RARE 2030

Final Evaluation Report

Deliverable 3.3

Rare 2030
Foresight in Rare Disease Policy

| **WP Participants:** |
| INSERM, UNEW, ISINNOVA, EURORDIS |

V1	15/3/2021	FTELE
V2		
V3		
Final version		All partners

Rare 2030
Foresight in Rare Disease Policy

Contents

1 Introduction

The final evaluation of the RARE 2030 project builds upon the interim evaluation submitted with deliverable 3.2 and focuses therefore on the achievements of the second part of the project (month 13 to month 27).

In this period, the major project milestones relevant for the evaluation were:

1. The expert workshop on scenarios' building held in Brussels in February 2020
2. The ECRD conference 2020 where the scenarios were presented to the rare disease community
3. The Young Citizen Conference held in July 2020 that completed the process of young citizen engagement
4. The ERN workshops held in autumn 2020
5. The final policy conference held in February 2021

This report is structured consequently, with:

- Section 2 offering the overview of the results achieved against the indicators defined in the evaluation plan (including also the indicators for the specific objective number 1 that were evaluated in the interim report);
- Section 3 presenting the feedbacks to the several events listed above organized in 2 paragraphs, one dedicated to the scenarios and one to the recommendations;
- Section 4 summarizing the outcomes of this structured evaluation process;
- Chapter 5 presenting Young Citizens' comments to the dedicated conference

To be noticed that all the above-mentioned events were planned to be in person but, due to the COVID-19 outbreak, were moved on-line (except for the first one that took place just few weeks before the first lock-down in Europe). Nonetheless, despite the massive impact of the COVID-19 pandemic on the project, the countermeasures adopted and the additional efforts by the partners allowed reaching the expected objectives. As the second year of the project, progressed, project partners gained additional experience and support in making

Revealing in advance the key messages coming from the whole report:

1. All the expected results were achieved;
2. All the feedbacks from the several and diverse stakeholder groups involved in the project were very positive;
3. Rare 2030 succeeded in engaging the rare disease community despite the additional and unpredictable obstacles caused by the COVID-19 pandemic.

2 Overview by indicator

According to the Evaluation Plan (D3.1) different indicators have been identified and are used to evaluate each specific objective:

- Specific Objective 1: 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
- Specific Objective 2: To reach the consensus on the most preferable RARE2030 scenarios by month 18
- Specific Objective 3: To create Policy Recommendations by end of the project

As presented in the interim report, at the end of year 1 (month 12) the first specific objective was successfully achieved. In the following periods (month 13 to month 27), **specific objectives 2 and 3 were also successfully achieved** as shown in the paragraphs below.

2.1 Specific Objective 1 - To reach the agreement of the Panel of Experts on the proposed trends, drivers, weak signals and wild cards (on rare diseases)

2.1.1 Process Indicators

Description	Target
Approval by the Research Advisory Board of the methodology for literature review	Yes/No

YES: The RAB approved the methodology

Description	Target
Composition, number and attendance rate of members in the Panel of Experts (PoE)	A minimum of 150 PoE members, with a balanced composition in terms of area of expertise, gender and geographical distribution.

ACHIEVED: 184 experts accepted to become member of the Panel representing 27 EU Member States (all except Estonia), 6 other European countries and 5 other countries outside Europe.

Description	Target
Organization of a consensus meeting of the PoE on Horizon Scanning	Balanced distribution of PoE members attending the meeting by area of expertise, country of activity, type of affiliation, gender.

ACHIEVED: 155 experts joined the consensus meeting already in November 2019, representing 15 stakeholder categories (ERN Hospital Manager, EU Policy Maker, Health economist, HTA/reimbursement authorities, Individual Expert, EU Joint Action for RD, Individual Researcher, International Initiatives, Journalist, National /Regional policy maker, Patient Advocate non PoE, Patient Advocate PoE, Pharma & Healthcare Industry, Regulatory Expert, Social care and social innovation expert) from 33 countries.

2.1.2 Output Indicator

Description	Target
Exhaustiveness of the trends, drivers, weak signals and wild cards identified in the horizon scanning phase (WP4)	Consensus of the invited stakeholders on the trends, drivers, weak signals and wild cards and ranking approved by the majority.

ACHIEVED: Answering a specific question, 97% declared to agree with the statement that "All the most relevant trends were identified and listed". More details on the results of the questionnaire will be presented in the specific chapter.

2.1.3 Outcome/Impact Indicator

Description	Target
Agreement of the Panel of Experts on the identified trends, drivers, weak signals and wild cards	At least 2/3rd agreement expressed by means of a questionnaire to be administered to PoE members attending the consensus meeting. See attached template)

ACHIEVED: 80% of the respondents to the feedback questionnaire distributed at the consensus meeting declared to be overall satisfied (somewhat satisfied or very satisfied) with the trends identification, validation and ranking.

2.2 Specific Objective 2 - To reach the consensus on the most preferable RARE2030 scenarios

2.2.1 Process Indicators

Description	Target
Response rate of the survey involving all stakeholders	At least 30%

ACHIEVED: as, due to COVID-19 pandemic, the ECRD was moved on-line, an unforeseen high number of participants registered for the conference. Partners then decided to run the survey on scenarios during the conference itself through instant polls. An audience of over 800 delegates was invited to vote on the Rare2030 scenarios with 314 votes (40%) regularly recorded through the instant polls system.

PARTIALLY ACHIEVED: In addition, just before the round of webinars hosted in summer 2020, a survey was launched involving the PoE (which represents all categories of stakeholders) in June 2020. The response rate to the survey was quite low, around 15%, but the outcome in terms of the preferred scenario was very clear with 85% of respondents selecting scenario 1 – Investments for Social Justice. To be considered that the survey followed an unstructured request to the PoE to express their opinions on the scenario. The survey was therefore conceived to facilitate those experts who did not provide their feedback, to do it in a structured and simplified format.

Description	Target
Completion rate of the survey involving all stakeholders	At least 75-80%

ACHIEVED: The survey for the PoE reached a completion rate of 96% with only one respondent who did not complete the survey.

Description	Target
Satisfaction of the participants to the scenario building workshops	70% of the participants report to be satisfied or very satisfied

ACHIEVED: 100% of the respondents (18) to the PoE feedback questionnaire reported to be either *Somewhat satisfied* or *Very satisfied* of the workshop. 82% (14) declared to be either *Somewhat satisfied* or *Very satisfied* of the work done on the scenarios.

2.2.2 Output Indicator

Description	Target
Production of Scenarios	Yes/No

ACHIEVED: Scenarios were produced, described in writing in deliverable D5.2 as well as in a video premiered at the ECRD 2020 conference and published on the project website.

