



Newsletter No. 2

UPDATE ON NICOLA

Dear NICOLA Participant,

A warm welcome to NICOLA's second newsletter. We hope to increase our communication with you over the coming months to inform you more about our research and the importance of the research work we carry out. More importantly we are keen to help you understand the importance of your continued participation in NICOLA. In each newsletter we will focus on a key topic of our research, this time it's about your memory and brain health.

This has undoubtedly been a difficult year marked by challenge and adversity as the world wrestles with the outbreak of COVID-19. While there has been much personal heartache and sorrow for many families across the world, there has also been remarkable advances in scientific research in understanding more about the virus. Through global research efforts significant progress has been made, with vaccines being rolled out to protect our communities and the most vulnerable of society.

With the public health measures in force to contain the coronavirus, we have experienced delays with the completion of certain elements of the NICOLA research and have had to revise some timelines for completion of data collection. Indeed, some of you may have taken part in a telephone or online interview instead of our usual home interview.

The first two waves of the study have been a great success, with 8500 people taking part from all across Northern Ireland. We would like to say a big thank you to everyone who participated and we do hope as many as possible will be able to take part again in future waves of data collection. We appreciate that we ask you a lot of questions when we conduct the interviews and send out questionnaires but the information you give us helps us build a detailed picture of what it's like to grow older in Northern Ireland. This not only helps us examine key research

topics but importantly it is used by policy makers in government, by charities and voluntary organisations, and by researchers, not only in this country, but throughout the world. This is important particularly as life expectancy continues to rise.

Earlier this year we also sent you a COVID-19 questionnaire for completion. The information you provide in this questionnaire is critical for understanding the impact of COVID on your life, your health and your wellbeing. It will give health authorities, policymakers, researchers, and the general public valuable insight into the effects of the pandemic and identify gaps in services for older adults in Northern Ireland in response to the impact of COVID-19.

The particular value and uniqueness of NICOLA is that we collect information from the same people over the years. This helps us get a much better understanding of how the experience of ageing changes over time.

Within NICOLA we have hope for the future. Our aim is to see the continued growth of NICOLA through your ongoing help and support. On behalf of the NICOLA team, I would like to thank you sincerely for your ongoing support and the time that you have devoted to NICOLA over the past few years and I trust that we can count on your continued support as we move forward through 2021 and beyond.

We hope you find this Newsletter informative and enjoyable reading.

Wishing you all well.

Professor Frank Kee
Scientific Director of NICOLA,
Centre for Public Health
Queen's University Belfast

About NICOLA

We are interested in different aspects of the lives of older adults such as health, social, lifestyle, and financial situations and how these factors interact with each other and affect health and wellbeing as we get older.

NICOLA is the...

Northern Ireland Cohort for the Longitudinal Study of Ageing

Some facts about NICOLA

- ❖ NICOLA is N.Ireland's largest public health cohort study
- ❖ Approx. 8500 men and women aged 50 years and over from across N.Ireland are taking part
- ❖ The study explores why and how social, economic and biological factors are changing the lives of older people and impacting on health and wellbeing
- ❖ Longitudinal: this simply means that we carry out repeated measures every few years: interviews every 2-3 years, health assessment every 4-5 years
- ❖ The purpose of NICOLA is to provide evidence based research on ageing in N.Ireland
- ❖ We draw on expertise from across various academic disciplines to examine what's important. These include experts from medical and health sciences, economics, management, social sciences, architecture and psychology

"Understanding today for a healthier tomorrow ..."

Some key findings from NICOLA

Waves 1 and 2 of the study (undertaken prior to COVID) are now complete. Here are some interesting things that we have found out so far.

- 8478 participants took part in Wave 1 with more than 6000 also taking part in Wave 2.
- The age of participants ranges from 50 years to 95 years, with just over half (51%) aged between 50 and 64 years.

Health and healthcare utilisation

- Over one third of participants reported having a limiting long term illness, which increased with age
- Just over half of respondents reported having very good or excellent mental health; there were higher levels of poor mental health in the 50-64 year old age group and in lower socio-economic groups
- Married or cohabiting older adults reported the best health
- 18% reported falling 1-5 times in the past year
- Living alone was associated with poorer reported health outcomes than those living with others
- Those living in the most rural areas reported better health than those in more populated areas
- A large majority (80%) had visited their GP at least once in the past year
- Participants reporting the highest use of GP and hospital services were more likely to:
 - self-report their health as poor
 - have difficulties with activities of daily living and/or have a limiting long term illness
 - live alone
 - live in the most socially deprived areas
 - be experiencing loneliness

Social connectedness and engagement

- One in four of NICOLA participants were living alone, and this increased with age
- A quarter of participants reported caring for family, friends, neighbours, or others with long-term physical or mental ill health, disability, or problems related to old age

