Frequently Asked Questions

WHAT? What is the Rare2030 project about?

The Rare 2030 study is organised as a **participatory foresight process** with the goals of producing a **state of the art of the current system, analysing trends** and building **scenarios** on the future of rare diseases (RDs). This work will serve to develop a better understanding of the **future governance of RDs** and identify the **emerging issues that will trigger needs for policies, regulations** as well as **innovative advice processes and tools**.

The scenario building process will have the following objectives:

- identify trends and changes that will influence the future EU and national RDs governance, diagnosis, care, treatment and quality of life of people living with a RD (general);
- identify those emerging technologies and social practices that will trigger the need for new regulations, demanding innovative tools and procedures (domain specific);
- inform policies in order to adjust regulations more quickly to social and technological changes;
- set priorities for investments in order to anticipate/adapt regulatory infrastructures and services supply (including human capital) to future needs.

As one of the consolidated and widely used tools of foresight activities, **scenarios** aim to serve as a “A description of how the future may unfold according to an explicit, coherent and internally consistent set of assumptions about key relationships and driving forces”\(^1\). Different from forecasting, scenarios explore uncertainties in order to identify policy options and possible trade-offs. The Rare2030 Scenarios are developed according to the *intuitive logics foresight school*\(^2\), which originated with RAND and is now strongly associated with Shell Oil and the Global Business Network. The overall process will be characterised by a highly participatory dimension, involving hundreds of experts and thousands of people living with RDs through surveys, workshops and interviews.

If you want to know more please visit: [https://www.rare2030.eu/](https://www.rare2030.eu/)

WHY? Why carrying out foresight process?

Foresight and other forward looking activities are recognised by the European Commission in the “Better Regulation "Toolbox"\(^3\) as tool to “complement quantitative modelling with a system thinking and long-term approach that is developed through qualitative and participatory methods involving all relevant stakeholders”. Main objective is to create a multi-stakeholders space for experimental and safe discussion in order to explore and discuss the consequences of events and changes and identify targets and new ways of policy interventions.

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1 Forward Thinking Platform and supported by The Global Forum on Agricultural Research (GFAR) “A Glossary of Terms commonly used in Futures Studies” (2014) 19
2 Bradfield R. et all “The origins and evolution of scenario techniques in long range business planning” Futures 37 (2005) 795–812
3 Better Regulation "Toolbox" This Toolbox complements the Better Regulation Guideline presented in in SWD(2015) 111

www.rare2030.org
Foresight initiatives are now established in strategic planning practice, and are already in use within the EU institutions, to name few:

- DG Research and Innovation finances and supervises important interdisciplinary foresight projects;
- Scientific Foresight Unit within the European Parliament Panel for future Science and Technology (STOA);
- Joint Research Centre (JRC) is a long-standing provider of foresight intelligence, performing foresight studies and developing methodological guides, training courses and networks on foresight;
- The European Strategy and Policy Analysis System (ESPAS) provides a framework for cooperation and consultation at administrative level, on a voluntary basis, between EU institutions. ESPAS manages ORBIS - an European Strategy and Policy Analysis System project aimed at strengthening the EU's efforts in the crucial area of forward planning.

The EC highlights four main functions and benefits of applying foresight to policy making as illustrated in the Table below:

<table>
<thead>
<tr>
<th>Function</th>
<th>Outcome</th>
<th>Benefit for policy</th>
</tr>
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<tbody>
<tr>
<td>Informing policy</td>
<td>Understanding change Visions of change</td>
<td>Long term orientation Additional source for information (based on a broad variety of views) Awareness of future challenges</td>
</tr>
<tr>
<td>Facilitating policy implementation</td>
<td>Networks, shared visions</td>
<td>Better receptivity of actors for policy objectives due to ownership of results and therefore easier implementation</td>
</tr>
<tr>
<td>Embedding participation in policy making</td>
<td>Transparency of policy making process</td>
<td>Better identification of citizens with policy (legitimacy)</td>
</tr>
<tr>
<td>Supporting policy definition</td>
<td>Generation of strategic options together with policy makers</td>
<td>Direct support in strategy development and implementation</td>
</tr>
</tbody>
</table>

Table 1 Tool #4. Evidence-based better regulation

Do you want to know more? Watch the video: https://ec.europa.eu/jrc/en/research/crosscutting-activities/foresight

HOW? How a foresight process is structured?

Foresight does not predict the future but aims to provide the elements to influence it. The process of Scenarios building can be broadly summarized in the following four phases:

- Horizon Scanning of trends, drivers, weak signals, wild cards;
- Combining drivers and build different, plausible Scenarios;
- Backcasting and identify pathways to move toward most desirables futures;
- Validation and consensus creation on scenarios and pathways.

