

Knowledge Exchange Seminar Evaluation Summary
Thursday 23rd February 2012

PRESENTATIONS

Management of depression in Palliative Care, Lauren Rayner

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | 10 | 18 |
| Session was useful | | | | 12 | 16 |

The AMBER care bundle, Jonathan Koffman and Ruth Caulkin

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | 14 | 13 |
| Session was useful | | | | 16 | 12 |

Clinical Perspectives on research questions, Helen Brewerton, Elmien Brink, Katherine Sleeman

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | 13 | 18 |
| Session was useful | | | 3 | 11 | 15 |

Palliative and End of Life Care in the Care Home Setting, Jo Hockley

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | 2 | 11 | 15 |
| Session was useful | | | | 15 | 13 |

'Coordinate my Care' electronic End of Life Register, Joy Ross

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | 12 | 18 |
| Session was useful | | | | 10 | 20 |

WORKSHOPS

Psycho-social care – what are the key challenges in delivery?

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | | 4 |
| Session was useful | | | | | 4 |

Achieving high quality end of life care (Coordinate my care, AMBER and LCP)

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | 4 | 2 |
| Session was useful | | | 1 | 3 | 2 |

Care in the community – home and care home settings

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | 1 | 4 | 1 |
| Session was useful | | | 1 | 3 | 2 |

Capturing clinical complexity and outcomes

| | Strongly Disagree | Disagree | Not sure | Agree | Strongly Agree |
|--------------------------------------|-------------------|----------|----------|-------|----------------|
| Session was clear and understandable | | | | 7 | 5 |
| Session was useful | | | | 7 | 5 |

COMMENTS:

It was a really positive and constructive afternoon.
Really enjoyed it, excellent discussions.
I was impressed with the level of preparation and input by the participants. Really pleased and will contact several people regarding further questions I have about my research (related).
Discussion group had only 1 non CSI member. Would have been nice to have been more mixed.
Discussions probably a bit too broad – might have been better to have more focussed questions for discussion.
Very good way of brainstorming and linking clinicians.
Well organised day session. Good mixture of people and representation from professionals / centres.
It was a nice forum to discuss current (limited) evidence.
Excellent to see colleagues from palliative care further afield i.e. St Josephs and Royal Marsden as well as those from local partners. Be useful to include local audit / local initiatives to share good practice.
Consider having poster presentations from different units over lunch.
Getting research into practice links with how palliative care engages with the 'right' people e.g. commissioning GPs/ Senior Clinicians. Engagement – demonstrate value (to patients. Admissions/ avoidance/ cost saving etc)
Excellent – great model for useful translation of science, innovating challenges, solutions...In addition to social media tools already suggested, consider 'Linked in'.
There is a huge need to link practitioner and researcher together – may eventually lead to more joint working.
Useful opportunity to bring clinical and research agenda together.
Presentations could be from researchers and practitioners. Discussions could have been opened up more between researchers and practitioners.
The workshop was particularly useful. It was very interesting to discuss issues with clinical colleagues.

CSI Knowledge Exchange Seminar: Workshop Notes

| | |
|---------------------|--|
| Group 1 | Psycho-social care – what are the key challenges in delivery? |
| Facilitators | Elmien Brink and Lauren Rayner |
| Scribe | Katie Stone |
| Members | Christina Ramsenthaler, Fiona Nash, Eloise Radcliffe, Kristina Clark |

What are the key challenges in delivering psycho-social care?

- Detection – detecting psychological distress; methods of detection e.g. formal, informal or intuitive; the HADS (Hospital and Anxiety Depression Scale) is often the last thing on the nurses' agenda; using a standardised tool like the POS can be beneficial.
- Psycho-social care under prioritised – Priorities should revolve around short-term relief in end-of-life care due to the unique patient group
- Time constraints – Patients discharged before psycho-social care can be utilised; discharged before psycho-social distress levels are assessed; not enough time for clinical staff to actually ask how the patients are; psycho-social taking longer than pain assessment in terms of assessment
- Training – Lack of training; staff lacking confidence to talk to individuals about psychological distress; staff attitudes; pathways to psychological care are clear but there is not always someone there to pick up the link i.e. no weekend resources
- Brief psychological interventions – Timely and focused.

Do you know of any evidence to address these challenges?

- There are standardised tools for detection but little evidence that they improve patient outcomes.
- Where does the value lie? There are some studies using bereaved relatives to measure value of care at end of life.
- Evidence relating to how bereaved children are supported (Christ & Christ)
- Limited research pertaining to attitudes on psycho-social care, and outcome measures

Can you identify 3 or 4 key research questions?

- How can we change staff attitudes, looking at the effect of training in psycho-social care, referral, and support?
- What are patients understanding of psycho-social care? What are carers understanding of psycho-social care?
- Do we create environments that are family friendly or easy to undertake the practice of offering psycho-social care and support? How best to do this. Emphasis on unit of care as the patients and family, not just the patient which makes palliative care unique
- Research on resilience rather than vulnerability. What are the coping strategies and mechanisms used by patients for dealing with the late stages of end-of-life? Looking at different factors of faith, support, etc.
- Effectiveness of assessments e.g. HADS. Should there be different tools to measure sadness and depression amongst palliative care patients, are there already too many tools? (over 250 tools monitoring depression).

| | |
|---------------------|---|
| Group 2 | Achieving high quality end of life care (Coordinate my care, AMBER and LCP) |
| Facilitators | Jonathan Koffman and Joy Ross |
| Scribe | Helen Horsley |
| Members | Katrien Moens, Tom Osborne, Julie Kinley, Jane Lewington, Shabnam Nawaz, Katie Emmitt, Jon Martin, Chioma Udechuku, Rupinder Gill |

What are the key challenges in delivering end of life care?

- KEY POINTS: Staff training and confidence, team working, preferred place of care and death and the challenges around patient/family/professional understanding of this, access to medication, resources, support for families, achieving targets.
- Capacity building and skills development for clinicians in training to have difficult conversations with patients and families.
- High rate of staff turnover and rotational work raises difficulties in training and sustainability. Need training to consistently build on existing skills.
- Translating intense communication skills training for smaller palliative care teams.
- Community teams do not receive any communication skills training at all.
- Lack of engagement for training from senior clinicians.

What are the key developments in CMC/ AMBER/ LCP and how can these be implemented?

- AMBER hopes to extend into training community teams in communication skills.
- LCP hopes to imbed in care homes and community teams in the future.
- CMC has key training developments and data to report improvements.
- Training can help professionals to introduce more economical and efficient working e.g. AMBER sticker in patient notes highlight that a proper entry has been made.
- CMC is electronic and will make systematic links to care homes that don't have Primary Care.
- Geriatrics work closely with palliative care and will find this useful – need to establish stronger contacts with 'unreachable' departments.
- AMBER/ CMC/ LCP not expensive and have different ways to engage people.
- Junior Doctors are always eager to train and learn but are not in a position to make decisions about care.

Are there gaps not addressed or poorly addressed by these initiatives?

- Training needs to be flexible and accommodate times that will help learning to take place.
- ICP needs to include more education and training.
- Primary Care colleagues are under pressure to discuss with patients and tick a box. Teams need to work together to address.
- End of life care, palliative care training and LCP training is not mandatory for doctors and nurses.
- Lack of senior engagement in patient care and consultant reluctance to put a patient on the palliative care pathways as they feel it removes the need for active management.
- Palliative care needs to be better understood – the label can be negative and patients may not receive the intervention they need if clinicians aren't looking for new problems.
- Mortality and Morbidity meetings tend not to focus on 'good' deaths. Should demonstrate that Amber works and can help with discharge/ length of stay problems.

| | |
|---------------------|--|
| Group 3 | Care in the community – home and care home settings |
| Facilitators | Jo Hockley and Claudia Bausewein |
| Scribe | Iris Groeneveld |
| Members | Sue Hall, Vera Sarmento, Hristina Petkova, Catherine Evans, Deborah Millen, Charles Reilly |

What are the key challenges in delivering palliative care in the community?

- Higher percentage of cancer patients in nursing homes (referrals to nursing homes from hospices are now more common)
 - Are deaths in nursing homes counted as home deaths?
- Nursing homes are often private organisations – they will be interested in research if there are financial benefits.
- Advance care planning in acute care settings is really done by nurses (and not by specialists because of costs)
 - This is very different in nursing homes, where care workers do this – language barriers can be profound
 - Important that staff know what ACP is about, and need to be able to fully engage to get full use
 - Education alone doesn't change practice
- Other approach is to have ACP 'Advocates'/Role model
 - Question is: how many do you need?
 - Agreement that we can learn from both good and bad role models
 - Is there (qualitative) evidence for the effectiveness of role models?
- There have been trials with ACP facilitators (someone specifically trained for ACP)
- More people are now dying in residential homes
 - JH notes that it has been much easier to work here, as people are more involved with patients/residents (they generally live there longer)
- In contrast, nursing homes have a much more medical view of dying, and tasks related to this are often seen as the medical staff's responsibility.
- Improvement in this will require team work, role modelling and leadership – education alone doesn't change practice.
- Patient's understanding of palliative care is limited
 - Need education/self-empowerment of patient
 - As well as empowerment of generalist care providers – how?
 - How do we engage the public?
 - What is the product and how do we market it? (how does it differ from what may be expected as "good care", what is specialist and what is specialist palliative care – specialist only for difficult cases)
- Lack of support for families.

Community

- Very difficult, if not impossible, to talk about ACP when there isn't even basic care.
- Experience massive variability in care in the community
 - Limited communication between different care providers
 - Limited time for delivery of services
- A lot of hidden need for care, especially in non-cancer conditions.
- We need to make a big jump in recognising need, we're not yet at the step of actually addressing need.
- Need to find a balance in different approaches to need:
 - Need linked to stages of illness (disease specific)

- Need not stage or illness dependent (complexity model)
 - Especially in residential care homes: people might not have a specific illness (general frailty/being elderly)
- Either way, there does need to be a standard for timing of assessment.

What are the major advances in evidence and how can they be implemented in practice?

- Impact of having/not having PC (more evidence available)
 - However, what if people are very ill in the community (effect of trying to transfer care from acute settings to the community)
 - Are services prepared to buffer increased needs in the community?
 - What happens further upstream when people who have been cared for in the community need to go into acute care?
- Needs to be more clear what is included in “the community” (does this include residential care, nursing homes, hospices, etc. – definitions vary)
- ACP and planning for palliative care: tools have certainly helped people
 - BMJ study Detering: RCT of ACT for elderly (<http://www.ncbi.nlm.nih.gov/pubmed/20332506>) → positive effects if delivered by trained facilitators
 - Changes in primary care practice (change in role of GPs) have had unwanted effect. Fiscal incentives can bring positive change (for example, locally enhanced incentives – Lambeth, gets GPs to nursing homes)
 - Gold standards framework (GSF) – risk that the use of paper form makes care provider lose eye for patient – it won’t work without a 1 to 1 relationship
- Patients do seem to know better what they want.

What are the key questions for the future?

- Coordination of care.
- Funding streams
 - Members of a multidisciplinary community team (GP, acute, SPC) have different financing streams, which might be competing
- Who are we dealing with in the community? Who are they?
- Lack of data: Hospital Episode Statistics (HES) – don’t know who were in their last year of life when they were using the services. Minimum dataset (MDS) is much more detailed, but only applies to SPC.
- Too much emphasis might be put on dying at home – “what is the fuss about”
 - ‘Only’ 50% have a preference for dying at home, and this preference may change over time (person may feel more safe/secure in hospital closer to the end of life, formal care can bring reassurance)
 - The debate should be about “dying in the community” in a wider sense (and as such, include dying in a hospice), as opposed to dying at home.

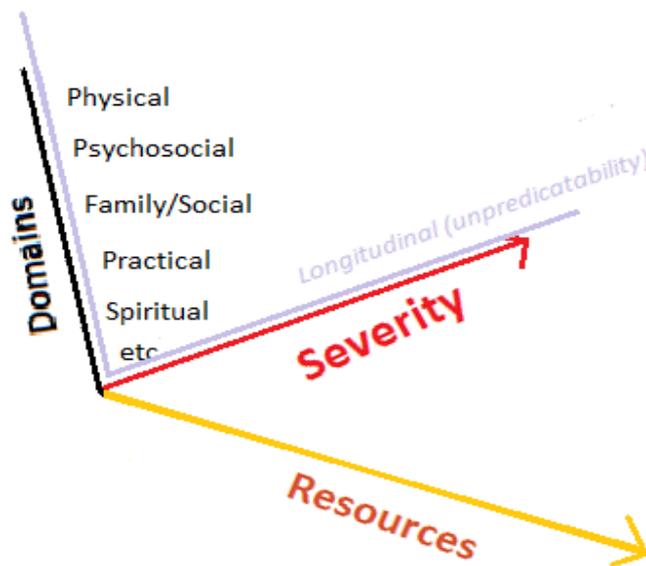
| | |
|---------------------|---|
| Group 4 | Capturing clinical complexity and outcomes |
| Facilitators | Wendy Prentice and Fliss Murtagh |
| Scribe | Yvonne Kaloki |
| Members | Cindy Fischer, Caty Pannell, Susanne de Wolf Linder, Barbara Antunes, Matthew Maddocks, Nick Gough, Brian Cassel, Rebecca Jennings, Clare Smith |

What are the key challenges in capturing and using complexity and outcomes with palliative patients?

