

Rare2030

Foresight in Rare Disease Policy

WILD CARDS: WHAT IF THEY ACTUALLY HAPPEN?

Foresight studies are used to create a multi-stakeholders space for experimental and fruitful discussion in order to explore and discuss the consequences of events and changes and identify targets and new ways of policy interventions. Through a series of qualitative and participatory methods participants:

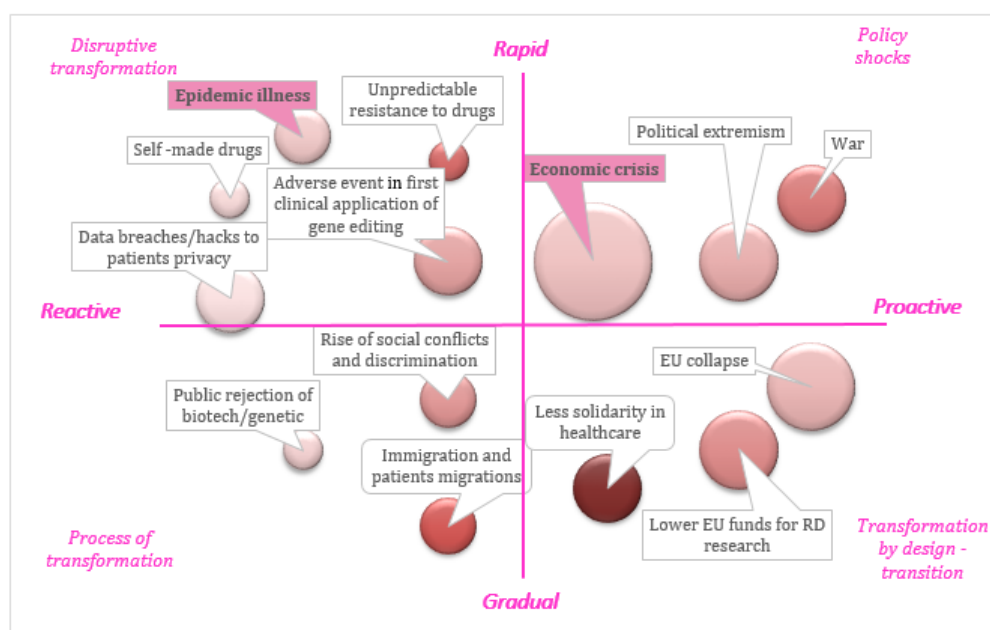
- 1) identify the trends and changes that might influence the future including “wild cards”
- 2) project multiple scenarios in which these trends may evolve
- 3) identify the new policies strategies and innovations needed to reach the future scenarios that are preferred and avoid those that are not.

In foresight jargon, wild cards or black swans are defined as disruptive events with low probability of happening but with high expected impact. What happens if they actually occur? The events classified as such are able to provoke drastic changes and modify the foreseeable trends development in unexpected ways: accelerating some, slowing-down others and creating new ones.

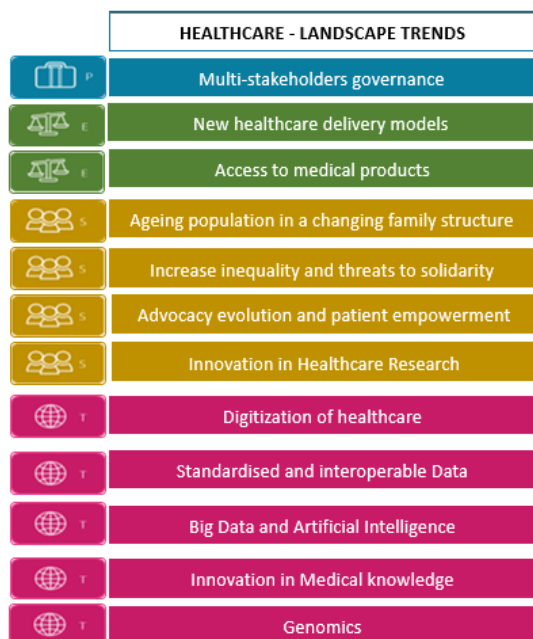
In October 2019, the RARE 2030 survey asked respondents to identify possible wild cards for the future of RD diagnosis, treatment and care. Not all changes proposed can be considered as wild cards or ‘unexpected events’ since they are strictly dependent on policy choices, strategies and programming and represent more deliberative changes than unexpected surprises.

