



WHO Collaborating Centre



# **Palliative care for people with HIV:** ***an essential component of care services***

**Professor Richard Harding**  
Cicely Saunders Institute  
King's College London

# HIV mortality in the UK

- PHE 2015:
  - 594 people with HIV infection died
  - 58% aged over 50
- All-cause mortality aged 15-59 per 1,000

	2005	2015
<b>PLWH</b>	10.2	5.7
<b>General population</b>		1.6

# Aging & comorbidity

- **Malignancies**

- **PLWH in Europe 5 yr estimates from 2011**
- IRM 28% decrease
- IURM 44% increase (Shepherd HIV Med 2017)
- **Increase in death non-AIDS cancer 2009-2011, EU, USA, Australia**
- 23% of all non-AIDS deaths (Smith Lancet 2014)

- **Comorbidities**

- UK over 50's 61% 2 comorbidities (Patel IJSTDA 2016)
- Dutch 28% ≥3 comorbidities by 2030 (largely CVD) (Smit LID 2015)

- **Cardiovascular disease incidence: men in USA by age 60**

- 20.5% HIV-infected under ART
- 14.6% HIV-uninfected high-risk persons
- 12.8% in US general population (Holloway CIHA 2017)

- **Older people's concerns UK**

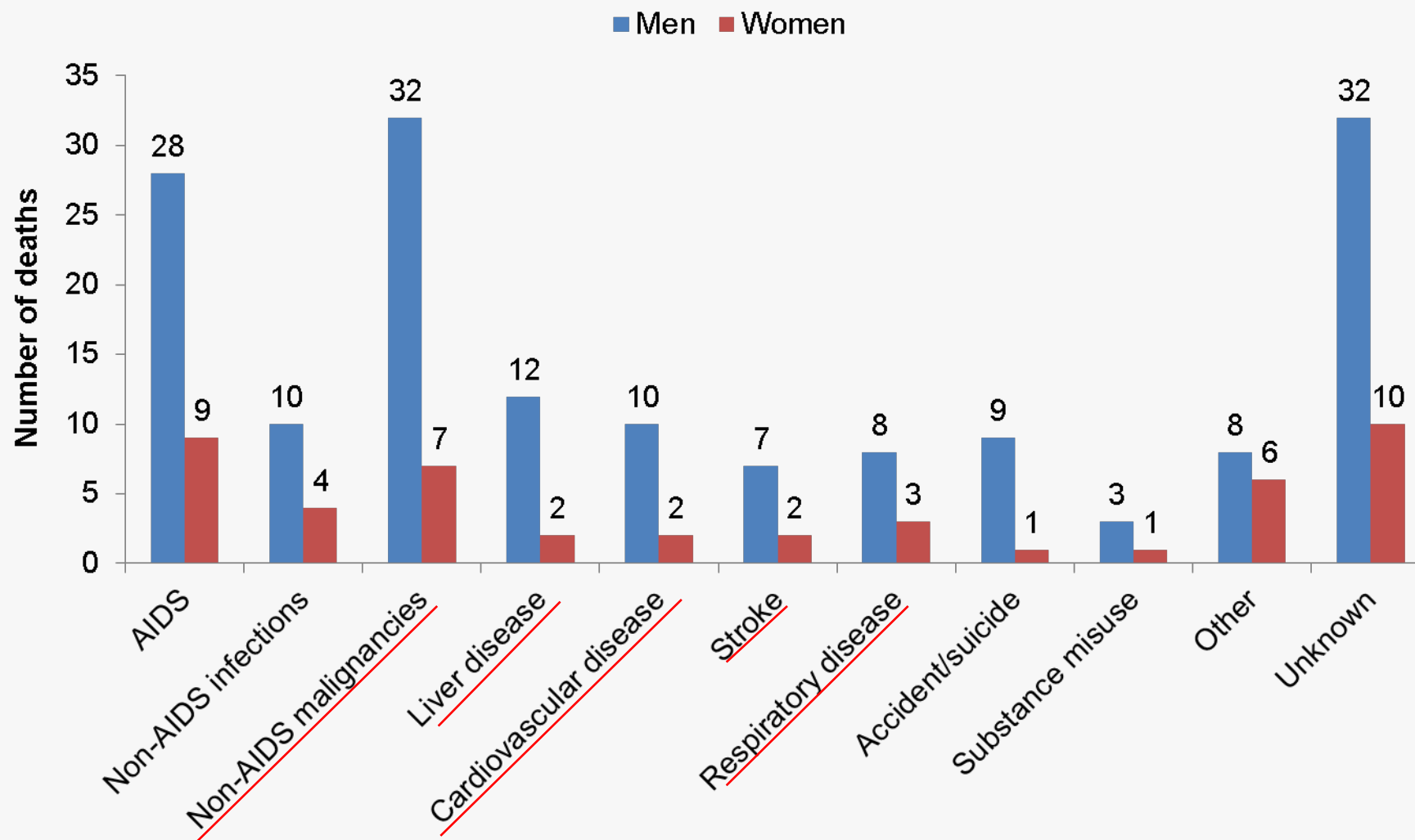
- HIV skills, coordination, confidentiality (Pollard IJSA 2017)

# London HIV mortality audit

- Aims:
  - Improve quality of patient care by reviewing the patient pathway of HIV+ patients who die in London, i.e. remediable factors
  - Identify particular scenarios that are worthy of further case investigation, including periodic public case presentation and audit
  - Public health benefit through identifying areas to focus outcomes measures to prevent people dying early
- Death data were submitted by 19 centres
- Total deaths reported in 2016: **206**

(Sarah Croxford)

# Cause of death by sex: London, 2016



# End of life care and expected death

- **66%** of expected deaths had an end of life care discussion (70% of men; 56% of women)
- End of life data only available for 57% of patients (N=118/206)
- Place of death among expected deaths:

	Men		Women	
	n	%	n	%
Hospital	48	60%	15	63%
Hospice	15	19%	3	13%
Home	12	15%	4	17%
Community	0	0%	1	4%
Nursing home	4	5%	1	4%
Abroad	1	1%	0	0%

# Place of death

- Majority of people (73.9%) would wish to be told of poor prognosis  
(Harding Psychooncology 2013)
- The majority of people (67%) wish to die at home  
(Gomes Annals Oncol 2012)
- HIV as underlying cause of death 2007
  - more likely to die in hospital in 11/11 high income countries compared to cancer deaths
  - UK 12.0% at home vs 28.1% cancer  
(Harding BMC Infect Dis In Press)

# Defining palliative care: WHO

- “Palliative care is an approach that improves the **quality of life** of **patients** and their **families** facing the problem associated **with life-threatening illness**, through the **prevention and relief of suffering** by means of **early identification** and **impeccable assessment** and treatment of **pain** and **other problems**, **physical, psychosocial and spiritual.**”



# Principles of palliative care (WHO)

1. Relief from **pain** and other distressing **symptoms**
2. **Affirms life** and regards **dying** as a **normal process**
3. Intends **neither** to **hasten** or **postpone death**
4. Integrates **psychological** and **spiritual aspects** of care
5. Help patients **live** as **actively** as possible until death
6. Help **family cope during** the illness and in **bereavement**
7. Team approach including **bereavement counselling**
8. Enhance **quality of life**, **positively influence** the course of **illness**
9. **Applicable early** in the course of illness, in **conjunction** with other **therapies** that are intended to **prolong life**, such as chemotherapy or radiation therapy

# Policy & effectiveness

- World Health Assembly resolution 67.19 (2014)
  - *“fundamental to improving the quality of life, well-being, comfort and human dignity of individuals being an effective person-centred health service”*
  - *“Integrate palliative care as an integral component of ongoing education and training”*
- ACP: voluntary process of discussion and review concerning preferences for future care
  - *Improves costs, preferred place of death, satisfaction, anxiety*  
(Dixon JPSM 2017)

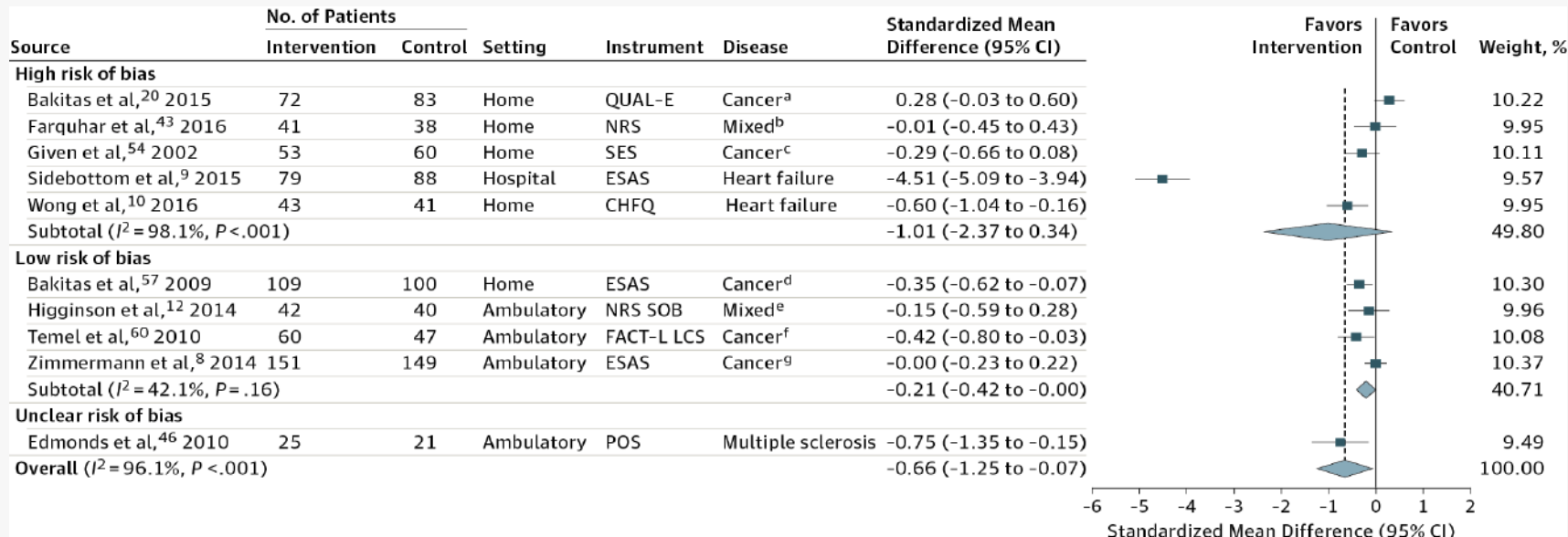
# Effectiveness

- Hospital based end of life care
  - Improves end-of-life discussions and documentation, psychosocial distress, satisfaction and concordance in care

