



# Communicating the value of research infrastructures to the public, to policy makers and to various sectors of society



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Head of External Relations*

[www.elixir-europe.org](http://www.elixir-europe.org)

# Matching treatments to cancers



- One in 10 women in the EU will develop breast cancer before the age of 80
- Cancer is a genomic disease
- Sequencing *cancers* helps us understand their form at the molecular level
- If we can identify patterns of genes that are active in different tumours, we can diagnose and treat cancers earlier with the most suitable medicines




# Genome-wide analysis of crop plants

- Population growth and climate change: major challenges to food security
- Traditional routes to crop improvement: too slow to keep up with demand
- Plant genomes: identify which species are most tolerant to drought, salt and pests while still providing optimum nutrition



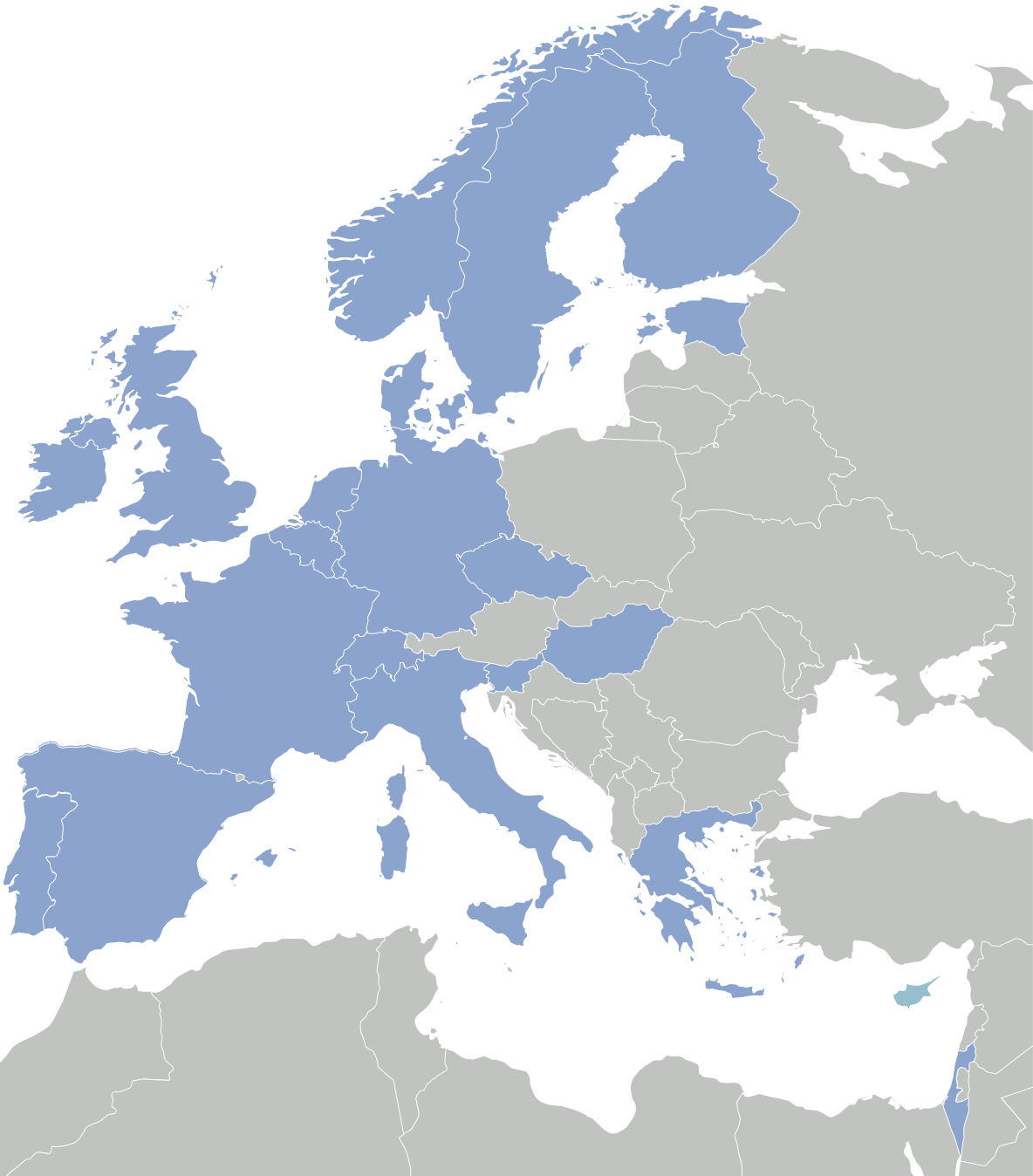


# ELIXIR Members

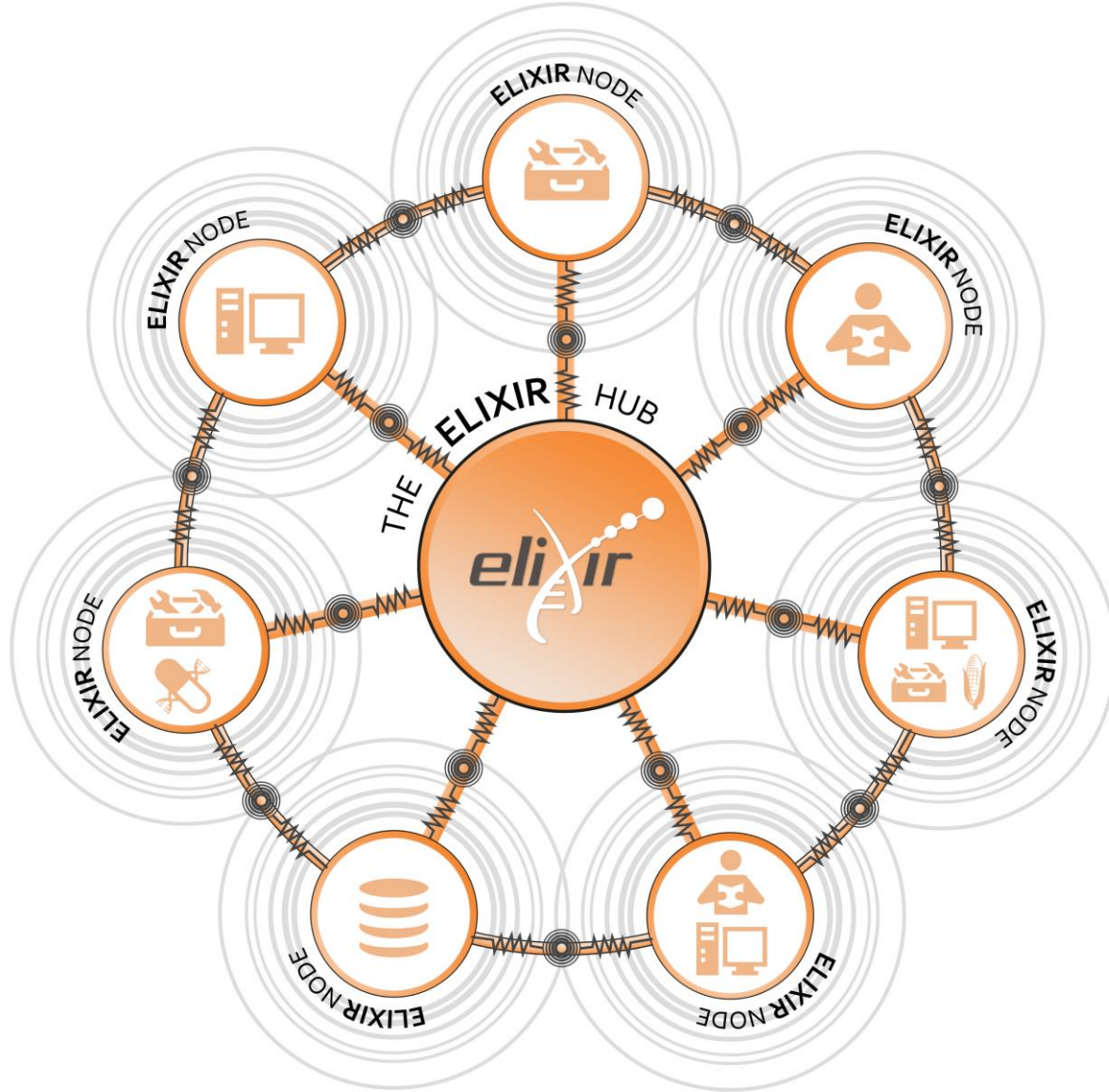
 Belgium	 Czech Republic	 Denmark	 EMBL
 Estonia	 Finland	 France	 Germany
 Greece	 Hungary	 Ireland	 Italy
 Luxembourg	 Israel	 Netherlands	 Norway
 Slovenia	 Portugal	 Spain	 Sweden
 Switzerland	 United Kingdom		

