

# Lived Experience 2021

What matters to older people in Northern Ireland



# Lived Experience...Contents

## What matters to older people in Northern Ireland

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# Foreword by Linda Robinson BEM Age NI CEO



## Northern Ireland has an ageing population – a fact that is both a cause for celebration and a challenge.

Age NI wants to start, and to be part of, a public conversation about our ageing society and what it means for each one of us, for every family, for local communities across Northern Ireland, and for our government.

Our hope is that the findings of the *Lived Experience 2021* survey can get that conversation underway. Our survey was open to older people as well as those involved with, or caring for, older people, or who have an interest in ageing. We wanted to hear about what's important to older people now, and as they look to the future. We also wanted the survey to inform our policy priorities and questions for Ministers at Age NI's Pensioners' Parliament 2021.

The response to *Lived Experience 2021* is generous and significant – over 750 people took time to consider and share their views on a broad range of topics. In our survey we heard from people from a wide age range, with the vast majority (99%) aged over 55. We heard from men and women living in urban and rural communities across Northern Ireland.

Overall, the most important issues identified in *Lived Experience 2021* are:

1. Listening to and engaging older people
2. Ageing well and addressing frailty
3. Equal access to appropriate healthcare and services
4. Rights of older people

In this report, older people have reflected on topics from ageism to the need for cash, from access to health and care services to free TV licences, from loneliness and isolation to the SmartPass...everything that's important in later life.

*Lived Experience 2021* presents a clear agenda for action for the Northern Ireland Executive and Assembly, for departmental policy makers and service providers.

We will use the findings from *Lived Experience 2021* to:

- Inform questions for this year's Pensioners' Parliament at the NI Assembly.
- Shape Age NI's manifesto for the NI Assembly election in 2022.
- Raise awareness and understanding of what matters most to older people as we respond to the implications of the changing age profile of our society.

Age NI believes that everyone in later life has a right to influence what happens to them as individuals and within wider society. I am particularly grateful to older people who, as members of the working group for the Pensioners' Parliament, supported us in the development of the survey. I also want to thank Age NI service teams who, along with colleagues in Age Sector Networks, Age Friendly Council leads and NI Age Friendly Network, helped to promote the survey and reach so many older people across Northern Ireland.

By working together, we can make sure that older people have their say and, importantly, are listened to.

# Getting ready for getting older

## Northern Ireland's ageing population

Almost 20 years ago, in the first in a series of reports<sup>1</sup>, the United Nations called global population ageing 'a situation without parallel in the history of humanity'.

Like the rest of the world, Northern Ireland is experiencing demographic shifts in terms of an ageing society.

Current statistics indicate there are over 39,000 people aged 85+, 80,000 older people who are living alone, and at least 15,000 carers over the age of 70.

By mid-2028, the proportion of the population in Northern Ireland aged 65 and over is projected to be 20.1%, overtaking that of children under 15 (19.6%) for the first time ever.

Our population is projected to age at a faster rate than the rest of the UK. Projections indicate that in the 25 years from 2016 – 2041, the number of people aged 65 and over in Northern Ireland will increase by almost two thirds (65.1%) to 491,700 people, while the proportion of the population aged 85 and over will double from 2% to 4.1% to reach 82,800 people.

## Adding life to years

This longevity is good news and presents us with the opportunity to focus on maximising the benefits of our ageing population and harnessing this demographic bounty. For too long the debate on ageing has been framed within a narrative of dependency, viewing older people as a 'burden' and a 'drain on the public purse'. Adding life to years as well as adding years to life should be our aspiration and goal.

To date, public discourse has largely focused on the impact of our ageing society on health and social care, an issue we wholly recognise. Age NI believes now is the time to give serious consideration to preparing and planning for *all* aspects of life and the changing needs of our population as the demographic shifts. This is a conversation that should involve all generations and all communities.

<sup>1</sup> United Nations World Population Ageing Report 2002

# Older people tell it how it is and how it should be

## Lived Experience 2020

Throughout the first months of the lockdown of the COVID-19 pandemic in the Spring of 2020, Age NI listened to older people talking about their experiences, their concerns and fears, as well as their hopes for a safer future. We captured people's views and voices in a short report called *Lived Experience – Voices of older people on the COVID-19 pandemic 2020*.

