Palliative Care Research Network
CAPACITY . COLLABORATION . CONNECTION

Palliative Care Research Network Forum

"So what have we learned?"

Research updates from our two PCRNV PhD scholarship awardees

20th July 2016

5:00 – 6:00 pm, followed by networking drinks and nibbles

Victorian Cancer Agency
Linking research and patient care

Australian Government
Department of Health and Ageing

4th AUSTRALIAN
PALLIATIVE CARE
RESEARCH COLLOQUIUM
LEARN. CONNECT. COLLABORATE.
27 - 28 October 2016 Melbourne Victoria

Centre for Palliative Care
Informing Choice. Enabling Care.

THE UNIVERSITY OF MELBOURNE

ST VINCENT'S HOSPITAL MELBOURNE

Registration Now Open!

The ***4th Australian Palliative Care Colloquium*** provides an invaluable opportunity for those actively involved in palliative care research and related fields to learn, connect and collaborate.

Date:	Thursday 27th October – Friday 28th October 2016
Venue:	Rendezvous Hotel, 328 Flinders Street, Melbourne
Cost (incl. GST):	**Both days** - $440.00 ($300.00 for students) **Both days & PCRN Workshop** - $450.00 **Thurs 27 Oct** - $260.00 **Fri 28 Oct** - $200.00
Registration:	http://www.cvent.com/d/vfqbl8

Go to www.centreforpallcare.org for more details and to register.

Workshop

27 October 2016

'Analyse This!'

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The PCRN is sponsoring a workshop as part of the ***4th Australian Palliative Care Research Colloquium***. Join us for presentations introducing the 'basics and beyond' of both quantitative and qualitative data collection, data handling and analysis. A panel of experienced researchers will also provide input and feedback on real-life methodological conundrums as presented by 3 early career researchers in relation to their current research projects .

Date: Thursday, 27th October 2016, 9:00 - 10:45 am
Venue: Rendezvous Hotel, 328 Flinders Street, Melbourne
Inclusions: Morning tea, presentations and discussion. All welcome.
Cost: $20.00 including GST
Registration: http://www.cvent.com/d/vfqbl8

Program

09.00-09.05 **Welcome & Introduction**
Speaker: Soula Ganiatsas *(PCRN)*

09.05-09.20 **Introduction to Quantitative Data Analysis**
Speakers: A/Prof Karla Gough (*Peter Mac*), Allison Dosdowsky (*Peter Mac*)

09.20-09.25 **Q&A**

09.25-09.40 **Introduction to Qualitative Data Analysis**
Speaker: A/Prof Jennifer Philip (*CPC, SVHM*)

09.40-09.45 **Q&A**

09.45-10.45 **Early Career Researcher SOS**
Speakers: Dr Danielle Ko (*Barwon Health),* Dr Chi Li (*Alfred Health*, *SVHM*) , TBC
Panel Members:
A/Prof Karla Gough (*Peter Mac*),
Allison Drosdowsky (*Peter Mac*),
A/Prof Jennifer Philip (*SVHM*),
A/Prof Clare O'Callaghan (*Cabrini Health, SVHM*)

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Program

5:00 – 5:05 pm	Welcome and Introduction *Soula Ganiatsas, PCRN Program Manager*
5:05 – 5:25 pm	The experience of music and music therapy for paediatric palliative care patients and their parents, who come from diverse cultural backgrounds *Ms Lucy Forrest, Senior Clinician Music Therapist, Children's Cancer Centre, Monash Children's Hospital*
5:25 – 5:30 pm	Audience Q & A
5:30 – 5:50 pm	Palliative care for patients with severe Chronic Obstructive Pulmonary Disease – understanding current practice and attitudes to palliative care and exploring a new model of integrated respiratory and palliative care *Dr Natasha Smallwood, Consultant Respiratory Physician, Royal Melbourne Hospital*
5:50 – 5:55 pm	Audience Q & A
5:55 – 7:00 pm	Networking Drinks and Nibbles

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Palliative care for patients with Chronic Obstructive Pulmonary Disease - understanding current practices and exploring a new model of integrated care

Dr Natasha Smallwood

Department of Medicine – University of Melbourne

Respiratory Physician - The Royal Melbourne Hospital

Chronic Obstructive Pulmonary Disease

- COPD is an incurable, non-malignant, progressive illness
- Airflow obstruction & respiratory failure

- By 2020 COPD globally
  - 3rd leading cause of death
  - 5th leading cause of disability

- In Australia 29% of over 75 yrs have COPD
  - At least 320 000 people affected
  - 5th leading cause of death – 6500 deaths pa
  - 72% of COPD patients die in hospital

COPD morbidity

- Significant symptom burden
  - **98%** of patients experience distressing breathless
  - Refractory breathlessness is undertreated
  - Cough, tiredness, weight loss, poor appetite
- Poor understanding of disease & prognosis
- Significant psychological & social issues
- Significant health service utilisation
  - 60 000 admissions pa
  - $929 000 000 pa

What is Palliative Care?

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Neither hastens or postpones death
- Integrates psychological and spiritual aspects of patient care
- Offers support to help patients live as actively as possible
- Supports families to cope during the illness and in their bereavement
- Enhances quality of life and may **improve survival**
- **Is applicable early in the course of illness**

Specialist or generalist palliative care

Palliative care

- Improved patient outcomes
  - Improved symptom control & reduced anxiety
  - Less aggressive treatment
  - Reduced hospital admissions and healthcare costs

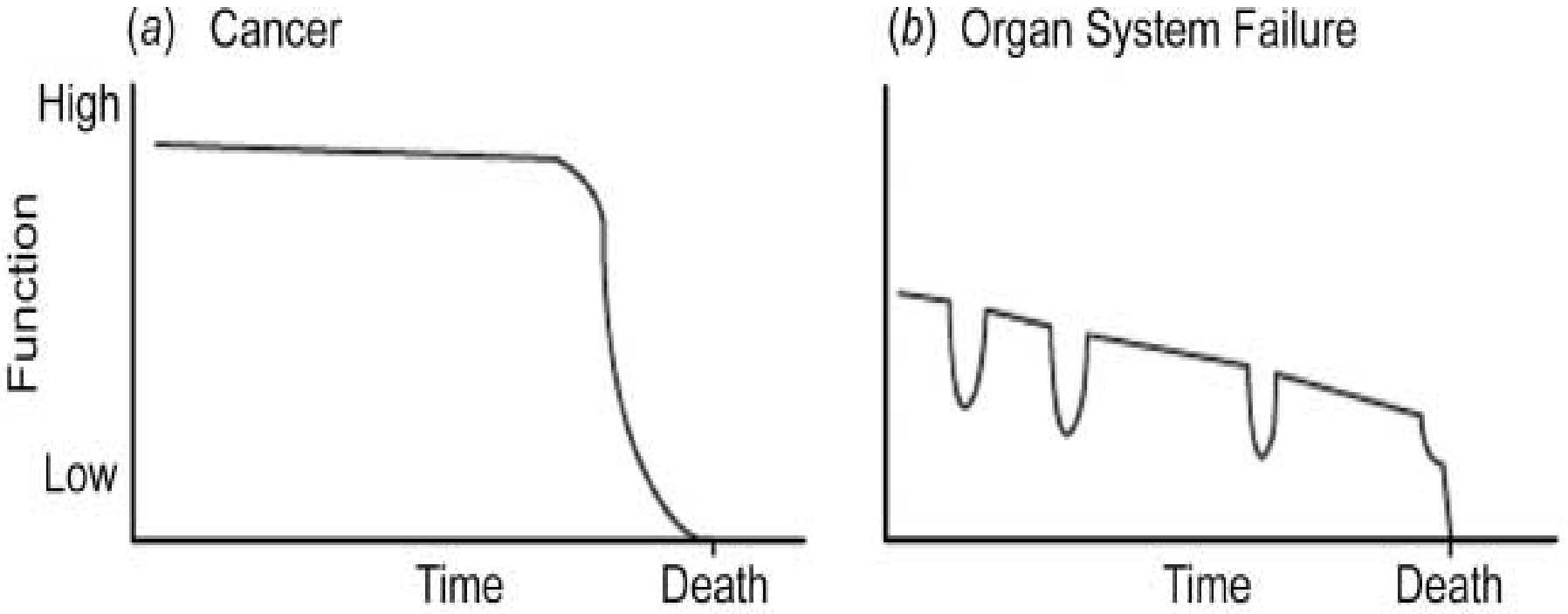
- American Thoracic Society Palliative Care Policy Statement
  - ALL patients with symptomatic or life threatening diseases
  - Occurs concurrently with active, life-prolonging care

- Only **2.6%** of all palliative care admissions are for COPD
- Only 18% of COPD patients access any palliative care compared with 68% of lung cancer patients

Why don’t we palliate symptoms and/or refer to palliative care?

- Lack of time
- Communication issues
- Lack of training
- Attitudes of health professionals and patients
- Determining the prognosis can be challenging

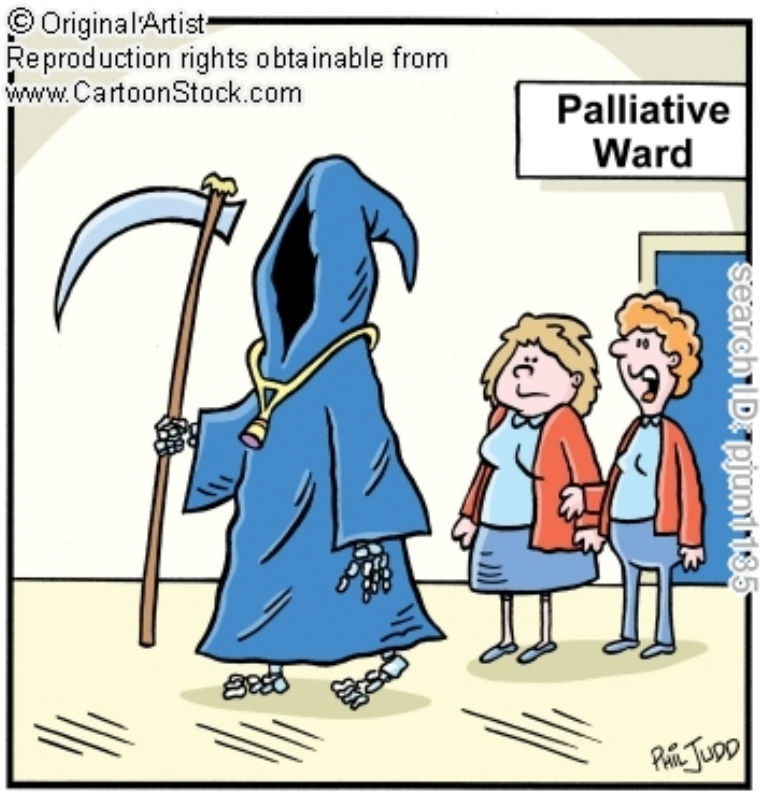
It is difficult to make an accurate prognosis



General trajectories of function and well-being over time in eventually fatal chronic illness. (Lynn 2001)

New models of integrated respiratory and palliative care

- Breathlessness Intervention Service - Cambridge
- “INSPIRED” Canada
- Breathlessness Support Service – London
- Advanced Lung Disease Service - Melbourne



“He’s our new Palliative Specialist!”