# ELIXIR Observers

 Cyprus
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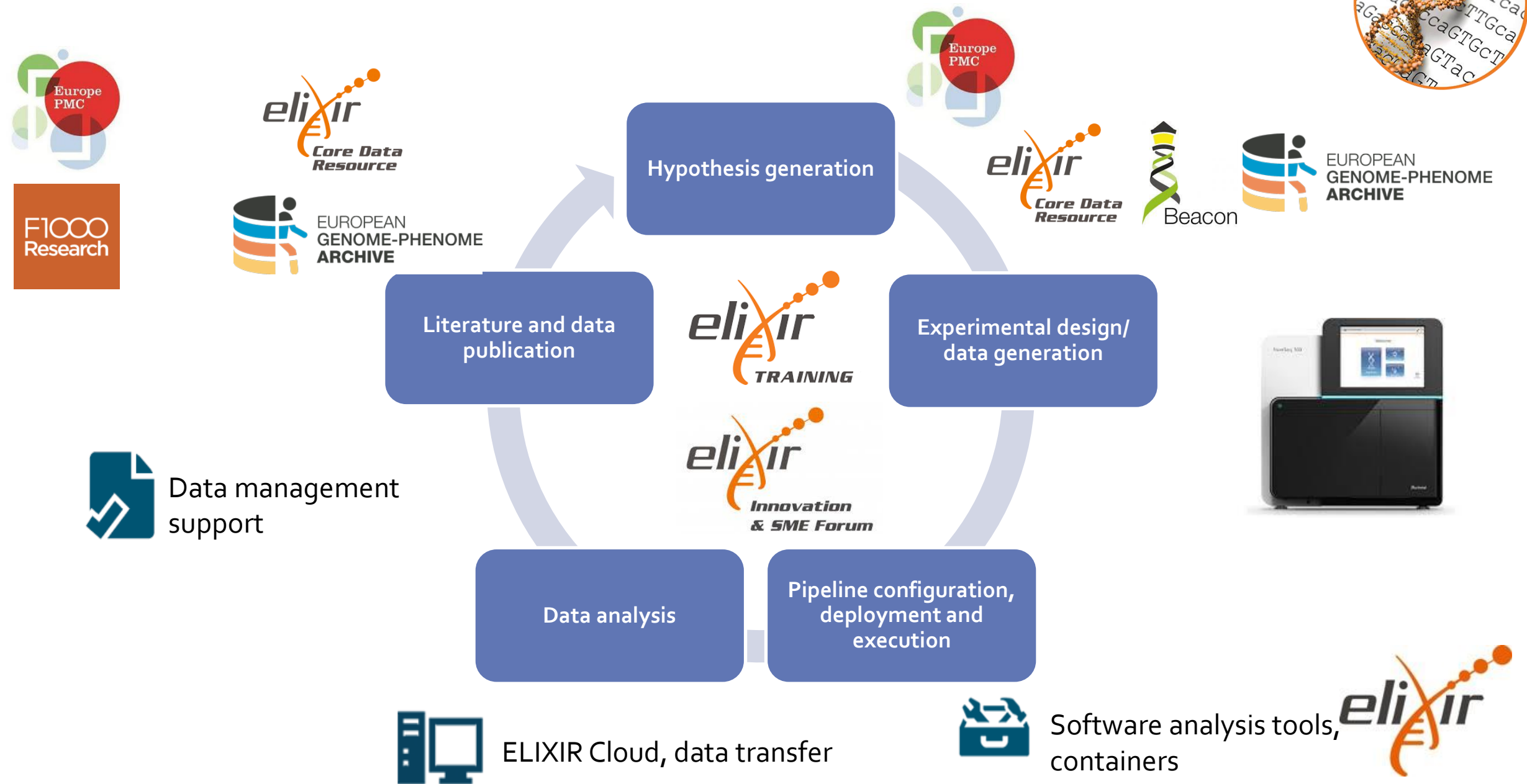


