Community Manager: Patient and Public Involvement and Engagement - AIM RSF

THE ALAN TURING INSTITUTE

There has never been a more significant time to work in data science and AI. There is recognition of the importance of these technologies to our economic and social future: the so-called fourth industrial revolution. The technical challenge of keeping our data secure and private has grown in its urgency and importance. At the same time, voices from academia, industry, and government are coming together to debate how these technologies should be governed and managed.

The Alan Turing Institute, as the UK's national institute for data science and artificial intelligence, plays an important part in driving forward advances in these technologies in order to change the world for the better.

The Institute is named in honour of Alan Turing, whose pioneering work in theoretical and applied mathematics, engineering and computing is considered to have laid the foundations for modern-day data science and artificial intelligence. The Institute's goals are to undertake world-class research, apply its research to real-world problems, driving economic impact and societal good, lead the training of a new generation of scientists, and shape the public conversation around data and algorithms.

After launching in 2015 with government funding from EPSRC and five founding universities, the Institute has grown an extensive network of university partners from across the UK and launched a number of major partnerships with industry, public and third sector. Today it is home to more than 500 researchers, a rapidly growing team of in house research software engineers and data scientists and a business team.

BACKGROUND

Many people suffer from multiple health conditions, particularly as they get older or are from less affluent areas. Most of the evidence base for medical care is about treating single conditions and we know surprisingly little about identifying and treating multiple long-term conditions (multi-morbidity) or MLTCs. Recently, this has become a strategic priority for the UK's National Health Service and research funders.

The Alan Turing Institute has been awarded a grant by the National Institute for Health Research (NIHR) to deliver a Research Support Facility (RSF) for the £23 million Artificial Intelligence for Multiple Long Term Conditions (AIM) investment. The NIHR AIM RSF team will support researcher teams from around the UK in their efforts to systematically identify new clusters of disease and the development of conditions over the life course. The research will develop insights into the identification and subsequent prevention of MLTCs.

The NIHR AIM RSF will be delivered jointly between the Turing's Tools, Practices and Systems and Health and Medical Sciences programmes, with collaborators from Swansea University, MRC Harwell and the University of Edinburgh. Together they will build capacity and capability in AI and MLTC-M research, foster a collaborative approach and a culture of shared learning, and provide a leadership role to facilitate impact from the AIM investment. The team will use their convening power and expertise to maximise the scientific impact and potential for patient benefit through five themes:

- Reproducible, secure and interoperable infrastructure
- Accessible, research-ready data
- Scientific community building and training
- Public and patient involvement and engagement (PPI/E)
- Sustainability and legacy

The <u>Tools</u>, <u>Practices and Systems</u> (TPS) programme at the Turing represents a cross-cutting set of initiatives which seek to build open source infrastructure that is accessible to all, and to empower a global, decentralised network of people who connect data with domain experts.

The <u>Health and Medical Sciences</u> programme at the Turing delivers research into the theory and methods of AI, statistics, and data analytics underpinning medical and health applications that will enable scientists to do better science, without compromising respect for privacy and patient trust.

<u>The Turing Way</u> is an open source community-driven guide to reproducible, ethical, inclusive and collaborative data science. The project goal is to provide all the information that data scientists in academia, industry, government and the third sector need at the start of their projects to ensure that they are easy to reproduce and reuse at the end.

<u>AutSPACEs</u> is a co-created, participatory, citizen-science platform which will be used to investigate how sensory processing differences affect the daily experiences of autistic people. The data management framework and the platform itself are open source and co-created in collaboration with a diverse community of autistic people and their relatives and carers. All software, and design and process documents, are available under permissive open source licences. The platform builds on the <u>Open Humans</u> framework to allow fine-grained control over contributor's data and how it is used. Open Humans is a foundation which enables research participants to have awareness and understanding of, as well as an agency over, their own data.

