



## Football Players Health Study Personal Network Web-based Assessment Consent



**Please read the following information carefully before making the decision to participate in this study on Personal Networks.**

### **Why are you doing this research?**

The Football Players Health Study is committed to the overall health of former football players. We have learned that social connections are an important part of your life. The core mission of the Study is to address the health of the “whole player”, therefore, this new study initiative is a vital step towards achieving this fundamental goal and to ultimately improve former player health.

The goal of this online assessment is to understand the effects of the **social environment** on former football players’ health. To do this, we will ask you to provide us information about yourself, and anonymous information about people in your life. We will use this information to build a map to show your connections to varying people in your life. We will also use this information to better understand the relationship of personal networks to health. If you have completed our health and wellness survey in the past, we will compare the information from this study with the information from that survey. This will provide crucial information on social networks and health in former players.

This is not a clinical evaluation, and it does not diagnose disability or medical conditions.

### **What will I have to do?**

To participate in this study, you will need access to a computer or tablet. This study can be accessed on a smartphone, but there is a lot of text-based entry and will be difficult to complete on a phone without an external keyboard.

This study can be completed in the privacy of your own home or on a computer/tablet of your choice.

You will be asked to answer a series of questions. The questions are about who is in your network, what are their connections, and what are their habits. Only first names or nicknames are used to protect privacy.

When you have completed the survey, you will receive an email with your personal network survey results, and information on how to interpret these results and use them to develop strong health-promoting networks.

### **How long will this assessment take?**

It should take approximately 15-20 minutes for you to complete this study.

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### **What do I get out of it?**

At the end of the assessment, you will get an image of your personal network and individualized feedback about your results within 48 hours. There is no compensation or payment for taking part in this study.

### **What are the benefits to taking part in this study?**

There are no direct benefits from participating in this study. All results in this study are for research purposes only and not for clinical diagnoses. However, this study will provide you with a unique personal network description and help us to better understand the impact of the social environment on former player health.

### **What are the potential risks to taking part?**

Some survey questions might make you feel uncomfortable. You have the option to skip or decline to respond to any question. You are also free to end the study at any time by closing your browser.

As with any collection of data, there is a potential for loss of privacy and confidentiality. We will take all reasonable steps to protect your privacy and those of the people you mention. We have included more detail about these steps below.

### **What steps are being taken to protect my information and privacy?**

The Football Players Health Study is using REDCap for this study. REDCap is a secure data tool that is often used in clinical research. Your responses are identified by a unique code. Only the Football Players Health Study research team members will be able to connect your code and your responses to you. Only a limited number of people will have access to this data. Our team is trained to handle highly confidential data.

The results of this study will be compiled and will not identify individuals in any publication or presentation.

### **What is a Certificate of Confidentiality?**

This research is covered by a Certificate of Confidentiality from the National Institutes of Health. This adds special protection for the research information that may identify you. The researchers may not disclose information that may identify you, even under a court order or subpoena, unless you give permission.

However, a Certificate of Confidentiality does not prevent researchers from disclosing your information or specimens if required by law (such as to report child or elder abuse, communicable diseases or harm to self or others); if you have consented (agreed) to the disclosure (such as for your medical treatment); or for use in other research as allowed by law.

The Certificate does not stop you from voluntarily releasing information about yourself or your involvement in this research. However, to more fully protect your confidentiality, it may be better



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to state that you support the Football Players Health Study in general terms, rather than making specific statements like, “I have completed the Football Players Health Study online personal network survey”.

If you want your research information released to anyone not connected with the research, you must provide consent to allow the researchers to release it. If others obtain your written consent to receive research information or specimens, then the researchers are permitted, but not necessarily required to disclose that information.

### **How the Football Players Health Study stores and shares your data**

The Football Players Health Study includes many research studies. We may combine the information collected from you during this study with results from other Football Players Health Study research studies that you have been involved in. Your information may also be connected to any future Football Players Health Study projects in which you participate. This includes studies that may be done by other researchers who work with the Football Players Health Study. We do not know how many future studies we will have, but there will be many over several years. When you participate in a Football Players Health Study research study, you are agreeing to allow us to collect and store the data from the project for several years. This is useful and important as it allows us to look at changes in health and wellness over time in former football players.

We may use information collected from you during this or other Football Players Health Study research studies to determine future research that you may be eligible to participate in. We will use your personal information in order to contact and inform you about these opportunities.

Your name and personal information (information that can identify you) are connected to a code that the Football Players Health Study has assigned to you. This code is connected to the data that is collected from you in any Football Players Health Study research study that you participate in (for example, answers to questionnaires, medical history or results of a scan). The key to this code is stored in a secure file that is kept separate from your study data. Only trained members of the Football Players Health Study staff will have access to the key to this code. All of your personal information is stored in a secure database at Harvard separately from the study results.

The Football Players Health Study works with other local researchers or researchers in other states or countries. If a researcher wants to use data from the Football Players Health Study, they must make a request in writing describing what type of research they want to do and what type of information they need. These proposals will be reviewed and approved by a committee of Football Players Health Study researchers. In most cases, we will share information that is assigned a code and the researcher will not receive any information that can identify you.



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There will be occasions that a researcher working with us will require access to your personal information. For example, if we are working with a researcher who is doing in-person research, they may need your name and contact information to make arrangements for you to come for the study. In such cases, we will not share the information without first contacting you to see if you are interested in the specific study and to get your permission to share your personal information.

### **What if I change my mind and don't want to do the study anymore?**

Your participation is completely voluntary and you may exit the study at any point. Your decision to withdraw does not involve any penalty or loss of benefits.

### **How is this study funded?**

The Football Players Health Study is an initiative developed by players, for players. It began in 2014 in part through an award from the National Football League Players Association (NFLPA). The Study largely utilizes funds allocated for research by the collective bargaining agreement. Many of the resources utilized by this initiative are shared across supporting Harvard institutions.

### **What if I have questions?**

If you have any questions, concerns or complaints about this research or experience any problems, you should contact Ann Connor, RN, MS, Principal Investigator, or our staff, by phone at (617) 432-5000 or email at [players@footballplayershealth.harvard.edu](mailto:players@footballplayershealth.harvard.edu).

You may also contact the Human Subjects Protection Office at (617) 667-0469 at Beth Israel Deaconess Medical Center in Boston, MA in the event that you would like to obtain information or to offer input about this research study. This office is independent of the investigator or investigator's research staff and can also assist with questions relating to your rights as a participant in research, which may include questions, concerns or complaints about your participation in the study.