Strategic Panel 4: Bringing VHT to society

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Navigating ethical and societal challenges in bringing VHT to society

Signe Mežinska

University of Latvia

EDITH

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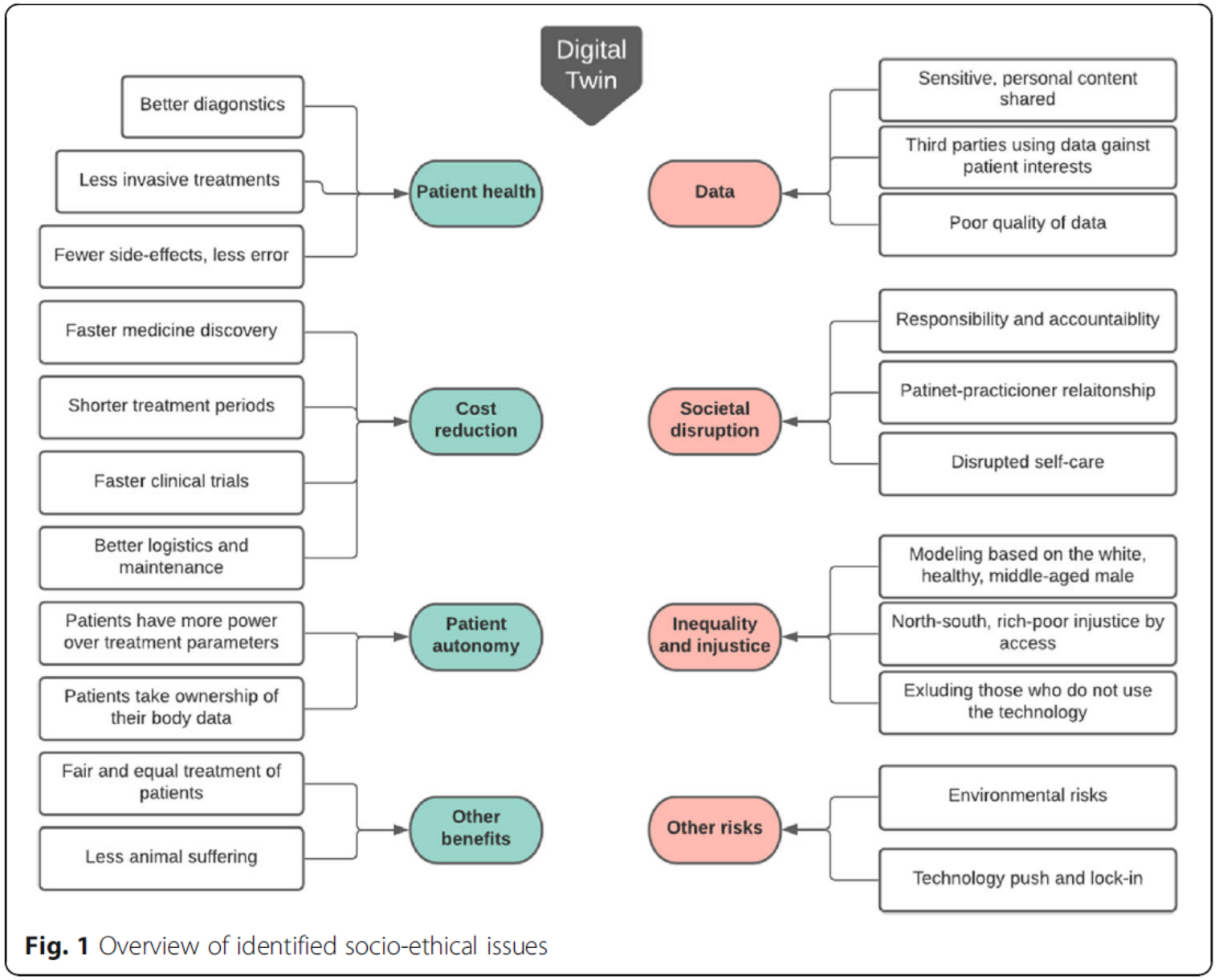


Fig. 1 Overview of identified socio-ethical issues

Popa, E. O., van Hilten, M., Oosterkamp, E., & Bogaardt, M. J. (2021). The use of digital twins in healthcare: socio-ethical benefits and socio-ethical risks. *Life sciences, society and policy*, *17*, 1-25.

Example: quality of informed consent

- How to ensure valid, voluntary and adequately informed consent both for research and clinical use?
- Can, for example, AI be involved in obtaining informed consent?
- Could dynamic consent be useful for VHT?

Example: personal data protection

"Data points that were previously considered anonymous can now — using the same underlying trends of big data, higher computing power and advanced algorithms — be de-anonymized. This frontier will likely continue to be pushed in the future. Large data pools that are necessary as foundations for machine learning models therefore face the issue of a trade-off between an individual right to privacy and solidarity with others that could benefit from the use of data."

Iqbal, J. D., Krauthammer, M., & Biller-Andorno, N. (2022). The use and ethics of digital twins in medicine. *Journal of Law, Medicine & Ethics*, *50*(3), 583-596.

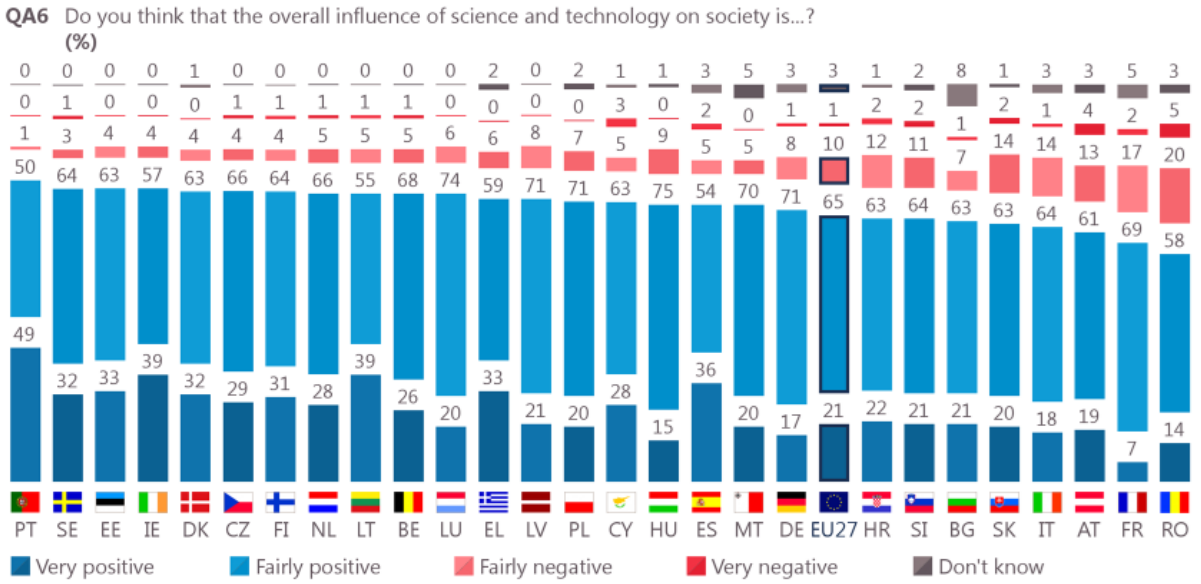
Example: responsibility and liability

"The digital twin pushes this in that the distinction between the sphere and responsibilities of the actors involved in medical decision-making will be blurred. [..] Who will be in charge and held liable when digital twins enter medical practice?"

Iqbal, J. D., Krauthammer, M., & Biller-Andorno, N. (2022). The use and ethics of digital twins in medicine. *Journal of Law, Medicine & Ethics*, *50*(3), 583-596.

What do EU citizens think about science and new technologies?

The influence of science and technology on society is overwhelmingly seen as positive in all EU27 Member States



SD segments more likely to say 'positive'