- Social engagement of participants was evident, with 39% involved in activity groups, and 18% involved in voluntary or charitable work. This was particularly apparent in those who were married or co-habiting, better educated and living in the least deprived areas. Telephone contact was also considered important, with 79% phoning relatives and 63% phoning friends each week
- Living alone was twice as common in the most deprived areas compared to the least deprived areas, and three times as common in urban areas compared to rural areas.
- 18% of older adults experienced loneliness (17% men, 19% women)
- Feelings of loneliness were more evident among the 50-64 year olds
- Loneliness was also higher among:
 - those living alone
 - permanently sick/disabled *versus* retired or in work
 - poor self-reported health
 - most deprived

Health behaviours

- Just under two thirds (61%) of participants reported that they drank alcohol on a regular basis, of which almost 1 in 3 (31%) consumed more than the recommended 14 units/week.
- 17% of participants reported being current smokers; the highest rates of smoking were in those who were single, younger, living in urban areas and/or the most deprived areas, and had the lowest educational levels.
- Just over half (57%) reported undertaking the recommended 150 minutes or more of physical activity per week.
- Low levels of physical activity were evident among women, and in participants who were older, single, living alone, had low levels of education, or living in areas of social deprivation.
- A large number of undiagnosed eye conditions were discovered in participants during the health assessment which suggests that older adults are not attending their optician for eye examinations as frequently as recommended.
- Hearing loss became more evident in the 70+ age group. Hearing aids can improve several aspects of life that have been compromised by hearing loss. However, despite the availability of hearing aids and major technical progress in the last decade, uptake of hearing aids is poor and only a relatively small proportion of adults with hearing impairment seek help for their hearing problems and use hearing aids.

- The majority of older adults performed well on the cognitive (memory) tests.
- Increasing age was associated with poorer cognitive performance. Cognitive performance refers to your ability to perform well in the memory tests which were conducted during the health assessment. For example, your ability to draw a cube correctly, being able to recall five words, naming animals correctly, counting backwards from 100 subtracting seven each time.
- Cognitive performance depended on level of education, marital status and level of deprivation. Participants with third level education, married and from less deprived areas tended to perform better in the cognitive tests compared to the comparison groups.
- Overall mental wellbeing was high in older adults although this varied according to age, marital status, education, level of deprivation and region.
- 18% of older adults showed signs of depression, with females reporting higher rates of depressive symptoms compared to males.

This is just a snapshot of some of our findings. There will be a lot more findings to follow in future newsletters. It's also worth checking the News Section on the NICOLA website where you will find out about some of our more in depth research findings from the data collected in NICOLA.

<https://nicola.qub.ac.uk/sites/NICOLA/News/>

NICOLA – Around the World

NICOLA isn't just about ageing in N.Ireland. NICOLA is part of a much larger worldwide group of studies of ageing.

NICOLA is part of a worldwide network of ageing studies monitoring the experiences of people aged 50 and over

around the world. In the Republic of Ireland a similar study called TILDA (**T**he **I**rish **L**ongitudinal **S**tudy of **A**geing) is taking place, in England a study named ELSA (the **E**nglish **L**ongitudinal **S**tudy of **A**geing) is being conducted and Scotland have aptly named their study HAGIS (Healthy Ageing in Scotland). Further afield, similar



studies are taking place in America, China, Korea, Mexico, Japan, Brazil, India and Costa Rica, and numerous other European countries.

Team meetings are held regularly between the studies to discuss current findings and future developments and also to discuss the best ways of capturing data that will be relevant to ageing research and the population. A key challenge is making sure that what we ask you in the questionnaires is useful for each country but that can also be compared internationally. We are trying to make sure that whenever possible these studies measure things in the same ways. That helps us to compare the results of NICOLA with those from other countries and allows us to see how the health and wellbeing of people in N.Ireland compares.

Become a NICOLA representative

Would you be interested in becoming a volunteer for NICOLA? This is a valuable role which would involve you helping the NICOLA research team in a variety of ways. For example, you could be asked to provide input into the future content of NICOLA, you might be asked to give your opinion on research applications wishing to access NICOLA data or you could be invited to participant panel days to find out more about the findings of NICOLA. These are just a few of the ways in which you could help us.

To express an interest in becoming part of this study panel, please phone Charlotte Neville on 07714 852310 or Angie Scott 07570 981020 OR email us at nicola-research@qub.ac.uk OR write to us at:

NICOLA study, Centre for Public Health, Grosvenor Road, Belfast, BT12 6BJ

Tell us your NICOLA story

We would love to hear from NICOLA participants. We are keen to find out more about your lives and your experience of taking part in the study. We would like to feature some of you in future communications about the study, with a short interview and maybe a photo if you are happy with this.