We set out a range of immediate and longer-term actions urging decision-makers to act, plan and prepare for life during and after the pandemic, and to learn from older people's shared experiences.

Responding to COVID-19 has continued to dominate government decision-making and the key issues raised in our 2020 survey remain pertinent, and the actions no less urgent.

## Lived Experience 2021

One year on, in the Spring of 2021, we wanted to find out from older people what is important to them now and looking ahead to the future. Their voices and views make up this report.

In *Lived Experience 2021*, older people reflect on what's important to them now and what they want for the future; they also share their ideas and views on how that future can be secured. Over 750 people responded to our survey. The responses range from the practical to the philosophical and are thoughtful and informed. They reflect the fact that life continues to be difficult for many older people and others, with the effects of COVID-19 still impacting on everyday lives. Concern for self is balanced and matched with concern for others and across generations. Older people's insight into the impact of the pandemic and its consequences, such as the loneliness experienced by people living alone, comes across in their responses.

# Older people tell it how it is and how it should be

It is clear that older people want to live as independently and be as well as possible. They remain concerned, however, about the lack of priority given to our ageing society.

They are fearful about the protection of their rights and question the value placed on the contributions they can and do make.

To address the issues raised in *Lived Experience 2021* we will need investment and sustained support for older people and in our age sector.

**Age NI wants older people, now and in the future, to live a life that is dignified and fulfilled, that promotes independence, provides choice and offers opportunities for participation and self-fulfilment.**

We believe that everybody should be able to play a full role in our communities, whether this is through work, volunteering or civic action, helped by age-friendly neighbourhoods, good transport links and digital technology that meets our needs.

## Calls to Action

Northern Ireland's Programme for Government does not contain a specific outcome on ageing and older people, nor any commitment to a process of planning and preparation for this future.

Now is the time for us all to work together to grasp the opportunity that is, and will be, our everyday reality. This report's calls to action set out a challenging agenda. They make it clear how important it is that our government is alert to, and responds to, the implications of our projected demographic.

There is work for everyone – for our Ministers, political leaders and representatives, decision and policy makers, planners and service providers, businesses and civic society.

What they can count on is the part that older people want to play in this work – a desire to be partners in a process of genuine co-design and collaboration.

# Survey Methodology



In conducting this survey, a mixed method approach was adopted, which combined both qualitative and quantitative data collection. To facilitate as many respondents as possible, the survey was promoted online and made available in hard copy and digital format.

The survey adopted a ranking approach based on themes that emerged from the Lived Experience 2020 report. Three themes were explored in the 2021 survey:

-  Support
-  Health and Social Care
-  Communication and Connection

 Five issues were listed under each of the three key themes and respondents were invited to rank each issue in order of importance to them. Respondents ranked these issues from 1 to 5, with 1 being most important and 5 being least important.

In addition to the key theme ranking questions, respondents were given the opportunity to share any questions they have for the next Pensioners' Parliament relating to the key themes or another theme of their choice. This provided some supplementary qualitative data.





# 1. Support



## Financial support, entitlements and State Pension

Older people told us they had concerns about the State Pension and people retiring into poverty. We know that around 38,000 pensioners are in relative poverty. Most pensioners living in poverty do not have personal or occupational pension provision in place.

The benefits and welfare systems should ensure an adequate income for older people and in retirement. All current and future pensioners should have enough money from State and private sources to live comfortably and participate fully in society.

## Advice service for later life

Older people can face difficulties when searching for clear information about accessing the help and support they need in their daily lives.

They may struggle to navigate their way through systems to find the right department or person to speak to.

They would value accessible and trustworthy sources of information and advice to help with financial planning and decisions for later life, for example, about insurance, paying for services and scams.

A specific advice service, such as a helpline, dedicated to supporting older people to make informed decisions about all aspects of later life would build confidence and reduce anxiety.

## Domestic, home help support and services

Most older people would like to live independently and comfortably in their own home for as long as possible.

Having access to a modest level of home help as well as reliable and affordable maintenance and repair services would enable older people to manage to do this.

## Housing and accommodation choice and options

Older people may want to downsize to different property, move to a different location to be closer to family and services or to live with others as their personal needs and circumstances change.

