Improving palliative care through point-of-care data collection, structured feedback and benchmarking

David C Currow, Samuel Allingham, Patsy Yates, Claire Johnson, Katherine Clark, Kathy Eagar

Measuring quality in palliative care

Why routinely measure performance?

What do we say are the ways in which palliative care value adds to the health and wellbeing of our communities?

Measuring quality in palliative care

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- Symptom control and personal care

- Prepare for the end of life
- Achieve a sense of completion
- Be consulted about treatment preferences
- Be treated as a 'whole person'

Steinhauser et al. JAMA 2000, Singer et al. JAMA 1999.

Measuring quality in palliative care

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- Symptom control and personal care as an enabler to ensure people can:

- Prepare for the end of life

- Achieve a sense of completion

- Be consulted about treatment preferences

- Be treated as a 'whole person'

Steinhauser et al. JAMA 2000, Singer et al. JAMA 1999.

Measuring quality in palliative care

What physical symptoms will people not volunteer (or systematically under-report)?

n=200;

Open questions followed by a 48 question check list;

Median age 65

Median Eastern Cooperative Group performance status 2

Homsi J et al. Support Care Cancer 2006

Measuring quality in palliative care

What physical symptoms will people not volunteer (*or systematically under-report*)?

Volunteered symptoms
- Median 1 (range 0-6)

Systematically explored symptoms
- Median 10 (range 0-25)

Homsi J et al. Support Care Cancer 2006

Measuring quality in palliative care

What physical symptoms will people not volunteer (*or systematically under-report*)?

Volunteered symptoms
- Median 1 (range 0-6)
83% moderate / severe. 91% distressing
Systematically explored symptoms
- Median 10 (range 0-25)

Homsi J et al. Support Care Cancer 2006

Measuring quality in palliative care

What physical symptoms will people not volunteer (*or systematically under-report*)?

Volunteered symptoms
- Median 1 (range 0-6)
83% moderate / severe. 91% distressing
Systematically explored symptoms
- Median 10 (range 0-25)
52% moderate / severe. 53% distressing

Homsi J et al. Support Care Cancer 2006

Measuring quality in palliative care

What physical symptoms will people not volunteer (*or systematically under-report*)? n = 200

69% of severe symptoms were not volunteered (n=522)

79% of distressing symptoms were not volunteered (n=1,393)

Homsi J et al. Support Care Cancer 2006

Measuring quality in palliative care

Dying from cancer: results of a national population-based investigation.

MAIN RESULTS:

At some stage in the last year of life ***patients***:

- 88% were reported to have been in pain (relatively poorly controlled often)
- More than half had loss of appetite, constipation, dry mouth or thirst, vomiting or nausea, breathlessness, low mood, and sleeplessness.

Addington-Hall J et al. Palliat Med. 1995 Oct;9(4):295-305.

Measuring quality in palliative care

Symptom burden and performance status in a population-based cohort of ambulatory cancer patients.

RESULTS:

The cohort included 45,118 and 23,802 patients' first ESAS and PPS, respectively.

Fatigue was most prevalent (75%)

More than half of patients reported pain or shortness of breath about half of whom reported moderate to severe scores

Nausea was least prevalent (25%)

On multivariate analysis, worse ESAS outcomes were consistently seen for women, those with comorbidity, and those with shorter survivals from assessment.

Lung cancer patients had the worst burden of symptoms.

Barbera L et al. Cancer. 2010 Dec 15;116(24):5767-76.

Cultural issues

- Palliative care has traditionally focused on measuring processes
- Has often been really happy with a draw full of thank you letters
- Always feel there are too few resources so care cannot improve

- All services sincerely believe that they are doing a great job (but some are doing a greater job than others)

Measuring quality in palliative care

Measuring and understanding patient outcomes at a systems level

Advancing the science of hospice care: Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE)

The Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE). CHOICE is a national network of hospices that use electronic health record-based data collection procedures to answer key questions relevant to clinical care and policy.

Casarett DJ et al. Curr Opin Support Palliat Care. 2012 Dec;6(4):459-64

Measuring quality in palliative care

Measuring and understanding patient outcomes at a systems level

QDACT

37 questions within five domains:

- **Demographics;**
- **Symptom management;**
- **Advanced care planning;**
- **Prognosis; and**
- **Transition / discharge**

Kamal AH et al. J Pain Symptom Manage 2011 Nov;42(5):663-7

Measuring quality in palliative care

Measuring and understanding patient outcomes at a systems level

Quality improvement in cancer symptom assessment and control: the Provincial Palliative Care Integration Project (PPCIP).

OBJECTIVES:

The project involved:

1) implementation of the Edmonton Symptom Assessment System (ESAS) for symptom screening;
2) use of "rapid-cycle change" quality improvement processes to improve screening and symptom management; and
3) improvements in integration and access to palliative care services.

Gibert JE et al. J Pain Symptom Manage. 2012 Apr;43(4):663-78.

The Australian Palliative Care Outcomes Collaborative (PCOC)

A national program funded by the Department of Health & Ageing to improve systematically the quality of palliative care service provision.

PCOC:

- Supports continuous ***outcome improvements*** in palliative care
- Uses benchmarking nationally that will improve practice
- Is improving the use of standardised palliative care clinical assessments
- creates a "common language" for clinicians including primary care

The aims of PCOC

- **Work with services to incorporate the PCOC data collection into routine practice**

in order to

- **Analyse the data and provide timely feedback on the results to individual services - reports every 6 months**

in order to

- **Facilitate benchmarking with other services**

in order to

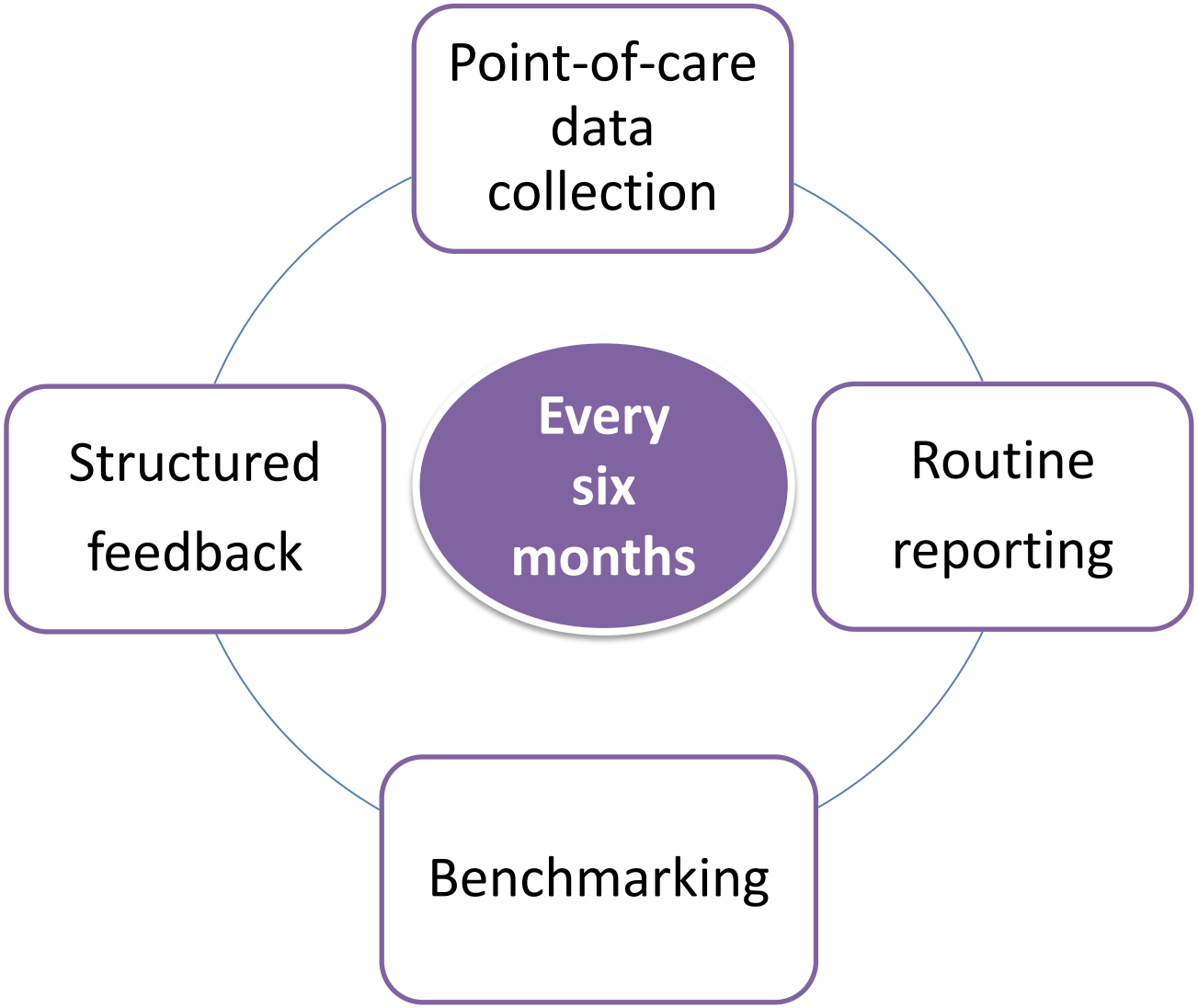
- **Improve systematically the outcomes delivered by specialised palliative care services**

PROGRESS TO DATE

- PCOC represents >85% of all palliative care patients referred to specialist services in Australia

- Incorporates
  - Direct inpatient care
  - Community care
  - Consultative care

PCOC cycle



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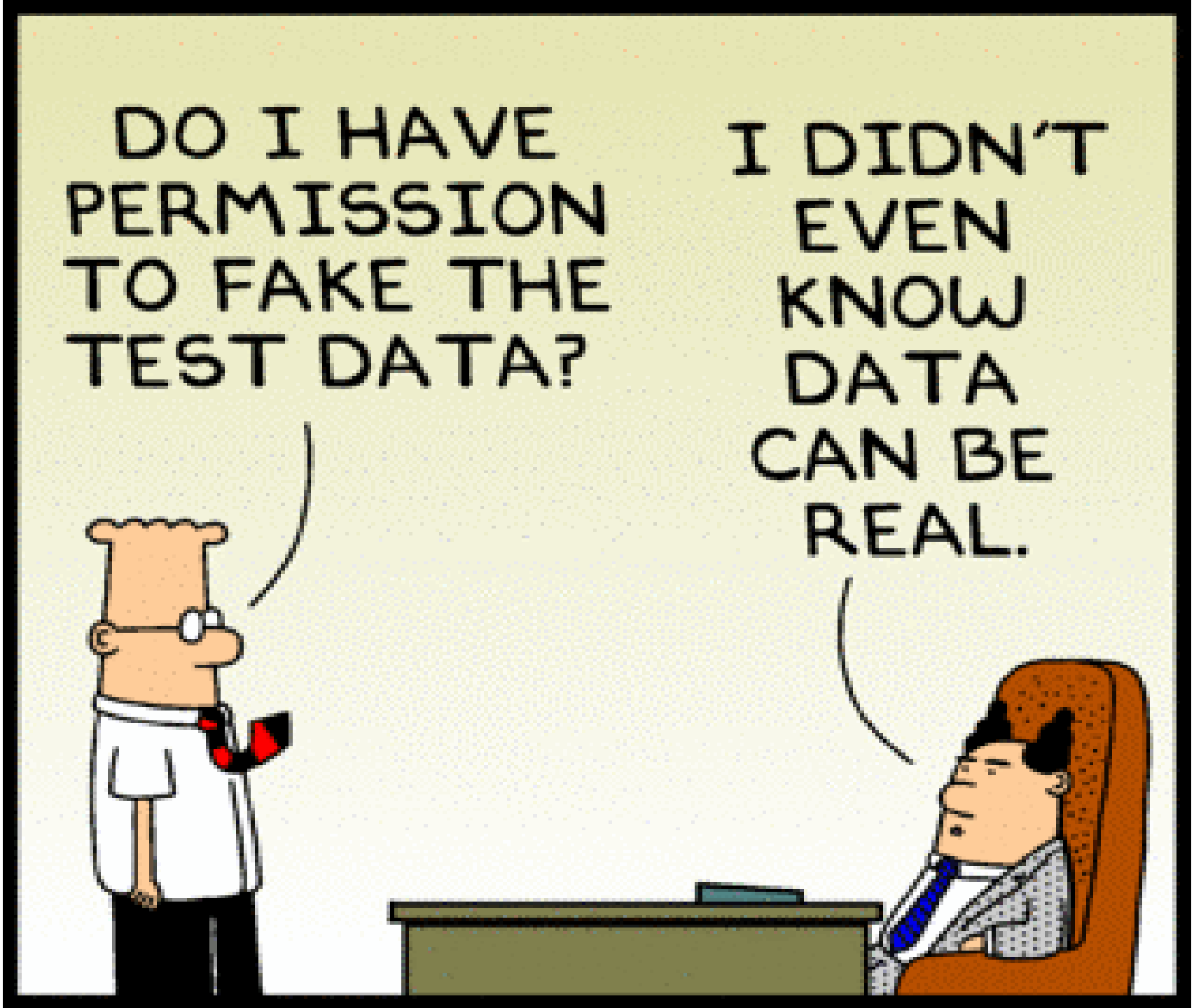
DO I HAVE PERMISSION TO FAKE THE TEST DATA?
I DIDN'T EVEN KNOW DATA CAN BE REAL.

PCOC Data

1. **Routine *voluntary* point-of-care data collection**

   (data owned by the participating service: captured at 3 levels (patient, episode, phase))

2. **Periodic (Snapshot) data collections**

   (e.g. patient and carer experiences)

3. **Developmental/experimental or one off collections**
   (testing items for future versions of the data set)

Data architecture

- **Patient/Demographic items – once only**
  - eg, age, sex, postcode
- **Episode – recorded with change of place of care**
  - eg, referral source, time between referral and first assessment, episode type, accommodation at start and end, level of support at start and end, place of death
- **Phase – recorded with change in clinical condition**
  - eg, Phase (stable, unstable, deteriorating, terminal, bereaved), function at start and end, symptoms at start and end, model of care, number of days seen

Point-of-care data collection

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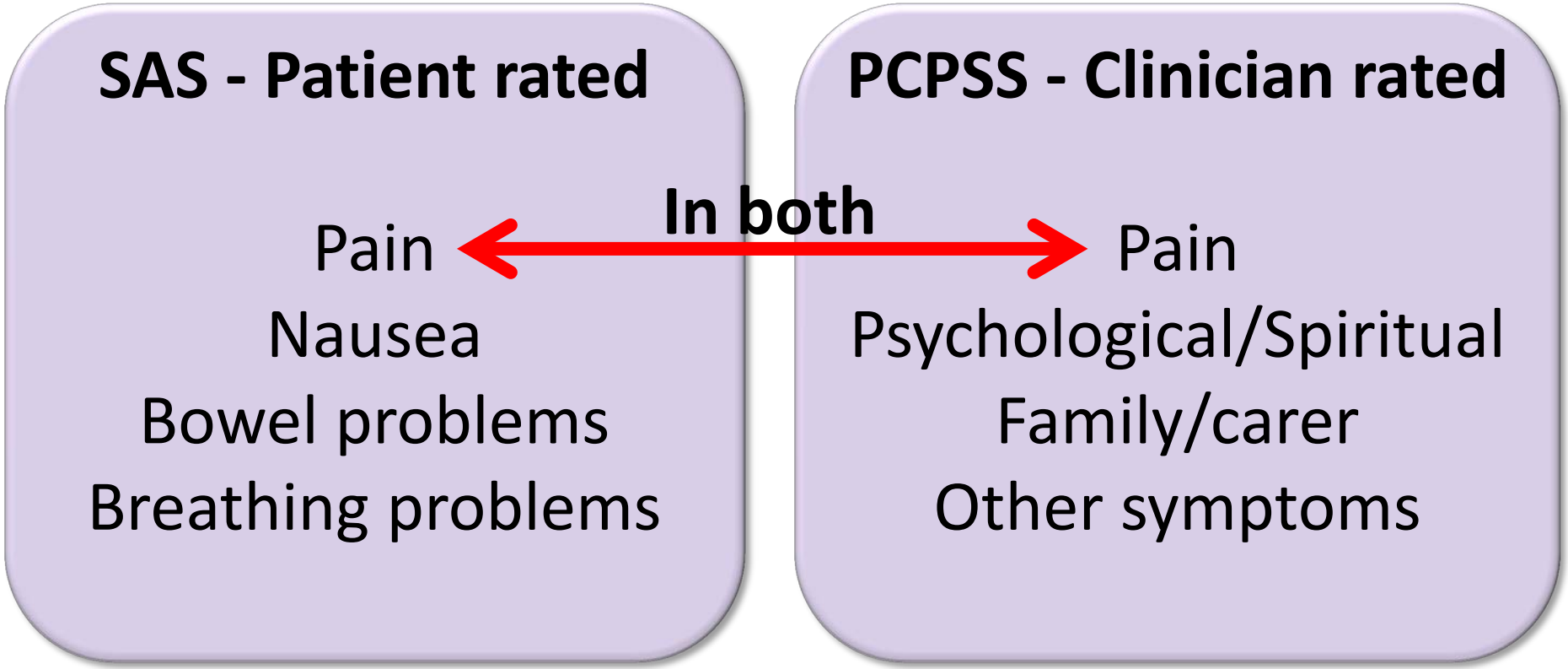
Five assessment tools

Palliative Care Phase (Phase)	Eagar et al, 2004
Resource Utilisation Groups – Activities of Daily Living **(RUG-ADL)**	Fries et al, 1994
Australia-Modified Karnofsky Performance Status **(AKPS)**	Abernethy et al, 2005
Palliative Care Problem Severity Score **(PCPSS)**	Eagar et al, 2004
Symptom Assessment Scale **(SAS)**	Aoun et al, 2004

Seven symptoms / problems



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Routine PCOC data

Symptom Measurement tools

Symptom Assessment Scale (patient reported)

- **7 domains: pain, fatigue, appetite, nausea, bowels, breathing and sleep**
- **0-10 numerical rating scale**

- **Palliative Care Problem Severity Scale (clinician reported)**
  - **4 domains (pain, other symptoms, psychological / spiritual and family / caregiver)**
  - **4 levels of (categorical) reporting**

Aoun SM et al. J Palliat Med 2011;14:315-21.
Eagar K et al. Palliat Med 18:217-226, 2004.

Understanding causes for variation

- **Variations due to the mix of**

  patients (the casemix)
- **Variations due to differences in**

  practices (administrative and clinical factors including resources and models of care)

in order to understand

Variations in patient-centred clinical outcomes

PCOC framework for improvement

Continues to support the embedding of routine clinical assessments and point-of-care data collection to drive improvement through:

- providing a feedback loop to individual services
- identifying individual improvement opportunity
- service to service benchmarking.

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Research question

Can patient outcomes be improved if outcomes are routinely measured at point-of-care?