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The identification and analysis of macro trends and emerging changes are used as basis to build future scenarios from which derive political and entrepreneurial options to be implemented today. The identification of alternative scenarios serve to recognize a Vision, a preferential scenario, and to elaborate a Roadmap, a way to achieve the defined objectives by establishing time and allocating resources.

The length of each phase and will be designed according to the purpose, the territorial level, the time and the resources available of the foresight activities. As example, the foresight cycle below was proposed by STOA to promote the undertaking Scientific Foresight activities at the European Parliament (individual EP and committee).

![Foresight cycle diagram](image)

**Figure 1 towards Scientific Foresight in the European Parliament**


**HOW? WHICH METHODS FORESIGHT ACTIVITIES USE?**

The toolbox for foresight is rich, but the fundamental task is to select and adapt the best research and participation methodologies to guarantee the optimal results.

The table lists the methods used in each of the phases often used in designing a systemic foresight process. “What these figures demonstrate is that although we tend to work with and focus on individual tools, our vantage points and mental acts and methods are inherently systemic and that it is the totality of the learning that provides the insight, not reliance upon a single tool. The tools listed above involve a certain degree of information input, creativity, expertise and participation.”

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8 Smith J., Saritas O. “Science and technology foresight baker’s dozen: A pocket primer of comparative and combined foresight methods” in Foresight 13(2):79-96 · April 2011

Annex 1 - Glossary

**Foresight**

"Foresight is a systematic, participatory, future-intelligence-gathering and medium-to-long-term vision-building process aimed at enabling present-day decisions and mobilizing joint actions. It can be envisaged as a triangle combining “Thinking the Future”, “Debating the Future” and “Shaping the Future”. Foresight is neither prophecy nor prediction. It does not aim to predict the future – to unveil it as if it were predetermined – but to help us build it. It invites us to consider the future as something that we can create or shape, rather than as something already decided”.

![Foresight Triangle](source: JRC-IPTS)

Definition adapted from [European Foresight Platform](https://www.foresight-platform.eu/)

**Horizon Scanning**

Horizon scanning is a technique for detecting early signs of potentially important developments through a systematic examination of potential threats and opportunities, with emphasis on new technology and its effects on the issue at hand. The method calls for determining what is constant, what changes, and what constantly changes. It explores novel and unexpected issues as well as persistent problems and trends, including matters at the margins of current thinking that challenge past assumptions.

Horizon scanning is often based on desk research, helping to develop the big picture behind the issues to be examined. Desk research involves a wide variety of sources, such as the Internet, government ministries and agencies, non-governmental organisations, international organisations and companies, research communities, and on-line and off-line databases and journals. Horizon scanning can also be undertaken by small groups of experts who are at the forefront in the area of concern: They share their perspectives and knowledge with each other so as to 'scan' how new phenomena might influence the future.

A solid 'scan of the horizon' can provide the background to develop strategies for anticipating future developments and thereby gain lead time. It can also be a way to assess trends to feed into a scenario development process.

Definition adapted from [Overview of Methodologies-OECD](https://www.oecd.org/innovation/industry-profiles/)

**Trends**

Trends are those change factors that arise from broadly generalizable change and innovation. They are experienced by everyone and often in more or less the same contexts insofar as they create broad parameters for shifts in attitudes, policies and business focus over periods of several years that usually have global reach. What is interesting about trends is that normally most players, organizations or even
nations cannot do much to change them – they are larger than the power of individual organizations and often nation states as well.


Drivers
Drivers of change are those factors, forces or events – developments which may be amenable to changes according to one’s strategic choices, investments, R&D activities or foresight knowledge and strategies. They are both presently accessible and future relevant.


Weak signal
The early signs of possible but not confirmed changes that may later become more significant indicators of critical forces for development, threats, business and technical innovation. They represent the first signs of paradigm shifts, or future trends, drivers or discontinuities.
Wild cards
Wild cards and shocks are those surprise events and situations which can happen but usually have a low probability of doing so – but if they do their impact is very high. These situations tend to alter the fundamentals, and create new trajectories which can then create a new basis for additional challenges and opportunities that most stakeholders may not have previously considered or prepared for.

Wild card/shock examples
- Gulf Stream shift;
- Nuclear bomb;
- Fusion power;
- Cyber collapse;
- Human aging breakthrough;
- Solar flare, asteroid impacts, discovery of an alien;
- Autonomous computers;
- The attacks of September 11, 2001, which created significant shocks to the global security, airport screening and intelligence systems and practices;
- A major pandemic or outbreak of a human focused communicable disease that has not been prepared for – such as SARS, Bird Flu and Swine Flu;
- Another internationally relevant disruption of energy systems on the scale of a Chernobyl nuclear accident.