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MACMILLAN CANCER SUPPORT

RESOLVE
Resolving Symptoms in Cancer

PCOM360
Clinical User Guide

Resources for Visualising Patient Centred Outcome Measures in Palliative Care

February 2023

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Executive Summary

"Do you want to know if you're really making a difference for your patients?"

"Are you collecting Patient Centred Outcomes data but are struggling on how best to analyse these in a way that enables you to inform and improve your service?"

PCOM360 aims to streamline analysing and displaying Patient Centred Outcome Measures (PCOMs) for all stakeholders in the palliative care space. This guide is to help end users pragmatically display PCOMs to better service delivery and patient care. The guide:

- Explains the high level system barriers to analysing and displaying PCOMs

- Arms front-line clinicians with a library of pragmatic views to help them improve care for people at the end of life through the four main PCOMs:

    o Palliative Phase of Illness (Phase)[1]

    o Australia-modified Karnofsky Performance Scale (AKPS)[2]

    o Modified Barthel Score for Palliative Care (Barthel)[3]

    o Integrated Palliative Care Outcome Scale (IPOS)[4]

Context

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Why have we conducted this work?
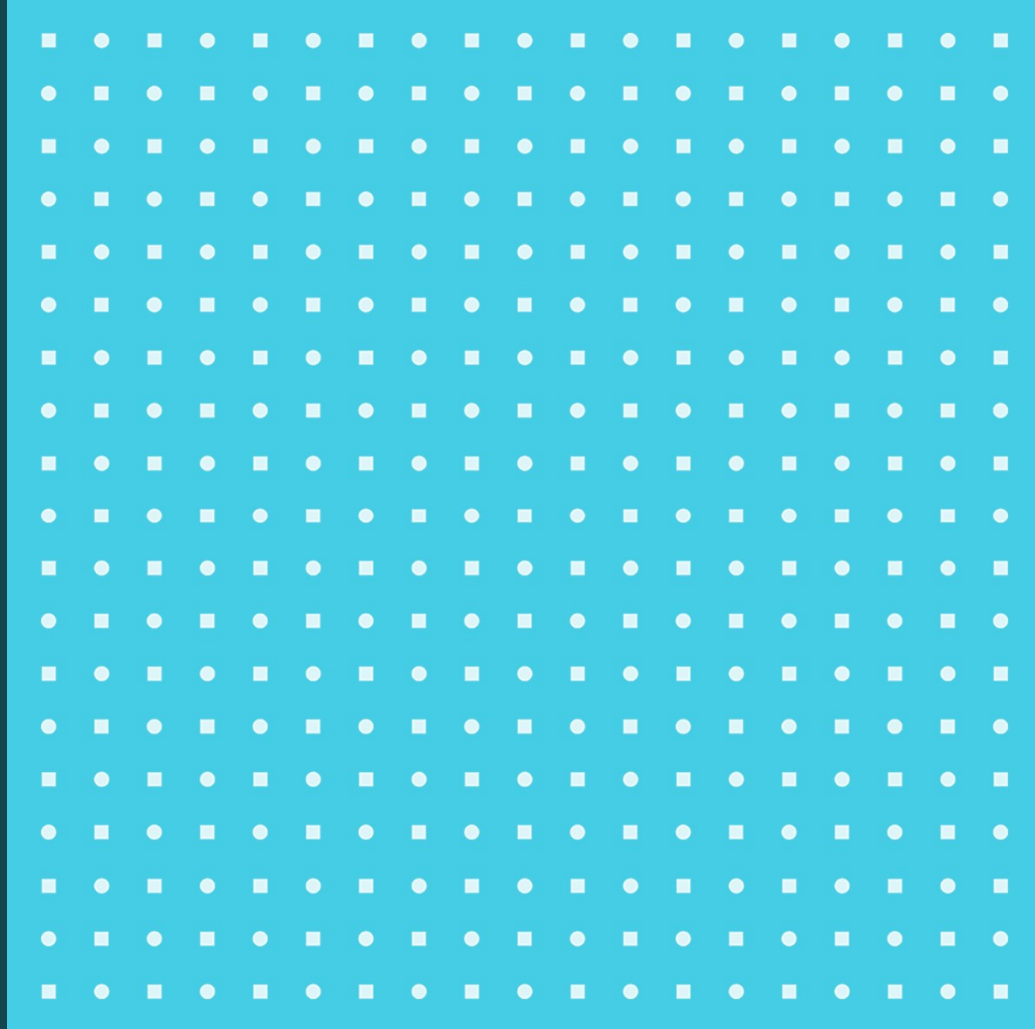
Collecting patient centred data doesn't ensure a service becomes patient centred

Social Finance has been engaged in improving palliative care through social investment since 2015 with over 13,000 people supported through our services to date. Outcomes are central to social investment but recent reflections highlighted that we need to **ensure that Patient Centred Outcomes which monitor quality care are equally embedded** in each investment.

Patient Centred Outcome Measures (PCOMs) have been built into our two most recent investments alongside an outcome metric on acute activity. PCOMs **help health and social care professionals assess and monitor changes in a patient's health and wellbeing across their last year of life**.[1]

However, after a local service has agreed to monitor an outcome measure, we have noticed our different sites face barriers to:

Collecting data	Analysing data	Displaying data	Sharing data

Understanding the different barriers from data capture through to data sharing is key to enable system change

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Notes: 1) The Outcomes Assessment and Complexity Collaborative (OACC) recommend a suite of four key PCOMs for use across different purposes and settings. The accompanying RESOLVE platform, hosted by Hull York Medical School, is a great source of information and training to build PCOMs into palliative care settings and services - Access RESOLVE training resources | Hull York Medical School (hyms.ac.uk)

Barriers were particularly acute when analysing and displaying data

Collecting data	Analysing data	Displaying data	Sharing data
• Conflicting asks for numerous metrics creates a data collection burden on the frontline and with analytical / admin support • Duplicate and overlapping data collection tools span multiple IT systems, adding to the resource burden	• Siloes between different organisations and teams make combining data around the patient journey more complicated • Qualitative data is often excluded from analytical scrutiny above individual case studies	• Visualisations created by analytical teams without clinical input reduces their benefit for the frontline team • Outcome measures typically provide snapshots of a patient's journey rather than a strategic view of change over time • Limited resource to create insightful visuals due to the high resource burden to clean, collect and analyse the data	• Siloes between different organisations prevent data sharing which could provide more insight into the individual patient experience • Anxiety around data sharing restricts strategic learning across organisations nationally

We particularly struggled to create meaningful data visualisations for frontline clinicians to implement change

We have built these resources to help end of life care services analyse and display data

| Collecting data | **Analysing data** | **Displaying data** | Sharing data |

Through our partnership with Hull York Medical School, we have built a suite of open access resources to help all stakeholders working in palliative care services **analyse and display** PCOMs. This specific guide aims to help clinicians pragmatically display PCOMs to improve service delivery and care. It is accompanied by an analytical build guide focusing on how to build each view. The guides should be used in partnership to understand what to analyse and subsequently how it can be built.

To support the use of these resources by all stakeholders across the palliative care space, we have published them open source on the Hospice UK website with a Creative Commons licence, signified by the adjacent logo. This license allows you to share and adapt the tool for your own needs, as long as you follow the terms by giving appropriate credit and not using the material for commercial purposes. Please see the appendix for the full licence.

At this stage we have limited resources on collecting and sharing data. We hope that by sharing these resources we can start to understand different data collection and sharing templates across different health and social care settings. To engage with these resources, we expect the audience to have a good understanding on PCOMs and their use in palliative care services. To learn more about the measures themselves, please visit RESOLVE training resources | Hull York Medical School (hyms.ac.uk).

These resources aim to improve the experience for people in palliative care; patients and staff alike

Overarching views for PCOM360

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Overview of the tool's over-arching structure and features present across all of the views

7
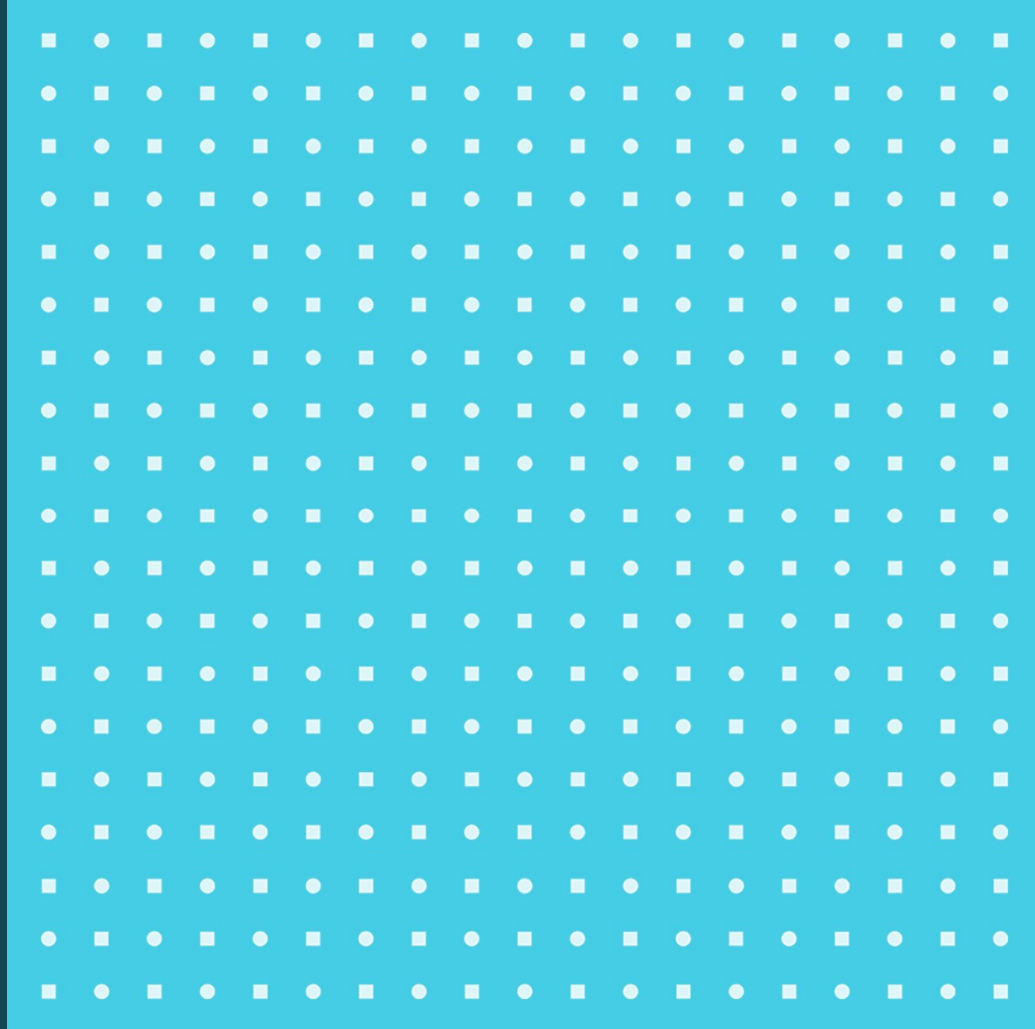
Why have we chosen Power BI?

PowerBI has been chosen to house PCOM360 because of its functionality. It is a fully interactive tool which can be tailored by individual users live; handing the analytical tools to those who know the patient and service best. Power BI is a type of Microsoft software which collates data from multiples sources into visual insights. Power BI desktop is free and Power BI Pro, which offers increased functionality such as sharing interactive dashboards, costs £7.50 a month per license.[1]

We encourage use of its functionality so that you can meaningfully interrogate the data independently, hinged on your own preferences to better inform your insights. The below guide will include screenshots of its functionality including:

- Dark grey call out boxes once you hover over a visual to make data extraction simple.

- Filter and selection boxes to set your own parameters for patient cohorts and even elements of specific PCOMs.

