

Public stakeholder consultation – Interim evaluation of the Joint Undertakings operating under Horizon 2020

Fields marked with * are mandatory.

This consultation aims to collect the views of the public about the implementation of the Joint Undertakings (JUs) under Horizon 2020 for the period 2014 to 2016. The outcome of this public consultation will provide input to the currently ongoing interim evaluation of the JUs, covering the same period. The results of the interim evaluation will be used as a basis to improve the performance of the JUs and will be communicated to the European Parliament and the Council, national authorities, the research community and other stakeholders.

This questionnaire consists of six parts and it will take around 20 minutes to respond.

A short introduction to Joint Technology Initiatives and Joint Undertakings

The Joint Undertakings (JUs) are formalised public-private partnerships involving companies at the European level. The JUs were first set up in 2007 under the Seventh Framework Programme (referred to as 'FP7') in five strategic areas: aeronautics and air transport, health, fuel cell and hydrogen technologies, embedded computing systems and nanoelectronics. The JUs bring together industry, the research community, in some cases Member States, regulators and the EU to define and implement common research agendas and invest in large-scale multinational research activities. They are practical examples of the European Union's efforts towards strengthening its competitiveness through scientific excellence, industry led research, openness and innovation.

The European Commission, as a co-founding member, was responsible for setting up the JUs. Once they had built up their legal and financial framework and demonstrated their capacity to manage their own budgets, the JUs were granted autonomy. The control over JUs is shared and the Commission has its own members in the Governing Board of each JU.

Based on the experience acquired under FP7, a second generation of public and private partnerships was set up^[1] by the European Commission under Horizon 2020, aiming to collectively pool more than €22 billion^[2] of research and innovation investments. This includes [seven JUs](#), namely: Bio-based Industries (BBI), Clean Sky 2 (CS 2), Electronic Components and Systems for European Leadership (ECSEL), Fuel Cells and Hydrogen 2 (FCH 2), Innovative Medicines Initiative 2 (IMI 2), Single European Sky ATM Research (SESAR) and Shift2Rail, that organise their own research and innovation agenda^[3] and award funding for projects on the basis of competitive calls.

[1] With the exception of SESAR JU for which the existing JU Regulation was extended.

[2] This amount represents the total investments under Art. 185 and Art. 187 initiatives under Horizon 2020.

[3] Exception is the SESAR JU the agenda of which is set by the Member States, various Air Traffic Management (ATM) stakeholders and the members of the PPP in the framework of the European ATM Master Plan.

A. Information about you

* A.1. In which capacity are you responding to this consultation?

- As an individual in my personal capacity
- In my professional capacity or on behalf of an organisation

A.1.1. Please enter your professional details

*First name:

Paul

*Last name:

De Raeve

*Professional email address:

efn@efn.be

*Name of the organisation:

European Federation Of Nurses Associations (EFN)

*Postal address of the organisation:

Clos Du Parnasse 11a B-1050 Brussels

A.1.2. Is your organisation included in the Transparency Register?

- YES
- NO

* A.2. My contribution,

Note that whatever option chosen, your answers may be subject to a request for public access to documents under Regulation (EC)No 1049/2001

- can be published with my personal information** (I consent to the publication of all information in my contribution in whole or in part including my name or my organisation's name, and I declare that nothing within my response is unlawful or would infringe the rights of any third party in a manner that would prevent publication)
- can be published provided that I remain anonymous** (I consent to the publication of any information in my contribution in whole or in part (which may include quotes or opinions I express) provided that it is done anonymously. I declare that nothing within my response if unlawful or would infringe the rights of any third party in a manner that would prevent the publication)

