December 2023 Issue 3



Welcome to the latest newsletter from NICOLA. Please accept our apologies for the delay in sending out this latest bulletin. The NICOLA team have been actively working on analysing the research information you have provided from the previous data collections, and also have been busy making critical steps to ensure NICOLA continues into the next wave.

Our aim with these communications is to provide you with a brief overview of activities undertaken or those planned, provide focus on a chosen health topic and from time to time provide supplementary information on general health and wellbeing.

Its hard to believe its December and with almost another year under our belt, a period of time, that has seen us presented with new challenges alongside substantial changes, we, as a population have had to adapt rapidly to this ever changing environment. At NICOLA we want to understand the impact these times are having on our communities in Northern Ireland. We want to raise pertinent questions from your life experiences so key decision making has supporting evidence to hand and that our research continues to make progress towards a means of healthy ageing. We thank you for your involvement thus far and would like to encourage you to continue your journey with us and take part in NICOLA Wave 3. It is only with your input can we work on making positive changes for the future.

Warm Regards .
The NICOLA study team.



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Special points of interest

- Important—Update your contact details
- · Good news Wave 3 plans
- Key findings from Eye research



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the post please use the link for the Contact Details Form found on Page 8 to make this request or contact the office directly using email or telephone. These contact details are also found on Page 8.

HEALTH FOCUS

EYES



In this issue we feature **Dr Ruth Hogg**, an Optometrist
and Epidemiologist in the
Centre for Public Health,
Queen's University Belfast.
Dr Hogg has a long term
interest in age-related eye

disease including age-related macular degeneration (AMD) glaucoma, diabetic retinopathy and cataract.

Tell us a bit about yourself?

I originally trained as an optometrist but as I always had an interest in research I moved quickly into a PhD at Queens University Belfast and focused on age-related macular degeneration (AMD). Over the last twenty years AMD has been the main focus of my research but I'm also interested in how our eyes change as we get older and the differences between ageing and the very earliest stages of age-related eye disease. After my PhD I spent some time doing research in Melbourne and Cambridge before returning to Queens University Belfast as a Lecturer in 2010.

"Good vision is important for quality of life and for ensuring successful ageing. It is probably safe to say that there is no other organ in the body that can be imaged so easily than the eye. We can measure different layers of cells in the retina including some that form part of the brain and central nervous system. High resolution images of retinal blood vessels can be carefully analysed to see how these structures relate to a person's general health, lifestyle and genetics." Dr Ruth Hogg



What advice would you give to people in order to maintain their eyesight as they get older? For example, we often hear that certain foods and supplements might help?

There has been a lot of research looking at the relationship between diet and the development and progression of AMD. The strongest evidence supports eating a healthy diet rich in colourful fruits, vegetables and fish and low in saturated fats. There is some evidence that antioxidant supplements can slow progression in those that have specific high-risk features in their retina but the evidence is not considered sufficient in the UK to enable these products to be prescribed within the NHS. A large UK trial is needed. Not smoking is also very important and more and more studies are showing the benefits of regular exercise.

HEALTH FOCUS

EYES

How often should older people get their eyes tested? Are regular eye tests important?

For most people having their eyes **tested every two years** is sufficient but for some such as children with glasses, those with diabetes, those with a family history of glaucoma or those aged over 70 years their optometrist may recommend they are seen more frequently. Regular eye tests are very important, particularly as you get older as diseases such as glaucoma can cause significant irreversible damage before you would be able to notice the difference yourself. As well as allowing an early diagnosis of eye disease, eye tests can also sometimes pick up systemic conditions such as diabetes, high blood pressure, high cholesterol and even brain tumours.

Have you found out anything interesting from the eye health data in NICOLA?

NICOLA has provided a wealth of information on how common the main age-related eye diseases are in Northern Ireland. We were surprised that only a third of those with glaucoma, 60% of those with sight threatening diabetic retinopathy and 8% of those with high risk AMD features were aware that they had these conditions. We have also used the retinal images to develop tools for evaluating diabetic retinopathy and visual function tests that can identify changes at an earlier stage.

Tunde Peto, Professor of Clinical Ophthalmology from the Centre for Public Health and leading researcher of NICOLA data said: "As our population ages, cases of AMD are becoming far more common, and we urgently need to find a cure. We hope our vital contribution to this research study will help catalyse the necessary steps needed to end avoidable sight loss for good."