We do know that most are more familiar with screenshots of infographics so the default settings for PCOM360 are built to enable screenshots with key data easily accessible by using the below key principles:
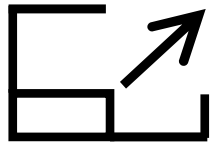
Percentage used as the main view for most of the visuals, with the total number (n = X) clearly framed at the top of the visual or on the relevant sub-section. Any screenshots can thus deduct the numbers involved.

Option to expand any visual by clicking on the icon shown in the top right hand corner of every visual and displayed on the left hand side here.

Power BI enables both analytical interrogation and clear visuals for easy, wider dissemination
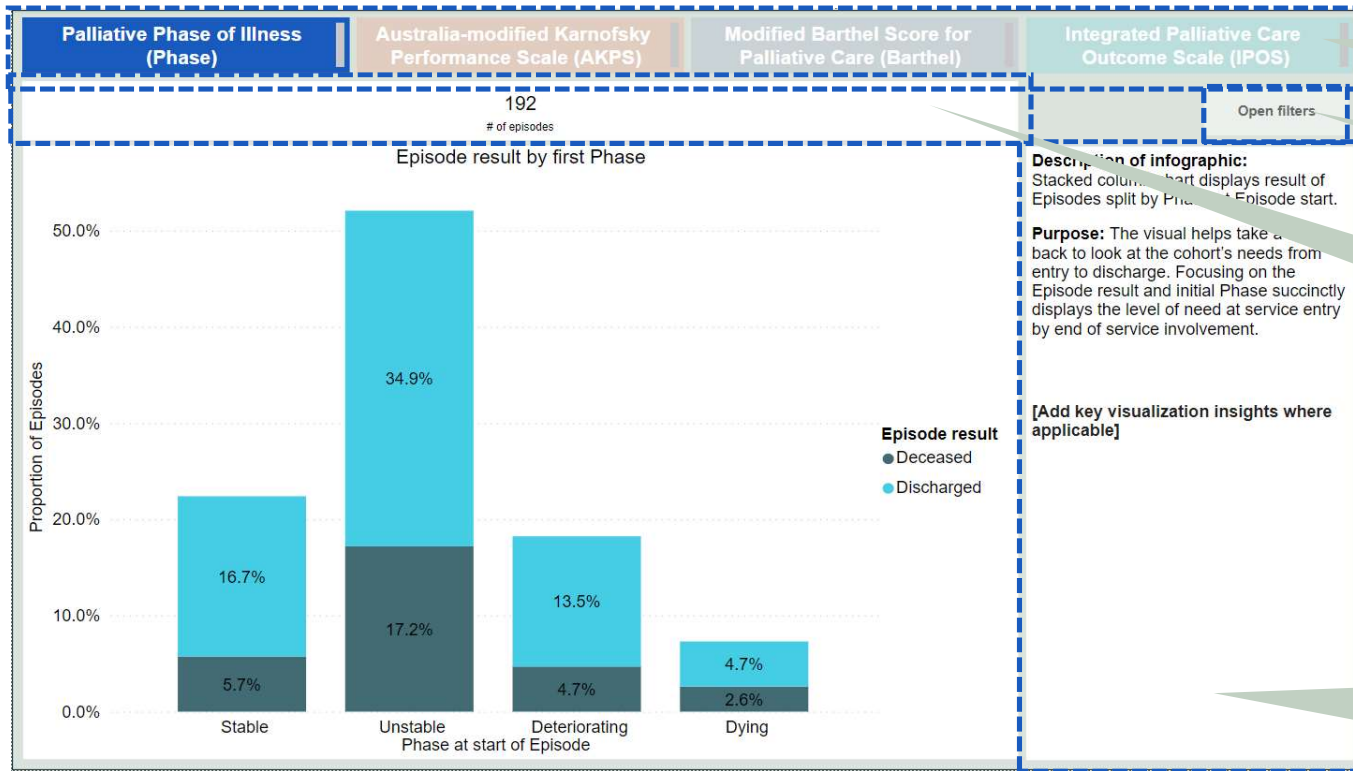
Contents and Navigation Page

Palliative Phase of Illness (Phase)	Australia-modified Karnofsky Performance Scale (AKPS)	Modified Barthel Score for Palliative Care (Barthel)	Integrated Palliative Care Outcome Scale (IPOS)
Cohort analysis			
Phase - 1. Heatmap	AKPS - 1. Heatmap	Barthel - 1. Heatmap	IPOS - 1. Heatmap
Phase - 2. First Phase analysis	AKPS - 2. Patient function <=30% at referral	Barthel - 2. Barthel score across an Episode	IPOS - 2. IPOS scores at start of Episode
Phase - 3. Phase across an Episode	AKPS - 3. AKPS across an Episode	Barthel - 2. Change in Barthel score during Episode	IPOS - 3. Changes over Episode (radar)
Phase - 4. Distribution of Phase length	AKPS - 4. Change in AKPS during Episode	Barthel - 4. Distribution of Barthel score at discharge	IPOS - 4. Any improvement in IPOS score
Phase - 5. Result of Episode by first Phase	AKPS - 5. Patient function <=30% at discharge		IPOS - 5. Significant improvement in IPOS score across Episode
Phase - 6. Journey across an Episode	Combo. AKPS + Phase at referral		Combo. IPOS and Phase across an Episode

PCOM 360
Last Updated 23 February 2023

This navigation tab at the front of the guide provides a succinct overview of each of the views for each PCOM.

The title of each button neatly correlates to a page in this clinical guide for easy cross reference and takes the user to the view in the tool itself.

We would not expect a PCOM360 tool with live data to show all 23 views but instead only show the 3 to 5 most suitable views.

Example of a Typical PCOM360 View (1/2)

| Palliative Phase of Illness (Phase) | Australia-modified Karnofsky Performance Scale (AKPS) | Modified Barthel Score for Palliative Care (Barthel) | Integrated Palliative Care Outcome Scale (IPOS) |

192
# of episodes

Open filters

Episode result by first Phase

Description of infographic:
Stacked column chart displays result of Episodes split by Phase at Episode start.

Purpose: The visual helps take a back to look at the cohort's needs from entry to discharge. Focusing on the Episode result and initial Phase succinctly displays the level of need at service entry by end of service involvement.

[Add key visualization insights where applicable]

Proportion of Episodes:
- 50.0%
- 40.0%
- 30.0%
- 20.0%
- 10.0%
- 0.0%

Stable: 16.7% / 5.7%
Unstable: 34.9% / 17.2%
Deteriorating: 13.5% / 4.7%
Dying: 4.7% / 2.6%

Phase at start of Episode

Episode result
- Deceased
- Discharged

Key on each page to indicate which Patient Centred Outcome Measure is featured on each page.

Button to access all filters. See the next page for an example of this view.

All views include a clear reference to the total number of the data points in the infographic. This ensures that all screenshots can be deduced to their underlying numbers.

Space for a box to explain the infographic depending on the complexity of the visual or for you to pull out clear insights on the actual data.

Example of a Typical PCOM360 View (2/2)
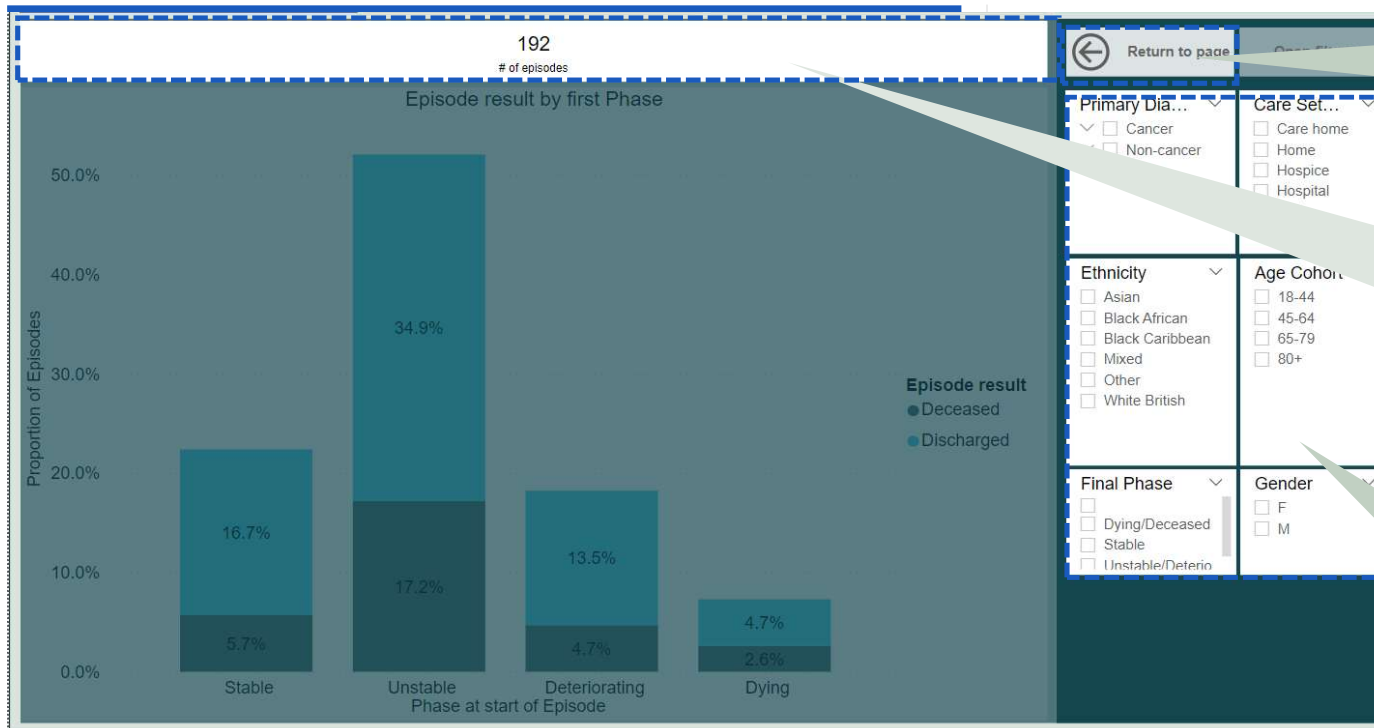
Button to return the user to the main view once they have selected the filter aspects they want to see.

All views include a clear reference to the total number of the data points in the infographic. This ensures that all screenshots can be deduced to their underlying numbers. This remains in the filter view to enable transparency re the numbers for any filter.

Set filters for each visualisation. These core filters can be adapted based on your specific service / local area's needs.