The NIHR RSF has been created to ensure that the funded research projects work together efficiently to answer questions relevant to patients and the general public. As part of the PPI/E workstream we will adapt the AutSPACEs citizen science platform to the MLTC community. This activity will be co-created with patients with a goal of sharing their experiences of navigating the health care system as people living with multiple long term conditions.

We are recruiting a Community Manager who will work to embed the expertise in the TPS, Turing Way, AutSPACEs and broader open source communities in the AIM consortium to ensure that this investment centres the voices of patients with lived experience of MLTCs, their families and carers following FAIR (findable, accessible, interoperable and reusable) principles and leaving a legacy that is greater than the sum of its parts.

ROLE PURPOSE

The AIM RSF Patient and Public Engagement Community Manager will create, nurture and protect the conditions required for successful communication across the diverse and distributed AI for Multiple Long Term Conditions PPI/E workstreams. described in the Turing's Values (see below).

The ideal candidate for AIM RSF PPI/E Community Manager will treat all members of the AIM PPI/E workstreams – and people with lived experience of MLTCs more broadly – with compassion. They will support people to share and promote the skills that they already have, understand the experiences of people from a range of diverse backgrounds, and identify what they need to effectively work together. They will undertake active outreach activities to identify people who are at risk of being left out of the co-creation process. The AIM investment can only achieve its ambitious goals if it is delivered by experts - including experts by lived experience - working together. The postholder will be integral in welcoming disabled and neurodivergent community members, facilitating connections with web designers and developers, and maintaining connections between patient advocacy groups around the UK. These groups include the NIHR PPI/E team, PPI/E teams advising and collaborating with individual research projects within the AIM investment, along with the existing Autistica, Open Humans, TPS and Turing Way communities.

As a steward of their community, the AIM RSF PPI/E Community Manager will see how individual pieces fit together as a whole. They will surface implicit knowledge and make information explicit so that everyone who wants to can participate. They will guide PPI/E members across the AIM investment to see how their individual skills can take the citizen science project forwards, identify gaps in team members' expertise, and organise "just in time" training to facilitate communication across the consortium. For example, ensuring that everyone understands - to the extent that they need to - data standards, open source project management on GitHub, web development in Django (Python), reproducible deployment in the cloud, inclusive participatory design, and responsible research and innovation practices.

The AIM RSF PPI/E Community Manager will collaborate with experts in the Turing institute and beyond. They will be an active contributor to the Turing Way, acting as bi-directional conduit to implement best practices for reproducible, ethical, inclusive and collaborative data science. We do not expect the applicants to already have all the skills within the scope of *The Turing Way* project. Rather that they will develop new expertise and grow in the role. They will also participate in the Tools, Practices and Systems programme, particularly in the development of responsible research and innovation practices. They will also participate in the Tools, Practices and Systems community, particularly connecting with experts in facilitating responsible participation, citizen science, and web development in Python.

The postholder will work closely with Dr Kirstie Whitaker and Prof Chris Holmes, lead investigators of the NIHR AIM RSF, and Mrs Lynsey Cross, AIM RSF Theme Lead for PPI/E and Public Engagement Officer for the Population Data Science Department at Swansea University. They will also collaborate closely with Dr Malvika Sharan, TPS Senior Researcher and co lead investigator (with Kirstie Whitaker) of *The Turing Way*, and Dr Bastian Greshake, Open Humans Director of

Research and a long term fellow at the Center for Research and Interdisciplinarity in Paris. Dr Kirstie Whitaker will be their line manager.

We particularly encourage applicants who consider themselves disabled or neurodivergent, or who have friends or family members who have lived experience of multiple long term conditions. We acknowledge the importance of understanding the intersectionality of these lived experiences with experiences associated with the candidate's gender, sexuality, race, and class. A community manager who has experienced any combination of these intersecting oppressions will be a strong leader and role model for team members across the AIM research and/or PPI/E teams.

