Working together: the way forward for palliative care

1 May 2013
Welcome and introductions

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Medical Director
St Christopher’s Hospice
London Cancer Alliance

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FRCGP FRCP MFMLM
Chair of The NCPC, Past Chair, RCGP
My thesis today

• The case for change remains very strong and urgent
• The advent of GP led commissioning (CCG) is an exciting, and unique opportunity to do something very special
• Despite best endeavors, the primary and community care offer needs to be much stronger, otherwise we will not deliver the required outcomes (home deaths).
• A breakthrough is needed… improvement is distinctly possible through integrated models of care achieved by collaborative working
• Leadership opportunity and challenge! - need to mobilize for action: inject energy
The case for change

- Most deaths still occur in hospital whereas people want to die at home
- At least 92000 people with an unmet need
- Health inequalities are rife - non cancer
- Hospices offer gold standard but cater for a minority of deaths
- 20% of acute beds occupied by dying patients
- 3.6 unplanned admissions in last year of life, Av LOS 26 d
- Complaints about hospital care often about end of life
- Reticence in talking about death and dying
- Number of deaths to rise by 2030 by 17%
Margaret managed to get her dying wish - will you?

The London Cancer Alliance West and South

What does good look like?
Reflections…inconsistent care

As GPs it can feel like going to play cricket with a broken bat

Inconsistent: Sense of struggle, and crisis management – lack of support in the community

Default is the hospital

Challenge for CCGs: Beef up primary and community offer
CCG agenda
(graphic from RCGP)

Four intersecting areas that relate to EOLC.
The End of Life Care Pathway

**Step 1**
Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion

**Step 2**
Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

**Step 3**
Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

**Step 4**
Delivery of high quality services in different settings
- High quality care provision in all settings
  - Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
  - Ambulance services

**Step 5**
Care in the last days of life
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

**Step 6**
Care after death
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

**Spiritual care services**

**Support for carers and families**

**Information for patients and carers**
Deciding Right - Planning Care in Advance  Life Care

Identification
- You are caring for someone who you feel may be coming to the end of their life
- GMC definition of end of life is recommended and Use the Surprise Question and SPICT Tool to include on practice register
- Discuss sensitively using appropriate communication skills to prepare patient and family for end of life

Deciding Right Care Plan
- Formalise Advance Care Plan: key decision on preferred place of care and DNA-CPR
- Give green bottle to family with DNA-CPR /copy of ACP/medical summary
- Discuss in MDT/convene MDT, agree goals
  (Follow separate guidance if patient does not have capacity)

Complete Primary Care Coding
- Complete core content standard specification on EMIS Web or SI (insert template product - this can include a specific emergency health care plan
- Templates are on the practice system

Handover
- Share information with OOH using special note
- Give Green Card to family
- Share via EPACCS (WHEN ESTABLISHED)
- Update key stakeholders as situation changes as necessary
Mrs Jones is 35 with metastatic melanoma. Had surgery and chemo for liver and lung metastases.

CT scans show progressive disease despite biological agents taken for the last 2 months which have now been stopped “to give them a rest”.

Appetite is poor and very fatigued. Two children under 5 worried about how her partner is going to cope.

The oncologist has offered more treatment if Mrs Jones feels “up to it”.

DN requests GP home visit because family is not coping.
Doctors – Bring Dying Back into People’s Homes

Medical profession: Doctors are trained to cure but as people live longer with LTCs including cancer, we need to change how they work with patients.

Bring dying back into people’s homes by:
better preparing patients and their families for death, dying and bereavement –

Systematic use of advance care planning would be a game changer
Good Commissioning

- Commissioning is the single key mechanism for making sure that the right services are available to meet local need, and that they are sensitive to the needs of those approaching the end of life regardless of their condition.

- (End of Life Care Strategy: second annual report, 2010)

- Commissioning is not contracts!
The London Cancer Alliance West and South
Increased numbers of those dying at the place of their choice

- 24/7 community services
- Workforce training
- Anticipatory care plans
- Urgent care – common 111 protocols
- IT systems, EPaCCS
- Specialist services in place
- Outcome specifications

Figure 9: Components in commissioning
The London Cancer Alliance West and South

The NHS Change Model

- Leadership for change: Do all our leaders have the skills to create transformational change?
- Spread of innovation: Are we designing for the active spread of innovation from the start?
- Engagement to mobilise: Are we engaging and mobilising all the right people?
- Improvement methodology: Are we using an evidence-based improvement methodology?
- System drivers: Are our processes, incentives and systems aligned to enable change?
- Rigorous delivery: Do we have an effective approach for delivery of change and monitoring of progress towards our planned objectives?
- Transparent measurement: Are we measuring the outcome of the change continuously and transparently?

Our shared purpose: Does this improvement meet our shared NHS purpose?
Specialists and Generalists working together

• Specialists and generalists working together by providing an integrated models of care
• Putting people at the heart of service commissioning
• NICE recommend collaborative working, host CCG type arrangement, active involvement of stakeholders including third sector
• Guidance and modeling available including NCPC, RCGP and APM on SPC
• Transformation, whole system change
Accountable Care Organisation (ACO)

• "one service co-coordinating all of one person's needs" - requires the identification of a "main contractor" or lead organisation,

- The main contractor would be to ensure delivery of an agreed pathway of care, working with a wide range of collaborating organisations and professions committed to integrated working rather than to a traditional organisational loyalty.

• - Programme budget and a set pricing and tariff model
What are you doing to raise local awareness?

Join Dying Matters Today…
Sign up for FREE at www.dyingmatters.org

• Dying Matters Awareness week
  May 13th – May 19th 2013

• Small actions; big difference

‘How people die remains in the memory of those who live on’ Dame Cicely Saunders
London Cancer Alliance

Dr Catherine Millington-Sanders
RCGP National Implementation Clinical Lead for EPaCCS
Richmond CCG Out-of-Hospital Care Lead
1st May 2013
Electronic Palliative Care Coordination Systems

- National Context
- EPaCCS – Approaches, Challenges and Learning
- Ensuring successful outcomes with EPaCCS
The End of Life Care Strategy

- Published in 2008

- Aims include to:
  - Improve the quality of care for people approaching the end of life
  - Enhance patient choice
  - Improve coordination of care
  - Reduce inequalities: for example national variation between, geographical areas and cancer vs. non-cancer patients

- Supported by NICE Quality Standard and Commissioning Guide 2011
Individuals approaching the end of life and their families must be able to rely on the right care, in the right place, at the right time under the care of the right professionals.

