



SAPHIRe
Securing Adoption
of Personalised
Health in Regions

The personalised future of healthcare in Europe

Identifying the regional
roadblocks for the
implementation of
personalised health

Introduction



Personalised medicine - Definition

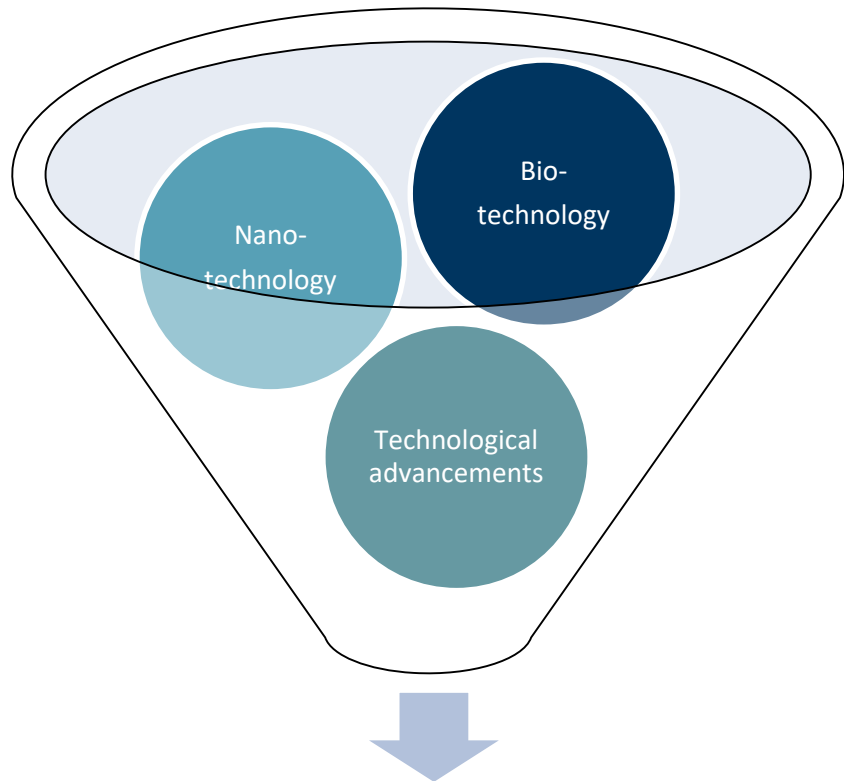
“A medical model using characterization of individuals’ phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention”

- H2020 Advisory group and Council conclusion 2015/C 421/03 (7-12-2015)



Personalised medicine

Healthcare shift from symptomatic treatment towards ensuring lifelong health



Profound understanding of
health, disease, aging



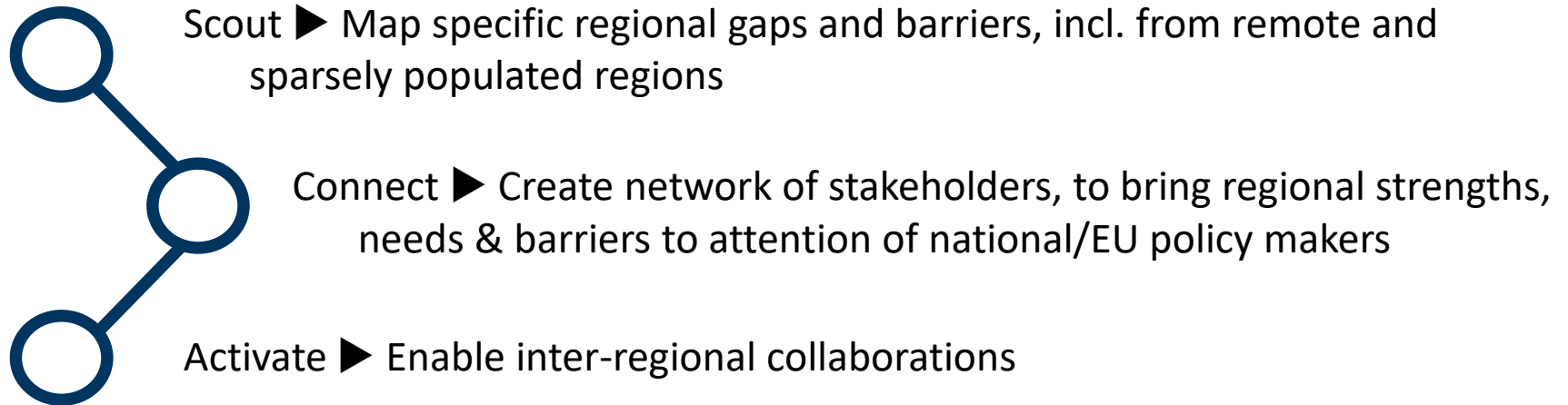
- Early, accurate diagnosis
- Increase healthy life years
- Sustainability of healthcare
- Boost development of new technologies, treatments & therapies