Cohort Analysis
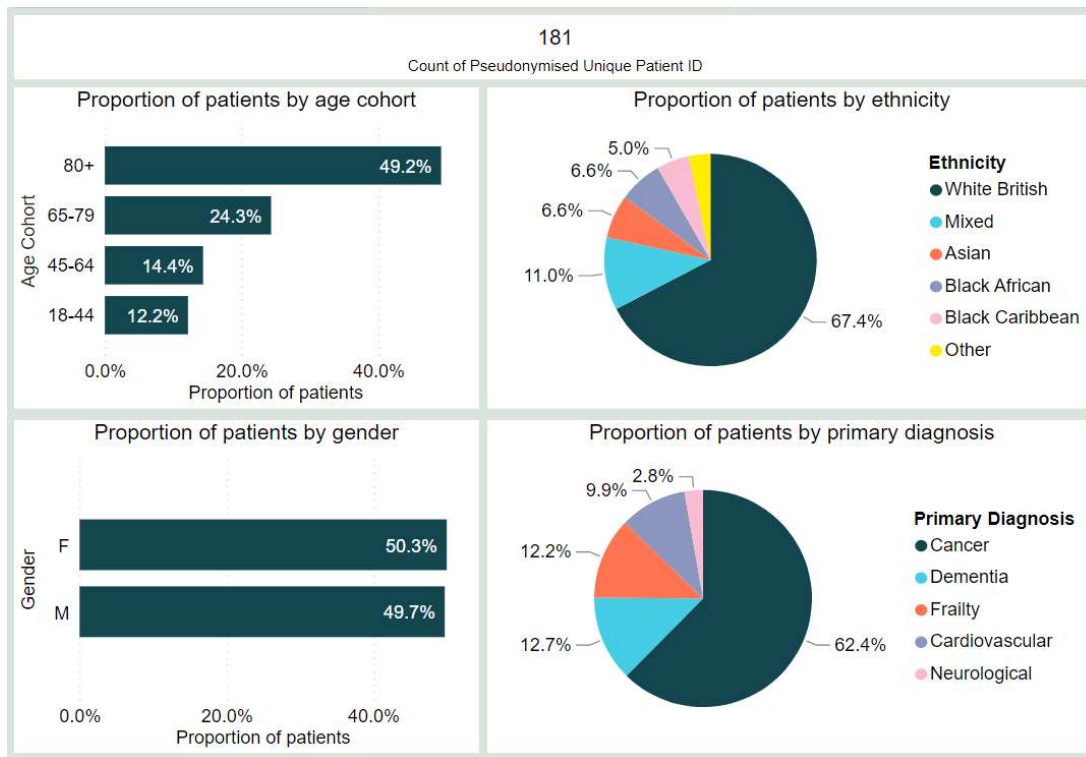
- • **Description of infographics (clockwise from top left hand corner to bottom left hand corner):**
  - ➢ Proportion of patients across four age cohorts are shown in a bar chart in the top left hand corner.
  - ➢ Proportion of patients by ethnicity are shown in a pie chart in the top right hand corner.
  - ➢ Proportion of patients by gender are shown in a bar chart in the bottom left hand corner.
  - ➢ Proportion of patients by primary diagnosis are shown in a pie chart in the bottom right hand corner.
- • **Purpose:**
  - ➢ The four infographics on this page enable clear understanding of the demographics of the cohort.
  - ➢ This is an essential view to ensure that any subsequent analysis is informed by how accurately the patients accessing the service reflect the demographics of the local community.
- • **Information to note:** Each of these demographic filters (age cohort, ethnicity, gender and primary diagnosis) can also be applied to each individual visual to interrogate differences in outcomes across different demographics as shown on page 11.

Palliative Phase of Illness

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- Measure Overview
- Views of Phase are:
  1. Phase – 1. Heatmap
  2. Phase – 2. First Phase analysis
  3. Phase – 3. Phase across an Episode
  4. Phase – 4. Distribution of Phase length
  5. Phase – 5. Result of Episode by first Phase
  6. Phase – 6. Journey across an Episode

Palliative Phase of Illness

Definition: Palliative Phase of Illness (Phase) is a measure which describes the urgency and complexity of care needs for a person receiving palliative care. It considers the care needs of both patient and family.

At the start of a contact, a "Phase" is derived and linked to a patient. There are five possible phases: Stable, Unstable, Deteriorating, Dying and Deceased. The first four Phases can occur in any order and a patient may move through a Phase multiple times, or not at all. A Phase can last any length of time.

Data Collection: To monitor changes in Phase, you need to assess Phase at two or more points within one Episode of care. In this guide, we define Episode of care as the time period between first and last assessment. If multiple assessments are made, then there could be multiple Phases in one Episode. You can define what an Episode of care is for your service e.g. whole service period, whole time the patient is in one element of your service such as day care etc. The key variables to review are; Phase, length of Phase (start date / time; end date / time) and care setting.

Purpose(s) of a dashboard: A Phase dashboard is useful across a multitude of care settings, hence why we offer multiple views in this guide suited for different settings and services. Not all of the dashboard views offer a Deceased view as it's not relevant for all palliative care services and can be added as and when required (e.g. for specific bereavement services).

**Views:** There are six views in the Phase section:

- Phase – 1. Heatmap
- Phase – 2. First Phase analysis
- Phase – 3. Phase across an Episode
- Phase – 4. Distribution of Phase length
- Phase – 5. Result of Episode by first Phase
- Phase – 6. Journey across an Episode

Phase - 1. Heatmap

199
# of episodes

First Phase	Second Phase	Final Phase
3.5%	8.5%	6.5%
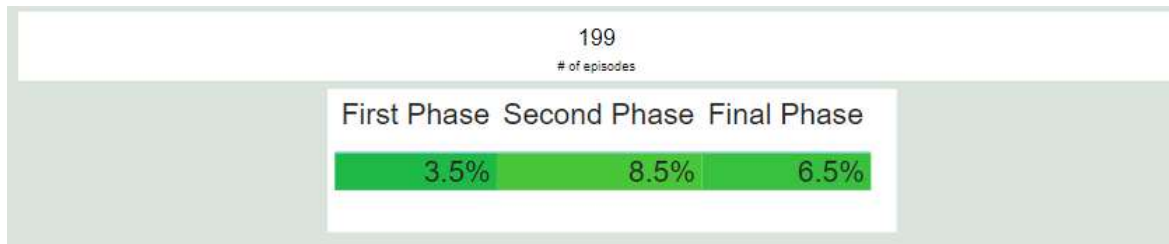
- **Description of infographic:** Table displays the proportion of missing Phase of Illness records across an Episode. The cells are colour coded with a gradient to show values as green when a low proportion of episodes have a missing score and red when a high proportion of episodes have a missing score.

- **Purpose:** To clearly highlight any limitations to the subsequent analysis and infographics for Phase.

- **Example:** A dark green box with 6.0% states that 6.0% of scores are missing.

Phase - 2. First Phase analysis
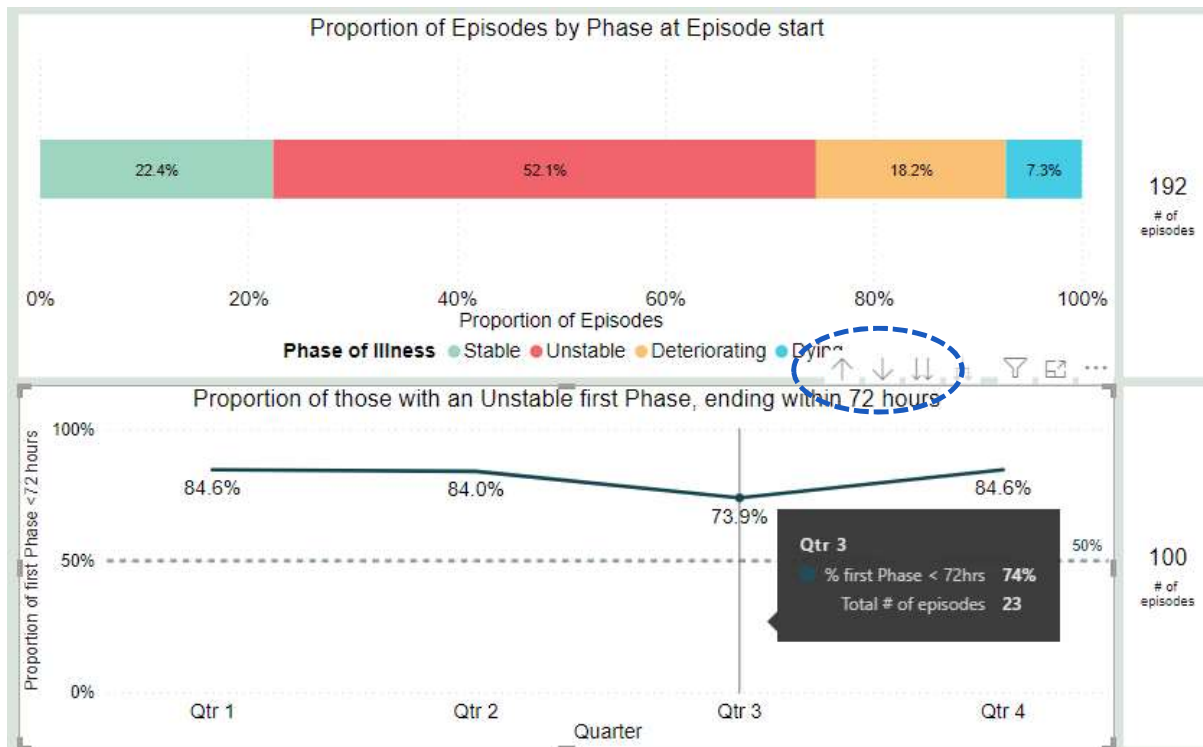
Proportion of Episodes by Phase at Episode start (top visual):
- **Description of infographic:** Stacked bar chart displays the proportion of Episodes by Phase at Episode start
- **Purpose:** A varied case mix by Phases at Episode start demonstrates differing level of needs and priorities for a service cohort.

Proportion of Episodes starting with an Unstable Phase that end within 72 hours (bottom visual):
- **Description of infographic:** Line graph displays the percentage of Unstable first Phases ending within 72 hours. The blue dashed line is a hypothetical target measure that 50% of those with an Unstable first Phase move out of that Phase within 72 hours.
- **Purpose:** A service's ability to move patents out the Unstable Phase within a specific time period.
- **Information to note:** The target can be altered based on the purpose and aim of the different services. The arrows circled in the top right hand corner also enable you to pick different time frames (month, quarter and year).

Information to note on both visuals: These infographics are shown together as clinical focus would be on patients with an Unstable first Phase. The second infographic demonstrates the impact of an intervention.

Phase - 3. Phase across an Episode
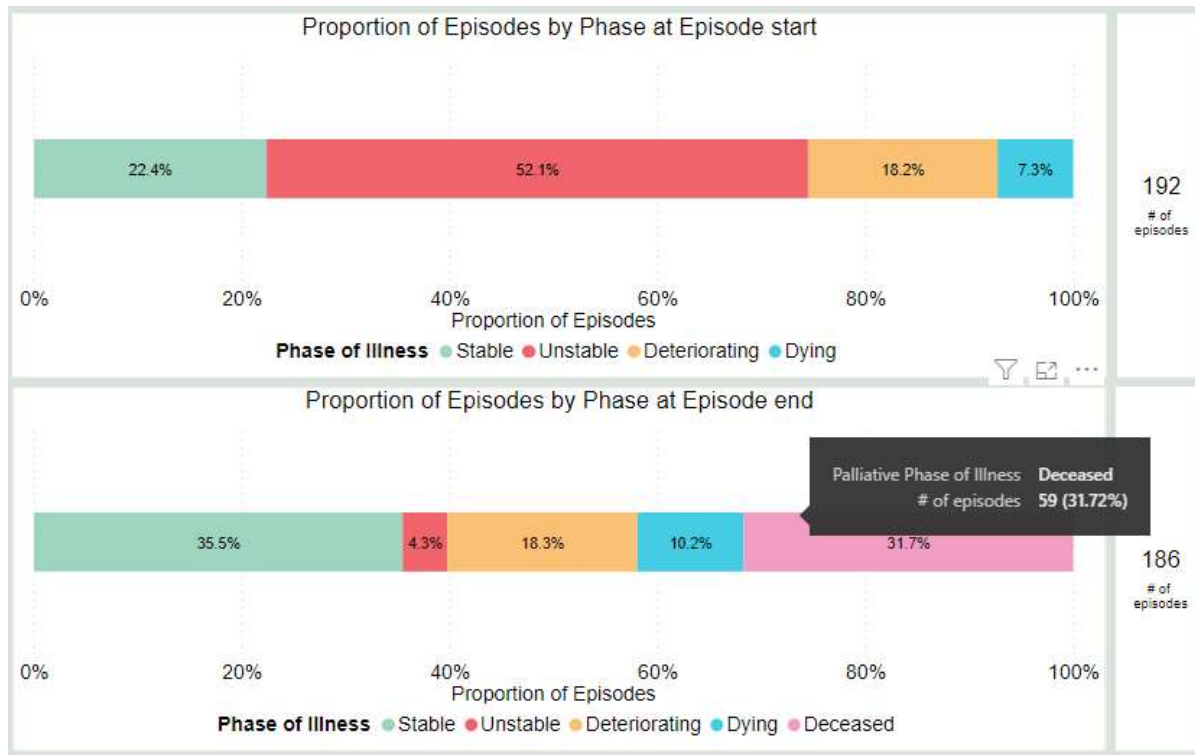
Proportion of Episodes by Phase at Episode start (top visual):

- **Description of infographic:** Stacked bar chart displays the proportion of Episodes by Phase at Episode start.
- **Purpose:** A varied case mix by Phases at Episode start demonstrates differing level of needs and priorities for a service cohort.
- **Information to note:** Note this is a duplicate of the view on "2. First Phase analysis".

