

# Evaluation Plan

## Deliverable 3.1

March 31 2019



WP Participants: FTELE
---------------------------

V1	29 March 2019	FTELE
V2	31 March 2019	EURORDIS
V3		
Draft version	To be updated M5	All partners



The Rare2030 project is co-funded by the European Union Pilot Projects and Preparatory Actions Programme (2014- 2020). This leaflet is part of the pilot project PP-1-2-2018-Rare 2030. The content represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission or any other body of the European Union.

# Contents

- Rare2030 Evaluation Plan ..... 3
  - Introduction ..... 3
  - Aims ..... 3
  - Activities ..... 3
  - Indicators ..... 3
  - Means and methods ..... 5
  - Workflow ..... 6
  - Timing ..... 6

# Rare2030 Evaluation Plan

## Introduction

RARE 2030's broad scope is to propose policy recommendations to guide future policies for people with rare diseases (RD), with the vision of maintaining RD as a public health priority. A participatory foresight approach, aimed at providing actors in the field with tools for making informed, evidence-based policy choices, and additional consensus building methods will be used to develop scenarios describing contrasting alternatives for the future of RD Policy in Europe 2020-2030. Dialogue among patients and key stakeholders in the European community will be continuously stimulated for the entire duration of the project about the implications of scientific, technological, social, political, financial and institutional transformations impacting upon rare disease policy.

In order to meet the goals stated in the project, a detailed plan of actions has been set out. A timely monitoring of activities and appropriate evaluation of the results (deliverables) obtained is necessary to streamline the process, stay in line with the stated objectives and appropriately assess impact both during and after the end of the project.

## Aims

The Evaluation Plan developed by WP3 is aimed at evaluating progresses, results and impact generated through WP4 (Knowledge base), WP5 (Scenarios building) and WP6 (Policy recommendations). Definition and execution of the Plan will be performed under the guidance of the Research Advisory Board (RAB) to monitor the progress of project activities and the achievement of milestones, and to assess the project's results and impact. Continuous monitoring of progress against the project work plan will enable early identification of any deviation and therefore allow corrective measures if needed.

## Activities

Evaluation activities will be addressed at three different aspects of the project.

Rare 2030 **progress** will be closely monitored to identify any deviation from the work plan. This Evaluation Plan defines monitoring dimensions and key indicators for each kind of activity. Monitoring results will be shared with the Coordination team (WP1) in order to allow corrective measures, if needed.

**Results quality assessment** will mainly rely on the revision by the RAB, to whom the deliverables will be submitted beforehand, and on the feedbacks from the stakeholders and experts engaged in the project activities. The **impact** of each product on the subsequent project activities will be assessed during the project's lifetime.

The final evaluation of **outcomes and impact** will be possible only some years after the end of the project, as this is the time required to check whether the policy recommendations developed are taken-up by policy makers and whether the implementation of such policies really contribute to realize the identified scenarios. However, during the project, potential impact can be estimated through a strict assessment of methodologies adopted in consultation with a wide and composite group of stakeholders and experts in the assessment.

## Indicators

Different kind of indicators have been identified and will be applied to each **specific objective** (see **Table 1**):

- **Process indicators** will measure the achievement and measurable qualities of steps proposed to reach these objectives (literature review, horizon scanning and stakeholder consultation on trends and drivers,

creation of scenarios, scenarios survey, Consensus conference, EU-level and regional workshops to draft policy recommendations, a policy conference to present recommendations).

- **Output indicators** will include reports detailing the results of these activities.
- **Outcome/impact indicators** will measure shared knowledge (through post-workshop surveys) and agreement on drivers of change, scenarios and recommendations (measured by percentages of agreement achieved).

