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Retrospective Study

Population-Based Projections of Place of Death for Northern Ireland by 2040

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ABSTRACT |

Background

There are global challenges in relation to an increasingly older population, rising numbers of deaths and the resulting need for end-of-life care. It is imperative for Health and Social Care to examine where people die and forward plan.

Δim

To establish the place where people have died 2004-2018 and project future place of death care setting by 2040.

Materials and Methods

Population-based trend analysis of place of death for people that died in Northern Ireland (2004-2018 from Northern Ireland Statistics and Research Agency) and projections using linear modelling (2019-2040 projections by Office of National Statistics).

Results

Deaths are projected to increase by 45.9%, from 15,922 in 2018 (of which 36.3% will be aged 85+ years) to 23,231 deaths in 2040 (39.8% aged 85+ years). Between 2004 and 2018, proportions of home and care home (defined as nursing and residential beds) deaths increased (24.5-27% and 16.3-19.4% respectively), while the proportion of hospital deaths declined (51.9-47.6%). If current trends continue, by 2040, deaths within the community (home and care home) will account for between 46.7-55.2% of all deaths. However, if care home capacity is limited at current levels (as of 2018), hospital deaths are projected to account for the largest proportion of deaths by 2040 (51.7%).

Discussion

Death at an increasing age has implications for end-of-life care provision. This study demonstrates an increasing need for end-of-life care over the next 20-years, particularly within community settings. Projections highlight the need for comprehensive planning to ensure service provision within the community meets the needs of the population.

Keywords

Trend analysis; Place of death; Community palliative care.

INTRODUCTION |

During the last three decades, the age at which people die has changed significantly. Of note, in 1990 nearly one-quarter of deaths were in children (<5-years). Yet, by 2017 the over-70s percentage of deaths have increased from a third to half of all deaths. This is representative of the world's aging population which continues to grow at an unprecedented rate. By 2043, the overall population growth rate in Northern Ireland is projected to be just over half of that in England, however, the pension age population will grow at a faster rate than anywhere else in the

United Kingdom (UK).³ Indeed, the Northern Ireland Statistics and Research Agency (NISRA) have estimated that by 2043 the number of people aged 85+ will grow by 106.4% and the number of people aged 65+ is projected to increase by 56.2%, representing 24.2% of the total population. A consequence of living longer is that older people are surviving with complicated health and social care needs. It is estimated that one in four people in the UK are living with multimorbidity, increasing to at least two-thirds of those aged 65+.⁴ Ultimately, the expected rise in the number of older people living with multimorbidity will mean increased pressure on services and the need for greater resourcing of these services, as

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well as workforce planning, infrastructure, investment and reconfiguration.⁵ The increase in our aging population presents several public health challenges that we need to prepare for, not least an increased demand on health and social services but also quality end-of-life care.

Approximately 14% of people in need of palliative care will receive such care.6 The reasons that some people miss out include, but are not limited to, workforce pressures (e.g. excess professional demands on current staff; need for informal carers to remain in the workforce)⁷ funding distribution,⁸ disconnected infrastructure, 9,10 barriers to care as a result of diagnosis, 11 issues in identifying palliative care need as well as social and culture taboos around dying and death.¹² Without addressing these issues collectively as research priorities, clinical practice cannot be transformed and therefore quality of life will not be improved. With the growing annual death rate, across the UK and Ireland, this also implies growing numbers of people involved in caring for the dying and who are bereaved.¹³ However, limited evidence also pertains to those with pivotal roles in palliative and end-of-life care as patients and families remain 'voiceless'. 14 Few prospective studies have examined basic questions such as preferences of place of death for those living and dying in Northern Ireland which is fundamental to identifying end-of-life care needs.

