

**Cross-Party Group in the Scottish Parliament  
on Palliative Care**

**Convener**  
Michael McMahon MSP

**Vice-Conveners**  
Jamie McGrigor MSP  
Dennis Robertson MSP

**Secretary**  
Mark Hazelwood

**Approved minute of the meeting of the Cross-Party Group  
in the Scottish Parliament on Palliative Care**

**Wednesday 10 February 2016 at 5.45pm  
Committee Room 4, Scottish Parliament**

**Present:**

Michael McMahon MSP (Convenor)  
Siobhan McMahon MSP

**Present:**

Frances Bailey, Chest Heart & Stroke Scotland  
Kirsty Boyd, NHS Lothian  
Pauline Britton, Scottish Partnership for Palliative Care  
Emma Carduff, Marie Curie  
Pat Carragher, CHAS  
Rev Stuart Coates, Forth Valley Spiritual Care Committee  
Josaleen Connolly, NHS Ayrshire and Arran  
Jean Davies, NHS Ayrshire and Arran  
Anne Finucane, Marie Curie  
Allan Grant, NHS Fife  
Diana Hekerem, Marie Curie  
Babs Henderson, CHAS  
Mark Hazelwood, Scottish Partnership for Palliative Care  
Sue Hogg, CHAS  
Annabel Howell, APM/ NHS Borders  
Jackie Husband, St Columba's Hospice  
Jennifer Layden, HIS  
Susan Lowes, Marie Curie  
Kirsty MacAlpine, MND Scotland  
Murdina Macdonald, NHS Fife  
Maria McGill, CHAS  
Margaret McKeith, Scottish Care  
Irene McKie, Strathcarron Hospice  
Margaret McMahon, Scottish Parliament  
Richard Meade, Marie Curie  
Michael Muirhead, ISD, NHS National Services Scotland  
Euan Paterson, RCGP Scotland  
Rebecca Patterson, Scottish Partnership for Palliative Care  
Yvonne Smith, Scottish Parliament  
Ian Somerville, GMC Scotland  
Tim Warren, Scottish Government  
Miriam Watts, St Andrew's Hospice  
Susan Webster, MND Scotland

Stewart Wilson, Cruse Bereavement Care Scotland

### **Apologies:**

Jackie Baillie MSP

Jamie McGrigor MSP

Janice Birrell, Scottish Government

Sandra Campbell, NHS Forth Valley

Derek Doyle, Scottish Partnership for Palliative Care

Joy Elliot, ACCORD Hospice

Donald MacAskill, Scottish Care

Elaine MacLean, Care Inspectorate

Gordon McLaren, NHS Fife

Anne Robb, NHS Tayside

Kim Rowan, Member of the Public

Lorna Stewart, NHS Fife

Amanda Ward, University of Glasgow

Julie Watson, University of Edinburgh

Craig White, Scottish Government

Mandy Yule, Ayrshire Hospice

### **1. Welcome, introductions and apologies**

Michael McMahon welcomed everyone to the meeting and noted that a list of apologies would be included in the minute.

### **2. Minute of previous meeting of Wednesday 02 December 2015**

The minute of the meeting of 02 December 2015 were approved as a correct record, pending the amendment of item 4 to read: "The study investigated the numbers of babies, children and young people with life-limiting conditions in Scotland, and what current evidence tells us about their, and their families', palliative and psychosocial support needs."

### **3. Matters arising from Wednesday 02 December 2015**

#### **3.1 Strategic Framework for Action on Palliative and End of Life Care**

The Scottish Government published its Strategic Framework for Action on Palliative and End of Life Care in December, accompanied by an Executive Summary and a Supporting Evidence Summary.

