

STATEMENT OF WORK NUMBER [X]

1. **Terms and Conditions.** This Statement of Work (“SOW”) is governed by and by this reference incorporates the Professional Services Terms and conditions set forth in Schedule 5 of the Open Science Platform and Services Agreement (the “Agreement”) between **SURFmarket B.V.** and **Elsevier B.V.** (“Elsevier”) dated 15 May 2020 (the “Terms”). Capitalized terms used herein that are not otherwise defined will have the meanings ascribed to them in the Terms. This SOW concerns a pilot to identify and analyze Dutch publications regarding rare diseases as identified by ORPHA codes and is entered into between **[Institution]** (“Institution”) and **Elsevier B.V.** (“Elsevier”).
2. Institutions and Elsevier agree to abide to the Collaboration Principles laid down in Section 1.2 of the Terms.
3. **Commencement and Duration of this SOW.** This SOW shall come into force on the date on which it has been signed by both parties and shall continue in force until 31 December 2024, unless extended in writing by the parties or unless terminated earlier by the Institution by giving a sixty (60) *days* notice in writing.
4. **Acceptance Steering Committee.** This SOW can only enter into force after approval of the Steering Committee. The Service may only proceed after approval of the Steering Committee (as per the ‘Governance Structure’ in Schedule 5.1 of this Agreement).
5. **Services.** Elsevier and participating Institutions shall perform a Service and provide a Deliverable(s) in accordance with the following agreed specifications, acceptance criteria, time schedule and other relevant terms as may be set out herein.
 - 5.1 **Description of the Pilot Service**

Elsevier shall pilot a service that will identify publications by Dutch institutions regarding specific rare (or orphan) diseases as identified by ORPHA codes (which are publicly available). With these lists of publications per disease, Elsevier will provide:

 - A dashboard that will show metrics about the quantity and impact of these publications (identified by single Orpha codes or by combinations of codes as they are focus areas of Expert Centres, European Reference Networks (ERNs) or patient associations) per NFU institution,
 - Lists will be made available to NFU institutions denoting Orpha codes and relevant publications (Orpha-DOI) so that they can be used in local systems and in public portals.

Institutions shall be part of the development and help make sure the service is valuable, by:

 - Testing data: check publication lists for relevance
 - Identify relevant metrics and representations
 - Providing general feedback
 - 5.2 **Description of the Deliverable(s)**

Elsevier shall provide the following specific Deliverable(s) under this SOW:

Name	Description
Analytics tool	The Rare Disease analytics tool will help stakeholders (experts, institutional coordinators, NFU, clinicians, and patient organizations) see where research into specific rare diseases (or combinations thereof) have taken place and what the academic impact of those publications has been
Institutional data on rare disease	NFU institutions will be provided with lists that provide information on which publications (by their own researchers)

	<p>have been produced related to rare disease, as defined by Orpha codes. These lists could help annotate CRIS or other research management systems (to support exposure in public portals and websites)</p> <p>NFU will also receive lists concerning the Netherlands for the purpose of Expert Center evaluation.</p>
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5.3 *Specifications*

The Service and Deliverable(s) under this SOW shall comply with the following specifications (as agreed between Elsevier and NFU) :

Name	Description
Analytics tool features:	The tool will be available in a generic analytics framework and will be made public, accessible to all.
Filter by Dutch institution	<p>For each institution show their main activities:</p> <ul style="list-style-type: none"> - Publications per Orpha code - Expert centres - ERN relevant research -
Filter by disease	<p>Diseases, and research groups specializing in a number of diseases, can be defined by Orpha codes, so that these codes can be the basis of filters in the tool.,:</p> <p>Filters that should be available:</p> <ul style="list-style-type: none"> - Single Orpha - Expert centres (only approved ones, ~300) - ERNs (24 official) - Patient associations (~250) - Ad hoc combinations: will be possible after Elsevier intervention, with a lead time of up to two weeks <p>For each code, the tool will display overall metrics of productivity and impact per institution, as per below.</p>
Metrics available	<ol style="list-style-type: none"> 1.Scholarly Output (default ranking metric) 2. % of outputs in Top (10%) Citation Percentile (sorting metric) 3.Citation Count (sorting metric) 4.Citations per Publication (sorting metric) 5. % of publications in Top (10%) Journal Percentile based on CiteScore (sorting metric)
Additional features:	
Export of DOI per Orpha per institution	In CSV
Timeline analyses	Annual data (and bar charts) for above filters and metrics
Updates	Data is annual and will therefore be updated once per year.
International comparison	Include other EU institutions in list of institutions

5.4 **Acceptance Criteria**

The Acceptance Criteria are that the pilot Service and the Deliverable(s) must comply with all the specifications and all the requirements of this SOW, the Terms and other parts of the Agreement.