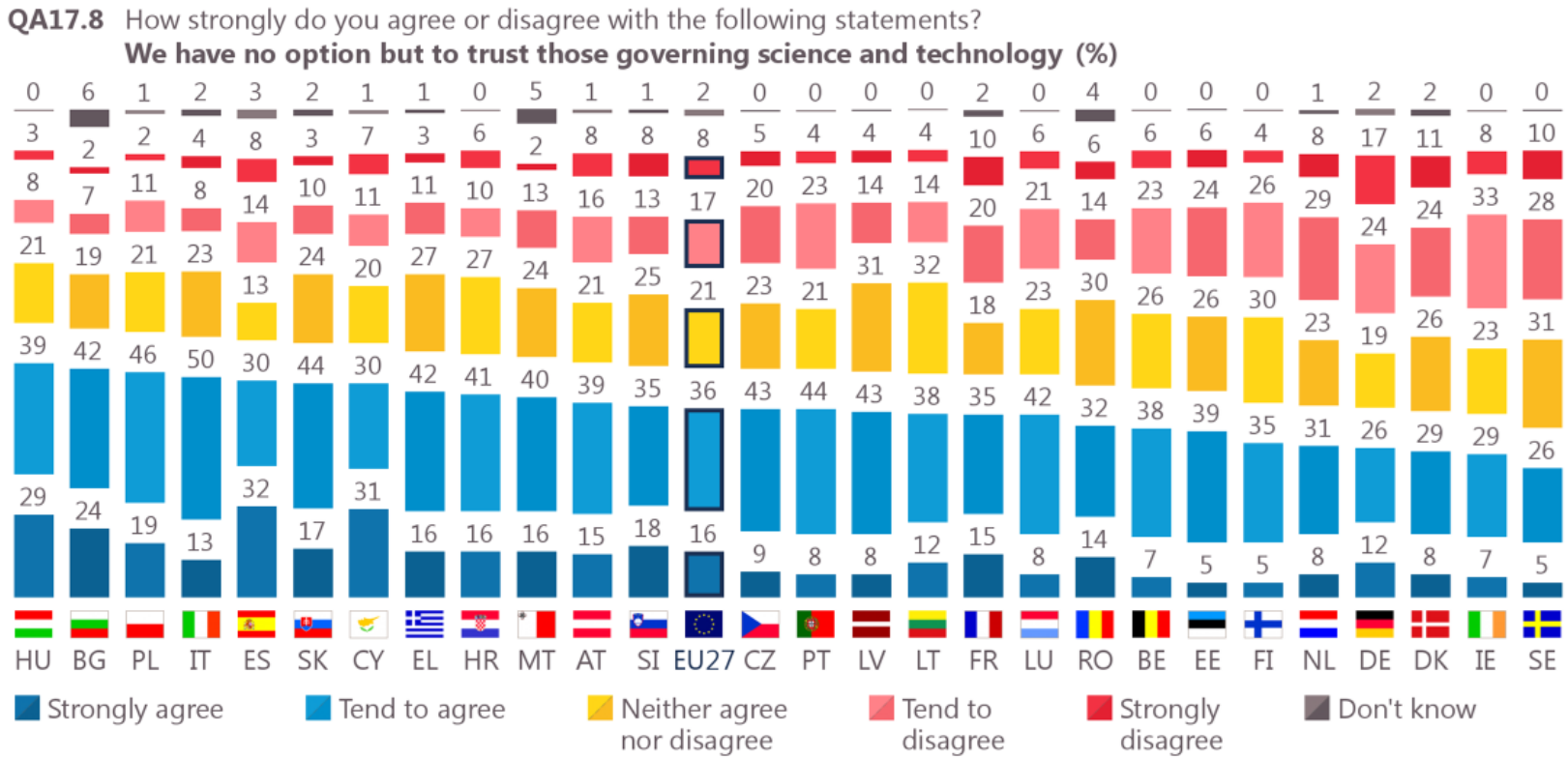
- Respondents who left education later
- Managers, students, self-employed people and other white-collar workers
- Respondents who never / almost never have difficulty paying bills
- People who score highly in the quiz

Base: EU27 respondents (26,827)

European Commission

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

In 18 Member States, 50% or more of respondents agree that they have no option but to trust those governing science and technology



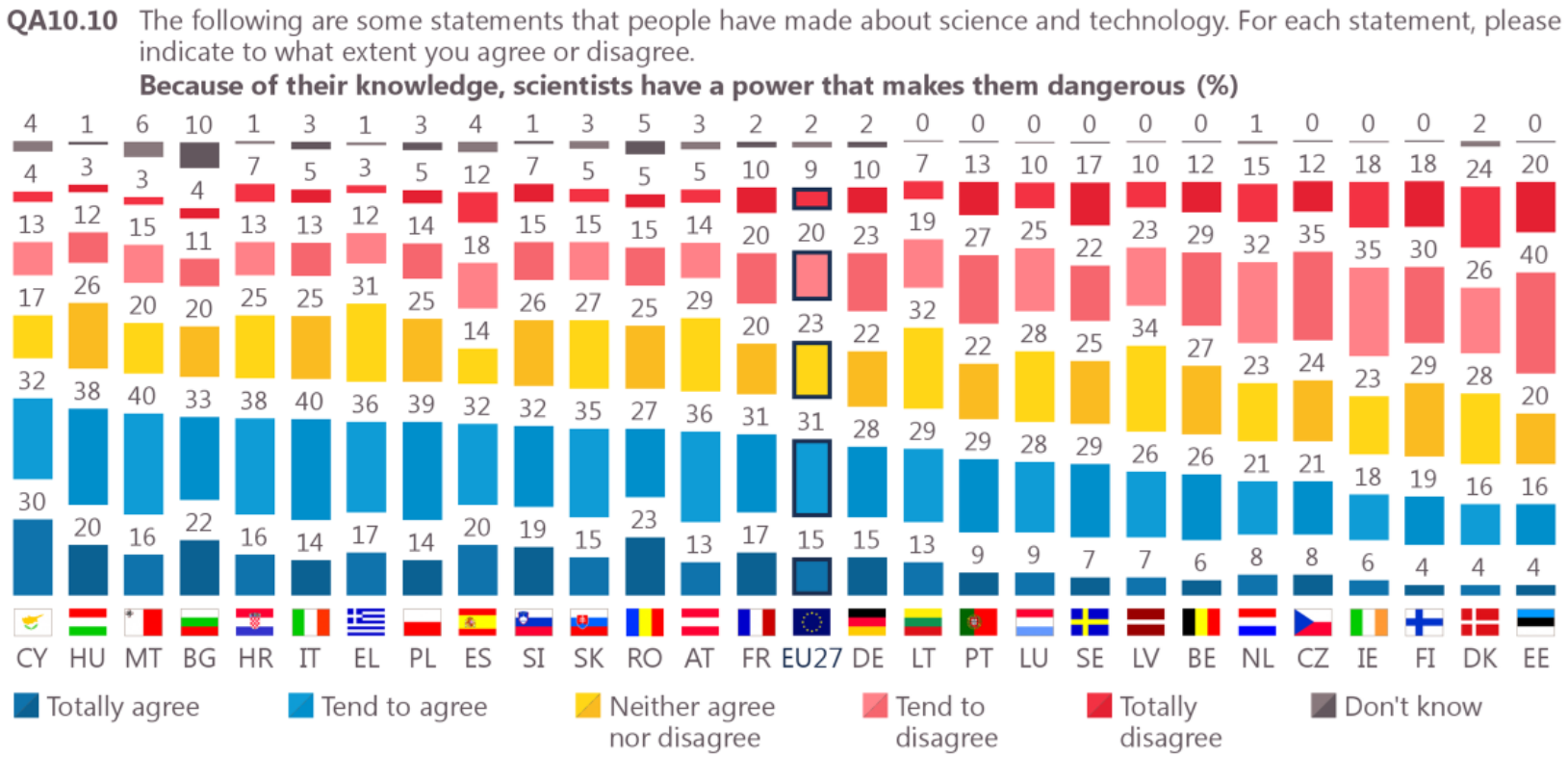
How to build trustworthiness?

Base: EU27 respondents (26,827)

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

European Commission

In 12 Member States, 50% or more of respondents agree that because of their knowledge scientists have a power that makes them dangerous



How to empower patients in the context of VHT?

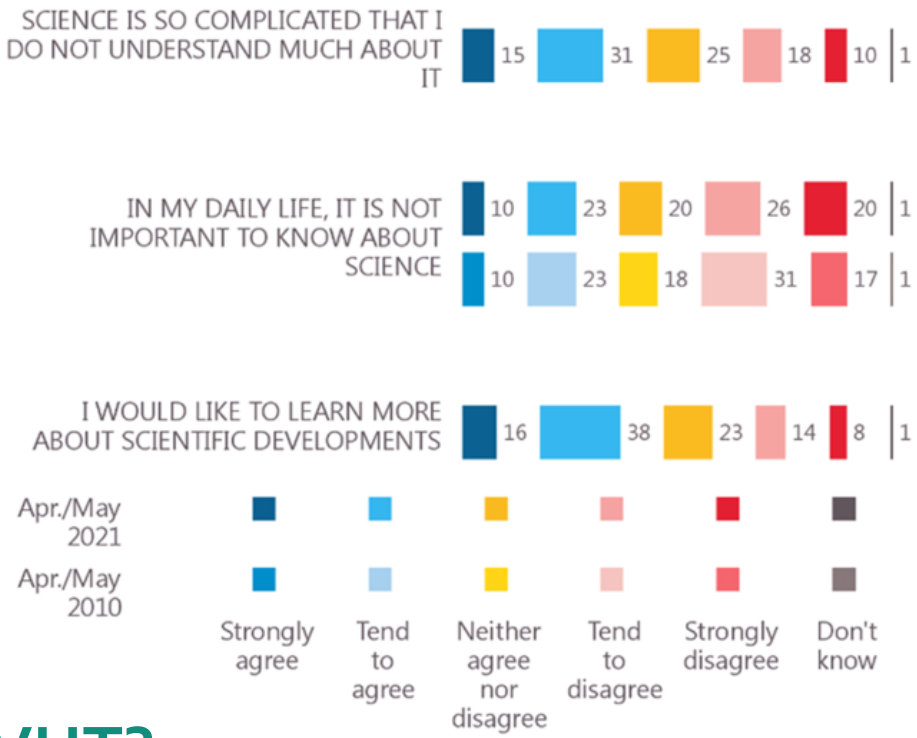
Base: EU27 respondents (26,827)

European Commission

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

More than half of respondents would like to learn more about scientific developments and almost half claim that science is so complicated that they don't understand much about it

QA9 The following are some statements that people have made about science or technology. For each statement, please indicate to what extent you agree or disagree.
(% - EU)



SD segments more likely to agree they want to learn more about scientific developments and disagree with the two other statements

- Respondents who left education later
- Managers and students
- Respondents who never / almost never have difficulty paying bills
- Respondents who use the internet everyday
- Younger respondents

