

Planning for End of Life on the Island of Ireland:

Evidence from
The Irish Longitudinal Study on Ageing (TILDA)
and the Northern Irish Cohort for the Longitudinal
Study of Ageing (NICOLA)

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Evidence from The Irish Longitudinal Study on Ageing (TILDA) and the Northern Irish Cohort for the Longitudinal Study of Ageing (NICOLA)

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Executive summary

Background

- > End-of-life care is a policy priority in Northern Ireland ('the North') and the Republic of Ireland ('the South') in the context of documented modifiable problems and growing population health needs.
- > Little is known about the end-of-life experience of people on the island of Ireland, and how this differs between the North and the South. The Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) and The Irish Longitudinal Study on Ageing (TILDA) provide high-quality comparable data on older people (aged 50+ years) on the island.
- > To inform planning for care and services in both jurisdictions, we addressed a series of inter-related research questions on health care use and death preparedness using NICOLA and TILDA data.

Key results

- > For place of death, about half of deaths occurred in hospital in both jurisdictions.
- > For high-intensity treatments near end of life, cancer surgery and chemotherapy were more common in the South of Ireland than the North; heart surgery in the last two years of life was a rare event in both jurisdictions.
- > For unplanned hospital admissions, emergency department visits and overnight hospital visits were both more common in the South than the North.
- > For death preparedness, having a will was more common in the South and having life insurance more common in the North
- > For advance care planning, formal engagement in the South was low. NICOLA does not yet record these data so we don't have equivalent information in the North.

Recommendations

- > Variation in high-intensity treatments near end of life and unplanned hospital admissions warrant further examination in the context of health system differences and population health needs.
- > NICOLA should follow TILDA's question protocol to record participants' advance care planning status both in participant interviews and interviews with a family member in the event that a participant dies.

Introduction

Background

Improving end-of-life care is a policy priority worldwide due to demographic ageing, and the associated shift in population health needs from predominantly acute, episodic care to ongoing supportive care of older adults living and dying with serious chronic disease.¹ Previous research in Ireland has shown significant scope for an improved experience for people approaching end of life and their families: from our recent research in TILDA, those in the last year of life widely report modifiable problems including unmanaged pain and other symptoms, falls, and repeat emergency hospital admissions.²

The need to improve care and supports is compounded by growing population health needs. The number of people dying annually on the island of Ireland will increase approximately 75% over the next 25 years. This growth is mainly accounted for by the Republic of Ireland, which has a younger population than that in Northern Ireland, but needs are growing in both jurisdictions.^{3,4} Not only will the number of deaths increase markedly but the types of supports required will change; those aged 85+ will account for a fast-rising proportion of deaths, and prevalence of dementia as a cause of death will increase significantly.³⁻⁵

Rationale and aims

Little is known about the end-of-life experience of people on the island of Ireland, and how this differs between the North and the South. The Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) and The Irish Longitudinal Study on Ageing (TILDA) provide high-quality data on the same questions for older people (aged 50+ years) on the island.

To inform planning for care and services in both jurisdictions, we addressed a series of inter-related research questions using NICOLA and TILDA data:

RQ1: Intensity of EOL care: What proportion of decedents in NICOLA and TILDA (a) died in hospital compared to other places, (b) had surgery and/or chemotherapy near the end of life, (c) unmanaged pain near the end of life?, (d) had unplanned (ED) hospital admissions in the last year of life?

RQ2: Death preparedness: What proportion of decedents in NICOLA and TILDA had (a) a will, and (b) a life insurance policy?

RQ3: Advance care planning: Since Wave 4, TILDA has asked participants about advance care planning, while NICOLA does not yet do this. We looked at scope to use the death preparedness measures in (RQ2) as a proxy for advance care planning in TILDA, and to explore associations between preparedness and the outcomes specified in (RQ1), in both datasets.

Methods

Data

Both TILDA and NICOLA are part of the Gateway to Global Aging Data family of studies.⁶ Each study collects information on a wide range of topics including health, economic, social and family circumstances for a population-representative sample of community-dwelling adults aged 50+ years. TILDA participants were selected using multi-stage, stratified random sampling that identified 640 geographical regions, defined by socio-economic characteristics, and selected households within each region.⁷ Details of sample maintenance have been published previously.⁸ Wave 1 was conducted between 2009 and 2011, with each participant completing a computer-assisted personal interviews (CAPI) and self-completion questionnaires (SCQ), and a comprehensive health assessment by a trained nurse.⁹⁻¹¹ Subsequent waves are biannual (Wave 2 in 2012, Wave 3 in 2014, etc). CAPI and SCQ follow-up occurs at each Wave; the most recent completed Wave was Wave 6 (2021, delayed from 2020 due to the COVID-19 pandemic).