(Waller BMC palliative care 2017)

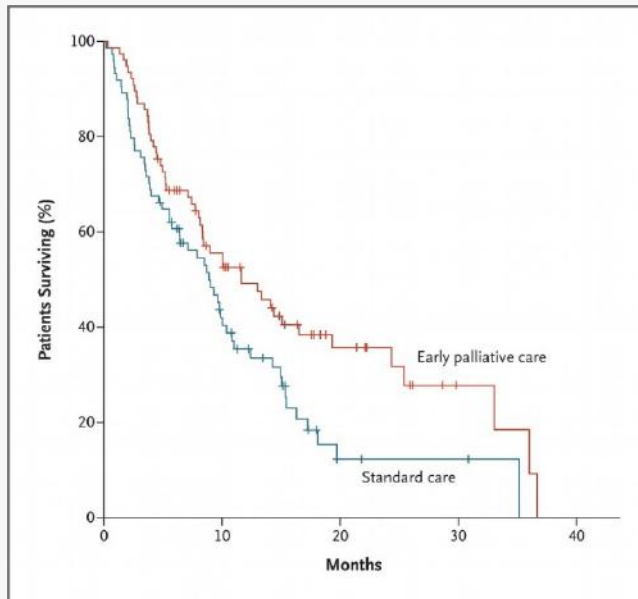
(JAMA 2016 Kavaleteros)