5.5 **Time Schedule**

The Services and the Deliverables shall be provided according to the following time schedule, or as may be adjusted by agreement in writing between the parties:

Date or Time Period	Description of Stage or Milestone
(internal): June 2022	Initial delivery of dashboard, to stakeholders only
(external): August 2022	Delivery of dashboard to public (based on stakeholder approval)

5.6 **Location**

In general the Services shall be performed by Elsevier at its premises. If so required, Elsevier shall attend such meetings at Institutions' premises as may be required for the efficient performance and delivery of the Service and the deliverable(s).

5.7 **Named Personnel**

Elsevier and participating Institutions shall use its best endeavours to ensure that the following named individuals shall perform the Services and Institutions' responsibilities, respectively, but each of Elsevier and these Institutions may substitute other personnel for such individuals provided that it has notified and agreed this in advance in writing with the other party.

Elsevier	Max Dumoulin (project management) Hosein Azaronyad (data & technology)
NFU	Ilse Nederveen (NFU & Erasmus MC) Rik Iping (NFU & Erasmus MC) Lieuwe Kool (NFU & Amsterdam UMC) Barry van der Strate (NFU & UMCG)
Institutions (wishing to subscribe to institutional data about rare disease, 'DOI-Orpha')	...

5.8 **Other Details**

It is the intention of the project to create insights in used algorithms. In order to do so members of the NFU team will have access to (and right to review) the technology. Details about the technology will be published in conference papers and a research paper is being prepared as a collaboration between parties.

6. **Acceptance for Deliverables.**

6.1 For any Deliverables, such Deliverables provided shall be checked by participating Institutions and Elsevier for compliance with the agreed specifications. Elsevier and participating Institutions

shall use reasonable efforts to modify the rejected Deliverable so that it meets the applicable specifications, and deliver the modified Deliverable for checking.

- 6.2 If the parties fail to modify a Deliverable that has been rejected so that it meets the specifications within the period specified in the applicable rejection notice, the parties may, at its option:
 - 6.2.1 terminate:
 - (a) the applicable Deliverable;
 - (b) the applicable SOW;
 - 6.2.2 perform additional corrections to the Deliverable or component thereof within a specified extended period; or
 - 6.2.3 accept the Deliverable despite its deficiencies.
7. **REPORTING.** IF REQUESTED BY THE STEERING GROUP WITHIN 15 DAYS AFTER THE END OF EACH MONTH, THE PARTIES WILL PROVIDE A FULL AND ACCURATE REPORT TO THE STEERING COMMITTEE SUMMARIZING ALL SERVICES ACTIVITIES PERFORMED THAT OCCURRED DURING SUCH MONTH.
8. **REVIEW MEETINGS.** IF REQUESTED BY THE STEERING COMMITTEE, APPROPRIATE PERSONNEL WILL PARTICIPATE IN FORTNIGHTLY STATUS REVIEW MEETINGS, WHICH MAY BE CONDUCTED BY TELEPHONE OR AT SUCH TIMES AND LOCATIONS AS MAY BE REASONABLY SPECIFIED. THE MEETINGS WILL BE FOR THE PURPOSE OF REVIEWING THE PERFORMANCE AND PROGRESS HEREUNDER AND DISCUSSING AND RESOLVING ANY PROBLEMS BETWEEN THE PARTIES. BOTH PARTIES CAN INITIATE A REVIEW MEETING AT ANY TIME THEY FEEL ONE IS NEEDED AND AN ALTERNATE MEETING SCHEDULE / FREQUENCY CAN BE AGREED UPON DURING THE TERM OF THE AGREEMENT IF CIRCUMSTANCES OR NEED CHANGES.
9. **ON-SITE TERMS.** WHEN ELSEVIER PROVIDES ANY SERVICES WHILE BASED ON ANY LOCATION, THE FOLLOWING TERMS SHALL APPLY:
 - 9.1 **On-Site Personnel.** While Personnel are based on Institution's locations in connection with the performance of any of the Services, Personnel shall comply with all of Institution's rules, regulations and policies, concerning such matters as working hours (which will be established by Institutions contact), holidays, and Institution's customary security measures. Prior to commencing the performance of any assignment, Personnel may be issued with an identification card which Personnel shall return to their Institution's contact on the last day of the performance of the Services. Institution shall supply Personnel with suitable work stations similar to those provided by Institution to its employees of a similar position, and Institution will furnish Personnel with the supplies and equipment they need to perform their assigned tasks. Within 2 weeks after the start of Personnel, Elsevier shall inform Institution in writing how much vacation time each Personnel member is entitled to take during the agreed period of the Services and when such vacation will be taken. Institution shall not be charged for vacation time taken by Personnel.
10. Governing law. This SOW is governed by the laws of the Netherlands.

**Agreed for and on behalf of participating
Institutions**

By: SIGNATURE_0001

Agreed for and on behalf of Elsevier

By: SIGNATURE_0002

Date:

Name:

Title:

Date:

Name:

Title: