Rare2030

Foresight in Rare Disease Policy

TRENDS ON THE HEALTHCARE SECTORS: IMPLICATIONS FOR RARE DISEASES

GIOVANNA GIUFFRE

SCENARIOS AND GOVERNANCE

ISINNOVA

Rare 2030
Foresight in Rare Disease Policy

THE FUTURE WILL BE DIFFERENT FROM TODAY.

WHAT DO YOU THINK ARE THE CHANGES -TRENDS AND WEAK SIGNALS -THAT WILL AFFECT THE FUTURE OF RD GOVERNANCE AND TREATMENT THE MOST?

HORIZON SCANNING PROCESS

- **Literature review of RD scientific publications and health and health care foresight and scenarios** 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

- **10 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).

HORIZON SCANNING: WHAT WE HAVE LOOKED AT

We plan to review 50 foresight studies. Preliminary findings drawn from 15

- **Subject:** health system and healthcare foresight studies. There is no specific rare disease related foresight study.
- **Geographical scale**: most of studies focused on EU (7), but we have included studies with a global (4) and national prospective (2).
- **Time horizon:** 2030 or longer.
- **Funding**: studies funded and conducted by public (7), public-private collaboration (6) and private institutions (1) .
- **Approach:** most of studies considered adopted a participatory approach (8).

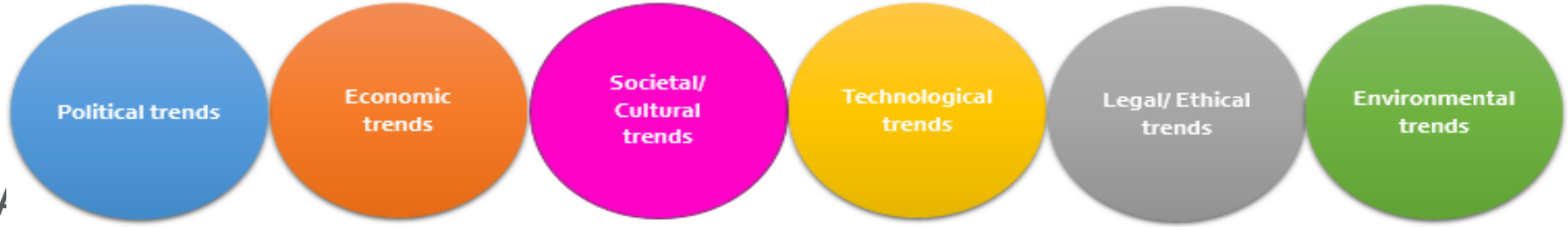
HORIZON SCANNING: WHAT WE ARE LOOKING FOR

Rare 2030
Foresight in Rare Disease Policy

- A **trend** is a *general tendency or direction of a development* or *change over time*. A trend may be strong or weak, increasing, decreasing or stable. There is no guarantee that a trend observed in the past will continue in the future. It can be called a **megatrend** if it occurs at global or large scale. Megatrends are the great forces in societal development that will very likely affect the future in all areas over the next 10-15 years.

- We define **drivers** as *developments causing change*, affecting or shaping the future. A driver is the cause of one or more effects.

