UNL-UKB/NFU/NWO Elsevier Open Science Services - Pilot evaluation template

As part of the governance process of the agreement, pilots (when delivered) will be reviewed and signed-off by the participating partners and the evaluation will be submitted to the steering group for approval. Once approved the pilot will transition to a service which runs for the remainder of the agreement.
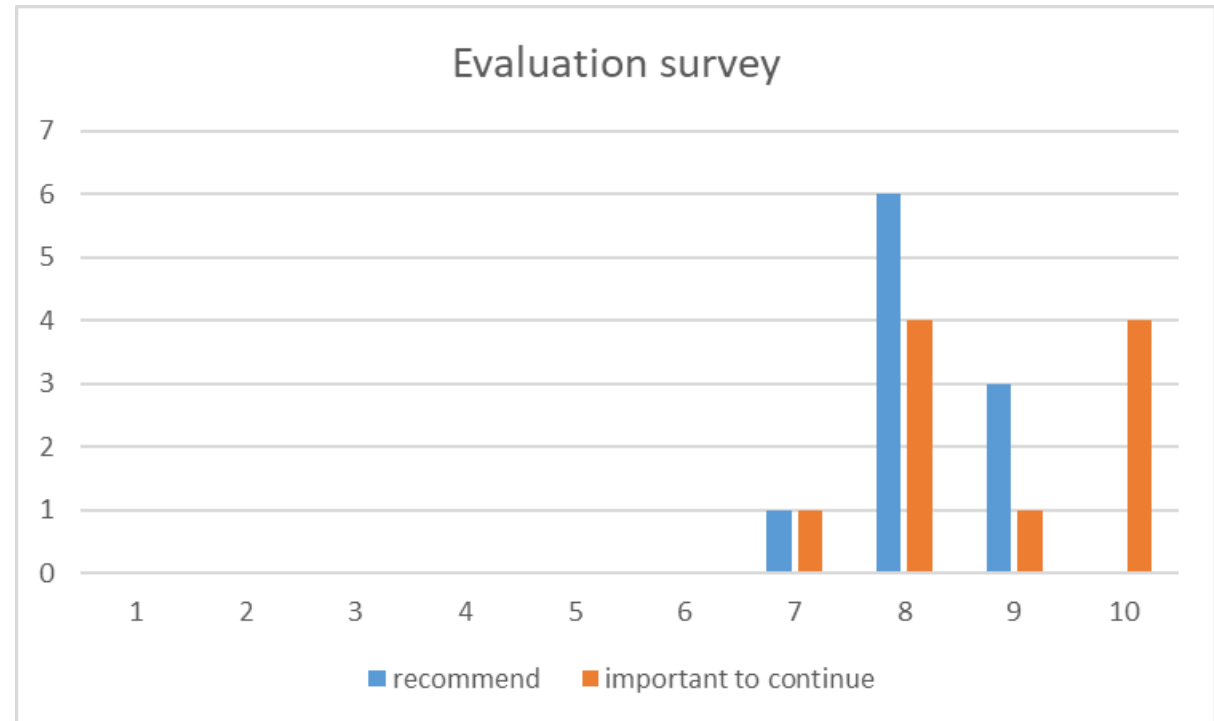
Pilot: Rare Diseases Monitor	Evaluation and sign-off partners	Comments
Did the pilot meet its main objectives (as stated in the SoW)?	Yes, a public analytics dashboard, covering almost all rare diseases (and expert centres and their research publications (and citations)) is available on epdos.nl for research and public use	See also the outcome of the questionnaire which was completed by staff from 6 of the 7 MCs. On the question if the dashboard should be maintained in the coming years, respondents scored a 8.8 (on a scale of 10)
Were all identified deliverables (as stated in the SoW) delivered and success criteria (if stated) met?	Yes, both the analytics tool and the lists of institutional outputs per Orpha code have been delivered. All specifications as stated in the SoW were met.	in addition, an integration with the Scopus and PubMed databases was released to make further analyses in the underlying research data possible.
What did the parties learn from the pilot and what (if any) future improvements are planned?	See also the responses to the questionnaire; scope of dashboard (beyond NL), access to publications, data export.	
How can the collaboration between the partners be characterized?	The collaboration was very active and constructive with bi-weekly calls to discuss progress and address issues. Following input from the partners, the initial beta version was upgraded.	Partners jointly published a preprint describing the underlying annotation and indexation methodology. NFU published a news item upon the launch of the service. The pilot was further communicated to European stakeholders and raised significant interest.
Will the pilot continue as a service (up to the end of the contract term) in its current form?	Yes. The service remains available on epdos.nl during the full term of the agreement.	
Approved by the steering group	Date: February 2024	