Advanced Lung Disease Service

- TEAM: Respiratory medicine, Palliative care & ED

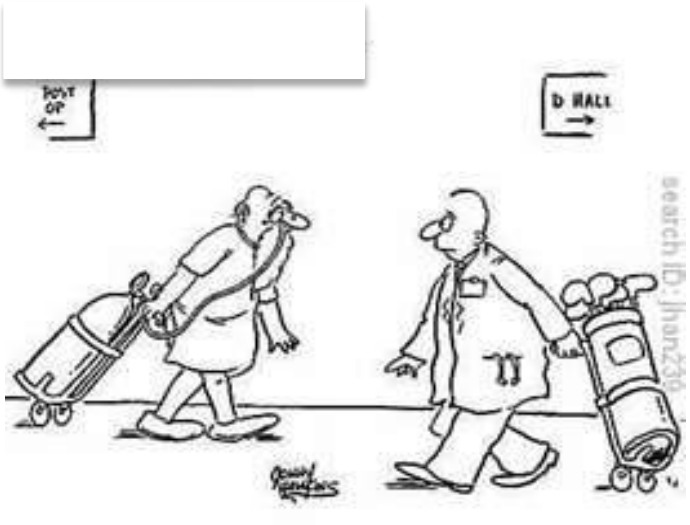
- Weekly multidisciplinary clinic
  - Rapid access
  - Long term continuity of care & longer consultations
- Monthly MDM
- Outreach nursing service
- Nursing telephone support service

What does the ALDS do?

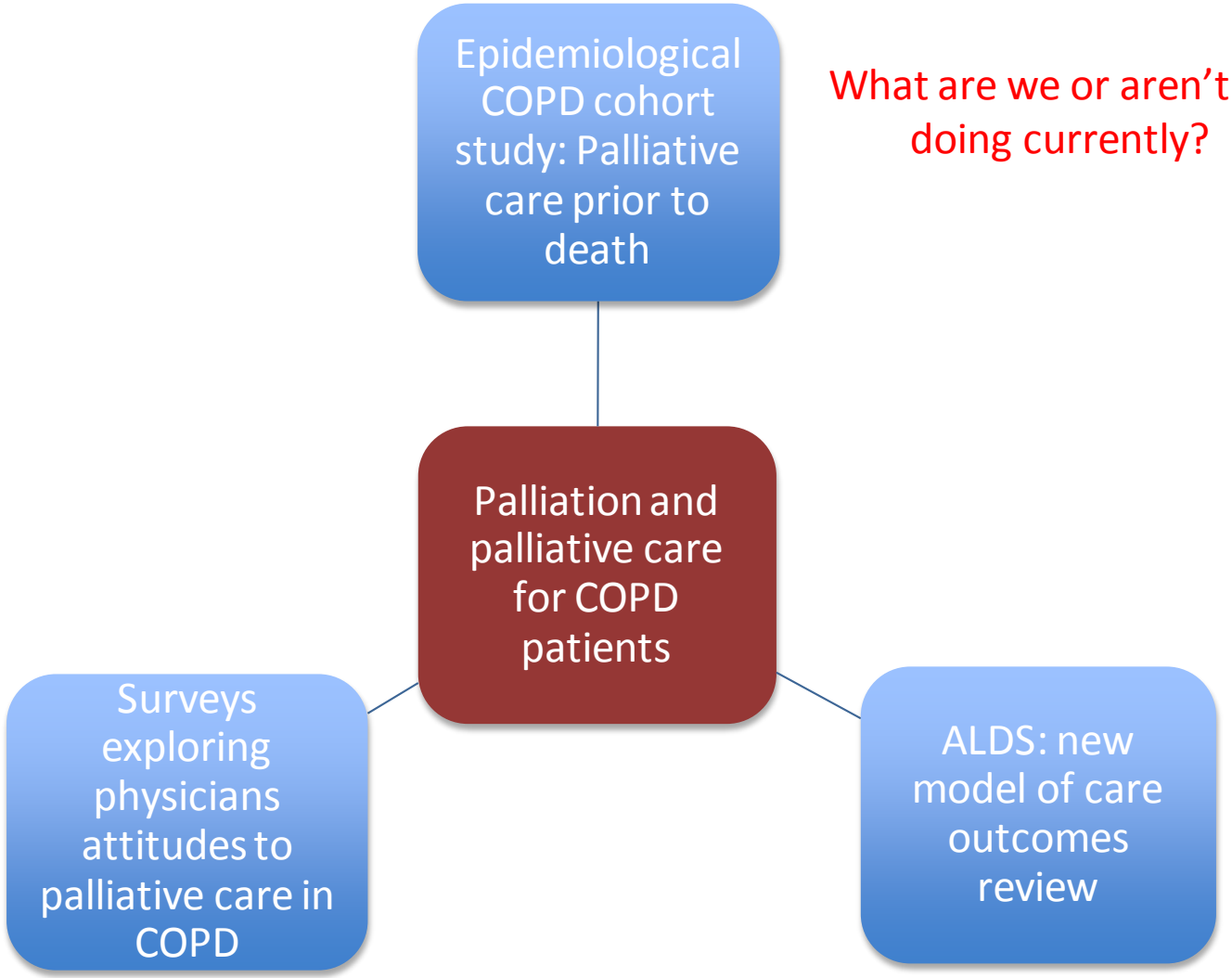
- Optimise respiratory management & care co-ordination
- Comprehensive symptom management
- Education & self management
- Lung function testing, oxygen assessment & co-ordination
- Psychosocial assessment & support
- Advance care planning
- Work with & support other health professionals
  - GP, community respiratory nurses & physios
- Facilitate access to specialist palliative care

Research question

How is palliative care currently delivered to patients with severe COPD, and what is the impact of a new, tailored model of integrated palliative and respiratory care?