EPaCCS does this by

- highlighting the need to identify 1% of patients in the last year of life
- allowing advance care plans to be recorded
- facilitating instant access to crucial information about patients approaching the end of life and the carers and professionals involved in their care
- providing a shared local electronic record for health and social care professionals.

EPaCCS allows truly integrated and co-ordinated care.
EPaCCS Pilot Programme

- Pilot programme initiated to test out the development and implementation of EPaCCS
- 8 pilots were selected, which explored a variety of different approaches
- Pilots ran between October 2009 and March 2011
- Ipsos MORI evaluation report of the pilot programme published summer 2011
- Nationally, EPaCCS enabled an additional 46,000 people die at home (Q3 2009/10 and Q2 2010/11)
Technology Challenges

Implementation presents some challenges:

- Double-entry and synchronisation between systems
- Managing multiple local “hubs” – differing boundaries
- Consistency of information and patients moving between localities
- Patient access to their record
- Information and Clinical Governance
- Reporting and monitoring outcomes
- Links with other care planning solutions
Learning from the Pilot Programme

- No ‘perfect’ system solution available
  - Adastra, SCR, SystemOne, SystemC, Graphnet, Emis Web

- ISB national standard developed and published
  - continuously reviewed, for example, new coding for best interest decisions

- Interoperability specifications published
  - continuous work with colleagues on national interfaces to address issues for example, development opportunities with SCR

- Workforce advance care planning and IT training required
“1 % of each GP practice list should be being identified as end of life, through the course of a year, with particular emphasis on nursing and residential homes”

Former National QIPP Lead for End of Life Care, Sophia Christie.
Background Facts

● Mismatch: over 70% of people want to die at home yet only around 40% achieve this.

● Difficult Conversations multi-professional training
  – Only 3% before training were very confident having end of life conversations (n=228)

● National After Death Audit revealed from practice-only held registers:
  – only 27% patients who died had been identified
  – 75% of deaths are non-cancer patients, yet only 29% were identified prior to death
  – Only 42% had an advance care plan recorded
  – Patients on registers received better coordinated care
Ensuring success of EPaCCS

Multi-professional workforce training is required to help:

1. Identify the patients (and their carers)

2. Have the conversations with patients, family and carers in order to establish their advance care plans.

3. Record them on EPaCCS in order to coordinate them between professionals
Workforce training enables EPaCCS outcomes

● Identification
  - Improved and earlier support for patients, families and carers

● Advance care planning:
  - Assessment of capacity for consent or best interest decisions
  - Patient-centred - records care preferences in line with choice commitment
  - Improved quality and experience of care
  - Instant access and therefore improved coordination of care between professionals and across services
  - Improved awareness of legal documents, for example Lasting Power of Attorney
  - Reduced number of avoidable ambulance transfers, hospital attendances admissions and bed days – aligned with patient choice
  - Auditable data tool for commissioners

● EPaCCS enables truly integrated and co-ordinated care
Results: Place of death

- Sites with EPaCCS vs England average

![Bar chart showing percentage of place of death for sites with EPaCCS and England average.]

<table>
<thead>
<tr>
<th>Location</th>
<th>Sites with EPaCCS (n=9)</th>
<th>England average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>54.5%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Care home</td>
<td>17.5%</td>
<td>17.8%</td>
</tr>
<tr>
<td>Hospice</td>
<td>11.8%</td>
<td>5.2%</td>
</tr>
<tr>
<td>Home</td>
<td>20.3%</td>
<td>20.3%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>7.6%</td>
</tr>
</tbody>
</table>

Places with EPaCCS: Data from 9 organisations
England average data: Other not recorded; hospital deaths do not include use of hospices within hospitals.
Collaborative working to enable high quality patient, carer and workforce experience

Although every individual may have a different idea about what would, for them, constitute a ‘good death’, for many this would involve:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends
Delivery

Implementation

• National + Local planning
  ➢ Whole System approach to common vision, tailored to local services – so that the CCG, services and workforce understands what they are trying to achieve

Outcome data

1. Patient and Carer experience
2. Independent staff rating of quality of EOLC

• High correlation with process outcomes being achieved
  ➢ For example: PPD, PPC, Pain and symptom control, ACP Documentation

• Other commissioning data: Hospital admissions, attendances, bed days, ambulance transfers, GP QOF points
Commissioning an EOLC Pathway for Ealing

Dr Vijay Tailor, Ealing GP and CCG EoLC Lead
Liz Evans, Ealing CCG Service Transformation Manager
Ealing CCG Commissioning Intentions for EOLC

• Increase the number of people being supported to die in their preferred place of death
• A reduction in the number of people admitted to hospital who die very shortly after admission or after extended stays
• A reduction in unscheduled admissions in the last year of life.
The % of deaths recorded in each area by place of death during a single year, 2010 (UK) - Hospital deaths *

* Includes deaths in specialist palliative care units/ hospices that are based in hospitals
The number of individuals recorded on the primary care (GP) Palliative Care Register in each area in 2010/11, as a percentage of the total number of individuals with palliative care needs in the same area.
Number of deaths in each area preceded by a hospital admission of more than 8 days in 2010/2011 as a percentage of all deaths in 2010, (UK)

- EALING: 24.1%
Analysis of the length of hospital stay for admissions ending in death for 2010/11

Proportion of all hospital admissions ending in death

- 3 or less days: 40.3% (EALING PCT), 40.3% (National average)
- 4 to 7 days: 36.0% (EALING PCT), 20.8% (National average)
- 8 to 20 days: 26.5% (EALING PCT), 19.3% (National average)
- 21 days or more: 16.8% (EALING PCT), 14.9% (National average)

Length of stay of admission ending in death
Community Palliative Care Rapid Response Service

• Marie Curie were commissioned to provide a Planned Care service
  – pre booked 8 hour shifts
• Rapid Response service – daily 6pm to 7am by telephone contact
• Aim to prevent crisis at home and avoidable hospital admission
• Provide palliative nursing care, advice and support to patients and carers
• Home visiting service by Marie Curie RN or senior HCA
The commissioning challenge

- Getting the setting of care right
- Agree a whole system model
- Ensure we are spending in the right place
The redesign task and the targets

- **Commissioning intention** – to commission an EOLC pathway

- **Targets**
  - 14% reduction in deaths in hospital in 13/14
  - 20% reduction in deaths in hospital in 14/15

- **Base line** – deaths in hospital in 2012/13

- **Other targets we could develop to measure our work**
  - NEL in last year of life
  - Number of people dying with advanced care plans
  - Reduce numbers of deaths in hospital preceded by a stay of >8 days
  - Others?
“The secret of getting ahead is getting started.

