Palliative care for people with HIV:

an essential component of care services

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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

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2015</th>
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</thead>
<tbody>
<tr>
<td>PLWH</td>
<td>10.2</td>
<td>5.7</td>
</tr>
<tr>
<td>General population</td>
<td>1.6</td>
<td></td>
</tr>
</tbody>
</table>
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

High number of unknown deaths as autopsy reports outstanding

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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:

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>Men</th>
<th></th>
<th>Women</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>48</td>
<td>60%</td>
<td>15</td>
<td>63%</td>
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<tr>
<td>Hospice</td>
<td>15</td>
<td>19%</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>Home</td>
<td>12</td>
<td>15%</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>Community</td>
<td>0</td>
<td>0%</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Nursing home</td>
<td>4</td>
<td>5%</td>
<td>1</td>
<td>4%</td>
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<tr>
<td>Abroad</td>
<td>1</td>
<td>1%</td>
<td>0</td>
<td>0%</td>
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</table>
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)

- Specialist teams

(JAMA 2016 Kavaleteros)

<table>
<thead>
<tr>
<th>Source</th>
<th>No. of Patients</th>
<th>Intervention</th>
<th>Control</th>
<th>Setting</th>
<th>Instrument</th>
<th>Disease</th>
<th>Standardized Mean Difference (95% CI)</th>
<th>Favors</th>
<th>Favors</th>
<th>Weight, %</th>
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<tbody>
<tr>
<td>High risk of bias</td>
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<tr>
<td>Bakitas et al,20 2015</td>
<td>72</td>
<td>83</td>
<td>Home</td>
<td>QUAL-E</td>
<td>Cancer(^d)</td>
<td>0.28 (-0.03 to 0.60)</td>
<td>10.22</td>
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<td>Farquhar et al,43 2016</td>
<td>41</td>
<td>38</td>
<td>Home</td>
<td>NRS</td>
<td>Mixed(^b)</td>
<td>-0.01 (-0.45 to 0.43)</td>
<td>9.95</td>
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<td>Given et al,54 2002</td>
<td>53</td>
<td>60</td>
<td>Home</td>
<td>SES</td>
<td>Cancer(^c)</td>
<td>-0.29 (-0.66 to 0.08)</td>
<td>10.11</td>
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<td>Sidebottom et al,9 2015</td>
<td>79</td>
<td>88</td>
<td>Hospital</td>
<td>ESAS</td>
<td>Heart failure</td>
<td>-4.51 (-5.09 to -3.94)</td>
<td>9.57</td>
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<td>Wong et al,10 2016</td>
<td>43</td>
<td>41</td>
<td>Home</td>
<td>CHFQ</td>
<td>Heart failure</td>
<td>-0.60 (-1.04 to -0.16)</td>
<td>9.95</td>
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<td>Subtotal ((I^2 = 98.1%, P &lt; .001))</td>
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<td>-1.01 (-2.37 to 0.34)</td>
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<tr>
<td>Bakitas et al,57 2009</td>
<td>109</td>
<td>100</td>
<td>Home</td>
<td>ESAS</td>
<td>Cancer(^d)</td>
<td>-0.35 (-0.62 to -0.07)</td>
<td>10.30</td>
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<td>Higginson et al,12 2014</td>
<td>42</td>
<td>40</td>
<td>Ambulatory</td>
<td>NRS SOB</td>
<td>Mixed(^a)</td>
<td>-0.15 (-0.59 to 0.28)</td>
<td>9.96</td>
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<td>Temel et al,60 2010</td>
<td>60</td>
<td>47</td>
<td>Ambulatory</td>
<td>FACT-L LCS</td>
<td>Cancer(^f)</td>
<td>-0.42 (-0.80 to -0.03)</td>
<td>10.08</td>
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<tr>
<td>Zimmermann et al,8 2014 151</td>
<td>149</td>
<td></td>
<td>Ambulatory</td>
<td>ESAS</td>
<td>Cancer(^g)</td>
<td>-0.00 (-0.23 to 0.22)</td>
<td>10.37</td>
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<td>Subtotal ((I^2 = 42.1%, P = .16))</td>
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<td>-0.21 (-0.42 to -0.00)</td>
<td>40.71</td>
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<td>Unclear risk of bias</td>
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<tr>
<td>Edmonds et al,46 2010</td>
<td>25</td>
<td>21</td>
<td>Ambulatory</td>
<td>POS</td>
<td>Multiple sclerosis</td>
<td>-0.75 (-1.35 to -0.15)</td>
<td>9.49</td>
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<tr>
<td>Overall ((I^2 = 96.1%, P &lt; .001))</td>
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<td></td>
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<td></td>
<td>-0.66 (-1.25 to -0.07)</td>
<td>100.00</td>
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</table>
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

- 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 recs
  • Know your patient’s beliefs
  • Assess spiritual distress
  • Know your local spiritual care providers
  • Invite providers into 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)
Global research & partnership activity

9000 POS users in 126 countries

Research partnerships & outputs

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

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

- Patients retained in community ACs: 97% (n=93,149)
- Patients who exited community ACs: 3% (n=2,413)

**REASONS FOR EXITING COMMUNITY ACS**

- RIP: 1%
- Transfer Out (CCMDD): 95%
- Back to Clinic: 1%
- LTFU: 3%

(n=580)
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