Research project structure



Phase 1. Epidemiological COPD cohort study - Palliative care prior to death: Study aims

1. To determine if timely palliative care was delivered during the final hospital admission, or in the two years before death, using data from two Victorian hospitals

2. To identify if the provision of palliative care varies according to geographical location and if so, why does this occur

3. To undertake a basic economic evaluation to determine the cost of care received by COPD patients during the final admission

Phase 1. Epidemiological COPD cohort study: methods & progress

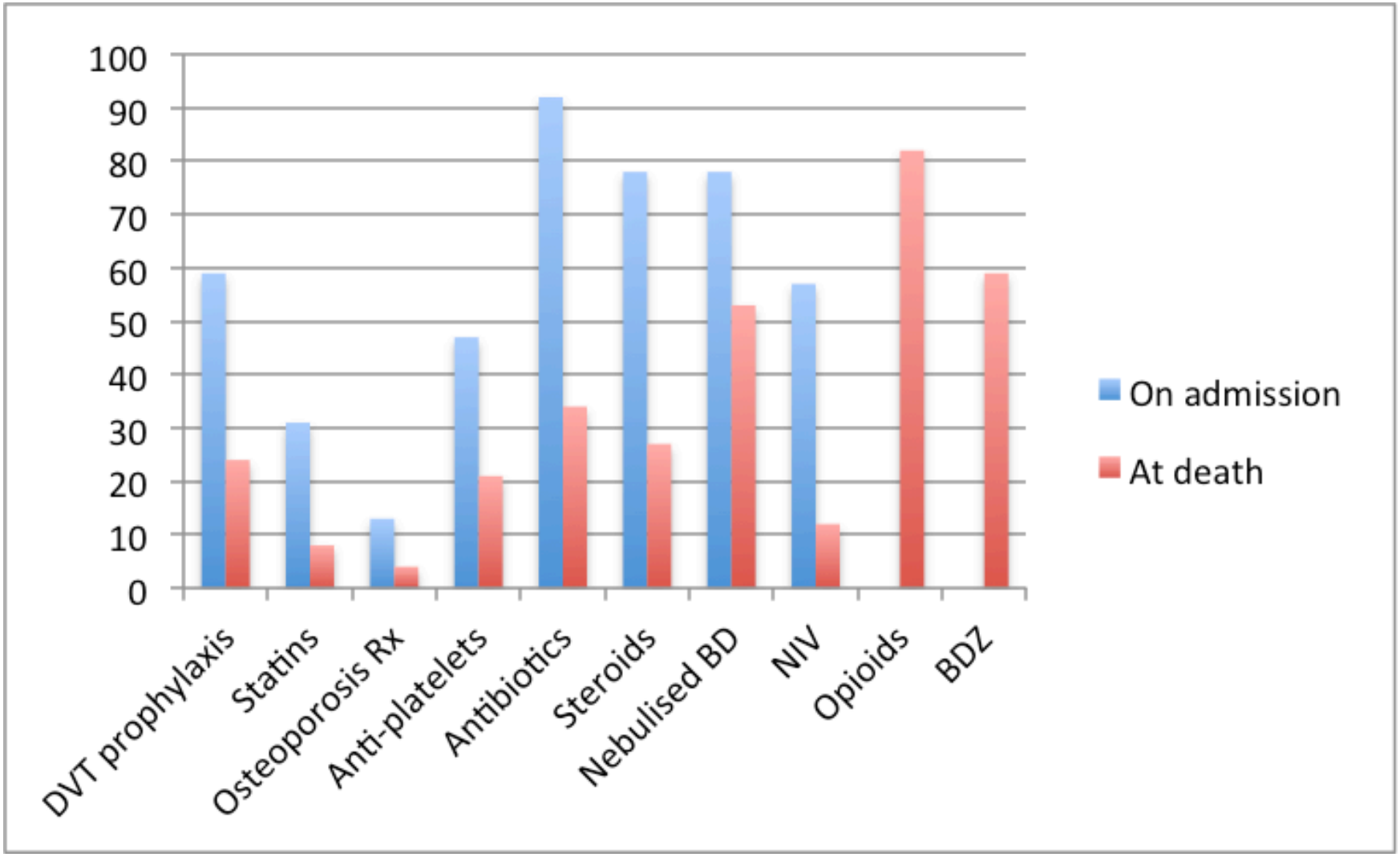
- Retrospective medical record audit at The Royal Melbourne Hospital (RMH) and Northeast Health Wangaratta (NHW)
- All COPD patient deaths 2004-2015 (n=703)
- Only patients who died as a consequence of COPD
- Review: preventive, therapeutic and palliative treatments, ACP & specialist referrals

- Ethics approvals obtained
- Data collection underway - 366 of 474 deaths at RMH, just started at NHW
- Preliminary findings presented at TSANZ ASM 2016 & ERS ASM 2016

Phase 1: Patient demographics (n=165/226)

Characteristic	N / Median*	SD
Age (years) *	80	8.7
Male	107 (65%)	
Ex-smoker	122 (75%)	
Domiciliary oxygen	87 (53%)	
FEV_1 (L) (n=102) *	0.8 (39%)	0.4
DLco *	9 (42%)	4.1
6MWT(m) (n=34)*	140	118.3
MMRC breathlessness score*	3	0.7
Number of COPD outpatient visits in past 2yrs (n=76)*	3	2.9
Number of COPD admissions in past 2yrs (n=94)*	1	2.3