We also know that with an ageing population and increasing numbers of older people living with frailty, there will be an increased need for housing that is fully accessible and supports older people in a range of housing models.



**“Pensions need to start at 60. More local bus stops within easy distance to shops, community group venues for activities or even a chat over a cup of tea, helping social and emotional needs and wellbeing.”**

**“Good social housing would improve the health and lives of older people. How can one plan for the final years if there is uncertainty and lack of availability of housing which suits the frail elderly.”**

**“Provision of retirement village/housing to facilitate community living with support facilities. People need to have options on how to manage independently that does not involve care homes. Such consideration should form part of the planning for the adult care system.”**



# 1. Support



“How do you ensure that the **rights of older people, specifically protection from abuse, are recognised and better protected by Government agencies.**”

“Home help would be of benefit because they would check on the pensioners, making a cup of tea and sandwich, as well as doing light housework and going to the shop if needed.”

“Impartial **investment advice for the over 75s.**”

“**Local groups are important to me** i.e. health, fitness, choirs etc.”

“Ask for recognition of the **importance of travel passes in keeping older people mentally astute, physically active and connected to the world outside.**”

“A fairer State Pension, not everyone has a private pension. **Disgrace that someone who has worked all their life retires into poverty.**”

“Why is everything now being geared towards online banking - **my freedom of choice is being taken away.**”



## 2. Health and Social Care



### Access to and funding for acute healthcare

Ageing well and addressing frailty are key issues for older people. Evidence indicates that there are, and will continue to be, significant increases in levels of frailty associated with the long-term health consequences of the pandemic. This is linked to people who have contracted the virus or have experienced delays in health or social care interventions. It is also those people who are affected by deconditioning because of a lack of opportunities for physical activity due to restrictions.

### Reforming and funding adult social care

Reform of social care is strategically important and vital to enabling older people to live independently, with dignity and security, having choice and control over how they manage their lives.

### COVID-19 planning and recovery

COVID-19 exposed and amplified health inequalities that exist in society, with deaths due to the virus higher in areas of deprivation and death rates of people aged over 75 nine times that for all ages. It has also shone a light on the lack of support for family carers during this health and care crisis. Older people highlighted a range of concerns including access to acute and GP services, protection and rights of people living in care homes and end-of-life planning.

### Care homes

The protection and welfare of older people living in care homes is of profound concern. This is due to the shocking level of heart-breaking deaths of residents due to COVID-19, as well as restrictions on how families and friends visit their loved ones and grieve those who have been lost.

### End of life care and planning

Everyone has the right to expect services and support that help them to achieve a dignified and pain-free death, with choice in how they are cared for in their final months and days, regardless of where they live or their diagnosis. This should include access to high quality palliative care services (including pain management) which supports physical, psychological and spiritual needs, respects personal choice (including where advance decisions are made) and maintains dignity.

### Carers

Family carers feel they were forgotten, ignored and not a priority during the pandemic. Family carers, many of whom were older people themselves, stepped in or increased the level of caring they provided for relatives, some while continuing their own paid work or other responsibilities. COVID-19 led to a significant reduction in the level of support provided to carers, even though they were providing more care than ever before. This has had a significant impact on their health and wellbeing with Carers UK reporting that almost three quarters (74%) of carers are feeling exhausted and worn out from caring throughout the pandemic.



“Review the role of care homes in creating meaningful experiences for elderly.”



## 2. Health and Social Care



“In the absence of an Equality Act in Northern Ireland, how can we **ensure that older people do not face discrimination in Health and Social Care.**”

“In view of so many being unable to see loved ones in care homes for much of the past year, **can services be improved to support families wishing to keep elderly relatives at family homes e.g. day care or packages to support family carers with better respite care?**”

“**Carers are forgotten people**, this needs to be a priority and should be recognised at the highest level.”

“**The law should be changed to enable older people, in particular, to die with dignity.** To watch a loved one take three or more weeks to die without food or water is too painful for the family and the loved one.”



# 3. Communication and Connection



## Digital and technological inclusion

A significant number of older people do not use or have access to the internet. Being online has been particularly important during the pandemic. It has meant access to services and support, keeping in touch with family and friends, and for older people, it has meant being able to meet up in the virtual world and have their voices heard.