- **Seeds of change:** 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



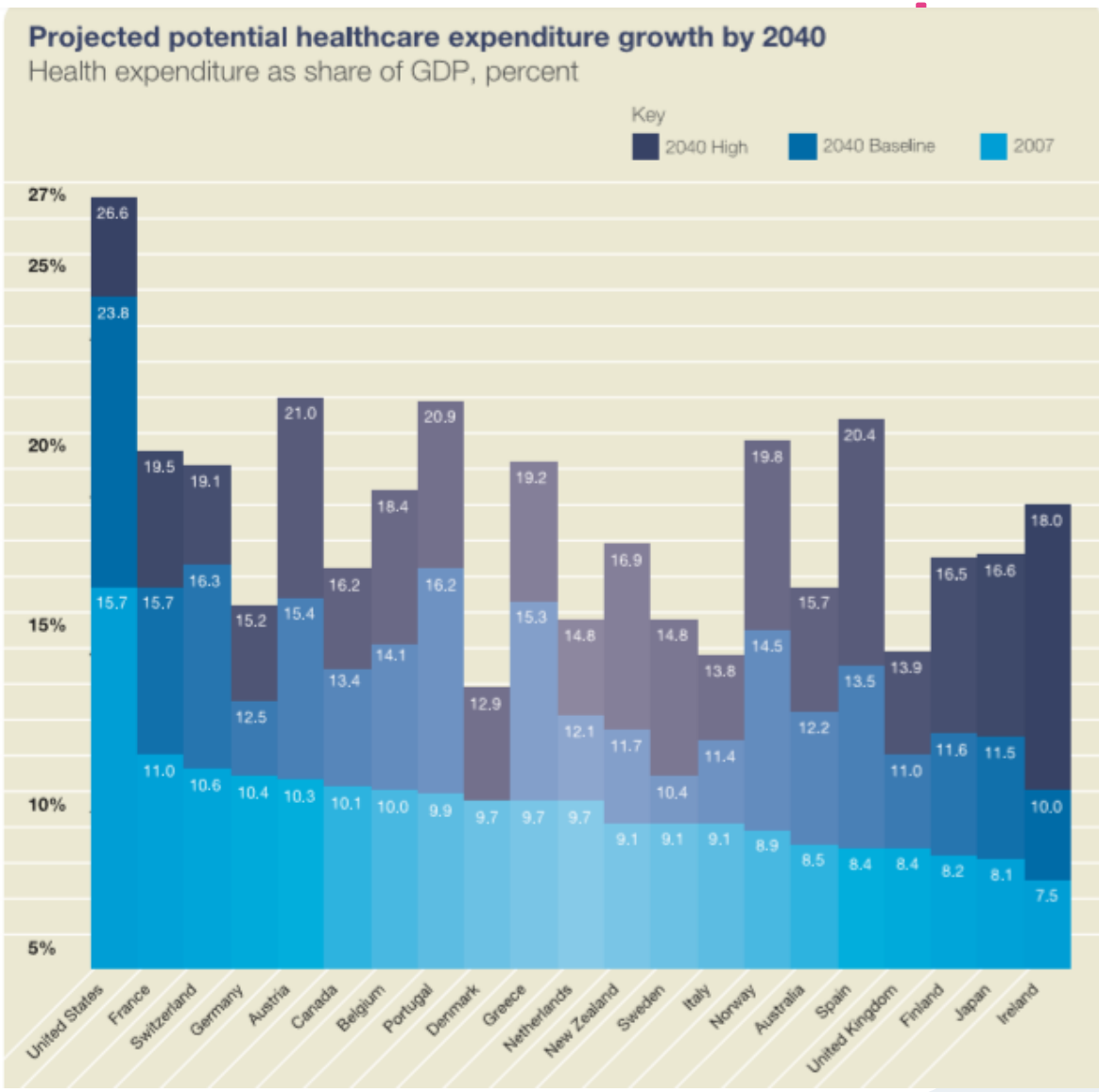
HORIZON SCANNING: HEALTHCARE TRENDS OVERVIEW

