Patient Engagement Survey

Dear Participant,

You are being invited to take part in an engagement project and by answering the survey, you agree to participate. Before you decide to participate it is important for you to understand why the project is being conducted and what participation is required. Please take your time to read the following participant information sheet carefully, before deciding to take part. If there is anything that is not clear or if you would like more information please contact Ph.D student Zhuo ZHI (zhuo.zhi.21@ucl.ac.uk). Thank you for your time.

participant information sheet

What is the purpose of the survey?
We are a multi-disciplinary group of researchers from University College London and Imperial College Healthcare NHS Trust. We are developing new AI baseed technology to improve the diagnosis of anemia (condition prediction, etiological analysis, medical advice and condition monitoring). This document is to survey participants' acceptance, perception, feedback and suggestions to help us develop, shape, and improve related technologies.

About our research
The traditional anemia diagnosis method is based on blood testing, hence it is invasive, costly and time-consuming. We aim to develop a non-invasive, low-cost, portable method. Our approach leverages subject data available in electronic health records (EHR) in an EHR system together with subject gathered data (e.g. photoplethysmography (PPG) signals collected using a portable PPG sensor or eyelid images taken with a smart phone) in order to deliver a diagnosis using artificial intelligence based models. Our approach will also eventually entail developing a smartphone-based system that uses additional portable sensors for data collection and deploys AI models in the phone for disease prediction, advice, diagnosis and patient status monitoring. This research is still in an early stage, so one will require years to turn these ideas into a viable clinical method, but our early results suggest that the approach is technically feasible. It is important for us to design our project with input/feedback from potential users, so we are reaching out to gather views.

Patient Engagement Survey

Why have you been chosen?

We are contacting a wide range of people from different groups, including NHS patients, students and charity members who are directly or indirectly influenced by anemia, to get an idea on your views of certain current and future treatments. This survey is only open to adults over the age of 18 years. All participants must have read the participant information sheet.

Do I have to take part?

Participation is voluntary, we will not ask for any identifying information, and your responses will be kept completely anonymous. If you do decide to take part in this survey you will be given a tick box to select, as a form of consent, to participate in our research at the beginning of the survey. If you do not tick this box your responses cannot be used.

Since this survey is completely anonymous it will not be possible to withdraw any data after you have submitted the survey.

What will happen to me if I take part?

You will be invited to answer some questions relating to
anemia diagnostic methods, artificial intelligence technology and privacy ethics
. The survey includes information at the start of each question set. It contains around 20 questions and should not take more than 10 minutes to complete. You will only need to take the survey once.

Will my taking part in this project be kept confidential?

The survey is completely anonymous. Personal data is any information that might identify you as an individual. We will not ask for any personal information and ask that you do NOT include information that could identify you in the open response boxes (e.g. name, exact age, address).

What are the possible benefits of taking part?

There will be no direct benefits to you from taking part in this survey. We will not be offering any monetary compensation. However, we intend to incorporate your views into our research work in order to develop anemia diagnosis technology that suits the needs of those that need it the most.

Patient Engagement Survey

What are the possible disadvantages and risks of taking part?
There are no risks for you to take part in the study. The questions are designed to encourage the participant to learn about potential technologies in anemia diagnosis, share their understanding about certain topics, and share their view about our research. You can stop taking part in the survey at any time, for any reason, and your responses will not be recorded.

Who is organising and funding the research?
This research is being organised by UCL Dept. EEE, UCL School of Phamarcy and Imperial College Healthcare NHS Trust. This research is being funded by the Engineering and Physical Sciences Research Council.

Complaints
If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff, then please talk to the researcher or the principal investigator (zhuo.zhi.21@ucl.ac.uk) about your complaint. If you then feel that the complaint has not been resolved satisfactorily, please contact the chair of the UCL Research Ethics Committee (ethics@ucl.ac.uk).

Thank you for reading this information sheet and for considering taking part in this survey.

1. Have you read and understood the information in the Participant Information sheet?
◯ Yes
◯ No

2. I consent to participate in this survey.
◯ Yes

Patient Engagement Survey

You will now be given a short description of the term ‘anemia’. Please read the following statement carefully:

Anemia is a blood disorder in which the blood has a reduced ability to carry oxygen due to a lower than normal number of red blood cells, or a reduction in the amount of hemoglobin. When anemia comes on slowly, the symptoms are often vague, such as tiredness, weakness, shortness of breath, headaches, and a reduced ability to exercise. When anemia is acute, symptoms may include confusion, feeling like one is going to pass out, loss of consciousness, and increased thirst.