One of the key challenges of capturing clinical complexity lies in:

Complexity can either be defined by the provider of services. There is an agreed understanding that there is a difference between Specialist Palliative Care (SPC) and General Palliative Care (GPC) where it is assumed that patients who receive specialist care require more trained professional input, hence being more complex. However, complexity is more than just the patients who receive SPC. There are numerous dimensions that encapsulate complexity, see below.

Chart 1: Dimensions of complexity in palliative care



The dimensions that capture complexity include

- Clinical domains include physical (pain, nausea,), psychological (anxiety, stress), social (family systems, practical issues), and spiritual. (*Y-Axis*)
- Patient’s problem severity (the Degree of difficulty in all the above domains). (*X-Axis*)
- Unpredictability (change over time - longitudinal)
- Resources available (*Z-Axis*)

Other dimensions influencing complexity (but not captured in the diagram) include:

- Perspectives – dependent on who is providing information (patient, family, professional, funders)
- Training Skills
- Prognosis

One of the challenges of clinical complexity is the element of choice, place of care and place of death. If patients are advised they are complex patients then they are more likely to influence their care.

How can complexity be measured clinically?

Complexity is measured clinically to address the following areas:

- 1) Costing/funding.
- 2) Unravel other information that would not otherwise been known during assessment or routine care. This can then be matched to the appropriate resources to ensure the need is met.
- 3) To distinguish the difference between Specialist and General Palliative Care.
- 4) Enable organisations to evaluate patients need. In the renal population outcomes are used to determine the complexity of a patient and if they need to go on the End-of-life Care register (EoLCR). Similarly hospices uses measures to evaluate a patients complexity and if they can be admitted for care.

Complexity can only be effectively measured clinically if there is communication between patients and clinicians.

What are the challenges of capturing and using outcomes in Palliative Care?

- 1) Outcomes are derived for differing purposes. Majority are patient-orientated. However, they can be
 - a. Patient-level – examine a patient’s level of need
 - b. Organisational – where patient outcomes are used to examine services.
- 2) Perceived choice vs. Realistic choice
 - a. We need to ensure that there aren’t any perverse incentives when capturing outcomes (patient and service-level). It is important that patient outcomes are capturing the patients need and not their hope that their outcome will influence the service they can receive.
 - b. We also want to capture accurate information on the quality of care being provided (service level).
- 3) How broad or specific should the outcome measure be?
 - a. Outcome measures highlight the patient’s complexity. However, complexity could be captured in a broadly comprehensive or a specific dimension. That is, the measure could capture a specific complexity domain or want to score the patients overall perceived health status
- 4) Before using an outcome measure in palliative care, some of these key questions must be addressed.
 - a. Who is benefiting?
 - b. What is the point of the outcome? What is it trying to capture and will it generate new information?
 - c. What is the outcome of the new information, i.e. how will the issues unravelled by the outcome measure be addressed? For example, will there be better care? Improve guidelines? etc

How can outcomes be used in practice?

Outcome measures can be used to evaluate either:

- 1) Patients need - they are used to capture patients needs

- 2) Services – it can be used to evaluate services in meeting patient need against best practice guidelines.

There should be an incentive (at both levels) to ensure practitioners and patients use outcomes to evaluate services and the quality of care being provided to inform best practice guidelines.

However, it is essential that the patient is at the heart of the measure and outcome.

They could be used as a benchmarking method. In Australia, the Palliative Care Outcomes Collaboration (PCOC) is a benchmarking programme that aims to improve palliative care outcomes by demonstrating service outcomes on different domains and matching services with low and high outcomes.

It is imperative that outcome measures are used to improve services by auctioning the revealed problems, highlighted by the results of the measure.

What research questions would be most helpful?

We have agreement that outcomes (and their measurers) and complexity cover a broader role than just uncovering the patients complexity as they can be used as a common language within single and multiple teams, such as MDTs. Also, given that complexity is linked to outcomes as well as costs we expect that patients who are more complex will require more resources and hence will be more costly. Therefore complexity and outcomes can verify these ideas, as well as, help services provide the appropriate care for all patients as measured by their complexity.

Therefore, as researchers it is important to define and capture the link between outcomes and complexity in a clinical context. It is also equally interesting to separate them and investigate the gap between them.

We should also investigate the trigger points that move patients into palliative care services, which is usually heavily dependent on:

- 1) The availability of services and resources available for each patient within their local area.
- 2) Decision makers who govern when active treatment should stop and the patient should begin receiving palliative care.
- 3) Any local requirements and government laws on outcome measurement and quality of care standards.

Summary

We agree that although patient orientated, the real value of measuring complexity and outcomes (and their measures) is politically driven.

Summary and Close from Irene Higginson

- Training and support – more than classes and training is needed → how to do this/ how do we innovate in this area?
- Dissection of problems in relation to access to care (how does 1 service limit/improve access to another)
- Sustainability for new initiatives → how to secure resource continuation + how to roll out successful initiatives at a larger scale
- Resources/ evaluation/ evidence/ outcomes → Have to prove that it's worth it
 - Resources - affect sustainability
 - Evaluation - additional while running service
 - Evidence – collect while service is running
- What next?
 - Summary of the day
 - Influences what we are doing?
 - Talk to 3 others
 - Formed a contact here
 - What else?

Joy: Distress in own fear. What we think is known about isn't. Considering sustainability and evaluation we can't do the best but we can do something with existing resources to make a start.

Helen: Wholeheartedly agree. Implementing the tools. How we can improve care on the ground as part of that tool and keep it simple.

Tom: New wisdom on AMBER to promote in hospitals. Talking about problems with Juniors and clinicians (coalface) and seniors. Problems need implementing at a high level.

Jonathan: Going global. Finding powerful people to sell the message and give payback in tons of resources for CMC, AMBER and an earlier trigger into palliative care.

Brian: Breadth and depth of clinical innovations: heart-warming/ stimulating and inherits clinical contacts and presenters. Use web portals for clinical notes access and perhaps gear them towards the end of life.

Katherine: I think on micro scale, whereas senior people think on a macro scale.

Irene: We need both macro and micro scales. Raises Jonathan's point.

Continued contact for the group through Twitter/ blog/ Facebook? Explore a CSI/Pall care/ Twitter network.



A study of depression at St Christopher's Hospice: Implications for clinical management

Lauren Rayner, Laura Goodwin, Annabel Price, William Lee, Richard Hayes, Barbara Monroe, Penny Hansford, Nigel Sykes , Irene Higginson & Matthew Hotopf

Why is it important to assess depression?

- There is an increased risk of depression in palliative care
- Depression in palliative care is under-diagnosed
- Depression is associated with:
 - ▣ Reduced quality of life
 - ▣ Higher levels of pain & fatigue
 - ▣ Poorer physical functioning
 - ▣ Increases in health care costs
 - ▣ Increased risk of mortality

Breitbart W. Supportive Care in Cancer 1995;**3**:45-60.

Katon WJ, Lin E, Russo J, Unutzer J. Arch Gen Psychiatry 2003;**60**:897-903.

Satin JR, Linden W, Phillips MJ. Cancer 2009;**115**:5349-5361.

Origins of the study



- To fill this gap in the evidence we undertook a large survey of depression at St Christopher's Hospice
- Aim: to provide new evidence on the nature, course and correlates of depression in this context, to inform assessment & management & improve patient outcomes

Key objectives of the study

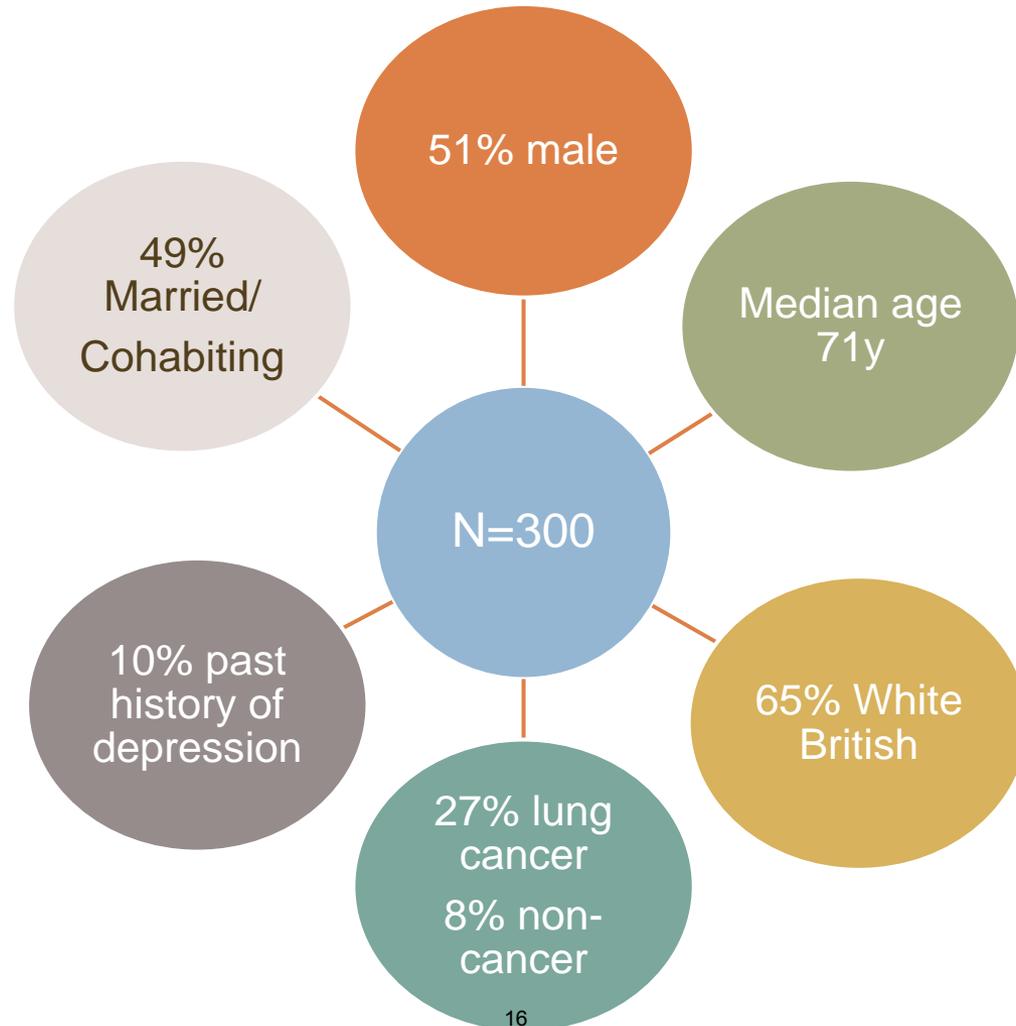
- 1 • To determine the prevalence and remission of depression in a specialist palliative care population
- 2 • To identify risk factors for depression in palliative care
- 3 • To examine predictors of non-remission of depression in palliative care
- 4 • To determine the prevalence and stability of desire for hastened death

Study design

2 cross-sectional assessments



Sample



Prevalence of depression at T1

DSM-IV Case definition

- 58 patients (19.3%) met criteria for Major Depressive Disorder (MDD) according to the Prime-MD PHQ-9
- 109 patients (36.3%) met criteria for 'Any depressive syndrome', which includes both MDD and minor depression

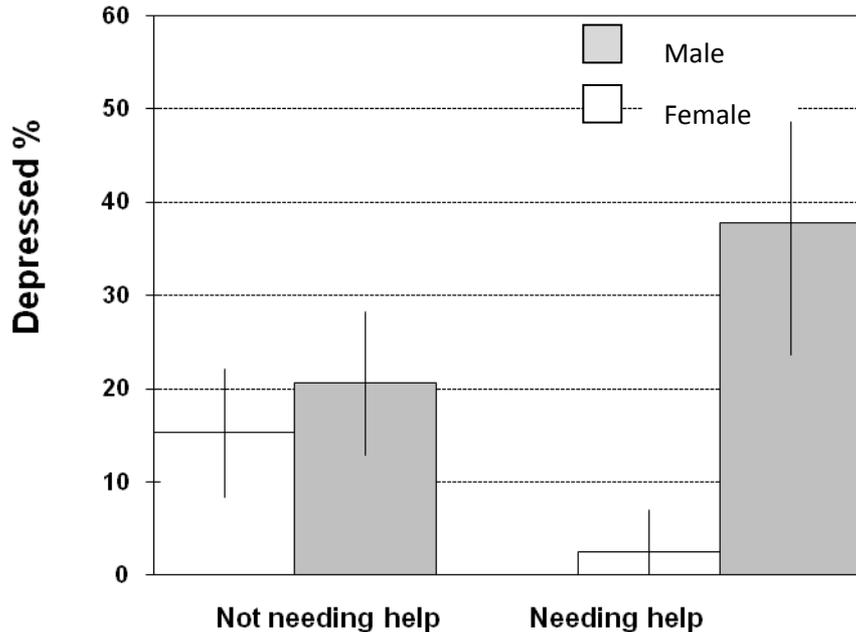
Severity of depression:

- 32 patients (11%) had moderately severe depression (PHQ-9 15-20)
- 15 patient (5%) had severe depression (PHQ-9 20-27)

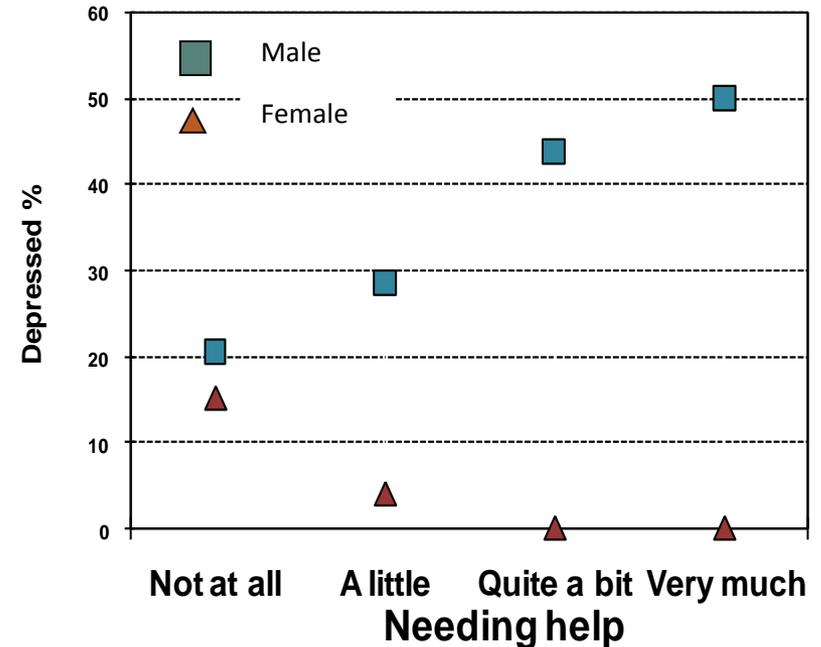
Risk factors for depression

- **Having a non-cancer diagnosis**
- **Poorer physical functioning (ECOG score)**
- **Higher levels of pain (EORTC)**
- **Desire for hastened death:**
“Do you ever wish that your illness would progress more rapidly so that your suffering could be over sooner”
- **Being male:**

Why are men at increased risk?



Depression and gender in palliative care, stratified by needing help with basic tasks



Dose response between depression and needing help with basic tasks for men and women

Stratified analyses indicated that 37.7% of men who needed help with basic tasks were depressed compared to only 2.4% of women who needed help

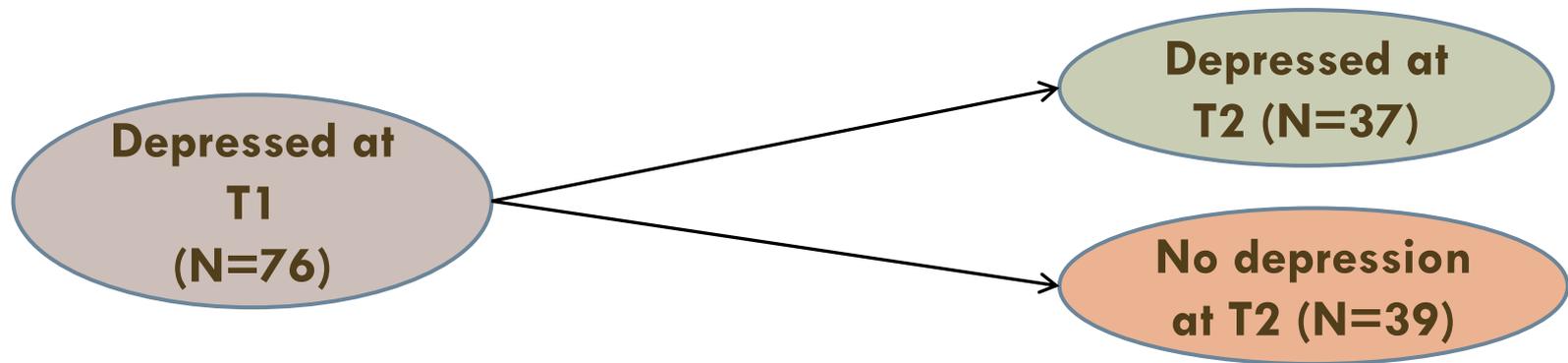
Remission of depression by T2

| | | 213 patients interviewed twice (Prime-MD PHQ-9) | | | |
|---------------------------------|----|--|-----------------------------|------------------------------|------------------------------|
| Major Depressive Disorder (MDD) | T1 | Depressed 39 (18.3%) | | Not depressed 174 (81.7%) | |
| | T2 | Depressed 12 (30.8%) | Not depressed 27 (69.2%) | Depressed 19 (11.0%) | Not depressed 155 (89.1%) |
| Any depressive syndrome | T1 | Depressed 76 (35.7%) | | Not depressed 137 (64.3%) | |
| | T2 | Depressed 37 (48.7%) | Not depressed 39 (51.3%) | Depressed 27 (19.7%) | Not depressed 110 (80.3%) |

- High rate of remission (Major depression 69%; Any depression 51%)
- Rate of new onset depression (MDD 11%; Any depression 20%)

Can we predict likelihood of remission?

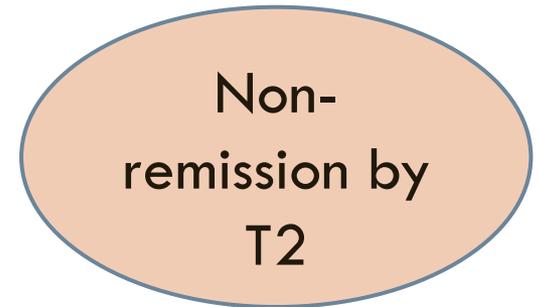
- **Aim: to examine a range of demographic and psychosocial factors at baseline in predicting non-remission**



If patients likely to have persistent depression could be identified at the time of referral this would provide clinically useful information

Predictors of non-remission of depression

- Low social support
- Non-white ethnicity



Predictors of remission of depression

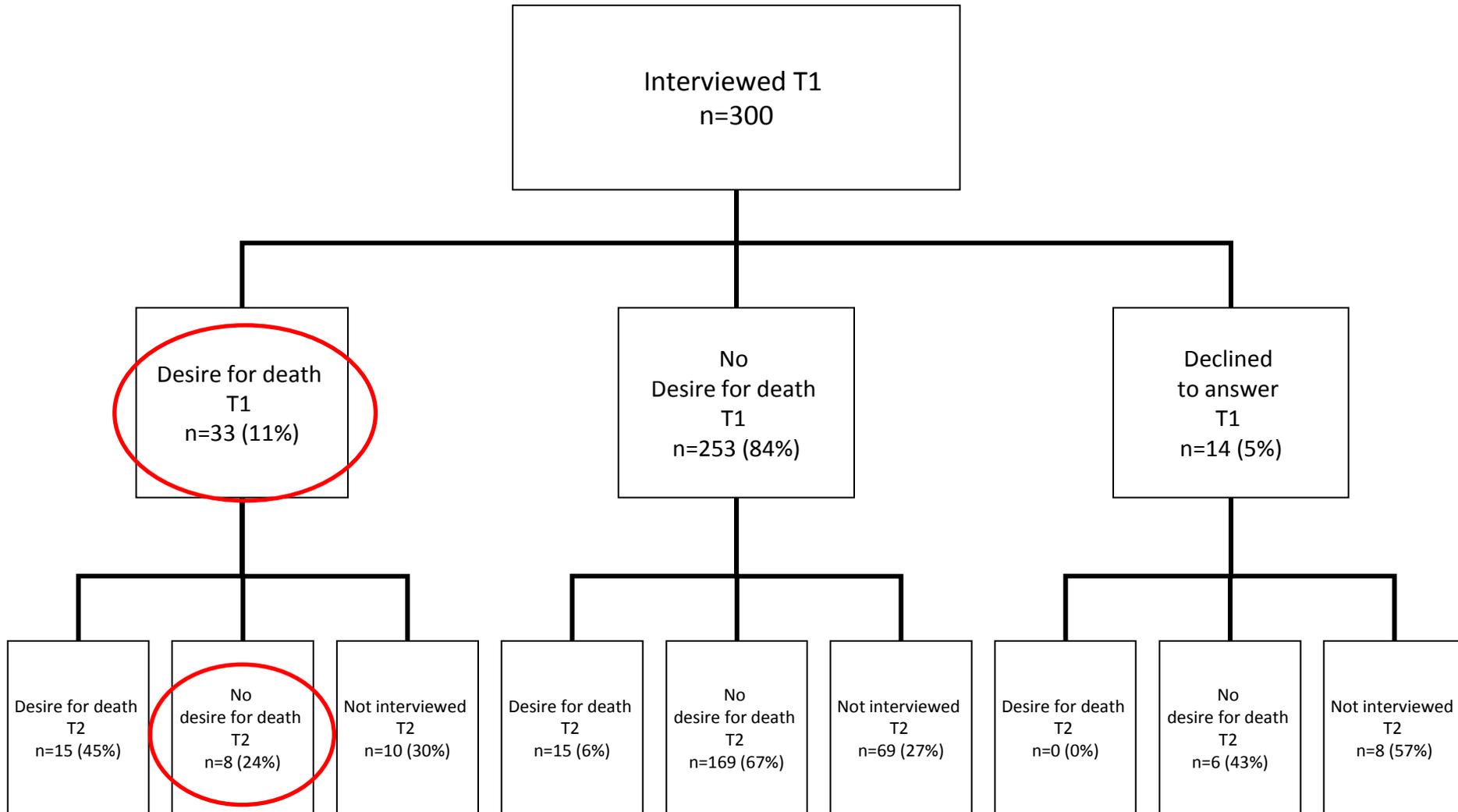
Improvements in:

- fatigue
- breathlessness
- nausea and vomiting
- loss of appetite



Remission of
depression
by T2

Prevalence & course of desire for death



Risk factors for Desire for death

- ▣ **Major depression:** (OR 4.71 95%CI 2.19-10.15)
- ▣ **Any depression:** (OR 3.85 95%CI 1.80-8.22)
- ▣ **Non-cancer:** (OR 4.15 95%CI 1.56-11.05)
- ▣ **Fatigue:** (OR 6.09 95%CI 2.53-14.67)
- ▣ **Loss of dignity:** (OR 5.05 95%CI 2.02-12.67)

No association - being close to death (< 4 weeks)
history of depression

Clinical implications: assessment

- There is an increased of depression in palliative care
 - ▣ Assessment of depressive symptoms should be routine

- Look out for patients at risk & offer extra support
 - ▣ - patients with non-cancer diagnoses
 - patients with high levels of pain or poor performance status
 - patients who express a desire for hastened death
 - gender ratio is different from other populations > males who need help with basic tasks may be particularly vulnerable

- Depression in palliative care is unstable
 - ▣ Regular reassessment and active monitoring of depressive symptoms is needed to capture changes in mood

Clinical implications: management

- High rate of remission 4 weeks after referral suggests that specialist palliative care may itself be a potent antidepressant
 - ▣ St Christopher's provides physical symptom control and psychological, social spiritual and practical support, which may have a positive impact on mood
 - ▣ The ability for good palliative care to alleviate depression suggests that patients with low mood should be referred early to specialist services for optimal support
 - ▣ Supported by RCT in NEJM (Temel et al 2010)

- Low social support is strongest predictor of non-remission
 - ▣ Assess the quality of patients relationships and facilitate communication
 - ▣ Provide extra psychosocial care; support groups/ day care etc
 - ▣ Early intervention for depression
 - ▣ Scope for developing specific social support interventions?

Wider implications

- Desire for death is unstable in this population and strongly associated with depression
 - ▣ Implications for the assisted dying debate...

- Improved access to psychological services
 - ▣ Most hospices do not have dedicated time from a psychologist/psychiatrist (Price 2006)

- Training in mental health for non-specialists
 - ▣ Evidence shows palliative care nurses can effectively deliver CBT (Moorey 2009)

- EPCRC guideline on managing depression in palliative care – www.epcrc.org



ANY QUESTIONS?

Lauren.Rayner@kcl.ac.uk

THANKS FOR LISTENING!