SAPHIRe

Securing the Adoption of Personalised Health in Regions

Aim - Support European regions to structure implementation of personalised medicine



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825046

Partners



Regional networking

Bring together

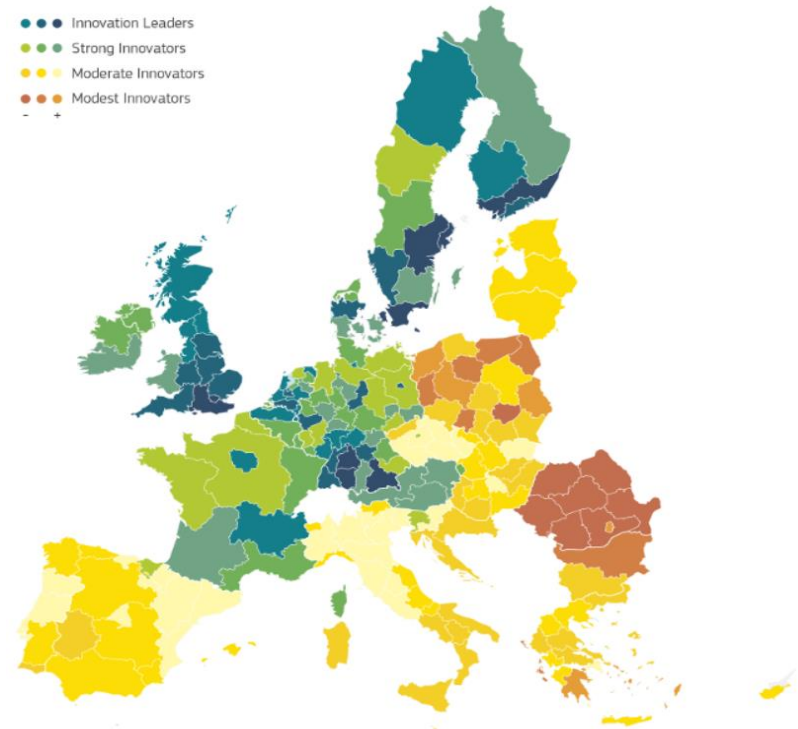
- Central & densely populated regions
- Remote & sparsely populated regions
- Different innovation levels

Identify

- Gaps & barriers
- Best practices
- Regional value chains
- Complementarities between regions

Link to

- [ICPerMed](#)
- Smart specialisation [S3P4PM](#)



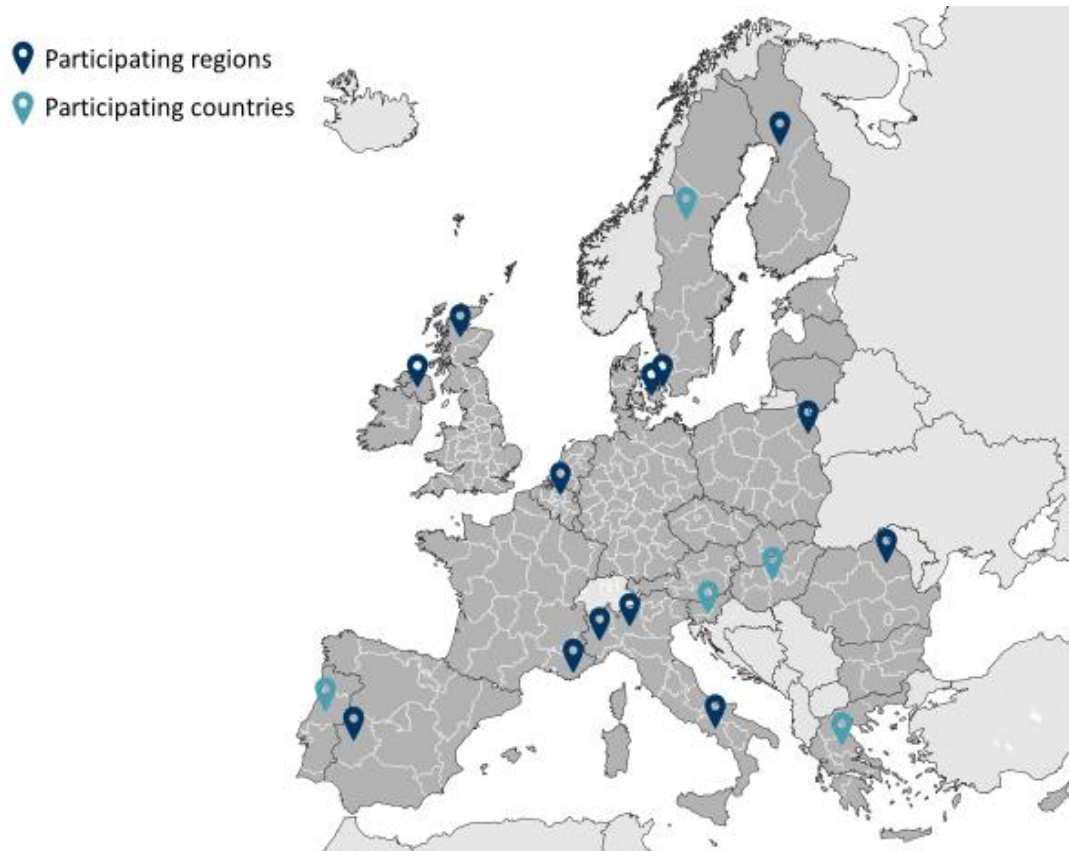
http://ec.europa.eu/growth/industry/innovation/facts-figures/regional_en



