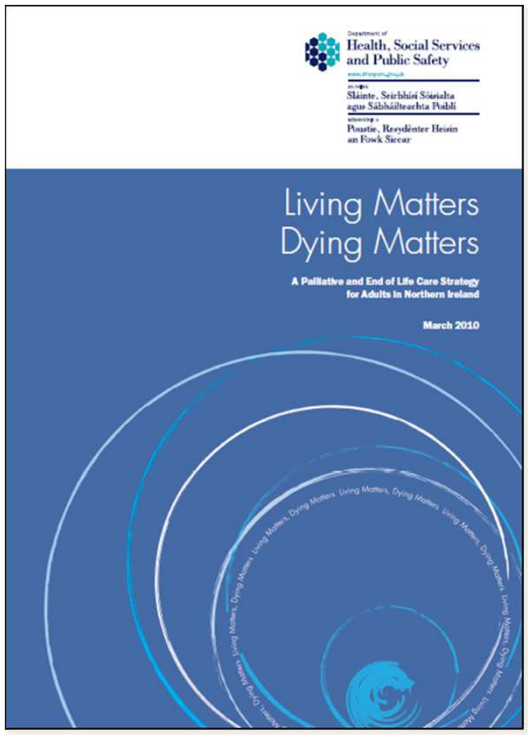
Making Life Better Palliative Care Seminar

Corrina Grimes

Palliative Care Clinical Lead, Public Health Agency on behalf of



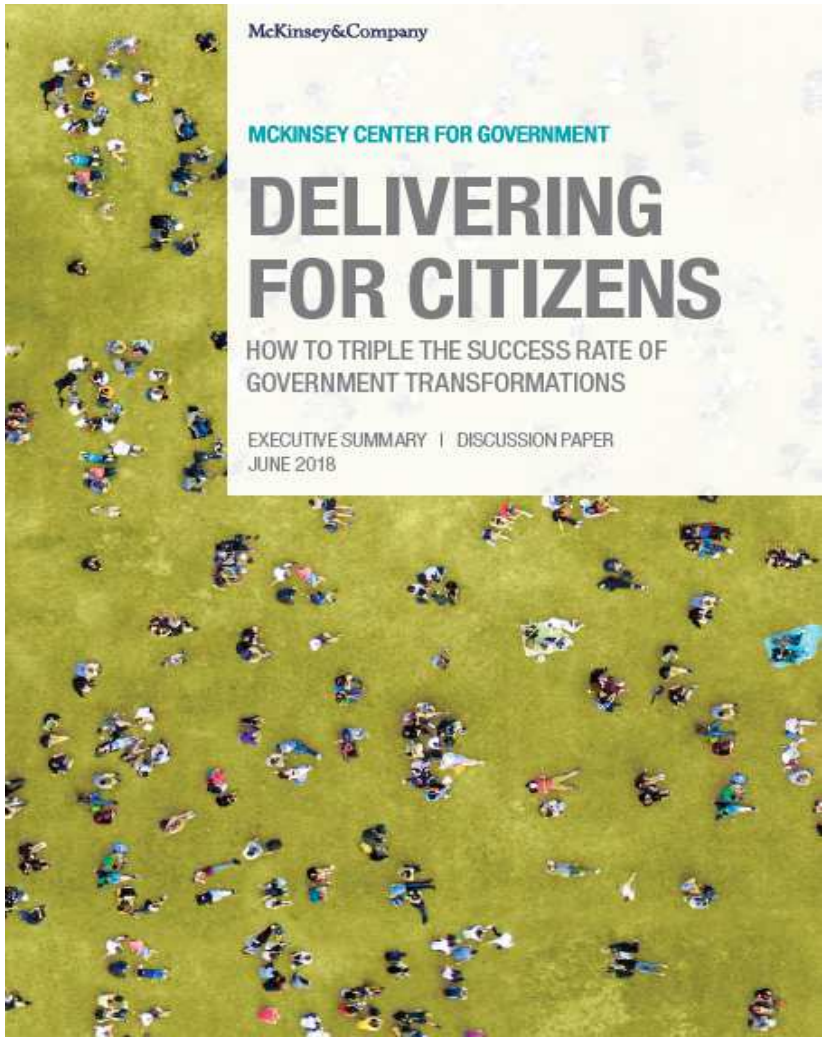
'***Palliative and end of life care is*** *the active, holistic care of patients with advanced progressive illness…. as a* ***continuum of care*** *that can evolve as a person's condition progresses.*

This is an ***integral part of the care delivered by all health and social professionals, and indeed by families*** *and carers, to those living with and dying from any advanced, progressive and incurable condition.*

Palliative and end of life care focuses on the person *rather than the disease and aims to* ***ensure quality of life for those*** *living with an advanced non-curative condition*