To express an interest in telling your story, please email us at nicola-research@qub.ac.uk or write to us at:

NICOLA study, Centre for Public Health,
Grosvenor Road, Belfast, BT12 6BJ

We're keen to hear from participants of all ages, from all backgrounds, to illustrate the range of experiences that NICOLA covers.



Meet the Researcher

You have provided us with so much information to date that we thought we would share a little more about us and the work we are currently undertaking. In each newsletter we are going to feature some of our core researchers and academics who are using your data to advance ageing research. You will get to know more about their interests and how they are using your data.

This month we feature **Professor Bernadette McGuinness**, a Consultant Geriatrician in the Belfast Health & Social Care Trust. In this interview, we catch up with Prof. McGuinness to find out more about her work, including the highlights and challenges and to help us understand more about the differences between cognitive impairment and Alzheimer's disease. We will also ask her about ongoing research into cognitive decline in the NICOLA study.



1. Tell us a little bit about yourself?

I am a Consultant Geriatrician in the Belfast Health & Social Care Trust and a Clinical Professor in Queen's University Belfast. I lead weekly memory clinics as part of my clinical job and we assess and treat people with a variety of cognitive complaints. I also lead several research studies investigating the role of inflammation in Alzheimer's disease pathology, the use of big data in dementia research and I am also interested in the prevalence of cognitive impairment and the factors associated with cognitive impairment and dementia within NICOLA.

2. Many people are familiar with Alzheimer's disease but perhaps more so with the advanced stages of the disease. As a Geriatrician you would see patients in the earlier stages of Alzheimer's disease – what are the typical symptoms that patients would have?

Many patients present with short term memory problems so they have difficulty remembering what happened recently. Long term memory is usually preserved in the early stages of Alzheimer's disease. Patients may also be repetitive, have difficulty with word finding, names and

navigation. Often patients also feel anxious about their memory or can have apathy. It is important to remember that most people lose some cognitive capacity (brain power) as they age but usually this does not signal the onset of a condition like Alzheimer's disease.

3. Is it difficult to diagnose Alzheimer's disease compared to other memory related problems?

All dementia diagnoses can be tricky. The history from a patient and their relatives is usually one where there is a gradual, subtle onset and progression of symptoms rather than a rapid onset and stepwise deterioration (this is where symptoms stay the same for a while and then suddenly get worse) that can happen with vascular disease for example. Patients may present with memory problems for a variety of reasons such as depression, anxiety, side effects from medication so the history from the patient and a family member are very important to enable us to tease out what exactly is happening. The diagnosis is a clinical one so in addition to the history we look at medications, physical signs, cognitive test results, neuroimaging results and blood results and we make an informed decision based on all these parameters.

4. Are there any treatments available to people with early stage Alzheimer's?

There are treatments available that help with the symptoms of Alzheimer's disease but unfortunately there is no cure. Nevertheless, we know that adopting healthy lifestyles (optimal nutrition, exercise, weight management, not smoking and control of risk factors such as high blood pressure) can prevent or delay the onset of conditions like Alzheimer's disease.

Social support for both the patient and the carer is very important and we encourage patients to keep as mentally and physically active as possible.

5. What is the prognosis following early diagnosis?

This varies a lot and depends heavily on other health issues a person may have. Some people can progress very slowly and really improve with drugs and support, whereas others may deteriorate much quicker.

6. What is your role in NICOLA?

I am Clinical Lead in NICOLA so I had oversight of the health assessment in Wave 1 and liaised regularly with the research team carrying out the health assessments. I am also leading two large research studies funded by the National Institute of Health in USA and the Economic & Social Research Council in the UK. We are investigating cognitive health in detail in 1000 NICOLA participants age 65 years and over and examining how the built environment and factors such as soil and noise pollution can impact upon brain health.

7. Have you found out anything interesting from the cognitive data in NICOLA?

From the tests carried out during the health assessment in Wave 1 we have found that most NICOLA participants performed well on cognitive tests. Increasing age was associated with poorer cognitive performance. Cognitive performance depended on level of education, marital status and level of deprivation. Those with third level education, those who were married and from less deprived areas tended to perform better in cognitive tests compared to the comparison groups.

8. Is there anything you can do to help your memory as you get older?

There is increasing evidence that up to 40% of the risk for dementia is modifiable. We can all help our brain health by eating healthily, not smoking, taking part in regular physical exercise, maintaining a healthy weight, keeping mentally active and socially active. It is important to get our vision and hearing checked regularly and wear hearing aids/glasses as required. There is increasing evidence that avoiding air pollution and excess alcohol are also important along with adequate treatment of diabetes and depression. We should try our best to adhere to the mantra 'what is good for your heart is good for your brain'.