# A distributed pan-European infrastructure



- 22 Nodes
- 650 scientists
- Over 220 institutes
- Databases
- Tools
- Interoperability
- Compute
- Training

# ELIXIR services in the bioinformatics value chain



# The challenges of impact assessment for ELIXIR

- Distributed infrastructure - 220+ institutes over 22 countries
- Over 200 services officially part of ELIXIR
- Huge number of users globally
- Virtual access provided – usually no application made
  - IP tracking
- Databases are linked and intertwined
- Collection of data around operating costs poses challenges

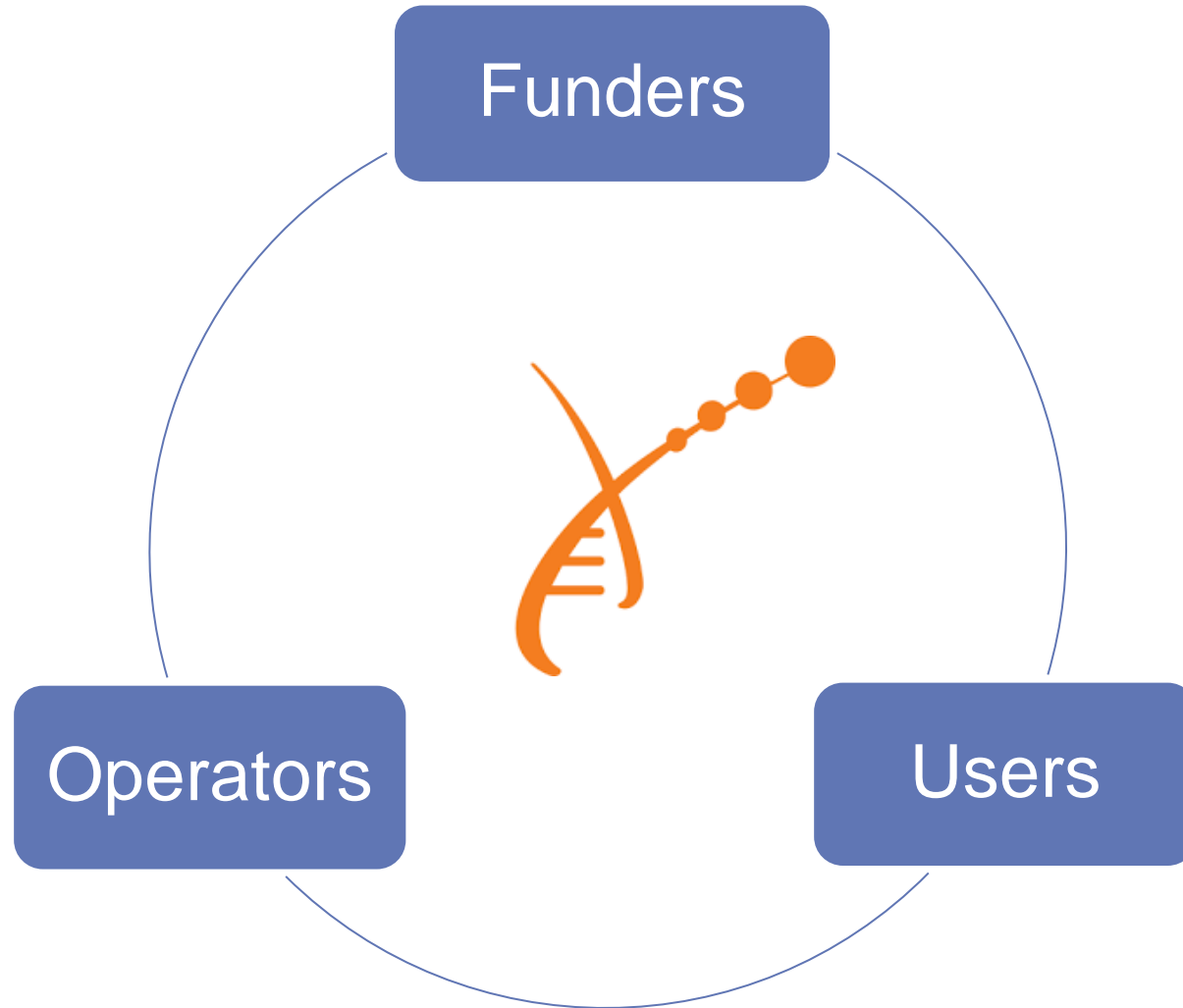


# How to place a value on societal challenges?





# ELIXIR's stakeholders: the holy trinity



Public?

Policy-makers?



# Stakeholders analysis

## Funders

- ELIXIR Board members
- European Commission
- IMI
- National governments
- National funding agencies

## Users

- Bioinformaticians
- Industry users
- 500,000 + life scientists
- Other infrastructures

## Operators

- ELIXIR Nodes
- 200+ institutes
- 650+ scientists
- External collaborators (other ESFRIs, e-Infras, International collaborators)



# What role for the public?

- Not a major stakeholder group
  - Limited capacity for dedicated outreach schemes