This shift to being online to carry out everyday tasks has left many older people excluded.

This is particularly so for those who are in the oldest population or live with a disability, those who are not digitally connected or confident, or whose broadband is poor; those who do not own a smartphone, tablet or computer or lack the knowledge and knowhow to operate such technology.

The absence of alternative approaches has left many older people and their carers feeling left out, excluded, lonely, isolated and forgotten.

## Loneliness, isolation and mental health

During the pandemic, through lockdown, shielding, self-isolation or social distancing, we have all been separated from family, friends, neighbours or colleagues so we understand how loneliness feels.

Loneliness is a normal human emotion. But chronic loneliness – when people always or often feel this way – affects one in 20 people in Northern Ireland, many of whom are older people. Loneliness can be very damaging to physical and mental health and wellbeing.

## Transport and travel

Free, accessible transport is a lifeline for many older people, enabling them to remain active, be part of, and contribute to, their local community, and access the services they need to stay well and remain as independent as possible.

As restrictions ease, the SmartPass, with effective hygiene and social distancing rules in place, will increase the confidence of older people and provide reassurance for anyone fearful and anxious about going out and leaving the protection of their own home.

An effective, affordable public transport system is also key to creating and promoting Age Friendly communities and societies for people and families of all ages.

## Engagement, participation, equality and inclusion

The vision of the Active Ageing Strategy is of “*Northern Ireland being an age friendly region in which people, as they grow older, are valued and supported to live actively to their fullest potential; with their rights respected and their dignity protected.*”

Older people tell us that they do not feel valued, listened to or respected and that much more needs to be done to make this vision a reality.

Older people feel invisible, not listened to and believe they are treated unfairly because of their age or because of disability and/or vulnerability. They are increasingly concerned and frustrated that, despite many promises, most recently in New Decade, New Approach (January 2020), the Northern Ireland Executive has failed to extend age discrimination legislation to goods, facilities and services.

“Loneliness – especially during lockdown – has been a major problem for many.”

### 3. Communication and Connection



“How will government communicate to older people about the financial help available to those who have to wait until they are 67 to receive the State Pension, but whose health is deteriorating and they can no longer work full-time?”

“Ask for careful thought and provision in making sure non - digital proficient older people are not left out of any initiatives.”

“How can we ensure that individual voices are heard in local government in small rural communities?”

“Those that need communication and connection most are the most difficult to connect with.”

“Please keep cross border bus / rail passes. We have worked hard all our lives we deserve to travel, visit and have leisure time - this will prevent health issues.”

# Calls to Action



By listening to and recording the issues and themes of greatest importance to our older people, now and looking to the future, *Lived Experience 2021* presents a clear agenda for action for the Northern Ireland Executive and Assembly, for departmental policy makers and service providers.

Age NI believes that everyone in later life has a right to influence what happens to them as individuals and within wider society.

Below are action points arising from what older people told us in the *Lived Experience 2021* survey. We will be taking forward issues highlighted in *Lived Experience 2021* to raise awareness and understanding of what matters most to older people, and to shape Age NI's manifesto for the Northern Ireland Assembly election in 2022.

The opportunity to give a voice to these issues begins with the Age NI Pensioners' Parliament on 17 September 2021 when questions will be put by older people to Ministers in the NI Executive.

# Calls to Action



## Protect, Respect and Engage

Promote the **rights of older people** and introduce **age discrimination legislation** for goods, facilities and services.



Co-design the next **Active Ageing Strategy** with older people to ensure its effectiveness and positive impact.



Put older people at the heart of **planning** for the future and our **ageing population**.



Promote and support **intersectoral, intergenerational approaches** to policy development, planning and provision.



Adopt and resource **Age Friendly initiatives** across Northern Ireland.



# Calls to Action



## Support

Recognise the key role played by **family carers** ensuring support is available in a way that works for them and their loved ones.



Ensure quality, **safe support for older people** in care homes and in their own homes.



Develop **housing strategy**, policy and plans with options to match the aspirations and needs of older people.



Resource and promote **bereavement** support.



# Calls to Action



## Health & Social Care

Commit to rebuilding **adult care and support** and provide immediate funding to deliver quality care services.