**Table 1.** List of process, output and outcome/impact indicators by objective

<b>Specific Objective 1</b>	<b>To reach the agreement of the Panel of Experts on the proposed trends, drivers, weak signals and wild cards (on rare diseases) by the end of the first year</b>
<b>Process Indicator(s)</b>	<b>Target</b>
Approval by the Research Advisory Board of the methodology for literature review	Yes/No
Number of experts involved in the Panel of Experts and stratification into sub-groups	150-250 with a minimum of 100
Organization of a consensus meeting on Horizon Scanning	Yes/No
<b>Output Indicator(s)</b>	<b>Target</b>
Exhaustiveness of the trends, drivers, weak signals and wild cards identified in the horizon scanning phase (WP4)	During the ranking phase (WP5), no more than 3 items (trends, drivers, weak signals and wild cards) are identified as missing.
<b>Outcome/Impact Indicator(s)</b>	<b>Target</b>
Agreement of the Panel of Experts on the identified trends, drivers, weak signals and wild cards	At least 2/3rd agreement
<b>Specific Objective 2</b>	<b>To reach the consensus on the most preferable RARE2030 scenarios by month 18</b>
<b>Process Indicator(s)</b>	<b>Target</b>
Response rate of the survey involving all stakeholders	At least 30%
Completion rate of the survey involving all stakeholders	At least 75-80%
Satisfaction of the participants to the scenario building workshops	70% of the participants report to be satisfied or very satisfied
<b>Output Indicator(s)</b>	<b>Target</b>
Production of Scenarios	Yes/No
Percentage of the participants to the <b>survey</b> agreeing on the scenario indicated as preferable	50% of the participants identify the same scenario as preferable
Percentage of the participants to the <b>Consensus Conference</b> agreeing on the scenario indicated as preferable	50% of the participants report to be satisfied or very satisfied with the selected scenario
<b>Outcome/Impact Indicator(s)</b>	<b>Target</b>
Suitability of the proposed scenarios to be used in WP6 for identifying actionable policies	Positive opinion by the Research Advisory Board.
<b>Specific Objective 3</b>	<b>To create Policy Recommendations by month 24</b>
<b>Process Indicator(s)</b>	
Organization of one high level European event and 5 regional events to draft recommendations	Yes/No
Number of participants to each of the 5 regional events to draft the recommendation	At least 12 from at least 3 different countries per each event
Representativeness (in terms of stakeholder categories and of power to influence policies) of the	At least 1 representative of the healthcare system + 1 representative of the patients + 1 representative of the

participants to each of the 5 regional events to draft the recommendation	government (national and/or local) for each of the involved country
Overall geographical coverage of the 5 regional events	A minimum of 20 EU countries
<b>Output Indicator(s)</b>	<b>Target</b>
Publication of the Policy Recommendation document	Yes/No
Satisfaction of the participants at the policy conference	2/3rds of the participants report to be satisfied or very satisfied
Satisfaction of the participants to the EU level and regional workshops	2/3rds of the participants report to be satisfied or very satisfied
<b>Outcome/Impact Indicator(s)</b>	<b>Target</b>
Number of Policy Makers and/or consultants of Policy Makers present at presentation of Policy Recommendations during the Policy Conference	Number to be identified during the project (and reported in the evaluation plan)
Awareness and satisfaction of the EU level policy experts and Parliamentary advocates for rare diseases on the Policy Recommendations document	At least 80% of satisfaction survey respondents are aware of the Policy Recommendations prepared by the project At least 50% of the respondents agree or strongly agree with the Policy Recommendations

## Means and methods

Specific actions to be evaluated encompass **webinars, workshops, conferences, surveys and interviews**.

**Webinars, workshops and conferences** will be evaluated through **feedback questionnaires**, prepared by WP3 jointly with the partners in charge of the relevant event. Timeliness of administration and response rate will be recorded. Live polls during an event, are preferable to paper surveys and can increase both response and completion rate if administered in a timely manner. Efficacy and effectiveness of the specific event will be measured through open or closed questions. Relevant partners will distribute the questionnaire to the webinar/workshops/conferences participants, collect feedbacks and send them to FTELE for analysis. Results will be presented to the RAB with a short report for validation and assessment. Results from questionnaires will be either qualitative and/or quantitative, depending on the stated objectives. Filled out questionnaires will be rapidly collected and analyzed to evaluate the degree of alignment with the objectives and the usefulness for the subsequent planned events/activities. In case of misalignment/partial alignment, corrective measures can be introduced in the following steps. Written reports, such as minutes, proceedings, brochures, full publications, can be produced to summarize results.

Rare2030 plans to use **surveys and interviews** as tools to interrogate selected groups of stakeholders on a relevant topic and gather consensus.

