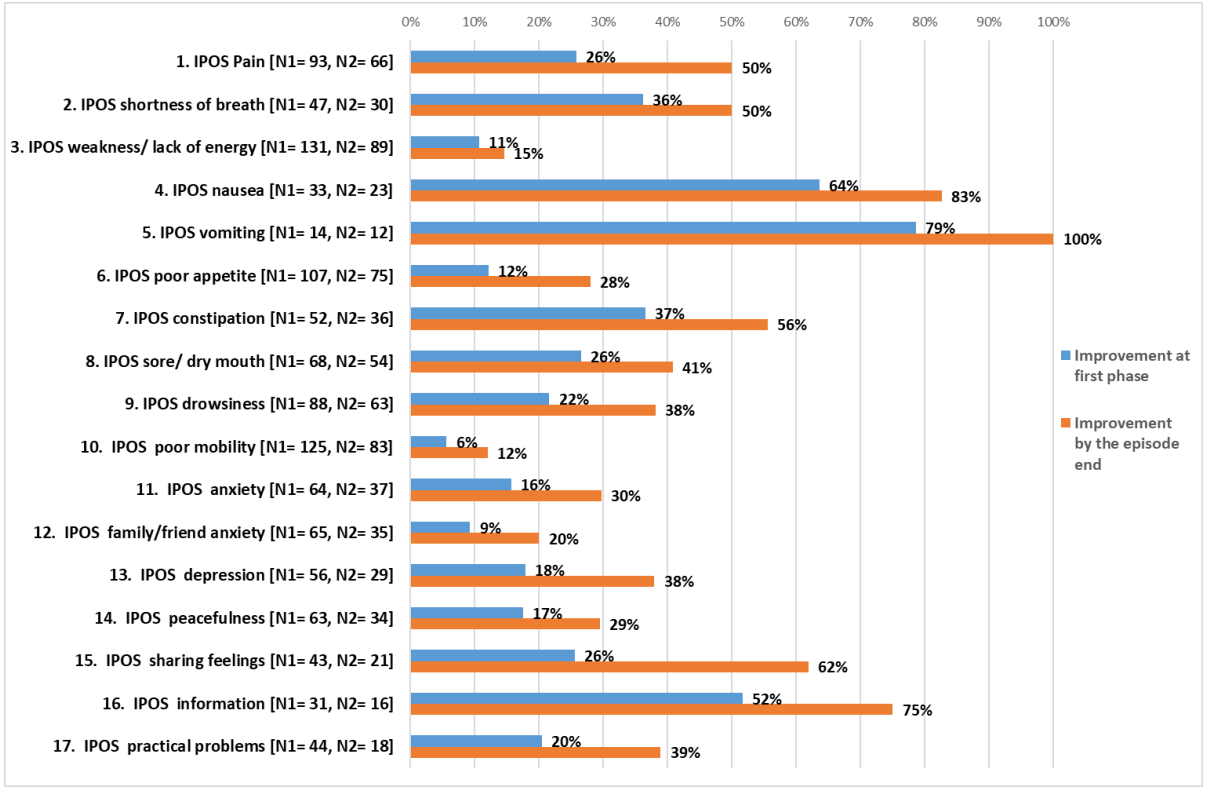
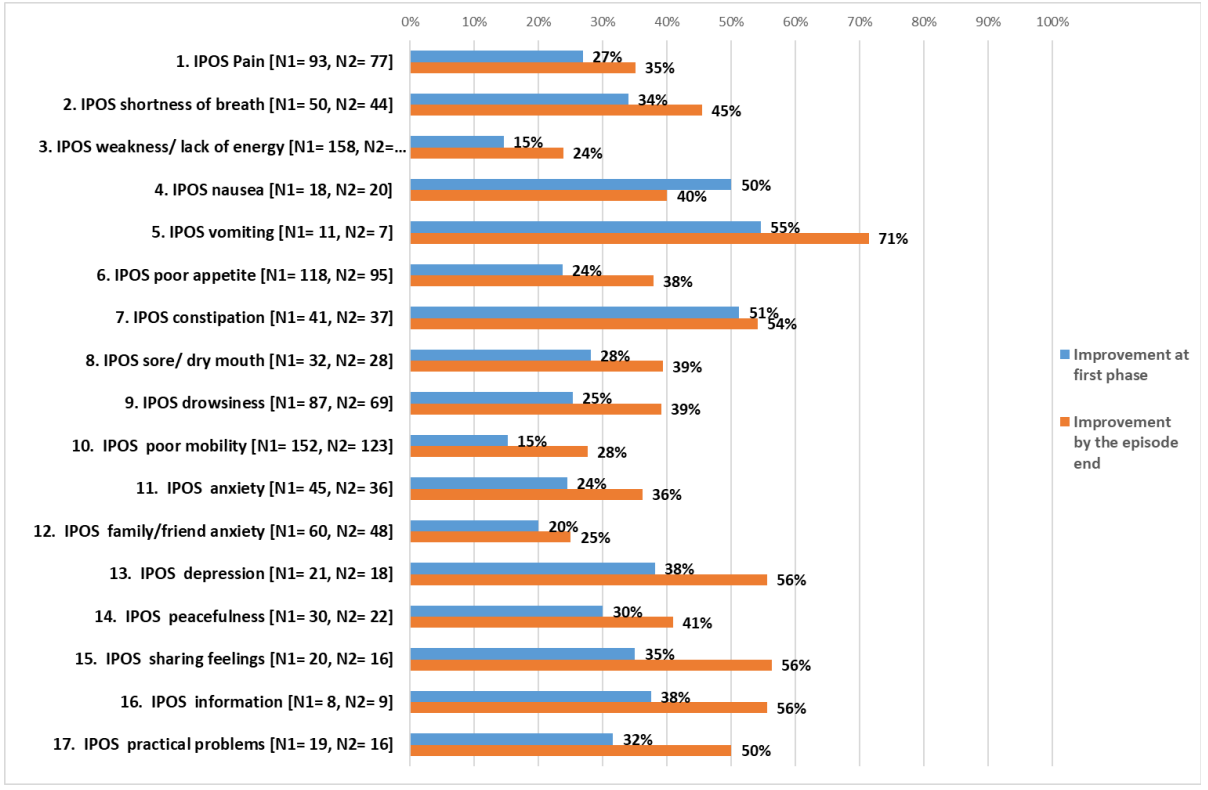
What proportion of moderate/severe/overwhelming symptoms improve with our care? (2019 data)