- Specialist teams

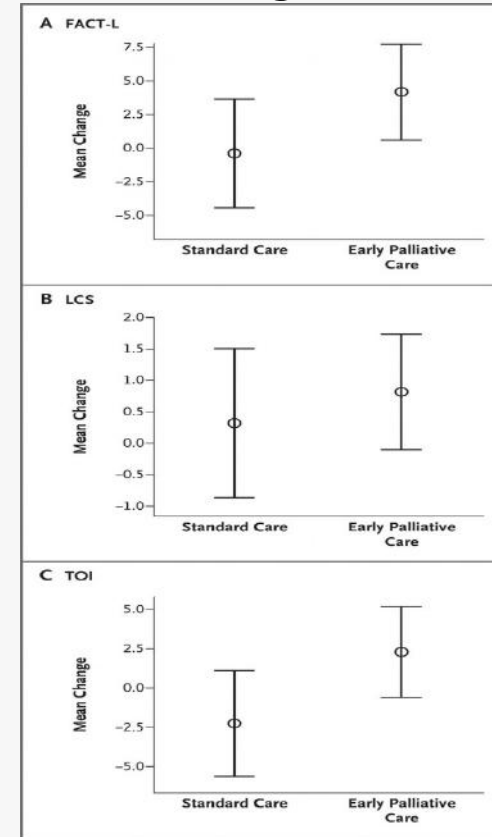


# Novel approaches in palliative care

- Temel NEJM 2010 metastatic non-small lung cancer

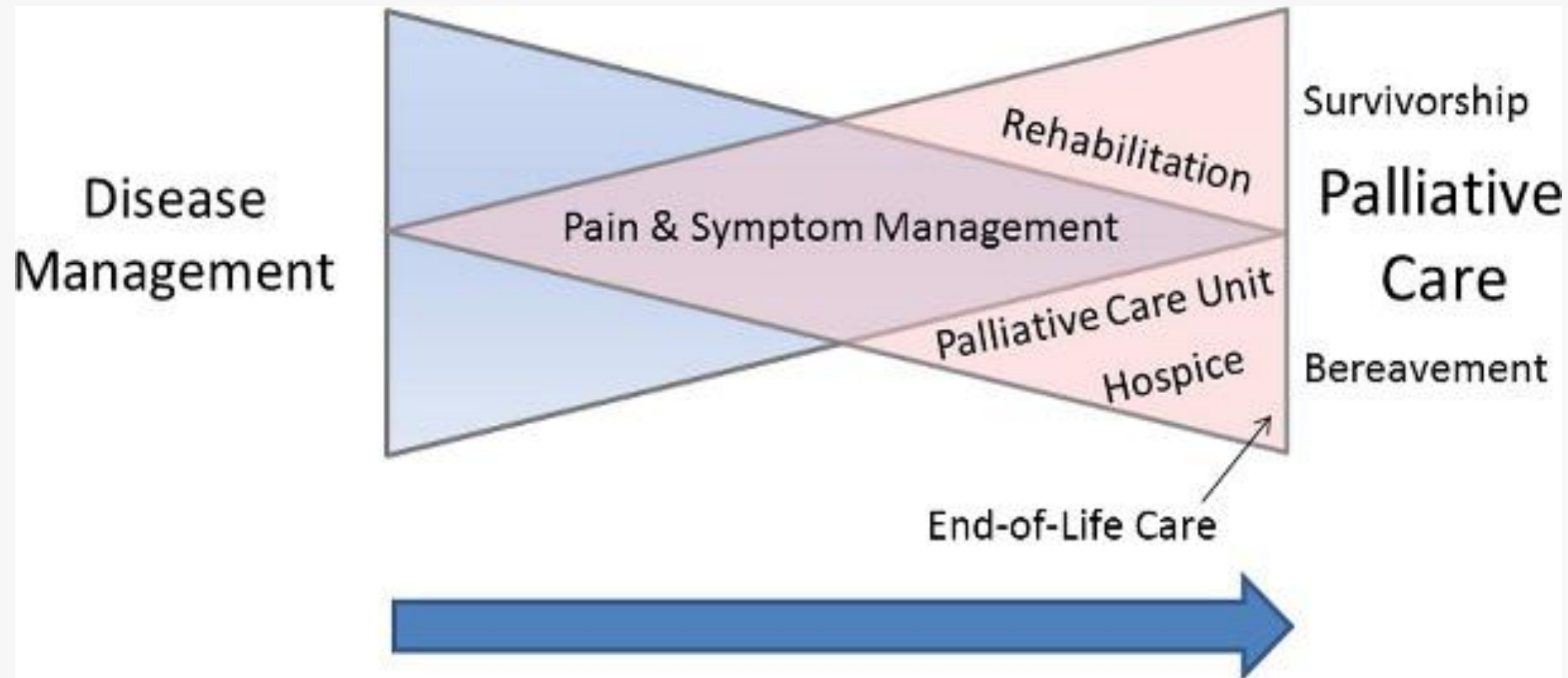


- Bakitas JAMA 2009 (cancer pts)
  - QoL, symptoms, mood
- Higginson Lancet Resp Med 2014 (breathlessness)
  - Mastery, QoL, survival



## Bowtie model (Hawley 2014)

- Palliative care should be part of maximum or optimal medical management



# HIV palliative care provision



Quality of Life Research, 1:33-47 (2012)

## Assessing the symptoms, anxiety and practical needs of HIV/AIDS patients receiving palliative care

E. Dubery,<sup>1</sup> I. Higginson, R. George, A. Simis and M. McCarthy  
<sup>1</sup>Department of Palliative Care and Public Health, University College London and Hadden's School of Medicine, 65-67 Gower Street, London WC1E 6BT, UK  
(E. Dubery, I. Higginson and M. McCarthy); Community Care Team, Bloomsbury and St. Mary's Hospital, Tottenham Hospital, Harington Road, London, N15 2LT, UK (R. George); St. Mary's Home Support Team, 25 Mary's Hospital, Finsbury Street, London, WC2N 3TH, UK (A. Simis).

We report the work of two community teams who care for people with AIDS/HIV related illness. The effectiveness of palliative referral, and the impact of the service on five aspects of quality of life. Data were collected from 106 patients (60 St. Mary's Home Support Team, 46 Bloomsbury Community Care Team) who were referred to and remained in the care of these teams until death. All patients were male, mean age 52.7 years, 116 were homosexual, most received care from generalist primary medical teams (GPs) or AIDS specialist (STs). There was a wide range of reasons for referral. All patients (62%) were in hospital and 38% at home. Mean time in care was 21 weeks (2 days). Fifty-seven per cent died in hospital, 20% at home and 23% in a hospice. The Support Team Assessment Schedule (STAS), consisting of 17 items of care, was used by the teams to measure aspects of quality of life. Throughout care with death hour STAS items which control symptoms, control patient anxiety and practical and any reported in death. Symptom control was a consistently severe problem at referral and throughout the teams had some success in improving this. Item 11 remained a serious problem throughout care. Whilst anxiety, item 10, remained a serious problem at referral, improved significantly throughout care. Pain control was less consistently severe at referral and improved significantly throughout care. Practical and in control, item 16, remained a serious problem at any stage of care.

Key words: Anxiety, male, community care, end-of-life, HIV/AIDS, pain, palliative care, quality of life, symptoms.

\* To whom correspondence should be addressed.

© 2012 Blackwell Publishing Ltd

## Introduction

Community support teams (palliative care and hospice) models have been developed in London and Bloomsbury Health Authorities, in Central London, to assist in the care of HIV/AIDS patients in the community and in hospital.<sup>1,2</sup> The two teams, the St. Mary's Home Support Team (SHT) and the Bloomsbury Community Care Team (BCT), are multidisciplinary teams and have been described in detail elsewhere.<sup>1,2</sup> Both teams support patients and their carers, and aim to increase their choice of place of care and death by offering symptom control, counselling for both patient and carer, 24 h on-call, bereavement follow-up, and both formal education and co-ordination within on diagnosis, nursing and terminal care needs. They co-ordinate and support visiting services (living with hospital and outpatient clinics and work with their services offering shared care and do not take over care).