Description	Target
Percentage of the participants to the survey agreeing on the scenario indicated as preferable	50% of the participants identify the same scenario as preferable

ACHIEVED: 85% of members of the PoE who completed the survey selected scenario 1 – Investments for Social Justice.

Description	Target
Percentage of the participants to the Consensus Conference agreeing on the scenario indicated as preferable	50% of the participants report to be satisfied or very satisfied with the selected scenario

ACHIEVED: 90% of the respondents to the instant poll during the RARE2030 plenary session at ECRD 2020 chose scenario 1 - Investments for Social Justice – as the future they would like to live in.

2.2.3 Outcome/Impact Indicator

Description	Target
Suitability of the proposed scenarios to be used in WP6 for identifying actionable policies	Positive opinion by the Research Advisory Board

ACHIEVED: the process of scenario building was shared and agreed with the RAB, which expressed positive opinion on the scenarios.

2.3 Specific Objective 3 - To create Policy Recommendations

2.3.1 Process Indicators

Description	Target
Organization of one high level European event and 5 regional events to draft recommendations	Yes/No

ACHIEVED: despite the impact of COVID on the organization of all the events initially panned, 4 regional events were organized (Italy, Croatia, France, Spain) + one European event focusing on ERNs + one conference involving Young Citizens

Description	Target
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

PARTIALLY ACHIEVED: the 4 regional conferences were organized (on-line) and each of them was attended by much more than 12 participants. However, the representativeness in terms of countries was low as the regional conferences were mostly attended by nationals of the country organizing it.

Description	Target
Representativeness (in terms of stakeholder categories and of power to influence policies) of the participants to each of the 5 regional events to draft the recommendation	At least 1 representative of the healthcare system + 1 representative of the patients + 1 representative of the government (national and/or local) for each of the involved country

ACHIEVED: all the regional conferences were organized by the respective National Alliance of RD patients and managed to engage several representatives of ERNs and of national and local governments.

Description	Target
Overall geographical coverage of the 5 regional events	A minimum of 20 EU countries
REVISED: geographical coverage of the consultation process on recommendations	A minimum of 20 EU countries

ACHIEVED: as, due to the limitation imposed by the COVID pandemic, the regional events could not have the planned geographical coverage, the consultation process with stakeholders was revised. Rare 2030 launched 2 surveys in autumn 2020 for a broad consultation of healthcare specialists through the ERNs and patients through the Rare Barometer. The survey of ERNs collected 204 complete answers while the Rare Barometer more than 3600.

2.3.2 Output Indicator

Description	Target
Publication of the Policy Recommendation document	Yes/No

ACHIEVED: the Policy Recommendation Document is published and available at
https://www.rare2030.eu/recommendations/

Description	Target
Satisfaction of the participants at the policy conference	2/3rds of the participants report to be satisfied or very satisfied

ACHIEVED: 88% of the respondents confirmed that the conference met their expectations

Description	Target
Satisfaction of the participants to the EU level and regional workshops	2/3rds of the participants report to be satisfied or very satisfied

ACHIEVED: The overall level of satisfaction from participants in the regional workshop was 90% in France, 90% in Italy and 75% in Spain. Almost 80% of participants to the EU level workshop rated the event 4 or 5 stars (over 5).

2.3.3 Outcome/Impact Indicator

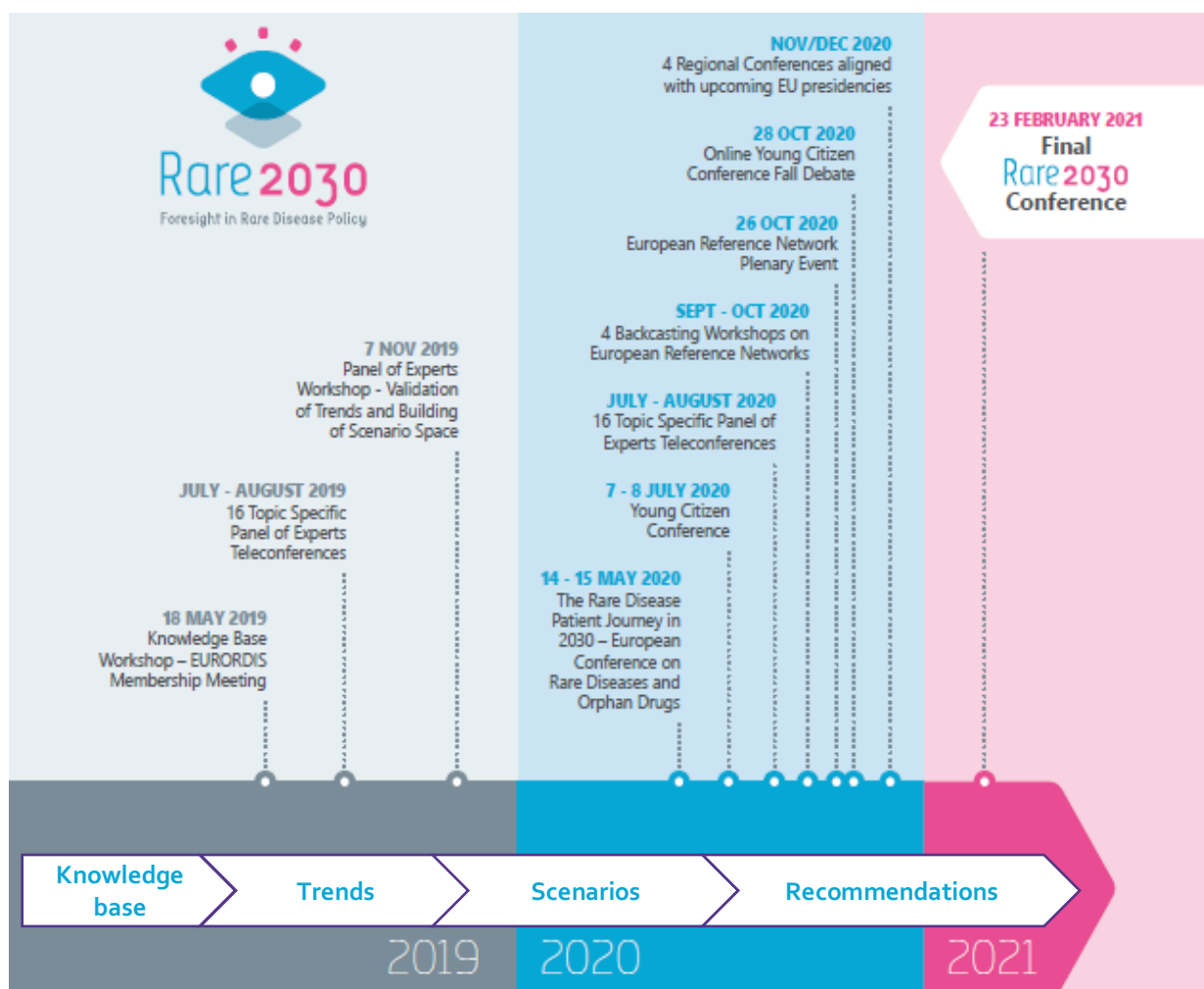| Description	Target
Number of Policy Makers and/or consultants of Policy Makers present at presentation of Policy Recommendations during the Policy Conference	5 at EU level + 5 national level

ACHIEVED: 7 EU level policy makers and 8 national policy makers attended the final conference

Description	Target
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

ACHIEVED: 76% of participants to the final policy conference agreed that the proposed recommendations will likely succeed in building the preferred scenario. 55% of participants to the policy conference reported to be moderately or completely familiar with the recommendations + another 35% reported to be slightly familiar with them; only 10% declared to be not at all familiar with the recommendations.