As our health focus has been eyes here are some technology options that may offer assistance for vision impairment:

- Seeing Al app
- Be MyEyes (www.bemyeyes.com)
- Robobraille(www.robobraille.org)
- Office 365 Dictate (Microsoft)

What is AMD?

Age Related Macular

Degeneration (AMD) affects
the middle part of your
vision, not your peripheral
vision (the edges) The first
symptom is often a blurred
or distorted area in your
vision. You may see straight
lines as wavy or crooked,
objects looking smaller than
normal, colours seeming
less bright than they used to
or see things that are not
there.

AMD can make things like reading, watching TV, driving or recognising faces difficult.

For more information www.macularsociety.org/ macular-disease/macular-

macular-disease/macula conditions/

Keeping your eyes healthy: www.visionmatters.org.uk or www.aop.org.uk/advice-and -support/for-patients



HIGHLIGHTS

NICOLA plays key role in research linking statin use with lowered risk of losing eyesight in later life

THE STUDY IN NUMBERS



8504 completed a 1st NICOLA survey



6120 completed a 2nd NICOLA survey



3514 biological samples (blood & urine)



3125 completed a Covid questionnaire

NICOLA eye data was part of collaborative work featuring other population studies from France, Germany, Greece, Ireland, Italy, Norway, Portugal, Russia and the UK. The study saw researchers from a consortium draw together information from 14 studies involving almost 40,000 people to assess the impact of statins on the risk of people developing AMD.

The researchers found that people taking drugs to lower cholesterol (statins) had a 15% reduced risk of developing AMD compared to those who were not taking the drugs. Meanwhile, people taking medicine to control diabetes (mainly Metformin) appeared to have a 22% lesser risk. No such associations were found for the other types of drugs investigated within the study.

This is the first large-scale study showing an association of using lipid -lowering drugs and antidiabetic drugs with **lower AMD prevalence** in the general population using data from multiple European cohort studies.

The NICOLA study has estimated that in Northern Ireland, 23.4% of those over 55 have AMD, with 1.6% having the late stage which is associated with sight loss.

Investigation of retinal biomarkers with depression and cognition in the Northern Ireland Cohort of Longitudinal Ageing (P I Gareth McKay) Access https://bmcgeriatr.biomedcentral.com/ articles/10.1186/s12877-021-02009-z#Sec1 for full publication Examination of the eye offers an opportunity to easily and non invasively measure changes in the tiny blood vessels (the microvasculature) in the retina which is the tissue at the back of the eye. Normal ageing commonly involves reduction in cognitive function or partial memory loss and previous research has identified associations between the size and pattern of the retinal blood vessels with cognitive function. As part of the NICOLA study we wanted to investigate variation in the retinal vessels to check for links with cognitive function and age and to see if other illnesses or factors such as loneliness or anxiety may also contribute to depression and cognitive function. Retinal blood vessels are normally straight or slightly and gradually curved. However, diseases that affect the blood vessels can cause these structure to become more tortuous with added twists and turns. Interestingly, older adults with depression were more likely to have lower levels of tortuosity in those vessels carrying oxygen to the eye. In terms of the relationship between eye health and memory, our findings showed no association between eye health and those individuals at an early stage of memory loss in this group of older community-based adults.



More details about all published research can be found on the NICOLA website @ www.qub.ac.uk/sites/NICOLA/

Over the next 2 pages we introduce 3 of your fellow participants who shared some of their story with us. We are very grateful for their time.



Meet the participants ...the Millars

Irvine and Irene Millar live in Belfast, though this hasn't always been the case. Irvine is originally from Scotland and Irene from Donegal. They met and married in London and moved to Northern Ireland in 1967 when Irvine got a job with Ulsterbus. They have 2 married children who live in England and Wales, 5 grand-daughters, and 1 great granddaughter.

