Stakeholder Engagement and Dissemination Plan

Deliverable 2.2

31 March 2019

WP Participants: EURORDIS

V1	26 MARCH 2019	EURORDIS
V2	29 MARCH 2019	ALL PARTNERS
Final version	31 MARCH 2019	ALL PARTNERS

Contents

1. Introduction

Rare2030 is a PPPA-AG Pilot Project & Preparation Action Grant. Pilot projects (PP) and Preparatory Actions (PA) introduce new initiatives that might turn into standing EU funding programmes. A Pilot Project is an initiative of an experimental nature designed to test the feasibility of an action and its usefulness and lasts not more than two years. A Preparatory Action - normally the successor of a successful pilot project on the same matter - is designed to prepare new actions like EU policies, legislation, programmes etc. with funding for not more than three years.

This pilot project, co-funded by the European Commission, brings together 8 project partners in 4 countries. Rare2030 is articulated in six Work Packages (WPs), three of which are cross-cutting (Coordination and management (WP1), Communication and Stakeholder Involvement (WP2) and Evaluation (WP3)) and three specific Work Packages. These are Knowledge Base and Mapping of Determinants and Drivers of Change (WP4); Scenarios Building (WP5) and Policy Recommendations and Impact (WP6). The six Work Packages consist of 24 deliverables.

Rare2030 started 1 January 2019 and the "kick-off" meeting took place on 21-22 January 2019 in Brussels. This Pilot project will last for a period of 2 years, until the end of December 2020.

This document, the Rare2030 Dissemination Plan, deliverable 2.2 of WP2, will be reviewed and updated by EURORDIS every six to eight months and disseminated to all partners in order to ensure that the information within it is accurate and relevant and that project progress and deliverables are well disseminated and stakeholders are involved in the most effective way.

2. Objectives

Rare2030

The purpose of the pilot project is to propose sustainable policy scenarios in the field of rare diseases for the period 2020-2030 and to address challenges and opportunities up until 2030 in a comprehensive and innovative manner, with particular emphasis on limited competences at the EU level.

Building upon the success of European policy in support of rare diseases (RD) to-date, innovative research-based methods will be used to best support future policy decisions for RDs. Specific objectives include:

1. To reach the agreement of the Panel of Experts on the proposed trends, drivers, weak signals and wild cards (on RD) by the end of the first year. By harnessing the expertise and experience of associated and collaborating project partners and a panel of experts (made up of representatives of beneficiaries of this project include all stakeholders in the RD community from the broad range of key target groups including healthcare professionals, researchers, industry, policy makers, patient organisations and the 30 million people living with RD and their families), we specifically seek to establish the baseline knowledge required to identify, agree on and rank scientific, technological, social, political, financial and institutional drivers for the future governance and care of RDs in Europe.

2. To reach the consensus on the most preferable RARE2030 scenarios by month 18 (between 4 and 8 scenarios will be constructed at the 2030 horizon). By exploring and combining trends and existing instruments, 4-8 consistent and plausible qualitative scenarios will be developed revealing the needs, perceptions and preferences of the RD Community and society at large as well as the policy options leading to these scenarios.
3. **To create Policy Recommendations by month 24.** In addition to drafting clear recommendations for a **road map of European RD policy 2020-2030**, we will anticipate the identification of solutions to sustain them beyond this timeline. The consortium will also evaluate the efficacy and appropriateness of foresight and other future studies methods for RD policy planning.

Work Package 2: Dissemination

WP2 2, Communication and Stakeholder Involvement, aims to maximise the impact of the Rare2030 project and to trigger effects among the targeted stakeholders and communities. Through organised communication and dissemination activities, WP2 intends to disseminate the results of RD-ACTION, which in turn will allow for sustainability beyond the project end.

Within WP2, objectives include:

To create long-lasting communication tools to engage the RD Community, including policy makers and society at large, to follow through with implementing these recommended policies. Specifically, this means:

3. Informing: partners and all stakeholders about the project scope/mission and activities;
3. Engaging: partners and all relevant stakeholders/networks of experts in project activities/research - in view of gathering their inputs as well as engaging them in planning of the sustainability/use of the project results/outcomes after the project's end (see additional considerations on stakeholder involvement below); engaging representatives of society at large to prepare as best as possible for project outcomes to integrate "mainstream" health policies;
3. Disseminating: project outcomes and results to all stakeholders and to society at large.