* A.3. Please enter the country where your organisation is currently based

- | | | | |
|----------------------------------|--|-------------------------------------|---|
| <input type="radio"/> Austria | <input checked="" type="radio"/> Belgium | <input type="radio"/> Bulgaria | <input type="radio"/> Croatia |
| <input type="radio"/> Cyprus | <input type="radio"/> Czech Republic | <input type="radio"/> Denmark | <input type="radio"/> Estonia |
| <input type="radio"/> Finland | <input type="radio"/> France | <input type="radio"/> Germany | <input type="radio"/> Greece |
| <input type="radio"/> Hungary | <input type="radio"/> Ireland | <input type="radio"/> Italy | <input type="radio"/> Latvia |
| <input type="radio"/> Lithuania | <input type="radio"/> Luxembourg | <input type="radio"/> Malta | <input type="radio"/> Netherlands |
| <input type="radio"/> Poland | <input type="radio"/> Portugal | <input type="radio"/> Romania | <input type="radio"/> Slovak Republic |
| <input type="radio"/> Slovenia | <input type="radio"/> Spain | <input type="radio"/> Sweden | <input type="radio"/> United Kingdom |
| <input type="radio"/> Albania | <input type="radio"/> Bosnia and Herzegovina | <input type="radio"/> Faroe Islands | <input type="radio"/> Former Yugoslav Republic of Macedonia |
| <input type="radio"/> Georgia | <input type="radio"/> Iceland | <input type="radio"/> Israel | <input type="radio"/> Moldova |
| <input type="radio"/> Montenegro | <input type="radio"/> Norway | <input type="radio"/> Serbia | <input type="radio"/> Switzerland |
| <input type="radio"/> Tunisia | <input type="radio"/> Turkey | <input type="radio"/> Ukraine | <input type="radio"/> Other |

A.4. For which Joint Undertaking would you like to provide your views:

(you may provide your views for more than one JU)

between 1 and 7 answered rows

	Choice
BBI	<input type="checkbox"/>
CS2	<input type="checkbox"/>
ECSEL	<input type="checkbox"/>
FCH2	<input type="checkbox"/>
IMI2	<input checked="" type="checkbox"/>
SESAR	<input type="checkbox"/>
Shift2Rail	<input type="checkbox"/>

The 'Innovative Medicines Initiative' Joint Undertaking

Introduction to IMI JU and IMI2 JU

The Innovative Medicines Initiative (IMI JU) under FP7 and its successor under Horizon 2020, IMI2 JU (*Council Regulation (EU) No 557/2014 of 6 May 2014 establishing the Innovative Medicines Initiative 2 Joint Undertaking*), is Europe's largest public-private initiative aiming to speed up the development of better and safer medicines for patients. It is a Joint Undertaking between the European Union and the European Federation of Pharmaceutical Industries and Associations (EFPIA). It brings together companies, universities, public laboratories, innovative SMEs, patient groups and regulators in order to boost pharmaceutical innovation in Europe. IMI2 JU has specifically the objective of significantly improving the efficiency and effectiveness of the drug development process with the long-term aim that the pharmaceutical sector produces more effective and safer innovative medicines.

IMI2 JU covers all areas of life science research and innovation of public health interest, as identified by the World Health Organisation report on "[Priority Medicines for Europe and the World](#)" which has been updated in 2013. The initiative should constantly seek to involve a broader range of partners from pharmaceuticals to sectors such as biomedical imaging, medical information technology, diagnostics and animal health industries.

[IMI2 JU](#) will run from 2014 to the end of 2024 and it will have a total budget of up to €3.276 billion, split as follows:

- Up to € 1.425 billion from the EU's Horizon 2020 programme, to match at least 1.425 billion from EFPIA and its constituent or affiliated entities
- Up to €213 million from the EU's Horizon 2020 programme, to match up to €213 million from other organisations that decide to join IMI2 as Associated Partners

* A.5. What type of organisation do you represent?

Please select one of the following:

- Not applicable (*I respond as an individual in my personal capacity*)
- Private for profit organisation, excluding education (PRC)
- Member State administration
- Regional/local administration
- Non-governmental organisation (NGO)
- Research organisation
- Academia
- Other

* A.7. Are you familiar with the objectives and activities of the Innovative Medicines Initiative Joint Undertaking (IMI2 JU)?