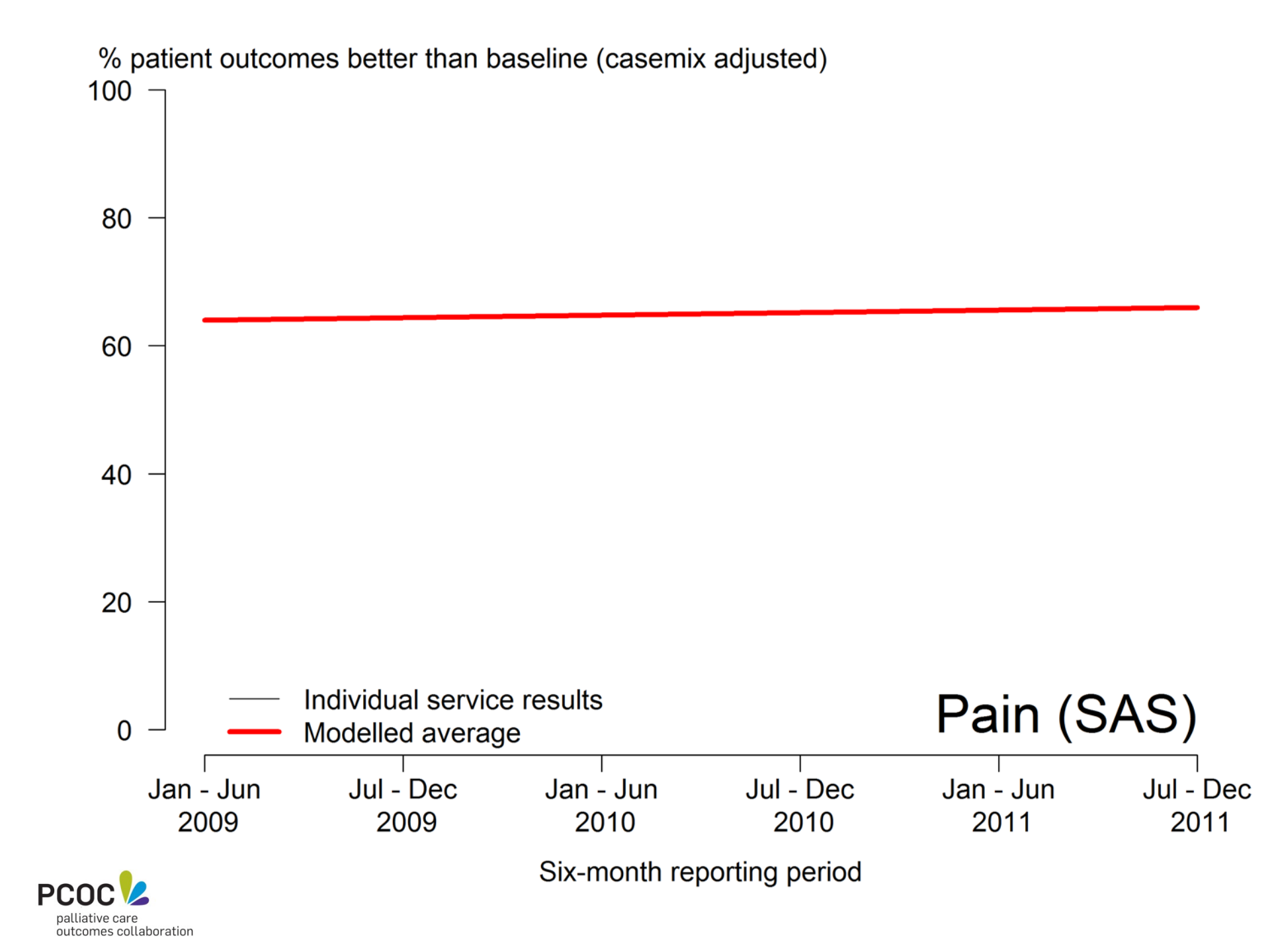
Initial method

- Analysis of 30 services participating in the PCOC cycle consistently between January 2009 and December 2011

- Assessing patient outcomes using both SAS and PCPSS

Initial results : 2009 - 2011

- 19,747 patients and 65,463 phases
- 46% female
- 85% malignant diagnosis
- Average age 70.9 years
- **Statistically significant improvements in all domains with the exception of pain**



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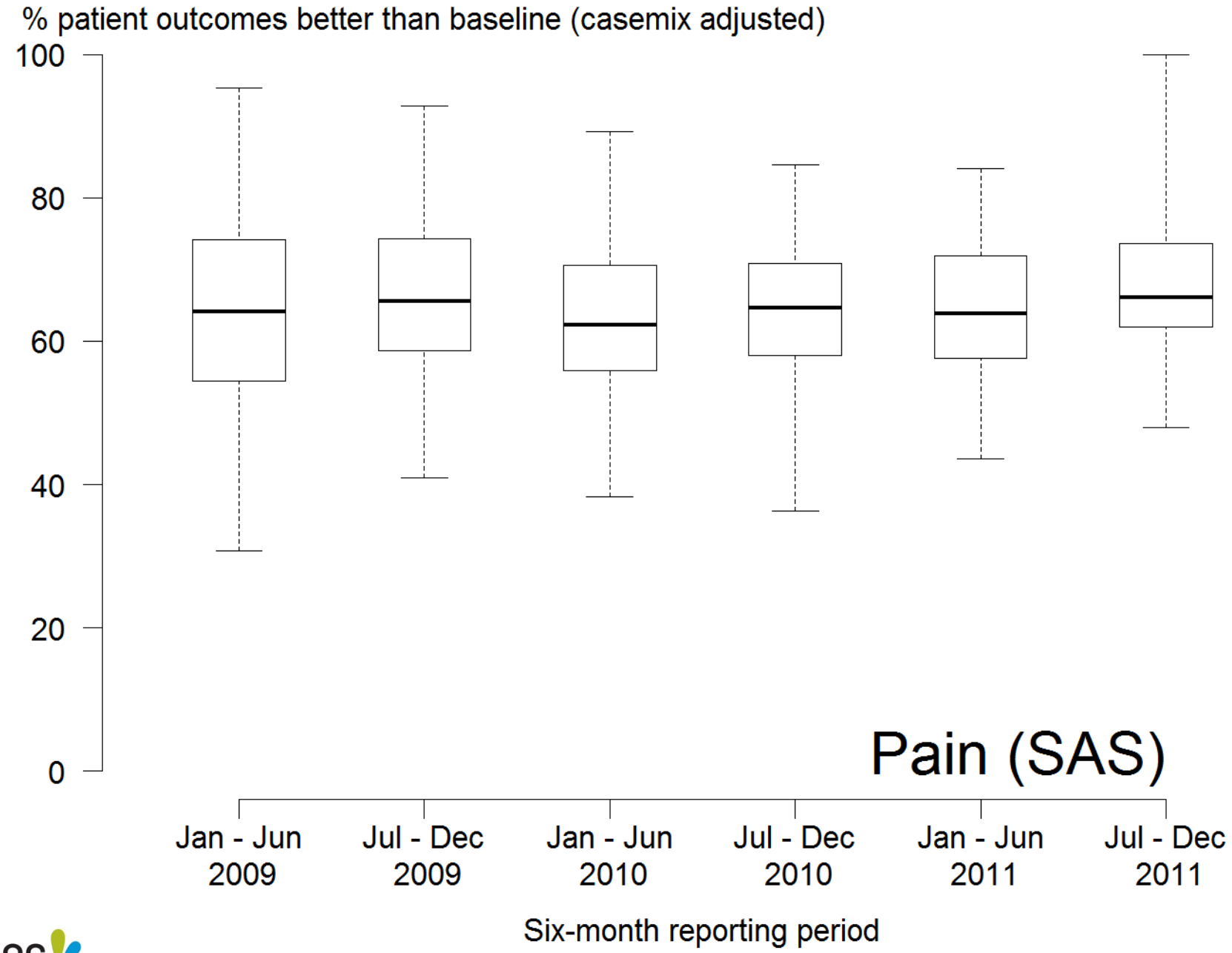

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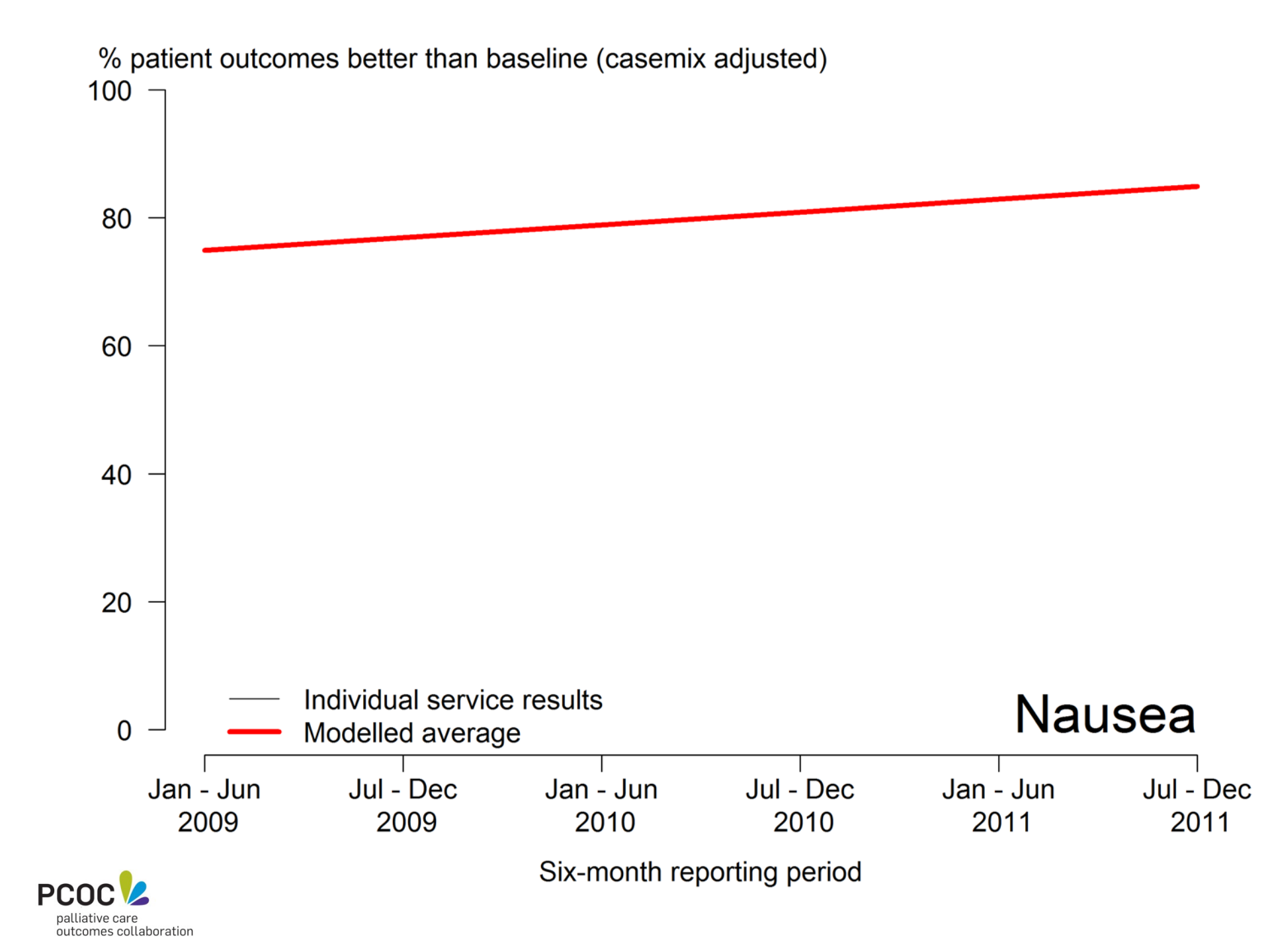

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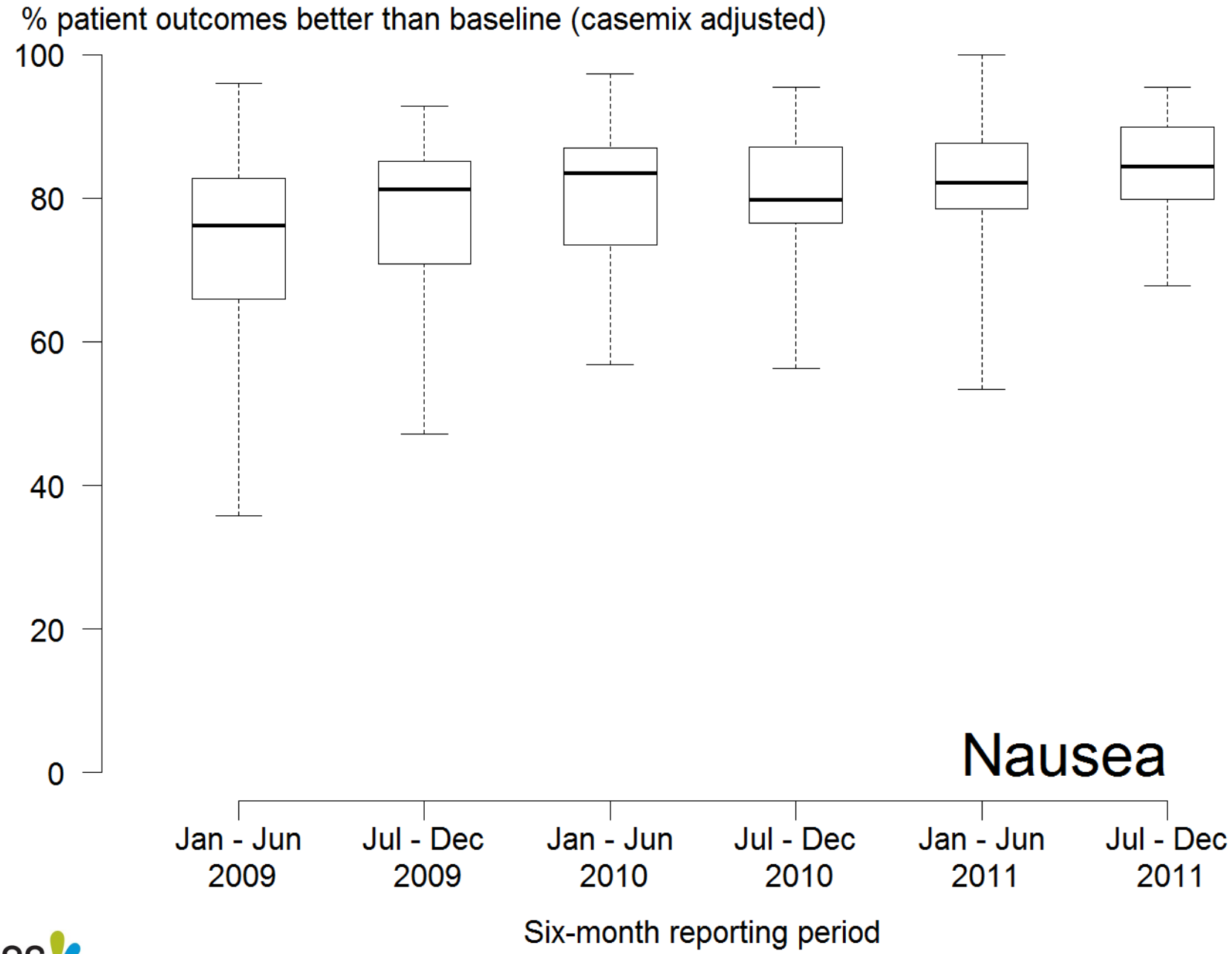

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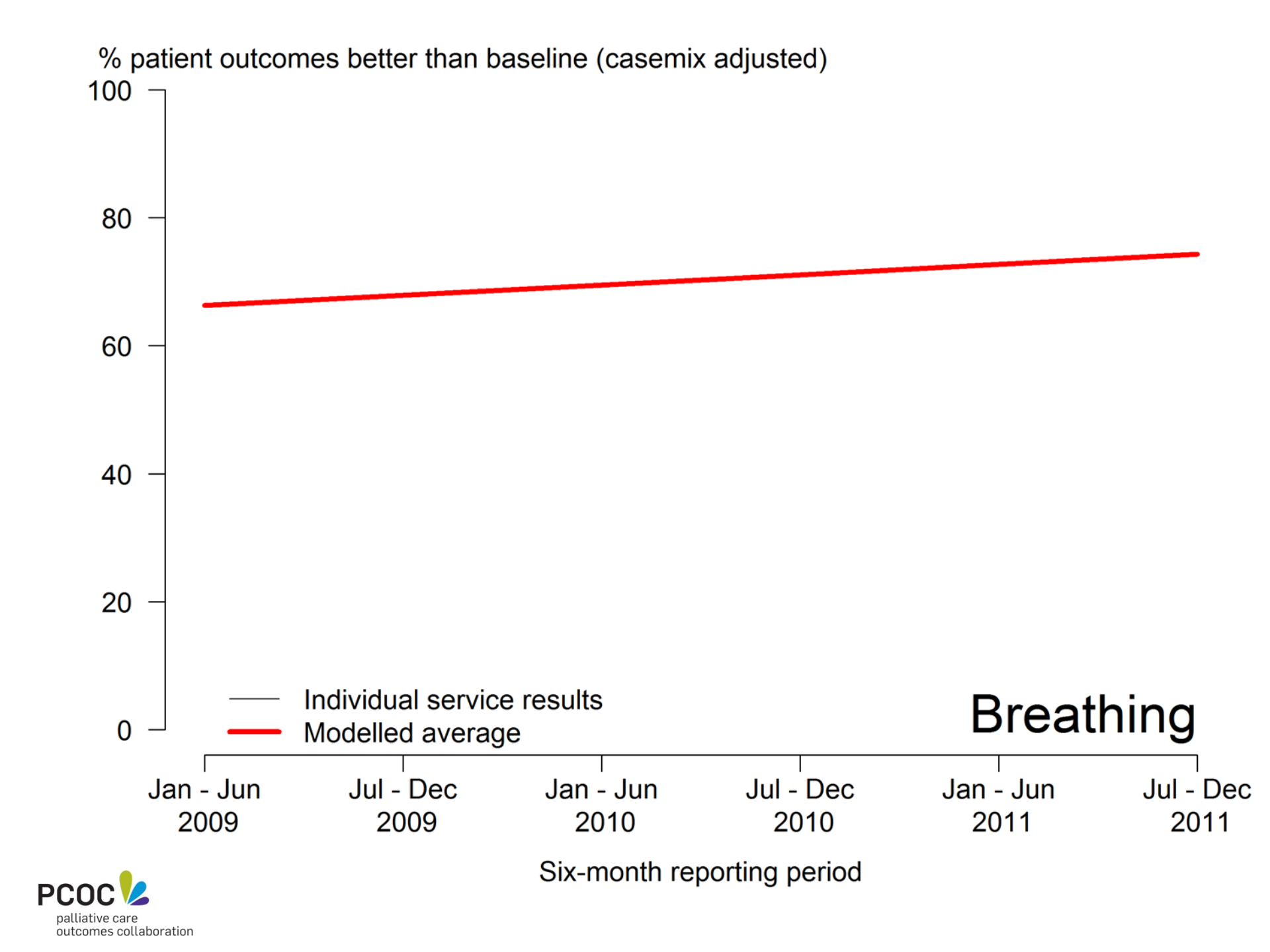

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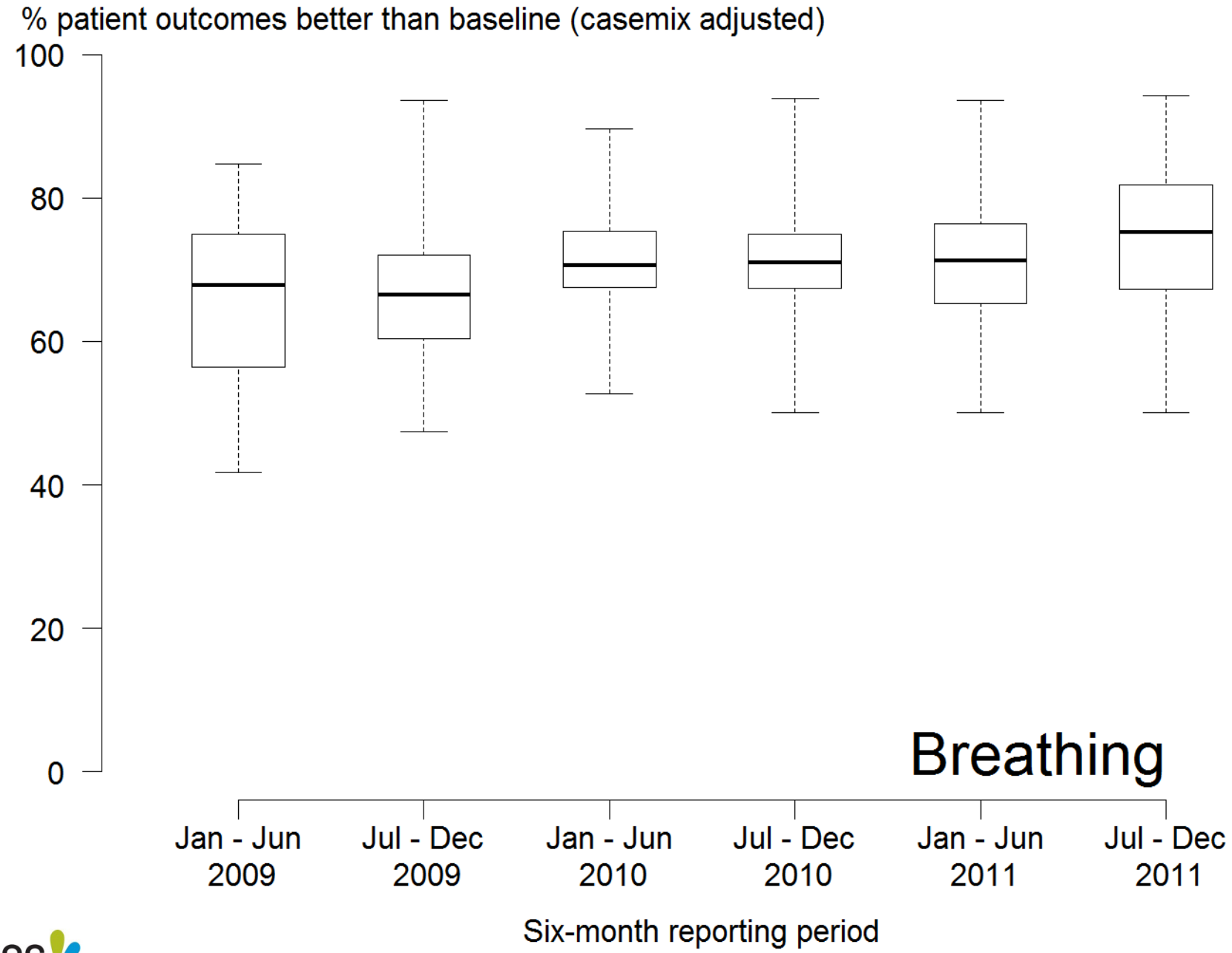