3 Monitoring and evaluation of the RARE2030 community engagement and consensus building process

Following the validation of the trends at the PoE workshop in November 2019, the RARE 2030 entered the phase of scenario building followed by the back-casting exercise to prepare the final recommendations. Both phases (in short: scenario building and back-casting for recommendations) followed the same participatory approach used, in the first 12 months of the project, for the trends identification. However, due to the COVID-19 pandemic, only one of the planned events was able to be held in person in Brussels while all the following were moved on-line. Here below a figure summarizing all the main events and consultation opportunities organized by the RARE 2030 project.

NOV/DEC 2020
4 Regional Conferences aligned
with upcoming EU presidencies

28 OCT 2020
Online Young Citizen
Conference Fall Debate

26 OCT 2020
European Reference Network
Plenary Event

23 FEBRUARY 2021
Final
Rare 2030
Conference

SEPT - OCT 2020
4 Backcasting Workshops on
European Reference Networks

JULY - AUGUST 2020
16 Topic Specific Panel of
Experts Teleconferences

7 NOV 2019
Panel of Experts
Workshop - Validation
of Trends and Building
of Scenario Space

7 - 8 JULY 2020
Young Citizen
Conference

JULY - AUGUST 2019
16 Topic Specific
Panel of Experts
Teleconferences

14 - 15 MAY 2020
The Rare Disease
Patient Journey in
2030 – European
Conference on
Rare Diseases and
Orphan Drugs

18 MAY 2019
Knowledge Base
Workshop – EURORDIS
Membership Meeting

Knowledge base | **Trends** | **Scenarios** | **Recommendations**

2019   2020   2021

Because of the on-line format, to increase both the engagement of the audience and the response rate to the feedback questions, instant polls were extensively used during the events. For some of them instant polls were even adopted as the main method to collect participants' feedback. While they are immediate and generally ensure a high response rate, instant polls limitations should not be underestimated, in particular the fact that they collect answers in the heat of the moment, without allowing participants a much deeper thinking.

As mentioned in the introduction, the following paragraphs present the main results of the several monitoring and evaluation activities carried out in year 2 of the project. These results are organized according to the project's specific objectives 2 and 3, respectively to reach a consensus on the scenario and to draft the policy recommendations.

3.1 Consensus on the most preferable RARE2030 scenarios

The process of scenario building started with the PoE workshop held in Brussels in November 2019. Another workshop was organized in Brussels in February 2020 involving project partners and 20 experts who were then invited to moderate sessions and/or members of the program committee of the ECRD 2020 conference.
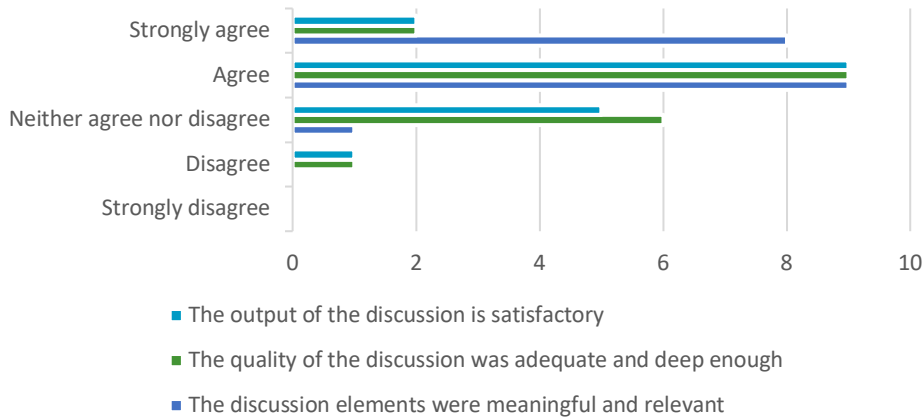
This February workshop was pivotal for the design of the scenario and, by chance, it was the last held face to face. The methodology of "world café" was adopted to facilitate the discussion among the participants and a specific question in the satisfaction questionnaire was dedicated to assessing the effectiveness of this methodology.

In brief, almost 50% of the participants completed the feedback questionnaire (18/38) expressing an overall satisfaction for the workshop (100% scoring either "somewhat satisfied" or "very satisfied"). In terms of

scenarios' building, **80% declared to be somewhat satisfied or very satisfied of the work done on the scenarios**.

The evaluation of the world café methodology was positive with a large majority agreeing that the discussion was adequate and the output satisfactory.
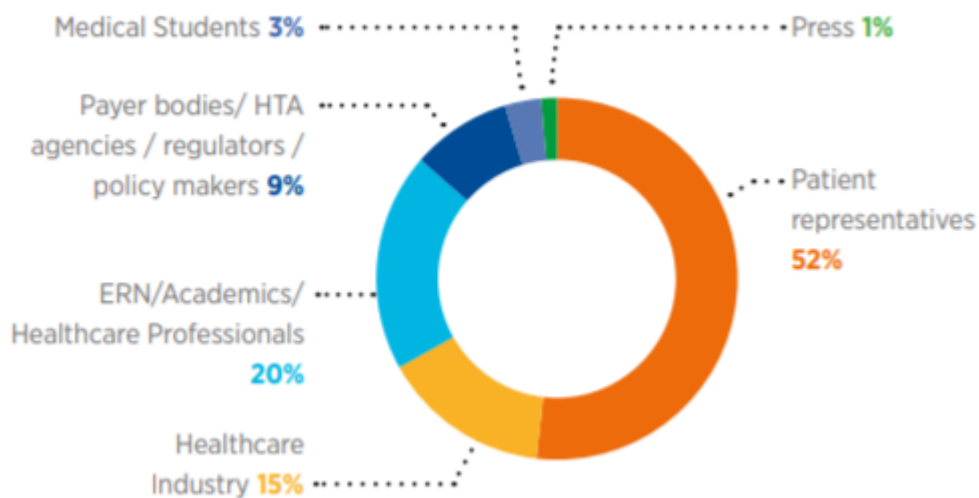
About the discussion during the world café session, please rate the following statements