Both Irvine and Irene have been involved in the NICOLA study since it started in 2013. They describe being recruited when someone from Ipsos Mori called at their door to ask if they'd be interested in taking part in the study. They agreed and an appointment was made for the following day. Neither Irvine or Irene had any hesitation in taking part in the study which they thought sounded interesting and was going to be useful for other people. "We felt it was important to play our part." They haven't viewed participating in the study as difficult, "we have the time now to complete questionnaires and would have no hesitation in encouraging others to become involved." They identify benefits of getting older and



challenges of getting older. Once they both retired they were free to travel more and stay away for longer periods of time. Quality time with grandchildren was also a bonus. "We looked after our 2 granddaughters in Yorkshire in the summertime when their mum was working. We had a campervan and took them away a lot. That was a tremendous benefit – we got a lot out of that and they got a lot out of it too. Our grandchildren have very happy memories of these times away. We talk about it all the time and so do they."

They both have varied interests. Irene is president of Inner Wheel – the ladies' version of Rotary, she embroiders and goes to an embroidery class once a week and has been the convener of the Abbeyfield committee, King's Road for 36 years.

Irvine is involved in Rotary. A recent Saturday was spent planting crocus bulbs near the boat club at Stranmillis as part of the Polio plus project to help abolish polio worldwide. The children's fingers are dipped in purple ink to show they've been vaccinated and the purple crocuses are to represent this. He also enjoys modelling and has set up a model railway in his basement.

Both Irvine and Irene describe challenges in terms of what age and health issues bring. Some things happen gradually and just "creep on", and some things become an impossibility, such as climbing hills or long staircases.

Household duties are split between them both and they say they work well together. In relation to the future the main concern they both have is that they may not be able to stay in their own home.

In the meantime, they are both keeping busy having lunch with friends, reading, doing crosswords, walking and attending church and they also enjoy breaks away to hotels and visiting family.

*Note: Some details may have changed from when the conversation was held

Please get in touch if you would like to feature in an issue of the newsletter. All contact details can be found on Page 8





Meet the participants ... Helen



Helen worked full time as a human resources manager, but she was hoping to reduce her hours as she had turned 60. She has one son in his 20s. He had a stroke as a result of Covid and had to return from university in Bristol where he was studying to be an occupational therapist. Apart from work which takes up a good bit of Helen's time she's a keen knitter, a member of a local church and is very involved with the development organisation Tearfund. Helen has been involved with the NICOLA study from the very beginning, initially completing a questionnaire which was followed up by a medical assessment at the Belfast City Hospital. She's had follow up questionnaires and interviews since being enrolled in the study. Helen says she was motivated to take part in NICOLA as she is an altruistic person and trained as a librarian so likes forms! "I like being part of something bigger and it seemed to me that this would be something very useful

to be involved in. "I enjoyed going through the assessment - I'm very competitive – in relation to the tests about memory and processing - I wanted to know what a good score was — who does better than me and all that kind of stuff." She also understood the importance of "hard data" in relation to evaluation and planning for the future.

Helen found everything in the study quite straightforward. The initial questionnaire was a lot more detailed than she expected. From the viewpoint of NICOLA she highlighted the importance of reflecting on all the different parts of society, and providing the opportunity for women's health needs specifically to be explored as they get older, as in some instances these are different from men. She would encourage others 100% to participate to help get an understanding of the health, aging and service needs for people in Northern Ireland. "We need to get the money in the right places which is why the study is really important and also to see how Northern Ireland is changing as a society."

Helen describes the benefits of getting older as "life experience, wisdom definitely, being a little less frantic, less concerned about what other people think about you, you've kind of seen it all and done it all, you have time to give back and have a bigger world view. I've been through serious illness, I've lost my dad, I've lost friends – you can choose what to do with that, but I think the benefit is I've gained a lot of resilience – maybe I'm naturally resilient but as well I've learnt an awful lot and that's why older people have a lot to give."

*Note: Some details may have changed from when the conversation was held

THE NICOLA HEALTHY AGEING PANEL

Have some input into NICOLA's future direction and join our Panel. You get to advise us on what would help in maximising the success of NICOLA from your perspective. Meetings are held either in person (expenses will be covered) or via

Zoom. Attendance is only expected when it suits your schedule and is entirely voluntary. We aim to provide both notice and some options for when a meeting is required to suit the majority. We are particularly interested in welcoming some younger members on board and also welcoming

We are particularly interested in welcoming some younger members on board and also welcoming those who still work, those unable to work for health reasons or otherwise and those that may have mixed feelings about the study. If interested please contact the NICOLA team at NICOLA@QUB.ac.uk or phone 02890 978921 or 07788320299.

NICOLA sub studies - what are they?