The development and implementation of an engagement and dissemination plan will ensure that project results and deliverables are available to all stakeholders and will be preceded by:

1. A stakeholder analysis: to identify relevant stakeholders and map the outreach of partners to relevant experts/networks.
2. An assessment of existing and needed communication channels/tools: specific project communication tools; existing channels/tools (media, events, networks, platforms) of the partners, of the RD community, of the European institutions and of other relevant fora at EU, national or "trend/topic" level.
3. The implementation of the engagement and dissemination plan will therefore rely on both the specific actions planned within RARE2030 as well as on the existing communication channels. The analysis of the stakeholders as well as of the necessary and existing communication tools will allow for the project to build an engagement and dissemination plan with wide and stakeholder-targeted outreach, while also streamlining resources. The networks of each project partner will be instrumental in ensuring complete and quality communication on results and encouraging broad and sustainable uptake by patients, stakeholders (including policy makers) and society at large. Other existing tools, such as the EU Health Policy Platform, will be explored as an opportunity to encourage sustainability of the policy dialogue initiated in the RARE2030 project, after its end. Via this WP, RARE2030 aims at engaging with the target groups outlined in Section 3 below.

3. Audiences

The Dissemination Plan aims to inform all key target groups of the actions undertaken to meet the needs of patients and their relatives, healthcare professionals, researchers, industry and policy makers.

The following target groups have been identified:

- Partners of RARE2030

- Advocacy and support groups/volunteers representing people living with a rare disease and their families - notably the Council of National Alliances, the Council of European Federations and other disease-focused organisations at national level
- EU policy makers - members of the EC, Members of the European Parliament (network of Parliamentary Advocates for Rare Diseases), former members of the Commission Expert Group on Rare Diseases, members of the ERN Board of MS and members of the Steering Group on Promotion and Prevention (SGPP), DG SANTE and DG RTD amongst others;
- Organisations involved in the European Joint Actions for Rare Diseases (EUCERD Joint-Action, RD-Action)
- National/regional competent authorities
- Health Care Providers, notably from ERNs and constituent Centres of Expertise; other relevant health care experts e.g. within integrated care (International Foundation for Integrated Care);
- Hospital managers
- Social care and social innovation experts e.g. European Network of Resource Centres for Rare Diseases, International Federation of Social Workers Europe, Centre for Social Innovation (ZSI, Austria)
- Academia, learned societies e.g. European Federation of Internal Medicine (EFIM); European Hospital & Healthcare Federation (HOPE); European Society of Human Genetics (ESHG); International Society for Pharmaco-economics and Outcomes Research (ISPOR)
- European networks and infrastructures: E-Rare and potentially the European Joint Programme Co-Fund for Rare Diseases (pending approval); EuroBioBank; ECRIN; BBMRI; RD-Connect; "RD-Bridge", scaling up shared tools across ERNs; SCOPE Joint Action; Solve-RD on undiagnosed diseases; EUPATI (IMI); ADAPT-SMART (IMI), "Care for Children" clinical research network (IMI); PARADIGM for good practices on the engagement of patient in product life cycle with all stakeholders (IMI)
- Pharmaceutical Industry and other health-related industries;
- Regulators
- European Medicines Agency relevant committees and task forces
- HTA bodies/reimbursement authorities e.g. HTA Network and its Stakeholder Forum, EUnetHTA Joint Action for Scientific Advice and Relative Effectiveness Assessments;
- International initiatives e.g. International Rare Disease Research Consortium (IRDiRC); Rare Diseases International (RDI); NGO Committee for Rare Diseases (United Nations, New York); International Conference on Rare Diseases and Orphan Drugs (ICORD); International Alliance of Patients' Organisations (IAPO)
- Other relevant European Not-for-Profit Organisations: European Patients' Forum (EPF); European Cancer Patient Coalition (ECPC); Rare Cancer Europe; Social Platform; European Disability Forum (EDF); Drug Information Association (DIA).

Stakeholders within Rare2030 stratify European, national, regional and local levels.

Stakeholders to be engaged will expand beyond the rare disease community and more direct stakeholders, including organisations and experts in other fields related to the important trends that will shape the future of rare diseases e.g. health economics, technology, social innovation, etc. An expert panel will be composed early in the project (WP4), gathering these relevant stakeholders, to ensure and facilitate their engagement all through the project.

