Policy imperative

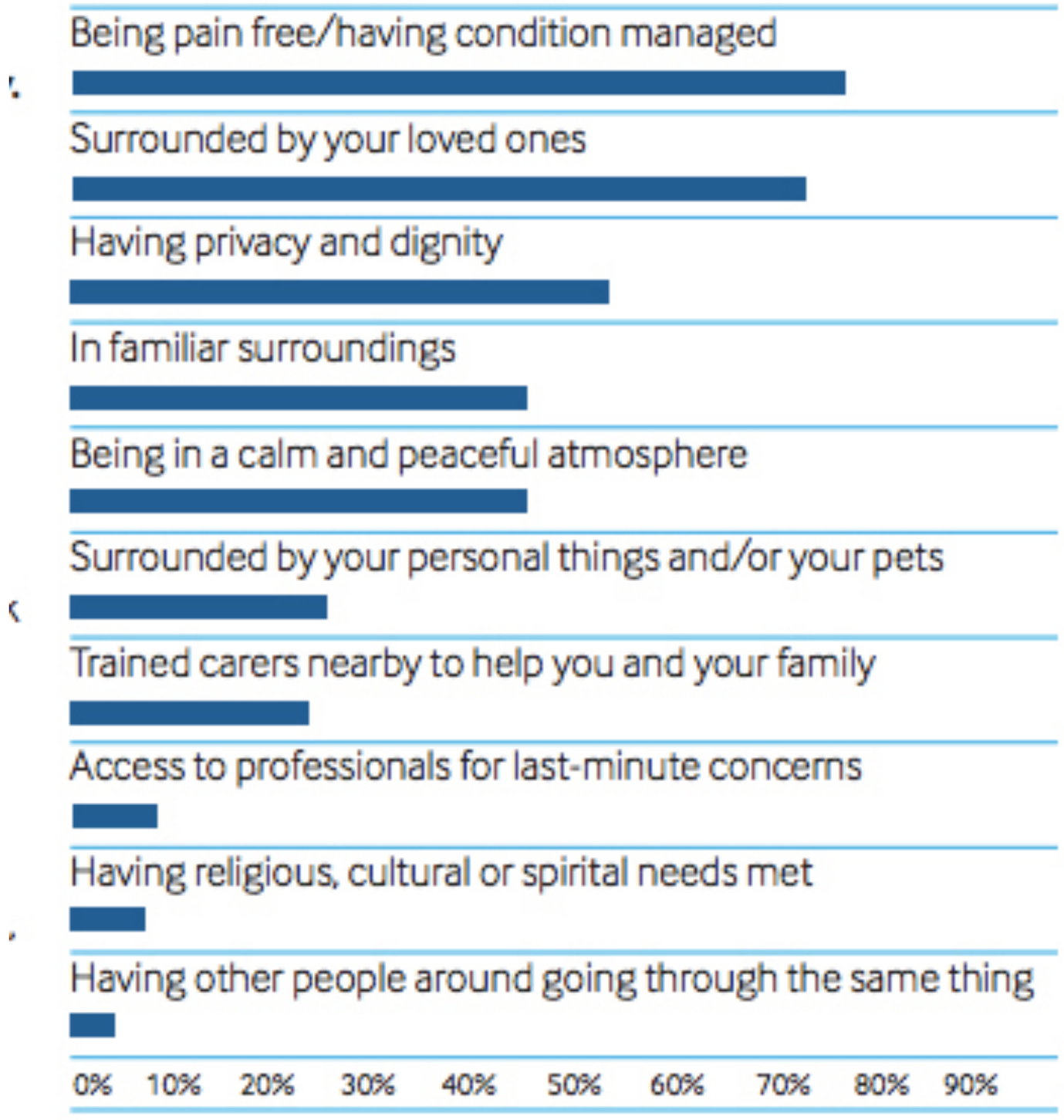
Actions for End of Life Care: 2014-16 :
Shift in focus from ‘place of death’ to the broader ‘experience’ of end of life care

Ambitions for Palliative and End of Life Care: 2015-20: collaboration and individual approach

National End of Life Care Intelligence Network:
Place of death in ‘usual place of residence’ ie home or care home - used as a proxy marker for quality. Key performance indicator

		Count	Value	Value	Value	Worst/ Lowest	Range	Best/ Highest
Hospital deaths (%), Persons, Aged 0 - 64 years.	2015	146	51.6%	48.9%*	45.5%	28.3%		64.2%
Hospital deaths (%), Persons, Aged 65 - 74 years.	2015	95	51.6%	53.6%*	48.9%	35.6%		67.6%
Hospital deaths (%), Persons, Aged 75 - 84 years.	2015	163	54.5%	57.2%*	50.4%	39.8%		72.5%
Hospital deaths (%), Persons, Aged 85 years and over.	2015	189	61.0%	52.3%*	43.7%	33.2%		67.2%
Hospital deaths (%), Persons, All Ages.	2015	593	55.1%	53.2%*	46.7%	36.1%		68.1%
Care home deaths (%), Persons, Aged 0 - 64 years.	2015	3	1.1%	2.1%*	2.9%	0.0%		13.5%
Care home deaths (%), Persons, Aged 65 - 74 years.	2015	8	4.3%	6.9%*	8.4%	2.8%		21.4%
Care home deaths (%), Persons, Aged 75 - 84 years.	2015	17	5.7%	13.1%*	19.5%	5.7%		31.4%
Care home deaths (%), Persons, Aged 85 years and over.	2015	45	14.5%	26.3%*	37.8%	13.6%		51.9%
Care home deaths (%), Persons, All Ages.	2015	73	6.8%	15.0%*	22.6%	6.7%		34.4%
Home deaths ((%), Persons, Aged 0 - 64 years.	2015	74	26.1%	30.2%*	33.7%	22.5%		46.6%
Home deaths (%), Persons, Aged 65 - 74 years.	2015	50	27.2%	27.5%*	30.6%	20.8%		39.3%
Home deaths (%), Persons, Aged 75 - 84 years.	2015	85	28.4%	21.9%*	23.2%	15.4%		30.4%
Home deaths (%), Persons, Aged 85 years and over.	2015	58	18.7%	17.5%*	15.5%	8.9%		27.1%
Home deaths (%), Persons, All Ages.	2015	267	24.8%	22.8%*	22.8%	18.2%		30.1%
Deaths in Other Places (%), Persons, Aged 0 - 64 years.	2015	25	8.8%	8.2%*	7.3%	1.1%		18.0%
Deaths in Other Places (%), Persons aged 65 - 74 years.	2015	8	4.3%	1.9%*	2.0%	0.0%		6.3%
Deaths in Other Places (%), Persons, Aged 75 - 84 years	2015	5	1.67%	1.27%*	1.30%	0.00%		5.84%
Deaths in Other Places (%), Persons, Aged 85 years and over.	2015	1	0.32%	0.91%*	0.97%	0.00%		6.33%
Deaths in Other Places (%), Persons, All Ages.	2015	39	3.62%	2.57%*	2.16%	0.88%		5.50%
Hospice deaths (%), Persons, Aged 0 - 64 years.	2015	35	12.4%	10.4%*	10.8%	0.0%		21.4%
Hospice deaths (%), Persons, Aged 65 - 74 years.	2015	23	12.5%	10.1%*	10.1%	0.0%		26.6%
Hospice deaths (%), Persons, Aged 75 - 84 years.	2015	29	9.7%	6.4%*	5.6%	0.0%		16.8%
Hospice deaths (%), Persons, Aged 85 years and over.	2015	17	5.48%	3.00%*	2.00%	0.00%		8.88%