Although dying at home is a common preference for individuals with a terminal illness^{15,16} when confronted with the consequences of a terminal illness, dying at home may not be viable.¹⁷ A Northern Ireland Public Health Agency¹⁸ survey of bereaved carers reported a greater proportion of carers did not know if the place of death was aligned with their loved one's preferences (37%) and when the preferred place of death was known, over one third (35%) reported their loved one's death did not take place in their preferred place of death. A study by Bannon and colleagues also reported 53.4% of patients who wanted to die at home achieved their preference, however, this was dependent upon certain factors including living in an affluent area, access to good district nursing care, previous conversations about place of death with health professionals, and the caregiver's preference for their loved one to die at home. 16 Increasing awareness about palliative care continues to be limited due to a reluctance to discuss death and dying and a lack of experiences with health services.12

Achieving preferred place of death matters to the patient and their immediate family and carers and is also considered a good quality marker for end-of-life care by service providers.¹⁹ In addition, such fulfilment helps with the bereavement process. However, it is not clear if these needs are being met within current palliative care provision in Northern Ireland. By conducting a trend analysis, we can provide the context by which to understand current and projected place of deaths in Northern Ireland to explicate service requirements for those at the end-of-life to meet the expected rising number of deaths from the growing elderly population.

METHOD |

Study Design

Population-based trend analysis was conducted using simple linear

modelling. Explicit assumptions to project where people will die in Northern Ireland, based on recent death registration data (2004-2018) were applied. Methodology was replicated and built upon from Bone et al² and Finucane et al.²⁰

Data Sources

The Northern Ireland Statistics and Research Agency provided the dataset. This included all registered deaths by place of occurrence between 2004 and 2018 categorised by sex, age (0-4 years, 5-14, 15-44, 45-64, 65-74, 75-84, 85 and over) and place of death ('hospital', 'care home', 'own home', 'hospice', and 'all other places'). Data was used to project future deaths and place of death in Northern Ireland (2019-2040).

Data Analysis

Projections by the Office of National Statistics (ONS) '2018-based national principal population projections' were used for all deaths in Northern Ireland up to 2040 (using age and gender specific proportions) with the observed place of death from 2004 to 2018 from NISRA. We applied estimated age and gender-specific proportions of deaths for place of death to the projected death, based on established methodology^{2,20} We modelled three scenarios:

- Scenario 1 assumed no change in the age and gender specific proportions of deaths observed in 2018 in each place of death.
- Scenario 2 assumed that the mean yearly change in age and gender specific proportions of deaths in each place of death that occurred between 2004 and 2018 continues to 2040.
- Scenario 3 assumed that the yearly change in age and gender specific proportions of deaths in each place of death that occurred between 2004 and 2018 continues to 2040, but that care home deaths do not increase above the number observed in 2018, with any additional deaths instead occurring in hospital.

Ethics

No ethical review was required as data was publicly available via the ONS and NISRA.

RESULTS |

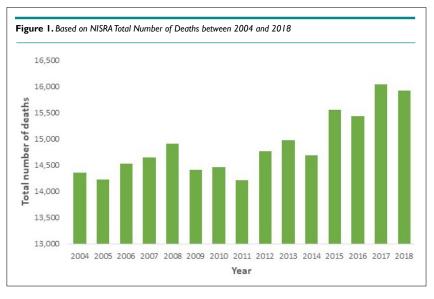
Figure 1 shows the number of deaths per year in Northern Ireland between 2004 (n=14,354) and 2018 (n=15,922).

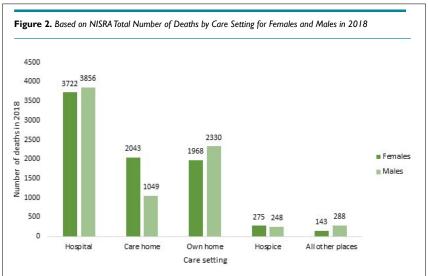
In Northern Ireland in 2018, more men died in their own home (30.0% vs. 24.1%), in hospital (49.6% vs. 45.7%) and 'All other places' (3.7% vs. 1.8%) compared to women. More women died in care homes (25.1% vs. 13.5) and hospices (3.4% vs. 3.1%) compared to men (Figure 2). See supplement files for data.