To structure the up-stream engagement of lay citizens in these discussions on EU policy on rare diseases, a citizen conference – an event to reach concerned citizens and bridge the gap between the general public, experts and politicians – will be organised.

Stakeholder Analysis

A Stakeholder Analysis (Table I) was carried out in order to better target key stakeholders and recognise the information that are important for and actions that are required of the aforementioned target groups.

This process has been carried out to clearly define stakeholders and their interest in the Rare2030 project, to prioritise stakeholders and to identify which messages and tools are best to reach them.

The purposes of dissemination have been divided into sections intending to:

- **Raise awareness**: let others know what we are doing
- **Engage**: get input/feedback from the community and encourage mobilisation of stakeholders
- **Inform**: educate the community on the progress made during the project and feedback to those who have contributed
- **Promote**: encourage the community to take ownership of outputs and results.

In many cases the purpose of dissemination will be multi-faceted; especially considering that one of the overall objectives of the Dissemination Plan is to encourage and facilitate the participation of targeted stakeholders. In this case the primary purpose of dissemination will be prioritised.

4. Messages

Rare2030 will relay different messages throughout the development of the project to reflect the outcomes.

Towards the beginning of the project, before there are any concrete outcomes, communications will be focused on raising awareness, providing information about Rare2030 and specifying opportunities for participation through project events (e.g. website and leaflet) to reach a wide audience and raise the profile of the project.

Rare2030 will then adapt to developing specific messages once the consultative process of the project begins. The messages will be disseminated amongst and targeted to different stakeholders depending on their role in Rare2030 and the purpose of dissemination, according to the Stakeholders Analysis in Table I.

Throughout the project, certain key, overarching messages in line with the objectives and specific milestones of Rare2030 will be shared with target audiences as the project evolves.

Finally the project's ultimate outcomes will be shared with all target audiences:

1. Recommendations for road map of RD Policy 2020-2030;
2. Conclusions on the efficacy of using foresight and other future studies methods for RD health policy planning;
3. Identification of solutions to sustain activities beyond project funding;
4. Communication tools to engage the RD community, including policy makers and society at large, to follow through with implementing these recommended policies.

5. Dissemination

Rare 2030 will use a wide variety of dissemination methods and tools to raise-awareness, inform, engage and promote the outcomes of the Joint Action. Dissemination is flexible, and will take advantage of media channels, formal materials, conferences, workshops and face-to-face meetings to share information amongst relevant stakeholders.

Many of the dissemination deliverables are assigned to the Project Coordinator. Nonetheless, all partners are expected to engage in the sharing of information within their networks.

The overall strategic approach is also flexible and open to adaptation in line with constant evaluation and feedback of the methods.

Media

Online media will be the most versatile and the most frequently used channel of dissemination.

Rare 2030 Website

www.rare2030.eu is the main point of communication for this project and other communication tools (social media, newsletters) can be channelled to the website. The website communicates all the project aims and objectives, in addition to providing information on the structural organisation of the project. News and announcements will be available on the website and it will be updated regularly to reflect the deliverables achieved. The website is accessible to all stakeholders and will provide an introduction for those who are not familiar with the project in addition to all the material produced by Rare2030.

Key points of interest on the website:

- 'About Rare2030' provides a brief introductory summary of the work that the project aims to achieve, making it accessible to a wider pool of stakeholders;
- 'Project Outcomes' provides a more in depth view of the project deliverables by Work Package and indicating who is coordinating them;
- 'How to Get Involved' includes information about conferences, workshops and online tools through which stakeholders can make their opinions about the future of rare disease policy heard;
- 'News' is a continually updated section showing the progress made and highlighting any events and advances that are of interest to the project, this section is of particular interest to those stakeholders that are close to the project.

The Project Coordinator is responsible for the creation, content and maintenance of the Rare2030 website. Partners send updates, new information and material to the Project Coordinator who will take care of uploading the information on the Rare2030 website once validated.

www.rare2030.eu went live on Rare Disease Day 28 February 2019 and is updated regularly.

Websites and social media of Rare2030 partners

All partners of the Rare2030 project are expected to include at least a link to the Rare2030 project website from their own websites.