Policy and Strategy Drivers

Transformation – A Global Theme



- Profound levels of demographic change
- High level of inequality

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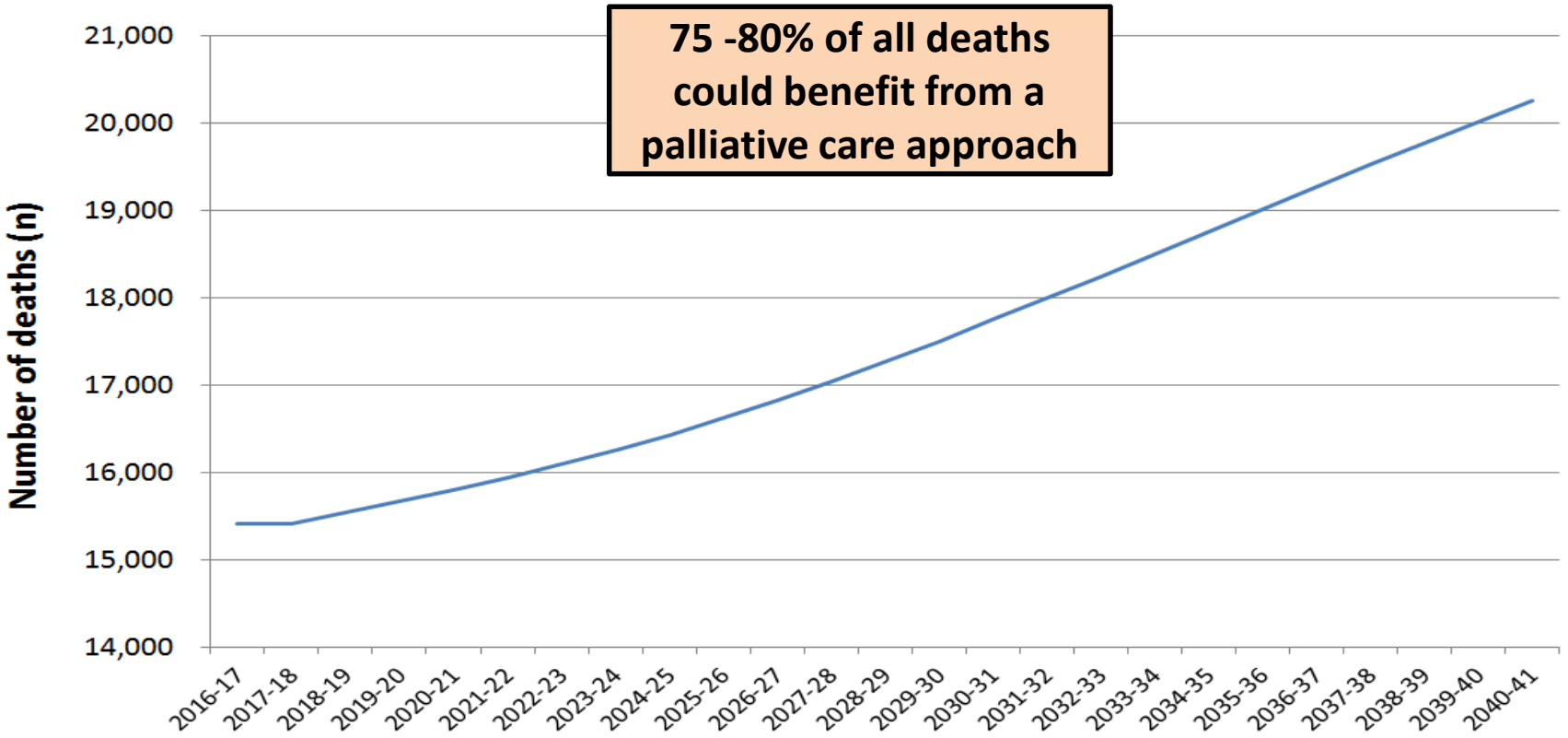
Changing Demographics

Number of projected deaths (2016/17 to 2040/41) non-zero y-axis



Source: Northern Ireland Statistics and Research Agency 2016-based Population Projections for Areas within Northern Ireland, 11 LGDs – projection summary (2016-2041) https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/SNPP16_LGD14_CoC_1641.xlsx

Projected Deaths and Palliative Care Need in Northern Ireland

	2016	2020	2030	2040
Deaths all ages (NISRA projected)	**15,401**	**15,800**	**17,750**	**20,261**
Projected Palliative Care Need*	**11,551**	**11,850**	**13,313**	**15,196**

* Using 75% of all deaths (Gomez and Batiste *et al*)

The Palliative Care Need of our population will **increase by 31%** by 2040!