The secret of getting started is breaking your complex overwhelming tasks into small manageable tasks, and then starting on the first one.”

- Mark Twain
Model of care

High level pathway

Central coordination

Specialist Palliative Care

Acute / Community / LAS

Disease & condition specific pathways

Patient outcomes

Training & Education generalist

Primary Care
Ealing EOLC Redesign Board

Model of care* and high level pathway**
Coordination of care

Advanced Care Planning
Training & Ed generalists

Primary Care
Cancer
Respiratory
CV Disease

ICP / LTC’s
CMC / Register
Central coordination point/team?

Older people / dementia
Care homes / sheltered housing

Other ideas suggestions?

* Ealing LTC’s model
** Nat EOLC Strategy
Redesign approach

• Agree
  – What are we trying to accomplish?
  – How will we know when the change is an improvement?
  – What changes can we make to deliver the improvement?
Project task approach

• Agree
  – What are we trying to accomplish? AIM
  – How will we know when the change is an improvement? MEASURE
  – What changes can we make to deliver the improvement? PDSA CYCLES
Project task approach

• Agree
  – What are we trying to accomplish? **AIM**
  – How will we know when the change is an improvement? **MEASURE**
  – What changes can we make to deliver the improvement? **PDSA CYCLES**
London Cancer Alliance
Palliative Care
Mapping Exercise

Dr Nigel Sykes
LCA Palliative Care Pathway Group Chair
Medical Director
St Christopher’s Hospice

Delivering world class cancer care for London
In August 2012, the 28 SPC teams across LCA hospitals, hospices and community teams were asked to participate in the first comprehensive audit / mapping exercise across Specialist Palliative Care services (NHS and non-NHS) in London.

27 (96%) of the teams responded.

West Middlesex University Hospital proved to have had no Specialist Palliative Care service for some months, due to recruitment problems.

- A Clinical Nurse Specialist in Palliative Care has subsequently been appointed.
Specialist Palliative Care services

Number of Specialist Palliative Care component services in London Cancer Alliance area

- In-patient (hospices): 10
- Hospital advisory: 17
- Community: 13
- Outpatient hospital: 3
- Outpatient hospice: 5
- Day therapy: 9
- Hospice at Home: 4

This range (7 types) and number (61) of services are provided by the 28 SPC teams – some providing 1 only (e.g. hospital advisory service), others providing 5.
NHS / non-NHS Palliative Care provision

NHS / non-NHS SPC provision

<table>
<thead>
<tr>
<th></th>
<th>Number of services</th>
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<tbody>
<tr>
<td>In-patient (hospices)</td>
<td>8</td>
</tr>
<tr>
<td>Hospital advisory</td>
<td>2</td>
</tr>
<tr>
<td>Community</td>
<td>10</td>
</tr>
<tr>
<td>Outpatient hospital</td>
<td>0</td>
</tr>
<tr>
<td>Outpatient hospice</td>
<td>5</td>
</tr>
<tr>
<td>Day therapy</td>
<td>7</td>
</tr>
<tr>
<td>Hospice at Home</td>
<td>4</td>
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<table>
<thead>
<tr>
<th></th>
<th>NHS services</th>
<th>non-NHS services</th>
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<tbody>
<tr>
<td>In-patient (hospices)</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Hospital advisory</td>
<td>15</td>
<td>2</td>
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<tr>
<td>Community</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Outpatient hospital</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Outpatient hospice</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Day therapy</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Hospice at Home</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>
Cancer/non-cancer split
(all SPC patients)

All SPC Patients presenting with cancer in local organisations in 2011

<table>
<thead>
<tr>
<th></th>
<th>All patients</th>
<th>Number of SPC pts with cancer</th>
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<tr>
<td>In-patient (hospices)</td>
<td>4065</td>
<td>3415</td>
</tr>
<tr>
<td>Hospital advisory</td>
<td>12985</td>
<td>8700</td>
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<tr>
<td>Community</td>
<td>15989</td>
<td>12631</td>
</tr>
<tr>
<td>Outpatient hospice</td>
<td>2886</td>
<td>2020</td>
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<tr>
<td>Day therapy</td>
<td>2155</td>
<td>1832</td>
</tr>
<tr>
<td>Hospice at Home</td>
<td>698</td>
<td>607</td>
</tr>
</tbody>
</table>
However, there will be overlap between these figures:

- Both Hospital and Hospice Outpatients and Hospice Day Therapy patients are likely to be included in the caseload of the other services.
- Hospice at Home patients are also likely to be included in Hospice Community Patients.
- And many Hospital palliative care patients will subsequently be looked after by Community or Hospice Inpatient services.
How adequate is Specialist Palliative Care provision?

- Annual number of deaths in the LCA area was 28,129 in 2011
- Based on DoH guidance, the annual number of LCA patients with palliative care needs is likely to be between 19,000 and 23,000
- Currently the number of patients seen by palliative care teams probably lies towards the lower of these estimates
  - With a bias towards those with a cancer diagnosis
Although not normally shown in the form of a line graph, these variables are displayed in a ranked formation (by absolute numbers of deaths), highlighting the very significant variation in overall need for End of Life services, and how these are highly skewed by the age breakdown.

