Home from Home:
a vision for the future in care homes
"Celebrating Quality Care"
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Overview of my lecture:

- Comparing palliative care and geriatrics
- Very brief results from my PhD looking at palliative care and care homes
- How this informed taking part in GSFCH project
- Results from five years working with GSFCH programme

Palliative care & geriatrics

"Both make the whole person and his or her family the focus of care, while seeking to enhance quality of life and maintain the dignity and autonomy of the individual. Judicious use of investigations is advocated and both eschew unwarranted treatment while providing symptom control and relief of suffering. Both are necessarily multi-disciplinary and both are areas which prompt phobic reactions from society at large. Finally both Geriatrics and Palliative Care are new medical technologies which challenge the restorative, often aggressive and increasingly technological practices in technological areas of medicine." *Mount, 2000*

Cancer Trajectory

Function

High

Low

Death

Time
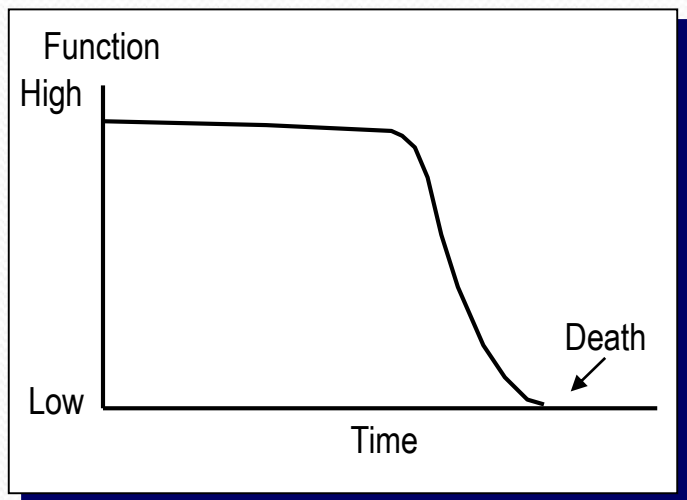
The Frailty Dementia Trajectory

Function

High

Low

Death

Time
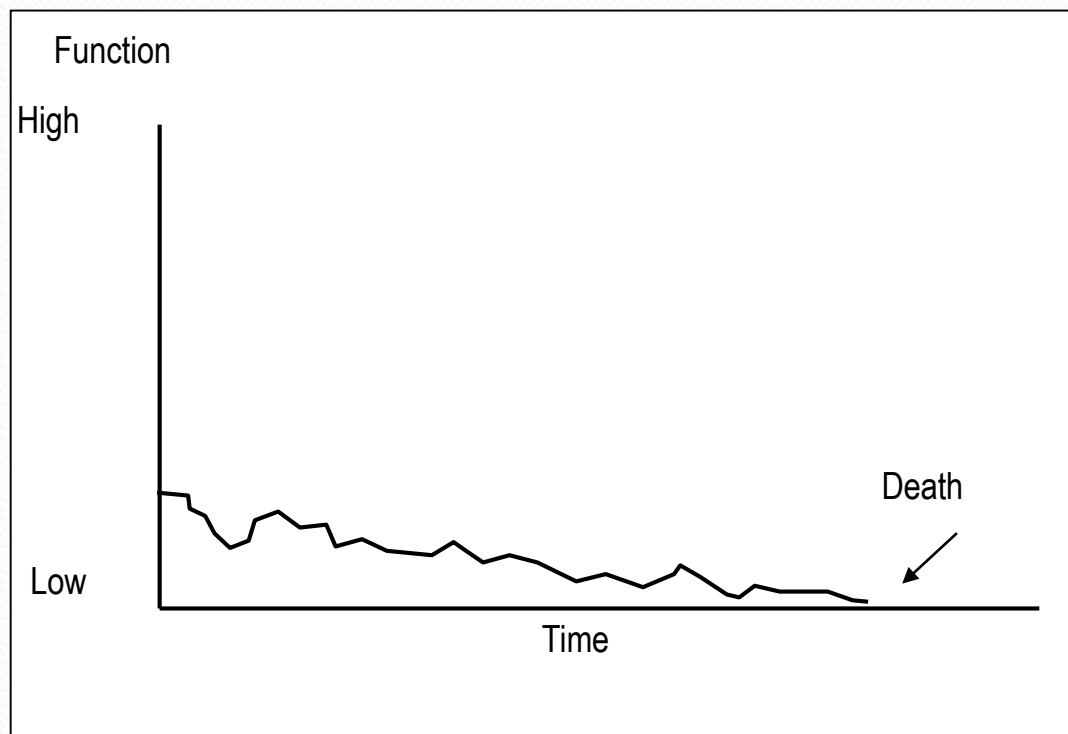
Staff & residents in an older people's care home in London.
Photograph: Frank Baron
http://www.guardian.co.uk/society/2009/jul/08/residential-homes-older-people-care