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Source: PHA, data on file (2017)

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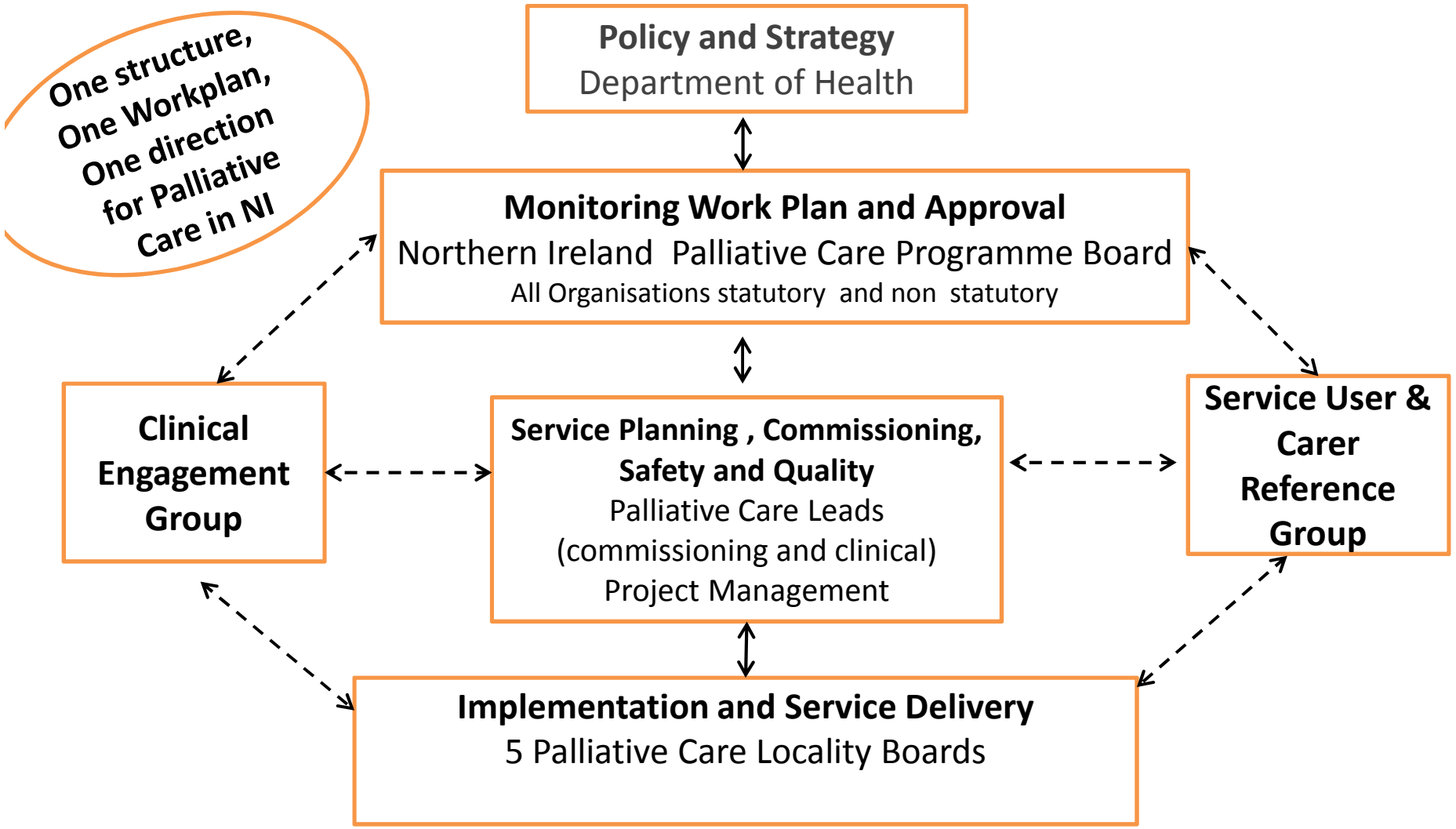
Our Approach



Please note: These structures may be subject to organisational change

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Our Objective

- Improve the **quality of life** for those with palliative and end of life care need, and to improve the experience of those important to them


