IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV-2015-485-235

UNDER	**The Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990**
BETWEEN	**LECRETIA SEALES**
	Plaintiff
AND	**ATTORNEY-GENERAL**
	Defendant

AFFIDAVIT OF MICHAEL ASHBY
AFFIRMED 23 APRIL 2015

RUSSELL McVEAGH

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I, MICHAEL ASHBY, consultant, of Tasmania, affirm:

Introduction

1. I am a Consultant in Palliative and Pain Medicine practising in Tasmania, and Professor of Palliative Care at the University of Tasmania, Australia.

2. I have been asked to give evidence concerning:

   (a) the palliative care that is available to a person in Lecretia's circumstances;

   (b) whether palliative care can alleviate end of life suffering in all cases;

   (c) whether palliative care is likely to alleviate Lecretia's end of life suffering; and

   (d) my experience in the field, concerning in particular end of life patients who have attempted or committed suicide due to unbearable suffering.

3. For the purpose of preparing this affidavit, I have been provided and reviewed copies of the affidavits of Lecretia Seales, [redacted] and [redacted]

Personal profile

4. I currently hold the following positions:

   (a) Clinical Director of Complex, Chronic and Community Care, and Director of Palliative Care, Royal Hobart Hospital;

   (b) Chair of Clinical Ethics Committee, Royal Hobart Hospital;

   (c) Professor of Palliative Care, Faculty of Health Sciences, University of Tasmania; and

   (d) Adjunct Professor, Menzies Research Institute.

5. I have held the following positions:

   (a) Past President of the Australia and New Zealand Society for Palliative Medicine, 2002 to 2004; and

   (b) Past Chairman of the Chapter of Palliative Medicine at the Royal Australasian College of Physicians, September 2004 to September 2006.

6. I am a fellow or member of the following professional associations:

   (a) Royal College of Physicians, London since 1981;

   (b) Royal College of Radiologists, London since 1986;

   (c) Royal Australian College of Physicians since 1992;

(d) Australian Chapter of Palliative Medicine;

(e) Royal Australasian College of Physicians since 2001;

(f) Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists since 2003.

7. I obtained my Bachelor of Medicine from the University of London in 1978. In 2001, I obtained a Doctor of Medicine from the University of Adelaide. In 2006 I was awarded the Bethlehem Griffiths Research Foundation medal for research in palliative care.

8. A full copy of my curriculum vitae is annexed as exhibit **"MA1"**.

9. To the extent I express opinions in this affidavit, I confirm that these matters are within my areas of expertise and experience. I confirm that I have read the High Court Code of Conduct for Expert Witnesses as set out in schedule 4 of the High Court Rules. I agree to comply with that Code.

Previous involvement in assisted dying research / discourse

10. I have received newsletters, spoken at pro-euthanasia meetings and given informal unpaid advice, but I am not a member or board member of any pro-euthanasia organisation. I have given advice to members of parliament and government ministers on proposed legislation, and appeared before parliamentary committees to give expert evidence. I was an expert witness in the cases of *Gardner*; *Re BWV* [2003] VSC 173, and *Carter v Canada (Attorney General)* 2012 BCSC 886.

The nature and effectiveness of palliative care generally

11. Palliative care adopts a holistic, multidisciplinary care model that attempts to help patients to deal with physical pain and symptoms, as well as emotional, spiritual and social/relational issues as death approaches.

12. Over the last three decades, modern palliative care has made great advances. There is almost always something that can be done to improve a person's symptom control, emotional, spiritual and psychological well-being.

13. However, palliative care also has its limitations. Palliative care is unable to relieve suffering in all circumstances for all people. Skilled palliative care can nearly always make a difference for the better, but can be challenged by symptoms such as refractory cancer pain, fatigue, loss of function and independence, and by 'existential' suffering.

Pain

14. Palliative care is generally effective in treating pain. However, a small but significant proportion of people will experience pain that is difficult to control, and such patients will tend to be more commonly referred to specialist palliative care services. The data from specialist palliative care sources reflects the effectiveness of pain control in respect of the group of patients referred to those services, as opposed to all terminally ill patients.

15. Australian national benchmark data shows that about 60% of patients in specialist services with moderate/severe pain will have absent/mild pain at the end of an episode of care, leaving about 40% with a moderate/severe degree of ongoing pain (Palliative Care Outcome Collaboration-PCOC, March 2015). A copy is attached as exhibit **"MA2"**. Where pain is unstable and refractory, higher levels of drug induced side effects may be experienced. In the terminal phase (last days of life) patients may be given higher doses of sedative drugs with consent, and this may result in unconsciousness but usually in the context of an established irreversible dying process.

16. Movement (incident) bone pain, pain that involves nerves, pain in the chest, posterior abdominal (retroperitoneal) or pelvic walls, and pain in the head and neck, are the most difficult to control. Headache from raised intracranial pressure responds best to high dose steroids, and can be more difficult to control with opioid analgesics particularly in the pre-terminal stages as pressure rises.

17. In some cases, the available methods for treating severe pain involve sedation. This is because: (i) the nature of pain is often such that it can only be controlled through the administration of sedatives; and (ii) when administered at high doses, many pain killers and analgesics have sedative effects.

Other physical symptoms

18. Many other physical symptoms of terminal illness can be eased to some extent through sensitive palliative nursing. However, there are limits. For example, I understand that Lecretia is already experiencing difficulty in swallowing. There is very little that can be done to address that symptom without recourse to measures such as a nasogastric tube insertion.

19. Other physical symptoms that are addressed by palliative care with varying degrees of acceptable outcome for patients include mobility issues, agitation, breathlessness, incontinence and choking episodes.

Psychological and emotional symptoms

20. Many mentally competent end of life patients experience high levels of psychological and emotional suffering. As noted, palliative care takes a holistic approach. Palliative care teams tend to include social workers, psychologists, nurses and pastoral care workers. While they do an admirable job, in my experience it is with psychological and emotional suffering that palliative care teams have to acknowledge significant limitations.

21. Whilst vigilance for treatment depression is important and effective medical treatment is available, it is important not to automatically medicalise unhappiness in the face of life's end, or requests for assistance to die. In this regard, the expression of a wish to receive aid in dying is not, of itself, an indicator of depression. Despite the best attempts to address the spiritual, emotional and social dimensions of dying, for some people, external professional or volunteer palliative care input still fails to make the dying process worth living through.

22. Statements from patients indicating a desire to die often arise from the psychological and emotional suffering they are experiencing. In particular, the combination of losing the ability to do the things a person used to do, that make a person feel happy and useful, combined with loss of independence (including as to bodily functions), and a sense that one's life has lost meaning are common reasons for desire to die statements from mentally competent patients.

23. In my experience, a person such as Lecretia is at significant risk of undergoing a prolonged period (weeks or even months) of bedridden total dependence before death, with high symptom burden and nearly complete immobility. Despite the best efforts of palliative care this is likely to be hard for her to endure, and given her resolve and independent character, her intellectual achievements and life of action, it can be anticipated that this would be unacceptable to her.

Experience of premature death

24. It is my experience that it is common for patients to express a wish for the dying process to be accelerated at some stage, perhaps in 10-20% of admissions to a hospice unit. It is less common for patients to make a clear and sustained request for such assistance (under 5%, which is close to figures in the literature).

25. Over the course of my career, I am aware of at least two of my patients with advanced malignant disease who have taken their own lives by overdosing on a combination of medicines, including opioids, anti-depressants and sedatives. So far as I am aware neither of these patients was suffering from clinical depression. In both cases, it is my understanding that the motivation to overdose was a wish to truncate the dying process. In both cases, the patients overdosed at a stage in their dying where they were still physically able to organise the combination of drugs for themselves and take them without the assistance or knowledge of others. In both cases, the patients were found by others while still alive. In each case, a decision was made not to attempt to revive them, as to have done so would have been contrary to their wishes, and this course of action was supported by family and medical attendants.

Palliative care available in Lecretia's circumstances

26. I have read Dr [redacted] affidavit concerning Lecretia's condition and the effects that she is presently suffering from as well as the additional effects that may manifest as the tumour advances.

27. In the circumstances, I consider that it is certainly possible that palliative care will be unable to adequately address Lecretia's suffering.

Typical symptoms / effects of adult malignant glial tumours towards the end of life

28. The palliative care needs of patients with adult malignant glial tumours ("**AMGT**") such as oligoastrocytoma tend to have more in common with patients suffering from head injuries, stroke and motor neurone disease rather than other types of cancers. Towards the end of life, the typical effects of AMGT include:

(a) significant mobility issues, including dependence on others for toileting and personal hygiene;

(b) lapsing consciousness, disassociation and drowsiness;

(c) neurodisability, including extreme fatigue;

(d) cognitive deficit, including reduced high level function and ability to communicate and interact with family and friends, particularly in the terminal phase;

(e) personality change, including mood swings, depression and anxiety.

Treatment

29. Typically, palliative care for a patient with an AMGT involves administering a combination of steroids, analgesics and painkillers.

30. It is almost always the case that patients with tumours of this kind will need to take steroids if they wish to prolong life. This is because as the tumour grows, the brain becomes waterlogged, a process known as intracranial oedema. The result of intracranial oedema is severe headache, nausea and vomiting, focal deficits and consciousness impairment. Often the resulting headaches do not respond to standard forms of pain relief. From my knowledge of Lecretia's condition, this process could happen at any point from now.

31. If Lecretia chooses to take steroids, the intracranial oedema should be reduced and her life prolonged to some extent. However, steroids have a number of side effects. The primary side effect is massive weight gain. She could expect to gain up to 20-50% of her present body weight before death. This in turn tends to further decrease mobility and increase the likelihood of bed sores, and usually has a devastating effect on body image and well being. Steroids also impair natural sleep and induce mood and behaviour changes as well as predisposing patients to gut ulcers and bleeding.

32. Steroids also give rise to an insatiable appetite and insomnia. I understand from reviewing Lecretia's affidavit that she has already experienced both of these symptoms.

33. Once intracranial oedema begins to take effect, Lecretia may choose to refuse steroids. The result of that is that her life is likely to be abbreviated. In the light of Lecretia's relative youth, and assuming her other vital organs are healthy, she may continue to live for some time. Without steroids she is likely to suffer severe headaches from the time oedema begins to affect her until her death. The nature of those headaches is that they tend to be difficult to control by morphine or other pain killers.

34. If Lecretia opts to take steroids, at some point they will in any case cease being effective. When this occurs, intracranial pressure will increase and she will likely begin to lapse in and out of consciousness. At this point, it is common practice in palliative care to increase sedation.

35. Generally, the ultimate result of increasing intracranial pressure as a result of AMGT is tonsillar brain herniation, otherwise known as "coning". This is when the brain herniates down into the spinal canal and puts pressure on the brain stem, causing the nervous system functions that control respiration and cardiac function to shut down. This is the usual method of death in a patient with Lecretia's condition.

Side effects of treatment

36. A significant side effect of morphine, other pain killers and analgesics when used at the high levels necessary to address the intracranial pressure and pain typically caused by AMGT is sedation/ drowsiness to the point where Lecretia's ability to think clearly and interact with her family and friends is likely to be severely affected.

Palliative sedation

37. Attached to this affidavit as exhibit "**MA3**" is a 2014 article I co-authored entitled "Goals of Care: A Clinical Framework for Limitation of Medical Treatment".[1] That article describes the distinction between the curative, palliative and terminal phases of terminal illness.

38. Once Lecretia reaches the terminal phase of her illness, palliative sedation may be used. Palliative sedation is a significant and well-accepted part of palliative care practice. When I use the term palliative sedation, I mean the administration of sedatives, normally benzodiazepines, anti-psychotics, and/or occasionally barbiturates to maintain comfort and dignity when agitated delirium or so-called terminal restlessness are present. The drug doses are titrated to induce relaxation, but this often results in sleep or a state of deep, continuous unconsciousness until the time of death.

39. Palliative sedation is generally employed in the terminal phase. However, sedation may be used as a last resort to manage pain, and for the relief of other refractory symptoms, such as delirium, agitation, or shortness of breath for the palliative care of patients who are in the palliative phase, ie not imminently dying. Use of sedation in the palliative phase is far less common than sedation in the terminal phase, and is much more controversial.

The availability / quality of palliative care in New Zealand

40. I am not directly involved with palliative care policy and clinical practice in New Zealand. I am aware that New Zealand palliative care is said to follow best practice, and therefore the palliative care available to Lecretia is likely to be as described in this affidavit.

AFFIRMED at Hobart, Tasmania this 23rd day of April 2015 before me:

Michael Ashby

A person duly authorised to administer oaths by the law of Australia

Michael Joseph Eli Cordover
Solicitor (Commissioner for Declarations)
M+K dobson mitchell allport
59 Harrington Street Hobart Tasmania

[1] Goals of Care: A Clinical Framework for Limitation of Medical Treatment, MJA 201(8), 20 October 2014.

"MA1"

Curriculum Vitae

of

PROFESSOR MICHAEL ASHBY

MBBS (Lond), MD (Adel), MRCP (UK), FRCR, FRACP, FAChPM, FFPMANZCA.

Director of Palliative Care
Royal Hobart Hospital and Tasmania Health Organisation (THO) South.

Professor of Palliative Care
School of Medicine
Faculty of Health Science
University of Tasmania.

Adjunct Professor
Menzies Research Institute, Hobart.

Consulting Editor and Member of the Board
Journal of Bioethical inquiry.

Member
Governing Council, THO South.

Chair
Tarrremah Steiner School Foundation.

Vice-President
Australian Centre for Grief and Bereavement.

This is the annexure marked "MA1" referred to in the affidavit of **Michael Ashby** affirmed at Tasmania this 23rd day of April 2015 before me

Signature .....
A person duly authorised to administer oaths by the law of Australia

Michael Joseph Eli Cordover
Solicitor (Commissioner for Declarations)
M+K dobson mitchell allport
59 Harrington Street Hobart Tasmania

PERSONAL DETAILS

Home Address	35 Osborne Esplanade Kingston Beach TAS 7050	
Office Address	Repatriation Centre 1st Floor - Peacock Building 90 Davey Street Hobart TAS 7004	
Phone	Home	+ 61 3 6229 6972
	Office	+ 61 3 6220 2457
	Fax	+ 61 3 6224 2451
	Mobile	0408 998 744
Email	michael.ashby@dhhs.tas.gov.au michael.ashby@internode.on.net	
Nationality	British and Australian (dual)	
Married	Wife	Jenny O'Bryan
	Children	Emma Fleming (3 December 1992) Dominic Ashby (29 December 1997) Julien Ashby (28 July 2003) Saskia Kate (23 March 2006)
Languages spoken	English and French	
Date of Birth	16 January 1954 (Redhill, Surrey, UK)	

MEDICAL REGISTRATIONS

- Medical Board of Australia
  Registration Number: MED0000941382
  Registration Date: 1 October 2010

- Specialist Register (European Specialist Medical Qualifications Order 1995)
  Advanced Cancer Care: 22 November 1999
  Clinical Oncology: 23 May 1996

- General Medical Council (UK)
  Registration Number: 2456517
  Registration Date: 5 February 1980
  Voluntary removal: 2002

MEDICAL INDEMNITY COVER

Full time contract at Palliative Care Services
Avant, member no 18572 (physician non-procedural)

CONTINUING PROFESSSIONAL DEVELOPMENT ACTIVITIES

2002	RACP Committee for Physician Training Workshop on Supervision of Advanced Trainees Stage 1 in Accreditation of Supervisors. 7 October 2002.
2001	RACP, Adult Medicine Division Maintenance of Professional Standards Program Enrolled 2001 – 2005 – 849 points
2000	RACP, Adult Medicine Division Maintenance of Professional Standards Program Certificate of Completion 1996 - 2000
2006	RACP, Adult Medicine Division Maintenance of Professional Standards Program Certificate of Completion 2000 – 2006
2006-2010	Five year cycle completed MyCPD, RACP
2010-	Registered with MyCPD, RACP.

PRESENT POSITIONS

January 2007 –

Director of Palliative Care
Royal Hobart Hospital and STHO

Professor of Palliative Care
School of Medicine
Faculty of Health Science
University of Tasmania

Credentialed Specialist Palliative Care and Pain Medicine Physician
STHO and Royal Hobart Hospital
Hobart Private Hospital
Calvary Healthcare Tasmania

Member
International Work Group on Death, Dying and Bereavement (2013-)

Other Major Roles
Member, Tasmanian Lead Clinicians Group (2012- present)
Member, Tasmanian Clinical Advisory Council (2009-12)
Clinical Leader, Palliative Care Network, DHHS, Tasmania (2009-2011)

Clinical Leader, Respecting Patient Choice Program, RHH (2007)
Chair, Clinical Ethics Committee, RHH (2007-present)

AHMAC. CTEP sub-committee Member (representing Tasmania), **National Advance Care Directive Working Party,** Chair Dr Simon Towle (WA) (NACDWG). (2012)

Coordinator

Theme 4, MBBS course: Personal and Professional Development.

Current Undergraduate teaching

CAM101 Orientation (20 mins)
CAM101 Introduction to Theme 4 (1 hr)
CAM101 Professionalism – History (1)
CAM101 Goals of Medicine (1)
CAM101 Introduction to Bioethics (2)
CAM101 Medicine & Humanities 1 (1)
CAM101 Medicine & Humanities 2 (1)
CAM101 Grief & Bereavement workshop (3)
CAM102 End of Life 1: Body, Death, Dying (1)
CAM102 Post-dissection Debrief (1)
CAM102 Doctor-Patient Relationship (1)
CAM102 Conscientious Objection (2)
CAM201 Advance Care Planning (2)
CAM201 End of Life 2: Long Lives & Cures (2)
CAM201 End of Life 3: To Treat or Not to Treat (2)
CAM202 Euthanasia (2)

Supervision of higher degrees

Cooper D.A.(2007) The doctor as a moral agent, with reference to the distinction between killing and 'letting die". PhD thesis. University of Melbourne, Faculty of Medicine, Dentistry and Health Sciences.

Fetherstonhaugh, D. M. A. (2007). Hobson's choice: dialysis or the coffin: a study of dialysis decision-making amongst older people. PhD thesis, Centre for Health and Society & Department of Medicine, The University of Melbourne.

Aslin GJ. Is there a role for rural ambulance paramedics in the provision of acute and non-acute care for palliative care clients? Candidate for MMedSci, University of Tasmania.

Hanley M. PhD candidate, UTAS, co-supervision started. 2011.