Workshop: regional needs and barriers



Participating regions and countries



Regions represented
Oulu (FI)
Zealand (DK)
Capital Region (DK)
Podlanskie (PL)
Schotland (UK)
Northern Ireland (UK)
Flanders (BE)
Nord-Est (RO)
Provence-Alpes-Côte d'Azur (FR)
Lombardy (IT)
Piedmont (IT)
Campania (IT)
Extremadura (ES)
Countries represented
Sweden
Hungary
Slovenia
Greece
Portugal



Participants ranked interference of possible barriers prior to workshop

ICPerMed Challenges

- Awareness and empowerment
- Integration of big data and digital solutions
- Translating basic research to clinical research
- Bringing innovation to market
- Sustainability of healthcare

Data-related challenges

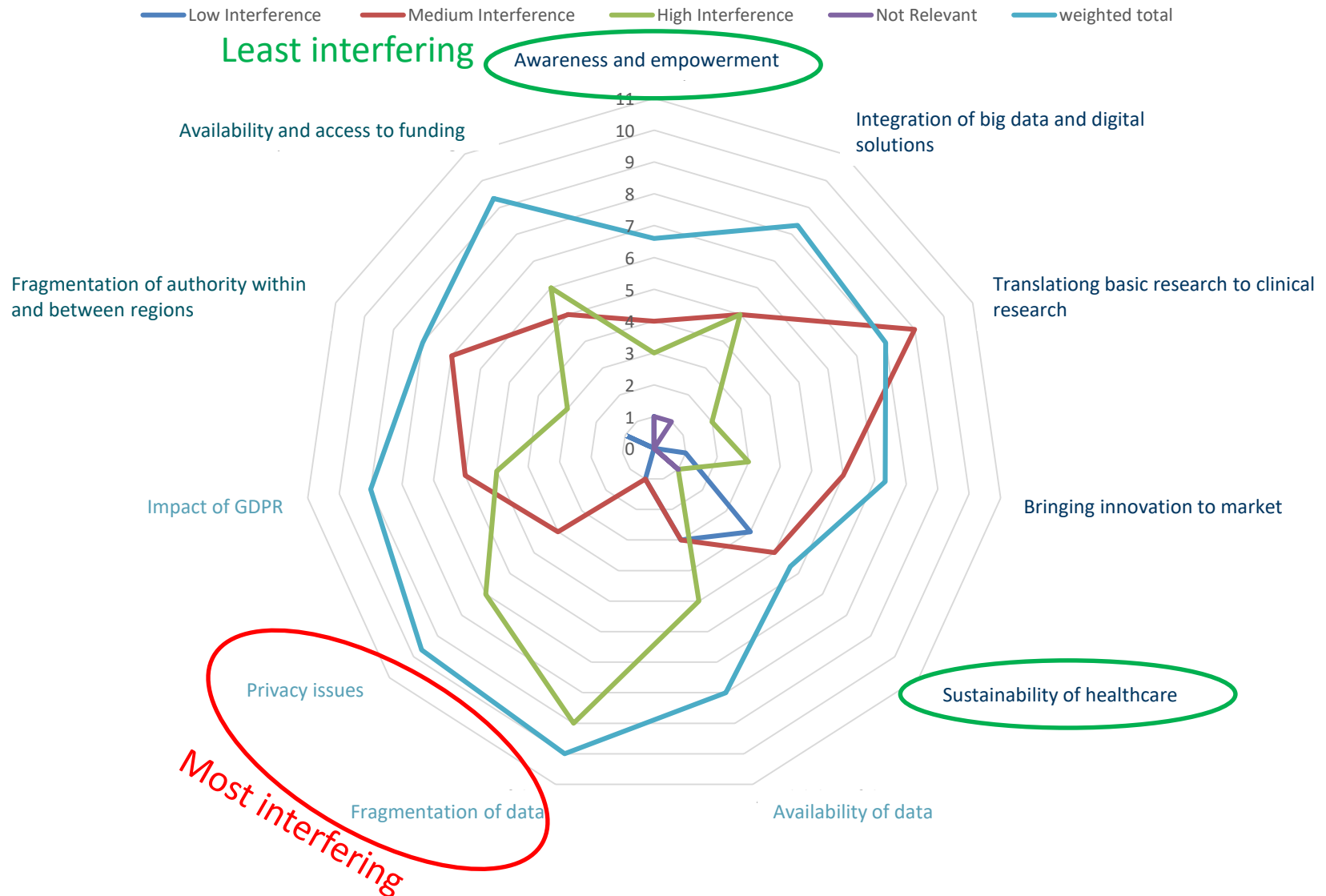
- Availability of data
- Fragmentation of data
- Privacy issues
- Impact of GDPR guidelines