Political	Economic	Socio-Cultural	Technological	Legal/Ethical	Environment
Unity or diversification Health systems, regulated at national level, are now coordinated through the Open Coordination Method – it is unclear if in the future the systems transformation will be led and harmonized at local, national or EU level.	**Sustainability of healthcare systems** Increase of healthcare spending with low GDP growth forces states to reform current systems towards efficiency and innovation.	**Patient empowerment and e-health culture** Citizens increased use of technological tools to generate and analyse health-related information, some of which could be fruitfully used for research and clinical decision-making.	**Genomics and personalised medicine** It is expected that genetic sequencing will be in widespread use by 2040 forming the first-line technology for healthcare and allowing to use stratified diagnostic and treatment with genetic biomarkers.	**Privacy and ethics concerns** The market for wearable and medical apps (e.g. more than 40,000 healthcare apps) is rising steeply challenging the health digital competences of citizens as well as national privacy laws and procedures	**Climate change** Increasing exposure to extreme weather events causing health problems
Shift to network governance Growing role of citizens, industries and scientists collaboration in health research, applications development and policies.	**Dynamics of equity** Increased inequality, worsened in the last 10years following the economic crisis. In addition, rise in the number of people reporting unmet needs for healthcare - 3.6% of the population.	**Community involvement** Increased participation of civil society and involvement of communities in health provision.	**Wearables and sensors** The diffusion of wearables and remote sensors allows continuous monitoring with automatic collection of data and transmission to doctors.	**Distrust** Distrust of evidence and of experts - supplemented by "folk" knowledge. In addition, online information - unlikely to be regulated/curated	**Pollution and contamination** Increasing exposure to chemical and biological agents creates problems for respiratory health and health in general
Open data and science The potential creation of repositories with large national data linked at international level and available to researchers, medical workers and policy makers.	**Shortage of medical workers** In the EU, potential shortfall of around 2 million healthcare workers, long-term care and ancillary professions coupled with reduction of graduates from medical schools.	**Request for new skills and multi-disciplinarily** The use of -omics data requires the acquisition of new skills and increased cooperation between health professionals, bioscientists and technologists.	**Big data and health data registry** Creation of information systems that can capture, help interpret, and share complex yet accurate patient data, including genomic information and medical data.	**Regulatory science** The exponential growth of the role of science into policy-making. Regulatory science serves to assess safety, efficacy, quality, and performance of new products and inform policy-making throughout its lifecycle.	

A SYSTEM UNDER PRESSURE AND IN SEARCH OF SUSTAINABILITY

- **Trend:** Over the past 50 years, **total healthcare expenditure in OECD countries has climbed faster than GDP,** at an average annual rate of 2%. With no reforms under way that would affect the fundamental drivers of healthcare expenditure, some **estimates suggest that by 2040 total expenditure could grow by another 50-100%.**

- **Drivers**: an ageing population, an explosion of lifestyle diseases, a rise in public expectations, the advent of new therapies and technologies and the poor allocation of resources in the healthcare delivery.



WEF "Sustainable Health Systems Visions, Strategies, Critical Uncertainties and Scenarios (2013)

SHORTAGE OF MEDICAL WORKERS AND MULTIDISCIPLINARY SKILLS

- **Trend:** The EC estimated the gap in supply of human resources in **health by 2020 to be approximately 1,000,000 health workers**. This means that almost **15% of the care for the EU population will not be covered**. Other scenarios could slightly increase or decrease the presented figures. In addition, the emergence of **personalized medicine will increasingly require health professionals to acquire new skills** and collaborate in multidisciplinary team with bioscientists and technologists.

- **Drivers:** an aging workforce, significant turnover, new technologies, methods and infrastructures.