Interviews are mainly planned as independent events, through conference calls, but can also replace feedback questionnaires at the end of an event, when a high response rate is required to measure both process and output indicators. Surveys and interviews will be prepared in accordance with the specific objectives, ensuring adequateness of the structure (e.g. open questions vs multiple choice answers), suitability of the questions for the relevant stakeholders and adequateness to measure the results, both at qualitative and/or quantitative level.

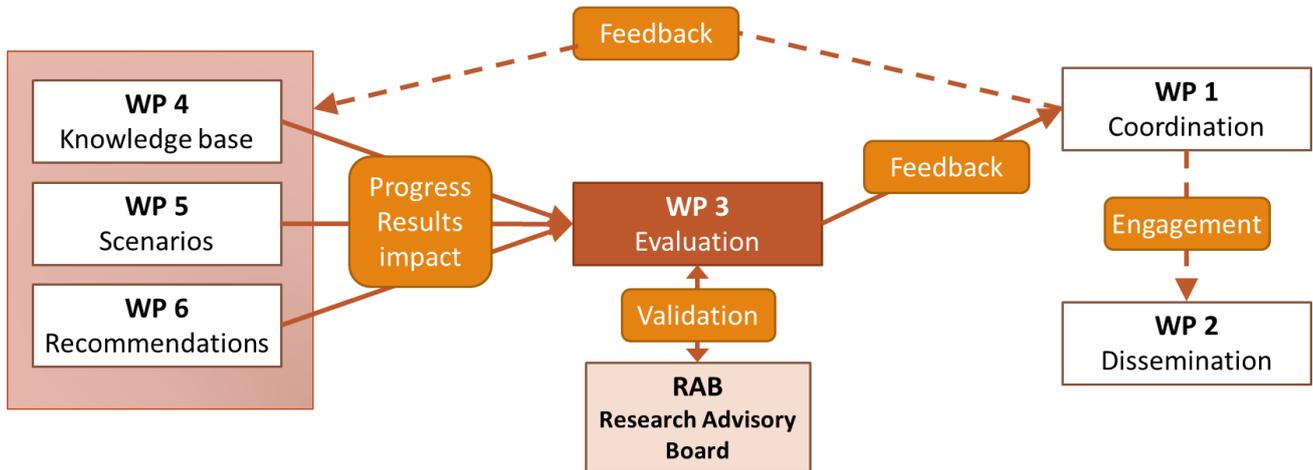
**Websites, newsletters and social media** can also be used to measure the level of consensus with the proposed scenarios among participants to the Survey and Consensus Conference. Indeed, monitoring the number and quality of comments on RARE2030 outputs will allow measuring on the one hand the efficiency and effectiveness of dissemination tools, while on the other to further measure consensus on the results from surveys and questionnaires.

# Workflow

Implementation of the Evaluation Plan will entail constant interaction with partners engaged in all WPs (Figure 1). In particular, evaluation will regard activities by WP4, WP5 and WP6, which will undergo assessment and analysis as envisaged in the Evaluation Plan.

Evaluation results will be shared with the RAB, whose feedbacks will be shared with the Coordination team (WP1) and relayed back to the relevant WPs. Relevant evaluation outputs will be shared with WP2 for appropriate dissemination actions.

**Figure 1:** Relation with other WPs (input/output)



# Timing

FTELE was supposed to provide the RAB with the evaluation plan for validation of the key indicators by month 3 (Milestone M3.1). However, a slight delay in the constitution of the RAB was experienced. By M3, 7 out of 10 members responded to the request, and only 6 accepted. Unfortunately, there was no time for the new RAB members to receive the evaluation plan, and therefore provide M3.1 'Brief on validation of the Key Indicators' within the original timeline. The new deadline for M3.1 has therefore been reasonably shifted to M5. Upon receiving feedbacks from the RAB, suggestions will be incorporated in the final version of the evaluation strategy. The evaluation strategy will then be implemented starting with a close collaboration with WP4 for initial set up of the evaluation process.

The first interim process and output evaluation is due at the end of the first year, when the first annual meeting with the RAB and executive committee (EC) will take place (M3.2). A final evaluation report, including outcome and impact assessment, is due at the end of the second, and last, year along with the second and final annual meeting with the RAB and EC.