Patient and Public Involvement Panel (PPIP) Member

Role Description

Project Title: *Ensuring the benefits of Artificial Intelligence for all: Designing a sustainable platform for public and professional stakeholder engagement*

For further details about this project, please contact: Nisha Shah, HeLEX Centre, Ewert House, Ewert Place, Summertown, Oxford OX2 7DD; Tel: 01865 287 896; Email: nisha.shah@law.ox.ac.uk

Project duration: January 2020 – December 2022 (36 Months)

PPIP duration: April 2020 – December 2022 (33 months)

This document outlines the role of panel members in the project, and how the panel will be supported.

The Patient and Public Involvement Panel

Members of the project Patient and Public Involvement Panel (PPIP) will from time to time meet with, or communicate with, researchers seeking input from patients and members of the public on a research project about Artificial Intelligence (AI) in healthcare jointly funded by the ESRC and JST.

Panel members may be able to help identify and comment on areas of interest and concern for patients and the public about AI in healthcare, to help define/refine some of the research questions, to produce helpful participant information documents, review study documents, and suggest how best to promote recruitment to studies.

You will:

- review the content and language used in participant questionnaires, information leaflets, and project summaries

- help to ensure that proposed methods are acceptable to potential participants

- comment on research study aims and objectives

- advise on ways to increase participation in research

- suggest ways to publicise research results

- be asked to participate in project workshops, conferences, and in dissemination of research findings where relevant

- You may be asked to take part in telephone conference calls or to work remotely via email, not meeting in person with the researcher or other PPI Contributors.

- As a representative of the project you are asked not to share confidential information you may have received as a result of your position. This should be discussed with the project group and / or contact person.

- You may be asked to provide feedback on the impact of your PPI role

The project PPIP will provide advice and guidance from their experiences and views on the topics for the project's research from initial study proposals to ways in which research findings may be used to influence policy and research on AI in healthcare, and sharing ideas about what a stakeholder platform could be for research, innovation, and dissemination of AI in healthcare. You will be asked to provide specific insights based on your own experience (or that of people you support) in relation to the delivery of healthcare.

While we ask that you speak directly from your own experiences, PPI work is not an opportunity for discussions about the specifics of your medical treatment. Your input should be aimed at helping the researchers to understand their work from the point of view of someone who experiences the topic of the research.

The panel may include current or past research participants, or even a lay members of patient and public community groups.

Roles and responsibilities of panel members

You will be asked to attend all face-to-face meetings outlined in the Timetable of Commitments. Some panel members will be asked to read and comment on relevant documents throughout each year of the project. You will contribute to project discussions and may be asked to represent patient/public views of the project at external meetings.

Additionally, you will provide feedback on documentation by email or at face-to-face meetings, however, for activities that involve working remotely, you will be able to choose which requests to respond to, according to your availability and interests. The Schedule of Commitments (See table at the end of the document) indicates how many panel members are required for each task.

Essential requirements

- Does not need any knowledge of digital technologies or artificial intelligence
- Be willing to talk about medical research
- Have the ability to confidently express your views at meetings and those attended by a range of professionals
- Have the ability to keep asking questions until you get enough information to fully understand what people are talking about; and challenge current thinking in ways that are both creative and supportive
- Be willing to listen to, and consider different perspectives and opinions; show awareness of and commitment to equality and diversity
- Must be able to maintain confidentiality about the research and declare any conflicts of interest if they arise
- Must have commitment to attend the agreed meetings (medical condition allowing); and respond to project emails or communications
- Must have the commitment to prepare for meetings by reading the information sent to you in advance
- Have access to email

Desirable criteria

- An understanding of the NHS or healthcare
- Knowledge of how the government supports health research

- Experience of taking part in research or knowledge of how research is conducted in a health setting

Why get involved?