Developing high quality end of life care in care homes: an action research study (Hockley 2006; 2012)

What problems do staff experience in caring for dying residents? What interventions do staff want to implement?

Action Research study to develop quality end of life care. An initial ethnographic phase found 'dying to be peripheral to the relatively weak care home culture'. <u>Two actions</u>, inductively derived, were interpreted using **Habermas's theory of SYSTEM & LIFEWORLD:**

Experiential learning through **reflective de-briefing** sessions following a death supported and valued the **LIFEWORLD** of staff

An **integrated care pathway** (ICP) for the last days of life as a **SYSTEM** to embed change

Hockley, J (2006) *Developing high quality end of life care in nursing homes: an action research study.* Unpublished PhD thesis: University of Edinburgh

# Simultaneous contribution to social science and social change

RdBSs …

valued the 'LIFEWORLD' of staff and at same time helped them learn about death & dying by reflecting on practice.

ICP …
an important SYSTEM to anticipate the complexities of care in the last days of life within the world of NHs

A DEVELOPMENT MODEL
Re-coupling of the 'lifeworld' and 'system' (Habermas 1987) to optimise high quality care at the end of life in NHs
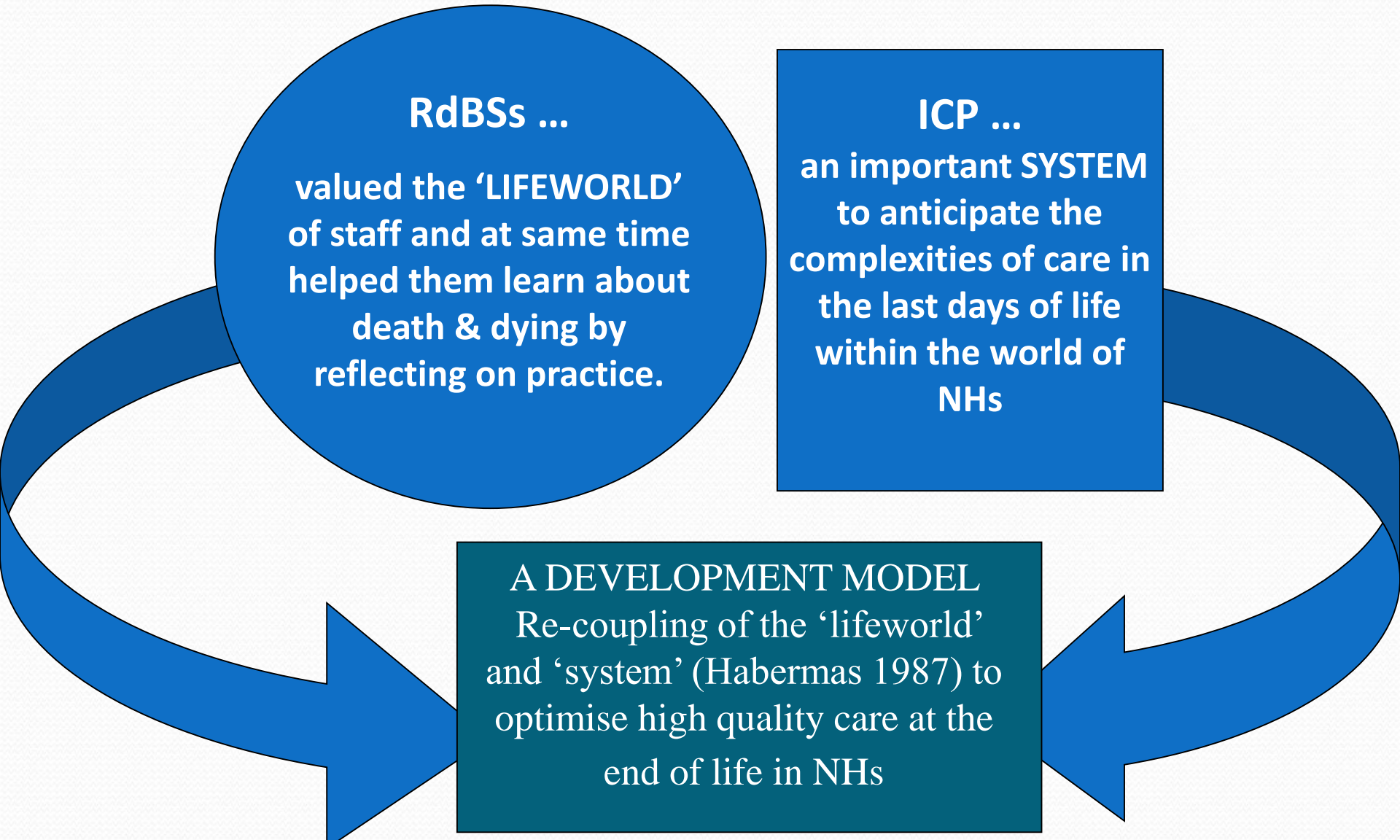
Changing cultures in care homes (Kitson et al 1998; Hockley et al 2010; Kinley et al 2014)

- Kitson et al argue the important relationship between:
  - CONTEXT – 'low' 'high'
  - EVIDENCE – 'low' 'high'
  - FACILITATION – 'low' 'high'