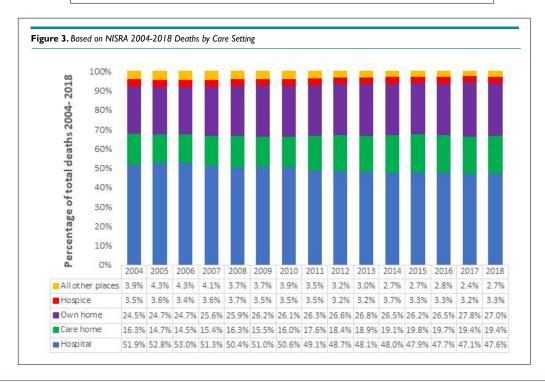
Figure 3 shows the most common place of death between 2004 and 2018. Hospital is the most common care setting however by 2018, deaths in hospital, hospice and 'all other places' decreases whereas deaths at home and care home increase.

Table 1 demonstrates between 2004 (14,354) and 2018 (15,922) deaths increased by 10.9% in Northern Ireland. There will be a (based on ONS projected deaths) 45.9% increase in the number of deaths in Northern Ireland by 2040. ONS projected deaths suggest deaths in Northern Ireland will increase from 15,922 in











2018 to 23,231 by 2040. The greatest increase in age group will continue to be 85+, accounting for 39.8% of all deaths by 2040. In addition, those aged 75 and above will account for 71.7% of all deaths by 2040.

	2004	% of Deaths	2018	% of Deaths	2040*	% of Deaths
0-4	144	1.0%	107	0.7%	97	0.4%
5-14	29	0.2%	22	0.1%	22	0.1%
15-44	612	4.3%	556	3.5%	574	2.5%
45-64	2150	15.0%	2204	13.8%	2174	9.4%
65-74	2697	18.8%	2717	17.1%	3733	16.1%
75-84	4813	33.5%	4544	28.5%	7385	31.8%
85 +	3909	27.2%	5772	36.3%	9247	39.8%
Total (% increase)	14354	-	15922	(+10.9%)	23231	(+45.9%)

By 2040, the majority of age groups show a decline in proportional percentage of deaths (0-4, 5-14, 15-44, 45-64 and 65-74). However, those aged 75-84 and those aged 85+ have a projected increase in deaths (3.3% and 3.5% respectively) (Figure 4).

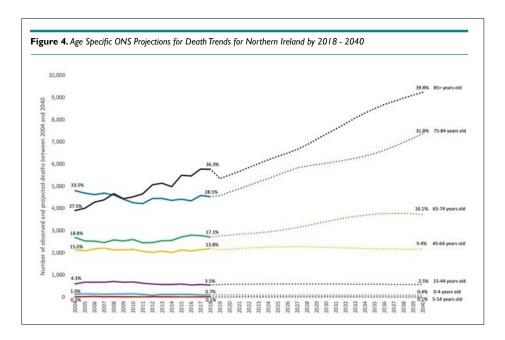
Scenarios

Table 2 provides summary data for scenario-based calculations.

Figure 5 (Scenario 1) shows that, if the proportional percentage of deaths in all care settings stay the same as of 2018 (adjusted for projected changes in age and sex), hospital continues to be the largest setting where deaths occur by 2040 (n=11,175). This is followed by deaths at home (n=6044), care home (n=4798), hospices (n=692) and other places (n=521).

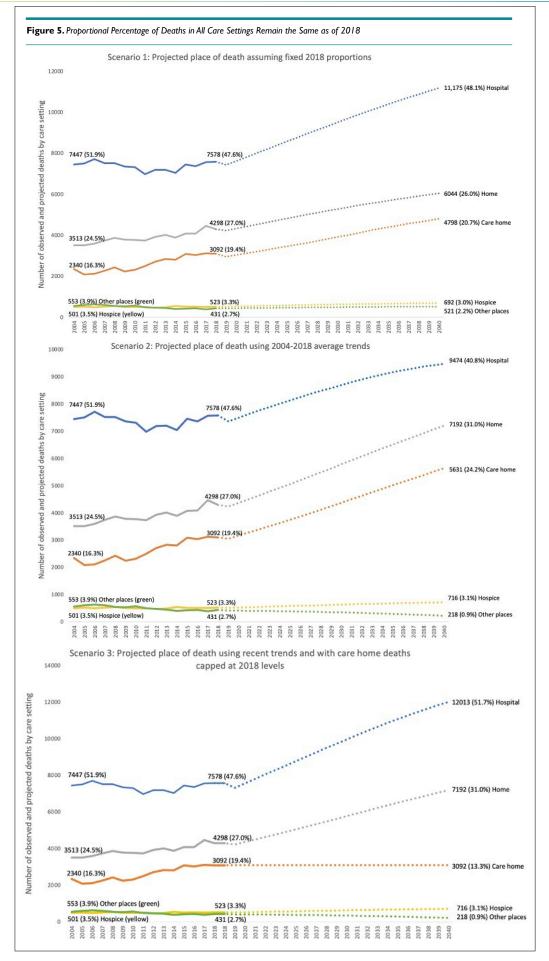
Figure 5 (Scenario 2) shows that, if the mean annual proportional percentage change trend continues between 2004 and 2018 at the same pace through to 2040, there will be a greater increase in home (+14.8%) and care home (+24.7%) deaths. Hospital deaths will experience a declining trajectory resulting in a reduction in the proportional percentage (-14.3%). Hospice (-6.1%) and 'other places' (-66.6%) will also see a decrease in deaths. By 2040, over 50% of deaths will occur in the community setting, however hospitals will continue to have the single greatest percentage of deaths.