By joining the project PPIP you will be contributing to our understanding of stakeholder engagement for Artificial Intelligence research and innovation in healthcare; and what matters to individuals and society as patients and members of the public. We will also provide initial training on being involved in research co-development; and develop opportunities for learning about this research field over the course of the project. There will be opportunities to network, chair meetings, influence our research and have your expenses paid!

Members may find the role interesting, rewarding and enjoyable, and involvement can provide opportunities to meet new people and develop new and existing skills.

Remuneration

We will reimburse your travel expenses up to £60.00 for face-to-face meetings in Oxford, or we can organise your travel for you, avoiding the need for you to spend on travel expenses and await reimbursement. Refreshments and catering will be provided where appropriate. We are able to pay PPIP members an honorarium for their time. The rates are as follows:

Meeting type	Payment	Description
Full day workshop/meeting	£150	Including preparation and follow-up
Half day face-to-face meeting	£50	No prep nor follow-up
Half day face-to-face meeting	£75	Including prep and follow-up
Short pieces of work, working remotely	£25	Reviewing short documents

Payments and travel expenses will be reimbursed in accordance with the Expenses and Payments policy. Further information is available in the remuneration policy.

Please note:

- If you are in receipt of state benefits, and you are offered a place on the panel, **we strongly advise you to speak with your benefits contact prior to your involvement**, and as early as possible. This is to ensure that there are no adverse effects to your benefits from your involvement on the project if you would like to accept payments for your time. Further details are available from Nisha Shah (Researcher).

- Panel members are not employees of the University of Oxford, and are responsible for their own pension contributions, national insurance (NI) and income tax. You will be responsible for declaring payments you receive from your work on the panel to the HMRC.

- You do not have to accept offer of payment.

Background of the project and what we hope to achieve

The UKRI-JST Funding bodies announced in January 2020 that they were funding 6 unique UK-Japan collaborative research projects for £2.4m and ¥180m to be rolled out over 3 years. Researchers at the Centre for Health, Law, and Emerging Technologies (HeLEX), University of Oxford, and the Department of Human Sciences and the Department of Biomedical Ethics and Public Policy, Osaka University, whose collaborative project was one of the 6 funded in the call are delighted to begin the research in collaboration with patients and members of the public.

The ability of Artificial Intelligence (AI) algorithms (a set of instructions designed to perform a specific task) to predict health outcomes, without direct human input, can impact not only the social acceptance of AI, but in turn could affect public trust in existing healthcare systems. For these reasons, it is important to involve people who will be most impacted by these technologies early on in any development process.

The central goal of this research is to provide evidence for a sustainable engagement platform targeting a range of stakeholders, to support decision-making and policy development on the use of Artificial Intelligence software and algorithms in healthcare within Japan and the UK. This will lead to an 'ecosystem' where the technology can be developed in alignment with the concerns of stakeholders, thereby leading to greater transparency, responsibility and public acceptance, while enabling broad use of AI for a variety of purposes beneficial to the health and wellbeing of society. We will place user-centred design at the heart of AI implementation in healthcare, by conducting a programme of research (which involves systematic collection and analysis of data) to elicit the views of patients and Health Care Professionals (HCPs) regarding:

> 1) The current and anticipated use of Artificial Intelligence in treatment, diagnostic decision-making and precision medicine (which takes into account individual variability in genes, environment, and lifestyle for each person);

2) The issues that stakeholders perceive will influence the adoption and implementation of AI in healthcare;

3) The types of engagement mechanisms, safeguards and regulatory controls they would like to see in place; and

4) How to develop a platform for engagement that can address issues of trust, responsibility, accountability and transparency, and influence routine practice in the future.