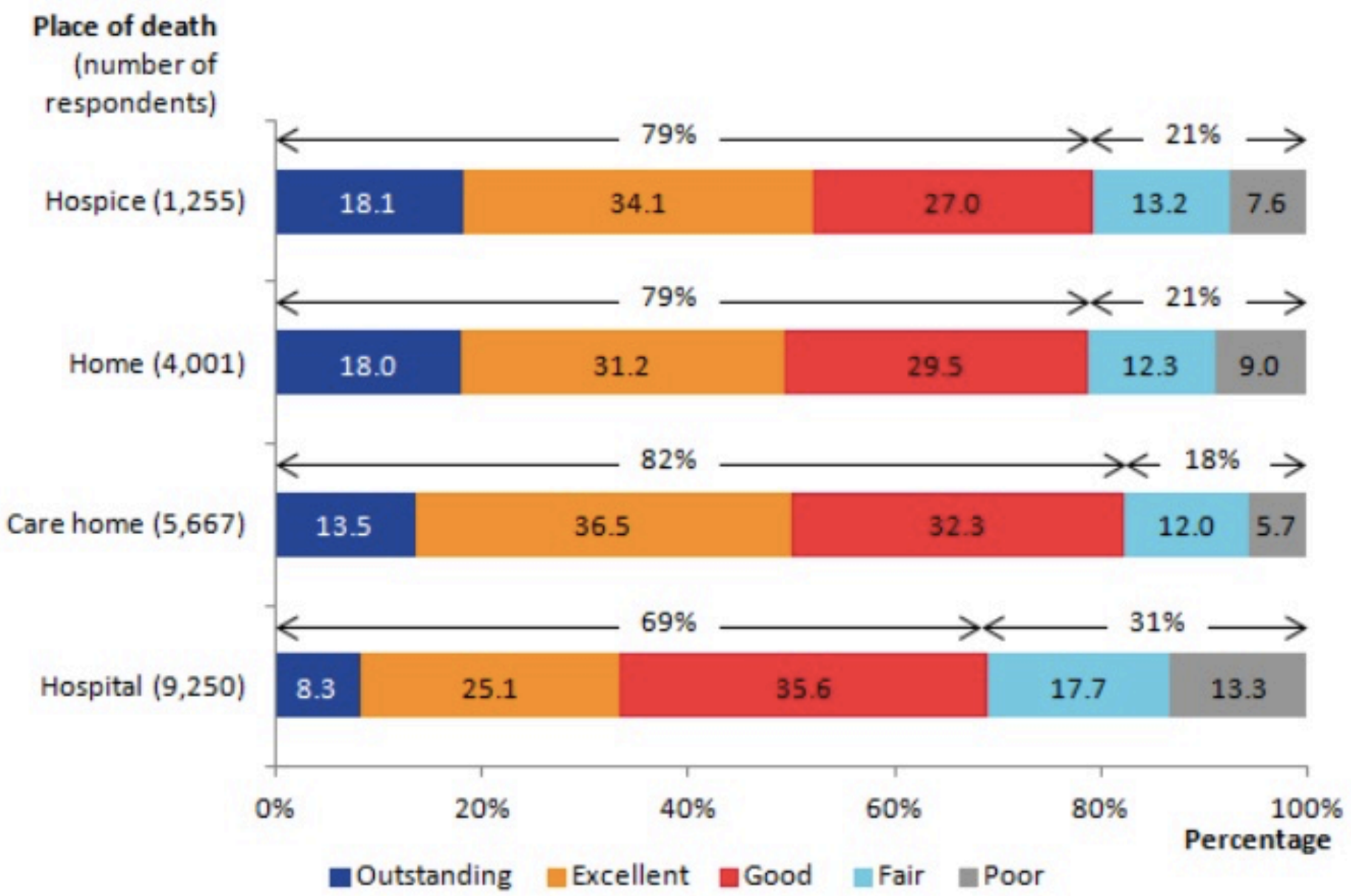
Which of the following would be most important to you regarding how you spend your final days?



ReSPECT video

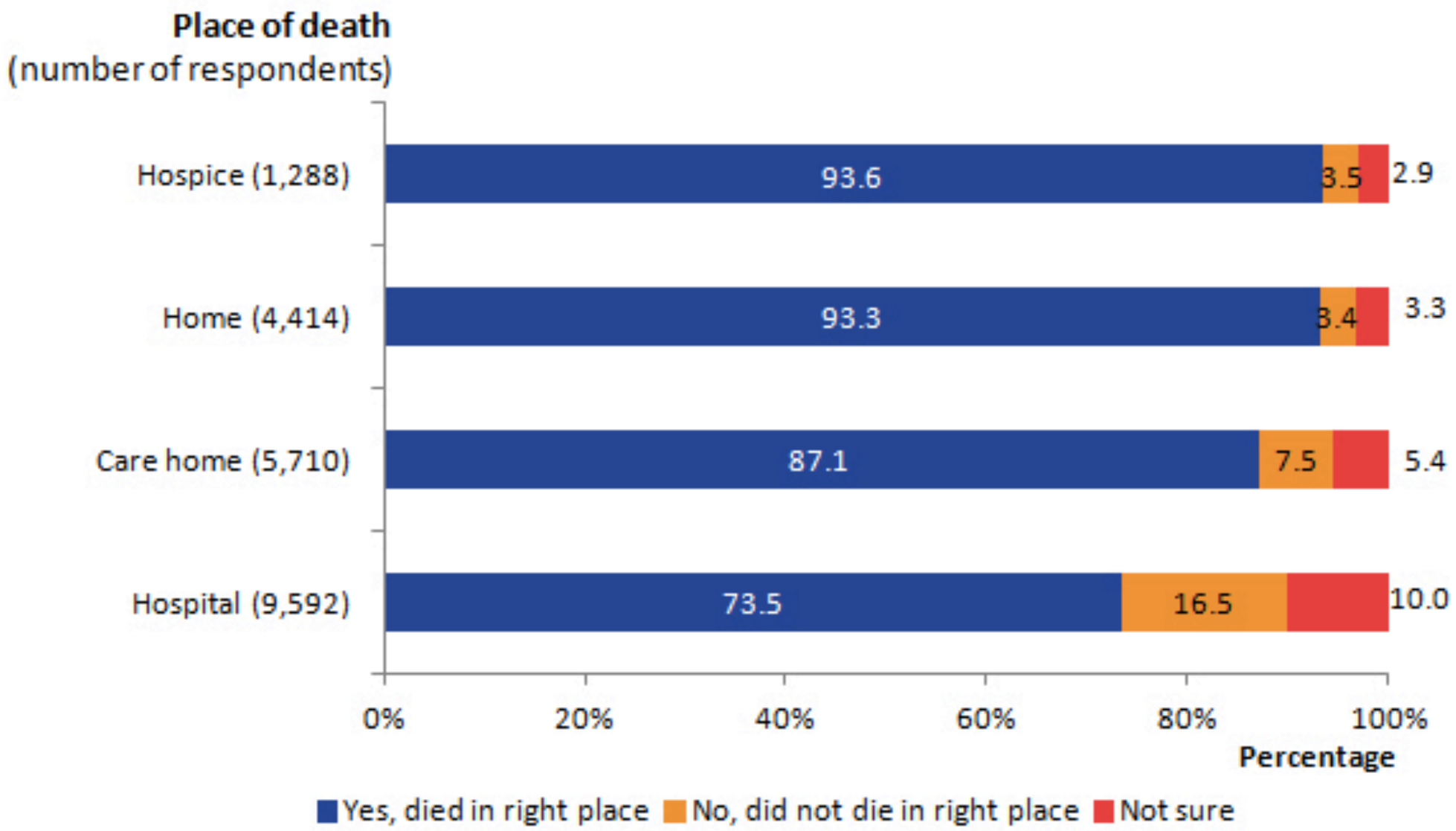
Quality / place of death:

Voices 2015 data

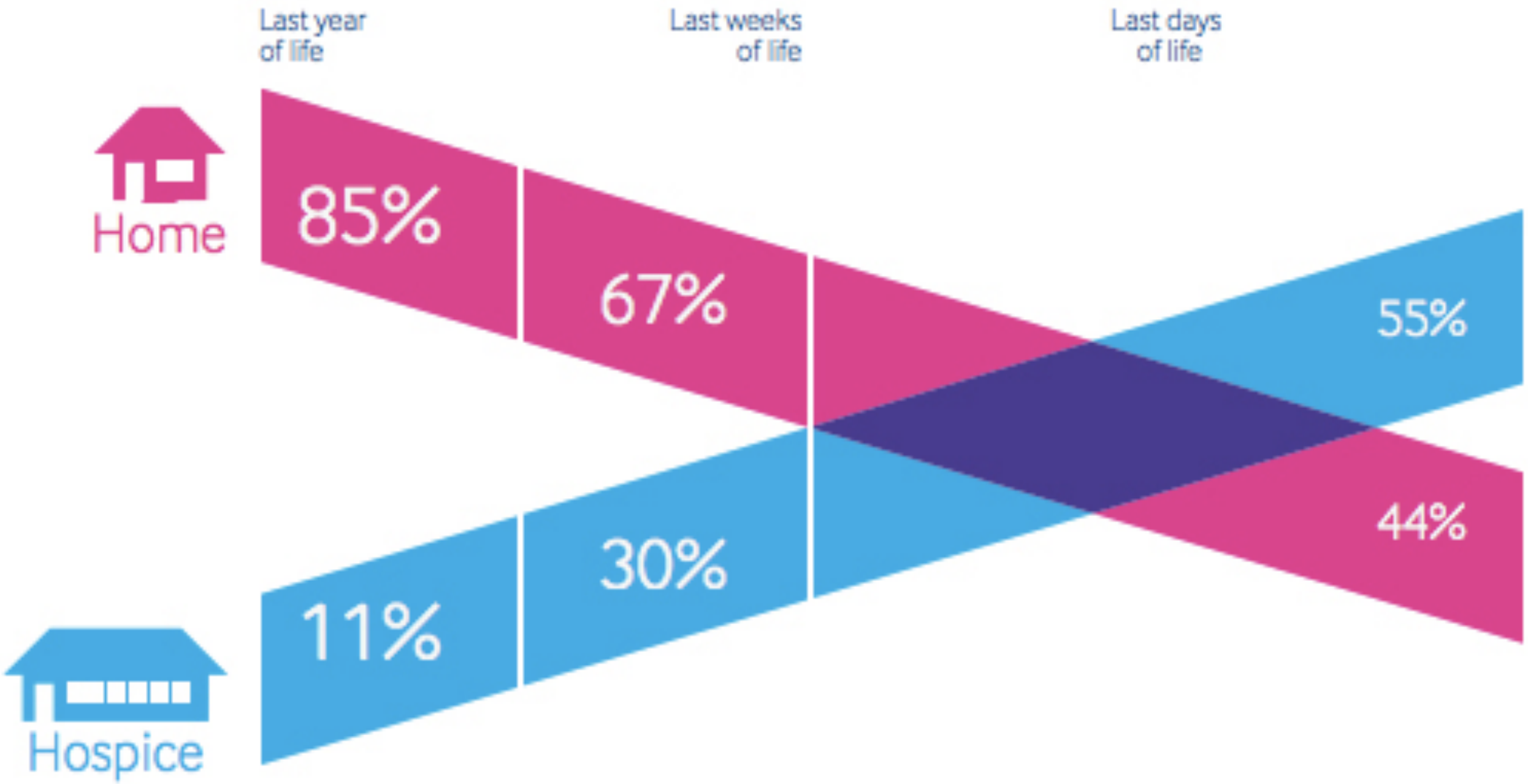


Right place of death?