3. Please select your age range from the groups below:

◯ 18-39
◯ 40-59
◯ 60+
◯ Prefer not to say

4. How have you personally been impacted by anemia?

◯ 1st hand (i.e., current patient/survivor of anemia)
◯ 2nd hand (i.e., family member/friend of patient who has been diagnosed with anemia)
◯ Not personally impacted

5. If you wanted to know whether you have anemia, which diagnosis would you prefer?

◯ Go to a hospital to take a blood test (invasive)
◯ Use self-operated anemia test strips (invasive)
◯ Use yourself non-invasive testing equipment (like finger clip hemoglobin test) at home (non-invasive)

Patient Engagement Survey

6. Who would you trust to provide information on anemia diagnosis. Please rank these options from most trustworthy (1), to least trustworthy (6):

	(1)	(2)	(3)	(4)	(5)	(6)
Clinicians/doctors						
blood charities						
NHS website and official resources (e.g., hospital flyers and brochures)						
Academic researchers						
Pharmaceutical/ private research companies						
Regulatory bodies (i.e., MHRA, European Medical Agency)						

7. Please select the 2-3 most relevant factors (out of the following ones) that would influence your selection for a particular anemia diagnosis method?

◯ Cost Efficiency (i.e. it is cheap)

◯ Non-invasiveness (i.e. it does not involve taking blood)

◯ Conveniency (i.e. it is not time-consuming, it can be done at home rather than hospital)

◯ Accuracy (i.e. it provides a very reliable diagnosis)

◯ Etiological analysis (i.e. Iron deficiency anemia) and medical advice (i.e. recommended medications)

◯ Operators (i.e. yourself or doctor) and test area (i.e. fingertips)

You will now be given a short description of the term ‘Machine learning (in disease diagnosis)’. Please read the following statement carefully:

Patient Engagement Survey

Machine learning techniques (i.e. methods underlying artificial intelligence) predict or diagnose diseases by leveraging/processing patient gathered data. This data can include patients' statistics (demographic, vitals, medicine history, etc), patients' images (e.g. from eyelids, fingertips), or other patient's data (e.g. from Instrument monitoring equipment). Machine learning – given this data -- offers a means to diagnose diseases (e.g. anemia) accurately, conveniently, and non-invasevely, which can also be complemented with medical advice / insights.

8. Please select the statement that best applies to you regarding machine learning:

◯ I have heard of machine learning and/or I understand what they are.

◯ I have not heard of machine learning and/or I **do not** understand what they are.

9. Would you consider trying / relying on machine learning based systems to diagnose anemia or other diseases?

◯ Yes

◯ No

◯ Need to know more

◯ Unsure

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):

You will now be given a short description of the term 'PPG sensor'. Please read the following statement carefully:

PPG technology is a simple inexpensive optical measurement method which uses a light source and a photodetector located close to the skin of a subject (e.g. fingertip, wrist, etc.) to measure volumetric variations of blood circulation in order to calculate the content of various components in the blood (e.g. hemoglobin).

Patient Engagement Survey

10. Do you think that a PPG sensor (integrated in a bracelet weared around a wrist) to facilitate prediction of low blood levels would be preferable to a blood test in an hospital?

◯ Yes
◯ No
◯ Need to know more
◯ Not sure

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):

11. Do you think that a special imaging technique (for example a photograph of your eye or skin) to predict low blood levels would be preferable to a blood test when in an hospital?

◯ Yes
◯ No
◯ Need to know more
◯ Not sure

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):

You will now be given a short description of the term 'EHR'. Please read the following statement carefully:

An electronic health record (EHR) contains patient medical history information and is stored in hospital's system, such as:

- *Administrative and billing data*
- *Patient demographics (age, gender, race, etc.)*
- *Vital signs (body temperature, pulse rate, respiration rate, etc.)*
- *Medical histories*

Patient Engagement Survey

EHR contains a wealth of information and is often used in research such as disease diagnosis, drug analysis, etc.

12. Would you feel comfortable providing access to your EHR to allow a machine learning based system to predict certain medical conditions before they happen or become more severe?

◯ Yes
◯ No
◯ Need to know more
◯ Not sure

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):

13. Would you feel comfortable sharing digital images of your eye or skin with the hospital to predict possible medical problems before they happen or become more severe?

◯ Yes
◯ No
◯ Need to know more
◯ Not sure

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):

14. Would you feel comfortable sharing your PPG signals with the hospital to predict possible medical problems before they happen or become more severe?

◯ Yes
◯ No
◯ Need to know more
◯ Not sure

Patient Engagement Survey

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):

15. Would you like to try a smartphone-based diagnostic system involving PPG sensors, imaging sensors (e.g. camera), and machine learning technology

- ◯ Yes
- ◯ No
- ◯ Need to know more
- ◯ Not sure

If you chose No/ Not sure, please explain your choice in maximum 100 words (this box can be left blank, please DO NOT include any information that could potentially identify you i.e., name, exact age, where you live, health status etc.):