Hospital2Home:

Electronic information sharing across acute and community services enabling patients to die at home

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1 Background: Across the UK, most patients prefer to die at home if given the choice

Current challenges

Marie Curie Cancer Care, one of the UK's largest charities, conducted a survey of the general public in 2004 regarding their views about dying at home:

64% of patients preferred to die at home, yet 49% die in hospital

In fact, in London, 66% of patients die in hospital[1]

Only 4% of patients die in hospice[1]

Furthermore, care for patients in the last fortnight of life in hospital costs 40% more than care in the community[2]

The UK National Audit Office estimates 5% total savings in cancer care nationally by redistributing hospital costs to the community

Palliative care outside the hospital costs less and is preferred by patients

54% of all patient complaints in the NHS[3] are about end of life care

1 From national NHS data
2 From Marie Curie and NHS data
3 As submitted to the Care Quality Commission

1 There are three main types of challenges which make it difficult to shift palliative care into the home

Challenge	Details
Structural	• Lack of integration between health and social services and a single contact point to coordinate care • Variations in average spend on specialist palliative care across Primary Care Trusts PCTs (£154 to £1,684 per death) • Absence of 24-hour response services and timely access to advice, medication, and medical equipment
Practical obstacles from patient perspective	• Constraints of time and physical effort this would put on family and friends • No available necessary medical facilities at home • Lack of available nursing care
Provider/staff obstacles	• Lack of end-of-life care training for nurses and doctors • Difficulty in having end-of-life care conversations with patients • Low confidence among providers in identifying point when end-of-life care should begin

2 Initiative details: Palliative care training and information sharing through electronic records is at the core of the program's approach

Royal Marsden's overall approach

Training of hospital consultants

Training consultants on how to recognize end of life care patients and how to break the bad news

Hiring and training of Hospital2Home clinical nurse specialists

Clear definition of roles and extensive training of Hospital2Home nurses. Care plan training (including anticipatory problems) + matching services to care plan.

Implementation and training on electronic care records across all relevant providers

- Collaboration across the sectors
- Training on data entry – simple and effective
- In particular, training on discussions around the issues prior to uploading data is significant (e.g., consent to register)

2 The programme's success largely lies in developing a care plan with the patient which is available to all relevant care providers

Clear process for all palliative care patients

	Patient referral	Assessment of patient	Care Conference	Handover to GP
Task	• Physicians and nurses determine if patients have reached end of treatment	• Nurse specialist assesses patient's needs in the community and sets up care conference	• Draws up a patient care plan with agreement of all parties	• Nurse emails discharge summary, care plan, and ambulance form to GP
Resources	• All physicians and nurse specialists trained for the H2H initiative	• Nurse specialist	• Patient plus family/friend, nurse specialist, GP/other community staff, social services	• Nurse specialist, GP

2 The patient care plan is developed at the case conference, where all stakeholders decide together how the patient's needs will be managed in the community

Case conference

- Nurse specialist leads conference where a care plan is developed to ensure patient's wishes to die in a preferred location are carried out
- The document is agreed among patient, nurse, and GP/other community staff
- Each stakeholder knows their specific role in the patient's end-of-life journey

Illustrative care plan

Current issues	What to do	Who to contact
• Dysphasia	• Give X medication of X dose kept in X location	• Could be GP, district nurse, out-of-hours GPs or ambulance
Anticipated problems		• Where to re-route patient (e.g., hospice) should they deteriorate further beyond home care facilities
• Haemoptysis • Bone pain • Liver pain • Constipation • Renal failure • Fatigue		