Ensure **equal and effective access to healthcare** services for older people including in-person GP visits, hospital appointments and treatments.



Invest in interventions which prevent and address increased levels of **frailty**.



Prioritise and value the skills and key role played by the **social care workforce**.



Develop and quality assure public **health messages** with older people.



Implement policy and practice on **advanced care planning** and support collaborative and compassionate **end of life plans**.



# Calls to Action



## Communication and Connection

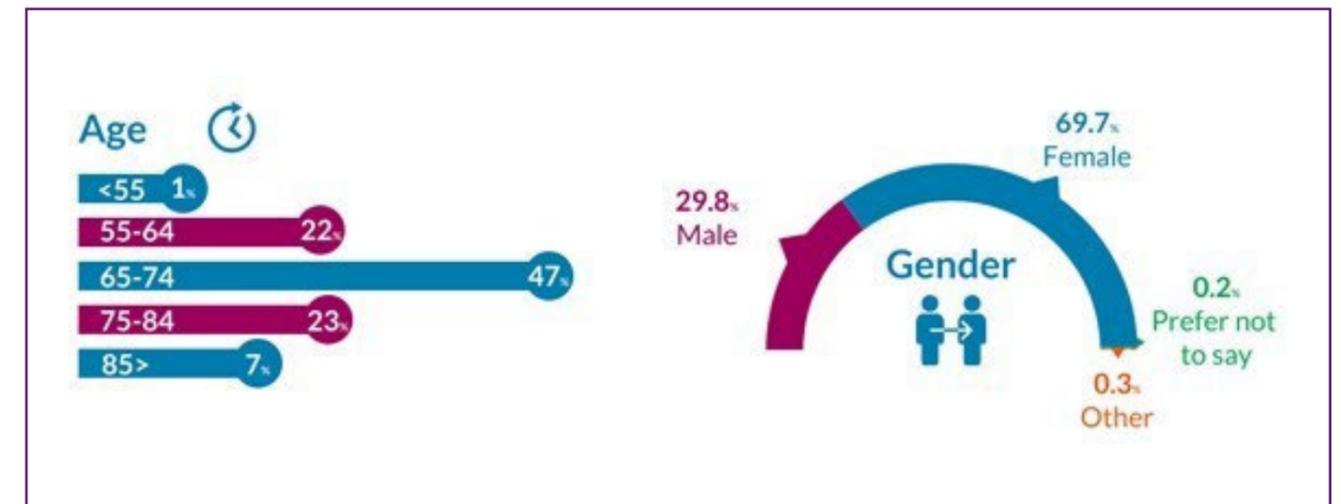
<p>Develop, deliver and resource a <b>loneliness strategy</b> to tackle loneliness and isolation and build personal resilience.</p> 	<p>Commit to community and voluntary <b>age sector funding</b> to secure sustainability of local networks and services.</p> 
<p>Develop community and <b>public transport</b> as part of creating an Age Friendly Northern Ireland.</p> 	<p>Ensure <b>cash and access to local banking</b> services are retained.</p> 
<p>Ensure <b>access to 4G</b> networks across Northern Ireland.</p> 	<p>Support ownership and confident use <b>of digital devices</b> for older people to promote communication, <b>connection</b> and accessibility.</p> 

