

Rare 2030

Foresight in Rare Disease Policy



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ISINNOVA

RARE₂₀₃₀ FORESIGHT
STUDY:
TRENDS IN HEALTH
AND HEALTHCARE

FORESIGHT AND SCENARIO BUILDING: AIMS AND SCOPE

*Foresight activities aim to provide "a set of **strategic tools** that support governmental and industry decisions with **adequate lead time** for societal preparation and strategic response"*

- Anticipate multiple, plausible futures (vs one future)
- Investigate uncertain changes (vs Forecast and trends extrapolation)
- Adopt a long horizon time 10 – 25 years horizon (vs planning)



FORESIGHT AND SCENARIO BUILDING: OVERALL PROCESS

- I. Horizon Scanning of trends, drivers, weak signals, wilds cards => Critical Uncertainties (CU)
- II. Combining CUs and build different, plausible Scenarios;
- III. Backcasting and identify pathways to move toward most desirables futures;
- IV. Validation and consensus creation on scenarios and pathways.



FROM HORIZON SCANNING TO SCENARIO BUILDING: CRITICAL UNCERTAINTIES

To build contrasted scenarios (real alternatives), the main trends considered must be :

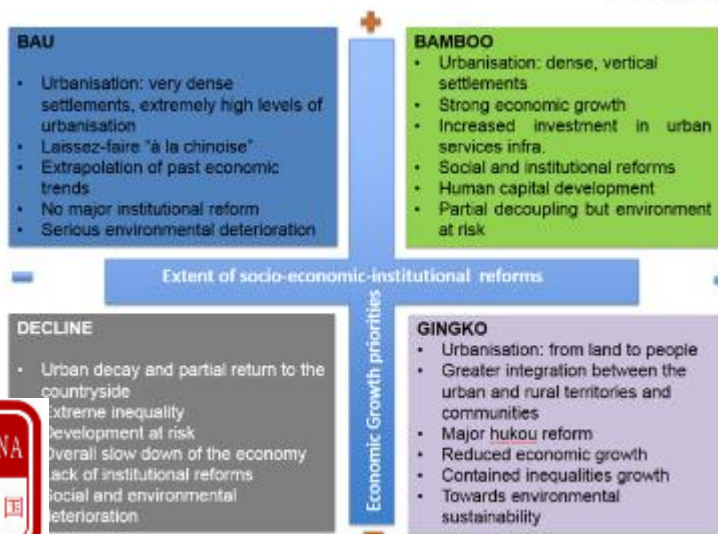
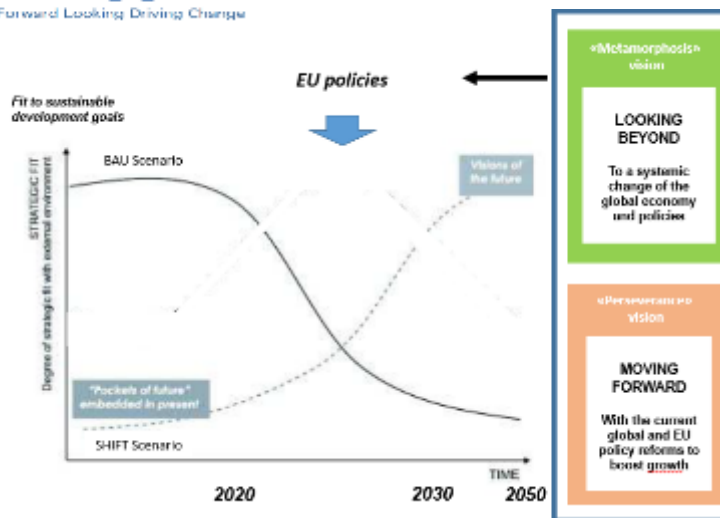
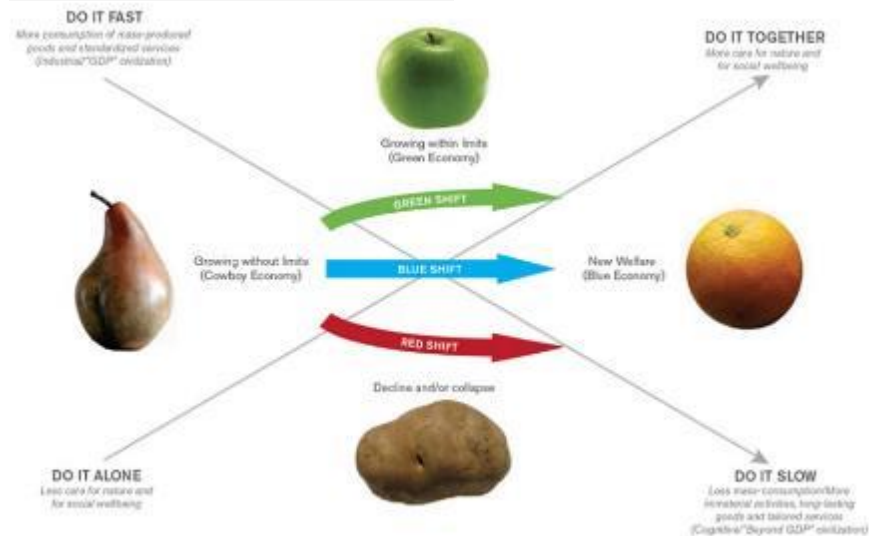
- > **Important:** any change in/deviation from the trend will have a visible effect on the outcome
- > **Uncertain:** Difficult to predict, and in principle amenable to changes according to strategic choices, investments, R&D activities
- > **Independent:** the main trends considered in a scenarios should not be interdependent