Policy challenges

- Fragmentation of authority level within and between regions
- Availability and access to funding



13/45 (29%) of invitees completed the questionnaire



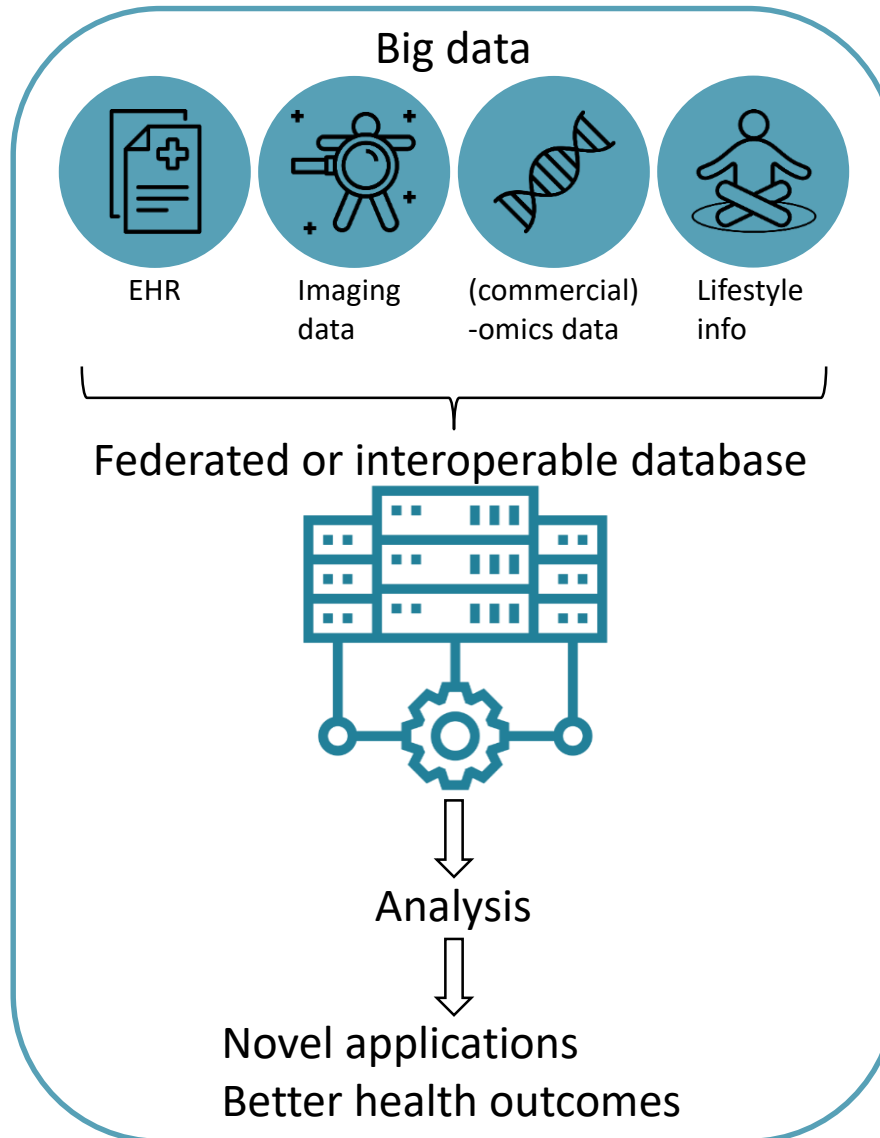
Challenges identified during the workshop