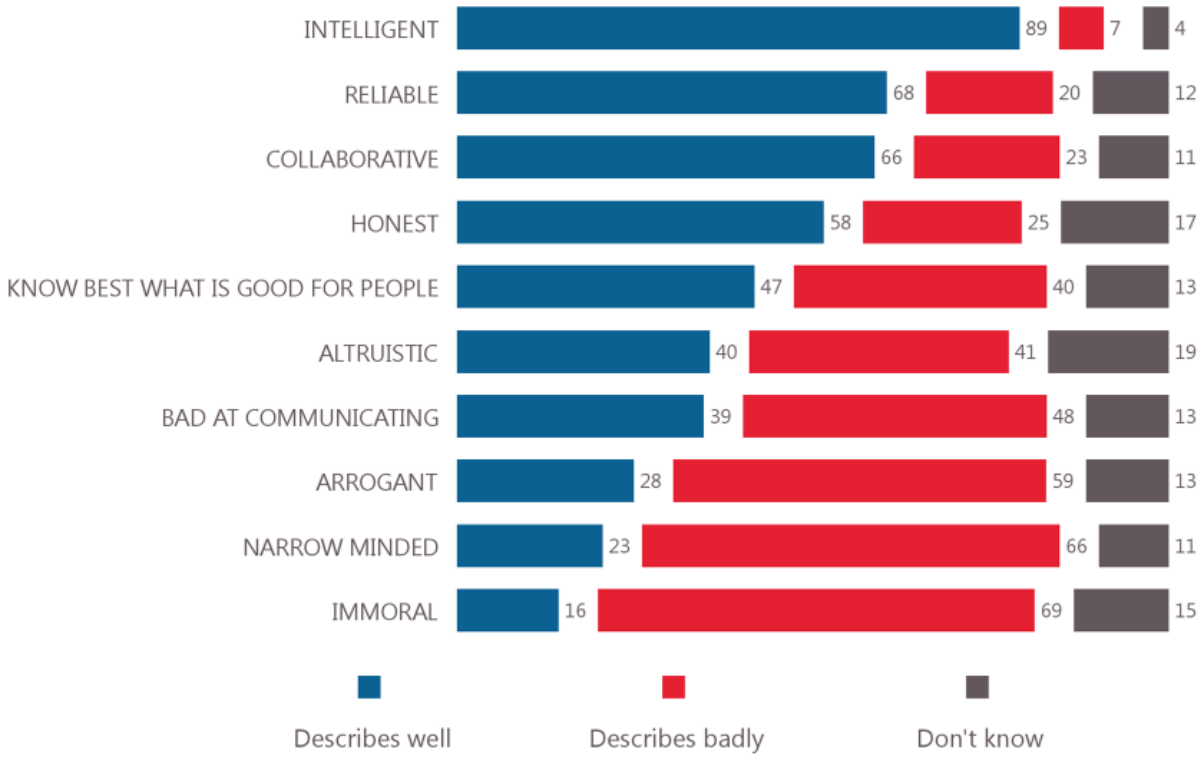
Base: EU27 respondents (26,827)

How to explain VHT?

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

Respondents see scientists mostly positively—as intelligent, reliable, collaborative, and more—though nearly four in ten also think that they are bad at communicating

QA12a The following is a list of characteristics that can be associated with scientists today. For each characteristic, indicate if you think it describes scientists well or describes them badly
(% - EU27)



SD segments more likely to have a positive view

- Younger respondents
- Respondents who left education later
- Managers and students
- Respondents who never / almost never have difficulty paying bills

Base: EU27 respondents (26,827)

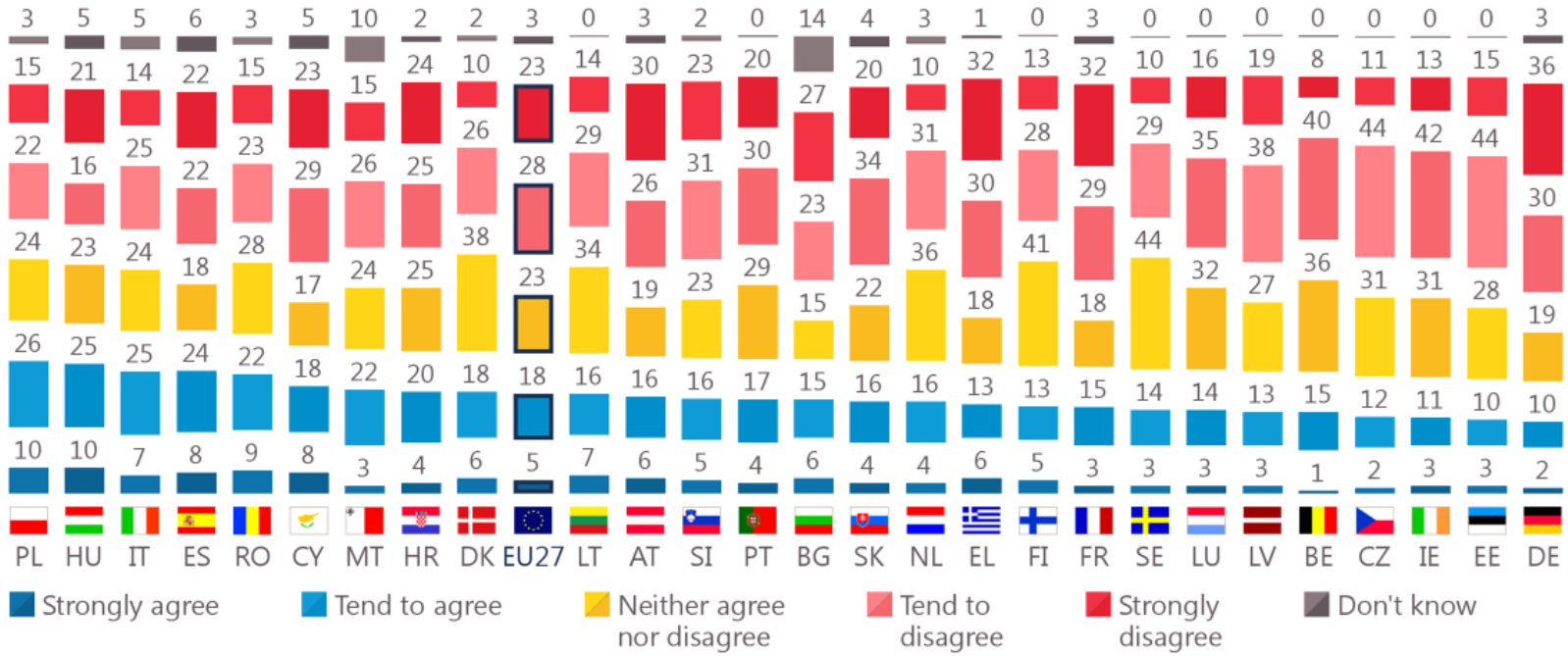
European Commission

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

In all Member States more respondents disagree that scientists spend sufficient time meeting people like them to explain their work than agree

QA9.3 The following are some statements that people have made about science or technology. For each statement, please indicate to what extent you agree or disagree.

Scientists spend sufficient time meeting people like me to explain their work (%)



Base: EU27 respondents (26,827)

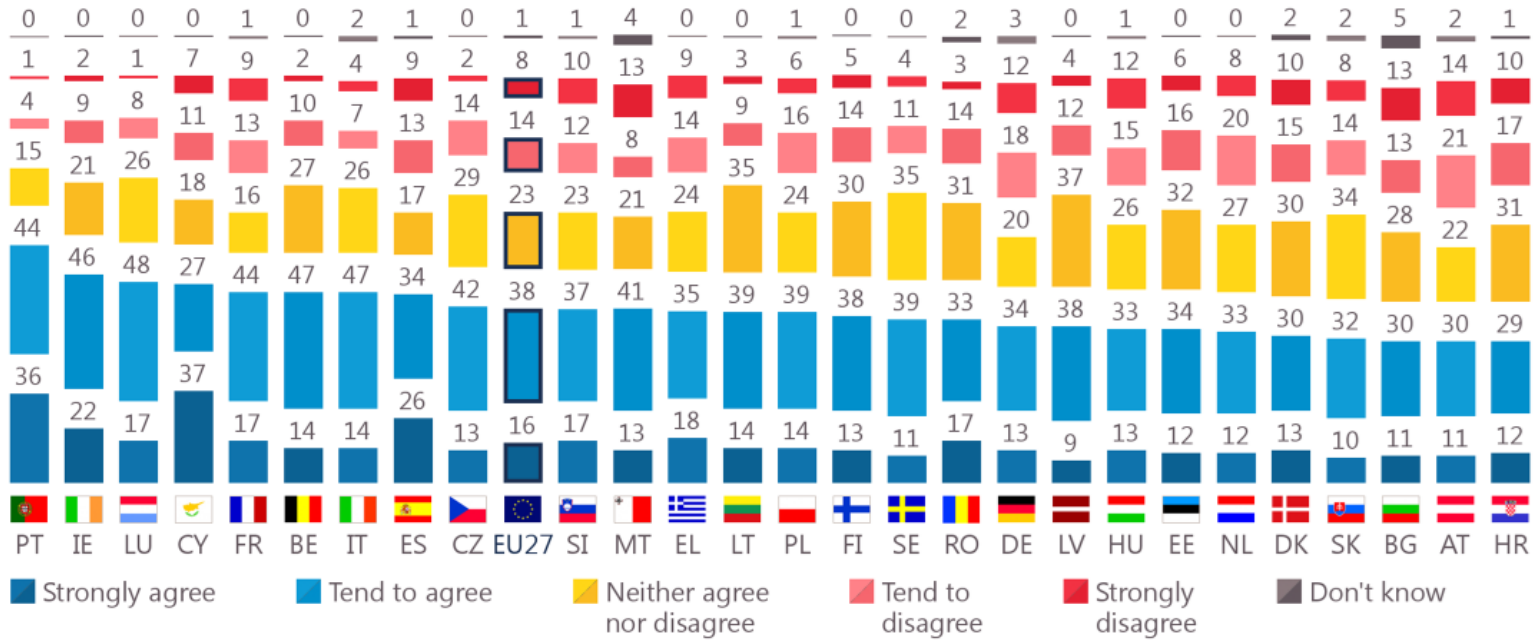
European Commission

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

In 17 Member States, at least half of the respondents agree that they would like to learn more about scientific developments

QA9.4 The following are some statements that people have made about science or technology. For each statement, please indicate to what extent you agree or disagree.

