

Artificial Intelligence-Based Phenotyping of Health from Photographs- Healthy Volunteer Study

Principal Investigator: Raymond Mak, MD

This is a research study conducted by Mass General Brigham to investigate how facial appearance may change over time and how it relates to biological age.

Purpose of the research:

We aim to examine how FaceAge estimates (a measure of biological age based on facial features) change across different time points and identify factors that may influence these changes. This will help us understand the consistency and reliability of the FaceAge algorithm and allow us to make improvements.

What information will be collected and how:

Daily FaceAge Variation: You may upload up to 10 face photos at a time, for as many days as you would like.

Questionnaire responses: You will complete a one-time general questionnaire collecting demographics and health questions and a daily questionnaire (optional) for each day of photos submitted..

Historical FaceAge Variation (): You will be asked to provide up to 10 photographs of yourself from previous years, if available (for example: ~5-10 photographs approximately every 5-10 years apart).

How we will collect this information:

You will take selfies using your own webcam/smartphone/device or provide us with face photographs you have previously taken).

You will complete questionnaires provided by the research team.

You will upload all photographs and questionnaire responses using a secure, encrypted link provided by the research team.

Sponsor of the research:

This study is sponsored by Mass General Brigham.

How we obtained your name and contact information:

You are receiving this information because you registered via the research website for this study.

Why we are asking you to participate, and how many people will participate:

We are inviting healthy adults (age 18 and above) to participate in this study. We aim to enroll 1000 participants to ensure a diverse representation of ages and racial backgrounds.

Confidentiality and data security:

All submitted photos and associated data will be de-identified upon receipt. We will use secure, encrypted methods for data transfer and storage. While we take extensive measures to protect your privacy, there is always a minimal risk of accidental disclosure of personal information.

Use of de-identified data in future research:

Your de-identified information may be used or shared with other researchers without your additional informed consent.

Use of collected information:

The information collected in this study is for research purposes only and will not be used in your clinical care. Only authorized research personnel will have access to your data.

Risks associated with participation:

The main risks are minor inconvenience due to the time commitment and possible feelings of fatigue from the repetitive nature of the task. There is also a minimal risk of social discomfort if taking selfies in public environments.

Participation is voluntary:

Your participation is entirely voluntary, and you can stop at any time. Deciding not to participate won't affect the medical care you receive at Mass General Brigham now or in the future, or any benefits you receive now or have a right to receive.

PI contact information for questions:

If you have any questions about this study, please contact Dr. Raymond Mak at:

Brigham and Women's Hospital, Department of Radiation Oncology
75 Francis Street
Boston, MA 02115
Phone: (617) 632-5734
Email: rmak@mgb.org

IRB contact information:

If you'd like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Mass General Brigham IRB at (857) 282-1900.

Certificate of Confidentiality

This research is covered by a Certificate of Confidentiality from the Mass General Brigham. This means that the researchers cannot release or use information, documents, or samples that may identify you in any legal action or suit unless you say it is okay. They also cannot provide them as evidence unless you have agreed. This protection includes federal, state, or local civil, criminal, administrative, legislative, or other proceedings. An example would be a court subpoena.

There are some important things that you need to know. The Certificate DOES NOT stop reporting that federal, state or local laws require. Some examples are laws that require reporting of child or elder abuse, some communicable diseases, and threats to harm yourself or others. The Certificate CANNOT BE USED to stop a sponsoring United States federal or state government agency from checking records or evaluating programs. The Certificate DOES NOT stop disclosures required by the federal Food and Drug Administration (FDA). The Certificate also DOES NOT prevent your information from being used for other research if allowed by federal regulations.

Researchers may release information about you when you say it is okay, including as described in this form. For example, you may give them permission, as you are doing in this form, to release information to insurers, medical providers or other persons not connected with the research. The Certificate of Confidentiality does not stop you from willingly releasing information about your involvement in this research. It also does not prevent you from having access to your own information.