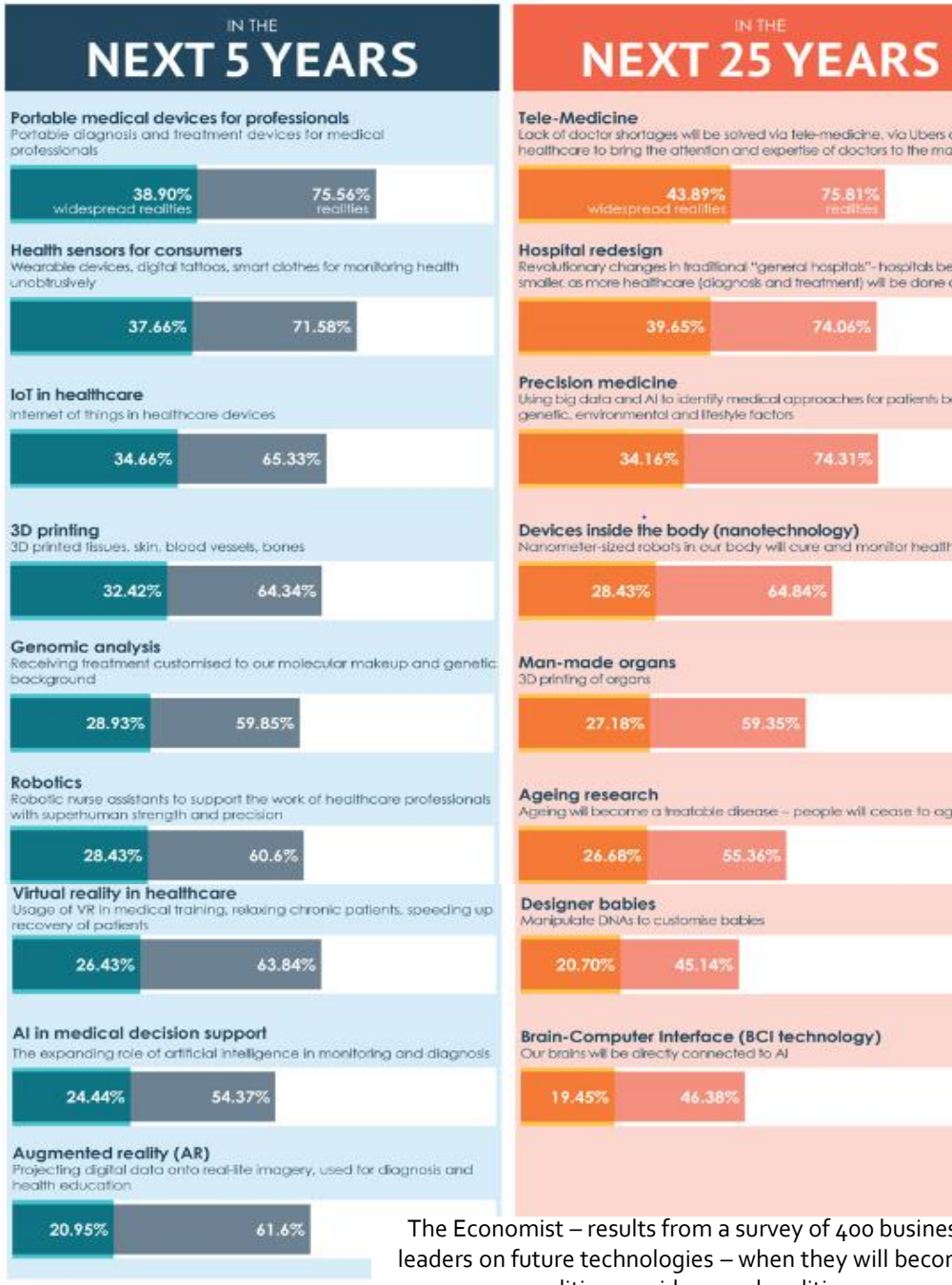
Health professionals or other health workers	Estimate shortage by 2020	Estimate % of care not covered
Physicians	230.000	13.5 %
Dentists, pharmacists	150.000	13.5 %
Nurses	590.000	14.0%
Total	970.000	13.8%

DG SANCO, 2010 - European Observatory on Health systems and policies " Investing in Europe's health workforce of tomorrow: Scope for innovation and collaboration"

ON THE EDGE OF A HEALTHCARE REVOLUTION?

- **Trend:** Potential medical revolution from transformative trends, resulting from biomedical sciences, engineering and computer science advances, new findings in genomics, stem cells, new pharmaceuticals, medical devices, diagnostic devices, new surgical approaches, digital medicine and the wireless application – **shift toward Predictive, Preventive, Personalized and Participatory medicine.**

- **Drivers**: technology advances promote the shift from one-size-fit approach towards a healthcare system tailored to needs and characteristics of the individual.