I would like to learn more about scientific developments (%)



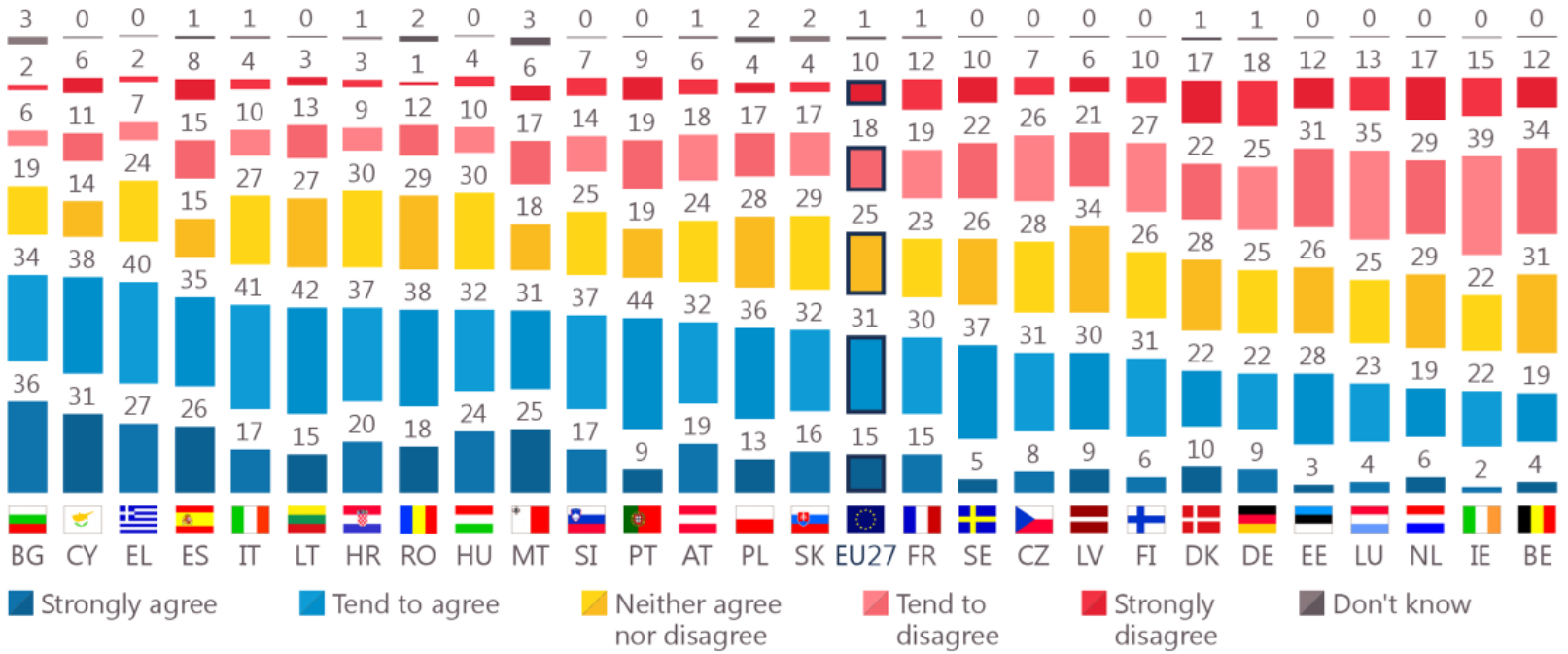
Base: EU27 respondents (26,827)

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

In 13 Member States more than half of respondents agree that science is so complicated that they don't understand much about it, with respondents in Benelux and Northern Member States most likely to disagree with this statement

QA9.1 The following are some statements that people have made about science or technology. For each statement, please indicate to what extent you agree or disagree.

Science is so complicated that I do not understand much about it (%)



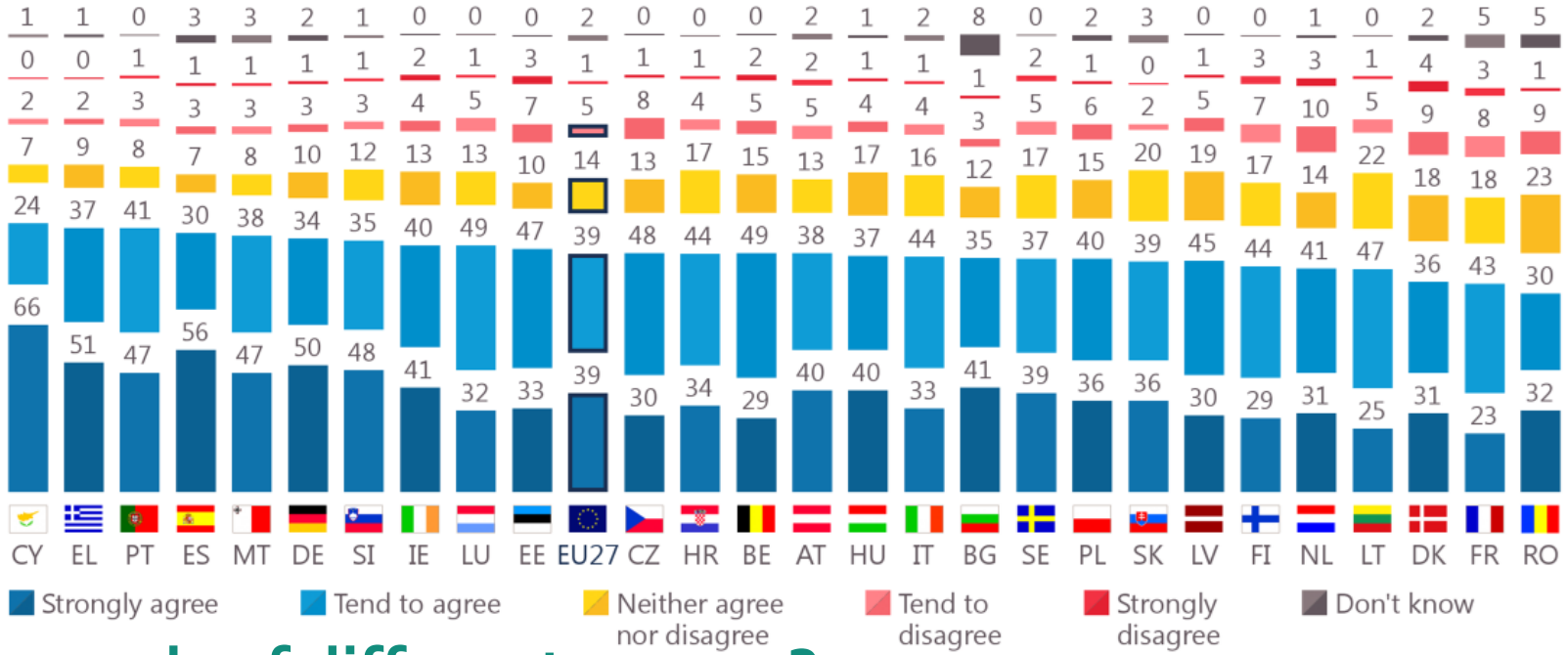
Base: EU27 respondents (26,827)

European Commission

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

In all but three Member States, seven in ten or more of respondents agree that science and technology should consider the needs of all people when developing new solutions and products

QA17.6 How strongly do you agree or disagree with the following statements?
Science and technology should consider the needs of all groups of people when developing new solutions and products (%)



How to address needs of different groups?

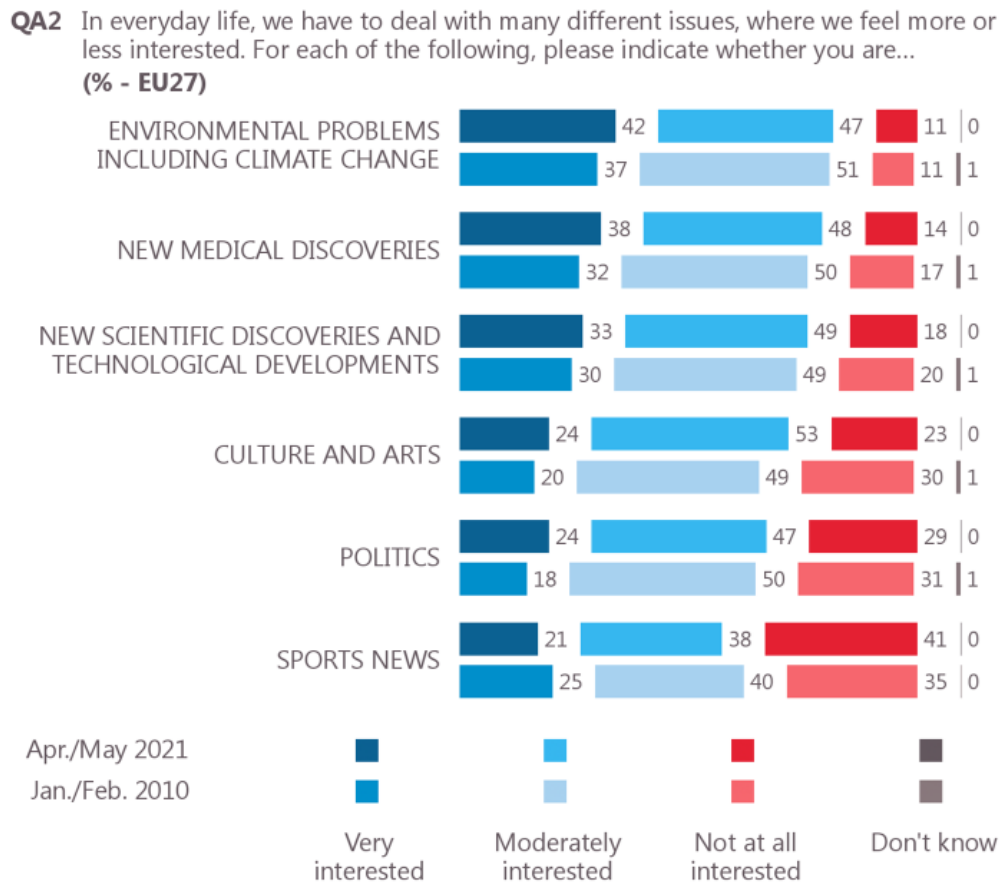
How to ensure fair access to health care?