A web section providing an introduction to Rare2030, outlining its objectives and outcomes, and including a link to the Rare2030 website and social media accounts, is especially encouraged. The web section is to be created within the first months of the project. This does not need to be updated regularly, although this is encouraged.

EURORDIS member news

Orphanews

OrphaNews reports the latest developments in the field of rare diseases and orphan drugs, and therefore will communicate on the outcomes of Rare2030.

The content of the newsletter is comprehensive of all updates in the rare disease community. Each newsletter is organised thematically, which enables more focused communication of the work packages' outcomes. This also makes it easier for stakeholders to access information particularly relevant to their field.

Other OrphaNews sections include:

- Editorial
- Spotlight on…
- National and International Policy Development
- Ethical, Legal and Social Issues
- New Syndromes
- New Genes
- Research in Action
- Patient Management and Therapy
- Orphan Drugs
- Grants
- Courses & Educational Initiatives
- What's on Where?

OrphaNews is freely available and electronic. It is designed to suit all stakeholders in the rare disease and orphan drugs community and to be easily accessible.

OrphaNews is sent to subscribers (around 16000) twice monthly, and all past issues are archived online at www.orpha.net.

Partners' newsletters

Those partners with newsletters are encouraged to include information on Rare2030 project according to the target group of the newsletter in order to inform on the development of the project and outcomes.

Each partner needs to adapt their own newsletter's content according to their audience and according to new information. Partners will be invited to reuse content generated for the Rare2030 and EURORDIS Member News.

When communicating about Rare2030 in other newsletters, partners must include the link to www.rare2030.eu to channel interested parties back to website.

Social media

Twitter and Facebook account:

The WP2 "Communication and Stakeholder engagement", led by EURORDIS has created the Twitter handle @rare2030 and Facebook page https://www.facebook.com/rare2030/

These accounts are used to create awareness of relevant news in current and future rare disease policies and, inform stakeholders about the project updates and upcoming events within Rare 2030 and promotes outcomes of the work being carried out by the partners.

Using these social media creates an engaging presence to enable interested parties to exchange information and further disseminate updates within their own networks. Therefore, when partners of Rare 2030 post updates on their own social media accounts they are encouraged to tag @rare2030 when relevant to the project, and also retweet messages from the @rare2030 handle to create a larger reach of the information and show support for the project.

Other social media tools:

For a wider reach a Facebook, LinkedIn or Google+ account could be created if the need arises.

Materials

Rare 2030 will also create materials that can be used to inform stakeholders of updates. Materials will be available on the Rare 2030 website and will be disseminated via the media channels aforementioned where relevant.

The logos of Rare 2030 and of the European Commission must always be displayed on any communication material related to an action of Rare 2030. The logos are available on request from EURORDIS.

See Table 1 in the Annexes for Dissemination Rules for Rare 2030

Leaflet

The Rare 2030 project has produced a short leaflet to engage participation and provide an overview of the aims and ways to get involved as well as an exhaustive list of partners. The leaflet will be disseminated to the public and is intended to create awareness about Rare 2030. Its content can be easily understood by people who are not familiar with the project and activities carried out in the field of rare diseases.

The leaflet will be available online on the Rare 2030 website. All partners are encouraged to widely disseminate it through their media tools and/ or at conferences or events they participate in.

http://download2.eurordis.org.s3.amazonaws.com/rare2030/rare2030_leaflet.pdf

Peer-reviewed Articles

Partners may contribute to peer reviewed articles about on-going progress in the field of rare diseases. Where content is in line with Rare 2030, articles will serve to inform relevant stakeholders.

Articles will be produced ad hoc. Upon publication, dissemination will be encouraged using media channels aforementioned where appropriate.

Orphanet Reports Series

Orphanet reports are a series of texts covering topics relevant to all rare disease stakeholders. Outcomes of Rare 2030 may be included in these comprehensive reports.

RD Action

RD-Action was an EU Health Programme funded Joint Action (2015-2018), promoting implementation of recommendations on policy, information and data for RD. As Rare 2030 continues reflections and promotion of implementation on many of the policy recommendations from RD-Action a link will be made between communication materials of both platforms where appropriate.

Posters and speakers' Presentations at conferences

Results of the project or announcements could be disseminated via posters or during presentations at workshops and conferences. Posters can serve to inform engaged stakeholders about the Joint Action in general, or by specific Work Package or deliverable.