AMBER care bundle

23rd February 2012

Ruth Caulkin, Jonathan Koffman
& Irene Carey

Issues around end of life care in an acute setting



- Case-note review (14/20 consecutive deaths) –
 - delayed recognition of possible eolc needs and poor management of uncertainty around a patients recovery
 - Suboptimal team work and medical decision making around escalation to critical care
 - Suboptimal involvement of pt and family in decision making and planning
- *Needed something seen as "adding to" care rather than "taking away"*
- Identification tool
- Best practice

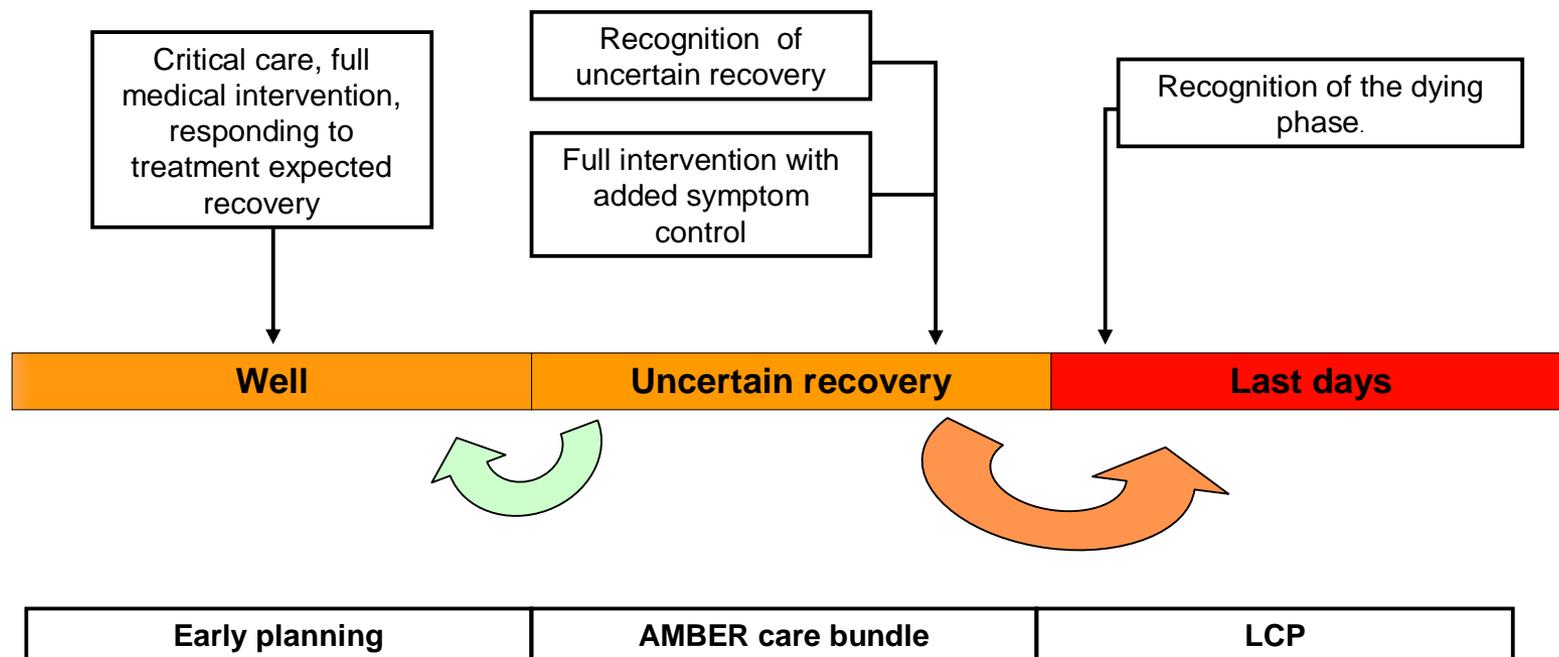
Identification questions



- 1. Is the patient deteriorating, clinically unstable and with limited reversibility?**
- 2. Is the patient at risk of dying within the next 1-2 months?**

Yes to both → proceed to AMBER

Patients whose recovery is uncertain



| | | |
|--|----------------|--|
| Patient Label | Date: Time: |  |
| <p style="background-color: #FFC000; padding: 10px; text-align: center;">Identification: Is the patient AMBER?</p> <ol style="list-style-type: none"> 1. Is the patient deteriorating, clinically unstable, and with limited reversibility? 2. Is the patient at risk of dying within the next 1-2 months? <div style="text-align: center; margin: 20px 0;">  </div> <div style="text-align: right; background-color: #E0E0E0; padding: 5px; border: 1px solid #ccc;"> Remember to apply the principles of the Mental Capacity Act (2005) </div> | | |

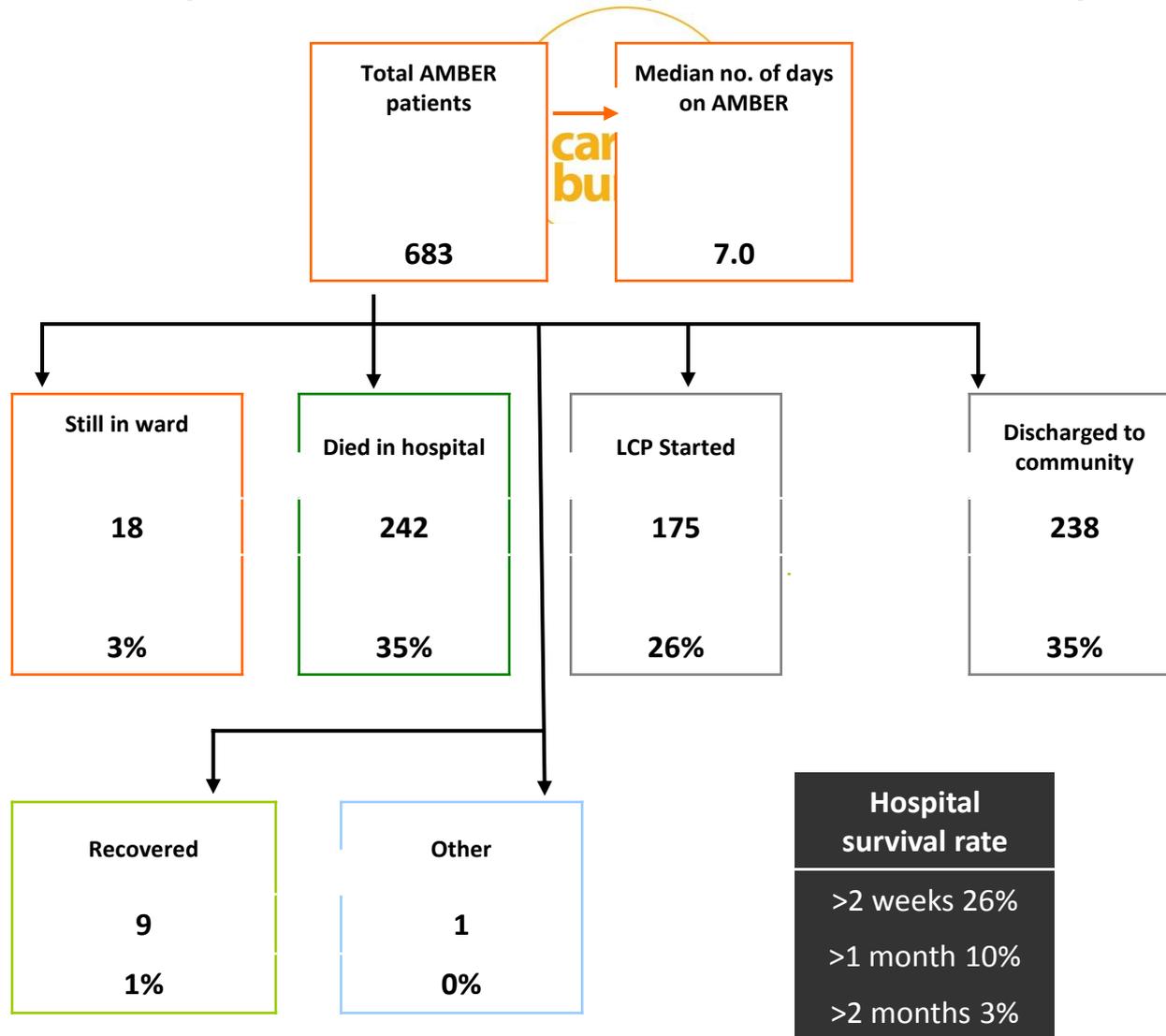
| | | ACTIVITY | ACTION | COMMENTS | NAME (Please print clearly) |
|----------------------|---------|--|--|----------|--------------------------------|
| Action within 4 hrs | Medical | Medical plan documented in patient record Including: current key issues, anticipated outcomes, resuscitation status | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| | | Escalation decision documented Including: <input type="checkbox"/> Ward only <input type="checkbox"/> Critical care | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| | | Medical plan discussed and agreed with nursing staff | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| Action within 12 hrs | Nursing | Patient ± carer discussion / meeting held and clearly documented Which may include: discussion of uncertain recovery and medical plan, preferred place of care, any concerns or wishes and who was present | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |



What it means to ward staff

- Day one: identification and initiation
- AMBER follow-up
 - A** "Is patient still **A**MBER?"
 - C** "Has medical plan **C**hanged?"
 - T** **T**ouch base with carers - Is everything OK?"

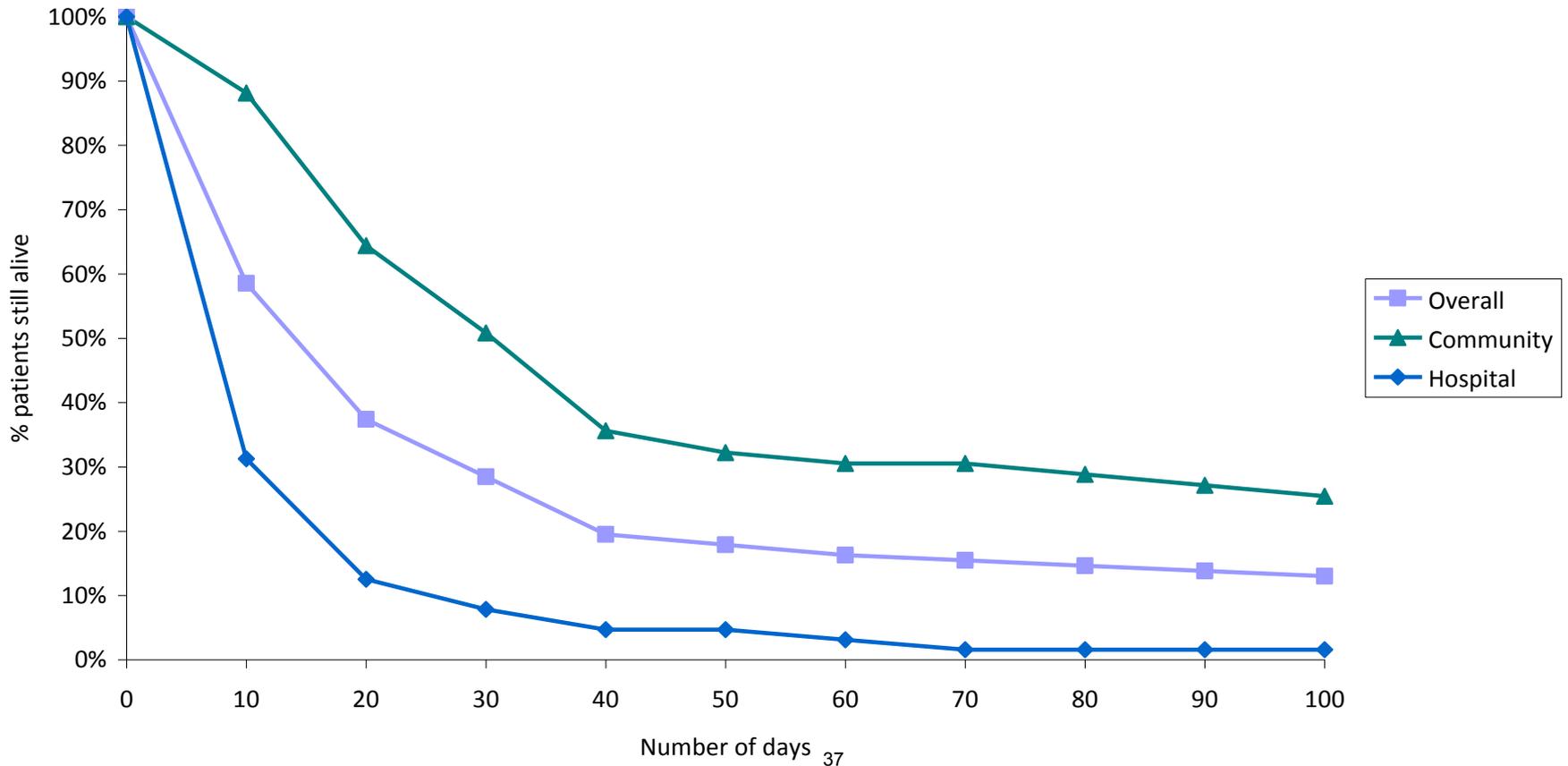
AMBER patients: 1st January '10 - 31st January '12



