



Bullet Point Newsletter

Issue 2 (August 2024)



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JARDIN Bullet Point Newsletter – Issue 2

Dear participants in the Joint Action JARDIN,

Dear members of the Board of Member States for ERNs,

Dear ERN coordinators,

Dear patients and patient representatives,

Dear friends and colleagues,

Very warm welcome again to the next issue of the Bullet Point Newsletter for JARDIN. Since we introduced the basic principles in the last issue already, this newsletter will focus on content matters only. If you missed the first issue for whatever reason, please contact us under jardin@meduniwien.ac.at and we will provide you with a pdf copy.

What did we achieve in the past weeks?

- The next set of deliverables (D2.1 “Communication and dissemination plan”; D1.6 “JARDIN Internal Newsletter No. 1”; D2.3 “Dissemination of the JARDIN Internal Newsletter”) has been completed and uploaded to the Funding & Tenders portal on time.
- **To better highlight, what the fulfilment of D1.6 and D2.3 means:** We produced and disseminated JARDIN’s first Internal Newsletter, addressed at all consortium members (hence “internal” newsletter, as it also contains individual tasks directed at WPs participants). We hope you liked it (as much as we did!) and would appreciate your feedback. Many thanks to all partners that helped to create it!
- **And as a follow-up to our communication offensive, our JARDIN website was launched** by our WP2 colleagues in July (29.07.24). As our WP2 colleagues wrote in their invitation mail, *“this initial version of the website has been developed to provide comprehensive information about our Joint Action, including its objectives, mission and vision, work packages, and ERNs. We extend our heartfelt thanks for your ongoing support and collaboration. This website reflects the collective effort and commitment of everyone involved. We look forward to continuing our journey together and achieving the JARDIN’s goals.”* You can access the website via the link <https://jardin-ern.eu>. Please have a look and enjoy the animation on the homepage and of course the full content.
Please note: The website will be an additional source of information, so make sure to visit it regularly in order not to miss anything that may be of particular interest to you.
- The first feedback round for the review of the JARDIN Consortium Agreement by the legal divisions of all JARDIN Competent Authorities was completed on 24.07.2024. We received feedback from four partners, ranging from complete agreement with the text to some

requests for specific text modifications. All feedback has been evaluated and commented on by our legal officer in charge of the Consortium Agreement in the comments section of the document, leaving the basic text for now unchanged. We have distributed this new commented version to all Competent Authorities again on 25./26.07.24 with a new deadline for comments on 07.08.24 EOB.

IMPORTANT – Please note: This second feedback round is also **the final feedback round**. After August 07, we will incorporate all feedback into the Consortium Agreement and prepare the signature process. **This means (as explained in our accompanying Emails to the draft versions) that if any beneficiary of JARDIN has not provided any feedback by this deadline, we will assume that this beneficiary agrees with the document, according to the principle of “silent agreement” (relevant for Competent Authorities only).**

What is ongoing?

- **The initial JARDIN surveys:**

The following surveys are still open:

- No. 3 “National Reference Networks and Undiagnosed Disease Programs”;
- No. 5 “Rare Disease Data Management”.

Please note:

- Not all surveys were sent to all stakeholders, instead the surveys are highly target-focused. Thus, you may have received an invitation only for (a) selected survey(s);
- Many thanks to all of you who completed the survey(s). **We highly appreciate your support, really!!!**
- For all others that have been invited to participate in the survey(s) and have not had the time to access and complete it, you can still participate. **The more individual data we can receive, the better and more detailed our analysis can be.**

- **The finalization of milestone (MS) 3:**

MS3 comprises the “List of new process and output indicators”, complementing the indicators we already developed for Annex A of the Grant Agreement (Description of the Action). WP1 has now taken the lead on this and linked it to the development of the roadmaps (see next point). As soon as we have all roadmaps together, we can finalize this task.

- **The finalization of the WP roadmaps for M6-M19:**

We are waiting for one WP (co-)lead to provide the necessary information.

- **Setting up the Multi-stakeholder Advisory Board:**

The joint invitation letter from JARDIN and DG Sante for several subgroups of our Multi-stakeholder Advisory Board (National Policy Contact Point Group; Hospital Managers Advisory Group, Data Management Advisory Group) has been sent to the Health Attaches of the Member States and Norway on 16.07.24 with a first deadline on 31.07.24. So far, we have received (in part incomplete) nominations from 7 Member States. DG Sante will soon send out a reminder to those that have not responded yet.

What is next?

- Summer holidays – probably and hopefully for many of you. While also some team members of the coordination will take a break soon, the coordination office is always staffed and ready to assist you as best as we can.
- Feedback to the second draft of the JARDIN Consortium Agreement. As soon as this is collected, we will prepare a final version that we will then circulate for signature by all Competent Authorities.
- Work package 9 has already started with its final analysis of survey number 4 (“National support options for ERN-HCP”), and the other WPs will follow soon.

Current tasks for JARDIN members and further stakeholders

- All stakeholders:
 - The initial JARDIN surveys:
As mentioned above, two initial surveys are still active. **If you have been invited to a survey but have not yet participated, please do so now.**

Suggestions and comments

- This is your part. We are happy for any
 - Additional information to be published in our next issue(s)
 - Further suggestions
 - Other kind of feedback

Many thanks for reading.

We wish all of you that are or will soon go on holidays a happy holiday time – and all others that you can still enjoy some moments of rest and fun / recreation beside your work.

Best wishes from Vienna

Till Voigtländer

For the JARDIN coordination team