3 Patient EOLC Record is accessible to all relevant providers through a single, centrally-accessible information system

GP produces and uploads Patient's End of Life Care record

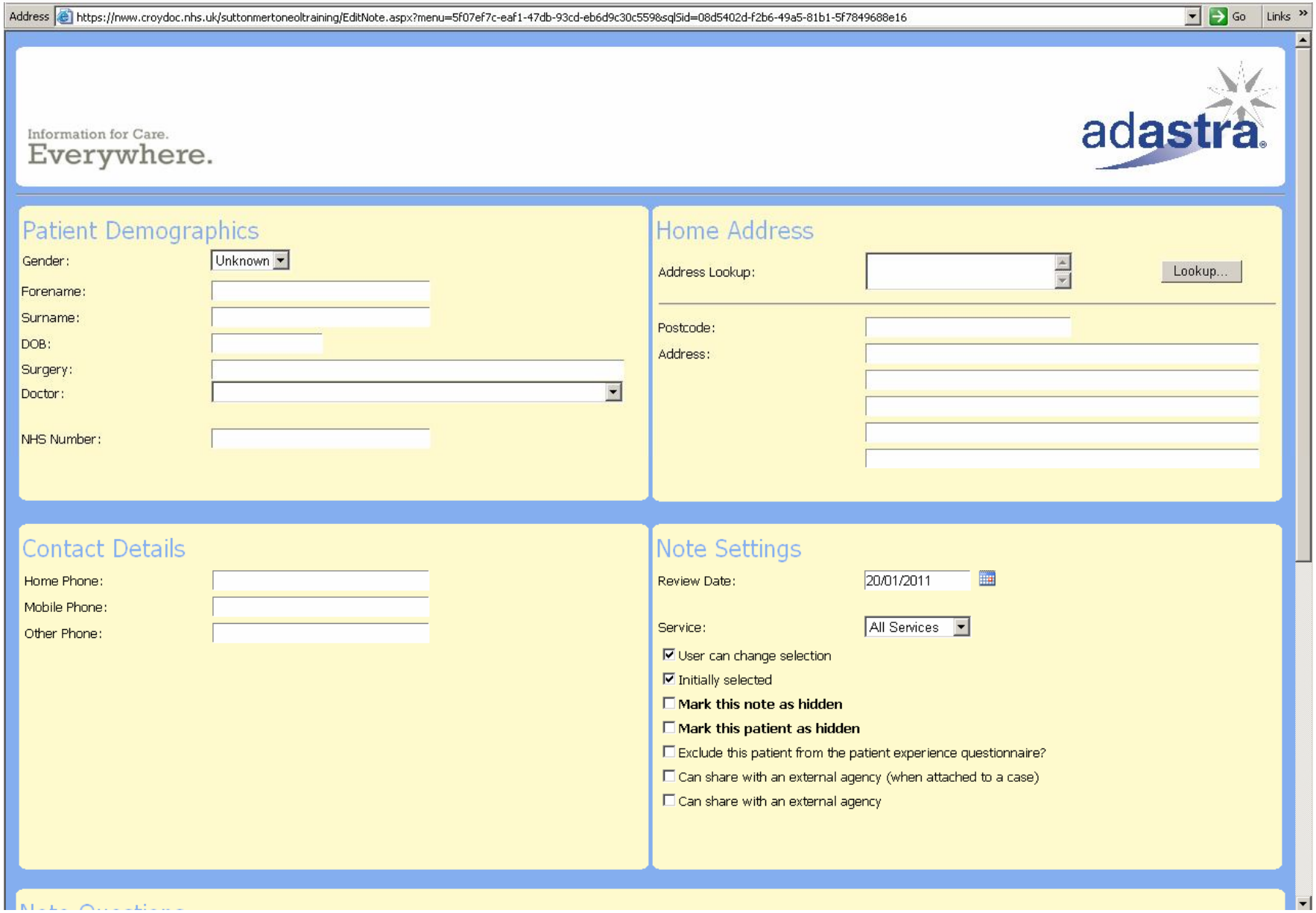
The information system

- Centrally-accessible system for all providers

- Royal Marsden has, over 4 years, developed a clinical data set agreed by multiple stakeholders including the London Ambulance Service (successfully used in paper version)
- System relies on specific software procured for London only, so not accessible outside this boundary
- Bespoke system developed for the Royal Marsden Hospital Pilot by ADASTRA (software)

- **Hospice**
- **Ambulance**
- **Patient**
- **Equipment supplier and other community staff**