Hospital and community survival rates: Jan 2010-Jan 2011



Percentage Survival Rates of AMBER Patients
Jan '10 - Jan '11 (N=123)





Outcomes

Emergency readmissions (30d):
14% vs 35%*

>70% die in their preferred place of care

Preferred place of care

(Jan 2010 – 5th May 2011)



| | | Actual place of death | | | | |
|-------------------------|---------------|-----------------------|---------|------|-----------|-------|
| | | Hospital | Hospice | Home | Care Home | Other |
| Preferred place of care | Hospital | 74 | 1 | 1 | 2 | 0 |
| | Hospice | 10 | 21 | 0 | 0 | 0 |
| | Home | 21 | 5 | 25 | 2 | 1 |
| | Care Home | 4 | 0 | 0 | 1 | 0 |
| | No preference | 3 | 0 | 0 | 0 | 0 |
| | Unrecorded | 2 | 0 | 0 | 0 | 0 |

70% PPOC achieved for all patients who have died to date



The AMBER Care Bundle in the hospital: does it improve the experience of patient and family care at the end of life? A pilot study

Dr Jonathan Koffman, Dr Irene Carey, Dr
Adrian Hopper, Dr Wei Gao, Dr Sue Hall,
Dr Ruth Caulkin, Dr Wendy Prentice,
Professor Irene Higginson

Modernisation Initiative

end of life care



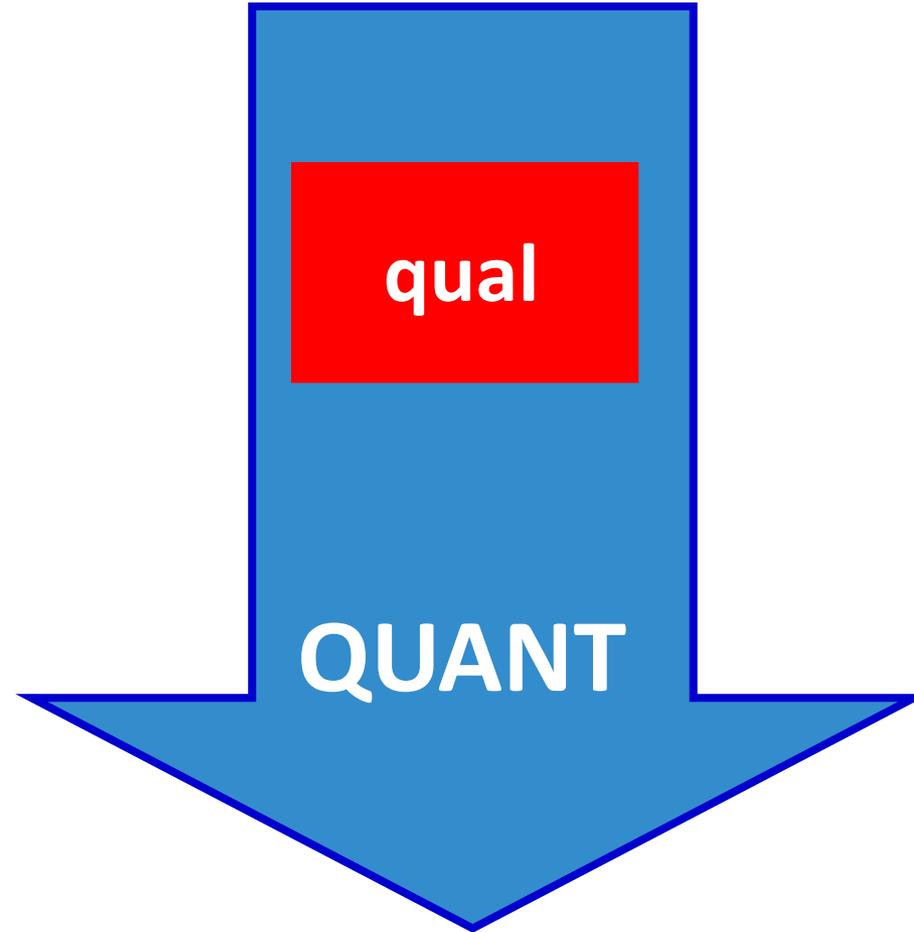
Pilot study aim

- To examine the feasibility and acceptability of the research methods used to evaluate the effectiveness of the AMBER Care bundle in improving the experience of advanced disease among patients and their informal caregiver where recovery is uncertain in an acute hospital setting

Concurrent 'nested' research design



- Primary purpose to gain broader perspectives than achieved by using predominant method alone
- 'Embedded' method (given less priority) addresses different questions than dominant method/ seeks different information



QUALYCARE RECRUITMENT PROCESS

AMBER Pts
GSTT/KCH

Death in
Hospital

Questionnaire sent
to relative/friend

Death after
discharge in
≤ 100 days

Death identified from
EPR/GP records

Questionnaire sent
to relative/friend

CONTROL Pts
KCH

Death in
Hospital

All hospital deaths to be
identified from:
- monthly mortality data
- EDLs/EPR

Exclude:

- Pts on AMBER wards
- Pts on Critical Care
- Sudden unexpected death
- Death related to
accident/violence/OD/Suicide

Send Questionnaire to the
relative/friend of all remaining
Pts that have died
(Oversample)

Match controls to AMBER
patients from Demographic
data in EDL/Questionnaire

Death after
discharge in
≤ 100 days

Death identified from
EPR

Exclude:

- Pts on AMBER Wards
- Pts on Critical care
- Sudden unexpected death
- Death related to
accident/violence/OD/Suicide

Send Questionnaire to the
relative/friend of all remaining
Pts that have died
(Oversample)

Match controls to AMBER
patients from Demographic
data in EDL/Questionnaire

Data collection



Study Id

Reference: 12/LO/0043 Version 1.0 15.12.11



The AMBER Care Bundle Study

This survey asks for **your** views and experiences of the care received by your relative or friend towards the end of his/her life. This information will help improve care for other patients and families in the future.

We realise there are a lot of questions to answer, but it would help a great deal if you could try to complete all the pages. We really appreciate your willingness to take the time and trouble to help.



Thank you very much for your time to answer these questions!

*The AMBER Care Bundle Study
Copyright © 2011 King's College London. All rights reserved.*

Some important instructions before you start...

1. Most of the questions can be answered simply by ticking the box next to the answer that best applies. Don't worry if you make a mistake; just cross out the mistake and tick the correct answer.
2. Usually, after answering a question, you should go on to the next one. Sometimes there will be an instruction telling you which question to answer next.
3. Sometimes you are asked to answer in your own words. Please write in the space provided and if necessary use the blank sheet at the end of the questionnaire.

Although the questionnaire may look long, by following the instructions you will miss out questions which do not apply saving you valuable time.

4. If you cannot remember, do not know, or are unable to answer a particular question, please write that in.
5. The information you give us is completely confidential and will not be used in any way that could identify you or your relative or friend personally.
5. The information you give us is confidential and will not be used in any way that could identify you or your relative or friend personally.

44

- Qualitative interviews with AMBER Care Bundle patients, their relatives and staff **(and those on control wards)**
- Non-participant ward-based observations of HCP and patient interactions

Examples of questions to relatives or close friends



28. Looking back, do you remember receiving information on a day-to-day basis that helped you understand the reasons for the care he/she received?

Yes, most of the time..... ₁

Sometimes..... ₂

No, not at all ₃

29. Looking back, did you receive consistent information about his/her condition?

Yes, most of the time..... ₁

Sometimes..... ₂

No, not at all ₃

30. Looking back, do you recall any delays in receiving information about him/her?

Yes, most of the time..... ₁

Sometimes..... ₂

No, not at all ₃

31. Looking back, do you feel you knew what to expect about his/her condition?

Yes, most of the time..... ₁

Sometimes..... ₂

No, not at all ₃

Face-to-face interviews: Examples of questions to patients



- *I'd like to explore with you to what extent you and your family has felt involved in making important decisions about your care and treatment.*
- *In what ways do you feel confident about the care and treatment the doctors and nurse have given you? Probe for examples and areas where participant does not feel confident, and why.*
- *Do you feel that the doctors, nurses and other health professionals (e.g. Physio, OT) worked well together? Give examples if possible.*



End of life care in care homes

Jo Hockley RN PhD MSc SCM

Nurse Consultant

Care Home Project & Research Team

St Christopher's Hospice



Care Home Project & Research Team

Practice Development

4.5 FTE (incl NC) + PA

- GSFCH – NHs
- Steps to Success in end of life care (DH 2010) - RCHs

Research & Audit

3.5FTE (incl NC) + *volunteers*

- NH last month of life 'drug audit'
- CRCT – facilitation of the GSFCH
- NAMASTE CARE programme for people with very advance dementia



Baseline review of medication provided to older people in NHs in last month of life (Kinley & Hockley 2010)

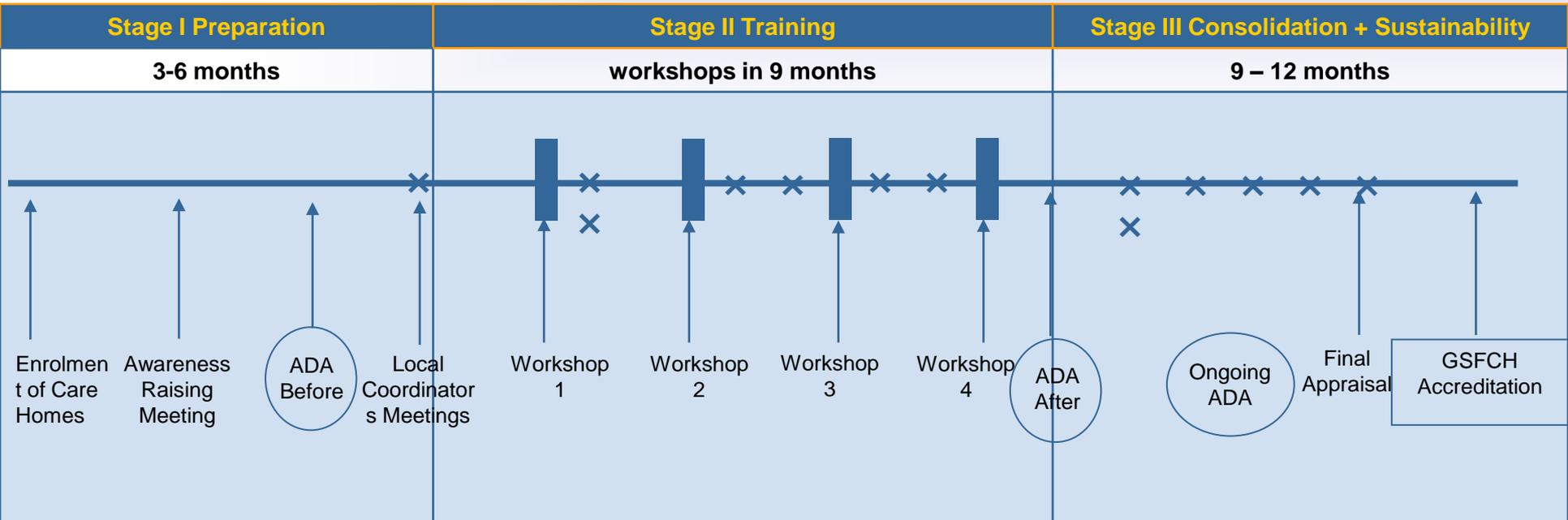
Across 7 NHs across one PCT:

- Retrospective review of notes of 48 deceased residents
 - 11/48 had medication via a s/driver
 - 8/11 had medication via s/driver for 1.5 days or less
- Questionnaire to 67 trained nurses (72% return rate)
 - 77% nurses had looked after resident with a s/driver
 - Competency of using a s/driver evaluated through a simple scenario
 - 33% could calculate the right dose
- **Conclusion:**
 - s/drivers may not be most appropriate way of administering end of life medications for very frail older people in NHs



St Christopher's regional training centre for the GSFCH programme

Preparation, training and consolidation + accreditation



Comparison of data on deaths in nursing homes – 2007 to 2011

| | 2007/2008 | 2008/2009 | 2009/2010 | 2010/2011 |
|--------------------------|--|---|--|---|
| | Percentage of deaths occurring in NHs [numbers of deaths] | | | |
| PCT 1 | 57% [34 / 59 deaths – across 4 NHs] | 63% 82 / 131 – across 7 NHs] | 62% [72 / 117 deaths – across 7 NHs] | 72% [157/218 deaths across 13 NHs] |
| PCT 2 & 3 | 57% [41 / 75 deaths – across 3 NHs] | 59% 121 / 204 deaths – across 8 NHs | 67% [136 / 204 deaths – across 8 NHs] | 72% [234/325 deaths across 14 NHs] |
| PCT 4 | 55% [63 / 115 deaths – across 8NHs] | 66% [248 / 375 deaths – across 23 NHs] | 71% [341 / 477 deaths across 23 NHs] | 76% [331/435 deaths across 25 NHs] |
| PCT 5 | 61% [46 / 75 deaths – across 4 NHs] | 76% [212 / 279 deaths – across 14 NHs] | 81% [220 / 273 deaths – across 16 NHs] | 86% [341/397 deaths across 19 NHs] |
| TOTALS | 57% [184 / 324 deaths – across 19 NHs] | 67% [663 / 989 deaths – across 52 NHs] | 72% [769 / 1071 deaths – across 53 NHs] | 76% [1063/1375 deaths across 71 NHs] |



Information and Resource Pack for Residential Care Homes



Adapted from the
NHS National End of Life Care Programme:
**The route to success in end of life care
- achieving quality end of life
care in care homes**

There are those who look at things the way they are, and ask why... I dream of things that never were, and ask why not?"

