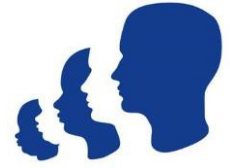


Dunedin Multidisciplinary Health & Development Study



PHASE 52 EXPLANATION OF PROCEDURES

Dear Study Member,

We are excited to outline our plans for Phase 52 of the Dunedin Multidisciplinary Health and Development Study. Please read this carefully. We hope you will agree to join us again in this very worthwhile research programme.

The big-picture purpose of the Study is to obtain a better understanding of the ageing process by studying the health and development of people at midlife. We have shown that despite not being old you can teach us about how people age. What we find out will be used to help researchers, health workers, and policy makers understand ageing and plan better services around the world.

As you are aware, involvement in the Study is completely voluntary and you are free to withdraw at any time.

ANY QUESTIONS?

If you would like to talk about any parts of the Study, please contact us:

Professor Reremoana (Moana) Theodore (Director)

Dr Sandhya Ramrakha (Research Manager)

Mr Sean Hogan (Cohort & Assessment Manager)

Call 0800 479 8508 (freephone in New Zealand) or +64 (0)212795550 for Sean Hogan.

WHAT KIND OF INTERVIEWS AND TESTS ARE INCLUDED THIS TIME?

The interviews and tests are described on the following pages.

We would like you to read this explanation of the procedures before you come to the Unit. ***If you do not wish to take part in any particular section, please cross it out on the consent form.*** Remember, you will get another chance to discuss any aspects of the assessments face to face when you come to the Unit.

OLD STUDIES AND NEW

Most of the studies are the same or very similar to those we have done in the past. All new studies are identified and described in detail to help you decide whether you wish to take part in them.

CONFIDENTIALITY

As always, all information is strictly confidential to the Research Unit and is never released to anyone unless you request this. All data are protected by an anonymous identification number.

ASSESSMENTS

CARDIORESPIRATORY HEALTH

As in the past, we will be taking your **blood pressure**, **heart rate**, and **body measurements** (e.g., height and weight), but we have dropped the bike fitness test!

In the Respiratory part of this session, we will ask questions about breathing problems, and we will conduct much simpler **lung tests** than at age 45: we have dropped the 'body box' and won't be giving you Ventolin. We will measure how much carbon monoxide is in your breath by having you breathe into a handheld machine. There are no risks associated with these tests.

If possible:

Please do not use any breathing inhalers on the day of your assessment but bring them with you; and please do not smoke on the morning of your assessment day.

HEALTH HISTORY

Again, we will also enquire about your **general health**, but with a slightly expanded list of conditions. Specifically, we will be asking about your recent medical history, use of medication, head injuries, pain, disability, sleep, and smoking, ability to do physical tasks, and what services you have accessed like GPs or specialists.

PHYSICAL FUNCTION

We are again carrying out several physical function tests, including measuring how you walk. We will also test your functional fitness by asking you to **step-in-place** and do **chair stands** to measure the strength of your legs. We will assess your **balance** by asking you to stand on one leg, your **hand grip strength** by using a special instrument, and your **hand-eye coordination and dexterity** by placing pegs in a pegboard. Three **NEW** tests will assess your **balance** by getting you to lean forward with your arm outstretched, assess your **arm strength** by getting you to do arm curls with a weight while seated, and finally reach around your back with your hands to see how **flexible** you are. We will also ask questions about what **physical activity** you do, as well as what your **diet** is like.



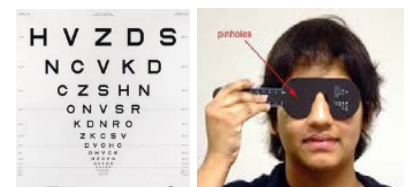
COGNITIVE FUNCTION

Like last time, we will be testing your cognitive functioning via tests of memory, attention, visuospatial ability, and analytic and verbal reasoning. If possible, please try not to use excessive alcohol or drugs the night before you come to the Unit, as a hangover can interfere with these tests.