NICOLA participants were selected from a randomised sample of Northern Ireland addresses obtained from the Business Services Organization (BSO) GP Register Database. Addresses were identified using a multi-stage, systematic approach and stratified according to geographical location and postcode thus ensuring a nationally representative sample.¹² Wave 1 was conducted between 2013 and 2018. Similar to TILDA, three methods of data collection were used in Wave 1: a CAPI conducted by trained fieldwork interviewers in the participant's home, an SCQ which also included a dietary questionnaire, and a comprehensive health assessment conducted by trained registered nurses at the Wellcome Trust-Wolfson Northern Ireland Clinical Research Facility (NICRF) located at the Belfast City Hospital, Belfast (95% of participants) or, where necessitated in the participant's home (5%). Wave 2 took place between July 2017 and 2019. A sample refresh of the 50-54 year old age category was also conducted at the end of Wave 2 between 2019 and 2022 (delayed due to the COVID-19 pandemic). Wave 2 data collection consisted of a CAPI and SCQ (including a separate COVID-19 questionnaire).

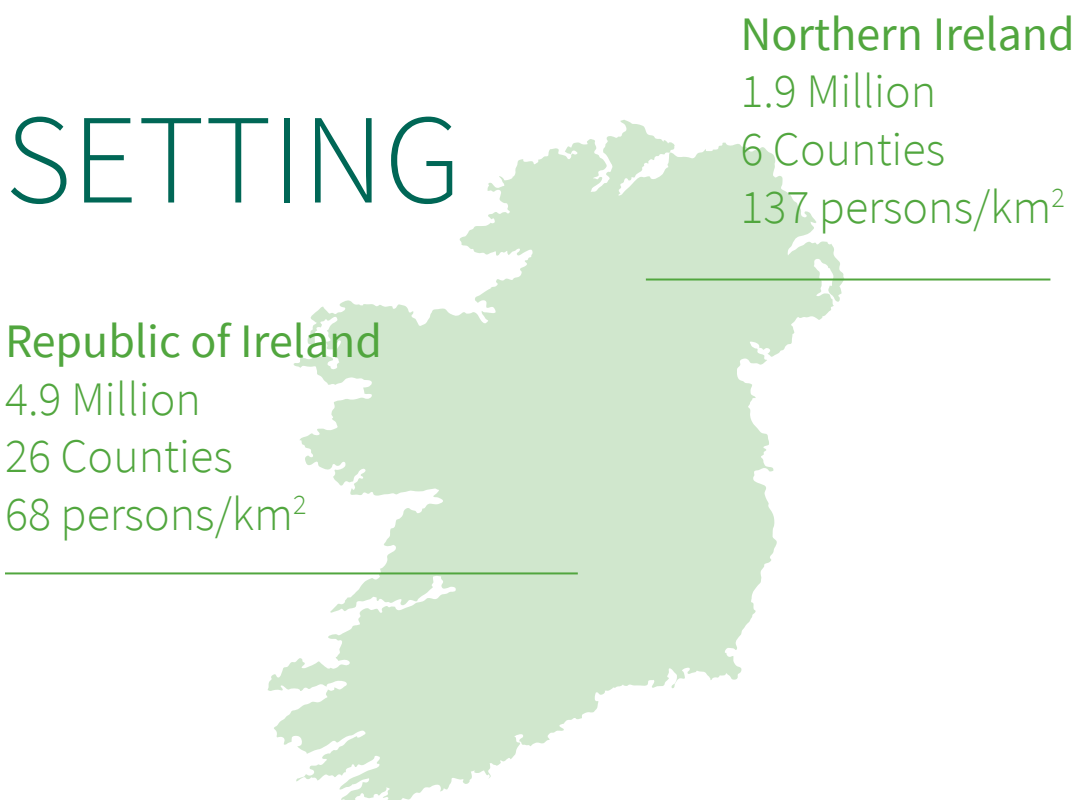
When a TILDA participant dies, family and friends are approached for a voluntary end-of-life interview (EOLI) on the decedent's experience in the last year of life. Details on this process are available elsewhere.² The EOLI covers demographics; disability and level of assistance; physical, behavioural and mental health; and utilisation and assets; and complements equivalent sections of regular TILDA participant interviews.¹³ This report uses all end-of-life interviews completed on behalf of a participant who died between Waves 1 and 6. Similar to TILDA, if a NICOLA participant dies, then a relative, friend, or carer is approached for a voluntary EOLI. The EOLI (introduced during the Wave 2 data collection period) covers cause of death; residence prior to death; I(ADL) and helpers; physical health; behavioural health; cognitive function; mood; healthcare utilisation including costs; assets and life insurance. This report uses all end-of-life interviews completed on behalf of a participant who died between Waves 1 and 2.