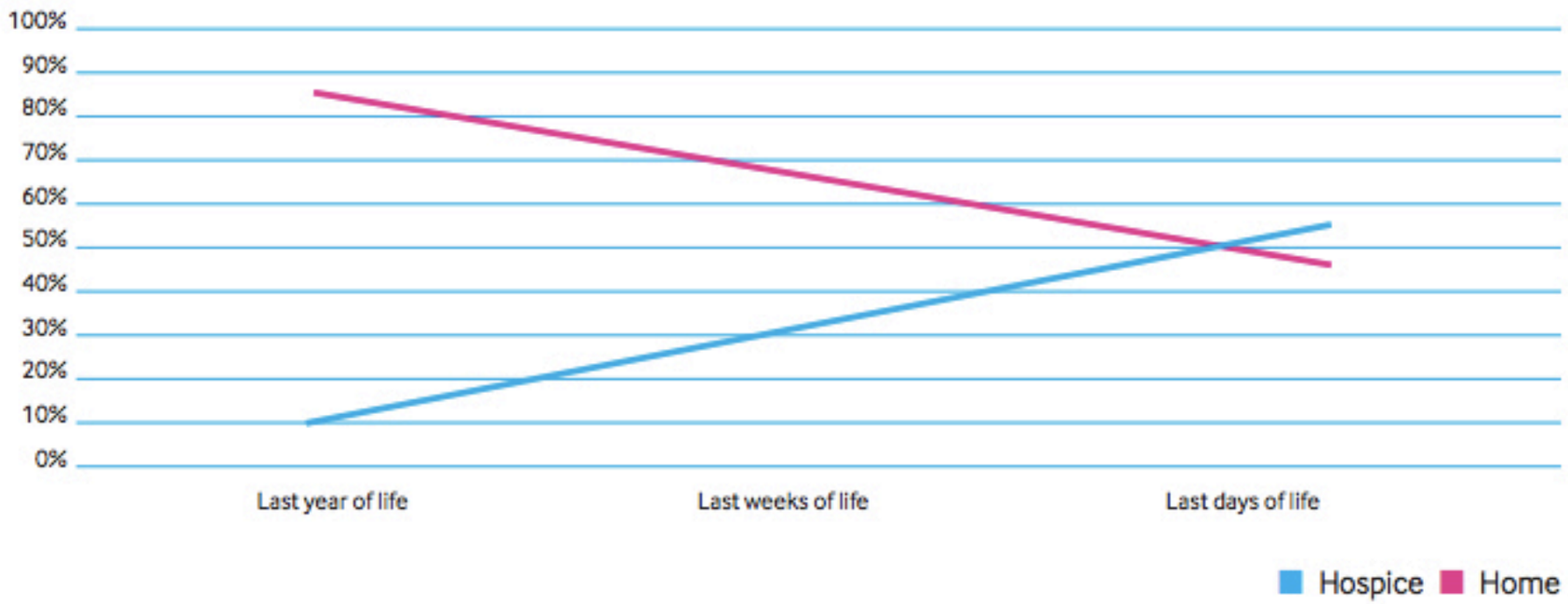
Voices 2015 data



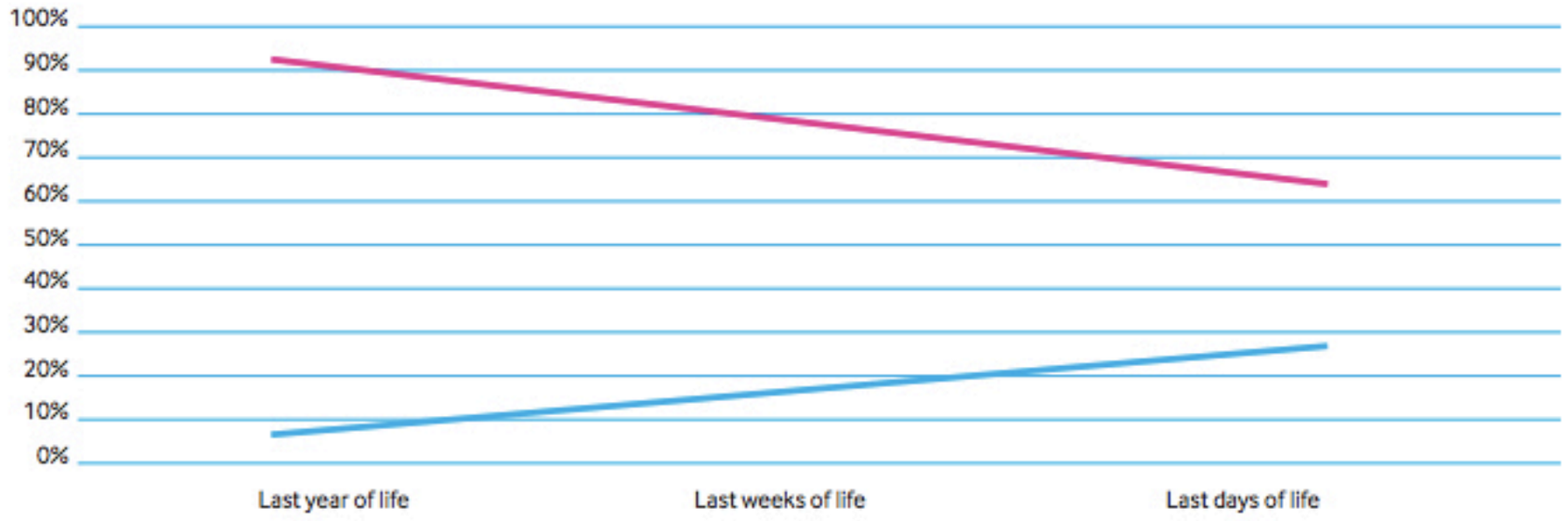
Where do people want to be cared for at the end of their life?



Where would you like to be? People with hospice experience.



Where would you like to be? Home vs. hospice



[37] A Paget and C Wood, 2013

Payne on practicalities

Policy makers “tend to have romantic and very middle-class notions of what homes are like”. But ….

- Housing stock
- Poverty?
- Fuel poverty?
- Laundry?
- Food for special diets?
- Adaptations too late / impractical / resisted?
- Carers able and willing - for long-term, heavy work?

Place of care isn't the same as place of death

Sleeman 2017: ED attendance by people with dementia

79% of people with dementia had one or more ED attendance in their last year of life

44% attended ED in their last month, and 21% in their last week of life.

Mean 2.4 ED attendances during the last year of life (during 2012-13 - up from 1.6 during 2008-9)

