

Attachment 1: Forums and groups

Open call for stakeholders to participate in TEHDAS Joint Action

Picture: groups and forums to apply for

Stakeholder forum	WP4	WP4	WP5	WP7	WP8
	Policy forum	Project forum	Work package permanent advisory group	Work package permanent advisory group	Work package permanent advisory group
Number of participants is not limited	At least three representatives per country (from different ministries)	Number of projects and participants is not limited	20-30 experts	15-20 experts in total representing both profiles (users and implementers)	15-20 experts

Stakeholder forum

All information about the forum is in the open call on the www.tehdas.eu website.

WP4: Project forum

General description

The aim of the project forum is to identify the relevant initiatives and projects across EU that TEHDAS needs to build on. European initiatives and projects are invited to join the project forum to share relevant outputs and discuss potential synergies to avoid duplication within the TEHDAS joint action. Through this forum, the different projects and initiatives are connecting to other relevant work packages (WPs) within TEHDAS where collaboration and synergies are possible. Finally, the connection with the different projects will also help TEHDAS achieve interoperable outcomes.

There will be four full-day meetings (if face to face) or four half days (online) during the joint action. If physical meetings take place, it will be possible to combine the project and policy forum back-to-back meetings.

Expected commitment

The project forum will be held approximately four times during the joint action. In addition, surveys and information requests may occur during the TEHDAS lifespan.

Benefits

Selected projects and EU initiatives will have the opportunity to be engaged in an important EU-wide initiative and to provide input to TEHDAS on important aspects for future data sharing through the EHDS. Additionally, interaction at this stage of the development of the future EHDS will ensure the outcomes and results of relevant projects and EU initiatives are taken on board.

The forum will also provide a space for initiating opportunities for synergies and additional future collaboration across projects, EU initiatives and the EHDS.

The outcomes of project forum discussions will contribute to the concepts developed for data sharing through a future EHDS. The deliverables of TEHDAS will form important input to the legislative proposals of the EU and to the further deployment of the EHDS by member states.

Specific selection criteria

Forum representatives include projects and EU initiatives that have experience in the secondary use of health data operating across and within European countries.

In this open call, projects and EU initiatives will be able to express their interest in joining the project forum. They will be contacted by the WP4 lead for further information. After the open call, WP4 will continuously screen the landscape for new projects and EU initiatives to be included.

Number of projects and participants is not limited. However, the number of participants may be adjusted based on the format of the scheduled forum: face to face, hybrid or virtual.

WP4: Policy forum

General description

The aim of the policy forum is to reach out and engage national and international policy and decision-makers, to reflect on their needs and expectations, and to explore views on the economic sustainability of an EHDS.

Member states / associated countries national authorities and international organisations are invited to take part in the policy forum. The progress of the different WPs will be presented and potential routes for sustainable interaction will be sought. The forum will provide a platform for sharing the views and experience of MS/AC national authorities with regard to the value of sharing secondary data across Europe through the creation of an EHDS. The policy forum will be held to discuss relevant topics on the political agenda.

There will be four full-day meetings (if face to face) or four half days (online) during the joint action.

This group will consist of at least three representatives per country (from different ministries).

Expected commitment

Policy forums will be held approximately four times during the joint action. Preparation for the forum includes providing targeted feedback on preparatory material. In addition, surveys and information requests may occur during the TEHDAS lifespan.

Benefits

EU policy and decision-makers will have the opportunity to be engaged in an important EU-wide initiative and to provide input on important aspects for the secondary use of data.

Additionally, interaction at this stage of the development of the future EHDS will ensure the interest and needs of member states are taken into consideration when developing the necessary concepts for the implementation of a future EHDS.

The outcomes of Policy Forum discussions will contribute to the development of a future EHDS. The TEHDAS deliverables will form important input to the legislative proposals of the EU and to the further deployment of the EHDS by member states.

Specific selection criteria

Members of the policy forum will be selected through a separate process for WP4 within the TEHDAS consortium. This open call provides an opportunity for additional policy and decision-makers to express their interest in staying informed about the developments and outputs of the forum. Experts are requested to provide contact details, their field of expertise and reason for interest in the policy forum. The WP4 lead will contact interested experts to further discuss the possibility of involvement.