# Appendix

## Who completed the Lived Experience 2021 survey?

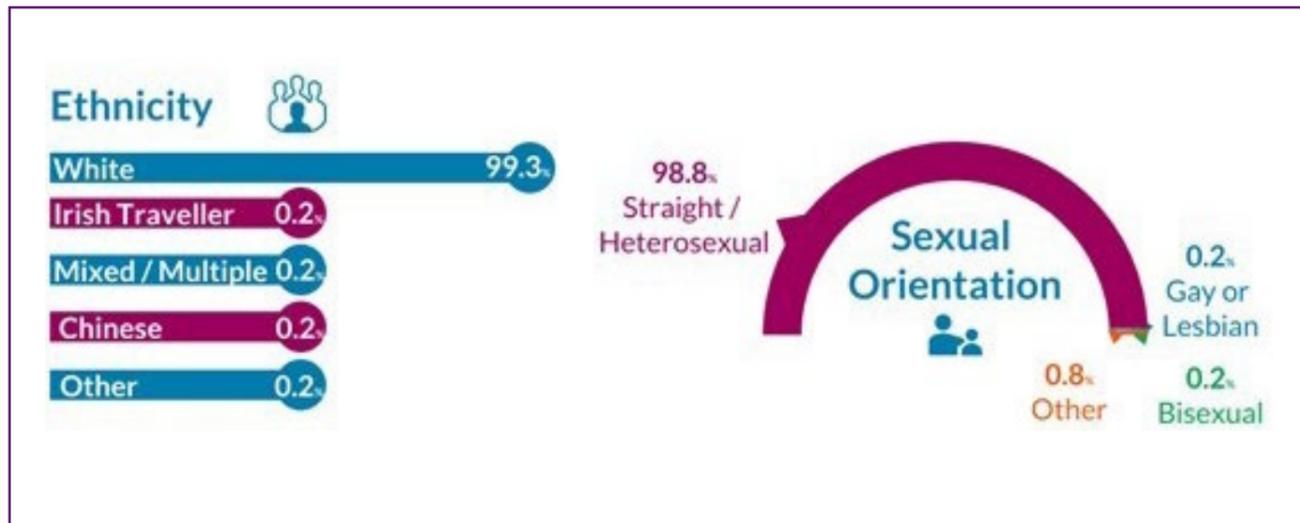
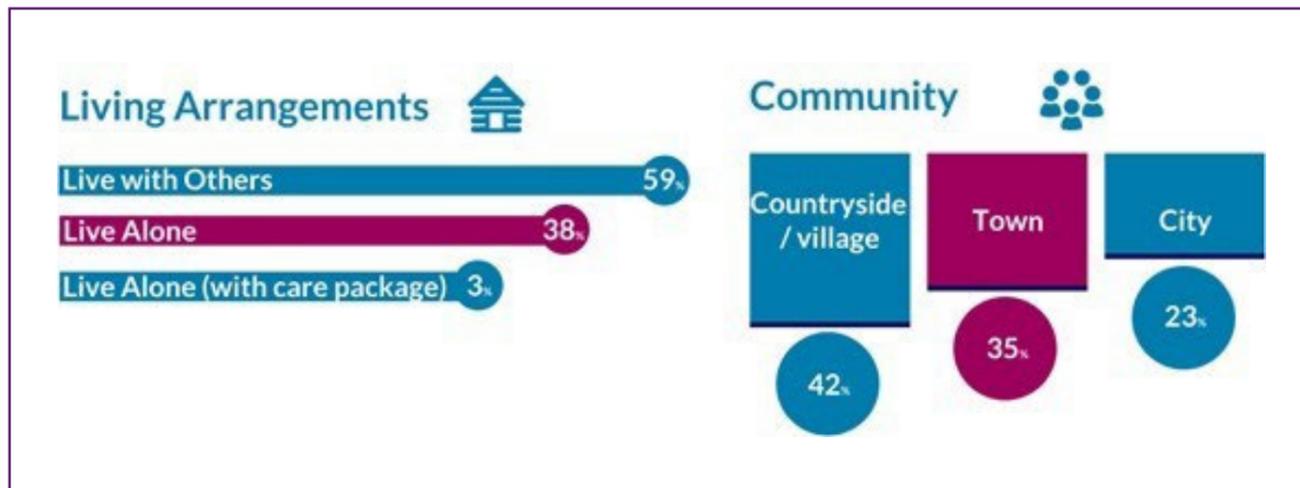