3 Walking through the electronic record system



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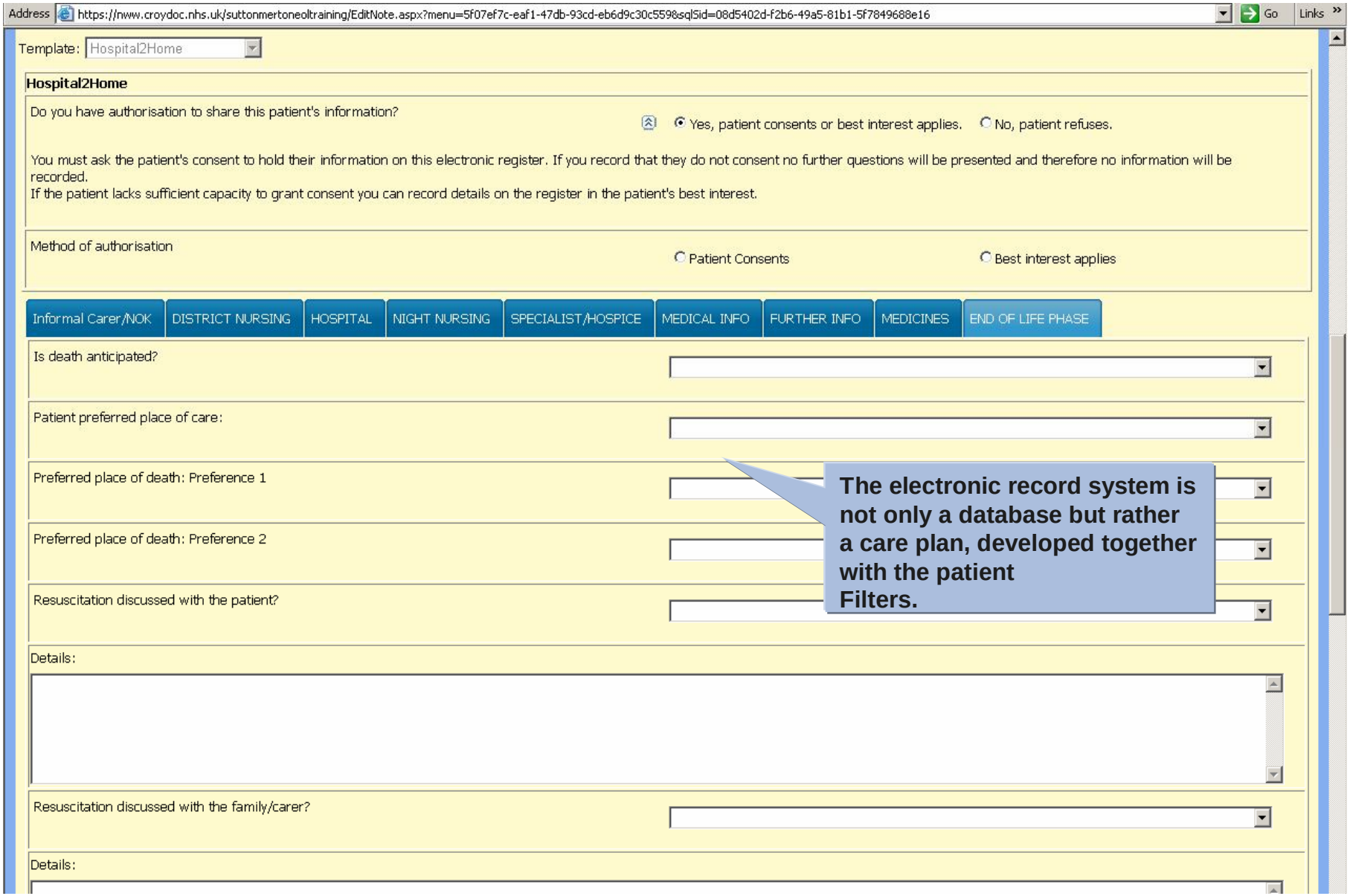
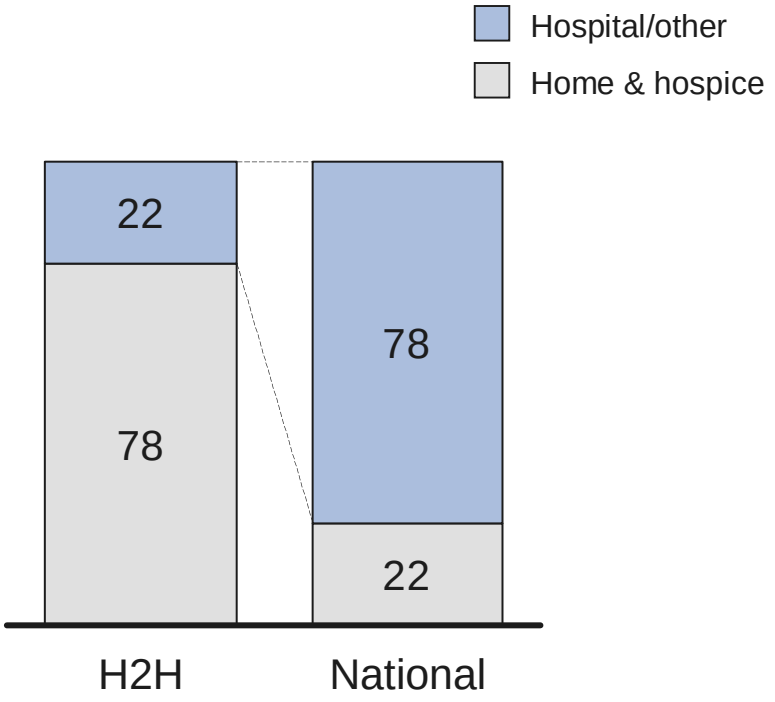