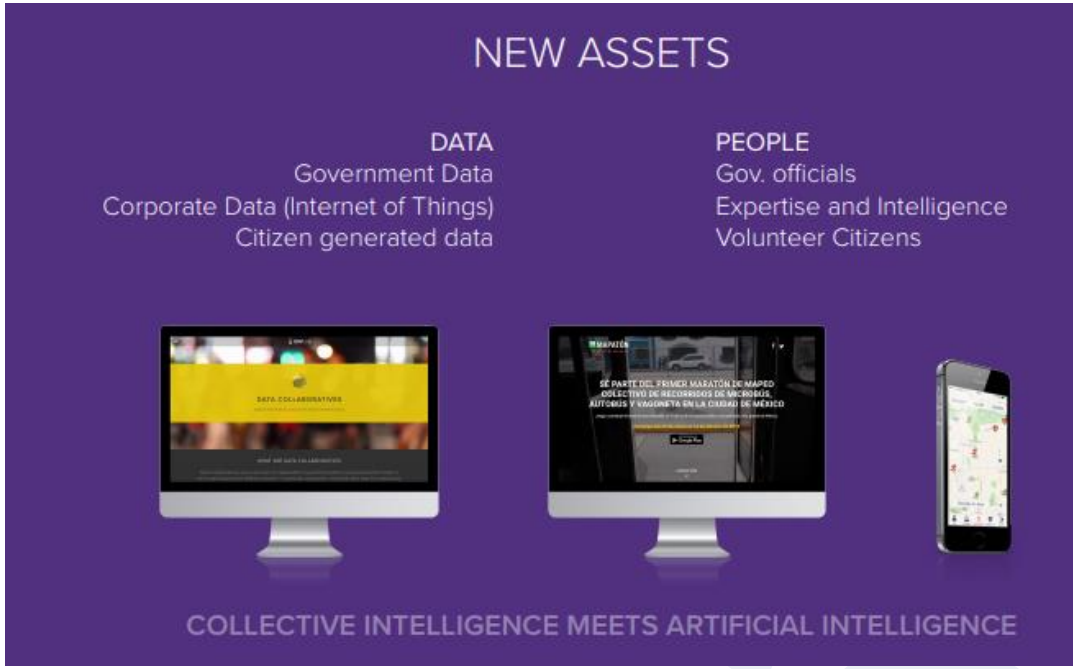


The Economist – results from a survey of 400 busines leaders on future technologies – when they will becor realities or widespread realities

BIG DATA AND HEALTH DATA REGISTRY

- **Trend:** Creation of information systems that can capture, help interpret, and share complex yet accurate patient data, including genomic information and medical data.