Base: EU27 respondents (26,827)

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

European Commission

Respondents show most interest in environmental problems, followed closely by new medical discoveries and new scientific discoveries and technological developments



SD segments more likely to say 'very interested' in areas related to science and technology

- Respondents who left education later
- Managers
- Respondents who never / almost never have difficulty paying bills
- Respondents who use the internet everyday

How to minimize environmental impact?

Base: EU27 respondents (26,827)

Eurobarometer (2021). European citizens' knowledge and attitudes towards science and technology.

European Commission

How to navigate?

- be reliable
- be honest
- be accountable
- show respect

Pixabay

ALLEA (2023) The European Code of Conduct for Research Integrity

Jolien Roovers

Department of Economy, Science and Innovation of the Flemish Government

EDITH

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Policy perspective in Flanders

Jolien Roovers – Flemish Department of Economy, Science & Innovation

DEPARTEMENT
ECONOMIE, WETENSCHAP & INNOVATIE

Vlaamse overheid

FLANDERS: Key Figures report 2023

a high-income region

with an open economy in the core of Europe

- **Population**: 6,77 million (= 58% BEL)
- **Language**: Dutch (NL)
- **Surface:** 13 521 km² (= 44% BEL)
- **GDP**: € 296 billion (= 59%; BE € 502,3 bn)
- **Export** : € 300 billion (BE € 370 bn)
- **GERD**: € 10 816 billion (+/- 2/3 of BEL), of which € 7 896 billion BERD
- **Research intensity - % GERD/ GDP**: 3,65% = 63% of BE R&D expenditure

- **Total public budget STI policy**: € 3 246 million, of which € 2 149 million R&D

The region has constitutional competences on research, innovation and economic policy

The Regional Innovation Scoreboard (RIS) 2023 → Flanders Region = "innovation leader"
23rd position in the list of EU (sub-)regions

Technological specialisations

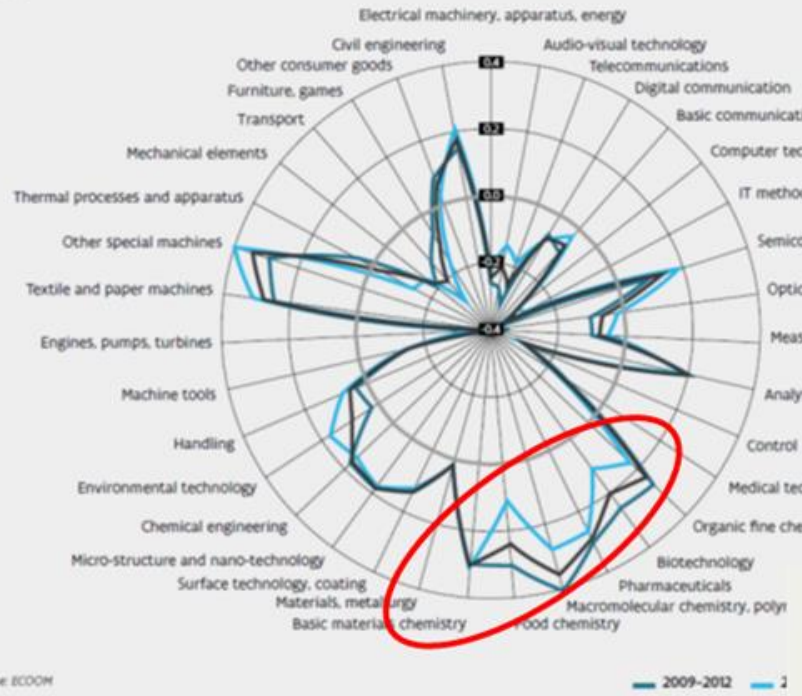
R&D expenditure per sector (2019)

Top 4 –sector (= 75%)

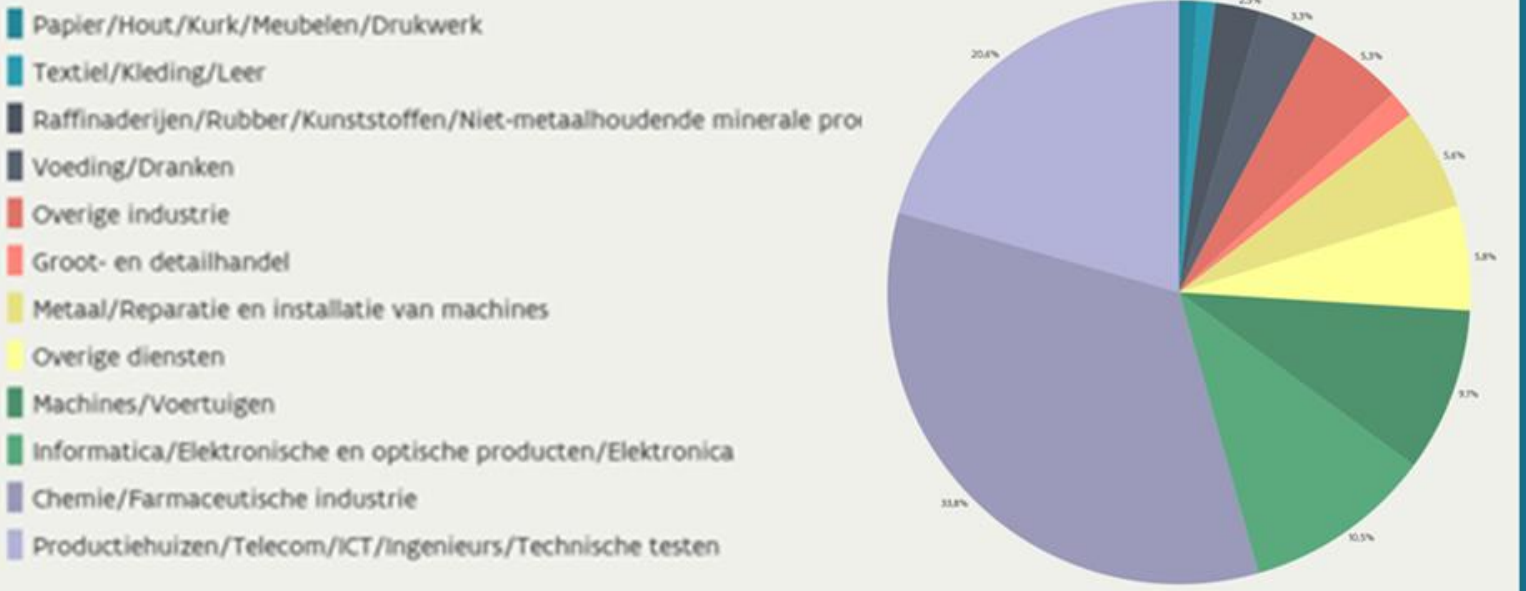
- Chemistry/ Pharma (34%)
- Manufacturing/ telecom/ ICT/ Engineering/ Technical tests (21%)
- Informatics, Electronic and optical products and electronics (10%)
- Machines/ Vehicles (10%)

TECHNOLOGICAL SPECIALISATION (RTAN) OF FLANDERS BASED ON THE EPO PATENTS, 2009-2012, 2013-2016 AND 2009-2016, INDEX BETWEEN -1 AND +1

