



SUMMER 2022-2023

WORLD-FIRST HEALTH AND AGEING STUDY IN OLDER ADULTS

THE FREQUENTLY ASKED QUESTIONS (FAQs) EDITION

This special edition of the newsletter is dedicated to answering **your** questions about your ASPREE project. Our team have collated a list of frequently asked questions (FAQs) about the ASPREE trial, the follow-up ASPREE-XT study, and sub-studies, asked by you, our participants.

While it's been a challenging year, there have been plenty of achievements too. The ASPREE team, together with you, continue to step closer to improved health for older adults in the future. We are very grateful that you attend study visits, take our phone calls and allow us to collect documentation about health events – you are the true heroes of this research! From all the ASPREE team, we wish you the happiest and safest of festive breaks and we look forward to catching up with you this year.

GENERAL QUESTIONS ABOUT THE STUDY

Q: What are you looking at now?

A: ASPREE-XT's main purpose is to help older adults stay well for longer. The study is investigating factors that can affect an individual's physical health, cognitive (thinking and memory) function and mental wellbeing as we age. The two main areas of research are:

1) The long-lasting effect of aspirin:

ASPREE-XT is investigating whether having taken aspirin for a period of time (during the ASPREE trial) helps prevent dementia and some types of cancers several years later. This is called a 'legacy' effect of aspirin.

Studies in middle-aged adults suggest that aspirin may reduce the development of cancer, particularly bowel cancer, some years after use.

ASPREE-XT is the first large scale study in the world to determine the long-lasting effects of aspirin on health in older adults.

No other study is investigating this aspect of aspirin only in older people.

To see whether aspirin has an effect on health some time later, researchers must compare health events of participants in the aspirin group with participants in the placebo group.

So everyone's health information – whether you are fighting fit or otherwise – is really important to answer this question.

2) Factors affecting health and independence:

The ASPREE-XT study also investigates factors that affect what matters most to older adults: physical ability, cognitive function and mental wellbeing.

The Australian population is ageing. **Older adults want to retain independence and quality of life during this longer lifespan.**

You are part of the largest longitudinal study of its kind in older adults. **Sharing your health journey over the years enables researchers to work out ways to preserve memory and thinking and physical ability for longer, and possibly to identify diseases earlier.**

Early identification of being at risk of a disease helps individuals and their doctors to put in place ways to slow down disease progress or even prevent it.

Studies that collect health information from the same people over an extended period of time (a longitudinal study) are a very powerful form of medical research. **Findings from past longitudinal studies have saved an untold number of lives.**

Many years ago, the Framingham study identified high blood pressure as a major risk factor for heart attack and stroke. Today, good blood pressure control is a mainstay of healthcare around the world. GPs follow heart health guidelines, whose origins can be traced back to findings from the Framingham longitudinal study!

Q: What do you mean by 'factors affecting health'?

A: ASPREE-XT collects diverse health information to learn why some older adults stay well, while others experience major declines in health and wellbeing.

Health factors being investigated include demographic (e.g. age and gender), genomic (our genetic make-up), environmental (e.g. diet, physical activity, social activity) and co-morbidities (existing health conditions such as diabetes or high cholesterol).

Your blood sample in the ASPREE Biobank sub-study enables

YOUR QUESTIONS

research into 'biomarkers' (such as hormones and proteins) that relate to disease, or to good health. Both sides of the coin are equally important to research.

A stool sample donated to the ASPREE-XT Microbiome study helps investigate the impact that micro-organisms (such as viruses and bacteria) in our gut have on our health.

No other study of this scale is investigating the factors that affect so many aspects of health in such detail.

Researchers will use information about new risk factors to target treatments to prolong independence and quality of life for older adults.

Q: How many are still participating in ASPREE?

A: More than 14,000 participants are being followed up in the ASPREE-XT study in Australia and the US.

Q: How long is this going to go on for?

A: ASPREE-XT is funded until 2024, but we have applied for an extension until 2029. We shall inform you as soon as we hear the outcome.

Q: How long have I been participating in ASPREE now?

A: Participants enrolled in the ASPREE trial between 2010 - 2014. This means that participants have been contributing to the project for at least 8 and up to 12 years. **We are very grateful to have your support for medical research.** You are actively contributing to new learnings about ageing health.

Q: Don't you just want healthy people in ASPREE-XT?

A: No. Whether you are in excellent health, or have some health problems, **everyone's** contribution is important to this medical research.

Some decline in physical and cognitive function as we age is normal. However, it is unknown why some healthy older adults will decline further, while others do not. We need a large group of individuals (with varying levels of health) to give a true picture of ageing and to learn ways to maintain good health and prevent illness.

Sharing your health experience with ASPREE-XT, teaches researchers a lot about ageing health in Australia.

