

WEBINAR

Call for Eol for the IMI pool of patient experts

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18.06.2019

Outline of the webinar

- Part one
 - About the Innovative Medicines Initiative
Mission, Governance, topics development, Call process, projects.
 - IMI and patient engagement.
- Part Two
 - The IMI Pool of patient experts.
 - The Call for EoI and how to apply
- Part Three
 - Q&A

Part One

What is IMI and how does it work ?

IMI – Europe's partnership for health

IMI mission

IMI facilitates open collaboration in research to advance the development of, and accelerate patient access to, personalised medicines for the health and wellbeing of all, especially in areas of unmet medical need.

How is IMI addressing the challenges in drug development?

Through IMI's projects we are trying to...

- **Put patients at the centre**
- **Share risk** (among public & private players)
- **Increase efficiency** (by developing common tools)
- **Reduce duplication of effort** (esp. at early stages)
- **Reduce timelines** (by using a personalised medicine approach)
- **Integrate the latest science** into drug development
- **Use data and knowledge management** to work more effectively

We do this by creating a **neutral platform** where **all involved** in drug development – academics, industry, SMEs, patients, regulators, others – can engage in **open collaboration** on **shared challenges**.

IMI2 funding

IMI FUNDING MODEL

(2014-2020)

efpia

IN-KIND PRIVATE CONTRIBUTION

€1.425 bn

EFPIA companies receive no funding

€ 3.276 bn
TOTAL IMI2 BUDGET



public contribution
€1.638 bn

funding from Horizon 2020

EU funding goes to ▶

SMES

UNIVERSITIES

PATIENTS, REGULATORS...

OTHER CONTRIBUTIONS
€213 MILLION

(Associated Partners, e.g. charities, non-EFPIA companies)

EFPIA contribute researchers, laboratories, generation of data, curation of compounds, and cash

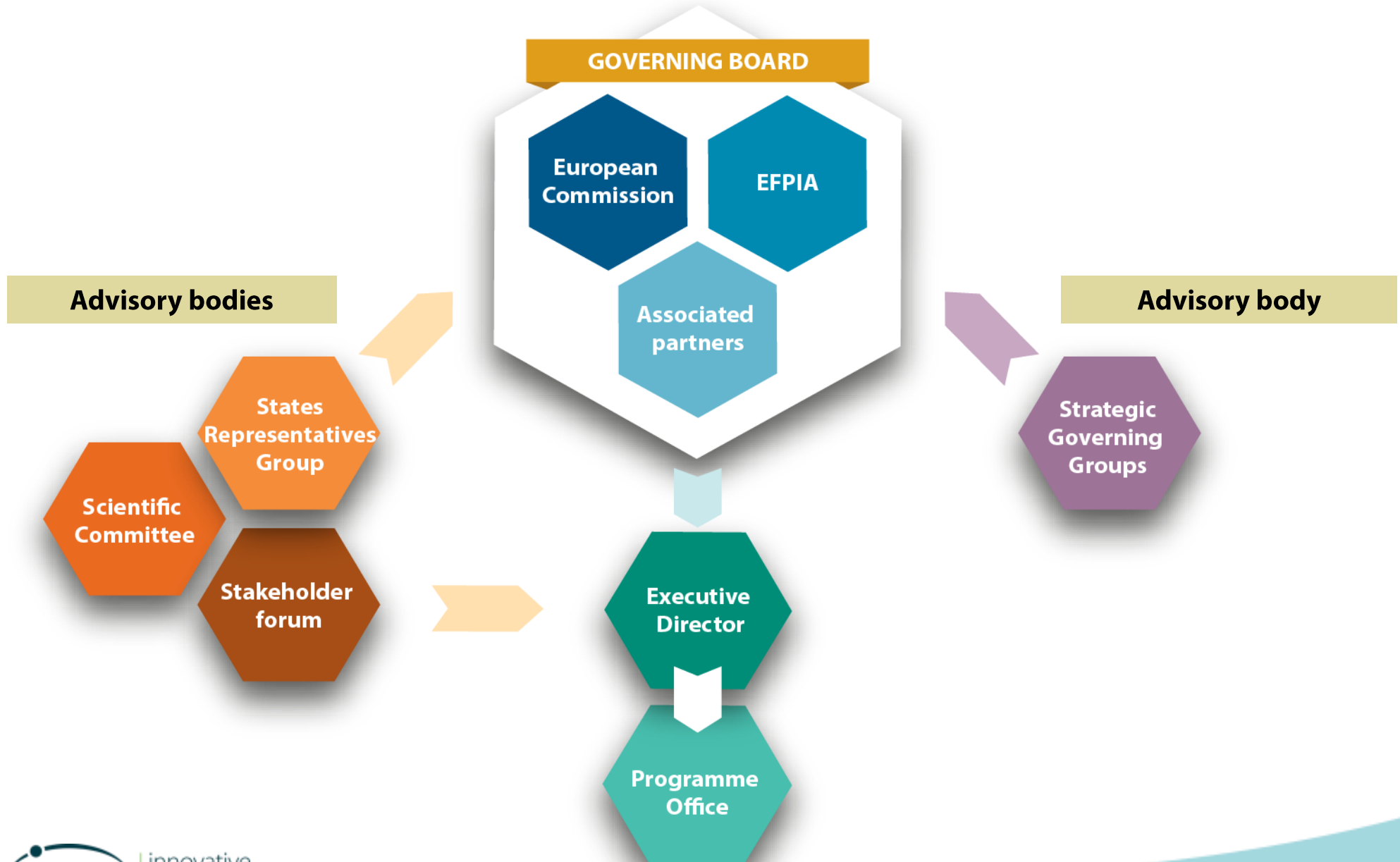
Public and private partners collaborate in IMI2 projects