Figure 6



Source: ECOOM



Health(y) ecosystem Flanders

Access to funding

PMV
DOE- EN DURFBEDRIJF

imec xpand

bioqube ventures

FLANDERS CARE

FLANDERS INNOVATION & ENTREPRENEURSHIP

Flanders State of the Art

V-Bio Ventures

DEPARTEMENT ECONOMIE, WETENSCHAP & INNOVATIE

Vlaamse overheid

Interregional / pan-European initiatives

EP PerMed

SMART HEALTH
VANGUARD INITIATIVE

B 1MG
Beyond one Million Genomes

BrainHealth
PARTNERSHIP

jpiamr

SAPHIRe
Securing Adoption
of Personalised
Health in Regions

elixir
BELGIUM

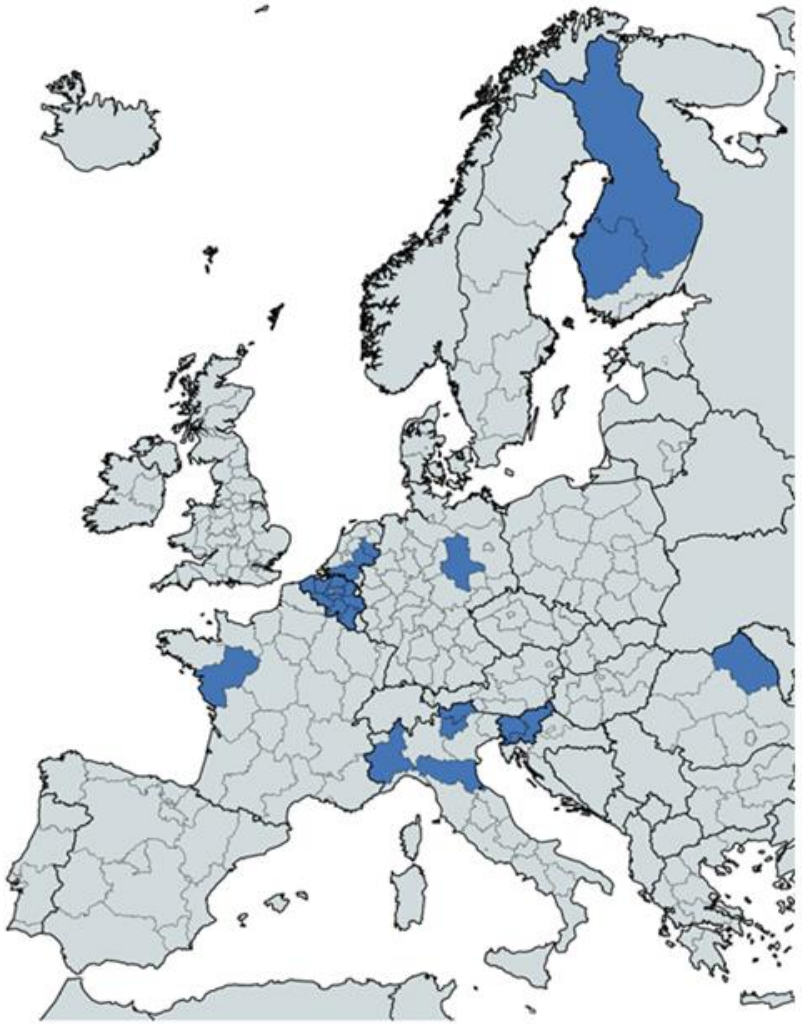
BE
READY
European Partnership for
Pandemic Preparedness

DEPARTEMENT
ECONOMIE, WETENSCHAP & INNOVATIE

Vlaamse
overheid

Vanguard Initiative Smart Health

VANGUARD INITIATIVE
New growth through smart specialisation



- Flanders, South NL, East NL
- Emilia-Romagna, North-Est Romania, East & North Finland, Piedmont, Slovenia, Trento, Tampere, Wallonia, Autonomous Province of Bolzano/Bozen – South Tyrol, Pays de la Loire, Saxony-Anhalt, Catalonia
- EIT Health
- **Open for new regions**

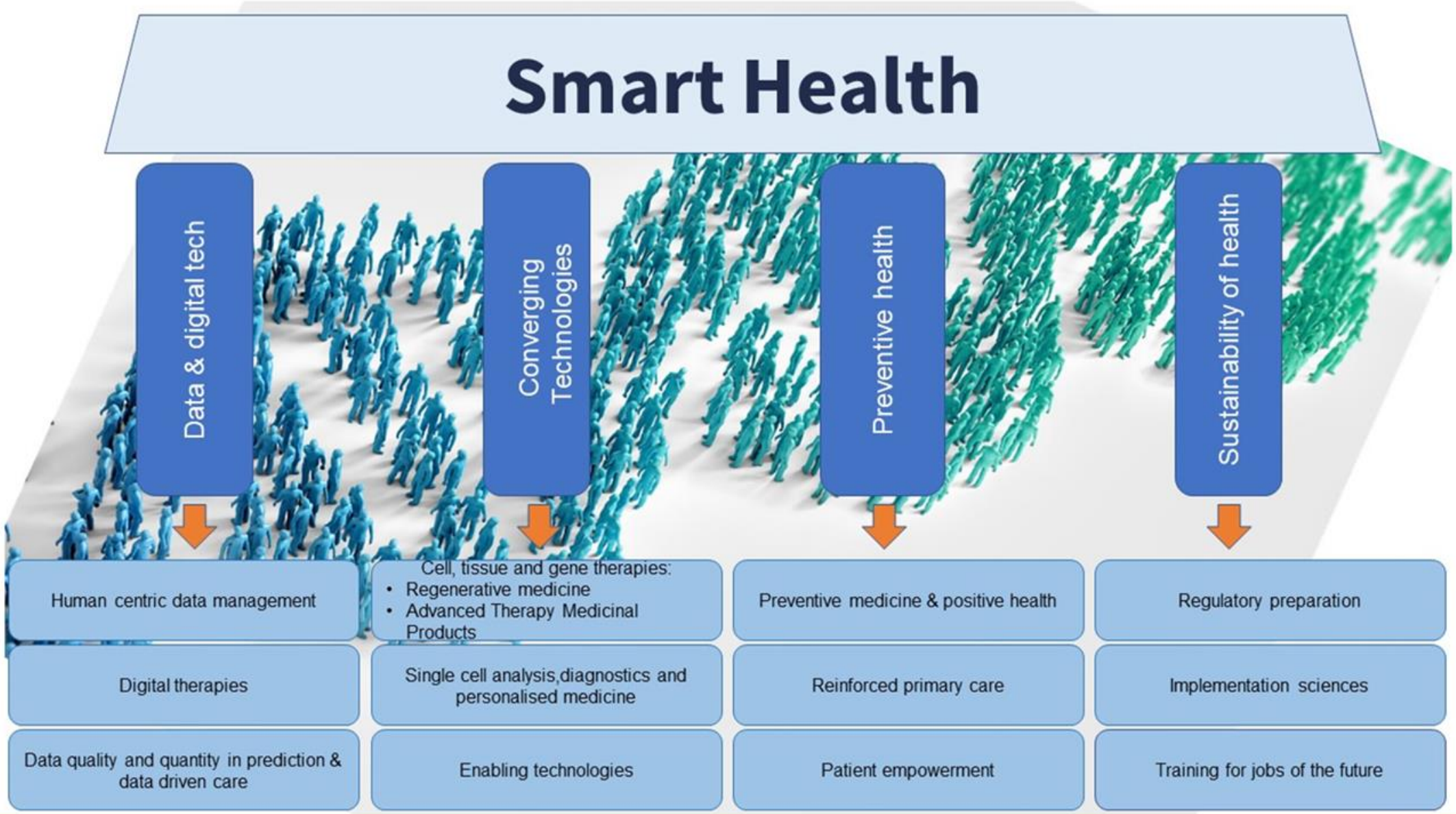
Bring regional ecosystems together

Boost implementation of personalised medicine and smart health across Europe

Investable interregional co-creation projects

More info on:
https://www.s3vanguardinitiative.eu/pilots/smart-health

VI Smart Health Scope



Thank you for your attention!

ewi-vlaanderen.be

Jolien.roovers@vlaanderen.be

Rossana Alessandrello

AQuAS

EDITH

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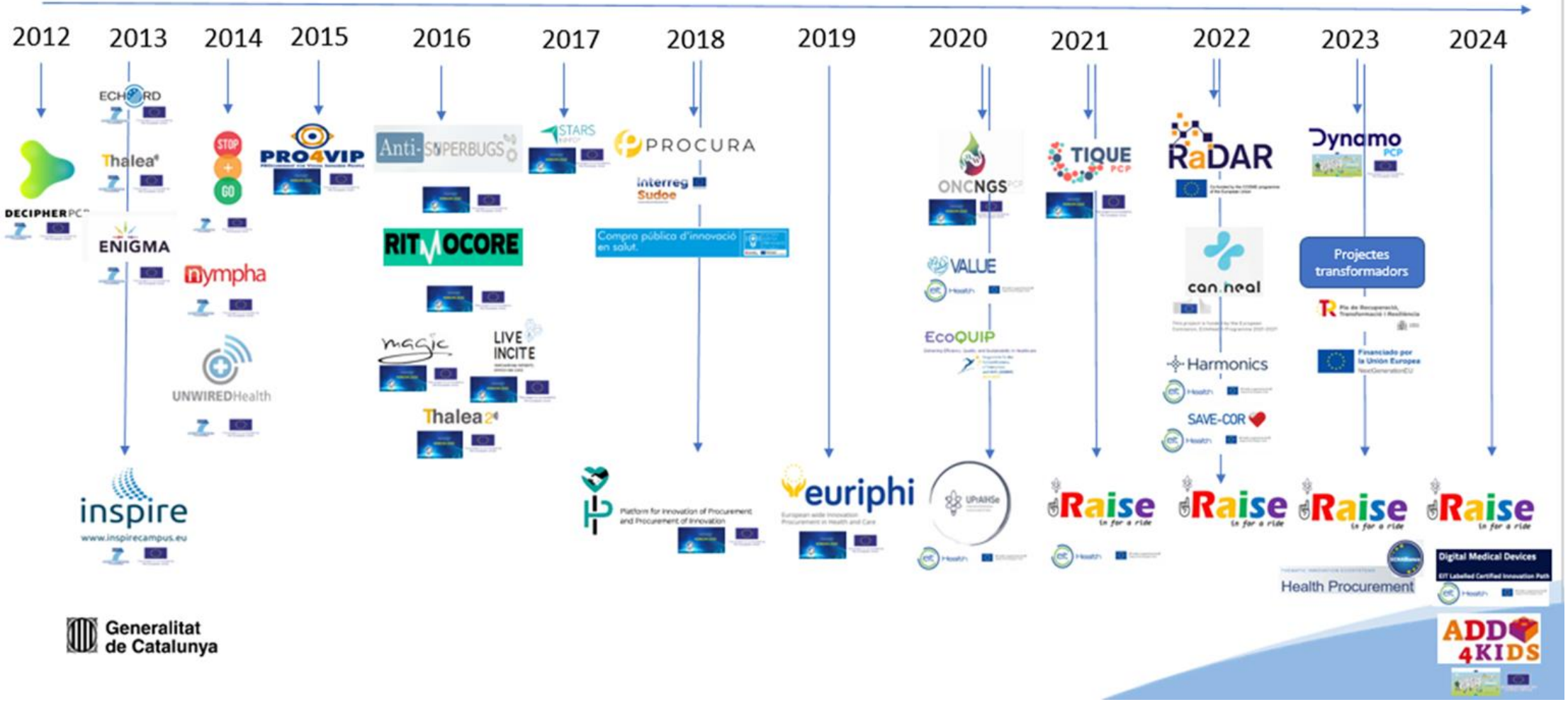
AQuAS and the Catalonian healthcare system journey towards the adoption of value-based innovations