PREVIOUS POSITIONS

January 2011-2012 - Director of Persistent Pain Service, STAHS and RHH

February 2005 – December 2006

Director
Centre for Palliative Care, St Vincent's Health

Professor of Palliative Care
Department of Medicine, St Vincent's Health, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne

Senior Principal Specialist In Palliative Care
St Vincent's Health

Director of Palliative Care
Melbourne Health, Royal Melbourne Hospital

Community Palliative Care Physician
Melbourne City Mission Palliative Care

Visiting Medical Officer
Bethlehem Hospital Inc, South Caulfield

March 1995 - December 2004

Head of the Palliative Care Unit
Southern Health
McCulloch House, Monash Medical Centre

Professor of Palliative Care
Department of Medicine
Faculty of Medicine, Nursing and Health Sciences
Monash University

January 1989 – January 1995

Director (Senior Consultant, Level 9 - Excellence level)
Palliative Care Medicine Unit, Internal Medicine Service
Royal Adelaide Hospital, North Terrace, Adelaide, SA 5000

Radiation Oncologist
Department of Radiation Oncology
Royal Adelaide Hospital

Clinical Senior Lecturer
Faculty of Medicine, University of Adelaide
Department of Medicine
Department of Clinical and Experimental Pharmacology

Director
Eastern and Central Adelaide Palliative Care Service

Medical Director
Mary Potter Hospice
Calvary Hospital Adelaide Inc

Associate Specialist in Radiation Oncology & Palliative Care Services:
Adelaide Children's Hospital

Visiting Consultant in Palliative Care
Modbury Hospital

February 1988 – November 1988

Visiting Radiation Oncologist
(Faisant fonction de medecin assistant)
Department of Radiation Oncology
Institut Curie, Paris, France

May 1987 – January 1988

Fellow in Radiation Oncology
(Staff Specialist)
Peter MacCallum Cancer Institute, Melbourne, Victoria 3000, Australia.

September 1986

Visitor to Radiotherapy Department
Institut Gustave Roussy, Villejuif, France

May 1986

Visitor to the Strathlentherapie Klinik
Universitatsklinik, Cologne, West Germany

May 1985 – April 1987

Clinical Lecturer
University of Cambridge School of Clinical Medicine

Honorary Senior Registrar in Radiotherapy & Oncology
(East Anglian Regional Health Authority)
Radiotherapeutics Centre
Addenbrooke's Hospital, Cambridge

Honorary Senior Registrar
North Bedfordshire Health Authority

Clinical Tutor
University of Cambridge School of Clinical Medicine

Attached Worker
MCR Clinical Oncology Unit
Radiotherapeutics Unit

Involvement in the organisation, design and day to day running of large randomised MRC clinical trials (BR 6-high grade glioma and MRC 6 small cell study).

September 1982 – April 1985

Registrar
Department of Radiotherapy & Oncology
Royal Marsden Hospital, London and Surrey (Internal training rotation)

April 1982 – September 1982

Registrar In Radiotherapy & Oncology
Regional Centre for Radiotherapy & Oncology
St Luke's Hospital, Guildford, Surrey

February 1982 – March 1982

Locum Lecturer & Tutor In Medicine
Riyadh Armed Forces Hospital, Riyadh, Saudi Arabia

February 1980 – January 1982

Rotating Senior House Officer In General Medicine
Southampton University Hospitals

Geriatric Medicine
Professor M R P Hall, Dr H D H Eastwood, Dr C Offer, Dr N Sterling, Dr R Briggs

Human Metabolism
Professor Dame Barbara E Clayton

Radiotherapy & Oncology
Dr P E Bodkin, Dr R D H Ryall, Dr V L Hall, Dr H Macdonald, Dr R B Buchanan

General Medicine, Lymington Hospital
Dr J R E Dathan

August 1979 – January 1980

House Surgeon
St Bartholomew's Hospital, London
Professional Surgical Unit (3 months)
Consultants: Professor G W Taylor, Professor J P S Lumley
Orthopaedic Surgery (3 months)
Consultants: Mr J A Fixsen, Mr T M Bucknill

January 1979 – July 1979

House Physician
University Hospital and the General Hospital, Nottingham

Consultants: Dr S P Allison, Dr R B Tattersall

PREVIOUS OTHER MAJOR ROLES

- Chairman (2004-2006), Australasian Chapter of Palliative Medicine
  Royal Australasian College of Physicians

- Committee member (2005 – present), Management Committee
  Centre for Grief Education

- Member (2004), Ministerial Taskforce on Cancer (Victorian government)

- Member (2003), Palliative Care Strategic Framework Working Party (Victorian government)

- Chairman (2001-2003), Education Committee, Chapter of Palliative Medicine
  Royal Australasian College of Physicians

- Member, Palliative Medicine Study Committee, Cancer Council of Victoria

- Chair, Palliative Care Clinical Research Group, Palliative Medicine Committee,
  Cancer Council of Victoria

- Member (representing St Vincent's Health), Committee of Management,
  Eastern Palliative Care

- Member, Trials management Committee, Palliative Care Clinical Studies
  Collaboration (PaCCS) (until 2008)

- Executive Council member (until 2004)
  Cancer Council of Victoria

- President (2002-2004)
  Australia and New Zealand Society of Palliative Medicine

- Medical Director (1996-2001)
  Southern Health Care Network
  Cancer and Palliative Care Program

- Committee member (until 1998)
  Department of Human Services, Aged Care Division, Palliative Care Task
  Force Implementation Steering Committee

- Committee member (until 1998)
  Southern Metropolitan Region
  Palliative Care Advisory Committee

- Committee member (1995 – 1997)
  Management Committee

Centre for Grief Education

- Member, Southern Health, Bioethics Working Party

MEMBERSHIP OF PROFESSIONAL ASSOCIATIONS

- Australia and New Zealand Society of Palliative Medicine (ANZSPM)
- Australian Bioethics Association
- Australian Institute of Health Law and Ethics
- Australian Pain Society
- Centre for Human Bioethics - Monash University
- International Association for the Study of Pain (IASP)
- Tasmanian Association for Hospice and Palliative Care (TAHPC)
- Association for the Study of Death and Society

REVIEWER FOR

- Anesthesia & Analgesia
- Australian Medicines Handbook
- Journal of Pain and Symptom Management
- Medical Journal of Australia
- Eureka Street

EDITORSHIPS

- Consulting Editor, Journal of Bioethical Enquiry
- Board of Editors, Journal of Palliative Care
- Board of Editors, Mortality

GRANT APPLICATION REFEREE

- Anti Cancer Council of Victoria
- NHMRC
- Various universities and hospitals

EDUCATION

General Education

At various schools in UK, France, Belgium and Australia before completing secondary education at grammar school in the UK.

1964	Ecole Communale, Wervicq-sud, Nord, France
1965	Athenee Royale, Comines, Hainault, Belgium
1965	Certificat d'Etudes Primaires, Belgium
1966-72	Reigate Grammar School, Reigate, Surrey, UK
1970	9 "O" levels (Oxford & Cambridge Examining Board)
1972	3 "A" levels (Oxford & Cambridge Examining Board) in English, French, History (grades ABB) "S" level History, Use of English, General Paper.

Undergraduate Medical Education

Oct 1972 Entered the first MB Course
St Bartholomew's Hospital Medical College
University of London

Electives

- Paediatrics at Royal Children's Hospital, Melbourne Australia
- Williamson Laboratory, St Bartholomew's Hospital
- Surgery, Radiotherapy & Oncology at Royal Marsden

Hospital Prizes

1972	Jeaffreson Exhibition (Entrance Scholarship in Arts)
1978	Matthews Duncan Prize in Obstetrics & Gynaecology

Examinations

Oct 1978	LRCS MRCS
Nov 1978	MB BS (London)

Postgraduate Qualifications

Nov 1981 MRCP (UK)

May 1986 FRCR

May 1987 Certificate of Accreditation of Higher Training in Radiotherapy & Oncology
Royal College of Radiologists
Specialist & Consultant Status Recognition in Australia
Commonwealth Dept of Community Services & Health, and
Medical Board of South Australia

Mar 1989 Specialist in Radiation Oncology

May 1992 Consultant Physician in General Medicine (Palliative Medicine)

May 1992 FRACP admitted under Bylaw 24(a)

2001 FAChPM

3rd Jul 2001 MD (Doctor of Medicine). Department of Medicine, Faculty of Health Sciences, University of Adelaide. Thesis entitled: Natural Death? Palliative care and death causation in public policy and the law.

1994-2002 MRACMA

2003 FFPMANZCA

RESEARCH AWARDS AND GRANTS

2010 Australian Government (DOHA) Local Palliative Care Grant Program - $593,000
Developing a model of practice development networks and dementia palliative care resource nurses to enhance the provision of palliative care for people with dementia and their families in residential aged care facilities. Wicking Dementia Research and Education Centre, Menzies Research Institute, University of Tasmania.

2008 Grant-in-aid from Office of the Public Guardian of Tasmania - $20,000.
What Do People Say In Their Advance Directives? A quantitative and qualitative analysis of a sample of Enduring Guardianship forms in Tasmania.

2006 Awarded Bethlehem Griffiths Medal by Bethlehem Griffiths Foundation for achievements in Palliative Care research

2006 CNSBio
Open label dose finding phase 2 trial of Flupirtine in the treatment of neuropathic pain associated with cancer.

2004 Nurses Board of Victoria
Nutrition and hydration at the end of life: Pilot study of a palliative care experience

2003 William Buckland Foundation - $250,000
William Buckland Palliative Care Research Project
Promoting effective and safe nursing use of the Graseby syringe driver in palliative care

2002 NHMRC - $100,000

Strategic Palliative Care Research Program
Renal dialysis abatement decision-making and social impact of the transition to terminal care

1995 Canadian Government Programs - $5,000
Canadian Studies in Australia and New Zealand
Faculty Research Program
Care of the Dying and Decisions at the end of life: current trends in Canada

REPORTS

1. Ashby MA, Kosky R, laver H, Sims E.
The Management of children who are dying and their families.
A Report to the patient Care Review Committee, Adelaide Children's Hospital. September 1989.

2. Ashby MA.
Oral and written evidence to Select Committee of the House of Assembly on the Law and Practice Relating to Death and Dying. Hansard, Parliament of South Australia., and
First Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliament of South Australia. Adelaide: August 1991.

3. Second Interim Report of the Select Committee of House of Assembly on the Law and Practice Relating to Death and Dying. Parliament of South Australia. Adelaide: November 1991.

4. Ashby MA.
Written Submission Regarding The Euthanasia Laws Bill 1996 to the Senate Legal And Constitutional Legislation Committee, Federal Parliament of Australia, Canberra. Melbourne, December 1996.

5. Ashby MA.
Written submission to Joint Standing Committee on Community Development, House of Assembly, Parliament of Tasmania, regarding Dying with Dignity Bill 2009.

PAPERS

1 Reid RI, Ashby MA
Ulnar nerve palsy and walking frames
British Medical Journal 1982, 285:778

2 Petersen MM, Briggs RS, Ashby MA, Reid RI, Hall MRP, Clayton BE
Parathyroid hormone and 25-hydroxyvitamin D concentrations in sick and

normal elderly people.
British Medical Journal 1983, 287:521-523

3 Ashby MA, Carnochan P
Review of: Cancer Therapy by hyperthermia, drugs and radiation.
National Cancer Institute Monograph 61
Clinical Radiology 1984, 35:250

4 Ashby MA
Erythema ab igne in cancer patients.
Journal of Royal Society of Medicine 1985, 78:925-927

5 Ashby MA
Retinopathy after irradiation and hyperbaric oxygen
Journal of Royal Society of Medicine 1985, 78:604-605

6 Ashby MA, Bowen D, Watson JV
Intracranial Hodgkin's disease: a primary presentation and access of cytotoxic agents.
British Journal of Radiology 1986, 59:1241-1242

7 Ashby MA, Harmer CL, McKinna A, Lennox SC
Infiltrative fibromatosis: a rare cause of fatal haemorrhage
Clinical Radiology 1986, 37:193-194

8 Ashby MA, Ago CT, Harmer CL
Hypofractionated radiotherapy for sarcomas
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PCOC

palliative care
outcomes collaboration

Tasmania

Patient Outcomes in Palliative Care

July – December 2014

March 2015

Australian Government
Department of Health

PCOC is a national palliative care project funded by the Australian Government Department of Health

www.pcoc.org.au

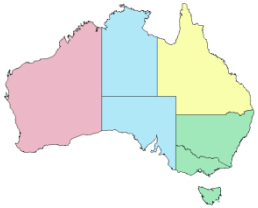
About the Palliative Care Outcomes Collaboration

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care for all Australians*. This is achieved via the PCOC dataset; a multi-purpose framework designed to:

- provide clinicians with an approach to systematically assess individual patient experiences,
- define a common clinical language to streamline communication between palliative care providers and
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

The PCOC dataset includes the clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

PCOC has divided Australia into four zones for the purpose of engaging with palliative care service providers. Each zone is represented by a chief investigator from one of the collaborative centres. The four PCOC zones and their respective chief investigators are:



Central Zone	**Professor Kathy Eagar**, Australian Health Services Research Institute, University of Wollongong
North Zone	**Professor Patsy Yates**, Institute of Health and Biomedical Innovation, Queensland University of Technology
South Zone	**Professor David Currow**, Department of Palliative and Supportive Services, Flinders University
West Zone	**Dr Claire Johnson**, Cancer and Palliative Care Research and Evaluation Unit, University of WA

Each zone is also represented by one or more quality improvement facilitators, whose role includes supporting services to participate in PCOC and facilitating ongoing service development and quality improvement. The national team, located within the Australian Health Services Research Institute at the University of Wollongong, coordinates the patient outcomes reporting, education program, and quality activities across the four zones.

If you would like more information or have any queries about this report please contact your local quality improvement facilitator or contact the national office at pcoc@uow.edu.au or phone (02) 4221 4411.

PCOC palliative care outcomes collaboration

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Introduction

The Palliative Care Outcomes Collaboration (PCOC) assists services to improve the quality of the palliative care they provide through the analysis and benchmarking of patient outcomes. In this PCOC report, data submitted for the July to December 2014 period are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve.

Patient outcomes are reported for a total of 18,310 patients, with 23,449 episodes of care and 53,467 palliative care phases. The information included in this report is determined by a data scoping method. See Appendix A for more information on the data included in this report.

Throughout this report, patient information for Tasmania is presented alongside the national figures for comparative purposes. The national figures are based on information submitted by 95 services, of which:

- 53 are inpatient services. Inpatient services include patients who have been seen in designated palliative care beds as well as non-designated bed consultations.
- 27 are community services. These services include primarily patients seen in the community as well as some patients with ambulatory/clinic episodes.
- 15 are services with both inpatient and community settings.

A full list of the services included in the national figures can be found at www.pcoc.org.au.

Interpretation hint:

Some tables throughout this report may be incomplete. This is because some items may not be applicable or it may be due to data quality issues.

Please use the following key when interpreting the tables:

na **The item is not applicable.**
u **The item was unavailable.**
s **The item was suppressed due to insufficient data as there was less than 10 observations.**

Section 1 Benchmark summary

1.1 Tasmania at a glance

Table 1 Summary of outcome measures 1 to 3 by setting

Outcome measure	Description	Benchmark	Inpatient		Community	
			TAS Score	Benchmark Met?	TAS Score	Benchmark Met?
1. Time from ready for care to episode start	Benchmark 1: Patients episode commences on the day of, or the day after date ready for care	90%	98.1	Yes	83.0	No
2. Time in unstable phase	Benchmark 2: Patients in the unstable phase for 3 days or less	90%	87.2	No	46.7	No
3. Change in pain	Benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end	90%	87.3	No	81.6	No
	Benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild pain at phase end	60%	49.1	No	58.4	No
	Benchmark 3.3: SAS Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end	90%	83.4	No	76.3	No
	Benchmark 3.4: SAS Patients with moderate/severe distress from pain at phase start, with absent/mild at phase end	60%	51.0	No	45.0	No

Table 2 Summary of outcome measure 4: Average improvement on the 2014 baseline national average (X-CAS)

Clinical Tool	Description	Average improvement on baseline	Benchmark met?
PCPSS	Benchmark 4.1: Pain	0.01	Yes
	Benchmark 4.2: Other symptoms	-0.10	No
	Benchmark 4.3: Family/carer	-0.16	No
	Benchmark 4.4: Psychological/spiritual	-0.08	No
SAS	Benchmark 4.5: Pain	-0.10	No
	Benchmark 4.6: Nausea	0.08	Yes
	Benchmark 4.7: Breathing problems	-0.21	No
	Benchmark 4.8: Bowel problems	-0.10	No

The benchmark for outcome measure 4 is zero.

For more information on the outcome measures and benchmarks, see Section 2.

1.2 National benchmark profiles

In this section, the national profiles for selected benchmarks are split by setting (inpatient or community) and presented graphically.

The selected benchmarks included are:

- Benchmark 1 Patients episode commences on the day of or the day after date ready for care
- Benchmark 2 Patients in the unstable phase for 3 days or less
- Benchmark 3.1 PCPSS: Patients with absent/mild pain at phase start, remaining absent/mild at phase end
- Benchmark 3.2 PCPSS: Patients with moderate/severe pain at phase start, with absent/mild pain at phase end
- Benchmark 3.3 SAS: Patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end
- Benchmark 3.4 SAS: Patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end

Interpretation hint:

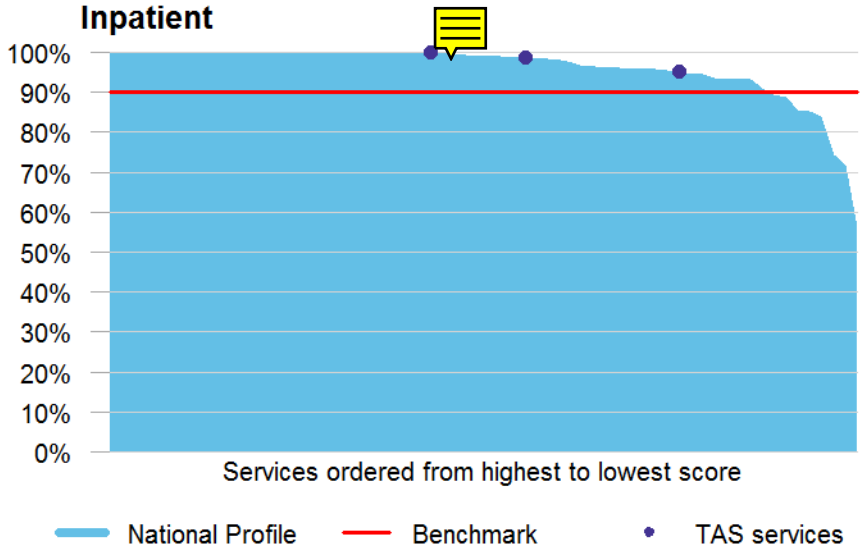
The national profile graphs on the following pages allows services to see how they are performing in comparison to other palliative care services participating in PCOC. In each graph, the shaded region describes the national profile for that outcome measure. Tasmanian services are highlighted as dots on the graph.