FORESIGHT AND SCENARIO BUILDING: MULTIPLE (CREDIBLE) FUTURES



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	DESOLATION HEALTH!	RICH GET HEALTHIER	WE WILL TREAT YOU	HEALTHY TOGETHER	
Increase of GINI index	Orange	Red	Red	Red	Decrease of GINI index
Stagnation/Decrease of living standards	Red	Red	Red	Red	Growth and higher living standards
Low cost-effectiveness in social terms	Light Purple	Light Purple	Dark Purple	Dark Purple	High cost-effectiveness in social terms
Low access to info for prevention & healthy life styles	Light Blue	Light Blue	Dark Blue	Dark Blue	High access to info for prevention & healthy life styles
Increase in extreme events and heat waves	Light Green	Light Green	Dark Green	Dark Green	Decrease in extreme events and heat waves
Decrease of healthy life years	Light Orange	Light Orange	Dark Orange	Dark Orange	Increase of healthy life years
	Light Green	Light Green	Dark Green	Dark Green	Decreased expenditure on air pollution
	Light Yellow	Light Yellow	Dark Yellow	Dark Yellow	Healthy diets

FRESHER
FORESIGHT AND TOOLKIT FOR EUROPEAN HEALTH POLICY APPLICATION

HORIZON SCANNING IN RARE 2030



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- > **Literature review of scientific publications and health and health care foresight studies** in order to gather information about emerging trends and developments that could have an impact on RDs and explore how these trends might combine and what impact they might have.
- > **1 workshop** with Patient representatives to collect ideas about emerging trends and drivers at European and national level
- > **9 interviews** with selected experts to improve our understanding of the relevant drivers, identify strategic issues that need to be addressed by policies.

The findings of the Horizon Scanning phase will be published in the report “**Report on determinants of health and drivers of change for RD**” (October 2019) and will be used to structure the **survey ranking the trends** (October 2019) and the **Panel of Experts workshop** (November 2019).



9 INTERVIEWS

> High level opinion leaders in foresight, innovative industries and health policy



Ruediger Krech
WHO



Ruxandra Draghia-Akli
Merck
(formerly DG RTD)



Robert Madeline
FIPRA
(formerly DG
SANTE, CONNECT)