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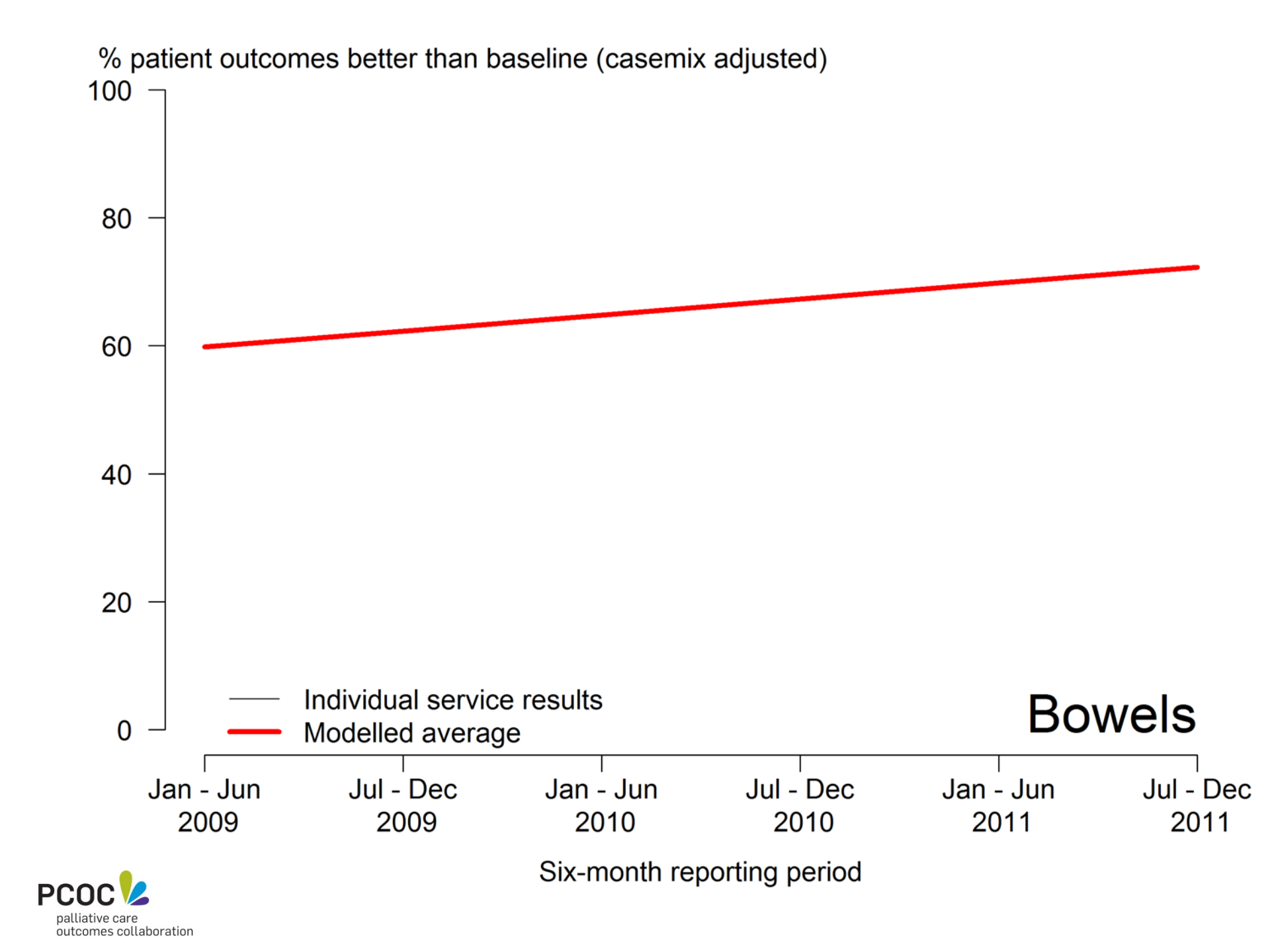

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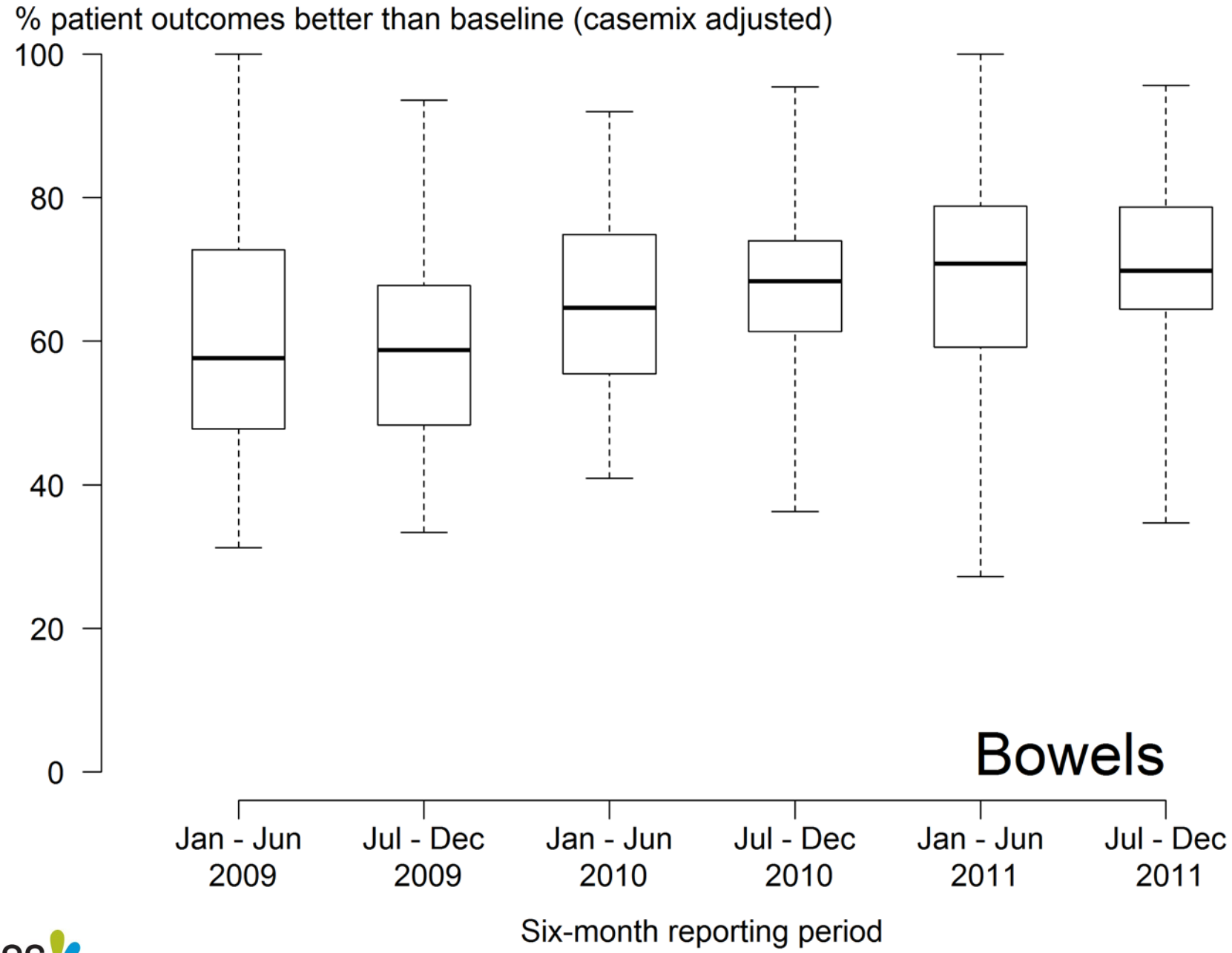

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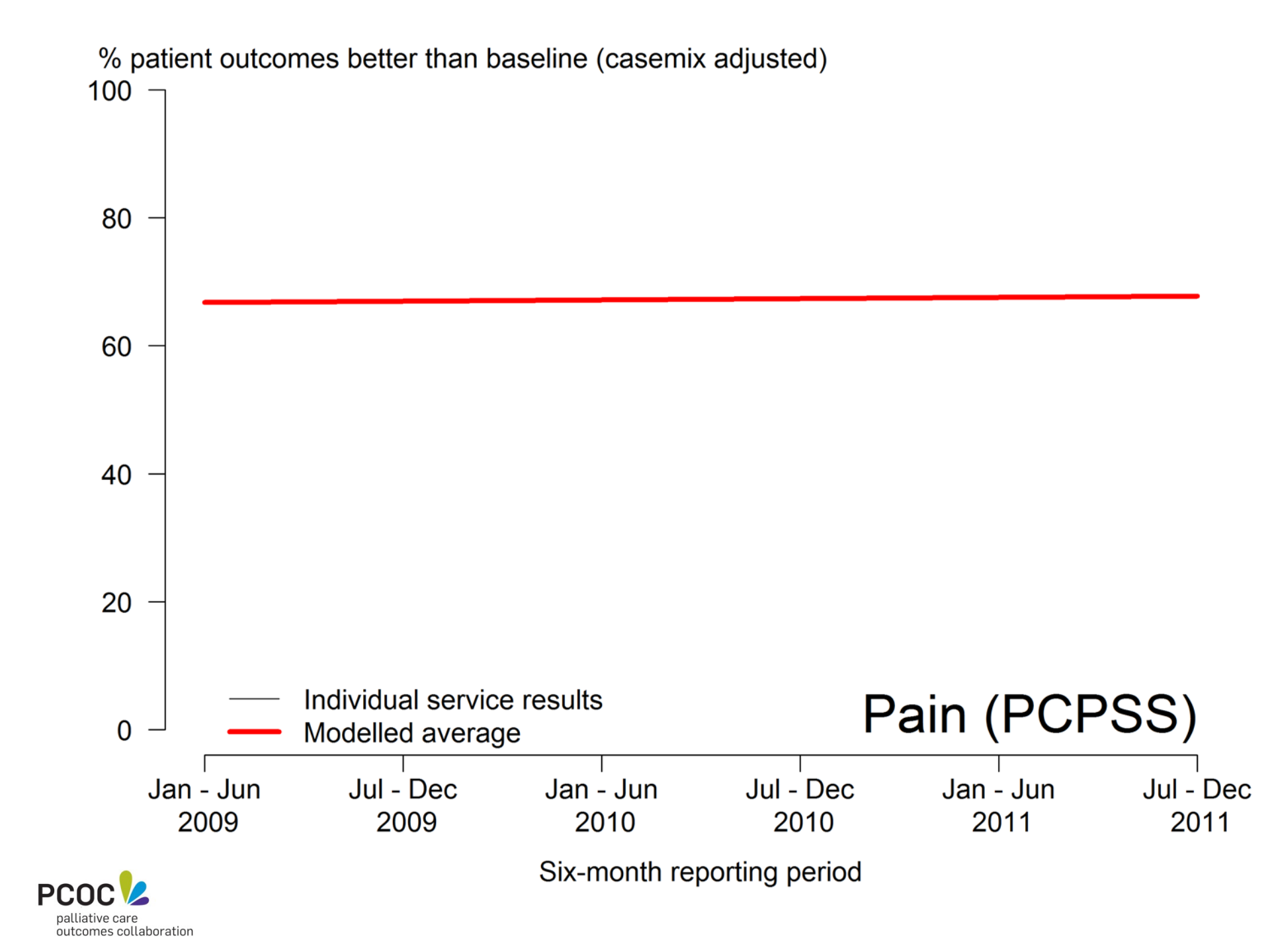

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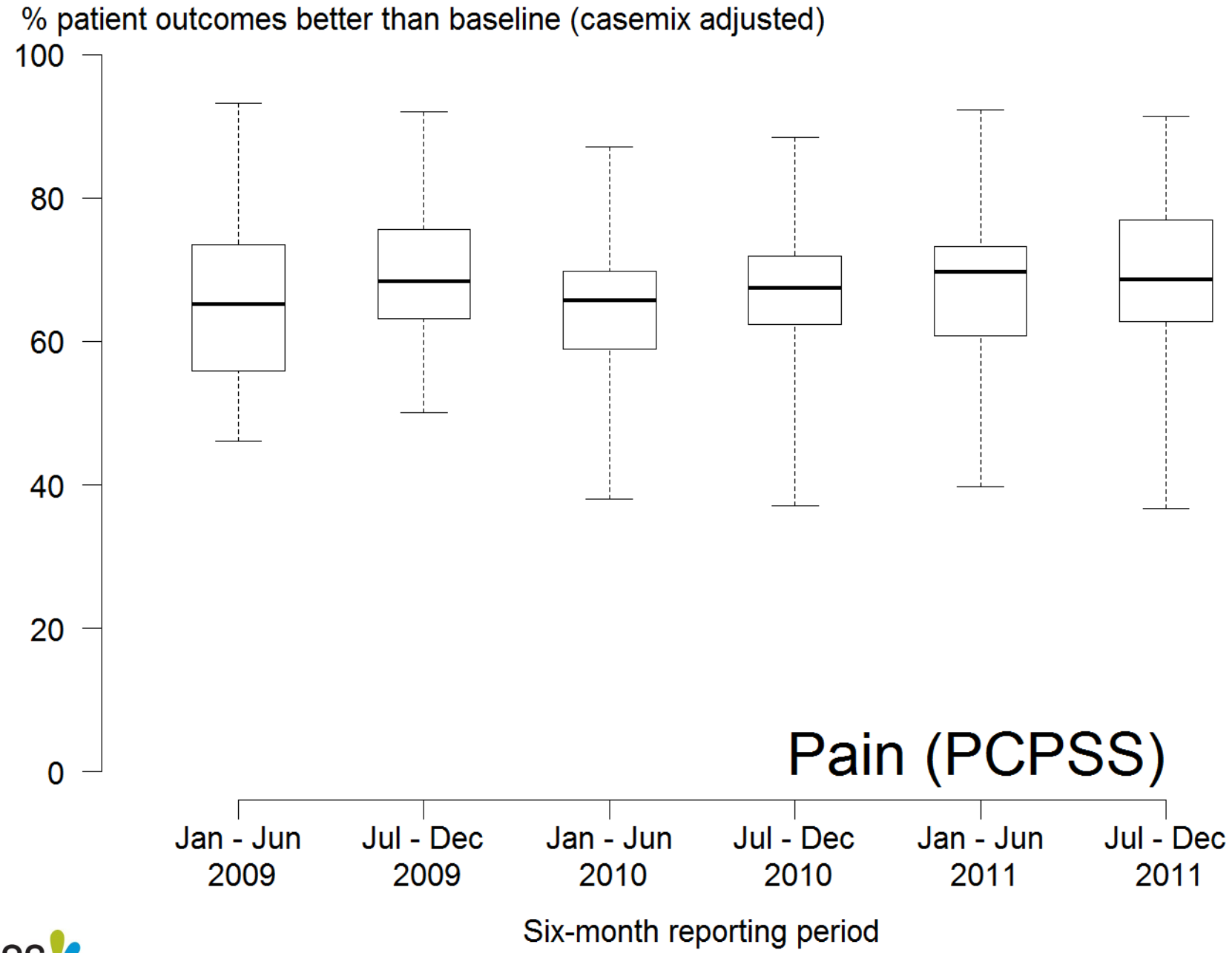

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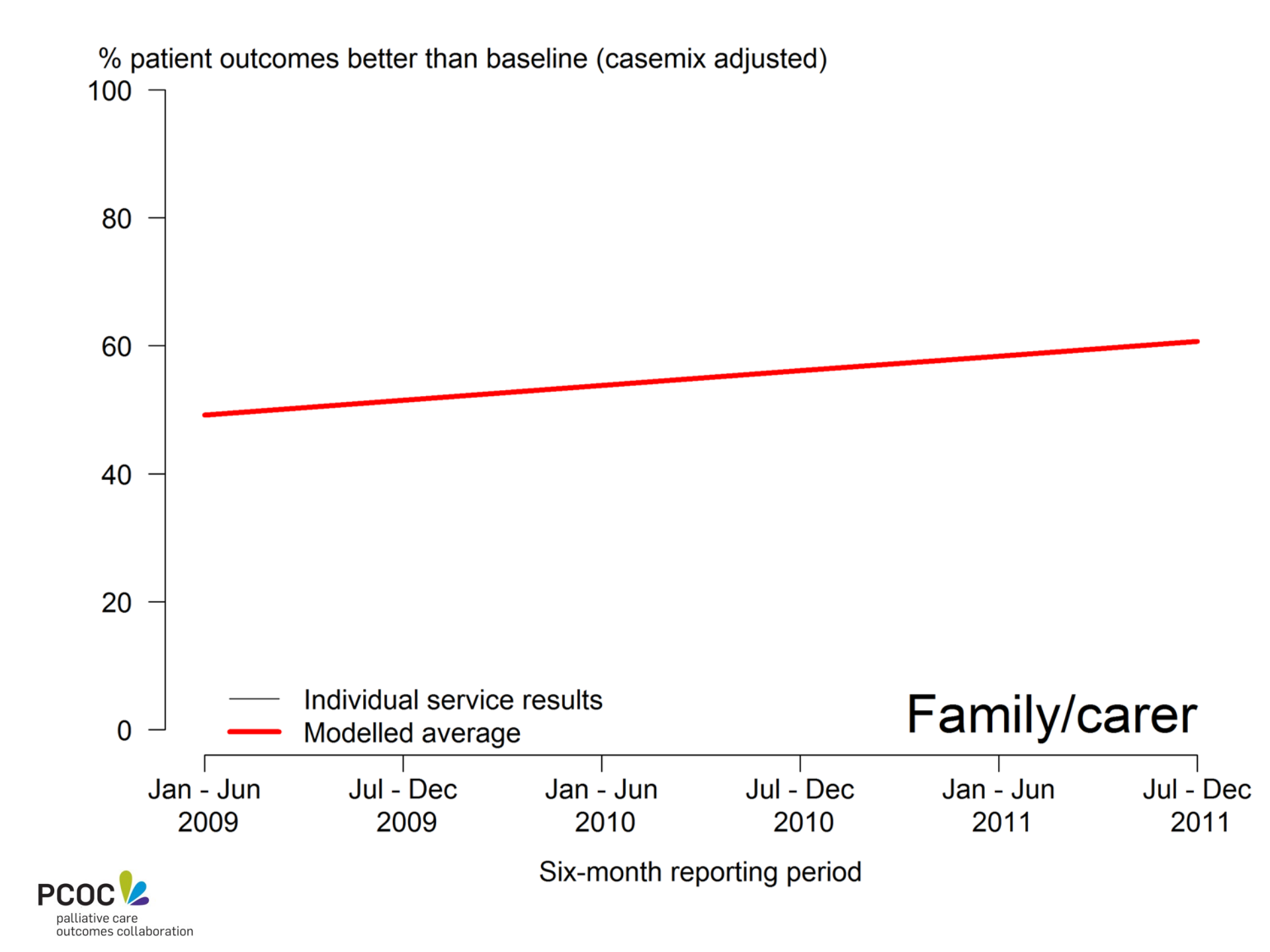

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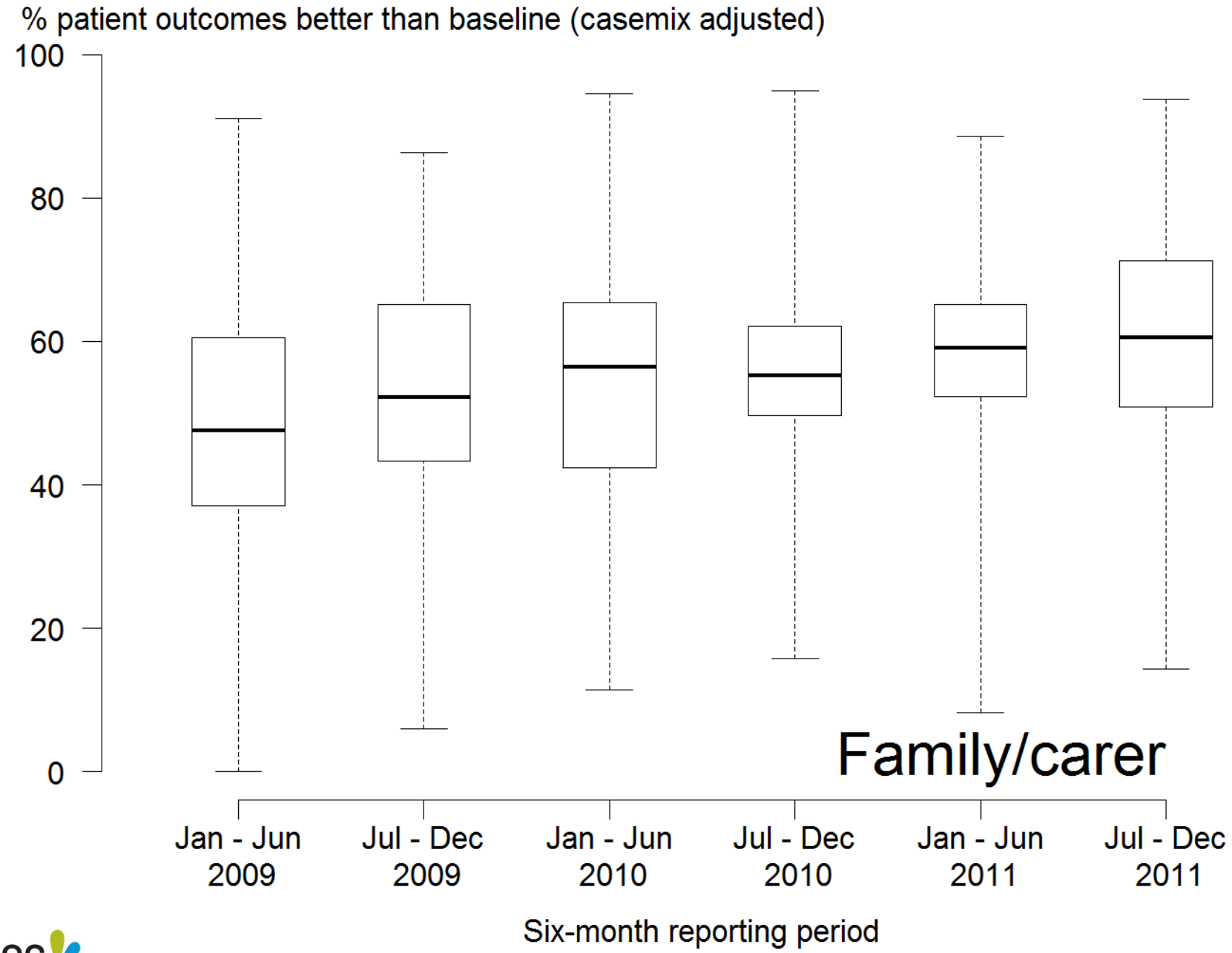