Accelerating research and development

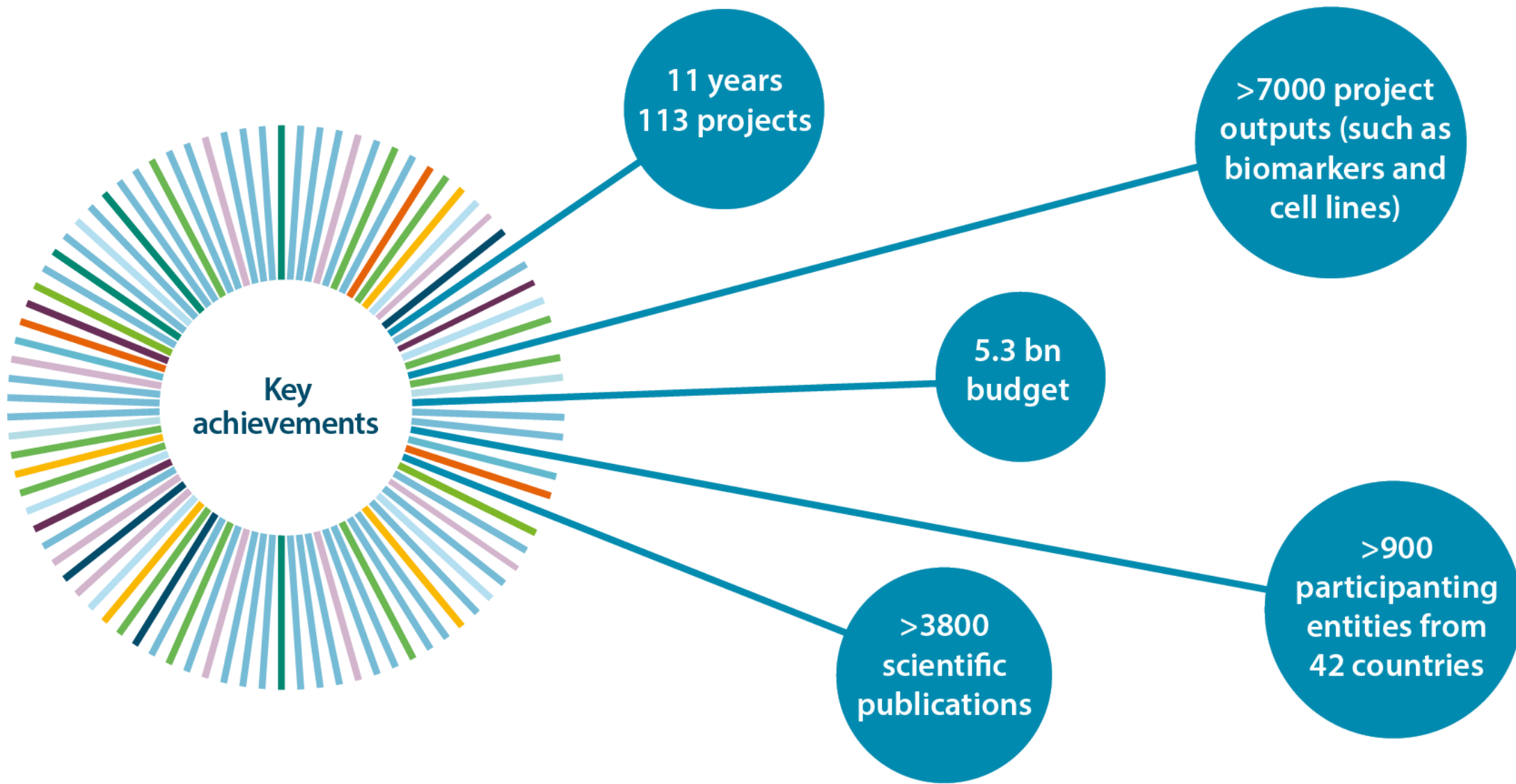
Speeding up patient access to innovative treatments