1. Data
2. Logistics and infrastructure
3. Awareness and empowerment
4. Bringing innovation to market
5. Skills of the future
6. Policy
7. Remote and sparsely populated regions



1. Data

Large scale integration of big data will create opportunities to improve healthcare



1. Data

Large scale integration of big data will create opportunities to improve healthcare

NEEDS

BARRIERS

Big data



EHR



Imaging
data



(commercial)
-omics data



Lifestyle
info

No standardisation of
data collection &
storage

Lack of uniformity &
integration: difficult
to share data
between and within
regions

Lack of user-friendly
user interfaces

Federated or interoperable database



Analysis

Novel applications
Better health outcomes

Availability & access

FAIR data
(findable, accessible,
interoperable, reusable)

Professional data
stewardship,
repositories, services

Development & adoption
of shared vocabularies,
ontologies, metadata
specifications, standards

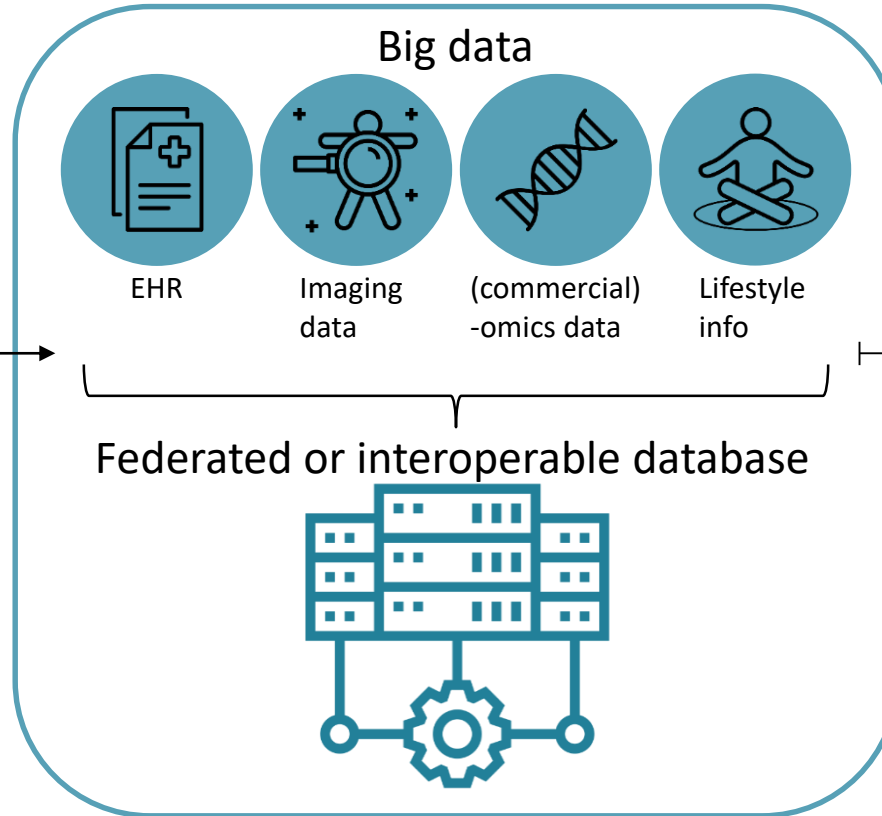
Artificial intelligence
adoption in healthcare

2. Logistics and infrastructure

Servers will have to store several petabytes of information

NEEDS

Investments in infrastructure & servers to be able to store enormous amounts of data



