



Bullet Point Newsletter

Issue 1 (July 2024)



Co-funded by
the European Union

Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency. Neither the European Union nor the granting authority can be held responsible for them.

JARDIN Bullet Point Newsletter – Issue 1

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,

A very warm welcome to the new, long awaited Bullet Point newsletter for JARDIN. Since this is the first issue, let me start with a few introductory remarks, indicating what you can expect from this format and what are its limitations.

Introduction – a guide through the Bullet Point Newsletter

Rationale

- JARDIN is a huge and complex project that is met with (very) high expectations from the EC level, as well as from the Member State's side;
- Its objectives are (very) ambitious, with a tight timeline and the pressure to implement pilot projects in different countries in many areas as:
 - Proof of concept and implementability of the output documents (the blueprints, guidelines and concise recommendations, etc.) and
 - Starting point for the seamless continuation of the JARDIN activities in the Member States as soon as the Joint Action is finished;
- To achieve these goals, we need a more intensive communication flow between all partners than originally planned and usual for many other joint projects;
- The solution to this requirement should be provided by a regular short newsletter.

Format

- Bullet points as quick information update;
- Information as short, but also as concise as possible;
- Fixed and additional facultative sections, if necessary.
- **This first newsletter will be longer, since we have to introduce the concept and to start at some point providing important information from past activities. This will not be necessary any more in the future based on the frequent release scheme of the newsletter.**

Limitations

- The Bullet Point Newsletter will not only provide information from the recent past, but also future plans including timelines; however, neither these future activities nor their timelines are set in stone, they can – and in many instances will – change to small or even bigger degrees (just recall the many changes we had with the survey strategy and the survey releases).
Please keep this in mind.
- Some of the content of the Bullet Point Newsletter will depend on information provided by the partners, in particular the WP (co-) leads.
Please join in and provide any information relevant to this newsletter.
- The Bullet Point Newsletter is “work in progress” and will mature over the time.
Please be patient and support us with suggestions and constructive feedback.

What did we achieve in the past weeks?

- The first amendment has been finalized and subsequently approved and signed by HaDEA. It is in force since May 13, 2024.
- The first two deliverables (D1.3: “Kick-off meeting report”; D3.1 “Evaluation plan”) have been finalized and uploaded on the Funding & Tenders portal in time.
- The joint invitation letter from JARDIN and DG Sante for several subgroups of our Multi-stakeholder Advisory Board have been finalized after many feedback loops and will be send to the Health Attaches of the Member States and Norway in the coming days. These subgroups are:
 - National Policy Contact Point Group;
 - Hospital Managers Advisory Group;
 - Data Management Advisory Group.
- The first draft for the JARDIN Consortium Agreement has been finalized after several rounds of internal revision at the MUW incorporating all the aspects and requests that got obvious only after we started our work. **For the further procedure, please refer to the fourth chapter (“Current tasks for JARDIN members”).**

What is ongoing?

- **The initial JARDIN surveys:**
So far, the Coordination Team has released four initial surveys:
 - No. 1 “Stakeholder contact details (mainly)”;
 - No. 2 “Current healthcare policies in Member States” (for **Competent Authorities, BoMS members and other Health Authorities only**);
 - No. 3 “National Reference Networks and Undiagnosed Disease Programs”;
 - No. 4 “National support options for ERN-HCP”

Please note:

- Not all surveys have been sent to all stakeholders, instead the surveys are highly target-focused. Thus, you might have received an invitation only for (a) selected survey(s);
- Many thanks to all of you that have completed the survey(s). **We highly appreciate your support, really!!!**
- Independent of the deadlines, all four surveys are still active and we will extract also these data in the near future. In case you did not have the time so far to access and complete a survey you have been invited to, it is still possible to join in and 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). **In principal a task of WP3, but we have a problem here and I will soon report more on this.**

- **The finalization of the WP roadmaps for M6-M19:**
WP (co-)leads have elaborated their roadmaps for the next 13 month. We are currently finalizing and harmonizing these roadmaps with the WP leads. As soon as this process is finished, we will send out these roadmaps to you to provide you with a detailed plan for the forthcoming activities.

- **The finalization of the combined deliverable D1.6/D2.3:**
D1.6/D2.3 cover the production and dissemination of the “JARDIN Internal Newsletter Issue 1”, a joint activity of WP1 and WP2, supported by all other WP (co-)leads. Delivery due until 31 July 2024.

- **The finalization of deliverable D2.1:**
D2.1 comprises the “JARDIN Communication and dissemination plan”, issued by WP2. The document is in the final review and feedback round. Delivery due until 31 July 2024.

- **The creation and release of the JARDIN website:**
Our WP2 colleagues from FIBHULP have finalized all contractual work in the context of the official JARDIN website and in a joint effort, WP2 partners have searched for and then decided on a suitable domain name. The WP2 team is now collecting the first website content from all WPs. The website will be officially released in the second half of July.

What is next?

- Release of the last initial survey on “Data management”, prepared by WP8 (release date soon);
- Feedback to the first draft of the JARDIN Consortium Agreement. **For the further procedure, please refer to the forth chapter (“Current tasks for JARDIN members”).**

Current tasks for JARDIN members and further stakeholders

- All stakeholders:
 - The initial JARDIN surveys:
As indicated in the previous chapter, all initial surveys released so far are still active. **If you did not participate so far, please do so now, if possible.** Attached you find a table with an overview of all surveys, their target groups and the respective links to the individual surveys.
- **Competent Authorities only:**
 - The Draft of the JARDIN Consortium Agreement has been sent to you yesterday (09.07.2024). **Please forward the draft to the legal department in your institution for their feedback.** The deadline for the first feedback round is 24 July 2024.

Suggestions and comments

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

Many thanks for reading and best wishes from Vienna

Till Voigtländer

For the JARDIN coordination team



Annex: Summary of JARDIN surveys

Survey	WP	Content	Stakeholders	Launch Date	Deadline
1	All WPs	Stakeholders identification https://ec.europa.eu/eusurvey/runner/Survey1JARDIN	- All JARDIN contacts - BoMS representatives - ERNs (contacted via ERN Project Managers Chairs)	May 7 th (ERNs received the survey on May 22 nd)	May 27th Survey is still active
2	WP4 and WP5	Current rare disease healthcare policies in Member States https://ec.europa.eu/eusurvey/runner/survey_no_3	- JARDIN Competent Authorities - BoMS representatives	June 3 rd	July 1st Survey is still active
3	WP7	National Reference Networks and Undiagnostic Disease Program https://ec.europa.eu/eusurvey/runner/Survey2JARDIN	- JARDIN Competent Authorities - BoMS representatives - Patient umbrella organizations - HCP management (extracted from survey 1) - 300 HCPs extracted from survey 1 (WP7.2) - ERNs (contacted via ERN Project Managers Chairs)	June 6 th	July 8th Survey is still active
4	WP9	National Support Options for ERN Healthcare Providers https://ec.europa.eu/eusurvey/runner/JARDIN_Survey_4	(contacts extracted from survey no. 1) - ERN center representatives - HCP Management - National authority representatives	June 21 st (ERN center representatives) June 24 th (HCP management and National authority representatives)	July 15 th