Ethical approval for each wave of TILDA is obtained from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin. Written informed consent is obtained for separate components of the study (i.e. interview, health assessment, blood samples); participants may refuse to take part in or withdraw at any time without justification.¹⁴ The EOLI is subject to particular care; an appropriate length of time is left before contacting next-of-kin.

Ethical approval for each wave of NICOLA is obtained from the School of Medicine, Dentistry and Biomedical Sciences Research Ethics Committee in Queen's University Belfast. Written informed consent is obtained from participants for separate components of the study (i.e., interview, health assessment, blood samples, urine samples); participants may refuse to take part in or withdraw at any time from the study without justification.

Setting

Ireland is an island in north-western Europe, divided into 32 counties, 26 of which make up the Republic of Ireland, which is an independent country, and the remaining six make up Northern Ireland, which is part of the United Kingdom. The two jurisdictions are often considered one epidemiological unit, for example in having a shared Institute of Public Health.¹⁵ Potentially relevant differences include population, which is approximately 4.9 million in the South and 1.9 million in the North, and population density, which approximately 68 persons/km² in the South and 137 persons/km² in the North.¹⁶ The Republic's healthcare is provided by a mixed public and private system, and in the North healthcare is generally provided publicly by Health and Social Care Northern Ireland.¹⁷



Variables

Outcomes of interest

All outcome variables were taken from questions in the EOLI of the TILDA and NICOLA studies. These questions and possible responses are listed in Table 1.

Table 1: Outcome measures, and their source in the NICOLA and TILDA interviews

Research question	Question in NICOLA/TILDA*	Answer in NICOLA/TILDA
1(a). Death in hospital	Where did [Name of deceased] die?	Hospital one of the specified, mutually exclusive options. We created a binary variable ‘died in hospital?’ Yes/No
1(b). High intensity treatments near end of life	In the last two years before <his/her> death, did <he/she> have surgery on <his/her> heart?	Yes/No
	What sort of treatments had [he/she] received for cancer?	Surgery and chemotherapy among the specified, not mutually exclusive options. We created two binary variables ‘had surgery?’ and ‘had chemotherapy?’ Yes/No
1(c). Pain	Was <he/she> often troubled with pain?	Yes/No
1(d). Unplanned admissions	Can you tell me how many times did [Name of the deceased] visit a hospital Emergency Department (sometimes called A&E or Accident and Emergency) in the last 12 months?	Respondent gives an integer
2(a). Will	Did [name of deceased] have a will?	Yes/No
2(b). Life insurance	Did the [Name of deceased] own any life insurance policies that were paid out on [his/her] death?	Yes/No
3. Advance care planning [§]	Have you made your wishes/preferences known about the kind of care that would like to receive in the event of serious illness?	Four non-exclusive answers: i. Informally by conversations with relatives/ significant others ii. Informally by conversations with medical professionals iii. Formally by documenting in writing [your/his/her] wishes for example completing a “Living Will”, “Advance Care/Healthcare Directive” or “Think Ahead” document? iv. None of these Three exclusive categories: i. Had a formal plan ii. Informal discussions only iii. Neither

*Each question was worded identically in both studies. †Don’t know and refuse to answer are options for all CAPI and EOLI questions.[§]All questions from the NICOLA and TILDA EOLIs except 3, which is taken from TILDA CAPI Wave 4; TILDA asks about advance care planning but NICOLA does not.

Explanatory variables

To define the sample, we extracted variables that we hypothesised were potentially associated with our outcomes of interest. These variables are listed in Table 2.

Age at death was calculated in years by combining date of birth (recorded via CAPI at study enrolment) and date of death (recorded via EOLI). Sex and educational achievement were recorded via CAPI at study enrolment. Marital status, cause of death, length of illness, functional limitations and time spent living in different places in the last two years of life were recorded via EOLI.