- That there has to be two 'highs' to counteract 'low'
- Care Homes
  - CONTEXT – 'low'
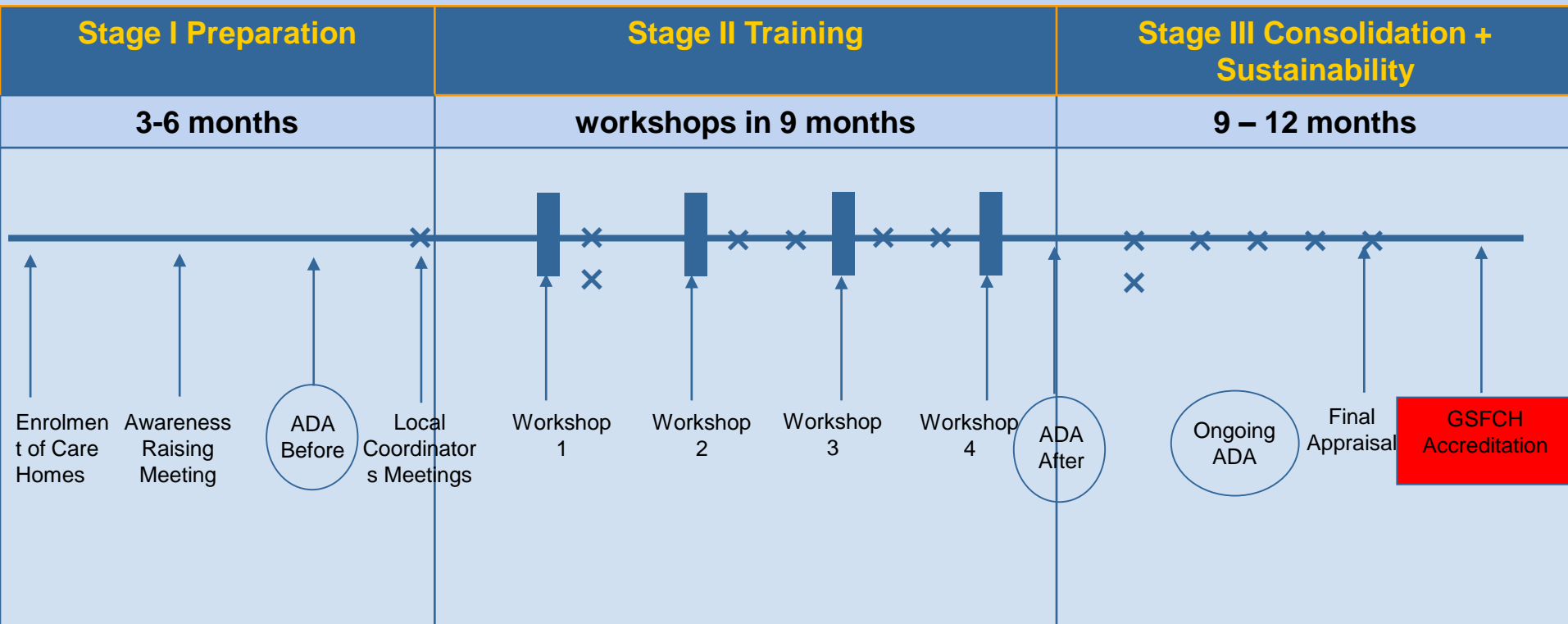 - EVIDENCE & FACILITATION – 'high'

Care Home Project & Research Team

- In 2008 St Christopher's Care Home project team became a regional centre for the Gold Standards Framework for Care Homes

- Team commenced 2008
  - 5.5 FTEs covering 5 clinical commissioning groups
  - 1.4 million population)
  - 71 nursing homes + 75 residential care homes for older people

- Development of end of life care through implementation of GSF (system) for greater PC approach + support of staff (lifeworld)

Process of GSFCH Implementation:
Preparation – Training – Consolidation – Accreditation

Stage I Preparation	Stage II Training	Stage III Consolidation + Sustainability
3-6 months	workshops in 9 months	9 – 12 months

Enrolment of Care Homes

Awareness Raising Meeting