- The output of the discussion is satisfactory
- The quality of the discussion was adequate and deep enough
- The discussion elements were meaningful and relevant

The main criticism expressed by participants was for the duration of the workshop (half/day) which was considered too short, probably affecting also the perception on the quality of the discussion. In answering a specific question, the majority of respondents stated that the workshop should have been longer (11/18 agree that one full day would have been preferable) with additional time allocated to the world café (40% state that the time allocated to world café was not adequate).
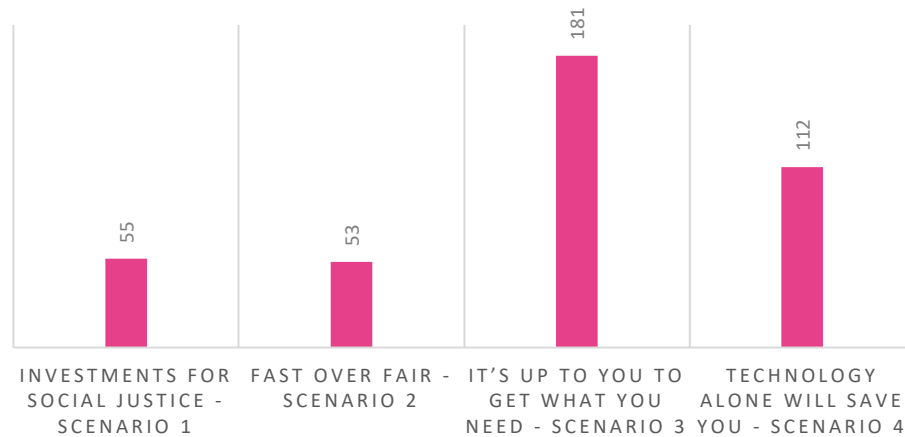
The following step in reaching a consensus on the preferred scenario was the ECRD 2020 conference. As mentioned, because of the COVID-19 pandemic outbreak, the event was moved fully on-line within a relatively short time (basically one month – April – as the event was held on the 14-15th of May 2020). This should always be considered when revising the results and the feedbacks.

Despite the difficulties of moving the conference on-line, participation was very high. Around 1500 on-line participants and 1042 unique visitors represented all the categories of stakeholders as reported in the graph below (*Source: ECRD 2020 Executive Summary*):

The plenary session on RARE 2030 scenarios was attended by more than 800 delegates, of which 314 regularly voted on the preferred scenario: over 90% (283/314) selected scenario 1 "investment for social justice" as the preferred scenario. It is therefore clear that a broad consensus was reached on that scenario being the preferred one. On the other side, a question on the least preferred scenario was also asked and here the answers were a bit more scattered even if Scenario 3 "It's Up to You to Get What You Need" is clearly the least preferred.
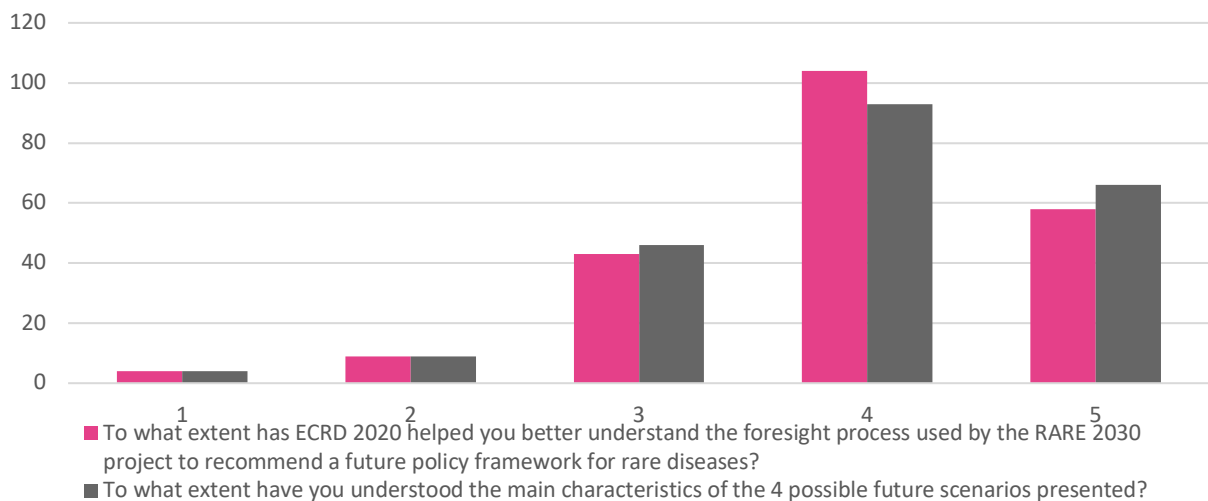
Which of the following scenarios would you least prefer?

The feedback survey on the conference also included some questions specifically linked with the RARE 2030 project. In particular, participants were asked:
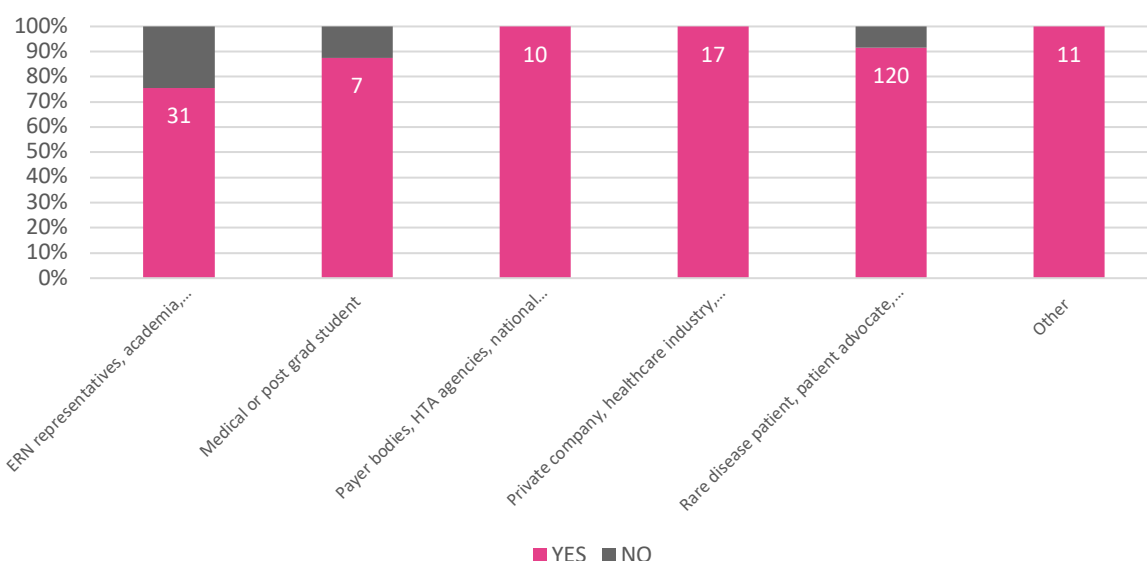
- To what extent has ECRD 2020 helped you better understand the foresight process used by the RARE 2030 project to recommend a future policy framework for rare diseases?
- To what extent have you understood the main characteristics of the 4 possible future scenarios presented?
- Are you interested in receiving further information on the RARE 2030 project and possibly contribute to its development?