- Not at all familiar
- Slightly familiar
- Moderately familiar
- Very familiar

* A.8. Have you applied for funding from the IMI2 JU?

- YES
- NO

* A.9. Are you directly involved with the IMI2 JU?

- YES
- NO

B. European added value

B.1. In your view, could the pharmaceutical industries along with other possible actors at national level but without the involvement of the EU, be able to overcome the barriers which hinder innovation and drive up costs in the life science sector?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

B.2. Do you agree with the EU cooperating with industry in the context of a public-private partnership so that the life science research brings better results to the patients and the market in Europe?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

B.5. "Leverage effect" is defined as the ratio between the total contributions provided by the members of the JU other than the EU and the EU contribution. The Council Regulation establishing IMI2 JU sets out the minimum leverage effect throughout its lifespan to 1 (i.e. for each euro of public money the EU contributes, the industrial partners have to contribute at least with €1). Please note that EFPIA itself, EFPIA companies and IMI2 JU Associated Partners do not receive any EU funding for participating in IMI2 JU projects. EU funding goes to Universities, SMEs, mid-sized companies, patient groups, etc. The current minimum leverage effect foreseen of 1 is:

- Too low
- Realistic
- Too high
- No opinion

B.5.1. In your opinion what would be the satisfactory leverage effect, and why?

600 character(s) maximum

Having one leverage is unrealistic. Universities, SMEs, mid-sized companies and patients groups or other NGOs have completely different budgets which need to be taken into account when deciding for the leverage. While 50-50 contribution might work profit-driven actors like companies, this is completely unrealistic for representatives of civil society.

B.6. Do you consider that IMI2 JU contributes to economic growth and job creation in the EU?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

B.6.1. Please use this space to provide a reason for your opinion

600 character(s) maximum

C. Openness - Transparency

C.1. Do you consider that the IMI2 JU website provides the general public and potential new members and participants with easy access to information?

Please provide your views on the following aspects:

a: Strongly disagree b: Disagree c: Agree d: Strongly agree e: No opinion

	a	b	c	d	e
C.1.1. The IMI2 JU website provides easy and effective access to information to the public	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C.1.2. The IMI2 JU website provides easily accessible and sufficient information about its funded projects	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C.1.3. The IMI2 JU website provides effective access to information and sufficient guidance to interested organisations facilitating their participation in proposals	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C.1.4. The IMI2 JU website provides effective access to information and sufficient guidance to interested organisations in order to facilitate them in becoming Associated Partners in IMI2 JU	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C.1.5. The IMI2 JU website provides easy and effective access to knowledge generated by the projects funded under this JU	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C.2. Do you consider that the IMI2 JU encourages the participation of SMEs?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

C.2.1. Please use this space to provide a reason for your opinion

600 character(s) maximum

SMEs and industrial actors are very much involved in the process, but it is necessary to equally include civil society and especially users of the final products designed (healthcare professionals and patients).

C.3. Do you consider that the process for engaging with Associated Partners of IMI2 JU is sufficiently open, non-discriminatory and competitive?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

C.4. Do you consider that the [current way](#) of defining topics for the calls of proposals is open and inclusive?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

C.4.1. Please use this space to provide a reason for your opinion

600 character(s) maximum

D. Relevance – Coherence - Effectiveness

* D.1. The scientific priorities addressed by the IMI2 JU are set in the [Strategic Research Agenda \(SRA\)](#) and are aligned with the 2013 update of the World Health Organisation's "[Priority Medicines for Europe and the World](#)" report.

Do you think that this framework is the most appropriate for defining the Scientific Research Agenda followed by the IMI2 JU?

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- No opinion

D.2. Do you consider other research and innovation areas not mentioned in the SRA as important to be addressed?