You are agreeing to the collection, use, and sharing of your identifiable information as described in this information sheet. In this study, we may collect identifiable information about you from medical records and from research procedures, including but not limited to research visits, tests, interviews, and questionnaires. Those who may see, use, and share your identifiable information include Mass General Brigham researchers and staff, sponsors of the study and those who the sponsor hires to help perform or audit the research, other researchers, the Mass General Brigham ethics board, groups that oversee the data and safety of this study, non-research staff at Mass General Brigham to conduct their

jobs, such as for treatment, payment (billing), or hospital operations, and those hired to conduct work for us, as well as federal and state agencies that oversee, evaluate and audit research, and public health and safety authorities, as noted above.

Authorization to Use or Release Protected Health Information for Research Purposes

Federal law requires Mass General Brigham and its affiliated hospitals to protect the privacy of health information and related information that identifies you. We refer to this information as “protected health information.” Your protected health information will be used and shared with others as explained below. You are agreeing to the collection, use, and sharing of your protected health information as described in this information sheet. If you have questions, you may ask the researcher who is reviewing this information sheet with you or you can contact the researcher listed above.

In this study, we may collect protected health information about you from:

- Past, present, and future medical records
- Research procedures, including but not limited to research visits, tests, interviews, and questionnaires

Why will protected health information about you be used or shared with others?

The main reasons include:

- to conduct and oversee the research described in this information sheet for this study;
- to ensure the research meets legal, institutional, and accreditation requirements; and
- to conduct public health activities (including reporting of adverse events or situations where you or others may be at risk of harm).

Who may see, use, and share your protected health information and why they may need to do so?

- Mass General Brigham researchers and staff involved in this study
- The sponsor(s) of the study, and people or groups it hires to help perform this research or to audit the research
- Other researchers and medical centers that are part of this study
- The Mass General Brigham ethics board
- A group that oversees the data (study information) and safety of this study
- Non-research staff within Mass General Brigham who need protected health information to do their jobs, such as for treatment, payment (billing), or hospital operations (such as assessing the quality of care or research)
- People or groups that we hire to do certain work for us, such as data storage companies, accreditors, insurers, and lawyers
- Federal agencies (such as the U.S. Department of Health and Human Services (DHHS) and agencies within DHHS like the Food and Drug Administration, the National Institutes of Health, and the Office for Human Research Protections), state agencies, and foreign

government bodies that oversee, evaluate, and audit research, which may include inspection of your records

- Public health and safety authorities, if we learn information that could mean harm to you or others (such as to make required reports about communicable diseases or about child or elder abuse)

Some people or groups who get your protected health information might not have to follow the same privacy rules that we follow and might use or share your protected health information without your permission in ways that are not described in this form. We share your protected health information only when we must, and we ask anyone who receives it from us to take measures to protect your privacy. However, once your protected health information is shared outside Mass General Brigham, we cannot control all the ways that others use or share it and cannot promise that it will remain private.

The results of this research study may be published in a medical book or journal or used to teach others. However, your name or other protected health information **will not** be used for these purposes without your specific permission.

For how long will protected health information about you be used or shared with others?

Because research is an ongoing process, we cannot give you an exact date when we will either destroy or stop using or sharing your protected health information. Your permission to use and share your protected health information does not expire.

Your Privacy Rights

You have the right not to agree to our use and sharing of your protected health information for research; however, if you don't agree, you can't take part in this research study. However, refusing to agree will not affect your present or future care and will not cause any penalty or loss of benefits to which you are otherwise entitled.

You have the right to withdraw your permission for the further use or sharing of your protected health information for this research study. If you want to withdraw your permission, you must notify the person in charge of this research study in writing. Once permission is withdrawn, you cannot continue to take part in the study.

If you withdraw your permission, then to the extent that we have retained any protected health information that can be linked to you, we will stop using and sharing the protected health information further for the research. However, we will not be able to take back information that has already been used or shared with others, and such information may continue to be used for certain purposes, such as to comply with the law or maintain the reliability of the study.

You have the right to see and get a copy of your protected health information that is used or shared for treatment or for payment. To ask for this information, please contact the person in charge of this research study identified above. You may only get such information after the research is finished.

Printed Name of Subject: [First Name, Last Name]

Would you like to upload photos daily? (Daily FaceAge Variation) ?

- Yes
- No

Would you like to upload photos from different stages of your life (Historical FaceAge Variation)?

- Yes
- No

I agree to participate in this research

- Yes
- No

Date Time _____