The third question can be considered as a good proxy of the success of the RARE 2030 project in triggering the interest of participants. The response rate to the survey was around 15% (218/1437) but it is quite representative of all stakeholder categories.

■ To what extent has ECRD 2020 helped you better understand the foresight process used by the RARE 2030 project to recommend a future policy framework for rare diseases?
■ To what extent have you understood the main characteristics of the 4 possible future scenarios presented?

Here below the graph summarizing the results to question 3 per category of stakeholder.

Are you interested in receiving further information on the RARE 2030 project and possibly contribute to its development?
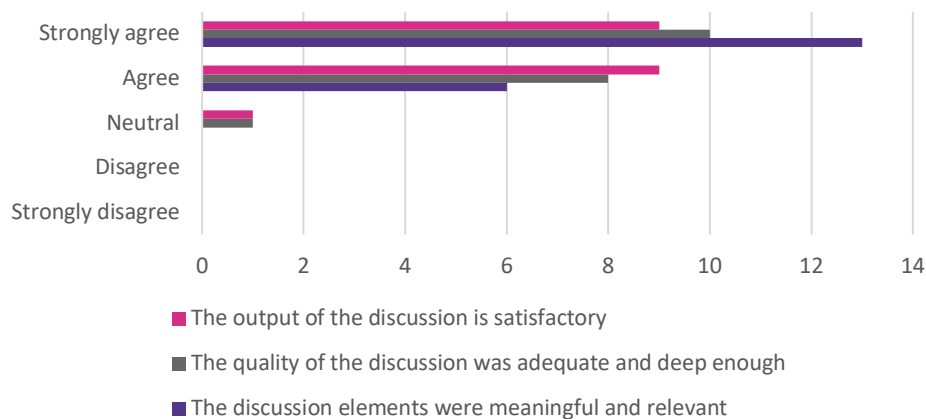

As shown in the graphs above, the overall satisfaction of participants was good and ECRD 2020 proved to be an effective way to disseminate the project and engage all categories of stakeholders.

These results were confirmed by both the Young Citizens, who expressed a unanimous preference for Scenario 1, as well as by the Panel of Experts, who also confirmed scenario 1 as the preferred one. Members of the PoE were invited to fill a dedicated survey on scenarios a couple of months after the ECRD 2020. Although the response rate to this last survey was not high (27/185 = 15%), the outcome is very clear as 85% of the respondents confirmed the preference for scenario 1. This survey kicked off the work with PoE on "back casting", moving the focus from scenarios to recommendations. Soon after the survey the members of the PoE were invited to a series of webinars to discuss the policy options to reach the preferred scenario and young citizens started also working with the same objective.

3.2 Co-creation of policy recommendations

In July 2020 Young Citizens attended a dedicated conference to work on policy recommendations. 28 Young Citizens coming from 12 European countries were recruited by EURORDIS through an online selection procedure. A structured feedback questionnaire was designed, and 19/28 participants (68%) filled it in. On a scale from 1 to 5, the average overall satisfaction of participants was 4,4 with only 2 scoring 3 and none less than 3. A similar result was registered also for the satisfaction against the expectations of each participant. When asked about the quality of the discussion, the answers were even more positive as shown in the graph below.

About the discussion WITH YOUR PEERS, please rate the following statemens

- ■ The output of the discussion is satisfactory
- ■ The quality of the discussion was adequate and deep enough
- ■ The discussion elements were meaningful and relevant

About the discussion WITH THE EXPERTS, please rate the following statemens

- ■ The inputs received by the experts were appropriate and useful
- ■ The discussion elements were meaningful and relevant
- ■ The quality of the discussion was adequate and deep enough

The survey also collected very informative qualitative feedbacks reported in Annex 1 (Chapter 5). It is interesting to notice that, despite the young age of the participants, the on-line format was still seen as an obstacle to the debate even if the technical solutions adopted were highly appreciated.
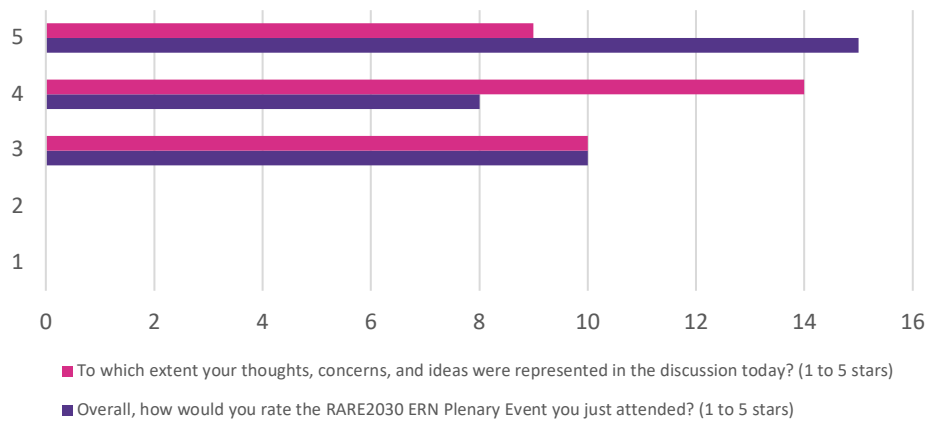
Another milestone for the preparation of the recommendations were the webinars with ERNs. Again, due to COVID-19, the face-to-face event originally planned was split into a series of 4 webinars (2,5 hours each) followed by an on-line plenary conference. The Plenary proved highly successful, with the participation of 80 people of whom 16 ePAG representatives, 21 ERN coordinator/ERN Healthcare Provider representatives, 13 Board of Member States representatives, 4 ERN hospital managers, 8 European Commission representatives, and 18 participants from EURORDIS and RARE 2030 partners. Feedbacks were collected for all the webinars and were very useful to adjust the agenda and the approach while progressing from the first to the fourth webinar.