Milan Macek
Orphanet,
Eurogentest,
RD Connect



Terkel Andersen
Danmarks Bløderforening,
EURORDIS



Didier Schmitt, former
advisor to EC on
Foresight



Natacha Assopardi-
Muscat
President EPHA



Kate Bushby
Former RD Action
leader



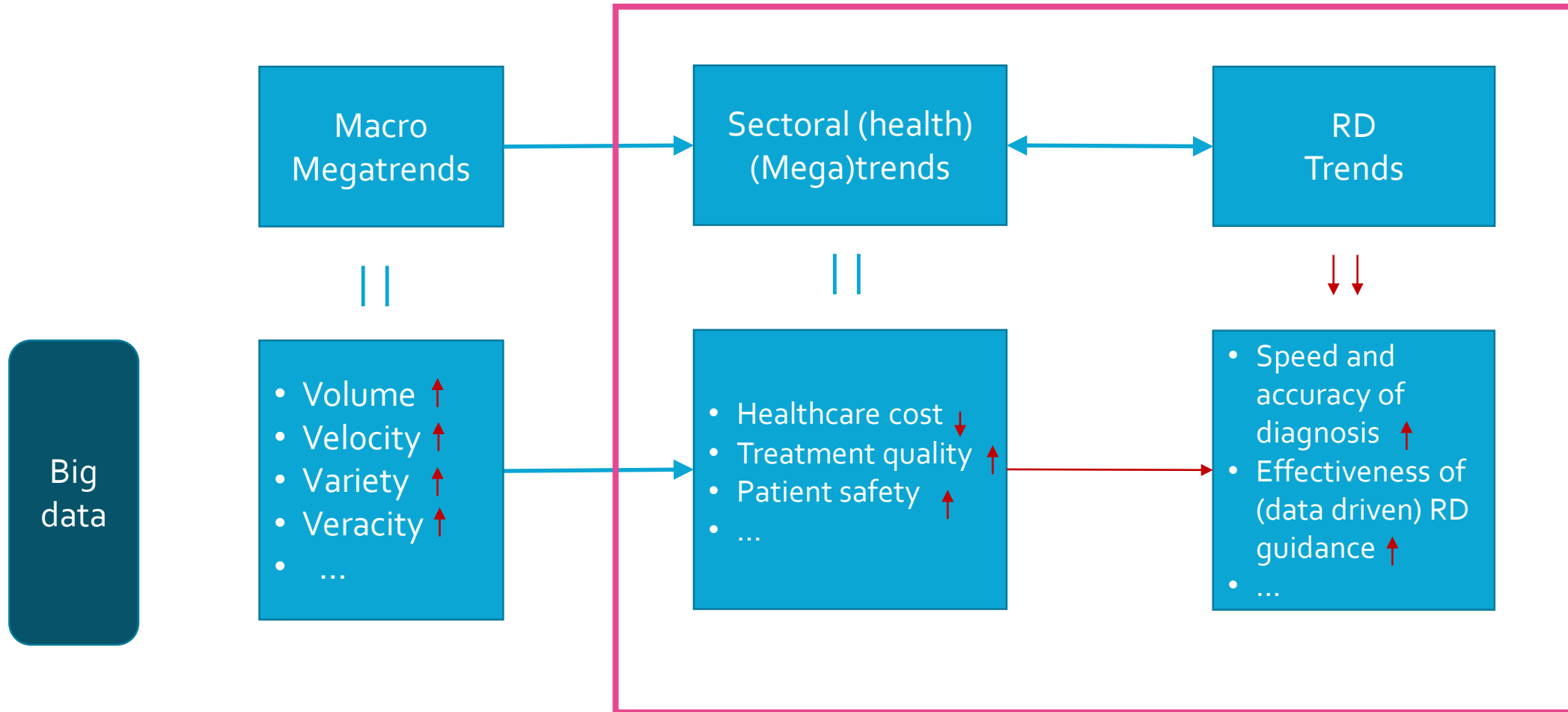
Tanja Braton
Fraunhofer Institute



TRENDS: OVERALL APPROACH IN HORIZON SCANNING



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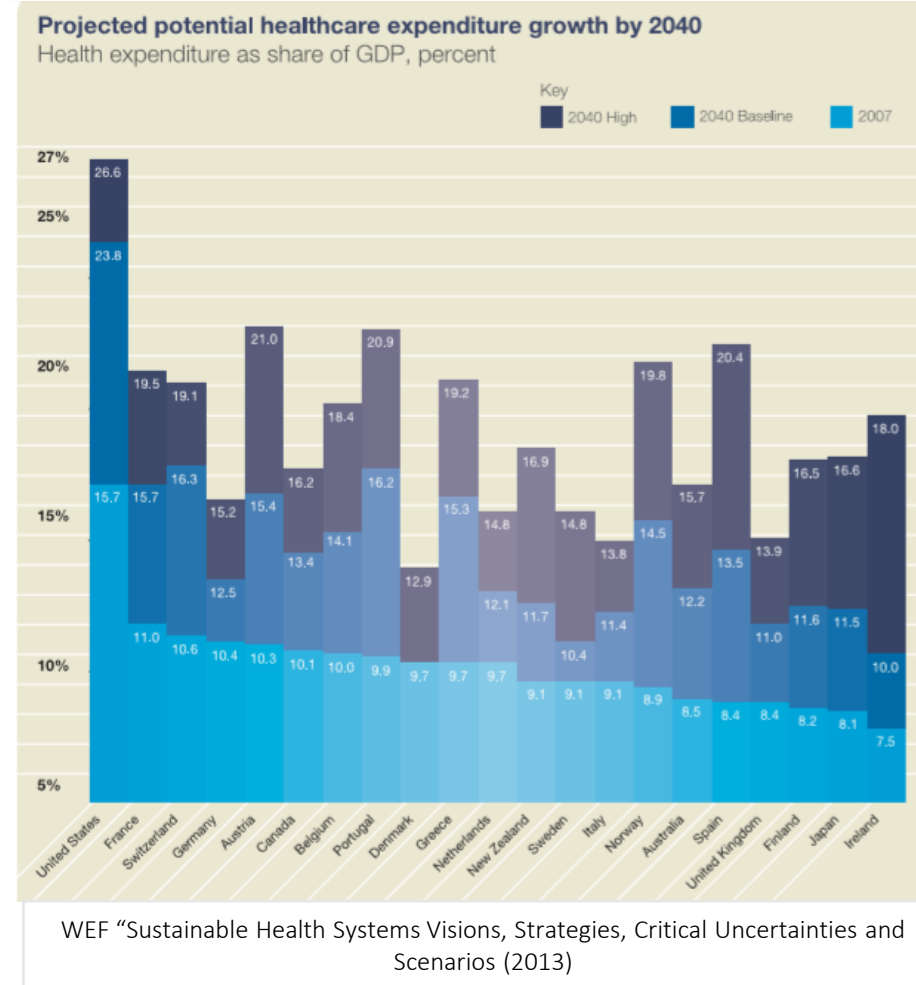
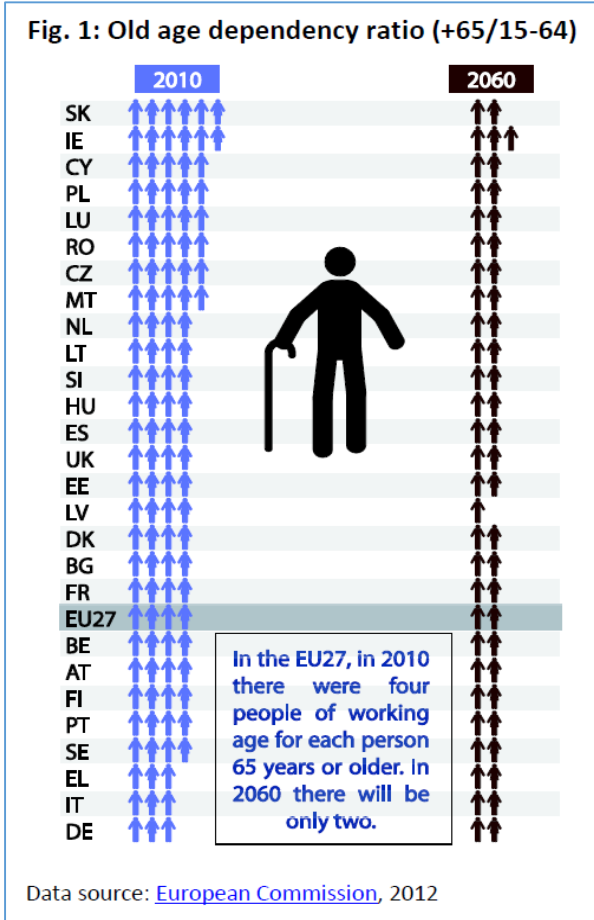
TRENDS IN HEALTH AND HEALTHCARE RELEVANT FOR RD