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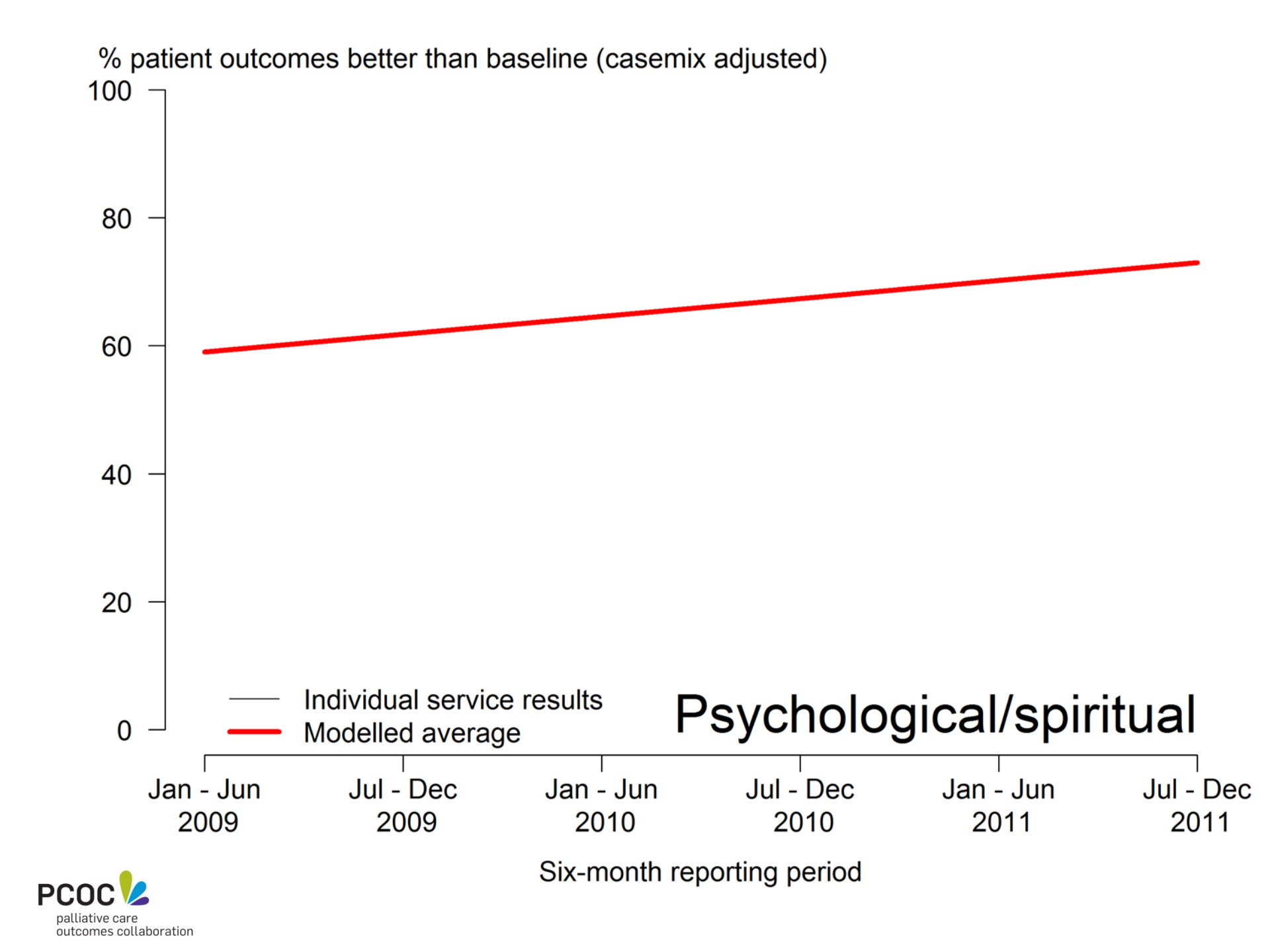

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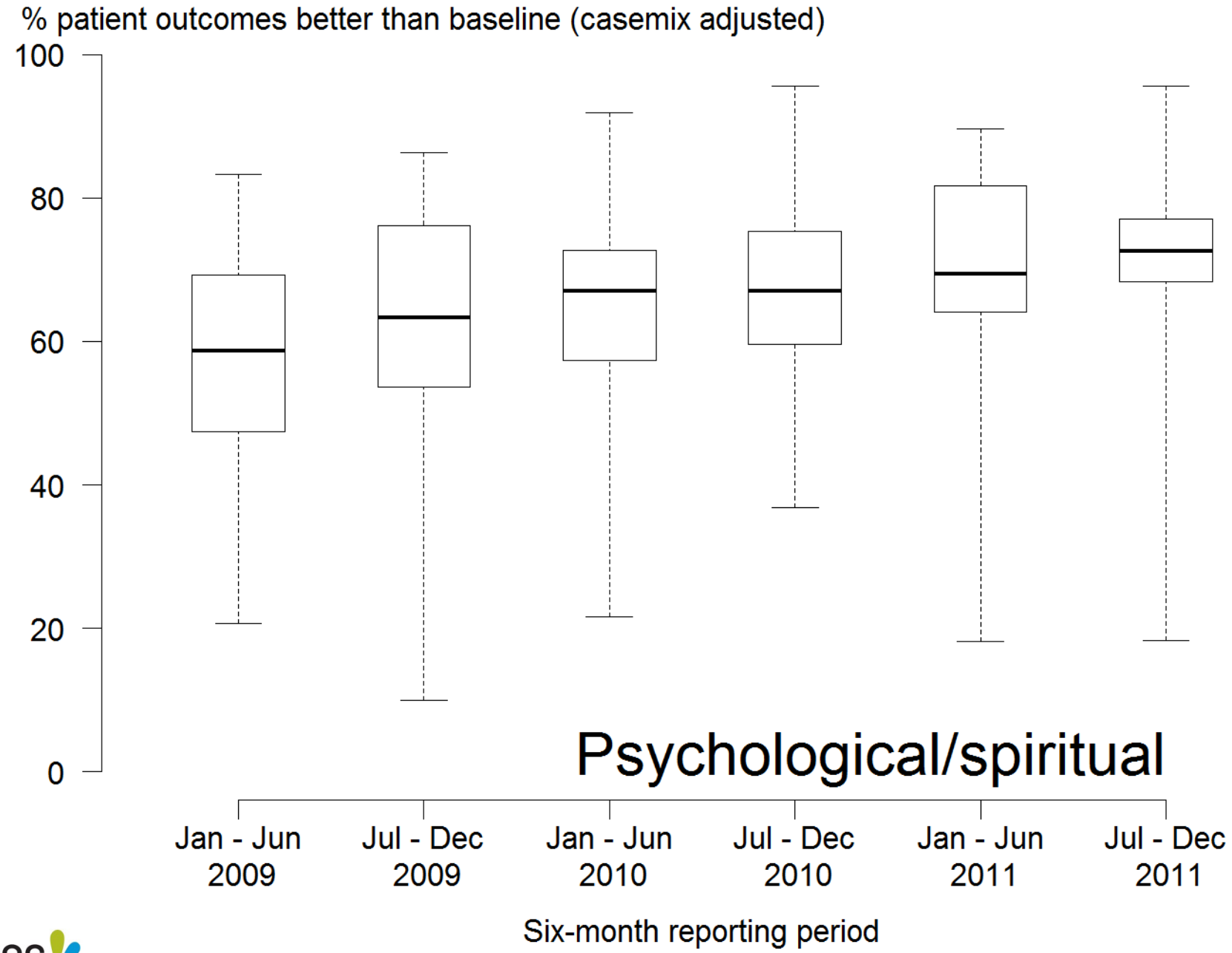

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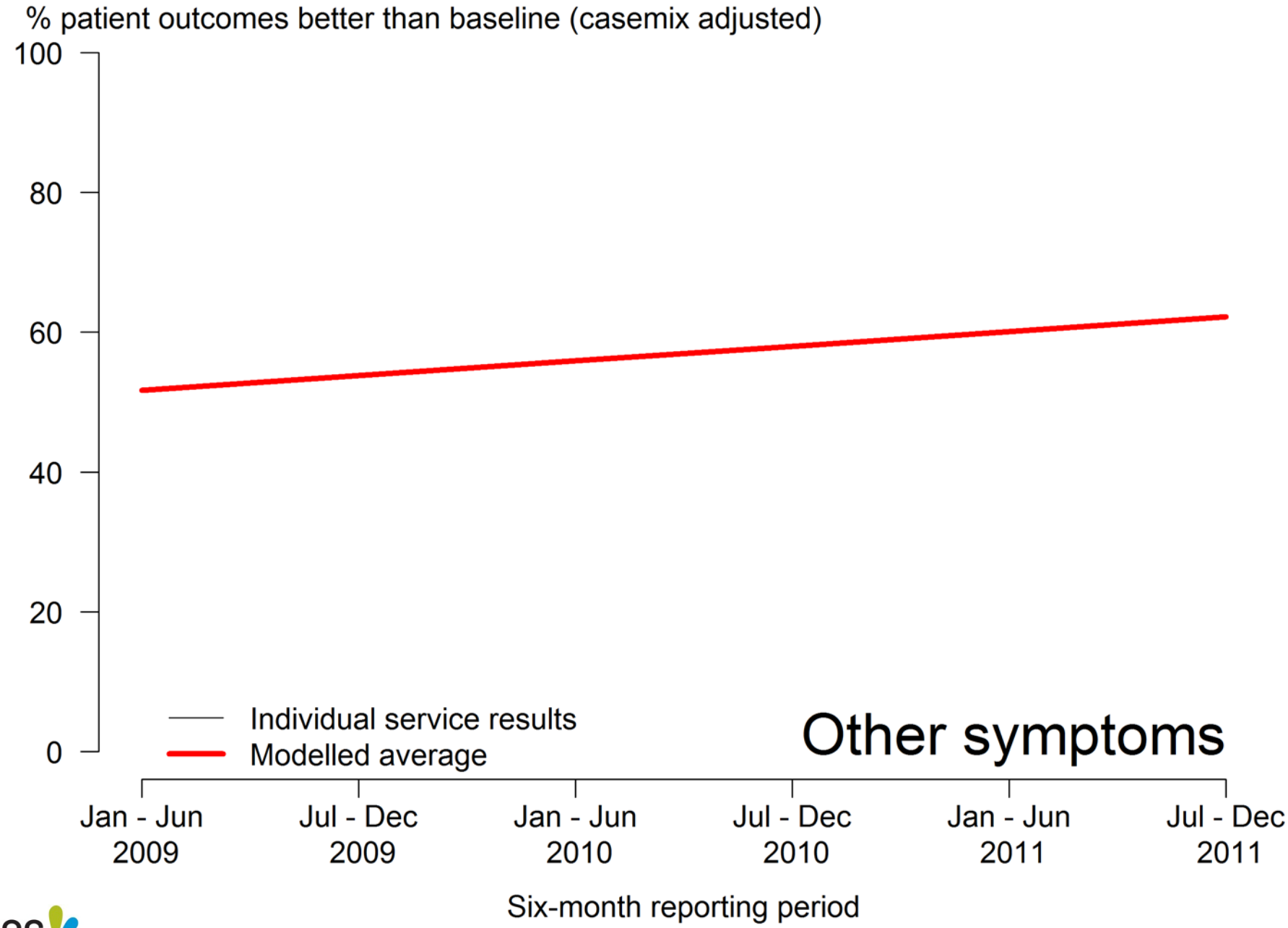

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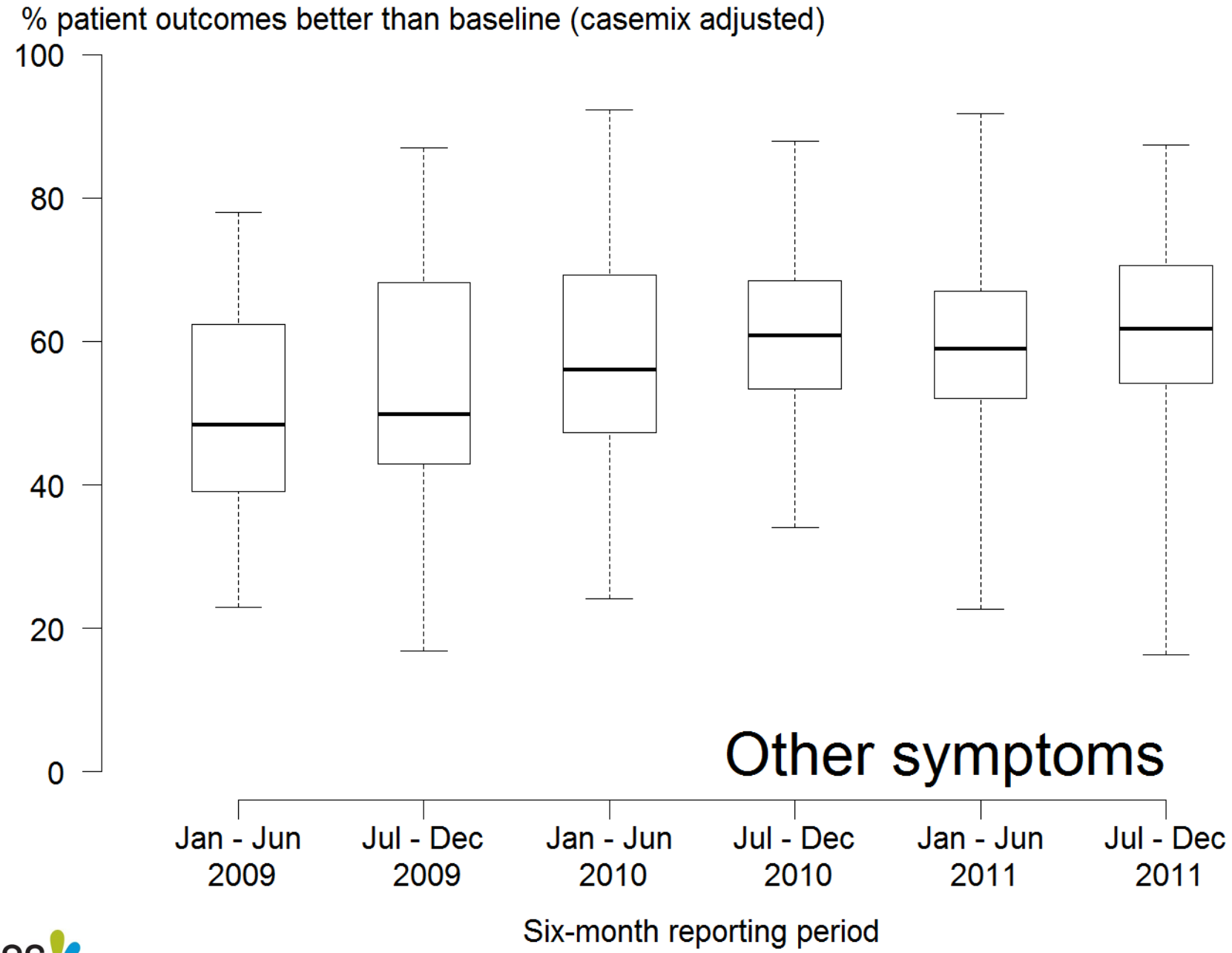

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Updated study : 2011 - 2014

- January 2011 – December 2014
- 45 specialist palliative care services of which 20 were also included in initial study
- Changes in study population caused by:
  - Improving data quality
  - IT system changes
  - Service restructuring

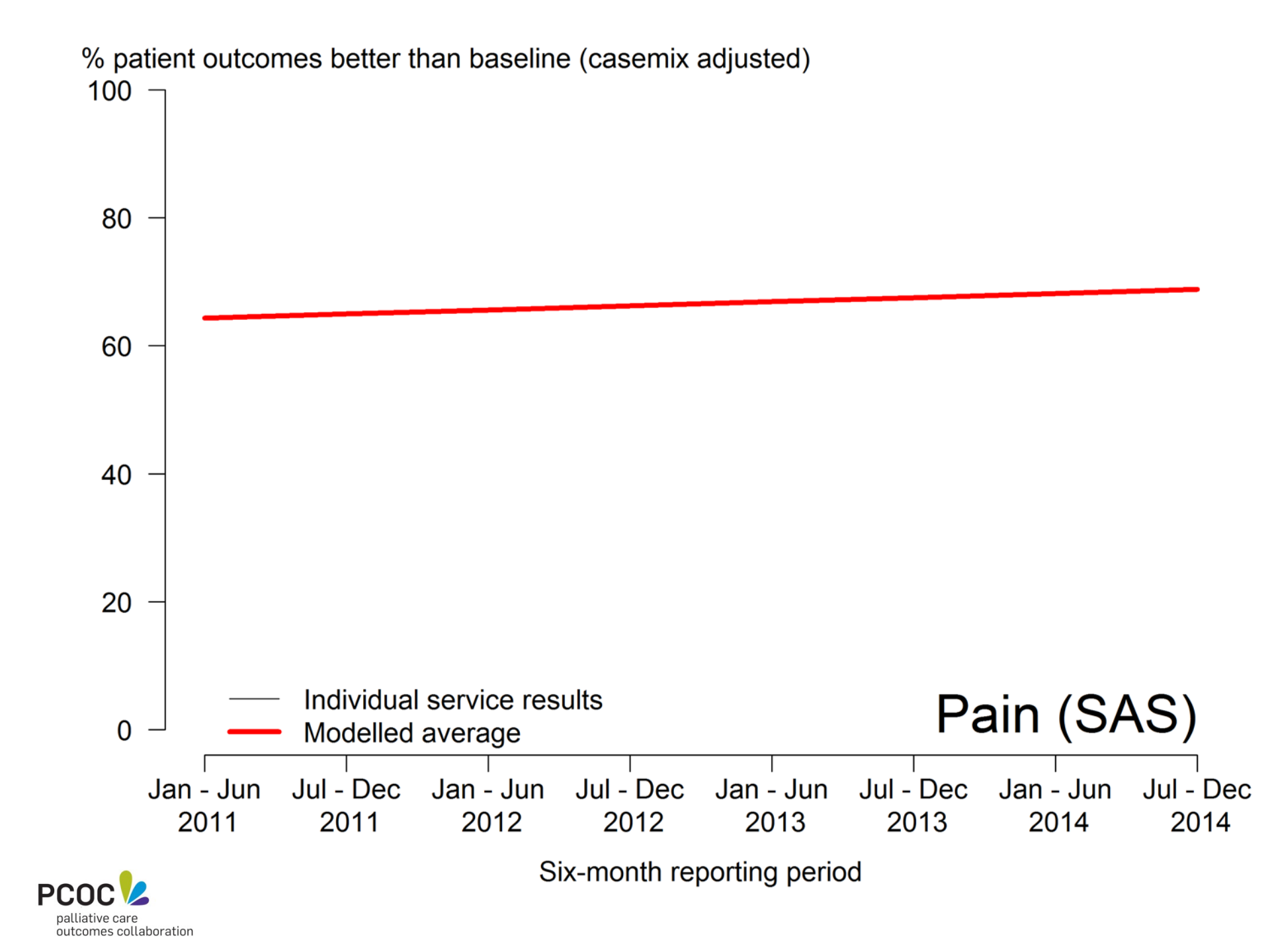
Updated method

- Analysis of 45 services participating in the PCOC cycle consistently between January 2011 and December 2014

- Assessing patient outcomes using both SAS and PCPSS

Updated results : 2011 - 2014

- 60,816 patients and 196,152 phases
- 47% female
- 79% malignant diagnosis
- Average age 72.7 years (SD 14.3)
- **Statistically significant improvements in all domains**



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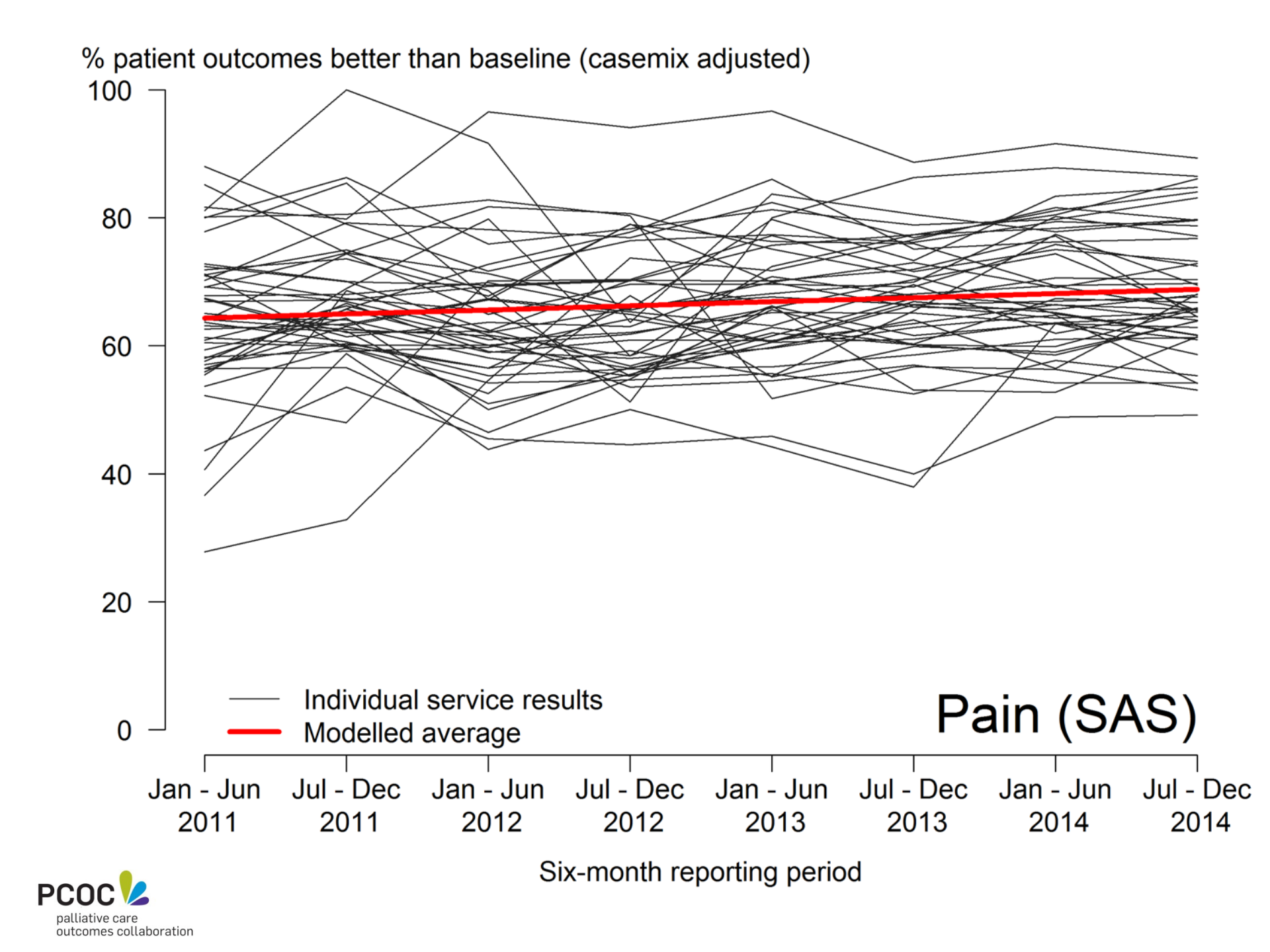