VISION

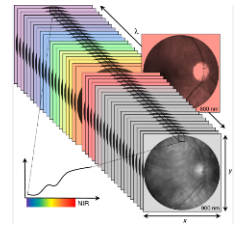
We will ask you questions about your eyes and whether you wear glasses or contact lenses, if you have any eye problems, and if eyesight difficulties affect your life in any way. In a **NEW** test, we will also measure your prescription from your glasses or contact lenses, if you wear them.

We will also run a number of tests using the latest technology. We begin with a **standard vision test**, the kind you would do at an optometrist. The test will measure what you can see using a standard eye chart.



We will again conduct a **contrast test** to look at the level of contrast the eye can detect. Like last time, we are also going to measure the shape of the surface of your eye, how much error there is when the eye is trying to focus, and the thickness of the cornea. This machine will also check the pressure of your eyes using a puff of air. This test is called **autorefraction**.

A **NEW** test will use a **hyperspectral camera** to look through to the back of the eye. This machine captures images from across the light spectrum, so it takes many pictures in one go, each looking at how a different wavelength of light is absorbed and reflected. We will be assessing what this can tell us about how protein is laid down in the back of the eye. Because this is a new and cutting-edge research machine, it has an extra description that the builders of the machine wanted us to tell you.



“Caution – The light emitted from this instrument is potentially hazardous. The longer the duration of exposure, the greater the risk of ocular damage. Exposure to light from this instrument when operated at maximum intensity will exceed the safety guideline after 25 minutes (~5,500 hyperspectral images).”

This means that tests showed that the light used in the machine that shines in your eyes is safe for up to 25 minutes use on maximum power. We will be using it on a lower power for only a few seconds. We are very confident this is a low-risk procedure.

The last test is a standard test undertaken in every eye department in New Zealand, which you did last time. It is like a photograph, and it analyses the back of the eye in fine detail. It will measure the **retinal nerve fibre layer** and the retinal blood vessels, with incredible resolution. This test lets us assess your nerve health by looking in your eye.

HEARING

Like last time, we will ask you questions about your hearing. Then we will move onto the hearing tests, all of which you did at Phase 45. We will begin with an examination called **otoscopy** which will involve a visual examination of the outer ear canal and eardrum.



We will then measure how well the middle ear bones, the eardrum, and small muscles in the middle ear are working. The sensation is similar to the pressure change when you go up in an airplane. This is a standard test called **tympanometry**.

We will also measure how sensitive your hearing is and your ability to hear speech in background noise. The first test (**pure tone audiometry**) will be carried out in a sound-proof booth, where a series of different tones at different pitches will be played to you at different volumes. In the second test (**speech in noise**), you will be asked to listen to a recording playing three voices speaking at the same time, and identify sentences spoken by one of the three voices.



UPDATE OF LIFE EVENTS

As at the last assessment, you will be asked about your life over the past seven years. We will ask about where you have been living, who you have been living with, and the jobs you have had. We will also ask about recent major life events, including over the COVID pandemic (**NEW**). As part of this, we are interested in your **housing security (NEW)** and will ask you about your addresses since age 45.

MENTAL HEALTH

As we have done at every assessment since age 11, we will ask you about your feelings and about any emotional problems or difficulties you may have experienced. We will also ask about your use of alcohol and drugs. The interview will cover a wide range of areas, including your use of mental health services.

LIFESTYLE

As in the past, we will ask you about your **sexual behaviour**, on a computer. We will also be asking about changes in physical functioning and your experience of health conditions associated with **sexual and reproductive function**. These questions will focus mainly on events and changes since the previous assessment.

We will again ask you about your **work experiences**, including qualifications and skills. We will also ask about your current and most recent job, about things that make your job stressful or demanding. We will ask you about your **financial situation**. We will continue to conduct studies aimed at understanding **ethnicity and identity**. Most of these questions are the same as previous assessments, but there are some **NEW** questions about your attitudes, opinions, and interests, as well as your experience of discrimination and ageing.