Improving patient outcomes and safety of medicines

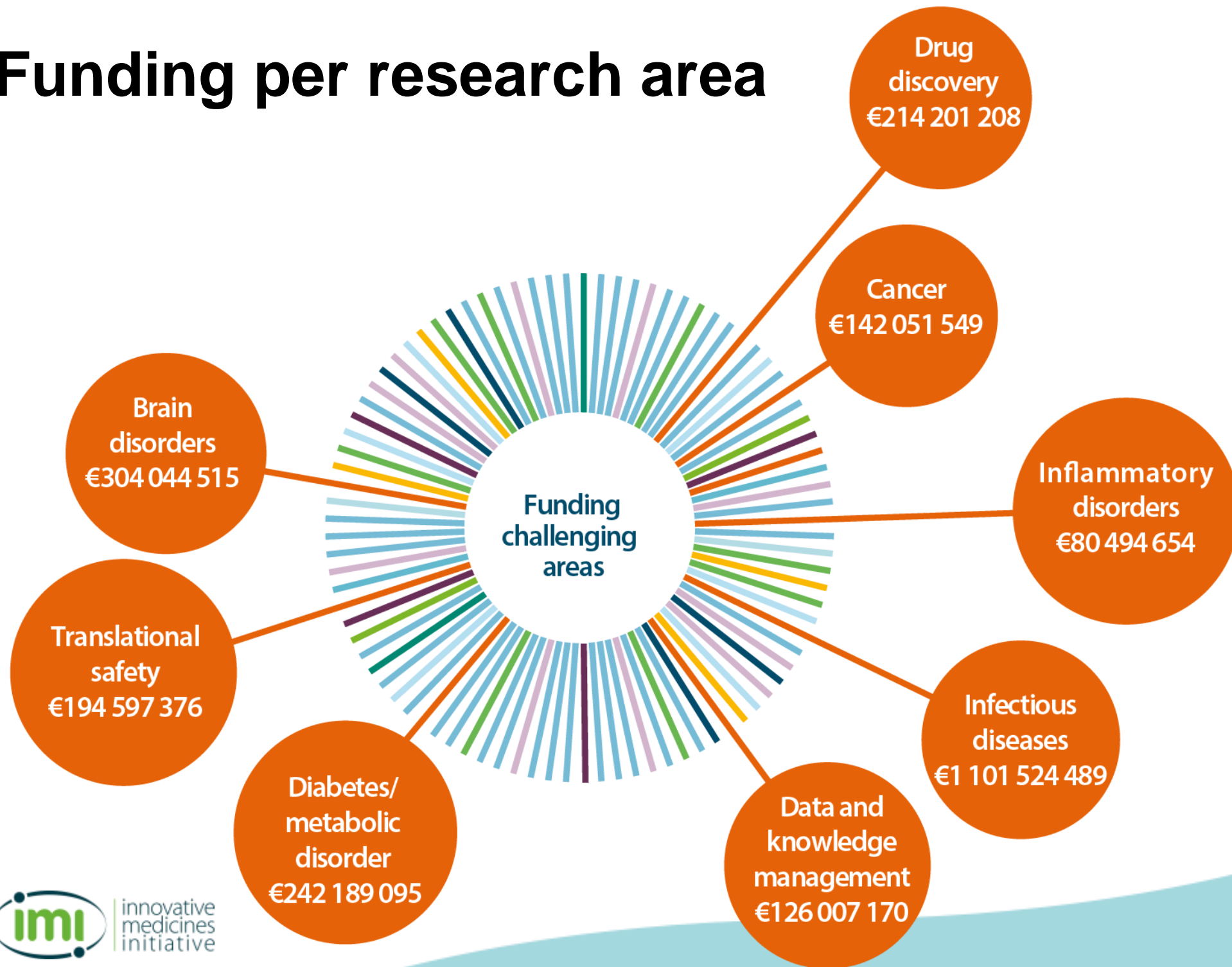
IMI Governance



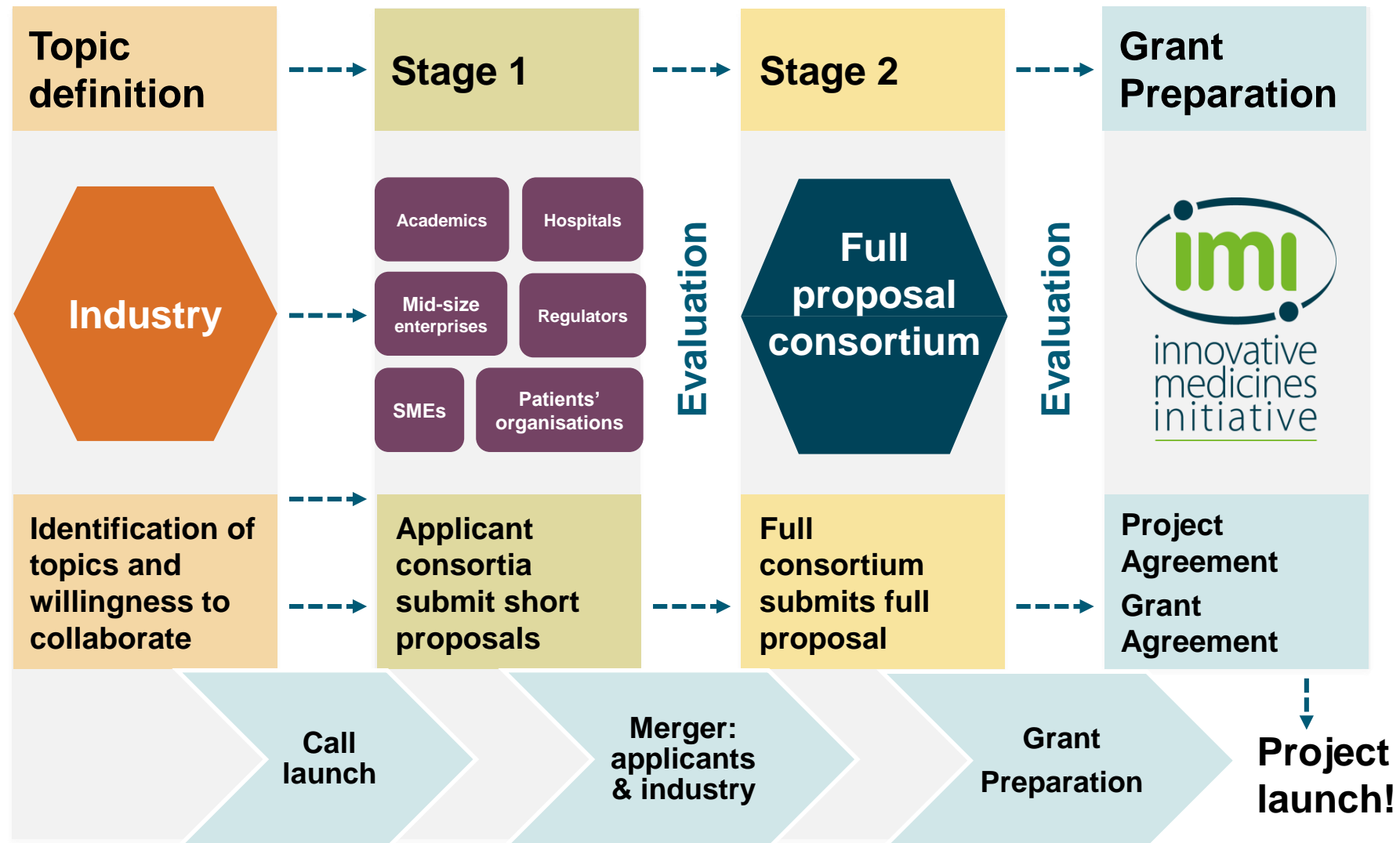
IMI in a nutshell



Funding per research area