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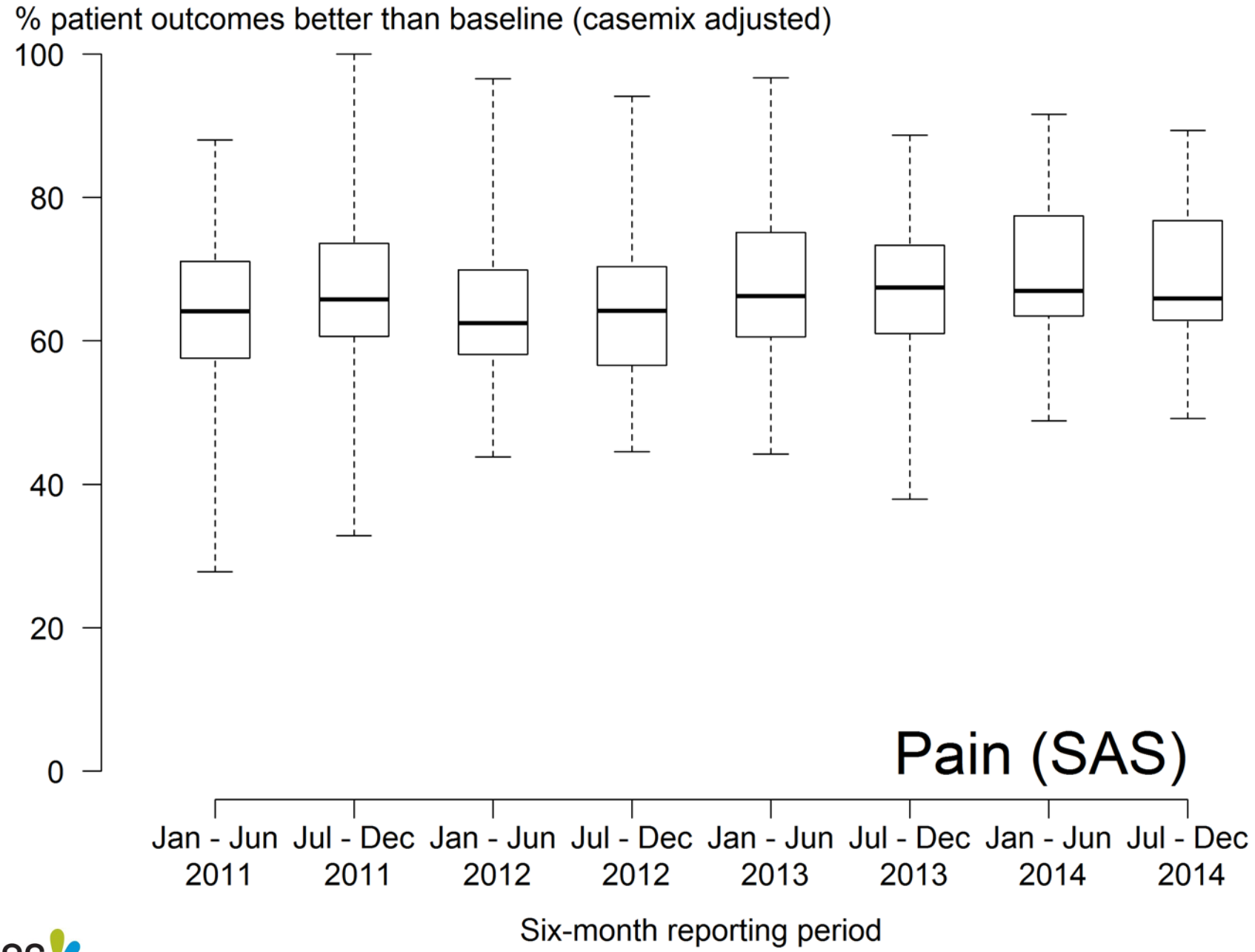

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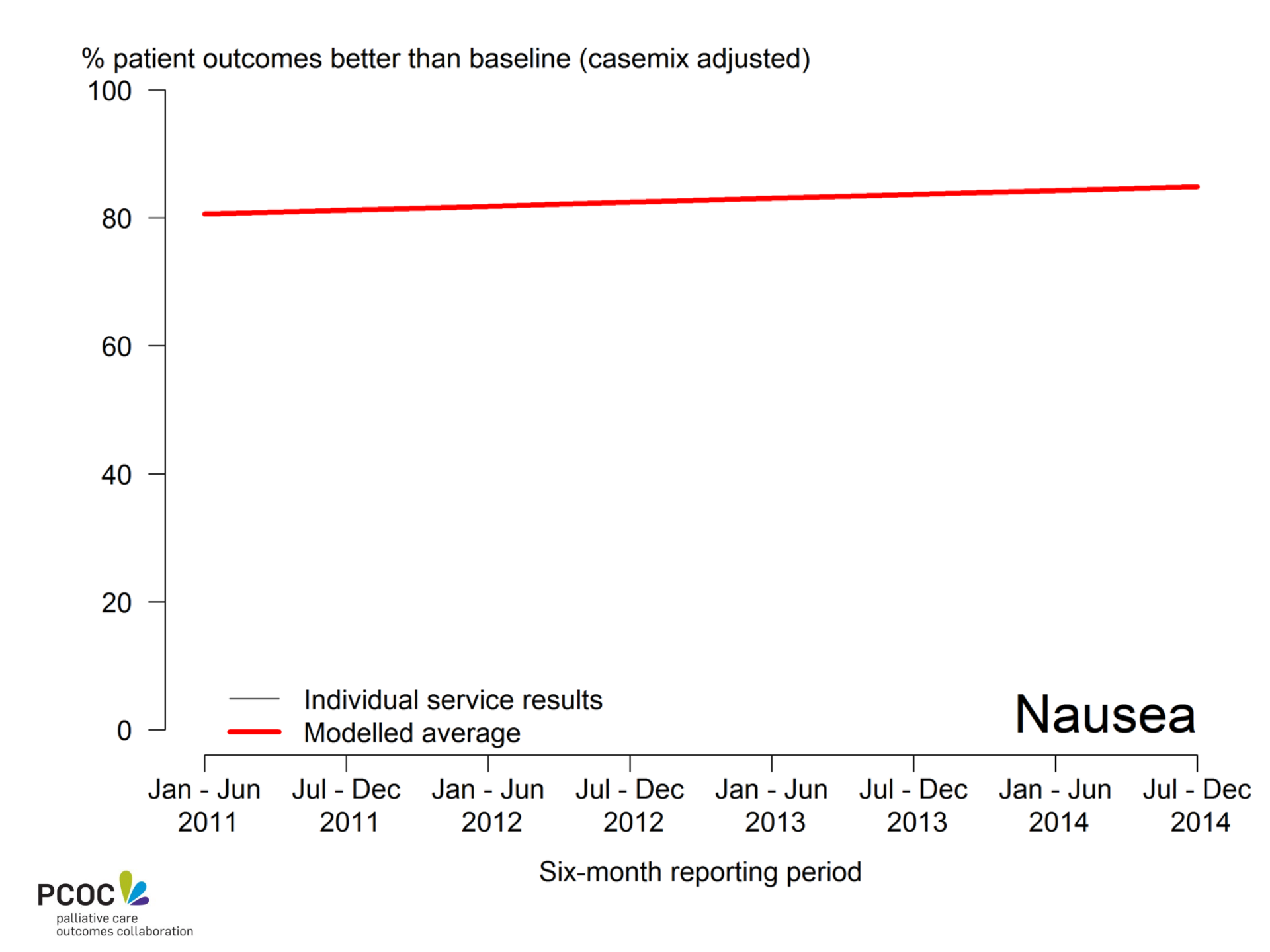

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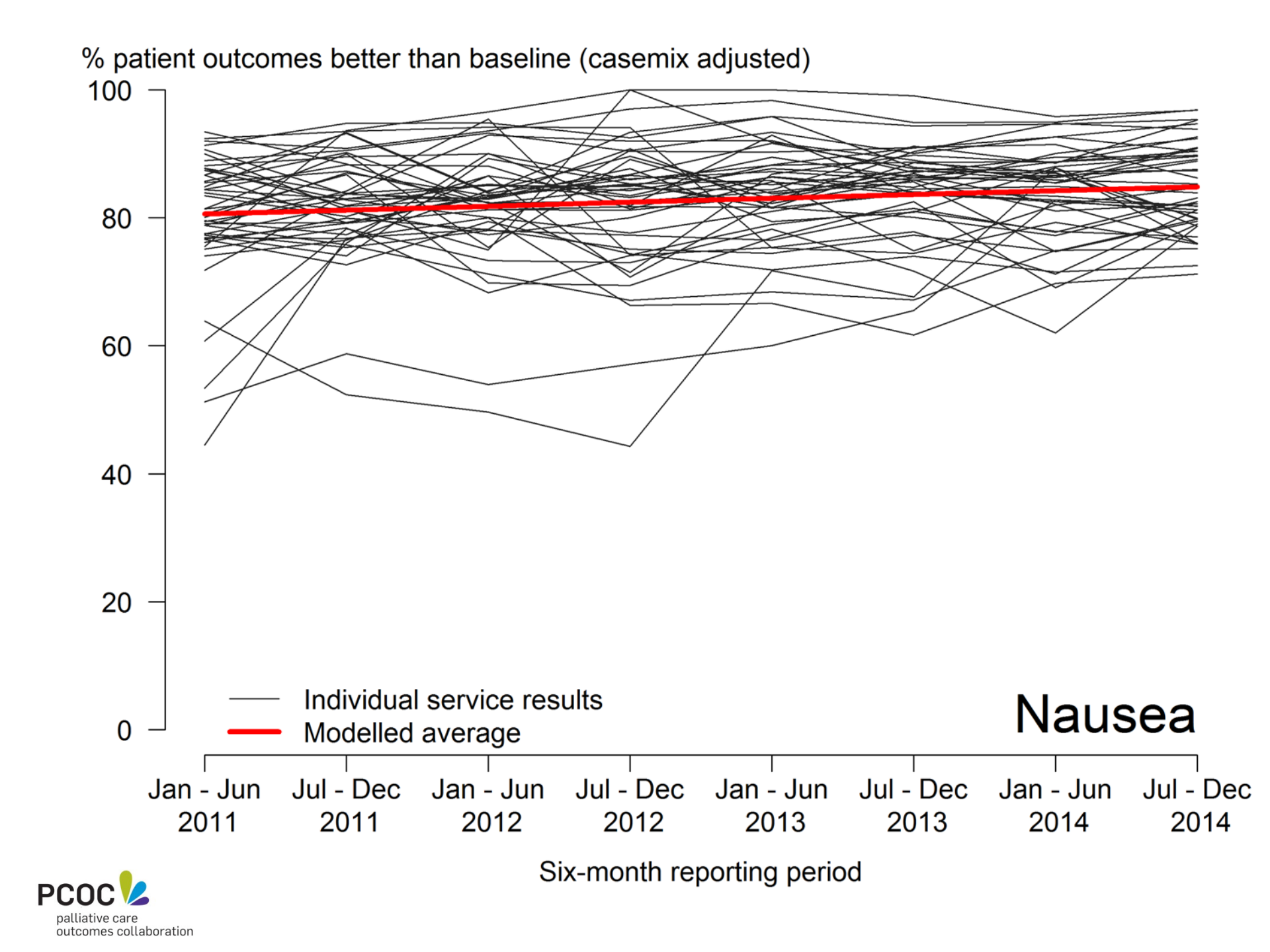

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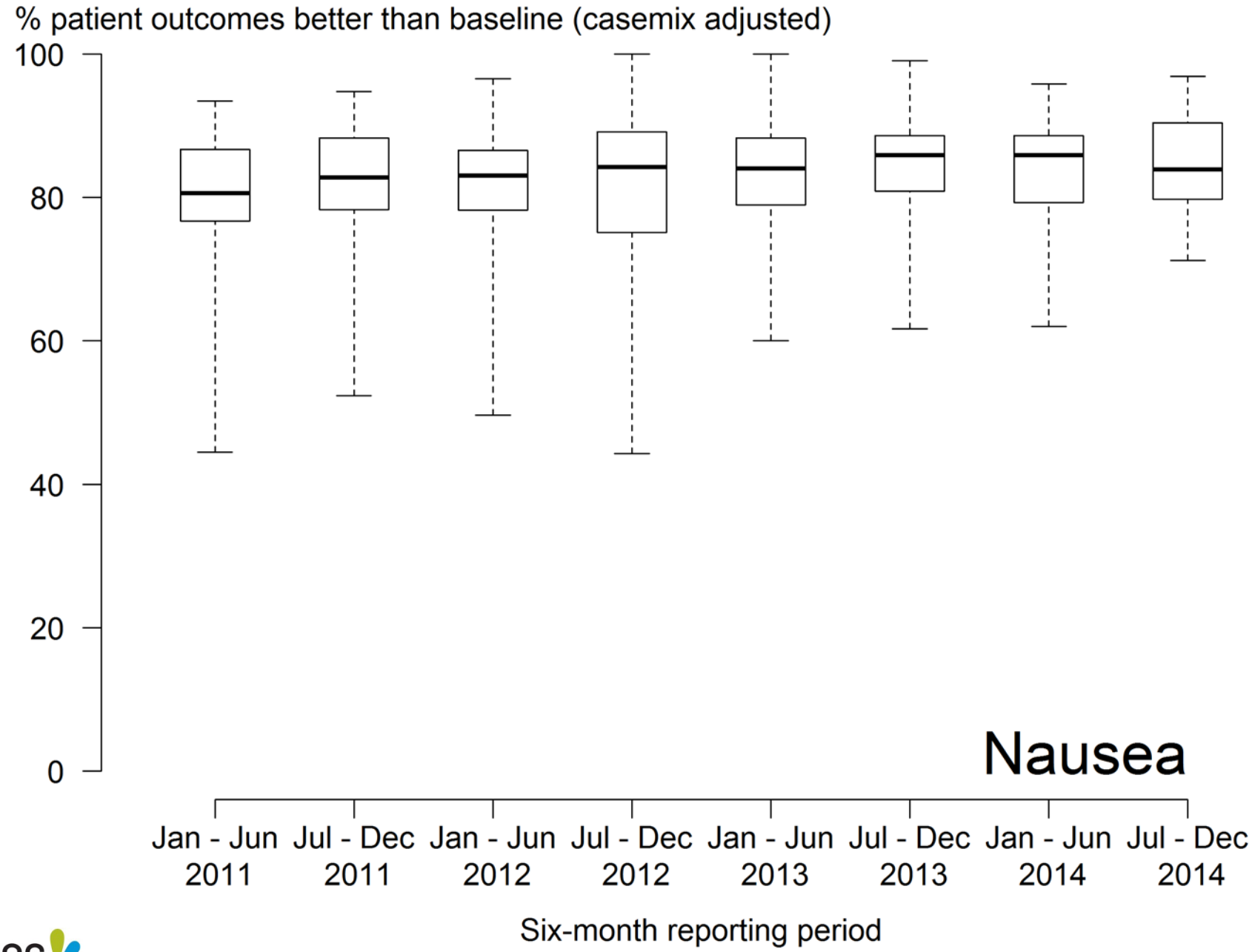

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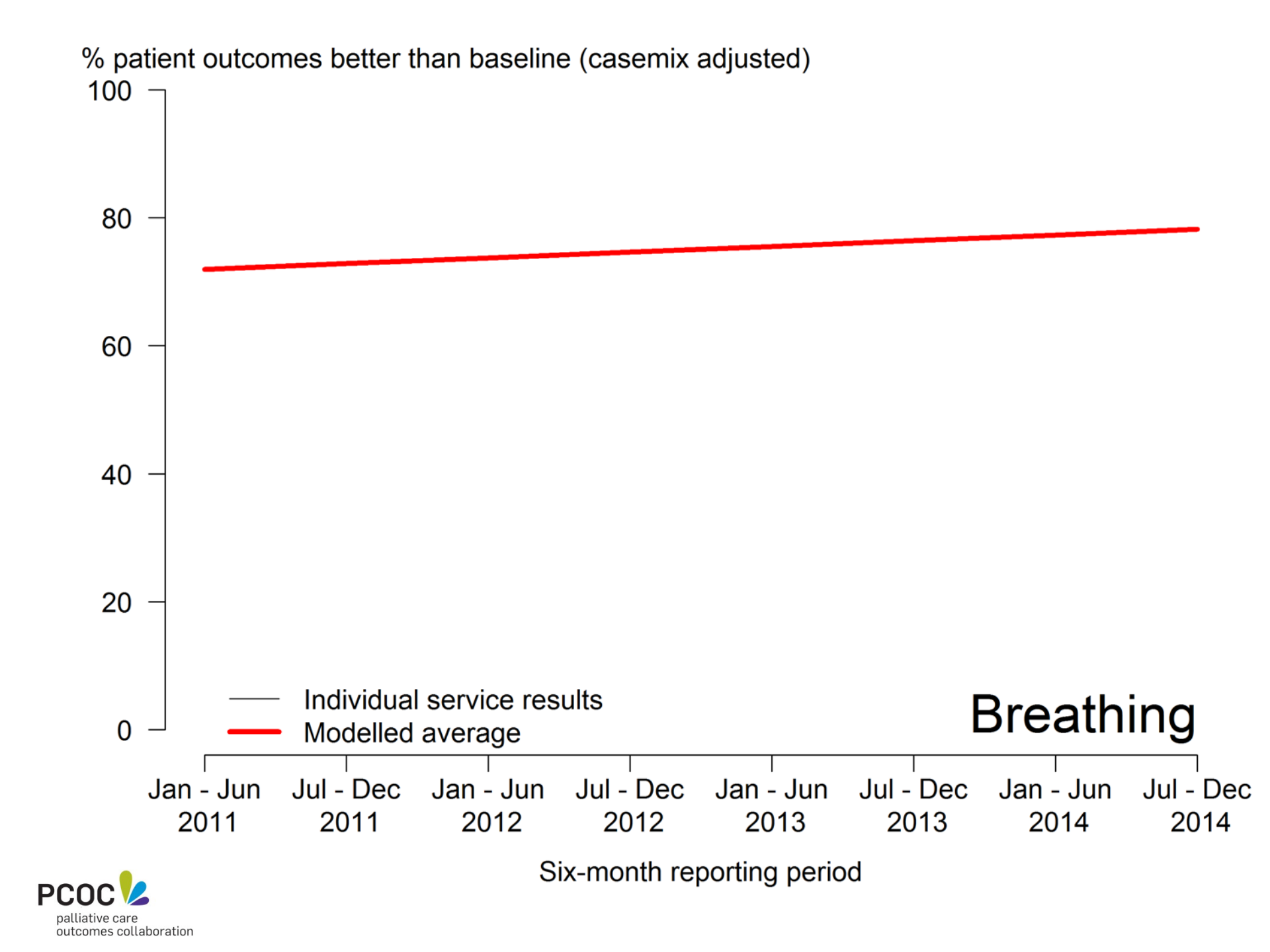