The feedbacks reported here refer only to the plenary session and were collected via instant polls during the event. Participants were asked 2 straight questions:

1. Overall, how would you rate the RARE2030 ERN Plenary Event you just attended? (1 to 5 stars)
2. To which extent your thoughts, concerns, and ideas were represented in the discussion today? (1 to 5 stars)
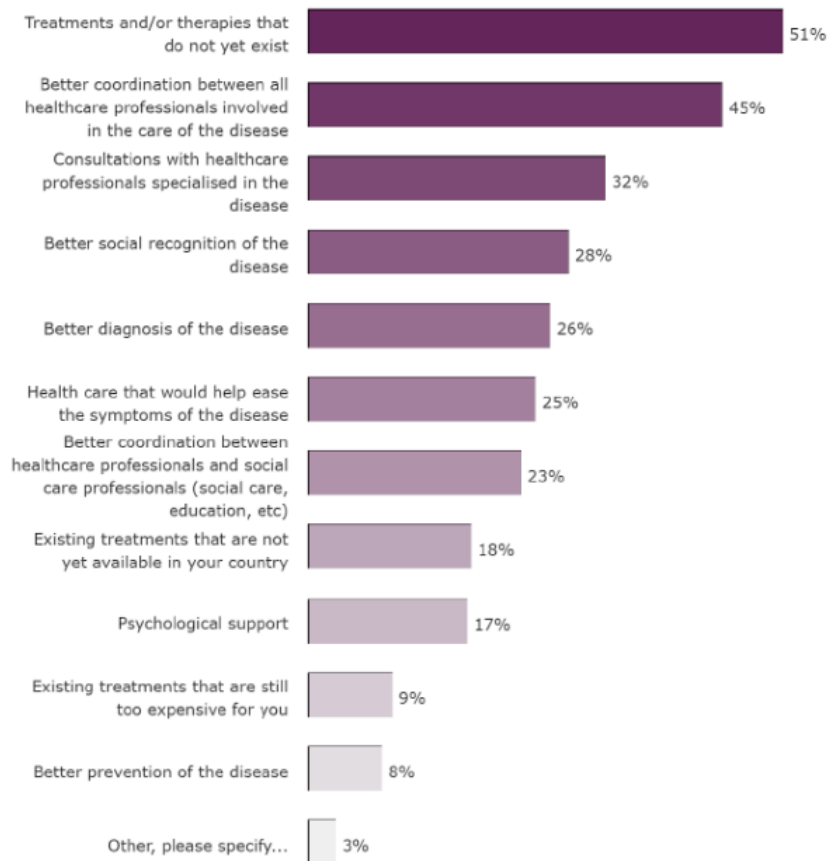
Thanks to the adopted technological solution (instant polls) the response rate was satisfactory (48/80 = 60%). The feedback was very positive, as for both questions around 80% of participants scored 4 or 5 stars. Cleaning the answers by not considering the feedbacks provided by RARE 2030 project partners, the score is still considerably high with an average of 4.17 for question 1 and 3,97 for question 2 with nobody scoring under 3.

ERN plenary conference - Rare 2030 parteners excluded

■ To which extent your thoughts, concerns, and ideas were represented in the discussion today? (1 to 5 stars)
■ Overall, how would you rate the RARE2030 ERN Plenary Event you just attended? (1 to 5 stars)

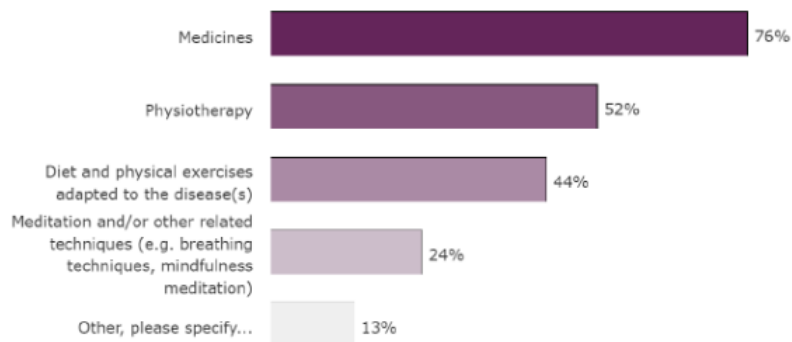Another key moment in the consultation process was the Rare Barometer survey conducted at the end of 2020 among people living with a rare disease (PLWRD) and their caregivers. While an extensive analysis of the data collected is reported in D6.1, some key results are included here as well. 3998 patients, carers and patient representatives expressed their needs and opinions on priorities for rare diseases within the next 10 years.

Graph 11. Within the next 10 years, the top 3 priorities to improve care for your rare disease would be to access to:

Priority	%
Treatments and/or therapies that do not yet exist	51%
Better coordination between all healthcare professionals involved in the care of the disease	45%
Consultations with healthcare professionals specialised in the disease	32%
Better social recognition of the disease	28%
Better diagnosis of the disease	26%
Health care that would help ease the symptoms of the disease	25%
Better coordination between healthcare professionals and social care professionals (social care, education, etc)	23%
Existing treatments that are not yet available in your country	18%
Psychological support	17%
Existing treatments that are still too expensive for you	9%
Better prevention of the disease	8%
Other, please specify...	3%

Several answers possible; 3 answers maximum.
The order in which modalities appeared was random and different for each respondent.

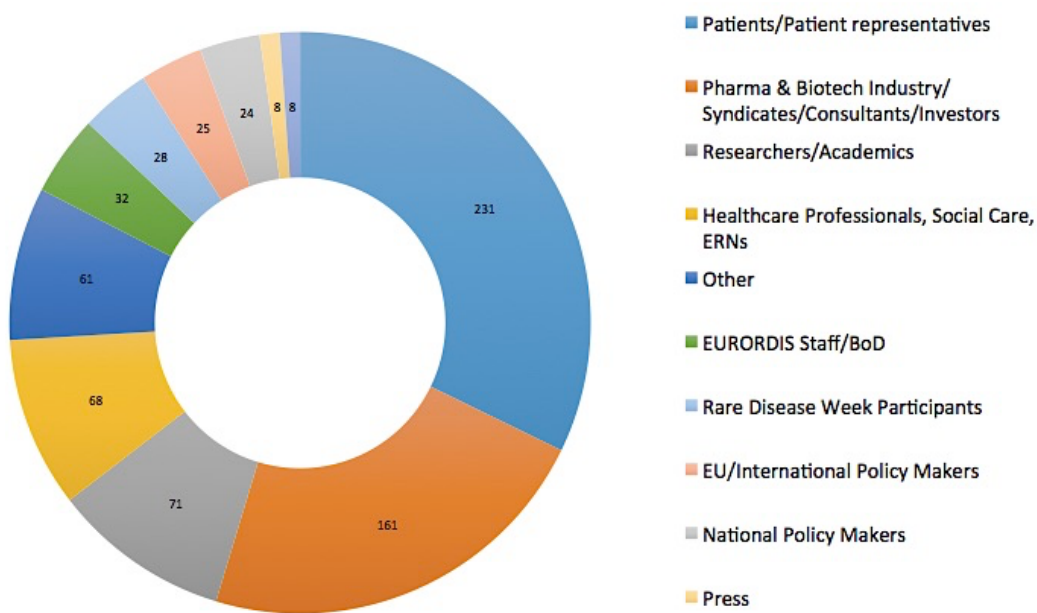**Graph 13. Within the next 10 years, in order to help ease the symptoms of your rare disease, you would need access to (N= 924*)**

	%
Medicines	76%
Physiotherapy	52%
Diet and physical exercises adapted to the disease(s)	44%
Meditation and/or other related techniques (e.g. breathing techniques, mindfulness meditation)	24%
Other, please specify...	13%

*Only respondents who cannot yet manage the symptoms of their rare disease but consider it possible and realistic within 10 years.