Overarching Trends in RDs	Relevant Broader Trends in Health and Healthcare	Type of Trend
1 Rise of pan-European multi-stakeholder networks to advance diagnostics, treatment and care for rare diseases	Multi-stakeholders governance	Political
2 Strains on the health care budget and the emergence of new care delivery models	New healthcare delivery models	Economic
3 Greater variation in access to treatments and care resulting in more inequality across Europe for people with rare diseases	Access to medical products	Economic
4 Demographic change of RD patients introducing new challenges	Ageing population in a changing family structure	Socio-cultural
5 Threats to solidarity equity, and the prioritization of rare diseases	Increase inequality and threats to solidarity	Social and Economic
6 Increasingly empowered rare disease patient and the patient advocacy evolution	Advocacy evolution and patient empowerment	Socio-cultural and Political
7 Rise in innovation-oriented, multi-stakeholder, needs-led (patient-led) research	Innovation in Healthcare Research	Socio-cultural and Political
8 Facilitation of knowledge exchange and local care delivery through digital health	Digitization of healthcare	Technological
9 Increased potential for large sets of standardised and interoperable data	Big Data	Technological
10 Rise in the use of AI for diagnostics, treatment and care, opening-up the potential of 'big data'	Big Data and Artificial Intelligence	Technological
11 New technologies and advanced therapeutics	Innovation in Medical knowledge	Technological
12 Application of Whole Genome Sequencing from the research to the clinical sphere	Genomics	Technological, Ethical and Legal

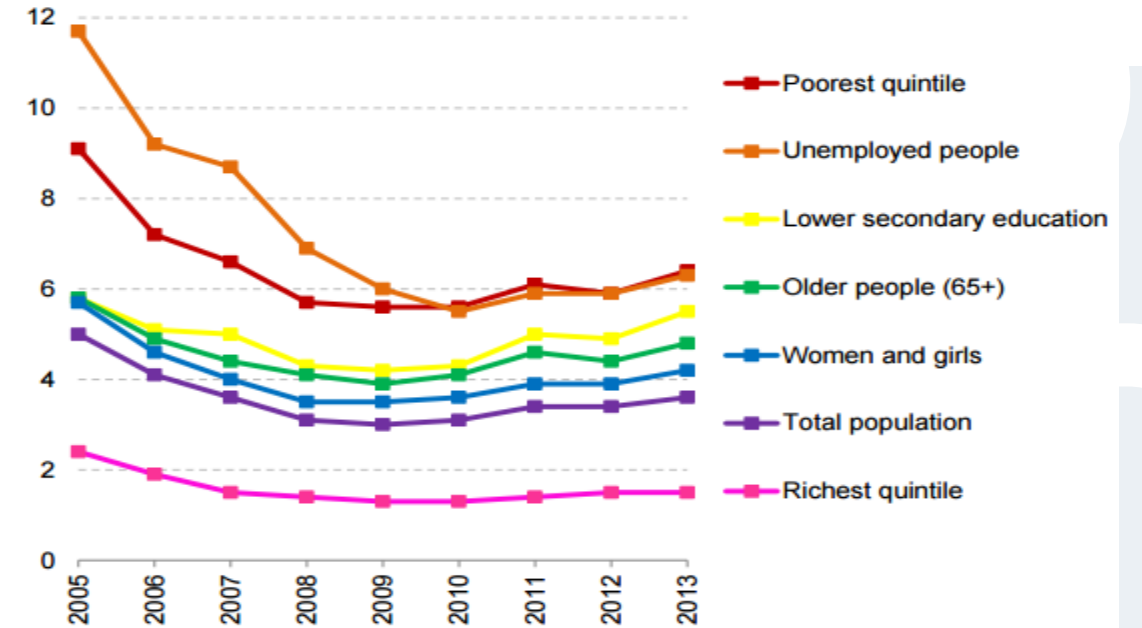
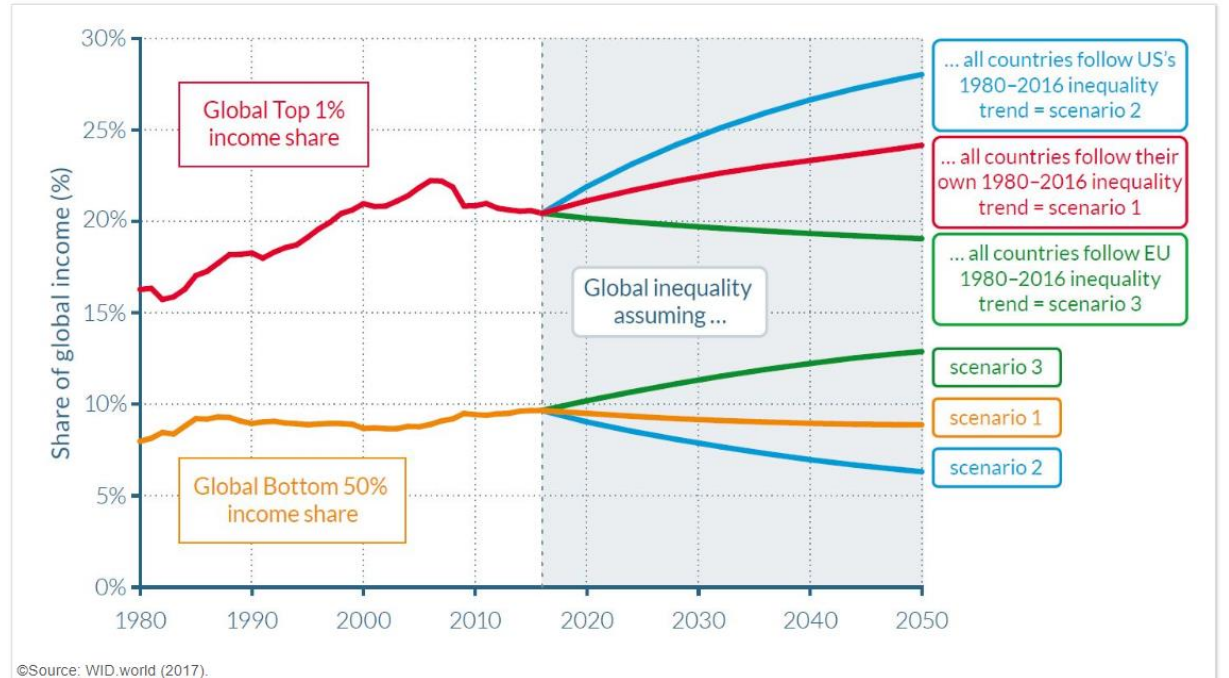
AGEING POPULATION IN A CHANGING FAMILY STRUCTURE & NEED FOR NEW HEALTHCARE DELIVERY MODELS