Being resident in a care home was associated with fewer ED attendances

Schwarze 2017: Scenario planning

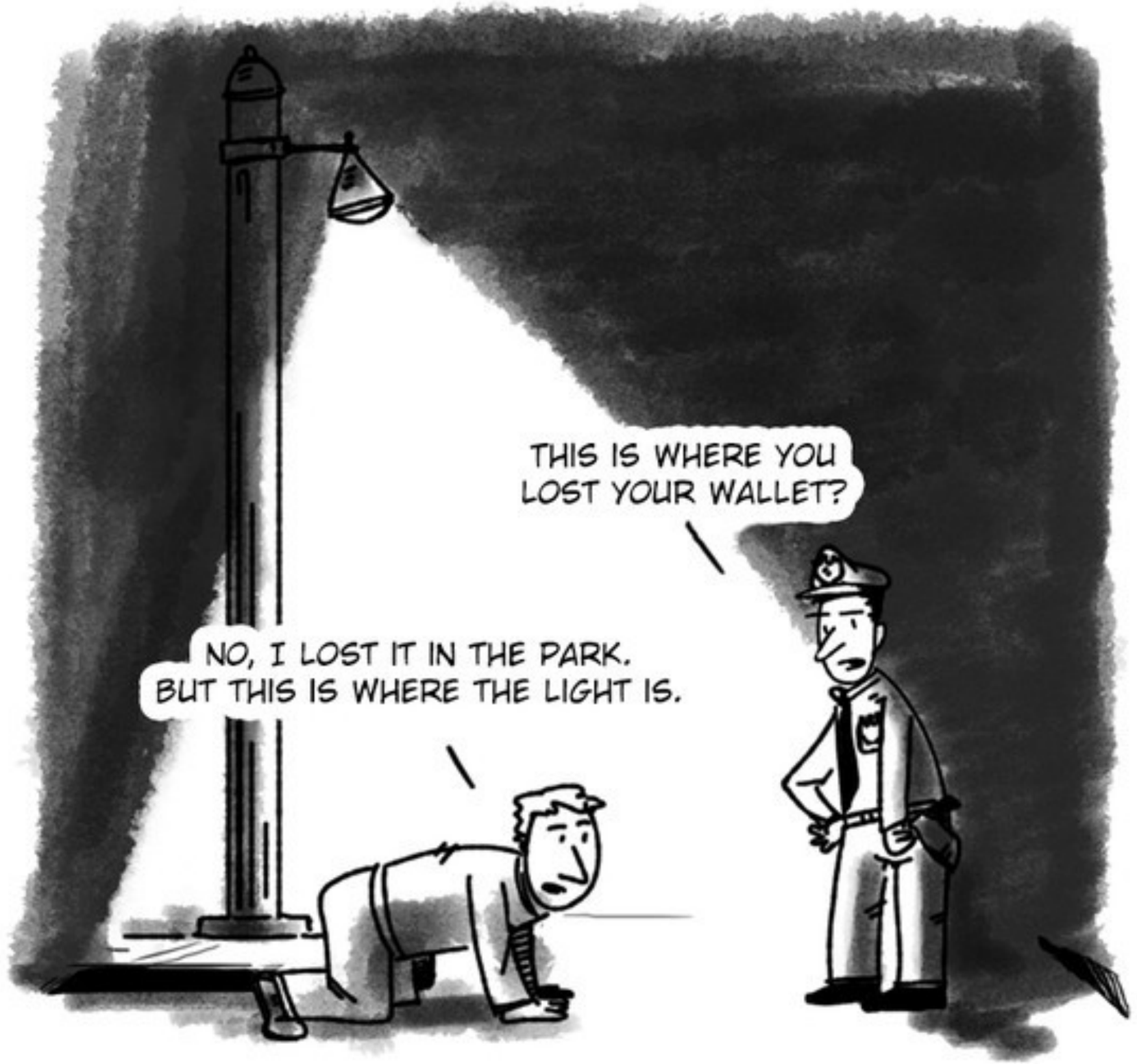
- Overwhelming information means … blind spots for poor outcomes
- Multiple plausible futures under various sets of assumptions
- Accept uncertainty and use it: think about events that have already happened or are likely to occur but whose sequelae are yet to unfold
- With patient, explore Best, Worst and Usual case
- Interplay between acute illness, coexisting conditions, and health outcomes
- Emotional preparation for treatment burdens

What’s not counted … doesn’t count

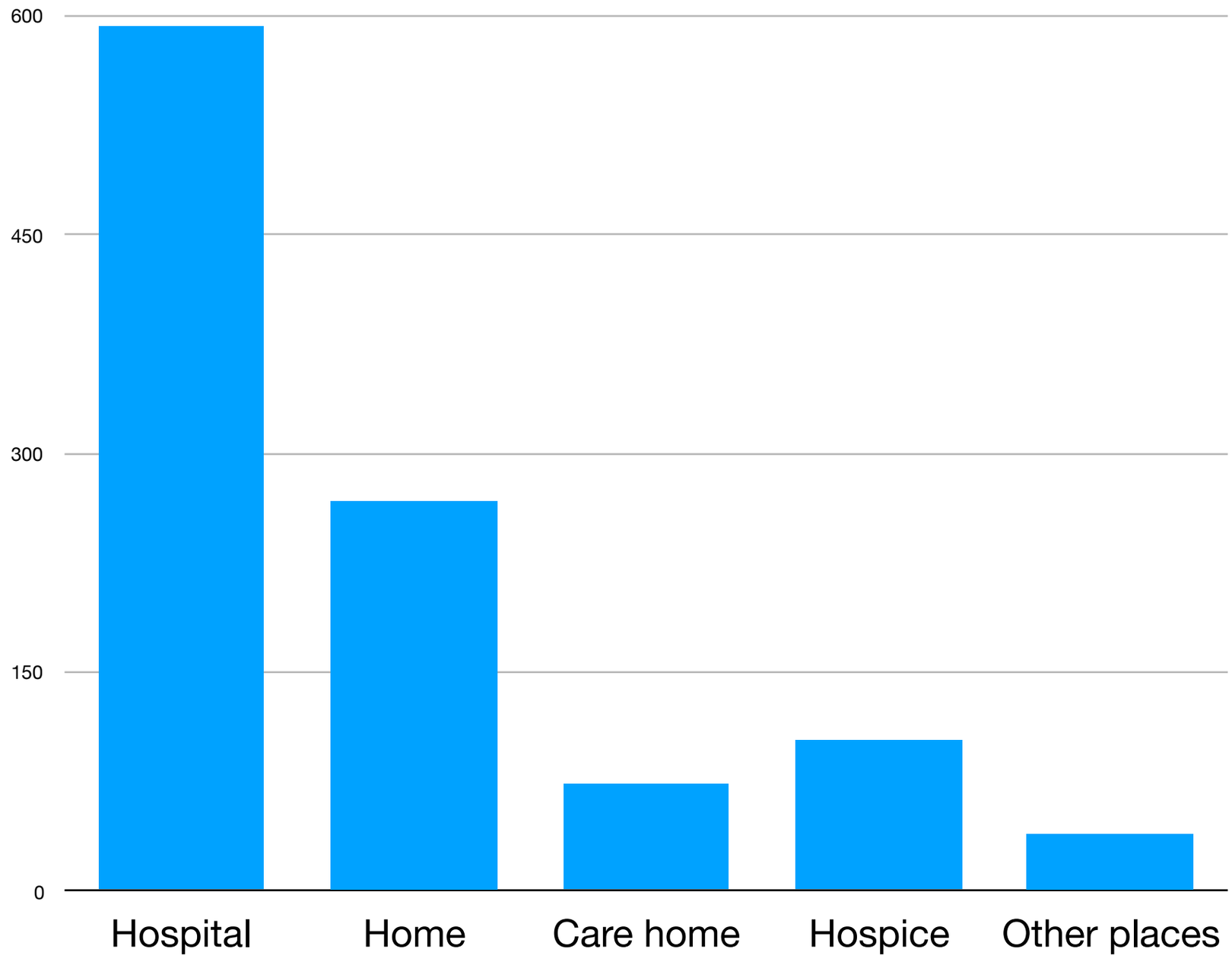
What’s not counted …

CEMD
(CONFIDENTIAL ENQUIRIES INTO MATERNAL DEATH)

SALSO
2016


THIS IS WHERE YOU LOST YOUR WALLET?
NO, I LOST IT IN THE PARK. BUT THIS IS WHERE THE LIGHT IS.