ADA Before

Local Coordinators Meetings

Workshop 1

Workshop 2

Workshop 3

Workshop 4

ADA After

Ongoing ADA

Final Appraisal

GSFCH Accreditation

Comparison of data on DNaCPR; ACP & ICP – 2009 to 2012

Care Home Project Team, St Christopher's, London

	PCT 1	PCT 2 & 3	PCT 4	PCT 5	Total
DNaCPR: 2009/10 2010/11 2011/12	43% (n=155) 45% (n=218) 75% (n=214)	41% (n=265) 74% (n=329) 84% (n=284)	68% (n= 384) 75% (n= 435) 86% (n=492)	54% (n=271) 71% (n=397) 76% (n=361)	52% 66% **80%**
ACP: 2009/10 2010/11 2011/12	48% (n=155) 62% (n=218) 76% (n=214)	44% (n=265) 61% (n=329) 60% (n=284)	60% (n= 384) 74% (n= 435) 83% (n=492)	51% (n=271) 63% (n=397) 79% (n=361)	51% 65% **75%**
ICP for last days: 2009/10 2010/11 2011/12	33% (n=155) 59% (n=218) 70% (n=214)	5.5%(n=265) 30% (n=329) 51% (n=284)	44% (n=384) 60% (n= 435) 72% (n= 492)	17% (n=271) 37% (n=397) 59% (n=361)	25% 47% **63%**

