



The IOC Olympian Health Cohort - a longitudinal, prospective cohort

PARTICIPANT INFORMATION SHEET

You are being invited to take part in research on Olympic athlete health. Principal Investigator Dr Debbie Palmer at the University of Edinburgh is leading this research. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The protection of athlete health are key mandates for the IOC and while there are known health benefits, sport participation at the elite level carries an associated increased risk of sport-related injury and illness. Injury and illness surveillance study that collect data on athletes during the Olympic Games provide important ongoing information, however these studies are limited to data capture during a 3 week window, once every 4 years. Longer-term musculoskeletal health and other health and well-being issues e.g. concussion, athlete mental health, abuse in sport, have emerged over the last few years. The purpose of the study is therefore to understand the magnitude of injury and illness and other health and wellbeing issues in Olympians across their entire sporting career. To protect short and long-term athlete health and wellbeing and to help inform risk reduction strategies, for the benefit of elite athlete health.

WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to participate in this study because you have competed at the Tokyo 2020/21 summer or Beijing 2022 Winter Olympic Games and are aged 16 or over. All National Olympic Committee (NOC) athletes aged 16 years or older will be eligible to take part in the study.

DO I HAVE TO TAKE PART?

No – it is entirely up to you. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your participation or selection in sport. Please note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to your withdrawal and so you are advised to contact the research team at the earliest opportunity should you wish to withdraw from the study.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

This is a 15 year longitudinal study aiming to track Olympian health throughout their careers and across in to retirement from sport. If you decide to participate you will receive a short survey once



every two years until the end of the study period. Each survey will ask you about your most recent sport-related injuries and illnesses and also questions around your general health and quality of life.

If you do decide to take part, you can download and keep a copy of this Participant Information Sheet. You will be asked to complete an electronic Informed Consent Form after reading this information (further below) to show that you understand your rights in relation to the research, and that you are happy to participate. Once you have provided consent to participate you will then be directed to the online questionnaire and asked to complete questions about your background, your Olympic career, any significant sport-related injuries and illnesses you may have suffered. You will also be asked questions about your current musculoskeletal and general health, and Quality of Life.

The questionnaire can be completed at home and in a safe environment at a time that is convenient to you. The questionnaire will take approximately 30 to 35 minutes to complete. NB: The survey will continue to be updated during the course of the research study. If the research project changes in any way, you will be provided with information about the changes and asked to re-consent to the amended study prior to any subsequent questionnaires. Any amended information will be shown on the project's website <https://www.ed.ac.uk/olympians>

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There will be a prize draw at the end of each survey time-point, the winner receiving an all-inclusive trip for two to Lausanne. All of those who return a completed questionnaire will be eligible to take part in the prize draw. By taking part in the survey and sharing your experiences with us, you will be helping Dr Debbie Palmer and the University to better understand the risk associated with elite sport participation. By taking part in this study you will be contributing to a large body of research being conducted by the International Olympic Committee that will provide insight in to the long-term health of Olympians, throughout their careers. The information gathered will help us develop a wider understanding of the issues, provide evidence-based recommendations and best-practice guidelines to benefit Olympians and other elite athletes. There is a dedicated study website, with resources, news and information on publications and other material related to the study - access via this link <https://www.ed.ac.uk/olympians> There will be an annual study newsletter and as a participant in the study at the end of each questionnaire you will be given the opportunity to sign up for newsletters that will keep you up to date with the studies progress.

ARE THERE ANY RISKS OR DISADVANTAGES ASSOCIATED WITH TAKING PART?

There are no significant risks associated with participation however some questions around injury or illness occurrence may be sensitive. Hence, injury/illness questions will not be mandatory and you are free to omit any questions you do not wish to answer. You can also withdraw from the study if you do not wish to continue to participate, and if you wish you can request your data up to that point to be deleted. NB: it may not be possible to remove your data if it has already been used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to your withdrawal request. Hence you are advised to contact the research team at the earliest opportunity should you wish to withdraw from the study. If you need support or advice you can get



in touch via the IOC athlete365 health and safeguarding site for more information.

<https://olympics.com/athlete365/what-we-do/integrity/safe-sport/>

WILL MY TAKING PART BE KEPT CONFIDENTIAL?

All the information we collect during the course of the research will be kept confidential at all time and there are strict laws which safeguard your privacy at every stage. Only the principle investigator will have access to the study data. Your data will be pseudonymised with study codes provided.

HOW WILL WE USE INFORMATION ABOUT YOU?

We will need to use information that you provide in the questionnaire for this research project. We will use the absolute minimum of personal data required for the study. This information will include your date of birth (month and year only) sex, Country of birth, country of residence, Olympic sport and email address. Your data will be pseudonymised whereby your email address will be removed from your questionnaire responses and a unique study code will be used to identify you in its place. Your email address and linked study code will be stored in a separate password protected file in a separate location and your unique study code will only be used to link your data from future questionnaire time-points. From these other personal data there may be a small chance that you are identifiable however every step will be taken to ensure confidentiality and anonymity at all times.

Only the principle investigator (DP) will have access to the raw data and all data including personal data will be 'coded' to remove specific identifiers. Only fully coded data will be shared with the wider study team. People will use this information to do the research or to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your email address. Your data will have a code number instead. We will keep all information about you safe and secure. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file. Your consent information will be kept separately from your responses in order to minimise risk. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study. There is potential for the anonymised cohort data to become a controlled access, international database for other research purposes. Formation of an oversight group including current and retired Olympians, will be created to set out guidelines on who is able to gain access. Only data that is coded and fully anonymised would be made accessible. Information regards this will be provided on the study website.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You can stop being part of the study at any time, without giving a reason. If you decide to withdraw you can request any data we hold about you to be deleted. (NB: it may not be possible to remove your data if it has already been used in the production of formal research outputs prior to your



withdrawal request). Where can you find out more about how your information is used? You can find out more about how we use your information at <https://www.ed.ac.uk/records-management/privacy-notice-research> by asking one of the research team (Olympians@ed.ac.uk) The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The University of Edinburgh will keep identifiable information about you and your anonymised data for a minimum of 15 years after the study has finished. This information may be used by the research team, in the event that a final longer-term follow up is conducted. The follow-up may take place up to 15 years after the initial study has finished. If you give your consent, the study team will contact you, but you can choose not to take part in the follow-up if you change your mind. You can ask to have your contact details removed at any time after the study has finished by contacting the research team.

WHAT WILL HAPPEN WITH THE RESULTS OF THIS STUDY?

The results of this study may be summarised in published articles, internal reports and presentations. You will not be identifiable from any published material or results. Key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name. With your consent, your anonymised information may also be kept for future research. A summary of the findings from the study will be made available to participants on the study website and via biannual participant newsletters. Newsletter will be online, or via email if you sign up to receive them.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This study has been organised by injury epidemiology researcher Dr Debbie Palmer and sponsored by the University of Edinburgh. The study is being funded by International Olympic Committee medical and scientific committee.

WHO HAS REVIEWED THE STUDY?

The study proposal has been reviewed by Moray House School of Education and Sport research Ethics Committee at the University of Edinburgh.

WHO CAN I CONTACT?

If you have any further questions about the study or any information contained within the participant information sheet, please contact the lead researcher, Dr Debbie Palmer (Olympians@ed.ac.uk) If you would like to discuss this study with someone independent of the study please contact Dr Christine Nash (c.nash@ed.ac.uk) If you wish to make a complaint about the study, please contact: The Research Governance Team (cahss.res.ethics@ed.ac.uk) or the Data Protection Officer (dpo@ed.ac.uk)