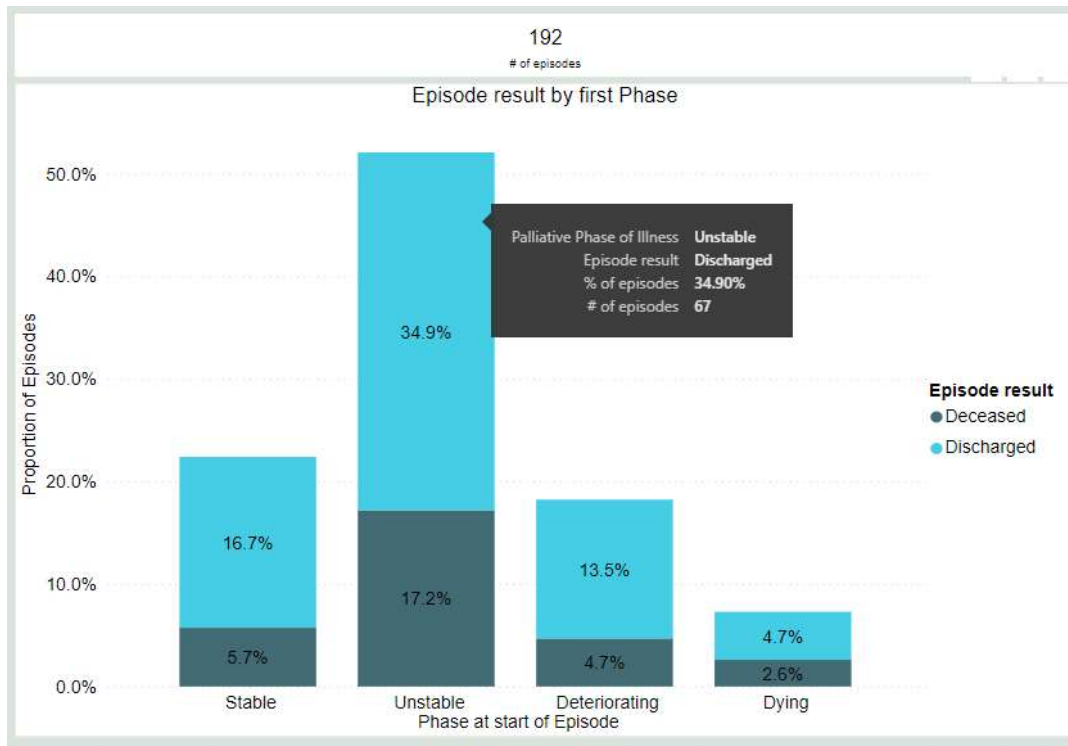**Proportion of Episodes by Phase at Episode end (bottom visual):**

- **Description of infographic:** Stacked bar chart displays the proportion of Episodes by Phase at Episode end.
- **Purpose:** Aim to reduce the proportion of patients who are Unstable by Episode end.

Information to note on both visuals: These infographics are shown together to demonstrate impact of an intervention; ideally in reducing the proportion of the caseload who are Unstable at Episode end.

Phase - 4. Distribution of Phase length
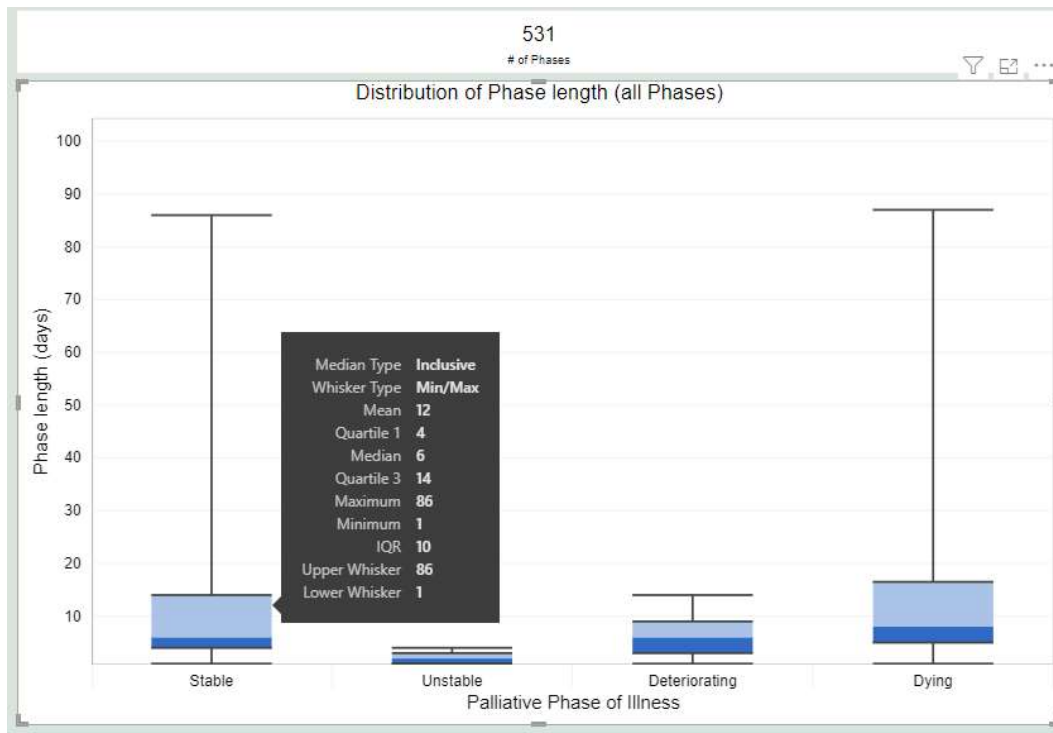
- • **Description of infographic (also on the dashboard):**
  - ➢ A box and whisker plot displays the distribution of Phase lengths by Phase of Illness. The plot summarises information about the lengths of different Phases, split out into the four types of Phase: Deteriorating, Dying, Stable and Unstable.
  - ➢ The capped vertical lines show the minimum (lower) and maximum (upper) Phase length.
  - ➢ The grey boxes in the middle show the second and third quartile of Phase lengths. The grey boxes show distribution of 50% of the Phase lengths. With all phases ordered by Phase length, these boxes show the Phases that sit between 25% and 75% in this ordered sequence i.e. only 25% of the Phases have lengths between the top of the upper box and the maximum.
- • **Purpose:** Distribution is most useful for services in acute settings. Services in community settings would have far longer episodes so the view may need to focus on the Interquartile range specifically.
- • **Information to note:** Distribution highlights the range of Phase lengths. The view could be simplified to focus on the Inter Quartile Range for relevant settings.

Context | View | **Phase** | AKPS | Barthel | IPOS | Licence

Phase – 5. Result of Episode by first Phase

- **Description of infographic:** Stacked column chart displays result of Episodes split by Phase at Episode start.

- **Purpose:** The visual helps take a step back to look at the cohort's needs from entry to discharge. Focusing on the Episode result and initial Phase succinctly displays the level of need at service entry by end of service involvement.

- **Information to note:**
  - ➢ Currently only shows Deceased and Discharged as Episode results. Depending on local definitions, there may be other options for Episode result beyond Deceased and Discharged.
  - ➢ This infographic shows quantitative figures over time and the time period (day, week, month, quarter) can be adjusted to suit the service model.

Phase – 6. Journey across an Episode
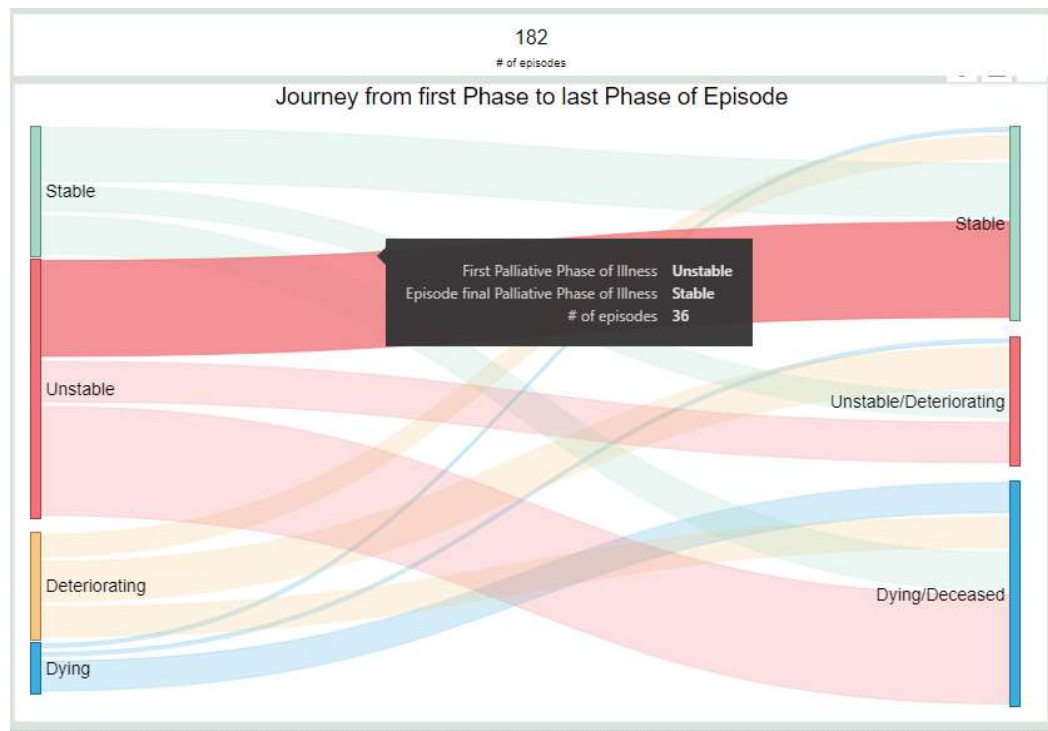
- **Description of infographic:** Sankey diagram displays transitions of patients from starting to final Phase over an Episode.

- **Purpose:** Comparing first and last Phase displays the full transitions of patients over time.

- **Information to note:**
  - Comparing first and last Phase is useful for services as it highlights the overall shift over time whilst each and every Phase would be too complex a view.
  - This focuses on outcomes from the whole Episode rather than variable activity throughout the Episode.
  - The Sankey helps align focus on individual patient journeys as well as at a cohort level. Focusing on the start and end point of a patient journey helps pull out the overall impact of interventions.

Australia-modified Karnofsky Performance Scale

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- Measure Overview
- Views of AKPS are:
  1. AKPS – 1. Heatmap
  2. AKPS – 2. Patient function < = 30% at referral
  3. AKPS – 3. AKPS across an Episode
  4. AKPS – 4. Change in AKPS during Episode
  5. AKPS – 5. Patient function < = 30% at discharge
  6. COMBO – AKPS and Phase at referral

Australia-modified Karnofsky Performance Scale

Definition: Australia-modified Karnofsky Performance Scale (AKPS) is a measure of the patient's functional status or ability to perform their activities of daily life. It is based on the patient's ability to perform common tasks relating to activity, work and self-care.

Low numbers indicate a reduced functional status. For example, 100% represents full physical function and 0% represents when the patient has died.

Data Collection: AKPS is scored by staff and consists of just one item. It should be measured at least at first assessment and at the end of Episode of care (including discharge or death). In this guide, we define Episode of care as the time period between first and last assessment. You can define what an Episode of care is for your service e.g. whole service period, whole time the patient is in one element of your service such as day care etc.

Purpose(s) of a dashboard: An AKPS dashboard is useful to measure functionality across an Episode, compared to other PCOMs, it is less likely that a patient will score a higher AKPS at point of discharge or death as deterioration in functionality is expected at the end of life.