WP5: Work package permanent advisory group (WPAG)

General description

Work Package 5 (WP5; Sharing data for health) has an overall objective of setting options for the operational framework and governance models for the European Health Data Space, for the exchange and secondary use of health data between European countries, respecting the principles of transparency, trust, FAIRness (data should be Findable, Accessible, Interoperable and Reusable), citizen empowerment and common good.

The WP5 WPAG's function will be crucial to regularly reviewing the ongoing work, with regular dialogue and multifaceted feedback on the different tasks.

This WPAG will be composed of representatives of the user categories studied, i.e. researchers and innovators from academia and industry and policymakers, in combination with experts from national designated bodies acting as permitors/providers of health data for secondary use in different countries. In total, the WPAG is expected to comprise 20-30 experts. Experts provide knowledge, support and feedback on the results of the work of WP5.

Expected input

Selected representatives and experts are expected to contribute an overall users' perspective (of researchers, innovators and policymakers) on the legal, policy or administrative aspects of accessing and exchanging health data on a spectrum of identifiability, encompassing personal data ranging from pseudonymized and anonymized to synthesized data. In addition to this, also cross-border exchange of data. The same applies to the selected representatives of data permit and/or provider authorities or similar designated bodies.

Expected commitment

WPAG meetings or workshops will start in early Spring 2021 and be held approximately four times per year, lasting a half to a full day each. Initially meetings will be online, however physical meetings may occur when COVID-19 travel restrictions have eased.

In between meetings, there may also on occasion be requests for surveys and information during the two years of the TEHDAS programme.

Members of the WPAG are expected to prepare for meetings and respect announced deadlines for surveys and feedback.

Benefits

Selected stakeholders will be in a prominent position to influence the evolution of the EHDS by expressing their opinions and views on the required services of the EHDS, and by participating in the validation of the proposed service options and infrastructure solutions.

The results of the WPAG work will contribute to the options and solutions regarding governance models for the EHDS services and infrastructure that will be delivered to the European Commission. The deliverables will form an important input to the EU's legislative proposals and to the further deployment of the EHDS by the member states.

Specific selection criteria

This work package will focus on the following aspects of the secondary use of health data:

- users: researchers and innovators
- users: policymakers
- permitors/providers of health data (such as data permit authorities)

Experts from these categories should preferably be nominated by a national or international/European organisation, association or institution which represent health data-related researchers and/or innovators from academia and/or industry, policymakers, and experts from national designated bodies acting as permitors/providers of health data for secondary use in different countries.

In addition to the above, experts may also represent relevant think tanks, key opinion leaders, topic specialists and lobbies engaged in issues regarding the secondary use of health data on a national and cross-border basis.

WP6: Work Package Permanent Advisory Group (WPAG)

WP6 will have a separate WPAG invitation only process to select the stakeholders. This is done outside of this Stakeholder Open Call.

WP7: Work package permanent advisory group (WPAG)

General description

The main objective of the TEHDAS Work Package 7 WPAG is to be a discussion forum connecting future users and implementers of the European Health Data Space (EHDS).

Future users (including researchers and policymakers) are invited to express their interests, desires and expectations on how the EHDS should help them in their day-to-day work, complementing the existing views on the necessary services to be provided. To further

complement this, the technological implementers (including representatives of the IT industry, computing centres, existing data hubs and/or research infrastructures) are invited to provide input to survey existing data-sharing initiatives and aid the proposed technical solutions for fulfilling the service requirements.

The WP7 WPAG will be a unique opportunity for members to sit together and discuss how to make the EHDS (technically) possible, while being attractive and usable for those that will, ultimately, profit the most from its existence: the users.

This group will consist of 15-20 experts in total representing both profiles (users and implementers).

Expected input

The selected partners are expected to provide their expertise in two main areas:

- Future users are expected to provide their expectations for the EHDS services.
- Technological implementers are expected to offer their expertise on assessing existing data-sharing initiatives, and on defining and/or validating the options for the services to be offered and the options for the infrastructural solutions, both elements to be delivered to the European Commission.

Thematic workshops will be organised to facilitate co-operation between the WPAG and the TEHDAS joint action representatives. During the first year of the joint action, the workshops will be focused on capturing the user requirements and expectations, so as to properly define the options for the services. During the second year, the workshops will move onto to working on validating the options proposed, both for the services and the infrastructure solutions. Due to the uncertainty caused by the COVID-19 pandemic, it is expected that the workshops will be mostly in virtual format. The workshops will be complemented by online surveys to facilitate efficient interaction.