Comparison of place of death across nursing care homes

2007 / 2008	2008 / 2009	2009 / 2010	2010/ 2011	2011/ 2012	2012/ 2013	2013/ 2014	2014/ 2015
Percentage of deaths occurring in nursing care homes							
57%	**67%**	**72%**	**76%**	**78%**	**77%**	**76%**	**79%**
[n=324 deaths across 19 NHs]	[n=989 deaths across 52 NHs]	[n=1071 deaths across 53 NHs]	[n=1375 deaths across 71 NHs]	[n=1351 deaths across 71 NHs]	[n = 1375 deaths across 72 NHs]	[n = 1232 deaths across 72 NHs	[n = 1474 deaths across 76 NHs]

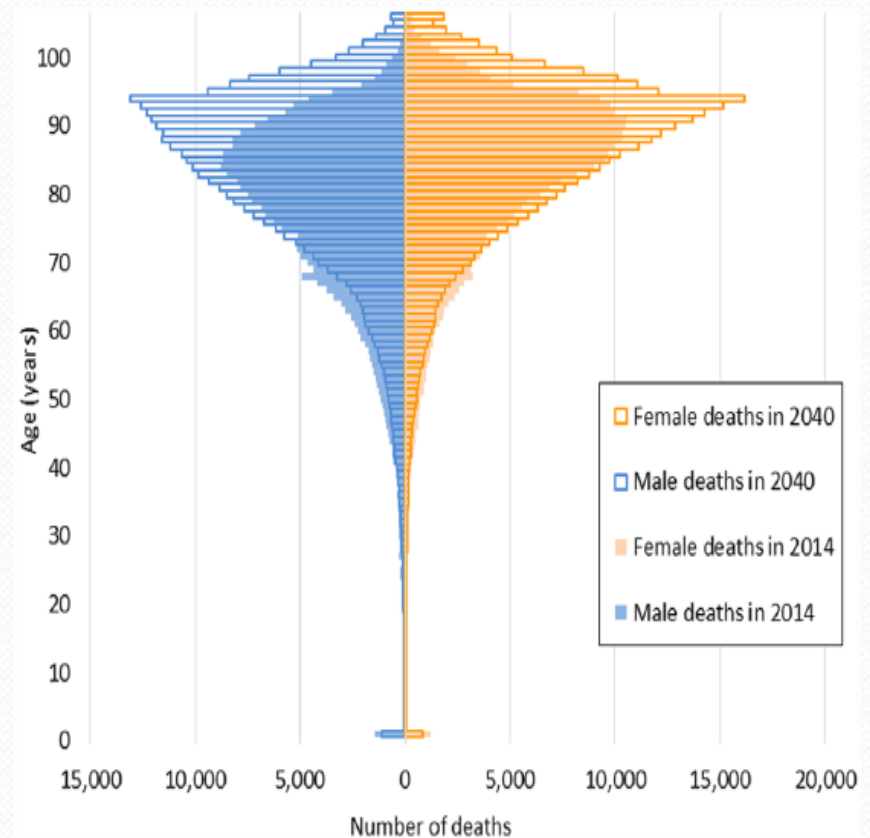# Type of death
[n=2369 – Kinley et al, 2013]

Sudden	Acute	Terminal	Dwindling
When a resident collapsed & died or found to have died totally unexpectedly	When deterioration occurred over a few days i.e. Following fractured femur or extension of stroke	Diagnosis of cancer, Parkinson's disease, motor neurone disease or admitted specifically for terminal care	Slow deterioration over a matter of weeks/months
4.3%	19.2%	26.2%	50.3%

Lessons we have learnt when developing end of life care in care homes

- Important to empower Care Home staff – not take over
- Any development has to be collaborative with a 'top down' + 'bottom up' strategy
- Importance of developing practice through various interventions but sustainability is not without cost
- End of life care for frail older people in care homes is different from SPC
- Involvement of the whole m/disciplinary team:
  - GPs; CPNs; psycho-geriatricians; SPC; district nurses (RHs)