## Profile of survey respondents



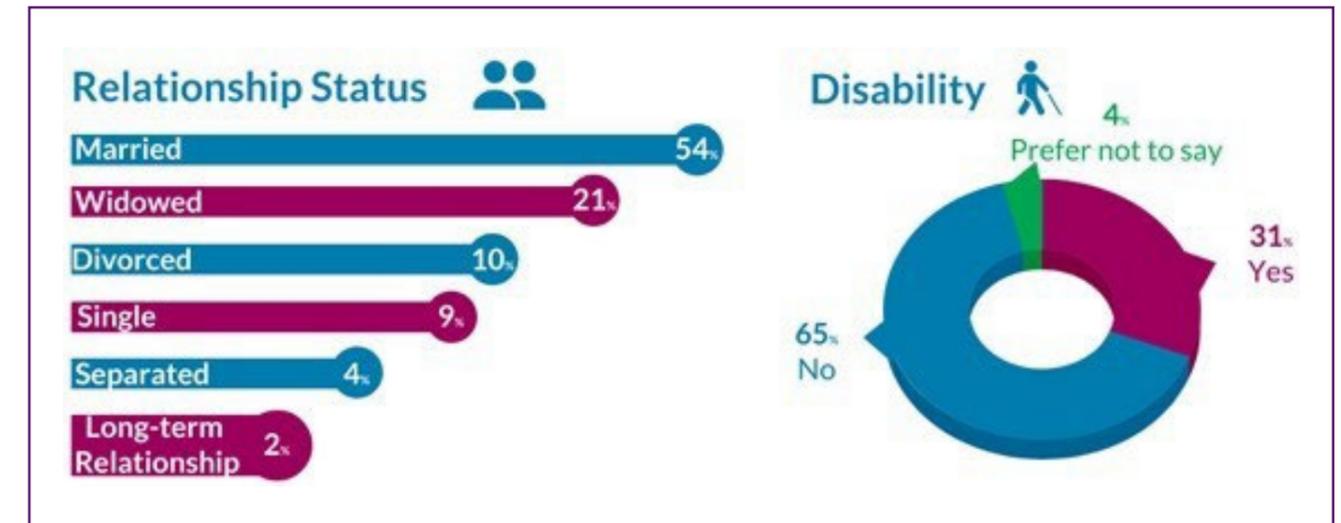
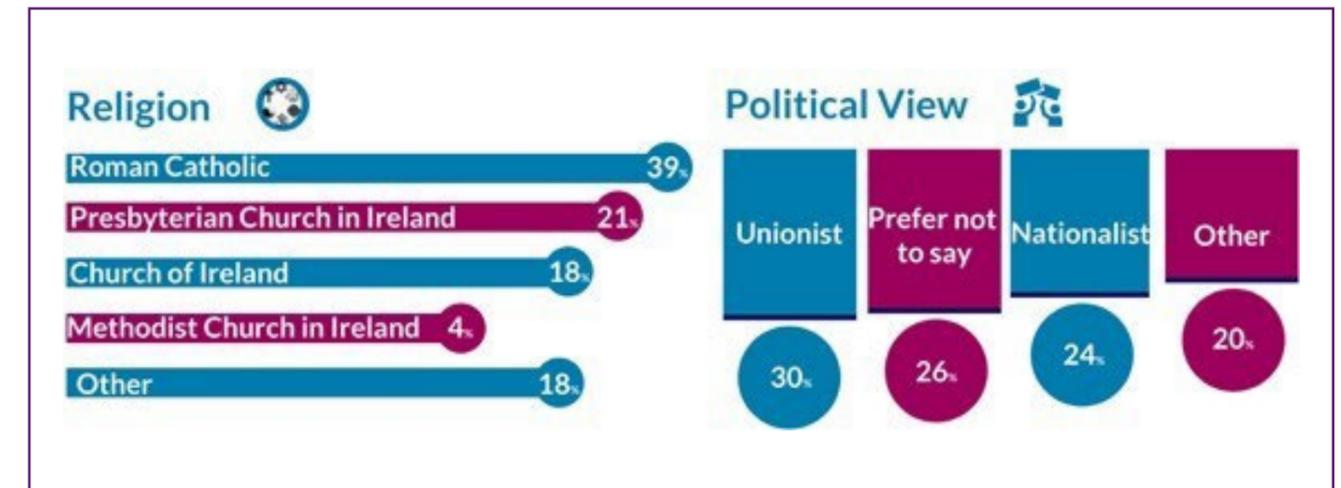
# Appendix

## Profile of survey respondents



# Appendix

## Profile of survey respondents





If you, or an older person you know, needs advice, information or practical support on issues including welfare benefits, community care, housing and health, contact the Age NI Advice Service to speak to a specialist advisor in confidence:

Age NI Advice Service: **0808 808 7575**  
Freephone (9am - 5pm Mon - Fri)

**Age NI**  
**3 Lower Crescent,**  
**Belfast, BT7 1NR**

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