BARRIERS

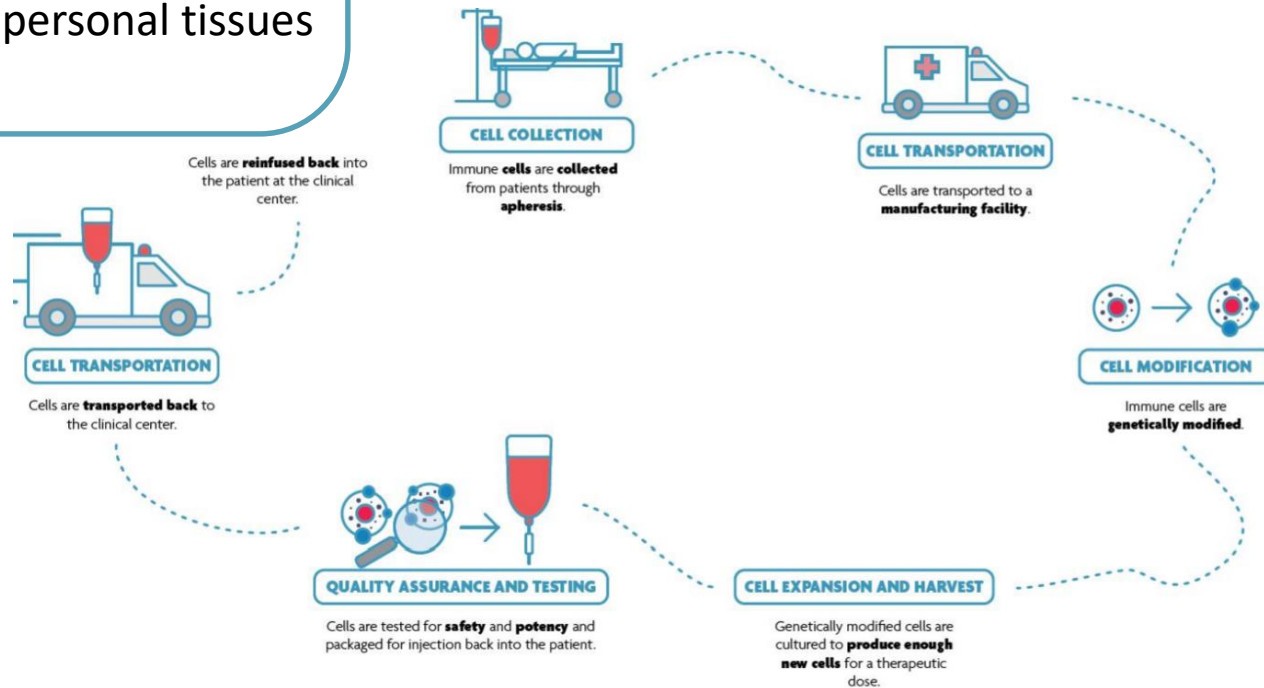
Storage cost of data

2. Logistics and infrastructure

Improve manufacturing in order to upscale personalised medicine

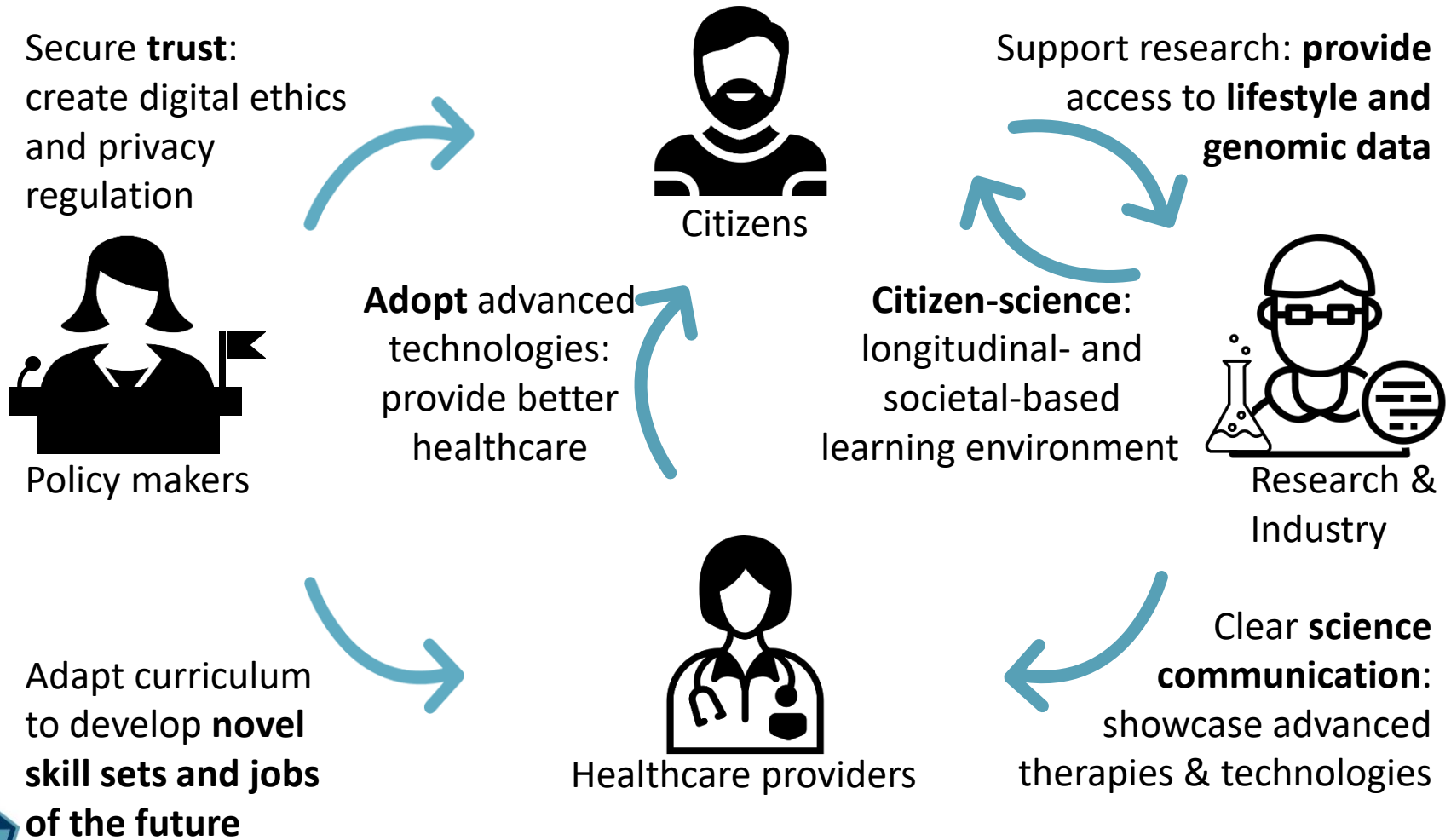
NEEDS

- Create protocols
- Optimise transport of cells and tissues
- Standardise procedures
- Automation of procedures
- Make standards interoperable
Regional ↔ National ↔ European level
- Create biobanks containing personal tissues & cells