Overall work with nursing/care homes across 5 PCTs

| | NHs: GSFCH | RHs: EoLC programme: “Steps to Success” |
|----------------------|---|---|
| PCT 1 | 10/11 NHs completed GSFCH GSFCH Accredited: 3/10 (30%) | PILOT [2 RCHs] 9/9 RCHs 2011/12 |
| PCT 2 & 3 | 14/16 NHs completed GSFCH GSFCH Accredited: 8/16 (50%) | Applied for funding 10/10 RCHs ?? 2012 |
| PCT 4 | 24/25 NHs completed GSFCH GSFCH Accredited: 16/24 (67%) | 4/27 RCHs 2012 |
| PCT 5 | 18/21 NHs completed GSFCH GSFCH Accredited: 7/18 (39%) | Need to find funding source 0/29 RCHs |
| TOTALS | 66/73 NHs completed GSFCH GSFCH Accredited: 34/66 NHs (52%) | No accreditation procedure OUTCOMES include: AUDIT data + Family Perception of Care |

Examining the effect of ‘high facilitation’ when
implementing GSFCH – CRCT
38 NHs

CLUSTER 1
(Intervention 1)
12 NCHs receiving
GSFCH ‘high’
facilitation +AL (NHMs)

CLUSTER 2
(Intervention 2)
11 NCHs receiving
GSFCH
‘high’ facilitation

CLUSTER 3
(Observational)
15 NCHs
receiving GSFCH
‘low’ facilitation

23 NCHs randomised from within St Christopher’s
catchment area [LSL, Bromley, Croydon]

15 NCHs to act as an
‘observational’ group from
outside St Christopher’s
catchment area

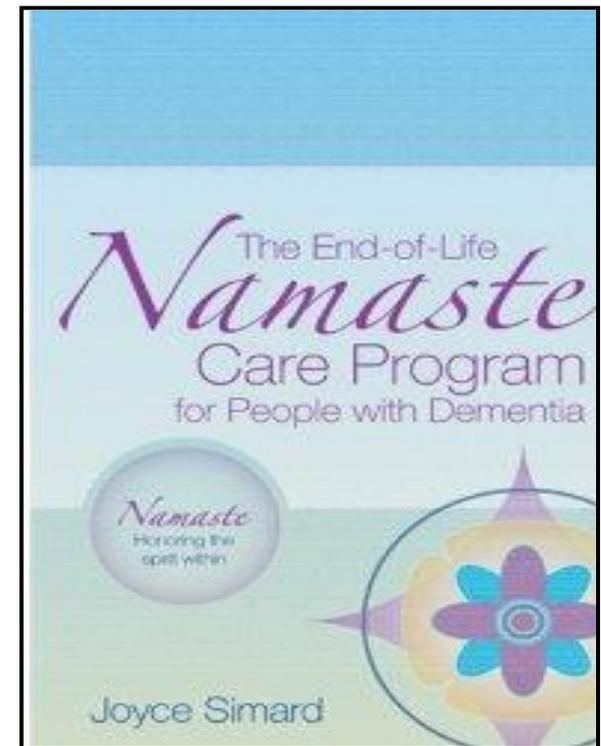


Outcome data – all collected

- Examined deceased residents notes (2,447) for last 6 months of life reviewing:
 - Medication, length of stay in NH, diagnosis, hospital visits, place & type of deaths, primary care involvement
- Staff teamwork
- Bereaved families
 - Voices 6mths (pre) + 6mths (post)
 - Family Perception of Care – 12 months

NAMASTE CARE programme

- Action Evaluation
 - Ethics & R&D approval
 - Commenced February 15th '12
 - 1yr project
 - 6 NHs
 - 2 SLaM care homes
 - 4 private NHs (EMI)





References

- Hockley J et al (2010) The integrated implementation of two end of life care tools in nursing care homes in the UK: an in-depth evaluation
- Kinley J & Hockley J (2010) A baseline review of medication provided to older people in nursing care homes in the last month of life. *IJPN*, Vol 16 (5): 216-223
- Froggatt J & Hockley J (2011) Participatory frameworks for evaluation: an action research perspective. *Palliative Medicine*, 25 (6)
- Kinley J et al (2012) The effect of policy on end of life care practice within nursing care homes: a systematic review. *Palliative Medicine* (on-line February 17, 2012)

Knowledge Exchange Seminar

Dr Joy Ross

Consultant Palliative Medicine
Royal Marsden and Royal Brompton Palliative Care Service
Honorary Clinical Senior Lecturer, Imperial College



A clinical service that coordinates care giving patients choice and improved quality of life

Outline

- Background
 - H2H
 - National End of Life Care Programme
 - EoLC register pilots
- What is CMC
- Data from Sutton and Merton
 - Challenges





Hospital 2Home

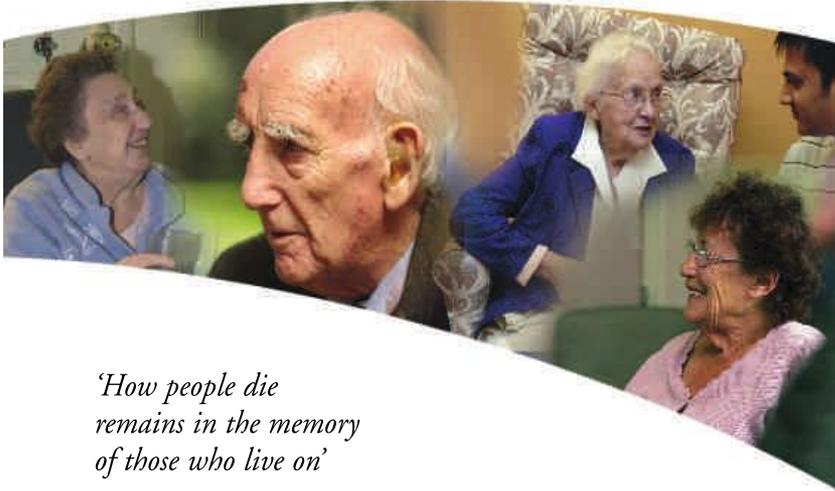


| Documentation of Care Package |
|-------------------------------|
| Medical |
| Nursing |
| Social services |
| Financial |
| Spiritual |
| Occupational Therapy |
| Physiotherapy |
| Carer support |
| DNAR |

86%
patients die
in PPD
(>400)

End of Life Care Strategy

Promoting high quality care for all adults at the end of life



*'How people die
remains in the memory
of those who live on'*

Dame Cicely Saunders
Founder of the Modern Hospice Movement

July 2008

'Nothing about me without me'

"Establishing a locality-wide register for those approaching the end of life"

8 DH Electronic Locality Register Pilots were awarded

- 18 months: Royal Marsden (DH), Camden (DH) and NHS Richmond (independent)



Raising awareness of dying, death and bereavement

Find Your 1% - helping GPs deliver quality end of life care

Most people are spending their final days in hospital, when they would rather be at home. Join the 'Find Your 1% QIPP campaign' to help you identify the 1% of your patients at the end of life and give them a better death at lower cost to us all.



Providing a good death

Everything you need to know about the Find Your 1% campaign



How to identify patients at the end of life

Essential tools to help you identify patients in the last 6-12 months of life



Having the conversation

Telling someone they are going to die is never easy. These resources can help



How to help your patients plan

Advance care planning is vital to ensuring end of life wishes are met



Supporting carers to cope

The right support for the carer and the patient can help ease their journey



Useful resources

A wealth of links to high quality education materials for end of life care



The recommendation is that PCTs/CCGs create locality-wide registers for people approaching the end of life so that they can receive priority care

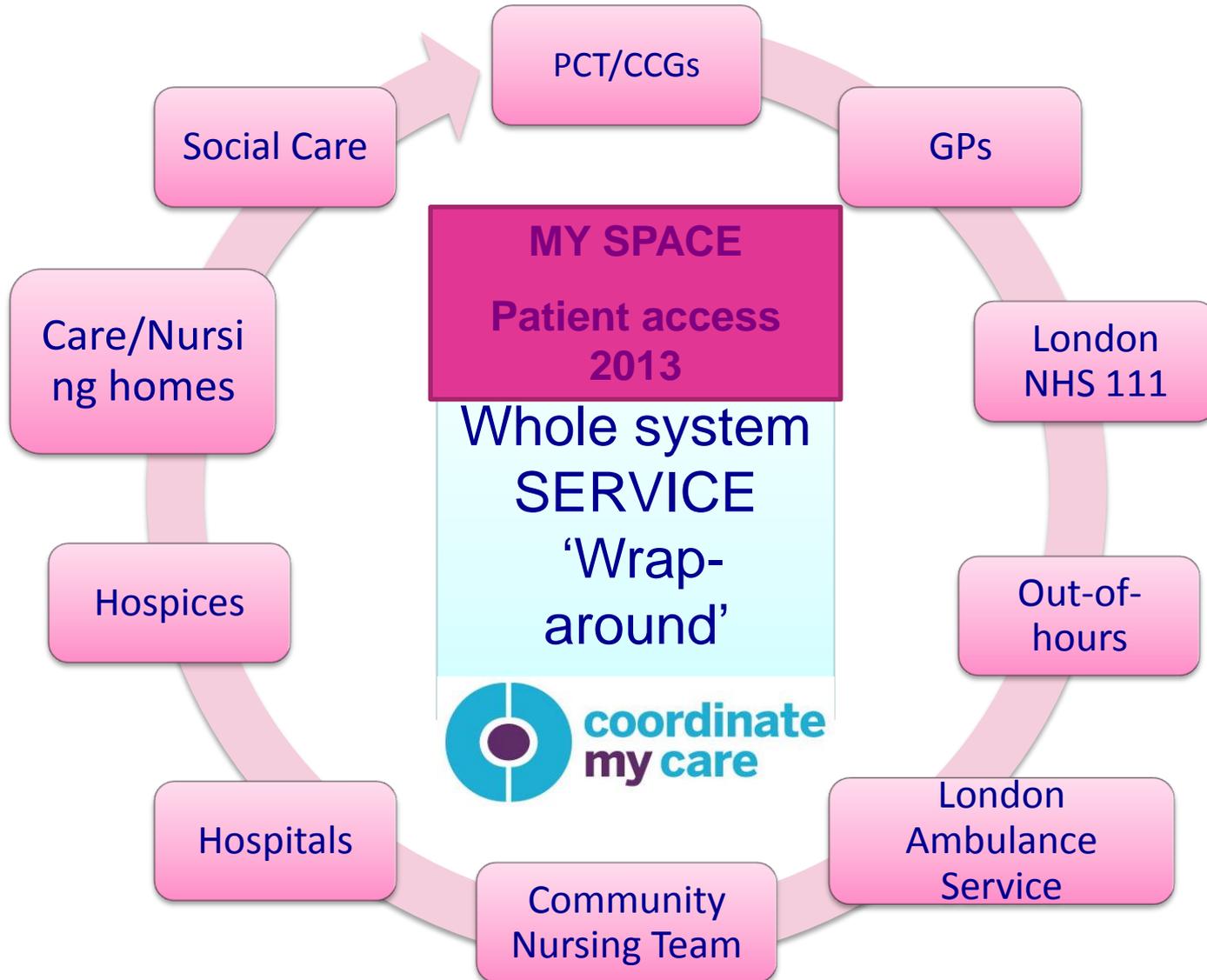
CMC is a service which

- encourages patient choice
- is dedicated to preserving dignity and autonomy at the end of life
- is a care pathway that enables health professionals from primary, secondary and community care to put the patient at the centre of health care delivery
- is designed to facilitate and strengthen communication across care settings
- enables health resources to be used in a more cost effective way
- is integrated with 111 service delivery

Comprehensive service delivery tool including clinical training, IT solution and supporting documentation