Figure 5 (Scenario 3) shows that, if capacity of care homes was capped at 2018 level (n=3092), the additional people would die in hospital. Hospital deaths would account for an in-



		Observed	Deaths			Proj	ected De	aths In 20)40	
	20	04	20)18	Scen	ario I	Scen	ario 2	Scen	ario 3
	n	%	n	%	n	%	n	%	n	%
Hospital	7447	51.9%	7578	47.6%	11175	48.1%	9474	40.8%	12013	51.7%
Care home	2340	16.3%	3092	19.4%	4798	20.7%	5631	24.2%	3092	13.3%
Own home	3513	24.5%	4298	27.0%	6044	26.0%	7192	31.0%	7192	31.0%
Hospice	501	3.5%	523	3.3%	692	3.0%	716	3.1%	716	3.1%
Other places	553	3.9%	431	2.7%	521	2.2%	218	0.9%	218	0.9%
	14354	100.0%	15922	100.0%	23231	100.0%	23231	100.0%	23231	100.09







creased proportion of deaths by 2040 (51.7%; +2539 deaths). See supplement file for data.

DISCUSSION

The current analysis suggests that if Northern Ireland trends continue, the need for end-of-life care will increase over the next 20-years, particularly within community settings. By 2040, deaths within the community could account for over 50% of all deaths (combined home and care home deaths across all projected scenarios; 46.7%-55.2%). Additional and effective provision of community capacity could decrease hospital deaths to 40.8%. However, with the continuing lack of sustainable social care resourcing, hospital deaths are likely to increase, accounting for approximately 51.7% of deaths. These findings for Northern Ireland align with death projections across Scotland,20 England and Wales,2 which reported a significant increase in people dying outside hospital by 2040. In addition, such forecasts are aligned with other ageing countries.²¹ Collectively, these studies draw attention to the urgent need for a shift of care and resources into care within the community across the United Kingdom.

However, despite an integrated structure for Health and Social Care in Northern Ireland, services for those at the end-of-life face a number of significant challenges. Issues with identification of palliative care needs and other barriers, such as challenges eliciting advance care planning discussions, mean that not every patient who could benefit from a palliative approach to their care in Northern Ireland receives it. This is evident, for instance, in the low number of people on the Northern Ireland Palliative Care Register relative to rates of chronic and incurable illness.

The underfunding of community services and other issues, including the care workforce, are significant problems in Northern Ireland²² and it has been recognized that 'radical' reform is needed to Northern Ireland's adult social care system in order to deliver higher-quality, sustainable services and an experienced and skilled workforce which is properly valued.²³ While community care, specifically the care home setting, will become increasingly important for end-of-life care-particularly in the context of the growing prevalence of dementia-the social care resourcing settlement in Northern Ireland has not kept pace with the growth in demand arising from demographic changes. For example, the number of nursing home beds in Northern Ireland increased by 10% between 2008 and 2018, but this is less than half the percentage growth of the 65+ population.11 The issue is also evident from the significant number of delayed hospital bed days attributable to shortages of domiciliary care packages and care home beds. In 2017/18, lack of domiciliary care packages was the single biggest cause of delayed bed days across Northern Ireland, accounting for 12,940 delayed bed days, with the shortage of care home beds accounting for a further 7,775 delayed bed days.²⁴ In the context of the issues outlined above, it will be a concern that the delivery of social care reform proposals, as set out under the Power to People report, has been assigned an amber risk warning in terms of potential delay due to the coronavirus disease-2019 (COVID-19) outbreak.23