**Views:** There are six views in the AKPS section:
- AKPS – 1. Heatmap
- AKPS – 2. Patient function < = 30% at referral
- AKPS – 3. AKPS across an Episode
- AKPS – 4. Change in AKPS during Episode
- AKPS – 5. Patient function < = 30% at discharge
- COMBO – AKPS and Phase at referral

AKPS - 1. Heatmap

199
# of episodes

First assessment	Second assessment	Episode end
10.1%	6.0%	1.5%

- **Description of infographic:** Table displays the proportion of missing AKPS records across an Episode. The cells are colour coded with a gradient to show values as green when a low proportion of episodes have a missing score and red when a high proportion of episodes have a missing score.

- **Purpose:** To clearly highlight any limitations to the subsequent analysis and infographics for AKPS.

- **Example:** A dark green box with 6.0% states that 6.0% of scores are missing.

AKPS - 2. Patient function <= 30% at referral
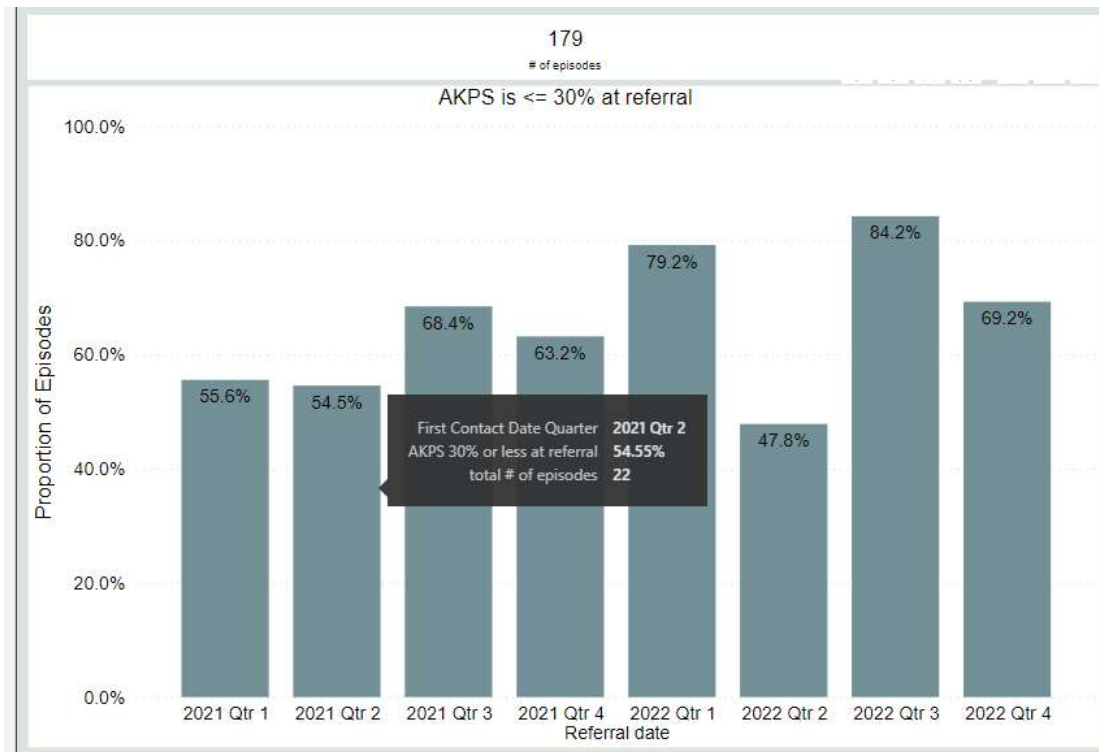
- **Description of infographic:** Column chart displays the proportion of patients joining the service with low AKPS scores (defined as 30% or less) over time.

- **Purpose:** To understand the needs of patients accepted onto the service with poor performance status.

- **Information to note:**
  - ➢ Highlights the care needs for referred patients as those with a 30% or lower performance status will have low function and therefore higher care needs.
  - ➢ A useful view across a cohort for though the volume of referrals may fluctuate, the service may still have high demand if more patients have lower performance status.

AKPS - 3. AKPS across an Episode
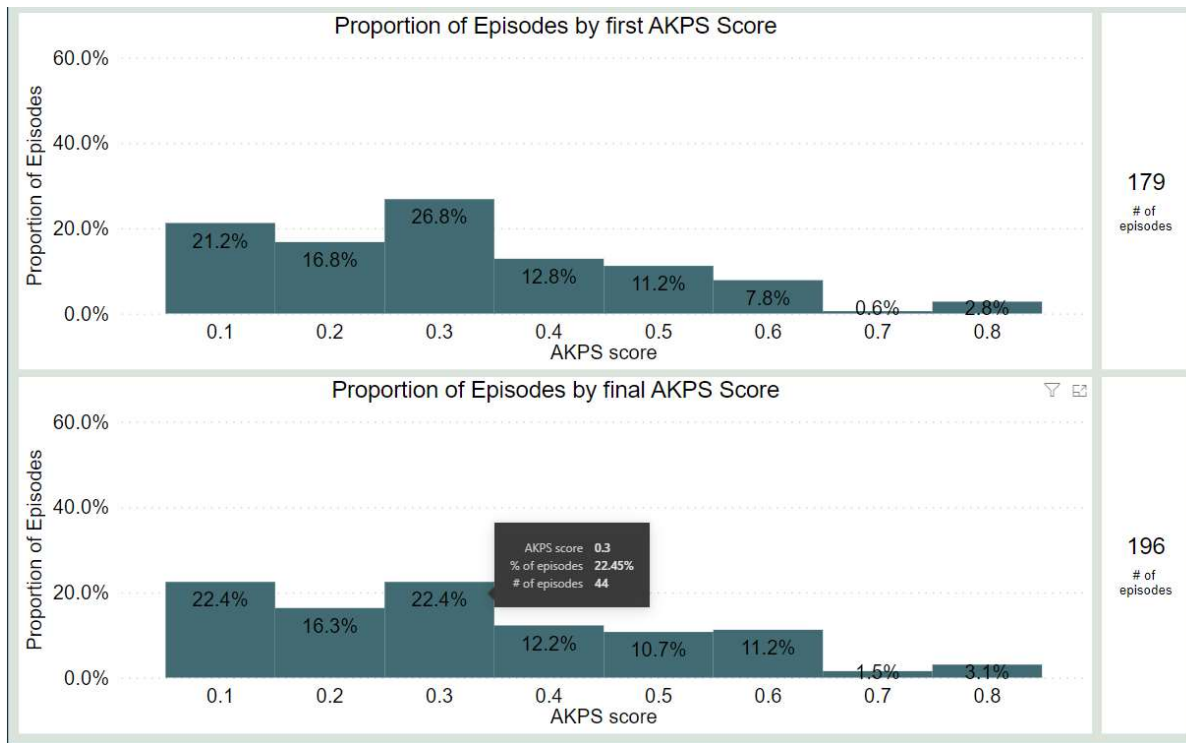
Proportion of Episodes by first AKPS Score (top visual):
- **Description of infographic:** Column chart displays the proportion of Episodes by first AKPS Score.
- **Purpose:** A varied case mix by AKPS at Episode start demonstrates differing levels of functional ability for a service cohort.

Proportion of Episodes by final AKPS Score (bottom visual):
- **Description of infographic:** Column chart displays the proportion of Episodes by final AKPS Score.
- **Purpose:** Reviewing functionality at discharge helps understand the ongoing care needs for the cohort.

Information to note on both visuals: These infographics are shown together to demonstrate the change in functionality of the patient cohort by the end of the intervention. A view of final AKPS score is more suitable for a service which is focused on discharge rather than a service where most patients are deceased at service end.

AKPS - 4. Change in AKPS during Episode

- **Description of infographic:** Stacked bar chart displays change in AKPS score from start to end of Episode. The bars are colour coded with a gradient to show values as green for when functionality has improved and red when functionality has reduced.

- **Purpose:** To show how performance status of patients shifts across the Episode.

- **Information to note:** A view of change in AKPS score is more suitable for a service which is focused on discharge rather than a service where most patients are deceased at service end.

AKPS - 5. Patient function <= 30% at discharge
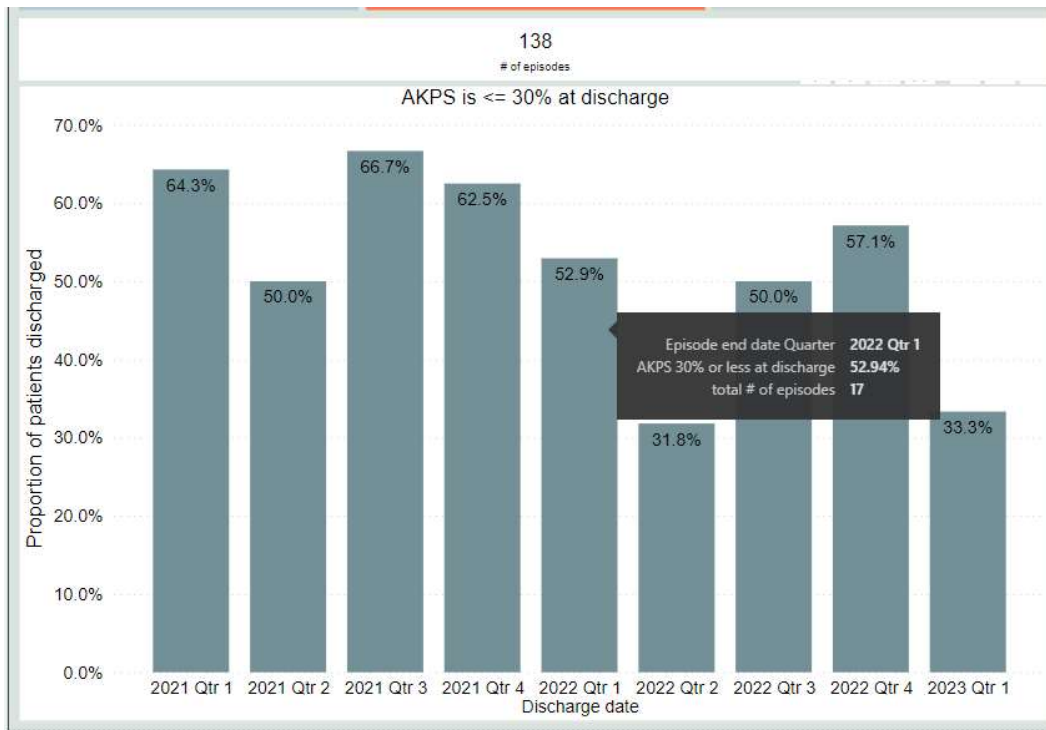
- **Description of infographic:** Column chart displays the proportion of patients leaving the service with low AKPS scores (defined as 30% or less) over time.

- **Purpose:** To understand the ongoing needs of patients discharged from the service with poor performance status.

- **Information to note:** This is only relevant for specific services where patients are not expected to die in the service and where they are referred onto other services.