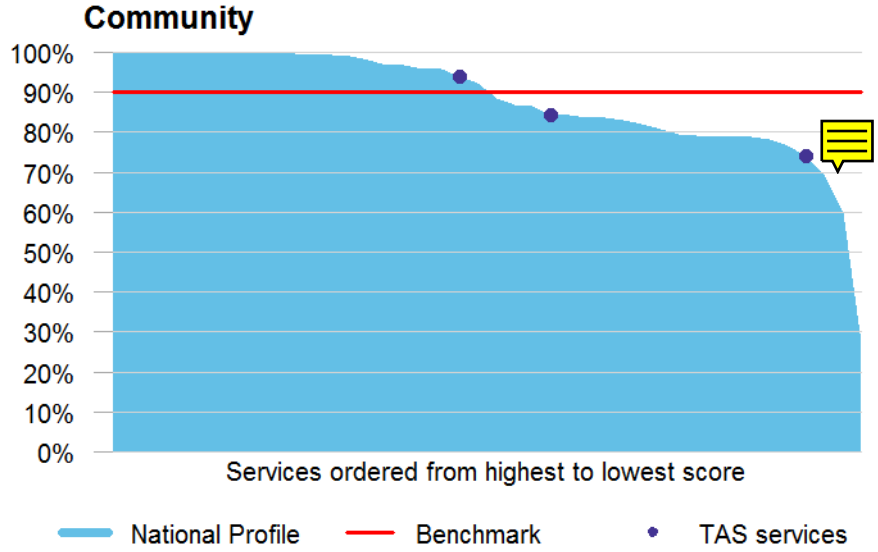
If no dot is present on a particular graph, this means that Tasmanian services has not met the criteria for inclusion in this measure. This may be caused by insufficient data item completion, or not having any data falling into a particular category, for example, no phases starting with moderate/severe SAS pain.

The red line on the graph indicates the benchmark for that outcome measure.

Outcome measure 1 – Time from date ready for care to episode start

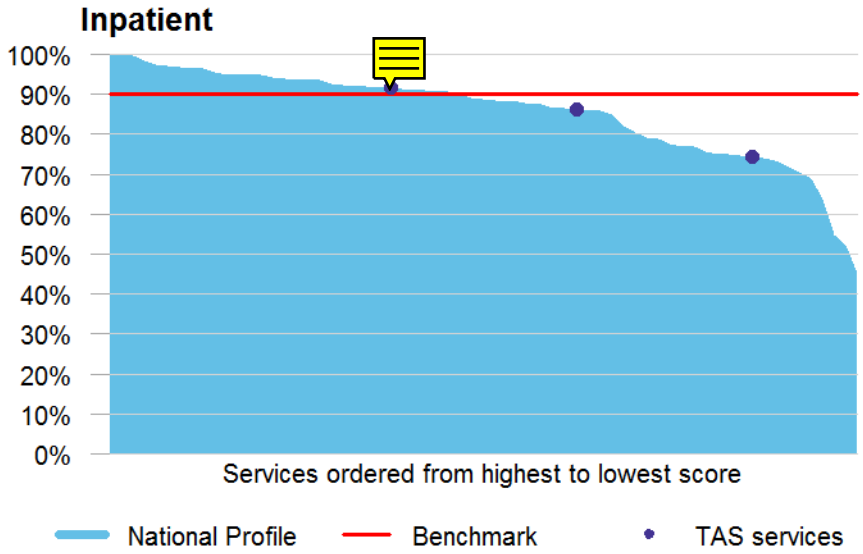
Figure 1 Percentage of patients with episodes started on the day of, or the day after date ready for care

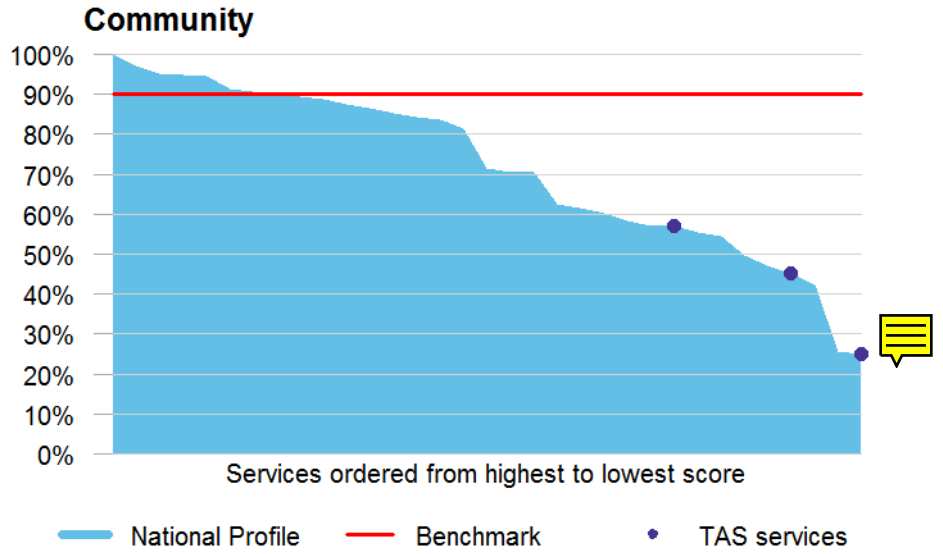




Outcome measure 2 – Time in unstable phase

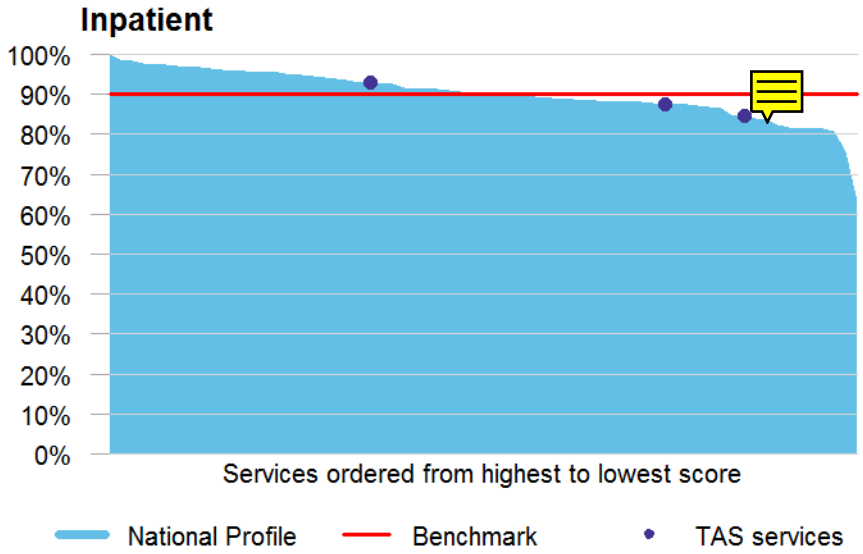
Figure 2 Percentage of patients in the unstable phase for 3 days or less





Outcome measure 3 – Change in pain

Figure 3 PCPSS: Percentage of patients with absent/mild pain at phase start, remaining absent/mild at phase end



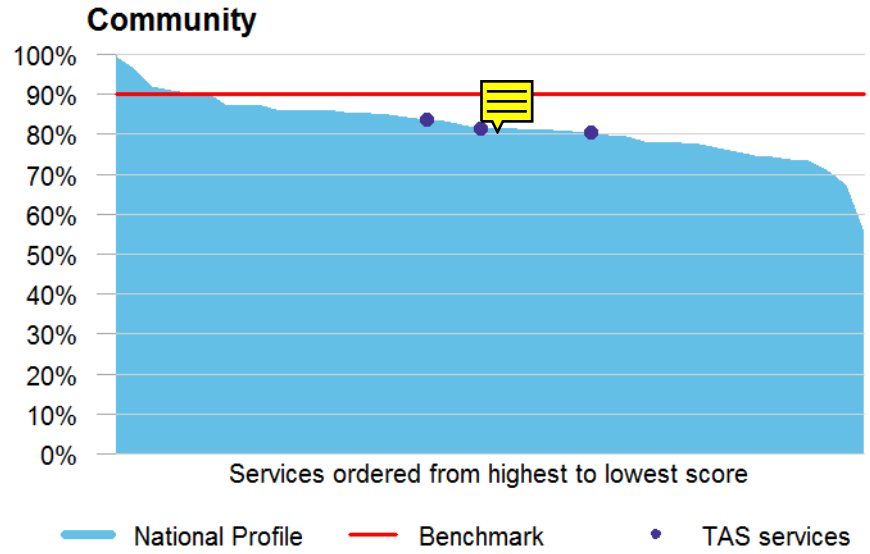
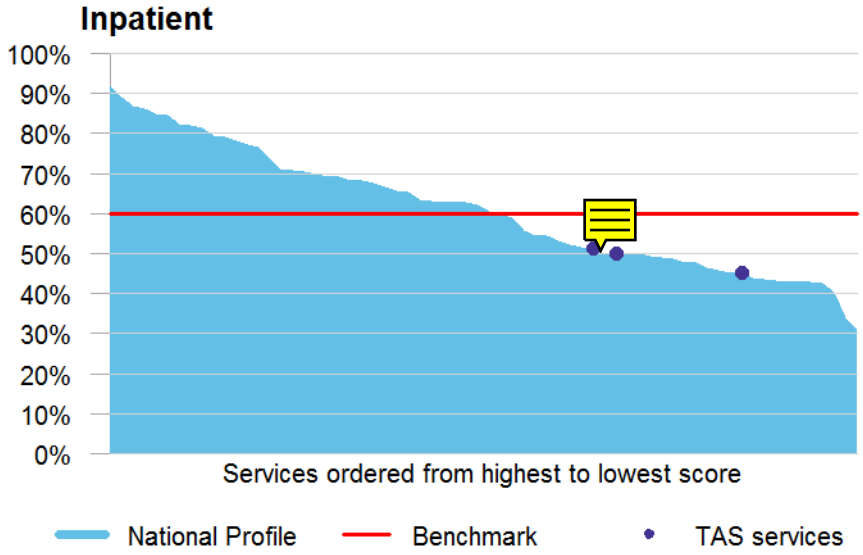


Figure 4 PCPSS: Percentage of patients with moderate/severe pain at phase start, with absent/mild pain at phase end



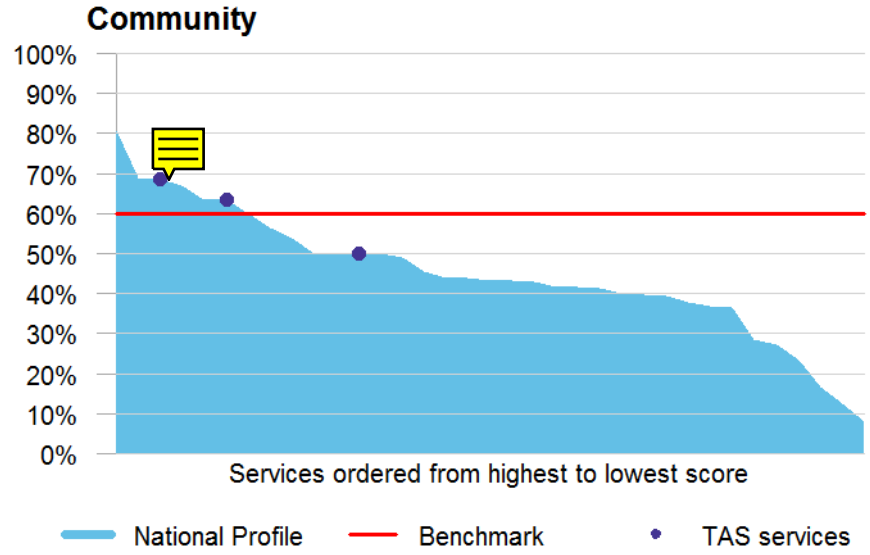


Figure 5 SAS: Percentage of patients with absent/mild distress from pain at phase start, remaining absent/mild at phase end

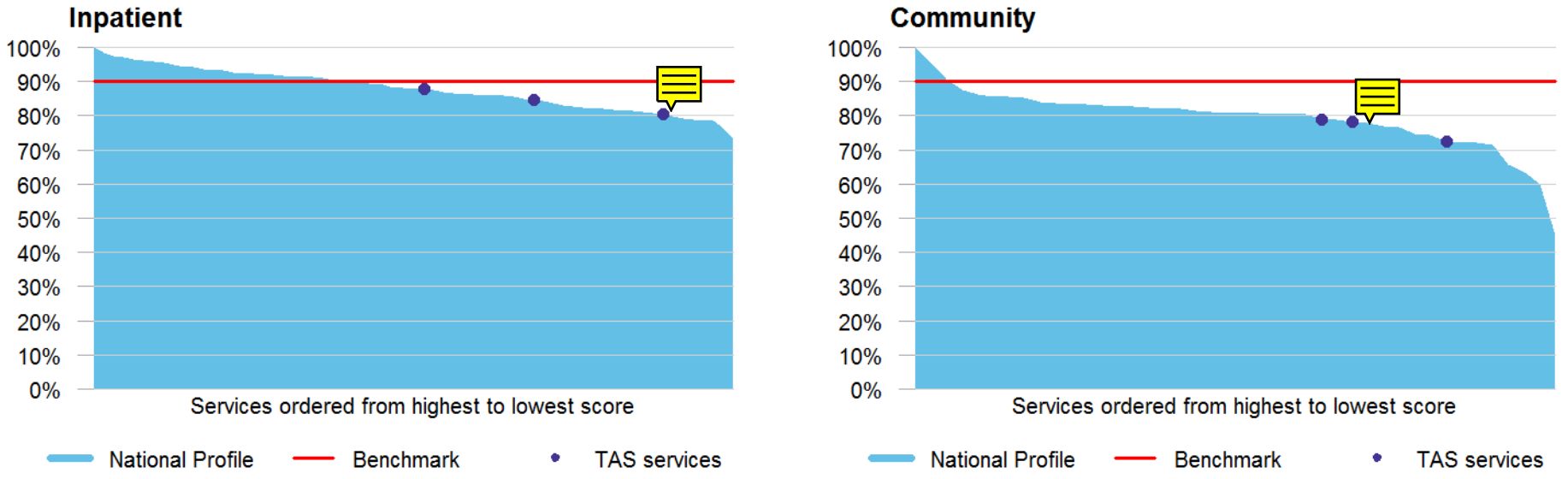
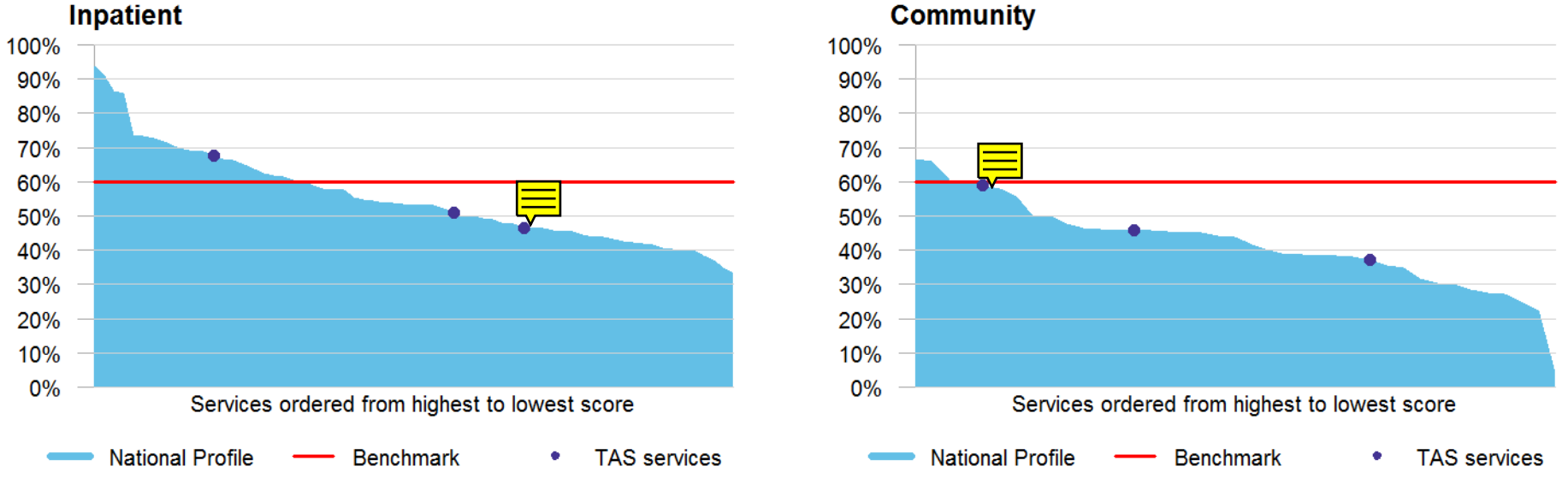


Figure 6 SAS: Percentage of patients with moderate/severe distress from pain at phase start, with absent/mild distress from pain at phase end



Section 2 Outcome measures in detail

2.1 Outcome measure 1 – Time from date ready for care to episode start

Time from date ready for care to episode start reports responsiveness of palliative care services to patient needs. This benchmark was set following feedback and subsequent consultation with PCOC participants. Service providers acknowledge that, whilst there is wide variation in the delivery of palliative care across the country, access to palliative care should be measured based on patient need rather than service availability. As a result, services operating five days a week (Monday to Friday) are not distinguished from services operating seven days a week (all services are being benchmarked together).

Benchmark 1: This measure relates to the time taken for an episode to commence following the date the patient is available and ready to receive palliative care. To meet the benchmark for this measure, at least 90% of patients must have their episode commence on the day of, or the day following date ready for care.