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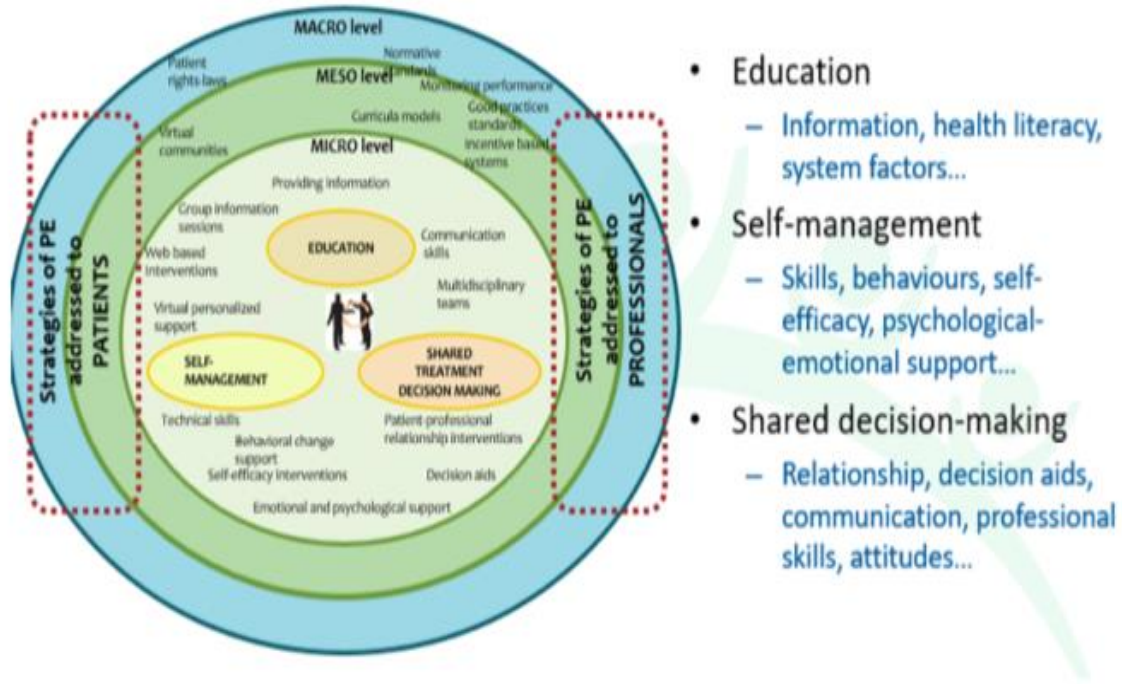


INCREASE INEQUALITY AND THREATS TO SOLIDARITY



Access to health services –summary of preliminary opinion - based in EU-SILC distance and waiting time, EU27, 2005-2013