Inpatient unit

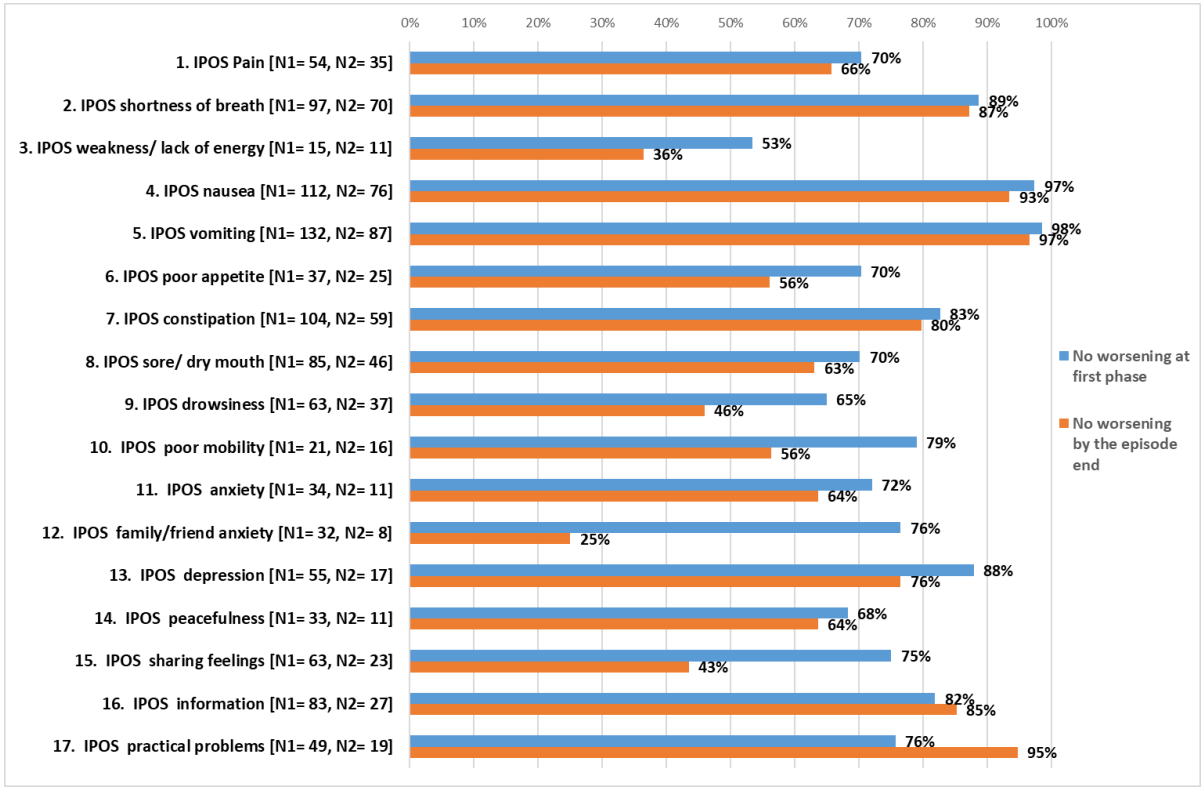


Community



What proportion of absent/mild symptoms do not worsen during our care? (2019 data)

Inpatient unit



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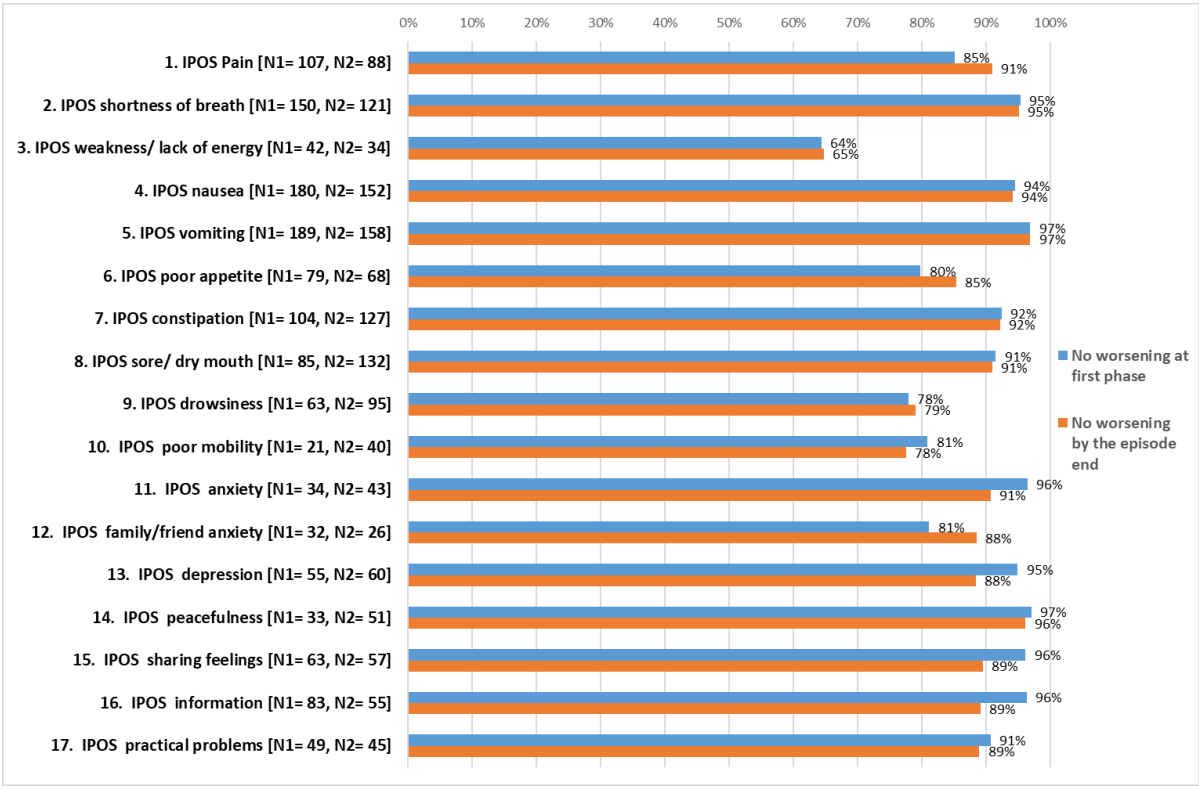