- However, support provided through many communications channels
- Why? We receive tax-payers money
- **Social media:**
  - Twitter: life science community, public
  - LinkedIn: industry, job postings
  - YouTube: Videos and webinars
  - Infographics



ELIXIR - Value of open bioinformatics resources to industry and SMEs



[@ELIXIREurope](https://twitter.com/ELIXIREurope)

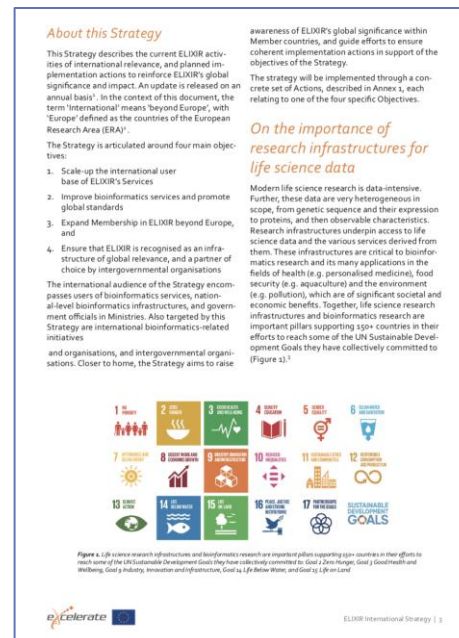


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# What role for the policy-makers?

- Major stakeholder group
- Shape policies of relevance to ELIXIR including
  - RI policy: long-term sustainability, business models for RIs
  - Other policy areas: Open Data, Open Science, Data Management Plans
- Channels used
  - Conferences
  - Annual reports
  - Infographics
  - F1000 channel
  - International Strategy





# Demonstrating socio-economic impact: partner with experts

## RI-Paths project

- Aims to develop a common methodology for assessing the socio-economic impact of RIs
- ELIXIR is a partner along with Cern, Desy and Alba



## OECD Global Science Forum

- SEIRI also aims to develop a model for assessing socio-economic impact
- ELIXIR engaged throughout the development and testing of the framework