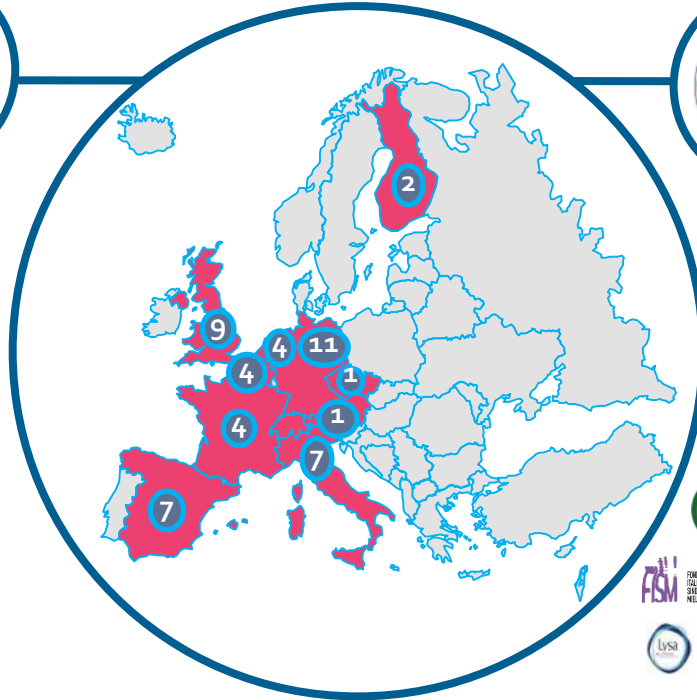
IMI's standard Call process



What does an IMI project look like?



HARMONY
Healthcare Alliance for Resourceful Medicines
Offensive against Neoplasms in Hematology