Statistical methods and missing data

For RQ1 and RQ2, we calculated prevalence of specific outcomes as well as mean hospital visits using simple descriptive statistics. Where an EOLI respondent refused or did not know the answer to a question, that participant was excluded from those statistics and the number of such cases quantified and reported.

For RQ3, we wanted to measure how well having a will (2a) or life insurance (2b) predicted advance care status in TILDA. To analyse the predictive power for a will and life insurance for advance care planning status, we estimated true positive rate and true negative rate of having a will and/or life insurance for having engaged in formal advance care planning.



Results

Sample

There were 328 completed EOLIs in NICOLA and 892 completed EOLIs in TILDA. The characteristics of the samples are presented in Table 2, as well as the absolute standardised difference (ABSD) quantifying difference between the two samples. ABSD is a widely used measure in descriptive statistics, where a rule of thumb is that <10% is a moderately sized difference and 25% is a substantial difference.¹⁸

Table 2: Sample characteristics in EOLIs

		NICOLA (n=328)		TILDA (n=892)		ABSD
		Mean or N	SD or%	Mean or N	SD or %	
Age	Years	77.9	11	79.6	10.2	15%
Sex	Male	187	57%	459	51%	11%
Education	<=Primary	141	43%	451	51%	15%
	Secondary	125	38%	362	41%	5%
	Tertiary	62	19%	77	9%	30%
	DK/RF*	0	.	2	.	
Marital status	Married/cohabiting	147	45%	373	42%	6%
	Never married	23	7%	111	12%	18%
	Separated/divorced	31	9%	33	4%	23%
	Widowed	126	39%	375	42%	7%
	DK/RF*	1	.	0	.	
Cause of death	Cancer	129	41%	304	35%	14%
	Cardiovascular	69	22%	246	28%	14%
	Respiratory	23	7%	104	12%	15%
	Other	90	29%	137	16%	32%
	DK/RF*	17	.	17	2%	
Length of illness	Not ill, died suddenly	41	13%	109	12%	1%
	<1 week	14	4%	46	5%	4%
	1wk-1mth	24	7%	82	9%	7%
	1mth-6mth	50	15%	176	20%	12%
	6mth-1yr	49	15%	138	16%	2%
	1yr plus	145	45%	341	39%	12%
	DK/RF*	5	.	0	.	
ADLs	None	155	47%	348	39%	16%
	1to2	30	9%	123	14%	15%
	3to4	42	13%	98	11%	5%
	5to6	101	31%	318	36%	11%
	DK/RF	0	.	5	.	
IADLs	None	140	43%	313	36%	15%
	1to2	30	9%	91	10%	4%
	3to4	61	19%	181	21%	5%
	5to6	97	30%	296	34%	9%
	DK/RF*	0	.	11	.	0
Lived in L2YOL	At home	305	93%	816	92%	5%
	Hospital	172	52%	355	40%	25%
	Hospice	15	5%	32	4%	5%
	Nursing home	42	13%	112	13%	1%

ABSD: absolute standardised difference. SD: standard deviation. (I)ADLs: (Instrumental) Activities of Daily Living.^{19,20} L2YOL: last two years of life. *Respondent didn't know or refused to answer; descriptive statistics (mean, SD, %) calculated from confirmed responses only.

The TILDA sample were on average older at death (79.6 years versus 77.9 years) and included fewer males (51% versus 57%). Cancer, cardiovascular diseases and respiratory diseases were the most common causes of death in both samples. The largest differences per ABSD were in achieving tertiary education level; cause of death not by cancer, cardiovascular or respiratory disease; and living for some time in a hospital in the last two years of life (all more prevalent in the NICOLA sample).

Main results

RQ1: Intensity of EOL care

Place of death for decedents in NICOLA and TILDA are presented in Table 3a. Hospital accounted for approximately half of deaths in both NICOLA (50%) and TILDA (47%). There were larger differences in home deaths (38% and 28% respectively), in hospice (4% versus 11%), and nursing home (8% versus 13%).

Table 3a: Where did the person die?

Place of death	NICOLA	TILDA
Home	38% (124)	28% (245)
Hospital	50% (162)	47% (407)
Hospice	4% (13)	11% (92)
Nursing home	8% (25)	13% (113)
ALL	324	857
Other place/DK/RF*	4	35

* Respondent didn't know or refused to answer, or died in another place [cannot be reported separately due to small cell sizes]; % calculated from confirmed responses only; number of people in brackets.