Phase1: Treatments received during the terminal admission (%)



Phase 1: Opioid use

- Only 11 (7%) patients used opioids for dyspnoea & received palliative care support pre-admission

- 135 (82%) used opioids in the terminal admission
- Median opioid dose (oral Morphine equivalent) for palliation:

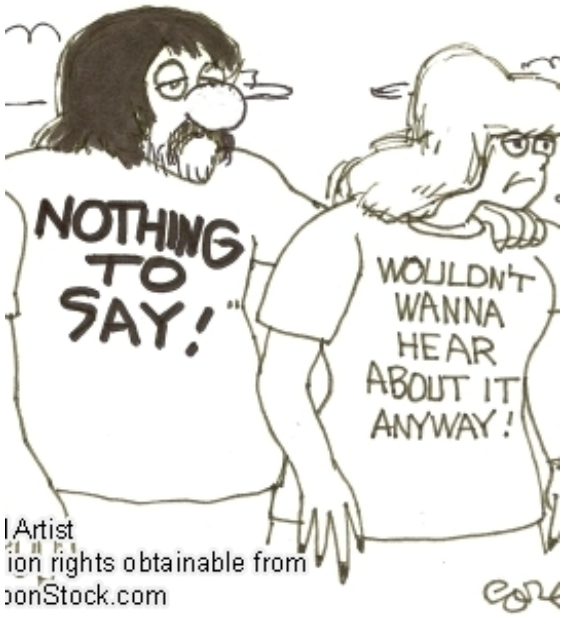
Initial dose taken:	8mg	(0-120mg)
Final dose taken:	15mg	(0-120mg)

Phase 1: Advance Care Planning

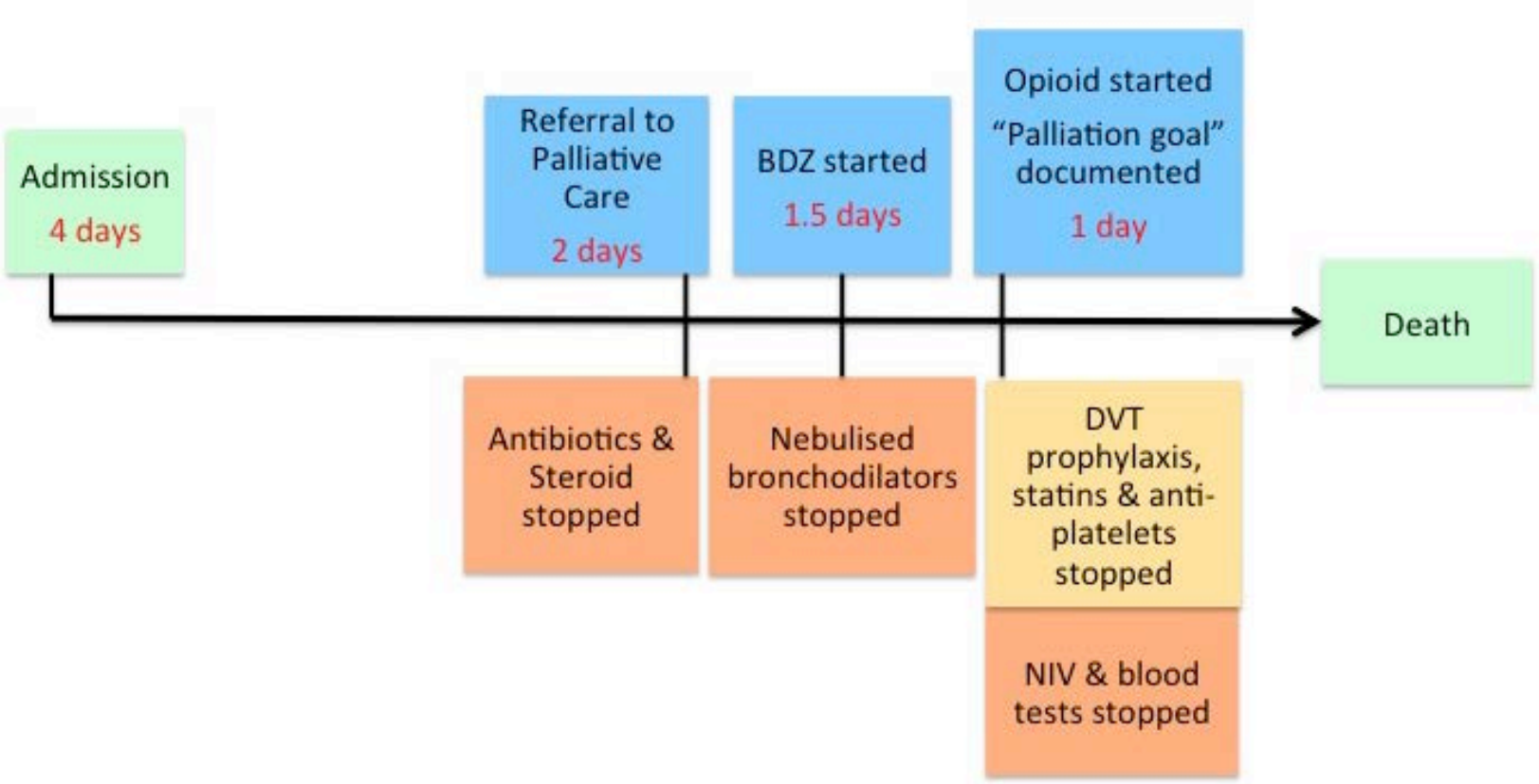
- 57 (35%) had a previous admission with a "Not for resuscitation form" completed