Expected commitment

The expected commitment to the participation will be around one to two week(s) of work. The work will be divided into the following activities:

- preparing and contributing to the WPAG workshops;
- gathering information and completing surveys;
- providing feedback on the survey questions asked to the existing data sharing initiatives;
- providing additional ad hoc information, as requested.

Benefits

Selected stakeholders will be in a prominent position to influence the evolution of the EHDS by expressing their opinions and views on the required services of the EHDS, and by participating the validation of the proposed service options and infrastructure solutions.

The results of the WPAG work will contribute to the options and solutions for the EHDS services and infrastructure that will be delivered to the European Commission. The deliverables will form an important input to the EU's legislative proposals and to the further deployment of the EHDS by the member states.

Specific selection criteria

Experts representing either of the following two profiles are invited:

EHDS user's profile: The profile includes experts accessing and analysing health data in their day-to-day activities (for example, researchers familiar with inquiring about data from existing registry controllers, biobanks, health data hubs, open data repositories, research infrastructures and research networks, and performing data integrations, data cleansing and/or data analytics tasks).

EHDS implementer's profile: The profile includes representatives of companies or institutions that develop software solutions for data management, security, storage, harmonisation and analysis (for example, IT experts involved in the design and deployment of infrastructure elements for data processing and management).

WP8: Work package permanent advisory group (WPAG)

General description

The TEHDAS Work Package 8 WPAG will be a discussion forum addressing questions of how to obtain concepts, studies and viewpoints of individuals on health data and their engagement with the European Health Data Space (EHDS). This group will consist of 15-20 experts.

Contributors are invited to express their interests, desires and expectations about how the EHDS should be designed from the perspective of citizens, thereby providing a more human vision to the EHDS and considering all aspects of data perception, data sharing, data portability, data altruism, ethics and much more.

The WP8 WPAG will be a place to discuss how to bring the EHDS closer to the individual.

Expected input

The selected partners are expected to provide their expertise in the following areas:

- Citizen and patient associations will provide their perceptions on and expectations for the EHDS.
- Think tanks, academia, the private sector, and citizen and patient associations will offer their own concepts and challenge the road map and recommendations set out for WP8.
- Those interested in improving and sustaining a trustworthy space for citizen health data are expected to identify the features for data altruism, as well as options for topics related to ethical, privacy and cybersecurity standards.
- Participants will be expected to provide information or studies that they would like to see highlighted and considered in this WP.

Two thematic one-day workshops will be organised each year to facilitate co-operation between the WPAG and the TEHDAS Joint Action representatives. During the first year, meetings will help to evaluate expectations and challenge the form that the deliverables take, whereas the second year will serve to issue and finetune recommendations that result from the conducted studies.

Due to the uncertainty caused by the COVID-19 pandemic, it is expected that the workshops will be mostly in virtual format.

Expected commitment

The expected commitment for the participation will be around two to three full days of work per year. The work will be divided into the following activities:

- preparing and actively contributing to WPAG workshops;
- gather information;
- providing additional ad hoc information, as requested.

Benefits

Selected stakeholders will play an important role in bringing the citizen perspective to the EHDS.

The results of the WPAG work will contribute to create viable options and solutions for the EHDS services and infrastructure, taking into account the particular accessibility and acceptability aspects of individuals, that will be delivered to the European Commission. The deliverables will form an important input to the EU's legislative proposals, in particular the Lex Specialis on the EHDS, and will help to promote the further deployment of the EHDS by the member states.

Beyond reflecting on the integration of the individual's perspective into the EHDS, TEHDAS will also offer a fertile ground for future collaboration and partnership opportunities among stakeholders and key national and European bodies.

Specific selection criteria

Experts who wish to apply should:

- send an application dossier to the WP8 leading group, including:
 - o a brief presentation of their organisation and area of expertise for WP8;
 - o a list of references, such as publications, articles and newsletters, relevant to the topics of WP8;
 - o their links to others within the citizen health data ecosystem.

If eligible, short interviews will be held between the work package leaders and experts to confirm the area of expertise, expected input and contribution. If selected, experts will receive an official nomination letter indicating his/her commitment to TEHDAS WPAG8 and the area of expertise.