HSC
Health and Social
Care Board


HSC
Public Health
Agency

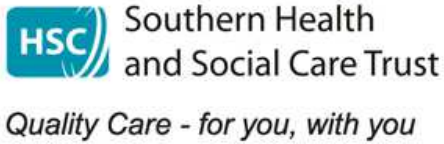

ihcp
independent health
& care providers


Marie
Curie
Care and support
through terminal illness


HSC
Belfast Health and
Social Care Trust
caring supporting improving together


HSC
Northern Health
and Social Care Trust


HSC
South Eastern Health
and Social Care Trust


HSC
Southern Health
and Social Care Trust
Quality Care - for you, with you


Department of
Health
An Roinn
Sláinte


HSC
Western Health
and Social Care Trust


RC
GP
Royal College of
General Practitioners


HSC
Northern Ireland Ambulance Service
Health and Social Care Trust


Northern
Ireland
Hospice


Patient and Client Council
Your voice in health and social care


ihcp
independent health
& care providers


FOYLE HOSPICE
TOGETHER WE CARE


BMA

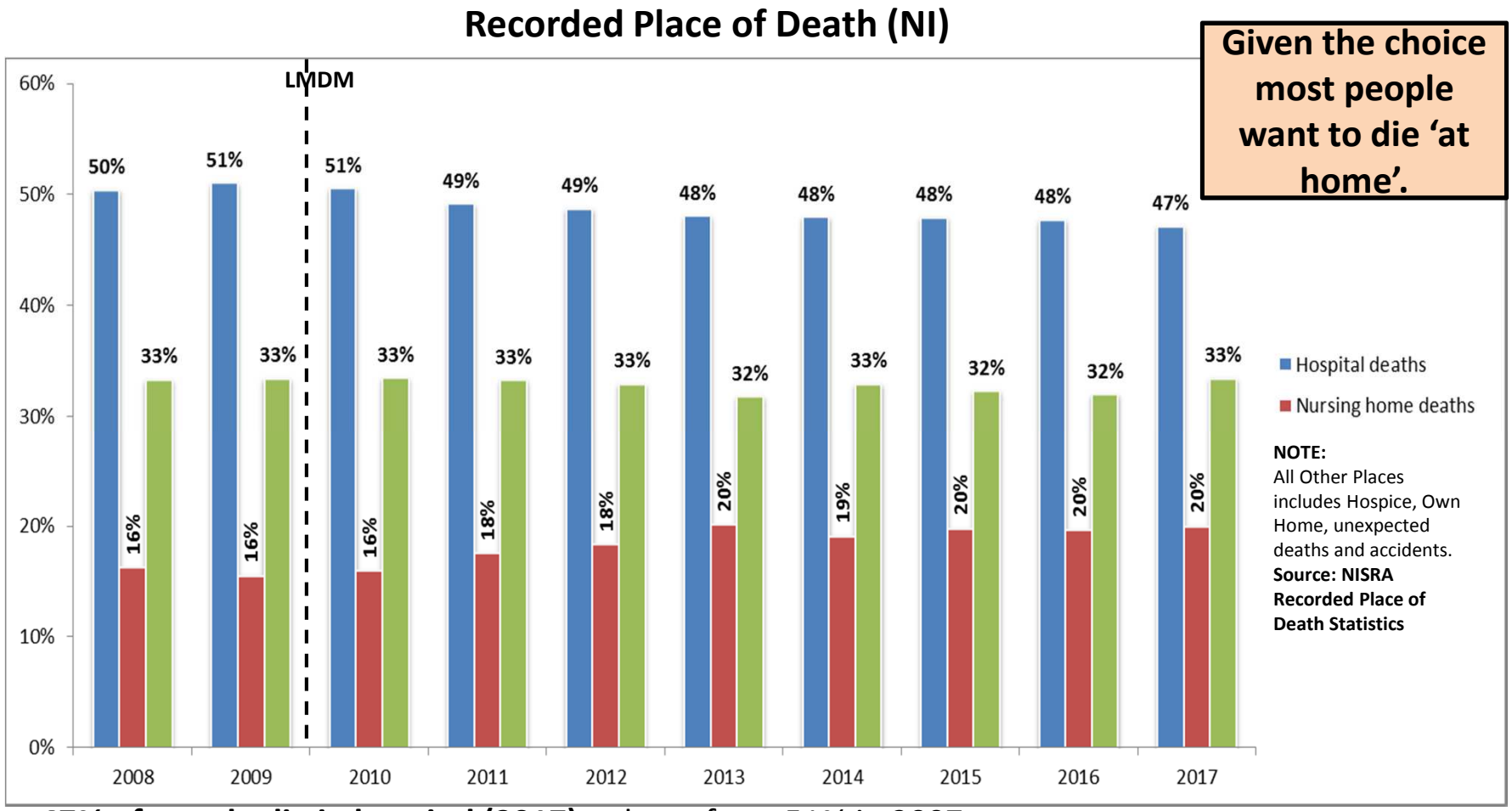

WE ARE
MACMILLAN.
CANCER SUPPORT


Integrated
Care
Partnerships
Health and Social Care


AIIHPC
All Ireland Institute of
Hospice and Palliative Care


Southern Area
Hospice Services

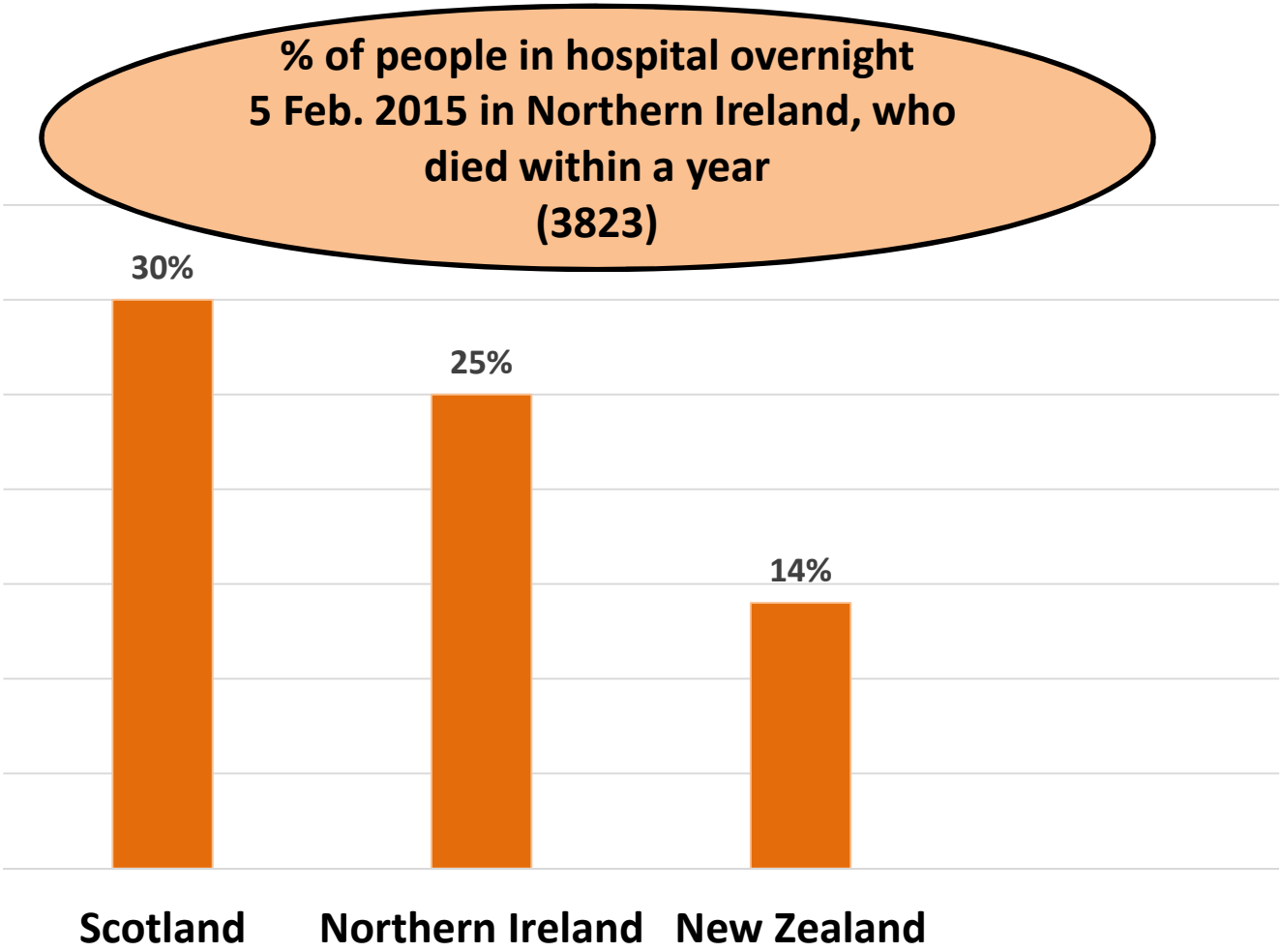
Citizen Choice and Impact on HSC System



- **47% of people die in hospital (2017)** – down from 51% in 2007
- However **the actual numbers of people dying in hospital is higher** due to increased numbers of deaths overall in the last couple of years
- With the projected increase in deaths and palliative care need, there could be an **additional 1,500 people per year dying in hospital by 2040.**

Source: PHA, data on file (2019)

How do we make life better for these people ?



Source ; Gott M, Broad J, Zhang X, et al. (2017);
PHA, data on file (2017)

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Vision

To provide the regional direction so that everyone **identified** as likely to benefit from a palliative care approach (regardless of their condition) is:

- Allocated a **keyworker**
- Have the opportunity to discuss and record their **advance care planning** decisions
- Be supported with appropriate generalist and **specialist palliative care services**

Priorities →

Identification	Keyworker	Advance Care Planning	Specialist Palliative Care Services

Regional good practice tools and guidance
Communication
Public Health Approach to Palliative Care

IDENTIFICATION: Why is it important?