#### **3.2 Scottish Parliament Health and Sport Committee: Inquiry into palliative care**

At its meeting on 26 January, the Scottish Parliament Health and Sport Committee took evidence on the Scottish Government Strategic Framework for Palliative Care and its response to the Committee's 15th report (2015) *We need to talk about Palliative Care* from Shona Robison, Cabinet Secretary for Health, Wellbeing and Sport, Janice Birrell, Senior Policy/Implementation Manager, and Professor Craig White, Divisional Clinical Lead, Chair, National Advisory Group for Palliative and End of Life Care, Scottish Government.

### **4. Presentations and Discussion: Commitment 9 of the Scottish Government's Strategic Framework for Action for Palliative and End of Life Care:**

"Commitment 9: We will ensure that data and evidence – including people's accounts of their experience of care – is used effectively to inform learning, improvement and the spread of high quality care by supporting improvements in the collection, analysis,

interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care in Scotland.”

The group heard three presentations (PowerPoint slides attached) providing different perspectives to spark discussion and inform development in this area:

- **Diana Hekerem, Divisional Business and Service Development Manager, Marie Curie** *Evidence Base Needed for Local Service Development*
- **Dr Kirsty Boyd, Consultant in Palliative Care, Royal Infirmary of Edinburgh** *Living and dying well with different illnesses; experiences of patients and carers*
- **Michael Muirhead, Information Services Division (ISD), NHS National Services Scotland** *Developing a picture of patient pathways in the last year of life*

Group discussion followed and included the following issues:

- ISD is aware that there are limits to the data they collect, and that interpretation of the data can be enhanced by talking to people who have knowledge of the real-life situations to which the data relates.
- ‘Primary cause of death’ doesn’t give a full picture – co-morbidities are very important, and affect the resources a patient needs.
- Marie Curie data indicated that employing more Band 3 carers led to a reduction in hospital admissions. Care home staff receive relatively low rates of pay, and the care Scotland’s care homes are able to provide is negatively affected by their 22% vacancy rate for staff. There is the potential to explore whether data can provide information about more efficient and effective ways of allocating resources.
- There is potential to explore what data can tell us about how to support children with palliative care needs to die at home rather than in hospital.
- Inequalities in access to palliative care are mainly associated with a person’s diagnosis, and whether or not they live alone. More children from areas of socio-economic deprivation have palliative care needs, and there are areas where dying under the age of 65 is more common. There may be potential to explore further what data can tell us about inequalities, for example, how quality of care might relate to Scottish Index of Multiple Deprivation categories.

## **5. Any other competent business**

### **5.1 Thanks to the Convenor**

On behalf of the group, Stuart Coates offered a sincere thanks to Michael McMahon for his long-term commitment to the cross party group, which dates back to when the group was originally convened in 1999, and is much appreciated by the palliative care community in Scotland.

### **5.2 Dissolving the cross party group**



Prior to the Scottish Parliament election in May, all cross party groups must be dissolved. It is hoped that the group will be reconvened after the election.

This minute has been approved and adopted as a true record of the meeting.