Survey results Rare Disease Monitor - summary

Responding institutions: 10

Representing:
- Erasmus MC
- Leiden UMC
- Maastricht UMC
- Radboud UMC
- UMC Utrecht
- Amsterdam UMC
- European Commission

Evaluation survey

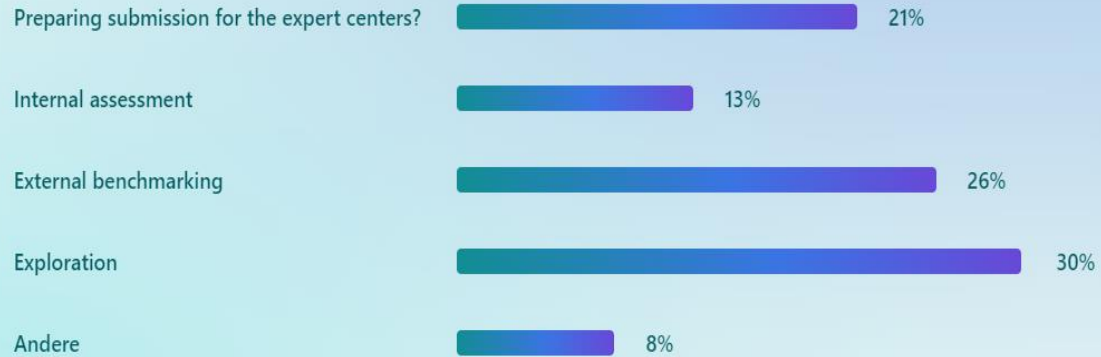(lowest: 1 – highest: 10)

	Average score
How likely are you to recommend this dashboard to a colleague?	**8.2**
How important is it for this dashboard to be maintained in the coming years?	**8.8**

What was the main interest for using the dashboard?

Interest	Percentage
Preparing submission for the expert centers?	21%
Internal assessment	13%
External benchmarking	26%
Exploration	30%
Andere	8%

What did you like about the dashboard?

I feel that the dashboard is easy to use and navigates intuitively, I can find relevant information easily. I particularly like the total shae of publications indicator.

Provides me with information I otherwise do not have and it gives me quite easily an overview. I especially use the Orphacodes page.

very clear and easy to grasp visualizations

It is a very usefull starting point and at least all Dutch centers and research is in the Dashboard, so it helps to compare or to find centers.

Clarity and easy to use

Het zicht op de publicaties, de mogelijkheid om te benchmarken en vergelijken op veel verschillende niveaus (aandoening, expertisecentrum, instelling, patiëntorganisatie, ERN), en de mogelijkheid om door te zoeken naar gerelateerde publicaties.

the overview

we miss a tool to evaluate performance of centers of expertise for rare conditions.

What could be added and/or improved?

I would be very interested in seeing this on a European level.

Insight in collaration / which institiutions publicate together on specific diseases + international instititions

maybe a term/phrase search to assist in the selection for those not so familiar with the ORPhAcode classification, even if the primary targeted users are essentially expert practitioners or knowledgeable patients organizations. It just depend what will be the overall scope of the monitoring platform. A link to the reference publications used for the analysis might be useful for some without fully mimicking a bibliometric search. It might have more value if the scope goes beyond Dutch institutions and scientists.
Also the possibility to export some of the data behind the visualization could prove to be valuable for some reuse of the output when user are looking to illustrate their argumentation. Its seems to be embedded into the Tableau functionalities but currently it is just a print screen type of extraction.

It would be wonderful to be able to access the publications directly, for instance to snowball the reference list;
Furthermore, to link the institutions to new trials/research and already published papers to trial registers.
If possible, a show a short link to a description of the disease (wikipedia) and to create a layers version explaining what the newest papers have added.

No suggestions

We zullen wat meer ervaring moeten opdoen om hier goed antwoord op te kunnen geven.
Wat wel opvalt is dat het gebruik van de tool via de laptop niet altijd goed werkt. Het lijkt erop dat de weergave niet goed aangepast wordt waardoor het niet mogelijk is om de knoppen te gebruiken.
I do not have a full screen on my laptop, therefor I wasn't able to use it properly without having a pc.

see above

easier access to the centers of expertise (and their subtopics)
easier download to excel or so

Accessibility of the dashboard, increased functionality, such as comparative features.