The figure below map the negative changes proposed in two dimensions: the speed of change (gradual vs rapid) and the policy influence over the event (reactive vs proactive). The processes classified as “transformation” and “transitions” - listed in the bottom part of these graphs - are systematic shifts that will be taken into account in the writing of the scenarios storylines. Conversely, those changes considered as “disruptive transformation” or “policy shocks” – presented in the top quadrants of the figures – will be included in the scenarios as wild cards. The bubble size reflects the number of times that the event occurrence was mentioned by the survey respondents.

Looking at the negative events, Epidemic illness and economic crisis were mentioned by respondents as possible wild cards and these two are now that ones we should consider in the RARE2030 Scenarios – imagining the impact they might produce on healthcare trends and their implications on RARE2030 narratives.



COVID 19: on the edge of a “new normal”?



Through history, pandemic represented turning points catalyzing change and shaping societies. The question rising today is to what extent and in which ways the coronavirus pandemic will create long-term structural change in the way we live, work, interact and care. How the 12 RARE2030 ‘landscape trends’ will change and to what extent the new reality will represent a challenge or an opportunity for rare diseases care, treatment and cure?

The prognosis is unclear because much is unknown on COVID-19 dynamics and lasting consequences: incubation period and length of the infectious, possible effective drugs and limited immunity after recovery – with possible virus recurrence later in 2020 and into 2021.

What we know now is that coronavirus pandemic has affected 3 million of people and caused 210.000 deaths¹ worldwide. The pandemic has required governments to strike a balance between health protection and economy development. On

one hand, healthcare systems are facing pressures never seen before in recent times, experimenting a shortage of healthcare workforce and devices, boosting intensive care and postponing elective care. On the other hand, many economies, currently suffering from the freezing of industrial production and trade, risk to enter into recession in the near future with devastating consequences at level of employment and welfare resources². In addition, psychological and social consequences of quarantine and isolation are highly feared, especially in view of a rise of the unemployment rate.

We look at the consequences of the COVID 19 pandemic in four different areas highlighting the opportunities and risks that they might bring.

A CHANGING GEOPOLITICAL LANDSCAPE

The Atlantic Council³ has proposed three scenarios on how Coronavirus pandemic could change the global political and economic balance of the future.

- Great accelerator downwards Scenario: sketches a world, long lasting health and economic crisis;
- China first Scenario: features a new dominant role of China in the global political and economic landscape and the approval of “wall building policies”

¹ ECDC. Situation update worldwide, as of 28 April 2020 <https://www.ecdc.europa.eu/en/geographical-distribution-2019-ncov-cases>

² BBC News. Coronavirus: a visual guide to the economic impact. 30 April 2020. <https://www.bbc.com/news/business-51706225>

³ Atlantic Council. What world post COVID-19? Three scenarios. April 2020. <https://atlanticcouncil.org/wp-content/uploads/2020/04/What-World-Post-COVID-19.pdf>

- New Renaissance characterized by a better cooperation between States and a greater cross-border collective responsibility and solidarity feeling.

As for the European Union, as European Commission President Ursula von der Leyen has said “the EU as a whole needs to be determined, coordinated and united⁴”, the need to be unite to cope and not succumb to coronavirus emergency and consequences could be the opportunity to concretely strengthen the EU achieving the “United States of Europe”. In the current emergency phase, populist waves are witnessing a decrease in their consent. However, a risk of surge of nationalism movements in response to the economic crisis cannot be underestimated.

ACCELERATION OF SCIENTIFIC COLLABORATION

One of the main positive aspects of the Coronavirus pandemic is the acceleration of the worldwide multi-stakeholder scientific collaboration in R&D⁵. All countries are now committed to collaborate to speed up research in vaccine and in new drugs in public private partnerships. The urgency to quickly develop and validate diagnostic tests could:

- foster the genomic technologies and the AI use in healthcare
- incentivize the pharmaceutical innovation in areas with “high public health value but relatively lower market value⁶”
- promote the de-bureaucratisation of the authorization process of devices, drugs and tests in healthcare⁷.



There are historical moments when the future changes direction. We call them bifurcations. Or deep crises. These times are now. The world as we know it is dissolving. But behind it comes a new world, the formation of which we can at least imagine.



Matthias Horx, German futurist

⁴ EC. Press corner. Von der Leyen on Coronavirus response: EU to be determined and united.

https://ec.europa.eu/commission/presscorner/detail/en/AC_20_466

⁵ Science Mag. A completely new culture of doing research. Coronavirus outbreak changes how scientists communicate. 26 February 2020

<https://www.sciencemag.org/news/2020/02/completely-new-culture-doing-research-coronavirus-outbreak-changes-how-scientists>

⁶ Vox. How the Covid-19 pandemic will leave its mark on US health care. 22 April 2020.

<https://www.vox.com/the-highlight/2020/4/15/21211905/coronavirus-covid-19-pandemic-medical-health-care-hospitals>

⁷ Harvard Business Review. We Need a Cheap way to diagnose coronavirus. 26 February 2020. <https://hbr.org/2020/02/we-need-a-cheap-way-to-diagnose-coronavirus>

ICT TECHNOLOGIES ON THE RISE

One of the foreseeable consequences of the COVID-19 pandemic is the rise of ICT (information, communication and technology) applications in all sectors of society: work, leisure, care, security.

Lockdown has taught us that we can be distant but connected and has opened the door to a new remote-everything era that “has become completely acceptable as well as technically feasible for almost everyone”⁸. Similarly, the 2003 SARS epidemics in China boosted the e-commerce activities changing dramatically the global market.⁷ However, to what extent ICT applications and opportunities will be accessible to all it is still to be understood as the phenomena of the “digital divide” could create new inequalities in accessing fundamental services such education and care.

For healthcare, the pandemic has led to the widespread use of telehealth (+ 50% in US) whose use has boosted to avoid intra-hospital infections⁹. Despite the aid that AI and advanced technology are carrying to the epidemic control, the current crisis has unmasked a global unpreparedness in the standardization, interoperability and cross-country sharing of data¹⁰. The EU as well as a global cooperation on ICT infrastructures could greatly increase to most of AI and digital health in the next future.

THE EMERGENCE OF A NEW SENSE OF RESPONSIBILITY?

Lacking a vaccine and an effective drug, Coronavirus has underlined that collective responsibility is the only preventive action we can rely on to stop the infection spreading. All citizens have been called to take action – stay at home – for a collective good. The lockdown could provoke long lasting changes in citizens’ empowerment and stakeholders’ collaboration on healthcare policies. As example, the Spanish flu has led to embrace the concept of a “free at the point of delivery” healthcare and increased cross-country health collaboration with the foundation of international health agencies¹¹. Coronavirus pandemic could also bring people to advocate for ensuring universal health coverage for vulnerable populations and advance request to increase and make more transparent the healthcare investments¹².

THE NEED TO IMAGINE A NEW WORLD

⁸ Gerd. Welcome to The Great Transformation: How Covid-19 changed our world: Futurist Gerd Leonhard looks back from the near Future. 24 March 2020.

<https://www.futuristgerd.com/2020/03/a-crisis-is-a-terrible-thing-to-waste-how-covid-19-changed-our-world-futurist-gerd-leonhard-looks-back-from-the-near-future/>

⁹ National Organisation for Rare Disorders. <https://rarediseases.org/update-on-nords-recent-advocacy-work-on-covid-19-for-the-rare-community/>

¹⁰ Financial Times. Can Data save us from coronavirus. 3 April 2020. <https://www.ft.com/content/1f7f748f-3077-401d-afd6-742d9006ef43>

¹¹ TIME. The World Changed Its Approach to Health After the 1918 Flu. Will It After The COVID-19 Outbreak? 7 March 2020. <https://time.com/5797629/health-1918-flu-epidemic>

¹² Devex. After the pandemic: How will COVID-19 transform global health and development? 13 April 2020

<https://www.devex.com/news/after-the-pandemic-how-will-covid-19-transform-global-health-and-development-96936>

Coronavirus emergency has strongly underlined the benefit of the foresight process as the way in which we cannot predict the future but we can be prepared to face with it. The shock of coronavirus pandemic can be seen as an opportunity to speed up/promote the social and technological advances we made in past years. As the German futurist Matthias Horx summed up “There are historical moments when the future changes direction. We call them bifurcations. Or deep crises. These times are now. The world as we know it is dissolving. But behind it comes a new world, the formation of which we can at least imagine”⁷.

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The health of 30 million people living with a rare disease in Europe should not be left to luck or chance. The Rare 2030 foresight study prepares a better future for people living with a rare disease in Europe by gathering the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations.

Since the adoption of the Council Recommendation on European Action in the field of Rare Diseases in 2009, the European Union has fostered tremendous progress to improve the lives of people living with rare diseases. Rare2030 will guide a reflection on rare disease policy in Europe through the next ten years and beyond.

PARTNERS



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