**Proposed by:** Rev Stuart Coates, Forth Valley Spiritual Care Committee



**Seconded by:** Dr Pat Carragher, Children's Hospice Association Scotland

Friday 11 March 2016



## End of Life Care Pathways – an emergent picture

Michael Muirhead  
NSS ISD

## Some facts and figures

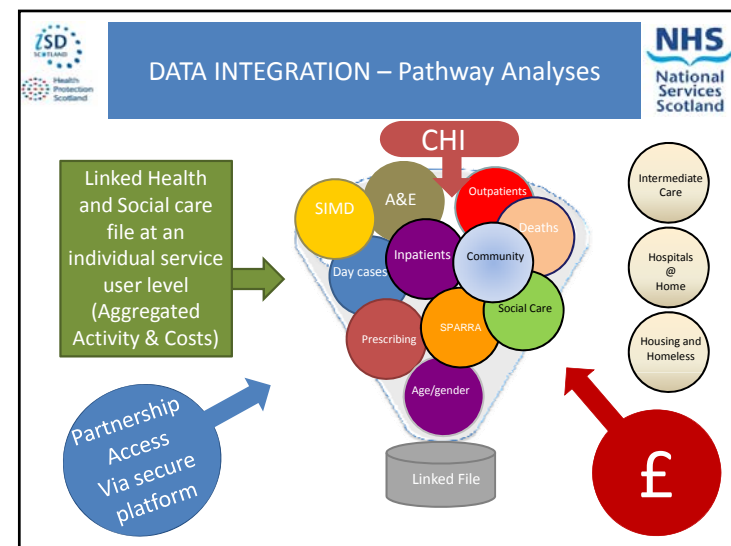
- c. 1,700 patients admitted to NHS Palliative care consultant led services p.a.
- 3 out of 4 patients have at least one hospital admission in 6 months prior to death
- 9% / 17 days spent in acute hospital in last 6 months, on average
- 16,000 patients received “syringe driver” medicines from community pharmacies

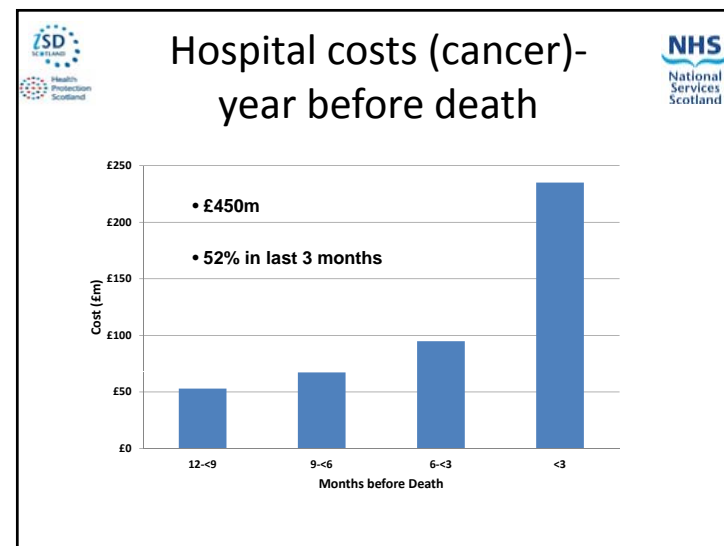
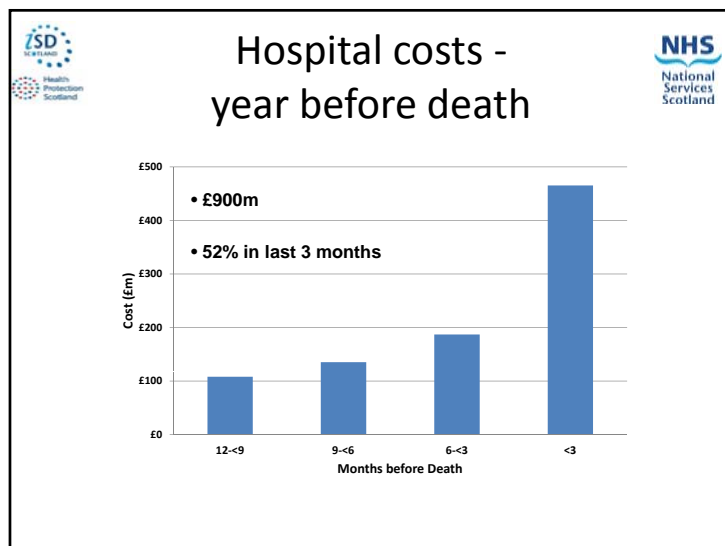