- Only 22 (13%) patients had discussed advanced care planning (ACP) before admission
- Only 11 (7%) had completed a written ACP before the final admission

- The goal of treatment was documented as palliation in 136 (82%) patients



Phase1: Terminal admission timeline



Patients were palliated but there were missed opportunities in the 2 years before death

Phase 3. Clinical audit of the Advanced Lung Disease Service: Study aims

1. To characterise the patients being cared for by ALDS
2. To determine the health care utilisation of ALDS patients
3. To determine if breathlessness is addressed in addition to disease management optimisation
4. To identify if ALDS patients access specialist palliative care
5. To determine if components of palliative care (psychosocial care, home care) are offered to all ALDS patients
6. To explore patient and carer satisfaction with the ALDS and identify areas for future development

Phase 3. Clinical audit of the Advanced Lung Disease Service: methods & progress

- Retrospective medical record audit

- Ethics approval obtained
- Data collected for 170 patients (April 2013 - May 2016)
- Data analysis ongoing

- Results presented at RMH Grand Round, MH research week & at ERS ASM

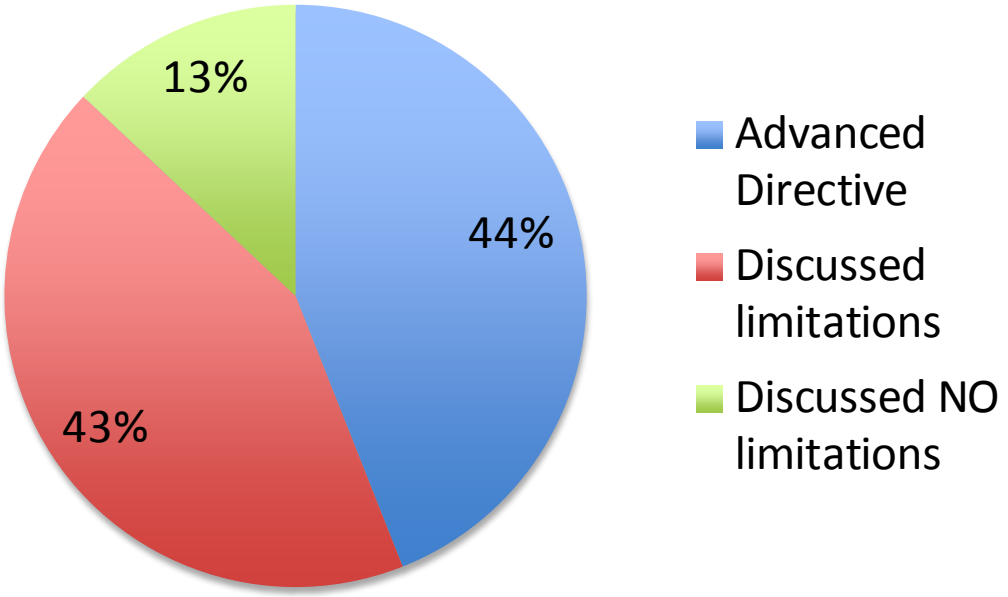
- Patient and carer survey designed, awaiting ethics approval

Phase 3 Preliminary results: ALDS patients

Characteristic (n=145)	N or Median
Male	82 (57%)
Age (years) *	75.3 (42-91.5)
COPD	122 (82%)
2nd Respiratory condition	89 (61%)
No of comorbidities *	6.4 (0-14)
Anxiety and/or Depression	98 (68%)
FEV_1 (L)	0.9 (40% predicted)
DLco	8 (37% predicted)
PaO_2 (mmHg)	57 (35-82)
Domiciliary oxygen	102 (70%)
MMRC	4
Length of follow up (months)	13.6 (0-40.3)
Died	49 (34%)

ALDS: Aim for Routine ACP – Ask everyone

ACP discussed n=129 (89%)