Some SPC teams (hospital teams in particular) cannot track their patients to specific CCGs.
The Mapping Exercise also examined:

- Staffing numbers and the completeness of the multiprofessional team
  - Access to psychiatry, welfare, bereavement and complementary therapy services are relatively poor in hospital services

- SPC services in terms of:
  - Ease of Access
  - User Outcomes assessment
  - Provision of Education
  - Involvement in Audit and Research
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Phone advice Mon-Fri</th>
<th>Phone advice Sat/Sun/BH</th>
<th>Visits Mon-Fri</th>
<th>Visits Sat/Sun/BH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greenwich &amp; Bexley Community Hospice</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs (TRIPS)</td>
<td>24 hrs (IPU)</td>
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<tr>
<td>Harrow Specialist Palliative Care Community Service</td>
<td>9am to 5/5.30pm</td>
<td>9am to 5/5.30pm</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Meadow House Hospice</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td></td>
</tr>
<tr>
<td>Michael Sobell House Hospice</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td></td>
</tr>
<tr>
<td>Princess Alice Hospice</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td></td>
</tr>
<tr>
<td>Pembridge Palliative Care Unit</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td></td>
</tr>
<tr>
<td>St John's Hospice</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td></td>
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<tr>
<td>St Luke's Hospice</td>
<td>24 hrs (IPU out of hrs)</td>
<td>24 hrs (IPU)</td>
<td>24 hrs</td>
<td></td>
</tr>
<tr>
<td>St Raphael's Hospice</td>
<td>9am-3pm</td>
<td>9am to 5/5.30pm</td>
<td>9am to 5/5.30pm</td>
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<tr>
<td>Trinity Hospice</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
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<tr>
<td>Chelsea &amp; Westminster Hospital</td>
<td>24 hrs. Own Team Mon-Fri, Trinity OOH</td>
<td>24 hrs (Trinity)</td>
<td>24 hrs</td>
<td></td>
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<td>Croydon University Hospital</td>
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<td>24 hrs</td>
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<td></td>
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<tr>
<td>Ealing Hospital</td>
<td>Out of hours advice through hospice</td>
<td>8am to 4pm</td>
<td>Telephone advice from hospice consultant with visit if appropriate</td>
<td></td>
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<tr>
<td>Epsom &amp; St Helier's Hospitals</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
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<tr>
<td>Guy’s &amp; St Thomas’ Hospital</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
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<tr>
<td>Hillingdon Hospital</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>8.30am to 4.30pm</td>
<td></td>
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<tr>
<td>Imperial College Hospitals</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>Extended day 8am-6pm or similar</td>
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<tr>
<td>King's College Hospital</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>8.30am to 5pm</td>
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<tr>
<td>Kingston Hospital</td>
<td>24 hours</td>
<td>24 hours</td>
<td>9am to 5/5.30pm</td>
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</tr>
<tr>
<td>Lewisham Healthcare</td>
<td>8.30am to 5pm. Service available to health professionals 24/7</td>
<td>8.30am to 5pm</td>
<td>9am to 5/5.30pm</td>
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<tr>
<td>North West London Hospitals</td>
<td>Standard day 9am to 5 or 5.30pm</td>
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<td>9am to 5/5.30pm</td>
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<td>Princess Royal University Hospital</td>
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<td>24 hrs</td>
<td>Other</td>
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<td>Queen Mary’s Hospital, Sidcup</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>9am to 5/5.30pm</td>
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<tr>
<td>Royal Marsden Hospital/ Royal Brompton Hospital</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>24 hrs</td>
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<td>St George’s Hospital, Tooting</td>
<td>24 hrs</td>
<td>24 hrs</td>
<td>9am to 5/5.30pm</td>
<td></td>
</tr>
<tr>
<td>Organisation</td>
<td>How do you assess patient experience?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>-----------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GBCH</td>
<td>Help the Hospices survey, other ad hoc surveys, looking to implement SKIPP and Voices in future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Harrow Community</td>
<td>Questionnaire</td>
<td></td>
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<tr>
<td>Meadow House</td>
<td>Biannual Help the Hospices survey</td>
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<tr>
<td>Michael Sobell</td>
<td>Patient experience tracker/dept comment cards/in-house patient survey conducted over 1 year/complaints/accolades reviewed at clinical governance meetings</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>PAH</td>
<td>SKIPP</td>
<td></td>
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<tr>
<td>Pembridge Unit</td>
<td>SKIPP, Help the Hospices survey,</td>
<td></td>
<td></td>
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<tr>
<td>St Christopher's</td>
<td>Patients are surveyed using St Christopher’s Index of Patient Priorities (SKIPP). Bereaved carers also complete a VOICES-SCH survey</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St John's</td>
<td>Questionnaires and Interviews</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>St Luke's</td>
<td>External Patient survey questionnaire and visitors questionnaire</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St Raphael's</td>
<td>Patient Outcome Scale</td>
<td></td>
<td></td>
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<tr>
<td>Trinity</td>
<td>Patient surveys</td>
<td></td>
<td></td>
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<tr>
<td>Chel &amp; West</td>
<td>Satisfaction questionnaire, last 2009</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CUH</td>
<td>Patient Survey</td>
<td></td>
<td></td>
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<tr>
<td>EHT</td>
<td>Patient and carer survey</td>
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<tr>
<td>Epsom &amp; St Helier</td>
<td>Patient SatisfactionSurvey</td>
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<tr>
<td>Hillingdon Hospital</td>
<td>Patient satisfaction questionnaire in Pall Care OP, patients satisfaction questionnaire for lung cancer patients, NHS Patient Experience Survey, NHS Cancer Patient Experience Survey</td>
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<tr>
<td>Imperial College</td>
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<tr>
<td>King’s College Hospital</td>
<td>Patient survey to all patients discharged from hospital alive, provided no cognitive impairment or other exclusion criteria</td>
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<tr>
<td>Kingston hospital</td>
<td>Patient survey</td>
<td></td>
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<td>PRUH</td>
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<tr>
<td>QMS</td>
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<tr>
<td>RMH / RBH</td>
<td>Survey</td>
<td></td>
<td></td>
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<td>St George’s, Tooting</td>
<td>Carer questionnare</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training</td>
<td>Hospital - No. of sessions</td>
<td>Hospice - No. of sessions</td>
<td></td>
<td></td>
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<tr>
<td>----------------------------------------------</td>
<td>-----------------------------</td>
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<td></td>
<td></td>
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<tr>
<td>Internal Education / Training</td>
<td>28-200</td>
<td>6-329</td>
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<td></td>
</tr>
<tr>
<td>External Education / Training</td>
<td>5-95</td>
<td>16-297</td>
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</tr>
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</table>