## Hospice Inpatients

**7,500 patient sample; 3 years; 11 hospices**

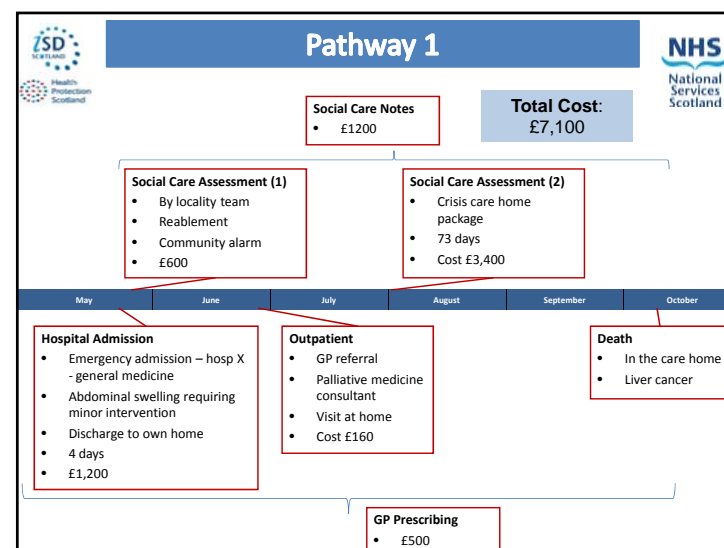
- 9 out of 10 have cancer diagnosis
- 22% Lung cancer      • 1 in 50 COPD
- 8% Breast cancer      • 1 in 100 MND
- 8% Colon cancer
- **1 in 3 patients** stay 1 week or less
- **3 out of 4 patients** stay 3 weeks or less

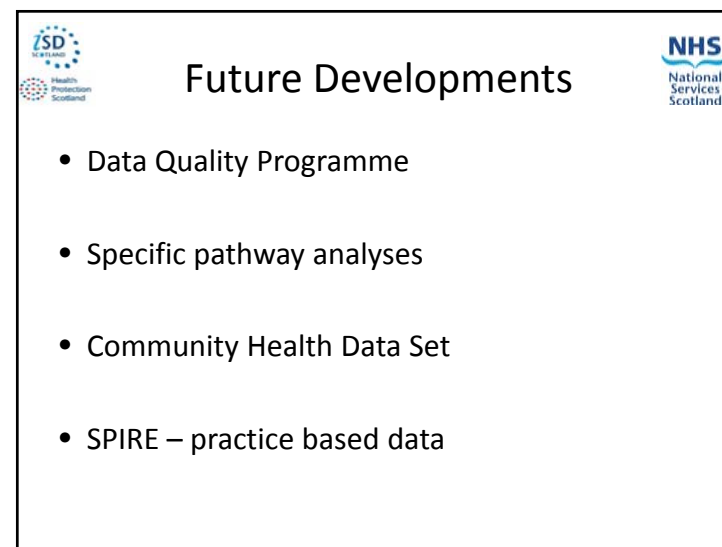
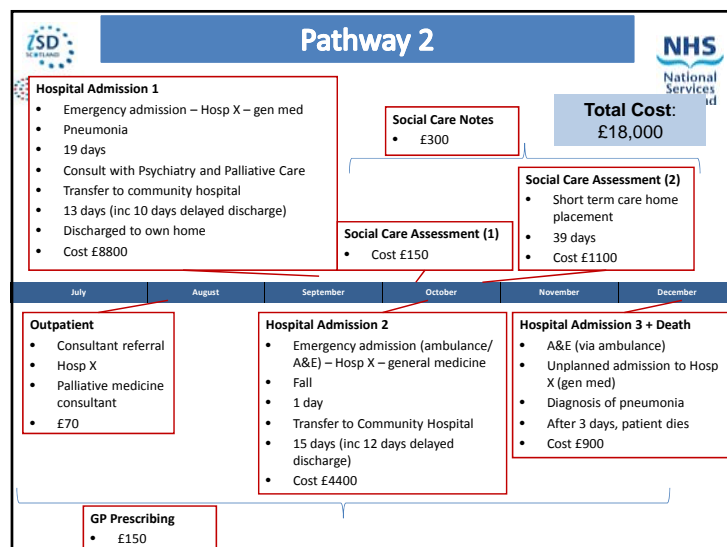