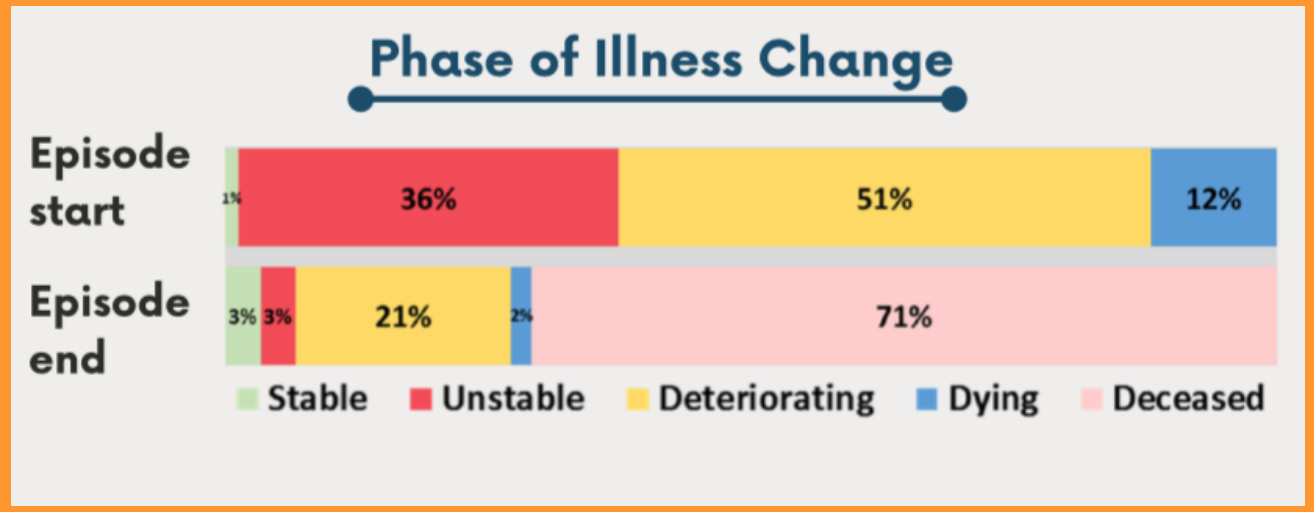
3. It allows us to protect resources where they add particular value eg inpatient unit

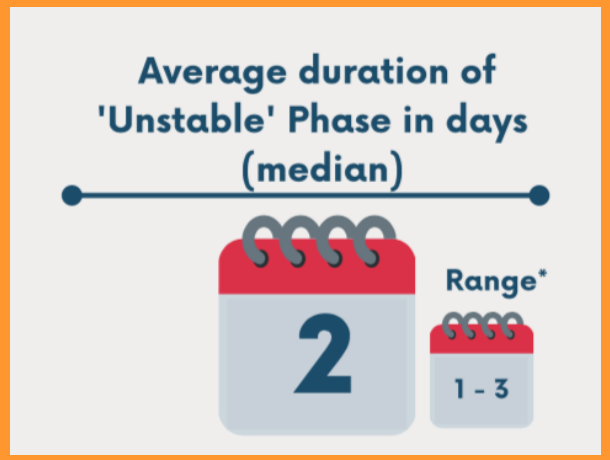
This is important because:

- We are expensive, even by hospice standards
- Our levels of nursing per patient are higher than local NHS providers of care
- We have input by teams that could be deemed unnecessary
- Our length of stay is relatively high
- We are perceived as “choosy” about who is admitted which can be frustrating to local referrers

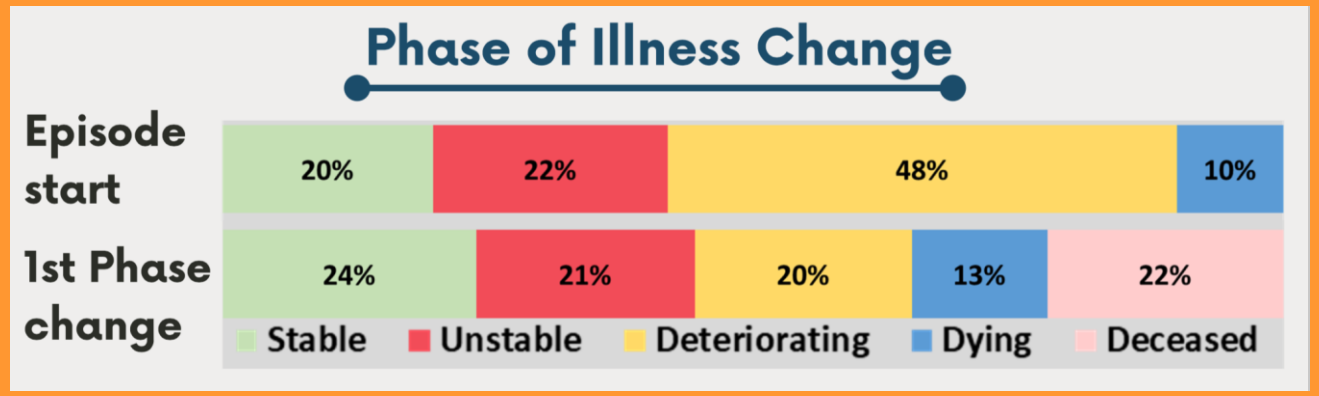
July 2019-June 2021 data (1200 inpatients: 5200 community patients)

