




**OACC outcome measures:
developing a data plan**

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Fliss Murtagh
Professor of Palliative Care


Considerations in this presentation:

1. OACC data has been collected and entered into a database
2. Collection and data entry issues are not being addressed here
3. **Presentation on extraction and reporting of OACC data – how to develop a data plan**

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First step: get to know your data



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Thinking about your data: what data?

1. Some demographic and clinical information
2. Phase of Illness
3. Australia-modified Karnofsky Performance Score (AKPS)
4. Integrated Palliative care Outcome Scale (IPOS)

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Not all the same type of data

1. **Demographic and clinical information**
2. **Also need information about the episode**
3. **Phase of Illness – changes within episode**
4. **AKPS and IPOS – Phase level data**

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Time-constant data – usually easier

1. Date of birth
2. Gender
3. Ethnicity
4. Primary diagnosis
5. Secondary diagnoses
6. Marital status
7. Usual residence
8. Lives alone?

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Some “time-constant data” may change!

1. Date of birth
2. Gender
3. Ethnicity
4. Primary diagnosis
5. Secondary diagnoses
6. Marital status
7. Usual residence
8. Lives alone?

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Think in terms of each episode of care:

1. Has the episode start date been captured?
Usually attached to referral.
2. Has the episode end date been captured?
Usually attached to discharge (or death, if died at end of episode).

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What other episode data do you need?

1. Start date
2. Source of referral
3. Reason(s) for referral
4. Care setting and/or team
5. End date
6. End outcome: discharged/where/died

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Time-varying data – occurs more than once

1. Phase of Illness
2. AKPS and IPOS

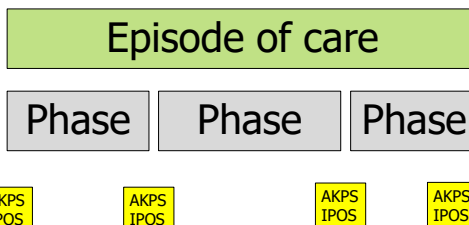
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Challenges:

1. Is your Phase data linked to episode or not?
2. Is your AKPS and IPOS linked to Phase or not?
3. If no for 1 or 2 above, **be sure to extract date of collection (and patient identifier)**

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Episode of care

Phase

Phase


Phase

AKPS
IPOS

AKPS
IPOS

AKPS
IPOS


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Data preparation: pre-analysis steps

- Choose which setting or team – easier to start with one
- Choose which time period – try for at least 6 or 12 months
- Can you extract your data 'linked' or is it 'piecemeal'?
- If 'piecemeal', **make sure you have patient identifier and dates attached**
- If 'piecemeal', do you know which episode and which Phase the AKPS and IPOS relate to?


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Data preparation: pre-analysis steps

- Extract the data – can be harder than it seems!
- Basic validation checks:
 - ✓ Is the time period covered?
 - ✓ Is it roughly the number of patients you were expecting?
 - ✓ Are the variables within an expected range?
- Clean up: rename, recode and generate new variables
- Decide the time period you will report

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Data preparation: Choosing how to group the data

What do you want to compare?

- Teams or wards
- Community patients and inpatients
- Diagnosis groups
- Referral routes and discharge destinations

Can you easily identify these groups in your data?


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Do what makes sense....



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It's a balancing act



Don't chop the data into too many small groups – there is value in larger numbers – certainly suppress <10

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Which time points?

- First and last in episode?
- Before and after intervention?
- Change in Phase of illness?



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Show your denominators – what and how much?

- How many patients seen?**
- How many episodes of care?**
- How many Phases of illness?**

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Not all the same type of data

1. Demographic and clinical information
2. Also need information about the episode
3. Phase of Illness – changes within episode
4. AKPS and IPOS – Phase level data

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Tackle each type of data singly first:

1. Demographic and clinical information
2. Episode: length and outcome
3. What Phase – first assessment only
4. Data about Phase – length of Phase, by Phase
5. What Phase – subsequent Phases

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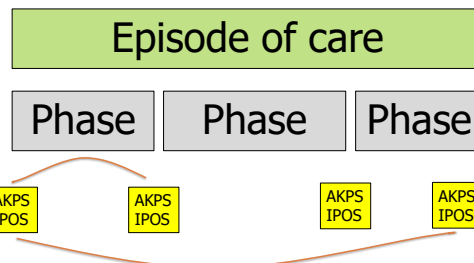


Tackle each type of data singly first:

6. AKPS at first assessment
7. IPOS at first assessment
8. Change in AKPS
9. Change in IPOS

see next slide ...