## CASE STUDY

### A tale of two pathways





**Pathway comparison**

	Pathway 1	Pathway 2
Total cost	£7,100	£18,000
Hospital admissions	1	3
Hospital bed days	4	51
of which delayed discharge	0	22
Hospital cost	£1,200	£14,700
of which delayed discharge	£0	£6,400
% days in hospital	2%	28%
Care home days	73	39
Care home cost	£3,400	£1,300
Home days	105	92
Home cost*	£1,100	£150
Other social care cost**	£1,200	£750
% days in community	57%	51%

\* Includes GP prescribing \*\* Estimated based on community care team notes

**End of Life Care**

	High Resource Users	Low Resource Users
Number of deaths	2,350	3,700
Average no of conditions	2.8	2.1
Age	71	71
Total cost	£63m	£12m
Costs/head	£26,800	£3,200
Deaths in homely setting	35%	55%
Last 6 months in community	72%	93%
Hospital bed days	155,000	31,000

## Living and dying well with different illnesses; experiences of patients and carers

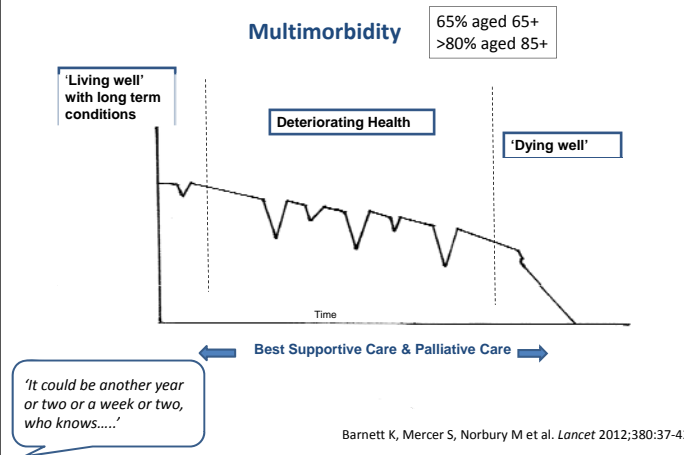


Dr Kirsty Boyd  
Consultant in Palliative Medicine, NHS Lothian  
Honorary Clinical Senior Lecturer  
The University of Edinburgh

"Whatever the setting, care will  
be provided to the highest  
standards of **quality** and **safety**,  
with the **person** at the centre of  
all decisions."  
2020 Vision



## People's journeys with advanced illness



## Cancer narratives: *dying v 'fighting'*



### Beginning

I was scared when they told me when they said there was a tumour. It knocked me for six. I thought, O my God, I am going to die...  
Mr C, patient with a brain tumour

### Middle

I honestly sometimes think there's nothing wrong with me....  
Mr E, patient with lung cancer

### End

The main thing is, how long am I going to live?  
Ms I, patient with lung cancer

## Living with organ failure: *just managing*

### Beginning

How it started is anybody's guess...Mr N, chronic lung disease

### Middle

It's one day on top and the next day back under again...Mr O, heart failure  
"I'm not afraid to die, but I want to live." Mrs J, heart failure

### End

I know it won't get better, but I hope it won't get any worse...  
Ms S, heart failure  
As long as it just keeps working the way it is working I'll be quite happy...  
Mr T, liver failure

## Living with frailty: *losing capacity and autonomy*

### Beginning

*It was all due to an accident [a fall] but I've never really been the same you see... Mr V*

### Middle

*It's just a gradual deterioration, you can't expect anything else... Mr X*  
*"Well it's just part of getting old..." Mrs P*

### End

*I said "I'm going home" I said "you're no putting me into any [nursing] home" Mrs X*