4 Impact: The Hospital2Home programme has increased the number of people who die in preferred place of death

H2H Impact

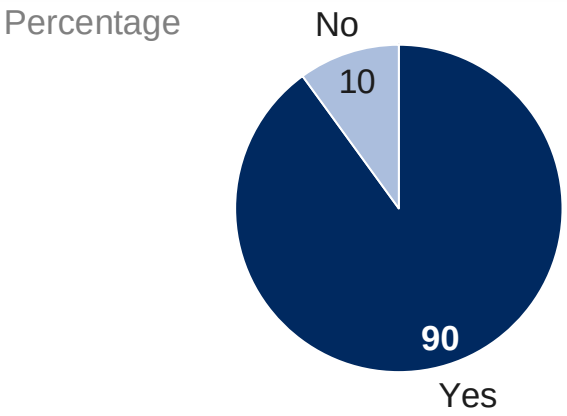
Since it's inception in 2007, H2H programme has **increased the number of people dying in preferred place of death from 39% to 78%** compared to only 22% nationally

Percentage by place of death, 2009



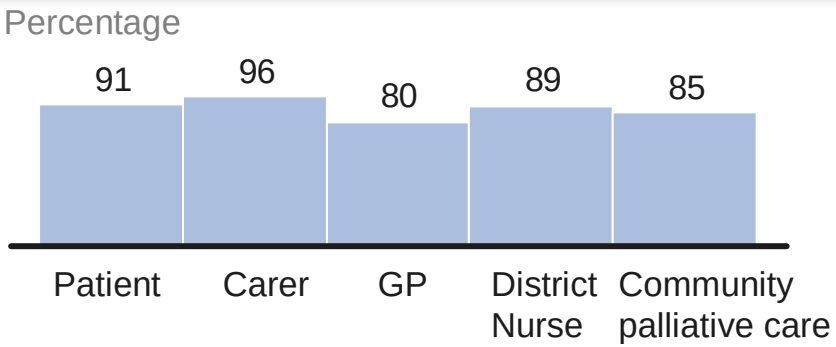
4 Most recent data from H2H suggests of all patients who had a preferred place of death document, 85% died in their preferred place of death

Of those who have died, was a Preferred place of death documented (PPD)?



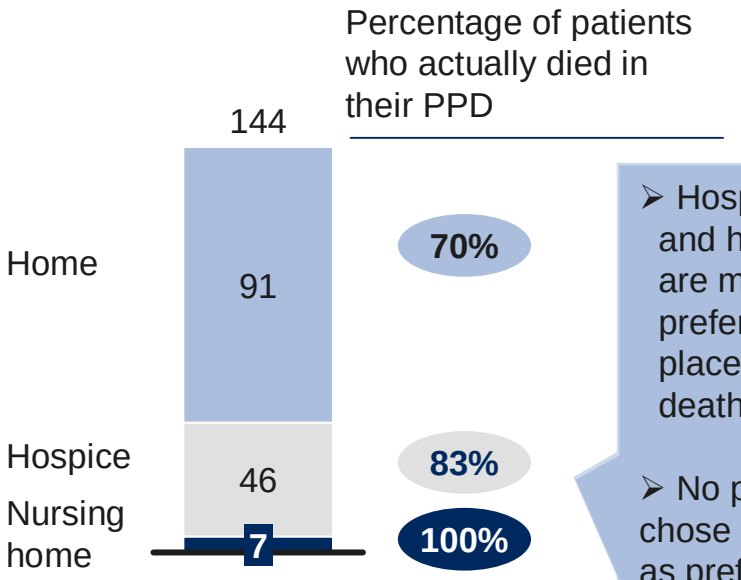
Even when patients know they are dying, some still won't want to talk about it

