

Call for expressions of interest for the Innovative Health Initiative Patient Pool

The Innovative Health Initiative Joint Undertaking (IHI JU) is launching a call for expressions of interest to select patients/caregivers as **members of the IHI Patient Pool.**

1 About the Innovative Health Initiative

IHI JU builds on the experience of the Innovative Medicine Initiative (IMI) which ran for almost 14 years and resulted in nearly 200 scientific projects. IHI JU is a cross-sector partnership in life sciences between the European Union, represented by the European Commission, and the European life science industry represented by the European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (COCIR), the European Federation of Pharmaceutical Industries and Associations (EFPIA), EuropaBio, MedTech Europe, and Vaccines Europe. Among them, these industry partners represent the pharmaceutical industry (which was a partner in IMI), as well as the medical technology, biotechnology, digital health, and vaccine industries. IHI is working to enable the integration of technologies, know-how, product, services, and workflows for people-centred healthcare. It does this by facilitating collaboration between the key players involved in healthcare research, i.e., universities, companies in the biopharmaceutical, biotechnology, digital health and medical technology sectors, small and medium-sized enterprises (SMEs), patient organisations, regulatory authorities, health care professionals/providers, health technology assessment bodies, and health care payers.

IHI's ambition is to support the delivery of timely, evidence-based prevention, diagnosis, and treatment. The partnership aims to help keep EU citizens in good health, and decrease the disease burden for patients, care givers and healthcare professionals. It intends to contribute to the sustainability and resilience of healthcare systems and to the competitiveness of the European health industry. IHI JU runs from 2021 to 2027 and has a budget of up to €1.2 billion provided by the European Union (from the Horizon Europe research and innovation programme), at least €1 billion provided by the member industry associations, and up to €200 million from Contributing Partners.

In addition, the IHI Programme Office continues to manage the projects launched under the IMI programmes.

For more information, please visit the IHI JU website: www.ihi.europa.eu.

2 IHI JU activities and patient/caregiver engagement

IHI's objectives are set out in the <u>legislation creating IHI under Horizon Europe</u>. In addition, IHI has a Strategic Research and Innovation Agenda (SRIA) which provides more details on the objectives and describes what our projects could do to meet the objectives. The aim of patients'/caregivers' participation in IHI activities is to bring a unique perspective based on their real-life experience with a disease, supporting and enhancing early and meaningful patient engagement in IHI.

IHI JU works by funding projects through competitive calls for proposals. For most IHI JU projects, the process of developing a call and launching and managing the resulting projects is as follows.













Ideas for potential call topics come from a range of sources, including the European Commission, industry partners, potential contributing partners, and other stakeholders in the health community. Once the most promising ideas have been discussed and refined by the IHI Science and Innovation Panel (which comprises experts from various stakeholder groups and sectors, including patient groups), the IHI Programme Office leads the drafting and finalisation of the topic texts. If needed, during this process, members of the IHI Patient Pool who have relevant knowledge and experience may be invited to contribute to the development of certain topics with their perspective. Once the IHI Governing Board has formally approved the topics, the IHI Programme Office launches the call for proposals with the approved topics via the IHI website and the EU's Funding & Tenders Portal.

IHI calls for proposals are open and competitive. Eligible proposals are evaluated by independent scientific experts, who score them based on three top-level criteria: excellence, impact, and quality and efficiency of the implementation. If the patient/caregiver's perspective is needed for the evaluation of the proposals, the IHI Programme Office may select the most suitable patient/caregiver from the members of the IHI Patient Pool to act as patient experts based on their knowledge, experience, and relevance to the topic. The results of the evaluations and the ranking lists are approved by the Governing Board. Once the Grant Agreement (which governs the relationship between the project and IHI), and the Consortium Agreement (which governs the relationship between the project partners) have been signed, the project can officially start.

- Once a project is up and running, it must submit regular reports to IHI describing its progress. The IHI
 Programme Office uses these reports and project outputs to ensure that projects are on track to deliver
 on their objectives and have an impact on health research and innovation, in line with the IHI objectives.
 IHI also runs project review meetings, for which the IHI Programme Office set up panels composed of
 independent scientific experts and, if needed, by patient experts who are selected from the members of
 IHI Patient Pool.
- After the end of a project, the IHI Programme Office organises a meeting with representatives of the
 project to discuss the main achievements and highlight impactful results. The meeting is public and the
 IHI Programme Office invites all members of the IHI Patient Pool to attend and receive updates about the
 most recent scientific advance in the field. Members can contribute to the discussion with their
 perspective and experience, and interact with the project representatives, the general audience, and
 other members of the IHI Patient Pool.