## Experiences of people living with advanced illnesses

### •Hoping

Patient: *"I've never broached the subject (of dying) cause I think like I'd rather be positive. I think "I'm not going to get worse."* (Female, 66: Liver failure, diabetes, IHD)

### •Coping

Carer: *"We deal with everything just as it is happening, just day to day stuff and things. We just manage."* (Carer for male, 87: renal failure, diverticular disease, mild dementia, prostate cancer)

### •Not 'planning for death'

Patient: *"I'm not afraid to die but I want to live"* (Female, 79: stage IV heart failure, renal failure)

*"I am quite happy to just float along as we are doing now."* (Female, 89: epilepsy, atrial fibrillation, hypertension, severe aortic stenosis)

Mason B et al. BMJ Supportive Palliative Care 2014;0:1-6. doi:10.1136/bmjspcare-2013-000639

## Talking about '*What Matters*'

### Future Care Planning

What do you know?

What are you expecting?

What's happening?

What matters?

What would help?

What we could do...

Advance care planning (ACP)  
'If and *When*' plans

Anticipatory care planning (AnCP)  
'*What we'll do if*' plans

Final days of life planning  
'*What matters now*' plans

### Plan the discussion

- Previous plans
- Key people
- Urgency
- Capacity
- Understanding/ readiness (*prognostic awareness*)

## Talking about future care together ✓

### ✓ Generalisation

- *Sometimes* people want to choose a family member or a close friend to make decisions for them if they get less well in the future. Have you thought about that

### ✓ Hypothetical questions

- *If you were* less well again like this in the future what do you think we should do?

### ✓ Hope linked with concern

- We *hope* the (treatment) will help, but I *am worried* that at some stage, maybe even soon, you will not get better.... What do you think?
- I *wish* we had treatment for, but ...

### ✓ Accept uncertainty, change and diverse views

- Can we talk about what is most important for you now, and how we might cope with not knowing exactly what will happen and when?



### Talking about future care together X

- × Euphemisms or long, vague explanations
  - causes confusion
- × Talking about 'trying' or 'the chances' if a treatment will not work or have a very poor outcome
  - directs people to 'want everything done'
- × Using language such as 'futile', 'treatment limitation' or 'ceiling of treatment/care', terminal, 'made palliative'
  - can make people think 'nothing will be done for them'
- × Moving on to treatment options and planning care before understanding what matters to this person and those close to them
  - People need to have a realistic understanding of their situation to formulate goals, then they can take part in decisions about options for treatment / care which fit with 'what matters' most to them.



1. Diagnosis of a new illness
2. Deteriorating health



And write these poems, which are funeral songs  
That have been taught to me by vanished time:  
Not only to enumerate my wrongs  
But to pay homage to the late sublime  
That comes with seeing how the years have brought  
A fitting end, if not the one I sought.

*Clive James New Yorker, May 28, 2013*

*Medicine is a science of uncertainty  
and an art of probability.*

William Osler



## Evidence Base needed for Local Service Development

Diana Hekerem, Divisional Business and Service Development Manager  
Scottish Parliament Cross Party Group - February 2016



## Strategic Plans – Palliative Care



"Who wants to live forever?"

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Care and support  
through terminal illness



## Strategic Plans supporting commissioning of Palliative and End of Life Care

Strategic Plans in general do not include:

- Data to support commissioning e.g. mortality rates, numbers with palliative care needs, admissions resulting in death, social care support with DS15000
- Focus on services to address needs when "living well" is no longer possible
- Reference to hospice services and pathways
- Recognition of dependency on voluntary sector for palliative and end of life care support

BUT

- In Scotland, it is estimated that around 40,000 of the 54,700 people who die each year need some palliative care
- With the number of people dying in Scotland due to increase by 13% over the next 25 years, this problem will get worse unless we act now.