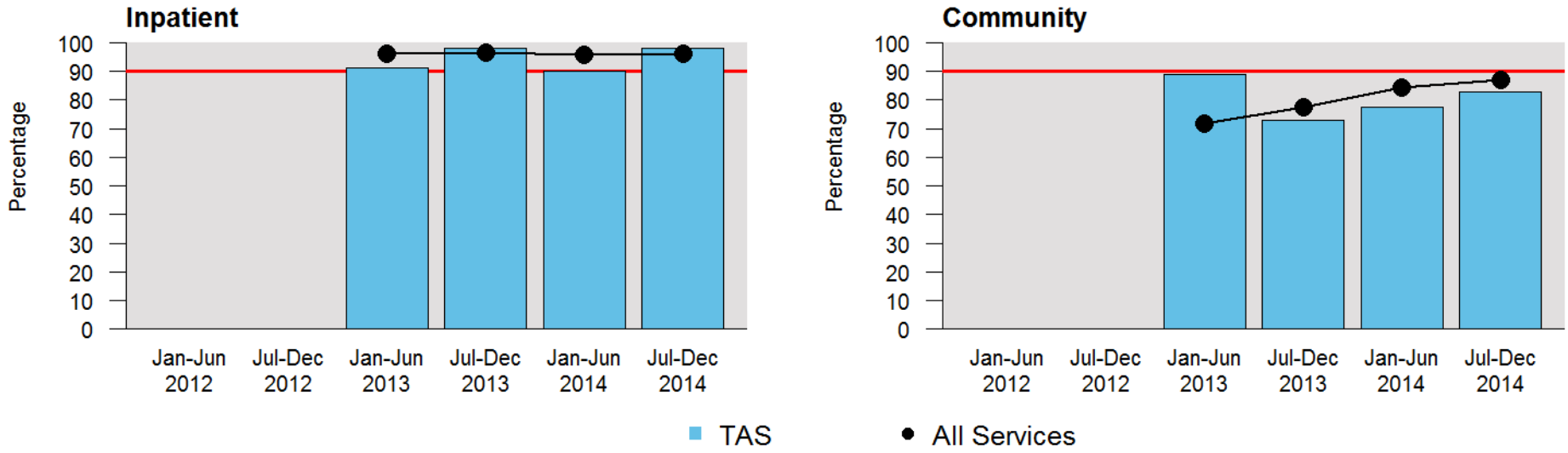
Table 3 Time from date ready for care to episode start by setting

Time (in days)	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Same day	323	88.0	10,032	89.5	502	78.3	8,240	82.2
Following day	37	10.1	768	6.8	30	4.7	493	4.9
2-7 days	6	1.6	380	3.4	71	11.1	953	9.5
8-14 days	1	0.3	22	0.2	26	4.1	203	2.0
Greater than 14 days	0	0	12	0.1	12	1.9	140	1.4
Average	1.1	na	1.1	na	2.4	na	1.9	na
Median	1	na	1	na	1	na	1	na

Note: Only episodes that started in this reporting period have been included in the table. Episodes where date ready for care was not recorded are excluded from the table. In addition, all records where time from date ready for care to episode start was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Interpretation hint:
Outcome measure 1 only includes episodes that have commenced in the reporting period. As a result, the number of episodes included in the calculation of this benchmark may not match the number of episodes in Appendix A. For more information on data scoping methods, see Appendix C.

Figure 7 Percentage of episodes that met outcome measure 1 over time



2.2 Outcome measure 2 – Time in unstable phase

The unstable phase type, by nature of its definition, alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those patients assessed to be in the unstable phase require intense review for a short period of time.

An unstable phase is triggered if:

- a patient experiences a new, unanticipated problem, and/or
- a patient experiences a rapid increase in the severity of an existing problem, and/or
- a patient's family/carers experience a sudden change in circumstances that adversely impacts the patient's care.

The patient moves out of the unstable phase in one of two ways:

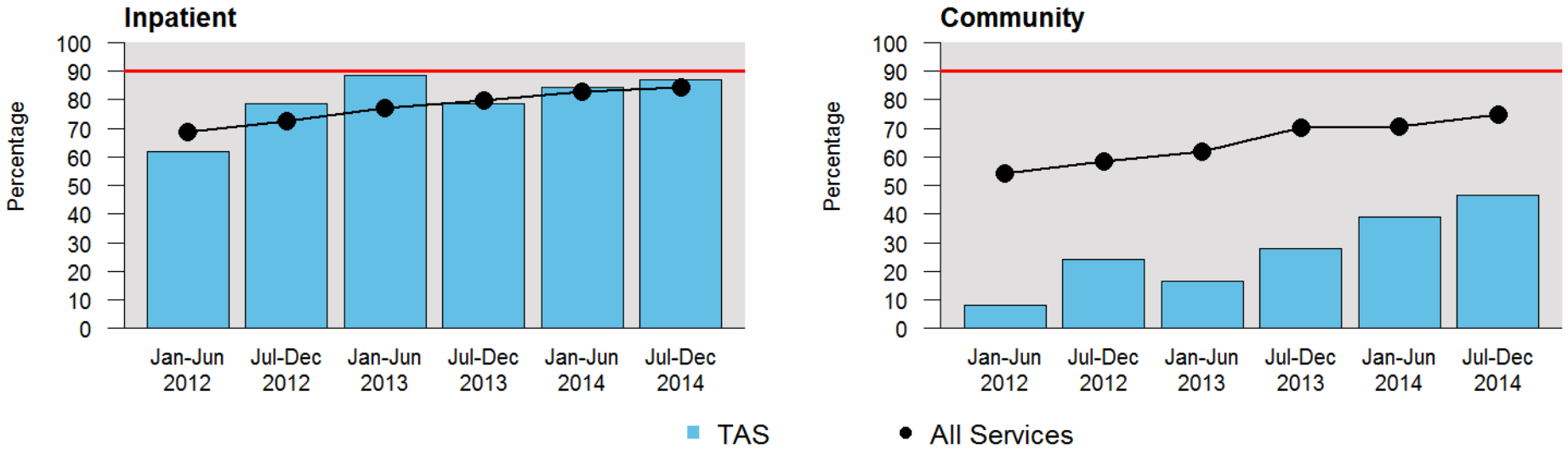
- A new plan of care has been put in place, has been reviewed and does not require any additional changes. This does not necessarily mean that the symptom/crisis has been fully resolved. However, the clinical team will have a clear diagnosis and a plan for the patient's care. In this situation, the patient will move to either the stable or deteriorating phase.
- The patient is likely to die within a matter of days. In this situation, the patient will be moved into the terminal phase.

Benchmark 2: This benchmark relates to time that a patient spends in the unstable phase. To meet this benchmark, at least 90% of unstable phases must last for 3 days or less.

Table 4 Time in unstable phase by setting

Length of unstable phase	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Same day	6	2.6	208	3.2	9	6.7	733	23.1
1 day	103	44.0	2,917	44.6	27	20.0	1,078	33.9
2 days	55	23.5	1,611	24.6	20	14.8	362	11.4
3 days	40	17.1	776	11.9	7	5.2	208	6.5
4-5 days	21	9.0	626	9.6	14	10.4	220	6.9
6-7 days	6	2.6	225	3.4	12	8.9	175	5.5
8-14 days	3	1.3	143	2.2	13	9.6	171	5.4
Greater than 14 days	0	0.0	38	0.6	33	24.4	233	7.3
Total	***234***	***100.0***	***6,544***	***100.0***	***135***	***100.0***	***3,180***	***100.0***

Figure 8 Percentage of phases that met benchmark 2 over time



2.3 Outcome measure 3 – Change in pain

Pain management is acknowledged as a core business of palliative care services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS) provide two different perspectives of pain. The PCPSS is clinician rated and measures the severity of pain as a clinical problem while the SAS is patient rated and measures distress caused by pain.

There are two benchmarks related to each tool: one relating to the management of pain for patients with absent or mild pain, and the other relating to the management of pain for patients with moderate or severe pain. Phase records must have valid start and end scores for the PCPSS and/or SAS clinical assessment tools to be included in the benchmarks.

Scores for PCPSS
0 absent
1 mild
2 moderate
3 severe

Scores for SAS
0 absent
1-3 mild
4-7 moderate
8-10 severe

Interpretation hint:

This outcome measure should be viewed in conjunction with **Error! Reference source not found.**, Table 28 to Table 31, Appendix B and supplementally document 'Severe Pain Summary'.

Benchmarks 3.1 and 3.3: These benchmarks relates to patients who have absent or mild pain at the start of their phase of palliative care. To meet these benchmarks, 90% of phases must end with the patient still experiencing only absent or mild pain.

Benchmarks 3.2 and 3.4: These benchmarks relates to patients who have moderate or severe pain at the start of their phase of palliative care. To meet these benchmarks, 60% of phases must end with the patient's pain reduced to being absent or mild.

Table 5 Summary of outcome measure 3

Benchmark	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N*	%	N*	%	N*	%	N*	%
Benchmark 3.1: PCPSS	480	87.3	15,589	90.9	305	81.6	14,943	84.8
Benchmark 3.2: PCPSS	214	49.1	5,346	57.1	125	58.4	3,933	50.1
Benchmark 3.3: SAS	435	83.4	13,526	88.1	262	76.3	13,991	82.7
Benchmark 3.4: SAS	259	51.0	6,541	52.8	149	45.0	4,879	45.4

*Total number of phases included in this benchmark.

Figure 9 Trends in benchmark 3.1: PCPSS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

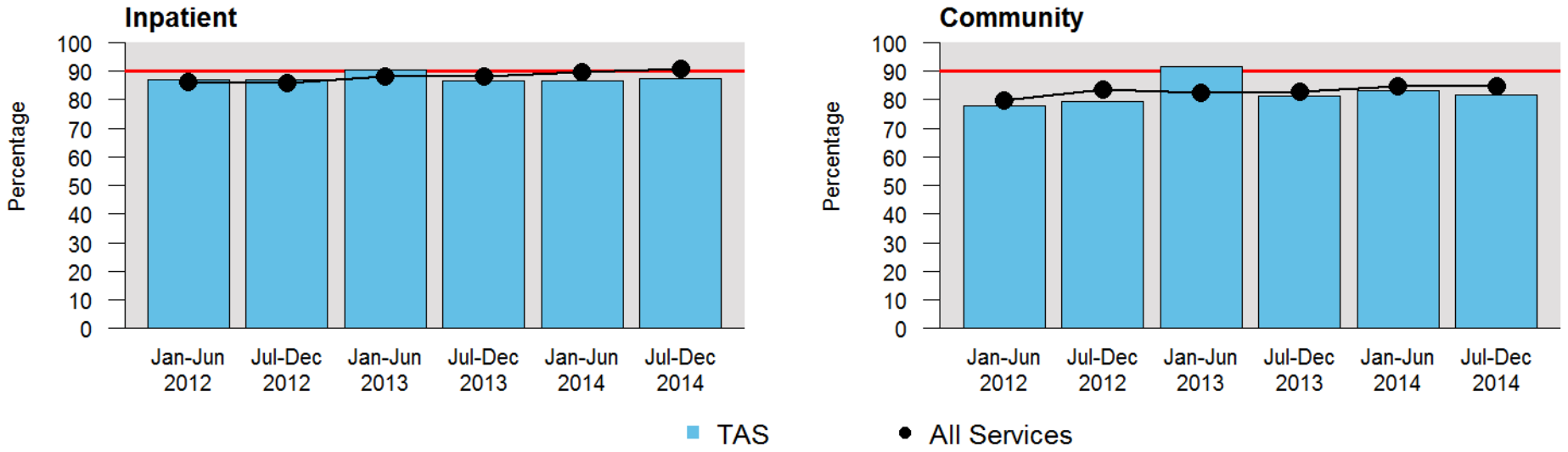


Figure 10 Trends in benchmark 3.2: PCPSS Patients with moderate/severe pain at phase start, with absent/mild at phase end by setting

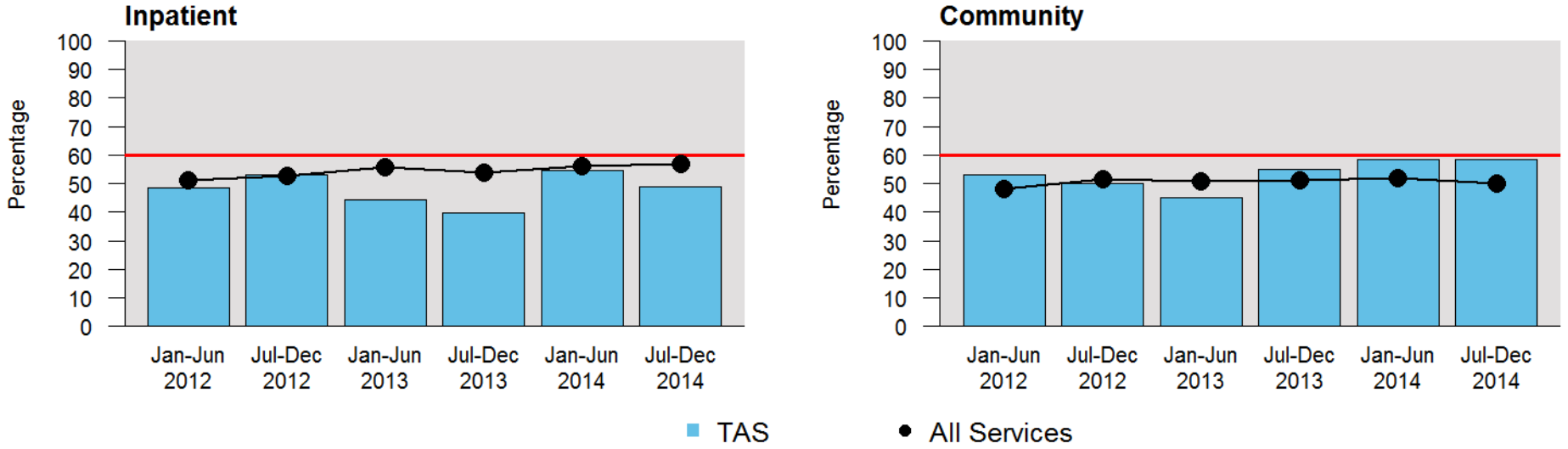


Figure 11 Trends in benchmark 3.3: SAS Patients with absent/mild pain at phase start, remaining absent/mild at phase end by setting

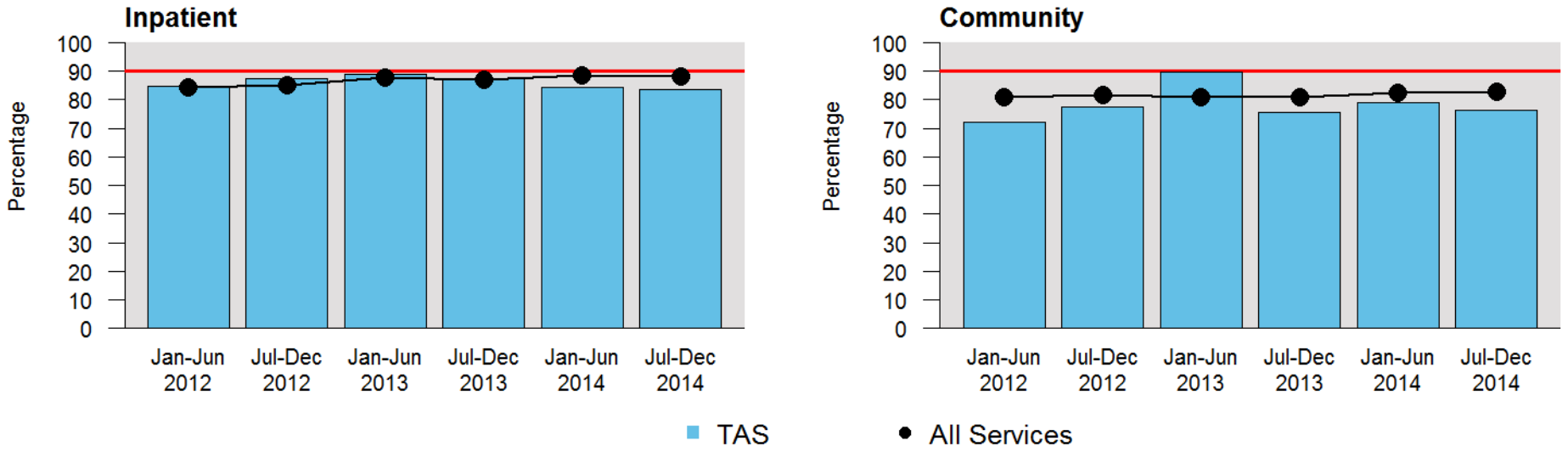
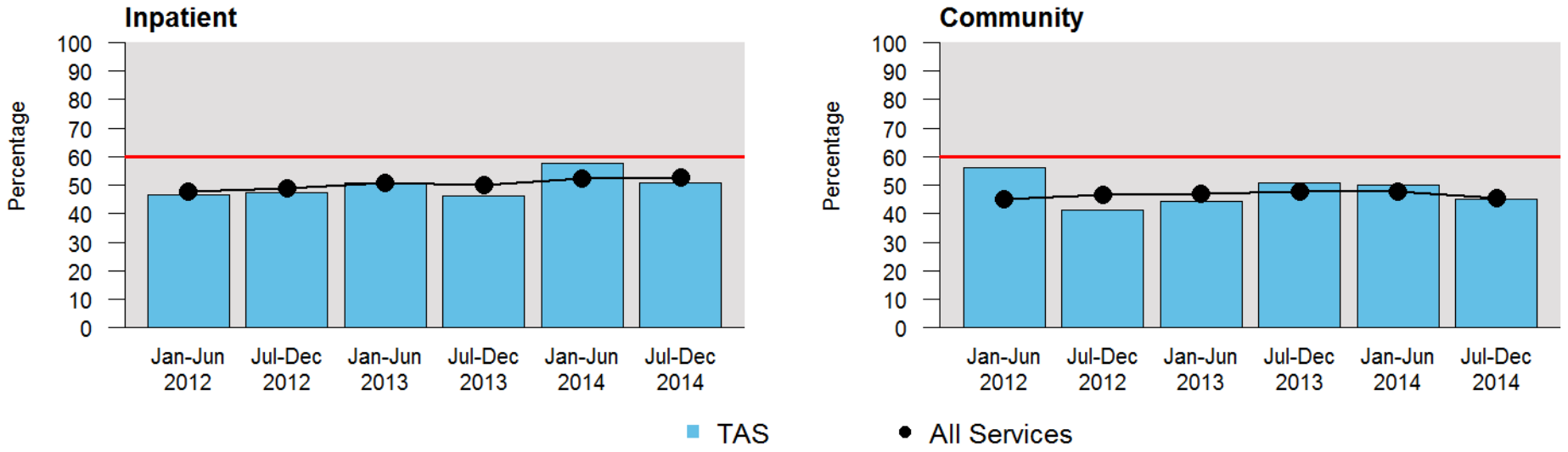


Figure 12 Trends in benchmark 3.4: SAS Patients with moderate/severe pain at phase start, with absent/mild at phase end by setting



2.4 Outcome measure 4 – Change in symptoms relative to the baseline national average (X-CAS)

Outcome measure 4 includes a suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in the same phase who started with the same level of symptom. Eight symptoms are included in this report and the baseline reference period is January to June 2014. The suite of benchmarks included in outcome measure 4 are generally referred to as X-CAS – *CAS* standing for *Case-mix Adjusted Score*, and the *X* to represent that multiple symptoms are included. As X-CAS looks at change in symptom, they are only able to be calculated on phases which ended in phase change or discharge (as the phase end scores are required to determine the change).