This study is an extension of an evaluation of palliative support teams which cared for cancer patients at home. The study with cancer teams began in 1985 with the development of an assessment schedule, the 'Support Team Assessment Schedule' (STAS). The STAS has been used to assess palliative and terminal care for by six cancer support teams and has been validated for use as a measure of aspects affecting quality of life.<sup>3,4</sup> It has a high level of inter-rater reliability.<sup>5</sup>

We report the characteristics of patients referred, and changing severity of four STAS items,

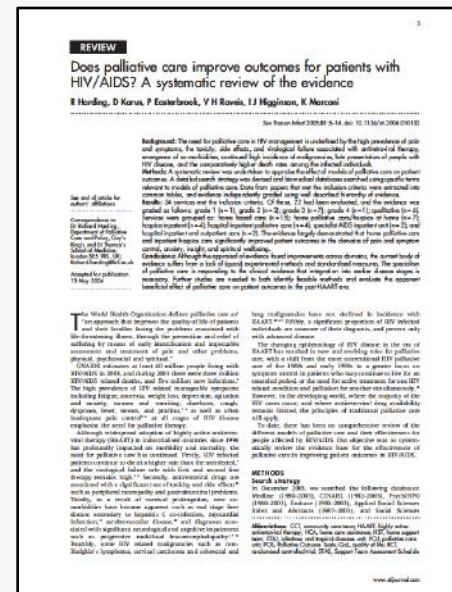


- No great heterogeneity in symptom burden across advanced conditions including AIDS (Moens 2014)

# Effectiveness of HIV palliative care

- “Home palliative care and inpatient hospice care significantly improve patient outcomes in the domains of pain and symptom control, anxiety, insight, and spiritual wellbeing”

# Harding BMJ STI 2005





# HIV palliative care skill base

- Moss AIDS 1990 *“It could be said that all care in AIDS is necessarily palliative, since no specific cure has yet been found”*
- Selwyn BMJ STI 2005 *“Early in the epidemic HIV care providers were by definition palliative care providers. Now the challenge is to reacquaint.”*
- Simms Lancet Infectious Diseases 2012 *“Modern palliative care offers effective ways to improve outcomes, not as an alternative or last resort”*



# ACCESScare

- *“it’s hard work going through twenty, thirty odd years of history... and you can’t get your breath... and you’re trying to explain and try and talk at the same time which makes it worse.”*

White British gay man 52, living with HIV and COPD



- *‘But not knowing what's out there or what's going on out there, I, I can, I find it difficult asking the right questions... And I finish up spending an hour or somebody's time just trying to work out what's good for me.*

White British gay man 64, living with HIV and Prostate Ca

(Bristowe Palliative Medicine 2017)

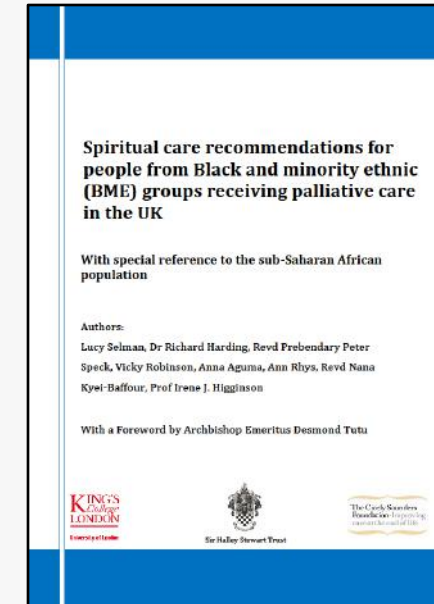
# Challenges to quality of care

- Multimorbidity with HIV
  - attention to communication when crossing specialty areas
  - additional support to decrease stressors from HIV stigma  
(Slomka JANAC 2017)
- Retrospective study of deaths Ontario
  - 570/264574 deaths were PLWH
  - dying younger 56.1 vs 76.6
  - more time in hospital 20/90 vs 12.1/90
  - costs last year of life \$80,885.62 vs. \$53,869.77

JAIDS Kendall 2017

# Spiritual wellbeing & cultural dimensions

- **Spiritual care reccs**
  - Know your patient's beliefs
  - Assess spiritual distress
  - Know you local spiritual care providers
  - Invite providers in to your setting
  - Encourage mutual training
- **Culture and pain**
  - Patients of African & Caribbean origin have under-treatment of pain (Hoffman 2016 Nat Acad Sci USA)
  - In UK advanced cancer pts pain as “*punishment*” and “*test of faith*” that doesn't need analgesia (Koffman Pall Med 2008)