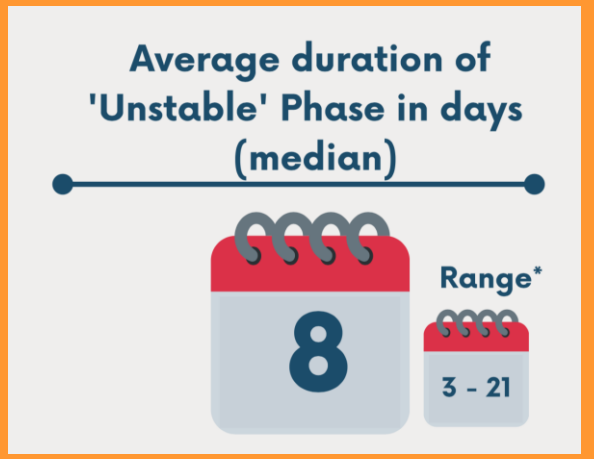
Inpatient data





Community patient data





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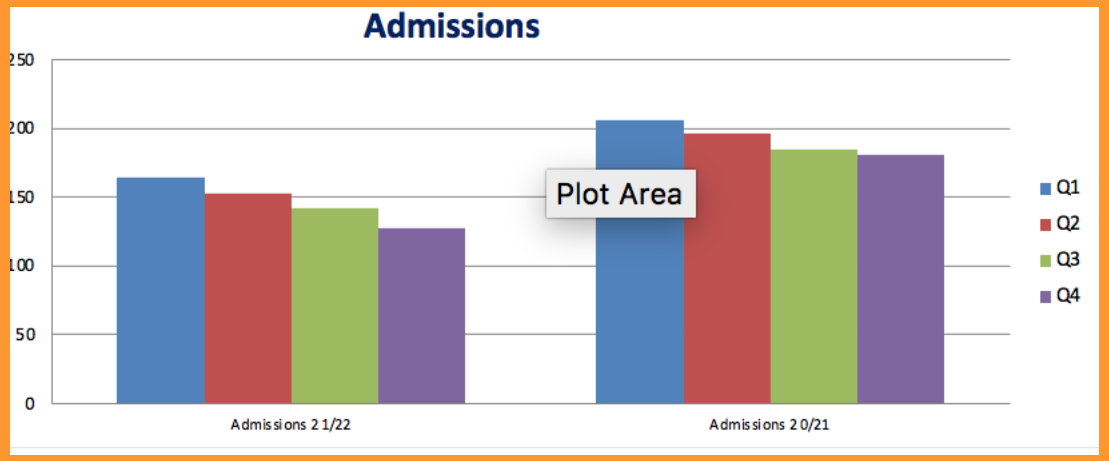
4. We can challenge historical beliefs about where resources should be directed in the future

This is important because:

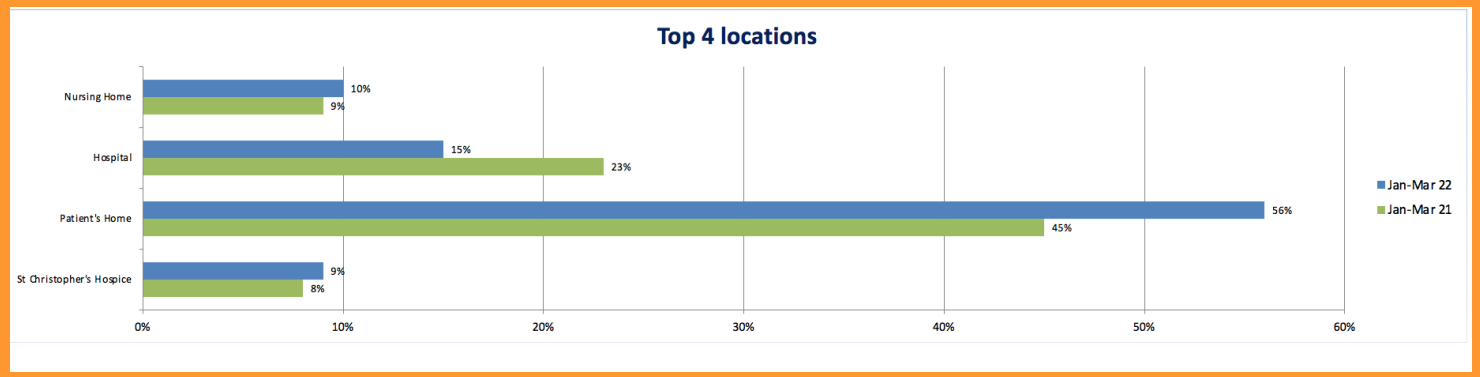
- Our funding is largely based on a historical pattern
- We are at risk of perpetuating historical emphases rather than thinking anew about where we focus our effort
- Our quality can vary across the different services/ contexts of care and some need redress
- Our patient population and their use of our services has changed in the course of the Pandemic