Table 6 Summary of outcome measure 4

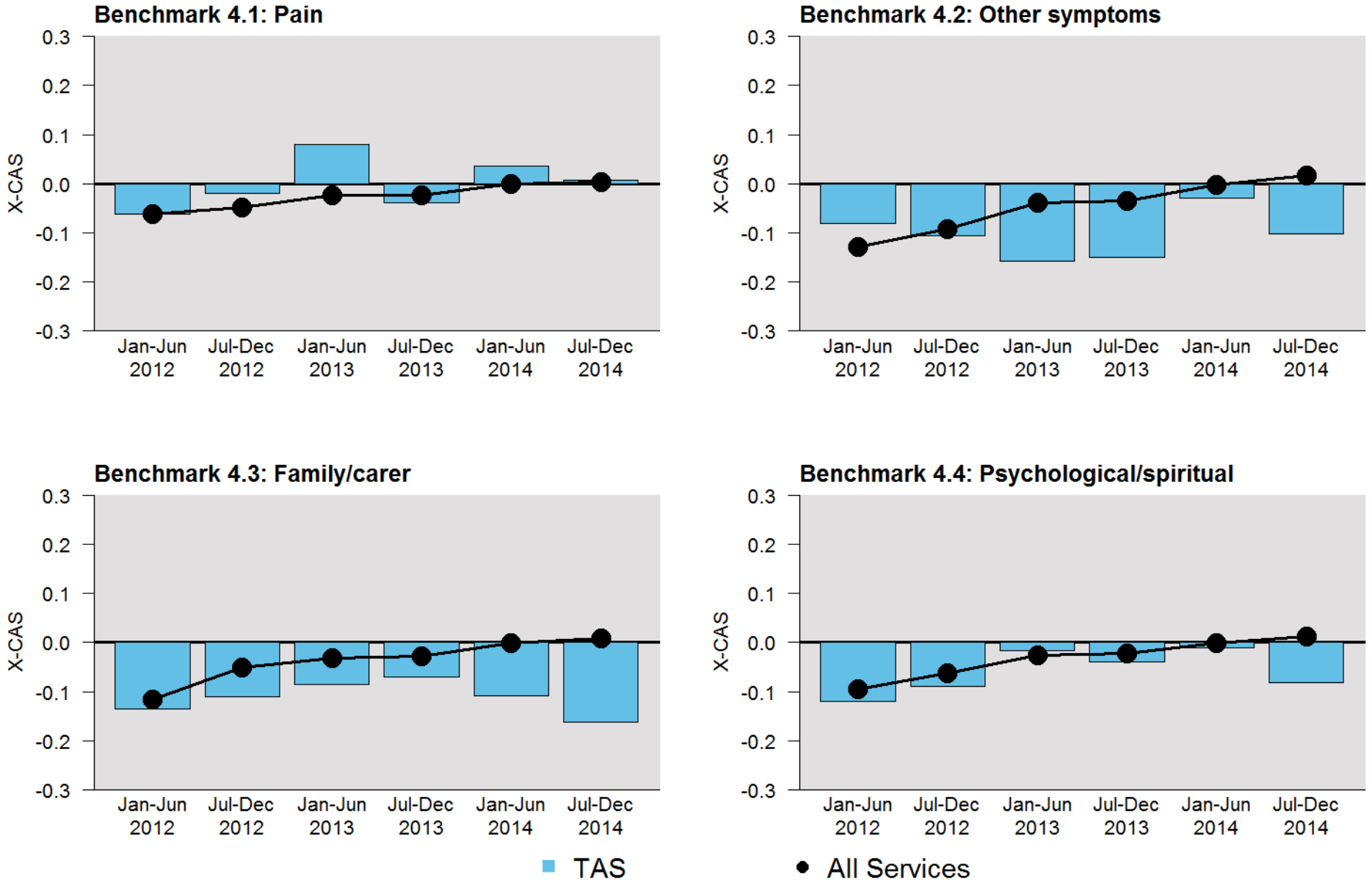
Benchmark: Symptom	TAS				All Services			
	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline	X-CAS	N phases included in measure	N phases at or above the baseline	% phases at or above the baseline
4.1: PCPSS Pain	0.01	1,124	661	58.8	0.00	39,811	23,009	57.8
4.2: Other symptoms	-0.10	1,110	584	52.6	0.02	39,616	24,870	62.8
4.3: Family/carer	-0.16	1,118	551	49.3	0.01	39,198	23,943	61.1
4.4: Psychological/spiritual	-0.08	1,122	538	48.0	0.01	40,087	20,819	51.9
4.5: SAS Pain	-0.10	1,105	684	61.9	-0.01	38,937	23,873	61.3
4.6: Nausea	0.08	1,103	958	86.9	0.02	38,580	31,707	82.2
4.7: Breathing Problems	-0.21	1,098	707	64.4	0.02	38,415	26,699	69.5
4.8: Bowel Problems	-0.10	1,100	786	71.5	0.03	38,024	27,132	71.4

Interpretation hint:

The X-CAS measures are calculated relative to a baseline reference period, which has been updated for this report and is now the period January to June 2014. As a result:

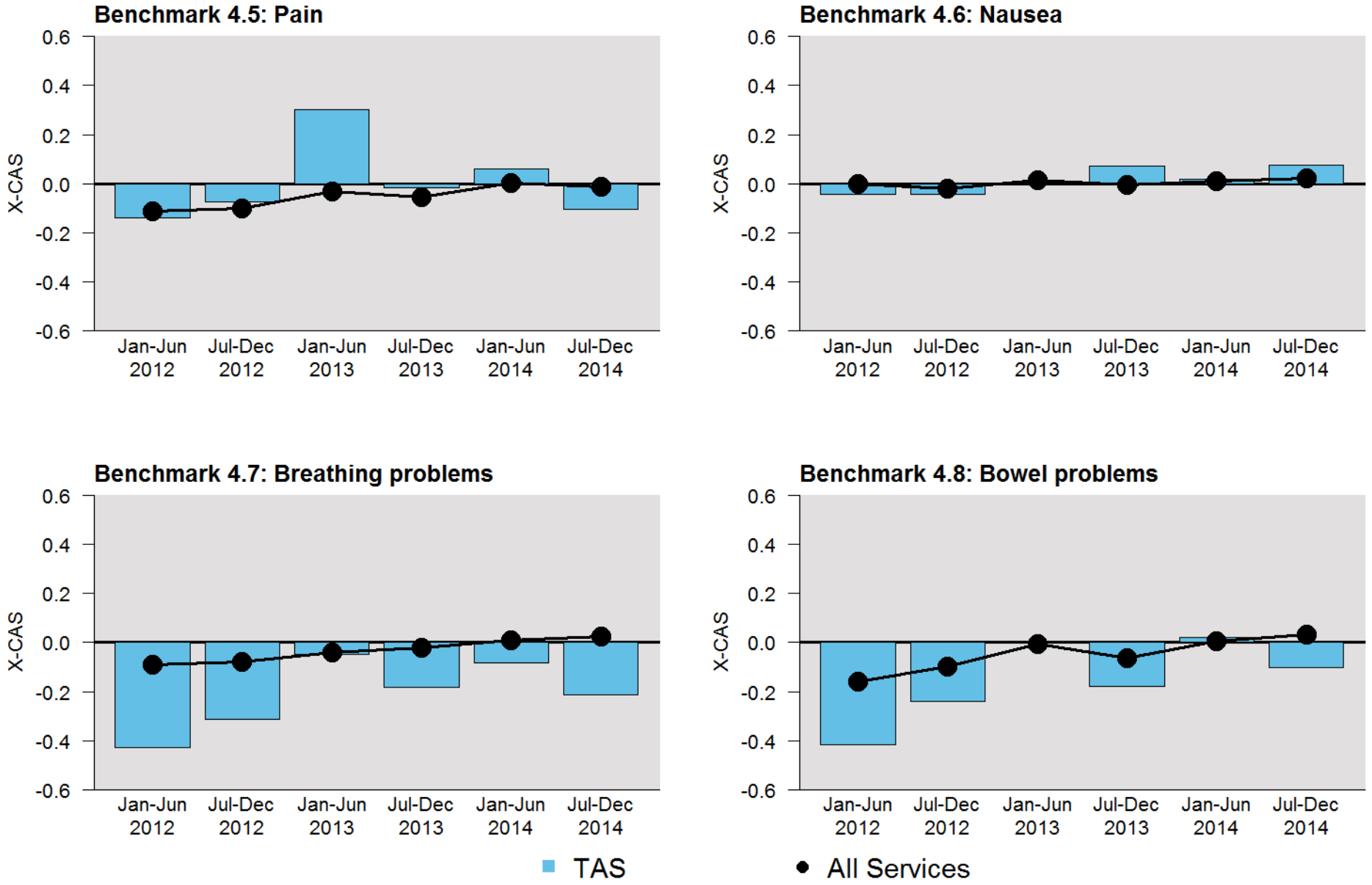
If X-CAS is greater than 0 then on average, patients' change in symptom was better than similar patients in the baseline reference period.
If X-CAS is equal to 0 then on average, patients' change in symptom was about the same as similar patients in the baseline reference period.
If X-CAS is less than 0 then on average, patients' change in symptom was worse than similar patients in the baseline reference period.

Figure 13 Trends in outcome measure 4 – Palliative Care Problem Severity Score (PCPSS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Figure 14 Trends in outcome measure 4 – Symptom Assessment Scale (SAS)



Note: Only services with 10 or more valid assessments are included in the above graphs.

Section 3 Descriptive analysis

This section provides descriptive information of the data submitted by Tasmania at each of the three levels – patient, episode and phase.

Patient level information describes demographics such as Indigenous status, sex, preferred language and country of birth. This information about the patient provides a context to the episode and phase level information and enhances the meaningfulness of patient outcomes.

Episode level information describes the setting of palliative care service provision. It also includes information relating to the facility/organisation that has referred the patient, how an episode starts/ends and the setting in which the patient died.

Phase level information describes the clinical condition of the patient during the episode, using five clinical assessment tools. These are phase of illness, the patient's functional status and performance, pain and other common symptoms, the patient's psychological/spiritual and family/carer domain.

Summaries of the national data are included for comparative purposes.

3.1 Profile of palliative care patients

PCOC defines a patient as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record. Family/carers are included in this definition if interventions relating to them are recorded in the patient medical record.

Table 7 shows the Indigenous status for all the patients in Tasmania and nationally.

Table 7 Indigenous status

Indigenous status	TAS		All Services	
	N	%	N	%
Aboriginal but not Torres Strait Islander origin	14	1.6	179	1.0
Torres Strait Islander but not Aboriginal origin	0	0.0	13	0.1
Both Aboriginal and Torres Strait Islander origin	0	0.0	13	0.1
Neither Aboriginal nor Torres Strait Islander origin	851	98.2	17,739	96.9
Not stated/inadequately described	2	0.2	366	2.0
Total	***867***	***100.0***	***18,310***	***100.0***

Table 8 shows the breakdown of deaths for all patients in Tasmania and nationally for the reporting period. All inpatient deaths are reported in the hospital category while the community deaths are reported in the private residence and residential aged care facility categories.

Table 8 Place of death

Place of death	TAS		All Services	
	N	%	N	%
Private residence	118	29.6	1,834	20.2
Residential aged care facility	28	7.0	647	7.1
Hospital	251	63.1	6,507	71.7
Not stated/inadequately described	1	0.3	88	1.0
Total	***398***	***100.0***	***9,076***	***100.0***

The following two tables show the country of birth and the preferred language respectively for all patients in Tasmania and nationally. To allow for comparison with the broader Australian community the list of country of birth in Table 9 is in descending order of the most frequent country of birth according to the 2006 Census (e.g. Italy was the fifth most common country of birth in the 2006 Census). The same approach has been taken with Table 10 (e.g. Greek was the third most frequently spoken language in the 2006 census). All other countries and languages have been grouped together to form the categories 'All other countries' and 'All other languages' respectively.

Table 9 Country of birth

Country of birth	TAS		All Services	
	N	%	N	%
Australia	708	81.7	11,458	62.6
England	59	6.8	1,410	7.7
New Zealand	9	1.0	363	2.0
China	1	0.1	170	0.9
Italy	8	0.9	679	3.7
Vietnam	0	0.0	138	0.8
India	2	0.2	139	0.8
Scotland	14	1.6	280	1.5
Philippines	3	0.3	76	0.4
Greece	2	0.2	390	2.1
Germany	8	0.9	233	1.3
South Africa	3	0.3	91	0.5
Malaysia	0	0.0	68	0.4
Netherlands	11	1.3	194	1.1
Lebanon	0	0.0	86	0.5
All other countries	36	4.2	2,270	12.4
Not stated/inadequately described	3	0.3	265	1.4
Total	***867***	***100.0***	***18,310***	***100.0***

Table 10 Preferred language

Preferred language	TAS		All Services	
	N	%	N	%
English	856	98.7	16,528	90.3
Italian	3	0.3	335	1.8
Greek	1	0.1	280	1.5
Chinese[(a)]	0	0.0	147	0.8
Arabic[(b)]	1	0.1	100	0.5
Vietnamese[(c)]	0	0.0	60	0.3
Spanish / Portuguese[(d)]	0	0.0	35	0.2
Filipino / Indonesian[(e)]	0	0.0	19	0.1
German[(f)]	1	0.1	31	0.2
Hindi[(g)]	0	0.0	22	0.1
Croatian / Macedonian[(h)]	0	0.0	116	0.6
Korean	0	0.0	16	0.1
Turkish[(i)]	0	0.0	32	0.2
Polish[(j)]	0	0.0	30	0.2
Maltese	0	0.0	35	0.2
All other languages	5	0.6	519	2.8
Not stated/inadequately described	0	0.0	5	0.0
Total	***867***	***100.0***	***18,310***	***100.0***

(a) Chinese includes: Cantonese, Hakka, Mandarin, Wu and Min Nan; **(b) Middle Eastern Semitic Languages includes:** Hebrew, Assyrian Neo-Aramaic, Chaldean Neo-Aramaic, Mandaean (Mandaic); **(c) Mon-Khmer includes:** Khmer, Mon; **(d) Iberian Romance includes:** Catalan; **(e) Southeast Asian Austronesian Languages includes**: Bisaya, Cebuano, Ilokano, Malay, Tetum, Timorese, Tagalog, Acehnese, Balinese, Bikol, Iban, Ilonggo (Hiligaynon), Javanese, Pampangan; **(f) German and Related Languages include:** Letzeburgish, Yiddish; **(g) Indo-Aryan includes:** Bengali, Gujarati, Konkani, Marathi, Nepali, Punjabi, Sindhi, Sinhalese, Urdu, Assamese, Dhivehi, Kashmiri, Oriya, Fijian Hindustani; **(h) South Slavic includes:** Bosnian, Bulgarian, Serbian, Slovene; **(i) Turkic includes:** Azeri, Tatar, Turkmen, Uygur, Uzbek; **(j) West Slavic includes:** Czech, Slovak

Table 11 and Table 12 present a breakdown of malignant and non-malignant diagnosis for the patients seen by Tasmania and at the national level. The primary diagnosis is the principal life limiting illness responsible for the patient requiring palliative care.

The primary diagnosis was not stated for 1 (0.1%) patients in Tasmania and was not stated for 58 (0.3%) patients nationally.

Table 11 Primary diagnosis - malignant

Primary diagnosis	TAS			All Services		
	N	% malignant diagnosis	% all diagnosis	N	% malignant diagnosis	% all diagnosis
Bone and soft tissue	6	0.9	0.7	220	1.6	1.2
Breast	49	7.2	5.7	1,116	7.9	6.1
CNS	13	1.9	1.5	281	2.0	1.5
Colorectal	88	12.9	10.1	1,610	11.4	8.8
Other GIT	58	8.5	6.7	1,406	10.0	7.7
Haematological	58	8.5	6.7	837	6.0	4.6
Head and neck	38	5.6	4.4	784	5.6	4.3
Lung	143	21.0	16.5	3,083	21.9	16.8
Pancreas	51	7.5	5.9	898	6.4	4.9
Prostate	57	8.4	6.6	960	6.8	5.2
Other urological	34	5.0	3.9	592	4.2	3.2
Gynaecological	29	4.3	3.3	707	5.0	3.9
Skin	17	2.5	2.0	528	3.8	2.9
Unknown primary	21	3.1	2.4	404	2.9	2.2
Other primary malignancy	16	2.4	1.8	494	3.5	2.7
Malignant – not further defined	2	0.3	0.2	143	1.0	0.8
All malignant	***680***	***100.0***	***78.4***	***14,063***	***100.0***	***76.8***

Table 12 Primary diagnosis - non-malignant

Primary diagnosis	TAS			All Services		
	N	% non-malignant diagnosis	% all diagnosis	N	% non-malignant diagnosis	% all diagnosis
Cardiovascular disease	47	25.3	5.4	818	19.5	4.5
HIV/AIDS	0	0.0	0.0	12	0.3	0.1
End stage kidney disease	21	11.3	2.4	418	10.0	2.3
Stroke	8	4.3	0.9	223	5.3	1.2
Motor neurone disease	12	6.5	1.4	165	3.9	0.9
Alzheimer's dementia	9	4.8	1.0	157	3.7	0.9
Other dementia	3	1.6	0.3	242	5.8	1.3
Other neurological disease	5	2.7	0.6	355	8.5	1.9
Respiratory failure	39	21.0	4.5	749	17.9	4.1
End stage liver disease	2	1.1	0.2	159	3.8	0.9
Diabetes and its complications	2	1.1	0.2	19	0.5	0.1
Sepsis	6	3.2	0.7	94	2.2	0.5
Multiple organ failure	5	2.7	0.6	104	2.5	0.6
Other non-malignancy	24	12.9	2.8	582	13.9	3.2
Non-malignant – not further defined	3	1.6	0.3	92	2.2	0.5
All non-malignant	***186***	***100.0***	***21.5***	***4,189***	***100.0***	***22.9***

3.2 Profile of palliative care episodes

An episode of care is a period of contact between a patient and a palliative care service that is provided by one palliative care service and occurs in one setting – for the purposes of this report, either as an inpatient or community patient.