Moreover, an ever-growing number of people are becoming carers in Northern Ireland, with an estimated 22% of adults now providing unpaid care.²⁵ This carries a significant additional burden for carers and families including mental illness and worsened physical health as a result of caring²⁶–particularly for those carers who themselves are aged 65+ and may also be coping with their own health complaints.²⁷ Despite this impact, Northern Ireland is lagging behind the rest of the UK in terms of updated strategies and legislation to support informal carers; unlike Scotland and England, which have taken measures including granting new rights to carers²² and introduced additional financial supports.

The current COVID-19 pandemic has further underlined the pre-existing problems facing community care, particularly within the care home setting. NIRSA reported, as of 21st August 2020, care home deaths accounted for 40.3% (n=351) of COV-ID-19 related deaths. In addition, deaths of care home residents during the pandemic accounted for 49.5% of all COVID-19 related deaths in Northern Ireland (81.4% occurring in care homes and 18.6% in hospital). A similar trend was reported showing dying in care homes trebled during the first 10-weeks of the COVID-19 pandemic in England and Wales.

Notwithstanding the COVID-19 pandemic, healthy life expectancy has increased, but not as much as life expectancy overall. This means more people are dying older and spending more years in poor health.¹⁵ To meet the increased population palliative care needs, Finucane et al²⁰ identified opening a realistic debate on death, dying and bereavement within society, which previous policies have precluded to, as a key priority.²⁹ However, despite efforts from the Department of Health, Public Health Agency and other stakeholders, Northern Ireland has made limited progress in this area.

Overall, this Northern Ireland research identified key priorities similar to the Scottish place of death trends research²⁰: (i) action to ensure health and social care services for those at the end-of-life are fully resourced and sustainable, in order to meet patient needs across care settings, (ii) focus on building supports and resilience for informal carers, and (iii) opening a realistic debate on death, dying and bereavement within society, which previous policies have precluded to. However, as previously discussed, Northern Ireland has additional challenges at policy, commissioning and service delivery levels which require urgent attention in order to meet these priorities. Palliative and end-of-life care research in Northern Ireland also lags behind the rest of the UK, with a lack of outcome-based studies. Palliative care research across Ireland has consisted of mostly needs-based and small-scale studies, with a lack of literature on minority groups such as those living in transitional housing, with mental health problems, pre-existing disabilities, homeless people and those who identify as LGBTQ+.14 As research is vital for informing policy and decision-making, funding for community-based palliative and end-of-life care research also needs to be a key priority going forward.

CONCLUSION

This study highlights the increasing need for end-of-life care over



the next 20-years, particularly within community settings across the UK. Death at an increasing age has serious implications for end-of-life care provision, and it is unclear at present whether health and social care services in Northern Ireland, as they are currently constituted and resourced, will be sufficient to meet future demand. This study's place of death projections, current policy and research evidence further demonstrate that Northern Ireland requires urgent prioritization for community care resourcing, and increased research capacity to ensure community settings can meet the fundamental care and specialist support needs of those at the end-of-life.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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SUPPLEMENTARY TABLES