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# Assessing impact



**2010-2015:**

**30 771 patents** used bioinformatics repositories to identify genes, enzymes, SNPs, ...



Vaccines



Pharmaceuticals

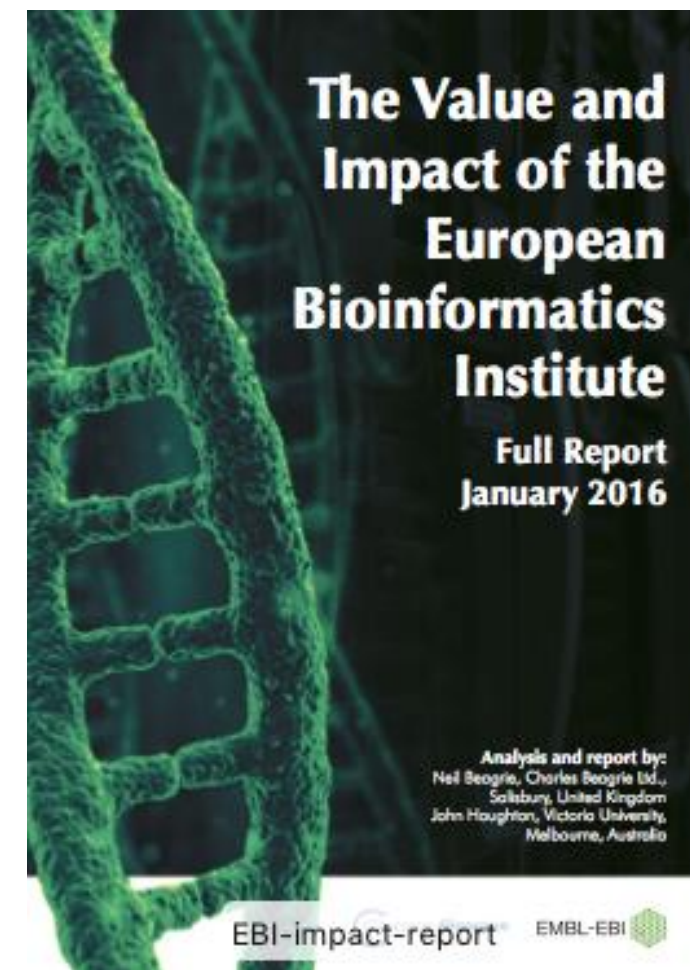


Beauty care



Industry enzymes

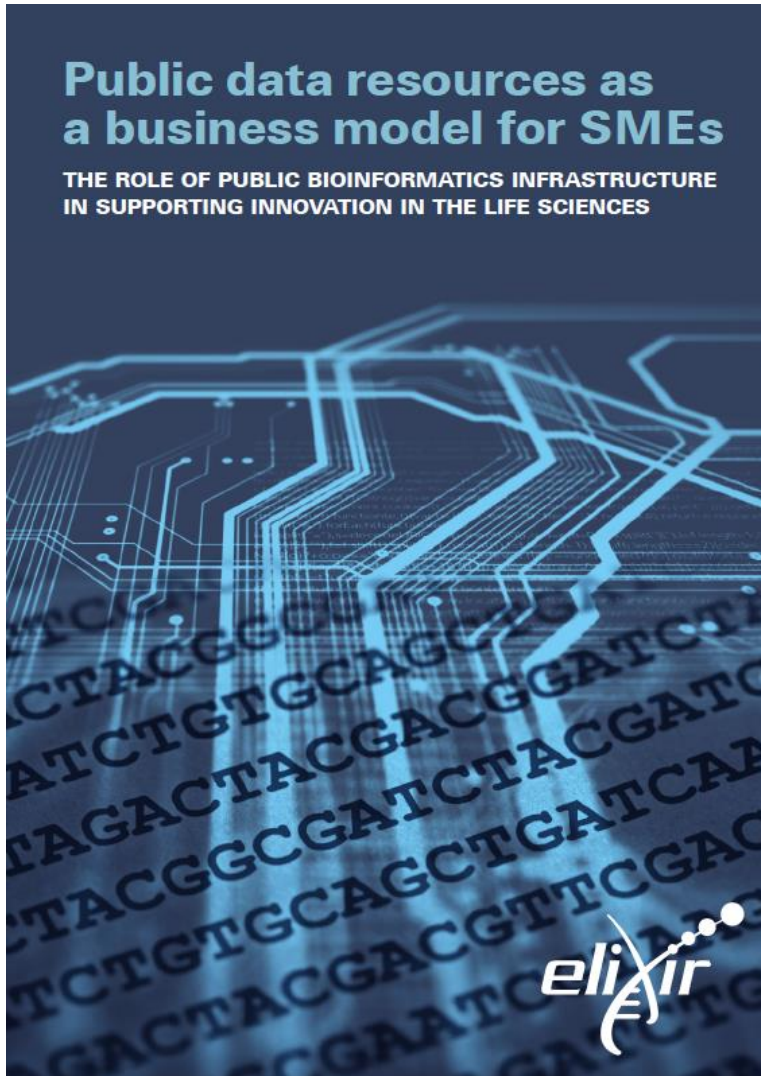
\*Bousfield D, McEntyre J, et al. *Patterns of database citation in articles and patents indicate long-term scientific and industry value of biological data resources*. F1000Research 2016