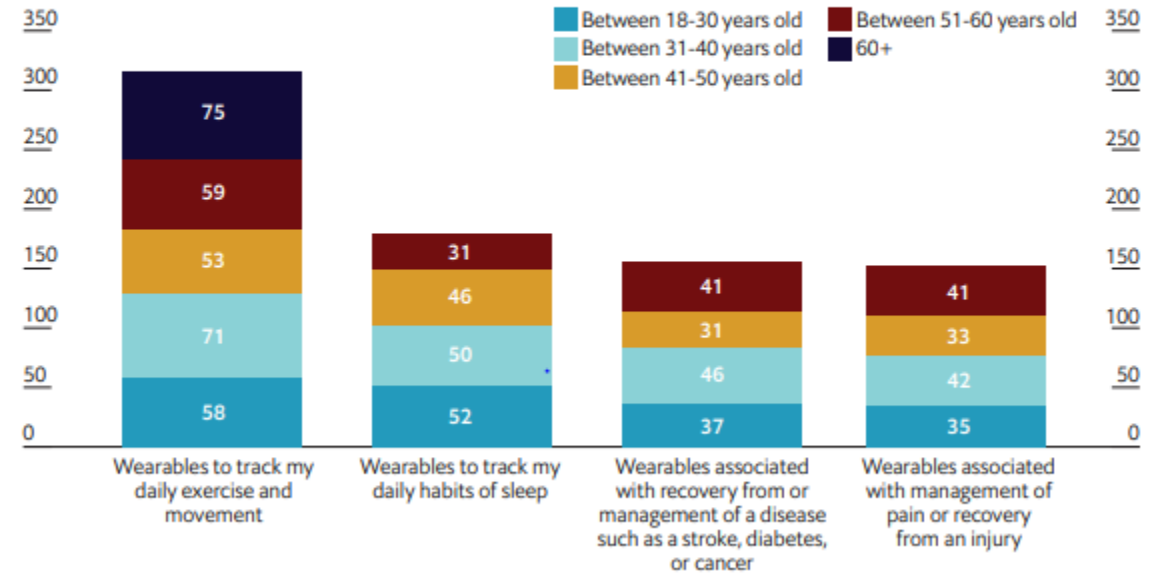
ADVOCACY EVOLUTION AND PATIENT EMPOWERMENT AND DIGITIZATION OF HEALTHCARE



Overview of the EMPATHIE study (“Empowering Patients in the Management of Chronic Diseases” 2014)

Figure I. What gets measured

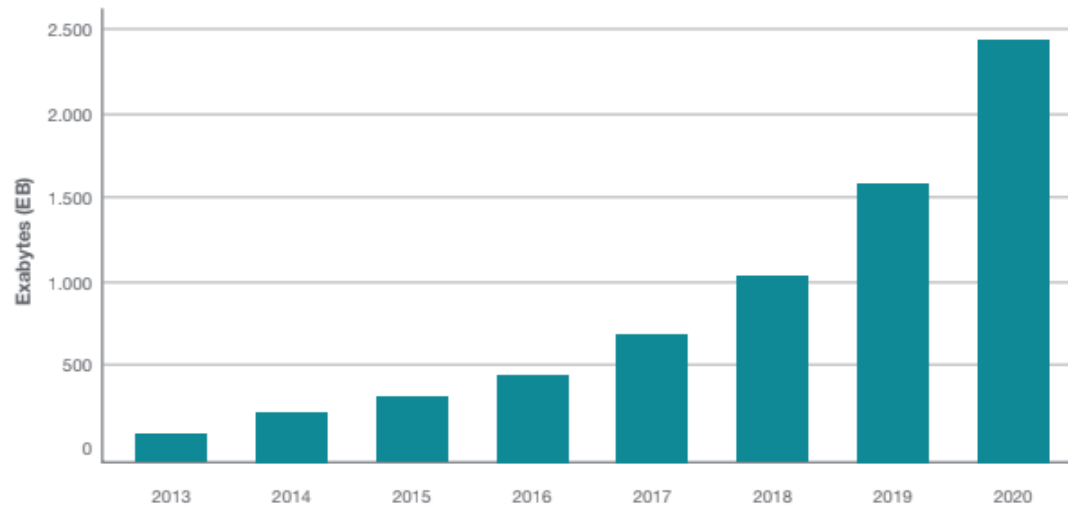
Which of the following wearables do you adopt for your health? Choose all that apply (excludes 7% of those who don't wear wearables). (% respondents)