Place of death: Tower Hamlets 2015



Downwards trend …

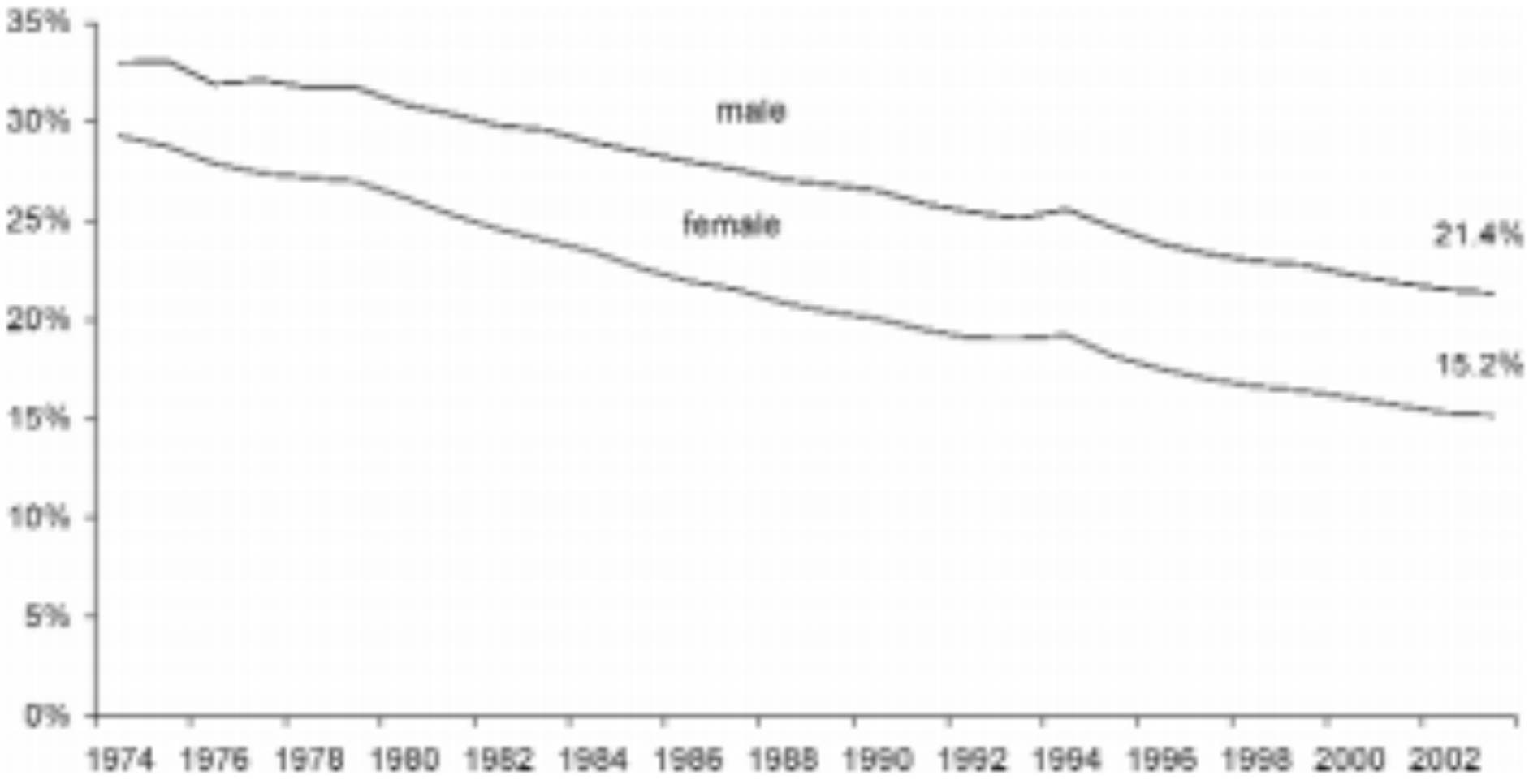
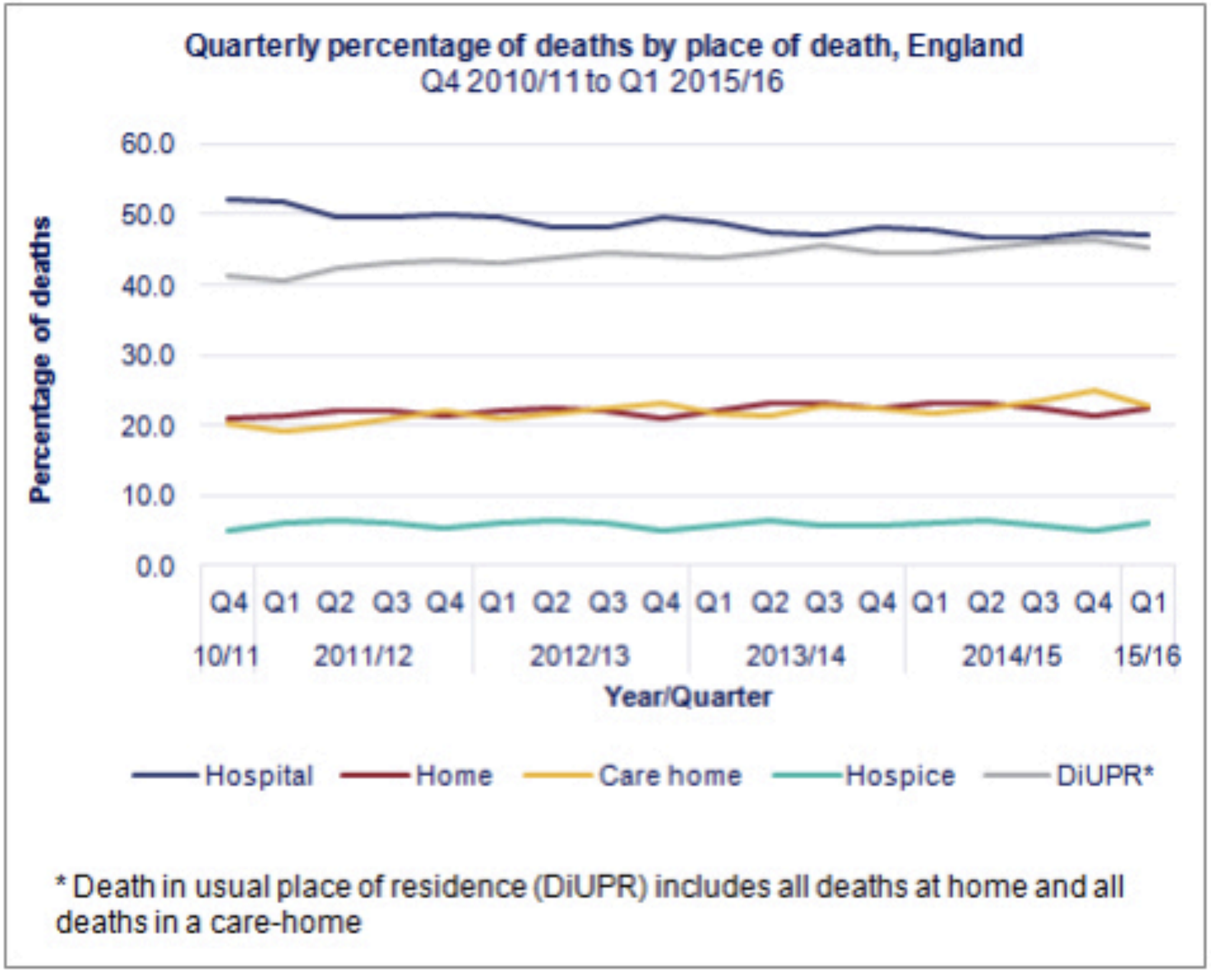