53 organisations from 11 countries, working across 7 hematological malignancies

Added value of IMI

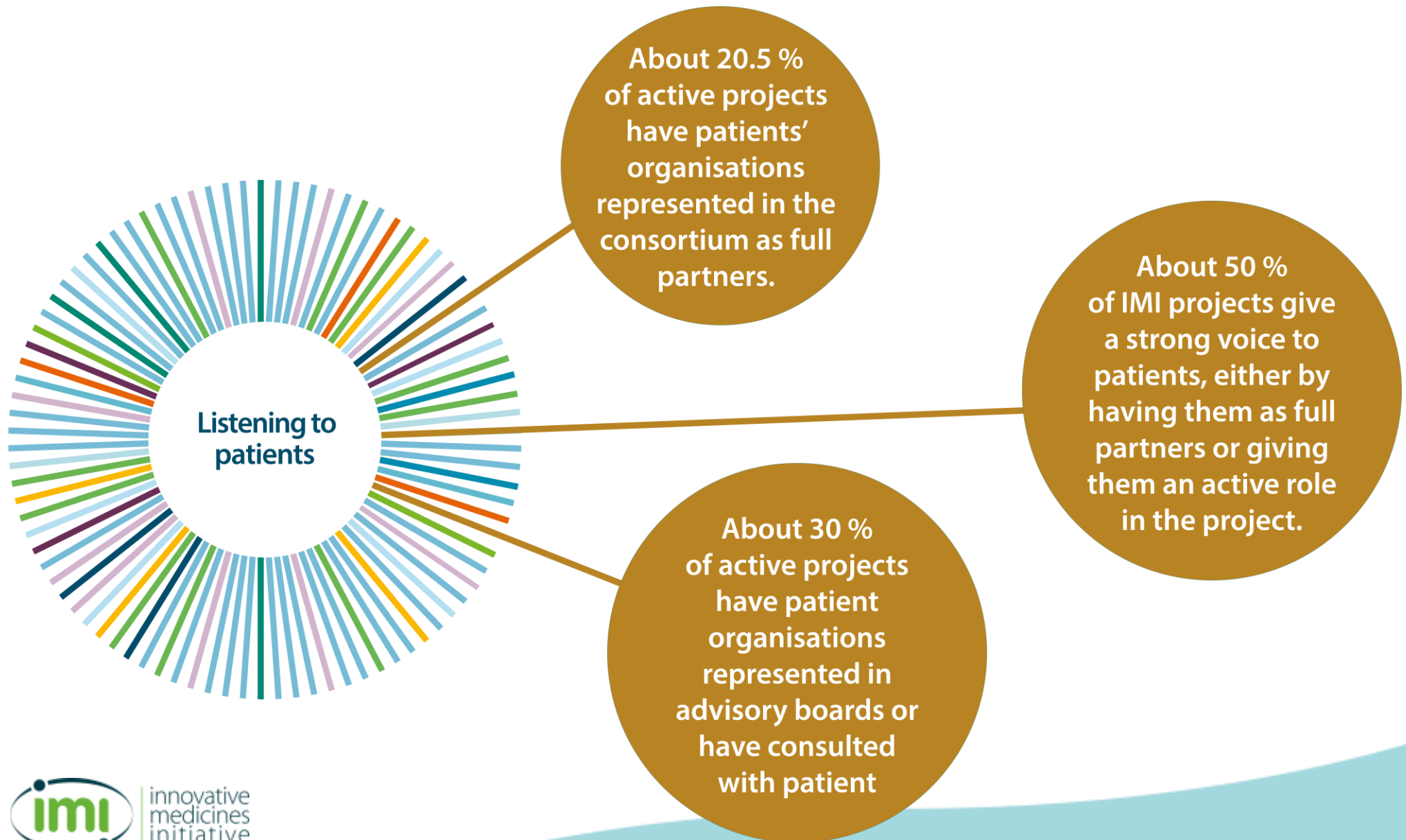
- Bringing together groups that would normally not work together, including competitors
 - Attracting new partners leading to a more diverse community
 - Creating new networks, maintained after projects end
- Addressing the most challenging diseases and cross-cutting issues
- Maximising the pooling of resources and amplifying scientific and financial investments
- Relevant outcomes for industry, direct benefits to patients, impacts on regulatory processes
 - Including elements of or dedicated to education and training activities
 - Increasing co-authored & cross-sectors publications with high citation impact

IMI and patients: a dynamic partnership for health

Paving the way: IMI's first steps to engage with patients

- Regular involvement of patients and patient representatives as speakers and panellists in IMI events.
- Surveys by the London School of Economics (LSE) on patient involvement in IMI projects and patients' opinion of IMI (2013).
- Events dedicated to patient outreach and involvement (2013 patient-focus meeting, 2014 Diabetes patient event).
- Patient engagement strategy workshop (2016).
- Patient-event co-organised with the European Patient Forum (EPF) with the IMI Stakeholder Forum (2017).
- Outreach to patients in IMI Calls for proposals.

Patient involvement in IMI projects



PARADIGM – for better patient engagement in medicines development

Mission

provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement and demonstrates the 'return on engagement' for all players



Objectives

- develop processes and tools for three key decision-making points: research priority setting, design of clinical trials and early dialogue.
- integrate the needs, perspectives and expectations of all actors (including vulnerable populations) involved and produce metrics to measure the impact of patient engagement.

EUPATI graduates - making a difference



- 150 graduates
- 58 disease areas, 31 countries
- 14 National Platforms in Europe
- More & deeper involvement in R&D thanks to EUPATI
- ✓ Sustainability (course, toolbox maintained by EPF)

Moving forward-from initial engagement to strategic/meaningful engagement

- IMI has a patient representative on its Scientific Committee
- Creation of the IMI pool of patient experts

How ?

- Launch an open Call for Expression of Interest.