Combo - AKPS + Phase at referral
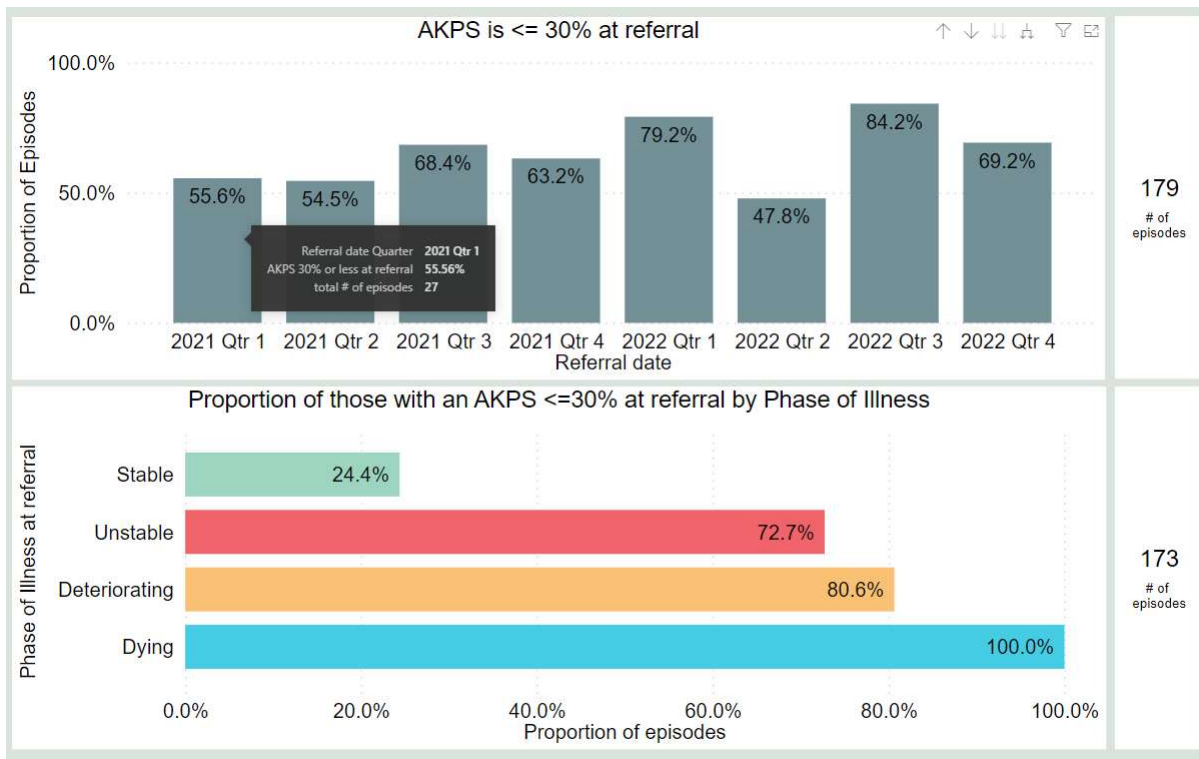
Proportion of patients with low AKPS scores over time (top visual):
- **Description of infographic:** Column chart displays the proportion of patients joining the service with low AKPS scores (defined as 30% or less) over time.
- **Purpose:** To understand the needs of patients accepted onto the service with poor performance status.
- **Information to note:** Note this is a duplicate of the view on "AKPS 2. Patient function <=30% at referral".

Bar chart displays the proportion of patients with low AKPS scores (bottom visual):
- **Description of infographic:** Stacked bar chart displays the proportion of patients, by their initial Phase of Illness, who also had low AKPS scores at Episode start.
- **Purpose:** To understand the correlation of need displayed by a low AKPS Score and Phase of Illness.

Information to note on both visuals: These two visuals help understand how functionality and Phase may interlink to display a patient's need at start of Episode.

Modified Barthel Score for Palliative Care

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- Measure Overview
- Views of Barthel are:
  1. Barthel – 1. Heatmap
  2. Barthel – 2. Barthel score across an Episode
  3. Barthel – 3. Change in Barthel during Episode
  4. Barthel – 4. Distribution of Barthel score at discharge

Modified Barthel Score for Palliative Care

Definition: The Modified Barthel score for Palliative Care (Barthel) is a measure of the patient's ability to perform ten common activities of daily living. There are different versions of the measure, but here we are referring to the modified Barthel short form, including: bowel function, bladder function, grooming, toilet use, feeding, transferring between bed and chair, mobility, dressing, use of stairs, and bathing. The highest score of 20 indicates complete independence and the lowest score of 0 indicates full dependency of the patient on others.

Data Collection: The scores are initially assigned by a health care professional during or following observation of a patient's ability to undertake the tasks. They can also be assigned during or following discussion with the patient and / or patient's family or carer if face to face assessment is not possible. It should be collected at or near referral, at relevant intervals throughout the Episode and at Episode end. In this guide, we define Episode of care as the time period between first and last assessment. You can define what an Episode of care is for your service e.g. whole service period, whole time the patient is in one element of your service such as day care etc.

Purpose(s) of a dashboard: A Barthel dashboard is particularly helpful to understand how a patient's dependency is changing over time and how that may affect their care needs and subsequent discharge planning.

**Views:** There are four views in the Barthel section:

- Barthel – 1. Heatmap
- Barthel – 2. Barthel score across an Episode
- Barthel – 3. Change in Barthel during Episode
- Barthel – 4. Distribution of Barthel score at discharge

Barthel - 1. Heatmap

	199	
	# of episodes	
First assessment	Second assessment	End of episode
8.0%	10.6%	2.5%
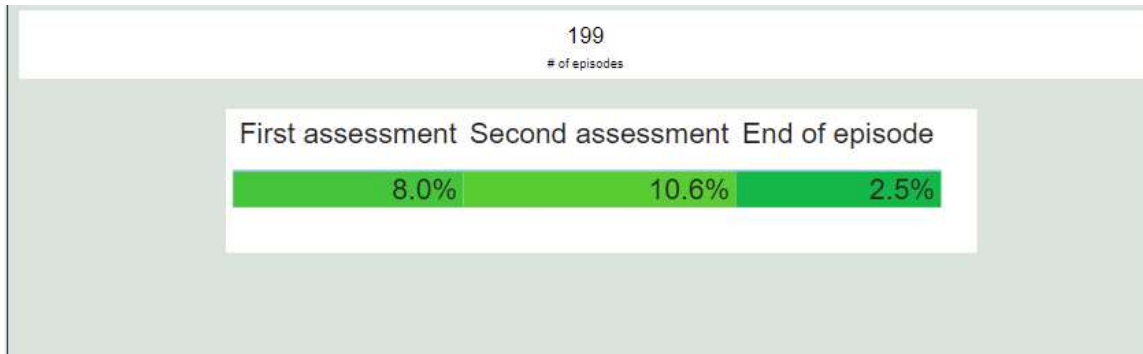
- **Description of infographic:** Table shows the proportion of missing Barthel scores. The cells are colour coded with a gradient to show values as green when a low proportion of Episodes have a missing score and red when a high proportion of episodes have a missing score.

- **Purpose:** To clearly highlight any limitations to the subsequent analysis and infographics for Barthel.

- **Example:** A dark green box with 6.0% states that 6.0% of scores are missing.

Barthel - 2. Barthel score across an Episode
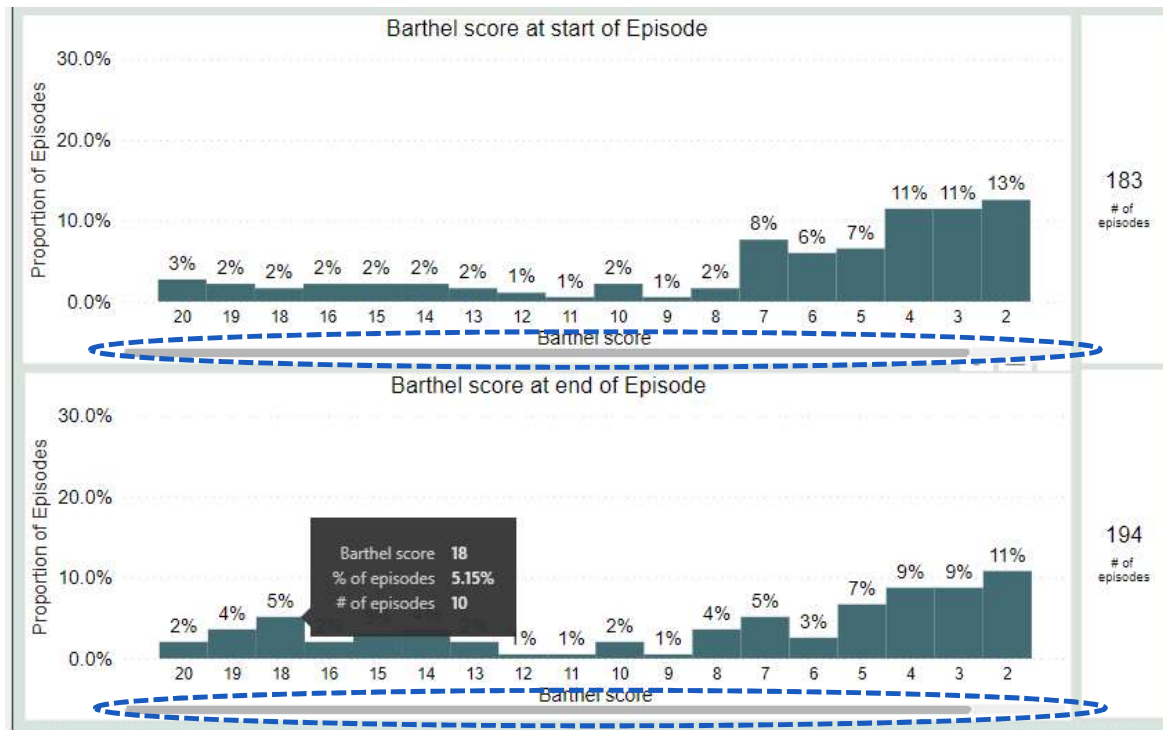
Proportion of Episodes by first Barthel Score (top visual):
- **Description of infographic:** Column chart displays the proportion of Episodes by first Barthel Score.
- **Purpose:** A varied case mix by Barthel Score at Episode start demonstrates differing levels of dependency across a service cohort.

Proportion of Episodes by final Barthel Score (bottom visual):
- **Description of infographic:** Column chart displays the proportion of Episodes by final Barthel Score.
- **Purpose:** Reviewing dependency at discharge helps understand the ongoing care needs for the cohort.

Information to note on both visuals:
- These infographics are shown together to demonstrate the change in dependency of the patient cohort by the end of the intervention. A view of final Barthel score is more suitable for a service which is focused on discharge rather than a service where most patients are deceased at service end.
- The full range of Barthel scores (0 to 20) can be viewed by scrolling left to right on the infographic with the bar circled at the bottom of each visual.

Barthel - 3. Change in Barthel score during Episode
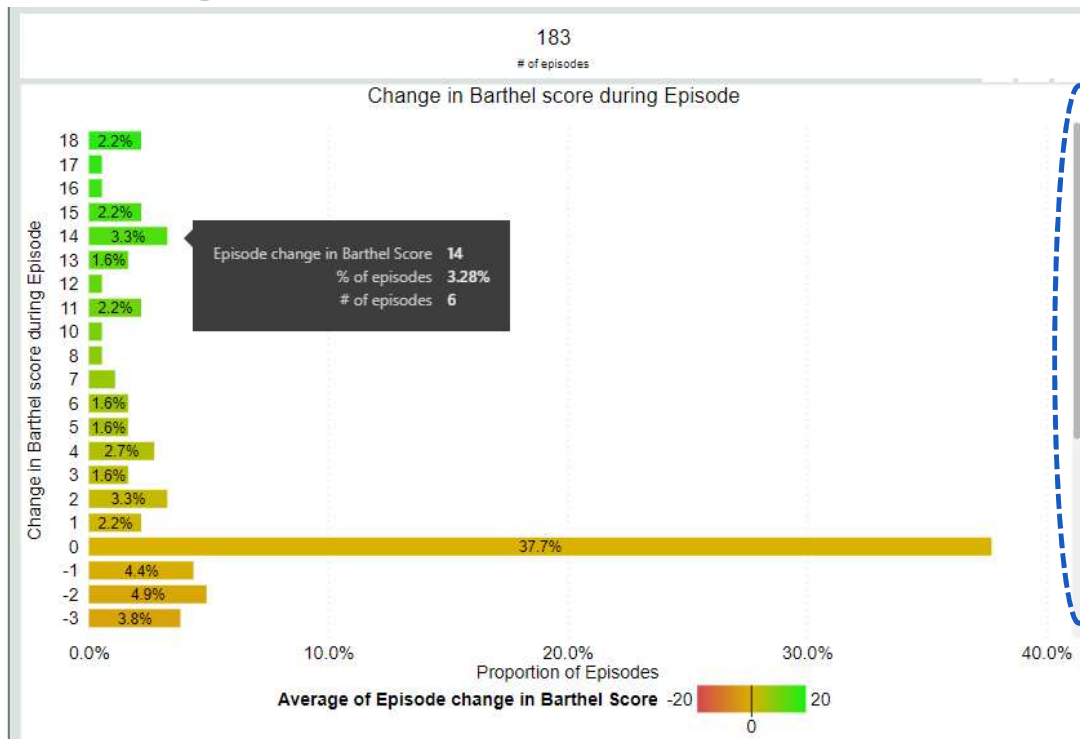
- **Description of infographic:** Stacked bar chart displays change in Barthel score from start to end of Episode. The bars are colour coded with a gradient to show values as green for when a patient has become more independent and red when a patient has become more dependent.
- **Purpose:** To show how dependency of patients shift across the Episode.
- **Information to note:**
  ➢ A view of change in Barthel score is more suitable for a service which is focused on discharge rather than a service where most patients are deceased at service end.
  ➢ The wider changes in Barthel Score can be viewed by scrolling up and down the infographic with the bar circled on the left hand side.