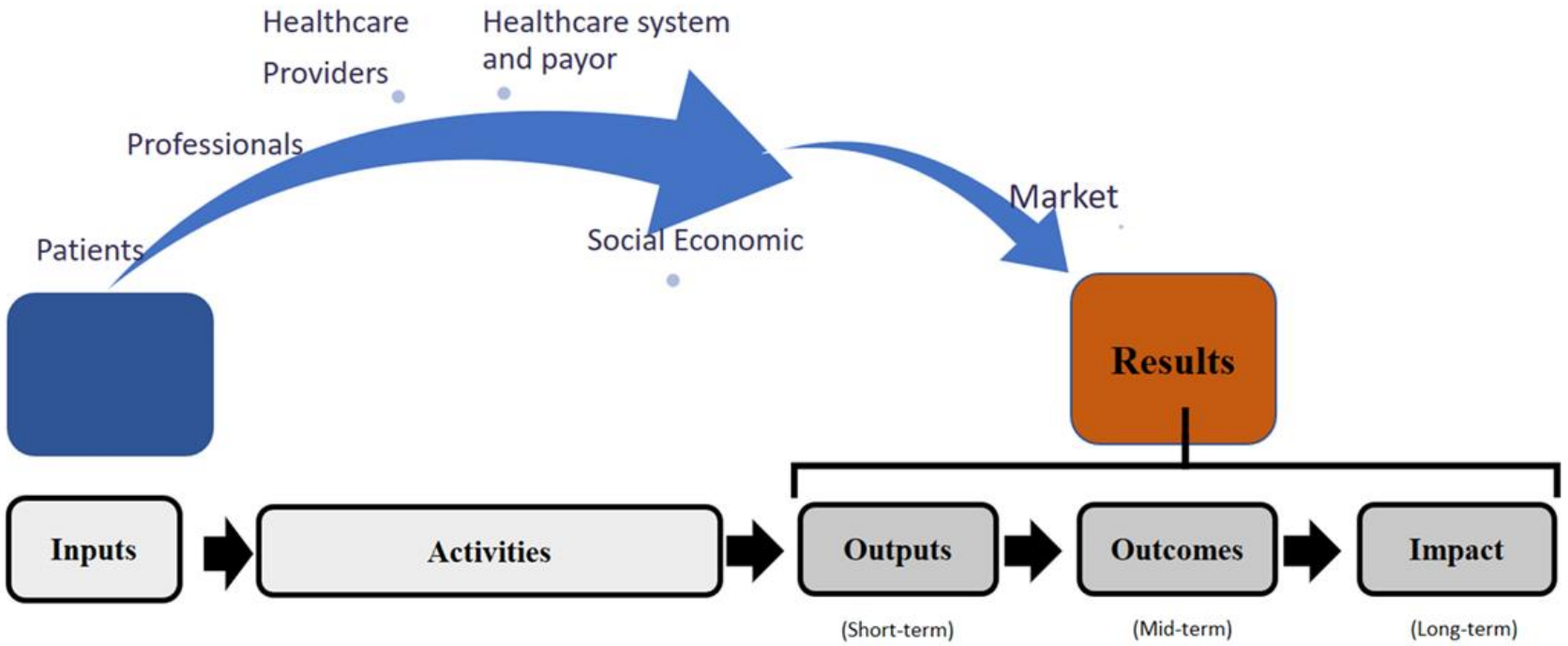
Salut/ Agència de Qualitat i Avaluació Sanitàries de Catalunya



Generalitat de Catalunya

Introduction to Value Based Procurement

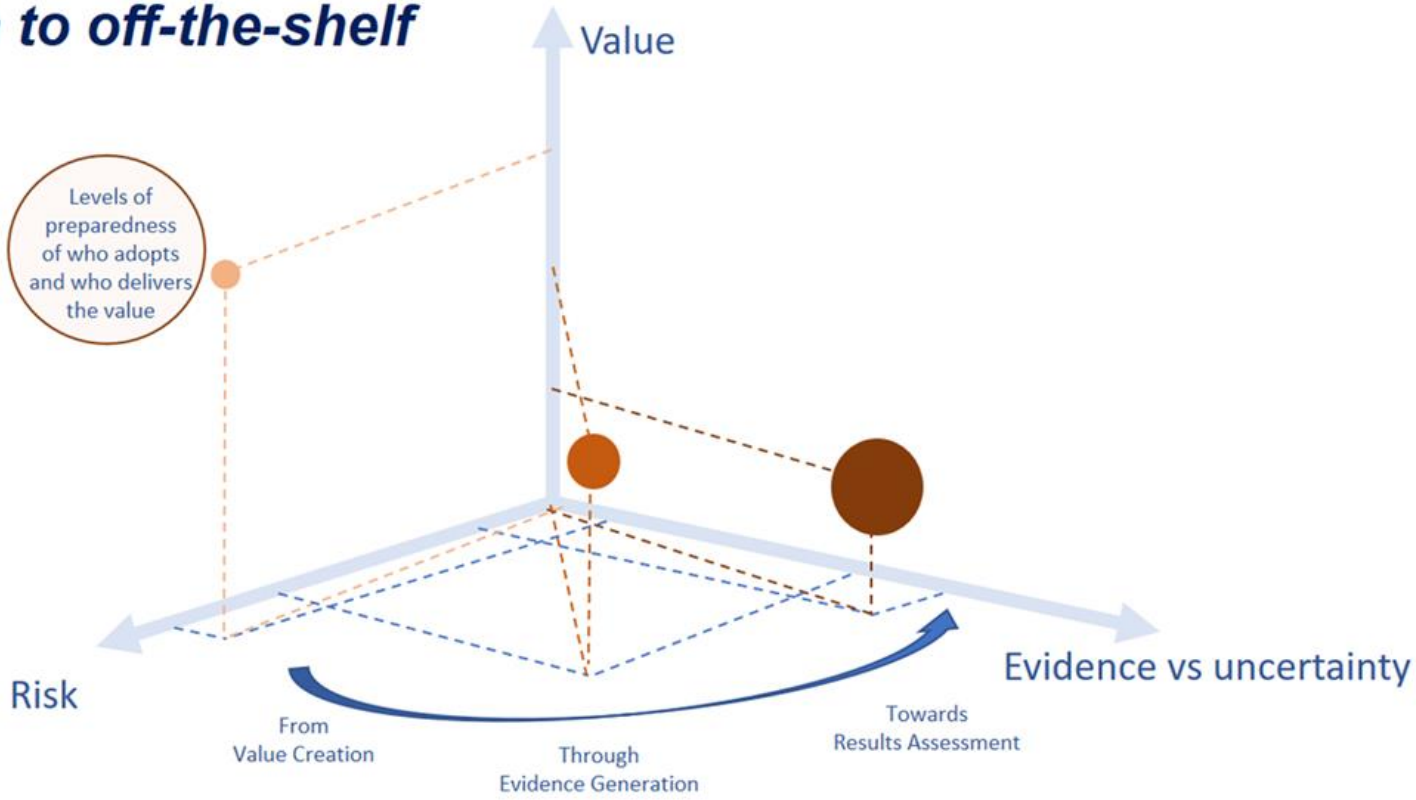
Value Based Procurement: Value Chain and Theory of Change



Rossana Alessandrello, Ion Arrizabalaga Garde, Uxío Meis Piñeiro, Olman Alonso Elizondo Cordero, Maria Sanchis-Amat, Ramon Maspons (2021). Teoria del canvi, resultats neutrals respecte al tipus de necessitats no satisfetes en l'àmbit de la salut i permeabilitat de les compres públiques d'innovació al valor. Annals de Medicina 2021;104:164-167 http://annals.academia.cat/view_document.php?tpd=2&i=17278

Generalitat de Catalunya

Value Based Procurement: from innovation to off-the-shelf



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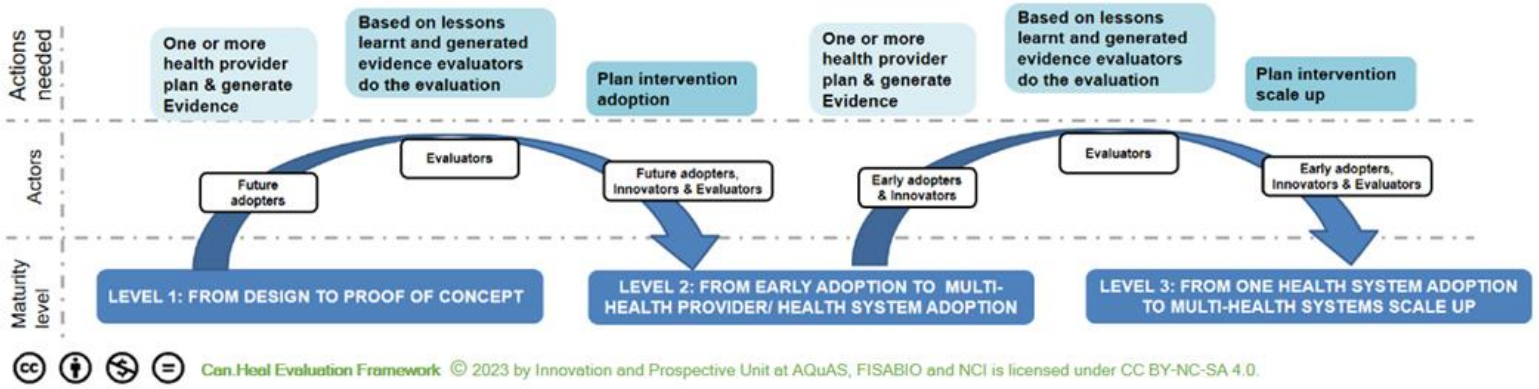
From proof of concept to scale up