<table>
<thead>
<tr>
<th>Audit &amp; Research</th>
<th>Hospital – No. of audits / research projects</th>
<th>Hospice - No. of audits / research projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audits</td>
<td>1-12</td>
<td>2-19</td>
</tr>
<tr>
<td>Research projects</td>
<td>0-8</td>
<td>1-14</td>
</tr>
</tbody>
</table>
Palliative Care Funding Review

Funding the Right Care and Support for Everyone

Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review

An independent review for the Secretary of State for Health by Tom Hughes-Hallett, Professor Sir Alan Craft and Catherine Davies
Palliative Care Funding Review

- July 2010: Palliative Care Funding Review was commissioned by the Secretary of State for Health
- Aims:
  - Create a fair and transparent funding system for both adult and paediatric palliative care
  - Deliver better outcomes for patients
  - Provide better value for the NHS
- A new funding mechanism is intended to:
  - Be fair to all sectors
  - Encourage the development of community-based palliative care services
  - Support choice
- July 2011 final report accepted by Government
What has happened since

- The Department of Health invited bids from consortia covering the whole range of palliative care provision in order to collect data and refine the proposals set out in the review
  - 8 consortia selected (one adult and one paediatric in London)
- Data collection commenced in April 2012 and will continue until late 2013
  - This is a costings exercise determining the input required in different care settings for patients at different stages of their illness
- Target date for tariff introduction April 2015
Outcomes in Palliative Care

Dr Fliss Murtagh
Consultant and Clinical Senior Lecturer in Palliative Care
Cicely Saunders Institute, King’s College London
Background

• What is outcome measurement?
• Why does it matter?
• Why is it challenging to capture in palliative care?
• What do we know so far?

• Some possible solutions
What is outcome measurement?

- Way of measuring changes in a patient’s health over time
- Outcome = “the change in a patient’s current or future health status that can be attributed to preceding healthcare” (Donabedian 1980)
What is NOT an outcome?

• A drawerful of thank you letters
• A satisfaction survey (on its own)
• *Satisfaction underpinned by expect*
  – *low expectations = high satisfaction*
  – *high expectations = poor satisfaction (however good the service)*
• % of hospital deaths on LCP
• Post-bereavement survey
  – Proxy
  – But may **reflect** outcomes if conducted carefully
What is NOT an outcome?

- The *current* NICE quality indicators
  - Action plan for delivery EoLC
  - Effective identification approaching EoLC
  - Care planning
  - Preferences and choices documented
  - Assess carer’s needs
  - Mechanism for care coordination
  - 24/7 availability of service
  - Standardised approach to last days (eg LCP)
  - Quality and output monitoring

- Mostly process measures
Outcomes after fractured neck of femur

- Relatively straightforward to measure:
  - Walking distance, use of walking assistance, range of motion, at a defined time post surgery
  - Other measures of functional ability: to put on shoes, climb stairs, use public transport etc
Outcomes in palliative care:
- what improves health status for patient/family?

• Reduction in distressing symptoms, better function
• Improved psychological health of patient and carer (including for carer, in bereavement)
• In wanted place of care / place of death (home most common preference)
• Quality of life & quality of death
• Quality of care, especially effective coordination
• Communication matched to preferences (most prefer open and honest communication, with more information)
• Life resolution: sense of completion, resolved fears/anger
• Reduced family burden
Domains and dimensions of outcomes
Outcomes in palliative care: making a difference to health status - what improves health status for patient/family

- Measure symptoms and function ability over time
- Record psychological health of patient and carer over time
- Map place of care/ place of death (concordance with preference)
- Measure quality of life & quality of death
- Measure care continuity/coordination
- Capture patient/family perspectives and feedback on communication
- (Life resolution)
- Assess family burden over time
Challenges in palliative care

1. The illness is getting worse
   – Functional ability worsens over time
   – Symptoms tend to worsen over time

2. Patients are generally very ill
   – 30-50% of in-patient palliative care patients have impaired capacity
   – Completing patient-reported outcomes often too burdensome

3. Generic outcome measures are not appropriate, not valid, and not reliable, in this group of patients
Professionals’ experiences with outcome measurement in palliative care

• Web-based online survey (2009/10)
  – Description of palliative care professionals’ use & experience with outcome measures in clinical care, audit & research
  – Sampling via National Palliative Care Associations, local, national and international contacts
  – 204 respondents from the whole range of professional backgrounds

Bausewein et al Health Qual Life Outcomes 2011
## Reasons for not using outcome measures

<table>
<thead>
<tr>
<th>Main reasons for having stopped/ not using tools (top 6)</th>
<th>(n = 204) %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time</strong> constraints</td>
<td>26</td>
</tr>
<tr>
<td>Tools are <strong>too burdensome</strong> for patients &amp; families</td>
<td>23</td>
</tr>
<tr>
<td><strong>Lack of training</strong> about how to use tools</td>
<td>21</td>
</tr>
<tr>
<td>Tools <strong>do not reflect the patient’s situation</strong></td>
<td>19</td>
</tr>
<tr>
<td>Tools are <strong>too burdensome for staff</strong></td>
<td>18</td>
</tr>
<tr>
<td><strong>Lack of guidance</strong> about how to use tools</td>
<td>17</td>
</tr>
</tbody>
</table>

**Under which circumstances would you start using tools? (multiple answers possible)**

- If more...
  - ... **information & guidance** provided (45%)
  - ... training provided (31%)

*Bausewein et al Health Qual Life Outcomes 2011*
### Measures used regularly

<table>
<thead>
<tr>
<th>Measure</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>KPS^24</td>
<td>69</td>
</tr>
<tr>
<td>ESAS^25</td>
<td>53</td>
</tr>
<tr>
<td>European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30)^32</td>
<td>48</td>
</tr>
<tr>
<td>Palliative care Outcome Scale (POS or African POS)^27,28</td>
<td>36</td>
</tr>
<tr>
<td>PPS^26</td>
<td>30</td>
</tr>
<tr>
<td>European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C15-PAL (EORTC QLQ-C15-PAL)^32</td>
<td>16</td>
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<tr>
<td>STAS^30</td>
<td>18</td>
</tr>
<tr>
<td>MQOL^35</td>
<td>15</td>
</tr>
<tr>
<td>Functional Assessment of Cancer Therapy-General^41</td>
<td>14</td>
</tr>
<tr>
<td>HADS^37</td>
<td>14</td>
</tr>
<tr>
<td>SDS^29</td>
<td>11</td>
</tr>
<tr>
<td>Schedule for the Evaluation of Individual Quality of Life^42</td>
<td>10</td>
</tr>
<tr>
<td>Cited less than 10 times</td>
<td>94</td>
</tr>
<tr>
<td>Total number of tools</td>
<td>106</td>
</tr>
</tbody>
</table>

^aMultiple answers possible.