- At least 1% of the population are likely to benefit from a palliative care approach at any one time (c.19,000 in NI)
- Between **15-16,000 people die each year** in NI
- Estimated **75 -80% of those could benefit** from palliative care approach
- QOF Palliative Care Registers recorded **5,427 people in 2017**- increased from 1,814 in 2010

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Lothian Early Identification Project

Mason et al. BMC Family Practice
DOI 10.1186/s12875-015-0313-z

BMC Family Practice

RESEARCH ARTICLE Open Access

Developing a computerised search to help UK General Practices identify more patients for palliative care planning: a feasibility study

Bruce Mason[1*], Kirsty Boyd[1], Scott A Murray[1], John Steyn[2], Paul Cormie[3], Marilyn Kendall[1], Dan Munday[4], David Weller[1], Shirley Fife[2], Peter Murchie[5] and Christine Campbell[1]

Abstract

Background: Approximately 600,000 people die in the UK annually, usually after months or years of increasing debility. Many patients with advanced conditions are not identified for appropriate support before they die because they are not seen as having "palliative" care needs. General practice information technology systems can improve care by identifying patients with deteriorating health so that their healthcare needs can be reviewed more systematically and effectively. The aim was to develop and test a computerised search of primary care records in routine clinical practice as a tool to improve patient identification for a palliative care approach.

Methods: An iterative process of search design and testing followed by implementation and extended testing of the search output in clinical practice. A three-phase feasibility study: developing a computerised search, determining its ability to identify patients with deteriorating health from any advanced condition, and assessing how primary care clinicians use the results to improve patient care. The setting was twelve primary care teams in two Health Boards in Scotland.

Results: The search identified 0.6–1.7 % of patients in each practice who were not already on the palliative care register. Primary care clinicians judged that 30–60 % of these patients were at risk of dying or deterioration over the next 6–12 months. The most common action taken by GPs was to start an electronic anticipatory care plan.

Conclusions: It is possible to significantly improve the identification of patients for palliative care needs assessment using a computerised search however barriers remain to GPs' finding it acceptable. Time-efficient systems were important as was a generic tool for anticipatory care planning not linked to 'palliative' care.

Keywords: Primary healthcare, General practice, Palliative care, Qualitative research

Background

Approximately 600,000 people die in the UK each year, usually after months or years of increasing debility www.ons.gov.uk/ons/publications/index.html [1]. UK health policy emphasises early identification, assessment and care planning for these patients [2, 3], and the need for a greater evidence base to support the provision of palliative care in the community [4]. Although most patients spend the majority of their last year of life at home, around 50 % eventually die in hospital [5].

Most patients are not identified for a palliative care approach before they die [6] because they are not identified as having 'palliative' care needs [7, 8]. A study of six Scottish general practices in 2012, found that only 29 % of deceased patients were on the palliative care register [9]. Only 30 % of deaths overall were from cancer, but 68 % of patients on the palliative care register had cancer [9]. A review of deaths in high income countries indicated that between 69–82 % of patients who die need

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- University of Edinburgh & Marie Curie project
- Developed an algorithm based on SPICT indicators
- Run directly on GP Clinical Systems (Vision IT)
- Identified patients who might be in their last year of life
- Tested in GPs in Lothian area with increased identification

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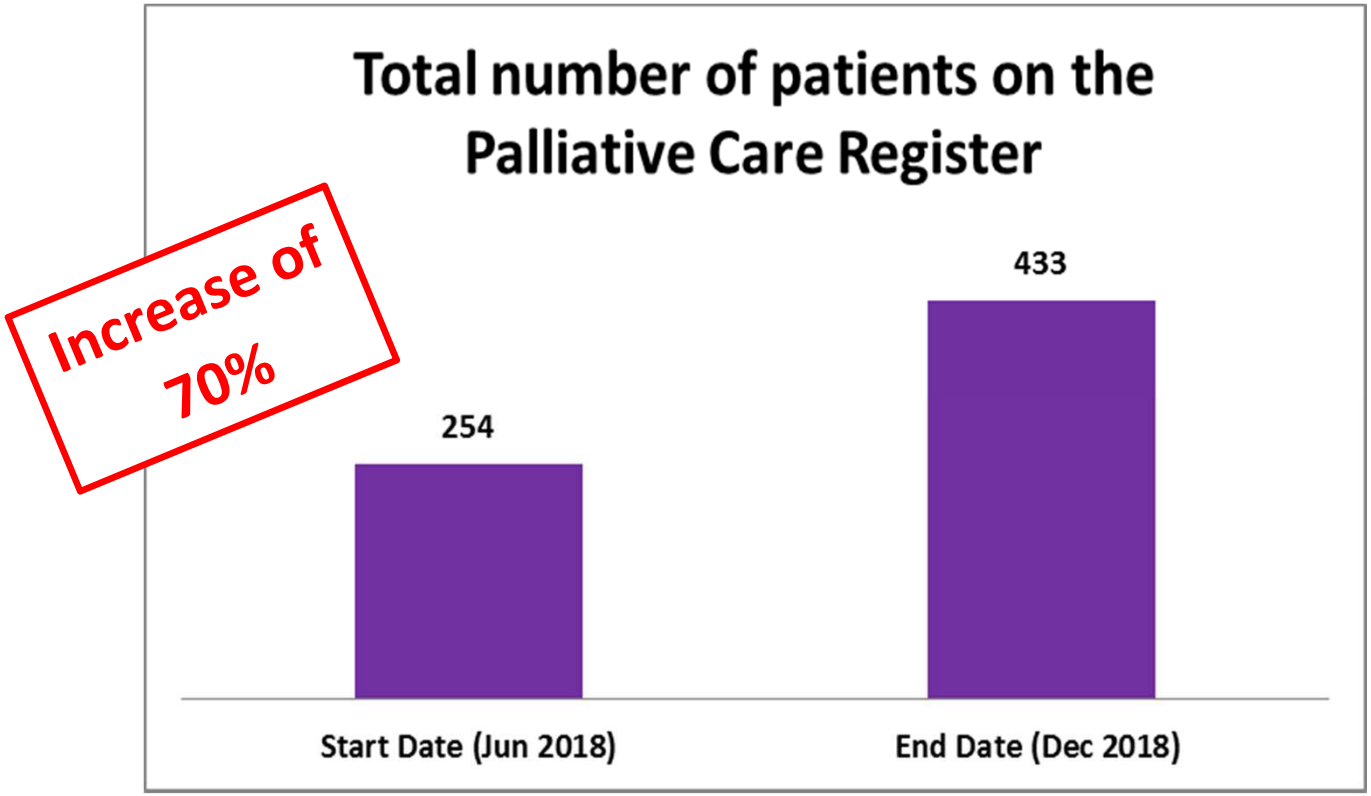
Preliminary Findings