People present at case conference



Physician engagement is possible, but how it is presented to physicians is important

Analysis of patients who documented PPD (N=144)



- Hospice and homes are most preferred places of death
- No patients chose hospital as preferred place of death

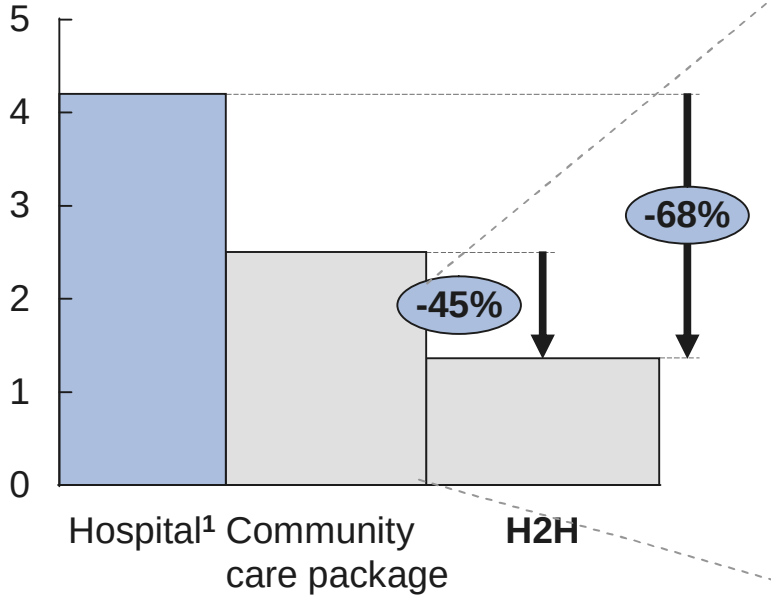
- Average case conference time: 53 minutes
- Time at home from case conference to death: 27 days median

SOURCE: Hospital2Home data July 2010 (unpublished)

4 Preliminary costing analysis suggests that H2H is cheaper than hospital care and the Marie Curie community care package for cancer

WORK IN PROGRESS

Cost of cancer patient for last fortnight of life



H2H care package[2]

- District Nurse, GP, Community Palliative Care Nurse, Hospital2Home Nurse: £752.24 for care conference
- £611.93 for nursing care (~1 visit per day for district nurse, 2 visits per day for carers), including cost of drugs and equipment loans
- **Total = £1364.18**

This is likely to be a conservative estimate as more data becomes available

1 Assumption of 14 days in hospital = £300 per diem, total = £4200 in 2003/04 prices based on ScHARR study findings, and DoH evidence to the Health Select Committee

2 Based on cost analysis of 3 patients with cost data taken from data published by Curtis et al. Unit Costs of Health and Social Care 2009. Found on the website: www.pssru.ac.uk/pdf/uc/uc2009/uc2009.pdf; based on £1355.30 for 31 days of care (median survival of the H2H population)