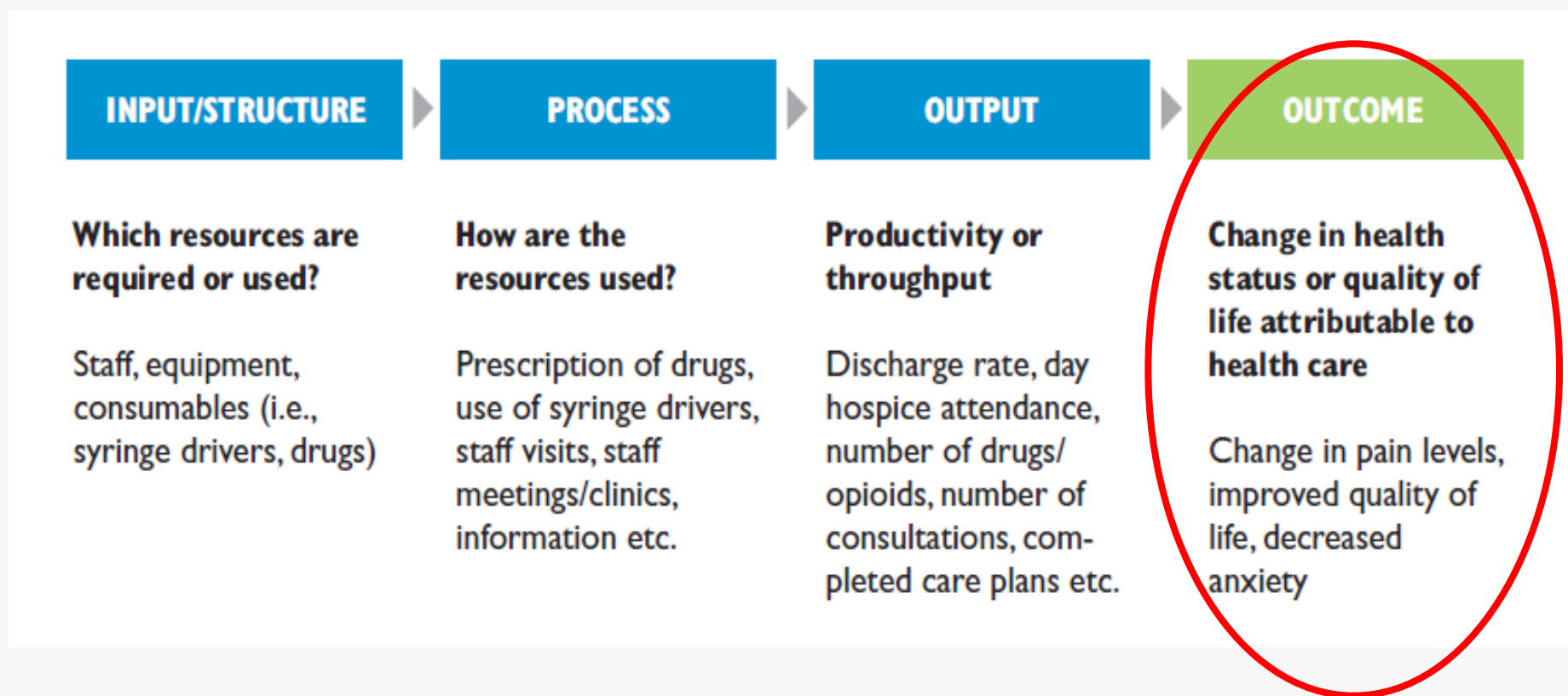


# PROMs in the UK

- NHS policy drive for use of PROMs
- PROMs are central to:
  - promoting patient-centredness
  - clinical care, audit & research
- Routine use of PROMs data can improve
  - communication with staff (Greenhalgh 2015)
  - outcomes for patients (Boyce 2013)
- In palliative care we are
  - using outcomes for minimum data set DoH & informing tariff
  - routine implementation through NIHR Programme Grant & CLAHRC

# What is an outcome?

**Outcome** = “the change in a patient’s current and future health status that can be attributed to preceding healthcare”  
(Donabedian, 1980)



www.pos-pal.org

The screenshot shows the homepage of the Palliative care Outcome Scale (POS) website. The header features the POS logo and the text 'Palliative care Outcome Scale' and 'A resource for palliative care'. A navigation menu includes links for Home, What is POS, How to use, Downloads, Publications, Training, FAQ, and About us. A search bar is located on the right. A dropdown menu is open under 'Downloads', listing various POS measures and translations. The main content area is divided into three columns. The left column contains a description of the POS and its use. The middle column has a 'Get involved' section. The right column features 'News and Events' and 'Tweets by CSI Palliative Care'.

**POS website**

**POS** Palliative care Outcome Scale  
A resource for palliative care

Home What is POS How to use Downloads Publications Training FAQ About us Enter Search... Search

Home You are not logged in. [Login or Register](#)

**The Palliative care Outcome Scale (POS)** is a resource for palliative care practice, teaching and research. This website has been established by a not-for-profit organisation to help advance measurement in palliative care. Free resources and training are available.

The POS measures are a family of tools to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instrument that can be used in clinical care, audit, research and training.

The POS measures are specifically developed for use among people severely affected by diseases such as cancer, respiratory, heart, renal or liver failure, and neurological diseases.

The POS measures are widely used globally including in Europe, Australia, Asia, Africa and America.

POS can be downloaded from this website and is available in [11 languages](#) including English.