(Phase 1 Jun-Dec 2018)

- 92,678 patients on the practice lists



Palliative Care Key Worker

'each patient identified as having palliative and end of life care needs should have a keyworker'

- Agreement for **Keyworker function** and **competencies**
- **Typically** District Nurse
- **Dedicated capacity** -Incorporated in to District Nursing Workforce review
- Commissioned Education
- **Community of Practice** – Project ECHO
- **Evaluation** – Focus group and IHI QI projects

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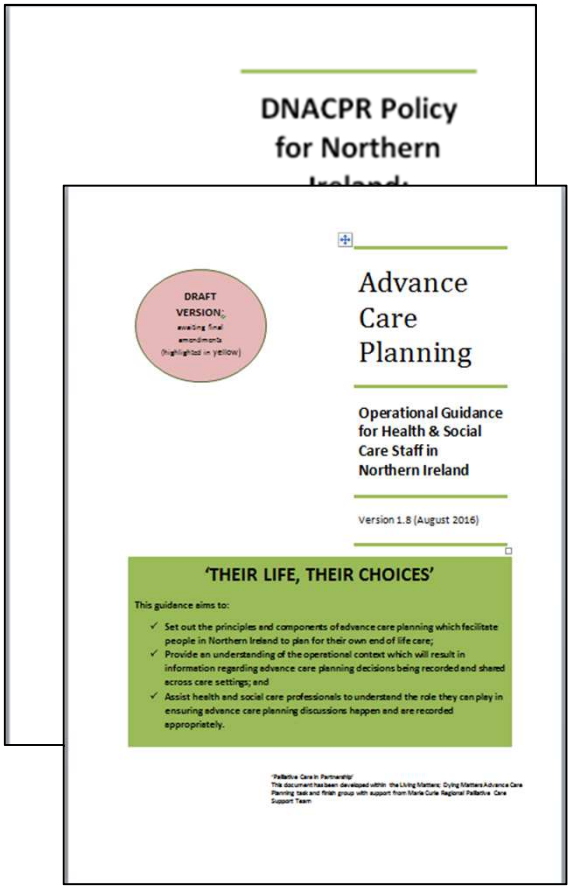
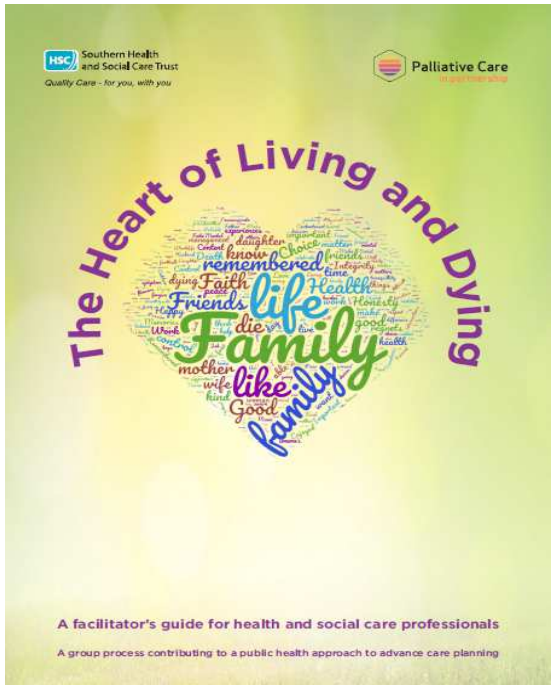
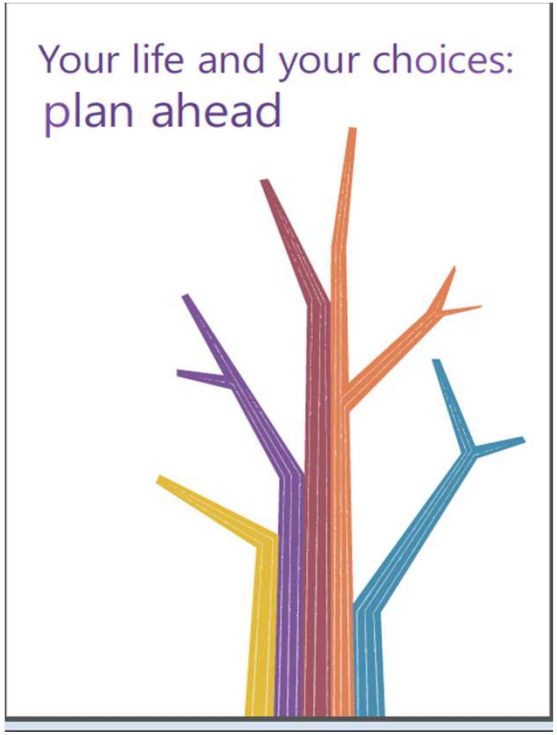
Advance Care Planning Tools:







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Advance Care Planning Engagement
Going to the Public

Specialist Palliative Care Workforce

Interdisciplinary approach to include **specialist palliative care** Dietetic, medical, nursing, OT, Pharmacy, Physio, social work and SLT staff groups

Key Aim of workforce planning;

- Identify the workforce required to meet the SPC population need up to 2024
- post grad education training

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Marie Curie
Care and support through terminal illness

RCGP Royal College of General Practitioners

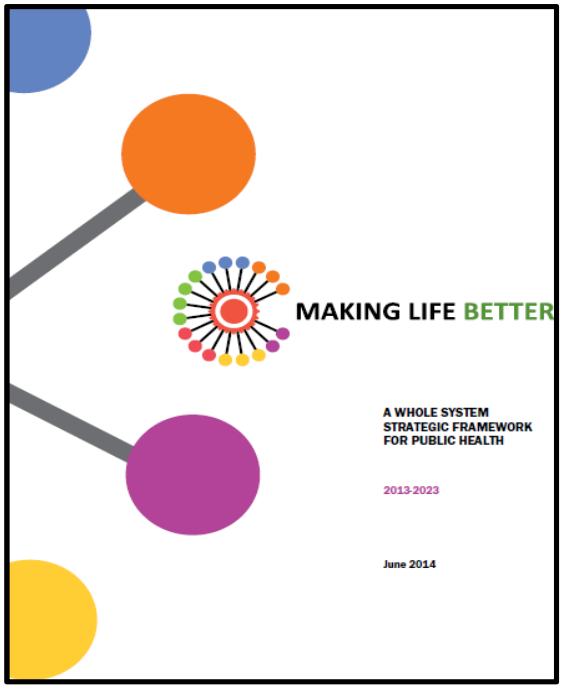
Helping Communities Care for their Own

Professionals are essential but not central

Dr Catherine Millington-Sanders
RCGP / Marie Curie National End of Life Care Champion
Compassionate Communities UK Board Member

22nd September 2016

c.millington-sanders@nhs.net



"The ethos of **supporting individuals**, **families** and **communities** to maintain and **improve their health needs** must be fully embedded as a normal way of working **right across all organisations**, environments and **activities within the HSC system**. This is not just in day to day interactions with every member of the public, but also as part of **commissioning and designing health services**. Service Frameworks are a key reference point for commissioning and designing services to secure better integration of service delivery along the whole pathway of care from prevention of disease /ill health to diagnosis / treatment and rehabilitation, and on to **end of life**."

MLB Approach

- *"Our approach to public health focuses on* ***working collaboratively*** *with* ***individuals, communities*** *and* ***partner organisations*** *to* ***address the factors that impact on*** *health and* ***wellbeing*** *in Northern Ireland"*.

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THE MAKING LIFE BETTER CHARTER

- Social justice, equity and inclusion
- Engagement and Empowerment *work with people to address agreed priorities and* ***build on the assets we have in our communities***
- Collaboration through both **policy** and **practice**
- Evidence and Effectiveness
- Addressing Local Need
- Our Resources - public resources as well as those **of our partners.**

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"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

"How people die remains in the memory of those who live on."

Dame Cecily Saunders, founder of the modern Hospice movement

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Thank You

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