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Only then can you start to combine:

1. Demographic and clinical information
2. Episode data: length and outcome
3. Which Phase and length of Phase
4. AKPS and IPOS – at baseline and subsequent changes

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Look at missing data

Phase number	1	2	3	4-7
n of phases	458	380	181	80
akps	0%	1%	1%	0%
ipos pain	12%	56%	67%	79%
ipos sob	12%	55%	67%	78%
ipos weak	12%	56%	71%	81%
ipos nausea	14%	56%	70%	80%
ipos vomit	12%	55%	68%	79%
ipos appetite	14%	58%	72%	81%
ipos constipation	14%	57%	69%	79%
ipos mouth	12%	55%	67%	78%
ipos drowsiness	12%	57%	71%	80%
ipos mobility	13%	57%	71%	80%
ipos anxious	25%	74%	81%	90%
ipos family	21%	67%	73%	83%
ipos depressed	25%	74%	82%	89%
ipos peace	26%	73%	80%	89%
ipos feelings	28%	75%	81%	91%
ipos information	27%	75%	81%	91%
ipos practical	27%	76%	82%	88%

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Missing data heat maps

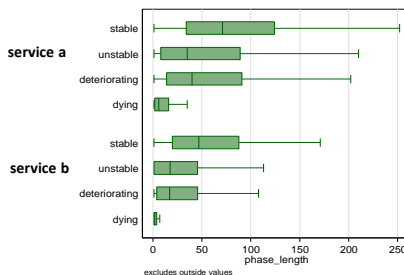
Points to consider:

- What level is the data collected at? **What is your denominator** – is it all patients or all Phases?
- What do you consider missing data? Completely missing? Or include 'could not assess'?
- What are your expectations – would you expect all variables to be complete?

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Phase length

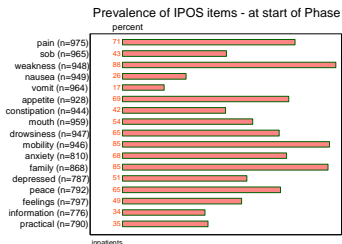


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What were patients symptoms like at the start of Phase?

% of patients who had moderate severe or overwhelming (2-4) for each IPOS item – at the start of Phase

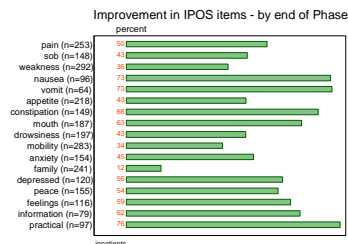


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How have patients symptoms changed by the end of Phase?

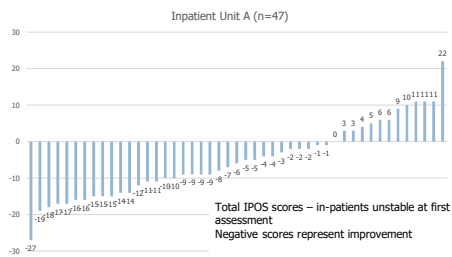
% of patients who had moderate severe or overwhelming (2-4) for each IPOS item at start of Phase – who had improved outcomes by the end of Phase (only patients with end of phase data are included)



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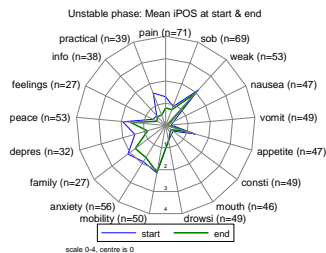
Individual change in total IPOS scores over first Phase



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Mean IPOS score for each item at start and end of unstable Phase



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- Queries to fliss.murtagh@hyms.ac.uk

Thank you

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