- **Drivers:** technologies advances, citizens participation, efficiency gains

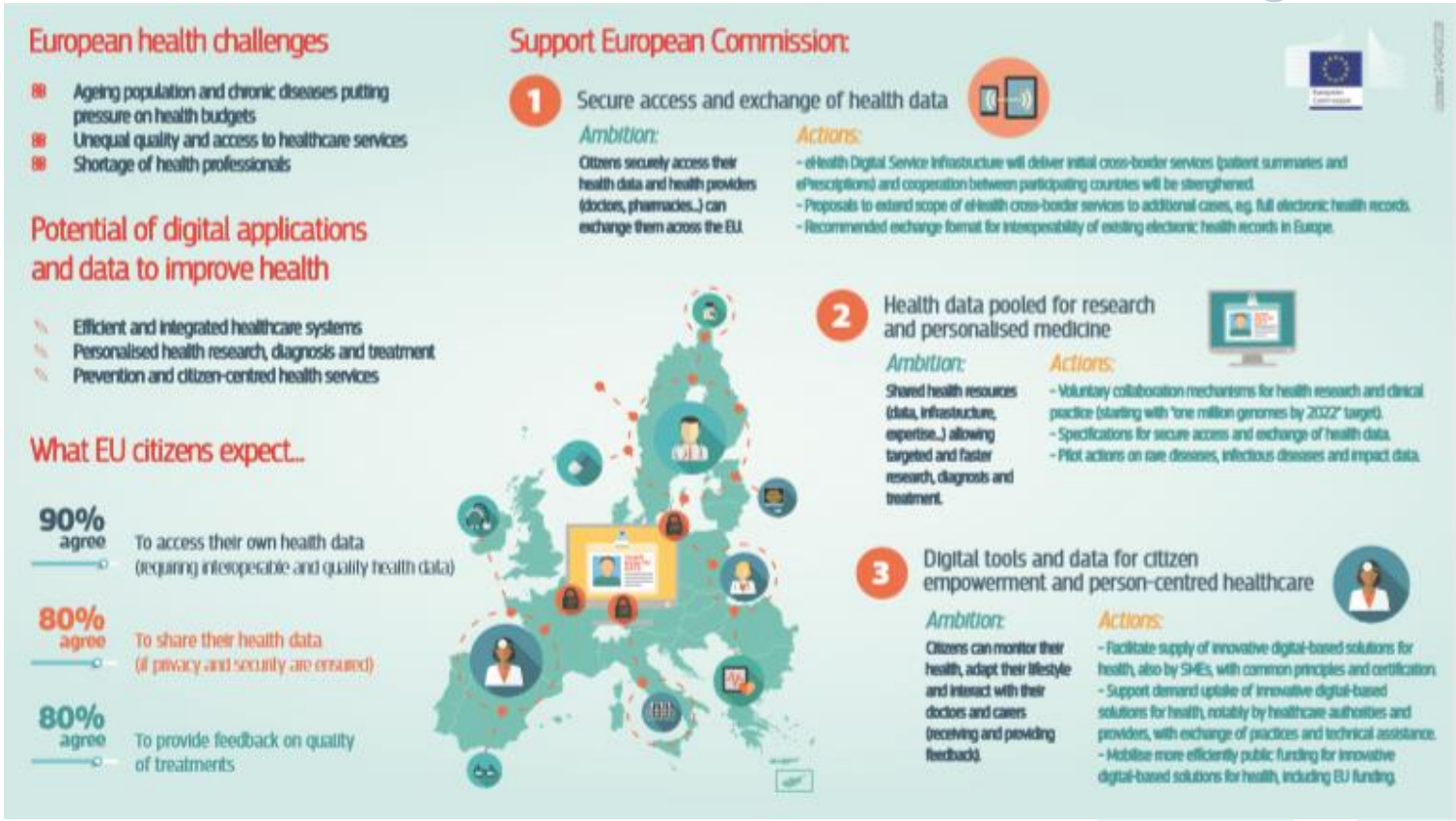


#Reimagining Governance, Verhulst S. The GovLab - FTA 2018 Conference, Brussels

E-HEALTH AND PATIENTS EMPOWERMENT

- **Trend:**Citizens increased use of technological tools to generate and analyse health-related information, some of which could be fruitfully used for research and clinical decision-making.

- **Drivers:** opportunity to access better services, increased awareness and knowledge, information exchange and co-creation of solutions.



EC- Transformation of health and care in the digital single market

THANK YOU FOR YOUR ATTENTION.

Giovanna Giuffrè: ggiuffre@isinnova.org
Svetlana Ivanova: sivanova@isinnova.org

ISINNOVA

Rare 2030
Foresight in Rare Disease Policy

LOOKING BACK AT THE PAST 20 YEARS WHAT DO YOU THINK HAS BEEN THE MOST IMPORTANT CHANGE IN THE RD CARE AND MANAGEMENT?

- 1 personal level
- 2national/european level

FOR NATIONAL PLAN AND STRATEGIES TOPIC, WHAT ARE THE OPTIMAL POLICIES PRIORITIES AND BEST PRACTICES AT THE NATIONAL LEVEL?

FOR THE PATIENTS PARTNERSHIP TOPIC, ARE THE CURRENT EFFORTS TO ENCOURAGE PARTNERSHIP WITH RD PATIENTS SUFFICIENT?

LOOKING TO THE FUTURE WHAT TRENDS DO YOU THINK WILL INFLUENCE RD DIAGNOSIS, TREATMENT AND CARE THE MOST AND WHY?