Partners of Rare 2030 are requested to use the graphic chart made available to partners, including the logos of the project and of the European Commission, the templates for power point.

Posters and presentations will be made ad hoc. Partners will be encouraged to share posters and presentations to add them to the Joint Action website.

State of the Art Reports of Rare Diseases Activities in Europe

Two overviews Reports on the State of the Art of Rare Diseases Activities in Europe constitute tasks in WP4. The country-specific RD summaries will constitute part of the Knowledge Base and provide the Panel of Experts with a knowledge base of current activities in rare diseases across Europe. They will be published on the Rare 2030 website.

This task will include the following steps:

- Re-evaluate, with RARE2030 Partners, the questionnaire collecting national level data, to ascertain if there are additional questions it would be helpful to pose in these regular updates (M1-January).
- Updated data collection M2-February 2019 and M16-April 2020.
- Generate topic-specific summaries, for areas which do not have these by 2019, and update existing topic-specific summaries, to act as a snapshot of transversal activity and trends between countries pertaining to issues such as existence/implementation of national plans/strategies for RD; approaches to RD registration at the national level; policies and programmes pertaining to new-born screening; etc. To be ready by M6 (June 2019).

Interim and Final Reports

The main outcomes of Rare 2030 are to be outlined in the Interim and Final Reports.

The Interim Reports will be published on Months 12 and 24 and the Final Report will be published at the end of the project.

Layman brochure Summarising the Rare 2030 final report

The layman brochure is a shorter, more succinct version of the final report. This will highlight the achievements and results of Rare 2030 in a way that is more accessible to the broader public. It will be disseminated more widely than the Final Report amongst external stakeholders.

The Layman Brochure will be published at the end of Rare 2030.

Press Releases

Press releases will be sent to journalists and to a list of correspondents in Brussels as and when there is newsworthy material from the project. They will also be made available on the Rare 2030 website and will be available for translation for partners who wish to send it to national and local press. It is not yet possible to determine what the press releases will be on, although some anticipated topics include:

- ECRD 2020
- Drivers of Change for rare diseases in the coming decade
- Alternative future scenarios for people living with rare diseases
- Policy recommendations to make preferred scenarios a reality
- Citizen engagement event
- Policy event

Press releases about or disseminated by Rare 2030 should include:

- The Rare 2030 logo;
- A boiler plate about Rare 2030;
- A link to the Rare 2030 website and twitter;
- Contact information.

Conferences and workshops

Conferences

ECRD 2020 – European Conference for Rare Diseases and Orphan Products (stockholm, 15-16 May 2020)

The European Conference for Rare Diseases and Orphan Products (ECRD) taking place on 15-16 May 2020 in Stockholm, Sweden, is a unique platform to bring together over 800 stakeholders in rare diseases across Europe and beyond. It serves as an opportunity to inform, educate, engage and promote and project the actions in the field of rare diseases, including those of the Rare 2030 project.

Although not yet confirmed, the theme of the conference will be forward looking and the programme focused around the main measures impacting on the rare diseases field that will be taken and implemented at national and European levels in the coming decades.

Rare 2030 may be specifically mentioned in the plenary address and at least one conference session will be dedicated to refine future scenarios.

Invitations to participate to these Rare 2030–specific events and the conference in general will be communicated through the channels described in this document. A link to the ECRD website will be made available on the Rare 2030 project website.

The partners are encouraged to use social media leading up to and during the conference to disseminate outcomes as they happen. A report on the outcomes will be produced and disseminated widely following the event.

Policy recommendations conference

The policy recommendations conference will address EU policy makers, notably the newly appointed European Commission and Members of the European Parliament, European Commission services, as well as national and local relevant policy-makers tasked with implementing policies. It will also address all other stakeholders responsible for implementing policies. The objective of the policy conference will be to present the recommendations coming out of this project and to feed into the definition of the sustainability rare disease strategy for the coming decades.

Citizen conference

Workshops

Reports based on the outcomes of workshops organised within Rare 2030 will be published on the Rare 2030 website:

Knowledge base, Horizon Scanning and Scenario building workshops

- Knowledge base workshop – Patient view (EURORDIS membership meeting, Bucharest 18 May 2019)
- Validation of Drivers – Panel of Experts Workshop (Brussels, November 2019)
- Scenario Building Workshop (European Conference on Rare Diseases, Stockholm 15-16 May 2020)

Regional Backcasting Workshops

Several workshops (in 5-6 regions of Europe) will be organised to integrate key priorities at the national level into the project's activities. Workshop attendees will be invited to refine Rare 2030 Scenarios to best reflect needs, expectations and realities at national and regional level and ultimately being integrated in the final policy recommendations.