We will ask you about your **relationships**, but not as much as in the past, as well as about **social support and wellbeing**. We will ask some **NEW** questions about your view of the **society and community** in which you live.

Just like last time, we will ask for your permission to send a short questionnaire about your emotional wellbeing and behaviour over the past year to three people nominated by you, who know you well. We can show you the questionnaire when you come in.

KIDNEY FUNCTION

Urine is a very sensitive marker of kidney health. Like last time, when you arrive at the Unit, we will ask you to provide a sample of your urine, before the start of the first session. Collection will be done privately in the bathrooms at our research unit.

DENTAL HEALTH

The dental part of the Study is concerned with tooth decay and gum disease, which are the two main oral diseases. We are also interested in your views on dental care and the effect that this has had on your dental health. As in the past, we will conduct a brief **dental examination** and ask you questions about your dental health. We will explain the results of the examination and give you a written report that you can take to your dentist if there are any findings that might be of help to you.

We also wish to conduct a **3D scan of your teeth** just like last time. This will be done using a tiny camera on a wand, which will be held over your teeth.

In a **NEW part of the dental theme**, we will ask you about your experience of dental care and dental problems—your dental story—and we will make an audio recording of your responses so we can understand them more fully.

FACIAL PHOTOS

Once again we will take a photo of your face. This is used to assess skin ageing, for example from sun exposure or smoking. If you wear makeup, you will be asked to remove it for this assessment and wipes will be provided for this purpose. We have moved this to the last item of the day as some people prefer not to remove their

makeup early in the day.

BONE LEAD

In a **NEW** test we are interested in how much lead is in your bones. To find out we will use a hand-held device that uses x-ray fluorescence (XRF) to analyse the lead in your shin bone. You will have to roll up a trouser leg or remove tights for the test, which will take 5 minutes or less and will involve only a small amount of X-ray exposure.



BLOOD TESTS

Just like at Phase 45, we would like to take a small sample of your blood, approximately 120mls (about half a cup). This will be taken towards the end of the assessment day by a trained nurse. The blood will be stored and analysed (in the areas below) to provide information about how these interact with lifestyle and behaviour to help us understand health and well-being.

- Hormones (e.g., testosterone, cortisol, oestradiol)
- Immune System (e.g., C-reactive protein, fibrinogen)
- Ions and trace elements (e.g., calcium)
- Cardiovascular function (e.g., cholesterol, apolipoprotein A1, triglycerides)
- Kidney and liver function (e.g., cystatin C, creatinine, albumin)
- Blood cell counts and haematology (e.g., platelets, basophils, glycated haemoglobin)
- Diet and vitamin levels (e.g., vitamin D)
- Nucleic acids (e.g., telomeres, DNA methylation, whole transcriptome gene expression)
- Detoxification processes (e.g., blood protein carbonyls)

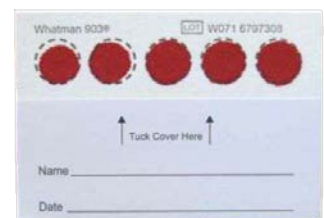
NEW BLOOD TESTS FOR BRAIN FUNCTION

All Study members are invited to have their blood tested for biomarkers that have been linked in other research studies to neurological problems of ageing including cognitive decline. These biomarkers are new, and they are not yet used in routine health care. The purpose of this new study is to gather information that will help scientists better understand how the blood tests relate to your health, for example, to measures of thinking and memory that you will take during the assessment day and measures of your brain's structure that were taken during the MRI brain scan.

As well as drawing blood, this time we would like to do two **NEW** procedures. We will ask for a blood spot and a cheek swab from everyone so that we can check that all the DNA results are the same whatever method is used to gather the sample.

BLOOD SPOTS

This involves a small prick to your fingertip. You will feel a quick pinch, but it shouldn't be very painful. We will then gently squeeze your finger to collect a few drops of blood onto a card like the one shown to the right.



CHEEK SWABS

We would also like to collect cheek (buccal) swabs. We will use a cotton swab and rub it against the inside of your cheek. This might tickle but should not feel uncomfortable. This test collects some of the cells from your mouth.