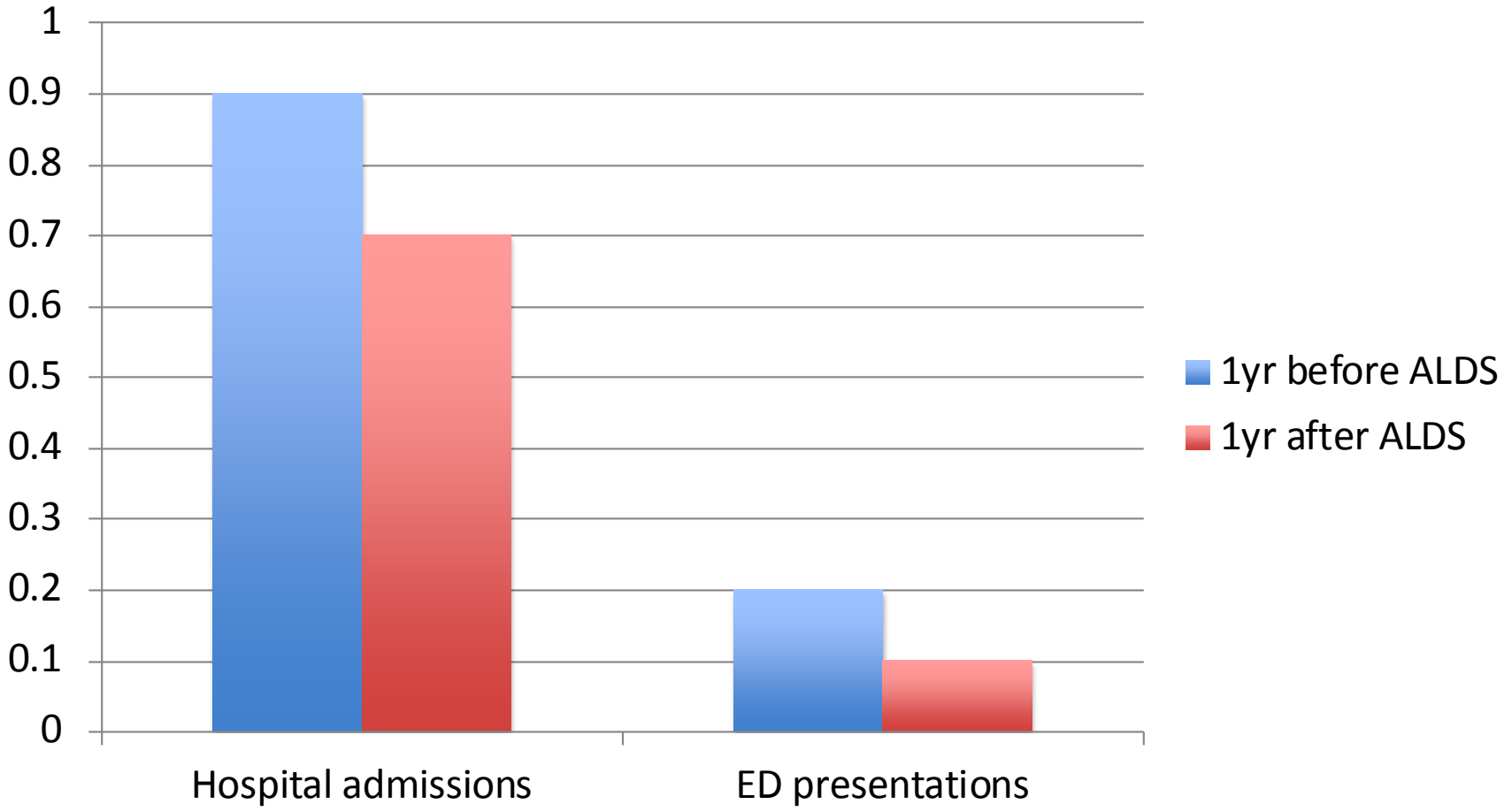


ACP not discussed n=16

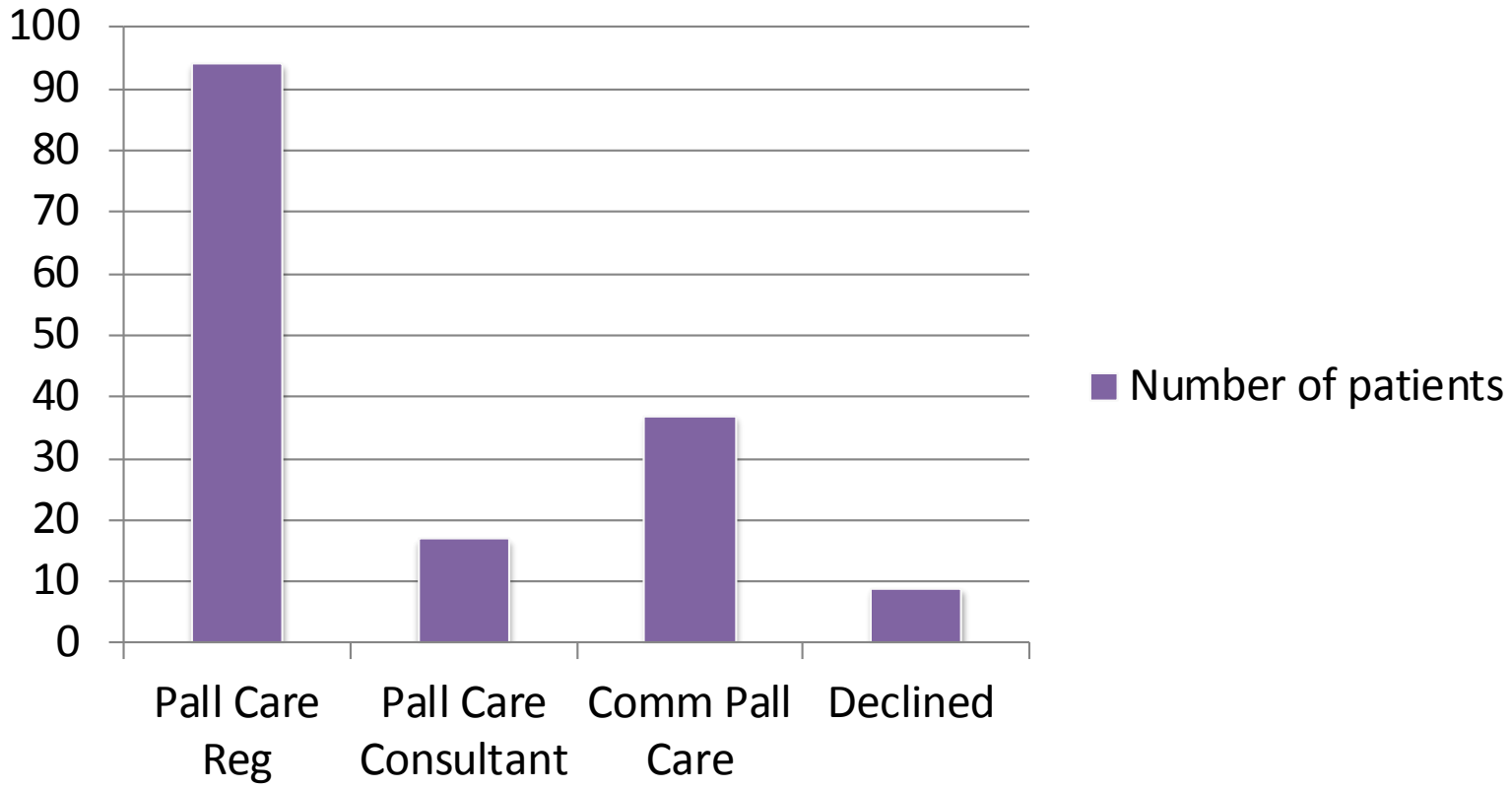
- No capacity (1)
- Only 1-2 appts (11)
- Anxiety/Depression (2)
- Not documented (2)