Each regional workshop will include 20-30 local ERN members and Centres of Expertise, national Orphanet teams, national RD alliances, and representatives from national Ministries of Health and Research and other local stakeholders.

As possible, workshops will be aligned with locations of EU presidencies between 2020 and 2023 covering the greatest number of Member States possible:

- 2020 – Croatia, Germany
- 2021 – Portugal, Slovenia
- 2022 – France, Czech Republic
- 2023 – Sweden, Spain

National Alliances of Rare Diseases will organise the workshops with the support of EURORDIS. National Alliances will help disseminate information about the event, and details will also be available through Rare 2030 communication channels.

The workshops will be organised between May and November 2020. Reports on the outcomes of the workshops will be disseminated and made available on Rare 2030 website.

EU Level Backcasting Workshop

In a continuation of the working methods established in the Joint Action RD-ACTION, a workshop, organised by UNEW, will facilitate the inclusion of the EU level perspective. This Workshop will invite the 24 ERN Coordinators, ePAGs, and all project partners and representatives of the Panel of Experts to consider national and EU level concerns in the draft of policy recommendations.

Policy conference

Policy recommendations will formally be presented to policy EU policy makers, notably the new appointed European Commission and Member of the European Parliament, European Commission services and national and local relevant policy-makers tasked with implementing policies.

.

Communication Tools Amongst Partners

Rare 2030 Drop box platform

Project partners will collectively comment on documents using Drop Box.

Teleconferenes

Partners will update each other via monthly teleconferences. Work Package leaders will organise regular calls with partners in each work package on a regular basis at their discretion.

Partners will meet face to face at 6-month intervals:

1. Kick off meeting
2. 1st interim meeting

3. Mid-term meeting
4. 2nd interim meeting
5. Final meeting

Rare 2030 Newsletter

A bi-annual newsletter will be circulated amongst project partners, members of the Panel of Experts, Research Advisory Board, participants of the Citizen Conference and any interested parties invited to subscribe.

The newsletter will feature updates on the progress of project work, upcoming events, partners news and any literature or resources related to the future of rare disease policy.

6. Evaluation

The dissemination activities will be evaluated continuously to measure the success of the strategies outlined in the Dissemination Plan.

The evaluation method will involve monitoring the content of the websites, newsletters, and other websites talking about Rare 2030; using questionnaires following workshops and conferences; discussions about the use of dissemination channels and materials amongst partners; measuring the number of citations of publications, and using in-built measuring systems on websites, newsletters and social media.

Feedback will be taken into consideration and will be implemented where possible to ensure the dissemination process is effective in achieving the objectives of the specific Work Package 2, and the whole project.

The evaluation process will be continuous, with specific attention at every evaluation report when the Dissemination Plan will be reviewed and updated taking feedback into consideration.

7. Annexes

Table I: Dissemination rules of Rare 2030

Table II: Stakeholder Analysis

Table III: Dissemination Chart

RARE 2030 DISSEMINATION PLAN

TABLE I – DISSEMINATION RULES

Co-funded by the European Union Pilot Projects and Preparatory Actions Programme

- The Graphic Chart of Rare 2030 and related logos can be requested from EURORDIS.

- For each communication related to Rare 2030, always displays:
  - **The logo of Rare 2030**
  - **The logo the EC logo to acknowledge the funding source**

Should you need assistance, please do not hesitate to contact the project lead at: anna.kole@eurordis.org

- On each presentation and communication material, always displays the following disclaimer:

The Rare2030 project is co-funded by the European Union Pilot Projects and Preparatory Actions Programme (2014- 2020). This [leaflet, presentation…] 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.