ONS (2014). 2012-based National Population Projections

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## Health and Wellbeing Outcomes – Gathering the right evidence for resources and service planning

**Outcome 1:** People are able to look after and improve their own health and wellbeing and live in good health for longer

**Outcome 2:** People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community

**Outcome 3:** People who use health and social care services have positive experiences of those services, and have their dignity respected

**Outcome 4:** Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services

**Outcome 5:** Health and social care services contribute to reducing health inequalities

**Outcome 6:** People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being

**Outcome 7:** People using health and social care services are safe from harm

**Outcome 8:** People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide

**Outcome 9:** Resources are used effectively and efficiently in the provision of health and social care services

Palliative Care Measures:

**Outcome 2: 15 - Proportion of last 6 months of life spent at home or in a community setting**

**Outcome 9: 23 - Expenditure on Last 6 months of life**

Also?

12. Rate of emergency admissions for adults.\*
13. Rate of emergency bed days for adults.\*
14. Readmissions to hospital within 28 days of discharge.\*
17. Proportion of care services graded 'good' (4) or better in Care Inspectorate inspections.
18. Percentage of adults with intensive needs receiving care at home.
19. Number of days people spend in hospital when they are ready to be discharged.
20. Percentage of total health and care spend on hospital stays where the patient was admitted in an emergency.
21. Percentage of people admitted from home to hospital during the year, who are discharged to a care home.\*
22. Percentage of people who are discharged from hospital within 72 hours of being ready.\*
23. Expenditure on end of life care.\*

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## Evidencing Impact of ICF Funding

**Outcome 1:** People are able to look after and improve their own health and wellbeing and live in good health for longer

**Outcome 2:** People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community

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**Outcome 9:** Resources are used effectively and efficiently in the provision of health and social care services

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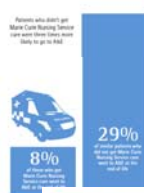
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OUTCOMES & OUTPUTS		
Demonstrate and evidence how the project is currently delivering its expected outcome(s) and the impact this has on:		
Healthier Living	Outcomes	Outputs
People are able to look after and improve their own health and wellbeing and live in good health for longer.	The provision of palliative care provides support to unpaid carers in pre and post bereavement and prevents carer breakdown and anxiety.	To achieve this we have...
Independent Living	Outcomes	Outputs
People, including those with disabilities, long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.	The service supports patients to live in a community setting for longer. Nuffield Trust evidenced patients with access to Marie Curie services have a significantly lower hospital use than those without.	To achieve this we have...
Positive Experiences and Outcomes	Outcomes	Outputs
People who use health and social care services have positive experiences of those services, and have their dignity respected.	This service has received excellent gradings from the Care Commission. Patients and Carers are encouraged to give feedback via patient response. Independent evidence from similar Marie Curie services in Scotland states 'Marie Curie staff as professional, sensitive, caring and helpful, always treating patients and carers with dignity and respect.'	To achieve this we have...
Quality of Life (NEW)	Outcomes	Outputs
Health and social care services are centred on helping to maintain or improve the quality of life of service users.	Evidence from similar Marie Curie services has shown reduction in stress and anxiety for patients and carers.	To achieve this we have...
Equality (NEW)	Outcomes	Outputs
Health and social care services contribute to reducing health inequalities.	Marie Curie monitors deprivation of patients postcodes of all referrals. To date this shows a spread across all 5 deprivation categories with the majority in the 1 <sup>st</sup> most deprived area. Marie Curie also provides the service free of charge to patients and families for all terminal diagnosis including those with a non-cancer diagnosis including heart failure and COPD.	To achieve this we have...
Careers are Supported	Outcomes	Outputs
People who provide unpaid care are	Marie Curie RHs will provide holistic support when	To achieve this we have...