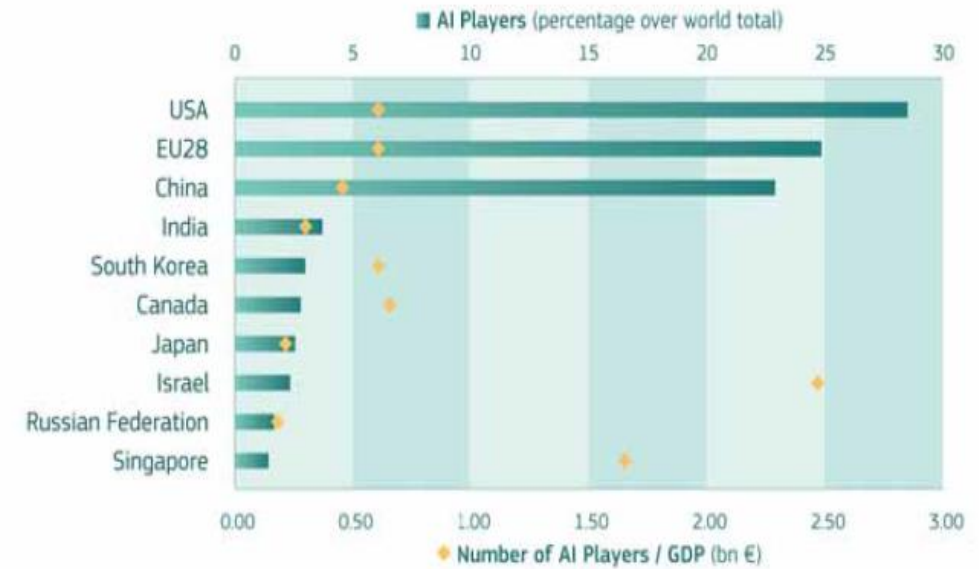
Source: The Economist Intelligence Unit

BIG DATA AND ARTIFICIAL INTELLIGENCE

Growth In Healthcare Data



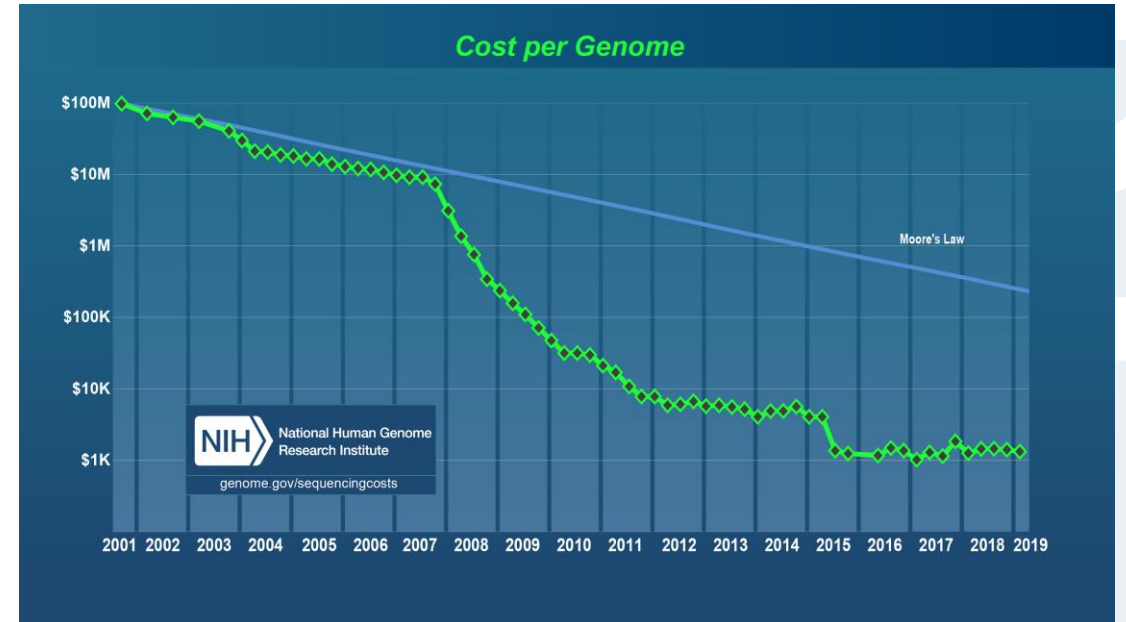
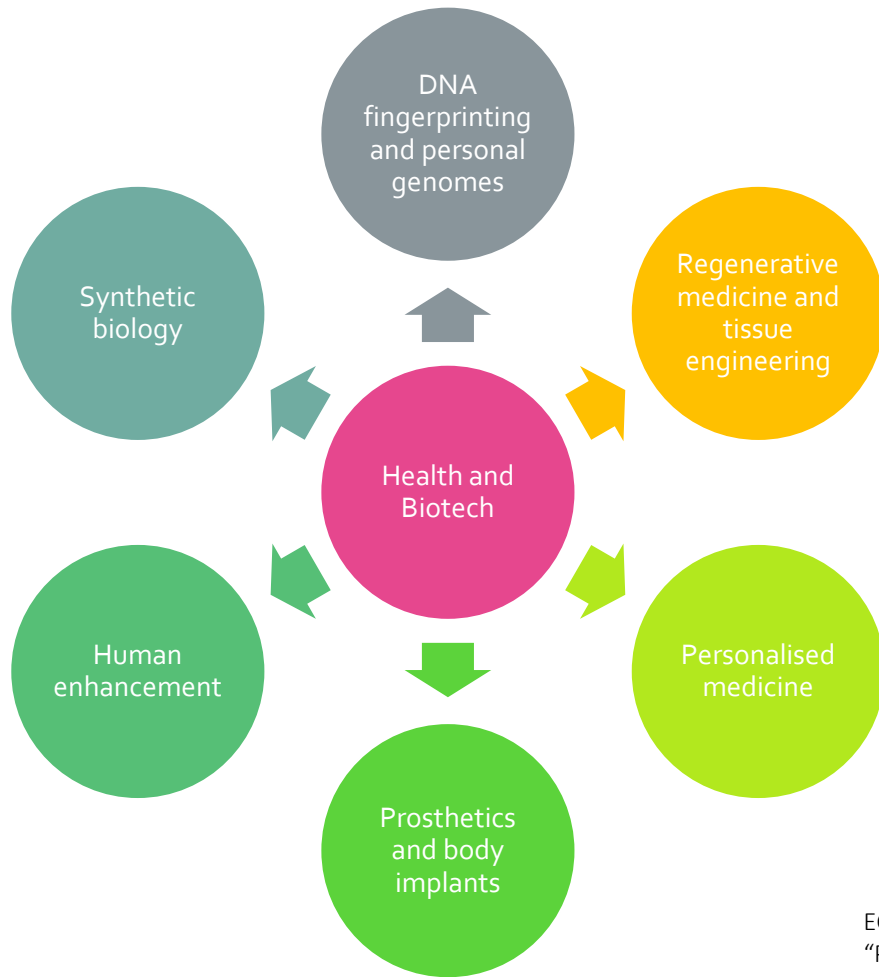
Source: EMC Digital Universe / IDC