RARE 2030 DISSEMINATION PLAN

TABLE II - STAKEHOLDER ANALYSIS

Stakeholder Group ***(WHO)***	**Interest in Rare 2030** ***(WHY)***	**Channels of Dissemination** ***(HOW)***
Partners of Rare 2030 - EURORDIS - ISINNOVA - Orphanet (central office) - University of Newcastle - Telethon Italia - University Hospital of Udine (Metab ERN) - IOR (ERN-BOND)	To integrate progress and information into their own work. Seek opportunities to input and influence decision making. Receive support on policy methodology. Production of data to support policy analyses and decisions.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
National and local competent authorities - Health ministries - Research ministries - Social affairs ministries - Regional level health competency authorities and their platforms - Health institutes - Local social service providers	Production of data to support policy analysis and decision making. To facilitate integration of EU policy into national and local policies. Support regional workshops.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.

Regulators	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
HTA bodies/reimbursement authorities	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
EU decision-makers - European Commission: DG SANTE (in particular Public Health and Health Systems and Products), DG CONECT, DG EMPL, DG RTD, CHAFEA - European Parliament: MEPs, ENVI and ITRE committees	Information about national RD initiatives. Recommendations to help drive European policy. Production of data to support policy analysis and decision; and to facilitate integration of EU policies. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases.

- Committee of Regions - Economic and Social Council		Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
Healthcare professionals - RD specific groups - GPs - Specialised MDs - Nurses - Paramedics - Case Managers - Social Workers - Hospital Managers	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
Industry (Health Related Private Sector) - Pharmaceutical and Biotech companies - Medical devices companies - Trade associations - (Bio) Informatics Companies - Insurance Companies	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.

Academia; researchers	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
Patients advocacy and support groups - EURORDIS member organisations - EURORDIS National Alliances - EURORDIS European Federations - RD patient organisations non -member of EURORDIS	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
Patients, families and their representatives	Production of data to support policy analysis and decision making. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners' website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners' newsletters Social media. Leaflet. Posters. Press releases.

		Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.
Beyond RD communities - Other Joint Actions and other disease areas e.g. Chronic diseases - Other policy areas e.g. eHealth - Other patient communities	Insight into work and activities carried out within Rare 2030 Data of interest. Update on cross-cutting issues. Obtaining information on relevant policy developments.	Websites: Rare2030 and all partners’ website. Newsletters: OrphaNews, Rare 2030 internal newsletter; all partners’ newsletters Social media. Leaflet. Posters. Press releases. Attendance at conferences and workshops: - ECRD 2016 - Project workshops Project meetings Rare 2030 Final Report. Layman version of the final report.Leaflet. Poster. Layman version of the final report.

Rare 2030 DISSEMINATION PLAN
TABLE III - DISSEMINATION CHART

Dissemination Activity	Frequency	Year 1												Year 2											
		Jan 2019	Feb 2019	Mar 2019	Apr 2019	May 2019	June 2019	July 2019	Aug 2019	Sept 2019	Oct 2019	Nov 2019	Dec 2019	Jan 2020	Feb 2020	Mar 2020	Apr 2020	May 2020	June 2020	July 2020	Aug 2020	Sept 2020	Oct 2020	Nov 2020	Dec 2020
		M-1	M-2	M-3	M-4	M-5	M-6	M-7	M-8	M-9	M-10	M-11	M-12	M-13	M-14	M-15	M-16	M-17	M-18	M-19	M-20	M-21	M-22	M-23	M-24
Online																									
Website and social media	*Continuous update*			■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Newsletters																									
Orphanews	*20 issues per year (twice a month):*				■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
EURORDIS e-news	*Sent every two weeks (Wednesday):*				■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
EURORDIS Member News	*Once a month:*				■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Other partners' newsletters					■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Materials:																									
Leaflet				■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
State of the Art Reports			■				■										■								
Peer reviewed articles	*Ad hoc*																								■
RD Action	*Ad hoc*																								

Posters and presentations	*Ad hoc*																								
Press Releases	*On notable events*													▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
Final Report																									▨
Layman Brochure of final report																									▨
Conferences, Workshops and Surveys:																									
Knowledge base workshop				▨	▨	▨	▨	▨																	
Horizon Scanning Panel of Experts Workshop								▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨						
European Conference on Rare Diseases and Orphan Products 2019, Stockholm								▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨						
Regional Backcasting Workshops														▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
European Backcasting Workshop																			▨	▨	▨	▨	▨	▨	▨
Citizen Conference																			▨	▨	▨	▨	▨	▨	▨
Policy Conference																			▨	▨	▨	▨	▨	▨	▨