The two answers selected above clearly indicate that the priority for patients is the development of new treatments for their diseases as well as a better coordination among the healthcare professionals. It is important to notice that treatments do not necessarily and only mean medicine but also physiotherapy and diet.
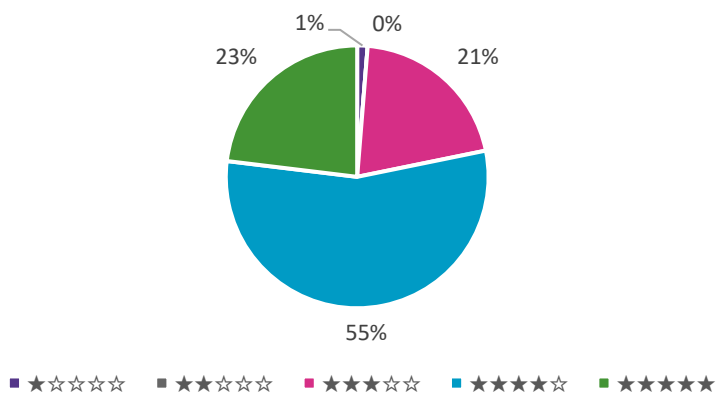
Finally, the last milestone of this structured and comprehensive consultation and engagement process was the Policy Conference held in February 2021. Again, being an on-line event, instant polls were used as the main tool to gather feedbacks from participants. 719 delegates attended the conference, with a fair representation of diverse stakeholder groups.

Rare 2030
Foresight in Rare Disease Policy

Legend:
- Patients/Patient representatives
- Pharma & Biotech Industry/Syndicates/Consultants/Investors
- Researchers/Academics
- Healthcare Professionals, Social Care, ERNs
- Other
- EURORDIS Staff/BoD
- Rare Disease Week Participants
- EU/International Policy Makers
- National Policy Makers
- Press

Of the 179 participants who responded to the question on whether they have contributed to the preparation of the recommendations, 66 (37%) replied "Yes", testifying the high level of engagement and collaboration in the preparation of the recommendations. Among those who answered "no", 61/100 (60%) scored 4 or 5 to the question "How likely do you think these recommendations will lead us to the preferred scenario?".
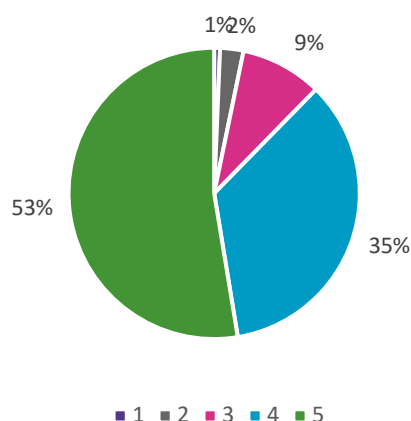
How likely do you think these recommendations will lead us to the preferred scenario*?

*(*only respondents who did not contribute to the recommendations)*

Legend:
- ★☆☆☆☆
- ★★☆☆☆
- ★★★☆☆
- ★★★★☆
- ★★★★★

The general feedback on the conference (154 respondents) was also extremely positive with an average score of 4.4 in a scale from 1 to 5.

Overall, how much did this session meet your expectations (score 1 to 5)?

| 1% | 2% | 9% |
| 53% | | 35% |

■ 1 ■ 2 ■ 3 ■ 4 ■ 5

One of the last questions asked was "How urgently do you think a new policy framework is needed to ensure long-term, concerted national plans across Europe?". Only 61 participants replied to this question (as the only survey platform did not allow all participants to respond), but the results are impressive as 66% scored 5 out of 5 and an additional 28% scored 4 over 5.

The results of the final conference demonstrate therefore that:

- The engagement process of stakeholders during the whole project was effective in producing a shared set of recommendations
- The identified recommendations are relevant and, if implemented, could lead to the preferred scenario
- There is an urgent need for a new European policy framework to guide the process that will likely lead to the scenario largely preferred by the rare disease community.

4 Final comments

The evaluation carried out during the project achieved 2 main results:

1. Improving the process by providing continuous feedbacks to the RARE 2030 partners
2. Register the success of the engagement of the rare disease community through the whole project, from trend identification to the selection of the preferred scenario and up to the policy recommendations.

It is important to notice that the COVID-19 pandemic heavily impacted on the project as more than half of the events planned were moved on-line. Thanks to the effort of the partners, this change was well managed, and the results achieved despite the obvious difficulties. In this situation the monitoring and evaluation of each step of community engagement was a precious tool to adjust the methods and improve the organization and management of on-line events to a scale never seen before.

As testified by the numbers presented in this report, RARE 2030 was a real collaborative effort by a broad community and project partners were excellent facilitators for the engagement of all the relevant stakeholders.

5 Annex I – Young CITIZENS CONFERENCE - comments by participants

5.1 Comments on the quality of the overall experience

- Amazing platforms thanks to the Wild is the Game facilitators team, fantastic exercises
- The quality of the conference was superb. I really like how everything was constructed and implemented.
- that was a greater experience than I expected when I joined! But I prefer the real meeting…
- Really loved the job of the facilitators. I think it was really useful to have the first experience on Miro and Discord because things were changed and improved. I think it worked really well, also split the day in two mornings were genial because. Was super well organized and the facilitators and experts were really helpful. The experts brought so many inputs and clarification!
- Better planning and responding to mails and don't forget to send essential mails.
- As good as it can get on an online platform
- I rated the conference higher than three, but I wanted to state that the only issue I had was the online format, although we had no other option
- The Conference was very good, maybe I would have liked to have a bit clearer image in mind previous to the attending
- Converting to an online system was a struggle but it definitely worked out better than expected. I feel I didn't connect with people as much as if we had met in person
- I am very happy with the overall experience. People are amazing, our moderators, mentors and everyone involved. I didn't face any problems while connecting to the meetings, everything was very well explained, and we had support with whatever wasn't clear. The topics we discussed were very well selected, not just randomly assigned.
- Very pleased with the conference, the facilitation and content were top notch
- I am just really sorry that we didn't meet in person. It would be way much comfortable for me.
- overall great, despite restructuring online, more focus/less broader tasks preferred from my side to have change to deliver something more meaningful and less general/generic
- It was excellent