Figure A Proportions of home deaths by gender, 1974–2003



* Death in usual place of residence (DiUPR) includes all deaths at home and all deaths in a care-home

Demographic time bomb

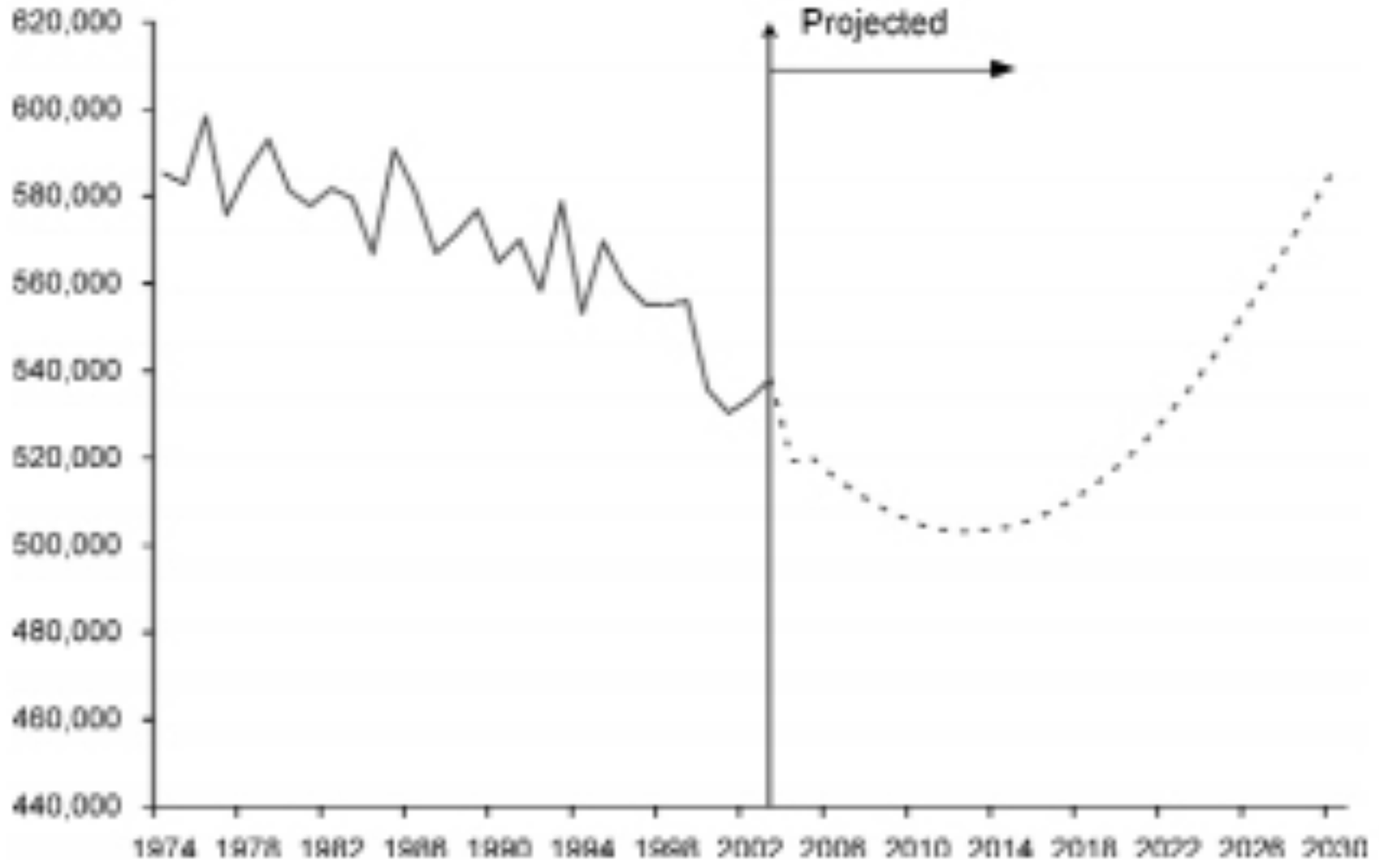


Figure 4 Actual and projected deaths, 1974–2030. Data

Hospital deaths: 593

Age group	Tower Hamlets	England
Overall - BIT HIGH	55.1%	46.7%
0-64: 146	51.6%	45.5%
85 plus - HIGH: 189	61.0%	43.7%

Home deaths: 267

Age group	Tower Hamlets	England
Overall - BIT HIGH	24.8%	22.8%
0-64 - LOW: actually 74	26.1%	33.7%
75-84 - HIGH: actually 85	28.4%	23.2%

Care home deaths: 73

Age group	Tower Hamlets	England
Overall - LOW	6.8%	22.6%
75-84 - LOWEST: 17	5.7%	19.5%
85 plus - LOW: 45	14.5%	37.8%

Older South Asians living in East London: Ramasamamy 2013

- 5 Focus groups and 29 interviews
- Dominant voices / young male researcher
- Exended family ‘knows what to do’: delegation of decisions. But ambiguity
- Avoidance as cultural norm / protection : talking as inauspicious and fearful
- Cultural transferability: language
- Second generation??

Hospice deaths: 104

Age group	Tower Hamlets	England
Overall: HIGH	9.7%	5.6%
0-64: largest age group: 35	12.4%	10.6%
75-84: HIGH: but only 29	9.7%	5.6%
85 plus: HIGH: but only 17	5.5%	2.0%

Sleeman 2015: changing demographics of inpatient hospice death

- Hospice deaths increased from 3.4% of all deaths in 1993 to **6.0% in 2012**

- Increase over time smallest for most **deprived areas** residence (3.3% 1993 / 5.3% 2010), and greatest for least deprived

- Only 5.2% had **non-cancer diagnose**s, though this increased over time. No info on dementia

- 50.6% hospice decedents men : though **“dying is a feminist issue”**

- Mean age 69.9. Likelihood of being over 85 increased over time

- “Age is not the most important issue in palliative care”
- Care homes, dementia and capacity
- Community initiatives

Deprived areas are “another planet”

- Least deprived areas: a quarter of people aged 75 have long term health problems or disability.

- Most deprived areas: healthy life expectancy only 53, with 17 years in bad health before death

- Multi-morbidity starts 10 years earlier: COPD and HF patients don’t subscribe to ‘revivalist’ model of ‘good death’ in specialist palliative care

- What’s ‘Geriatrics?