3 Objectives of the call for expressions of interest

Building on the work of the Patient Pool set up under IMI2, IHI is now launching a new call for expression of interest to select patients/caregivers, with a strong interest in fostering patient-centred innovation, to become members of the IHI Patient Pool and support IHI activities with their perspectives and experience.

The members of the IHI Patient Pool may be invited, as attendees or speakers, to participate in project meetings, scientific events, webinars, or trainings organised by the IHI Programme Office alone or jointly with the IHI members or other EU bodies/initiatives. During these events, which may last 2 or 3 hours, the members of the IHI Patient Pool will have opportunities to contribute to the discussions, bringing their perspectives and experience and providing input on projects' results and their implementation in research, regulatory and medical practice.

When needed, the IHI Programme Office may select members of the IHI Patient Pool based on their knowledge and experience, and invite them, in their personal capacity, to act as patient experts for the evaluation of scientific proposals (which generally includes participating in virtual and/or on-site meetings lasting 1 to 3 days) or for the review of ongoing projects (which generally includes participating in a one-day virtual and/or on-site meeting day). The IHI Programme Office may also select and invite members of the IHI Patient Pool to participate in panels/workshops to provide advice on scientific ideas for future calls, scientific

portfolio strategy, annual scientific priorities, or to review the content of documents prepared for public events organised by IHI.

A member of the IHI Patient Pool who is invited to participate in an IHI activity, is always free to decide whether to accept the invitation.

4 Profile of participants

4.1 Eligibility criteria

An expression of interest may be submitted by individuals who meet all the following eligibility criteria:

- Individuals must be either
- a patient with a chronic and/or lifelong illness/condition, or
- a family member/informal carer of a patient with a chronic and/or lifelong illness/condition
- Be resident of one the following groups of countries: a) Member States of the European Union, b) Third countries associated to Horizon Europe.
- Possess a working knowledge of English. A working knowledge of English, at least at an upper intermediate level or B2 (based on the <u>Common European Framework of References for Languages</u>), is necessary.

4.2 Compulsory information to be included in the application

Applicants must also indicate which of the following **disease/condition area of interest** is most relevant to them:

- Cancer
- Cardiovascular disease
- Metabolic diseases (metabolic syndrome, etc.)
- Diabetes
- Mental disorders
- Neuro-psychiatric disorders and brain diseases including pain
- Neurodegenerative diseases
- Musculoskeletal disorders
- Respiratory diseases
- Aging related disorders
- Paediatric diseases
- Inflammatory and Immune (and auto-immune) system diseases
- Infectious diseases (bacteria)
- Infectious diseases (viral)
- Rare diseases
- Disability and rehabilitation
- Reproductive and fertility disorders (endometriosis, uterine fibroids, pelvic inflammatory disease, polycystic ovary syndrome, etc.)
- Eating disorders (obesity, anorexia, bulimia)
- Nutritional diseases
- Endocrine disorders
- Haematological (blood) diseases
- Rheumatological diseases
- Ophthalmological (eye) diseases
- Dermatological (skin) diseases

- Transplantation
- Other

4.3 Additional information useful to qualify the application

In addition to the eligibility criteria, applicants are invited to state in the application form, where relevant, if they possess any of the following:

- 1. Knowledge and/or experience in using telemedicine applications/tools, mobile medical apps, or any other digital, remote, wearable technologies in medical healthcare (i.e. consultation, monitoring treatment).
- 2. Knowledge and/or experience in reporting patient experience, preference, outcome, etc.
- 3. Being a member of a patient organisation.
- 4. Knowledge and/or experience of patient engagement and/or patient involvement activities and/or experience of participating in health or patient-centric meetings organised for example by companies, patients' organisations, scientific projects, EU initiatives/bodies (i.e. European Commission, European Medicines Agency, IMI/IHI, EU agencies, etc.) or any other national/international health organisations.
- 5. Knowledge and/or experience of IMI/IHI and its activities (i.e. evaluating proposals, reviewing projects, participating close out meetings and webinars, etc.).
- 6. Knowledge and/or experience of research and innovation activities and/or public-private partnerships.
- 7. Knowledge of health industries, namely the pharmaceutical, medical technology, imaging and diagnostics, biotechnology, digital health and vaccine industries.
- 8. Knowledge of ethics and/or regulatory processes and/or experience of working/interacting with different stakeholders in medicines/medical device development and evaluation such as health technology assessment (HTA) bodies, regulators, payers, medical practitioners, etc.

The application will not be disqualified if the additional information section is incomplete. The purpose of this section is to obtain detailed information on the knowledge and experience of the members of the IHI Patient Pool. This will enable the IHI Programme Office to identify the people with the most suitable profile when patients'/caregivers' contribution to IHI activities is needed as mentioned above.