Q: What's happening with all this data, are they finding anything interesting?

A: Researchers and scientists from around the world are regularly publishing new and important findings from ASPREE and ASPREE-XT in Australian and international medical journals.

Aspects of ageing studied so far include: genetics, dementia, cancer, cardiovascular disease (diseases of the heart and blood vessels), sleep apnoea (excessive snoring), medicine use, mental and social health, physical ability, falls, alcohol intake, kidney disease and hormones to name a few.

These studies are the tip of the iceberg. (Almost 500 applications by researchers to analyse ASPREE data have already been approved!)

Researchers are working towards disentangling how various factors affect aspects of physical ability, memory and thinking and mental wellbeing.

Each new learning means we are getting closer to new targets for prevention. You are actively contributing to this process!

Q: What will happen to all the data collected after the study finishes?

A: There will be many, many analyses of high-quality, diverse data never before captured in a large group of older adults over the long term. Data will contribute to health and wellbeing of older adults around the world, for many more years to come.

All data stays de-identified. This means your health information has been given an ID number and is NOT linked to personal details.

Q: Will we get results like last time?

A: Later this year, we will send you a personalised letter of your journey in ASPREE-XT that summarises your measures taken over the study period so far. The letter will be similar to the summary of your measures sent to you in 2019.

Published reports from analyses of ASPREE data will continue to be shared via the ASPREE newsletter and website: aspree.org

Q: Will there be another study update?

A: Yes! We will have 'online' study updates, over Zoom, in early 2023. If you have provided your email address, you will be sent an invitation to join an online study update. (If you have a NEW email address, please let us know by emailing aspree@monash.edu)

In-person study updates were delayed to reduce the risk of transmitting COVID in group settings. We expect in-person study updates in your area to start later in 2023, once the current COVID wave has passed.

QUESTIONS ABOUT STUDY VISITS

Q: What happens if it's difficult for me to attend study visits?

A: We will always tailor study activities to your needs at the time. We understand that personal circumstances do change. If this happens to you, please call to discuss with our team on 1800 728 745.

Whether you are living with memory loss, or reduced physical ability, researchers are learning a lot from your experience. Study participants living with dementia often like to bring a 'study buddy' so they can continue to contribute to dementia aspects of research.

Q: Why do we do the grip and gait tests?

A: How we move involves several co-ordinated systems in the body, such as nerves, muscles and bones, and balance. Studies show

that changes in a person's hand grip strength and gait (walking) speed may indicate changes in physical and/or cognitive health.

Grip and gait measures that you provide at each study visit helps researchers to investigate the link to underlying physical and cognitive health in older adults over the longer term. The research could be used to help prompt lifestyle changes (such as increasing exercise) or other healthcare to reduce the risk of illness.

Q: Why do you take blood pressure from the right arm and not the left arm? Will speaking increase my blood pressure?

A: All study measures are collected in the same way each year. Consistent data collection is vital in research, and is one of the reasons why the quality of ASPREE data is so highly regarded by researchers.

ASPREE-XT field staff conduct all study visit activities in exactly the same way. This includes taking a blood pressure on the same arm while at rest and not speaking. (Talking can raise your blood pressure and skew your reading higher.) If we didn't conduct study activities in the same way, study findings would not be reliable.

Q: Why do you ask about diagnoses of diseases such as Parkinson's disease?

A: Many diseases can lead to disability and loss of independence for some older adults and not others. The ASPREE-XT study is investigating the impact of a range of diseases and conditions on quality of life and lifespan.

Q: Will I or my doctor receive feedback about my performance in the memory and thinking exercises and other parts of the study visit?

A: Unless you tell us otherwise, we will notify your GP of significant changes in health measures observed at study visits, for follow up care. Examples include members of the study team detecting an irregular heart rate (pulse), very high blood pressure or significant changes in thinking and memory. ASPREE-XT collects data intended

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for research purposes, but medical diagnoses and healthcare rightly remain with your GP.

In the past, significant health measures forwarded to GPs have led to detection and treatment of many conditions, including atrial fibrillation (an abnormal heart rhythm).

Q: There has been no change to my health since the last ASPREE-XT visit. Is there any point in completing the questionnaires?

A: Yes, it is important that you complete all the questionnaires please. Whether there has been a significant change in your health or not, YOUR journey matters.

Your contribution continues to make a difference to how the scientific community will understand health and ageing.

Q: Why are the memory and thinking exercises the same each year?

A: Each of the cognitive exercises collect data about different aspects of thinking and memory, such as decision making, long term memory, short term memory, word recall, visual interpretation and how the brain processes information.

Repeating the same exercises each year enables researchers to identify changes over the study period. If there are changes, the exercises help identify what aspects of thinking and memory may be most affected and why.