- Carers in their 20s looking after deprived ill parents

- Inverse care law: Single-condition people have easy, expensive elective interventions AND policy-makers think least deprived is ‘normal’

Place of death a feminist issue …

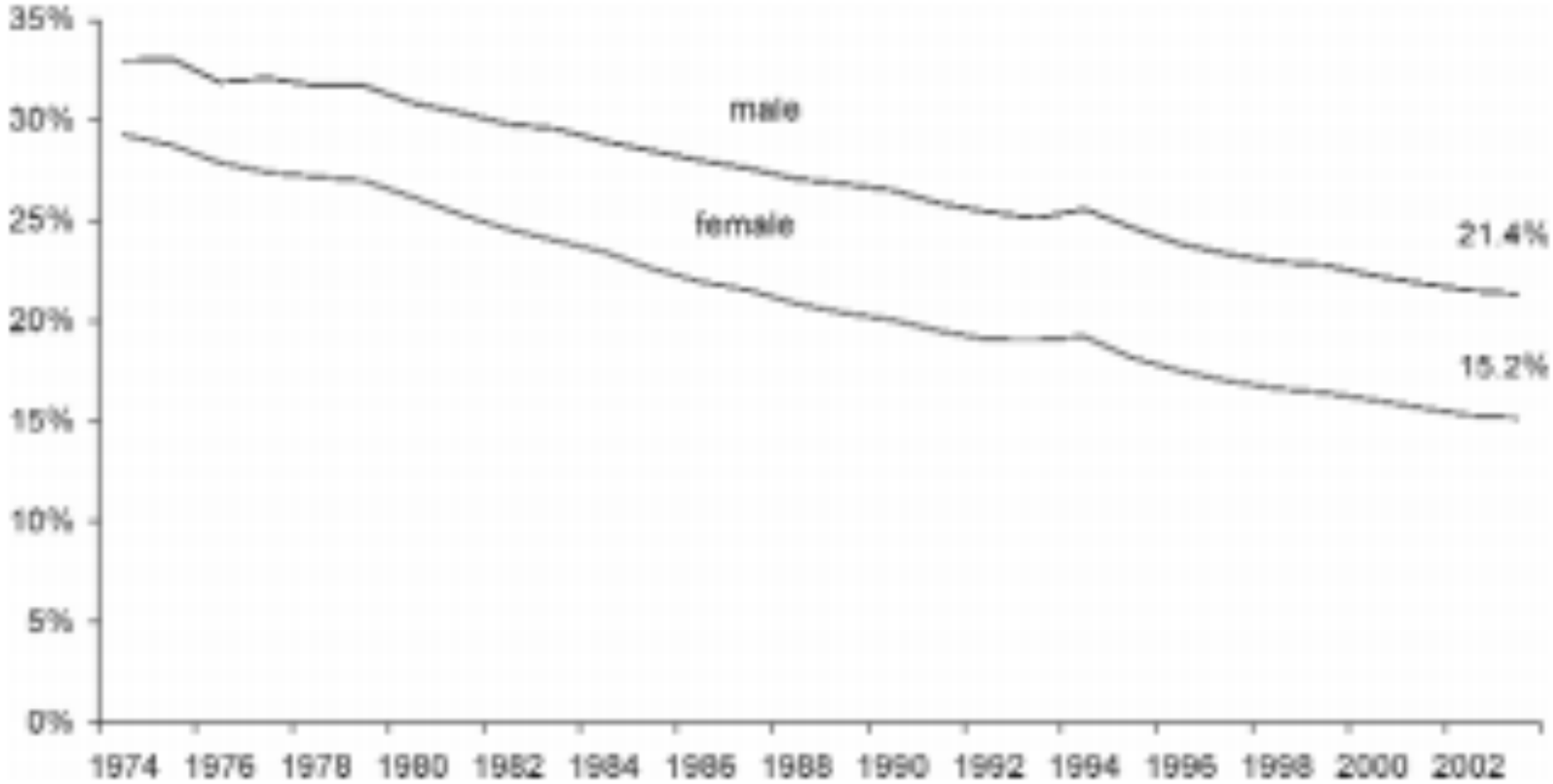


Figure A Proportions of home deaths by gender, 1974–2003

Women and Care homes

Women die later than men - after they've looked after their husbands

- Scotland 1999-2012: 16% drop in hospital deaths and 30% increase in care home deaths

- Scotland 2012/3: 13% male deaths in care home 26% of female deaths

So why does hospice have 50% men? Equitable?

2017 Care home survey

- About specialist palliative care - not overall / generic (except respondent 116) : Silos

- Staff self-reports of good practice (“was thought to”) and ‘challenges’

- Data issue - are they imaginative enough?

- Dementia previously noted as gap: not much detail here

- Bereavement hardly mentioned

- How does ‘revivalist’ model fit with ‘frailty’?

Care / nursing homes

- Care rated highly overall … but
- The choice is: stay where you are / get admitted to hospital

- Median life expectancy in nursing homes is 15 months

One in four residents die within the first year

- 80% care home residents have dementia or other mental impairment

Two-thirds live with urinary or faecal incontinence or both

Home closures …

Janet Finch-Saunders AM/AC

Assembly Member for Aberconwy
Aelod Cynulliad dros Aberconwy

Shadow Secretary for Local Government
Ysgrifennydd yr Wrthblaid ar gyfer Llywodraeth Leol

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Ref: TYH/JFS/HM
5th October 2016

<u>Re: Plas Isaf nursing home</u>

Dear Cllr Roberts, Dilwyn,

I am writing to you to express my own concerns following the announced closure of Plas Isaf, due to being 'financially unviable'. Whilst situated in Rhos-on-Sea, this closure will directly affect my own constituents, and I am currently in the process of making representation for one family in particular. I understand that the situation currently leaves some 21 elderly and vulnerable residents requiring EMI placements and that these need to be acquired within just 17 days.

There are, of course, implications for the health and care workers employed there also.

My primary purpose therefore in writing to you is to request, as a matter of some urgency, an explanation as to how your authority will be dealing with the impact of this imminent closure. Further, I would wish to also seek some clarity as to how those residents affected will be provided with new placements and within the county of Conwy.

Indeed, enquiries made by my office in November 2015 requesting the number of available EMI placements, at that time, identified only 2 potential available EMI nursing placements, and approximately 4 available EMI residential beds. As you can appreciate, this current situation has the potential to place a significant number of elderly and vulnerable residents, to include their families, facing much uncertainty.

I do hope that you understand the concerns raised and I look forward to hearing from you at your earliest opportunity.

Yours sincerely,

Janet

Janet Finch-Saunders AM/AC

‘Community’: Walshe 2016

- First RCT of volunteer effectiveness
- Wait-list trial : Usual care plus volunteers now, or after 4 week wait
- No sig differences in rate of change of QOL, loneliness, use of health / social services. No adverse effects.
- Positive trends. Maybe a dose effect?
- Clinicians can confidently refer. Policy makers should continue to promote

Problems with Walshe / challenges for volunteer services

- What's the important outcome? How to aggregate eg 3 wishes?
- Getting client referrals
- Matching / finding / accrediting volunteers
- Low or no English clients (and volunteers)
- Urgent referrals near death?

Key points

- Do people actually want home deaths .. or home care?
- Whats not counted doesnt count
- Demographic time-bomb
- Age isn’t most important issue - deprivation / gender / ethnicity-culture
- Scenario planning
- Revivalist model?
- Walshe : methodological problems are pointers