Applicants will also be asked to indicate in their application if they were included in the IMI Patient Pool which was launched in 2019.

Motivation for applying

In the application form, all applicants will be asked to state, in maximum one page, their reasons for applying to this call and participating in IHI JU activities.

5 Selection procedure

All expressions of interest received by the deadline will first undergo a check to make sure all the minimum eligibility criteria listed in the section above are fulfilled.

All applicants who meet the eligibility criteria and have provided in their application the compulsory information will be part of the IHI Patient Pool.

6 Reimbursement/allowances

Members of the IHI Patient Pool who are invited to participate in IHI activities will be entitled to reimbursement and allowances for certain activities. The reimbursement and allowances will depend on the nature of the task the member is requested to perform. For example, members who act as patient experts for the evaluation of

proposals or project reviews will have the same contract as all other experts. Under the standard expert contract, they will be entitled to a fixed fee of €450 per working day, plus the reimbursement of travel, accommodation, and subsistence expenses in case of in-person meetings.

Alternatively, members of the IHI Patient Pool may be invited to speak at an IHI JU event virtually or in person. In the latter case, they will be entitled to reimbursement of travel, accommodation, and subsistence expenses in line with the applicable IHI JU rules.

Allowances may be increased for experts with disabilities (see below).

Experts with disabilities.

If an expert's disability requires that a person accompany him/her when travelling, then the travel expenses of that person will also be refunded upon prior request. IHI JU will also pay accommodation allowances and daily allowances to the accompanying person.

7 Transparency

Members of the IHI Patient Pool who are invited to act as patient experts to perform tasks and roles associated with evaluation of proposals and/or project reviews **will be requested** to register in the European Commission register of experts. Additionally, the names of patient experts who have been assigned to such tasks **will be published** on the general Horizon Europe 'Funding and Tenders Portal' as for the other scientific experts involved in the tasks.

8 Rules of engagement

Once invited to contribute to a task, patients/caregivers will be expected to provide input based on the real-life experience of those affected by a disease and its current therapeutic environment. Their role will be for short-term assignments on an occasional basis. There is no guarantee of a minimum assignment of tasks/activities for each member of the IHI Patient Pool. Furthermore, at this stage, no indication can be provided about when and how often individual members of the pool will be selected and invited to act as patient experts to perform activities/tasks for IHI. IHI JU will strive to involve members of the pool in its activities whenever it would be of added value. Whenever a need for a patient/caregiver input arises, the IHI Programme Office will assess the profiles of the members of the pool to identify the most suitable member(s) to act as patient expert(s) for the task(s). When selected, patient experts should enjoy their full legal capacity to participate in IHI JU activities/tasks.

Tasks/activities assigned may be carried out at the IHI JU premises in Brussels, at any other premises where an IHI JU event is taking place, or remotely, using electronic communication tools (Webex, Teams, etc.).

Patient experts will be required to abide by the rules of procedure of any IHI JU bodies / groups they participate in.

Patient experts will act in their personal capacity. They must respect the confidential character of the proceedings in which they participate and protect any information whose disclosure could damage the interests of IHI JU.

Members of the pool who are invited to act as patient experts will be requested to sign a declaration of non-conflict of interest for the task(s) they have been assigned, to ensure that there is no financial or any other interest that could affect their impartiality.

The pool will remain active until 31 December 2026, subject to possible renewal by IHI JU.

9 Application procedure and closing date

Patients/caregivers who want to be part of the IHI JU Patient Pool are invited to submit their expressions of interest via this website: https://cloud.ihi.europa.eu/web/pool-of-patient-platform.

Expressions of interest must be completed in English.

The online application form must be filled in, documenting how the individual fulfils the criteria listed above. All applicants will be requested to certify that the information contained in their application is correct and complete.

To facilitate the process, applicants may download the word version of the application form and use it to fill in the relevant information offline. Once ready, they can copy/paste each section in the online application form (https://cloud.ihi.europa.eu/web/pool-of-patient-platform) prior to formal submission.

Expressions of interest must be submitted by the 8th of June, 17:00 CEST / Brussels time.

10 Data protection

All personal data provided by candidates will be dealt with in compliance with Regulation (EU) 2018/1725 of 23 October 2018 on the protection of natural persons with regard to the processing of personal data by the Union institutions, bodies, offices and agencies and on the free movement of such data, and repealing Regulation (EC) No 45/2001 and Decision No 1247/2002/EC. For more information, candidates are invited to read the IHI JU Privacy Policy on Personal data protection: www.ihi.europa.eu/legal-notice-and-privacy.

For any further information, please contact the IHI JU Programme office: Patients@ihi.europa.eu