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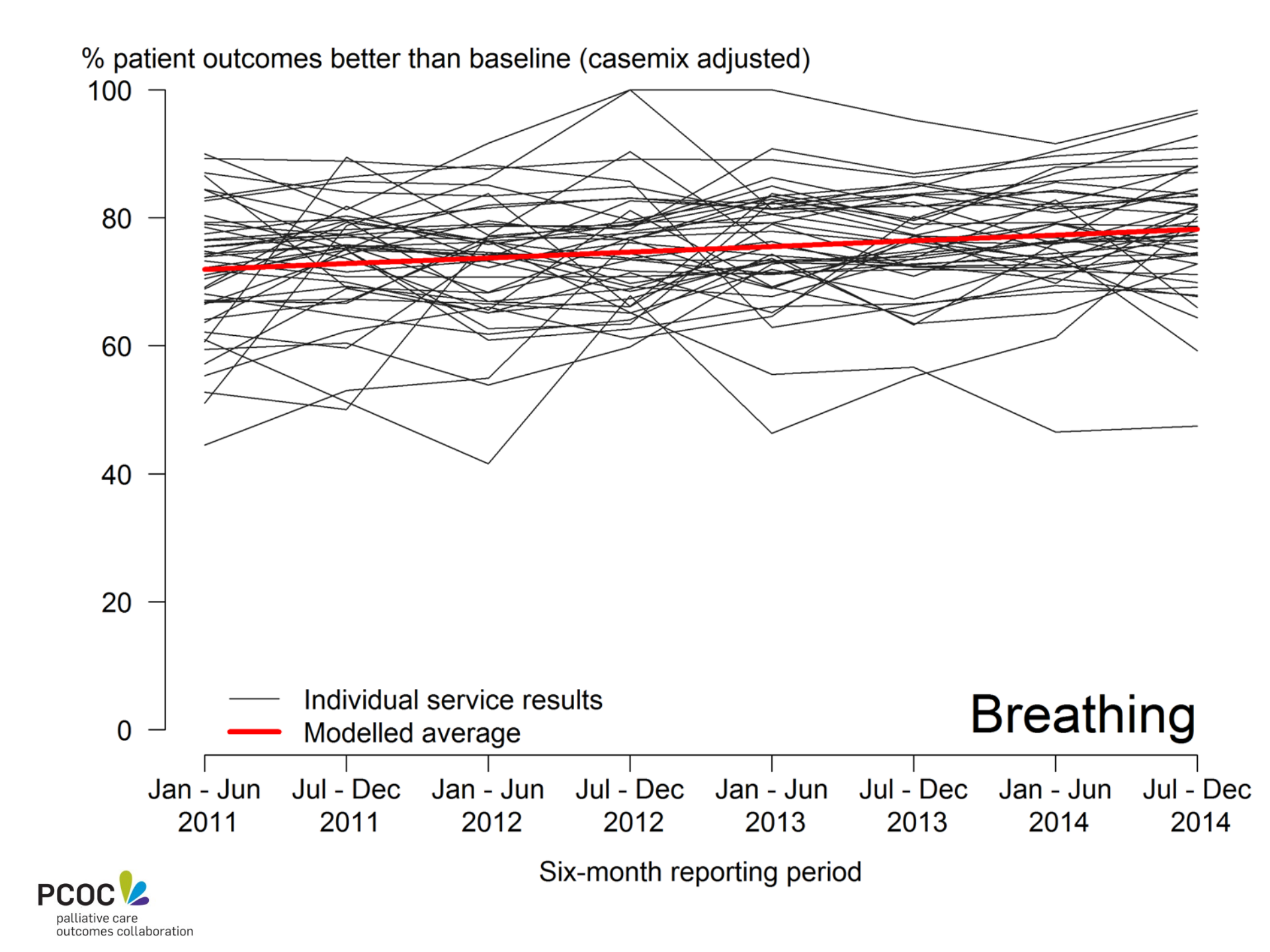

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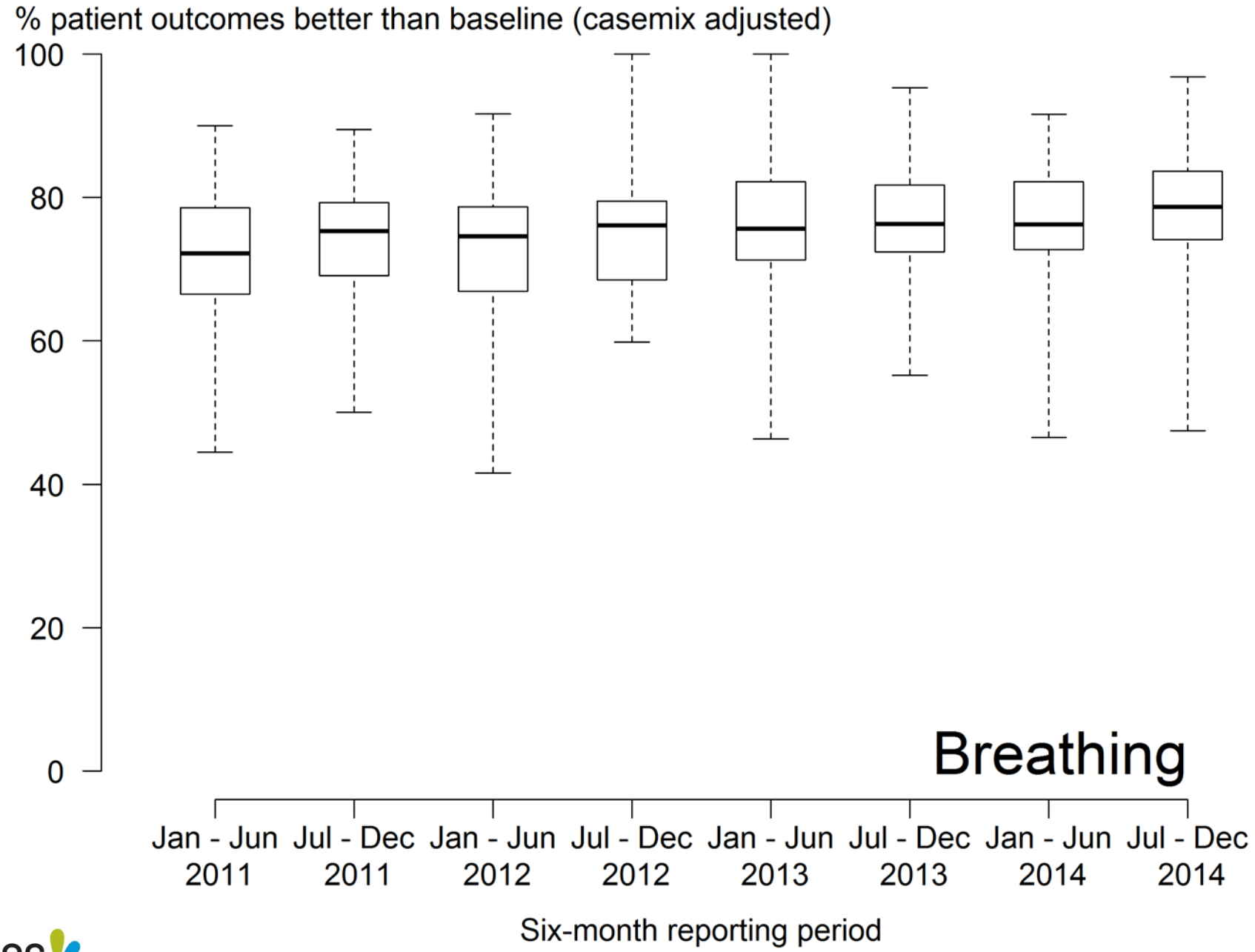

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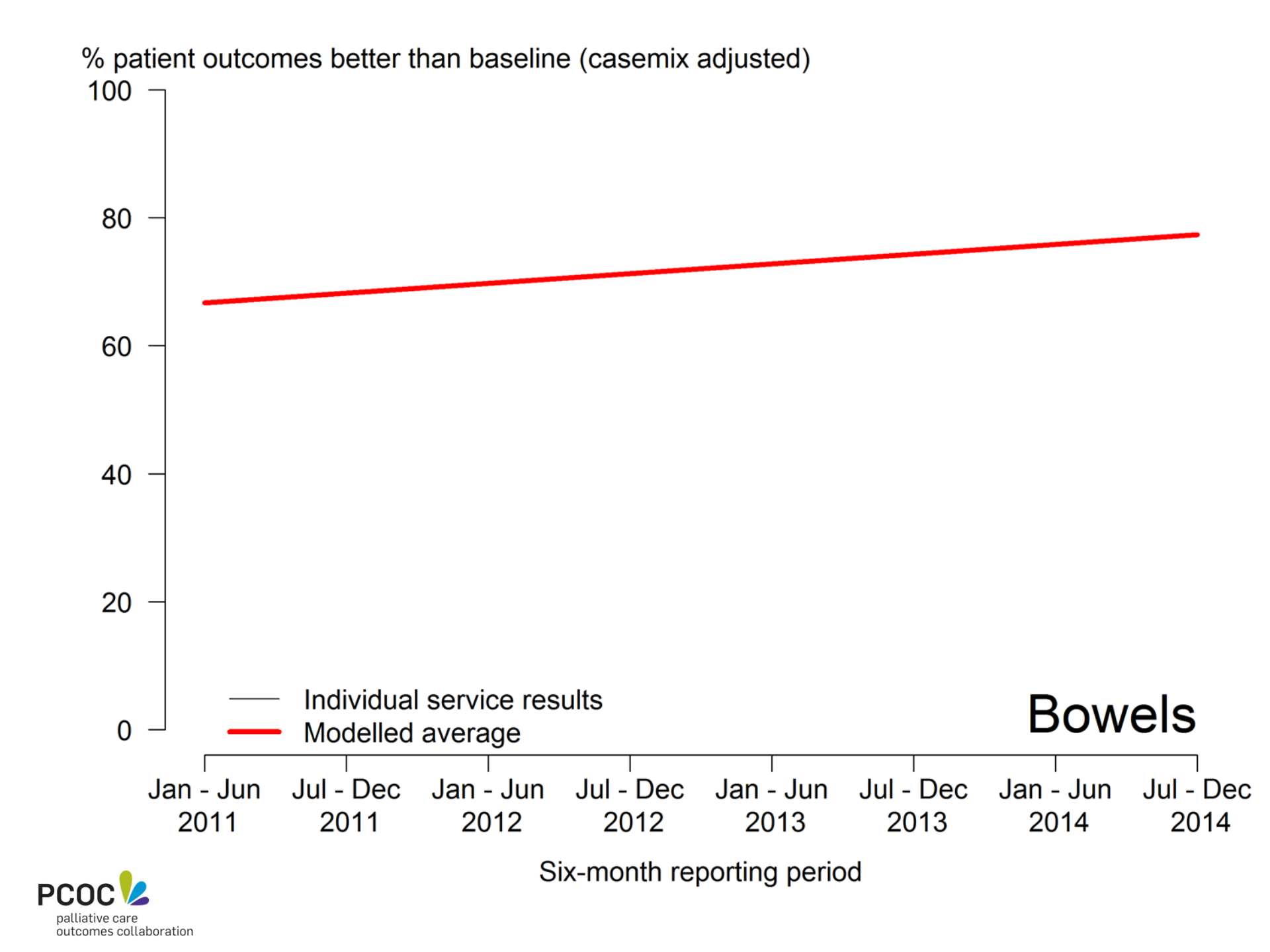

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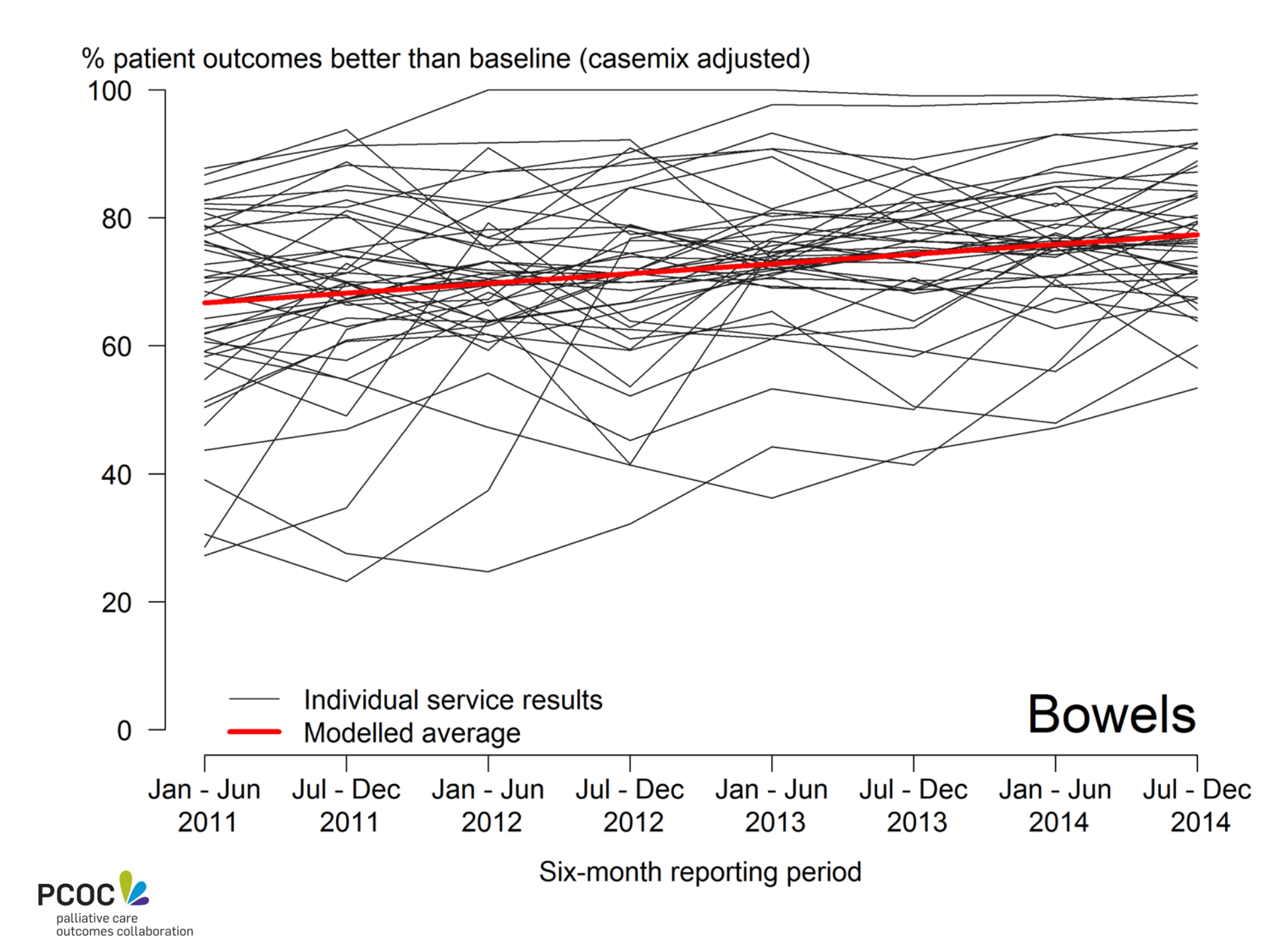

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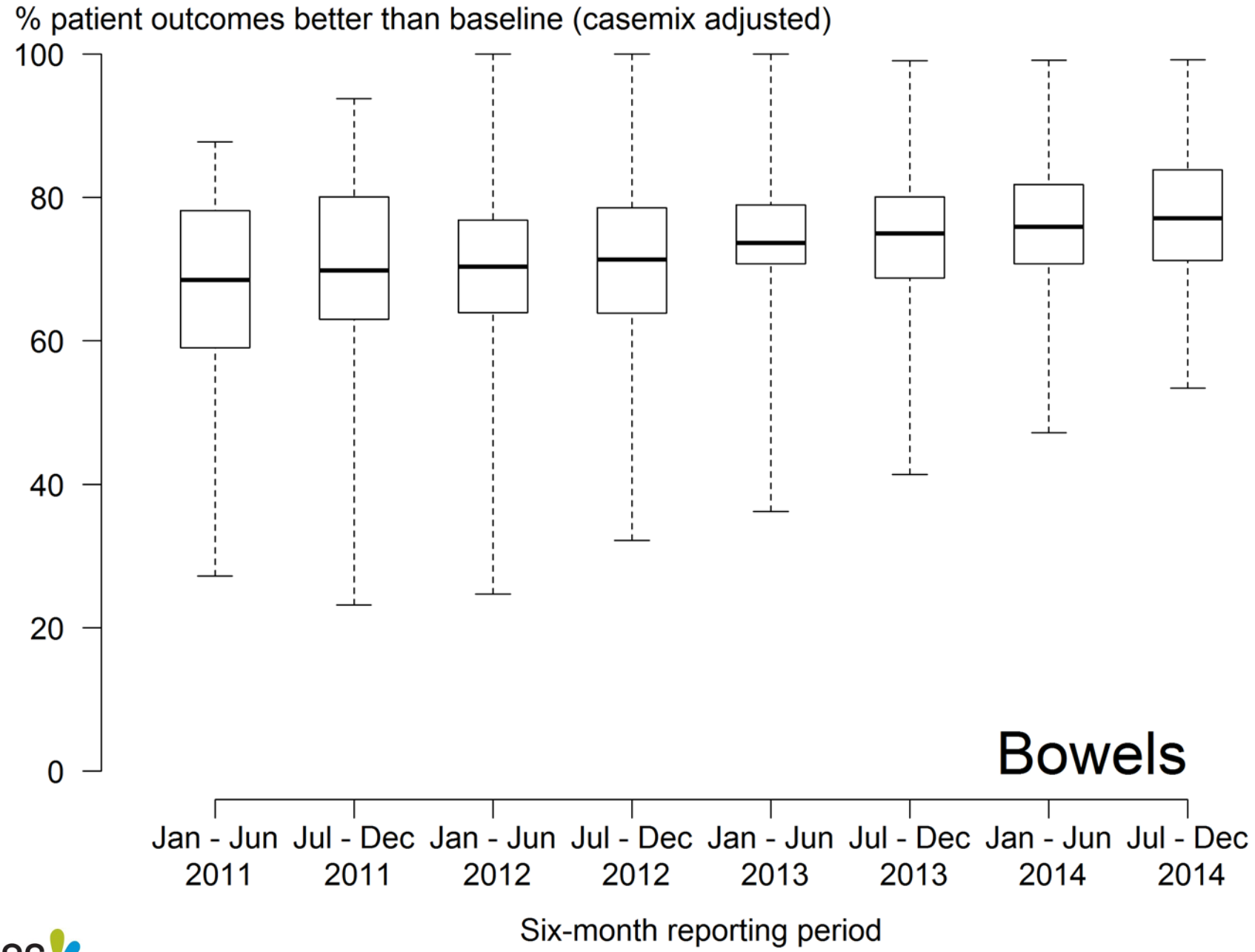

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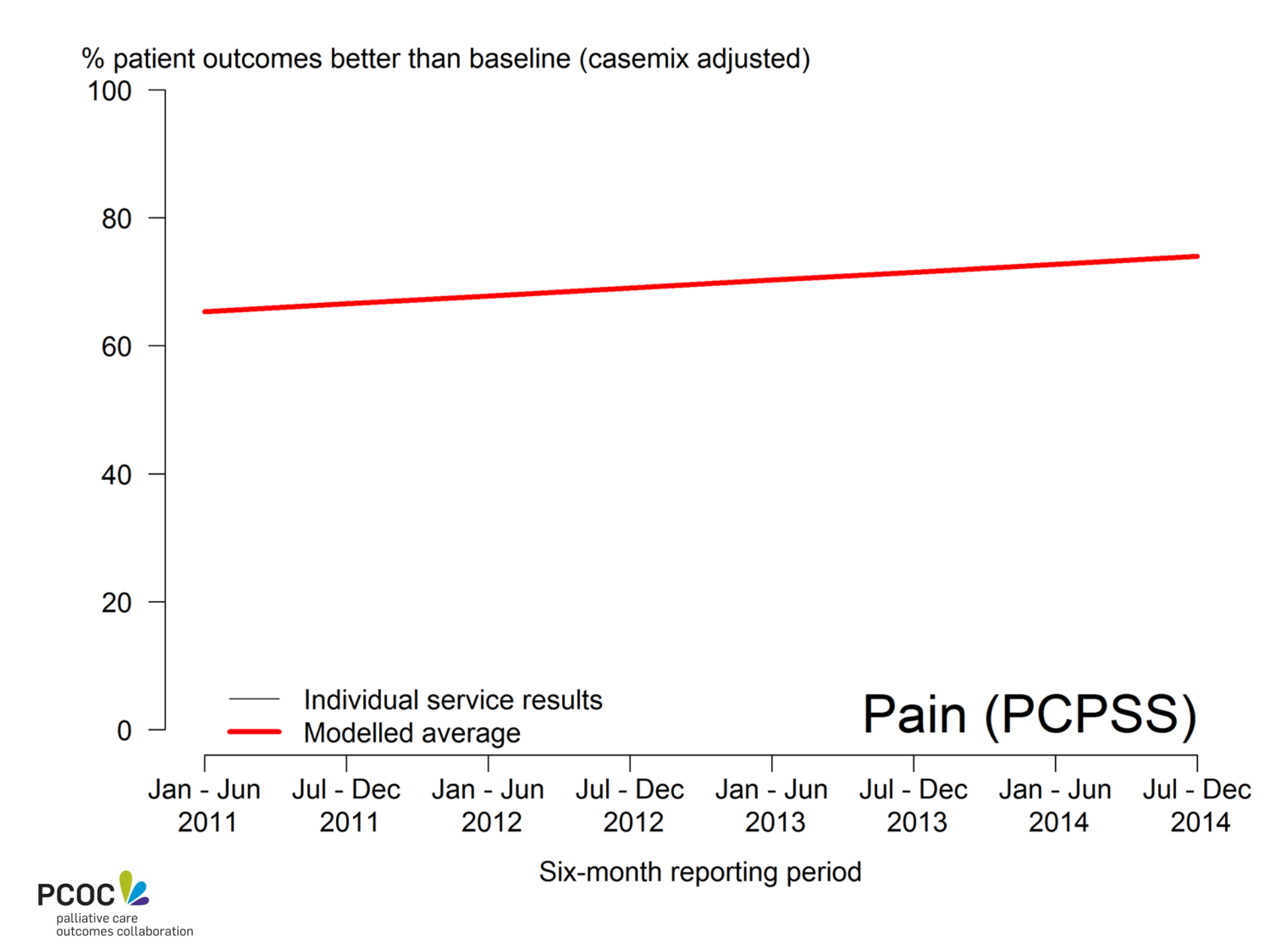