An episode of palliative care starts on the date when the comprehensive palliative care assessment is undertaken and documented using the five clinical assessment tools.

An episode of palliative care ends when:

- the patient is formally separated from the current setting of care (e.g. from community to inpatient) or
- the patient dies or
- the principal clinical intent of the care changes and the patient is no longer receiving palliative care.

Table 13 below presents the number and percentage of episodes by age group and sex for the patients seen by Tasmania and at the national level. Age has been calculated as at the beginning of each episode.

Table 13 Age group by sex

Age group	TAS				All Services			
	Male		Female		Male		Female	
	N	%	N	%	N	%	N	%
< 15	1	0.2	0	0.0	31	0.2	28	0.3
15 - 24	0	0.0	1	0.2	42	0.3	42	0.4
25 - 34	0	0.0	5	1.0	90	0.7	103	0.9
35 - 44	15	2.7	14	2.9	279	2.2	398	3.6
45 - 54	22	3.9	41	8.5	767	6.2	943	8.5
55 - 64	91	16.2	105	21.8	1,913	15.4	1,748	15.8
65 - 74	151	26.9	99	20.5	3,374	27.2	2,491	22.6
75 - 84	192	34.2	140	29.0	3,793	30.5	2,868	26.0
85+	90	16.0	77	16.0	2,128	17.1	2,411	21.9
Not stated/inadequately described	0	0.0	0	0.0	0	0.0	0	0.0
Total	***562***	***100.0***	***482***	***100.0***	***12,417***	***100.0***	***11,032***	***100.0***

Note: Records where sex was not stated or inadequately described are excluded from the table.

Referral source refers to the facility or organisation from which the patient was referred for each episode of care. Table 14 presents referral source by setting.

Table 14 Referral source by setting

Referral source	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Public hospital	151	40.5	6,397	52.3	291	43.4	5,458	48.6
Private hospital	50	13.4	1,534	12.5	97	14.5	1,206	10.7
Outpatient clinic	2	0.5	53	0.4	8	1.2	26	0.2
General medical practitioner	9	2.4	386	3.2	79	11.8	1,523	13.6
Specialist medical practitioner	12	3.2	605	4.9	41	6.1	384	3.4
Community-based palliative care agency	137	36.7	2,717	22.2	19	2.8	327	2.9
Community-based service	0	0.0	54	0.4	38	5.7	168	1.5
Residential aged care facility	4	1.1	99	0.8	15	2.2	927	8.3
Self, carer(s), family or friends	6	1.6	156	1.3	67	10.0	371	3.3
Other	2	0.5	163	1.3	13	1.9	302	2.7
Not stated/inadequately described	0	0.0	60	0.5	3	0.4	533	4.7
Total	***373***	***100.0***	***12,224***	***100.0***	***671***	***100.0***	***11,225***	***100.0***

Table 15 provides a summary of the time between referral to first contact by setting of care. The time from referral to first contact is calculated as the time from the date of referral received to either the date of first contact (if provided) or the episode start date.

Table 15 Referral to first contact by episode setting

Time (in days)	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Same day or following day	355	95.2	11,383	93.1	396	59.0	5,932	52.9
2-7 days	13	3.5	716	5.9	212	31.6	3,711	33.1
8-14 days	2	0.5	61	0.5	45	6.7	883	7.9
Greater than 14 days	3	0.8	61	0.5	18	2.7	697	6.2
Average	1.1	na	1.2	na	2.5	na	2.8	na
Median	1	na	1	na	1	na	1	na

Note: Episodes where referral date was not recorded are excluded from the table. In addition, all records where time from referral to first contact was greater than 90 days were considered to be atypical and were assumed to equal 90 days for the purpose of calculating the average and median time.

Table 16 gives a summary of the length of episode for patients in Tasmania and nationally. Table 17 details the length of episode by setting. The length of episode is calculated as the number of days between the episode start date and the episode end date. Bereavement phases are excluded from the calculation and episodes that remain open at the end of the reporting period (and hence do not have an episode end date) are also excluded.

Table 16 Length of episode (in days) summary by setting

Length of episode	Inpatient		Community	
	TAS	All Services	TAS	All Services
Average length of episode	10.1	10.6	42.9	35.8
Median length of episode	6.0	6.0	35.0	24.0

Note: Records where length of episode was greater than 180 days were considered to be atypical and are excluded from the average calculations. Only episodes ending during the reporting period are included.

Table 17 Length of episode (in days) by setting

Length of episode	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Same day	20	5.5	681	5.7	12	1.9	799	8.0
1-2 days	60	16.6	2,304	19.1	22	3.5	597	6.0
3-4 days	69	19.1	1,777	14.8	19	3.1	501	5.0
5-7 days	56	15.5	2,044	17.0	37	5.9	745	7.5
8-14 days	87	24.1	2,586	21.5	75	12.1	1,234	12.3
15-21 days	26	7.2	1,106	9.2	64	10.3	906	9.1
22-30 days	25	6.9	729	6.1	58	9.3	871	8.7
31-60 days	16	4.4	659	5.5	143	23.0	1,736	17.4
61-90 days	0	0.0	106	0.9	58	9.3	834	8.3
Greater than 90 days	2	0.6	50	0.4	134	21.5	1,776	17.8
Total	***361***	***100.0***	***12,042***	***100.0***	***622***	***100.0***	***9,999***	***100.0***

Note: Only episodes ending during the reporting period are included.

Table 18 How episodes start – inpatient setting

Episode start mode	TAS		All Services	
	N	%	N	%
Admitted from community*	235	63.0	7,522	61.5
Admitted from another hospital	109	29.2	3,088	25.3
Admitted from acute care in another ward	20	5.4	1,343	11.0
Change from acute care to palliative care – same ward	3	0.8	173	1.4
Other**	6	1.6	92	0.8
Not stated/inadequately described	0	0.0	6	0.0
Total	***373***	***100.0***	***12,224***	***100.0***

* includes: admitted from usual accommodation, admitted from other than usual accommodation

** includes: change of sub-acute/non-acute care type and other categories

Table 19 How episodes end – inpatient setting

Episode end mode	TAS		All Services	
	N	%	N	%
Discharged to community*	103	28.5	4,331	36.0
Discharged to another hospital	5	1.4	877	7.3
Death	251	69.5	6,507	54.0
Change from palliative care to acute care**	2	0.6	74	0.6
Change in sub-acute care type	0	0.0	38	0.3
End of consultative episode – inpatient episode ongoing	0	0.0	98	0.8
Other	0	0.0	111	0.9
Not stated/inadequately described	0	0.0	6	0.0
Total	***361***	***100.0***	***12,042***	***100.0***

Note: Only episodes ending during the reporting period are included.

* includes: discharged to usual accommodation, discharged to other than usual accommodation

** includes: change from palliative care to acute care – different ward, change from palliative care to acute care – same ward

Table 20 How episodes start – community setting

Episode start mode	TAS		All Services	
	N	%	N	%
Admitted from inpatient palliative care	101	15.1	4,137	36.9
Other*	566	84.4	7,035	62.7
Not stated/inadequately described	4	0.6	53	0.5
Total	***671***	***100.0***	***11,225***	***100.0***

*includes: patient was not transferred from being an overnight patient

Table 21 How episodes end – community setting

Episode end mode	TAS		All Services	
	N	%	N	%
Admitted for inpatient palliative care	91	14.6	2,792	27.9
Admitted for inpatient acute care	115	18.5	2,677	26.8
Admitted to another palliative care service	15	2.4	133	1.3
Admitted to primary health care	45	7.2	611	6.1
Discharged/case closure	209	33.6	1,065	10.7
Death	147	23.6	2,569	25.7
Other	0	0.0	144	1.4
Not stated/inadequately described	0	0.0	8	0.1
Total	***622***	***100.0***	***9,999***	***100.0***

Note: Only episodes ending during the reporting period are included.

3.3 Profile of palliative care phases

The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence. See Appendix D for more information on the definition of palliative care phase.

The clinical assessments are assessed daily (or at each visit) and are reported on admission, when the phase changes and at discharge.

Table 22 Number of phases by phase type and setting

Phase type	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Stable	231	24.4	7,330	25.8	362	38.6	9,334	37.2
Unstable	234	24.7	6,544	23.0	135	14.4	3,180	12.7
Deteriorating	264	27.9	8,978	31.6	368	39.2	10,424	41.6
Terminal	217	22.9	5,557	19.6	73	7.8	2,120	8.5
Total	***946***	***100.0***	***28,409***	***100.0***	***938***	***100.0***	***25,058***	***100.0***

Note: Bereavement phases have been excluded due to inconsistent data collection and bereavement practices. Bereavement phases are not included in the total phases count.

Table 23 Average phase length (in days) by phase type and setting

Phase type	Inpatient		Community	
	TAS	All Services	TAS	All Services
Stable	7.1	6.9	32.9	19.8
Unstable	2.1	2.3	9.9	4.4
Deteriorating	4.4	5.5	24.5	12.7
Terminal	2.1	2.1	6.7	3.0

Note: Phase records where phase length was greater than 90 days were considered to be atypical and are excluded from the average calculations.

Table 24 presents information relating to the manner in which stable phases ended, both for Tasmania and nationally. A stable phase will end if a patient moves into a different phase (phase change), is discharged or dies. Figure 15 summarises the movement of patients out of the stable phase for the inpatient and community settings. This movement from one phase to another is referred to as phase progression. The phase progression information is derived by PCOC.

Similar information is presented for the unstable (Table 25, Figure 16), deteriorating (Table 26, Figure 17) and terminal (Table 27, Figure 18) phases on the following pages.

Table 24 How stable phases end – by setting

How stable phases end	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	136	58.9	3,681	50.2	117	32.3	6,076	65.1
Discharge/case closure	91	39.4	3,539	48.3	230	63.5	2,972	31.8
Died	4	1.7	103	1.4	15	4.1	247	2.6
Not stated/inadequately described	0	0.0	7	0.1	0	0.0	39	0.4
Total	***231***	***100.0***	***7,330***	***100.0***	***362***	***100.0***	***9,334***	***100.0***

Figure 15 Stable phase progression

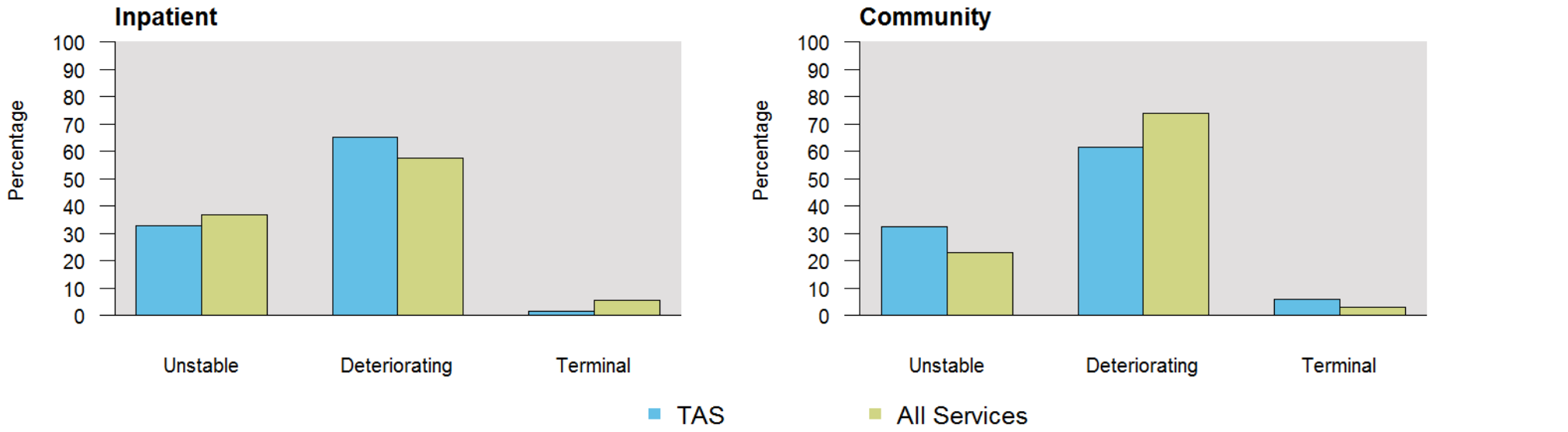


Table 25 How unstable phases end – by setting

How unstable phases end	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	219	93.6	6,022	92.0	79	58.5	2,147	67.5
Discharge/case closure	7	3.0	367	5.6	49	36.3	963	30.3
Died	8	3.4	148	2.3	7	5.2	63	2.0
Not stated/inadequately described	0	0.0	7	0.1	0	0.0	7	0.2
Total	***234***	***100.0***	***6,544***	***100.0***	***135***	***100.0***	***3,180***	***100.0***

Figure 16 Unstable phase progression

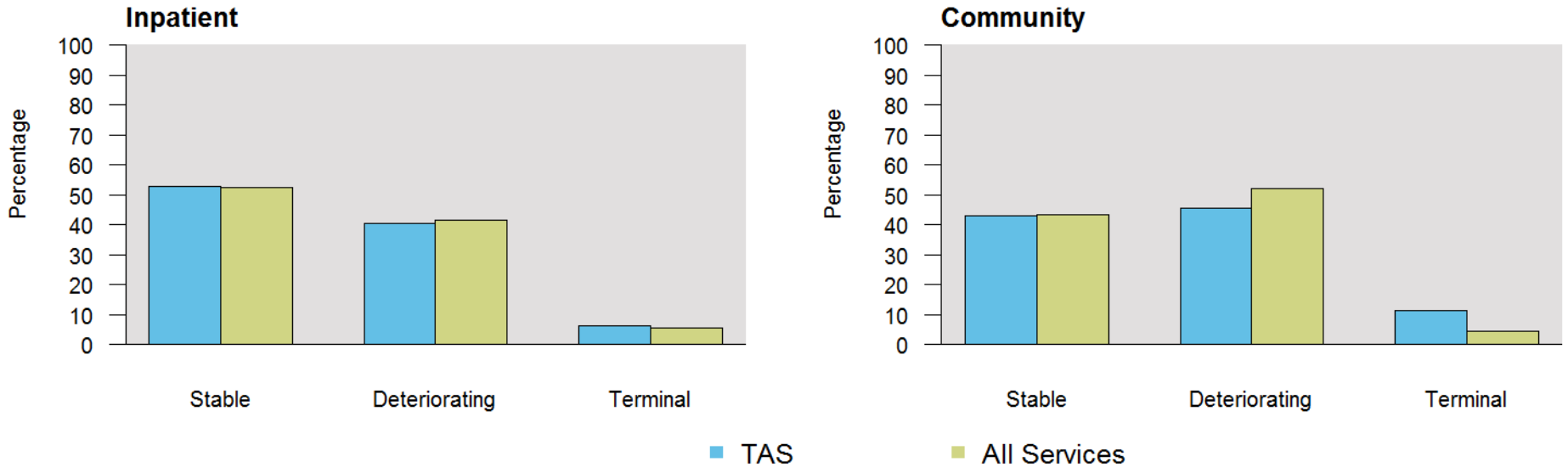


Table 26 How deteriorating phases end – by setting

How deteriorating phases end	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	221	83.7	6,444	71.8	119	32.3	6,442	61.8
Discharge/case closure	12	4.5	1,501	16.7	186	50.5	3,209	30.8
Died	31	11.7	1,027	11.4	63	17.1	762	7.3
Not stated/inadequately described	0	0.0	6	0.1	0	0.0	11	0.1
Total	***264***	***100.0***	***8,978***	***100.0***	***368***	***100.0***	***10,424***	***100.0***