Impact of population ageing

- The disabled older population will increase by over 80% and those with dementia by 50% by 2030 (Jagger et al 2009)

- By 2040, it is predicted that 40% UK population will die in care homes (Bone et al, 2017)

Age (years)

Number of deaths

Legend:
- □ Female deaths in 2040
- □ Male deaths in 2040
- ■ Female deaths in 2014
- ■ Male deaths in 2014

Bone et al (2017) What is the impact of population ageing on future provision of end-of-life care. Pall Med
https://doi.org/10.1177/0269216317734435
Jagger et al (2009) The effect of dementia trends and treatments on longevity and disability: a simulation model based on the MRC Cognitive Function and Ageing Study (MRC CFAS) *Age and Ageing* 2009; 38: 319–325
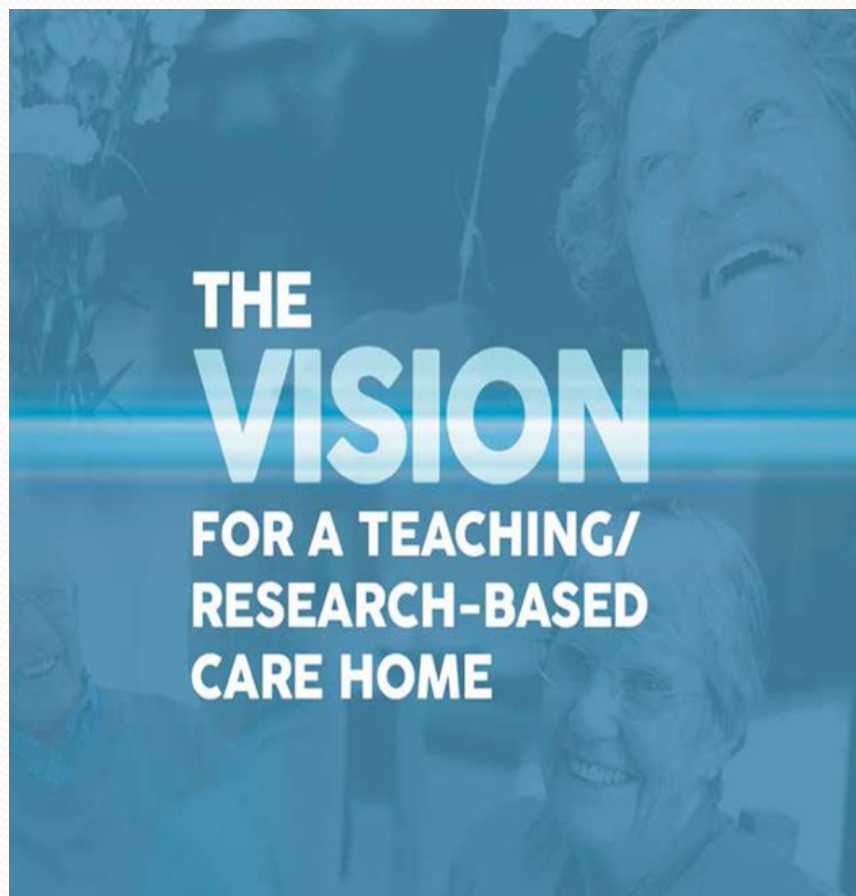
Sustainability is not without cost!

(Hockley & Kinley, IJPN 2016)

However, sustainability can be cost effective!!

THE
VISION
FOR A TEACHING/
RESEARCH-BASED
CARE HOME

To bring a sea-change to the perception of care homes
both public + professional
just as hospices brought a change in the perception of
end-of-life care for people with cancer

Thank you!
Any questions?

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References:

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Hockley J & Kinley J (2016) A practice development initiative supporting care home staff deliver high quality end-of-life care. International Journal of Palliative Nursing, 22(10): 474-481.

Kitson et al (1998) Enabling the implementation of evidence based practice: a conceptual framework. Quality in Health Care, 7:149–158