High-intensity treatments in the last two years of life for decedents in NICOLA and TILDA are presented in Table 3b-Table 3d. Chemotherapy (44% in NICOLA, 54% in TILDA) and surgery (30% and 36% respectively) were both fairly commonplace among those with cancer. Heart surgery was much less common (5% and 4%) among those potentially eligible.

Table 3b: Did the decedent receive high-intensity treatments in last two years of life?

Chemotherapy	NICOLA	TILDA
Yes	44% (27)	54% (52)
No	56% (34)	46% (46)
ALL	61	97
INEL/DK/RF*	267	795

* Respondent didn't know or refused to answer, or decedent did not have cancer and so was not eligible; % calculated from confirmed responses only; number of people in brackets.

Table 3c: Did the decedent receive high-intensity treatments in last two years of life?

Heart surgery	NICOLA	TILDA
Yes	30% (18)	36% (35)
No	70% (43)	64% (62)
ALL	61	97
INEL/DK/RF*	267	775

* Respondent didn't know or refused to answer, or decedent did not have cancer and so was not eligible; % calculated from confirmed responses only; number of people in brackets.

Table 3d: Did the decedent receive high-intensity treatments in last two years of life?

Heart surgery	NICOLA	TILDA
Yes	5% (8)	4% (11)
No	95% (140)	96% (239)
ALL	148	250
INEL/DK/RF*	180	642

* Respondent didn't know or refused to answer, or decedent did not have cardiovascular disease and so was not eligible; % calculated from confirmed responses only; number of people in brackets.

Prevalence of pain in the last year of life is presented in Table 3e. Approximately half of decedents in both NICOLA (48%) and TILDA (51%) were often troubled by pain.

Table 3e: Was the decedent often troubled by pain in the last year of life?

Pain	NICOLA	TILDA
Yes	48% (152)	51% (446)
No	52% (162)	49% (436)
ALL	314	882
DK/RF*	14	10

* Respondent didn't know or refused to answer; % calculated from confirmed responses only; number of people in brackets.

Hospital admissions for the last year of life are presented in Tables 3f-g. In NICOLA, 50% of decedents and in TILDA 60% were admitted to the ED. Mean ED visits were similar across the two studies. For overnight visits, 70% of NICOLA decedents and 76% of TILDA decedents stayed overnight in a hospital at least once in the last year of life. Mean number of visits was 1.62 in NICOLA and 2.17 in TILDA.

Table 3f: Was the decedent admitted to the emergency department in the last year of life?

Hospital ED	NICOLA	TILDA
Yes	50% (155)	60% (494)
No	50% (152)	40% (335)
ALL	307	829
DK/RF*	21	63
Mean visits	1.44	1.40

* Respondent didn't know or refused to answer; % calculated from confirmed responses only; number of people in brackets.

Table 3g: Was the decedent admitted to hospital overnight in the last year of life?

Hospital overnight	NICOLA	TILDA
Yes	70% (217)	76% (627)
No	30% (91)	24% (202)
ALL	308	829
DK/RF*	20	63
Mean visits	1.62	2.17

* Respondent didn't know or refused to answer; % calculated from confirmed responses only; number of people in brackets.

RQ2: Death preparedness

The numbers of decedents in NICOLA and TILDA with a will are presented in Table 4a. In NICOLA, 186 decedents were reported as having a will, which is 66% of the 281 confirmed responses. In TILDA, 678 decedents were reported as having a will, which is 78% of the 871 confirmed responses.

Table 4a: Did the decedent have a will?

Will	NICOLA	TILDA
Yes	66% (186)	78% (678)
No	34% (95)	22% (193)
ALL	281	871
DK/RF*	47	21

* Respondent didn't know or refused to answer; % calculated from confirmed responses only; number of people in brackets.

The numbers of decedents in NICOLA and TILDA with a life insurance policy are presented in Table 4b. In NICOLA, 68 decedents were reported as having a life insurance policy, which is 29% of the confirmed responses. In TILDA, 174 decedents were reported as having a life insurance policy, which is 21% of the confirmed responses.

Table 4b: Did the decedent have a life insurance policy?

Life insurance	NICOLA	TILDA
Yes	29% (68)	21% (174)
No	71% (170)	79% (662)
ALL	238	836
DK/RF*	90	56

* Respondent didn't know or refused to answer; % calculated from confirmed responses only; number of people in brackets.