RMH 10yr COPD mortality audit to 2013 (n=226) – only 33 (15%) completed ACP

Average number of RMH admissions with respiratory illness

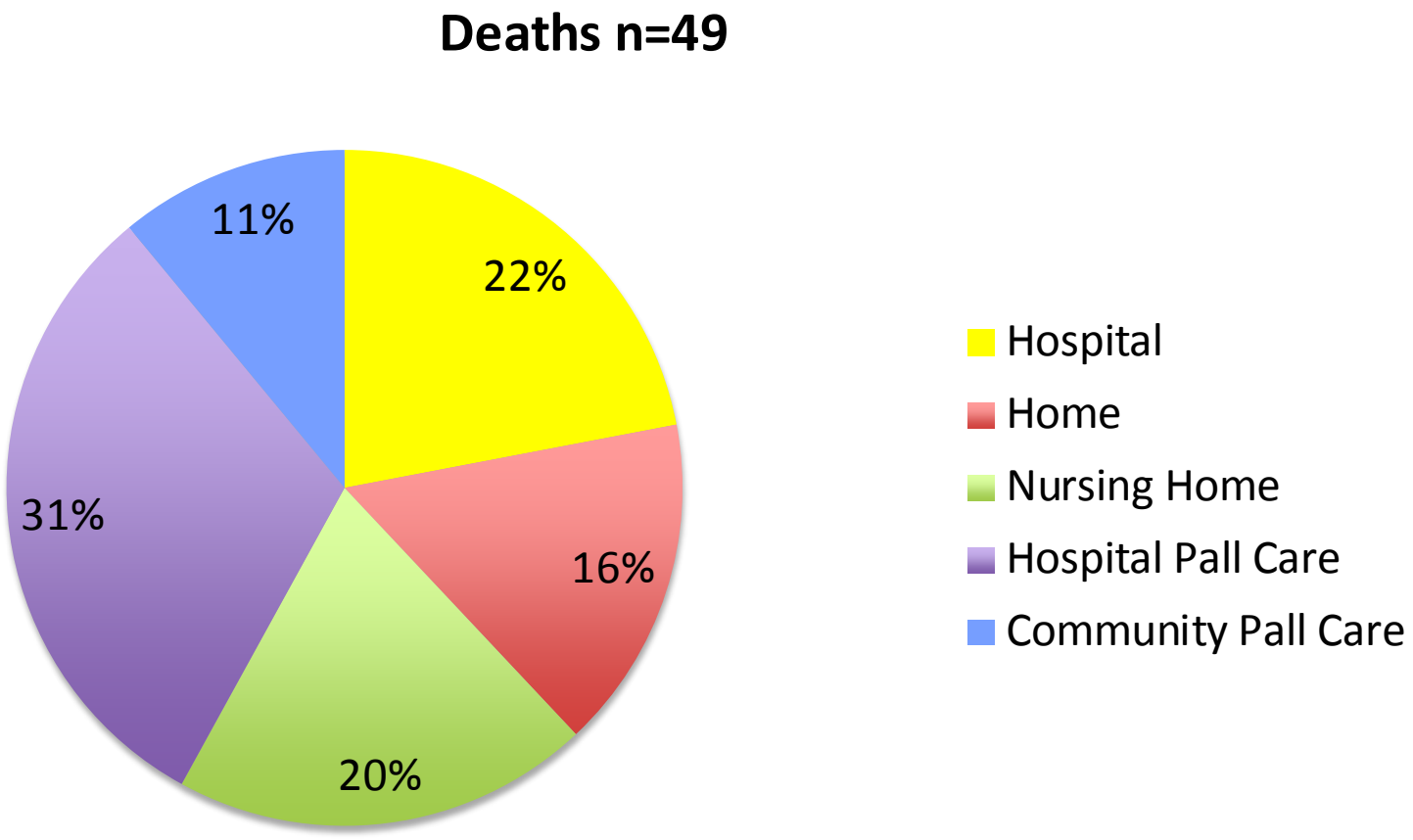


ALDS: Access to Specialist Palliative Care



113 (78%) patients have accessed Specialist Palliative care

ALDS: Where do our patients die?



By contrast in Victoria 72% of COPD patients die in an acute hospital bed (VAED data n=1178 deaths)

Phase 3. Clinical audit ALDS: preliminary conclusions

- ALDS facilitates access to;
  - symptom control measures
  - specialist palliative care
  - opportunities for communication & ACP

- ALDS supports patients, families and other health professionals, so that patients can receive more care at home and die out of hospital.

Acknowledgements

Prof Terry O'Brien
A/Prof Jenny Philip

A/Prof Brian Le
A/Prof Lou Irving
Michelle Thompson
Dr Peter Eastman
Amy Noble
Dr Nicola Walsham
Peter Fish

Prof David Currow
Prof Danny Liew
Dr Sara Booth
Dr Anna Spathis
Dr Andreas Baisch
Dr Nicole Gaffney
Dr John Taverner
Dr Lauren Ross
Dr Claire Bartlett