DUTIES AND AREAS OF RESPONSIBILITY

- Foster communities of citizen scientists with lived experience of multiple long term conditions and open source
 developers, with a particular focus on growing the overlap between those two groups. Bring together domain
 experts to design, adapt and build the citizen science platform and responsibly manage the data.
- The specific implementations of the co-created web platform and content moderation processes will require a combination of social and technical expertise. We do not expect the postholder to be expert in all of the following tasks, rather that they are able to identify and link up the right people from across the Turing Institute, AIM investment, Open Humans and broader PPI/E communities. Tasks that have been identified to date are:
 - Mentor volunteer open source web developers to build the citizen science platform. Support their communication with senior developers to make sure that their pull requests are easy to review and in line with project goals.
 - Ensure that volunteer contributors who have lived experience of MLTCs can give feedback on the design and development of the citizen science platform. Particularly focus on the accessibility of the platform, including the data consent and moderation processes. This is likely to include delivering digital skills training to allow all members of the PPI/E communities to engage in the co-creation of the platform.
 - Engage with researchers and policy makers across the multiple long term conditions research landscape to ensure that the platform is developing in line with their goals of delivering a health care system that can best support people from diverse backgrounds and with lived experience of MLTCs.
- Catalyse connections and collaboration between people with lived experience of MLTCs, their families and carers, policy makers, researchers in MLTC research and/or participatory citizen science, and open source web developers. This could come in the form of synchronous regular meetings but the discussions may also occur asynchronously, for example, through active engagement on distributed communication channels such as Slack and the maintenance of public and private GitHub repositories.
- Be an active contributor to *The Turing Way* project exemplifying the practices we want to promote within the community. This may include identifying gaps in the current material, writing new content, reviewing existing chapters, giving presentations about the project to new audiences, welcoming members of your own project communities to join *The Turing Way*, and contributing to the design of governance and decision making processes. Our vision is to build an interconnected web of open source communities in applied data science. We expect all community managers to attend regular co-working sessions and participate in discussions on research best practices across a project lifecycle.
- Foster a community of patients and members of the public who want to share personal experiences of navigating
 the health care system with symptoms of multiple long term conditions. Implement practices as defined in The
 Turing Way, and beyond to ensure these team members demonstrate the highest standards of reproducible,
 ethical, inclusive and collaborative data science in their work. Some but not all of these practices include:
 - Onboard and welcome new community members. This will likely include running 1:1 inductions and continuously updating documentation to ensure that resources remain easy to find for new starters and existing team members alike.
 - Design, organise and facilitate innovative, inclusive events remote and in person for a broad range of community members and collaborators. These can range from small group focused meetings, through

team 'coffee chats' to build community, informal mentorship and training, to collaborative contribution events such as hackathons, documentation sprints, or design scoping workshops.

- Review code, analysis, visualisation and infrastructure process documentation. Support community
 members to participate in the collaborative review using pull requests or merge requests via the GitHub
 repository. This will likely require proactive 'just in time' training in using version control using git, and
 project management in public or private GitHub repositories, as appropriate.
- Promote the sustainable use of research outputs by facilitating high-quality analysis, modelling and reporting documentation, and training materials, in collaboration with researchers, developers and domain experts.
- Curate and finalise regular newsletter updates to capture impact stories, showcase community member contributions, and share progress for both internal and external audiences.
- Communicate technical topics to colleagues and external partners by preparing and presenting reports, blog
 posts, organising and delivering presentations, and taking an active role in meetings and discussions.
 Communications may be synchronous or asynchronous, remote or in person, and must be prepared at the
 appropriate granularity of detail for the audience.
- Publish as a lead or co-author peer-reviewed research articles, open source training curricula, and/or perspective, opinion and commentary articles, as appropriate. This responsibility will be defined to be aligned with the successful candidate's personal career goals, through collaborative discussion when they are in post.

Please note that job descriptions cannot be exhaustive, and the post-holder may be required to undertake other duties, which are broadly in line with the above key responsibilities. This job description is written at a specific time and is subject to changes as the demands of the Institute and the role develop.