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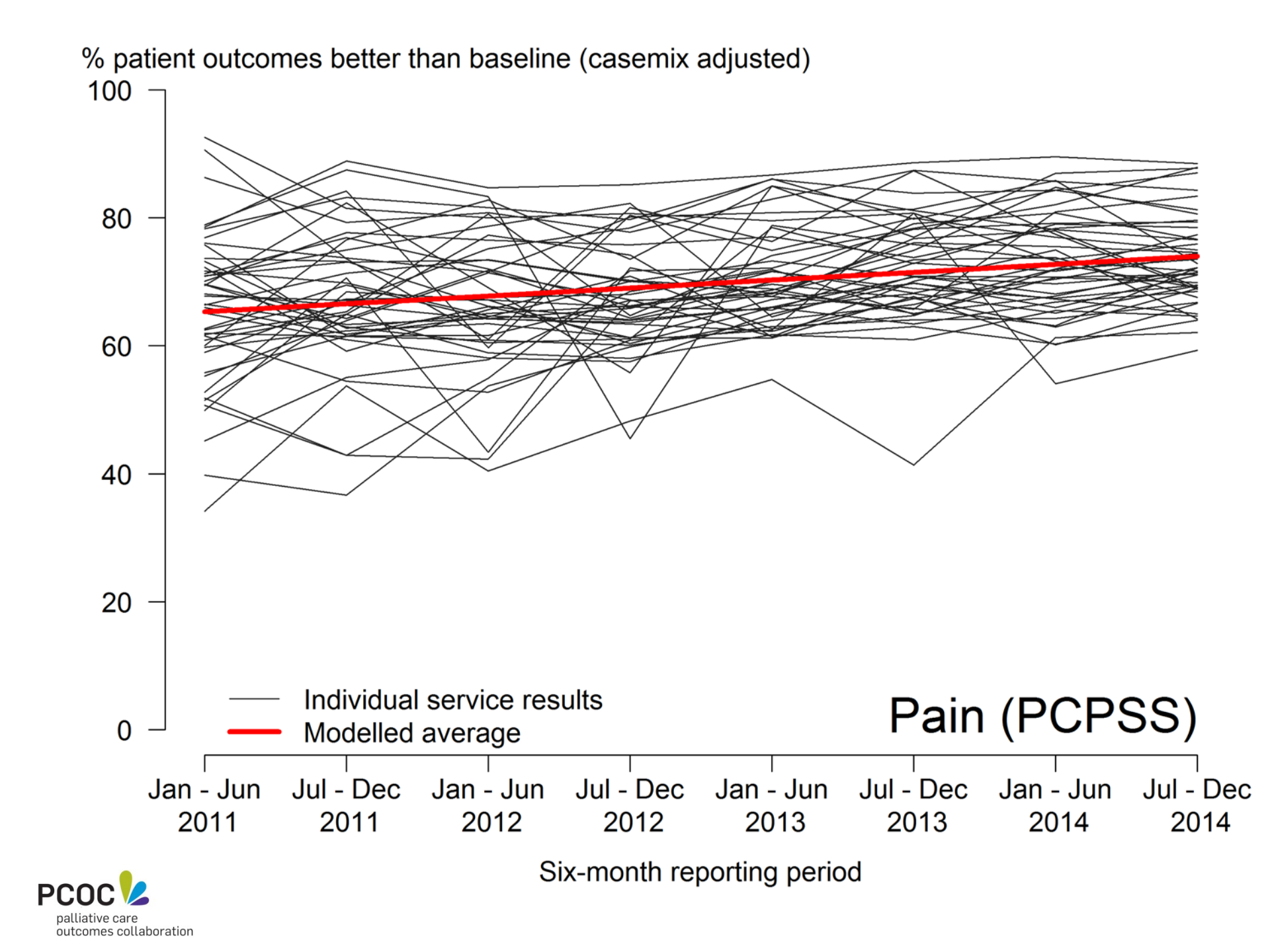

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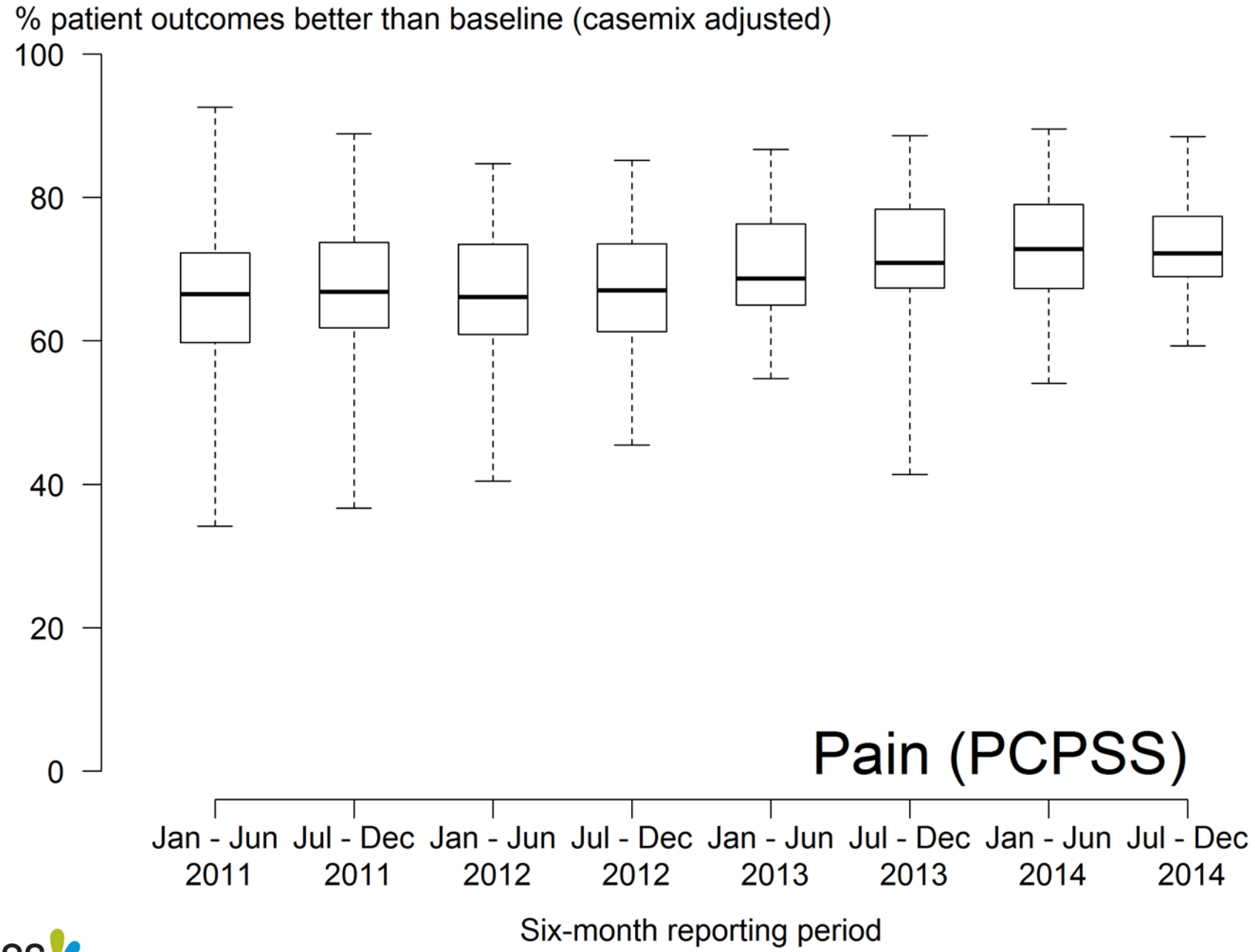

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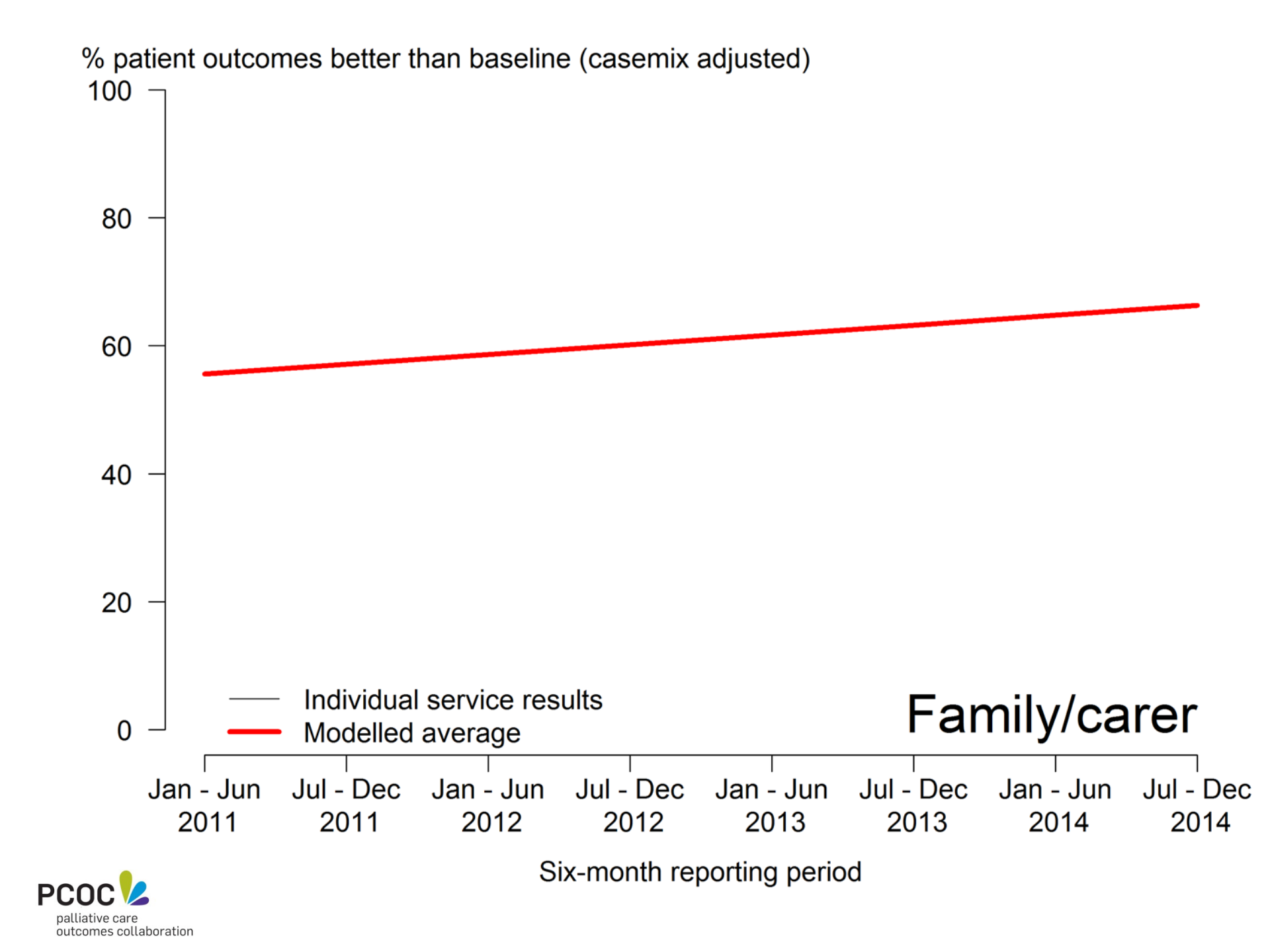

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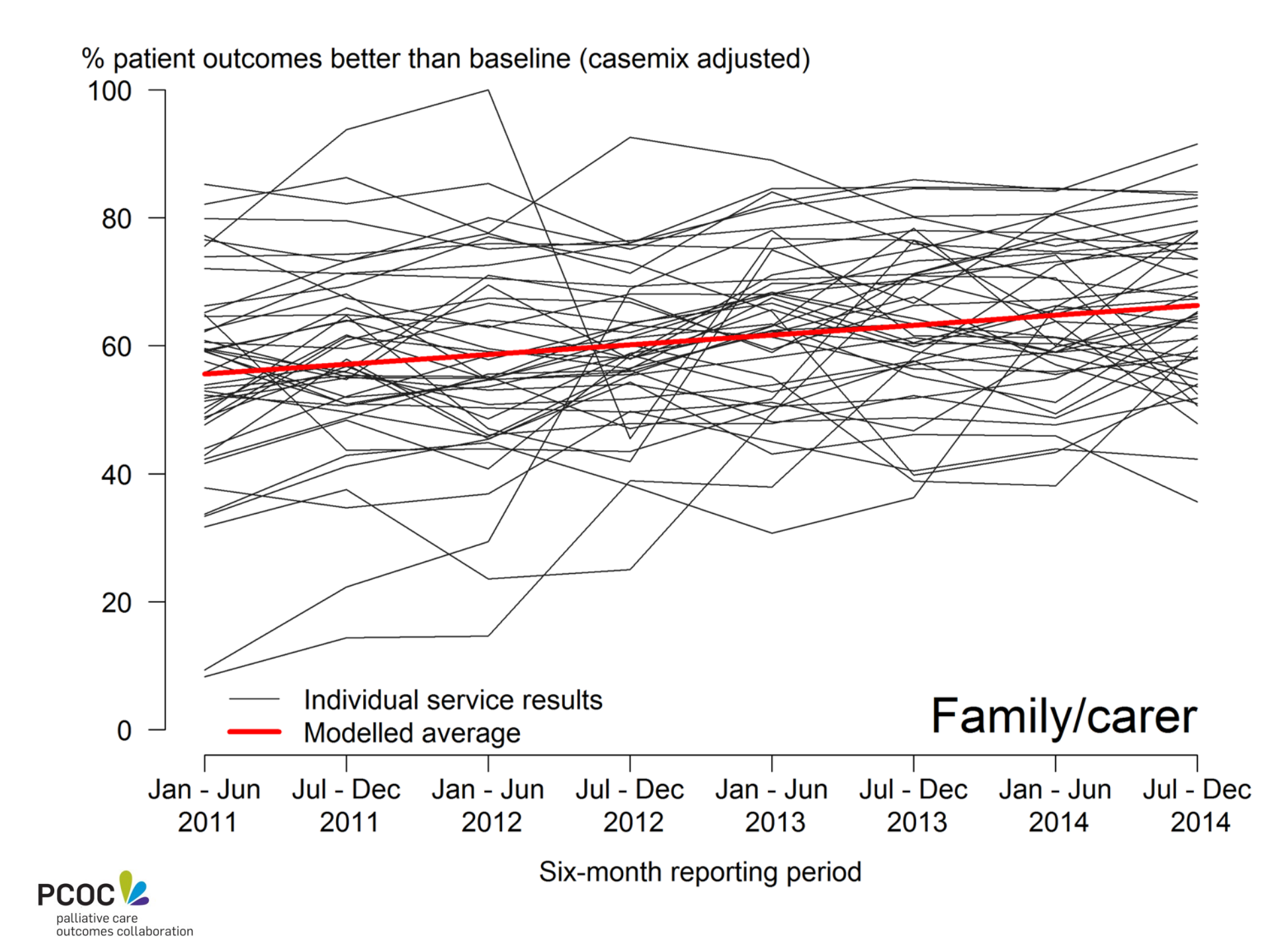

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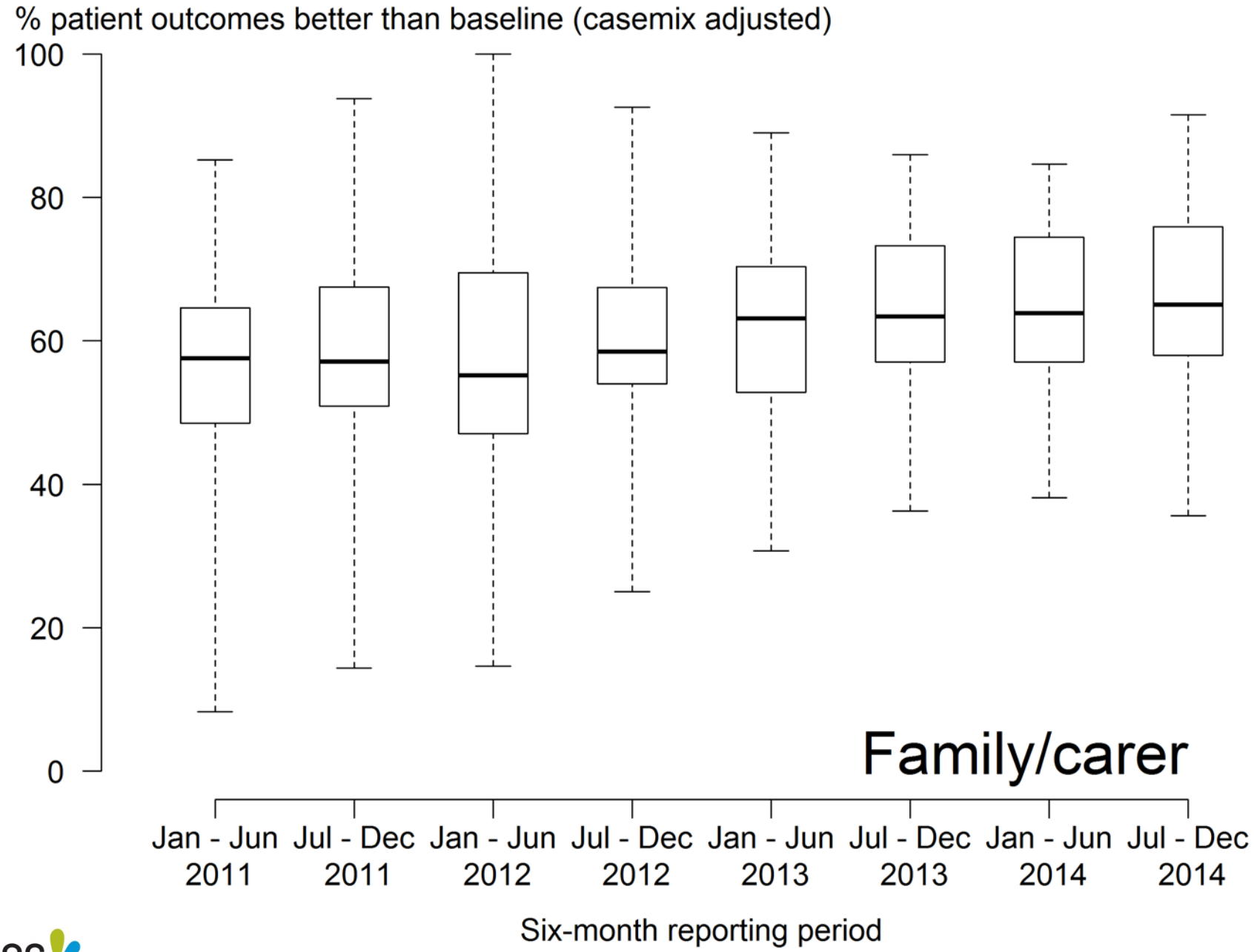

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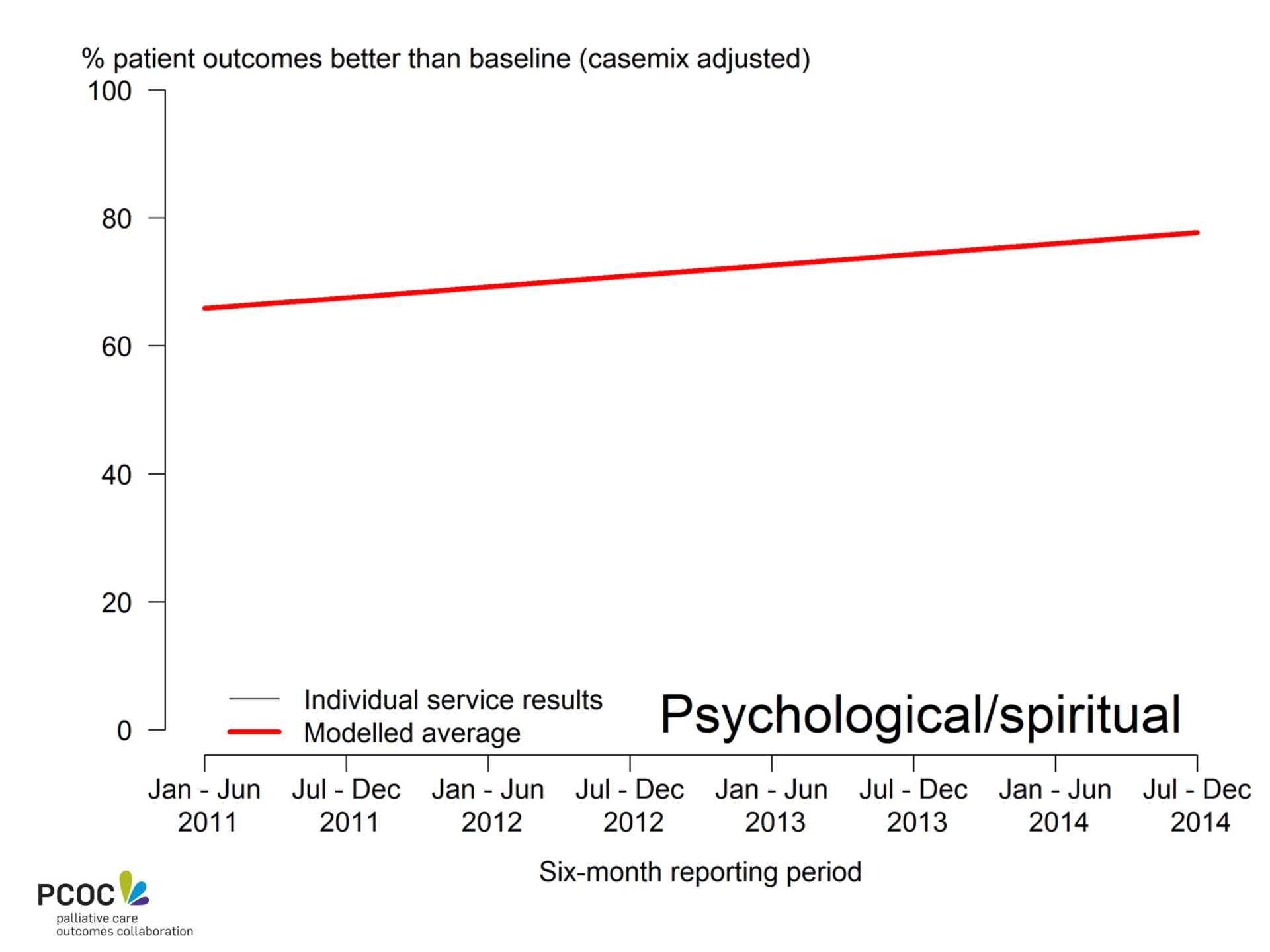