---

**Functional status**

**Problem severity**

**Quality of life**

*Harding et al*  
*JPSM* 2011
Outcome measurement by palliative care providers in the LCA area

Phase of illness
HADS
Modified Karnofsky Performance Score
Palliative care Outcome Scale
Clear evidence that

- A wide variety of outcome measures are used in palliative care
- Uncertainty over which is best and when
- Place of death is at best an indicator not an outcome – needs to be matched to preferences and assessed in the light of quality of care
- Need for:
  - Training & guidance on outcome measurement
  - Consensus on core set of measures
  - Optimisation of existing tools, rather than the creation of new ones
Benefits of outcome measurement in palliative care

• Clinical care
  – Assess patients’ symptoms, as well as families’ & patients’ needs
  – Monitor changes in patients’ health status or quality of life
  – Facilitate communication with patients/families & healthcare team
  – Aid clinical decision making

• Audit, governance, and commissioning
  – Establish standards of practice & assess care given against established standards
  – Benchmark or compare standards of practice in one organisation with another organisation

• Research
  – Screen whether patients meet inclusion criteria for a study
  – Measure or describe patients’ symptoms, quality of life & care
  – Evaluate the effect of interventions, care or services
Completion & frequency

• Completion of measure
  – Gold standard: patient
  – Proxy rating: family, health care provider
  – Only few measures with proxy scales (e.g. Palliative Care Outcome Scale (POS))

• Frequency of measurement
  – Dependant aim of measurement and rate of change (symptoms – daily; quality of life – e.g. monthly)
  – Completion time (more frequent use – shorter measures)
  – Note that change over time needed for outcome measure

• Use of results in clinical practice, to shape service delivery, and to inform commissioning
What are the solutions?

- Ill patients, need to reduce burden
- Busy professionals, enable implementation without excessive burden
- Uniform measures, consistent use

- Brief measures, use proxies (both family and staff)
- Provide training and guidance to staff
- Consensus on core measures
Training and guidance on outcome measurement

www.csi.kcl.ac.uk/files/Guidance on Outcome Measurement in Palliative Care.pdf

Regular training workshops

Outcome Measurement in Palliative Care
The Essentials
Bausewein C, Davey B, Bernal H, Simon ST, Higginson IJ
Approaching consensus on core measures

- **Phase of illness**
  - stable, unstable, deteriorating, terminal, bereavement

- **Functional status and dependency**
  - Australian modified Karnofsky Performance Scale
  - (modified short-form Barthel for in-patients only)

- **Patient problem severity**
  - Brief measure with proxy versions (family carer and staff)

- **Family carer burden**
  - Brief measure e.g. Zarit short form
Thank you

Contact fliss.murtagh@kcl.ac.uk at the Cicely Saunders Institute for more details
Panel Q &A Session

followed by tea/coffee break
April 2013
Julia Riley

The Royal Marsden NHS Foundation Trust
Over 5,000 professionals trained to use CMC

Target met 6 weeks early

111 ‘go live’ on target

2013/14 Conversations ACP DNAR

1:1 training Daily webinars Groups Protected learning GP Masterclasses RCGP - CPD
Patient Safety

1. Quality review and auditing records

2. Clinical Incidents

MITIGATION BY CMC TEAM

Weekly reviews of clinical quality Audit

Investigation and reports
- Consent
- DNAR
- Blogging

Users – extensive training
Processes – review
System – software developments
CMC update: April 2013

- 5,025 Clinicians trained
- 5,296 CMC patient records
- 1,462 deaths (75.6% died in PPD)
- 55% of all CMC records created by community professionals (36% community and 19% GPs)
- 79% patients died outside acute sector

Where patients have a CMC record, 21% die in acute hospitals\(^1\).

(Nationally, 53% die in acute\(^2\)

In London, 60% die in acute)

\(^1\) CMC report: 18 Feb 2013
\(^2\) National End of Life Care Intelligence Network, NEOLCIN, 2008-10
Recorded place of death profile

Where patients had a CMC record **21% died in hospital, 35% died at home**

This report is based upon 1119 patients with a CMC record where the place of death was recorded.

1 National End of Life Care Intelligence Network, NEOLCIN, 2008-10
2 CMC Data (from August 2010 – April 2013)
CMC has the potential to assist care providers in the following areas:

>> Reduction in number of unnecessary hospital admissions
>> Reduction in the cost of hospital stay
>> Reduction in length of stay in hospital
>> Increases the number of patients with an advance care plan
>> Preferred place of care and dying achieved
>> Integrated service provision from all primary care sources

>> Reduction in number of unnecessary hospital admissions
>> Reduction in the cost of hospital stay
>> Reduction in length of stay in hospital

DATA – May 203
CMC development roadmap

- Auto flagging in place today
- Interoperability with GP and community nursing systems
CMC development roadmap

- OOH GPs
- Community teams
- Defined access for patients and carers
CMC development roadmap

- Hospices
- Nursing and care homes (374 in London)
CMC development roadmap

- Secure messaging between systems
- ITK
- ISB
CMC development roadmap

- Professional mobile working
- Patient access to own record
CMC for Long Term Conditions

CMC platform coordinates care across many providers

CMC patient view captures information from many providers
Any questions?