For more information about Alzheimer's disease, and how to access support, take a look at the Alzheimer's Society website <https://www.alzheimers.org.uk/> and Dementia NI <https://www.dementiani.org/>

What stage is NICOLA at ?

NICOLA continues to grow!

NICOLA is proving to be an invaluable resource for understanding what it means to be an older person in N.Ireland, and is providing a rich data source for researchers and policymakers alike.

NICOLA Wave 1 has been completed and Wave 2 has been underway for the past 2 years. Plans are currently being prepared for a third wave of data collection. This will hopefully include a short home based health assessment.....keep an eye out for further information.



This additional data will not only enhance this resource further by enabling the study of changes in key outcomes over time, but will also introduce new topics such as the use and efficiency of publicly funded health and social care services, housing and transport needs. We anticipate further reports from Waves 1 and 2, as well as bespoke reports on specific age-related topics.

In the words of NICOLA's former Principal Investigator, Professor Ian Young *"NICOLA will help us change the way we live for the better and those participating in the study will leave a tangible legacy for future generations."*

What Next ?

Memory Matters in NICOLA !

In the next few months, all NICOLA participants who are aged 65 years old and over will also be receiving a letter inviting them to participate in the NICOLA 65+ Memory and Thinking Study.

The number of people worldwide living with dementia and cognitive impairment is increasing, mainly due to people living longer. It is therefore important for researchers to gather much needed data to try and understand who is more likely to develop cognitive ill-health, such as dementia, and what may have caused them to develop it.

The NICOLA 65+ Memory and Thinking Study aims to investigate dementia risk in older adults. The study which is part of an international research collaboration funded by the National Institute on Ageing in the United States of America aims to produce data on cognition, mild cognitive impairment and dementia and will help us better understand healthy cognitive ageing and identify risk factors for cognitive decline. The study has already been conducted in the UK, US, Mexico, India, China, and South Africa.

Prof. Bernadette McGuinness, Consultant Geriatrician and Clinical Professor from the Centre for Public Health at Queen's, who is lead investigator on the NICOLA 65+ Memory and Thinking study, said: "This cross-national research project combining data from Northern Ireland and Ireland will lead to a better understanding of the differences in dementia prevalence and trends and will provide valuable information for population based research into population risk factors for dementia."

NICOLA has recently received ethical approval for the study, so we plan to roll it out within NICOLA in the autumn of 2021 in collaboration with colleagues working on The Irish Longitudinal Study of Ageing (TILDA) in the Republic of Ireland. Keep an eye out for an invitation in the post asking you to join this important area of NICOLA research in 2021.

The NICOLA 65+ Memory and Thinking study will look at in-depth cognitive assessments of 1000 participants over 65 years old. The study will involve a research nurse coming out to visit you at your home where they will carry out a range of cognitive tests to assess your memory. As part of the study we will be examining your levels of physical activity so we will also be inviting you to wear a device called an accelerometer. We will randomly select individuals to participate in this study.



Other research ?

Apart from NICOLA, researchers within the Centre for Public Health at Queen's University Belfast are also conducting some other new research projects which will study the various factors affecting brain health as we age.



One such study called the SPACE (Supportive environments for Physical and social Activity, healthy ageing and CognitivE health) study, funded by UK Research and Innovation (UKRI) will look at how where we live affects dementia and brain health as we get older.

To do this, researchers will analyse anonymised cognitive data from NICOLA and link this to information about where you live, the amount of air pollution, the toxins in soil, or how walkable your neighbourhood is, and we will explore how different environmental factors relate to brain health.

Dr Ruth Hunter, Reader in Public Health from the Centre for Public Health at Queen's explains: "The complex social and physical environments where we live make some people more vulnerable than others to developing cognitive impairment. We do not yet know how these factors interact to make urban environments a problem for brain health, nor which are the best policies for promoting healthy ageing and brain health for our poorest communities. The SPACE project will provide evidence for policies and practices that provide supportive urban environments to promote healthy ageing, including promoting brain health."

Did you know?



You can find out a lot more about NICOLA from our website. Just click on the different sections to find out more about our research and news updates.

Did you know that NICOLA also has social media channels. Link into our twitter page [@NICOLA_QUB](https://twitter.com/NICOLA_QUB)

**Moving house or updating your contact details?
Please let us know.**



You are a valuable and irreplaceable member of NICOLA and we are very grateful for your continued support for the study – we can't do this valuable research without your continued participation!

KEEP IN TOUCH

We are keen to make sure that you do not miss out on participating in the next part of NICOLA. If you have changed address, or will be away from your address for an extended period, please let us know by writing, phoning or emailing us. We also welcome any comments you may have on the study.

NICOLA CONTACT DETAILS

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Write to: The Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA), Centre for Public Health, Queen's University Belfast, Grosvenor Road, Belfast, BT12 6BJ.