- YES
- NO

D.2.1. Please use this space to write your ideas about other research and innovation areas not currently addressed

600 character(s) maximum

dementia, chronic conditions

D.3. In your view how effective has IMI2 JU been in terms of:

a: Not at all effective b: Somewhat effective c: Very effective d: No opinion

	a	b	c	d
D.3.1. Supporting the development and implementation of pre-competitive research and of innovation activities of strategic importance to the Unions in the life science sector	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D.3.2. Increasing the success rate in clinical trials of priority medicines identified by the World Health Organisation	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
D.3.3. Reducing the time to reach clinical proof of concept in medicine	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
D.3.4. Developing new therapies for diseases for which there is a high unmet need and limited incentives to bring to market (such as Alzheimer's disease and antimicrobial resistance)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
D.3.5. Developing diagnostic and treatment biomarkers	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
D.3.6. Reducing the failure rate of potential new vaccines	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
D.3.7. Improving the drug development process	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
D.3.8. Contributing to personalised medicine	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D.4. Should the JU undertake any other tasks in order to achieve the objectives set out in the Regulation?

- YES
- NO

D.4.1. Please use this space to write your ideas about other tasks that the JU should undertake

600 character(s) maximum

Involve relevant stakeholders like patient groups, healthcare professionals and civil society more in the process!

D.5. Do you think that the IMI2 JU can contribute towards improving the competitiveness and industrial leadership of Europe in the life science sector?

- In the short term: over the next five years
- In the medium term: over the next ten years
- In the long term: over the next twenty years
- No opinion

D.5.1. Please use this space to provide a reason for your answer

600 character(s) maximum

D.6. Which would you consider as major benefits of participating in an IMI2 JU project?

a: Strongly disagree b: Disagree c: Agree d: Strongly agree e: No opinion

	a	b	c	d	e
*D.6.1. Direct financial support for innovative research and development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
*D.6.2. Greater visibility across Europe for your entity/Reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
*D.6.1. Direct financial support for innovative research and development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
*D.6.2. Greater visibility across Europe/Reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
*D.6.3. Greater understanding of the drug development process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
D.6.4. Enhanced access to new markets, business opportunities and funding sources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
D.6.5. Inclusion in open innovation networks, with direct contact to leading researchers in universities and the industry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

D.7. Please use this space to write about other benefits not mentioned above

600 character(s) maximum

Those benefits are only achieved if a balanced stakeholder group is engaged. If only industry and pharmaceutical companies are involved (which is the case now), none of them will be achieved.

D.8. Do you consider that IMI2 JU projects have resulted in specific scientific and/or technological successes?

- YES
- NO

D.8.1. If yes, please use this space to write which ones you have specifically in mind

600 character(s) maximum

The voice of the end-users (patients and professionals) is lacking. It is impossible to have a substantial impact if this is missing!

D.9. To what extent are the activities of the IMI2 JU coherent with other activities of the Horizon 2020 programme?

- Not at all coherent
- Somewhat coherent
- Very coherent
- No opinion

D.9.1. Please use this space to justify your opinion

600 character(s) maximum

D.10. What is the relation of the IMI2 JU with other Union funding programmes and/or with similar international, national or intergovernmental programmes

- Complementarity
- Synergies
- Potential overlaps
- No opinion

D.10.1. Please use this space to justify your opinion

600 character(s) maximum

D.11. Do you have any experience in combining different sources of EU funds and/or with national funds for research and over the innovation value chain?

- YES
- NO

E. Efficiency

E.4. You consider that the IMI2 JU overall budget (public and private) in relation to its objectives and expected outcomes is:

- Too low and therefore it should be increased
- Appropriate
- Too high and therefore it should be partly used for other types of research and innovation actions in this area
- No opinion

E.5. Please use this space to provide your comments

600 character(s) maximum

F. Overall

F.1. Please provide here any further comments

600 character(s) maximum

Contact

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