DATA LINKAGE

As we have done before, we wish to take advantage of other sources of information that are held about you to further flesh out our understanding of the topics we study. Information from other sources is sometimes more detailed than what you may be able to supply from memory. This information is, of course, subject to strict security measures to maintain confidentiality. **Importantly, no information that we hold about you will ever be retained by any of the agencies listed.**

Just like at age 45, we will ask you for permission to collect the following information:

Agency	Examples of use: in the studies of
Police and Justice Records	illegal behaviour
Hospital Records Records about your health held by National Collections and Reporting, Health New Zealand/Te Whatu Ora GP Records Emergency Service Records ACC Records Traffic Accident Reports Ambulance Records	injury and health
Police Traffic Reports	injury, health, and drink driving
Credit Checks Government Benefits	work and finance
Social Welfare Records	work and well being
Education	work, finances, and health
Student Loans and Allowances	finances

We will ask your permission to obtain information about your COVID-19 testing and vaccination history. **This is a NEW request** and will support the information we ask about your COVID experience to get a good understanding of it.

We seek permission to collect all these records up until the time of your next assessment, hopefully when you are aged 60—but this, of course, depends on funding!

BIOLOGICAL STUDIES

Study researchers conducting genetic research (using DNA and RNA) look for genes that make people resistant to health problems or stressful experiences. RNA is produced by DNA and measuring it allows us to better understand how our genes work and how they influence health. As in the past, we plan to conduct studies about genetic risk or protection, and the development of behaviour problems, such as depression, or the development of physical health problems, such as poor lung function. We will continue our work in these areas, with studies focusing on cardiorespiratory and brain function, gum disease, cognitive difficulties, risk for diabetes, and good and poor ageing. In a nutshell, we will try to understand how genes interact with life experiences to influence health and development, and how this might change as people age. In the long term, it is possible that the Unit might make discoveries that can lead to medically useful diagnostic tests, or new treatments, cures, and preventions.

Importantly, none of the material stored in the biorepository will be used to identify individuals for any forensic or clinical purposes. The DNA and RNA will *not* be used to test for any known disease, and no ‘test result’ will be generated. As a Research Unit, we are not equipped to provide clinical genetic testing or the genetic counselling that must accompany such testing. Should a Study Member require clinical genetic testing in the future, a new tissue sample would be easily obtainable, without accessing the Dunedin Study Biorepository. If you are ever asked (for example, by an employer) whether you have undergone genetic screening, it is correct to reply that you have not. Genetic data will be analysed in group comparisons only and are for confidential research only. No feedback can be given to individual Study Members or their GP about their genes; although, as usual, the broader findings of the research will be shared with Study Members in newsletters and other publications.

THE DUNEDIN STUDY BIORESPOSITORY

Samples (e.g., blood, urine) and DNA and RNA will be frozen and stored in special, locked freezers that belong to the Dunedin Study, at laboratories here at the University of Otago and at Duke University, Durham, USA (with Professors Moffitt and Caspi). No names will be on the test tubes, only barcode labels will be used.

Scientists seeking to access the Dunedin Study Biorepository for *future* research projects will require:

- 1) Approval from the Study’s Director (Professor Moana Theodore), Associate Director (Professor Terrie Moffitt), and Assistant Director, Biorepository (Professor Stephen Robertson), and
- 2) Ethical approval from their host institutions and/or appropriate ethics committees in New Zealand.

RESPONSIVENESS TO MĀORI IN THE RESEARCH

The Dunedin Study has a Māori research policy. This policy includes protocols for the collection, storage, analysis, and disposal of samples collected as part of the research. It also includes protocols for the collection and analysis of data from questionnaires in relation to Māori. The Māori research team has a role of providing kaitiakitanga (guardianship) for Māori aspects of the Study. Copies of the detailed policy are available at the Research Unit.

UNIT NON-INTERVENTION POLICY

Our policy is not to intervene in people's lives except in two exceptional circumstances where an individual is deemed to be:

- 1) An immediate threat to themselves; or
- 2) An immediate threat to the safety of others.