Emerging insights

- Our patient population is changing – age, diagnoses
- Preferences: Fewer people are accessing inpatient services as a proportion of the total patient population
- Role and relationships eg with care homes. Residents have increasingly complex needs and more need specialist input. More of our patients are dying in that setting



Location of deaths of St Christopher's patients



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Emerging insights

- Many of our patients at home and on the inpatient unit have increasingly complex and multiple needs than previously

Inpatient data

at Start of Episode

9 out of 10 patients had moderate, severe, or overwhelming:

- **lack of energy, poor mobility, & family anxiety**

7 out of 10 patients had moderate, severe, or overwhelming:

- **pain, poor appetite, drowsiness, anxiety, & lack of peacefulness**

Community patient data

at Start of Episode

6 out of 10 patients had moderate, severe, or overwhelming:

- **lack of energy, poor mobility, & family anxiety**

4 out of 10 patients had moderate, severe, or overwhelming:

- **pain, poor appetite, drowsiness, & anxiety**

5. Outcomes help commissioners and the hospice think differently about how we might operate in the future

This is important because:

- Causes of death are changing and we are in a position to test and refine new manifestations of palliative care
- Places that people die are shifting and we may want to change the locus of our effort
- People's demands and expectations are changing and we must respond accordingly to achieve "person centred care"

Engagement in a recent winter pressures project

Our starting point:

Frail elderly patients were being admitted to and/or dying in hospital

…likely to increase with onset of Winter and new variants of COVID

Our offer to the system:

Mitigating actions to reduce hospital admissions

Increased understanding of the problem and where might we influence most

Insights into the use of limited resources to meet emerging clinical need

Agreed approach:

Build on learning from previous pilot

Bring together key stakeholders to agree way forward

Agree outcome measures;

Create opportunities to ‘learn and reflect on the job’

Aspirations for the project ….

right care at right time in right place from right professional(s)

- **Care Home patients**
  - Triage (clear individualised ACP and ceiling of treatment)
  - Timely assessment
  - Support to staff in Care Home
  - Communication with families
- **Frail Elderly accessing Emergency Department**
  - Awareness of ACP discussions sharing of goals/wishes
  - Mobilising resources to the meet need of changing clinical picture
  - ‘Turn around time’
- **Proactive Initiatives**
  - SC Fluids
  - IV antibiotics
  - Oxygen
  - Access to medications
  - Huddle meetings
- **Key Clinicians holding risk**
  - Who should they be?
  - Where were they based?
  - How to access them in and out of hours?
  - Joining up the dots ….

Lots of interesting data collected including:

Demographic data:

- Age
- Gender
- Location
- Diagnosis
- Frailty score
- Barthel scale
- Place of death

What happened after referral:

Response time

Interventions including:

- Treatment escalation plans
- Coordinate my care records
- engagement with relatives
- Symptom management
- Advance care planning
- Medication prescriptions
- Sub cut fluids and medications
- Fast track referrals

Case studies of individuals

With attention to:

Outcomes such as comfort, survival of COVID

System benefit eg hospital avoidance

Improved experience of EOL eg dignity

Measured with attention to symptom burden, ability to undertake activities related to daily living, phase of illness and complexity of needs

Final thoughts: Working together could enhance early efforts to use outcomes to influencing policy

- Agreeing key outcomes that we will all measure (and in the same way)
- Sharing our data with each other
- Creating a picture of similarity or difference
- Benchmarking performance and working towards improvement
- Enhancing outcomes for new groups of users

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