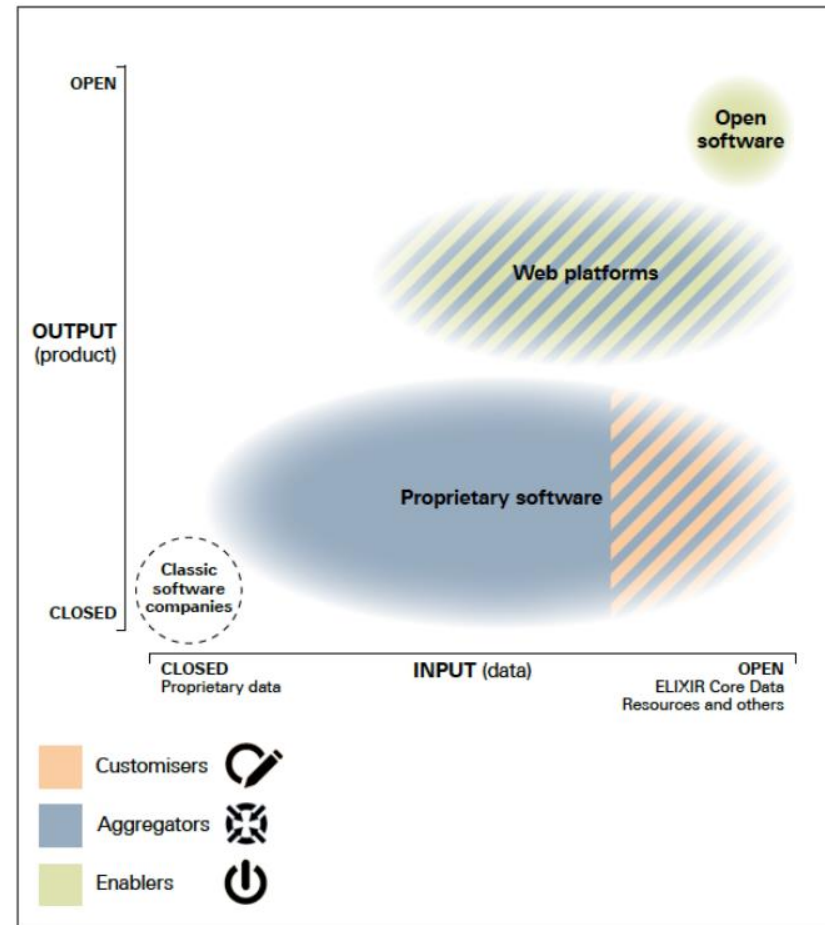
Full report: <https://beagrie.com/static/resource/EBI-impact-report.pdf>



# Public data resources as a business model for SMEs



Interaction with public data resources:



eagle<sup>®</sup>  
genomics

Mind  
the Byte | SaaS  
for Drug  
Discovery

RiboCon

ONTOFORCE

REPOSITIVE

General  
Bioinformatics

thehyve



# Thanks!

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[www.elixir-europe.org/excelerate](http://www.elixir-europe.org/excelerate)



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