5.2 What were, according to you, the 3 main success factors of this online experience?

- Collective energy throughout the discussion and dynamism; networking with people from different backgrounds and expertise; and the surprisingly good flow and structure of the conference despite being online
- The whole changing (not sticking to just one) of small-group with and without the experts + everyone present at once; having zoom + Miro at the same time
- digital tools, flow, preparedness
- Digital tools used, rhythm of the sessions, interaction of the peers
- Digital tools used. I liked Miro. ; 2. The way the conference was facilitated; 3. Excellent coordination between Wild is the Game and EURORDIS team
- the good will of everyone. We were working together in the same goal with the same wish to succeed 2) nice informatic management and good knowledge of software. The training session helps a lot. 3) communication for event and mail for "waking up" the team.
- Rhythm of the flow, digital tools and the participant's motivation
- Digital structure with small groups, possibility to visualize ideas and connect them. No traveling time

- Miro online dashboard, background music, half day conference
- Digital tools, friendly atmosphere, information and resource access
- Fun and knowledgeable facilitators, digital tools, agenda structure and selected topics
- engaging attitude of facilitators, fast pace, highly structured
- I truly liked the different digital tools, the "mood" that the facilitators managed to create (with the music and so on), but I also think that having had the chance to interact with them previously also helped a lot
- I really liked the MIRO - we could write it down asap and work with that. Then how smoothly we were instructed to groups etc. and overall energy that Wild is the Game tried to maintain although we couldn't be together.
- Agenda structure, motivation of the facilitators (and participants), rhythm of the flow
- strict time keeping, user friendly tools, clear instructions of what is expected
- Wild is the game, JULIEN who, for me will be forever remembered as the heart and soul of this project and the experts ready to work with us.
- The digital tools used, Zoom and Miro; the feedback from experts; the availability from Wild is the Game team
- I was impressed how we managed to use online tools, teams were able to create meaningful points and we had time to exchange opinions and experiences.

5.3 List 3 things which could have improved your digital experience as participant

- Actual exercises on Miro before the conference; collaborative assignments to get to know each other better and to start the work of the conference; and maybe adding a third day to go even further in some aspects (e.g. a full day devoted to reporting and feedback)
- A tool to find group members on the board or even larger arrows pointing where we are at (I only attended day 2 and had trouble understanding Miro in the evening of 1 to get on track)
- time spent on each exercise, at the end of the timer in breakout session we were cut in the discussion. would need extra seconds or a countdown until we get back in the plenary
- Having everyone on board for the discussion
- I believe that the conference was very well organised. The only thing i am not satisfied is that sometimes Miro tends to go into freeze and slow motion, but that is not connected to the organisers, but rather to the user end (internet connection)
- more ice-breaking session because the first contact is harder online that it is in real life. 2) if it is possible, looking for less heavy software to run because some of us reach connection troubles. 3) English was not easy to use for everyone and I think that is harder online... Maybe some translating help? 4) where is the sangria???? (supposed to be face-to-face in Barcelona
- Not having a first problem with Miro (a bug) that wasted me my time, but I was saved by Olivier ;); a bit more practice to not remove items from their original place ; have more time to discuss and write, sometimes we lost time with small things with no interest (like making a square; or reshaping etc) (but actually the last time I think it worked really ok!)
- Even smaller groups to cover even more topics, including a specific preparation of only one topic
- longer breaks, not to be suddenly cut off in a discussion because have to move onto the other rooms
- I truly enjoyed the experience; thus it is a bit hard for me to identify something to improve. The only thing I actually remember as least positive about the digital experience was that I felt the introduction to MIRO was not that straightforward. So, just ensure that you choose the tools not only according to the overall tech skills of participants, but also taking into account the time participants have to get familiar and truly explore the tools.
- I would appreciate more focused topics from the beginning so we could focus and go deep into the topic. Maybe overall outcome - I want to go through all of the groups. I don't have the third one.
- Digital tools (Miro),

- the facilitator sometimes jumped in to check and interrupted without letting people finish their sentence, disruptive for the discussion. For Miro: better to freeze more things on the board to it doesn't move around when people accidentally click. I really didn't like the "warming up task" of selecting a gif of what or expecting. Might work in real life settings when people can immediately react but felt weird online
- I wish I had more time so I would have been able to get to know Miro better before the conference, we needed more "slack" to the conversations and discussion within the group, and food - GOD I was hungry all the time and wasn't really able to eat while entering the discussions and the conference. I am hypoglycaemic (low blood sugar) so this was maybe only an issue for me......
- I can only say that I wish the conference would maybe take 1 or 2 more days so we, as a team, could better discuss the topics assigned to us
- I am very satisfied with my experience.

5.4 List 3 things they should definitely keep doing because they facilitated your digital experience

- Working with an external partner expert in digital event (like Wild is the Game); working on tools such as Miro; Inviting participants to other events such as the ECRD
- The Whatsapp discussion was awesome, though maybe we could have had it even before for some chit-chat?
- keep being as dedicated and nice!
- Working on a shared platform, help by facilitators, feedback from the experts always available
- Keep the great spirit; 2. Keep the hard work and dedication; 3.
- 1) keep being smiling and happy. This is very encouraging when we reach problem. 2) ice-breaking and joking because I find those digital experience very stressful. 3) being ready to solve any trouble with kindness
- giving support during the conference/anytime something happened; previous explanations to start using the tool experience and time to be familiar with the tool
- Small groups, Miro to facilitate notes, short brakes
- Miro interactive platform
- group chat, multiple platforms to communicate, constant contact with the progress and plans with the changing environment
- Keep the positive spirit, continue being supportive and reachable, continue following new trends in digital world
- online "whiteboard" was very helpful, funny breaks/ music, good balance between open discussion and structured presentations
- Keep making it as personalised as possible; keep creating a sense of proximity, and whenever possible introduce participants to new tools, because the experience or rather, the learning experience is maximised. Congratulations on all your work and the best of luck!
- MIRO - I loved it. Then keeping it flowing with some short game. I found out very helpful that we could ask for help anytime of the conference.
- Zoom, discord,
- Miro, great platform, strict time keeping, working in small groups in zoom
- 1. Julien, 2. Wild is the game, 3. The experts
- Give voice to patients and encourage this exchange of perspectives; invite experts to the discussion
- Be consistent, create more games such as done by Wild is the Game and be positive