Part two: Call for EoI for the IMI pool of patient experts

Purpose of the Call

Identify patients/patient informal carers interested in participating in IMI activities both at strategic and operational levels



Drawing from this Patient Expert Pool, the IMI Programme Office will invite patients with the most suitable profile, to perform a variety of roles and tasks depending on the need and topics discussed



Their input will contribute in shaping the IMI portfolio and improve quality of IMI projects from patient perspective through early and meaningful engagement

The role of patient experts

Patients and patient carers can bring a unique perspective based on their real-life experience with a disease.

Patient experts will be invited to provide input to the IMI Programme Office and to the IMI Advisory Bodies through:

- Input on the IMI scientific strategy;
- Participation in early consultations to identify research areas for future Call topics;
- Participation in reviewing proposals submitted within an IMI Call, or reviewing IMI projects;
- Participation in panels to review IMI patient-related communications content;
- Participation in IMI events, e.g. Stakeholder Forum.

What's in it for patients?

- **Influence** research, and **identify gaps** from the perspective of patients and carers
- Receive **funding**
- Form **networks** with leading researchers
- **Access** to the latest science
- Take part in IMI work to help **improve health and wellbeing** in Europe
- Provide **patient perspective** to help shape IMI's portfolio and improve quality of IMI projects
- Contribute to **enhancing transparency** and trust between IMI and patients

Who can be a member of the IMI pool of patient experts ?

Eligibility criteria

- ✓ Be a patient or a patient informal carer
- ✓ Be resident of one the following groups of countries :
 - a) Member States of the European Union,
 - b) Countries associated with the EU's research framework programmes.
 - c) Residents from the broader European Region as defined by WHO
- ✓ Possess working knowledge of English

Applications are submitted online. Deadline for submissions **16 July 2019** at **17:00** CEST Brussels Time

We strongly recommend that you read the Call document carefully before applying.

Organise targeted/meaningful interactions

Invitations/assignments will be assessed in advance by the IMI Programme Office and will be based upon patient expert profile. Patient expert profile =(A+B+C)

A) Disease/condition area of interest based on IMI Strategic research agenda (S.R.A)

- Neuro-psychiatric disorders and brain diseases including pain
- Inflammatory and Immune-mediated diseases
- Cancer
- Metabolic diseases including cardiovascular diseases
- Rare/orphan diseases
- Neurodegenerative diseases
- Infectious diseases.

A specific disease/condition of an area. e.g. type 1 diabetes.

B) Skills related to IMI activities

- Knowledge and/or experience of research and innovation activities.
- Knowledge and/or experience of the pharmaceutical sector/medicines development cycle.
- Knowledge and /or experience of IMI and public-private partnerships.
- Experience of working/interacting with different stakeholders in medicines development such as HTAs, regulatory authorities, payers, medical practitioners, etc.

C) Motivation for applying

IMI

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Rules of engagement.

- Tasks/activities assigned to patient experts may be carried out at the IMI2 JU premises in Brussels, at any other premises where an IMI2 JU event is taking place, or remotely, using electronic communication tools.
- Experts will be required to abide by the rules of procedure of any IMI2 JU bodies / groups they participate in.
- 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 IMI2 JU.
- All experts who are part of the pool will be requested to sign a declaration of interests form. Experts assigned to certain tasks may be required to sign a declaration of non-conflict of interest for that specific task.

Reimbursement /Allowances

- Invited experts will be entitled to reimbursement and allowances only for the activities they are requested to perform. The reimbursement and allowances will depend on the nature of the task each expert is requested to perform.
- Allowances may be increased for experts with disabilities

Transparency

- Experts invited to perform tasks and roles associated with the evaluation of project proposals and/or the monitoring of projects **will be requested** to register in the European Commission Register of experts. Additionally, the names of experts who have been assigned to such tasks **will be published** on the general H2020 'Funding and Tenders Portal'.

Privacy Policy and Data Protection

All personal data will be dealt with in compliance with the [Regulation \(EU\) 2018/1725](#) of the European Parliament and of the Council 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.

For more information please visit:

- <https://www.imi.europa.eu/legal-notice-privacy>

How to apply: step by step guide

Please go to:

<https://www.imi.europa.eu/get-involved/patients/imi-pool-patient-experts>

**For any further information please
contact the IMI2 JU Programme
Office :**

Patients@imi.europa.eu

Part three: Q&A



Thank you