What is Coordinate My Care



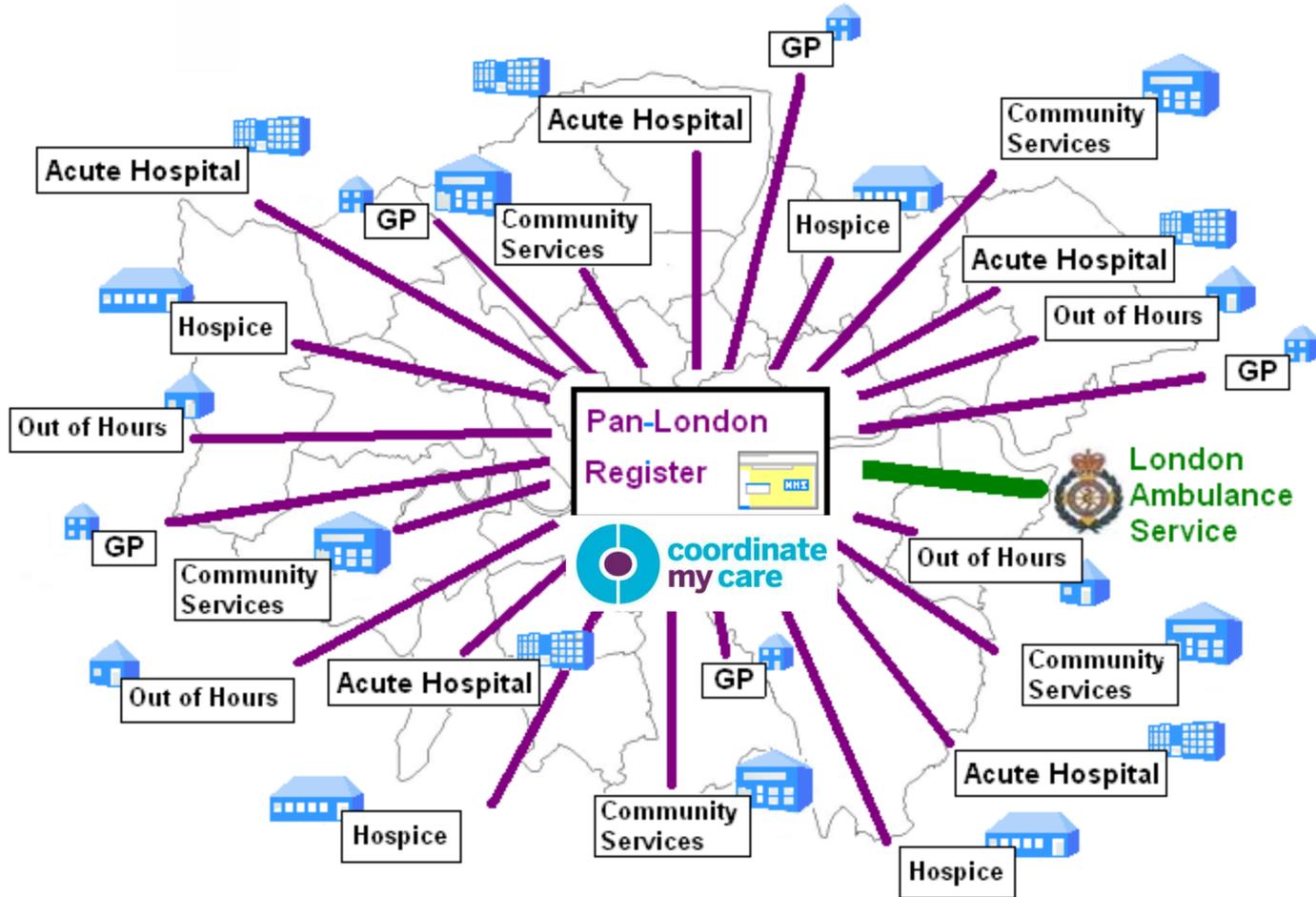
The CMC service is supported by an electronic register (disruptive technology)

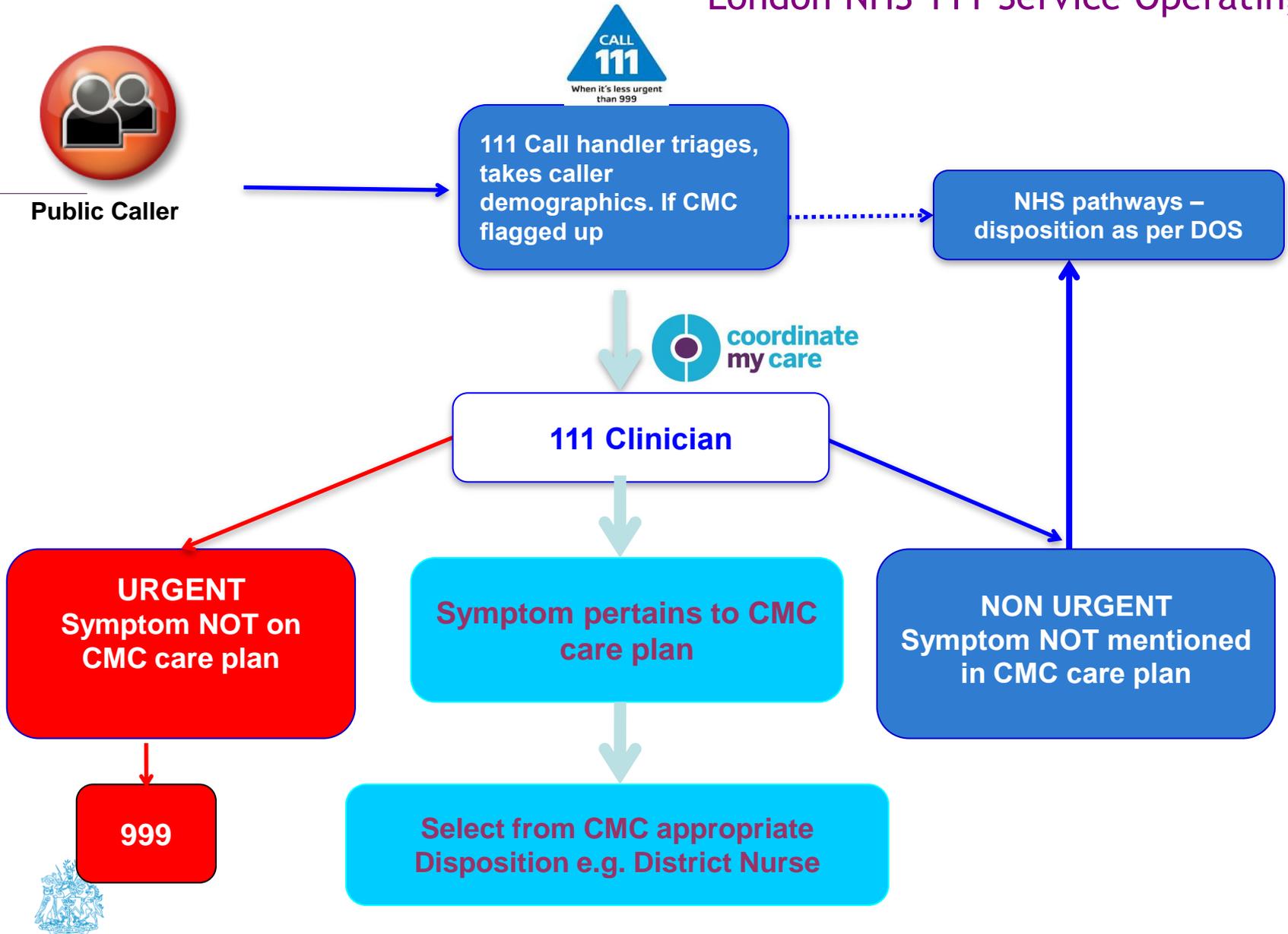


-
-
- cross all care settings (health and social care) 24/7
- Contemporaneous and easy to update
- Streamlines care - current & advanced care plans
- Interoperable with LAS and 111
- Information governance (detailed program, in line with 111 and LAS)
- Decreases hospital admissions
- LIVE - currently in use



What is Coordinate My Care





| Metastatic cancer of Lung @ home |
|----------------------------------|
| ACP + CMC |
| PAIN - clear instructions |
| GP |
| LAS |
| discussion as per CMC |
| no ambulance |
| District nurse |
| Syringe driver |
| Dies PPD |

| Dementia @ nursing home |
|----------------------------------|
| ACP + CMC |
| FALL - clear instructions |
| LAS |
| laceration |
| A&E |
| Hospice |
| Died PPD |



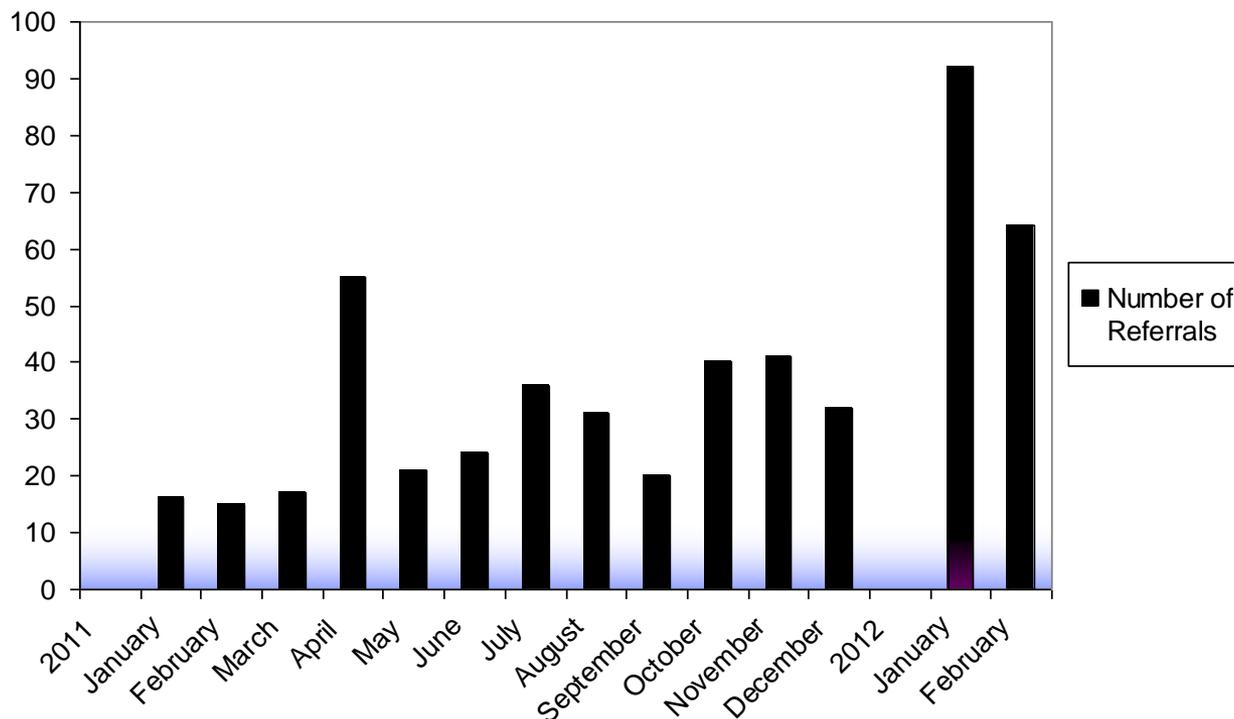
High quality care, right time, right place, less cost