Top 10 players in the world and relation with GDP by geographical zones, 2009.2018 Artificial Intelligence – An European Perspective



INNOVATION IN MEDICAL KNOWLEDGE AND GENOMICS

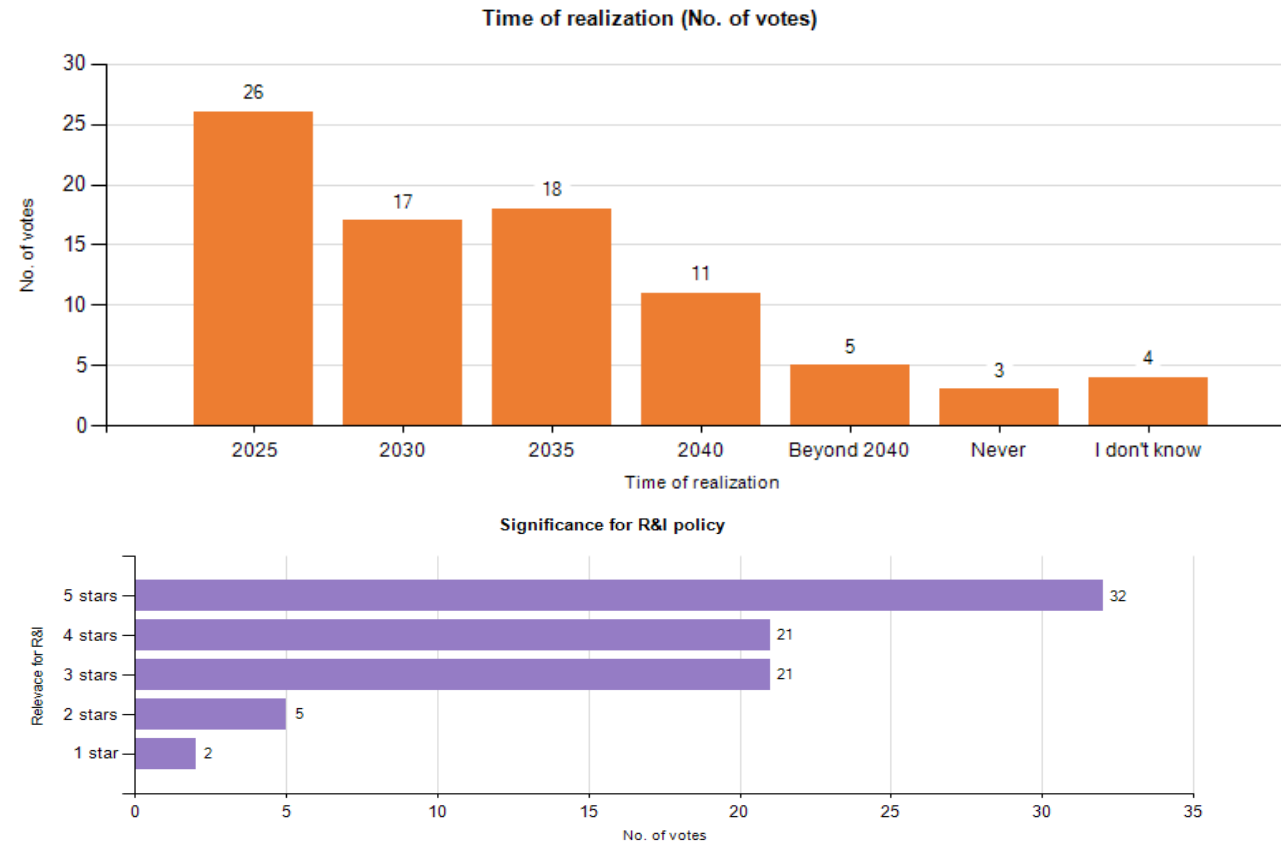


EC - Foresight network fiches 2030 Working document
"Preparing the Commission for future opportunities"



INNOVATION IN MEDICAL RESEARCH

Educational systems in the EU give equal weight to competitive and collaborative learning practices



Beyond the Horizon. Foresight in Support of the Preparation of the EU's Future Policy in Research and Innovation (BOHEMIA)



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THANK YOU FOR YOUR ATTENTION.



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