Google

Coordinate My Care

Twitter

Coordinate My Care
CPR, LCP & Anything else that’s out there

Rob George
Three Domains

Change

- WORK DIFFERENTLY
  - EDUCATE differently
  - EVALUATE differently
  - COLLABORATE properly

Values

- COMPASSION (FRANCIS)
  - Implementation team
  - Spending time in SPC services at the moment
  - RCP considering its response
- COLLABORATION (LCP, CPR etc)
  - Boundaries and Balance etc in decision-making

Process

- CPR and DNACPR
  - Tracey Appeal
  - 2013 refreshment by RC UK
- ICD devices
  - Deactivation Recommendations
- Anticipatory Care Planning
Hillingdon Nursing Home Project
(Two models of care)

Dr Yolande Saunders, Palliative Medicine Consultant, Hillingdon Hospital
Maura St George, Clinical Service Lead, Community SPC Team,
Hillingdon Community Health
Hillingdon Nursing Home Project

• In 2005/06 47% patients registered as living in a Care Home in Hillingdon died in the acute sector (Public Health Annual Mortality Files, 2006).
• Project aim-reduce inappropriate admissions from nursing homes to the acute sector at the end of life
• Improve quality of end of life care for patients in care homes
• Using a proactive approach we now have less than 4% patients identified as approaching end of life, known to SPCT dying in the acute sector.
Hillingdon Nursing Home Project

- Project implementation
- Evaluation
- Results: Primary outcomes
  - 10/11
    - 216 patients identified. 135 RIP. 130 in care home
  - 11/12
    - 199 patients identified. 111 RIP. 104 in care home
  - 12/13
    - 258 patients identified. 179 RIP all in care home

- Results: Secondary outcomes
- Challenges
- Sustainability
HCNH beds
Community based palliative care intermediate beds

- Based in nursing home (NH)
- Clustered in one wing
- Health funded
- Medium term (up to 3/12)
- Supported by specialist palliative care team (SPCT)
  - Weekly consultant ward round
  - Regular meetings with relatives
  - Weekly community palliative care CNS round
- Admission criteria
- Nursing home staff trained in basic palliative care
- Fast access
- SPCT is gatekeeper
<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010/11</th>
<th>2011/12</th>
<th>2012/13</th>
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<tr>
<td><strong>Admissions Per year (number)</strong></td>
<td>28</td>
<td>47</td>
<td>76</td>
<td>98</td>
<td>124</td>
<td>95</td>
<td>104</td>
</tr>
<tr>
<td><strong>length of stay days (median)</strong></td>
<td>33</td>
<td>24</td>
<td>15</td>
<td>17</td>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Referral source Hospital</strong></td>
<td>93%</td>
<td>55%</td>
<td>54%</td>
<td>47%</td>
<td>44%</td>
<td>61%</td>
<td>63%</td>
</tr>
<tr>
<td><strong>Referral source Primary care</strong></td>
<td>0</td>
<td>40%</td>
<td>38%</td>
<td>46%</td>
<td>44%</td>
<td>23%</td>
<td>29%</td>
</tr>
<tr>
<td><strong>Referral source Hospice</strong></td>
<td>7%</td>
<td>1%</td>
<td>8%</td>
<td>6%</td>
<td>8%</td>
<td>16%</td>
<td>6%</td>
</tr>
</tbody>
</table>
• CMC electronic register for patients with life limiting conditions
  • Community Trust
  • Acute Trust GSF blended learning programme in care homes
  • ‘Identify, assess, plan’
  • Multidisciplinary regular team meeting involving GPs
  • Separate training for GPs attached to care homes on the blended learning GSF programme
• Cross boundary working
London Cancer Alliance
Palliative Care event

Working together: the way forward for palliative care

St Christopher’s Care
Social Care projects

Penny Hansford Director of Nursing
Nigel Hartley Director of Supportive Care
St Christopher’s Group

May 2nd 2013
St Christopher’s Care

Two projects:

- 18 month pilot project across Croydon
- Hospital discharge project in Bromley (awaiting funding confirmation early May)
1. The Croydon project

- 18 month pilot project (including planning)
- set up provision of personal care for those people in the last year of life (on or eligible to be on the GSF/CMC register)
- at the point of referral not CC1 but if became CC1 whilst receiving Social Care, we would continue to deliver care)
- to recruit, train and support up to 25 carers
- to provide up to 200 hours of care a week (around 30 clients at any one time)
- service available between 6am and 11pm – 7 days a week
- to respond to referrals within 48 hours during normal working hours
- cost – around 200k per annum – same as
- added value – experience in EOLC, reputation, training & support, volunteer programme, back-office
Aims of the project

- to provide high quality care at the same cost as any social care agency
- care would be free at the point of delivery
- To link people’s health & social care
- To increase home deaths
What we have done so far...

- recruited 20 carers to date
- inducted, trained and receive monthly supervision
- 143 referrals to date
- exceeded 200 hour service delivery in February 2013 – on budget
- currently 77% of home deaths
- reporting – monthly ‘highlight’ reports and quarterly in-depth reports
Data – per quarter

Number of hours care delivered per week

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Hours</th>
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<tbody>
<tr>
<td>1</td>
<td>55</td>
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<tr>
<td>2</td>
<td>105</td>
</tr>
<tr>
<td>3</td>
<td>125</td>
</tr>
<tr>
<td>4</td>
<td>234</td>
</tr>
</tbody>
</table>

% of home deaths

<table>
<thead>
<tr>
<th>Quarter</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>29</td>
</tr>
<tr>
<td>3</td>
<td>70</td>
</tr>
<tr>
<td>4</td>
<td>77</td>
</tr>
</tbody>
</table>
## Outcomes (target of 75%)

<table>
<thead>
<tr>
<th>Quality of life (QOL) ratings:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. % of clients who say their QOL has been maintained or improved at 6 and 12 weeks = 100%</td>
</tr>
<tr>
<td>2. % of clients who say that they are usually/always able to exercise choice and control in relation to the care they have received at 6 weeks = 86% and 12 weeks = 100%</td>
</tr>
<tr>
<td>3. % informal carers who feel that the intervention has provided them with some respite at 6 and 12 weeks = 100%</td>
</tr>
<tr>
<td>4. % informal carers who feel involved in developing the care plan at 6 and 12 weeks = 100%</td>
</tr>
<tr>
<td>5. % informal carers who feel fully satisfied with the support given ( quite a lot/very well) at 6 and 12 weeks = 100%</td>
</tr>
</tbody>
</table>
What is going well

- Recruitment of high quality carers
- ‘St Christopher’s’ name – not a problem, but actively helpful
- Project management – helpful to link health & social care
- quickness of response
- met and exceeded all targets including staying on agreed budget
- Home death rate – surprised us all
- Everyone died! – accurate assessment of people suitable for project (no-one has lived longer than 20 weeks)
What are the challenges?