Q: I feel like I struggled with the memory and thinking “tests”, does it mean that I have dementia?

A: No. Memory and thinking (cognitive) exercises at study visits are not an assessment or test for dementia, and they cannot diagnose the disease.

The cognitive exercises are a tool that captures a snapshot of thinking and memory in a form that can be used for medical research.

Information from the cognitive exercises is vital to learn about factors that affect memory and thinking as we age.

It is normal to find cognitive exercises tricky at times, particularly as some parts are designed to be challenging. (If they were too easy, they wouldn't help research.)

ASPREE field staff, who do the same cognitive measures as part of their training, also find them challenging!

Stress, fatigue or poor sleep and several other factors can affect everyone's thinking and memory on any one day.

All that matters is that you do the best that you can and try to give all parts a go.

Q: Why don't you collect data on over-the-counter (OTC) medication use and ask about COVID-19 at study visits?

A: Due to time constraints at study visits, information about OTC medication use and COVID-19 can be given in the ALSOP sub-study questionnaires that can be completed at home.

Q: What do blood and urine tests show?

A: Blood and urine tests check for indicators of health, such as how well the kidneys are working. We also look at levels of a protein called haemoglobin, which is low when someone is anaemic, and levels of non-fasting cholesterol.

Q: I recently did a blood/urine test through my doctor. Do I have to get another blood/urine test for ASPREE?

A: Possibly. If all the measures we require were included by your GP, then no. But there may be some elements not included in that recent blood test that ASPREE-Xt has an interest in. If so, an extra test is voluntary and if it's not something you wish to do, please let your ASPREE staff member know.

QUESTIONS ABOUT SUB-STUDIES

Q: I'm very old now, is there any point in me participating in the ASPREE Biobank and Microbiome studies?

A: Good health and wellbeing are important for all ages! There are very few studies examining the gut microbiome and its role in health and disease in older age. We expect the ASPREE Microbiome study to make an important contribution in this area of research. No one is too old to

participate in either sub-study.

Q: If you find any serious health concerns with my stool samples in the Microbiome-Xt study, will you let me know?

A: The measurements that will be done on your stool sample are very different from those done in a bowel cancer screening test (looking for blood in the stool). Our microbiome analyses do not produce the type of information required to diagnose health concerns. This sub-study captures an overall picture of the microbial environment (such as types and levels of bacteria, viruses and other microbes) in the gut.

Researchers are investigating how the microbes present in stool (poo) are related to health or disease outcomes that may occur many years down the track.

Q: Why do I have to delay collecting the Microbiome sample if I am taking antibiotics or have been admitted to the hospital?

A: Antibiotics and some treatments given in hospital can change the types and amounts of microbes in your gut, and it can take a few weeks for these to return to whatever is usual for you. For these reasons we might ask you to hold off taking a microbiome sample until your gut microbiome has returned to your 'normal'.

Q: What about if I take antibiotics constantly or regularly? When should I take my microbiome sample?

A: Some people are on long-term antibiotics, and take them regularly or daily. If this is the case for you, you don't need to delay the stool sample collection and you can note your antibiotic use



Above: An illustration of the microbiome

on the Stool Sample questionnaire in the kit.

Q: I am having trouble with the collection, who can I speak to?

A: Please call the Microbiome team on 1800 728 745 and we would be happy to answer any questions you have or post out another kit if you would like to have another attempt at taking a sample.

MORE INFORMATION

We hope you have enjoyed these FAQs about your study. If you have a question (or need to update your details), you are always most welcome to speak to a member of the team on 1800 728 745 (toll free from a landline) or via email to aspree@monash.edu

Where to find out more about ASPREE and ASPREE-Xt research:

- 1) The ASPREE website (aspree.org) has a dedicated section for study participants and holds much more information about the project than we can include here (or in regular newsletters). Click on 'news' at the top of the website to read more about a range of research findings.
- 2) Join us at study updates! These informal get-togethers are a fun way to catch up on study happenings and ask questions. Alternatively, if you have an email address and travel is an issue, you can join us at an online update.

Staying in touch with you is very important

Thank you for being in ASPREE-Xt. Your ongoing participation in the study enables researchers to learn from your experience of ageing to drive better health in the future.



CALL:
1800 728 745

(toll free from a landline)

Email: aspree@monash.edu

Website: www.aspree.org

ASPREE-Xt Funding Organisations

- National Institute on Aging (NIA/NIH in the USA)
- National Cancer Institute (NCI/NIH in the USA)
- National Health and Medical Research Council of Australia (NHMRC)

ASPREE-Xt Collaborating Organisations

- Monash University
- Menzies Institute for Medical Research, University of Tasmania
- Australian National University
- The University of Adelaide
- Berman Center for Outcomes & Clinical Research (Minnesota, USA)
- 22 study sites across the USA