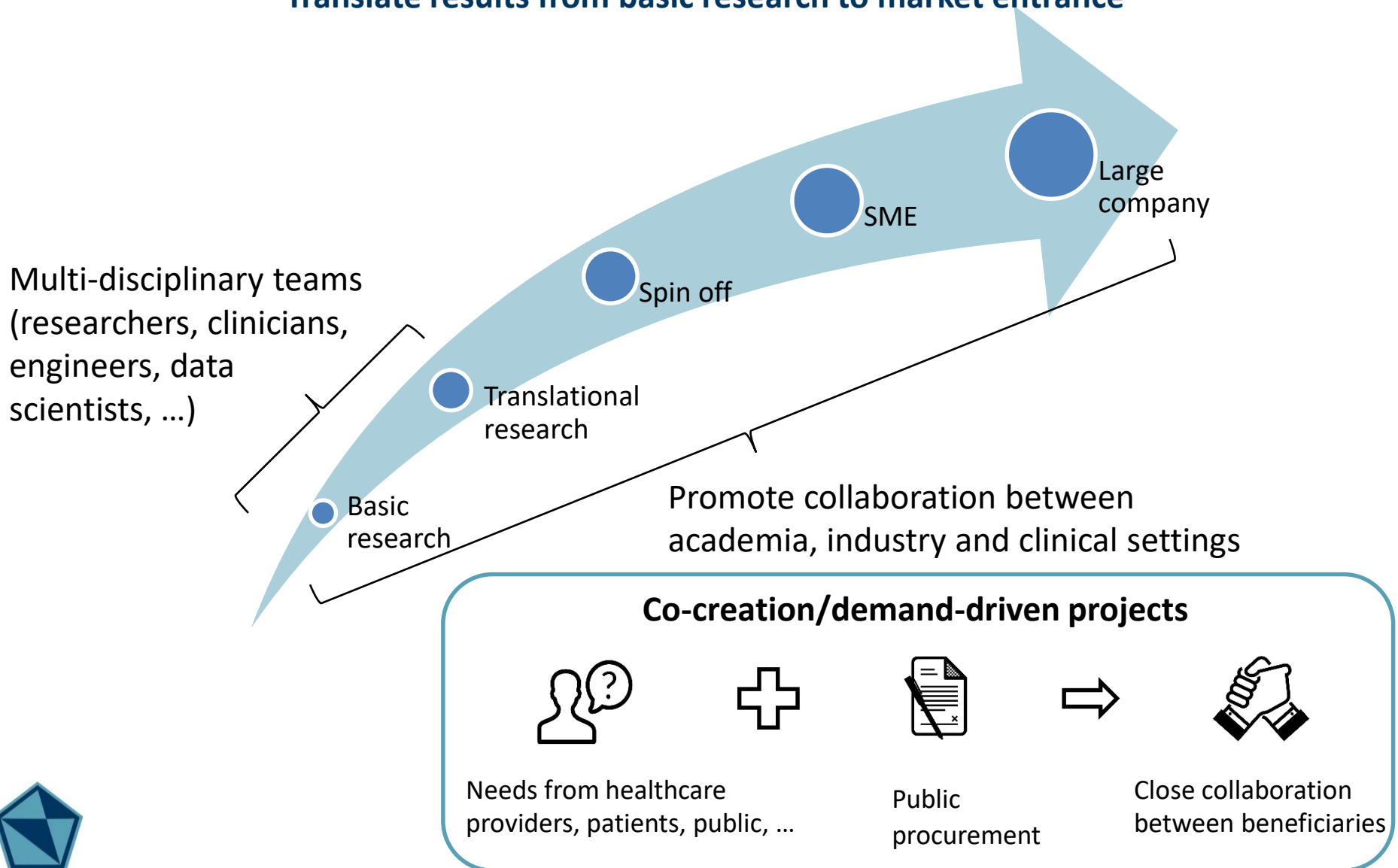
3. Awareness and empowerment

Empower all stakeholders to support personalised medicine



4. Bringing innovation to market

Translate results from basic research to market entrance



4. Bringing innovation to market

Health system payers need evidence that therapy/test gives clinical added-value before making reimbursement decisions

BARRIERS

- Regulatory evidence for reimbursements \neq standardised
- Healthcare in Europe = fragmented (control @ regional \leftrightarrow @ national level)
- No strategy for preventive medicine

NEEDS

- Dialogue between regions & countries:
 - Create common vision in Europe towards industry
- Increase predictability of reimbursements \rightarrow create incentive for investing in PM
- Role of regulatory offices



5. Skills of the future

Innovation in personalised medicine needs novel skill base and knowledge sets

Training of young professionals

Lifelong learning

Clinical geneticists &
genetic counselors

Healthcare
professionals

Digital
health & care

Biomedical
researchers

IT specialists
Data science &
stewardship

Implementation of
digital technologies

Cross-disciplinary programmes



6. Policy

Creation of a strong regulatory framework

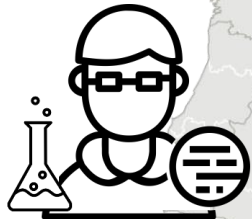
Uniformity within European regions will

- Promote interregional collaboration & data sharing
- Provide safe governance of personal data
- Ensure quality of data
- Create trust between stakeholders



Who can collect data?
Who can access data?
For what purpose?
Opportunities GDPR vs
CLOUD Act?

Collect input from



Scientific experts



Policy makers



Ethical specialists



Social scientists



7. Remote and sparsely populated regions

Remote regions may face additional barriers related to their less centralised location



Long distances to
medical doctor/hospital



Lack of specialised
healthcare professionals



Unique genetic background
& founder mutations

eHealth and telemedicine

Location-specific treatments

Location-specific carrier screening



Overview of implications



1. Data

- Share data within and between regions