## Evidence Base: Nuffield, OPM studies and local reviews

Hospital admissions



Source: Nuffield Trust: *The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life 2014.*

Source: OPM Evaluation Marie Curie Nursing Service. Dec 15

**Hospital admissions:**  
86 patients (107 admissions) - matched cohort  
58 patients (64 admissions) - pilot cohort.  
**A&E attendances**  
28 patients - matched cohort  
9 patients - pilot cohort.  
**Overall 22% reduction in non elective bed days.**



**Place of death for the matched cohort was**  
29.1% home, 56.8% hospital, 8.5% and 5.6% in hospice or care home.

**Place of death for the pilot cohort was**  
73.7% home, 19.2% hospital, 6.1% in hospice and 0.9% care home.

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## Time Spent in the Community

An increase in time spent in the community in the last 6 months and last month of life with a reduction from 20.5% to 11.3% spent in hospital in the last month of life.

91% of respondents to the patient/carers survey stating the service allowed them to be cared for where they want to be.

Cohort Group	Months prior to death	Time in Hospital (%)	Time in the Community (%)
Matched	6 months	9.4%	90.6%
	1 month	20.5%	79.5%
Pilot	6 months	5.6%	94.4%
	1 month	11.3%	88.7%

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## Spend on Palliative Care

When someone is cared for at home by Marie Curie Nurses it saves the NHS an average of **£1,140** in hospital costs

**Review of palliative care services in Scotland**

Health and Sport Committee  
**NHS boards budget scrutiny 2015-16**

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## Impact on discharges

**"Delighted that mum got home on Saturday" - the North Glasgow Palliative Care Fast-track Discharge Service**

**Fife:**

*'In the past we've had patients fit enough to go home but by the time the service [homecare] was available they weren't and so they ended up stuck in the hospital until they died' (hospital-based staff).*

*'I recently had a letter from a family who we'd involved Marie Curie Fast Track service with and that meant we got her discharged on Friday afternoon and she died in the early hours of Monday, and we wouldn't have been able to get that in place so quickly without Marie Curie.' (hospital-based staff)*

31 of the 37 (84%) patients surveyed undergoing a discharge from hospital reported that they were happy with the amount of time it took to be discharged.

Notes:

OPM Evaluation December 2015. [mariecurie.org.uk/fife](http://mariecurie.org.uk/fife)  
NHS Scotland Conference Poster 2014

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## Evidence base for Social Care planning?

DCP Argyll & Bute: Projects and findings

Locally coordinated Marie Curie Nursing Service: supported more patients before they reached a crisis point, improved patient equity and provided more, flexible daytime visits.

Palliative Care training and support for care homes: trained 84 staff members from 5 care homes, in partnership with local Macmillan Clinical Nurse Specialists, with clear benefits for staff knowledge and confidence in various palliative and end of life care issues.

Guidance and support for carers: carer training sessions in Oban addressing the various palliative care issues faced by informal carers, in partnership with North Argyll Carers Centre and NHS Highland.

'Remote and Rural Helper' service: unique volunteer service developed for people living with a terminal illness, in partnership with 3 local voluntary organisations, to address the challenges of a remote and rural environment.

Guidance on transport for rural patients: transport information booklet developed in partnership with NHS 24, NHS Highland, Scottish Ambulance Service and other community transport providers.

Health Promoting Palliative Care activities: community events encouraging individuals and communities to have open conversations about death and dying, including Power of Attorney.

What changes do you believe the Marie Curie service has had to the health and social care system of end of life patients in Fife? - HCP survey

	Decreased	Unchanged	Increased	Don't know
Emergency hospital attendances	19	5	0	13
Planned hospital admissions	16	10	0	10
GP surgery attendances	12	6	1	17
GP call outs	10	8	1	17
District Nurse attendances	16	11	1	8
Home care (social services)	14	8	2	12

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**For more information contact:**

Diana Hekerem  
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Marie Curie  
Email: [diana.hekerem@mariecurie.org.uk](mailto:diana.hekerem@mariecurie.org.uk)  
Follow us on Twitter @mariecurieSCO

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