POS in English  
IPOS in English  
IPOS-5 in English  
IPOS-Renal  
IPOS Views on Care  
POS translations  
IPOS translations  
POS-S in English (Renal, MS ...)  
POS-S translations  
MyPOS  
African APCA POS  
**Resources**  
Useful sites

**Get involved**

We are always looking for academic and clinical centres interested in translating and validating POS measures in new languages, settings and disease groups. [Contact us](#).

We also want to hear from professionals using POS measures locally and nationally.

**News and Events**

POS 2016 workshops: Clinical day Thurs 11<sup>th</sup> and Research day Fri 12<sup>th</sup> February 2016, [programmes now available on the Courses and Workshops page. Click here to book.](#)

Quality of life in multiple myeloma: Recent international research and future developments, Thursday 31st March 2016. [For more information and to book click here.](#)

Now available; a Clinical Decision Support Tool for using POS in clinical practice & Guidance for Implementing PROMS in clinical care; including a newly published paper. [Free to download.](#)

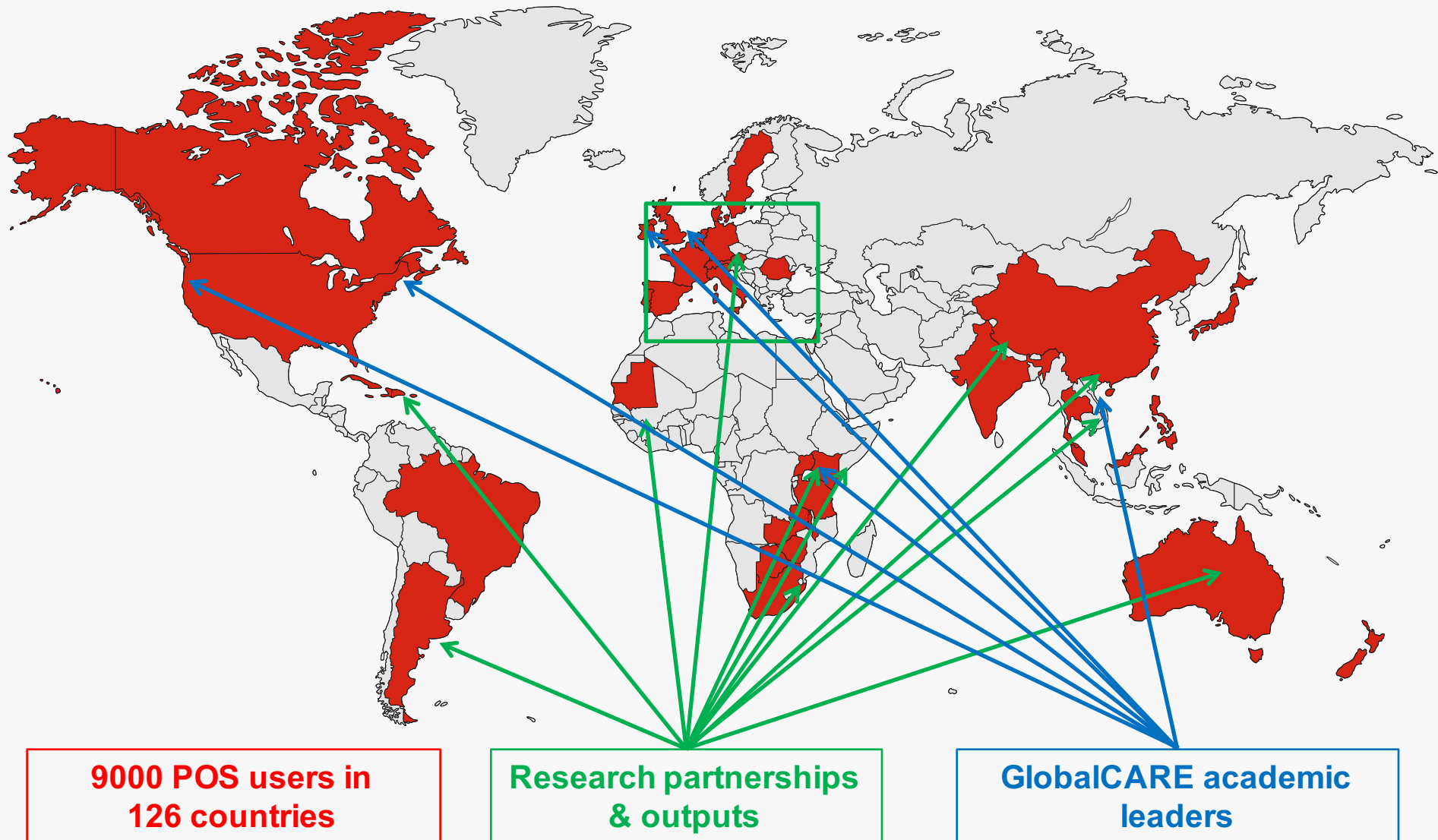
POS mentioned in a Marie Curie recent publication "[triggers for palliative care: improving access to care for people with disease other than cancer](#)" see executive summary