Both Japan and the UK are investing heavily in national programmes to accelerate the implementation of AI in healthcare delivery, yet very little has been done to date, to develop sustainable engagement platforms to guide the introduction of this technology. Our project will focus on two institutions- the Oxford University Hospital Foundation Trust (OUHFT) in the UK and the Osaka University Hospital (OUH) in Japan – which are case study exemplars for the adoption of AI into healthcare. Both initiatives involve collaborations with commercial partners and represent 'islands of innovation' within universal healthcare systems where digital adoption is piecemeal across both nations. In both countries, there are doctor and expertise shortages despite increasing complex healthcare demands from an aging population, which are compounded by immigration policies. While there are similarities in healthcare provision, translation of AI into practice occurs against very different socio-cultural, political, ethical and economic backdrops. By comparing the two approaches we hope to generate insights that will be valuable for both nations.

Purpose of the PPIP

Involving patients and the public in research projects can enhance the benefits of the process and outcomes of the research in several ways. Former Chief Medical Officer Dame Sally Davies stated that "Patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably make studies more effective, more credible and often more cost efficient as well" (Staley, 2009).

Further information and resources

- AI project website (forthcoming)

- Voice is an organisation that aims to capture the publics' vast experience, ideas, opinions and expectations about the research, innovations and policies affecting their lives. They support members of the public, of all ages and backgrounds, to become actively involved in contributing their insights and visions. Through this platform researchers are able to engage in discussions with members, as well as post opportunities for involvement in their research

  https://www.voice-global.org/

- NIHR INVOLVE Jargon Buster

  https://www.invo.org.uk/resource-centre/jargon-buster/

- EUPATI Glossary

  https://www.eupati.eu/glossary/

Support

Panel members are able to access support and advice from the project key contact. Please email **Miss Nisha Shah at Nisha.Shah@law.ox.ac.uk** or call her on **01865 287896** to find out more about our work and how to get involved.

Timetable: PPIP schedule of commitments

Month/Year	Duration[t]	Location	Task type	Task	Description	Number of people from panel to be involved
February-March 2020	-	Oxford / Skype / Telephone	Face-to-face/ Skype/telephone interview	Informal Interviews and panel recruited	Successful candidates will be notified in March	Up to 6 recruited
April 2020	2-3 hours	Oxford	Face-to-face meeting	Welcome and induction	- Project overview - Roles and responsibilities of project members including the panel - Building confidence in sharing views and reviewing research	All
September 2020	Half day	Oxford	Face-to-face meeting	Comments and feedback on WP3	- Presentation of summary of background research by research team - Invitation to feedback on review summary of scoping literature review and Twitter analysis - Feedback on support panel would like on reviewing project literature	All

Month/Year	Duration[t]	Location	Task type	Task	Description	Number of people from panel to be involved
December 2020	Half day	Oxford	Face-to-face meeting	Comments and feedback on WP4	• Presentation of results from AI research being conducted at Oxford • Invitation to feedback on the research cases, views on potential impact on patients and the public • Workshop ideas for research questions to propose for WP5	All
February or March 2021	1-2 hours	Work Remotely	Review from home	Review focus group and interview questions for WP5 study	• Feedback on the questions for focus groups with patient and public participants • Feedback on interview questions to healthcare professionals	2
October 2021	3-4 hours	Work remotely	Review from home	Review statements	• Summary of results of WP5 to panel • 2 members to sense-check statements for the Q-sort exercise study in WP6	2
December 2021	1-2 hours	Work remotely	Review from home	Review lay summary of WP5 results	• Review and feedback on lay summary of WP5 results for public dissemination	2

Month/Year	Duration[t]	Location	Task type	Task	Description	Number of people from panel to be involved
October 2022	1-2 hours	Work remotely	Review from home	Review lay summary of WP6 results	• Review and feedback on lay summary of WP6 results for public dissemination	2
November 2022	Full day	Oxford	Face-to-face meeting	Attend final project workshop	• Discussion of overall project findings • Learnings from results from panel's perspective • How to disseminate results widely • Workshop towards the development of a platform for stakeholder engagement in AI for healthcare	All

*WP = Work package; t Half day = 4 hours, Full day = 8 hours

If this schedule changes at any point you will be informed with plenty of notice and given the option to extend your involvement if appropriate.