Figure 17 Deteriorating phase progression

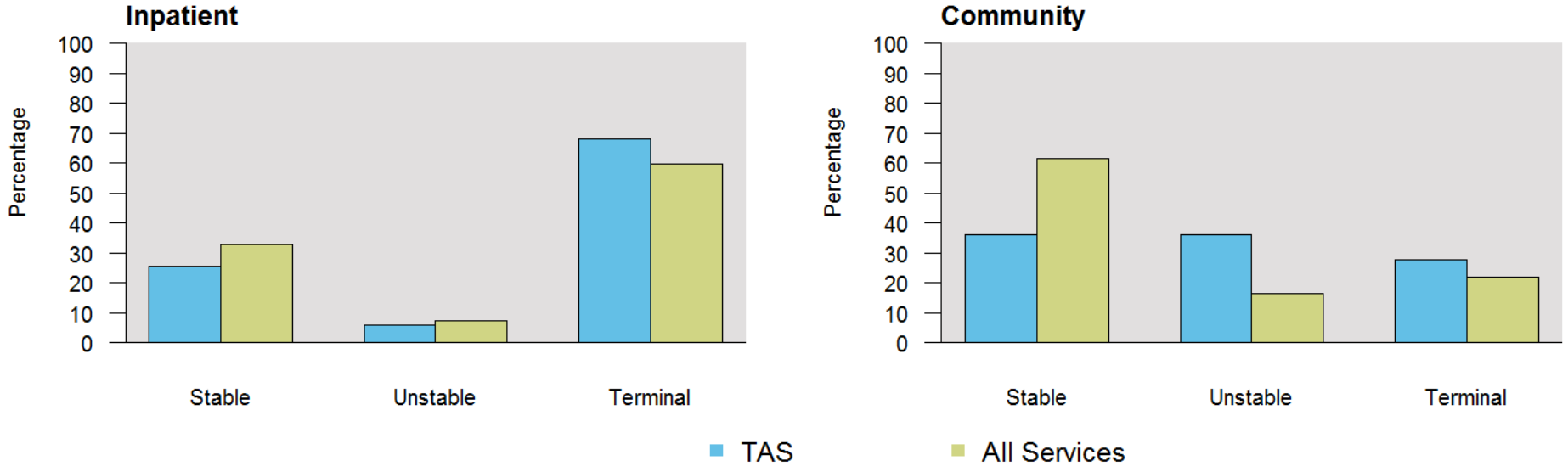
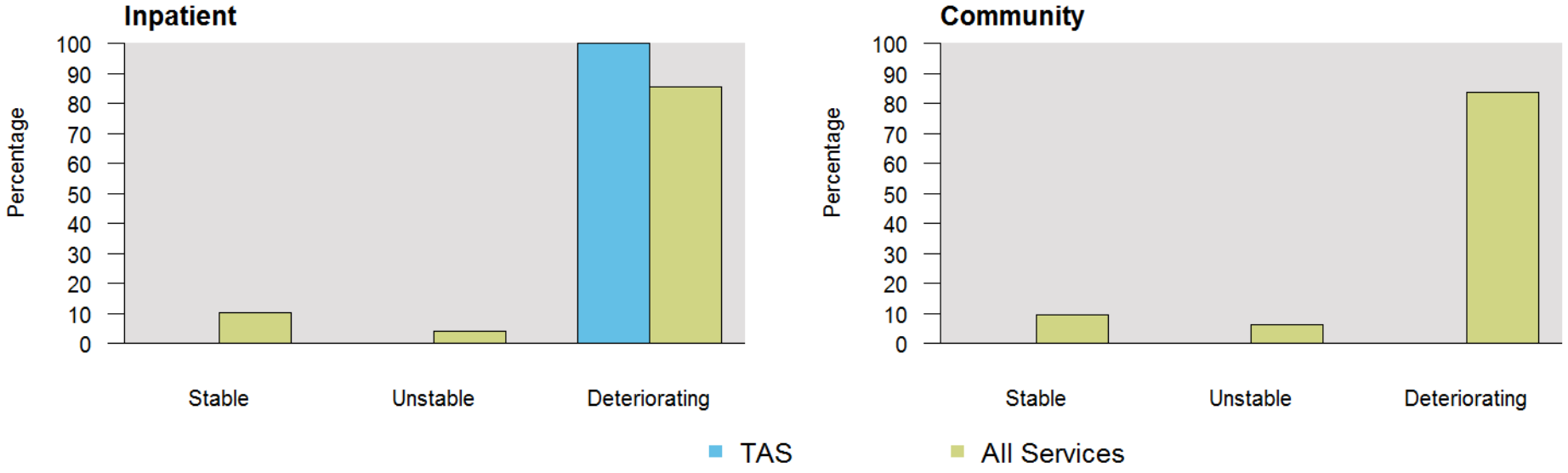


Table 27 How terminal phases end – by setting

How terminal phases end	Inpatient				Community			
	TAS		All Services		TAS		All Services	
	N	%	N	%	N	%	N	%
Patient moved into another phase	9	4.1	215	3.9	0	0.0	330	15.6
Discharge/case closure	0	0.0	106	1.9	11	15.1	241	11.4
Died	208	95.9	5,236	94.2	62	84.9	1,548	73.0
Not stated/inadequately described	0	0.0	0	0.0	0	0.0	1	0.0
Total	***217***	***100.0***	***5,557***	***100.0***	***73***	***100.0***	***2,120***	***100.0***

Figure 18 Terminal phase progression



The Palliative Care Problem Severity Score (PCPSS) is a clinician rated screening tool to assess the overall severity of problems within four key palliative care domains (pain, other symptoms, psychological/spiritual and family/carer). The ratings are: 0 - absent, 1 - mild, 2 - moderate and 3 - severe.

Table 28 and Table 29 show the percentage scores for the inpatient and community settings, respectively, for both Tasmania and nationally.

Table 28 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)

Phase type		TAS				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	48.5	35.1	11.7	4.8	48.8	37.6	11.0	2.5
	Other symptoms	15.6	47.2	28.6	8.7	25.8	51.9	19.1	3.3
	Psychological/spiritual	26.4	50.2	18.6	4.8	32.7	52.6	12.2	2.5
	Family/carer	37.2	43.3	16.0	3.5	40.6	43.1	12.8	3.4
Unstable	Pain	32.5	27.4	22.6	17.5	30.5	30.9	25.6	12.9
	Other symptoms	7.7	27.4	41.0	23.9	13.8	34.1	38.3	13.8
	Psychological/spiritual	15.0	42.7	32.9	9.4	23.8	44.1	24.8	7.4
	Family/carer	21.4	36.3	30.3	12.0	26.1	40.8	24.2	8.9
Deteriorating	Pain	33.7	32.6	25.0	8.7	38.4	35.9	19.7	5.9
	Other symptoms	8.7	23.9	41.3	26.1	15.3	40.8	33.5	10.4
	Psychological/spiritual	15.9	39.4	37.5	7.2	24.9	47.8	21.6	5.7
	Family/carer	23.9	30.7	29.9	15.5	27.6	41.6	23.0	7.8
Terminal	Pain	41.0	27.6	21.7	9.7	48.1	32.7	14.0	5.1
	Other symptoms	23.5	21.2	30.4	24.9	33.6	35.0	21.8	9.6
	Psychological/spiritual	29.5	28.1	29.5	12.9	51.1	31.8	12.5	4.6
	Family/carer	8.3	24.9	31.3	35.5	21.9	35.6	30.2	12.4

Table 29 Profile of PCPSS at beginning of phase by phase type –community setting (percentages)

Phase type		TAS				All Services			
	Problem severity	Absent	Mild	Moderate	Severe	Absent	Mild	Moderate	Severe
Stable	Pain	56.3	31.0	9.5	3.2	41.0	50.8	7.6	0.6
	Other symptoms	34.6	42.2	18.6	4.7	14.9	66.3	17.5	1.3
	Psychological/spiritual	44.7	37.5	12.1	5.8	30.2	58.5	10.2	1.1
	Family/carer	35.3	42.4	15.3	7.1	31.1	53.6	13.5	1.7
Unstable	Pain	25.6	19.4	26.4	28.7	18.3	28.7	33.6	19.4
	Other symptoms	29.9	19.7	26.8	23.6	5.4	28.0	48.4	18.3
	Psychological/spiritual	24.8	32.6	28.7	14.0	12.1	45.6	34.4	7.9
	Family/carer	12.8	30.4	30.4	26.4	14.1	34.8	39.3	11.8
Deteriorating	Pain	40.3	32.2	17.9	9.5	28.4	49.3	19.5	2.8
	Other symptoms	25.8	31.6	29.0	13.6	7.0	48.7	39.2	5.1
	Psychological/spiritual	31.1	39.2	16.8	12.9	18.4	58.0	20.8	2.9
	Family/carer	20.8	40.8	22.0	16.3	19.1	47.9	28.5	4.5
Terminal	Pain	54.5	16.7	9.1	19.7	35.7	44.4	15.8	4.1
	Other symptoms	29.7	26.6	25.0	18.8	20.9	40.9	29.6	8.6
	Psychological/spiritual	47.0	18.2	18.2	16.7	40.0	42.0	15.0	3.1
	Family/carer	10.4	31.3	29.9	28.4	12.6	40.1	36.8	10.5

The Symptom Assessment Scale (SAS) is a patient rated (or proxy) assessment tool and reports a level of distress using a numerical rating scale from 0 - no problems to 10 - worst possible problems. The SAS reports on seven symptoms, these being difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. It provides a clinical picture of these seven symptoms from the patient's perspective. The SAS scores are grouped in Table 30 and Table 31 on the following pages using the same categories as the PCPSS i.e. absent (0), mild (1-3), moderate (4-7) and severe (8-10). Additional information on the SAs profile by phase can be found in Appendix B.

Table 30 Profile of SAS scores at beginning of phase by phase type – inpatient setting (percentages)

Phase type		TAS				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	64.9	17.3	13.4	4.3	67.8	18.1	11.5	2.6
	Appetite problems	61.5	23.4	12.1	3.0	55.0	23.3	17.7	4.0
	Nausea	89.2	7.4	2.6	0.9	79.7	13.2	6.0	1.0
	Bowel problems	68.0	14.3	13.0	4.8	61.8	21.7	13.5	3.1
	Breathing problems	53.7	17.3	19.0	10.0	64.8	18.2	13.6	3.4
	Fatigue	26.4	18.6	44.2	10.8	27.3	25.0	38.4	9.3
	Pain	44.6	28.6	23.8	3.0	46.3	31.9	18.9	3.0
Unstable	Difficulty sleeping	60.7	10.7	17.5	11.1	57.6	17.5	18.7	6.1
	Appetite problems	52.1	19.7	21.4	6.8	41.8	22.4	25.8	10.0
	Nausea	74.8	11.5	8.5	5.1	68.3	14.3	12.2	5.3
	Bowel problems	58.1	14.1	20.1	7.7	50.9	21.2	20.7	7.3
	Breathing problems	49.6	17.5	19.7	13.2	55.2	17.2	18.6	8.9
	Fatigue	21.8	13.7	41.5	23.1	21.2	17.1	43.4	18.3
	Pain	32.5	26.9	22.6	17.9	30.9	24.6	31.8	12.7
Deteriorating	Difficulty sleeping	67.0	16.7	10.2	6.1	67.5	15.3	14.0	3.2
	Appetite problems	59.1	17.4	18.9	4.5	50.9	19.0	22.1	7.9
	Nausea	78.0	10.2	8.3	3.4	76.2	12.3	9.2	2.3
	Bowel problems	65.2	12.5	17.4	4.9	59.5	20.3	15.9	4.3
	Breathing problems	51.5	13.3	20.5	14.8	55.5	18.1	18.6	7.8
	Fatigue	26.9	9.8	41.7	21.6	24.8	14.7	41.0	19.5
	Pain	37.1	20.1	31.8	11.0	38.2	29.1	26.7	6.0
Terminal	Difficulty sleeping	88.9	5.5	3.7	1.8	90.0	4.8	4.2	1.1
	Appetite problems	91.7	3.2	3.7	1.4	87.8	3.7	5.0	3.5
	Nausea	95.4	2.3	2.3	0.0	93.0	3.7	2.4	0.9
	Bowel problems	87.6	3.2	5.5	3.7	84.4	7.7	5.8	2.2
	Breathing problems	70.5	7.4	11.1	11.1	67.6	12.4	13.4	6.6
	Fatigue	71.0	1.8	13.4	13.8	71.0	4.7	12.0	12.3
	Pain	53.0	17.5	23.5	6.0	56.3	22.4	16.9	4.3

Table 31 Profile of SAS scores at beginning of phase by phase type –community setting (percentages)

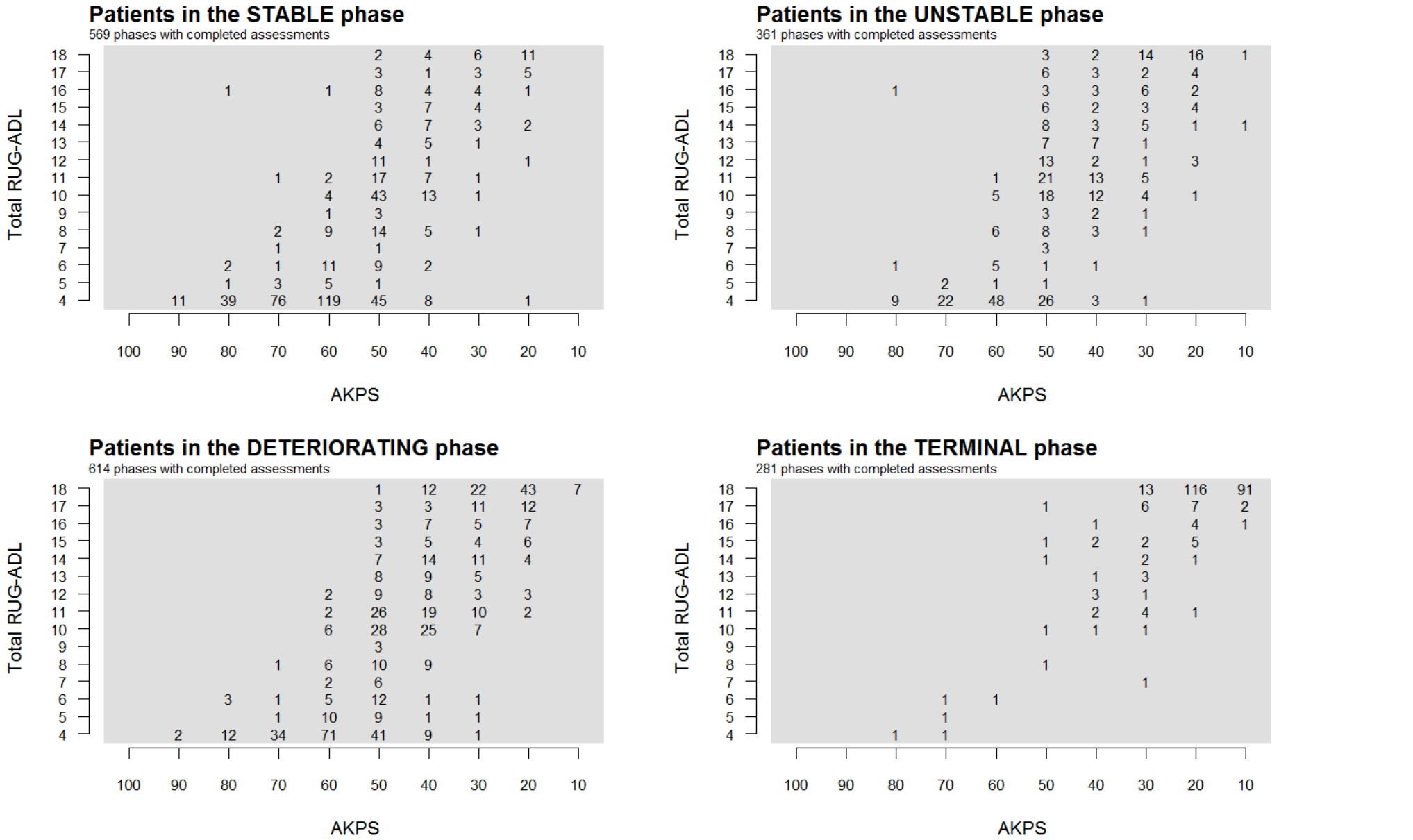
Phase type		TAS				All Services			
	Symptom distress	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)	0 (Absent)	1-3 (Mild)	4-7 (Moderate)	8-10 (Severe)
Stable	Difficulty sleeping	69.7	15.0	12.4	2.9	63.5	25.9	9.6	0.9
	Appetite problems	51.4	24.9	21.4	2.3	48.4	33.3	16.4	1.9
	Nausea	79.9	14.1	4.6	1.4	80.5	15.9	3.3	0.3
	Bowel problems	61.8	19.8	16.1	2.3	67.7	24.3	7.1	0.9
	Breathing problems	45.1	24.3	26.9	3.8	54.4	30.2	13.6	1.7
	Fatigue	10.1	20.8	56.4	12.7	15.6	34.3	44.6	5.5
	Pain	48.4	31.7	16.4	3.5	44.3	41.8	12.8	1.1
Unstable	Difficulty sleeping	58.2	9.8	21.3	10.7	44.7	25.6	23.8	5.9
	Appetite problems	38.2	12.2	35.8	13.8	34.9	26.4	29.5	9.2
	Nausea	69.4	9.7	13.7	7.3	61.0	17.6	15.1	6.2
	Bowel problems	47.5	14.8	28.7	9.0	52.9	26.4	15.4	5.3
	Breathing problems	51.2	24.4	19.5	4.9	47.2	26.2	20.0	6.6
	Fatigue	4.8	8.8	46.4	40.0	10.0	18.2	52.6	19.2
	Pain	26.2	14.3	30.2	29.4	20.3	24.1	35.9	19.7
Deteriorating	Difficulty sleeping	52.4	18.7	23.9	4.9	57.0	27.5	13.5	2.0
	Appetite problems	35.0	22.3	35.0	7.7	39.0	30.4	25.7	5.0
	Nausea	72.0	17.4	9.4	1.1	73.0	18.7	7.3	1.1
	Bowel problems	48.9	25.1	22.3	3.7	61.7	25.9	10.6	1.7
	Breathing problems	42.4	20.1	28.7	8.9	47.6	30.7	18.7	3.1
	Fatigue	5.4	10.6	59.4	24.6	10.6	22.3	54.5	12.7
	Pain	35.7	30.3	25.1	8.9	32.3	40.9	23.2	3.6
Terminal	Difficulty sleeping	76.7	11.7	5.0	6.7	75.7	13.6	8.4	2.2
	Appetite problems	62.3	9.8	14.8	13.1	78.1	6.6	7.3	8.0
	Nausea	77.0	11.5	8.2	3.3	85.0	8.9	4.9	1.2
	Bowel problems	55.7	14.8	23.0	6.6	74.1	15.7	8.4	1.8
	Breathing problems	54.1	11.5	24.6	9.8	55.5	22.8	17.0	4.6
	Fatigue	21.3	3.3	21.3	54.1	57.4	5.0	13.7	23.9
	Pain	50.8	9.8	21.3	18.0	40.9	35.5	19.6	4.0

The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 0 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care.

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence. The RUG-ADL are assessed daily (or at each visit) in practice but for PCOC reporting purposes are reported on admission, when the phase changes and at discharge. The total score on the RUG-ADL ranges from a minimum of 4 (lowest level of functional dependency) to a maximum of 18 (highest level of functional dependency).

AKPS and RUG-ADL can be used together to provide a profile of both patient dependency, equipment requirements, need for allied health referrals and carer burden/respite requirements. Figure 19 on the following page summarises the total RUG-ADL by the AKPS assessments at the beginning of each phase.

Figure 19 Total RUG-ADL by AKPS at beginning of phase by phase type



Appendix A Summary of data included in this report

A1 Data summary

During the reporting period, data were provided for a total of 18,310 patients who between them had 23,449 episodes of care and 53,467 palliative care phases. These total numbers are determined by a data scoping method. This method looks at the phase level data first and includes all phases that ended within the current reporting period. The associated episodes and patients are then determined (Appendix B contains a more detailed explanation of this process). Table 32 shows the number of patients, episodes and phases included in this report – both for Tasmaina and nationally.