A sub-study asks separate research questions from the main or parent study (NICOLA) but contributes to the parent study objectives and uses either all or a subset of the parent study participants.

NICOLA has 2 sub studies running currently—the **65+ Memory and Thinking Study** and the **SPACE Study** (Supportive Environments for Physical and Social Activity, Healthy Ageing and Cognitive Health)



Our age **65+ Memory and Thinking Study** has completed its recruitment with 1035 taking part. The team would like to express their gratitude to each of these participants for their valuable contribution and hope to speak with them again in a few years with the 2nd stage of the study.

Many countries around the world are taking part using standard assessments to assess memory and thinking. The intention of this work is to produce data on memory and brain health that can be compared with the other countries collecting the same in an effort to identify risk factors for cognitive decline and dementia.



The SPACE (Supportive Environments for physical and social activity, healthy ageing and cognitive health) Project looks at the impact of the environment on healthy ageing and cognitive health. The number of people worldwide living with dementia and cognitive impairment is increasing, mainly due to people living longer, so we want to understand how where we live affects dementia and brain health as we get older. Some research suggests that where we live might influence our brain health, for

example, poor air quality in towns and cities, can lead to a decline in brain health. As more of us now live in towns and cities, it is important that the environment where we live is scientifically designed and improved to maximise our brain health. The complex social and physical environments where we live make some people more vulnerable than others to developing cognitive impairment. In other words, the factors that account for who is most likely to develop cognitive ill-health due to the environment has less to do with 'how' we live and more to do with 'where' we live.

For more information on SPACE: www.qub.ac.uk/sites/space/VideosandFactsheets/



Did you know that October was positive ageing month. This annual month-long campaign across the country aims to celebrate the contribution of older people within our local communities while empowering them to lead full and active lives. It includes activities to suit all interests from guided walks, arts, sports and cultural activities to online training sessions, employment advice clinics and other workshops or talks. If you didn't get to partake this year we hope you get the opportunity to next year. Details are usually found on a number of websites or in community centres.



On the horizon — exciting future plans @ NICOLA

We are very pleased to say that we have received the financial support to continue the work of NICOLA and so are making preparations for our **third wave** of data collection. Our aim is to focus on key areas of interest which ideally should result in a shorter home survey. We hope you will find the time once again to help us. We will also be offering a Health Assessment during this wave which you may find of benefit as selected feedback will be provided.

The provisional date for commencing this next stage of NICOLA is early 2024 to permit us adequate time to prepare for the various components

Further information will be provided as we begin to finalise details and we look forward to keeping you informed about this next stage of NICOLA.

Please make sure we have your correct contact details so you can be kept up to date. We would encourage you to keep involved with the study as **your** input is truly our greatest strength.

What happens to your data?



In summary the answers that you provided by completing any of the following;

- -Home interview
- -Self Completion Questionnaire
- -Health Assessment
- -Dietary Questionnaire
- -Covid Questionnaire

are securely stored against a unique identifier which ensures anonymity. All of your direct contact details e.g. name, address, telephone number etc. are separated and held securely elsewhere with restricted access.

We adhere to policies and procedures to ensure your data is treated lawfully and with integrity and confidentiality. Approved research projects are provided with access to the requested anonymised data only.

Full details regarding how we process your data can be found in the **NICOLA Privacy Notice**. This can be found on our website @ www.qub.ac.uk/sites/NICOLA/

We are happy to post you a hard copy should you prefer.



PLEASE HELP US CONFIRM WE HAVE THE CORRECT CONTACT DETAILS FOR YOU - it will only take a minute

To provide this information any of the following methods can be used :

Phone ① 07788320299 or 02890 978921

Email inicola@qub.ac.uk

Online <a>https://forms.office.com/e/90d7gSSQ1r

Scan the QR code



Post
NICOLA study
Centre for Public Health, Queen's University Belfast
Grosvenor Road, Belfast, BT12 6BJ

What happens to your samples?



The blood and urine collected from you are divided up into smaller volumes, with biomarker analysis performed and stored at -80 degrees in our restricted access research freezers. Researchers

wanting to look specifically at samples have to submit an application explaining their area of research which requires approval from the data access team. All samples are stored with a unique identifier to ensure anonymity.

You are free to withdraw from NICOLA at any stage.

With your consent though we can continue to use your anonymised data & samples which permits key ongoing research even if you no longer want to actively take part.