Thankfully, these situations rarely occur, but we have procedures in place should they be required. We do not provide Study Members with formal feedback about their data collected during the day, except if results show an immediate risk to the Study Member's health. We will continue to provide you with information and contact details (e.g., addresses for GPs or specialised clinics and services) if you want this.

SECURITY OF INFORMATION

All information collected by the Research Unit is kept secure. Information is linked to anonymous numbers and special security procedures are in place to prevent the information being linked to the names of Study Members. No material that could identify any individual is ever used in any reports of the Study. Only approved Dunedin Study researchers will have access to the anonymised data.

CONFIDENTIALITY

Finally, we want you to be reassured that **ALL** information we collect is for research purposes only. It is strictly confidential and is *never* released to anyone unless you request it. **Under no circumstances would we share information about you with anyone**, including partners, parents, or children.

ARRANGEMENTS FOR PHASE 52 ASSESSMENT

WHERE?

The assessments will be carried out again at the Research Unit in our building at the corner of Union Street and Anzac Avenue (see enclosed map on the last page), opposite Logan Park and the Stadium.

WHAT TIME?

Please arrive by 8:30am at the latest, as we need to start promptly to talk through the consent process and sign the consent form.

From 9am to 12.35pm, there will be four 50-minute assessments, with a tea break. We ask you to **bring any medication you are currently taking** so we can accurately record this information. If you wear glasses and/or contact lenses, please bring them and also **your contact lens case** as one of the assessments will require you to remove your contact lenses for a short time. We would also like you to **bring contact details of your family and friends** as, once again, you will be asked to nominate three people to provide information.

We will serve a lovely lunch!

The afternoon sessions will begin at 1pm consisting of two 85-minute sessions broken up by a tea break, and then a round robin of three shorter interviews including the dental examination and blood donation, finishing at about 5:00pm.

REFRESHMENTS

We will provide you with lunch, and morning and afternoon tea.

AND PLEASE REMEMBER...

- To be on time (8.30am).
- To bring any medication you are currently taking.
- If you wear glasses and/or contact lenses, please bring them and your contact lens case.
- To bring contact details (email addresses, phone/mobile phone numbers, mailing addresses) of your family and friends whom you might nominate to provide information.
- To wear casual or loose clothing as you will be doing some active tests.
- Because a number of the assessments we are conducting can be affected by substance use and/or recent food intake, we ask that you please:
 - ☺ Try to have a light breakfast.
 - ☺ Try not use excessive alcohol or drugs the night before you come to the Unit.
 - ☺ Try hard not to smoke or use an inhaler (or any non-prescription medications) on the morning of your assessment day.

ACCIDENT COMPENSATION CORPORATION (ACC)

In the unlikely event of a physical injury as a result of your participation in this Study, you will be covered by the accident compensation legislation within its limitations. If you have questions about ACC please feel free to ask the researchers for more information before you agree to take part in the Study.

RISK

The American National Institute on Ageing is funding some of the assessments. They have asked us to specifically inform you about the risks of these studies. The risks are:

- 1) Possible emotional upset and worry that could be caused by discussing your recent life events or mental health;
- 2) Slight discomfort when giving blood; and
- 3) Possible loss of confidentiality if the Unit's security measures were ever to fail. Please consider these risks before you decide to participate in these assessments.

STUDY MEMBERS' RIGHTS

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research, you may contact the Committee through the Human Ethics Committee Administrator (humanethics@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

***THANK YOU FOR YOUR HELP.
WE LOOK FORWARD TO SEEING YOU AGAIN SOON!***

**Professor Moana Theodore
DIRECTOR**

Dunedin Multidisciplinary Health & Development Research Unit, Department of Psychology,
University of Otago, New Zealand.

**Professor Terrie Moffitt
ASSOCIATE DIRECTOR**

Department of Psychology, Duke University, USA; Institute of Psychiatry, Kings College, London,
United Kingdom.

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