A consequence of the data scoping method is that it is likely that not all phases related to a particular episode are included in this report. Hence, the average number of phases per episode calculation shown in Table 32 may be an underestimate (due to episodes that cross-over 2 or more reporting periods) as it only includes phases that ended within the current reporting period.

Table 32 Number and percentage of patients, episodes and phases by setting

	Inpatient		Community		Total	
	TAS	All Services	TAS	All Services	TAS	All Services
Number of patients*	330	10,311	582	8,963	867	18,310
Number of episodes	373	12,224	671	11,225	1,044	23,449
Number of phases**	946	28,409	938	25,058	1,884	53,467
Percentage of patients*	38.1	56.3	67.1	49.0	100	100
Percentage of episodes	35.7	52.1	64.3	47.9	100	100
Percentage of phases	50.2	53.1	49.8	46.9	100	100
Average number of phases per episode***	2.5	2.3	1.4	2.0	1.9	2.2

* Patients seen in both settings are only counted once in the total column and hence numbers/percentages may not add to the total.
** Bereavement phases are excluded from this count.
*** Average number of phases per episode is only calculated for closed episodes that started and ended within the reporting period and excludes bereavement phases.

Table 33 shows the number of completed episodes and phases by setting for each month in the current reporting period for Tasmaina. This table allows a service to identify any change in patient numbers during the reporting period.

Table 33 Number of completed episodes and phases by month and setting

		Jul	Aug	Sep	Oct	Nov	Dec
Inpatient	No. of completed episodes	60	48	52	67	72	62
	No. of completed phases	143	145	148	170	193	147
Community	No. of completed episodes	118	92	107	108	98	99
	No. of completed phases	158	133	151	161	165	170

A2 Data item completion

As shown in Table 34, Table 35 and Table 36 below, the rate of data completion is very high. In reviewing these tables, it is important to note that in some cases some data items are not required to be completed. For example, place of death is only required for patients who have died. Hence the complete column in the following tables only refers to the percentage of complete records where the data item was relevant.

PCOC strongly encourages services to complete and submit the whole data set on every patient as non-completion may result in services being excluded from relevant benchmarking activities or erroneous conclusions being drawn. Low completion of data items may also distort percentages and graphs in some sections.

Table 34 Item completion (per cent complete) - patient level

Data item	TAS	All Services
Date of birth	100.0	100.0
Sex	100.0	100.0
Indigenous status	99.8	98.0
Country of birth	99.7	98.5
Preferred language	100.0	100.0
Primary diagnosis	99.9	99.7

Note: This table is not split by setting to be consistent with the patient level analysis throughout this report.

Table 35 Item completion by setting (per cent complete) - episode level

Data item	Inpatient		Community		Total	
	TAS	All Services	TAS	All Services	TAS	All Services
Date of first contact	100.0	100.0	100.0	100.0	100.0	100.0
Referral date	100.0	100.0	100.0	100.0	100.0	100.0
Referral source	100.0	99.5	99.6	95.3	99.7	97.5
Date ready for care	100.0	94.7	100.0	100.0	100.0	97.2
Mode of episode start	100.0	100.0	99.4	99.5	99.6	99.7
Accommodation at episode start	99.6	99.9	100.0	96.3	99.9	97.7
Episode end date*	99.5	99.8	94.2	92.2	96.1	96.2
Mode of episode end	100.0	100.0	100.0	99.9	100.0	99.9
Accommodation at episode end	100.0	98.6	100.0	91.8	100.0	96.5
Place of death	na	na	98.7	96.6	98.7	96.6

* Episode end date item completion may be affected by open episodes.

Table 36 Item completion by setting (per cent complete) - phase level

Data item	Sub-Category	At phase start						At discharge					
		Inpatient		Community		Total		Inpatient		Community		Total	
	(where applicable)	TAS	All Services	TAS	All Services	TAS	All Services	TAS	All Services	TAS	All Services	TAS	All Services
RUG-ADL	Bed mobility	100.0	99.7	97.0	97.4	98.5	98.6	100.0	92.3	31.3	63.2	44.2	75.7
	Toileting	100.0	99.7	97.0	97.3	98.5	98.6	100.0	92.3	31.3	63.2	44.2	75.6
	Transfers	100.0	99.7	96.9	96.7	98.5	98.3	100.0	92.3	31.3	63.2	44.2	75.6
	Eating	100.0	99.5	97.0	95.6	98.5	97.7	100.0	92.3	31.1	62.8	44.0	75.4
PCPSS	Pain	100.0	97.8	95.9	97.5	98.0	97.6	100.0	91.1	29.6	62.9	42.8	75.0
	Other symptom	100.0	97.6	93.8	96.7	96.9	97.2	100.0	91.1	29.4	62.5	42.7	74.7
	Psychological/spiritual	100.0	99.4	95.8	97.2	97.9	98.4	100.0	92.2	29.6	62.8	42.8	75.4
	Family/carer	100.0	97.3	94.6	96.0	97.3	96.7	100.0	88.0	29.6	62.2	42.8	73.2
SAS	Difficulty sleeping	100.0	92.9	93.3	93.8	96.7	93.3	100.0	81.3	27.9	60.4	41.5	69.3
	Appetite problems	100.0	93.1	93.7	95.0	96.9	94.0	100.0	81.5	28.2	61.7	41.6	70.2
	Nausea	100.0	93.2	94.1	96.4	97.1	94.7	100.0	81.7	28.6	62.4	42.0	70.6
	Bowel problems	100.0	93.0	93.9	95.0	97.0	93.9	100.0	81.5	28.8	61.3	42.2	69.9
	Breathing problems	100.0	93.2	93.7	96.0	96.9	94.5	100.0	81.6	28.8	62.0	42.2	70.4
	Fatigue	100.0	93.2	94.0	96.1	97.0	94.5	100.0	81.6	28.4	62.3	41.8	70.5
	Pain	100.0	93.2	94.2	97.3	97.1	95.1	100.0	81.6	29.0	63.0	42.3	71.0
AKPS	-	100.0	94.8	94.3	97.6	97.2	96.1	100.0	89.7	29.0	63.2	42.3	74.5

Data item	Inpatient		Community		Total	
	TAS	All Services	TAS	All Services	TAS	All Services
Phase End Reason	100.0	99.9	100.0	99.7	100.0	99.8

Appendix B Additional information on profile of SAS scores

Figure 20 Profile of SAS Score by symptom – inpatient setting

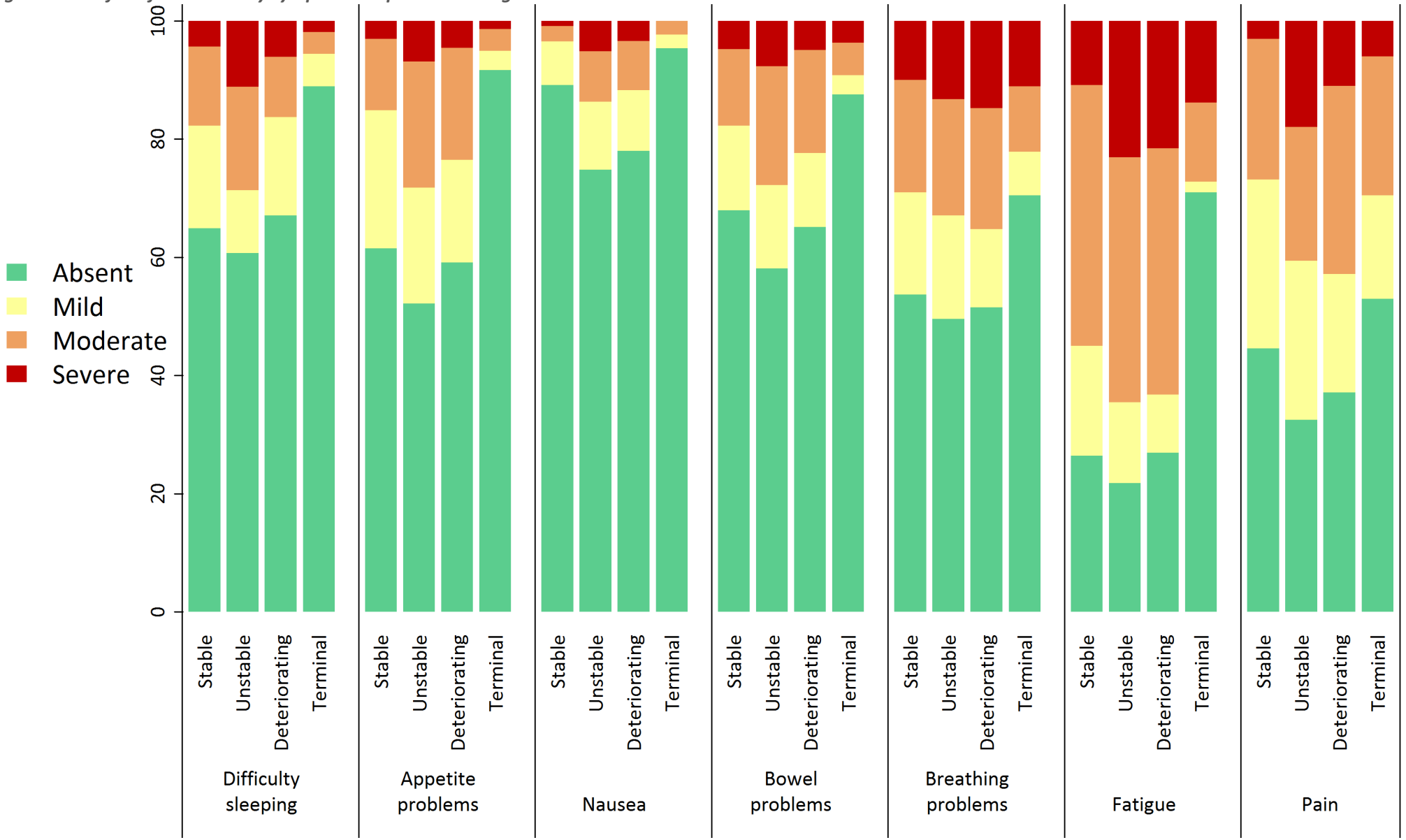
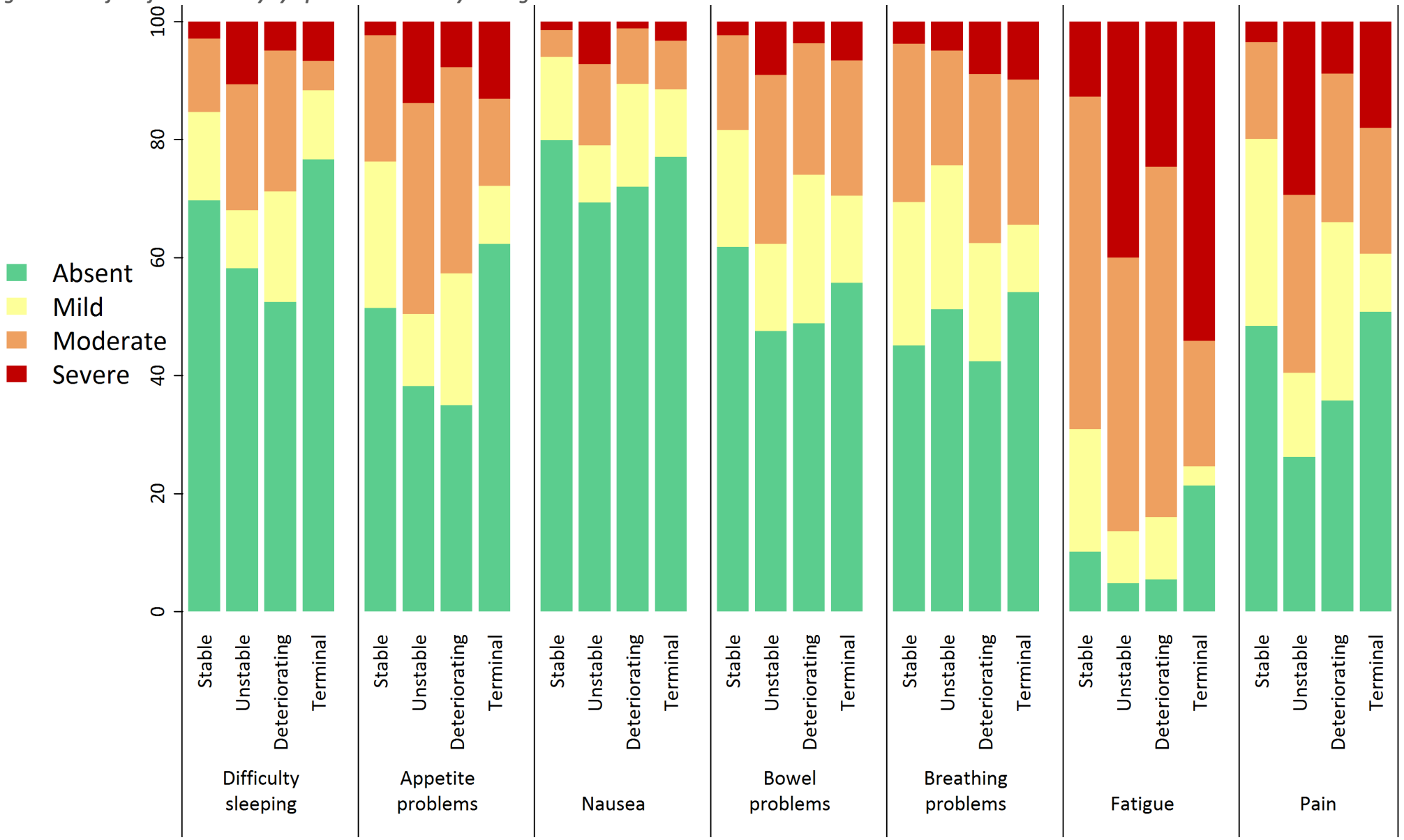


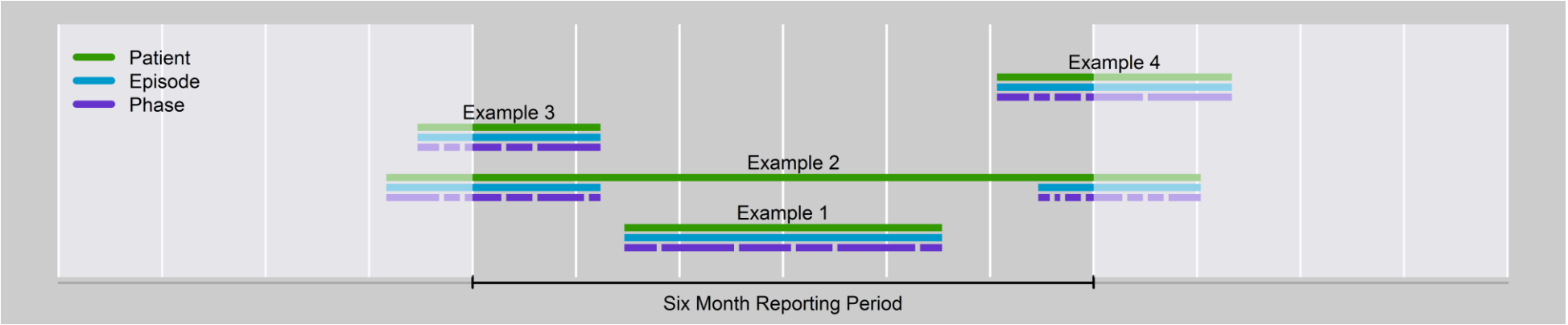
Figure 21 Profile of SAS Score by symptom – community setting



Appendix C Data scoping method

The method used to determine which data is included in a PCOC report looks at the phase level records first. All phase records that end within the 6 month reporting period are deemed to be "in scope" and would be included in the report. The episode and patient records associated with these phases are also deemed to be "in scope" and hence would also be included in the report. Figure 22 below displays four examples to help visualize this process.

Figure 22 Diagram of the PCOC data scoping method



In Example 1, the patient (represented by the green line) has one episode (represented by the blue line). This episode has six phases (represented by the purple line segments). All six phases would be included in the report as they all end within the reporting period. Hence, the episode and patient would also be in the report.

In Example 2, the patient has two episodes - the first having six phases and the second having seven phases. Looking at the phases associated with the first episode, the last four will be included in the report (as they end within the reporting period). The first two phases would have been included in the previous report. For the phases relating to the second episode, only the first three end within the reporting period, so only these would be included in the report. The following four phases would be included in the next report. Both of the episode records and the patient record would also be included in the report.

In Example 3, the patient has one episode and five phases. Only the last three phases will be included in the report as they are the only ones ending within the reporting period (the first two phases would have been included in the previous report). The episode and patient records would be included in the report.

In Example 4, the patient again has one episode and five phases. This time, only the first three phases will be included in the report (the last two phases will be included in the next report). Again, the episode and patient records would be included in the report.

Appendix D Palliative Care Phase definitions

START	END
1. Stable	
Patient problems and symptoms are adequately controlled by established plan of care **and** ▪ Further interventions to maintain symptom control and quality of life have been planned **and** ▪ Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care.
2. Unstable	
An urgent change in the plan of care or emergency treatment is required **because** ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** ▪ Patient experiences a rapid increase in the severity of a current problem; **and/or** ▪ Family/ carers circumstances change suddenly impacting on patient care.	▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and/or** ▪ Death is likely within days (i.e. patient is now terminal).
3. Deteriorating	
The care plan is addressing anticipated needs but requires periodic review **because** ▪ Patients overall functional status is declining **and** ▪ Patient experiences a gradual worsening of existing problem **and/or** ▪ Patient experiences a new but anticipated problem **and/or** ▪ Family/carers experience gradual worsening distress that impacts on the patient care.	▪ Patient condition plateaus (i.e. patient is now stable) **or** ▪ An urgent change in the care plan or emergency treatment **and/or** ▪ Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** ▪ Death is likely within days (i.e. patient is now terminal).
4. Terminal	
Death is likely within days.	▪ Patient dies **or** ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
5. Bereavement – post death support	
▪ The patient has died ▪ Bereavement support provided to family/carers is documented in the deceased patient's clinical record.	▪ Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

Acknowledgements

Contributions PCOC wishes to acknowledge the valuable contribution made by the many staff from palliative care services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible.

Disclaimer PCOC has made every effort to ensure that the data used in this report are accurate. Data submitted to PCOC are checked for anomalies and services are asked to re-submit data prior to the production of the PCOC report. We would advise readers to use their professional judgement in considering all information contained in this report.