PERSON SPECIFICATION

	Essential (E)	Tested at application (A)
Skills and Requirements	Desirable (D)	Tested at interview (I)
•	20011 4310 (2)	(1)
Post holders will be expected to demonstrate the following		
Education/Qualification		
PhD or equivalent level of industry experience.	D	А
Bachelor's degree or a Master's Degree in a discipline which provides a good basis for understanding statistics, data science and programming.	E	А
Knowledge and Experience		
Experience in:		
Basic coding skills in any programming language.		
 Git for version control and Github or GitLab for project management. 		
 An understanding of the importance of good practices for producing reliable software and reproducible analyses (e.g. version control, issue tracking, automated testing, package management, literate analysis tools such as Jupyter and Rmarkdown). 	E	A/I
 Experience managing, structuring and analysing research data. 		
Experience in:		
 Open research, open source software, participatory and community-led co-creation or team science. 	D	A/I
Contributing to, maintaining and/or leading open source research software projects.		
Knowledge of, or interest in learning about:		
 Facilitating research using sensitive health data, or other sensitive data, including an understanding of information governance requirements. 	D	A/I
 Track record of <u>any combination</u> of: Publishing articles, FAIR data sets, and/or open source software libraries for an academic audience. Publishing articles, blog posts, for a general audience. Publishing white papers or policy briefings for an audience of decision makers in 	E	A/I
government, industry or the charity sector.		
Communication		
Outstanding communication skills, both oral and written.	E	A/I
Teamwork and Motivation		
Works as a proactive and collaborative member of the community team. Proactively looks for issues or problems, and escalates accordingly.	E	A/I
Liaison and Networking		
Networks with others with shared interests, collaborating on projects and strengthening future relations.	E	A/I
Project Delivery or Project Management		

Promptly deals with requests related to process improvement and supports the Community with aspects of project management.	E	A/I
Decision Making		
Ability to guide others by presenting options and choices to inform their decision making.	D	I
Planning and Organising		
Suggests ways of improving working practice and use of resources. Creates realistic plans to effectively manage own workload, prioritising work to meet personal and team objectives.	Е	I
Initiative and Problem Solving		
Considers possible solutions to identify those which offer wider benefits. Obtains evidence to support thinking.	E	A/I
Analysis and Research		
Gathers data rigorously and conducts robust analysis, questioning assumptions and existing knowledge. Reports findings to wider community and is able to withstand challenge by relying on evidence gathered and processes used for analysis.	E	A/I
Other Requirements		
Commitment to meeting deadlines	Е	A/I
Commitment to EDI principles and to the Organisation values	E	I

OUR VALUES

The Alan Turing Institute is committed to equality diversity and inclusion and to eliminating discrimination. All employees are expected to embrace, follow and promote our <u>EDI Principles</u> and Our Values.



APPLICATION PROCEDURE

If you are interested in this opportunity, please click the apply button below. You will need to register on the applicant portal and complete the application form including your CV and covering letter. If you have questions about the role or would like to apply using a different format, please contact them on 020 3970 2148, or email recruitment@turing.ac.uk

CLOSING DATE FOR APPLICATIONS: 06 February 2022

TERMS AND CONDITIONS

This full-time post is offered on a 2.5 year, fixed term contract basis (funding ends October 2024). The annual salary is £37,000-£42,000 plus excellent benefits, including flexible working and family friendly policies, https://www.turing.ac.uk/work-turing/why-work-turing/employee-benefits.

EQUALITY, DIVERSITY AND INCLUSION

The Alan Turing Institute is committed to creating an environment where diversity is valued and everyone is treated fairly. In accordance with the Equality Act, we welcome applications from anyone who meets the specific criteria of the post regardless of age, disability, ethnicity, gender reassignment, marital or civil partnership status, pregnancy and maternity, religion or belief, sex and sexual orientation.

Reasonable adjustments to the interview process will be made for any candidates with a disability.

Please note all offers of employment are subject to obtaining and retaining the right to work in the UK and satisfactory pre-employment security screening which includes a DBS Check.

Full details on the pre-employment screening process can be requested from HR@turing.ac.uk.