can.heal

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Generalitat de Catalunya

Frank van Praat

KPMG-NL, AMdEX

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Marco Verdicchio

SURF

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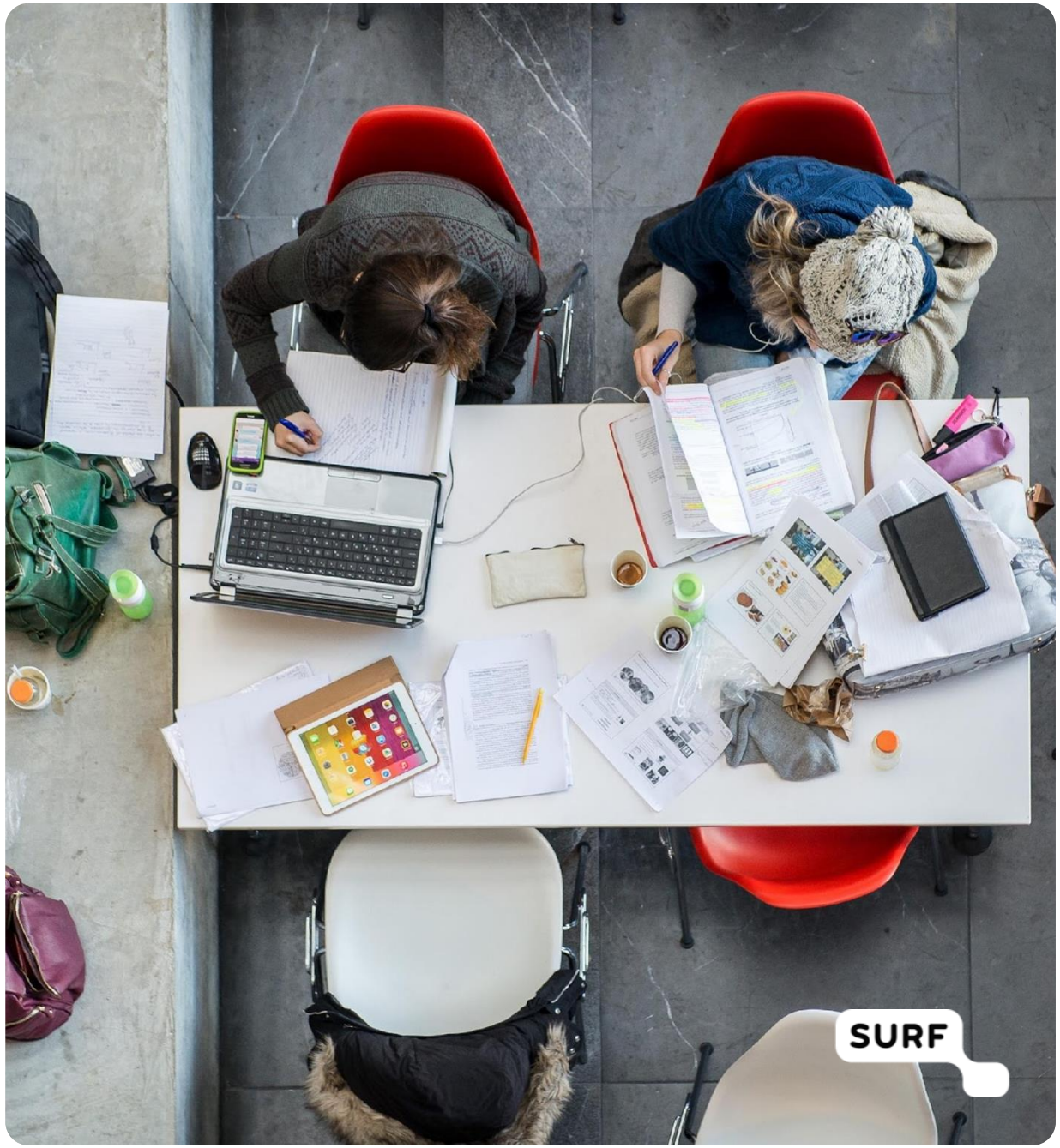
SURF is an ICT cooperative for education and research

SURF is a cooperative association of Dutch educational and research institutions.
We work together to acquire or develop the best possible digital services, and to encourage knowledge sharing through continuous innovation.
with the aim: making education and research better and more flexible.



SURF

Reliable, secure and innovative ICT infrastructure

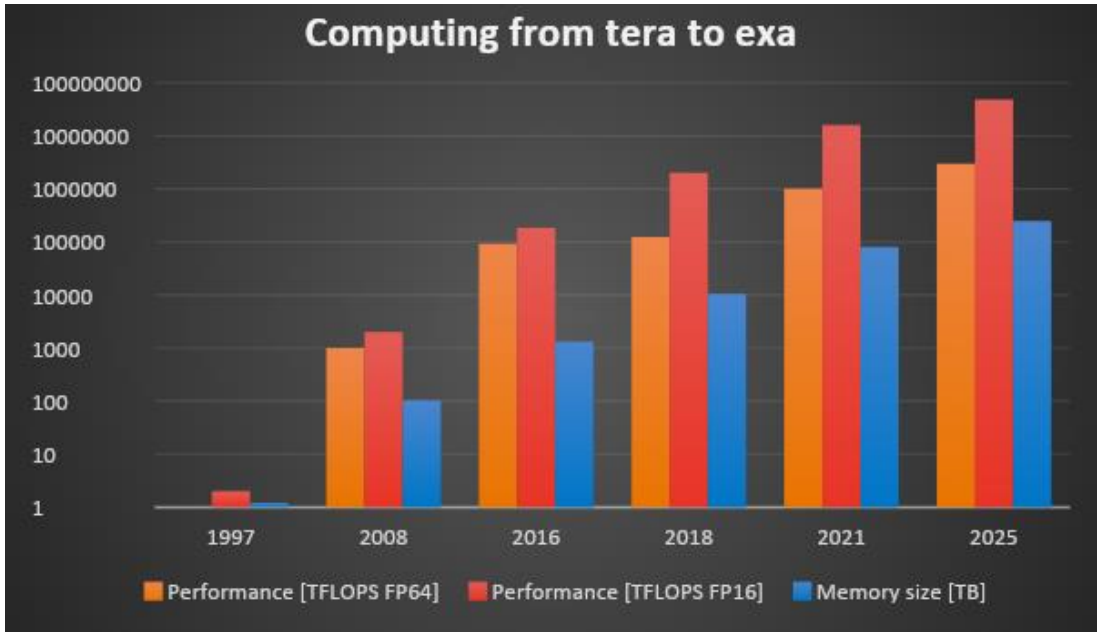
Digital innovation and transformation of education and research

Knowledge exchange and trainings

Services development and integration with EU initiates

It’s far more than just big systems

- As scientific problems become more complex:
  - collaborations will grow
  - data sizes will grow
  - e-infrastructure HPC systems will grow
  - requires integration of compute and data



- For todays and future e-infrastructure development this means advances and collaborations in the complete e-infrastructure ecosystem:

  community services + software (system, middleware, libraries, applications) + algorithms + programming models + workflows + hardware (compute, data, network) + datacenter + operations + support + data management + training + education + integration + federation

SURF Infrastructure Ecosystem

Digital workflow management

Research Software Directory

Application enabling

Training

AI /GPT-NL

Extended Reality

Futuring

Netherlight

Autonomy

Data Storage

HPC

HTC

Quantum

Neuromorphic

Data management

Sustainability

Network to Institutions

Expertise

Security

Identity

Infra Interoperability /collaboration

eosc

Jules Verne

LUMI

NL Regional TIER-2

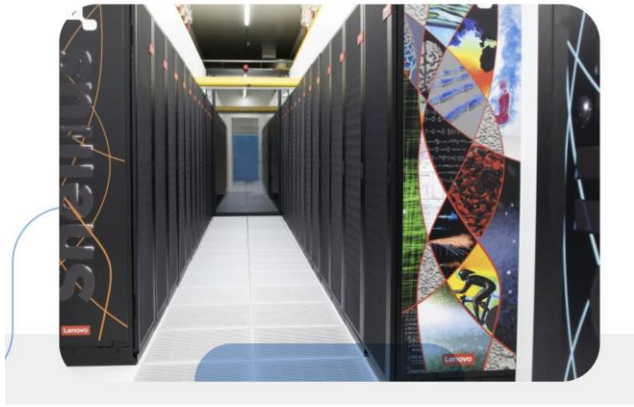
aws

Azure

Google Cloud

SURF

E-infrastructure access and support



- **User Support systems access**
  Assist users with troubleshooting technical problems and resolving issues related to the HPC system, services and applications.

- **Consulting and workflow development and support**
  Domain specific consulting (e.g. ML/DL) and co-development research applications and workflows

- **Experimental hardware assessment and co-design**
  Access to experimental hardware within a community driven technical environment for experiments.

- **National and International projects and collaborations**

E-infrastructure access and support

Compute and Data services for Health and Medicine

- Health-RI initiative www.health-ri.nl
- Alzheimer Genetic Hub alzheimergenetics.org
- CompBioMed CoE
  www.compbiomed.eu

Secure Supercomputer for sensitive data processing

- CBS Microdata are linkable data at the level of individuals, companies and addresses (highly sensitive!!!)
- HPC environment that meets the requirements of CBS in legal, technical and security requirements

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