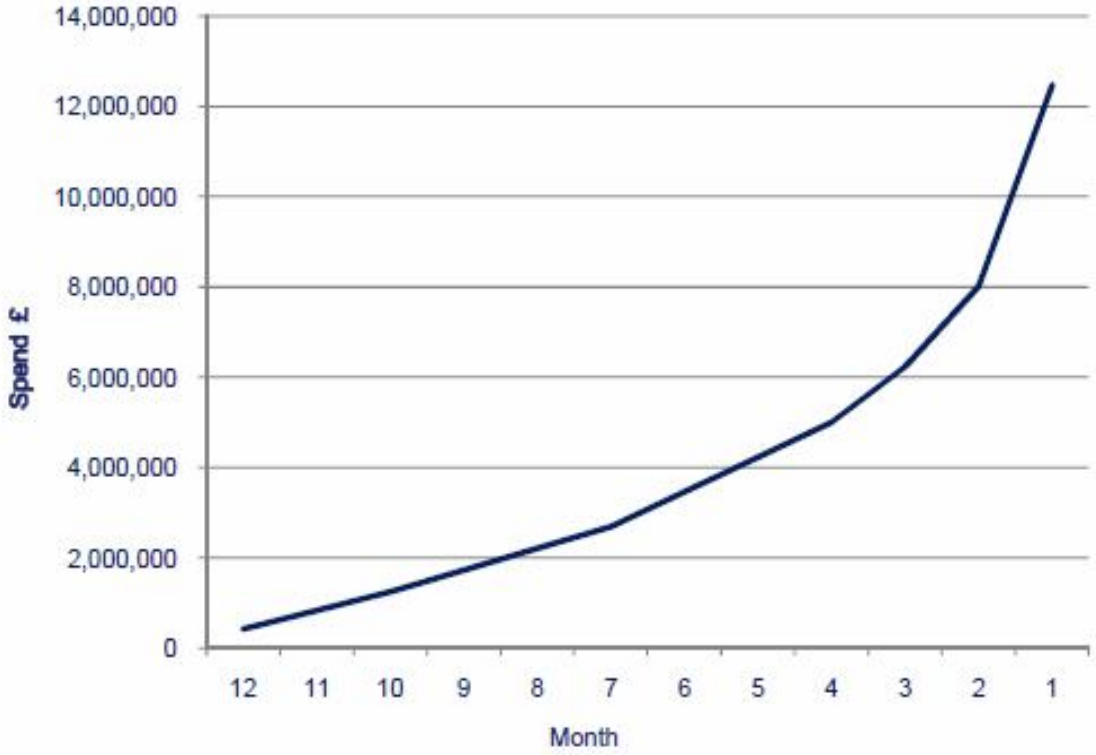
5 London DGH

Number of deaths per annum	**538**
Number of emergency admissions which took place within last 12 months of patients' death	**1071 –** 1 x 10 admissions 2 X 9 admissions 2 X 8 admissions 4 x 7 admissions 9 x 6 admissions 18 x 5 admissions 34 x 4 admissions 61 x 3 admissions 138x 2 admissions 280 x 1 admission
Cost per admission	**£3,140.36** per admission
Total Cost	**£3 362, 339.00**

5

Acute spend prior to death

Commissioning Support for London



This is a clear illustration of the pattern of expenditure (including market forces factor) on hospital admissions during the 12 months prior to death. The graph demonstrates that the rate of expenditure on hospital admissions increases closer to death.

6 Quality of patient care as well as clinician and overall system satisfaction have improved.

Patients

Royal Marsden delivers choice of care, and takes away the anxiety and emotion

Professionals

Feel better informed and more empowered to make better clinical decisions

Carers

Feels emotional peace of mind because care is co-ordinated professionally, “I didn’t know he was dying until we were told”

NHS

- Better use of resources e.g., decreased unnecessary admissions and death
- Fewer complaints to CQC[1] (54% of complaints are about end of life care)
- Meeting patient wishes supported by auditable data

1 Care Quality Commission (CQC) The Care Quality Commission (CQC) is the independent regulator of all health and adult social care in England

7 Key success factors & proposed funding

Key success factors	Details
Training hospital clinicians and GPs	• Clinicians across the hospital are trained to ensure they know when a patient has reached end-of-life and refer them to the H2H programme • GPs have more confidence in caring for patients in the community setting
CARE PLAN - Hiring and training clinical nurse specialists	•Royal Marsden hired nurse specialists specifically for the H2H programme •Nurse specialists are responsible for assessing patients' needs at discharge and coordinating care conferences in the community •Ensure all patient care documents are centralised with the GP, and all stakeholders understand their roles in the patient's care at home
Development of an IT system accessible to various providers	• DH pilot for London to ensure patient record is available to GPs, ambulances, hospices, and the patient, and that these stakeholders have sufficient training in the use of these records
Primary care involvement across the pathway	• Shared programme of care between health and social services

7 Key success factors for future

Key success factors	Details
Community palliative care services	• Develop innovative services to help patients die at home e.g. Hospice@home, domiciliary bisphosphonate infusions, Domiciliary IV antibiotics, insertion of ascitic drains
Rapid Response service	• Crisis intervention during the OOH periods e.g. Marie Curie RR service
Logistics service	•For example, a single medical equipment provider is being procured to ensure timely access for all patients

KING'S FUND REPORT

'lack of choice in end of life care is frequently due to inadequate services design, poor co-ordination of care at a local level, lack of communication between health care professionals and inadequate support for carers.'

Health Service Journal 28 October 2010

Questions on implementation?