The ROYAL MARSDEN

NHS Foundation Trust

Sutton & Merton Data

Monthly Referrals in Sutton & Merton Since January 2011



2011 348

January 16

February 15

March 17

April 55

May 21

June 24

July 36

August 31

September 20

October 40

November 41

December 32

2012 156

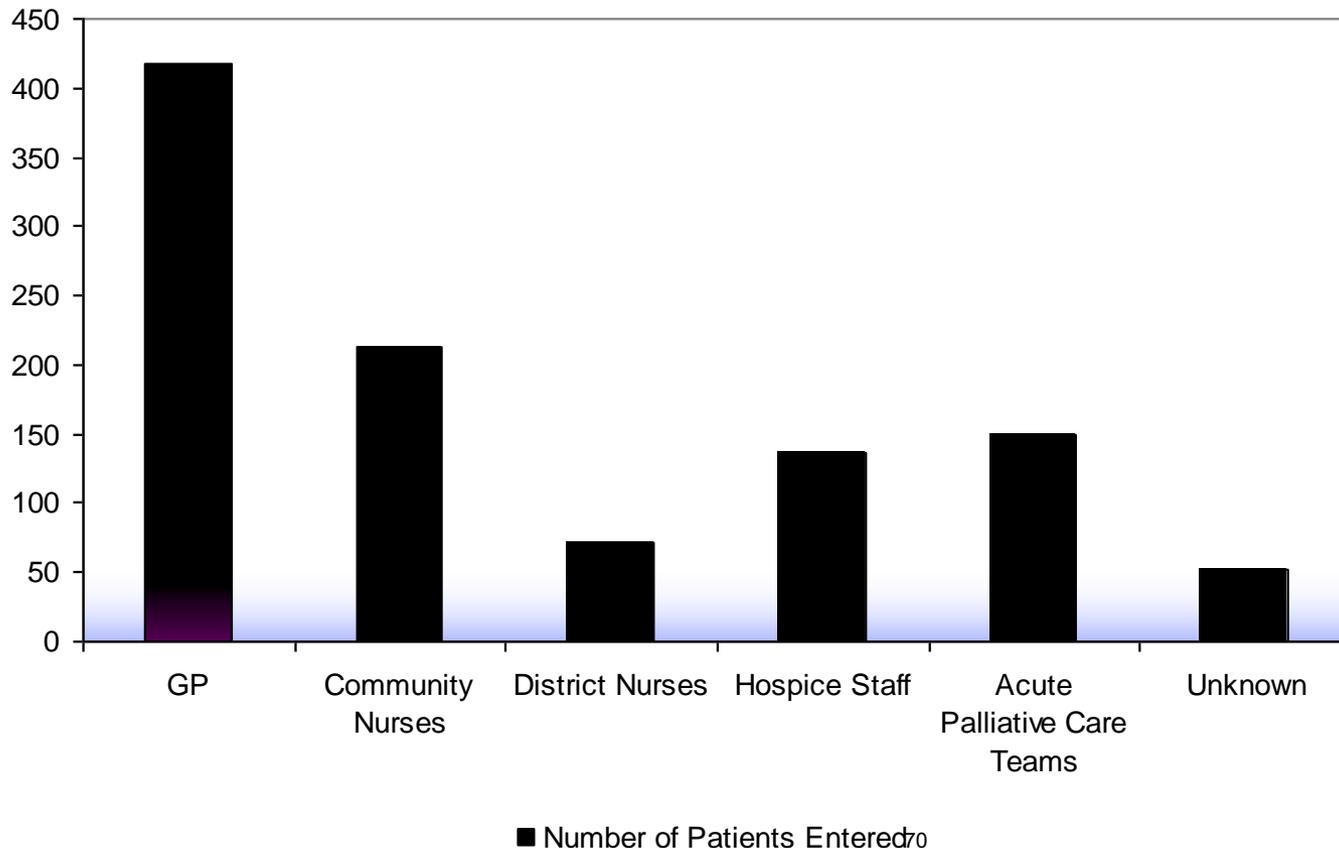
January 92

February 64



Patients entered onto system by different professional groups

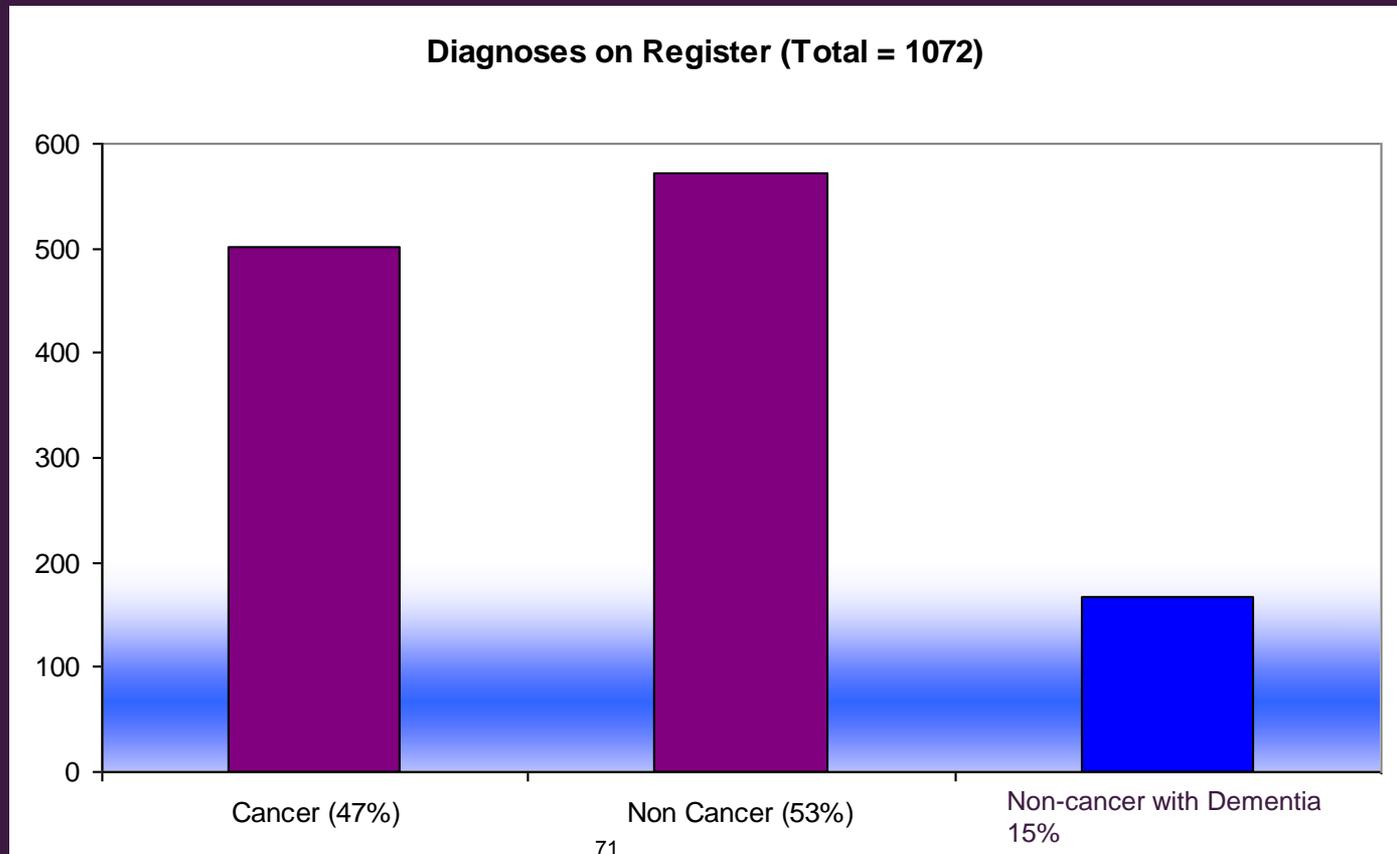
Professional Group Entering Information



Professional Group Entering Information

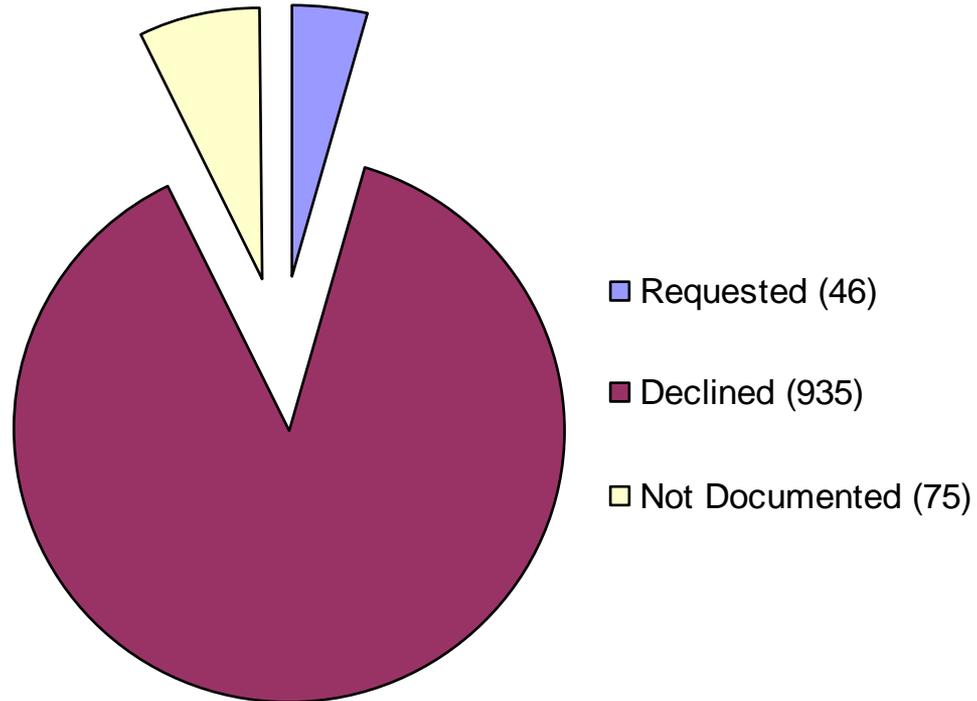
| | |
|-----------------------------|-----|
| GP | 418 |
| Community Nurses | 213 |
| District Nurses | 72 |
| Hospice Staff | 136 |
| Acute Palliative Care Teams | 149 |
| Unknown | 52 |

Numbers of diagnoses – cancer/non-cancer/dementia



Number of requests for hard copy information

Requests for Hard Copy of Register Information



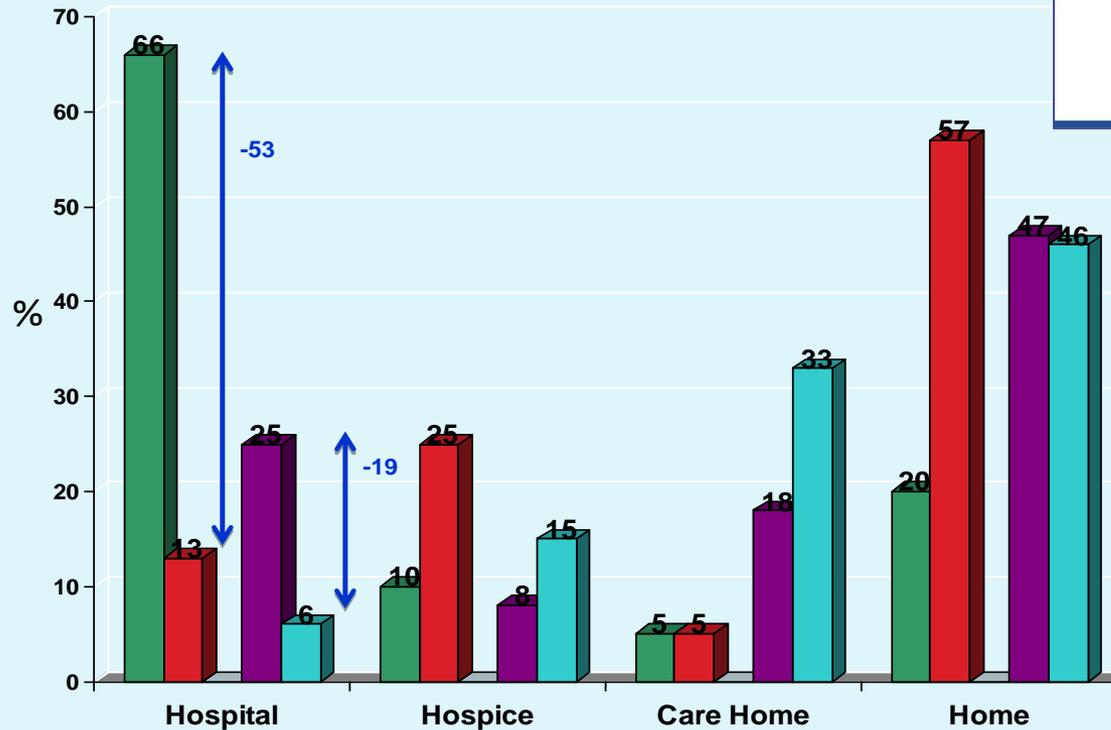
| - | PPC | PPD |
|-----------|-----|-----|
| Home | 243 | 156 |
| Hospice | 31 | 75 |
| Care home | 99 | 95 |
| Hospital | 5 | 5 |
| Other | 11 | 15 |
| Undecided | 43 | 86 |

- 55% of patients known to hospice team
- 103/440 (23.8%) died
- Median time to death 20 days (range 0-421 days)
- 74% achieved first PPD
- 19 pts hospital death (3 had chosen as PPD)

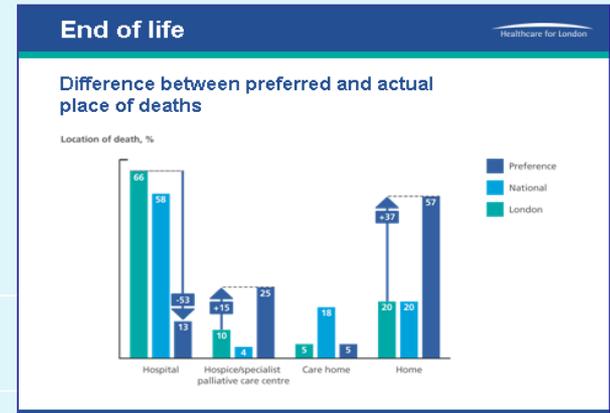


Evidence from pilot suggests a turnaround in preference
 therefore financial savings can be made

Comparing CMC with other data



Actual v. preferred place of death



- London actual
- Nat Pref
- CMC actual
- CMC Pref



Financial analysis – London wide savings with CMC

Across London the potential annual saving is £16.3M

This is based on a minimum 10% admission reduction

Evidence from the pilot indicates use of CMC achieves a 40% reduction in admission rates

This would mean an estimated **£65M** annual saving across London alone





A clinical service that coordinates care giving patients choice and improved quality of life

Any Questions ?

Acknowledgements: Dr Julia Riley and CMC Team

Contact Telephone Number: 02078118513

Contact Email: cmc.rmh.nhs.uk