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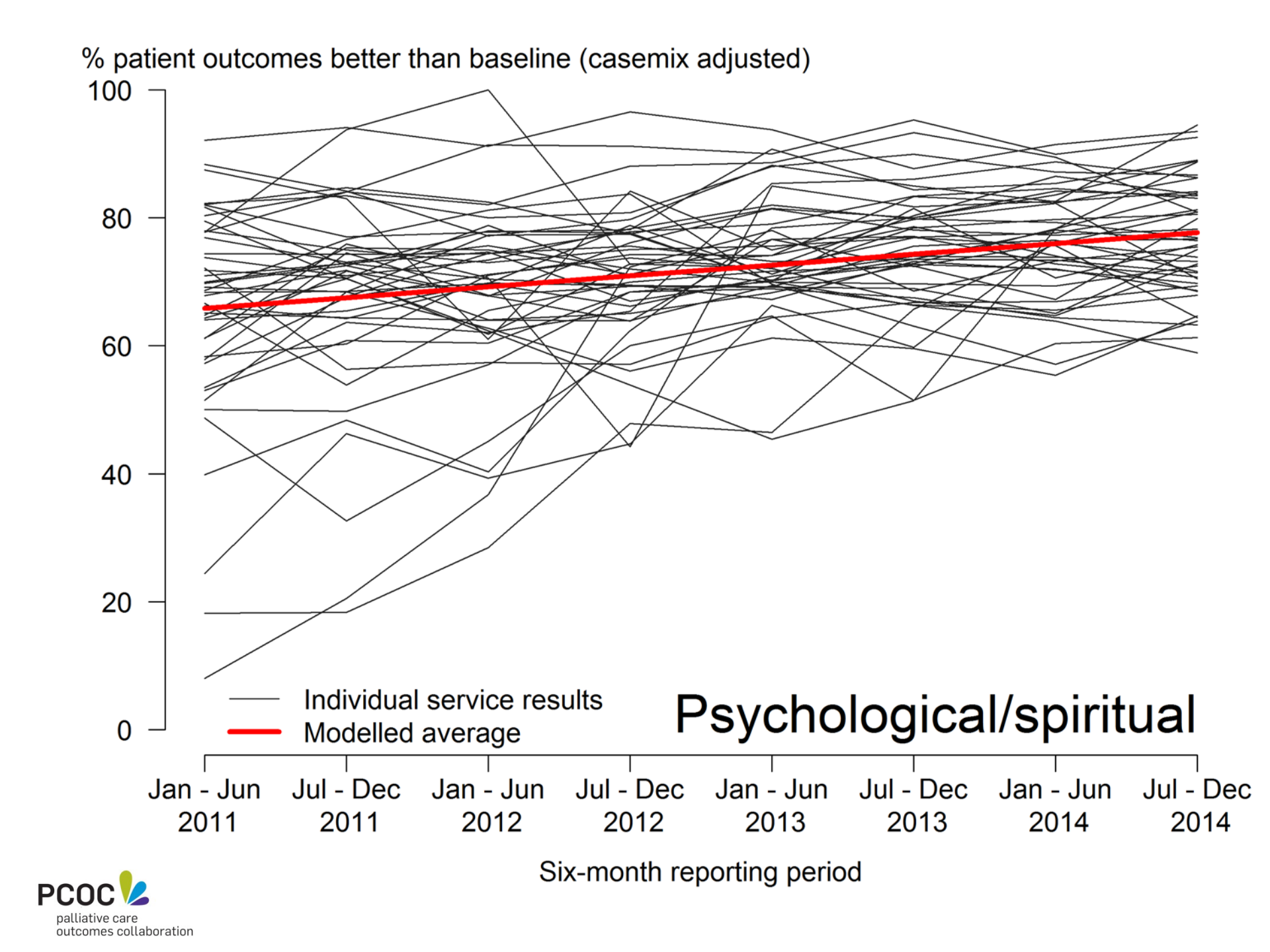

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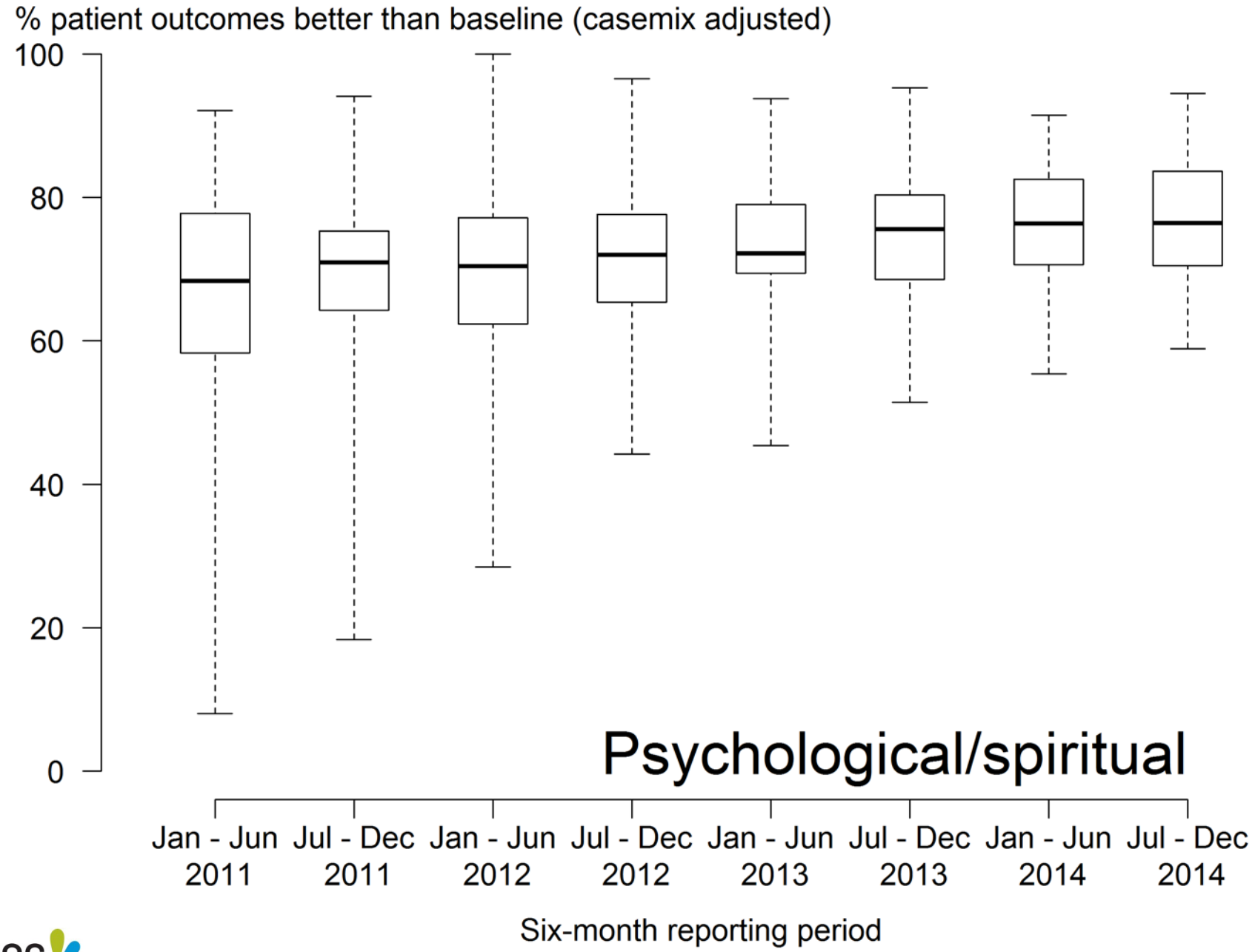

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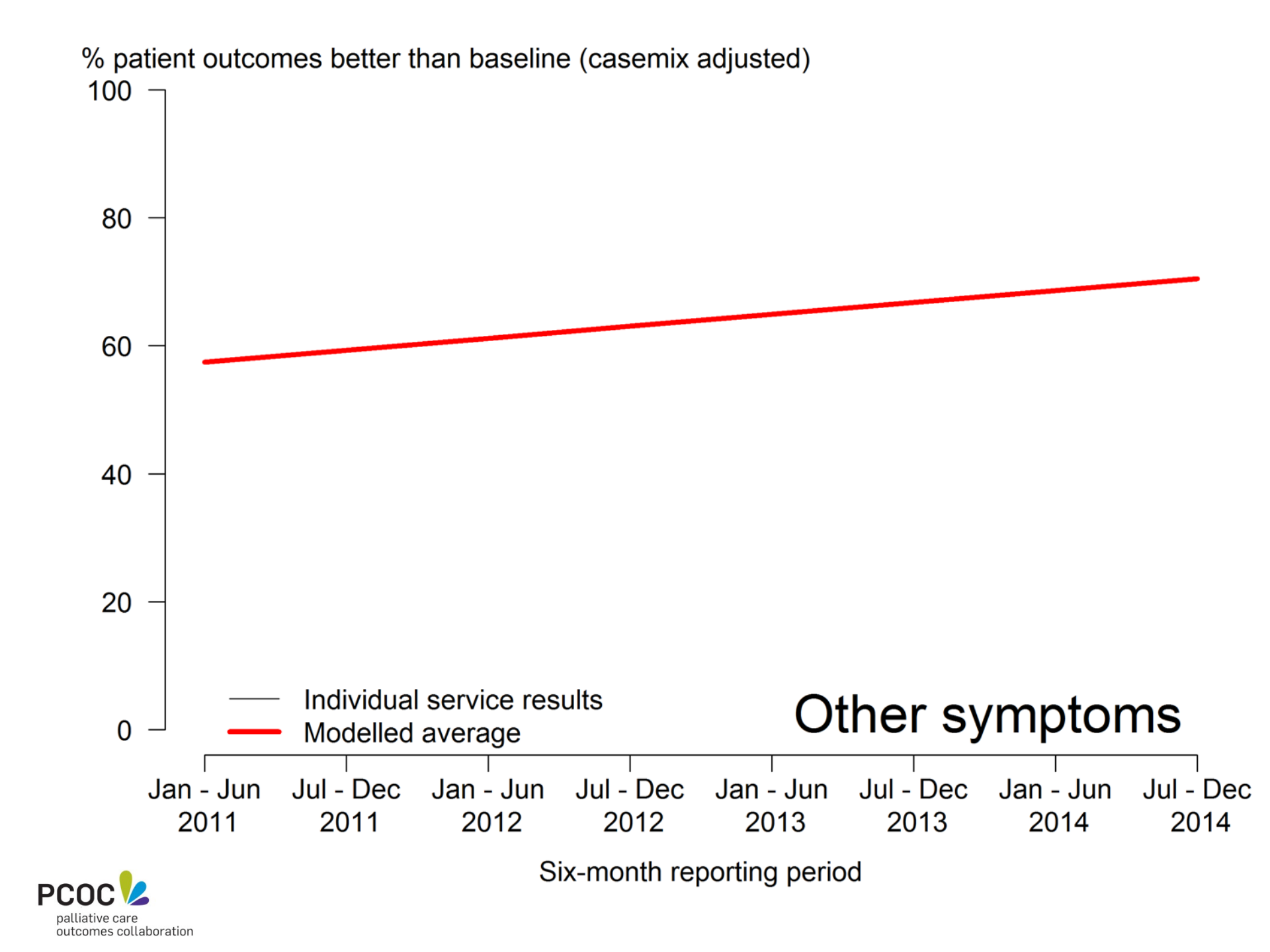

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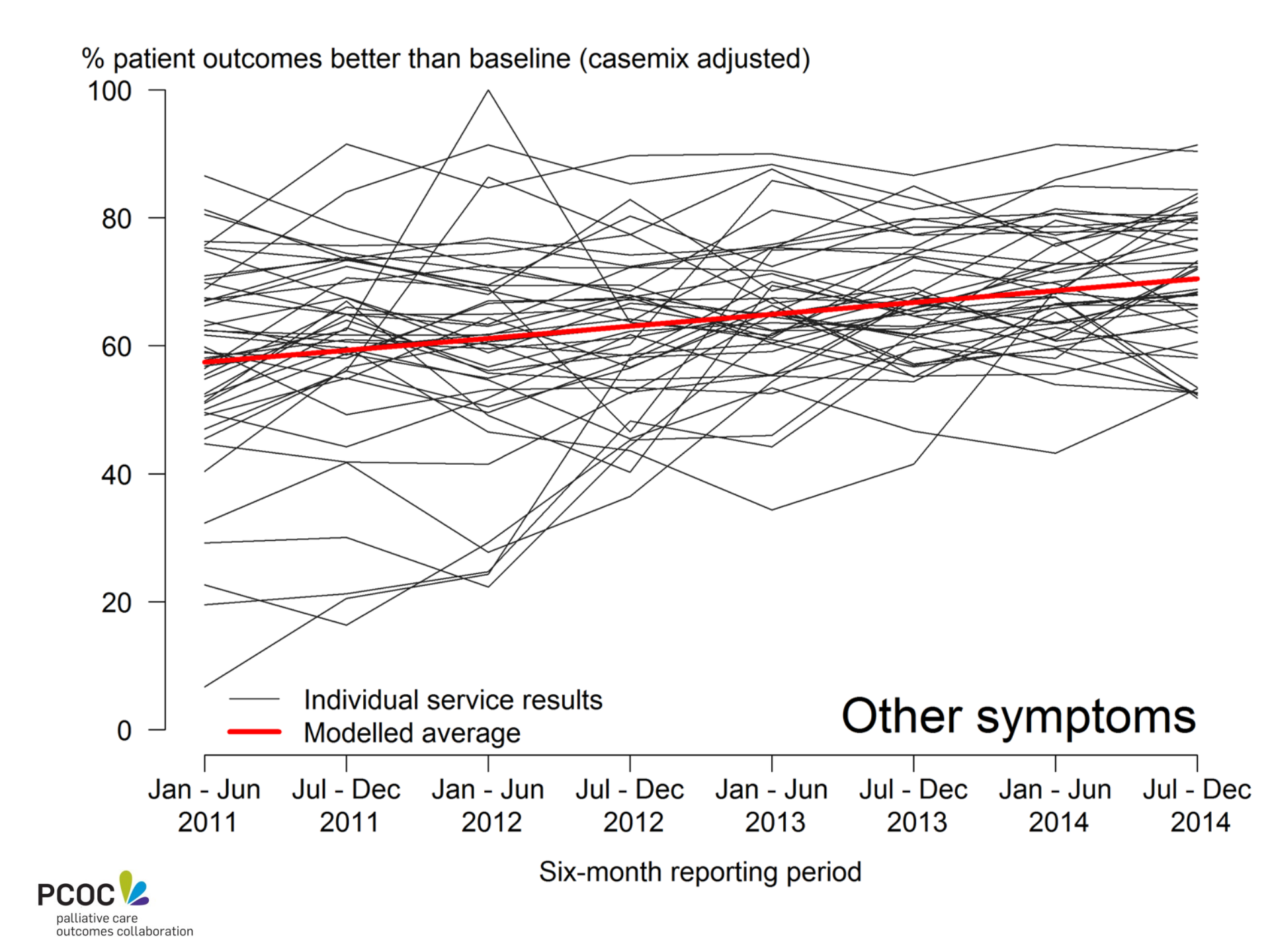

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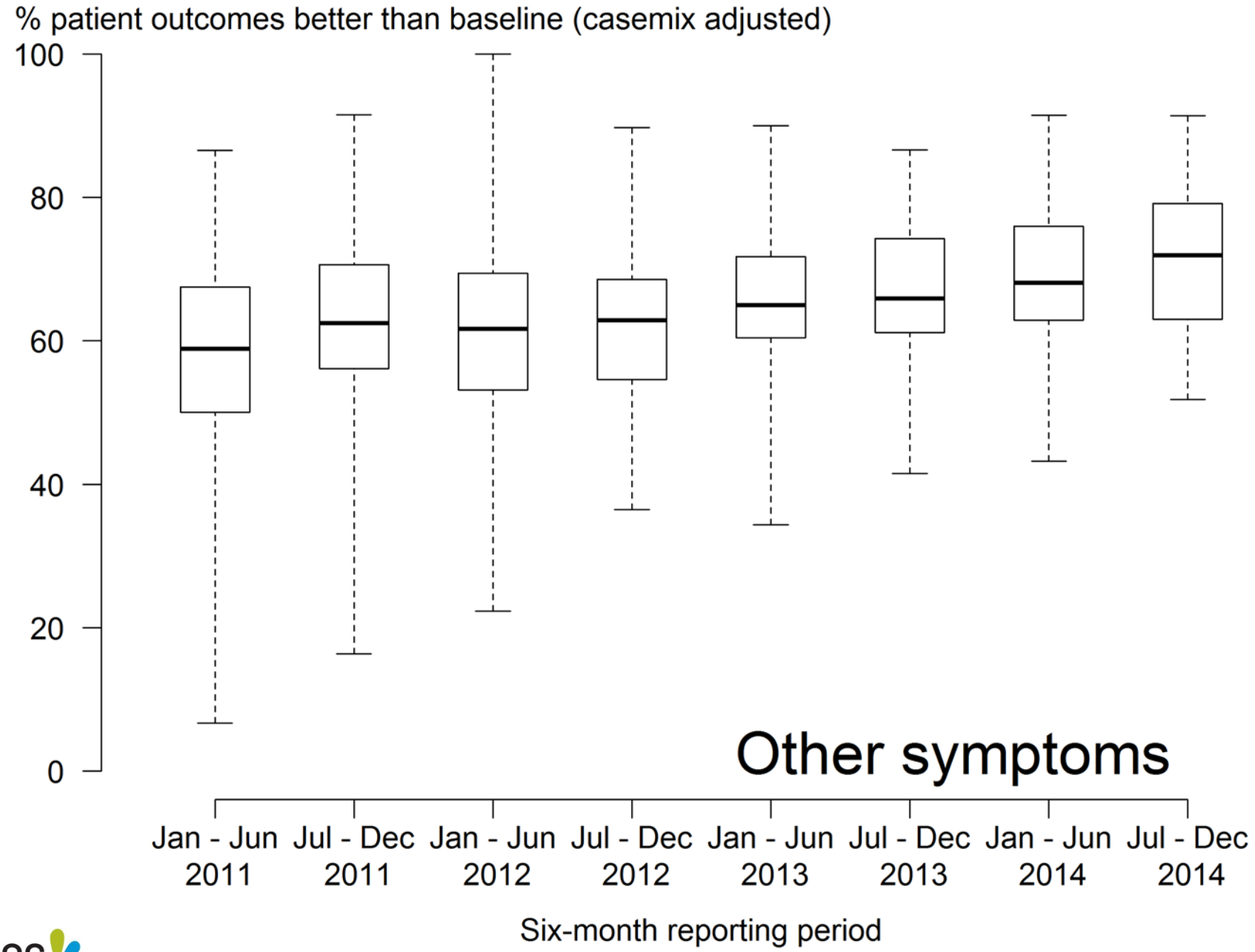

PCOC
palliative care outcomes collaboration

Summary of results

- Statistically significant improvements in all seven symptoms and problems
  - Now including pain, the last symptom to significantly improve

- Less variation in service level outcomes
  - More equity of patient outcomes across Australia

Summary

PCOC outcome measures show consistent improvement in palliative care over time

A broad range of quality improvement activities have resulted from PCOC reporting

A culture of quality improvement is firmly embedded in services participating in PCOC

Systematically improving palliative care outcomes

- **Variations seen are not simply because of resources.**

- **Some well resourced services are doing quite poorly and some poorly resourced services are delivering great patient outcomes**

Measuring quality in palliative care

- **Evidence that highly relevant data collection can be feasibly built into routine care**

  in order to

- **Compare and contrast current patient-centred outcomes**

  in order to

- **To learn from each other in service provision and resourcing**

  in order to

- **Continue to drive the best possible outcomes for patients and their caregivers**

Acknowledgements

Services that participate in PCOC and the 45 services included in this study

PCOC is a national palliative care project

funded by the

Australian Government Department of Health