SUPPLEMENTARY TABLE I

Hospital Care Home Home Home Home Home Home Home Hom								₹		1			Female					Male		
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0	0	12	89	101	77	20	281	2	0	0	76	62	77	21	248	_	0	01	89	75	72	91	242	2	0	4	98	76	70	61	257
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m	0	61	29	75	17	34	269	0	0	15	87	72	63	20	257	0	2	15	69	80	74	61	259	0	_	4	80	72	89	61	244
4	4	93	326	344	513	460	1744	12	2	85	325	360	470	456	1710	9	2	87	301	305	425	469	1595	4	4	87	270	318	463	470	9191
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9	6	292	865	845	1103	748	3868	15	7	249	834	883	9501	736	3780	12	4	281	825	857	1023	770	3772	=	9	267	766	108	1058	827	3736
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136	28	200	958	1360	2576	2257	7515	135	91	237	096	1327	2465	2215	7355	152	15	207	666	1382	2369	2187	7311	115	80	219	926	1244	2262	2156	0869
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0 to 4	5 to 14	15 to 44	45 to 64	65 to 74	75 to 84	85+	Total	0 to 4	5 to 14	15 to 44	45 to 64	65 to 74	75 to 84	85+	Total	0 to 4	5 to 14	15 to 44	45 to 64	65 to 74	75 to 84	85+		0 to 4	5 to 14	15 to 44	45 to 64	65 to 74	75 to 84	85+	Total
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1 1	22	4 5	296	847	0	0	2	29	801	334	492	965	0	0	4	28	93	301	503	929	0	0	2	32	102	337	557	1033
611	531	716	1216	3551	99	01	911	544	763	1147	606	3555	83	01	122	487	230	1132	840	3464	74	6	134	292	826	1200	626	3787
17	32	26	4 4	156	0	0	61	26	20	46	32	143	0	0	61	61	21	32	34	125	0	0	17	31	15	33	44	140
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126	123	47 2	∞ ₹	466	0	-	115	125	89	88	55	453	0	0	122	105	59	64	47	397	0	0	118	115	99	89	89	425
70	139	131	130	470	4	_	20	149	<u>+</u>	128	35	478	4	4	33	191	891	134	4	545	3	2	24	156	148	136	14	210
250	162	198	1120	3924	7	ĸ	240	835	847	1177	903	4012	5	4	219	790	811	1136	923	3888	7	4	214	815	868	1170	970	4078
8	49	741	747	2708	0	0	3	52	179	773	1824	2831	0	0	2	19	177	758	1808	2809	0	0	9	59	194	805	2018	3082
504	925	1256	2376	7188	8=	91	198	923	1319	2290	2330	7194	125	8	961	006	1354	7772	2169	7039	128	13	233	966	1423	2251	2409	7453
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171	842	1022	2248	7662	56	8	190	821	1057	2244	3331	7077	47	12	193	854	1084	2206	3258	7654	59	7	189	968	1154	2110	3538	7953
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63	8	371	1228	1597	2209	1954	7430	57	13	408	1277	1605	2391	2164	7915	53	4	371	1297	1553	2364	2119	1777
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			ì	2018							7	/107								2018			



SUPPLEMENTARY TABLE 2

v	Но	spital	Care	Home	Own	Home	Но	spice	All Oth	ner Place
Year	n	%	n	%	n	%	n	%	n	%
2004	7447	51.90%	2340	16.30%	3513	24.50%	501	3.50%	553	3.90%
2005	7506	52.80%	2085	14.70%	3512	24.70%	515	3.60%	606	4.30%
2006	7705	53.00%	2111	14.50%	3594	24.70%	490	3.40%	632	4.30%
2007	7520	51.30%	2259	15.40%	3745	25.60%	523	3.60%	602	4.10%
2008	7515	50.40%	2427	16.30%	3868	25.90%	550	3.70%	547	3.70%
2009	7355	51.00%	2241	15.50%	3780	26.20%	505	3.50%	532	3.70%
2010	7311	50.60%	2309	16.00%	3772	26.10%	501	3.50%	564	3.90%
2011	6980	49.10%	2496	17.60%	3736	26.30%	501	3.50%	491	3.50%
2012	7188	48.70%	2708	18.40%	3924	26.60%	470	3.20%	466	3.20%
2013	7194	48.10%	2831	18.90%	4012	26.80%	478	3.20%	453	3.00%
2014	7039	48.00%	2809	19.10%	3888	26.50%	545	3.70%	397	2.70%
2015	7453	47.90%	3082	19.80%	4078	26.20%	510	3.30%	425	2.70%
2016	7362	47.70%	3032	19.70%	4087	26.50%	514	3.30%	435	2.80%
2017	7559	47.10%	3118	19.40%	4461	27.80%	508	3.20%	390	2.40%
2018	7578	47.60%	3092	19.40%	4298	27.00%	523	3.30%	431	2.70%
Mean annual % change*	-0	.31%	0.:	22%	0.	18%	-0	.01%	-0	.08%