RQ3: Advance care planning

Prevalence of advance care planning in Wave 4 of TILDA has been published previously.²¹ We summarise the prevalence of advance care planning in Table 5. Fewer than 3% of TILDA participants reported a formal plan, although a further 24% had engaged in informal discussions with family and/or clinical practitioners. Of these respondents at Wave 4, 290 have since died and a family member or friend has completed an EOLI.

Table 5: Do you have an advance care plan (TILDA Wave 4)?

Advance care plan	TILDA	Of whom, have an EOLI
Formal plan	3% (153)	5% (14)
Informal discussions only	24% (1,419)	29% (85)
Neither	74% (4,392)	66% (191)
ALL	5,964	290
DK/RF*	11	

* Respondent didn't know or refused to answer; % calculated from confirmed responses only; number of people in brackets.

We were interested in associations between death preparedness and end-of-life outcomes (RQ1). In the absence of an advance care planning question in NICOLA, we explored whether the will and life insurance measures were predictive of advance care planning, and so could be used as a proxy for advance care planning in NICOLA. For the 290 TILDA participants at Wave 4 with EOLIs, we created a binary advance care planning variable, 'at Wave 4, had they engaged in either a formal plan or informal discussions?', and we calculated sensitivity (true positive rate) and specificity (true negative rate) of four death preparedness measures that feature in the EOLI of both NICOLA and TILDA: having a will, having a life insurance policy, having both a will and a life insurance policy, and having either a will or a life insurance policy.

The results for TILDA are presented in Table 6. Having a will, or having either a will or life insurance, have high sensitivity but low specificity. Having life insurance, or having both a will and life insurance, have high specificity but low sensitivity. We therefore considered that none of these death preparedness measures was a suitable proxy for advance care planning activity in NICOLA.

Table 6: Does having a will and/or a life insurance plan predict advance care planning at end of life in TILDA?

		Advance care plan		Sensitivity	Specificity
		None	Formal/ informal		
Will	No	45	17	83%	24%
	Yes	146	82		
Life insurance	No	156	74	21%	83%
	Yes	33	20		
Both	No	161	79	17%	85%
	Yes	28	16		
Either	No	40	12	88%	21%
	Yes	151	85		

Discussion

Our analyses provide a first-of-their kind snapshot of end-of-life experience for older people on the island of Ireland. **For place of occurrence**, hospital deaths were similarly common in both jurisdictions (about 50%). These data are consistent with national statistics.^{22,23}

For high-intensity treatments near end of life, cancer treatments were more common in the South than the North; heart surgery in the last two years of life was a rare event in both jurisdictions. Emergency department visits and overnight hospital visits were also both more common in the South than the North. These results are not surprising in the context of the South's historic reliance on acute hospital care and relatively weak primary and community care.²⁴ Nevertheless they warrant further examination to explore the extent to which these high-intensity treatments are appropriate. If the high-intensity treatments are appropriate then potentially those in the North are underserved. If they are inappropriate they may reflect poorer management of resources that could be better directed to supporting people in other settings. If there are systematic differences in preferences in the two jurisdictions, then they differential patterns may be justified in both cases.

For death preparedness, a majority of people in both jurisdictions had a will and a minority had life insurance. Comparing across jurisdictions, having a will is more common in the South and life insurance more common in the North. Neither individually nor in combination did these measures predict advance care planning status in TILDA, which constrains our capacity to understand associations between **advance care planning** and outcomes across the border. NICOLA should follow TILDA's question protocol to record participants' advance care planning status both in the CAPI and in the EOLI.

Limitations

A key interest of this paper was the association between advance care planning and end-of-life outcomes, but NICOLA does not currently record advance care planning status. Future NICOLA waves should collect advance care planning status in the CAPI and in the EOLI, using language consistent with TILDA to facilitate comparisons.

Some differences in outcome may reflect differences in the sampling. For example, TILDA started collecting data in 2010 and NICOLA in 2014, so there are not only more decedents in the TILDA EOLI sample than the NICOLA EOLI sample, but these groups differ: the NICOLA group contains more deaths at a younger age and that were unexpected, and this may explain differences such as the much higher proportion of home deaths in the NICOLA sample.

Data restrictions within each study prevent pooling the data into a single dataset to examine whether observed differences are statistically significant. Maximising the research and policy potential of the data requires that the data may be pooled; technological solutions for such pooling certainly exist, but require consideration of the studies' respective approaches to data security.

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