- Extract data for re-use and re-analysis
- Implementation of artificial intelligence
- No standardisation
- Lack of integration

2. Logistics & infrastructure

- Infrastructure for the storage of big data
- (Manufacturing) protocols to upscale PM
- Storage costs for big data
- No standardisation of procedures

3. Awareness & empowerment

- Longitudinal- & societal-based learning environment
- New skill base & knowledge set
- More active involvement of patients & citizens
- Lack of awareness healthcare professionals

4. Bring innovation to market

- Better transition from basic research > clinical trials > market
- Gap between academics, clinicians & industry
- Fragmentation of healthcare systems in Europe

5. Policy

- Strong regulatory framework at European scale
- Evidence base for PM
- Who can collect and access data? For what purpose?



Securing the Adoption of Personalised Health in Regions

- Create data standards and agree on semantics
- Make data FAIR
- Create user-friendly user interfaces for databases
- Investments and funding
- Education: skills of the future (data scientists and data stewards, ...) + training of MDs

- Investments in infrastructure and standardisation
- Creation of servers and biobanks
- Standardise (manufacturing) procedures
- Showcase benefits of EU standards
- Create frameworks to make regional standards interoperable

- Include citizens/patient (organisations) in policy making
- Showcase regional success stories
- Education: curricula to prepare for the skills of the future (medical geneticists, genetic counsellors, ...)

- Funding & investments
- Co-creation projects
- Protective time for research
- Disseminate results to general public
- Robust evidence base for PM
- Increased collaboration between regions related to medical reimbursements

- Get input from all stakeholders to create regulatory framework, incl. ethicists and social scientists
- Robust evidence base for PM



A graphic on the left side of the slide consisting of several overlapping triangles in shades of blue and teal, creating a geometric, crystalline shape.

SAPHIRE

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