◆ Getting referrers to identify ‘end of life’
◆ N. of patients referred and N. who declined:
  • Died prior to assessment
  • Felt they could manage alone at present
  • Already had care package in place
  • Not in last year of life following assessment
  • Had continuing care already
◆ High quality service with small number of people and small number of staff
◆ Continuing care – funding
Case Study

Ron – 88 yrs – heart failure and Parkinsons

◆ Married to Daisy – 84 yrs
◆ 2 grown-up children (not much contact)
◆ Referred by a relative: GP agreed to our involvement
◆ Started with twice daily care package
◆ Received care package for three months before dying at home
◆ Last two weeks of life care package increased to four times daily
◆ On-going issues with breathlessness and anxiety from both Ron and Daisy
◆ Referred by project team to DNs in last week of life
◆ Volunteer sat with Ron weekly whilst Daisy went to the hairdressers
2. Hospital Discharge project in Bromley

- A personal care service offering initially up to six weeks of personal care for those people who are being discharged from the Princess Royal University Hospital.
- These people been identified as being in their last year of life using the Gold Standards Framework Prognostic Indicators.
- The aim of the service is to promote speedy discharges from hospital and to prevent re-admission where there is no medical reason for an inpatient stay.
- Care will be delivered in residential care homes and extra care housing as well as the patients own home.
Why is this service needed?

- Bromley is a large local authority with a population of 312,580 people
- It has a higher than average older population
- 2,600 people die each year in the borough
- Of these it is estimated that 20% will die suddenly leaving 80% predominantly dying of cancer or a long term condition
- Currently Bromley has a 56% hospital death rate
- The St Christopher’s Group currently has 800 of the 2,600 referred for specialist care each year
- Of the people we care for, we reverse the trend of hospital deaths to 54% home (incl. care homes) death rate and a 20% hospital death rate
The new service in detail

- The service will operate from 8 am-11pm, seven days a week and will take on 8-10 new patients each week.
- The PACE team, PRUH palliative care team and hospital discharge team will act as ‘casefinders’.
- They will forward referrals for care and will make recommendations for the care needed for the first 48 hours.
- St Christopher’s will arrange and put in the care package.
- After 24-48 hours the St Christopher’s Care Manager will assess the patient and amend the care plan as necessary.
- St Christopher’s will provide support and back up the carers during the hours the service is operating.
- After 4 weeks the St Christopher’s Care Manager will re-assess the patient using the health needs checklist.
- If the patient meets the criteria for continuing care funding (CC) the CC assessment will be completed and forwarded to the CC team for approval.
- If the patient is not eligible for continuing care the patient is then referred to social services and at or before six weeks post-discharge the patients care is transferred to social services for a package of care which will be means tested.
- The St Christopher’s care team will continue to deliver care to those who meet the criteria for continuing care but this care has a different funding mechanism to the hospital discharge project.
Evaluation and outcomes

- These will be based on similar measures used for the Croydon Social Care project
THE FUTURE...
Panel Q &A Session
Key Take Home Messages for Palliative Care in the LCA

Dr Shelley Dolan
LCA Associate Clinical Director
The Critical importance of “getting it right”
The last year of life

• In my several roles one of the issues that patients and families bring to my door for different reasons is the quality of their death.
• From patients there are discussions about ceasing active treatment but being frightened to admit “failure” to clinicians, family and friends.
• There are also discussions about how their death will be: clarity often about not wanting resuscitation, but how will pain control work, and what happens to breathing?, how will my family cope? where will I be?
• Finally from patients coming off a phase 1 trial a sense that now they have “failed” even that and what more is there.
Board lead for Governance and External Reviewer for complaints

- Incidents / complaints re not getting the death right for the family.
- In many of these instances a common theme is a mismatch in understanding between families / professionals and sometimes the patient.
- In many instances for various reasons a Palliative Care team has not been introduced or if it has been... “very late”.
- Delays in a local hospice bed being available or delays in community care packages being available.
As I listen to families and patients and actually the personal experience of losing a neighbour and close friends I often reflect that what makes a difference is the “permission” or facilitation of talking about death with skilled professionals early enough (where possible) to allow patient and family to start to absorb and plan for this event.

I would also add something that a very wise Palliative Care Clinician once demonstrated to us in the Intensive Care Unit: that even in the face of acute deaths this conversation can still allow hope and reduce much of the fear and concerns re lack of control.

It is of course one issue to improve the experience of hospital patients but even more of a challenge getting this right – where most citizens are: in their homes or care homes.
Rationale for the Case for Change and the Model of Care

• **First Principles:**

• To reduce unwanted variation and improve quality of care, and the experience of care for 4.8 million Londoners.

• If we listen to what patients tell us they want most surveys show the same:
What do Patients with Cancer say they want?

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Participation in decisions and respect for preferences
- Clear, Comprehensible information and support for self-care
- Attention to physical and environmental needs
- Emotional support, empathy and respect
- Involvement of, and support for, family and carers
- Continuity of care and smooth transitions.

*Europe Picker Institute (2010)*
Many of these apply equally to active care and palliation and end of life care

• Particularly the last four:

• Attention to physical and environmental needs
• Emotional support, empathy and respect
• Involvement of, and support for, family and carers
• Continuity of care and smooth transitions.

We have heard much today about how the palliative care community is working hard to get this right.
It has been evident today that key agencies: Health and Social Care, Commissioners and Providers in all settings are part of a virtuous circle to get this right for patients and their families.

Whenever I am privileged to work with palliative care clinicians I am impressed by the energy, passion, determination and innovation and today is such an example.
In Conclusion

• The need is enormous
• The product needs to be able to be varied / flexible and responsive
• The delivery needs to be effective in many different care settings
• All of this requires effective coordination, communication and planning between all our care agencies.
• The LCA gives us a vehicle within which to make continuous improvements and really make a difference to 4.8 million Londoners.
Key Take Home messages

- Everything we plan needs to be able to be implemented in any setting
- Needs to be affordable
- We need to plan together: commissioning and providing not two sides – but a virtuous circle
- We need to be able to plan, communicate and implement care across all settings with the patient and their family at the centre
- Need to plan the research studies and audits proactively to ensure we meet all the above challenges and where possible ask the patient and the family – Did we get it right? What more can we do?
Thank you

Dr. Nigel Sykes LCA Palliative Care Pathway Group Chair
Maureen McGinn LCA Palliative Care Pathway Group Project Manager
All of the speakers today
Everyone who has attended
Thank you all for the work you are doing and will continue to do