**Tweets by CSI Palliative Care**

CSI Palliative Care @CSL\_KCL  
Register now for #Myeloma Conference 31st March with speaker from @MyelomaUK [goo.gl/DkFRHB](#) [#hpm pic.twitter.com/vAr5wWdZLa](#)



# Global research & partnership activity





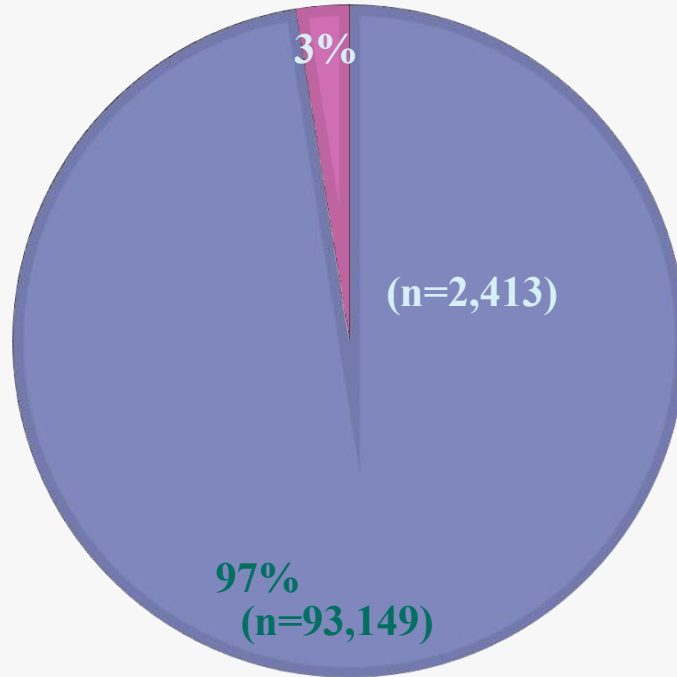
# Principles of palliative care in practice (TOPcare, Lancet HIV 2015)

	Variable	Coefficient (95% CI)	P value
MOS-HIV (Health related quality of life)	Physical Health sub-scale (in quartiles)	0.44 (-0.02- 0.91)	p=0.06
	Mental Health sub-scale (in quartiles)	0.61 (0.13-1.10)	p=0.01*
GHQ-12 (Psychiatric morbidity)	GHQ-12 (in quartiles)	-0.50 (-0.97- -0.03)	p=0.04*
APOS (Multidimensional palliative care needs)	Total APOS (in quartiles)	0.69 (0.26-1.12)	p=<0.01*
	Symptoms	-0.05 (-0.39-0.29)	p=0.78
	Worry	-0.37 (-0.09-0.83)	p=0.11
	Ability to share (in quartiles)	0.93 (0.28-1.57)	p=<0.01*
	Feeling life worthwhile (in quartiles)	0.23 (-0.48-0.94)	p=0.52
	Feeling at peace (in quartiles)	0.37 (-0.18-0.93)	p=0.19
	Help and advice for family to plan for the future (in quartiles)	0.78 (0.28-1.28)	p=<0.01*

# Hospice Palliative Care Association SA

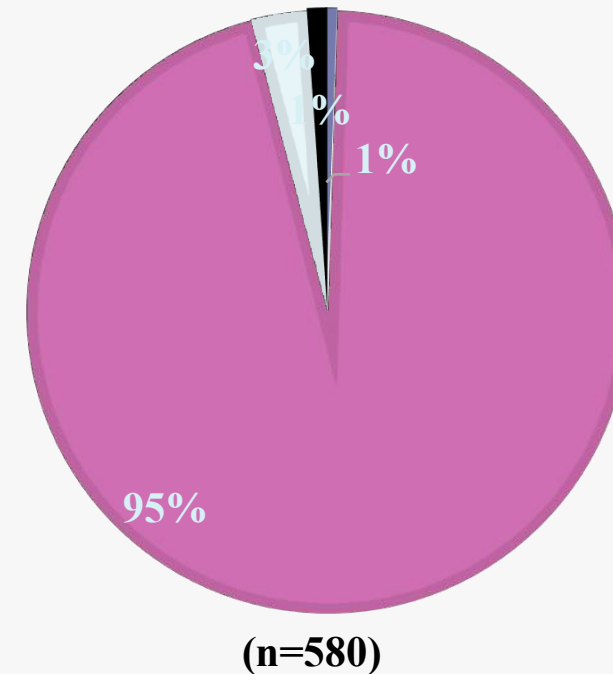
## NUMBER OF PATIENTS WHO EXITED COMMUNITY ACS

- Patients retained in community ACs
- Patients who exited community ACs



## REASONS FOR EXITING COMMUNITY ACS

- RIP
- Transfer Out (CCMDD)
- Back to Clinic
- LTFU



# Conclusions

- “There is **never** nothing we can do”
- Increasing needs for
  - education & training
  - “generalist” palliative care (Murtagh BMJ 2015)
  - collaborative working & decision making
  - clear information sharing
  - early palliative care
  - professional comfort with death & dying
- BHIVA standards 2018
  - enable audit
- Anticipate, plan, communicate
  - for optimal clinical management, quality of care & life