Context   View   Phase   AKPS   **Barthel**   IPOS   Licence

Barthel - 4. Distribution of Barthel score at discharge
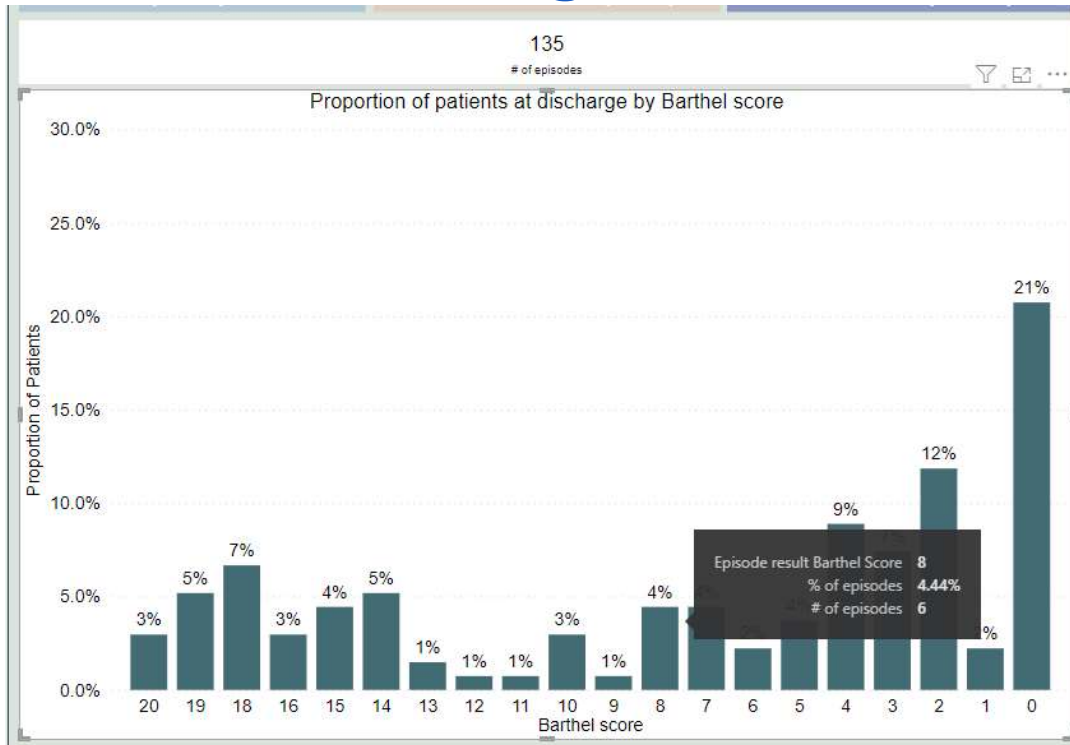
- **Description of infographic:** Column chart displays the distribution of Barthel score at Episode end.

- **Purpose:** To understand the dependency levels and thus ongoing care needs of patients at discharge.

- **Information to note:** This is relevant for specific services where patients are not expected to die on the service.

Integrated Palliative Care Outcome Score

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- Measure Overview
- Views of IPOS are:
  1. IPOS – 1. Heatmap
  2. IPOS – 2. IPOS scores at start of Episode
  3. IPOS – 3. Changes over Episode (radar)
  4. IPOS – 4. Any improvement in IPOS score
  5. IPOS – 5. Significant improvement in IPOS score across Episode
  6. COMBO – IPOS and Phase across Episode

Integrated Palliative Care Outcome Score

Definition: The Integrated Palliative Care Outcome Score (IPOS) measures are a family of tools to measure the symptoms and other concerns which patients affected by advanced illness most often report.

Data Collection: IPOS is compiled of 17 different measures and not all 17 measures are used for each patient. An IPOS Score should be collected at two or more points across an Episode for most of the views in this guide. In this guide, we define Episode of care as the time period between first and last assessment. You can define what an Episode of care is for your service e.g. whole service period, whole time the patient is in one element of your service such as day care etc. We also offer views between first and second assessment in cases where more than one assessment is conducted across an Episode (see slide view "IPOS – 4. Any improvement in IPOS Score" for more detail).

Purpose(s) of a dashboard: An IPOS dashboard helps condense the information from a complex PCOM to enable easier clinical viewpoints on:

• Change over an Episode, or first and second assessment, across the 17 measures.
• Each of the measures in isolation and in combined over-arching groups.
• The difference between "significant change" and "any change" in an IPOS score.

**Views:** There are six views in the IPOS section:

- IPOS – 1. Heatmap
- IPOS – 2. IPOS scores at first Phase
- IPOS – 3. Changes over Episode (radar)

- IPOS – 4. Any improvement in IPOS score
- IPOS – 5. Significant improvement in IPOS score
- COMBO – IPOS and Phase across Episode

IPOS – 1. Heatmap

199 Count of IDep			
IPOS	First Phase	Second Phase	Final Phase
Pain	5.0%	19.6%	3.5%
Shortness of breath	5.0%	21.6%	3.5%
Weakness	6.0%	20.1%	6.0%
Nausea	4.5%	18.6%	2.5%
Vomiting	6.0%	19.1%	4.0%
Appetite	4.5%	18.6%	2.5%
Constipation	2.0%	20.1%	3.0%
Sore mouth	3.5%	19.1%	4.0%
Drowsiness	3.0%	21.1%	3.5%
Mobility	17.1%	33.7%	23.6%
Anxiety	13.1%	30.7%	14.6%
Family anxiety	7.0%	29.6%	7.5%
Depression	8.5%	27.6%	6.5%
Feeling at peace	8.0%	28.1%	7.0%
Sharing with family	20.6%	38.2%	22.1%
Information about treatment	8.5%	31.7%	13.1%
Practical matters	16.1%	28.1%	15.1%

- **Description of infographic:** Table shows the proportion of Episodes with missing scores for each IPOS measure. The cells are colour coded with a gradient to show values as green when a low proportion of Episodes have a missing score and red when a high proportion of Episodes have a missing score.
- **Purpose:**
  - To highlight any gaps and challenges at the frontline in collecting specific IPOS data points.
  - To clearly highlight any limitations to the subsequent analysis and infographics for IPOS.
- **Example:** A dark green box with 6.0% states that 6.0% of scores are missing.

Context View Phase AKPS Barthel IPOS Licence

IPOS – 2. IPOS scores at start of Episode
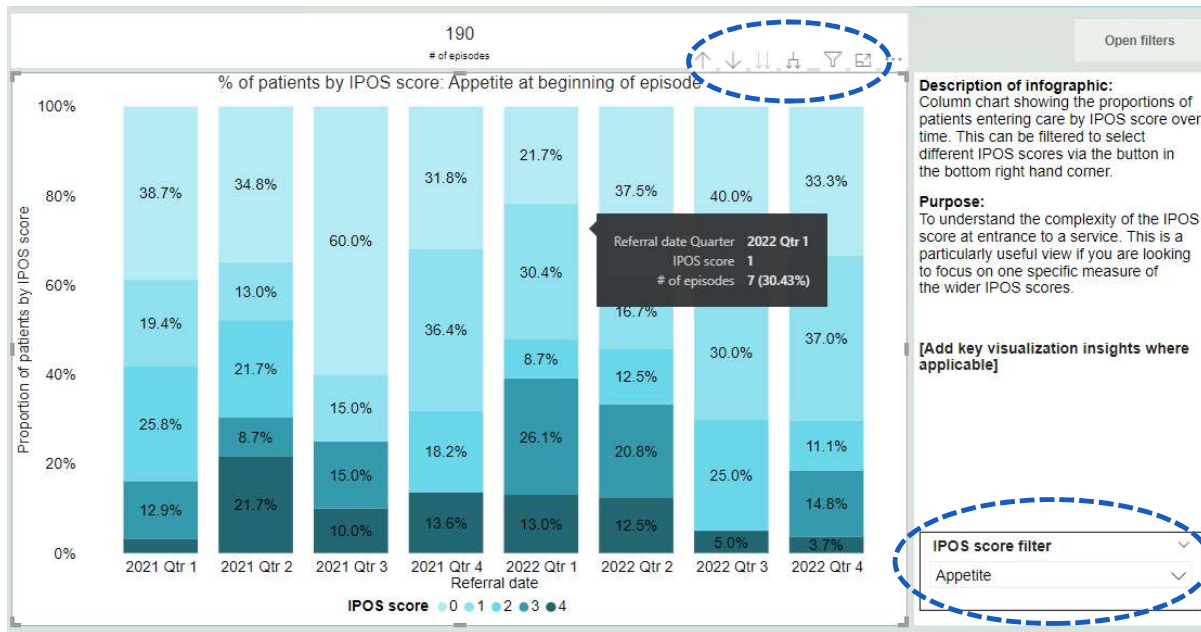
- **Description of infographic:** Column chart showing the proportions of patients entering care by IPOS score over time. This can be filtered to select different IPOS scores via the button in the bottom right hand corner.

- **Purpose:** To understand the complexity of the IPOS score at entrance to a service. This is a particularly useful view if you are looking to focus on one specific measure of the wider IPOS scores.

- **Information to note:** The time frames can also be altered by the icon arrows in the top right hand corner of the visual to view, by year, quarter or month.

IPOS – 3. Changes over Episode (radar)
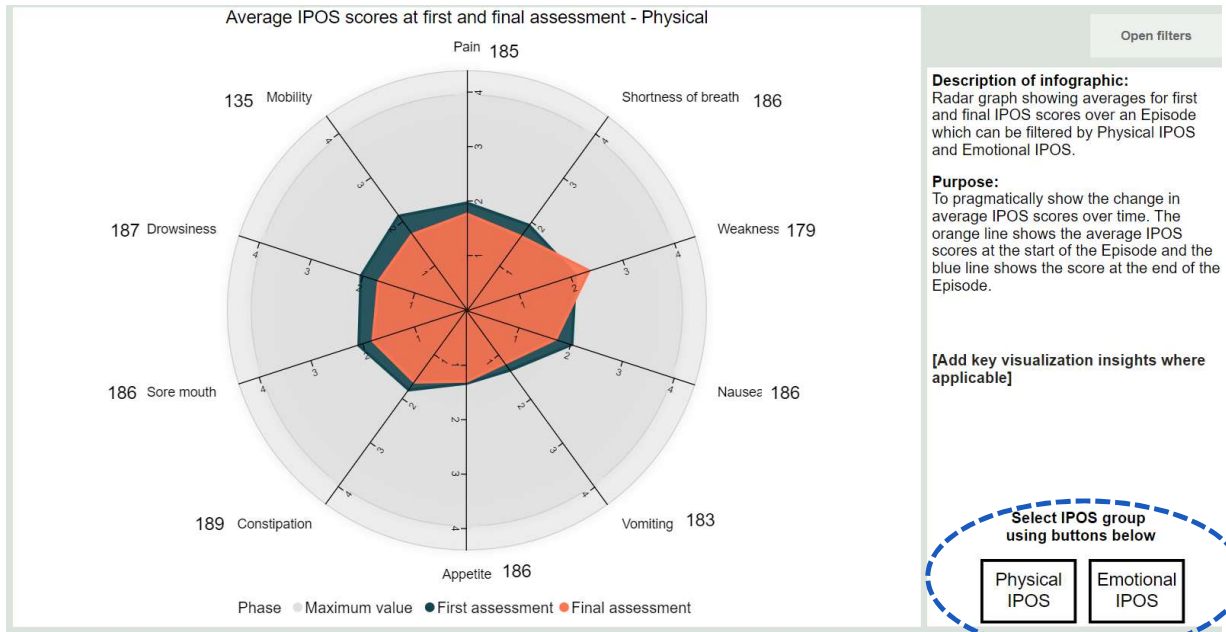
Average IPOS scores at first and final assessment - Physical

Description of infographic:
Radar graph showing averages for first and final IPOS scores over an Episode which can be filtered by Physical IPOS and Emotional IPOS.

Purpose:
To pragmatically show the change in average IPOS scores over time. The orange line shows the average IPOS scores at the start of the Episode and the blue line shows the score at the end of the Episode.

[Add key visualization insights where applicable]

Select IPOS group using buttons below

Physical IPOS   Emotional IPOS

Phase   Maximum value   First assessment   Final assessment

- **Description of infographic:** Radar graph showing averages for first and final IPOS scores over an Episode which can be filtered by Physical IPOS and Emotional IPOS.
- **Purpose:** To pragmatically show the change in average IPOS scores over time. The orange line shows the average IPOS scores at the start of the Episode and the blue line shows the score at the end of the Episode.
- **Information to note:**
  - The numbers at the end of each spoke display the "n=" to ensure that any analysis has sight of the total cohort before any conclusions are made.
  - The two buttons circled in the bottom right hand corner enable the radar to switch between the physical and emotional IPOS scores.
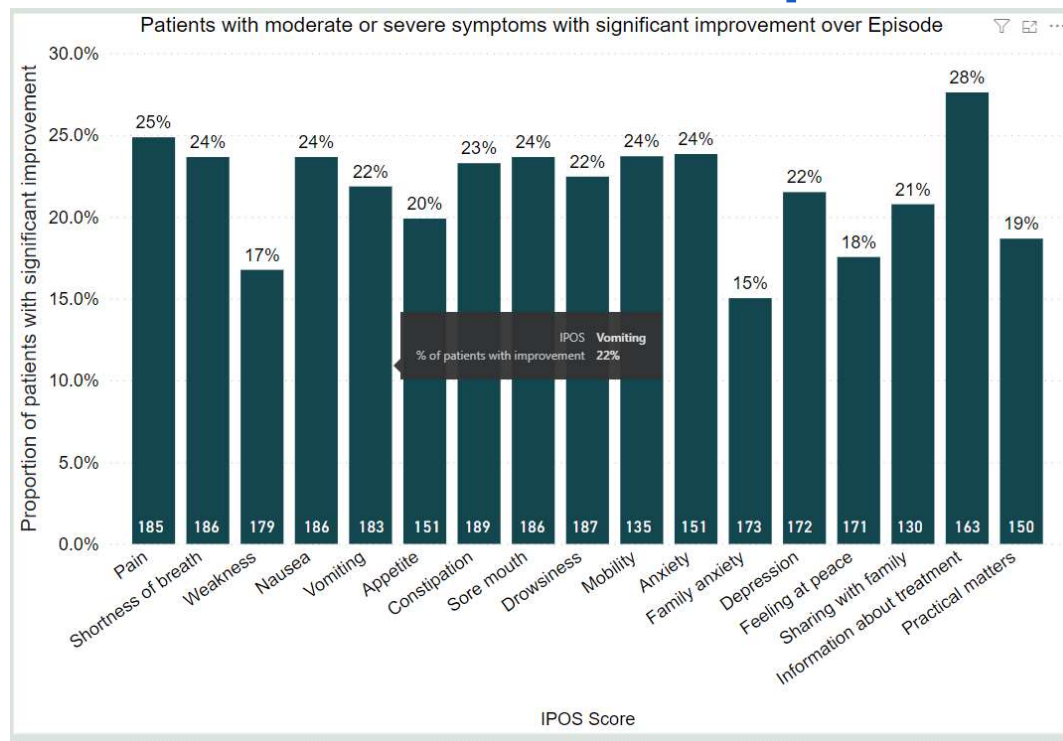
IPOS – 4. Any improvement in IPOS score
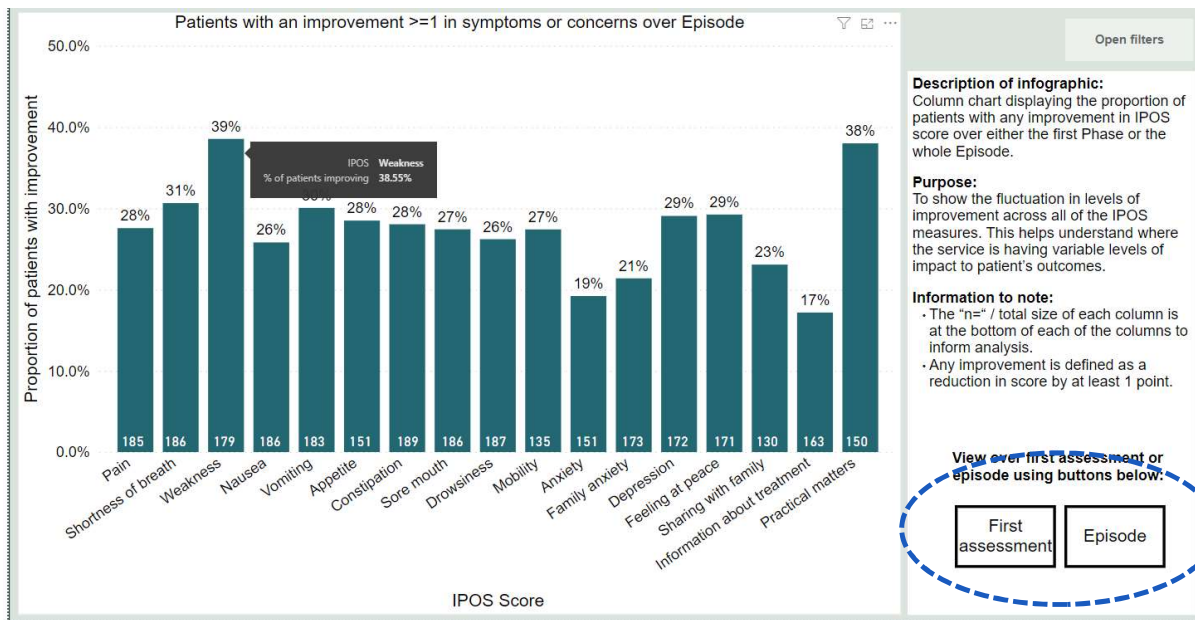
- **Description of infographic:** Column chart displaying the proportion of patients with any improvement in IPOS score over either the first Phase or the whole Episode.
- **Purpose:** To show the fluctuation in levels of improvement across all of the IPOS measures. This helps understand where the service is having variable levels of impact to patient's outcomes.
- **Information to note:**
  - The "n=" / total size of each column is at the bottom of each of the columns to inform analysis.
  - Any improvement is defined as a reduction in score by at least 1 point.
  - Analysis can be conducted on either across the whole Episode or between referral and second score by using the buttons in the bottom right hand corner.

IPOS – 5. Significant improvement in IPOS score across Episode

Patients with moderate or severe symptoms with significant improvement over Episode

- **Description of infographic:** Column chart displaying the proportion of patients with a significant improvement from moderate or severe symptoms in an IPOS score over an Episode.
- **Purpose:** To show the fluctuation in levels of improvement across all of the IPOS measures. This helps understand where the service is having the most significant level of impact to patient's outcomes.
- **Information to note:**
  - ➢ A moderate or severe symptom is defined as having a score of 3 or 4.
  - ➢ A significant improvement is a change of 2 or more. Both the starting point and level of significant improvement can be altered.
  - ➢ We are only showing across an Episode as we believe this is the most meaningful view to show whereas a view between first and second contact may not be as meaningful.

Combo - IPOS and Phase across Episode
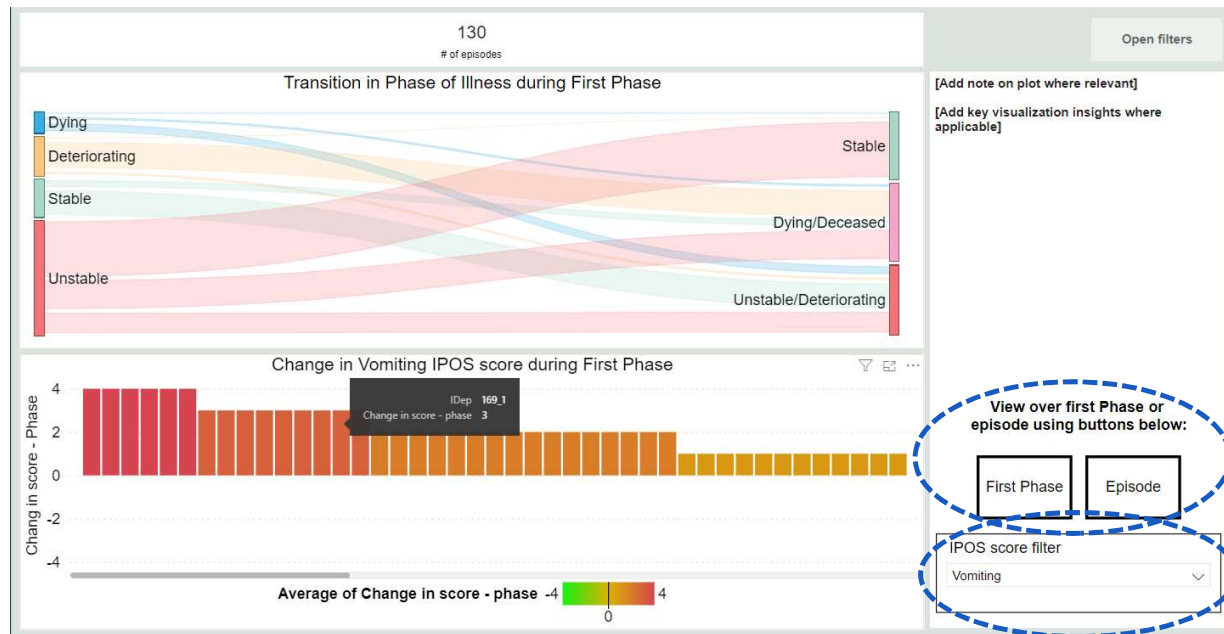
- **Description of infographic:** Sankey diagram displays the transition in Phase of Illness alongside the IPOS scores in the column chart below. This can be filtered to select different IPOS scores via the button in the bottom right hand corner.

- **Purpose:** To enable a combination view of both IPOS and Phase transitions for services that collect both measures.

- **Information to note:** Includes buttons to focus on transitions across the whole episode or the first and second score. Depending on how many data scores are collected, this view may be the same.

End Notes and Full References for each of the PCOMs

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Modified Barthel Score for Palliative Care - Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud. 1988;10(2):61-3.
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Integrated Palliative care Outcome Scale (IPOS) - Murtagh FEM, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST, Denzel J, Bernhardt F, Schildmann EM, Oorschot B, Hodiamont F, Streitwieser S, Higginson IJ, Bausewein C. A Brief, Patient- and Proxy-Reported Outcome Measure in Advanced Illness: Validity, Reliability and Responsiveness of the Integrated Patient Outcome Scale (IPOS). *Palliative Medicine,* 2019. Vol. 33(8) 1045–1057.

https://doi.org/10.1177/0269216319854264

Palliative Phase of Illness (Phase) - Eagar K, Green J and Gordon R. An Australian casemix classification for palliative care: technical development and results. Palliat Med 2004; 18: 217-226. DOI: 10.1191/0269216304pm875oa.

Masso M, Allingham SF, Banfield M, Johnson CE, Pidgeon T, Yates P, et al. Palliative Care Phase: inter-rater reliability and acceptability in a national study. Palliat Med 2015; 29: 22-30. 20140923. DOI: 10.1177/0269216314551814.

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